

SIP 2017

Abstract & Background



MALTA
EU2017



SIP
Societal Impact of Pain

**STRUCTURED COOPERATION BETWEEN
HEALTH CARE SYSTEMS TACKLING THE
SOCIETAL IMPACT OF PAIN!**

#SIP2017





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Societal Impact of Pain (SIP) Symposium 2017

STRUCTURED COOPERATION BETWEEN HEALTH CARE SYSTEMS TACKLING THE SOCIAL IMPACT OF PAIN!

SIP 2017 is made possible with the support of the Maltese Ministry for Health Malta and financial support provided by the Maltese Ministry for Finance. It takes place under the auspice of the agenda of the 2017 Maltese Presidency of the Council of the EU.



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The SIP symposium is arranged in compliance with the applicable laws and regulations, including the Codes of Conduct of the European Federation of Pharmaceutical Industries and Associations (EFPIA) and as implemented in the national Codes of Practice.

The format and content of the SIP 2017 Symposium has been pre-approved as being in line with the code of conduct of the Pharmaceutical Research Based Industry Malta Association (PRIMA)



MINISTRY FOR HEALTH

Dear Reader,

Welcome to the 7th European Symposium on the Societal Impact of Pain (SIP 2017): "Structured cooperation between health care systems tackling the societal impact of pain."

Under the auspices of the Maltese Presidency of the Council of the European Union, I welcome all the stakeholders in the area of pain: patients, doctors, insurers, employers, policy makers, and politicians to debate the increasingly pressing issue of pain as a quality indicator for health care systems, building platforms to address the societal impact of pain, the impact of pain on labour and pain's challenges, models and lighthouses.

Chronic pain affects around 20% of the adult population in Europe yet it remains poorly managed and under-treated, affecting not only patients, but society at large. It results in more than 500 million sick days per year in Europe, costing the European economy more than €34 billion and is responsible for nearly half of all absences from work lasting more than three days in Europe. It is among the top five causes of disability in every region of Europe and increases the risks of other health problems, social exclusion and poverty.

During Malta's Presidency, we have focused on pursuing coordination in several fields of healthcare: from rare diseases to chronic conditions. One of the key outcomes of our Presidency will be the Council conclusions on structured cooperation between European healthcare systems.

During the SIP symposium 2017, I hope we pick up the work initiated by the Italian Presidency at the informal Health Ministers meeting in 2014 on the key issue of pain therapy and palliative care. Back in 2014, European countries agreed on the need to create a European network ensuring training of professionals in pain care and exchange of information on the effectiveness of therapies for the weakest population groups. Acknowledging that networks for paediatric pain therapy and palliative care are still not evenly developed throughout Europe, health ministers gave advice on the development of palliative care and pain therapy for other vulnerable groups, such as the elderly.

We believe this is a key area where the European Union can increase cooperation to ensure better life standards for its citizens.

As a doctor, I know all too well the fundamental importance of European cooperation in the area of health. In these uncertain times, Europe must face its common problems together to ensure that its citizens get the best healthcare possible. I am certain that a platform such as the Societal Impact of Pain is an example of a vehicle towards achieving this goal.

A handwritten signature in blue ink that reads "Chris Fearné".

Hon. Minister
Chris Fearné

The Societal Impact of Pain (SIP) symposium takes place under the high patronage of the Italian Ministry of Health.



Ministero della Salute

Ufficio di Gabinetto

Ministero della Salute
GAB

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I. s. b. b./2012/5073



Z20667213

Prof. Dott. Bart Morlion
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c/o

e, p.c.

Presidenza Consiglio Ministri
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Roma

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Con riferimento alla richiesta, pervenuta allo scrivente Ufficio, si comunica la concessione del patrocinio del Ministero della Salute al Simposio "Impatto sociale del dolore" in programma a Malta dall'8 al 9 giugno 2017.

Al riguardo, si chiede di attenersi a quanto assicurato con Vs. nota del 9 marzo u.s..

Si formulano i migliori auguri per la riuscita dell'iniziativa.

Il dirigente

Dear Reader,

Welcome to the 7th European Symposium on the “Societal Impact of Pain (SIP 2017): “Structured co-operation to tackle the Societal Impact of Pain”. In 2016, we made great strides forward in articulating a series of policy recommendations for EU leaders. When taken forward collectively, we believe these recommendations would transform the lives of pain patients and alleviate the impact of pain on society. We now look forward to an update on all that we achieved in 2016, and to see what more needs to be done to make the case to politicians and other stakeholders to highlight the importance of this issue.



Chris Wells
President
European Pain Federation EFIC®



Bart Morlion
EU-Liaison Officer and
President Elect
European Pain Federation EFIC®

Chronic pain affects almost 1 in 5 European citizens; around 100 million individuals and 50% of the older population. Chronic pain is one of the major reasons why people exit the labour market prematurely and causes 500 million days of illness per year, costing the European economy more than €34 billion. As the European economy continues its slow path to recovery and structural reform, factors that affect employment and growth, such as early retirement and absence through illness, will need to be addressed. It is our role to highlight the figures and to provide advice on what can be done. So far, we have received a warm reception from policy makers and we hope this continues.

At the European Pain Federation EFIC®, the multidisciplinary professional organisation in the field of pain research and medicine, we are making progress in our own field to promote a wider and deeper understanding of pain. In March this year we held the first examination for the European Diploma in Pain Medicine. Our educational activities will grow, and hopefully we will see more healthcare professionals with an understanding of the impact of pain, as well as its treatment. Coupling this with an approach to governments, to ensure an appropriate policy framework for pain care and pain patients is a noble ambition and we hope to see it succeed in the coming years.

This year, there are five strands to the agenda of the SIP Symposium:

We will once again focus on two central issues to pain policy; the use of pain as a quality indicator for health systems and the impact of pain on labour and employment.

We will also take the opportunity to look at how a platform to address the societal impact of pain could function, as well as different challenges, models and lighthouses in pain policy at national and European level.

Finally, we will look at evolving concepts in the definition of chronic pain, to define a consensus statement for policy purposes on the definition of chronic pain.

We look forward to joining you in Malta, and to seeing our ideas manifested in policy in the near future.



Chris Wells
President
European Pain Federation EFIC®



Bart Morlion
EU-Liaison Officer and President Elect
European Pain Federation EFIC®

“Structured cooperation to tackle the Societal Impact of Pain”

Dear Participants of SIP 2017,

In October 2016, I started as the Global CEO of Grünenthal, a science-driven pharmaceutical company with a strong commitment to innovations in pain indications. Pain has many faces. It can be pulsing, aching, sharp, dull or even drilling.

Even when comprehensive pan-European data quantifying the effect of pain on society are missing, what we know already is deeply concerning. Pain is one of the most common reasons for which people seek medical attention. The estimated direct and indirect healthcare costs for chronic pain disorders in European Member States vary from 2 % to 3 % of GDP. For 2016 this estimate would result in 294 – 441 billions of €. This is an impressive sum.

Pain is a healthcare problem impacting functioning and quality of life, associated with sleep disorders, anxiety, depression, and low self-esteem, among many other symptoms. For pain as a health condition, expertise is spread unevenly across the EU member states. Quality standards on postoperative pain and access to pain therapy are urgently required. Patients dealing with headache, in need of cancer pain treatment or palliative care often have poor access to adequate pain treatment. For patient’s daily suffering with complex regional pain syndrome (CRPS), Bladder Pain, Vulvodynia, Spina Injury or fibromyalgia adequate treatments need to be developed.

Hurdles for patients to access adequate pain therapy include lack of training of medical professionals, restricted resources and access to medicines, cultural attitudes as well as regulations and policies not addressing the societal impact of pain. However, these hurdles are not unconquerable. They can be addressed by working together. If all stakeholders involved join forces we can achieve a lot to relieve the societal impact of pain for both: the individual patients and society.

At Grünenthal we consider it our responsibility to develop innovative solutions in pain treatment. Our scientists have defined a pain landscape containing over 100 different pain conditions. Many of these indications are yet to be fully understood and often lack a proper medical treatment. Therefore we see it as our commitment together with patient representatives, academia and policy makers to develop new life changing innovations bringing benefit to patients in areas with a high unmet medical need. With this in mind I was impressed when I heard first time about the fantastic platform “Societal Impact of Pain” (SIP). SIP is an outstanding initiative where patient representatives, healthcare professionals, politicians, insurances, health authorities, regulators and budget holders are working closely together in a structured way. The SIP platform builds a strong foundation to raise awareness, exchange information and best practices and to develop and foster policy strategies & activities for an improved pain care in Europe.

The SIP 2017 symposium is a great chance to bring multiple stakeholders together to evaluate and discuss the societal consequences of pain and to consequently follow-up on the policy recommendations from the previous year’s events. This year’s meeting is a special event as it takes place under the auspice of the agenda of the 2017 Maltese Presidency of the Council of the EU. The frame of the Maltese presidency gives the societal impact of pain an enormous potential for political attention. Inspired by the Maltese presidency **“Structured Cooperation between Health Care Systems tackling the societal impact of pain!”** has been chosen as the title for SIP 2017 which underlines the ambition to really make a difference.

On behalf of Grünenthal I am very proud to be part of this initiative to welcome you to this unique event. I would like to thank all who have been involved in the preparation of this impressive event, especially the many involved at the European Pain Federation EFIC®, Pain Alliance Europe (PAE), Active Citizenship Network (ACN), Malta Health Network (MHN), the No Pain Foundation and our sponsors Alliance for Patient Access (GAfPA) and the German Maltese Medical Society (GMMS) as well as the sponsors supporting the initiatives of ACN and PAE during this event. But most of all I thank you, participants of SIP 2017 for your effort and dedication to address the societal impact of pain. The excellent cooperation of all SIP partners is a benchmark for national and European initiatives to striving for a consistent pain policy.

I wish you fruitful discussions and a very successful SIP 2017.



Gabriel Baertschi
Global CEO of the Grünenthal Group



Gabriel Baertschi
Global CEO
Grünenthal Group

Dear Reader,

Pain Alliance Europe (PAE) is a pan-European organization of national/regional associations involved in chronic pain regardless of what the underlying condition may be. At this time, PAE has 34 members from 17 different EU countries which in turn represent over 350,000 individual chronic pain patients. PAE's mission is: improve the quality of life of people living with chronic pain in Europe. It sees itself as the voice of people with chronic pain.

PAE was founded in 2011 in response to the need of the stakeholders to have a patients' association to cooperate with. Since then, PAE has proven to be a transparent, trustworthy and reliable association. From those early days it has almost doubled its members and increased the involved member states by 50%. PAE realizes that there is still a long way to go to get all EU countries involved.

The main focus is on the European options regarding improving the quality of life of people living with chronic pain. In that way our involvement and cooperation with SIP is totally logical.

As well as the SIP activities, PAE has created the Pain Patients Pathway Recommendations project together with Active Citizens Network (ACN). It runs the Red Balloon project aimed to increase the awareness for chronic pain. It is the leading partner in a new grant project aimed on innovating patient-centered research. It is a member of the patients' liaison committee of the European Pain Federation (EFIC). It is a jury member of the ACN-lead European civic prize on chronic pain. It was a partner in a European project on E-Health for primary care physicians. It is a valued member in various research proposals in development.

PAE is also busy running surveys amongst European chronic pain patients which will be analyzed by the university of Rotterdam, Erasmus. We are aiming to do one survey each year on three different issues: health related, work related, one related to societal issues. All of which are also areas of work within the SIP structure. After completing the three surveys, we aim to repeat them to see if any improvements have been made.

PAE involves its members as much as possible in developing activities as they are the backbone of our association and they know the questions of the chronic pain patients best. Communication with members is via newsletters and personal letters.

PAE can be reached by:

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Joop van Griensven
President
Pain Alliance Europe (PAE)



Joop van Griensven
President
Pain Alliance Europe (PAE)

- 1 www.activecitizenship.net
- 2 www.sip-platform.eu/news/details/IMI_pain_agenda.html
- 3 <http://sinedolore.org>
- 4 www.interestgroup.activecitizenship.net/115-june-21st2016-pain-therapy-and-the-degree-of-patient-s-pain-in-the-age-of-cross-border-healthcare.html
- 5 <http://sinedolore.org/sine-dolore-world-park/>

“Pain Euro-Mediterranean Coalition”, the new platform addressing the societal impact of pain

The eight policy recommendations coming from the SIP 2016 stood for an important starting point in the development of a better European policy addressing chronic pain management, and Active Citizenship Network appreciates the decision made by the Innovative Medicines Initiative (IMI) on December 2016 to add pain to its agenda .

However, it is crucial not only to identify priorities and recommendations, or get the commitment of the Institutions, but also to promote concrete activities involving all the stakeholders to transfer achievements in the European agenda into the European culture, including extra EU countries too. With the same aim, and - in general - to contribute to make chronic pain visible, Sine Dolore and Active Citizenship Network have promoted the “Pain Euro-Mediterranean Coalition”.

The idea of this Coalition came out on June 2016 during the event realised at the EU Parliament “Pain therapy and the degree of patient’s pain in the age of cross-border healthcare” , which was supported by the MEPs Interest Group “European Patients’ Rights and Cross-border Healthcare” . However, the Coalition will be officially presented in May 2017 in Minorca (Spain), in the framework of the “Sine Dolore World Park” .

In response to the slogan of SIP 2016 “Time for Action” , there is the willing of Active Citizenship Network and Sine Dolore to cooperate for the development of concrete efforts against unnecessary pain.

This Coalition aims to be:

- The agora of operators of good practices on pain, encouraging the exchange of experiences among health professionals, healthcare providers, Institutions, civic associations and Patient Advocacy Groups (PAGs);
- An open multi-stakeholder platform mainly addressed to the constituency dealing with pain relief at local and national level across Europe rather than to EU umbrella organisations;
- The fusion of experiences coming from pain and patients’ rights constituencies;
- The missing piece necessary to integrate the scientific research on pain with the “civic information” approach on the topic;
- A bridge on pain built in the Mediterranean area but intended to overcome EU borders and reach non-EU countries as well;
- Facilitator for advocacy and policy actions on chronic pain at local, national and European level.

The Coalition has the scientific support of the European Multidisciplinary Network in Pain, Research and Education/Efhre International University.

The first enthusiastic actors who have decided to join the Coalition (but applications for membership are still open) are: Acción Psoriasis, Federación Española de Diabetes, Foro Español de Pacientes, Asociación Española de Trasplantados, Alianza General de Pacientes, Sociedad Balear del Dolor, AEPAC-Asociación Española de Pacientes con Cefalea, Plataforma de Organizaciones de Pacientes (Spain); Association Francophone pour Vaincre les Douleurs (France); Croatian Association for the Promotion of Patients’ Rights (Croatia); Patients’ Rights Association in Kosova and Professional Health Association (Kosovo); Together for Life (Albania); Headache Association of Ticino (Switzerland); National Patients’ Organisation (Malta), Azorian Association of Chronic Pain Patients (Portugal), Anaste-Associazione Nazionale Struture per la terza età (Italy).

In particular, evidence shared by the Albanian partner seems extremely relevant: «Last year, in Albania, “Together for Life” dealt with patients with cancer, stage IV, who did not receive palliative care and as such, they lived in terrible pain. “Together for Life” has discussed with doctors and learned that many of them did not know that palliative care existed in Albania and so they did not tell the patients about it. We have raised this issue publicly in different activities, and in our own health media to change the situation, but we are conscious that more has to be done, especially on chronic pain. So we really do appreciate what Active Citizenship Network is doing with “Sine Dolore” and the Coalition, and of course we would like to be part of it».

The diversity of members within the Coalition will strengthen collaborations among all the relevant stakeholders. At the same time, the different perspectives shared will enrich European and national experiences, expertise, data and benchmarking on chronic pain.



Mariano Votta
Director Active Citizenship Network



Mariano Votta
Director
Active Citizenship Network

Welcome to Malta to the Societal Impact of Pain (SIP) 2017 International Symposium

For the Malta Health Network (MHN), co-hosting the Societal Impact of Pain (SIP) 2017 international symposium is very significant. It is a milestone which we have been looking forward to for the past 2 years.

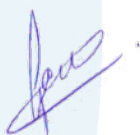
The MHN was set up in 2007 with the aim of representing in the EU and internationally, the interests of patients and the health of the community in Malta, by developing better collaboration and capacity building through exchange of best practices. MHN currently counts close to 40 Maltese organisations. It supports initiatives to protect patients' health and is active in advocating for patient's rights especially through the promotion of the European Charter of Patients' Rights.

MHN strives to give patients a voice through its member organisations on health related issues in Malta and beyond. MHN participates in consultation sessions related to health and patient issues and has regular communication with local health and other governmental authorities.

The MHN has put Chronic Pain on its' agenda following an invitation to participate in the SIP 2013 Symposium. Since then, MHN has been organising events to promote the World Day Against Pain, on an annual basis. MHN has worked on the awareness of pain self-management by organising training seminars for patients and professionals and making 'Pain Toolkit' available in the Maltese language. We are also currently carrying out a prevalence study of chronic pain in Malta.

Why are we concerned about chronic pain? For many individuals, pain, with its concomitant physical, emotional, social and economic impacts, is part and parcel of the daily life. Pain arises from many conditions and addressing pain means helping a significant number of patients. Chronic pain leads to other difficulties such as mental health problems and emotional difficulties. Pain can effect the patient's employability, decrease socialisation and lead to a poor quality of life. These, then, are the main reasons why MHN is working hard with its member organisations on this issue and the ultimate aim is giving pain patients a better life. Patients and their health care professionals are demanding that chronic pain is recognised as an illness in its own right, whatever its cause since very often chronic pain is the greatest issue faced by the patient, greater than the underlying cause.

We have learned much since our collaboration with SIP Europe in the preparations leading up to the SIP 2017 Symposium and we would like to sincerely thank SIP Platform Europe for their help and collaboration. We have brought together various stakeholders to set up the SIP Malta Platform which, although still in it's early stages, we hope will be the catalyst for many initiatives carried out at local level and aimed at improving the lives of patients with chronic pain and their families. Keeping this important aim in mind, we sincerely hope this conference results in the agreement and commitment on concrete actions with measurable outcomes taken on a national and European level . We wish all a fruitful conference.



Gertrude Buttigieg
Hon Secretary
Malta Health Network



Gertrude Buttigieg
Hon Secretary
Malta Health Network

The burden of chronic pain

Pain is a common health state in many chronic diseases and Chronic Pain (CP) itself can be considered a chronic health condition in respect to health care policy. Although CP is common, there is currently little published robust pan-European and Maltese epidemiological data on CP and its impact on sufferer's quality of life and economical burden for sufferers, their families and health and social systems.

As we know chronic pain occurs in 19% of European adults, negatively affecting their daily, social, and working lives; most patients do not receive pain treatment and 40% receive an inadequate one. Indeed, according to published data (Pain in Europe Survey/Eurostat), it is estimated that there are more than 95 million people (15-65 years of age) suffering from CP in Europe. Chronic Pain has a significant negative economical impact on health systems, affecting daily activities and the ability to work of chronic pain sufferers. In fact, CP persons are more frequently absent from work and are also forced to retire from work earlier than other people at working age. In Europe, the number of leave-days taken because of CP is estimated to be about 500 million. The total cost for European systems for CP is equivalent to about 300 billion euro/year.

Technically, CP is an on-going or recurrent pain lasting longer than the time of normal healing for an illness or injury, or lasting more than 3 to 6 months. As such it is a major global health issue as it affects approximately 37% of individuals in developed countries.

Aside its ample prevalence CP causes a substantial burden to the individual and the individual's family as it contributes to the sufferer's physical and mental dysfunction and disability. Accordingly, CP impedes activities of daily living, work and work efficiency, and often reduces quality and quantity of life.

In Malta there is still much work to do on pain management and in order to implement congruent health-care policies there is an urgent need to evaluate the prevalence of chronic pain condition within the Maltese population and to explore how individuals perceive their pain, the impact it has on their lives, their perception of the attitudes of others towards their pain, treatments received and its adequacy.

No Pain Foundation - with the approval of the Maltese Health Ethics Committee and the support of the Directorate for Health Information & Research (DHIR) of the Maltese Ministry for Health - is carrying out a nationally representative survey on the extent and the nature of chronic pain in the Maltese population. This is indeed an area of increasing public health concern, especially in view of an ageing demographic and the association of increased longevity and morbidity with chronic conditions. No Pain Foundation's research project titled "Chronic pain in Malta: prevalence, treatment and its impact on social and daily life". The large scale prospective and observational study is based on the administration of an ad hoc questionnaire using phone-call-survey methodology and the study population will be Maltese resident adults, speaking Maltese and/or English. It is planned to approach about 5,000 people (\geq 18 years of age).

All findings will be communicated to national government to improve policy-making regarding the societal impact of pain in Malta.

The SIP Symposium 2017 is for Malta an important event which will help us to address concrete steps directed at Maltese government in order to improve policy making regarding the societal impact of pain.



Silvana Fanalista
President
No Pain Foundation



Silvana Fanalista
President
No Pain Foundation



eu 2011.hu



“The Societal Impact of Pain A Road Map for Action”

In 2001, the European Federation of the International Association for the Study of Pain Chapters (EFIC[®]) published its Declaration on Pain which called on national governments and the EU Institutions to increase the level of awareness of the societal impact of pain. Ten years on from the EFIC Declaration on Pain, national and EU policy action has been very limited. At the same time, basic and clinical science have demonstrated the feasibility of pathways out of pain for many types of acute and chronic pain, but health care systems currently do not guarantee general access to these.

According to the 2007 Eurobarometer survey on “Health in the European Union”, almost one third of respondents experience musculo-skeletal pain which affects their day-to-day life. The burden of suffering that pain imposes on individuals and the enormous costs that society has to bear not only by healthcare systems but also the social, economic and employment sectors only illustrate the urgency for European governments and the EU Institutions to act and to put, as a priority, the societal impact of pain on their policy agenda.

We call on European governments and the EU Institutions to:

1. Acknowledge that pain is an important factor limiting the quality of life and should be a top priority of the national health care system.
2. Activate patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management.
3. Raise awareness of the medical, financial and social impact that pain and its management has on the patients, their family, care-givers, employers, and the healthcare system.
4. Raise awareness of the importance of prevention, diagnosis and management of pain amongst all healthcare professionals, notably through further education.
5. Strengthen pain research (basic science, clinical, epidemiological) as a priority in EU framework programme and in equivalent research road maps at national and EU level, addressing the societal impact of pain and the burden of chronic pain on the health, social, and employment sectors.
6. Establish an EU platform for the exchange, comparison and benchmarking of best practices between member states on pain management and its impact on society.
7. Use the EU platform to monitor trends in pain management, services, and outcomes and provide guidelines to harmonize effective levels of pain management to improve the quality of life of European Citizens.

This “Road Map for Action” to address the societal impact of pain in the EU has been endorsed by many organisations and was signed at the Symposium “Societal Impact of Pain 2011”, 3-4 May 2011, Brussels.

¹ Eurobarometer survey on “Health in the European Union”, Special Eurobarometer 272e, September 2007 http://ec.europa.eu/health/ph_publication/eb_health_en.pdf

The most current version of this document can be found online at www.efic.org



Informal Health Conclusions Italian Presidency, Informal Health Council

Debate on Palliative Care and Pain Therapy 22-23 September 2014, Milan

During the informal EU Health Ministers meeting in 2014, the Italian Presidency placed pain therapy and palliative care at the top of their agenda .

The 28 EU health ministers pledged to further promote the use of palliative care and pain therapy in the EU member states. The common position that was reached put forward the need to create a European network ensuring the training of professionals in the health sector and the exchange of information on the effectiveness of therapies for the most vulnerable population groups.

Health Ministers also acknowledged that networks for paediatric pain therapy and palliative care were not evenly developed throughout Europe. The Ministers also put forward guidance on the development of palliative care and pain therapy for other vulnerable groups, such as the elderly.

Ministro della Salute, Italy

Comunicato stampa n. 147

Conclusione sessione cure palliative e terapia del dolore:

23 settembre 2014; http://www.salute.gov.it/portale/news/p3_2_4_1_1_1_stampa.jsp?id=4355

Societal Impact of Pain (SIP) 2016

8 policy recommendations: Time for Action

The organizing partners of the SIP platform formulated the following key recommendations directed at the institutions of the European Union and national governments:

1. Implementation of article 8.5 of the Cross-border healthcare Directive

The institutions of the European Union and national governments should ensure the flawless implementation of article 8.5 of Directive 2011/24/EU in all member states, in order to prevent the refusal of prior authorisation by national health authorities when the patient is entitled to healthcare which cannot be provided on its territory within a time limit which is medically justifiable, based on an objective medical assessment of the patient's medical condition, the history and probable course of the patient's illness, the degree of the patient's pain and/or the nature of the patient's disability at the time when the request for authorisation was made or renewed.

2. Establish an EU platform on the societal impact of pain

In order to empower pain patients, their family, relatives and care-givers through the availability of information and access to pain diagnosis and management, the institutions of the European Union and national governments should establish an European platform for the exchange, comparison and benchmarking of access, quality and best practices of healthcare services in pain management and its impact on society.

3. Integrate chronic pain within EU policies on chronic diseases

The institutions of the European Union and national governments should acknowledge that pain is a common health state in many chronic diseases and chronic pain itself can be considered a chronic condition in respect to healthcare policy. Therefore the European Commission and member states should integrate pain care within Commission work and Joint Actions (e.g. JA CHRODIS) as well as the expected trio council conclusions on fighting non-communicable diseases.

4. Ensure that pain care is a part of policies and strategies on cancer

Within the framework of the Joint Action on Cancer Control (JA CanCon) and national cancer strategies, the institutions of the European Union and national governments should dedicate adequate attention to the relevance of pain in cancer care, including but not limited to survivorship and rehabilitation.

5. Initiate policies addressing the impact of pain on employment

Within the context of the Europe 2020 Strategy and European Semester framework of economic governance, the institutions of the European Union and national governments should promote policies that reflect the link between pain care and employment, and recognise the interconnection of health, employment and social protection policies and systems.

6. Implement workplace adjustments for people with chronic pain

The institutions of the European Union and national governments should enforce or implement legislation providing for reasonable, flexible workplace adjustments by employers that can help people with chronic pain stay in work or reintegrate into the workforce.

7. Increase investment in pain research

The institutions of the European Commission and national governments should increase investment in research (basic science, clinical, epidemiological) on the societal impact of pain as a priority in future EU framework programs, involving chronic pain patient associations in the development of research priorities, and undertake research on involuntary causes of early retirement and unemployment due to pain across Europe.

8. Prioritise pain within education for healthcare professionals, patients and the general public

The institutions of the European Union and national governments should prioritise and stimulate the prevention of the impact of pain on society by education and providing information on diagnosis, and management of pain amongst all healthcare professionals, patients and the general public through education and training.

PROGRAMME OVERVIEW

Wednesday, 7 June 2017

- 13:00 **Opening Registration & Marketplace**
- 13:30 – 17:00 **GAfPA Workshop** “Effective lobbying for pain and SIP advocates”
- 14:30 – 18:30 **Pre-Symposium** “The Societal Impact of Pain on Malta”
- 15:00 – 18:00 **Pre-Symposium** “Bladder pain special interest group”
- 18:30 – 19:30 **Red Balloon Project**
- 20:00 **Welcome Reception**

Thursday, 8 June 2017

- 08:00 **Opening Registration & Marketplace**
- 09:00 – 15:00 **Parallel Sessions (Working Group 1-4)**
- 15:30 – 17:30 **Plenary Session I** “Evolving concepts in the definition of chronic pain: a dynamic process”
- 20:00 – 22:00 **Award ceremony** “European Civic Prize on Chronic Pain - Collecting Good Practices”

Friday, 9 June 2017

- 08:00 **Opening Registration & Marketplace**
- 07:30 – 9:45 **Breakfast Session:** “Schmerztherapeutische Versorgung im Gesundheitssystem”
(German language)
- 10:00 – 12:00 **Plenary Session II**
- 12:45 – 16:30 **Plenary III**
- 17:00 – 19:00 **GMMS Lecture and PAE General Assembly**

Saturday, 10 June 2017

- 09:00 – 11:00 **General Assembly ENFA**

Thursday 08 June 2017 – Working Group 1

Pain as a quality indicator for healthcare systems

Background

Pain lasting more than three months is defined as chronic pain. Pain is a personal, subjective experience that arises in the conscious brain, typically associated with actual or potential tissue damage, or described in terms of such damage. As it is a subjective emotional sensation, reliable tools are required to facilitate the diagnosis and treatment of pain in clinical practice. Evaluation of whether pain therapy is effective should account for patients' experience and sensation.

Equally, because pain is a central element of the patients' experience within many healthcare settings (chronic primary pain, postoperative pain, oncological pain, neuropathic pain, headache and visceral pain), the level of pain can be considered as an indicator of the general quality of a country's healthcare system.

Policy opportunity

As a part of a renewed collaboration between the OECD and the European Commission, the initiative of the "State of Health in the EU" was launched. Designed to support EU member states in their evidence-based policy making and to further align with the 2014 European Commission Communication on effective, accessible and resilient health systems, **Health at a Glance: Europe**, in its fourth edition, presents key indicators of health and health systems in the 28 EU countries, 5 candidate countries to the EU and 3 EFTA countries. Two main areas of influence: the links between population health and labour market outcomes and the challenge of resilience, efficiency and sustainability of health systems in Europe.

Experts and stakeholders have been invited to participate in the **ICD revision** by making comments or proposals on ICD units. Through the ICD-11 online platform interested parties may become appointed reviewers, participate in field testing or contribute to language translations. Structured input provided by these participants will be peer reviewed by experts in the field. WHO has welcomed the active participation of researchers, health information managers, health care providers and others interested in the classification. All Member States are expected to use the most current version (ICD -11) for reporting disease statistics, thereby facilitating the collection and storage of data for analysis and evidence-based decision-making.

At the informal Council of EU Health Ministers in Milan, 22 September 2014, national governments committed to the use of quality indicators on pain management. The European Commission should follow up on this to facilitate the sharing of best practice.

Institutional timeline

- EU Health at a Glance Report – **pain included as an indicator in the OECD and European Commission work**
- Revision of ICD – **inclusion of pain in the ICD 11**
- Maltese Presidency of the European Union – **The implementation of the Cross-Border Healthcare Directive is currently among the Presidency priorities**

Thank you very much for contributing to the activities of this working group. Please try to add your expert perspective on the topic. Focusing your comments on the current EU policy context and political processes will make these conclusions papers more effective for communicating to policy-makers. We of course welcome examples at national level that are likely to be replicable in an EU policy context.

References

- An English explanation of the Italian law 38/2010 on measures to ensure access to palliative care and pain therapy is available here
http://www.activecitizenship.net/files/patients_rights/develop-eu-pain-patient-pathways-recommendations/SPIZZICHINO_Bruxelles_28_10_201.pdf
- The cross-border healthcare Directive is available at
<http://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:32011L0024>
- The Expert Panel on effective ways of investing in health's opinion on Cross-border Cooperation is available at
http://ec.europa.eu/health/expert_panel/opinions/docs/009_crossborder_cooperation_en.pdf
- The Commission opinion on the implementation of the Cross-Border Healthcare Directive is available at
http://ec.europa.eu/health/cross_border_care/docs/2015_operation_report_dir201124eu_en.pdf
- The discussion paper for the 24-25 September 2015 Informal meeting of Health Ministers in Luxembourg concerning "The Cross-Border Healthcare Directive: Stocktaking two years after transposition" is available at
http://www.eu2015lu.eu/en/actualites/notes-fond/2015/09/24-25-info-sante/Backgroundpaper_Cross-border-Healthcare_Informal-Health-Council-_Luxembourg_.pdf



Thursday 08 June 2017 – Working Group 2

European and national platforms addressing the societal impact of pain

Background

Policy makers at EU-level and in national government ministries are slowly waking up to the fact that pain impacts many areas of their policy-making and spending. Health ministers, finance ministers, social welfare ministers, and others need to quickly realise that tackling the societal impact of pain is of cross-governmental relevance.

In order to steer policy-making away from a silo approach, wherein each minister only looks at what is immediately relevant to their department, governments and EU officials need to be given advice on cross-cutting issues such as pain. We describe this as establishing a 'platform'; a structure or way of working that allows policy-makers to join up the dots and tackle challenges that are bigger than one ministry alone.

A 'platform' on the societal impact of pain could allow policy makers access to best practices and important data that lead them to implementing changes that improve the lives of pain patients, but also achieve significant financial savings, improve employment rates and increase wellbeing throughout society.

Objective

How such a 'platform' could function, who should contribute to it, and how it fits alongside regular structures of government should be explored during this working group. Examples of where governments currently seek advice from civil society on the subject of pain or other healthcare issues should be explored, as well as future opportunities to establish such platforms.

Thank you very much for contributing to the activities of this working group. Please try to add your expert perspective on the topic. The consensus paper produced during this working group will be of a practical nature, providing best practice advice for the SIP partners and allies, on how best to work with governments to improve policy-making. Focusing your comments on existing examples and future opportunities will make this consensus paper more effective for communicating to policy-makers. We of course welcome examples at national level that are likely to be replicable in an EU policy context.

References

DG SANTE Advisory groups and action platforms

http://ec.europa.eu/dgs/health_food-safety/advisory_groups_action_platforms/index_en.htm



Thursday 08 June 2017 – Working Group 3 Impact of Pain on Labour and Employment

Background

The European Union and its Member States are facing a substantial challenge in terms of among others ageing population, chronicity, and the need to address involuntary early retirement and workforce sustainability. In several European countries, chronic pain is one of the most common causes of long term sick leave and disability. In the 2017 annual growth report the European institutions state that: **the effects of demographic developments (...); the impact of ageing populations on pension and healthcare systems in the EU; will have a significant impact on public finances.**

The European Commission has found that health status is a major predictor of labour supply. Therefore, decreasing the incidence of diseases and disabilities results in increases to the total number of years active in the labour force with higher quality of life for the individual and decreases in public expenditures.

According to the study “Fit for Work Europe” conducted across 23 European countries by the Work Foundation, half of all EU citizens suffer from back pain at some stage during their lives. Approximately 15% of people with back pain remain off work for more than one month. More days are lost due to back, neck and muscle pain than any other cause.

Finding solutions to these issues will not only help those who have to cope with the chronic diseases in everyday life, but will also help us preserve the health systems that we all cherish. Together we can find solutions to create sustainable systems of care for the future.

Policy opportunity

The European employment strategy dates back to 1997, when the EU Member States ventured to establish a set of common objectives and targets for employment policy. It now constitutes part of the **Europe 2020 growth strategy and is implemented through the European semester**, an annual process promoting close policy coordination among EU Member States and EU Institutions.

The European Semester, the system of economic and fiscal policy guidance by the Commission to Member States, presents an opportunity to show that better pain care has a role to play in improving social and employment policies, which in turn can support Member States’ fiscal sustainability. Any guidance coming from the Commission should be based on the best evidence available on the financial impact of pain care policies.

Institutional timeline

- **European Semester process** –provide evidence to DG ECFIN, DG EMPL and European Member State Finance Ministries
- Data collection on the impact of pain on the European work force and the savings that could be made if chronic pain was acknowledged and treated or managed effectively.

Thank you very much for contributing to the activities of this working group. Please try to add your expert perspective on the topic. Focusing your comments on the current EU policy context and political processes will make these conclusions papers more effective for communicating to policy-makers. We, of course, welcome examples at national level that are likely to be replicable in an EU policy context.

References

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https://ec.europa.eu/info/publications/2017-european-semester-annual-growth-survey_en
- Musculoskeletal Disorders in the European Workforce:
<http://www.fitforworkeurope.eu/Website-Documents/Fit%20for%20Work%20pan-European%20report.pdf>
- Sickness absence in the labour market: February Bevan et al 2014:
<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/labourproductivity/articles/sicknessabsenceinthelabourmarket/2014-02-25>
- Is work Good for you Health and Well-being? (Waddell & Burton, 2006)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/214326/hwwb-is-work-good-for-you.pdf
- Health-related constraints to raising Retirement Ages in the EU: A probabilistic Markov-Model of age-related disability rates for selected disease causes and related impacts on public payer cash benefit expenditure (Maria Gheorghe & Pieter van Baal) and Ecorys Nederland B.V Ilaria Mosca)
http://ec.europa.eu/health/sites/health/files/systems_performance_assessment/docs/retirement_ages_en.pdf



Thursday 08 June 2017 – Working Group 4

Challenges, lighthouses and best practices in pain policy

Background

Pain and chronic pain affects a large proportion of the population. In fact, one in five Europeans suffers from chronic pain, which translates into millions of patients facing pain every day (100 million people in the 28 European Union countries alone). The distress of individual patients is coupled with the financial burdens caused by the condition and a general burden on society: impacting caregivers and families, the workplace and causing changes in relationships with other people. Governments and individual payers, pay high costs for pain-related care and disability support. However, the costs of care are often hidden in budget across all ministries, not only in the Ministry of Health and Social Affairs.

Pain is a problem across Europe, and policy makers, patient advocates, campaigners, academics and administrators have approached the subject of pain in a multitude of ways in different areas of Europe. The Societal Impact of Pain platform benefits from its wide variety of partners and allies, and from the opportunities for experience sharing provided at the Symposium.

Objective

During this working group, a wide selection of local, national and international projects addressing the societal impact of pain will be discussed. The goal is to identify and disseminate best practices as well as to share ideas for better data collection, legal frameworks, pain education and patient involvement. There will be presentations of innovative projects aiming to gain insights into issues related to pain and costs caused by pain which have been initiated in Europe.

Thank you very much for contributing to the activities of this working group. Please try to add your expert perspective on the topic. The **consensus paper** produced during this working group will be of a practical nature, providing best practice advice for the SIP partners and allies, drawing upon the experiences of SIP allies. We of course welcome examples at national level that are likely to be replicable in an EU policy context

References

European Charter of the Rights of Citizens over 65 with chronic pain

Societal Impact of Pain (SIP) 2017
European Economic and Social Committee
14 - 15 May 2012



SIP
Societal Impact of Pain



The Societal Impact of Pain "A Road Map for Action"

One of the key results from the 2nd European symposium on the "Societal Impact of Pain" (SIP 2011) in the European Parliament in Brussels/Belgium, published on 4 May 2011 (www.sip-platform.eu).

In 2001, the European Federation of the International Association for the Study of Pain Chapters (EFIC) published its Declaration on Pain which called on national governments and the EU Institutions to increase the level of awareness of the societal impact of pain. Ten years on from the EFIC Declaration on Pain, national and EU policy action has been very limited. At the same time, basic and clinical science have demonstrated the feasibility of pathways out of pain for many types of acute and chronic pain, but health care systems currently do not guarantee general access to these.

According to a recent survey on "Health in the European Union", almost 10% of the population suffer from chronic pain which affects their day-to-day life. This has significant implications for the social, economic and employment costs that society bears. National governments and the EU Institutions to act on their policy agenda.

EU Institutions to:

Factor limiting the quality of life and should be addressed in the national health care system.

Address the societal impact of pain through the availability of resources.

Improve the management of pain and its management in the healthcare system.

Support the medical, research, care and management of pain through the EU.

PLENARY SESSION I

Thursday 08 June 2017

Evolving concepts in the definition of chronic pain: a dynamic process

Problem definition

For policy makers, the different views on the definition of chronic pain held by health care professionals can be confusing. In particular, the issue of whether chronic pain can be considered a diagnostic entity, or even a condition in its own right, can lead to consternation. In some cases, the lack of certainty over this issue appears to cause reluctance to address pain in policy measures.

Session objectives

- To define a consensus statement for policy purposes on the definition of chronic pain.
- To address a fundamental issue related to the societal impact of pain: to what extent, and in which circumstances, should chronic pain be considered a disease in its own right, rather than a 'symptom'?
- To gain insights on how to overcome the reluctance of policy makers to address pain in policy initiatives addressing chronic diseases.
- To offer policy makers guidance on how to address the problem.
- To invite participants to draw attention to policy initiatives of relevance in this area.

Proposed consensus statement

Chronic pain can either co-exist with other conditions, or be the only diagnosis (Chronic primary pain). When it coexists with other conditions initially, it may frequently outlast those other conditions (e.g. cancer, rheumatoid arthritis, herpes zoster, etc.)

Impact for policy makers

With the introduction of chronic primary pain as a 'diagnostic entity', a broad group of patients with pain may now receive appropriate care, where previously they may have been neglected, if they stay in their primary disease entities (e.g. osteoarthritis or neuropathic pain) We hope that this description strengthens the representation of chronic pain conditions in clinical practice, research and policies, addressing the societal impact of pain.

Background

Pain is a common element of numerous chronic health conditions, such as cancer and musculoskeletal diseases, and often persists past normal healing time (Bonica, 1953). Usually pain is regarded as chronic when it lasts or recurs for more than 3 to 6 months (Merskey & Bogduk, 1994). Although acute pain may reasonably be considered a symptom of disease or injury, chronic and recurrent pain is a specific healthcare problem, leading to typical co-morbidities such as sleep disturbances, anxiety, depression and low self-esteem among others. Thus, chronic pain develops into a typical syndrome and could even be considered a disease in its own right. While acute pain by definition is a brief and self-limiting process, chronic pain comes to dominate the life of the people concerned and often also family, friends and caregivers.

Chronic pain and its definition are of major societal importance due to the high cost burden that chronic pain can place upon healthcare systems. People with chronic pain consult their general practitioner five times more frequently than those without chronic pain complaints (Von Korff, et al., 1990). Overall, individuals reporting chronic pain have a significantly higher health care system utilisation than individuals without chronic pain complaints (Eriksen, et al., 2004)

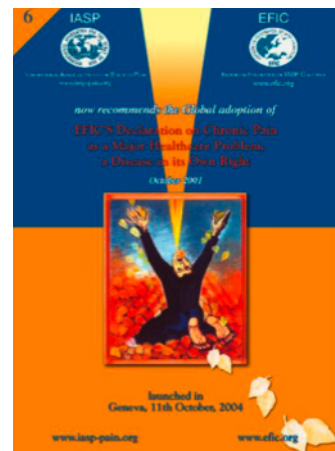
The most widespread chronic pain conditions, such as low back pain, arthritis, and recurrent headache (including migraine) are so common that they are often seen as a normal and unavoidable part of life. In addition to the erosion in quality of life and financial burdens caused, chronic pain often sets the stage for the emergence of a complex set of physical and psychosocial changes that are an integral part of the chronic pain problem, greatly adding to the burden upon individual patients.

Context

Chronic pain represents a challenge for individuals and health systems across Europe. This is partly due to chronic pain being so common and having such a negative impact at the societal level, but also because the underlying complex disease mechanisms require individualised management and holistic treatment.

Unfortunately, throughout the EU, chronic pain patients report insufficient pain control and dissatisfaction with treatments (Breivik, et al., 2006). Chronic pain is often not only under-diagnosed but also under-, over- or just wrongly-treated (Dietl & Korczak, 2011). In some indications, elderly persons get less access to pain treatment than the general population as chronic pain is often overlooked by health professionals (Booker, et al., 2016) (WHO, 2015) The definition of chronic pain, to what extent, and in which circumstances, it can be considered a disease in its own right have a major impact on the treatment offered.

Some policy makers are starting to wake up to the issue of definition and classification of chronic pain. For example. in 2012, via a Parliamentary Question, a UK Health Minister answered: "The Department (of Health) recognises chronic pain as a long-term condition, either in its own right or as a component of other long-term conditions" (Chronic Pain Policy Coalition (CPPC), 2012) (UK Department of Health, 2012). Progress is slow, however. Experts have called for changes to policies and resource allocation in pain care; from a biomedical model, dealing with pain as a symptom, to a biopsychosocial model, taking into account the biological, psychological and social factors affecting the societal impact of pain (Vandenbroeck, et al., 2016) (Behrendt, et al., 2016).



Besides the lack of dedicated policies and budgets, one of the factors contributing to inadequate treatment of persons in pain is the often inadequate medical training in pain management available (Pergolizzi, et al., 2013). Pain medicine is increasingly recognised as an important field of study, though a weak understanding of chronic pain conditions persists across the wider medical profession. International experts have called for strategic prioritisation and co-ordinated actions to address the unacceptable and unnecessary burden of uncontrolled chronic pain that plagues European communities and economies (Breivik, et al., 2013).

Chronic pain can be seen as a disease in its own right in carefully described circumstances, for example, when its causes cannot be fought (chronic neuropathic pain), when pain represents the sole or by far the most important origin of the patient's suffering and disability (chronic non-specific back pain). There are several conditions within the range of rheumatic and musculoskeletal diseases where this would also be true, such as fibromyalgia. For people living with these painful conditions, the issue is not which medical specialty treats them, it is the impact of the pain on their lives, as people and **citizens, that matters most.**

One of the bigger challenges for policy makers is to allocate a budget to pain management. For this purpose, the World Health Organization (WHO) International Classification of Diseases (ICD) is often used as a guideline. The current version ICD-10 includes some diagnostic codes for chronic pain conditions, but these diagnoses do not reflect the actual epidemiology of chronic pain, nor are they categorized in a systematic manner (Treede, et al., 2015). In response, a group of experts has proposed a new classification of chronic pain (MJ60 and sub codes thereof) in the upcoming ICD-11 that is now part of the "frozen release" for morbidity and mortality statistics of April 02, 2017 (ICD-11 2017). This new classification is based on the following definition:

**Chronic pain is pain that persists or recurs for longer than 3 months.
Such pain often becomes the sole or predominant clinical problem in some patients.
As such it may warrant specific diagnostic evaluation, therapy and rehabilitation.**

SIP 2016

On 23 May at the 2016 Societal Impact of Pain (SIP) symposium, a working group met in the European Parliament to discuss the topic "Chronic Pain: a disease or symptom?" (SIP-Platform, 2016). Participants discussed whether pain that becomes chronic should be considered a disease on its own or a symptom of other diseases. Participants made their point clear that chronic pain could be seen as a disease in its own right in carefully described circumstances, for example, when its causes could not be fought and it had no diagnosed cure. At the end of the four-hour seminar, participants presented a number of promising national and European level actions that should be used as best practices. The group, which was the largest of all four working groups attending SIP 2016, closed the session formulating 10 policy recommendations.

10 "call to action" policy recommendations from SIP 2016 working group 2 "Chronic Pain: a disease or symptom?"

1. The European Commission should include pain prevention (primary and secondary) as an integral part of its ongoing work on its chronic diseases initiative.
2. The European Commission should encourage member states to integrate pain care within the work of the Joint Action on Chronic Diseases (JA CHRODIS).
3. The European Commission should fully consider and implement, where appropriate, the expected trio council conclusions on fighting non-communicable diseases, including chronic pain.

4. The European Commission should issue calls for proposals to develop knowledge on the diagnosis, prevention and management of chronic pain (often a disease on its own), in the framework of the next Research Programme. The European Commission should promote studies on the prevalence and impact of chronic pain.
5. The European Commission should create a platform of the concerned parties (healthcare authorities, patient organisations, doctors) at EU level to ensure the integration of basic and clinical sciences.
6. The European Commission should facilitate the development of European quality criteria for pain institutions, including undergraduate and postgraduate certification.
7. National governments should develop multidisciplinary, patient centred strategies to appropriately manage chronic pain.
8. National governments should develop guidelines and recommendations to address chronic pain management.
9. National governments should design policies focused on self-management to empower people with chronic pain to support themselves effectively.
10. National governments should prioritise pain care within all healthcare professional education and training and initiate patient education programmes, training and information campaigns in order to create public awareness of the consequences of chronic pain.

Literature

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SUPPORTING INITIATIVES

Wednesday 07 June 2017



SIP MALTA

Our Mission is to provide a local platform, on a national level, that mirrors what is occurring in other platforms dealing with pain and relevant policy. This is always done with the ultimate goal to benefit all those persons who constantly live with chronic pain as a reality in its own right. Advancement of the interests of this aspect of society is therefore our driving ethos.

A Brief introduction: The Maltese islands may be small in size, but that never defined the sizes or ideas that came out of its midst. Historically, Malta has always been a keen believer in providing care for the most vulnerable, a value ingrained through centuries of constant practice, from providing shelter to travelers of the seas, and later through contact with patients in its role as 'nurse of the Mediterranean'.

This entire preamble serves to picture the state of play, when SIP kicked off in June 2016. The Malta Health network, utilized its influence to introduce the notion of the potential of having a Maltese platform, dedicated to addressing the Societal Impact of Pain. Through the support of other similar organizations, mostly SIP and EFIC and the invaluable support of Grünenthal, a kick-off meeting was held and the rest came about fairly quickly. The interest in SIP Malta was very strong, and soon enough there were enough participants to boost the confidence that SIP Malta could really make a difference as a key player on a National level when it came to tackling pain and Policy. It was decided that in order to make the most out of the Maltese presidency of the EU Council in 2017, SIP Malta needed to act fast so as to be an active participant and contributor in the next SIP symposium which was going to be held in Malta. The SIP symposium has built a distinguished reputation of being a key global event in issues relating to pain policy, and eventual implementation.

Our first commitment as newly formed SIP Malta was quite gargantuan in its ambition, we decided that in order to build a valid argument as to why pain should be a primary consideration when implementing social policy, we first had to remove any notion of subjective interpretation. We needed to build our argument on a solid, scientific base, with irrefutable objective data. Thus SIP Malta set out to oversee a project whereby Malta would, for the first time, have its own data as regards the number of persons suffering from chronic pain.

SIP Malta is made up of an array of patient representative groups, individuals and professionals, both representing their organizations or in their personal capacity. We hope to keep this momentum going, and to date we are still actively seeking collaboration opportunities with whoever might be interested in contributing.

Even though SIP Malta is primarily aimed at tackling pain policy and providing recommendations on a national level, we hope to be an active contributor to others who share a similar mission, far beyond our shores, so that once again Malta shows its true compassionate nature as champion of the vulnerable.





A MALTESE CONSENSUS PAPER FOR CHRONIC PAIN.

Preamble:

The Maltese stakeholders with an interest in Chronic Pain fully endorse the Societal Impact of Pain 2016 Policy Recommendations: Time for Action and The Societal Impact of Pain, "A Road Map for Action" It is also recognized that the successful implementation of the 8 Policy Recommendations is dependent on collaboration between EU member states.

The following document is being proposed by **Malta Health Network, No Pain Foundation** and **SIP Malta**.

Our recommendations are guided by five factors, namely:

- **Ease of implementation**
- **Cost-effectiveness**
- **Urgency**
- **National Priorities**
- **Major impact on patients.**

The Maltese Stakeholders listed above are therefore making the following recommendations, in relation to the Maltese scene:

1. Chronic Pain to be included as an independent condition. The amendment of the National register and formulary would facilitate access to treatment. Chronic pain should be recognized as a disease in its own right and not as a symptom of other diseases.
2. A 'Chronic Pain Prevention' Campaign should be run to raise awareness about chronic pain. Such a campaign should be conducted in a wide variety of settings, targeting all groups at risk of developing persistent pain.
3. Restructuring of the Local Pain Management policies and services within our national hospital. Aiming to be more streamlined towards European policies and guidelines.
4. Research into pain to be given more importance. The relevant authorities and institutions should recognize, prioritize and fund research and projects in the area of chronic pain.
5. Closer inter-ministerial collaboration stemming from the recognition of the wide-ranging implications of pain.
6. Pain to be included as a key indicator in the outcomes of medical and surgical interventions.
7. Setting up of necessary facilities so that specialization in the field of pain is made possible. Recognition of the importance for health professionals to be able to specialize in such a crucial subject.
8. A call for a better understanding of the condition, and therefore for the Maltese authorities to enforce and implement the necessary legislation for a reasonable, flexible workplace adjustment, so that those suffering from chronic pain would be able to stay or reintegrate into the workforce. (The ability to reintegrate chronic pain sufferers into the work-place through vocational retraining and collaboration with public and private employers)
9. The establishment of a National pain platform and the implementation of a National Pain Plan by 2020.

Any organisation or individual wishing to endorse this document is invited to contact any of the above organisations.

SUPPORTING INITIATIVES

Wednesday 07 June 2017

GAfPA WORKSHOP



**The Global Alliance for Patient Access:
the international network of physicians and advocates for patient access**

The **Global Alliance for Patient Access (GAfPA)** is a network of physicians and patient advocates with the shared mission of promoting health policies that ensure patient access to approved therapies and appropriate clinical care. GAfPA accomplishes this mission through educating physicians and patients on health policy issues and developing educational material and advocacy initiatives to promote informed policymaking. GAfPA is a not-for-profit organisation with a board of physician directors.

GAfPA is an offshoot of the Alliance for Patient Access (AfPA), a United States based network of physicians advocating for patient access that was first established over a decade ago. Out of this organisation grew GAfPA, which over the past two years has successfully been developing its networks of physicians and partner patient organisations in Europe, Latin America and beyond.

GAfPA seeks funding through associate membership dues, grants, donations, and sponsorships. As a project of the AfPA, GAfPA currently receives funding from nearly 30 different pharmaceutical companies and organisations, with interests across a wide variety of therapeutic areas.

GAfPA's health policy priorities

GAfPA educates patient representatives and physicians on the policy issues impacting patients' ability to receive the therapy the physician prescribes. GAfPA promotes informed policymaking by ensuring the perspectives of physicians and patients are shared with policymakers as they consider issues impacting patient care. GAfPA works across a broad range of disease state and therapeutic areas, including pain management, biologic therapies, infant health, Hepatitis C and oncology. Similarly, GAfPA works with physicians across a wide variety of specialties, always with the goal of promoting health policy that supports patient access to the best clinical care and practice.

GAfPA's work in Europe

Over the past year GAfPA has held a number of workshops with patient advocacy organisations and physicians across Europe, including in Barcelona, London, Copenhagen, Brussels and Budapest.

GAfPA at SIP: Can Davids beat the Goliaths?

GAfPA is delighted to be asked to hold a workshop at the SIP conference this year. Chronic pain is an area in which we work closely and we know it is of great importance to physicians and patients alike.

GAfPA's workshop on June 7th is entitled 'Can Davids beat the Goliaths?' and is focused on policy advocacy – showing how even the smallest organisations and advocates can be empowered to have loud voices and to effect change with policymakers. The workshop will be split into three parts: the first will see Brian Kennedy, Executive Director of GAfPA, share his knowledge of successful advocacy and discuss the keys to effective lobbying with policymakers. The second part will feature a panel discussion with leaders from three of the official partner organisations responsible for the SIP programme in 2017 (Pain Alliance Europe, EFIC and ACN) who will describe the challenges, learning and successes they have experienced whilst engaging in advocacy work in chronic pain over recent times. The final hour will feature an interactive breakout session when attendees will be able to put in to practice the advocacy skills and knowledge they will have gained, addressing some of the themes which will feature in the main SIP programme. The aim is for attendees to leave the session armed with the right tools to effectively advocate to policymakers in their own countries around the very important issues surrounding chronic pain.

Brian Kennedy

Executive Director

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SUPPORTING INITIATIVES

Wednesday 07 June 2017

#RED BALLOON PROJECT

Pain Alliance Europe's mission is to improve the quality of life of people living with chronic pain. One of our main objectives is to raise awareness with politicians and policymakers, healthcare providers, employers and the general public. There are over 100 million people suffering with chronic pain in Europe. Chronic pain has a huge societal and economic impact and can affect any one of us in our lifetime. The Red Balloon Campaign aims to raise awareness of the critical impact of chronic pain on the individuals, their loved ones and us as a society. We want to make a change and improve pain management across Europe for today and for future generations. In order to do so we need your help to spread the word and 'Release the Pain' ...because together we can achieve so much more!

During the SIP 2016 symposium Pain Alliance Europe (PAE) in cooperation with Boston Scientific launched the Red Balloon project "Release the Pain". In a photo booth people attending SIP could have their picture taken while bursting a Red Balloon. This was followed by several activities across Europe. Results of that can be found at www.theredballoonproject.eu.

Now during SIP 2017 on Malta we will close this project with an event in the early evening of June 7th.

We are looking forward to welcome you to this event!

Read more about that on www.pae-eu.eu

Thank you for your support.

Joop Van Griensven

PAE President



Thursday 08 June 2017

GERMAN BREAKFAST SESSION

Pain therapy and treatment in the different health care systems of the DACH Region

The treatment of chronic pain is one of the most complex medical care settings: pain therapy treatments are not only oriented towards interdisciplinarity and interprofessionalism, they also require intensive patient involvement and continuous integration of the patient into the treatment process.

However, with its inherent complex treatment setting pain therapy is not solitary: Nearly all chronic diseases require a therapeutic environment in which different disciplines and professions should continuously accompany and attend to the patient in varying degrees. Within the universe of medical education and care, which is highly fragmented into many different subdisciplines, there is currently little to be seen of such approaches. This is all the more dramatic, since the treatment and care setting of chronic diseases in industrialized societies is now almost at 80 per cent of the total cost expenditure of care, while only 20 per cent can be attributed to acute care.

Taking this into account, it is a worthwhile endeavor to derive deficits and development potentials from the current pain therapy and care settings of the respective health care systems. The thesis put forward is that care systems are all the more prepared for the challenges of the treatment of chronic diseases, the more comprehensive pain patients and their therapeutic teams are found and the more treatment processes are presented administratively within the system.

The discussion is based on the following publications from the German Health Care Reporting Section of the German Robert Koch-Institute [„Gesundheitsberichterstattung des Bundes des deutschen Robert Koch-Instituts“]: No. 2 (“Palliative Care”), No. 7 (“Chronic Pain”) and No. 53 (“Back Pain”). In addition, the different expert opinions of the Council of Healthcare Advisors [„Sachverständigenrat Gesundheit“] as well as the different health reports of the health insurance funds could serve as a basis for this discussion. Health policy-makers from the different health care systems of the DACH region are invited to participate and discuss this cohesion among themselves and with the auditorium.

Dr. Albrecht Kloepper
Büro für gesundheitspolitische Kommunikation

SUPPORTING INITIATIVES

Friday 09 June 2017

GMMS LECTURE



Lecture on palliative care organized by the German Maltese Medical Society (GMMS)

Palliative care began with an attention on the care of the dying patient.

In the late 1950s Dr. Cicely Saunders announced her revolutionary concept regarding modern humane hospice care. Saunders important recommendation was that an interdisciplinary team of physicians, nurses, massagers, psychologists, pastors could relieve the pain pressure of a dying person significantly. In the 1960s, Dame Cicely said the frequently quoted phrase, hospice could „not to add days to the life, but life to the days“. This was revolutionary fifty years ago. Now in the next millennium we know, hospice in a good cooperation with palliative care is able to do both „to add life to the days and days to the life“. This is a revolutionary knowledge also, but in spite it is even unknown amongst curative professionals as well as palliative care providers. To change this is our task and mission; in Austria, in Germany, in Europe and world-wide, since 2016 with special support of the Holy See.

In the 1970th, palliative care was a real foreign word in Germany and Austria too. Dying patients were often separated in hospital bathrooms and the knowledge referring an effective pain therapy was very low.

Since 1983 with the establishment of the first palliative department at the University of Cologne and in 1986 the formation of the first hospice in Aachen an enormous development of palliative care has started in Germany and Austria. Endowed professorships for palliative medicine early founded in Bonn (1999 by Mundipharma) and Aachen (1999 by Grünenthal) gave the starting shot for multiple reestablishments of palliative hospitals with professorships in hole Germany and Austria. The speakers of this session will give an informative look inside the present situation and future developments in palliative care in both countries.

Meanwhile, in 2017, we come to the point that the real problem in practice are not the technical or medical questions of symptom control. No one has to fear severe suffering in end of life care. With the available skills control of symptoms is quite easy to learn and to use.

But alas, in spite of the undisputed symptom burden of the patient, frequently it comes to difficult situations, partly as a result of

1. lack of medical knowledge or
2. lack of experience,
3. partly through the incorrect presentation of legal conditions,
4. partly also as a result of the ethical positions of those involved.

So we come to the most important conclusion: **We need awareness for patient's problems and early integration of palliative care in any therapy of a life-threatening disease even in curative setting.**

Dr Maria-Iris Felice Klaumann

Specialist in family medicine, MD MSC

President of the German Maltese Medical Society (founded in 1998)

Chairmen of the lecture "In pain and breathless – Terrifying symptoms at the end of life"



SIP

Societal Impact of Pain





MALTA
EU2017



SIP
Societal Impact of Pain

Background information on speakers and workshop chairs, moderators, secretaries, and reporters, including supporting Members of the European Parliament, in alphabetical order by their last name

The scientific framework of the “Societal Impact of Pain” (SIP) platform is under the responsibility of the European Pain Federation EFIC®. Cooperation partners for SIP 2017 are Pain Alliance Europe (PAE) and Active Citizenship Network (ACN). The SIP 2017 symposium is co-hosted by the Malta Health Network and the No Pain Foundation. The pharmaceutical company Grünenthal GmbH is responsible for funding and non-financial support (e.g. logistical support).

www.sip-platform.eu





CLARA EUGENIA AGUILERA GARCÍA

Member of the European Parliament, Spain

Group of the Progressive Alliance of Socialists and Democrats (S&D)

I fully support the Societal Impact of Pain platform and consider the symposium the greatest forum to unite healthcare professionals, patients, policy makers and politicians to discuss how to move forward to address the quality of life of pain patients at the European level.

Clara Eugenia Aguilera García has been Member of the European Parliament for the Progressive Alliance of Socialists and Democrats in the European Parliament since 2014. In the European Parliament, she is a member of the Committee on Fisheries, and a Substitute of the Committee on the Environment, Public Health and Food Safety (ENVI). She began her political career after having obtained her degree in Law from the University of Granada in 1983, when she started militating in the Partido Socialista Obrero Español de Andalucía (PSOE-A) (Spanish Socialist Workers' Party of Andalusia). In 2000, she was elected as member of the Andalusian Parliament, where she served as spokeswoman for agriculture. Between 2004 and 2008, she covered the role of Secretary of Agriculture and Rural Development on the Executive Committee of the PSOE-A. Between 2009 and 2012, she was appointed Minister of Agriculture, Fisheries and Rural Development of the Junta de Andalucía. Ms Aguilera has extensive knowledge of the agricultural sector, having worked for more than twelve years in agricultural cooperatives, as Manager of the Federation of Agricultural and Livestock Cooperatives (FECOAGA) in the province of Granada, and in the Andalusian Federation of Agrarian Co-operatives (FAECA).



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**Pain and its impact
in society should be
addressed by the
European Union.**



JUTTA AHMERKAMP-BÖHME

Board Member

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**How can we expect to
be heard if we do not
talk?**

Jutta Ahmerkamp-Böhme studied Economics and Literature at the University of Gießen. She then worked as a marketing/public relations expert for several companies in the tourism industry. Since 2013, she is running her own business as a freelance writer and translator.

My professional experience as a writer helped a lot when I decided to face the biggest challenge of my career, a job within the German patient organisation "Jung und Parkinson" (JuP) in 2016. I appreciate the work as a board member for several reasons.

First of all, it forces me to be active. People who have to live with a chronic disease should not wait and see how the disease influences and finally changes their life. We need to move! We should be the ones to decide where to go, not the disease!

Furthermore, the societal and political aspects of this work need to be mentioned. We can not expect people to know how we feel if we do not tell them. And how can a politician measure what is most important if we do not share our experience? The GafPA workshop is a great possibility for an international exchange. We definitely need to join forces and profit from each other's experience.

PROF TIT ALBREHT

Head of Centre

National Institute of Public Health

Joint Action Cancer Control (CanCon) is a project dedicated to advise policymakers on some of the key aspects of cancer care, which need improvement, more attention and/or more structuring across Europe.

One of the topics raised in the framework of this project is also treatment and overall comprehensive management of pain. Given the nature and chronicity of their disease, nature of their different treatments and potential recurrences and palliation, cancer patients have clear needs with respect to pain management. There is an explicit need to include this topic in all documents aiming at addressing policy-relevant issues, advice, recommendations, guidance and guidelines concerning cancer care. The identification of needs for treatment of pain needs to include: acute (on presentation of the disease, immediate to interventions, whether diagnostic or therapeutic, on recurrence, etc.), chronic as a symptom of the disease or its recurrence, or as a symptom accompanying patients in need of palliative and end-of-life care. This means that pain treatment needs to be made available to patients at all stages of the disease, at all different phases of treatment. It should be an inseparable part of comprehensive cancer care.

In CanCon there is a special focus on palliative care within the topic of survivorship, where the issue of pain comes to the front as a highly relevant one. However, treatment and management of pain has also the implications, such as patient rights, where it has to be a part of all services and all patient pathways, it should not depend on the patient's ability to pay but it should be reimbursed as other cancer services instead. Adequate treatment of pain in acutely managed cancer patients and in those with life prolonging therapies can reduce the need for sickness absence and disability and can provide better quality of life to all cancer patients, regardless of their age, gender or employment status.

Dr Tit Albreht is a senior researcher of health services at the National Institute of Public Health of Slovenia (NIPH). He was promoted as a PhD at the University of Amsterdam in the field of health services research and has dedicated an important share of his career to health system research and policy development in different topics, such as health workforce planning, hospital reporting and reimbursement system and cancer policies. He is actively involved in cancer policy since 2007 when Slovenia and the NIPH were preparing for the Slovenian Presidency to the Council of the European Union. He is currently the co-ordinator of the Joint Action CanCon. Institution National Institute of Public Health of Slovenia is the key national public health institution, providing professional and expertise work in all subfields of public health with professional support to the policymakers, educational and training programmes in public health and research in many different disciplines of public health.



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Pain is an important problem in cancer care as it can be present as a symptom of the disease, a consequence of treatment during its course or remain afterwards. Addressing pain is therefore essential in comprehensive cancer care and needs to become both a part of clinical protocols and pathways as well as a special topic in the Survivorship Care Plan.



DR NATASHA AZZOPARDI MUSCAT MD, MSC, PHD

Consultant Public Health

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Dr Natasha Azzopardi-Muscat is President of the European Public Health Association. She is a founding member and former President of the Malta Association of Public Health Medicine.

Natasha is a former Chief Medical Officer for Malta. As a public health civil servant she occupied various senior positions in the Ministry of Health in Malta between 2001 and 2013. She currently works as a Consultant in Public Health Medicine at the Directorate for Health Information and Research and is a senior lecturer at the University of Malta. Her main research interests are European health policy and health systems in small states. She has authored several publications on these topics.

What do we need to do to convince you that pain policy in Public health is a very important area for the EU citizens?

GABRIEL BAERTSCHI

Chief Executive Officer

Grünenthal Group

Grünenthal, a science-driven pharmaceutical company with a strong commitment to innovations in pain indications. By investing in research and development we demonstrate our commitment to innovation in order to treat unmet medical needs and deliver value-adding products to patients.

At Grünenthal we consider it our responsibility to work on innovative solutions in pain treatment. Our scientists have defined a pain landscape containing over 100 different pain conditions. Many of these indications are yet to be fully understood and often lack a proper medical treatment. We are convinced that the complex nature of pain calls for a holistic effort from prevention, through early diagnosis, to most effective treatment. This effort has to involve the patient from the beginning and has to embrace the multidisciplinary aspects of chronic pain management. In practice this means that policy makers, healthcare professionals, budget holders, and industry need to work together in order to modernize the entire approach.

About Gabriel Baertschi

In October 2016, Gabriel Baertschi took over the position as the Global CEO of the Grünenthal Group, an independent, family-owned, international research-based pharmaceutical company headquartered in Aachen, Germany. Grünenthal is a fully integrated research & development company with a long track record of bringing innovative pain treatments and state-of-the-art technologies to patients.

From 1999 until 2016 he worked with AstraZeneca in different positions and regions, as a company president for Germany, Thailand and lastly from 2013-2016 for Japan leading Commercial, R&D & Manufacturing functions. Before, he was working from 1996-1999 with Servier in Switzerland in the sales area.

From 1993-1997 he studied at the University of Neuchâtel, Switzerland and made his Master Thesis in Molecular Biology Research.



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We see it as our commitment together with academia, patient representatives and policy makers to develop new life changing innovations bringing benefit to patients in areas with a high unmet medical need.



HEINZ K. BECKER

Member of the European Parliament, Austria

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**Together with SIP I
want to continue rais-
ing awareness of the
impact of pain and iden-
tify policies at European
level to improve pain
care.**

I fully support the Societal Impact of Pain platform. Our strategy on active ageing in Europe has to take into account the impact that untreated pain can have on the quality of life of elders as well as their age of retirement and inactivity.

Heinz K. Becker is Member of the European Parliament for the European Peoples Party since 2011 and Vice President of the European Seniors Union since 2013. In the European Parliament he is a member of the committee on civil liberties, justice and home affairs and substitute member and vice coordinator of the committee on employment and social affairs.

He is active in politics since 2001, when he became general secretary of the Austrian Seniors Association, which is the biggest and most powerful seniors association in Europe with over 300,000 members. Before he became a full-time politician he was self-employed with his own advertising company, based in Vienna.

NICOLA BEDLINGTON

Secretary General

European Patients Forum

Nicola Bedlington (British, born in Scotland) studied business and HR management in the UK and France. Nicola Bedlington is EPF's Secretary General since September 2014 and was previously the Executive Director since the setting up of the EPF Secretariat in June 2006.

From 2004 to 2006, she worked for the Swiss Government, leading the Environment and Schools Initiatives Secretariat, an international government-based network set up by OECD focussing on innovation, action research and policy development in the field of Education for Sustainable Development.

She worked as an external expert for the European Commission on disability policy and NGO cooperation and during the 90s was the first Director of the European Disability Forum, an umbrella organisation uniting over 70 European NGOs and National Councils of Disabled People to advocate for the human rights and inclusion of disabled citizens in Europe.



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Patients are facing unacceptable barriers to healthcare services, resulting in aggravated health and financial situations. Our campaign on Access will collect patients' testimonies and call for an EU strategy on the different areas of access based on the recommendations from all relevant parties.



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The complexity of pain requires new approaches. This is the reason why the European Commission is pursuing the path of personalised medicine and develops patient-centered approaches.

DR KARIM BERKOUK

Directorate-General for Research & Innovation, Dir E - Health
Non-communicable diseases and the challenge of healthy ageing Unit

European Commission

There is a high unmet medical need for improving therapy and management of pain for a broad variety of underlying pathophysiologies and conditions with a potential high or devastating impact on health and quality of life of patients. The complexity of pain requires a multidisciplinary research approach which will enable the understanding of underpinning physiological mechanisms. The development of innovative, more efficient, safer and cost-effective treatment options is a challenge requiring comprehensive approaches on European, multinational level to enable scientific groups and infra structures to team up and bringing together the needed expertise, capabilities and resources. In the last 10 years, the European Commission has invested some €195 Million in basic research and better understanding of related pathways and pathophysiologies, innovative treatments and diagnostics as well as in better management of pain and related social and socioeconomic implications and advancements of health care systems to improve the health status and wellbeing of patients suffering on pain conditions. In particular EC effort in pain research addresses acute and chronic pain, mechanisms, biomarkers, imaging, epidemiology, technology, prevention, early detection, palliative care, migraine.

Dr. Karim Berkouk is the deputy head of non-communicable diseases and the challenge of healthy ageing Unit in the Health Directorate of the Research & Innovation DG of the European Commission. He develops and implements research policies on ageing, cancer, brain, cardiovascular, chronic diseases, diabetes and obesity. Previously, he was head of sector for the EC Marie Curie Actions. Prior joining the EC, he held various research positions on prosthesis specific to patients, improvement of nuclear brain images and brain connectivity, respectively in Exeter (UK), the French National Institute of Health and Medical Research (INSERM, FR) and Cambridge (UK). He graduated in fluid mechanics at the University of Paul Sabatier (Toulouse, FR) and holds a PhD in bio-fluid mechanics from the University of Warwick (UK), where he developed a new mathematical model for the understanding of the pathogenesis of Syringomyelia, a rare disease of the spinal cord.

DR PAMELA F. BELL

MB, BCH, FFARCSI, FRCA, FFPMCAI, FPPMRCA

Consultant in Pain Medicine (retired), Chair

Pain Alliance of Northern Ireland

Dr Pamela Bell graduated in Medicine from Queens University Belfast in 1980. She trained in anaesthesia and held Consultant Posts in the Ulster, North Down and Ards Hospitals where she set up the first Pain Clinic at Bangor Hospital. In 1995 she was appointed to Musgrave Park Hospital, Northern Ireland's centre for orthopaedics and rehabilitation, where she established a Pain Clinic and developed a specialist interest in the management of children and adolescents with long term pain, the first in Northern Ireland.

Strongly interested in supporting training and professional development of others in the field of pain management, she was instrumental in setting up a Masters Degree in the Science and Practice of Pain at the Queens University of Belfast.

Since retirement she has been actively involved in raising awareness of the burden of long term pain to the individual, their families and carers, and society through the work of the Pain Alliance of Northern Ireland of which she is the Chair. She remains committed to lobbying for access to effective pain management for all who suffer long term pain regardless of cause. She is a Trustee of Pain Concern, a charity that supports those who live with long term pain in the UK, where she oversees their research programme. She also sits on the Board of the Faculty of Pain Medicine of the Royal College of Anaesthetists as the Corresponding Member for Northern Ireland.



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Persistent pain knows no boundaries. It affects people regardless of age, gender, or nationality. It degrades physical and mental health and places a burden on the individual and their families. SIP must continue to raise awareness of this impact across all European countries and in each of their Governments if this burden is to be minimised for all who suffer.



NEIL BETTERIDGE

Director

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Chronic pain should be a far greater priority in policy terms, both as a dimension of other diseases where appropriate and in its own right where patients are otherwise insufficiently supported by healthcare systems oblivious to its personal and social impact.

Neil Betteridge has first-hand experience of living with chronic pain, having grown up with severe juvenile arthritis.

Professionally, he has over 25 years' experience working in strategic leadership, public affairs and high level communications in this area, acting as a representative and ambassador of the rights of people with long-term conditions.

After standing down as CEO of Arthritis Care in the UK 4 years ago, Neil now runs his own company, Neil Betteridge Associates, acting as an independent patient representative, working with the NHS, not-for-profit organisations, clinician organisations and industry to promote patient focus. Roles in this period have included Strategy Adviser to the British Society for Rheumatology and Patient Involvement Lead to the Royal College of Physicians.

Additionally he is currently:

- Co-Chair of the Chronic Pain Policy Coalition
- International Liaison Officer, Public Affairs, EULAR
- Patient and Public Voice, Clinical Reference Group, Specialised Pain Services
- Patient and Carer Adviser, Professional Record Standards Body

PROF STEPHEN BEVAN

Head of HR Research Development

The Institute for Employment Studies

As the European workforce ages and has to retire later, young people starting work today can look forward to working lives of 50 years or more. But with longer life expectancy comes an elevated risk of developing work-limiting chronic illness and chronic pain meaning that the quality of life and productivity of working age people with health conditions can be severely limited. Policy-makers across the EU are attaching great importance to policies which support their wider goals for ‘more and better jobs’, to reduce health inequalities, to improve social inclusion and cohesion, to support active and healthy ageing – including extending working lives. Despite this, the policy landscape both within the Commission and among Member States only rarely gives indications that the ‘siloes’ between policy domains can be broken down to deliver holistic, cross-disciplinary and coherent policy responses to the need for working age citizens living with chronic pain to receive the support they need.

The presentation will make the case for policy-makers to attach greater priority to measures which support working age people with chronic pain to remain in, or return to work, and what clinicians, employers and policymakers need to do to ensure that chronic pain does not become an insurmountable barrier to living a healthy, fulfilling and productive working life.

Professor Stephen Bevan is Head of HR Research Development at the Institute for Employment Studies (IES). Stephen was, until March 2016, Director of Research at The Work Foundation, Lancaster University. Stephen has a special interest in workforce health and wellbeing, having led a number of national and international projects focusing on workforce health and the impact of chronic illness on productivity and social inclusion.

Stephen is an advisor to a number of UK government departments and has advised employers and policymakers in Europe, Asia-Pacific, Australasia and North America. He has received a special award from GAMIAN-Europe for his contribution to the field of mental health and is a reviewer for several academic journals, including The Lancet; a regular columnist for HR Magazine; a judge at the Global Healthy Workplace Awards; and is a member of Public Health England’s Health & Work Advisory Board. Stephen has also been Chair of the Fit for Work Europe Coalition.



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This presentation will assess how much progress has been made in raising the policy priority given to chronic pain as a societal and employment issue & highlight where further effort should be concentrated.



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Pain needs research, resources, and dedicated stakeholders of all professions to make sure that patients living with chronic pain can be adequately helped.

PROF DAVID BOZIDAR VODUŠEK MD, PHD

Professor of Neurology, Faculty of University of Ljubljana; Chair, Liaison Committee

EAN

Education and Research in European Neurology

For neurologists, the European Academy of Neurology (EAN) raises awareness and provides up-to-date information also in the field of pain - neuropathic pain in particular.

The European Academy of Neurology (EAN) is the pan-European scientific neurological society, uniting 47 European national neurological societies with their members as well as 800 individual members. The EAN consists of an Assembly of Delegates of institutional and individual delegates; the Board of elected officers; 4 committees (+ 2 sub-committees), and 31 subspecialty Scientific Panels.

The Aim of EAN is Excellence in Neurology in Europe.

EAN is a non-profit organisation and identifies itself with the following five values:

- Professionalism. The EAN will strive to reach the highest scientific standards and to deliver unbiased information in its research and educational activities;
- High ethical standards. The EAN will apply high ethical standards in all its activities within science, education, liaison, and administration, complying with applicable regulations and codes of ethics;
- Involvement. The EAN will strive to involve its members and collaborators in the organisation of research, education and liaison activities;
- Independence. The EAN will operate as a professional and scientific organisation, independent from the political or commercial interests of external companies or organisations;
- Transparency. The EAN will provide transparency in the organisation of all its scientific and administrative activities.

EAN has among its Scientific panels, dedicated to particular fields in neurology, the panel for Neuropathic Pain.

About Professor David B. Vodusek

Dr. Vodusek is a neurologist and clinical neurophysiologist and full professor of neurology at the Medical Faculty, University of Ljubljana, Slovenia. He lists neuropathic pain among his interests. He is at present Chair of the Liaison Committee, European Academy of Neurology and thus in charge to build bridges to partner societies wishing to cooperate with EAN.

GERTRUDE A. BUTTIGIEG

Honorary Secretary

Malta Health Network

Gertrude A. Buttigieg qualified as a Speech & Language Pathologist in 1995 and has been employed by the health division and worked mainly in the field of Speech-Language Therapy for 17 years within the Primary Care Department.

Ms Buttigieg has practised in all areas of the profession from paediatric to geriatric care within a community and rehabilitation setting. In June 2013 she was recruited as Allied Health Practitioner (SLP) and Communications Officer within the Office of the Commissioner for Mental Health.

Gertrude's face and voice are familiar to the Maltese audience as she has participated for a number of years on various TV and Radio programmes educating the general public on Communication difficulties and Speech Therapy. On a voluntary basis she has been serving on the committee of the Association of Speech Language Pathologist since 1995 – 10 years as Secretary, 9 years as President and as Vice-President since 2014. In 2007 she was elected Honorary Secretary of the Malta Health Network. Since 2012 she has served on the Civil Society Committee of the Malta Council for Economic and Social Development as representative for the sectors of Health and Elderly. In 2005 was elected Honorary Secretary of the Malta Federation of Professional Associations. Since 2014 Gertrude has been serving as council member on the Malta Council for the Voluntary Sector.

Gertrude has participated as speaker and participant in several conferences locally and abroad and considering the vast professional practice and years of experience in the voluntary sector, she brings along a rich baggage to the various fields she works in. Over the past 10 years she has become a Patient advocate and has contribute to raise awareness on a national level of Patients' Rights and issues related to the Health sector such as patient education, patient empowerment, safety and access to services in an equitable and timely manner. Ms Buttigieg was instrumental to starting the debate on Chronic Pain in Malta in 2013.



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Hosting the Societal Impact of Pain Symposium 2017 in Malta is a dream come true; this is not the end but the beginning to raising more awareness of Chronic Pain in Malta.



CLAUDETTE BUTTIGIEG B.A (MELIT) D.LIT (D.A.M.S)(BO)

Shadow Minister for Health

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Patients, relatives and NGOs with a common goal and message should join forces. Their voices will not only be heard louder by politicians and policy makers but their efforts will be more effective. NGOs forming part of platforms will learn more about the works of others and the areas they should specialize in to avoid overlapping of work and services offered to assist patients and relatives.

Why do politicians need platforms addressing the societal impact of pain?

Claudette Buttigieg is the Shadow Minister for Health. She contested the general elections for the first time in 2013, was elected and appointed spokesperson for Social Dialogue and Civil Liberties. In January 2015 she was appointed Shadow Minister for Health.

Claudette has a long career in media and entertainment which spans for over 20 years. She worked in the Ministry of Health as Communications Co-Ordinator between 2009 and 2011. Apart from her political work, Claudette is also the HR Manager at Media.link Communications.

DR JOHN M. CACHIA MD, MSC, FFPH(UK), MMCFD

Commissioner for Mental Health

Ministry for Health

The Office of the Commissioner for Mental Health (CMH-Malta), promotes and safeguards the rights of persons suffering from a mental disorder and their carers was established by the Mental Health Act, Chapter 525, Laws of Malta. The vision of CMH-Malta is an all-inclusive society, wherein persons with a mental disorder are fully empowered to maximize their health. This will enhance their contribution to the community in all spheres of life including the labour markets and society at large. Mental health is part of person's life and thus the CMH-Malta has been active at promoting mental health and wellbeing through a life-course approach and intrinsic to all experiences of a person's life, be they positive or negative, and includes family and social life, traumas, chronic health conditions, workplace and education.

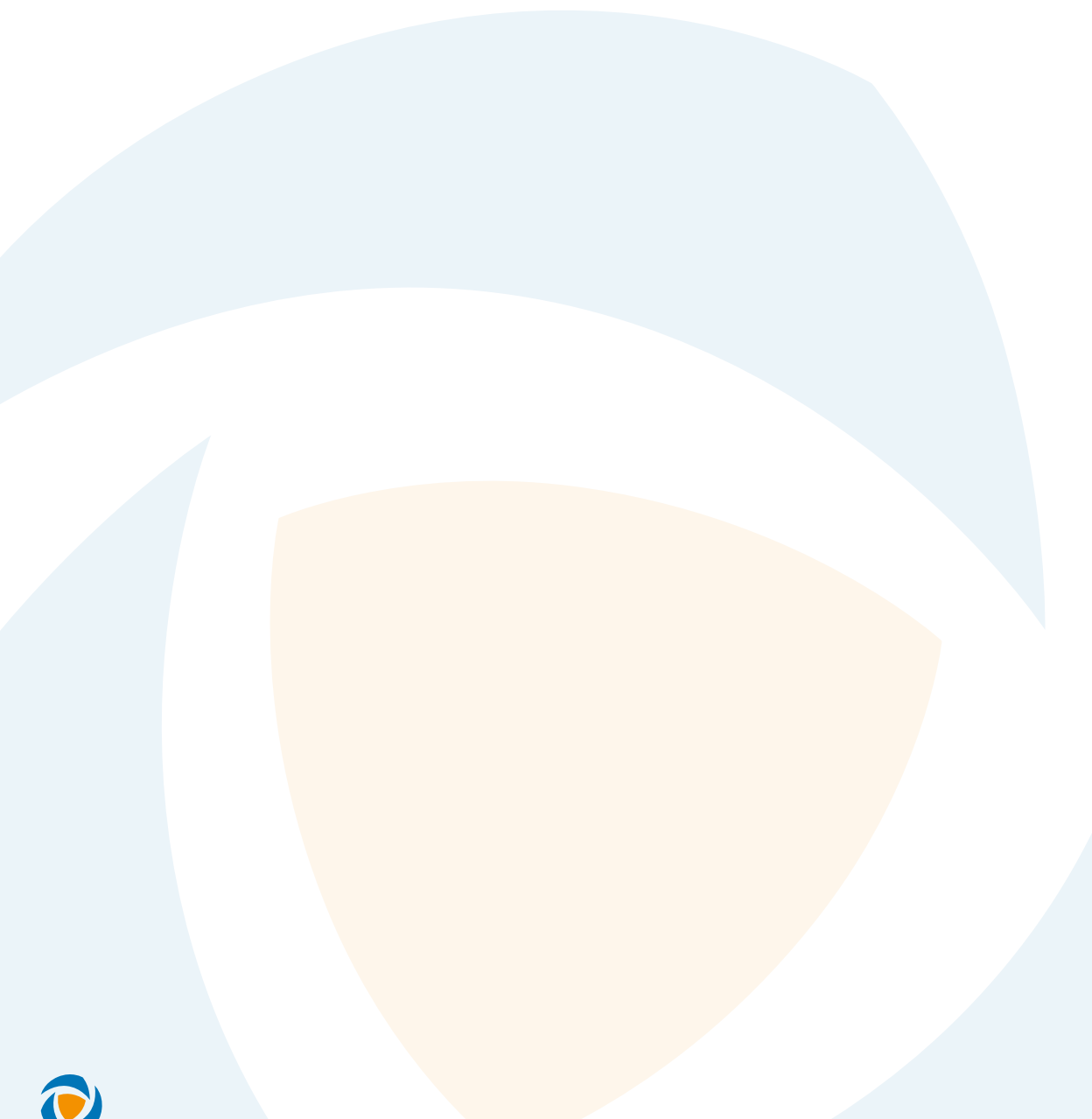
Dr. Cachia graduated as Doctor of Medicine in 1982. Consultant in Public Health since 1991. Specialist in Family Medicine since 2005. Currently Commissioner for Mental Health responsible for promoting and protecting the rights and interests of persons suffering from mental disorders (2011 to date). Has extensive experience in the governance of health care services, having occupied very senior management positions within the Maltese health care system where he was responsible for strategic direction and the monitoring of performance of hospitals, health centres and other health care entities (1986-2011). Senior Lecturer in Public Health Medicine and Health Service Management at the University of Malta (1985 to date). Past President and Governor for Malta in HOPE – the European Hospital and Healthcare Federation (1999-2012). Founder member and Past President of the Malta Association of Public Health Medicine (1995 to date). Member of the International Scientific Committee of EUPHA – the European Public Health Association (2012 to date).



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The vision of CMH-Malta is an all-inclusive society, wherein persons with a mental disorder are fully empowered to maximize their health.

C



SOLEDAD CABEZÓN RUIZ

Member of the European Parliament

Group of the Progressive Alliance of Socialists and Democrats (S&D), Spain

What the EU can do to improve pain care

Soledad Cabezón Ruiz has been a Member of the European Parliament for the Spanish Socialist Workers' Party since 2014. She is a Coordinator for the Group of the Progressive Alliance of Socialists & Democrats in the European Parliament's committee on petitions (PETI), a member of the committee on the environment, public health and food safety (ENVI), and a substitute member in the industry, research and energy (ITRE) committee. She focuses in particular on health systems strengthening issues, health and energy policies. She sits on the board of IDEAS Foundation for progress, a Spanish think tank that works on political ideas and proposals for the Spanish Socialist Workers' Party (PSOE).

A cardiologist by profession, Cabezón worked for several years at the Hospital Universitario Virgen del Rocío. She has been active in national politics since 2003. She served as mayor of Albaida del Aljarafe between 2003 and 2011, and was elected to the Congress of Deputies, the lower house of Cortes Generales in 2008, representing Seville Province.

In the 2008–2012 period, she served as secretary of equality in the executive committee of the PSOE.



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Pain and chronic pain are issues that impact European society. Pain patients should be granted access to healthcare services and treated in all countries with the highest standards. From the European Parliament we should push for the proper implementation of the Cross-Border Healthcare Directive which already states that pain should be a quality indicator to grant this overdue European access.

C



Revised version

DR ANTOINETTE CALLEJA

Chairperson, Presidency, Ministry for Health, Director International Affairs and Policy Development, Department for Policy in Health, Ministry for Health

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All individuals deserve a good quality of life. Chronic pain is associated with an increase in mortality and higher rates of depression, anxiety and sleep disturbances. It is important that we come together and that this item is placed high on the agenda to help people with pain have the life they deserve.

Antoinette Calleja is a Ph.D. graduate from the University of Hull, UK. Her doctoral studies focused on EU Public Procurement and its impact on society with implications for policy-making. Antoinette has worked as Director, Compliance within Malta's central purchasing department and presently works as Director, International Affairs and Policy Development at the Ministry for Health. She is also the chairperson responsible for leading and coordinating the preparations relating to the Malta EU Presidency of the Council within the Ministry for Health.

Antoinette qualified as a nurse in 1984 and as a midwife in 1986. Her background as a nurse and a midwife working one to one with patients and child bearing women has given her a good exposure of how pain affects the individual and families as a whole.

Antoinette further pursued her studies and completed a Master's Degree in Health Services Management and a Master's Degree in Business Management. She truly believes that chronic pain does not only affect the quality of life of the individual related to health and social issues, but also places a huge burden on national economies.

Antoinette has published various articles and is the author of *Unleashing Social Justice through EU Public Procurement* published by Routledge in 2015 (<http://www.routledge.com/products/9781138930896>).

DR NEVILLE CALLEJA

Director DHIR

No Pain Foundation

Department for Policy in Health - Health Information and Research



Meet the Maltese person in pain – a profile

Around 14% of the Maltese adult population reported moderate to severe bodily pain over the previous four weeks in 2015. The European Health Interview Survey (EHIS) was conducted in 2015 on a representative sample of 4000 individuals aged 15 and above in Malta and Gozo and included this specific question amongst a number of other questions relating to socio-demographic variables, lifestyle and health.

Chronic pain is associated with substantial disruption of one's participation in societal life and, consequentially loss of economic productivity. Hauser et al, 2014 reports a higher utilisation of health care services, even when adjusted for other socioeconomic drivers. In later life, chronic pain can lead to debilitation and ultimately long-term care in institutional settings.

Malta is no exception. The intensity of bodily pain is significantly positively correlated with all healthcare services. In the case of hospital stays, the number of separate visits does not appear to be associated but the length of stay most certainly is.

As in most other chronic conditions, health inequalities have been observed in chronic. Nakamura et al, 2014, reports an association between chronic pain and gender, occupation, educational level, smoking and alcohol. Similar associations were observed in EHIS data, plus others – such as age, region and occupation. Indeed, residents of the South-Eastern and Western regions of Malta have reported higher incidence of chronic pain. Whilst easily dismissed as a confounding effect of age or level of education differences between regions, multivariate analysis suggests that this association is independent. Additionally, it appears that the single most occupational group most at risk of chronic pain in the workforce in Malta are agricultural workers.

These findings and others are just the tip of the iceberg using a single question in a generic health survey. Nonetheless they already suggest that there will always be context specific factors that justify research in specific geographical areas. For this reason, the Directorate for Health Information & Research (DHIR) is supporting the No Pain Foundation's initiative to study chronic pain at a national level in Malta and explore the nature and the triggers of such pain and associated factors in Malta. Such information would be priceless for the planning not only of health services but also of health educational campaigns intended to minimise the risk in high-risk populations.

Dr Neville Calleja qualified as a medical doctor in 1999 and proceeded to study Medical Statistics and Public Health after his medical training. He qualified as a specialist in public health medicine in 2006 and was awarded Membership of the Faculty of Public Health in the UK in 2011. In 2013, Neville completed his PhD studies on the statistical correction of misclassification of disease status between self-reported and examined health surveys. He has been employed at the Directorate for Health Information and Statistics within the Ministry responsible for Health since 2001, taking on its helm in 2007, and also served as Acting Chief Medical Officer during 2014. DHIR is responsible for the collation of national health statistics on behalf of the National Statistics Office. Since 2007, the Directorate took on a research role, conducting a series of epidemiological surveys on a national scale, including two Health Interview Surveys, a survey on Elderly Needs Assessment, and a Sexual Health survey. Dr Calleja has thirteen years of experience lecturing medical statistics, epidemiology and public health to all health care professionals, together with ethical and scientific review of projects at local and international level.

MINISTRY FOR HEALTH - 95

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The Directorate for Health Information & Research (DHIR) is supporting the No Pain Foundation's initiative to study chronic pain at a national level in Malta and explore the nature and the triggers of such pain and associated factors in Malta. Such information would be priceless for the planning not only of health services but also of health educational campaigns intended to minimise the risk in high-risk populations.

C



DR PAUL CAMERON PHD (MEDICINE), MCSP, HCPC

National Lead Clinician (Acting) – Chronic Pain, Scottish Government; Lead Physiotherapist, NHS Fife Pain Management Service; Honorary Lecturer; Division of Population Health Sciences, Medical Research Institute, University of Dundee; and Course Organiser – MSc Clinical Management of Pain, University of Edinburgh.

Scottish Government / NHS Fife, Scotland

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Dr Paul Cameron qualified through the internationally recognised Physiotherapy department of Queen Margaret University, Edinburgh, with a BSc (Hons) Physiotherapy. He then spent a number of years gaining experience across a number of clinical areas including Paediatrics, Neurology, Geriatrics, Respiratory, and Cardiology, before specialising in Neuro-Musculoskeletal diagnosis and treatment, and Pain. In addition to working clinically Dr Cameron pursued further qualifications in Prescribing, Orthopaedic Medicine, Pain, and Managing Change in Healthcare, prior to completing a PhD (Medicine) with the University of Dundee.

Dr Cameron is the current National Lead Clinician in Chronic Pain, for the Scottish Government, and Lead Physiotherapist working for the NHS Fife Pain Management Service. He also holds an Honorary Researcher and Lecturer position with the Division of Population Sciences, Medical Research Unit, University of Dundee, jointly overseeing a Government funded project on Core Outcome Measures and Data Collation in Chronic Pain. In addition to these roles Dr Cameron is on the Editorial Board of peer-reviewed journals 'Pain and Rehabilitation' and the 'British Journal of Pain', and acts as manuscript reviewer for a number of other scientific journals.

Over the last few years, Dr Cameron has contributed to key national, and international, documents furthering the treatment and management of chronic pain including SIGN Guideline 136, Management of Chronic Pain (2012), and the Faculty of Pain Medicine's publication 'Core Standards for Pain Management Services in the UK (2015).

Dr Cameron regularly presents at international, national and regional conferences and events on varying aspects of pain management, research and policy including countries such as Albania, Italy, Austria, Russia, Turkey, United Arab Emirates, and Finland, and is an elected Council Member and Board Trustee of the British Pain Society, and current Chair of their Pain Education Committee.

MATTHEW CAMILLERI

Managing Physiotherapist / Vice- President

The Pain Clinic / Malta Association of Physiotherapists

Matthew Camilleri is a physiotherapist with a special interest in persistent pain management. He works in an inter-disciplinary team focusing on providing bio-psychosocial, holistic pain management to patients who have not benefited from a bio-medical model of intervention.

His presentation focuses on the non-medical aspects of pain management available both locally and internationally. He hopes to highlight the importance of introducing non-medical methods of pain management to Malta in order to better the level of care locally.



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The role of non-medical methods in pain management is a well-researched and important area.

Awareness regarding various non-medical pain management techniques is slowly growing both locally and internationally but have still not received the recognition they deserve.



NICOLA CAPUTO

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I am supporting the SIP symposium as I would like to work with pain experts to ensure that the Cross-Border Healthcare Directive functions in the way it was intended, namely protecting patients' right to seek treatment outside their home country when they are experiencing a high degree of pain.

As a MEP I have a strong interest in defending the rights of European citizens. One of those rights should be the ability to access medicines and treatments in other Member states, when required. I am supporting the Societal Impact of Pain symposium as I would like to work with pain experts to ensure that the Cross-Border Healthcare Directive functions in the way it was intended, namely protecting patients' right to seek treatment outside their home country when they are experiencing a high degree of pain. This implies that Member States have properly transposed the Directive into their national legislation and, consequently, put in place mechanisms to assess the patient's level of pain.

Nicola Caputo started his mandate as a Member of the Group of the Progressive Alliance of Socialists and Democrats in the European Parliament on 1 July 2014. He is currently a member of the agriculture and rural development (AGRI), the environment, public health and food safety (ENVI) and the fisheries (PECH) committees. Since his election Mr. Caputo has shown increased interest in public health issues and in particular the one related to access to medicines and treatments. He is an active member of the S&D Group Task Force on "Access to medicines" and he has been working hard to fight against unfair and unequal access to healthcare in the EU via a series of initiatives (motions, written questions, etc.). As member of the ENVI committee, Mr Caputo has been monitoring the enforcement of the directive on "the application of patients' rights in cross-border healthcare" which represents a major breakthrough for EU patients as it means empowerment in particular through greater choice of healthcare and easier recognition of prescriptions across-borders. Nicola Caputo is a professional business adviser, specialized in commercial law, finance and administration of local authorities. He holds a degree in Economics from the Federico II University and has extensive experience in the agriculture, wine and automotive industries. Before joining the European Parliament, Nicola Caputo served 2 mandates (2005-2014) as Councillor for the Campania Region in Italy. As Regional Councillor and member of the Regional Health committee, Mr Caputo launched a series of initiatives in order to improve fair and equal access to medicines and treatments in his constituency.

DR ANTONELLA CARDONE

Executive Director

Fit for Work

Antonella Cardone is Executive Director of the Fit for Work Global Alliance (FfW GA). The FfW GA is a multi-stakeholder coalition championing change in health and work policy and practice, to benefit people with chronic health conditions. For over a decade, the FfW GA, led by The Work Foundation (Lancaster University, UK), has driven change for better lives worldwide.

Prior to joining the FfW GA, Antonella Cardone was Director of the Global Smokefree Partnership of the American Cancer Society, leading a movement of over 100 organisations in support of the development of smokefree laws in 40 countries. She has managed over 30 large EU projects, involving many organisations across all EU member states, in sectors such as health, employment, social inclusion, human rights, education, training and urban regeneration. Ms Cardone has also led, among others, projects at the World Heart Federation, The International Union against Tuberculosis and Lung Disease, and the European League Against Rheumatism.



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Good work, which is work that is fulfilling, promotes health and is productive, is an essential part of our life. Along with volunteering, hobbies, friends, faith, and family, good work gives us a sense of purpose. Working with pain can be a challenge and has a high impact on productivity at the workplace both in terms of absenteeism (lost workdays) and presenteeism (reduced performance while at work).



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Pain is a priority health problem because of its frequency, its impact in person life's quality, its high societal and economic impact, so that a whole biopsychosocial approach is required. It also requires an integrated and coordinated health care system. Managing pain is essential to ensure a correct healthcare quality on chronic diseases.

DR PALOMA CASADO

Deputy Director of Quality and Cohesion

Spanish Ministry of Health, Social Services and Equality

As part of this Strategy, various projects and areas of work are being developed in order to carry out the implementation of the Strategy. For instance, we can highlight a Project of Stratification of the Population, A Network of Health Schools for Citizens, The Chronic diseases management project (an IT tool for the clinical decision support which includes managing of pain as principal task) and a Framework document for the Improvement of pain in the NHS. Which was set on 2014. Having this framework in our NHS is essential in a decentralized system as our healthcare system is, and it must ensure: healthcare quality in managing pain, equity on accessibility and procedure's efficiency. Improving quality of care of patients with pain in the NHS, contributes to improve people's quality of life.

The d includes: Acute pain, non-oncological chronic pain, Oncological chronic pain, surgical pain, Pain related to diagnostic and therapeutic procedures, in adults and so in children.

This is a framework document that contains such strategic lines, objectives and recommendations in order to promote correct assessment of pain, to improve early detection and prevention of pain, and to encourage integrated care of people with pain, in order to provide a biopsychosocial approach.

The Spanish framework document to address pain is structured into four strategic lines:

1. Mainstreaming

- a. Pain as a priority in the frame of strategies and health policies
- b. Integrated approach
- c. Patient's Empowerment
- d. Reducing inequalities
- e. Training and research

2. Prevention

- a. Prevention of pain and its chronification
- b. Promotion of healthy lifestyles
- c. Chronic pain risk identification
- d. Pain prevention on diagnostic and treatment procedures
- e. Systematized assessment of pain: 5th sign
- f. Patient centered healthcare

3. Treatment: Patient safety and Therapeutic appropriateness

4. Coordination and Continuity of care

Paloma Casado Durández, MD specialist on Clinical Chemistry and Laboratory Medicine, is a Health Quality Management expert with 20 years of experience, and she has managed as Medical Director different Hospitals in Madrid. Since 2014 she is working for the Spanish Government as Deputy Director of Quality and Cohesion in the Ministry of Health, Social Services and Equality. She also participates in different Masters and professional events as Quality instructor and speaker.

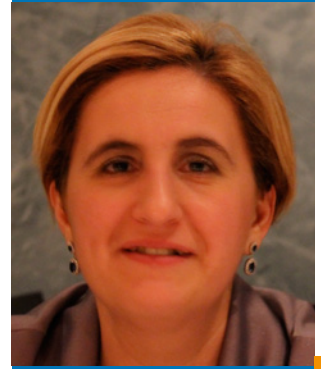
DR MARILYN CASHA

Consultant in Anaesthesia and Pain Management

DaVinci Hospital

Dr Marilyn Casha is the only full time Pain Management Consultant in the Maltese Islands, working at Mater Dei, Sir Anthony Mamo Hospitals and in private practice.

She developed a dedicated Oncology Pain Clinic in 2009 and introduced spinal column stimulation in 2012. Currently she is working on the further development of the concept of the multidisciplinary approach to pain management. As a lecturer at the University of Malta, she takes a keen interest in promoting the teaching of Pain Management to medical students and is promoting the use of audits of pain management services to students as an exercise to attract young minds to speciality in order to see continuing development of the speciality.



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**Pain is an extremely common problem which almost certainly affects everyone at some point in their life. Therefore my bold question to politicians, to care workers, to people suffering from chronic pain is:
Have I done enough to help or am I skirting the issue? In view of European value of solidarity - Could I have done more and how can each of us do his/her contribution to improve this problem?
All of us can do more together.**



MARTINE CHAUVIN

Founder of AFVD

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« Living Better with » is :
Caring for the person
in order to promote
his autonomy and his
decision-making, through-
out his pathway. Taking
psychological aspects
into account to help
people better live their
disease.
The expert patient is an
essential link in thera-
peutic education.

Martine Chauvin, founder and administrator of AFVD, Association Francophone pour Vaincre les Douleurs, a patient association for patients, working in partnership with healthcare professionals, created in December 2006 following my personal journey of pain. I have written 2 testimonials:

« Balle de Match » The Mastery of Suffering by Neurostimulation
« Jeu Set et Match » The Victory of Neurostimulation

I organized lectures which led me to meet many chronic pain patients, all with different profiles and pathways, but all with one common point: lack of solutions for their pain. I also created blogs, websites.

Thanks to my reconciliation with my pain, I have taken a degree course in Therapeutic Education of the Patient in chronic diseases in order to put to the benefit of others my skills acquired throughout my care path. I work with patients in the pain structures of Niort (79) and Poitiers (86), France, as an "expert patient". I organize chronic pain patient accompanying clinics with health professionals.

This diploma allowed me to become a jury during the defense of the students of this same course. I am today coordinator of a program "Living Better With" filed with the Regional Health Agency of the region New Aquitaine (France) in March 2017.

ANTONY CHUTER

Chairman

Pain UK

Antony is a someone who has lived with pain for over 25 yrs. During this time he lost everything, his home, his job, his relationship fell apart and he found that he had lost his purpose in life.

After a number of years and with support, Antony has returned to the workplace and now holds a number of roles where he supports patients who live with pain and acts as an ambassador for patient and public involvement. He has also been the co author on a number of publications where he ensures the patient/public voice is key. Antony is currently a Trustee and Chair of Pain UK, Pain UK is an alliance of 30 charities providing a voice and support for people who live with chronic pain. During 2015 Pain UK launched its Call to Action to all Members of Parliament and during 2016 they launched a chronic pain charter. Antony also initiated the work on the UK Pain Messages - a set of key messages about the state of pain in the UK. He is also the current chair of the Patient Liaison Committee at the British Pain Society, The Patient Liaison Committee is responsible for ensuring that the views of patients are represented within the Society

Previously he was also the chair of the Royal College of General Practitioners Patient Partnership Group where he ensured that the patient was at the centre of all the work of the College, he was also the lead author on 'It's your practice' a guide to general practice for patients. In 2013 he was awarded the Colleges highest award 'Honorary Fellowship'. Antony has also published several editorials in the College journal 'The British Journal of General Practice' (BJGP).

Antony is the Patient and Public involvement lead and grant holder on a NIHR Programme Grant at The University of Edinburgh, Usher Institute of Population Health Sciences and Informatics 'A multidisciplinary collaboration to inform important national deliberations on the safe, effective and efficient procurement and implementation of ePrescribing systems into hospitals in England.'. This was a collaboration of institutions in Edinburgh, Harvard, Nottingham and Birmingham.

Antony has similar roles on a number of programme grants and studies at the University of Nottingham - all focused on patient safety in general practice. He has held similar roles on studies at the University of Birmingham and Cardiff University.

Last year, Antony won the prestigious 'Dangerous Idea' competition at the Society of Academic Primary Care conference in Dublin.

Antony has represented patients/public on a variety of groups and workstreams during the last 10 years

- Patient/Lay member of the 'Innovators Forum' at the Royal Pharmaceutical Society
- Co Applicant - NIHR - Characterizing the nature of primary care patient safety incident reports in England and Wales and identifying feasible and priority interventions: mixed methods study
- NICE - External Contractor to support the ongoing development of indicators for the Quality and Outcomes Framework
- Collaborator - NIHR - Meanings, costs and consequences of Patient and Public Involvement (PPI)
- Co Applicant - NIHR - Investigating the implementation, adoption and effectiveness of ePrescribing systems in English hospitals: a mixed methods national evaluation
- Co Applicant - DoH - Understanding and Appraising the New Medicines Service in the NHS in England
- Co Applicant - NSPCR - Developing, testing and implementing the NSPCR Patient Safety Toolkit in general practices in England
- Member of the RAPPORT project advisory group - RAPPORT: ReseArch with Patient and Public involvement: a RealisT evaluation
- **HSCIC** Lay member of the GPES Patient Consultation Group - an advisory group established to advise the GPES team.
- Lay member at the Wellcome Trust conference which wrote 'Towards Consensus for Best Practice : The use of patient records from general practice for research'.
- Expert Panel Member for the NHS Centre for Involvement for the document - 'a guide to patient and public involvement in urgent care'. And also a further document 'a guide to patient and members of the public with long term conditions
- Connecting for Health Evaluation programme - Lay Member - project 001 'NHS CFHEP 001: Extension The Impact of eHealth on the Quality and Safety of Healthcare'
- Connecting for Health Evaluation Programme 010 report - Lay Member - An evaluation of the effect of IT on interactions between healthcare workers and patients.
- Connecting for Health Evaluation Programme 005 report - Lay Member - An evaluation of the adoption of the NHS Care Record Service in secondary care.
- Patient member on the 'Informatics Data Standards Board' at the 'Information Centre for Health and Social Care'.
- Lay member of the Royal College of General Practitioners 'Patient Partnership Group'.



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There is a life after developing long term pain!



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H.E. MARIE-LOUISE COLEIRO PRECA

President of Malta

Government of Malta

Marie-Louise Coleiro Preca is the ninth President of Malta, being unanimously approved by Parliament, after being active in politics for forty years, and serving in Parliament for sixteen years. Ms Coleiro Preca graduated as Bachelor in Legal and Humanities, and as Notary Public, at the University of Malta.

Marie-Louise Coleiro Preca dedicated her life to the wellbeing of the most vulnerable in society, and brought about effective changes in the social policies of Malta. Her major achievements since taking the Oath of Office as President, including founding The President's Foundation for the Wellbeing of Society.

Marie-Louise Coleiro Preca is acclaimed internationally, being awarded the Crans Montana Prix de la Fondation 2014, for her endeavours in striving for peace, freedom and democracy; Honorary Life Presidency of the Arab-European Forum for Dialogue and Development; Honorary Professorship at the University of Warwick in the UK; and 'Agent of Change' by the United Nations.

Marie-Louise Coleiro Preca is a member of the Patron's Council of 'Missing Children Europe'; Head of the Executive Advisory Council of the Flinders University, Centre of 'Student Wellbeing & Prevention of Violence' in South Australia; Member of the World Women Leaders; and Adviser to Women in Parliaments.

DR BEVERLY COLLETT O.B.E., F.R.C.A., F.F.P.M.R.C.A

Chair

Chronic Pain Policy Coalition (CPPC)

Dr. Beverly Collett is an Emeritus Consultant in Pain Medicine at the University Hospitals of Leicester NHS Trust.

She has been a Board member and examiner for Faculty of Pain Medicine of the Royal College of Anaesthetists. She chaired the Professional Standards Committee and was coordinator for Core Standards for Pain Management Services UK - the first standard setting document for the provision of multidisciplinary Pain Management Services in the UK - which has been adopted by the Care Quality Commission.

She is a past Treasurer and Council member of the International Association for the Study of Pain (IASP). She is a Past-President of the British Pain Society and of the International Pelvic Pain Society and is a past Honorary Secretary of the European Federation of IASP Chapters. She was Chair of the Chronic Pain Policy Coalition (CPPC) – an umbrella organisation of patients, parliamentarians and health care professionals promoting policy solutions that contribute towards the improvement in the quality of life of those affected by chronic pain.

In 2015, she was awarded an OBE, a Queen's honour, for her services to pain management



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The EU Civic Prize on Chronic Pain-Collecting good practices launched by Active Citizenship Network is a fantastic new initiative awarded for the first time this year. It will give us all the opportunity to consider how these excellent examples of good practice can be rolled out more widely for the benefit of people living with pain.

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TERESE COMODINI CACHIA

Member of the European Parliament, Malta

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This year too, I support the Symposium dealing with the impact of pain because of its significance & implications on our everyday life. I congratulate the Malta Health Network for their work in building joint-platforms with our European counterparts to address this challenge. Let us join forces to lend a helping hand towards helping people live a better life.

Therese Comodini Cachia is a lawyer by profession working in the field of human rights. She has been representing victims of human rights violations since 1997 through court proceedings both before the Maltese courts as well as before the European Court of Human Rights. She has also been heavily involved in non-governmental organisations having acted as their legal advisor. Her work with non-governmental organisations has kept her abreast with the perceptions held by and the social needs of different groups in society. She believes in respect for the dignity of each individual. She is a lecturer at the Faculty of Laws of the University of Malta and coordinates the Masters degree in Human Rights and Democratisation. She also lectured at the University of Utrecht, in Holland and at the Europa-Viadrina University in Germany. In May 2014 Comodini Cachia was elected Member of the European Parliament. She is a member of the Culture, Education, Youth Policy, Media and Sport Committee (CULT), the Legal Affairs Committee (JURI), Human Rights Subcommittee (DROI) and also serves on the Committee of Inquiry into Money laundering, tax avoidance and tax evasion (PANA). She is also a member of the delegation for relations with the Palestinian Legislative Council, that to the Parliamentary Assembly of the Union for the Mediterranean and the Delegation for relations with the People's Republic of China. She has worked on Digital Single Market related files such as that of geo-blocking, cultural and creative industries, 5G as well as on the implementation of Infosoc. She is currently rapporteur for the Copyright Directive report in Committee on Legal Affairs. In March 2016, Comodini Cachia was named MEP of the Year by The Parliament Magazine in the field of corporate governance. In March 2017 Comodini Cachia placed 27th in the POLITICO's list of the MEPs who matter in 2017. Comodini Cachia has actively participated in the Partit Nazzjonalista and was a member of the Commission for the revision of the Statute and Party Structures. She is also seen as a point of reference for the Parliamentary Group having contributed to a number of positions including amendments to the Constitution of Malta. Currently she coordinates the Policy Fora of the Nationalist Party. In January 2015 she was appointed shadow Minister for Education and Employment. Comodini Cachia graduated in law in 1997 and holds a Ph.D. in human rights law. She is married to Vladimiro and mother of a daughter, Laura.

SARAH COPSEY

Project Manager

European Agency for Safety and Health at Work

Too often chronic pain leads to an early exit from the workplace. However, as I know from personal experience, with the right employer attitudes and workplace adjustments combined with support from the public health system many pain sufferers can continue working.

Sarah has been employed as a project manager for the European Agency for Safety and Health at Work (EU-OSHA) since 1998. Her work has mainly focused on the identification and promotion of good practices and she has developed and managed a variety of projects to this end. Her areas of responsibility have included various diversity issues such as young workers, mainstreaming OSH into education, gender and occupational safety and health (OSH), disabled workers, good practices in the prevention of occupational risks in road transport and projects on worker participation in OSH. Recently she was the coordinator for a major project on OSH and the ageing workforce which was carried out for the European Parliament and is currently part of a team developing a large-scale project on musculoskeletal disorders and the workplace.

Sarah has worked in health and safety since 1988. Before joining the EU-OSHA she was Head of Health and Safety at UNISON - the national trade union for public service and health care workers in the UK. Her academic background is in psychology and ergonomics. She started her working life at Nottingham University, on projects concerning stress and shift work.



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Occupational safety and health has an important role to play in a multidisciplinary approach to pain management.



VIORICA CURSARU

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**There is a need for
minimum standards
of health for all EU
patients.**

Ms Cursaru is the president of Myeloma Euronet Romania, an organization founded in 2006 when her late husband Mihai Cursaru was diagnosed with multiple myeloma. She has a bachelor's degree in English Literature and worked for the United Nations for 20 years prior to retirement. For the last 10 years, she was actively involved in patients' advocacy, mainly focusing on health system inequalities within Europe, the need for minimum standards of medical treatment, access to medication and a more patient-oriented policy at EU level.

Presently, Ms Cursaru is a board member of Pain Alliance Europe (PAE), an European organization comprising 33 members in 16 European countries. The mission of PAE is to have chronic pain recognized as a disease on its own and, in this respect, it is actively advocating at the European Parliament, EU Health Commission and other European organization.

PROF MAURIZIO CUTOLO MD, FACR

Past President

EULAR

Chronic pain in Rheumatic and Muskuloskeletal Diseases (RMD) is characterized by a circadian rhythm and in cases of long-term persistency, pain causes severe depression and social discomfort for the patient affected. Pain is an early symptom that signals a pathological inflammatory condition and early correct diagnosis and treatment of the causes is followed by the decrease/disappearance of the pain. Treatment of pain without temptatives to remove the causes is unsuccessful. Prof. M Cutolo and his TEAM studies the neuroendocrine and immunological causes of RMD. Best results in the control of the pain are obtained by the strict cooperation between the rheumatologists and the patients, with the support of the health professionals. The European league against rheumatic diseases (EULAR) is engaged in several initiatives to optimise pain control and several recommendations have been published. In addition, since pain has a circadian rhythm, with highest levels during the night, the chronotherapy of the inflammatory reaction with drugs acting during the night has been found more successful.

Actually Prof. Maurizio Cutolo, M.D. is professor of Rheumatology and Internal Medicine; he serves as Director of the Research Laboratories, Clinical Academic Division of Rheumatology and of the Academic Postgraduate School of Rheumatology at the University of Genova. Prof. M Cutolo is co-chair of the European (EU) ERN network ReCONNECT on Rare Connective Tissue Diseases. M Cutolo is PI in a national site, for an HORIZON 2020 project (2015-2019). He is Past EULAR President and Past Chairman of the International Society of Rheumatology (ILAR). He has been Advisory Editor of the Journal Arthritis & Rheumatism and actually is Associate Editor of the Journal Clinical and Exp. Rheumatology. He was the Vice President of the Italian Society for Rheumatology and also Vice President of the International Society for Neuro immuno modulation (ISNIM). M Cutolo Co-founded in 1999 and he was the Chairman of the Study Group on Neuro Endocrine Immunology (NEI) at the American College of Rheumatology. M Cutolo is chairman of the Study Group on Capillaroscopy and RMD at ACR. He served as a Member of the Scientific Committee of EULAR from 2004 to 2007 and Executive Committee until now (2017). M Cutolo published 500 peer reviewed papers (Pub Med). M Cutolo is expert on management of chronic RMD with the use of glucocorticoids (GCs), biologicals, biosimilars. disease modifying anti inflammatory drugs (DMARDs), non steroidal anti-inflammatory drugs (NSAIDs). M Cutolo has started the fearly studies about the chronotherapy of RMDs and the endocrine extrabone activities of Vitamin D.



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Almost all Rheumatic and Muskuloskeletal Diseases (RMD) are characterized by the presence of acute/chronic pain. Pain is an early symptom that signals an inflammatory/degenerative condition. Early correct diagnosis and treatment of any pathological condition is followed by the disappearance of the pain.

C



D·O·M·ECCLESIAM·HANC·COLLEGIATAN

MIRIAM DALLI

Member of the European Parliament, Malta

Group of the Progressive Alliance of Socialists and Democrats (S&D)

Better pain treatment at an early stage is fundamental for our patients' wellbeing. Awareness, education and further budget allocations are the required tools to address pain as a condition in its own right. Ultimately, our citizens' health should always be our main priority.

Miriam Dalli is a Maltese MEP, after being elected in May 2014. She serves as the Socialist & Democrats' Coordinator on the Committee on the Environment, Public Health and Food Safety (ENVI). Dalli advocates a proactive European approach on Public Health concerns, with particular attention to Mental Health, Autism, and Cancer. She believes that such a proactive stance would yield more immediate and adequate support, and allocates greater resources to prevention. The Maltese MEP also regularly pushes for progressive and ambitious targets on environmental issues which may leave a positive impact on public health such as waste minimization & management, air quality, emissions control and use of clean energy sources. Her efforts in these sectors were recognized with MEP awards in Public Health (2017) and Energy (2016).



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D

**The European Union
must provide guidelines
to all Member States,
to consider pain in its
own right.**



DR SASKIA DECUMAN

Expert Research and Development, Department of Benefits of the National Institute for Health and Disability Insurance

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Participation of people suffering from (chronic) pain is one of the points of attention of the centre of knowledge in work incapacity of the National Institute Of Health and Disability Insurance (NIHDI, Belgium). Several studies are currently being launched in with focus is on how to reintegrate this people into the labour force.

Belgium has one of the highest prevalence of chronic pain. Moreover the problem is significant in people within the labour active age. Consequently we have high absenteeism (21% does not work due to a pain-related problem) and presenteeism (more than 1/3 is limited in functioning while at work) (Breikvik, 2006; WIV, 2008). Nevertheless research shows that this people want to work (VPP, 2014). In the figures about work incapacity MSD are found as one of the major causes of sickness absence, with pain without any doubt as one of the most significant contributing factors. But also in other diseases like cancer we see that, as survival augments focus is also on participation and coping with factors such as pain.

The center of knowledge in work incapacity, installed in the Department of Benefits of the National Institute of Health and Disability Insurance (NIHDI), focuses since some years on this topic in the study program they launch. This program is executed in collaboration with experts and serves policy development. Some months ago a research was finalised in which the current situation on the social-professional reintegration of chronic pain patients was mapped. The results of this project are used in several follow-up studies the centre has launched in 2016-2017. In this studies, the focus will be on development of the trajectory to work for people with pain followed-up in Belgian pain centres. Besides that we plan to support several research projects on cancer and return to work (RTW). In all projects attention will be on early intervention, transmurality, communication between stakeholders.

Besides research, the NIHDI foresees formal systems which stimulate RTW. One of the tools is the possibility to RTW in an adapted way (level of time, task, ...), while remaining on work incapacity. This gives important benefits for employer and employee (eg. earlier RTW). The NIHDI has also conventions with regional employment services and the social insurance companies to support updates of competences, and education to another job, in order to make sure the insured worker can, nevertheless his disability RTW. Reintegration to the former job within the same employer as first objective, but if not possible other options are elaborated.

Dr Decuman is OT and MSc in medical-social sciences (health education and promotion). In 2014 she achieved a Phd degree for the work she performed on "work participation in people with systemic sclerosis" at the department of Rheumatology of the Ghent University. Currently, she is expert research and development at the Department of Benefits (NIHDI).

She is scientific coordinator of the center of knowledge in work incapacity which has as main aims (inter)national networking and supporting research in order to be able to guide policy. Beside that she's project leader for the implementation of the disability management curriculum as developed by the National Institute of Disability Management and Research (Canada). With this educational framework the NIHDI wants to support their stakeholders to develop the necessary competences in job retention and reintegration.

DR RODRIGUE DELEENS

Doctor

University Hospital

Dr. Rodrigue Deleens is a pain specialist practicing at the University Hospital of Rouen (Normandy) and Cochin (Paris).

After training in general medicine, he worked in China and Myanmar before starting his career in the management of chronic pain in public hospital in France. He is trained in the management of chronic pain, palliative care, child pain and therapeutic education of patients. He is involved in many activities to promote the fight against pain: organization of the first Franco-Chinese exchanges of pain at the 2010 Universal Exhibition in Shanghai, member of the French Society for the Study and Treatment of Pain, coordinator of a pain news site and a member of several scientific groups.

Interested in therapeutic patient education, he collaborates actively with several patient associations, including the AFVD, to improve the programs implemented as well as the policies promoting these programs. He participates in teaching, clinical research and therapeutic education programs in Rouen and Paris.

Therapeutic education is a modern approach to pain medicine and it involves paradigm shifts for caregivers and patients.

Enabling the greatest number of people to benefit from it is a major current challenge, public health policies must go in this direction, and in order to do so, collaboration with patient associations is essential. Working together from the development to the animation of workshops and evaluating impacts on the quality of life of the patients being followed are the main points of our actions to be carried out.



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D

The therapeutic education of patients is a challenge, let's work together to improve the management of chronic pain and the quality of life for patients!



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In order to tackle the challenges posed by brain disorders, further research that adopts a multidisciplinary approach is needed.

Brain and pain disorders are amongst the greatest challenges for Europe

Frédéric Destrebecq has been the Executive Director of the European Brain Council since October 2014.

The European Brain Council (EBC) is a non-profit organization gathering patient associations, major brain-related societies as well as industries. Established in March 2002, its mission is to promote brain research in order to improve the quality of life of those living with brain disorders in Europe. EBC's main action areas are: fostering cooperation with its member organizations; promoting dialogue between scientists, industry and society; interacting with the European Commission, the European Parliament and other relevant international institutions; raising awareness and promoting education on the brain; and disseminating information about brain research and brain diseases in Europe.

EBC currently has a series of policy-based work, led by the Call to Action and Consensus Statement launched last year, calling for the need to expand brain research in Europe and to improve prevention, treatment and management of brain disorders for humanitarian, medical, scientific, societal, political and economic reasons. Further projects involve a focus on mental health in the workplace through the Not Myself Today initiative, providing tools and resources for organizations and a policy recommendation taskforce on suicide prevention.

Furthermore, EBC currently runs a landmark project on the Value of Treatment, of which the main objective is to assess the socio-economic impact of clinical interventions, or the lack thereof, and to provide evidence and tools that can assist policy makers and healthcare actors in shaping effective policy responses to some of the most prevalent brain disorders.

EBC has supported SIP since its foundation and is happy to contribute to the SIP Symposium in Malta.

DR JANINA DIEBER MSC

Abteilung für Anästhesie & Intensivmedizin / Schmerzzambulanz

Landeskrankenhaus Hartberg

Janina Dieber is an anaesthetist and pain therapist at Landeskrankenhaus Hartberg in Austria where she is the Head of the Interdisciplinary Outpatients Pain Department. She is a member of the working group "Key Figures and Outcome" of the Austrian Society for Anaesthesia, Reanimation and Intensive Care (ÖGARI) and is currently working on the development of quality indicators in pain medicine.



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For the best possible care of chronic pain patients in Austria it is highly urgent that our health system is establishing a structured multi-stage concept in pain care.



DR MED WOLF DIEMER

Senior Consultant

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Though there are some improvements in pain medicine and palliative care, there is still a lack in the number and funding of multidisciplinary pain clinics for out- and inpatients. The SAPV-law of 2007 declared the right to specialized palliative care for all patients in need. But up to now we do not find a nationwide coverage in end of life care.

We have achieved some change for the better in pain medicine and palliative care in Germany. Nevertheless there is still a lack in the number and funding of multidisciplinary pain clinics (Schmerzambulanzen und -praxen sowie Schmerzkliniken) for out- and for inpatients.

The SAPV- (Specialized Palliative Care for Outpatients) law of 2007 (§ 37b SGB V) declared the right to specialized palliative care for all patients in need. But the development and the funding of SAPV-Teams differs very much in the 16 federal states of Germany.

So we have no reason at all to celebrate this jubilee as we do not find a nationwide coverage in end of life care even after ten years.

Concerning the qualification of physicians in Palliative Medicine and in Pain Medicine there is only a one-year training as a sub-specialization. Following the UK example in Palliative Medicine a 4- to 6-years training as a specialty should be implemented for both qualifications.

Dr. Wolf Diemer is senior consultant in palliative medicine and pain medicine and head of the Center for Palliative Medicine at the Protestant Hospital (EvK) in Herne, Germany.

He did his academical training in the University Hospitals Münster in Anesthesiology and Pain Therapy and then headed the Pain Clinic at Greifswald University Hospital. From 1996 till 2004 he conducted the Cancer Pain Initiative Mecklenburg-Vorpommern: This demonstration project of the German Ministry of Health became the prototype for the law on Specialized Palliative Care for Outpatients (SAPV). After extended lobbying it was adopted (as § 37b SGB V) by the German Bundestag in 2007. He also works as a lecturer and trainer for Palliative Medicine for the Academy of the Board of Physicians in the Federal State (Westphalia, part of NRW).

Dr. Diemer is a member of the IASP International Association for the Study of Pain, DSG German Pain Association, DMKG German Migraine and Headache Association, DGP German Association for Palliative Medicine, EAPC European Association for Palliative Care, DGAI German Association for Anesthesiology and Intensive Care, AEM Academy of Ethics in Medicine and member of the of the Hospice and Palliative Care Association of NRW, Germany. Main previous office was the board membership of the German Hospice and Palliative Care Association 2006-2012. Dr. Diemer authored Vol. 7 "Chronische Schmerzen [Chronic Pain]" of Health Reports of the Fed. Rep. of Germany 2002: http://www.rki.de/DE/Content/Gesundheitsmonitoring/Gesundheitsberichterstattung/GBEDownloadsT/schmerz.pdf?__blob=publicationFile

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“CHANGE PAIN®” Initiative for Healthcare Professionals

This initiative aims to understand the needs of pain patients and develops solutions to improve the management of pain.

It was founded by Grünenthal GmbH in 2009 and is endorsed by the European Pain Federation EFIC®. The European Society of

Regional Anaesthesia & Pain Therapy ESRA endorses the aims of the CHANGE PAIN® acute campaign. In the meantime the initiative has been discussing various needs in the broad field of pain management. As a result, there is a comprehensive offer of services and materials for healthcare professionals as well as for patients. It adds to the improvement of daily practice in pain management. www.change-pain.com

To provide the best possible service it is important to understand the needs of pain patients and to develop solutions to improve the management of pain.



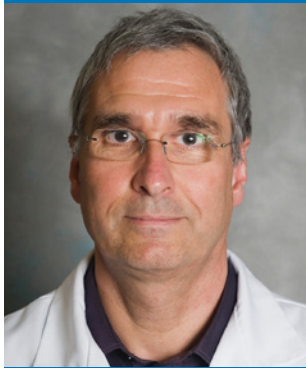
my pain feels like...

“MY PAIN FEELS LIKE” Initiative for Patients

It is crucial that patients are able to describe their symptoms as detailed as possible to allow early diagnosis and effective treatment – an insight which has motivated us to develop the “My pain feels like...” initiative, aiming at facilitating communication between patients and physicians.

This patient initiative has been developed by Grünenthal GmbH in collaboration with the Pain School, Italy. www.mypainfeelslike.com

Being a chemist by training, in my almost 20 years of professional experience in the pharmaceutical industry in various national and international, commercial roles there is one consistency: I have always worked in the area of pain management.



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Because pain is complex, it is time to move forward towards peri-operative pain service. The specific treatment should be started as soon as the preoperative period and continued during the per and postoperative period. This personalized treatment can be well realized by a specialized organization and will be cost saving

On the one hand, it is now clearly describing the link between some preoperative factors and the risk of a high level of postoperative pain. It was also confirmed that the presence of postoperative pain is highly correlated with the risk of persistent postoperative pain. On the other hand, the Acute Pain Service (APS) have clearly demonstrated their effectiveness in the treatment and/or prevention of postoperative pain in patients in a targeted manner or in a more systematic way. Their organization depends largely on socioeconomic influences.

Some of these preoperative factors could be treated or ameliorated, such as addictive behaviours (alcohol, tobacco, benzodiazepines or other sleeping medication, opioids tolerance), psychological disturbance, and/or pain. All these factors could be preoperatively improved with a specific organization and expertise as demonstrated by the APS. It is also at this time that the preoperative anaesthesia protocol be determined as a function of all these factors (e.g., regional anaesthesia). It could be a good moment for patient education. The answer would not be based on or only with opioids. Many publications have demonstrated; not only on the best-known old side effects of opioids (e.g., nausea and vomiting); but more on aspects most recently highlighted (such as tolerance, hyperalgesia, increased risk of cancer recurrence or metastasis).

With such APS organizations, we could expect to improve all the enhanced rehabilitation programs. At this time, the cost efficacy of the APS could be clearly demonstrated. This is particularly true if the specific billing is attributed to such activity. So, there is an urgent need that funding of these APS is recognized. It is important that all the medical insurance companies (private or governmental) recognize the importance of the APS for the further benefit of the patient and thus reimburse the cost of its daily functionality. Eventually, it would save money since the post-surgery patient would need less postoperative management and will go back to work sooner.

Jean-Pierre Estebe, MD, PhD, has a recognized international expertise on pain.

Apart from his activity as anaesthesiologist, he was responsible for a Chronic Pain Centre (University Hospital of Rennes, France), and then head of an Acute Pain Service (Trauma Centre, University of Washington, Seattle, USA). Currently, he is the president of the association for Opioid Free Anaesthesia (OFA) and he is actively involved in the realization of numerous meetings on general anaesthesia, regional anaesthesia and more especially on pain management.

He is elected a member of the Directory Board, and member of the Scientific Board Committee of the French Society of Anaesthesiology. He is also a member of Subcommittee Acute and Chronic Pain Management of the European Society of Anaesthesiology. He has written numerous articles in clinical and experimental research, has contributed to the writing of numerous books, and he has actively contributed to the production of French and European medical guidelines.

DAVIDE FARAONE

Secretary to the Ministry of Health

Ministry of Health

Davide Faraone is an Italian politician and since December 2016 the Parliamentary Secretary to the Ministry of Health of the Gentiloni Government.

Before, from 2014 until 2016 he has been the Secretary of State of the Ministry of Education, University and Research in the Renzi Cabinet. In March of 2013 he has been scheduled for the House of representatives in Sicily. Since 2009 he has been a group leader of the Democratic Party in the city of Palermo. In November 2001, he was elected town councilor in Palermo, and was re-elected in 2007. In March 2000 he was elected as the Secretary citizen of the Democratic Left of Palermo.

Since 2000, he was enrolled in the graduate program in Political Science at the University of Palermo and the degree was awarded on 1 March 2016.

He began his political activity in Youth Left, in Palermo suburbs (especially the former Zen), taking care of the area schools and serving as academic senator.

David Faraone was born in Palermo in 1975.

Davide Faraone distinguished himself for the battles waged on the transparency of administrative acts.

Since 2015, he is the President of the Italian Foundation for Autism, which promotes awareness of the disorder and to be a reference point for families, teachers, and territories.



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Adequate management and treatment of chronic pain is very important because untreated pain impacts on sufferer's quality of life, it is an economical burden for sufferers, their families and social systems. It is therefore crucial to raise awareness and educate professionals and patients on chronic pain issue.

Chronic pain cannot be ignored

The chronic pain domain is a complex one and is often contradictory, since everything rotates around the patient but the distress also spreads out to the familial, emotional, social and economic strata. A chronic pain patient represents a whole universe around which rotate feelings, persons and needs. And yet to this day our system has not taken into consideration these persons' needs.

Chronic pain affects an estimated 100 million people across Europe. During these last years, awareness on chronic pain has increased, however there is still a gap in policy and holistic information at a European level that safeguards the interests of patients with chronic pain.

Chronic pain has a very significant negative impact on the quality of life of patients, affecting daily activities and even the ability to work. In fact, persons affected by chronic pain are more frequently absent from work and are also forced to stop working earlier than others. The total cost for European systems for chronic pain is equivalent to about 300 billion euro/year. However, in order to calculate the real socio-economic impact of pain, it is also necessary to calculate the intangible costs (poor nutrition, sleep disorders, social isolation and so on), which in negative way impact the quality of life of patients suffering from chronic pain.

As a consequence of the picture I gave you, today the chronic pain domain and its socio-economic impact represent a priority area for action within European and national health policies. There are a lot of goals to achieve in chronic pain field. And to reach these goals a cultural change is required. Such a change requires a comprehensive and multi-disciplinary approach.

It is estimated that around 20% of European adults suffer from chronic pain, and the trend is growing. In other words, adopting policies that address the needs of these patients who are ultimately also EU citizens would have a wide ranging impact both in the short, medium and long term. The following impacts are expected:

- collection of data on chronic pain from all EU Member States which is comparable to each other;
- the implementation of an EU policy, which addresses the needs of persons suffering from chronic pain;
- NGO representatives, professionals and experts who are more aware and actively engaged in policy making on an EU level;
- better management of chronic pain in Europe;
- improved quality of lives as a result of the policies adopted at European and national levels;
- enhanced European networks and cooperation to combine resources and enhance cooperation at European level;
- better understanding by direct and indirect participants of the role and contribution of the EU in policy making.

No Pain Foundation (NPF) has been established in Malta to create a non-profit organisation for the purpose of carrying out social, educational as well as research and development activities in the field of pain management and pain therapies. All our activities are aimed at improving quality of life of patients suffering from chronic pain by raising doctors and citizens awareness and supporting patients suffering from chronic pain. The No Pain Foundation aims to influence health related policies and practices for the welfare of the patients suffering from chronic pain.

NPF is affiliated with Pain Alliance Europe (PAE), a Pan-European umbrella organisation of 33 national associations in 16 EU Member States. NPF is Contributing Member of the European Pain Federation-EFIC (which is a multidisciplinary professional organisation in the field of pain research and medicine, consisting of the 37 chapters of the International Association for the Study of Pain-IASP).

JOSÉ INÁCIO FARIA

Member of the European Parliament, Portugal

Group of the European People's Party (EPP)

Born in 1962 in Viana do Castelo. Lawyer with a postgraduate degree in Environmental Law and currently preparing a PhD thesis in International Public Law at the Universidad of Cáceres. As a lawyer, José Inácio Faria provided legal support to the Lisbon City Hall from 1992 to 2012. His responsibilities included running the City Hall International Relations Office, assisting several Environment aldermen, and providing legal advice directly to the Mayor's Office and to the Institutional and Social Departments of the City Hall. From 2012 to 2014 he provided legal and political support to the Partido da Terra Political Group at the Lisbon Municipal Assembly. President and Electoral Coordinator of Partido da Terra-MPT (2014-). MEP since 2014.



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Our health systems need organizational improvement in order to deal, in the best way possible, with pain patients; we are often concerned with the financial aspects of our national health systems, but first of all, we must prioritize quality of care, and promote patient-centred healthcare provision.



HON DR MARLENE FARRUGIA

Member of the Maltese Parliament

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With my professional hat on I have seen people who's life stops because of pain and I have helped within my professional competence. With my political hat on I want to make a difference to the life of people with Chronic Pain.

Marlene Farrugia is a Maltese Member of Parliament and founder and leader of the Democratic Party. She was formerly a member of the Nationalist Party, with whom she contested the General Elections in 1996 and 1998, and the Labour Party, with whom she was elected in 2008 and 2013, before resigning in 2015[1] and forming the Democratic Party in 2016.

Hon Dr Farrugia is a dentist by profession and she sees her work as a means of helping society. From a young age she was involved in Civil Society and has at heart Maltese traditions, heritage and what makes the Maltese what they are. She is known for her outspoken nature and has been a vocal critic of matters in which she believes in even if it means criticizing her party on a number of issues.

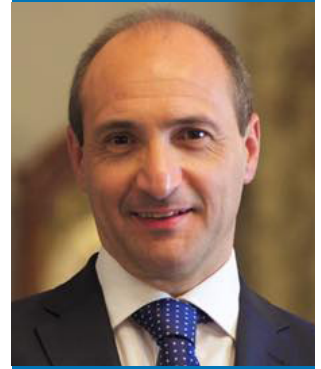
When I was invited to participate in the Societal Impact of Pain 2017, Pre-Symposium I accepted willingly as in my dual role as a health professional and politician I believe that I can contribute to the development of future pain policies in Malta. Using one of my favorite quotes "Do unto others as you would have them do unto you" Luke 6:31 I want to contribute to people's lives as if they were part of my family, especially people in pain where there is no gender, race, belief or social status.

DR CHRIS FEARNE

Minister for Health

Maltese Government, Department for Health

Hon. Christopher Fearne was born in Attard, Malta on 12 March 1963. Prior to his appointment as Parliamentary Secretary for Health in April 2014 he worked as a Consultant Paediatric Surgeon and Clinical Chairman at Mater Dei Hospital. He is a Member of Parliament for the ruling Labour Party and was the Chairman of the Foreign and European Affairs Committee at the Maltese House of Representatives. Hon. Fearne has been working as a doctor and surgeon for the last 27 years. He received his formal education at St. Aloysius College and at the University of Malta graduating in Medicine and Surgery in 1987, becoming a Fellow of The Royal College of Surgeons of Edinburgh. Hon. Fearne worked and studied in a number of children's hospitals in England, including the Great Ormond Street Hospital in London. Hon. Fearne is a founding director of the Malta Institute for Medical Education and the chairperson of the Celebrities for Kids, voluntary NGO promoting children's rights. As a student, Hon. Fearne was involved in a number of youth organizations. He has served as Secretary General of the Maltese Federation of Youth Organisations, officer within the University Students' Council, KSU, and in the Malta Medical Students' Association, MMSA.



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As a doctor, I know all too well the fundamental importance of European cooperation in the area of health. In these uncertain times, Europe must face its common problems together to ensure that its citizens get the best healthcare possible. I am certain that a platform such as the Societal Impact of Pain is an example of a vehicle towards achieving this goal.

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LAURA FERNANDEZ MALDONADO

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Can chronic pain coping and management be improved through an online training strategy?

Laura Fernandez

In 2000 she joined the Foundation as project manager and researcher, where she works as responsible of Patients' and Citizens Area and the Patients' University Project. Masters Diploma of Advanced Studies in Sociology, her key qualifications comprise to engage patients' and citizens in their self-management, empowerment and active aging, by means of providing skills and tools to help them to cope with their health status. She has been working in research projects to have a better knowledge about the factors that interact in quality of life perception, the patient centered care model, disease monitoring (including treatments adherence), and the acceptance of technology in health. She has also contributed in the design and patients' engagement of a series of advocacy and health educational programs across Spain, Latam and Europe. Since 2016, she has been coordinating the Online Chronic Pain Fundació Grünenthal Lecture Room (Patients' University). She develops research link to patient's views and preferences to increase their participation, in addition to health literacy. She has worked with multiple stakeholders in health Spanish System. She collaborated from 2004 to 2011 with the Spanish Patient Forum and she was the director of the Catalan Patient Forum. Since 2008 he has the Chronic Disease Self-Management Program Master Training certification by the Stanford University.

Fundació Salut i Envel·liment UAB

Expert centre in the field of ageing and health. The Foundation performs research on all aspects of health promotion and active aging, both clinical and social, with a long history of research among others on chronic diseases, dementia (including mild cognitive impairment and Alzheimer's disease), physical activity, falls, frailty, nutrition, disability assessment, as well as assistive technologies for the elderly. FSIE is an assessor of the Catalan government in the matters of chronic diseases and long term care for the patients and elderly, and we have frequent contact with patients, caregivers and elderly people associations, as well as nursing homes, long term care centres, etc.

DR MARIA FELICE-KLAUMANN MD, MSC FAMILY MEDICINE

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Malta and the aging population: The new challenge: Palliative Care

Malta's attraction is its geographical location. Lying in the middle of the Mediterranean Sea. It is steeped in history, and throughout the ages has been invaded by many nations and civilizations. Today Malta is part of the European Union and is still as attractive as in the past. A lot of people migrate in winter to the sunny island or come and retire here. Mediterranean people have a longer life expectancy. This is a new challenge for the medical profession.

My personal life is full of migration. My parents lived in Malta and I was born here. The professional career of my father influenced the whole family, so that we moved to the Caribbean and back to Germany. Malta remained at my heart and so I came back to participate in my Famulatur in Malta. When I met my husband, and decided to stay in Malta once more, I started to work in the NHS. Coming from a University hospital in Düsseldorf, I had to learn differences in dealing with the patients. In Malta, the family played an important role in the treatment, consultations etc. Decisions would be taking by the whole family.

When I started working in private practice, I learned about the support these big Maltese families would give each and every family member. Palliative care was taking mostly place in the family home with the family doctor. 1989 the Malta Hospice Movement was founded and nowadays is helping over 1000 patients a year. It is a non-profit-making organisation, which has to finance 75% of its expenses from donations and volunteers. Since Mater Dei Hospital opened in 2007 the pain clinic and the palliative care unit were introduced. The demand on the pain clinic has grown steady. The government is now joining into a partnership with the church and the Malta Hospice Movement and will open a palliative care hospital in the near future.

Seeing that Malta is attractive for a lot of northern European nationals to come and to retire here, with no or limited family support, added to this the longer life expectancy in the Mediterranean, as well as the smaller family constellations, the importance of this project is so much needed.

Education

- 1980-1984 Catholic Primary School Pulheim
- 1984-1993 private school of the Ursulinen in Cologne which led to A-level and qualification for university
- October 1993 started course of medicine university of Rostock
- Summer 1997 Physikum-State exam Rostock
- October 1997 Heinrich-Heine University (HHU)Dusseldorf
- 1998 1st State exam at the HHU Dusseldorf
- 2000 2nd State exam at the HHU Dusseldorf
- 2009 Master of Science in Family Medicine
- Since 2003 working in private practice

Palliative care is becoming a very important sector and needs further development, especially here in Malta.



PROF PATRICE FORGET

Vice President

Belgian Pain Society

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Chronic pain prevention and management are still unresolved issues. Searching for new avenues as sharing existing best practices is not only ideal, these are our responsibilities for the community.

Prof. Patrice Forget, M.D. Ph.D., attended medical school at the Université catholique de Louvain (UCL). He is anesthesiologist teaching and taking patients in charge in the operating room and the chronic pain management unit at the Universitair Ziekenhuis Brussel (UZ Brussel).

He is involved in clinical research, studying pain and the impact of surgery and anesthetic drugs (non-steroidal anti-inflammatory drugs) on cancer outcomes at the Vrije Universiteit Brussel (VUB). For the last ten years, as main investigator and/or national coordinator, he published more than 80 articles, letters and/or abstract. He is vice-president of the Belgian Pain Society, Cochrane and REDCap consortia member.

DR BRONA FULLEN

Physiotherapist

Health Science Centre, University College Dublin

Dr Brona Fullen is a lecturer in the UCD School of Public Health, Physiotherapy and Sports Science, Dublin, Ireland. She holds a BSc Physiotherapy (UUJ), MSc Healthcare (Acupuncture, UCD), and PhD (UCD) degrees. Clinically Brona specialized in the topic of pain working in Pain services at Massachusetts General Hospital, Boston, St Vincent's University Hospital and Tallaght Hospital Dublin.

In UCD she teaches in the area of pain science to both undergraduate and postgraduate students. She is Director of the UCD Centre for Translational Pain Research. Her research areas of interest include the assessment and rehabilitation of people with chronic pain in a range of conditions including musculoskeletal dysfunction, obesity, and spinal cord injury. She has supervised MSc and PhD students to completion, and has presented her research at national and international meetings.

Brona is a past President of the Irish Pain Society (Chapter of the International Association for the Study of Pain), and the first Chartered Physiotherapist to be elected to the European Pain Federation EFIC® Executive Board.



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The burden and cost of pain to society needs to be addressed by all stakeholders.



JUAN GARCIA BURGOS

Head of Medical & Health Information

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The European Medicines Agency (EMA) praises the work of patient organisations to improve health outcomes and patients' quality of life.

EMA is committed to continuously develop meaningful methods of collaboration to ensure patients' needs, views and concerns are timely considered in medicines development and evaluation. Pain Alliance Europe (PAE) is one of the several organisations with whom EMA works closely together according to its specific eligibility criteria.

Juan Garcia Burgos is Qualified Medical Doctor from the University of Autonoma in Madrid, specialised in urology. Juan worked as an urologist surgeon at the hospital Gregorio Maranon in Madrid. He joined the European Medicines Agency in 2002 in the scientific Units and was responsible for coordinating the preparation of EU clinical guidelines for drug development. He took up new responsibilities in 2005 where he was appointed Head of Medical and Health Information, being directly involved in the interaction with Patients, Consumers and HealthCare Professionals' Organisations and the preparation of information on benefit-risk of medicines for lay audiences. In January 2017, he was appointed Head of Public Engagement Department (ad interim) and is Co-chair of the EMA patients' and healthcare professionals' working parties.

MARIA SOLEDAD GARCIA PENALTA

Member of the Management Board

PAE (Pain Alliance Europe)

Maria Soledad García Penalta lives in A Coruña, Spain. She works as a Senior Officer Assistant for the CorBI Foundation (Coruña Biomedical Institute Foundation: <http://www.corbifoundation.org/>). This institution promotes biomedical research, education for young researchers, and brings science to citizens through a series of lectures and workshops.

With a background in International Relations and Immigration Law, she is a lifelong volunteer, supporting different causes, from acting as a pro-bono paralegal for immigrants seeking asylum in the United States and also victims of domestic violence under the Violence against Woman Act (VAWA) to her current volunteer positions on the Management Boards of PAE and ASPERGA.

She is an activist and a patient’s advocate and considers that in order to change the society we live in we must take responsibility and get involved.

She is a member of the management board of Pain Alliance Europe (PAE), an institution that aims to promote awareness for chronic pain, promoting a European policy to reduce the impact of chronic pain on the European society on all areas. A chronic pain patient herself, she firmly believes that the experience of pain represents a substantial burden on both individuals and the economy, not only with reduced participation in the labour force and increased absenteeism and presentism, but with substantially higher patterns of healthcare resource utilization. Changes are necessary and time for patients and professionals to work together to pressure the legislatures to update and universalize health systems across Europe to establish more equal and effective coverage for everyone.

She became involved with the ASPERGA (Asociación Galega de Asperger: <http://www.asperga.org/>) in 2009. As a mother to a teenager with Asperger Syndrome and being exhausted from having to deal with a system that lacks resources and governmental support to deal with the issues of children presenting with this pathology, she decided to join this association, seeking professional and personal support. She became a member of the management board of ASPERGA in 2014 and was elected its president in June 2016.



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At PAE (Pain Alliance Europe), we believe in giving the patient the right to choose the best possible solution and support to live their life according to their possibilities and wishes. We must act as patient’s advocates to change the system.



PASCAL GAREL

Chief Executive

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Promoting good practices, showing how active patient, professionals and researchers are in fighting chronic pain are major driving forces.

HOPE joined last year the Active Citizenship Network initiative "European Civic Prize on Chronic Pain - Collecting Good Practices" concluding in Malta on the occasion of this symposium. Healthcare systems are extremely diverse in Europe and they have a lot to gain to share practices and knowledge.

HOPE was created 50 years ago, to promote such exchanges in the field of hospital and healthcare organisation and still does today in various fields including pain.

Pascal Garel is Chief Executive of HOPE (European Hospital and Healthcare Federation). Educated in political science and European law, he became Hospital Manager with the diploma of the French National School of Public Health. Following a twelve-year experience in hospitals, he created the International Department of the French Hospital Federation, worked in French Ministry of Health, and teaches (Paris Dauphine and National School of Public Health).

ELENA GENTILE

Member of the European Parliament, Italy

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We know people with neurological and chronic pain conditions may find it difficult to get or keep a job because of stigma and social bias or because of physical, behavioural or cognitive limitations that are symptoms of the disease or side-effects of treatment.

We know integrating people with a chronic pain or a chronic brain condition in employment is socio-economically beneficial. Getting people who want to work, back to work decreases the volume of disability allowance and early retirement payments.

Elena Gentile (2 November 1953) was born in Cerignola (Province of Foggia, Italy), where she currently lives. She successfully graduated in Medicine at the University of Padova in 1978 and worked as paediatrician at the hospital of Cerignola from 1981 to 2005. Ms. Gentile dedicated over 30 years working in regional and local politics. In 1985 she was elected to the Municipal Council of Cerignola and from August 1985 to July 1986 she was Vice-Mayor of Cerignola, responsible for health, environment and social services.

From September 1990 to June 1991 she was Councillor for urban planning and budget administration. In July 1991, she was the Mayor of Cerignola. From May 2005 to June 2014, she was member of the Regional Assembly in Puglia and she held high-profile ministers in the regional government, being responsible for Welfare and Social Affairs and then for Health. From December 2013, she is also Member of the National Board of the Democratic Party in Italy. In 2014, Ms. Gentile was elected to the European Parliament representing the electoral district of Southern Italy and joined the group of the Progressive Alliance of Socialists and Democrats (S&D).

Ms. Gentile is currently Full Member of the Committee on Employment and Social Affairs and of the Delegation to the EU-Montenegro Stabilisation and Association Parliamentary Committee. She is also substitute member in the Committee on Regional Development, in the Committee on Environment, Public Health and Food Safety and in the Committee of Culture and education as well as in the Delegation for relations with Bosnia and Herzegovina and Kosovo.

G
Keeping workers healthy has a direct and measurable positive impact on productivity, and contributes to improving economic growth.



ILARIA GIANNICO

Secretary General

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The European private hospitals support quality, safety and painless treatments for all patients.

Graduated in Italy and Belgium, and trained at international level, Ms Ilaria Giannico holds an Advanced Master in Interdisciplinary Analysis of European Construction and she speaks four languages.

Ms Ilaria Giannico is experienced in EU Affairs and EU funding programmes. Her professional background includes the collaboration with the Belgian-Italian Chamber of Commerce and the activity at Confindustria Delegation to the EU, working in close relationship with the EU institutions. She was appointed UEHP Secretary General in July 2016.

NELIA GOUVEIA

PHD

NOVA CRU Manager

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EpiReumaPt Team aimed to estimate the burden of Chronic Low Back Pain (CLBP) in the adult Portuguese population, under the scope of EpiReumaPt study.

EpiReumaPt (Portuguese Epidemiological Study of Rheumatic Diseases) was the first national large population-based and prevalence study of rheumatic and musculoskeletal diseases (RMD). It was performed among a randomized and representative sample of 10,661 adult Portuguese subjects recruited in Mainland, Azores and Madeira Islands, from September 2011 to December 2013.

To avoid recall bias, active CLBP was defined based on self-reported pain on the day of the interview and for most of the time for at least 90 days (independently from cause). LBP was defined as pain in the back area from the lower margin of the twelfth ribs to the lower gluteal folds, with or without pain referred to the lower limbs. Burden was measured taking into account the following outcomes: quality of life, function, healthcare resources consumption, analgesic and other pain relief drugs intake, anxiety and depressive symptoms. Results showed that the healthcare consumption and social burden of CLBP among adult Portuguese population were enormous, and the disability caused by CLBP among subjects in a working age provides high rates of absenteeism (work loss) and poor quality of life, with a consequent socioeconomic burden.

The research work also confirmed that the prevalence of anxiety and depressive symptoms among adult Portuguese subjects with active CLBP was high. Regarding pharmacological therapy, the intake of analgesic and other pain relief drugs was higher among subjects with anxiety and/or depressive symptoms, when compared with subjects without these psychological symptoms. Anxiolytics, sedatives and hypnotics, antidepressants and NSAIDs intake had higher usage rates among these subjects. The pain intensity mean was also higher among this subjects and function and health status was worse.

CLBP is a common health problem among adult Portuguese population contributing to disability and affecting labor performance, and the well being of subjects. It is also responsible for considerable healthcare resource consumption. Anxiety and depressive symptoms are common among subjects with CLBP and provided an additional burden among them.

CV Background:

Nélia Gouveia is pharmacist since 2003, and medical student since 2016. She has dedicated the last 10 years to clinical research. Since March 2011, Nélia Gouveia was co-investigator and study manager of EpiReumaPt (Portuguese Epidemiological Study of Rheumatic Diseases). Currently, Nélia Gouveia is Investigator in NOVA Chronic Diseases Research Center (Lisbon, Portugal) as well, the NOVA Clinical Research Unit (NOVA-CRU) manager. NOVA CRU is the Clinical Trial Unit (CTU) of NOVA Medical School of Universidade Nova de Lisboa (NMS|UNL) and aims to support academic research, providing national and international networking.

When it becomes chronic, Low Back Pain causes an enormous economic burden on individuals and society - it is one of the leading causes of loss of productivity and economic independence through absenteeism, presenteeism and work disability.

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BORIANA GORANOVA

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Directorate-General for Economic and Financial Affairs

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Chronic pain can have a severe impact not only on the individual's quality of life, but can also be associated with considerable societal and economic costs. Finding and implementing innovative and cost-effective measures to improve the situation of chronic pain patients can have numerous and wide-ranging positive effects, deserving the efforts made in order to achieve them.

Boriana Goranova is working as a policy analyst on sustainability of public finances with special focus on health and long-term care systems at the Directorate General for Economic and Financial Affairs in the European Commission. Previously she has been involved in the European Commission's work on health systems in their social protection function and on further developing health information systems.

Boriana Goranova has an educational background in International Economic Relations and Business Administration from Universities in Bulgaria and Germany. She holds a PhD in Health Economics from the University of National and World Economy in Sofia.

**DR MARIO GRIXTI
MD, FMCFD, DIP CLIN ONCOL (LOND),
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Spec in Palliative Medicine, Spec in Family Medicine

Department of Primary care

Impact of Pain in Maltese Citizens

The Primary objective of this research is to collect data about chronic and severe pain in Malta. The burden of pain in Malta will be characterized by collection of Quantitative data about severity and burden of pain will be collected by using certified questionnaires SF-36v2 1. The collected data will serve as a baseline measure to assess the current quality of pain care and to assess the socio-economic burden of pain in Malta; The outcome will be used to convince policy makers and other decision makers to ensure an adequate pain care and to improve the situation of the patients as needed.

Having worked in oncology and palliative medicine for twelve years in secondary care, I am now directing my efforts to address the accessibility of patients with chronic pain to therapeutic interventions at primary care level. It is imperative that in Malta we start by gathering quantitative data on severity and accessibility of the population to therapy clinics and to patient outcomes and needs. At present ,this data is lacking and until such a study is carried out one cannot properly quantify the social impact and economic burden of pain in Malta and address patients needs.



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HERESA GRIFFIN

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Throughout my political career I have held the strong belief that everyone should have access to quality employment – regardless of their circumstances. One difficult and under-debated barrier into work is poorly managed pain. Chronic pain and lack of proper holistic pain management often pushes individuals into early retirement, or keeps them out of work, when they would otherwise chose to keep working.

In May 2014, Theresa was elected to the European Parliament, as the top Labour Party candidate in her region, to represent the North West of England. Theresa is a member of two committees in the European Parliament. She is a full member and Labour Party Spokesperson for industry, research and energy and a substitute member on the transport and tourism committee. Theresa also follows the Disability Rights, the Digital Agenda for Europe, Children's Rights and Well-being, LGBTI, SMEs, Tourism, Trade Union and Urban Intergroups. Theresa has been a Labour Party member for 26 years; an active campaigner at local, constituency, national and European levels. She was a member of Unite's North West Political Committee and represented the North West Constituency Labour Party on the National Policy Forum. As a Liverpool City Councillor in the 1990s, she was lead member for Economic Development and Europe and was instrumental in bringing Objective One status and billions of pounds of investment to the Liverpool city region. In the European Parliament, Theresa has been working on issues concerning fuel poverty, regional funding, equalities and disability rights, the promotion of a digital single economy, and climate change. Theresa is a committed trade union activist and has campaigned closely with all unions on employment rights, rights for young people and against the far-right.

FRANÇOISE GROSSETÊTE

Member of the European Parliament, France

Group of the European People's Party (EPP)

On 11 October 2001, I hosted the launch, in the European Parliament, of the inaugural EFIC European Week Against Pain. The purpose of the Week was to raise awareness of chronic pain as a disease in its own right amongst decision-makers, doctors and the general public, with a view to improving access by patients to the treatments available for it. 10 core objectives of the Week were identified. Three of them are as follows:

- To inform decision-makers of the significant impact that chronic pain has on patient morbidity and quality of life, avenues for improvement, and anticipated social and economic benefits for Europe.
- To inform decision-makers of the cost-effectiveness of available pain relief modalities and encourage their incorporation into health fund coverage and management modalities.
- To seek ways of reducing governmental obstacles to analgesic availability and use.

15 years and many "European Weeks Against Pain" later, there is little evidence that these objectives have been heard by European governments, let alone met. Most critical of all, however, is that the fundamental message of the "European Week Against Pain", that chronic pain is a disease in its own right and should be treated as such, continues to be ignored. Whilst strategies are developed to combat other diseases across Europe, there is no such strategy for chronic pain, only an irregular hotchpotch of policies that provide little by way of a framework for improvement.

I therefore whole hardly support the objectives of the symposium on the Societal Impact of Pain where all stakeholders seek to improve pain policy under the motto "Time for Action!"

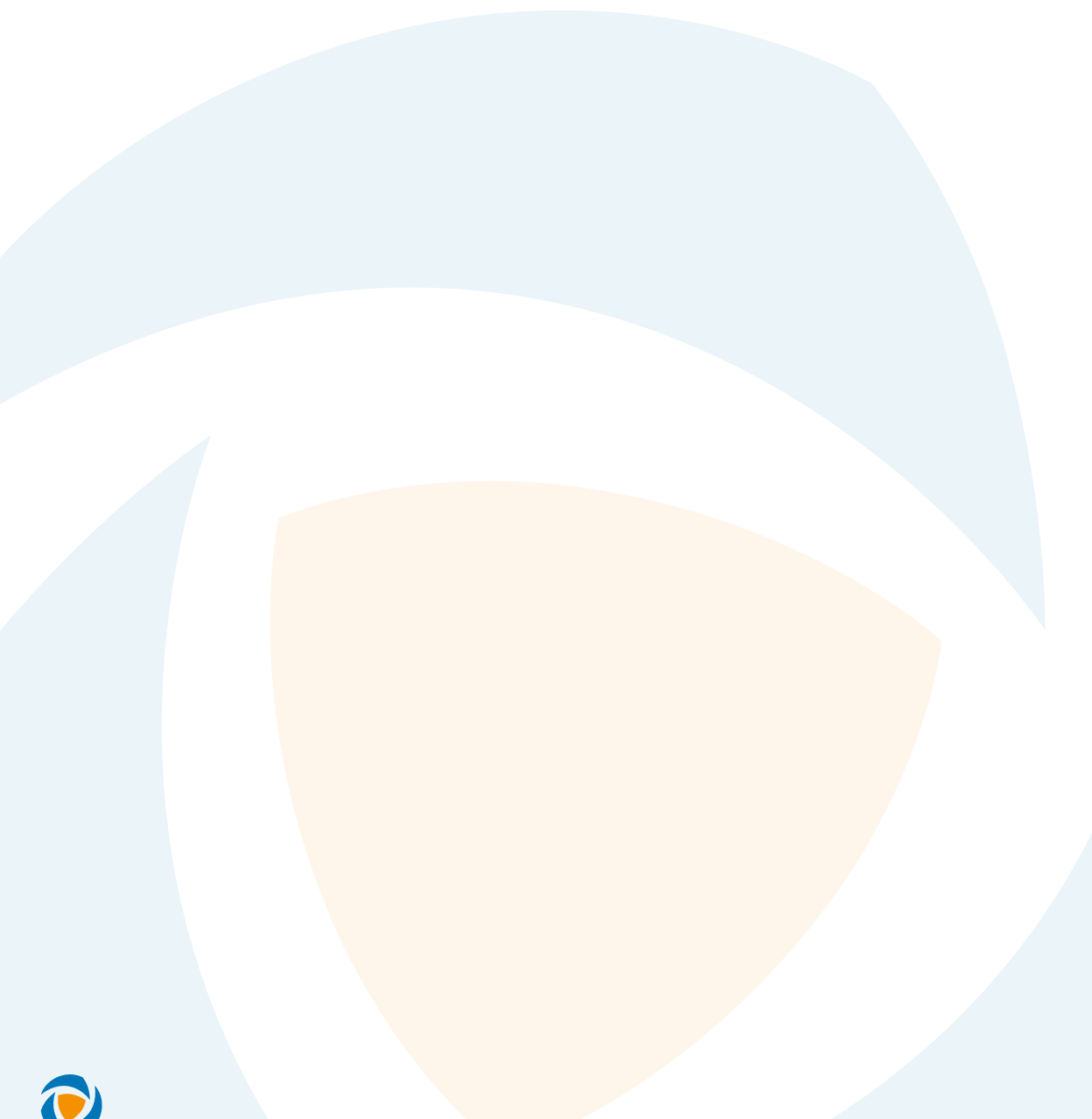
Françoise Grossetête is a Member of the European Parliament and 1st Vice-Chair Group of the European People's Party (EPP - Christian Democrats). She has been a French Member of the European Parliament since 1994 and was previously a municipal councillor then deputy mayor of Saint-Etienne (France, Rhône-Alpes). She is a member of the committee on environment, public health and food safety (ENVI) and substitute member of the committee on industry, research and energy (ITRE). Françoise Grossetête is Chairwoman of The European Alliance Against Alzheimer's and of the European Cervical Cancer Association which are multinational and cross-party groups that unite Members of the European Parliament.



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I whole hardly support the objectives of the symposium on the Societal Impact of Pain where all stakeholders seek to improve pain policy under the motto "Time for Action!".



MARIAN HARKIN

Member of the European Parliament

Group of the Alliance of Liberals and Democrats for Europe (ALDE), Ireland

Marian Harkin is an Independent MEP representing Ireland in the European Parliament since 2004. Marian is a member of the Employment and Social Affairs Committee, a substitute member on the Economic and Monetary Affairs and substitute member of the Petitions Committees.

Her legislative work has included the EU Globalisation Fund, which assists redundant workers to access education and training or start their own businesses, where she was Parliament chief negotiator during the last term.

Other dossiers this term include the rapporteurship of the Employment Committee's Opinion on Recommendations on the negotiations for the Transatlantic Trade and Investment Partnership as well as following files on the guidelines for the employment policies of the Member States 2016, the framework agreement on parental leave and the post-electoral revision of the MFF. Marian will lead for ALDE on the anti-discrimination directive and is currently the ALDE shadow for EMPL opinions on the European Accessibility Act and the proposal for a new European Structural Reform Support Programme.

As well as her legislative work Marian has a deep interest in Social and Public Health issues. She is Chair and founding member of both the Carers Interest Group and the Volunteering Interest Group and is also Vice Chair of the Mental Health Group, Epilepsy Support Group, the Brain, Mind and Pain Group. She is a member of the MEP Heart Group, LGBTI Intergroup, and MEPs against Cancer Group, the Intergroup on Ageing and Solidarity between Generations, and the Social Economy Intergroup.

Other areas where Marian remains active include her support for Credit Unions, her support of independent living for persons with disabilities and for adequate services for children with special needs, as well as work in the area of political transparency. Marian visits schools on a very regular basis to debate and explain her work and makes every effort to link in with and support community endeavours.



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The Societal Impact of Pain is a campaign I have supported for a number of years. Chronic pain can have a significant impact on patients individually as well as on our health systems and societies. This year I want other Members of the European Parliament to join me to push for improved policies affecting pain care.

H



TAKIS HADJIGEORGIU

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Chronic pain affects a large proportion of the adult population in Europe. It is our duty as elected representatives of this people to do our utmost to ensure that European policies in the health sector have at their core this population group.

As Vice-Chair of the intergroup for rheumatic and musculoskeletal diseases, I closely track the developments in the health sector and I must say that Europe is still far away of achieving that “basic need” of universal access to health care and to provide to people affected the essentials for their living.

Takis Hadjigeorgiou is a Cypriot politician, who has been serving as a Member of the European Parliament since 2009. Coming from the Progressive Party of Working People (AKEL) in Cyprus. He has also served as Member of the Cyprus House of Representatives for two tenures. He is currently Vice Chairman of the EU-TURKEY Joint Parliamentary Committee as well as Member of the committees on foreign affairs (AFET) and petitions (PETI) respectively. Takis Hadjigeorgiou is also Vice Chair of the European Parliament Interest Group on rheumatic and musculoskeletal diseases (RMDs). Since his completion of his academic studies in Law and Journalism, his political and social activities have had an active and lasting impact in Cyprus society.

DR ROBERT JAKOB

Medical Officer

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The International Classification of Diseases (ICD) 11 in development

The International Classification of Diseases (ICD) is a key instrument of the World Health Organization. Initially developed for coding causes of death, continuous evolution now renders ICD useful for coding morbidity, as well as recording specific diseases, injuries, signs, symptoms, complaints, social circumstances, reasons for presentation and external causes of both injury and disease. ICD informs public health bodies, clinicians and researchers alike in the evolving environment of increasingly complex health systems, ensuring the provision of language and system-independent definitions that are applied for:

- National and international health statistics (mortality and morbidity);
- Epidemiology, surveillance, and monitoring;
- Individual patient records and electronic health records;
- Reimbursement and health system financing;
- Reference for treatment guidelines, scientific literature and research;
- Quality assessment at the level of individual cases up to assessment of health system outcomes and monitoring.

Developing countries bear a large burden of disease with many of their health systems lacking resources in the face of an overwhelming tide of urgent and life threatening demands. Effective deployment of ICD-derived tools would facilitate the use and collection of health information under such challenging circumstances and therefore facilitate quantitatively informed decisions. Historically, ICD is revised approximately every 10 years, with the exception of the 20-year period between the last two revisions, ICD 9 and the most recent version, ICD 10. The WHO Secretariat provides support for the transition from ICD 10 to ICD 11.

Goals for the ICD revision: ICD 10 to ICD 11

1. Update ICD to accommodate new scientific, clinical and public health knowledge
2. Accommodate the use cases mortality, morbidity, primary care, casemix, quality and patient safety
3. Define diseases and categories with a pattern of symptomatology and manifestations, etiology, course and outcome, treatment response, and genetic factors and environmental factors
4. Integration and cross-referencing with health-related terminology systems, making ICD fit for use in electronic health information systems
5. Harmonize with ICD-related and derived classifications as well as other members of the WHO Family of International Classifications
6. Work in multiple languages
7. Use of internet-based technologies for information gathering, integration and sharing, and digital curation, allowing for broad, participation and consultations
8. Planned field tests
9. Electronic and print copies
10. Accelerate global implementation plans with particular focus on developing countries

Some 160 experts in over 15 groups are reviewing and proposing edits to the classification. The results of this work can be seen in real time (4 to 48 hours delay) in the ICD-11 Alpha browser online on the WHO website. Experts are invited to review relevant sections of the classification. Volunteers can register online to contribute to the reviews (<http://www.who.int>).

ICD Revision Timelines

May 2011: Open ICD-11 Alpha Browser to the public for viewing; July 2011: Open ICD-11 Alpha Browser to the public for commenting; May 2012: Open ICD-11 Beta to the public; WHO will engage with interested stakeholders to participate in the ICD revision process; May 2015: Present the ICD-11 to the World Health Assembly

Individuals will be able to:

- Make comments
- Make proposals to change ICD categories
- Participate in field trials
- Assist in translating

The ICD is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use. The new design makes ICD-11 fit for electronic health records, includes scientific updates, and acknowledges the needs of its de facto uses (mortality, morbidity, casemix, primary care, quality and patient safety). Pain is a relevant aspect in health. The needs and ways of reflecting pain in the international classification of diseases need to be laid out and addressed in discussion with the specialty tags and the reviews.

J



DR WOLFGANG JAKSCH

President (until May 2017), afterwards Past President

Austrian Pain Society

The supply of care for approx. 1.8 million Austrians with chronic pain is not guaranteed due to lack of a comprehensive demand planning of pain care facilities. One of the most important issues to set up a multi-stage concept in pain care is quality assurance. We need a high qualification of the health care providers in pain care and on the other hand clear quality criteria and classification of management facilities.

Under the patronage of the Austrian Pain Society, various national specialist societies have defined the structure and quality criteria for pain management centers in Austria, include, among others, proof of training, cooperation in interdisciplinary teams or minimum number of new patients per year, depending on the different classification of the institution.

This stepwise concept of care provision for pain patients is intended as first step to help improve the care of pain patients in Austria!

Dr. Wolfgang Jaksch is

- Diplomand of the European Academy of Anaesthesiology
- President of the Austrian Pain Society until May of 2017
- Member of the scientific board of the No Pain Foundation
- Head of Pain Medicine – Acute Pain Service, Department of Anaesthesiology, Wilhelminenspital, Vienna.



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We have to pool all our forces and to act in concert to reach our objective: A nationwide coverage of high quality pain management, which meets international criteria!

J

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ROBERT ANDREW JOHNSTONE FRSA

Patient Advocate; Chair: Access Matters, Midstream; Board Member; European Patients Forum (EPF), Healthcare Quality; Improvement Partnership (HQIP).

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Having had Rheumatoid Arthritis for nearly 60 years from the age of three, I have a wealth of experience as a user of health services.

Since 1990 I have voluntarily represented people with disabilities & chronic conditions locally, nationally & internationally.

“The people have the right & duty to participate individually & collectively in the planning & implementation of their healthcare”
Alma Ata Declaration – Principle IV, 1978
World Health Organisation

AGNES JONGERIUS

Member of European Parliament, The Netherlands

Group of the Progressive Alliance of Socialists and Democrats (S&D)

It is my sincere believe that we should take pain and especially chronic pain seriously. Pain can have a devastating effect on people's physical and mental wellbeing. Although our knowledge of pain and how to prevent it has increased in the past years, I believe that there is still a long way to go.

Agnes Jongerius (1960) is a member of the European Parliament for the Dutch delegation of the Socialists and Democrats group since 1 July 2014. Jongerius is vice-chair of the Committee on Employment and Social Affairs. Born in Vleuten, a small village in the Netherlands, she started her career at the Dutch trade union of the transport sector. From 2005-2012 she was chair of the Dutch federation of Trade Unions (FNV). Thereafter she was an associated researcher at the expert centre for institutions of the Open Society at Utrecht University, where she studied the question how citizens can be better involved in the European Union.



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More research on pain therapy is needed and successful therapy should be promoted more, as well as training to cope with pain. It is time for real action.

J



LIISA JUTILA

Vice President

Pain Alliance Europe (PAE)

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Chronic pain changed everything, the rate of finding the right treatment, rehabilitation and not forgetting the financial situation. These are issues all patients need to deal with. Institutions, associations, volunteers and professionals are key to easing our lives.

Mrs Liisa Jutila, the vice-president of Pain Alliance Europe (PAE) lives in Tohmajärvi, Finland. She has lived with chronic pain for 19 years and knows very well all the steps from the beginning of the fight to everyday life acceptance.

From the age of 10 she has dreamed of working in the field of logistics. After vocational school she worked for several years as a truck driver before continuing her studies to BSc. During and after these studies she worked as a transport manager and her expectations were high when she graduated from University of Plymouth as a MSc in international logistics.

Unfortunately, towards the end of her studies, a slipped disk changed her plans and the ensuing chronic pain forced her retirement. In 2002, she started work as a volunteer at the Finnish pain association (Suomen Kipu ry), which works to increase the knowledge of chronic pain and its impact on everyday life and to improve conditions of people living with chronic pain. With her own experience she knew how important awareness and information is not just for the patient but also to their family and friends. Cooperation with politicians and decision makers and healthcare professionals is essential. In 2005 she became a president of the Finnish pain association.

She continues her work for patients at Pain Alliance Europe. She was one of the founders, starting as a board member and later becoming the vice president. At the same time, she stepped down from the Finnish pain association presidency and become a delegate for international affairs.

She strongly believes that all countries and also Europe need a strong organisation that will promote awareness of chronic pain and help remove its stigma; an association which works closely with all the people and institutions whose aim is allow chronic pain patients and their close ones to live better and more easily. It is time for cooperation with policy makers, professionals and patients.

AMIRA KARKIN TAIS

President of Bosnian Pain Association APTBH

Bosnian Pain Association APTBH



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The initiatives of APTBH for the "pain treatment and SIP" in B & H remains the same until further notice "The need for institutional solutions, capacity development and awareness raising"

1. Occupation

- Gen. Surgery-Dept of Anaesthesiology, July 1974 - 1996
- Chief of Anaesthesiology
- Medical coordinator/ Anaesthesiologist and Pain therapist,
- Acupuncturist, Pain Therapy Center; Avgust 1996 - 2011
- HOPE 87, Sarajevo
- Doctor practitioner in Pain therapy department in the Private polyclinic, 2011 - 2017
- EUROFARM, Sarajevo

2. Establisher of Pain Therapy Center HOPE 87, Sarajevo

Establisher of Assotiation for Pain Therapy BiH, Nov 1996 - April 2004

- President of APTBH, 2004/2017

3. Lecturer and leader continuing Pain education for B&H, 2006 - 2017

4. Medical presentation, Projects, publication etc.; Book " Lijecenje bola" - autor Karkin-Tais, ISBN 9958-41-026-5, COBISS-ID 6521862 Publ. TKP Sahinpašić, jun 1999

- Broshure about ATPBH
- Guideline for job description in Pain praxis for 7 new Pain Centres and their work in BiH
- Guideline for diagnostic and therapy of Headaches on 20 pages, in 800 copies for BiH

5. Organiser and coordinator Joint Pain Symposium with INPS from London (UK.2007) for 200 participants from BiH, Serbia, Balkan

6. Author and Coordinator of Projects (UNESCO, JICA, Austria Government), 1995/98 - 2013

7. Coordinator in HOPE87 together with APTBH on Pain project "Establishing a Pain Management Network in Bosnia-Herzegovina", 2007/11

- Efficiently organised 7 Pain Units on University Clinical Centres and Hospitals based on community and institutional support.
- Education Activities: Organize in-country seminars on pain and continuing education.
- Efficiently organised 1 Pediathric Pain Units on University Clinical Centres
- Efficiently organised Pain in CBR(comunity based rehabilitation)

8. Organiser and coordinator I Pain Congress in BiH with international participation

9. Member of IPS Executive Committee) IASP Pain Declaration, Montreal

10. Member of EFIC Board for Education

11. Analyze an epidemiological and health economic data of the chronic pain population (Author, organizer, lecturer and coordinator for the projects:

- Prevalence of Chronic pain in in BiH
- Analyze an epidemiological and health economic data of the chronic pain population in BiH

12. On 2013 Monitoring on projects "Comprehensive Pain Management at UNITS in B & H"

Our goal is common,
and that is to help
patients who suffering
from pain as a cancer,
and non- cancer, chron-
ic costing health more
than a well-organized
system of treatment
pain.

K



DR DOEKE KEIZER

General Practitioner

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It is my strong belief that people with chronic pain deserve better healthcare, outside the hospital walls. In order to achieve this goal, healthcare professionals need to co-operate on a structural basis. Such co-operation should be financially stimulated by the authorities and healthcare providers.

Dr. Doeke Keizer is general practitioner in the small town 'Harkema', in Friesland (The Netherlands). He has a broad experience with working as a doctor in a multidisciplinary setting at the Pain Center of the University Medical Center Groningen (UMCG), where he obtained his PhD in 2009. Doeke Keizer has published in leading national and international journals and (co-)authored three books on the subject of pain. On behalf of the Dutch College of General Practitioners (NHG), he participated in the two taskforce groups that established national guidelines for the management of pain in the Netherlands.

In 2011, he was one of the founders of Transcare-pain (TP); a co-operation of healthcare professionals that aims to improve the care for patients with chronic pain. The Transcare-method is evidence-based, and in its view every type of pain needs integrated bio-psycho-social diagnosis and treatment. The TP-method turned out to be successful, and other Transcare-teams have been implemented in the North of the Netherlands throughout the last two years.

Doeke Keizer's presentation will be about this Transcare-pain co-operation. Does it work and how does it work? What is needed to co-operate adequately? How is it funded? What are the pitfalls?

BRIAN KENNEDY

Executive Director

Global Alliance for Patient Access

Since its founding in 2006, Brian Kennedy has served as Executive Director of the Alliance for Patient Access, a U.S. based network of physicians with the shared mission of promoting health policy that ensures patient access to appropriate clinical care and approved therapies. AfPA accomplishes this mission through educating physicians on health policy issues and mobilizing them to be effective patient advocates.

Along with its physician leadership, Mr. Kennedy has led AfPA to be the nation's largest multi-specialty physician organization solely focused on health policy issues impacting patient access. On behalf of AfPA and the related Institute for Patient Access, and the Global Alliance for Patient Access, Mr. Kennedy has overseen the development of dozens of policy and advocacy initiatives including those relating to biologic therapies, prescription drug abuse and balance pain management, infant health, clinical trials awareness, cancer treatments and respiratory care.

Prior to founding AfPA, Mr. Kennedy's professional career spanned the practice of law, campaign politics, government relations and corporate public affairs consulting. Over the course of his career, Mr. Kennedy has served as the organizer, manager and/or a strategic consultant to over a dozen coalitions and associations including the Alliance for Patient Access. Mr. Kennedy received a Bachelor of Arts in Political Science from Iowa State University and his J.D. from Drake University Law School. He is a member of the Iowa State Bar Association.



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The voices of patients and their healthcare providers are essential to ensure informed policymaking.

K



DR MED KRISTIN KIESELBACH MD

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A comprehensive and high-quality medical care for all patients suffering from chronic pain should be centered in health care policy and pain therapy. Federal social policy can facilitate the interaction of different health care structures.

German Federal Land – tailored approaches as a comprehensive model to a nationwide improvement of pain health care, e.g. Baden – Württemberg, Germany.

The medical care of patients suffering from chronic pain poses an important and urgent challenge in respect to individual suffering and the reduction of the health care economical impact. For Baden – Württemberg, an advisory board for pain health care, so-called “Landesbeirat Schmerzversorgung”, who counsels the Ministry of Social Affairs, was founded in the year 2000. In the same year, the advisory board developed and approved a concept for the improvement of centered pain –care, which could be implemented in most instances. By designation of certificated so-called Regional and Supraregional Pain Centers a major contribution to the improvement of pain health care could be achieved. These facilities were integrated in a graded pain care system. Beyond that structural criteria, processes and results in pain therapy were determined.

Currently the existing range of specified diagnostics and qualified pain therapy often still doesn't reach many patients with chronic pain in Baden – Württemberg sufficiently. Therefore the advisory board for pain health care of the Ministry of Social Affairs, the “Landesbeirat Schmerzversorgung”, updated the concept for the improvement of pain based on the current pain health care situation and in respect to the demographic development and defined appropriate recommendations. Essential elements therefore are the establishment and further development of comprehensive networking in respect of medical – sectors and the establishment of integrated health care programs. Besides residential (pain care) specialists, also comprehensive psychotherapeutical and physiotherapeutical supply has to be established and integrated. A stronger involvement of patient organisations has to be put in practice as well. These approaches shall optimize the health care situation and quality of life of patients suffering from chronic pain timely and locally. The meanwhile implemented cooperative network also serves as a platform for further education and multicentric research.

Kristin Kieselbach, MD, specialist on neurosurgery and pain therapy, is since 2011 Medical Director of the Interdisciplinary Pain Center of the Medical Center, University of Freiburg. The Interdisciplinary Pain Center works since 2012 as a self-directed organization. Patients are treated in an outpatient manner, in a day-care clinic and in an inpatient ward with multimodal and interprofessional pain care “under one roof”. Kristin Kieselbach is engaged in health care policy and contributes to the medical chair of the advisory board for pain health care of the Ministry of Social Affairs Baden - Württemberg, the “Landesbeirat Schmerzversorgung”. She also participates in several working groups of the German Pain Association and has a leading part in collegiate education and education for residential specialists.

PROF DR PER KJÆRSGAARD-ANDERSEN

Head of Section / 2. Vice President

Section for Hip & Knee Replacement, Department of Orthopaedics, Vejle Hospital, South Danish University, Denmark / European Federation of National Associations of Orthopaedics and Traumatology (EFORT)



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Clinical experience

2007: Associate professor in Orthopaedic Surgery at University of Southern Denmark

2002: Head of Sector for Hip and Knee Replacement, Department of Orthopaedics, Vejle Hospital, Denmark

Earlier Employments within Orthopaedic Surgery at Odder Hospital, Kolding Hospital, Aalborg University Hospital, Vejle Hospital at South Danish University, Aarhus University Hospitals and The Orthopaedic Hospital, Aarhus in various positions a.o. Administrative Consultant

Administrative experience

2016: 2. Vice President, European Federation of National Associations of Orthopaedics

2012: Secretary General, European Federation of National Associations of Orthopaedics and Traumatology (EFORT)

2011: President for 12th EFORT Congress in Copenhagen, Denmark

2010: Consultant Chairman for the Norwegian Government regarding Health Task Organisation within Orthopaedic Surgery in Norway, Region South-East

2010: Board Member in Danish Medical Association for advising the Danish Government / Danish Health Institute in organisation of the medical specialities

2008: Editor-in-Chief for the Orthopaedic Newsletter "Orthopaedics Today Europe"

2008: Chairman of the Danish National Board of Health task group concerning specialist planning in orthopaedic surgery

2008-2010: Chairman / president of the Danish Orthopaedic Society

2007-2011: Co-opted member EFORT Executive committee

2001-2006: Chairman / president of the Danish Society for Hip and Knee Surgery

1998-2011: Expert Advisor in the Danish Health Authorities Patient Complaints Board

Teaching

- Clinical Lecturer at University of Southern Denmark since 2004;
- Clinical Lecturer at Aarhus University Hospital 1994-1998;
- Annually since 2002: Lecturer at "A seminar" in hip joint arthrosis for orthopaedic residents.

Most surgeries performed within the speciality of Orthopaedic Surgery – are performed due to pain. Therefore, naturally the patients expect to be either pain free or have reduced pain after surgery. As this cannot always be obtained, we as surgeons MUST both learn about types of pain, pain treatment programmes – and also to communicate to patients that pain will not always totally disappear with surgery.

K



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It is time to move from raising awareness and attention to committing to action on pain treatment. Chronic pain is one of the largest cost blocks in healthcare and one of the largest economic cost blocks resulting from job losses. SIP provides a platform to learn from one another. We must use the opportunity to learn from the diverse approaches used by different countries.

DR ALBRECHT KLOEPFER

Secretary General

Büro für gesundheitspolitische Kommunikation

Dr. Albrecht Kloepfer is a political adviser, journalist and a literary scholar, who has taught at various universities in Berlin and Tokyo from 1987 to 1999. From 1996 to 2001 he was correspondent of the magazine "Deutschland", published by the Germany Federal Foreign Office and the German Federal Press Office. Since 2000, he has supported companies and associations from all areas of healthcare as a moderator and strategic consultant.

Since 2002 he has been editor of the "GesundheitsPolitischer Brief" ("Health Policy Letter"), a weekly news overview on German health policy, as well as head of the Berlin "Büro für gesundheitspolitische Kommunikation" ("Office for Public Health Communication").

Since 2006, he has been hosting the "Gesundheitspolitischen Kamingsgespräche" ("healthcare policy making get-togethers") on a weekly basis at the Hotel Adlon in Berlin.

Since 2007 he has supported the "Berufsverband der Ärzte und Psychologischen Psychotherapeuten in der Schmerz- und Palliativmedizin in Deutschland e.V. (BVSD)" ("Association of physicians and psychological psychotherapists in pain and palliative medicine in Germany") as their political adviser.

Since 2013 he has been the honorary director of the non-profit organization "MetaForum - Innovation for More Health".

In 2014 he founded the "iX – Institut für Gesundheitssystem-Entwicklung" ("iX – Institute for Health System Development"), whose management he has been responsible for since its inception.

DR ANDREAS KOPF

Oberarzt

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The key to meet the patient's needs for adequate pain management is awareness and the tool for awareness is implementing pain medicine as a mandatory cross-sectional field of teaching in the undergraduate and postgraduate education. Such an initiative should be multidisciplinary and multi-professional.

K



DR EVA KOSEK MD, PHD

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Eva Kosek, MD, PhD is holding a position as full Professor in Clinical Pain Research at Karolinska Institute, Stockholm, Sweden. She received her medical degree from the Uppsala University in 1986 and her PhD from the Karolinska Institute in 1996. She is a specialist in rehabilitation medicine and pain relief and currently active as senior consultant at Stockholm Spine Center, Sweden. Dr. Kosek's research focuses on pathophysiological mechanisms in chronic musculoskeletal pain, with special reference to central pain modulation in fibromyalgia, chronic low back pain, osteoarthritis and rheumatoid arthritis. The research is hypothesis driven and the research group uses a wide variety of techniques such as genetics, quantitative sensory testing and imaging (functional magnetic resonance imaging, positron emission tomography).

The understanding that chronic pain is not necessarily a symptom but can result from altered nociceptive function and thus constitute a condition in itself is not reflected in the current IASP terminology. Therefore a third mechanistic descriptor is much needed.

Dr. Kosek is an elected Councilor of the International Association for the Study of Pain (IASP) and Chair of the Terminology Task Force. She is a member of several professional associations such as Scandinavian Association for the Study of Pain (SASP), the Swedish Medical Association and the Swedish Medical Association for Pain Relief. Dr. Kosek is a reviewer for several scientific journals and has published many articles, book chapters and abstracts. She has lectured at conferences and symposia worldwide.

SAM KYNMAN

Executive Director

European Pain Federation EFIC

Taking on the role of Executive Director at the European Pain Federation EFIC in March this year was an exciting challenge. I worked in politics for five years in the UK and, focusing in the final two years on EU health policy. After working for a global public affairs agency on EU health policy for a further three years, the opportunity at the European Pain Federation presented itself. The Societal Impact of Pain platform was my major project whilst working for the public affairs agency, and I have grown familiar with the challenges faced by the European Pain Federation, and the opportunities ahead of it to grow in significance and impact.

The last Societal Impact of Pain symposium was a major milestone on the path to achieving significant change within health policies and, eventually, health systems. The policy recommendations that emerged from the 2016 symposium should be built on by the partners and collaborating organisations taking part in this year's symposium. I have personally seen that the door of the European Commission is open for our ideas.

Beyond the Societal Impact of Pain platform, the European Pain Federation are making great strides in terms of establishing a Europe-wide educational approach to pain medicine, via a Core Curriculum, an Examination, and a Diploma. Some policies are fundamental to tackling the societal impact of pain, but we will also hopefully see positive change via a wider understanding of pain medicine and the elevation of healthcare professionals with a deeper grasp of pain conditions.



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The societal impact of pain is poorly understood and still massively underappreciated. Pain medicine is growing in importance, and healthcare practitioners, represented by the European Pain Federation EFIC, will need to play a crucial role in mitigating the impact of pain on individuals and society in the future.

K



MERJA KYLLÖNEN

Member of the European Parliament, Finland

Confederal Group of the European United Left - Nordic Green Left

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In our modern society where the ability to work and be a productive and important member of a workplace defines our perceived position among our peers to a high degree, to be able to live a meaningful and contributing life even with chronic pain, has an imperative meaning to all of the patients and their families.

Last year here in Brussels, I wanted to address the huge toll that chronic pain takes on patients, their families and also the society, and the positive impact of adequate pain treatment for healthcare systems. This year I would like to draw your attention to the impact of pain in labour and employment.

It is estimated that every fifth Finnish person of working age suffers from pain that has become chronic that is so intolerable that it may lead to losing the ability to work. According to reports, the easy and swift access to adequate treatment is still on an insufficient level along with significant regional differences in accessibility, as well as quality.

Besides causing unnecessary and completely avoidable burden on patients who are suffering from chronic pain and cancer pain, this leads to huge societal costs. According to statistics, the total annual cost of back pain and musculoskeletal disorder, which are among the most frequent causes of chronic pain, can range from 1.1 billion euros in Finland to the staggering 300 billion euros in the whole the European Union.

With early and correct diagnosis, followed by adequate and efficient pain treatment that is designed to meet with every patient's individual needs and circumstances, most of these costs could be reduced and redirected for example to new job creation or management of the impacts of mass migration to the EU.

But most importantly, in our modern society where the ability to work and be a productive and important member of a workplace defines our perceived position among our peers to a high degree, to be able to live a meaningful and contributing life even with chronic pain, has an imperative meaning to all of the patients and their families.

With this, I would like to offer my support to the Societal Impact of Pain in 2017 and send my warmest wishes to those among you, who I had the pleasure to meet with and learn from last year here in Brussels, when the symposium was held last year in the European Parliament.

Merja Kyllönen (born 1977) is a Finnish Member of the European Parliament in the GUE/ NGL Group, representing the Left Alliance. Ms Kyllönen is a member of the committee on transport and tourism and a substitute member in the committee on environment, public health and food safety. She is also a member in the committee of inquiry on emission measurement in the automotive sector, which recently concluded its work. Ms Kyllönen is a former Minister for Transport in Finland (2011-2014). She started her political career at 19, and served as a councillor in her home town Suomussalmi from 2000. She was a member of the Finnish parliament 2007-2014. Before concentrating on full-time political work, she had a career as a professional in healthcare, working e.g. in hospital and pharmacy.

GIOVANNI LA VIA

Member of the European Parliament, Italy

Group of the European People's Party (EPP)

Mr. Giovanni La Via is a Member of the European Parliament since 2009. He is a Member of the Environment, Public Health and Food Safety Committee (ENVI) and of the Budgets Committee (BUDG). He has been Rapporteur for the new Common Agricultural Policy 2014-2020 and General Rapporteur for the EU budget 2013. After the re-election in July 2014 as MEP, he has served as Chairman of the Committee on Environment, Public Health and Food Safety (ENVI) of the European Parliament. He has served as Regional Minister for Agriculture and Forest in Sicily (2006-2009). He is full Professor at the University of Catania. As a delegate of the Rector of the University of Catania, he started and co-ordinated the "European Office" working on European projects planning and management between 1994 and 2000. He has been responsible for several research projects such as Sprint, Ritz and Fair. He has been named as expert evaluator of the 5th RTD Framework Programme. He is the author of many scientific papers and articles which have been published in referred national and international journals.



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L



DR TEA LALLUKKA

Academy Research Fellow

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Pain is a serious public health and societal challenge. A notable proportion of working aged people suffer from chronic pain, which can lead to work disability and early exit out of the paid employment. The risk of early exit can potentially be shaped e.g. via modifiable risk factors.

Biograph:

Tea Lallukka, PhD (social epidemiology), is an adjunct professor in nutrition and public health, from Helsinki, Finland. Her current work is focused on mental and musculoskeletal epidemiology, and labor market participation. She has more than 100 international peer-reviewed publications, with most studies done using occupational cohort data and focus on e.g. socioeconomic inequalities, working conditions and work disability.

Background for presentation:

Since musculoskeletal conditions remain as a key cause for both sickness absence and permanent exit out of the paid employment due to disability, more evidence about risk groups and potential for modification of risk factors are needed for prevention and intervention across ageing populations. Such evidence can be further applied in social and health policies, decision making and used as a basis for national and EU level recommendations to promote work participation, extend work careers, and prevent work disability.

Previous research has shown that pain is a prevalent, persistent and recurrent condition in employed people, and people with pain have poorer functioning, more sickness absence and a high risk of disability retirement. Pain also disproportionately affects people with low socioeconomic position. Thus, pain is a notable burden not only on individuals and public health but also at societal level and economics due to high cost related to absenteeism and loss of productivity at work places. While pain is not a sufficient cause for disability pension, it could be an important trigger which highlights the importance to tackle its risk factors at an early phase.

The talk covers key socioeconomic and work-related determinants of pain outcomes during life course, and the current state of evidence about the role of pain in loss of work ability and transitions out of paid employment. Future directions to extend work careers are discussed based on the evidence.

DR BRITTA LAMBERS

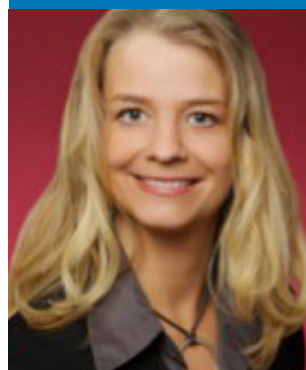
Engineer of Biotechnology, Scientist in Medical Research - Fresenius, University of Applied Science, Cologne, Germany; Member of the German Association for Patients with Chronic Pain Syndrome (SchmerzLos e.V.); Member of the German Pain Association (Deutsche Schmerzgesellschaft e.V)

University of Applied Science Fresenius; Skip. Institute

In general, the separation of health sectors for in- an out-patient care lead to solitaire work areas with reduced continuous therapy supervision and patients' adherence. Overcoming those system-inherited borders in the field of chronic pain, time and cost are a major factor due to the multiple health care instances and multimodal interventions. Therefore, cost reduction through defining therapy standards for interventions in the context of chronic pain has become one of the main focus for the future. Those European-wide discussions have been leaded by medical experts, but constantly, less attentions are being given to the patient perspectives. Patients do offer the only uninterrupted and continuous perspective on all health care processes. This sector-overarching and integral experience is also highly relevant for economical evaluations and therapy outcome in quality management.

Based on the bio-psycho-social aetiology of the chronic pain syndrome, multimodal interventions should be set up trans-sectoral and cover all three influencing components. Especially social-context focused interventions are still underrepresented, even though patient's ability to work is defined as a relevant yellow-flag influencing the progression of the illness. Therefore, the adjustment of the patients' physiological and psychological constitution with the job environment in combination with the team work of all involved sectors should be a constant part of medical guidelines – even expandable on other chronic illnesses. This would improve the intangible benefit for the patient, ensure the transfer of therapy targets in daily work and in general, increase the quality of multimodal settings.

Britta Lambers, with her professional background in basic medical research, has developed herself as a scientist and associate professor in the field of health economics at University of Applied Science, Fresenius. Furthermore, she is involved in the working group of patient information at the German Pain Society, consults the steering committee of the German Association for Patients with chronic pain syndrome (SchmerzLos), and represents the patients' perspective. For years, she has become a health consultant helping patients with chronic pain syndrome to get back to their job and has acted as a case manager.



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Facing the demographic development, there is one question to raise importantly - which nation will be able to afford the increasing numbers of early retirement caused by chronic pain syndrome? Also from patients' view, there is a strong need to include job preservation as one of the main therapy targets.

L



PROF FRANÇOISE LAROCHE MD, PHD

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Chronic pain is not only an acute pain with long duration. It is a multi-dimensionnal illness which requires a bio-psycho-social approach. Developed countries have to deal with this major issue because of population becoming older and because of heavy socio-economic burden of chronic pain.

In France 30% of the population suffers from chronic pain but only 3% has access to pain departments.

Professor Françoise Laroche is a rheumatologist with a special interest in pain management. She currently heads the pain clinic of the Saint-Antoine Hospital, Paris, in France. Professor Laroche is the one of the founder and current vice-president of the French group of rheumatic pain specialists (CEDR) in 1997, an organization that links the French Society of Rheumatology (SFR) with the French Pain Society (SFETD).

She is in charge of coordination of teaching Pain Medicine at Pierre and Marie Curie - Paris Sorbonne University.

She has obtained a PHD in neurobiology and pharmacology in pain (2013), University Paris.

She is expert and therapist in Cognitive Behavioral Therapy (diploma 2000-2003) and has her psychotherapist French agreement (Agence Regional de Santé - France). She is supervisor of psychologists and medical doctor in CBT training. She works with the most important CBT association in France (ATTCC). She is the director of the only diploma of CBT for chronic pain in France (Pierre and Marie Curie - Paris Sorbonne University).

She has participated in several workshops to establish national guidelines on pain management. She has co-ordinated studies on rheumatology in the field of pain. Professor Laroche has worked on induced antiaromatase pain in breast cancer for several years at the French national medical research institute (Institut National de la Santé et de la Recherche Médicale [987 Inserm Unit – Physiopathology and clinical pharmacology of pain (A Paré Hospital, Boulogne), since 2007]).

Her primary areas of interest are fibromyalgia, osteoarthritis, low back pain and cognitive behavioral therapy in rheumatology.

She is currently expert at the French Drug Agency for analgesics, member of different editorial boards of pain journals. She is member of international scientific societies in pain and rheumatology: IASP, EULAR.

She is Medical Editor and Journalist for french rheumatology and pain journals, since 1993 and implements and organises of Permanent Medical Education In Rheumatology and Pain management, since 1993.

ROBERT LAUNOIS

Scientific Director

REES France

Robert Launois studied economics in Rennes, Paris and Cambridge Mass. He is an accredited fellow of the Facultés de Sciences Economiques, a graduate of the Paris Institute of Political Science and Commonwealth Fund of New York Harkness Fellow (Harvard University).

Professor of economics, he teaches health economics at the Paris V University Faculty of Pharmacy. Robert Launois is the Chief economist of the Network for Health Economics Evaluation (REES France 2000-2017) and a consultant to the administrative authorities and the pharmaceutical industry. His research interests are the evaluation of diagnostic and therapeutic strategies, health technology assessment and analysis of French and foreign social protection systems.

He has been a member of the Commission for the General Classification of Professional Procedures (NGAP Ministry of Health 1991-1994) and a member of the Laennec Hospital board (Paris Public Hospitals Health Service 1994-2000).

He was an economic expert to the Committee for the Common Classification of Medical Procedures (National Health Insurance Funds for Employed Workers 2004), member of the Health Accounts Commission (1996-2014), member of the national committee of experts for innovations (DHOS Ministère de la Santé 2014 – 2017), expert to the Haute Autorité de Santé (HAS 2009-2017) He is President of the Société Française d'Economie de la Santé (SFES).



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**Reinforce the battle
against pain, acute and
chronic pain, during
the care pathway is the
responsibility of all**

L



JEROEN LENAERS

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We have to focus on retention and integration of people affected by chronic diseases as well as to support reasonable adaptation of workplaces, which will ensure a timely return to work; we call on the European Commission to promote integration and rehabilitation measures for people with disabilities and to support Member States' efforts by raising awareness and identifying and sharing good practices on accommodations and adjustments in the workplace

Jeroen Lenaers graduated from the Master program in European Studies in 2008 and started working in the European Parliament as a policy assistant to the Dutch Christian Democrat delegation in the EPP Group. His main focal points during these 5 years were Foreign Affairs and Social Affairs & Employment. In 2014, after a successful campaign, he got himself elected Member of the European Parliament for the same delegation. Jeroen Lenaers is a member of the Committee on Social Affairs & Employment and a substitute member in the Committee on Civil Liberties, Justice and Home Affairs. Next to that he is the vice-chair of the DASE Delegation (South-East Asia).

DR LANA LEKIC

Head of Department

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Background

APTBH Initiatives and the development of the action plan of Pain management (EU policy) in Bosnia and Herzegovina were adopted, however not been applied in the practice and the situation remained unchanged. Main issues:

- Access to palliative care.
- Legislation on the accessibility of opioids for cancer pain.
- Absence of waiting lists for pain drugs and drugs that are funded by the Solidarity Fund.

Current state

Identified barriers for the implementation: dysfunctional government, complex health system, lack of strategies. From everyday experience pain is inadequately treated because of different reasons:

- Limited availability of opioids and other control drugs in pain treatment
- Lack of specialized pain services (Palliative care)
- No systematic approach in patients' access to pain management options.

Activities

'APTBH - Time for Action' – 2 documents have been translated (November 2016)

1. Societal Impact of Pain 2016 policy recommendations: Time for Action and
2. Recommendations of APTBH on the Action Plan on PM and B&H

Both documents have been resubmitted to relevant ministries in December 2016: Ministry of Civil affairs B&H (Government), Ministry of Health of the Federation and RS, Cantonal Ministry of Health and National Drug agency. Deputy Minister announced the Federal MoH started working on overall strategy for palliative care in which there is one segment of pain therapy. Concerning education on pain therapy, APTBH made a good progress through CME (2004/2016) - pain school in line with EFIC "Pain Management" curriculum for the Faculties of Medicine in Europe. The agreement has been reached with the Medical Faculty of the University of Sarajevo to include pain therapy in curriculum. Communication with the Ministry of Civil Affairs in the Government (Council of Ministers) is ongoing and there is a visible progress in development of strategies based on documents provided on December 2016.

Conclusion

There are big challenges in front of us because country is in the process of joining the EU. The initiatives of APTBH for the "pain treatment and SIP" in Bosnia and Herzegovina remain the same until further notice "The need for institutional solutions, capacity development and awareness raising". Our goal is common - to help patients suffering from both cancer, and non- cancer pain, the conditions which are, if not treated properly, more costly for society than a well-organized system of treatment pain.

Pain is strong

Together, we are
stronger!

Take control!

L



DR ANDRE LJUTOW

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The lack of an official recognition of chronic pain as a disease of its own right and the lack of an official recognition for pain medicine leads to a fast growing number of self-declared pain specialists/ special units with unknown quality in Switzerland. Awareness is slowly growing, that this situation leads to even more costly and inefficient treatments. To intensify the dialogue concerning this matter between medical professionals, politicians, insurance companies and other stakeholders is necessary.

André Ljutow started a surgical education after completing his medical studies at the University of Bonn in 1983. He received a training as an orthopaedic surgeon at the university of Lübeck and furthermore added a special training in rheumatology in Wiesbaden. He took the chance to enter the Pain Centre in Mainz, the first clinical unit for interdisciplinary pain medicine in Germany, as a senior consultant. Until the retirement of the chef and founder of the centre, Prof. Gerbershagen, he stayed twelve years in the interdisciplinary team. Since 2004 he took a leading role in the interdisciplinary enlargement of the Centre for Pain Medicine at the Swiss Paraplegic Centre in Nottwil/Lucerne, Switzerland. The centre is build following the IASP recommendations as a comprehensive pain centre, including eleven different medical, psychological and therapeutical professions, treating all kind of pain, performing education and research. From 2007 to 2009 he participated in a master study at the university of Vienna in interdisciplinary pain medicine ISMED. In 2013 he became head of the department in Nottwil. Since three years he is president of the Swiss Association for the Study of Pain SASP, the national chapter of IASP.

ISABELLE MACAL

President

Association Francophone pour Vaincre les Douleurs

Many years of chronic illness and the accompanying pain, encounters with other patients who also lived this daily life, allowed me to mature my reflection about the loss of control, on its existence, that the sick person is going through. On the basis of this observation, I wanted to consider the possibilities open to her to regain a power to act in her life course

It is on the basis of my experience and through the Therapeutic Education of the Patient (TEP), taking into account the reality of the patient's experience, his posture as an actor and the alliance with the healthcare team, that I started my training course.

After a university diploma in TEP, then a Bachelor of Science in Education, I continued on a Master TEP Project Engineering.

I am now a framework coordinator in a structure supported by the Regional Health Agency of Brittany. I work with institutional bodies in Public Health and support teams in the construction and implementation of therapeutic education programs.

I developed my training organization and intervened with healthcare professionals wishing to be trained in therapeutic education, either in initial training in university or training institutes for future doctors, nurses, physiotherapists ... or in lifelong learning.

This course led me to be a member of the jury in training of Therapeutic Education of the Patient.

The writing of posted papers or oral interventions at various conferences, congresses, allow me to address the approach of the patient, the work in interdisciplinary and the wealth brought in this new care management.



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This patient association works in partnership with people with chronic illnesses, with their entourage and with health professionals in support in the management of pain.

M



SOUZI MAKRI

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**Cooperation between
all stakeholders is
pivotal for the wellbeing
of the patient!**

Souzi Makri has been working as volunteer with the Cyprus League Against Rheumatism (CYPLAR) since 2008 and she is currently the Executive Secretary of the Central Committee and the coordinator of the Limassol office (her home town). As a volunteer, she is one of the trainers the of the "self-management" workshop. As a member of the volunteers' force, Souzi is actively involved in organizing events, conferences, and various other activities for fund raising.

Souzi has been trained as a Patient Research Partner by EULAR and she has become a EUPATI Fellow, after completing a 14-month course in the research and Development of medicines. As a patients advocate she is a on the list of Expert Patients of the EMA.

Souzi has been elected Chair of AGORA (Platform) Organization for representing people with Rheumatic diseases in Southern Europe) in September 2011. Since January 2015, she is the President of ENFA (European Network of Fibromyalgia Associations).

Souzi has a BA degree in Economics and has completed two one- year courses at the Open University UK, in the field of Psychology.

ALBA MALARA

Scientific manager

European Confederation of Care Home Organisation (E.C.H.O.)

Alba Malara, MD, is a Geriatrician, she works as Medical Director in a Residential Facilities and Rehabilitation Centers as well as in several other nursing homes in Calabria. Since 2007 she works as Scientific Coordinator of the "Scientific Committee of National Association of Third Age Residences" (ANASTE). Since 2011 she is a scientific manager for the European Confederation of Care Home Organisation (E.C.H.O) Brussels, Belgium. Since January 2015 she is Chairwoman of Italian Society Gerontology and Geriatrics (S.I.G.G.) Calabria. She has participated in several multicenter studies and in April 2014 she led the multiregional study "Project Pain in RSA Italian: Support Network for Non-cancer Pain," in collaboration with the Center HUB Policlinico Umberto I, Rome.

She coordinated the scientific committee of various national and international conferences and the organization of several training courses for all health professionals. She is author of several scientific publications.

Dr Malara has set up a research methodology based on daily utilization of multidimensional geriatric assessment tests used for clinical practice in a network of nursing homes in Italy. Sharing the same assessment tools results in a wider database collecting of elderly patients' evaluations for a longer period of observation. In particular Dr Malara's research is focused on geriatric multidimensional assessment, dementia, behavioural problems, pain, polypharmacy and complexity, care of and of life, care quality and patients' quality of life.



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In elderly people and in dementia patients, pain is often ignored and under-treated. Dementia complicates the assessment of pain, because it impairs memory and verbal communication. Chronic pain can cause depression, agitation, and aggression in elderly and dementia patients if not adequately treated.

M



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The key to optimal management of chronic pain is a comprehensive assessment of the patient with persistent pain, rather than pain, per se. This assessment needs to take into account not only the site, duration, intensity and quality, and impact of pain, but also a wide range of possible contributors to the person's experience of pain, disability, and emotional distress. Furthermore, the importance of viewing pain through a multi-faceted lens allows one to understand pain as an interdisciplinary problem.

Chronic pain should not be underestimated anymore

The social impact of chronic pain on a national and community level should be considered as an urgent matter not to be underestimated anymore.

As Secretary General of the No Pain Foundation, and myself being a chronic pain patient, I think it is important to explain what Pain actually means, especially from a patient's point of view.

Pain means also dignity in the form of ability of the sufferer to fight pain, especially when it seems to take over and when the person's vested rights seem to be trampled over and irreversibly taken away.

Chronic pain not only represents a serious concern related to health ethics and social equality, but also places a huge burden on national economies.

I would like to refer to an article published in 2012 in Journal of Pain, in which it is noted that the Pain disease is linked to an estimated socio-sanitary cost of 600 billion dollars a year.

Chronic pain has a very significant negative impact on the quality of life of patients, affecting daily activities and in particular the ability to work. In fact, persons affected by chronic pain are more frequently absent from work and are also forced to stop working earlier than others.

In Europe, the number of leave days taken because of pain is estimated to be about 500 million, which represents an economic burden equivalent to approximately 35 billion euro annually. The total cost for European systems for chronic pain is equivalent to approximately 300 billion euro/year.

Pain is a subjective symptom and as such difficult to fit into one clear-cut definition. Chronic pain has always been considered a symptom of an illness, which needs to be diagnosed and treated accordingly. In reality, however, pain should be considered as an illness in itself, given that its chronic nature does not correspond to temporal but to physio-pathological criteria.

In spite of positive premises, the wider availability of evidence-based guidelines and the availability of pain-treating medication, a significant proportion of the European population still suffer from pain.

Chronic pain remains a challenge for medics and paramedics and remains a main health issue on a global level, both because of population ageing and because of the increase of chronic-degenerative diseases.

The chronic pain aspect, its socio-economic effect and most evident shortcomings in terms of support are priority areas for action within European and national health policies. The effective treatment of pain not only significantly improves quality of life but also prevents secondary disabilities.

VICTORIA MASSALHA SRP MHSC MMAP

President

Malta Association of Physiotherapists (MAP); Representative of European Region of the World Confederation of Physical Therapy (ER-WCPT)

Ms Victoria Massalha has been President of the Malta Association of Physiotherapists since 2014. Before this, she had actively contributed to chairing the Focus group formulating the Declaration of Principles on Continuous Professional Development as well as being highly involved in the MAP-ping process defining the future of Physiotherapy in Malta. She currently forms member of the Professional Issues Working Group of the European Region of the World Confederation of Physical Therapy for the term 2016-2018.

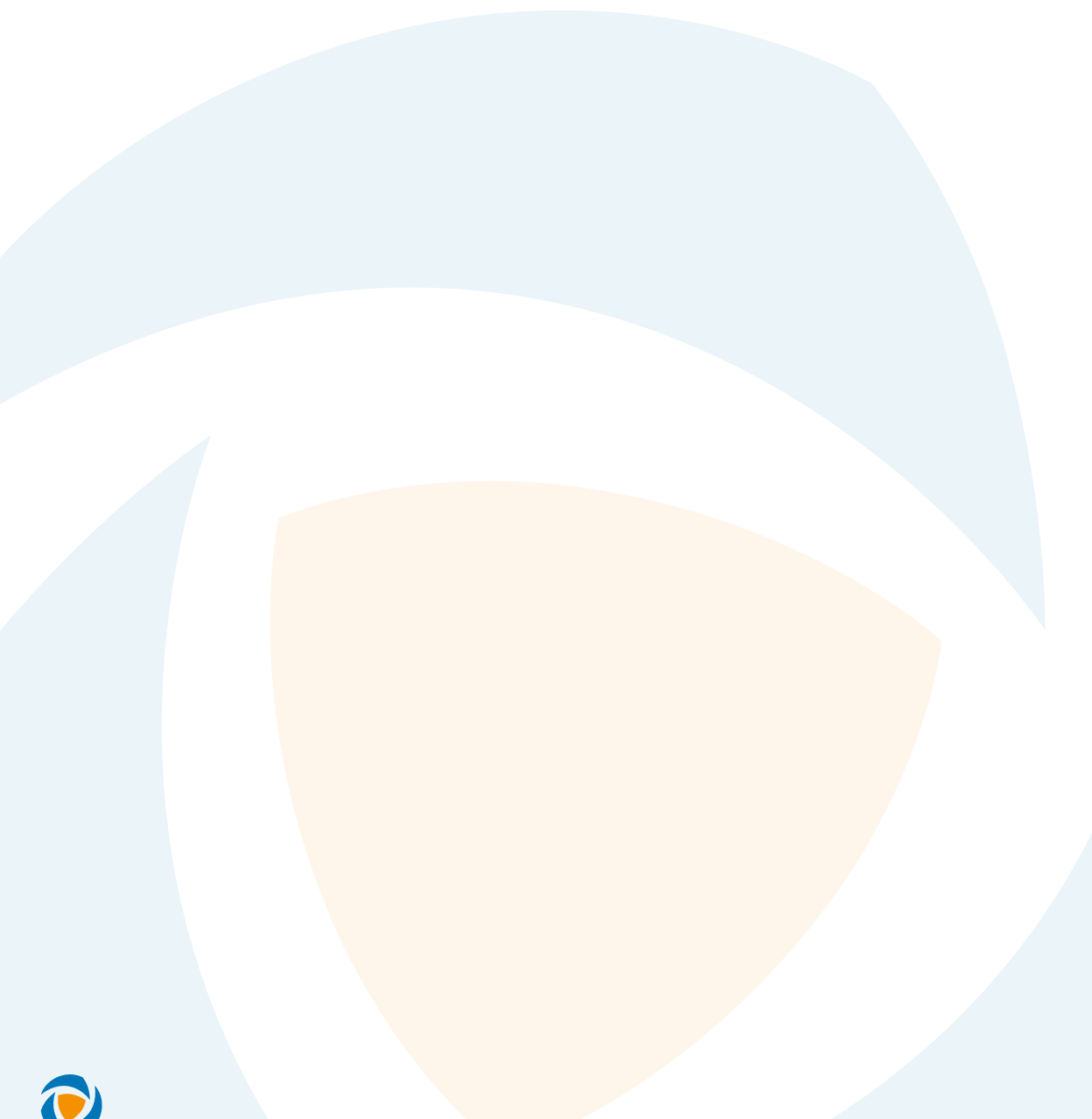
Throughout her career of thirty years as a Physiotherapist Ms Victoria Massalha has always strived to advance the Physiotherapy Profession and the role of the Physiotherapist. She currently holds the position of Professional Lead of Physiotherapy Services in the Ministry For Health and continues with determination to focus all efforts to bringing the Profession to the forefront on all issues and levels.

Ms. Victoria Massalha is also an Educator and has held the post of Senior Lecturer with the University of Malta since 2005.



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DR ELSA MATEUS

PHD IN ANTHROPOLOGY

President of the Board

Portuguese League Against Rheumatic Diseases (LPCDR)

More Participation, for a better health

We know that, in Portugal, rheumatic and musculoskeletal diseases (RMDs) are prevalent in 56% of the Portuguese population, and that Chronic Pain affects 30% of the adult population. Rheumatoid Arthritis, Osteoarthritis and Fibromyalgia are amongst the 4 most common causes for Chronic Pain. According to recent studies, self-reported RMDs are highly associated with early retirement, mostly driven by pain and disability, and representing an estimated annual indirect cost of € 910 million (around 0.5% of the Portuguese GDP).

Therefore, early retirement attributable to RMDs is an important public health issue, since its economic impact highlights the need for sustainable health policies.

In Portugal, the National Health Plan for 2012-2016 and its extension to 2020 consider citizenship-based strategies, including the involvement of patients/citizens and their representatives, as a key strategic axis to maximize health gains. However, concrete actions have been limited to a couple initiatives without significant patient or public involvement. Following the work developed by several patient and citizen organizations, advocating for increased and meaningful involvement in health decision-making, a working group was established with representatives from 13 patient organizations, 1 consumer organization and a research centre, under the project «More participation, better health – Promoting public involvement in health». A Charter for Public Involvement in Health, including the principles, scope, guidelines and means of participation was developed, using participatory action research methodology.

By promoting public involvement in health, so that the patients' perspectives can be taken in account, we believe we can contribute to enhance the general quality of our healthcare system.

Elsa Mateus has been diagnosed with Juvenile Idiopathic Arthritis in 1977. She is PhD in Anthropology (speciality Anthropology of Health). Since 2007, she has been involved as volunteer and patient representative in several rheumatic and musculoskeletal diseases (RMDs) patients' organisations, either at a national or European level. She is President of the Board of the Portuguese League Against Rheumatic Diseases (LPCDR), since 2015.

In 2014, LPCDR established a Chronic Pain Patients' Group, to raise awareness on the invisibility of pain, to share coping strategies and to reinforce patients' advocacy on this area. Representing LPCDR, Elsa Mateus is also involved in several projects with other patients' and consumers' organisations, that aim to ensure that the patients' perspectives and their rights are considered by the decision-makers.



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Meaningful involvement of patients' representatives as stakeholders in the decision-making processes, health care assessment and design, is required to improve the quality of chronic pain prevention and management.

M



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**Pain Do Check Act
in Pain Management
Policies and Center
Implementation. We
must learn from quality
management.**

Dr Philippe Mavrocordatos was born in Greece and grew up in Switzerland. He studied medicine in Lausanne University Medical School, Switzerland. Diploma in 1988. After training in Internal Medicine, he specialized in Anesthesiology (Board certified in 1995). His training in Anesthesiology was achieved in Switzerland and Australia where he completed his fellowship in Multidisciplinary Pain Management (Royal North Shore Hospital, Sydney).

Back in Switzerland in 1997 he was appointed « Head of the Departement of Anesthesiology Intensive Care and Pain Management » in the Centre Hospitalier du Nord Vaudois. He also opened during this period (in 1999) the Multidisciplinary Pain management in Clinique Cecil in Lausanne.

In 2002, he decided to return to a more academic activity and was appointed Médecin associé, in Geneva University Hospital. With his colleague, they developed the Interventional Pain Management Center. This center was ISO 9001 certified in 2003. The Clinic Cecil pain management center created in 1999 was also ISO 9001 certified in 2004.

He is the founder and CEO of the Swiss Pain Institute since October 2016. The institute took over the activity of the Cecil Pain center and is currently developing a new pain management concept based on a real interdisciplinary model associated to a specific diagnostic strategy in pain.

He is Fellow of Interventional Pain practice (FIPP) since 2006, examiner for the Budapest FIPP exams since 2008 and Chairman of WIP for Switzerland until 2015 and Honorary secretary since.

PROF DR WINFRIED MEISSNER

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Quality indicators (QI) are widely used in health systems to give an indication of quality of care. So far, most QIs are linked to parameters as mortality, complications, and resource use. Quality of life, pain or other “subjective” dimensions are rarely covered by QI. QI may measure quality directly (outcome) or indirectly (structures and processes). Indirect (surrogate) parameters should only be used if they are strongly linked to outcome quality. As a prerequisite, it is necessary to define “good outcome” for determining the appropriateness of QI. Most QI are based on quantifiable routine data. Patient-reported outcome measures (PROMs) – essential in the area of pain – are rarely used as QI. On the one hand, they are often considered as less “objective” than other data, on the other hand, assessment is resource-demanding because it needs direct interaction with the patient. An indicator should fulfill several conditions: it should be medically relevant and usable in (more or less) daily routine. In the area of pain, several QI have been proposed and/or used:

- Structure: Availability of dedicated personnel (e.g., Acute Pain Services), devices (e.g., PCA pumps)
- Processes: Regular pain assessments, use of protocols and treatments, prevention of complications, patient involvement, avoidance of i.m. injections
- Outcome: PROMs (e.g., pain intensity, pain reduction, perception of care), complications, duration of stay, costs, long term consequences. So far, few of these QI have been used in the context of generic quality assurance programs, and results are conflicting. Some process-related QI might even decrease overall quality by triggering over-treatment (“pain assessment as fifth vital sign”). On the other hand, other parameters have clearly been shown to be linked to increased quality of care (e.g., procedure and patient-specific pain management). In the talk, the potential benefits and problems of PROMs as QIs will be discussed.

After his residency as an anesthesiologist at University Hospital Berlin-Steglitz, Prof. Meissner was appointed head of Jena University Hospital’s Pain Unit in 1994, and head of the Palliative Care department in 2009. Since 2013, he is also head of the interdisciplinary Day Pain Unit.

His clinical expertise covers all aspects of pain management with a focus on acute pain and palliative pain treatment. He coordinates the two well-known acute pain registries QUIPS and PAIN OUT (www.pain-out.eu).

Patient-reported outcome measures (PROMs) are an essential part of monitoring quality of care in pain management; however they have carefully to be chosen and applied.

M



ROBERTA METSOLA

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People in chronic pain should not have to suffer in silence. Too often their plight is overlooked or underestimated and together we can do something about that. We need to raise awareness as to the impact that chronic pain can have on people, those who care for them and on their ability to work and enjoy life. Dealing with chronic pain must be put on EU Member States' health care agenda. It cannot be ignored.

MEP Roberta Metsola [PN, EPP] was elected to the European Parliament in 2013, becoming one of Malta's first female Members of the European Parliament. Professionally she is a lawyer who has specialised in European law and politics. She has previously worked at the Permanent Representation of Malta to the European Union and as legal advisor to the High Representative of the European Union for Foreign Affairs and Security Policy. MEP Roberta Metsola is the EPP Coordinator of the Committee on Civil Liberties, Justice and Home Affairs (LIBE), where she is the lead MEP on migration issues. MEP Roberta Metsola was also the co-rapporteur on the situation in the Mediterranean and the need for a holistic EU approach to migration. MEP Roberta Metsola is the Vice-Chair of the European Parliament Committee on Petitions (PETI) and a member of the Delegation for relations with the United States (D-US). She is also the Chair of the European Parliament Interest Group on Rheumatic and Musculoskeletal Diseases (RMDs), as well as a substitute member of the Committee on the Internal Market and Consumer Protection (IMCO) and the Delegation for relations with Australia and New Zealand (DANZ).

MIROSLAV MIKOLASIK

Member of the European Parliament, Slovakia

Group of the European People's Party (EPP)

Pain represents a complex phenomenon both from a medical and societal point of view. Quality of life of persons suffering from pain, either acute or chronic, is in most cases necessarily lowered due to numerous challenges they are encountered with on daily basis. People afflicted by pain are often not capable of performing their work duties and sometimes are may be even completely excluded from the job market. Taking part in social and family activities can be equally problematic and at times not possible at all. Despite a whole range of barriers patients have to deal with I worry that our society still does not pay enough attention and has not yet fully recognised seriousness of this problem. Therefore, I am grateful for the platform embodied by the Societal Impact of Pain symposium where stakeholders from relevant scientific fields, as well as policy makers can engage in fruitful discussions, and more importantly – agree on the importance of taking concrete steps. I deem crucial that we continue in our endeavour to push through the issue of pain further on the agenda both on EU and national levels. I believe that in 2017 it is finally time for European society to fully acknowledge a need to talk about pain, and to take the necessary action to effectively fight its negative implications so we could provide for more joyful and fulfilled life without barriers and deprivations for people who suffer mainly from chronic forms of pain caused by long-term or incurable diseases.

Miroslav Mikolášik, born in 1952 in Dolný Kubín, Slovakia, holds a postgraduate diploma in general medicine, anaesthesiology and reanimation. He completed his studies at the Faculty of Medicine of Charles University in Prague. During his political career, he was appointed Ambassador of the Slovak Republic to Canada in 1999. In 2004, he was elected Member of the European Parliament, re-elected in 2009 and 2014. As a member of the Christian Democratic Party in Slovakia, which is a part of the European People's Party, Mr Mikolášik sits in the European Parliament's Committee on Environment, Public Health and Food Safety (ENVI), Committee on Regional Development (REGI) and the Subcommittee on Human Rights (DROI). He is also a Vice-President in the Euro-Latin Parliamentary Assembly (EuroLat). He is the founder and honorary president of the non-profit association Donum Vitae. In the periods of 1978-1990, 1992-1994 and 2002-2004 he was practising medicine. Dr. Mikolasik performed his research in the Institute of Medical Ethics and Bioethics in Bratislava where, as a true advocate for the human dignity, presented numerous lectures on the role of ethics in medicine. Currently he serves as the Chairman of the EPP Working Group on Bioethics and Human Dignity in the European Parliament.



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I deem crucial that we continue in our endeavour to push through the issue of pain further on the agenda both on EU and national levels

M



PROF DR JORDI MIRÓ PH.D.

Chair in Pediatric Pain URV – Fundación Grünenthal

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Chronic pain in youths is a neglected, highly misunderstood problem, and under-treated. But this can be changed, and must be changed.

Pain in youth, particularly chronic pain, is a serious public health problem. Available studies show that between 20 and 30% of youths report suffering chronic pain. And there is mounting evidence that chronic pain severely impacts the quality of life of these youths and that of their families, resulting in enormous costs to society. However, the study, assessment and management of chronic pain in youths is not addressed with the same interest and enthusiasm as in adults. In fact, the limited information on pediatric chronic pain has been used to inadequately justify the status quo. In order to move the field ahead, the barriers and needs for a proper treatment are to be identified. And to this objective, we are all called: clinicians, scientists, patients and politicians. As a society, we have to be able to effectively respond to this challenge. In fact it should be unacceptable medically and socially to continue ignoring the suffering of youths with chronic pain.

Jordi Miró is Doctor in Psychology. Professor of Health Psychology at Universitat Rovira i Virgili (URV; Catalonia, Spain) and ICREA-Acadèmia distinguished researcher. He is the Director of the Unit for the Study and Treatment of Pain at URV, and Chair in Pediatric Pain URV – Fundación Grünenthal. He is the coordinator of the Special Interest Group on Pediatric Pain of the Spanish Pain Society and of the recently created Spanish Network on Pediatric Pain Research and Director of the Iberoamerican Network for the Study and Treatment of Pediatric Pain. He has received several awards for his research on pain. Recently, he has been awarded the recognition for research excellence by the Government of Catalunya (ICREA-Acadèmia), and the prize for his research career in pediatric pain by Fundolor. He has also received awards for the results of research by the Foundation Prince of Girona and the Mobile World Capital Barcelona, for technological developments to facilitate the assessment and treatment of individuals with chronic pain.

MARLENE MIZZI

Member of the European Parliament, Malta

Group of the Progressive Alliance of Socialists and Democrats (S&D)

Marlene Mizzi was born in Rabat, Malta. She studied at St Dorothy's Convent, Junior College, and the University of Malta, where she graduated with an honours degree in Economics. Subsequently, she read for a Masters degree at the Maastricht School of Management, the Netherlands. Her field of specialisation is Corporate Governance. Marlene speaks Maltese, English, and Italian fluently and has basic understanding of Spanish German and French. Marlene Mizzi is Chairman of Amca Ltd, and has also served on the Board of Directors of Bank of Valletta. She is also a founding member of the national think-tank Today Public Policy Institute and has also served as Chairman of Sea Malta Co Ltd., the national shipping line, from 1997 to 2005. Marlene Mizzi was the first Maltese woman elected to the European Parliament. She is a member of the Group of the Progressive Alliance of Socialist and Democrats. She is the Vice-President of the Petitions Committee, Member of the Internal Market and Consumer Protection Committee and substitute member of the Culture, Education and Sports Committee. She is also an active member of various parliamentary Intergroups, which address different issues and a member of the ACP-EU and China delegations. Marlene Mizzi is also an Ambassador for the Erasmus for Young Entrepreneurs Programme 2016-2017.



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By improving the quality of life of people with chronic pain we would be also improving the lives of the ones around them and those caring for them. We have to do so by raising awareness, strengthening research and working on new policies on European level.

M



PETE MOORE

Founder

Pain Toolkit

United Kingdom

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www.paintoolkit.org

With the ever-increasing problem of persistent pain in Europe, SIP has become essential event to bring key decision makers (political, healthcare professionals, health industry and patient groups) together to discuss and action plan pain management solutions to the pain problems in Europe.

Biography

Pete's story is very typical of that of a pain patient. He was, like many pain patients looking for that magic bullet to take away his pain. Managing pain was like playing a game of snakes and ladders – a game of luck. Most days melted into the next and he became a very poor pain self-manager. He did not exercise or generally look after his body and when something went wrong with it, he expected the doctor to fix him.

My Turning Point!

In July 1996, Pete attended the INPUT Pain Management Programme (PMP) London. It was described to him as a programme that could help me to increase his confidence and mobility and provide him with life-long skills to self-manage his pain.

Pain Toolkit www.paintoolkit.org

Pete authored the Pain Toolkit a simple patient booklet which was supported by the Department of Health and now used extensively in the UK and overseas. 950,000 copies are in circulation in the UK. It's been translated into 10 languages and adapted for Australia, Canada, Ireland and New Zealand.

Memberships

- British Pain Society (honorary member)
- The International Association for the Study of Pain (IASP)

PROF DR BART MORLION MD, PHD

President Elect and EU Liaison Officer, European Pain Federation EFIC

Director of the Multidisciplinary Pain Centre of the University of Leuven, Belgium
Hon. Assoc. Professor, University of Groningen, The Netherlands

Bart Morlion is director of the multidisciplinary pain centre at Leuven University in Belgium.

He has been appointed president-elect of the European Pain Federation EFIC® and will take office in September 2017. Bart also acts as EFIC® EU-Liaison Officer, representing the Federation towards European policy makers and the European pain community. Between 2006 and 2012, Bart Morlion was the President of the Belgian Pain Society – the Belgian Chapter of the International Association for the Study of Pain (IASP) and represented Belgium as councilor in EFIC®. He steers the Organizing Committee of the Belgian Interuniversity Course of Algology and is also an active member of several committees in international scientific societies, including the International Association for the Study of Pain (IASP).

Bart Morlion teaches pain management and pharmacology at the Leuven University and several higher institutions. He has given more than 400 international and national invited lectures and seminars on pain management, and has authored a number of primary manuscripts, reviews, books and book sections. He is deputy editor of the European Journal of Pain and a regular reviewer for several international journals. His professional interests include all aspects of multimodal chronic pain management, analgesics, and quality management.



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Policy makers at EU and national level need to understand the severe impact of pain upon society. It is our job at EFIC and in the SIP platform to highlight this impact, and to point to positive changes that could be made.

M



DR JORDI MOYA RIERA MD, PHD

Director

European Multidisciplinary Network in Pain Research and Education

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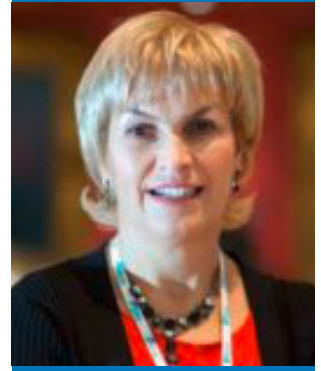
Treating pain, alleviating
suffering, improving the
quality of life of patients

- Bachelor of Medicine and Surgery (1989), University of Oviedo (Asturias).
 - Specialist in Anesthesiology, Resuscitation and Pain Therapy (1995), University Hospital of Canarias (Tenerife).
 - PhD of Medicine and Surgery (1994), Faculty of Medicine, University of La Laguna (Tenerife). Master in Underwater and Hyperbaric Medicine (1998). University of Barcelona.
 - Medical Assistant Department of Anesthesiology, Resuscitation and Pain Therapy of the Virgen de Monte Toro Hospital, Menorca (1995-2006).
 - Head of Pain Unit of the Mateu Orfila Hospital (2007), Mahon (Menorca).
 - Medical permanent position in the Spanish Public System of Health (2005).
 - Medical Director of the Clinical Institute of Pain in Menorca (1998).
 - Office-Based Anesthesia in Odontology in Menorca (1998).
 - Head of Anesthesiology, Resuscitation and Pain Therapy at the Menorca Clinic and Virgen de Gracia Polyclinic (since 2005).
 - Founder of the Association Against Pain: SINE DOLORE (2004).
 - Director of Multidisciplinary Mediterranean Pain Forum since 2006
 - Director of European Multidisciplinary Pain Meeting since 2011
 - Member of the International Spine Intervention Society (ISIS) (since 2001).
 - International School Sine Dolore for Pain patients and relatives Director
 - SINE DOLORE WORLD PARK Director since 2015
-
- Publication, articles, communications and presentations at European and international scientific meetings
 - Publication of Adamic Books:
 - "MEDITERRANEAN MULTIDISCIPLINARY FORUUM AGAINST PAIN". 2009
 - "A MULTIDISCIPLINARY APPROACH TO PAIN". 2010
 - "LEX ARTIS IN THE TREATMENT OF PAIN" 2011
 - "LEX ARTIS IN MULTIDISCIPLINARY PAIN MANAGEMENT" 2012.
 - "GUIDELINES IN MULTIDISCIPLINARY PAIN MANAGEMENT" 2013
 - "UP DATE IN MULTIDISCIPLINARY PAIN MANAGEMENT" 2014
 - "HOT TOPICS IN MULTIDISCIPLINARY PAIN MANAGEMENT 2015"
 - "Latest developments in multidisciplinary pain management" 2016
-
- Director of the Sine Dolore Research Chair of EFHRE Interenational University (EIU)

KATHERINE MURPHY

Chief Executive

The Patients Association



Katherine joined The Patients Association in 2003 as Head of Communications having come from a career in Nursing. She was appointed Chief Executive in 2008. As Chief Executive, Katherine has been at the forefront of most of the recent campaigns at The Patients Association, and has initiated a number of other high profile initiatives that have featured prominently in the media including:

- The Care Campaign
- Patient Stories
- Malnutrition
- Pain
- Dignity and Compassion
- Reform of the NHS Complaints System

Katherine is a dedicated and tireless campaigner with a very strong interest in the rights and responsibilities of the patient and a true patient advocate. She is passionate about making sure the patient's voice is central to every decision and that the patient voice is heard and translated into genuine quality improvement for all. The co-creation of policy and partnership decision making must be present in all health and social care encounters.

Katherine continues to set the strategic direction of the Patients Association; during her time with the organisation Katherine has worked with the Department of Health, NHS England, Care Quality Commission, Cabinet office, Medicines and Healthcare products Regulatory Agency (MHRA), Royal College of Nursing, Nursing and Midwifery Council and all the of Medical Royal Colleges and other health and social care regulators.

Katherine represents the patient voices on many committees and boards, making sure the rhetoric from politicians and senior health and social care professionals are translated into reality for patients and the public.

More recently Katherine has also dedicated her time and energy working in partnership with many NHS Directors of Patient Experience, cascading good practice through joint conferences on the patient journey in the hope that this will translate to good patient experience and outcomes.

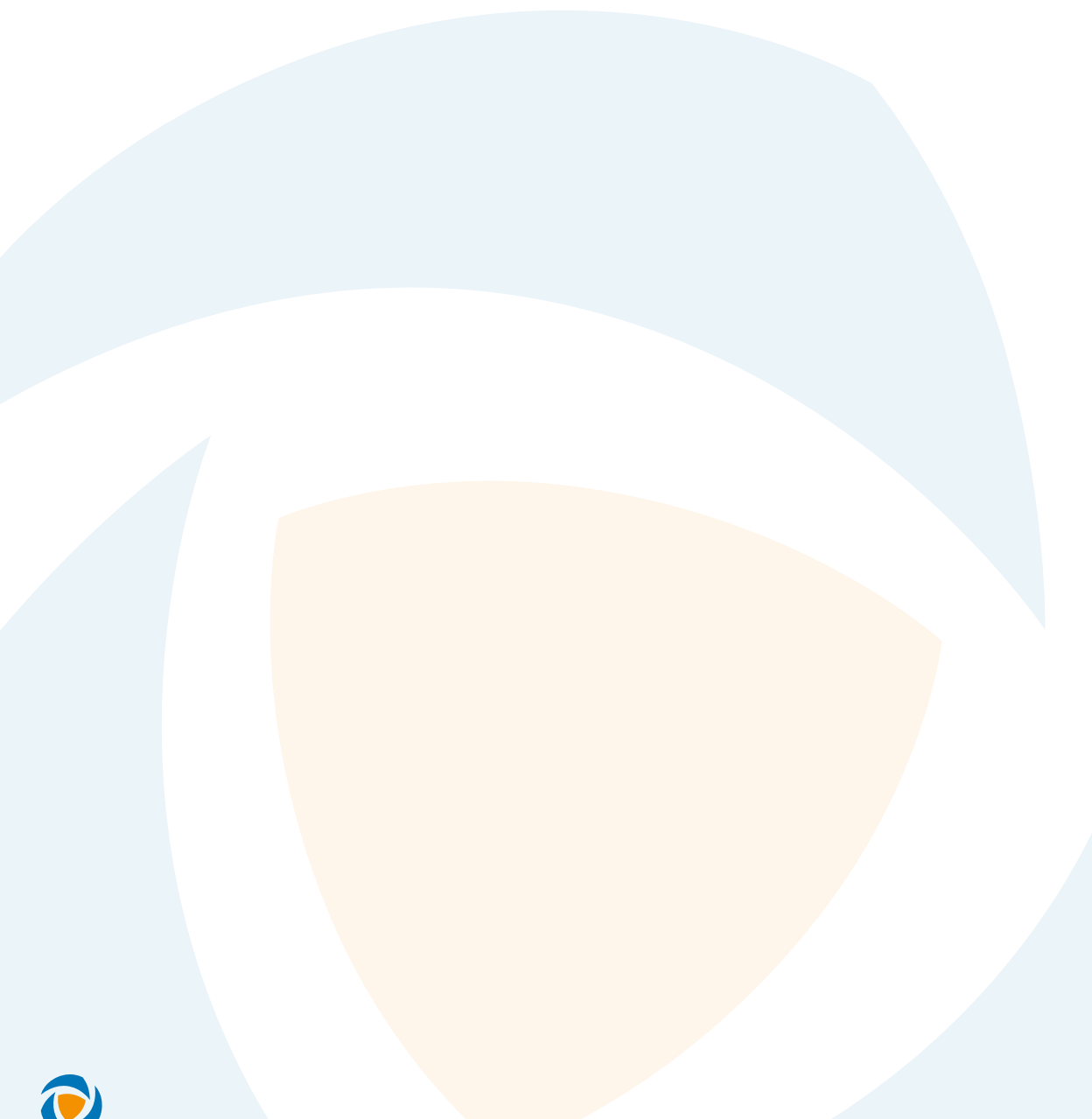
Katherine was a member of the Prime Minister's Nursing Care Quality Forum and is a member of the Equality and Diversity Forum.

In 2011 Katherine was nominated by the London Evening Standard as one of the capital's 1000 most influential people.

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Katherine represents the patient voices on many committees and boards, making sure the rhetoric from politicians and senior health and social care professionals are translated into reality for patients and the public.

M



PROF RICHARD MUSCAT PHD

University of Malta

Use of controlled medicines in the treatment of drug dependence

At present on behalf of the Malta Presidency of the EU, I chair the Council working party known as the Horizontal Drug Group that is engaged in EU drug policy and is currently drawing up the second Action Plan on Drugs that will cover the period 2017-2020 as part of the requirements of the EU Drug Strategy 2013-2020. In it the access to controlled medicines is taken into account to make such more available to treat heroin dependence as well as prevent unnecessary overdose deaths which have risen in the EU of late.



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One of the keys to treating drug dependence, especially that related to heroin addiction, is access to controlled medicines such as methadone and more lately, buprenorphine. In addition, the authorised use of naloxone in the form of a nasal spray may prevent the unnecessary number of overdose deaths throughout Europe.

M

Revised version



Official Residence of the Prime Minister

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DR JOSEPH MUSCAT

Prime Minister of Malta

Government of Malta

Dr. Joseph Muscat was born on the 22nd January 1974.

He graduated with Honours from the University of Malta in Public Policy and later as Master of European Studies.

In 2007 he attained a Doctorate of Philosophy in Management Research from the University of Bristol.

He successfully contested the first European Parliamentary elections in Malta in 2004.

In 2006 he was the recipient of the Outstanding Young Person of the Year.

In June 2008 he was elected as the Leader of the Partit Laburista.

Dr Muscat took office as Prime Minister of Malta on the 11th March 2013.

Prime Minister Muscat is currently the Commonwealth Chair-in-Office and is leading Malta's Presidency of the European Union in the first half of 2017.

He is married to Michelle and they have twin daughters, Etoile Ella and Soleil Sophie.

JOACHIM NADSTAWEK

Leiter

Schmerzzentrum an der Janker Klinik

Multimodal pain therapy implicates always interdisciplinary treatment of patients. The German health system and the structure of supply make an interdisciplinary cooperation hardly possible because all specialist disciplines work mostly with a tunnel vision for their own. So it might happen, that a patient with unspecific low back pain, who was not seen first of a pain specialist, undergoes several unnecessary surgical procedures, because the system creates the wrong incentives. This procedure has very often no benefit for the patient and creates so a patient with chronic pain. Several integrated supply concepts in the treatment of those patients in Germany could impressively demonstrate, that an inter/multidisciplinary pain therapy helps the patient and avoids in about 80% unnecessary surgical interventions. The health system should be encouraged in promoting these projects and to transfer this kind of treatment in the general supply to stop the so called lone fighters. Interdisciplinary medicine has to be honoured by the health system so that all patients with chronic diseases can have a benefit!



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Practised integrated supply concepts for patients with chronic pain should be transferred to the general supply of those patients to guarantee a real inter/multidisciplinary therapy. Therefore a change of thinking in the health system of Germany is absolutely necessary. Inter/multidisciplinary medicine is the chance for the future and has to be honoured and has to be paid.

N



MARIAN NICHOLSON

Director

Herpes Viruses Association and Shingles Support Society

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At Shingles Support Society we supply information / advice on medical treatment and self help for post herpetic neuralgia (PHN) which particularly in older patients may follow shingles (herpes zoster). Early treatment gives a greater chance of eliminating PHN.

Marian Nicholson has worked in many different fields, including a two-year contract with UNICEF in Paris. Since 1985 she has been a volunteer for the Herpes Viruses Association and Shingles Support Society. This introduced her to the sometimes intense and long-lasting pain that can be a result of shingles. From 1993 she has worked full-time for the charity and is now the director.

On the topic of shingles (herpes zoster) and post-herpetic neuralgia, Marian has published articles in the Practice Nursing (guest editorial), Dermatological Nursing and Nursing in practice as well as many consumer magazines. On herpes simplex, she has had four posters accepted for display at the annual conferences of the British Association for Sexual Health and HIV/American STD Association in 2003, 2004 and 2016. Articles have been published in the British Journal of Sexual Medicine and SHINE. In 2012 she became a trustee of the umbrella organisation Pain UK and shortly afterwards became the UK representative on the board of Pain Alliance Europe.

The work of the Shingles Support Society involves educating patients regarding the nature of the infection, giving self-help advice and supporting them in obtaining appropriate treatment when they are affected by post-herpetic neuralgia.

PROF DR JULIEN NIZARD MD, PHD

Director of the Multidisciplinary Pain, Palliative and Supportive care Department (CHU, Hôpital Laënnec); Director of the Pain and Neurosurgery Research Unit, and EA3826, University Hospital (Nantes)

Nantes University Hospital

Impact of pain on labour and employment

Julien Nizard, M.D., Ph.D., is a rheumatologist, geriatrist and pain physician, director of the Multidisciplinary Pain, Palliative and Supportive care and Ethics Department, Nantes University Hospital (France).

Associate Professor of Pain and Palliative care Medicine, he leads pain, palliative and supportive care university degrees at Nantes University, as well as complementary medicines university degrees (hypnosis, acupuncture, and manual medicine).

He leads the Pain and Neurosurgery Research Team, Nantes University, specialized in invasive and non-invasive neuromodulation techniques for the treatment of chronic pain syndromes.



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In order to improve return and maintain to work of patients offwork because of chronic pain, it is important to promote a better cooperation between pain physicians, rehabilitation specialists, and occupational physicians.

N



PROF TONY O'BRIEN

Consultant Physician in Palliative Medicine

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Uncontrolled pain is a global public health issue. Most of the world's population cannot access necessary pain expertise or vital therapy. Opioids must only be initiated by competent clinicians as part of a multi-faceted treatment programme in circumstances where more simple measures have failed.

Uncontrolled pain is a major public health concern. The Declaration of Montreal (IASP, 2012) states that pain management is inadequate across most of the world. The personal and socio-economic impact of uncontrolled pain is incalculable. Patients experiencing pain that is not responding quickly to standard therapies must have ready access to skilled specialist clinicians who are capable of performing a comprehensive pain assessment and who will devise an appropriate multi-faceted treatment programme.

Opioids are indispensable in the management of pain. They are not a panacea for all pains and are only introduced when strictly necessary and as part of a multi-faceted strategy that includes all necessary adjuvant analgesics, non-drug interventions, psychological support and rehabilitation.

Worldwide, lack of access to opioid medication due to inappropriate restrictions on their availability and accessibility is considered to be one of the most significant barriers to optimal pain management. Opioids are clearly not a panacea for all pains and the EFIC position Paper is solely concerned with the scientific use of opioid medications in selected and supervised chronic pain patients as part of a comprehensive, multi-modality, multi-disciplinary approach to treatment. There are enormous variations in opioid use across the globe and even within regions, similar variations are observed. This is particularly the case in Europe with staggering variations in opioid use between Western Europe and Eastern Europe.

With due regard to the facts that chronic pain affects 20% of European citizens and disrupts the lives of millions of people with its negative impact on quality of life and physical / psychological well-being, the EFIC position paper seeks to provide a fair, balanced and evidence-based guide to the non-specialist prescriber regarding the role of opioid therapy in pain management.

Prof Tony O'Brien is a consultant physician in palliative medicine at Marymount University Hospital & Hospice / Cork University Hospital and clinical professor of palliative medicine at the College of Medicine & Health, University College Cork, Ireland. Prof O'Brien undertook his post graduate training at St Christopher's Hospice, London in the mid-1980s and has held his current position since 1991. He chaired the Irish Government's National Advisory Committee on Palliative Care and subsequently was appointed as Chairperson of the National Council for Specialist Palliative Care. He also served as chairperson of the Council of Europe Expert Committee on Palliative Care. Prof O'Brien has published and lectured extensively on various aspects of pain and palliative care.

PIERNICOLA PEDICINI

Member of the European Parliament, Italy

Europe of Freedom and Direct Democracy Group

Through my previous experience as an expert in radiation and oncology, I am familiar with the links between cancer and pain. The SIP symposium is an important opportunity to address the issues of pain and cancer care, in terms of pain caused by tumours, pain experienced through radiotherapy, chemotherapy and surgery, as well as post-operative chronic pain.

Piernicola Pedicini was born on 22 May, 1969 in Benevento in the south of Italy. He has a wife and two sons. Piernicola took a Degree in Physics in 1998 and a Medical Physics Specialisation in 2006 at the University Federico II of Naples, Italy. He worked as a Medical Physicist at the Department of Radiation Oncology in Rionero in Vulture, Potenza, Italy, since 2008 as health Director, until his recent election as a Member of the European Parliament. He has been involved in political activities with the Five Star Movement since its foundation, with a specific eye on healthcare and environmental issues, always defending patients' rights. He is a member of the environment, public health and food safety (ENVI) committee.



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**The SIP symposium
is an important
opportunity to address
the issues of pain and
cancer care.**

P



DR RAUL PEREIRA MD

Medical Doctor

Unidade Local de Saúde do Alto Minho

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We present an innovative and replicable model on the implementation of a chronic pain consult in a primary care setting. This model allows a rapid first observation and follow-up of the patient and potentiates an improvement in the quality-adjusted life years of our patients.

Chronic Pain Management in Primary Care - an innovative approach

The burden associated with chronic pain has a social and economic impact that justifies a new framework for its management.

Pain management consults in primary care units can become a vital component for improving the quality of life of individuals suffering from chronic pain. This will inevitably lead to less disability days and have a major positive impact in the social and economic condition of a country.

We developed a referral protocol for a primary care unit in Portugal, with approximately 16000 patients. In this protocol, patients are referred to the chronic pain consult by their physician. In this consult the patient is assisted by a primary care physician specialized in pain management, working in the same primary care unit.

This enables a fast-track for patients suffering from chronic pain, offering the patient a rapid first observation in their primary care unit. Furthermore, there is a quicker access to a follow up visit which leads to a greater efficacy in pain relief of these patients.

Raul Marques Pereira is a medical doctor and a board certified family physician. He also holds a master's degree in evidence-based healthcare.

Nowadays, in addition to his activity as a physician, he teaches medical students and family medicine residents. He dedicates himself to clinical research in a primary care setting with special attention to chronic pain management and palliative care.

PROF DR ROBERTO PEREZ

Research Pain, Pain Therapy and Palliative Care

Dept. of Anesthesiology, VU University Medical Center



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Chronic pain is a prevalent health care problem, associated with reduced quality of life, high health care consumption and loss of ability to work. Based on a bio-psycho-social approach, a comprehensive guideline of care for chronic pain has been drawn up. Chronic pain is the resultant of a reciprocal process of biological, psychological and social factors, whereby pain influences social activities, cognitions, emotions, expectancies, physical fitness and behaviour, and vice versa. Targets for treatment have to be identified using an integral assessment of mechanistic, neurobiological, cognitive, emotional, behavioural and contextual factors. A stepped care framework based on a thorough bio-psycho-social assessment would lead to a matched care approach to treatment. Care is described from a patient perspective, and placed within a dynamical set of agreements about care and self-management. The background of this comprehensive guideline for chronic pain, as well as the Dutch health deal which uses the guideline as a reference will be discussed.

Roberto Perez started his research career in 1995 at the department of Anesthesiology of the VU University Medical Center. Dr. Perez received his Ph.D. degree in 2002 based on the thesis entitled "Complex Regional Syndrome Type I: 'A randomized controlled study into the effects of two free radical scavengers and evaluation of measurement instruments", and subsequently started as Assistant Professor in the same department.

At this moment, Roberto Perez is supervisor of several Ph.D. students and research coordinator for the research program Pain, Pain Relief & Palliative Care. His fields of expertise concern chronic pain (in particular CRPS) and palliative care, whereby he focuses on clinical trial methodology, epidemiological, diagnostic and clinimetric aspects of pain and palliative care research. His research activities mainly focus on diagnosis and prognosis, development of measurement instruments and symptom control of chronic pain and terminally ill patients. He has contributed to the development of evidence based multidisciplinary treatment guidelines of CRPS and Cancer Pain, and participates in national and international research collaborations and consortia, and is the current chair of the Special Interest Group "Complex Regional Pain Syndrome" of the IASP.

**Targets for treatment
have to be identified
using an integral
assessment of various
contextual factors**

P



JUAN JESÚS PÉREZ CAJARAVILLE

Clinical Director

Multidisciplinary Pain Management Center for HM University Hospital in Madrid.

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Clinical Director of the Multidisciplinary Pain Management Center for HM University Hospital in Madrid. Associate Professor of Medicine and Anaesthesia at CEU University in Madrid and Senior Management in Health Institutions. IESE. Madrid. European Diploma in Pain Medicine (EDPM).

Board Member of the Spanish Pain Society (SED). Spanish Councillor for EFIC-European Pain Federation Federation. Expert Consultant on chronic pain for European Medicines Agency (EMA). Medical Adviser for Ministry of Health and Social Policy. Spanish Government.

Member of editorial boards at National and International journals. Membership of several recognized National & International Pain Societies.

More than 100 publications including book chapters and articles, 12 clinical trials as principal investigator and more than 200 national and international lectures.

PROF SERGE PERROT

MD, PHD

President

French Pain Society

Professor Serge Perrot is a rheumatologist and a pain specialist. He currently heads the Pain Center of Cochin Hospital, in Paris, France, with a specific interest on pain in musculoskeletal conditions. He is currently the President of the French Pain Society (SFETD). He is the founder and president of the French group of rheumatology pain specialists (CEDR), an organization that links the French rheumatological society with the French pain society.

He is professor of clinical therapeutic at Paris Descartes University.

He was an expert for the French Drug Agency (AFSSAPS) and French transparency agency (HAS) for 10 years.

He is involved in IASP/WHO new International Classification of Diseases 11, in the chapter on musculoskeletal pain.

He has participated in several workshops to establish national and international guidelines on pain management and has coordinated more than 50 studies on rheumatology in the field of pain. He has published more than 150 papers on pain in musculoskeletal disorders and painful rheumatological conditions. His primary areas of interest are: opioids in rheumatology, musculoskeletal pain conditions like fibromyalgia, low back pain, complex regional pain syndromes and osteoarthritis. He is currently working on Patient Reported Outcome Measures in rheumatic pain. He has developed a screening tool in fibromyalgia, the FiRST (Fibromyalgia Rapid Screening Tool) and a specific questionnaire for pain in osteoarthritis.



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**It is the duty of our
future leaders to write
a new chapter of pain
management and ours
to accompany them
to develop a medicine
that is accessible to all,
democratic and ethical,
and of great quality.**

P



SIRPA PIETIKÄINEN

Member of the European Parliament, Finland

Group of the European People's Party (EPP), Finland

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Ms. Sirpa Pietikäinen is a Finnish member of the European People's Party (EPP) in the European Parliament since 2008. Ms. Pietikäinen is former Finnish Minister of Environment (1991-1995). Her career at the Finnish parliament is extensive, ranging from the year 1983 to 2003. At the European Parliament, Ms. Pietikäinen is member of the economic and monetary affairs committee and Committee of Inquiry into Money Laundering, Tax Avoidance and Tax Evasion, and a substitute member of the environment, public health and food safety committee as well as the women's right and gender equality committee.

Over 100 million people in Europe live with chronic pain. Chronic pain has an underestimated, critical impact on personal and societal wellbeing, even though it is not considered a life-threatening condition. Reducing functional capacity and performance, chronic pain impacts family and work life. To address limited alternatives for pain management, increased focus should be given to the development and sharing of European best practices in treatment and care. Sufferers of chronic pain should have access to combinations of care and employment adaptation schemes best suited for their personal situation and needs.

PROF WILLIAM RAFFAELI

Founder (1993) and President of ISAL Foundation

Institute for Research and Educational programs on Pain



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Evolving concepts in the definition of chronic pain evolving concepts in the definition of chronic pain: pain as disease

The acknowledgment of pain as a pathological entity in its own right remains debated. We need to review our notion of pain as a disease looking at its several conceptualizations and report the main evidence supporting this notion. We believe that a clear definition of pain as a disease is necessary, especially considering the enormous global burden of this condition. Indeed, the recognition of pain as a definite pathological state is crucial to raise awareness about this neglected global health problem and to promote the exploration of new specific therapeutic approaches.

- Born in Santarcangelo di Romagna in 1951
- Graduated In Medicine (Bologna 1977)
- Specialization diploma Anaesthesia and Intensive Care (Siena 1983) - Applied Pharmacology (Modena 1988)
- He worked as anesthesiologist in Rimini's Hospital where he was the head of acute and chronic pain units from 1989.
- Director of Pain Therapy and Palliative Care (Hospice) Unit (2000-2011).
- Director of the first Master on pain research - Bologna University (2008)
- University Activity : Professor of Anaesthesia and Reanimation of Parma University(2004 till today

Institutional Positions in Pain Therapy and Palliative Care

Health Ministry

2004 – 2006 Member of the Oncologic National Committee of Health Ministry

2006 – 2007 Member of Pain Therapy, Palliative Care and Dignity of End-of-Life Committee of health Ministry

2008 – 2015 Member with expert position of the Welfare Ministry Committee for the program on Pain – Member of the Expert Group who wrote the Italian Law (38/10) on Pain and palliative care.

Emilia-Romagna Region

- Coordinator of the Emilia-Romagna Working Group for the institution of Hub – Spoke Pain centers 1999-2001
- Member of the Emilia-Romagna Committee of Palliative Care, which built the Regional Plan of Application of the Palliative Care Network
- In charge Member of the Emilia-Romagna Regional Committee of "Pain-Free Hospital"

He won as principal Investigator five grants :

Emilia Romagna Region

1. Biennials Research Projects "The spinal cord stimulation **1992**
2. The Telemedicine as a system of TQM (Total Quality Management) for excellence in Palliative care Network : what impact on processes operational models and procedural innovations (2004)
3. The Home Care Network of Rimini Telemedicine: extension to neurodegenerative geriatric - Vascular – psychiatric diseases (2005)

Ministry of Health

4. The role of telemedicine and teleassistance in the management of palliative care. Special Program" 2001/2003
5. Research IRCS 2006/2007. Subproject "Pain Therapy and Palliative Care - models in comparison

Founding Member of Scientific Societies:

- Italian Association of Clinical Pain (1988)
- Italian Society of pain clinicians (1991)
- Italian Chapter of INS – international neuromodulation society (1998)
- Federdolore – National Coordination Center of Pain Therapy and Palliative Care (2004)

We believe that a clear definition of pain as a disease is necessary, especially considering the enormous global burden of this condition.

R



CARINA RAPOSO

Nurse

Pain Unit, Centro Hospitalar do Porto, Porto Portugal

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In Portugal, the Prevalence of Chronic pain was published after a Population-Based Nationwide around Study 36.7%. The Management of Chronic Pain in Chronic Pain unit are with Multidisciplinary teams and Multimodal approach however we don't have in the country any multidisciplinary program. We decided on the basis of literature review to do what we read over the world: have an interventional patient group to foster insights of self-efficacy.

“School for People with Pain” – Psychoeducational pain program

Implemented by Chair on Pain Medicine - Faculty of Medicine of the University of Porto, Portugal – the 1st in the country.

Delivered 3 programs: **1st Ed. 2013** (participants with CP recruited in the Chronic Pain Unit at CHP and HSJ); **2nd Ed 2014 and 3rd Ed. 2015** (participants with CP recruited from GP)

Psychoeducational group: 15/20 participants

Facilitators: Multidisciplinary HCPs team Nurse, Anaesthesiologist, Rehabilitation physician, Psychologist

Duration: 6 weeks with 2 h30 of group sessions per week /Saturday Afternoon.

The general objectives were **General objectives:**

- Promote the clarification of chronic pain, erroneous beliefs and myths
- Empower People with chronic pain to use a variety of strategies to deal with issues related to chronic pain / chronic illness
- Optimize the participation of People with chronic pain in therapeutic activities
- Improve behaviors related to chronic pain
- Adopt lifestyles / healthy habits adjusted to the person with chronic pain
- Reduce the impact of chronic pain

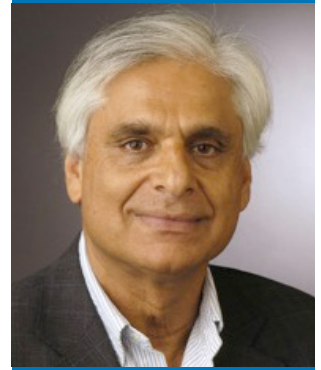
Carina Raposo - Nurse

- Graduation Degree in Nursing – 2001 - ESESt Maria, Porto City - Final grade of 17 values
- Postgraduate in Anesthesiology Nursing – 2002- ICBAS – Porto City - Final grade of 16 values
- Postgraduate in Hospital Management and Administration – 2004- Portucalense University – Porto City - Final grade of 16 values
- Specialist in Rehabilitation Nursing- 2010- – ESEP – Porto City Final grade of 16 values
- Graduate in Advanced Nursing- 2010 – ESEP- Final grade of 16 values
- Course: “Psychology of Pain: Multidimensional Assessment of Pain” – 2013 - Faculty Of Psychology – Final grade of 18 values
- Course: “Coaching for the development of personal and professional competencies” – 2016 - Faculty Of Psychology – Final grade of 18 values
- Other Formation in Pain management, Oncology, Palliative care
- Work as Pain Nurse in the Chronic Pain Unit of the Centro Hospitalar do Porto since June 2005
- Coordinator of the Project in the Chair of Medicine of Pain of Faculty of Medicine, Oporto University : “School for People with Chronic Pain” - since 2013
- Coordinator of the Pain Working group of the Portuguese Oncology Nursing Association - AEOP - since 2013
- Author and Co-author of Booklets/ Facts sheets in cancer pain published by AEOP
- Secretariat of the Bureau of the Regional Assembly - North Regional Section of the Ordem Dos Enfermeiros (2016-2019 mandate)
- Coordinator of the Working Group “Evaluation of the Person with Pain” of the Portuguese Association for the Study of Pain - APED - since 2016
- Trainer and Consultant in the area of Pain (Chronic Pain, Acute Pain and Palliative Care)
- Collaborator in Nursing and Medical classes in Pain Management
- Speaker at various congresses in the area of Pain Management
- Author and Co-author of published articles and posters at national and international congresses

PROF DR NARINDER RAWAL

Professor in Anaesthesiology

Örebro University, Department of Anaesthesiology and Intensive Care



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Professor Narinder Rawal, MD, PhD, FRCA (Hon), EDRA is graduated from India and working in Sweden since 1974. He is Professor in Anaesthesiology, Department of Anaesthesiology and Intensive Care, Örebro University, Sweden. He has been visiting Professor at University of Texas, Houston, USA (1987- 2007), University of L'Aquila, Italy (1999-2007) and Benares University, Varanasi, India (since 2008) and been invited by over 100 institutions.¹ He has written over 180 original papers, over 90 book chapters and review articles and published/edited 15 books.² Prof. Narendra has been member of Editorial Board of over 10 international Anaesthesia or Pain Journals. He received awards/honors from over 30 societies/institutions for distinguished services in teaching of regional anaesthesia and pain medicine including:

- Italian Society of Anaesthesiology (SIAARTI) 1994
- ESRA Poland 1995
- ESRA Portugal 1998
- ESRA Turkey 2005
- Indian Society for Study of Pain 2005
- Acta Anaesthesia Foundation (Helsinki) 2006
- ESRA Spain 2009
- SAARC. Karachi, Pakistan 2009
- Selection to Royal College of Anaesthetists (FRCA) 2009
- Carl Koller Award 2010. European Society of Regional Anaesthesia and Pain Therapy (ESRA)

Following awards from American Society of Regional Anaesthesia and Pain Medicine (ASRA):

- ASRA Lecture 1998
- Distinguished Service Award 2000
- Nils Lofgren Award 2002
- Labat Award 2010

Indian Society of Regional Anaesthesia (AORA) 2012. He has been secretary General of European Society of Regional Anaesthesia (ESRA) (2000 - 2009).³ Prof. Narinder is member ESRA Examining Board: European Diploma in Regional Anaesthesia and Pain (EDRA) examination. (2009-present). Chair of EDRA part 1 examination (2016-present). And Member Examining Board EFIC (2016-present).^{4,5,6}

Main interests and contributions:

- Regional anaesthesia and postoperative pain management
- PhD thesis on spinal opioids
- Development of official monitoring recommendations for patients receiving spinal opioids
- Spinal opioids: special issues such as urodynamic effects, neurotoxicity, use in grossly obese patients
- Combined Spinal-epidural technique: first controlled study, introduced technique in USA (with Prof. Abouleish), epiduroscopy, EVE concept
- Organization of Acute Pain Services: introduced specialist nurse-based models, audits, nursing role
- Introduced patient-controlled regional techniques for pain management at home after ambulatory surgery
- Wound catheter and other infiltrative techniques for pain management after ambulatory surgery and in inpatients
- Development of procedure-specific, evidence-based postoperative pain management guidelines (PROSPECT)
- Pioneering contribution in educational activities in the field of regional anaesthesia by starting a diploma examination in regional anaesthesia under the auspices of European Society of Regional Anaesthesia and Pain Therapy (ESRA)

1 Faculty opponent for PhD theses 11

2 Editor: International Monitor on Regional Anaesthesia and Pain Therapy (IMRAPT): 1994-2004

3 Editor: What's new in Regional Anaesthesia and Pain Therapy 2009-present (www.whatsnew-esra.org)

4 Editor: PainOut Electronic Knowledge Library (www.pain-out.eu)

5 Member PROSPECT group (Procedure specific postoperative pain management) www.postoppain.org, (2005- present)

6 Associate Editor: Pain Practice (2016-present)

Acute postoperative pain continues to be a major societal challenge worldwide, there is an urgent need for quality standards in organisation and implementation of pain services.

R



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**Because good work
is good for health and
wellbeing, work contrib-
utes to good patient
care.**

PROF DR MICHEL RENEMAN

Center for Rehabilitation & Rehabilitation Medicine,
University Medical Center Groningen

Demographic trends tell us that in an ageing workforce and a higher retirement age the incidence of chronic conditions will be increasing. Natural aging processes and (multiple) chronic diseases will have a negative impact on work capacity.

Evidence tells us that early and appropriate clinical interventions aimed at and organized to support staying at work or return to work, can be both cost-effective and have a significant impact on workforce productivity and quality of life. At the moment, however, there are some substantial challenges that are barriers to a broad implementation of evidence based and cost-effective services for many EU citizens.

Among those are:

1. Evidence based and cost-effective services are at present not available for all EU citizens.
2. Modified work is not available for all EU citizens.
3. 'Healthcare' and 'work' systems function independently, yet they are mutually dependent.
4. Work is not considered a desirable or attainable clinical outcome by many healthcare professionals. Because good work and good health are related, this narrow perspective may actually harm patients.
5. Beliefs of 'the public' about pain and work are often not based on evidence.

Michiel Reneman is Professor of Rehabilitation Medicine. His main focus areas are pain rehabilitation, vocational rehabilitation, and work participation. He is co-chair of the Pain Alliance in Netherlands (P.A.I.N.) member of the SIP Platform, and member of the Fit for Work Netherlands.

DR MARCELO RIVANO FISCHER PHD

Head of Department

Dept. of Pain Rehabilitation

Marcelo Rivano Fischer, born 1956, married, five children. PhD Psychology (1988) and Licensed Psychologist (1992). Head of Department of Pain Rehabilitation at Skane University Hospital since 2015. Manager of the Swedish National Registry of Pain Rehabilitation. Researcher affiliated to Lund University in the fields of Pain Rehabilitation and Rehabilitation Medicine. Chairman of Region Skane Board of Insurance Medicine. Former President of Swedish Pain Society (2006-2013). Former Head of Department of Rehabilitation Medicine (2002-2013). Presented a summary of research up to date regarding Pain and Culture at the National Meeting of the Swedish Pain Association and collaborated in several research projects focused on the problem of Chronic Pain and Culture. As the manager of the National Registry of Pain Rehabilitation I became aware of the problem of accessibility to services for patients not fluent in Swedish language. Research shows that health and pain are bigger problem in minority culture groups other than the predominant one, regardless of the country under study



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Pain problem presented by sufferers from minority groups, other cultures, ethnical groups other than majority, tend to be neglected and undertreated. There are systemic, patient-related and provider-factors playing a role in the problem

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CAROLE ROBERT

President

Fibromyalgie France

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For 20% of the population, chronic pain is a source of disability and major deterioration in the quality of life. Chronic pain leads to a significant consumption of health care and work stoppages, which have a heavy impact on health systems and have a profound impact on family, vocational, educational and social life.

Carole Robert is co-founder and president of the national association Fibromyalgie France, founded in April 2001. She has been suffering from chronic pain for 50 years after a major infectious episode at the age of 15, diagnosed with fibromyalgia only in 1998.

Since 2001, she has been committed to associative action to recognize fibromyalgia at the institutional, medical and social levels. In fact, she was interviewed by the European Network of Fibromyalgia Associations (ENFA) in 2008 as a public affairs officer at the Council of Europe to present "living with fibromyalgia".

At the level of France, she worked with the team of volunteers for recognition of fibromyalgia at the level of the National Academy of Medicine and the High Authority of Health. More recently, the association Fibromyalgie France has obtained a collective assessment on fibromyalgia by INSERM (National Institute of Health and Medical Research).

This expertise will be published mid-2018. The association regularly conducts national surveys, for example concerning "Loss of autonomy and quality of life of the chronic pain fibromyalgia", "habits, behavior, beliefs about the drug".

Fibromyalgia France is a partner of SFETD (French Society for the Study and Treatment of Pain) and intervenes during the annual congress. Carole Robert also works at the University as part of the continuing education of health professionals on "living with chronic pain". Joint meetings are held at the Ministry of Health. A book was written in partnership with a rheumatologist and a health historian "Fibromyalgia, so long a road".

As part of the French "Loi de Santé", the administrators of Fibromyalgie France are representatives of users (patients) in healthcare institutions (hospitals - ministries, etc ...) and are also trained at the ETP (Therapeutic Education of the Patient).

PROF DR MED ROMAN ROLKE

Chair and Director

Department of Palliative Medicine, Medical Faculty RWTH Aachen University

Palliative Care (PC) aims to increase quality of life of patients and relatives by relieving burdening symptoms such as pain. Political decision-makers need to bring more action into the increase of the total number of connected PC and hospice services across Europe. Moreover, the connected approach of such services needs medical education, qualification and reimbursement. Current EAPC goals include standardization of medical education. These efforts have already paved the way for similar approaches in Latin America, India, China or Africa. Knowledge transfer for reducing pain across different stakeholder groups will be one of the most important issues for the future.

Prof. Rolke is the current holder of the first University Chair of Palliative Medicine in Germany located at the University of Aachen. As a trained neurologist and palliative care specialist his interests include pain in neurological disorders, neuropathic cancer pain and transitional pain research. He has been working for the research committees of the German Palliative Care Association (DGP) and German Pain Association (German IASP chapter), the second largest pain association worldwide.



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Pain is a key symptom in cancer. Despite increasing knowledge about palliative care for delivering pain relief, such services are still rare across Europe, when calculating their numbers per inhabitants. We need more palliative care and hospice services to address the societal burden of pain.

R



DR JOSÉ ROMÃO MD

Steering Committee Coordinator

“National Strategic Plan for Prevention and Pain Control”
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I strongly believe that the implementation of a strategy for pain control at a national level is absolutely essential to change the state of the art of pain control.

In Portugal, since 1999, the Directorate-General for Health, APED (Portuguese IASP Chapter) and several experts in the pain field, have been working together for the definition of a national strategy for a better management of pain. From this team work resulted in 2009 the creation of a “National day Against Pain”. Since then PAIN has raised attention of professionals, health authorities, media and general society.

In 2011 the 1st National Plan Against Pain” was published and triggered several achievements. In June/2013 the Directorate-General for Health published a regulation, which declared pain to be the Fifth Vital Sign. As such, it has since become considered good clinical practice and mandatory to evaluate and record pain intensity regularly, in all health care services. In 2004 the Portuguese Medical Association created a Competence in Pain Medicine, as a way of promoting and recognizing the specialization of physicians dedicated to this field of medicine. In 2008 strong opioid reimbursement was increased from 37 to 90%.

The Directorate-General for Health published guidelines regarding: the use of opioids for the treatment of non-cancer pain, management of procedural pain in childhood, management of pain in elderly, among others. Guidelines on the organization of acute pain units have also been published.

The 3rd National Plan for Prevention and Pain Control- is being implemented.

Dr José Romão is Consultant in Anesthesiology with Competence in Pain Medicine and Coordinator of the Pain Unit – Centro Hospitalar do Porto (Portugal); Invited Associate Professor in Instituto de Ciências Biomédicas Abel Salazar (Porto-Portugal); Steering Committee Coordinator of the “National Strategic Plan for Prevention and Pain Control”.

PROF DR JUDITH ROSMALEN

Professor of Psychosomatic Medicine

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Medical research is traditionally focused on diseases, but how we feel is determined by symptoms. Most symptoms remain medically unexplained. We cannot identify their cause, or the cause is gone but nevertheless the symptoms remain. Estimates are that in primary care up to one third of symptoms remain unexplained, and in secondary care this rises to two thirds. Examples of unexplained health problems include syndromes like fibromyalgia, chronic fatigue syndrome and irritable bowel syndrome. In the absence of a detectable biomedical cause, no simple treatments exist. Many European citizens have to live with their symptoms every day.

We develop an innovative eHealth solution called Master your symptoms. This online system will provide patients personalized self-help guidance to enable them to get a grip on their symptoms. Their healthcare professionals are simultaneously trained with an online course focused on patient-centered healthcare. This course was developed in collaboration with Pain Alliance Europe, and with the help of an EIT Health grant. These tools will enable healthcare professionals to empower patients to manage their lives and their functioning with symptoms.

Prof. Dr. J. (Judith) G.M. Rosmalen is appointed as a professor in psychosomatic medicine at the departments of Psychiatry and Internal medicine of the University Medical Center Groningen. She studied medical biology (University of Utrecht 1995) and psychology (University of Leiden 1998, cum laude), and obtained her PhD on interactions between immune and endocrine system (Erasmus University Rotterdam 2000). Her multidisciplinary research focusses on interactions between biomedical and psychosocial aspects of health problems, with a focus on medically unexplained symptoms. She is project leader of the consortium developing the online system Master your symptoms. This system supports healthcare professionals and patients in personalized healthcare for medically unexplained symptoms, by an online training and an eHealth solution. Implementation of this system will be studied in the course of the Horizon 2020 project ImpleMentAll.

Current healthcare typically focuses on the question “What is the matter with you?”. We aim for a paradigm shift towards patient-centered healthcare, as reflected in the question “What matters to you?”

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ALFRED SANT

Member of the European Parliament, Malta

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From the patient's aspect, pain is not always a temporary symptom of a disease. In fact, it could also become chronic with the need of specific treatment. Sadly, too few chronic pain patients receive treatment with devastating effects on their quality of life, and eventually on that of their families. Figures show that in Malta, one in five people are feeling pain.

The SIP 2017 symposium aims at having a lasting political impact by addressing the issue of 'pain' within one of the health priorities being addresses by the Maltese Presidency of the Council of the EU: 'Structured cooperation between healthcare systems'. The official recognition that the Maltese government is giving to this year's conference, also gives a unique opportunity to the EU and its member states to act on this urgent matter. Based on the above, and on the work being done through the platform 'Societal Impact of Pain', I fully endorse and support the goals of this conference.

Alfred Sant studied physics and maths at the University of Malta, diplomacy at the Institut International d'Administration Publique (now amalgamated with the ENA) in Paris, and business administration at Boston and Harvard Universities. He worked as a diplomat at Malta's Mission to the then EEC in Brussels (1970 – 1975), as executive deputy chairman of the Malta Development Corporation (now Malta Enterprise) during the late seventies/early eighties, as a management consultant in between and later.

He was chairman of the Labour Party's information department (1982 – 1984), President of the Party (1984 – 1988), a Labour M.P. (1987 – 2013), Labour Leader and Leader of the Opposition (1992 – 2008) and Prime Minister (1996 – 1998). Over the years Sant wrote plays for the theatre, radio and TV, as well as novels and short stories in the Maltese language; was editor of three magazines and for thirteen years a correspondent of the Economist Intelligence Unit; and he wrote extensively in English and Maltese for the political and economic press.

Alfred Sant was elected Member of the European Parliament in May 2014.

Pain imposes a heavy burden on individuals' private lives and leads to enormous costs for healthcare systems as well as for our societies and economies.



PROF DR BOAZ GEDALIAHU SAMOLSKY DEKEL MD, PHD

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Free access to pain facilities, medications and treatments, sharing best-practices across the EU and the awareness of the relevance of pain's impact on our societies, social, health and economic systems are lacking. Individual's comprehensive needs should be the center of each curative approach.

Chronic pain (CP) is a spectrum that entails comorbid neuropsychological and social manifestations; its expression depends upon genetic, environmental, and lifespan experiential interactions, and thus establishes individual patterns of physiological, cognitive, emotional, and behavioral responses; all these, in an encompassing approach, should be considered by the clinician to direct the best, technically right, and morally sound, course of care and to meet the patients' needs and values.

Moderate/severe CP occurs in 19% of European adults, seriously affecting their daily, social and working lives. Most patients do not receive pain treatment, and 40% receive treatment that is inadequate. Moreover, there are no clear guidelines to determine when and how to refer CP patients to secondary or tertiary health-care providers.

A prognostic model may be a tool for CP patients screening and referring to different proficiency facilities of CP management. Prognosis refers to the risk of future health outcomes in people with a given health condition. A prognostic model can influence patient outcome or the cost-effectiveness of care when changes in clinical management are made based on the prognostic information provided. It is the core of the so called 'stratified medicine', which is central to the progress of health care. It refers to the targeting of treatments and making the best decisions according to the risk characteristics shared by sub-groups of patients. Indeed, it was reported that adequate patient selection by health care professionals, interdisciplinary assessments and severity adapted treatments resulted in significant reduction in pain and functional improvement in disabled back pain patients. Moreover, outcome prediction, as a function of pain-chronicity stage, may allow patients and professionals to formulate a management plan and to identify risks for poor prognosis. Prediction rules showing good performance may change physicians' decisions, improve clinically relevant process parameters, improve patient outcome and reduce costs.

Dr. Samolsky Dekel, MD, PhD is the Scientific Director of NoPain Foundation, Malta. He is an Aggregate Professor and Investigator of Anaesthesia, Intensive care and Pain Medicine at the department of Medical and Surgical Sciences of the University of Bologna, Italy.

Senior Anaesthesia, Intensive care and Pain Medicine Consultant at the University of Bologna Teaching Hospital Policlinic S. Orsola Malpighi; the Hospital's inpatients Acute Pain Service and the Centre of Pain Therapy for outpatients with chronic pain.

Fields of interest and research: postoperative pain, chronic pain evaluation and treatment, opioids for chronic pain, cancer and breakthrough pain, pain in high risk persons.

DR MED MICHAEL SCHENK MD

Head Pain Clinic Berlin, Consultant in Anesthesiology, Pain Medicine,
Palliative Care Medicine and Addiction Medicine

Pain Clinic Berlin (Schmerzlinik Berlin), Center for integrative Multimodal
Pain Medicine and Center for Neuromodulation

Chronic pain (CP) is a pressing issue in Europe. 17 % of the European population suffers from CP, of which 30% have strong pain and 10% of these need a hospitalization (Breivik 2006). The economic consequences are enormous: The indirect expenses (unfitness for work, early retirement) for CP were assessed at more than 29 billion Euros in Germany (Dietl 2011). In the German healthcare system 6-8% of the costs are caused by treatment of CP (Neumann 2002). Unfortunately there is a mistreatment with an overuse of invasive procedures and operations and a lack of problem-adequate appropriate measures like MultiModal Pain Therapy (MMPT). For the treatment of chronic pain MMPT is considered as the gold standard (Guzmán 2002).

Besides a good quality, the intensity and length of treatment (e.g. between 14 and 21 days) must be adequate (Bendix, Härkäpää). Long-lasting effects on quality of life and restoration of working capability are only proven for interdisciplinary multimodal pain treatments (Chou 2007, Guzmán 2002, Van Tulder 2006, Williams 1996). Multimodal approaches have a clear advantage compared to unimodal approaches regarding return to work 81% vs 29% und 54% vs 20% (Hazard 1989, Flor 1992).

Fortunately, in Germany exists a structure for an adequate reimbursement of treatment expenses of intensive programs of MMPT in hospitals. The „pain-DRG’s“ (B47, I42, U42), are triggered by a pain-diagnosis (ICD-10) and a complex pain procedure (OPS 8-918). The costs for MMPT are covered by the health care providers.

But there exist still some unsolved issues: Specialized pain clinics are still not part of the German hospital plans. This resulted in an arbitrary historically caused non-symmetric distribution of pain clinics with many facilities in the south (e.g. Bavaria) and a big lack (e.g. Berlin).

Ambulant multimodal structures are not economically supported by the health care providers. Exceptions are some smaller „lighthouse-projects“, which do not reach the broader patients’ population.

Dr. med. Michael Schenk is consultant in Anesthesiology, Pain Medicine, Palliative Care Medicine and Addiction Medicine. He works as a clinician in the field of chronic pain. He began his career at the Charité University in Berlin and is now the head of the Berlin Pain Clinic. He is member of the executive board of the professional association of pain specialists in Germany (BVSD) and the 2nd speaker of the Special Interest Group (SIG) of Cancer Pain in Germany. He gives many national and international lectures and is honorary professor at the National Medical University in Kharkiv/Ukraine, where he helps to establish pain medicine.



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To fight chronic pain effectively, a structured approach is indispensable to achieve these goals: Screening programs for early detection of patients at risk, a stepped approach to meet the patients’ demands in a multilevel care system with outpatient and inpatient multimodal integrative programs.

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PROF DR CHRISTINE SCHIESSL

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Pain is still an unresolved problem in European healthcare systems. Bringing specialists knowledge and individual treatments to patients, is a challenge, especially in rural areas. The use of mobile techniques and e-health is a chance to overcome distance and borders.

Christine Schiessl, MD, PhD, is a Professor of Anesthesiology and Palliative Care at the University of Erlangen and Head of an Interdisciplinary Pain Center at a private hospital in Munich. She is anesthesiologist and pain specialist by training and holds a Master in Medical Education (MME).

Her special research and clinical interest is the diagnosis, treatment of acute and chronic low back pain with special emphasis on the prevention of the development of chronic pain. As Master of Medical Education, she is particularly interested in patient-oriented education and patient-physician communication in multi-modal pain therapy. Currently, she is also member of the Pain Center at the Technische Universität München, working as Executive Director of a research program of the Innovation-Fonds Germany for the development of e-Health and m-Health in back pain, including electronic documentation, telemedicine and application of App-Technology.

WILLEM SCHOLTEN

PHARMD MPA

Consultant – Medicines and Controlled Substances

Currently he is working on a campaign by six medical associations including EFIC to stimulate the medical press to ban imprecise, stigmatising, non-respectful and judgemental terminology because there is evidence that such languages impairs patient access to controlled medicines.

Studied Pharmacy and Public Administration

- 10 years in retail pharmacy (pharmacy management; patient information; quality assurance; cost containment) (1981 - 1991)
- 21 years in public administration (Ministry of Health: cost containment, legislation, production and distribution of controlled medicines; WHO: substance evaluation access to controlled medicines) (1991 - 2012)
- Currently Consultant - Medicines and Controlled Substances

Specialties: Pharmaceutical regulatory affairs and drug control policies. Special interest in realizing access to adequate pain management for those 5 bn. people who have not.

Willem Scholten is an independent consultant on regulation of and policies related to psychoactive substances. Examples of his work include conducting workshops on availability of pain management, providing information on controlled substance policies, the review of cannabis and the application of the International Nonproprietary Name. This has included work for the World Health Organization, non-governmental organizations and the pharmaceutical industry. He serves also as an expert of various expert groups. He is a Board Member for International Doctors for Healthier Drug Policies. In the past he worked in retail pharmacy, in the Dutch Ministry of Health and as the Team Leader for Access to Controlled Medicines in the World Health Organization.

Recently he published on the increasing number of lethal opioid intoxications in the United States and he found that the picture often is distorted. Usually pain patients are accused to be the driving force of this epidemic, but he was able to show that this is not really true. Furthermore, he demonstrated that the Centers for Disease Control and a lobbyist groups use forged consumption figures, exaggerating the situation. Soon he will also demonstrate that CDC's guidelines on chronic pain treatment were developed with anti-opioid lobbyists who failed to declare their background.

Currently he is working on a campaign by six medical associations including EFIC to stimulate the medical press to ban imprecise, stigmatising, non-respectful and judgemental terminology because there is evidence that such languages impairs patient access to controlled medicines. During SIP 2017, he will elaborate on this issue, explain which words not to use and what instead and how one can make a switch to sound language easily.



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Choice of language can impede access to medicines both for the treatment of pain and opioid dependence. Referring to a person as a “substance abuser” rather than “a person with substance use disorder” evokes stigma and there is evidence that it reduces patients’ access to appropriate treatment. Moreover, imprecise terminology may result in misunderstanding of the nature of pain treatment and the management of substance use disorder. In turn, politicians and administrators may establish irrational public health policies, and patients may decide not to take their medicines

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PROF PAT SCHOFIELD

Deputy Dean Research and Income Generation

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The older population is on the increase, and we know there is a high incidence of pain in this group. But they are not a homogenous group and so we to work with older adults to develop self-management strategies that are acceptable to them.

My work is primarily in the field of nursing research. But I have led a number of multidisciplinary cross University, cross Healthcare sector programmes of research into various aspects of pain and ageing or dementia.

I am currently involved in three major programme of research around pain in older adults. The first is a cross council programme of research under the Lifelong Health & Well Being banner which is **Engaging with Older Adults in Designing and Developing Strategies for the Self Management of Chronic Pain (EOPIC)** and the second project is **New technologies to support older people at home: maximising personal and social interaction** funded by dot.rural and the third project is an EU funded programme **Pain Assessment in Patients with Impaired Cognition, especially Dementia**. I have just completed a local study funded by HIEC looking at education of staff to improve the management of pain in adults with dementia within an acute trust. I have over 150 books and publications in the area.

OLIVER SCICLUNA

Commissioner for the Rights of Persons with Disability

Oliver was born with Spina Bifida in Saint Luke's hospital on the 14th July, 1986. Mr Scicluna attended Kalkara Primary school, in which later on he started attending De La Salle College. He continued his studies on Computer Software Programming at MCAST and later on graduated with a degree in software programming from Cambridge University. Currently he is reading another degree in Youth and Community Studies at the University of Malta. He founded and presided over several NGO's such as Hip Hop Malta and Breaking Limits. Oliver worked in several projects which touched varies sectors such as youth, culture, inmates, disability and immigration. He served as the Chairman of the Kumitat Azzjoni Socjeta Gusta, which was a committee who served as an advisory for the preparation of the National Disability Policy. On the 28th of March 2014 he was appointed as the Chairman of the National Commission for Persons with a Disability. Currently he is also serving the Malta Community Chest Fund as a board member and FITA as the deputy Chairperson. Oliver was appointed as the first Commissioner for the Rights of Persons with Disability on June 2016. He is also now serving on several boards representing the rights of persons with disabilities.



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MARTIN SEYCHELL

Deputy Director General

European Commission DG Health and Food Safety (SANTE)

A graduate in chemistry and pharmaceutical technology, Mr. Seychell specialized in Chemical analysis. He has held important positions on several government boards and commissions in Malta, including the Food Safety Commission and the Pesticides Board. Mr. Seychell occupied the post of Head of Directorate at the Malta Standards Authority between 2001 and 2006. He has been responsible for the implementation of a number of EU directives in the areas of risk assessment, food safety, chemicals and cosmetic products legislation, and has actively participated in negotiations on major technical proposals such as the new chemicals legislation, REACH, and in screening processes in the areas of free movement of goods, environment and agriculture during the process leading to Malta's accession to the EU. He held the post of Director of Environment in Malta between 2006 and 2011. As Director, he was responsible for a broad range of functions arising from the Maltese Environment Protection Act. He was appointed Deputy Director General for Health and Consumers at the European Commission in March 2011. Responsible for directorates dealing with Consumer affairs, Public health and Health systems and products (SANCO). 2014 - to date: Deputy Director-General for Health in the Health and Food Safety Directorate-General (SANTE).

PROF ANTHONY SERRACINO INGLOTT

Chairperson

Malta Medicines Authority

Professor Anthony Serracino-Inglott is the Chairperson of the Malta Medicines Authority and the founding Chairperson of the Malta Laboratories Network. He studied at University of Malta and University of Cincinnati where he carried out research in **clinical pharmacy** with a completion of a residency programme under the supervision of the eminent Professor Don E Francke. Professor Serracino Inglott established the Institute of Healthcare now the Faculty of Health Sciences and has published hundreds of peer reviewed publications.



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People with chronic pain want a coordinated, holistic service, providing ongoing medical, physical and emotional support by compassionate, understanding health professionals.

Health care decision making can only be if decision makers understand the lived experience of chronic pain sufferers.

Louise has worked in Health and Social Care for some 37 Years working in community care, acute hospital settings, as well as at Government Departmental level. Since 2009, Louise has been employed as Head of Operations for the Patient and Client Council which is a statutory body established to provide an independent voice for patients, clients, carers and communities in health and social care across Northern Ireland. Louise also works as a Lay Magistrate for the Northern Ireland Courts and Tribunal Service. Louise is married with one grown up daughter and her interests include farming, theology and Irish Sport Horse Breeding.

In 2013 she established a small working group of patients and professionals, and worked collaboratively with the Pain Alliance of Northern Ireland (PANI) to develop a specific project.

Based on the lived experience of 2,500 people who experience chronic pain we produced the Painful Truth report. The key findings included:
Pain affects three of the most central areas of people's everyday life – ability to work, home life and leisure activities. Many people also commented on the 'invisibility' of pain.

Getting a diagnosis can be difficult and, often, a lack of understanding by some health professionals contributed to a delay in their diagnosis.

Health professionals should spend more time working with their patients to find more effective treatments, other than medication, to manage their pain.

People with chronic pain want a coordinated, holistic service, providing ongoing medical, physical and emotional support by compassionate, understanding health professionals in the future.

The Painful Truth made 10 key recommendations that were endorsed by the Minister for Health. Following the publication of findings, the Department of Health acknowledged that chronic pain is a condition in its own right. Eight of the 10 recommendations are all in the process of being implemented. The report has also been acknowledged by other regions/ organisations in the UK as setting the context for their work.

This presentation will provide an overview of the report and will more especially focus on our journey in Northern Ireland and the UK to advocate on behalf of people who live with chronic pain and will provide an update on progress made to date and difficulties/ challenges we still need to address.

DR MED THOMAS SITTE

CEO

Deutsche PalliativStiftung

Sitte studied medicine in Bochum, Bonn and Würzburg, and did finish 1986 in Berlin. After this he worked in different fields of patient-related medicine as well as laboratory, before he became an Anaesthetist. In the early 90th he specialized in pain therapy and with a focus in outpatient and inpatient palliative care for people of each age.

Right now he works in specialized outpatient palliative care (SAPV) for children and younger adults and leads in part time a palliative care unit in hospital for adults. With his formerly palliative care team in Fulda he played an important role as a pioneer in caring outpatients at home in Germany.

Triggered by the needs of outpatient palliative care he developed with a pharmacist in 2003 a very simple method to applicant nasal fentanyl in every desired concentration for symptom control of breathlessness, pain and distress at home.

For this he received a special prize at the 2008 at the German Congress for Pain and Palliative Care and the "German Pain Prize" in 2011, the last also for his success establishing the national SAPV. Beside some other awards for social entrepreneurship he received the Palliative Award 2016 for his 2015 the dissertation with the title „Suicide in specialist out-patient palliative care. Comprehensive survey in the form of empirical social research regarding palliative carers in all SOPC teams in Saarland and Hessen, together with child SOPC teams in Germany “.

He wrote the thesis at the age of 56, because there was a specific need for valid data for a political discussion he was involved. He supported the legal ban of organized assistance of suicide (the law forbids regulations like in Oregon or in Switzerland).

Sittes medical interest focus principles of careful decision making in end of life questions, adequate control of symptoms without shortening life with easy to use methods in home care, palliative sedation, development of outpatient palliative care and dissemination of the necessary knowledge, thinking und doing.

Since several years Sitte is asked regularly as an expert by the German Government or High Courts to the subjects mentioned above.

The Academia Pontificale Pro Vita invited Sitte as an expert to the international PAL-LIFE study group, an "International Advisory Working Group on Diffusion and Development for Palliative Care in the World for the Pontifical Academy for Life".

Sitte published many German and international articles, books and chapters of book about his special interests in papers. His utmost concern is to spread knowledge about the existing excellent possibilities of palliative care as the alternative for the wishes to hasten death because people are afraid to suffer unbearable at the end of life, whereas he makes demands on following the standard f. e. the EAPC standards for sedation in end of life care.



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For dying patients cared for by real specialists it may be assumed that these palliative care teams may also function as an effective form of suicide prevention. We need awareness for patient's problems and early integration of palliative care in any life-threatening disease even in curative setting.

S



DR MONIQUE STEEGERS MD, PHD, FIPP, ASSPROF

Anaesthesiologist for pain treatment

Radboud University Nijmegen Medical Centre, Anesthesiology, Pain- and Palliative Medicine

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Improving peri-operative
pain management
demands 'good' pain
assessment.

Dr. Steegers is anesthesiologist, registered pain specialist and coordinator of the department of Pain and Palliative medicine and associate professor at the Radboud University medical centre. Additionally she is member of the executive board, and Consultant in Anaesthesiology and Pain Medicine at the Department of Anaesthesiology, Pain and Palliative Medicine at Radboud University Nijmegen Medical Centre in the East of the Netherlands. She is registrar and responsible for the Fellow in Interventional Pain Practice examinations of the World Institute of Pain since 2015.

Her main research interests include:

- acute pain and the organization of an acute pain service and quality indicators
- pain chronification, particularly after surgery
- chronic pain, particularly neuropathic pain
- multidimensional interdisciplinary pain diagnostics
- pain and treatment outcome prediction for individualized pain management
- treatment and prevention of chronic (postsurgical) pain
- effective education

Clinical experience:

- consultant acute pain management (head of the acute pain service), cancer pain and chronic pain,
- registered pain specialist in chronic pain, Fellow International Pain Practice (World Institute of Pain) and interventional pain techniques especially neuromodulation
- consultant in anaesthesiology, day care anaesthesia and member of the independent donor procedure team

Management experience:

- Coordinator pain and palliative care
- Member of the executive board of the department (+/-150 employees)
- Member of the executive board of the department of pain and palliative medicine
- Organizer of the monthly meeting for regional multidisciplinary consultations
- Member of the national health safety management program: early recognition and treatment of pain

University teaching experience:

- Associate Professor at the Radboud University
- Junior Principal Lecture
- Coordinator of undergraduate course on pain and pain management at Radboud University medical school
- 14 years of teaching experience
- Lecturer at the teach the teacher course for consultants
- Contribution to local and national education boards for anesthesiology and pain care
- Registrar FIPP
- Contribution to x textbooks on pain
- Published y articles related to her research interested.

PROF AUDUN STUBHAUG MD, DMEDSCI

Professor, Head of department

Oslo University Hospital and University of Oslo

Individual level national registers are unexploited sources for gaining new information about the societal impact of pain. By linking individual data from registers like the prescription register, the patient register, the sick leave/pension database and the primary care register with high quality epidemiological studies/registers unique opportunities arise. Longitudinal data may detect causal relationships that can guide preventive strategies/interventions. Furthermore, resource allocation, and disease trajectories can be studied. Both politicians and health need these high quality register data to improve health care and reduce the societal impact of pain.

Audun Stubhaug is Professor of anesthesiology at University of Oslo and head of Department of Pain Management and Research, at Oslo University Hospital, one of the largest multidisciplinary pain centres in Scandinavia. Stubhaug has been active in pain research and pain treatment for 25 years and has more than 150 publications. His research covers human experimental pain and pain mechanisms, studies of pharmacological treatment, the studies of transition from acute to chronic pain. He has the last 10 years been in the lead of a large epidemiological study of pain (Tromsø Pain Study, N=20 000) with detailed information on both pain patients and healthy individuals. By linking individual data with national registers, his group has started the search for finding new causal relationships and he aims to find both clinical and genetic identifiable risk factors, and potentially develop preventive treatment. Stubhaug is a frequent lecturer at international congresses, and he is in the editorial board of several journals.



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High quality registers are needed both to gain new knowledge about pain and for continuous evaluation of resource allocation and treatment results. Linking epidemiological studies and national health registers is a powerful way to get important information for politicians and health care providers.

S



DR MARIANNE TAKKI MD

Policy Officer

European Commission

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Dr Marianne Takki is a policy coordinator in the European Commission. She is currently working on developing European Union policy on non-communicable diseases and in this context she manages the Steering Group on Promotion and Prevention. Marianne has worked as an official in the Commission since 2003 and she has a long experience on various public health issues. Her background is medicine and public health.

ANN TAYLOR

Reader

Cardiff University School of Medicine



Ann is a Reader in Cardiff University working initially in education and establishing and running level 7 courses for multiprofessional groups. Her PhD work examined pain related fear and anxiety using fMRI finding that the brain in those with musculoskeletal chronic pain, compared to health controls processed pain words and pictures of activities of daily living through pain and fear centres despite having low kinesiophobia on a self report questionnaire. She was the lead author of the Chronic Pain Directives published in 2008 when Welsh Government endorsed pain as a long term condition and is now working on updating pain policy.

She is on the British Pain Society Council and chaired the primary care Map of Medicine pain pathway, was a member of a group developing a template on how pain can be introduced into an undergraduate curriculum and one reviewing terminology associated with routine recording of pain in clinical practice.

Ann has also been involved in raising pain awareness with the Faculty of Pain Medicine, Royal College of General Practitioners and Chronic Pain Policy Coalition. She is the project lead for 'problematic/complex pain', a pre-screening tool for early management of patients who are likely to develop chronicity which arose from the English Pain Summit. For the RCGP, was one of the lead authors on a publication supporting clinicians in the commissioning of pain services and the competency document for PwSI in Pain and the lead author of the pain commissioning support documents. For the Chronic Pain Policy Coalition, was a member of the public health task force - making pain a 'high street' condition and one of the authors of the English Pain Summit report.

Ann was on the Eular Fibromyalgia Guidelines update group and was an OMERACT fellow for the Pain Special Interest Group and attended the joint OMERACT IMMPACT meeting as a speaker and was the lead author or contributing author on a number of papers. One of the papers has significance to the SIP campaign, that is 'Is Chronic Pain a Disease in Its Own Right? Discussions from a Pre-OMERACT 2014 Workshop on Chronic Pain'.

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There has been a groundswell of opinion that persistent pain needs to be reclassified and if we accept, for instance, that it is more than just a symptom, then the philosophy of care should change from a biomedical model to that of a bio-psychosocial one that views persistent pain as a disease or LTC.

T



DR JOHANNES THORMAEHLEN

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Since August 2008 Dr. Thormaehlen is CEO of GWQ ServicePlus AG.

From 2001 until the middle of 2008, he was responsible for the health management division at 4sigma, before joining the management in 2005 and starting the company as CEO in 2007. From 1996 to 2001, he worked as a research assistant and project manager in the field of care research at the Technical University of Munich. He studied human medicine at the Ludwig-Maximilians-University, Munich, and earned the title of Master of Health Administration at the University of Berne, Switzerland, as part of a continuing professional training course.

The treatment of many pain patients is insufficient. A more tailored treatment can help to prevent chronification of pain and to reduce associated costs. A quick access to qualitative and needs-based treatment can prevent unnecessary operations and work disability.

DR DAVID SEN WIE TJONG PHD. CENG. FIMECHE.

Global Director, Health, Safety & Environment

Ideal Standard International

Why should an employer care?

We have the commitment in “Building Ideal Standard to be the best place to work by creating, together, a safe and healthy workplace.”

As an active partner of the EU-OSHA’s campaign on “Healthy Workplaces for All Ages”, Ideal Standard hosted a campaign workshop for Good Practice Exchanges last year.

Applying sound ergonomics principles and practices, we are continuously improving our equipment and processes, from a traditionally manual operation to a more automated processes with assisted devices, in creating a better working environment for our employees.

This is also essential for our operation, with the increasing ages of employees.

David is a Chartered Mechanical Engineer and Fellow of the Institute of Mechanical Engineers.

He is also a member of European Union OSHA Steering Committee for Healthy Workplace Good Practices Exchange, actively involve and lead EU-OSHA Good Practices Exchange events and activities. David is responsible for leading and coordinating Health, Safety and Environment improvement processes for Ideal Standard International. Under his leadership over the last 15 years, the company has achieved a reduction in accident rates of more than 90%.

He is a regular speaker at International and European Health & Safety Seminars and Summits, and a speaker at 2014 European Commission’s Workshop on Industrial Safety.



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**‘Care for Our Wellbeing’
is one of Ideal Standard
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We are committed in
building a process
focused on prevention
of injuries and illnesses.**

T



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The International Classification of Diseases (ICD) is used for morbidity and mortality statistics. However, the introduction of a code for chronic pain with somatic and psychological factors (F45.41) in Germany 2009 made it the major indication for multimodal pain treatment and influenced health care funding since 2013. IASP and WHO have proposed chronic pain diagnoses for ICD-11 that hopefully will have a similar effect worldwide.

PROF DR ROLF-DETLEF TREEDE

Full professor, Chair of Neurophysiology, Vice Dean for Research, Managing Director of the Center for Biomedicine and Medical Technology Mannheim

Medical Faculty Mannheim, Heidelberg University

Education

- 1974 - 1980 Medical school at the University of Hamburg, Germany
- 1977 - 1980 Studies of computer sciences at the University of Hamburg, Germany

Academic positions

- 1981 Dr. med., University of Hamburg
- 1980 - 1988 Postdoc and assistant professor (C1) at the University Hospital Eppendorf, Hamburg
- 1988 - 1990 Visiting Scientist, Department of Neurosurgery, Johns Hopkins Medical Institutions, Baltimore, USA
- 1988 Habilitation (venia legend) in Physiology, University of Hamburg, Germany
- 1990 - 1992 Assistant professor (C1), Institute of Physiology, University Hospital Eppendorf, University of Hamburg
- 1992 - 2007 C3-Professor for Neurophysiology, Institute of Physiology and Pathophysiology, Johannes Gutenberg-University, Mainz
- 1996 Facharzt für Physiologie (as a medical specialty)
- since 2008 W3-Professor, Chair of Neurophysiology, Medical Faculty Mannheim, Heidelberg University
- 2011 - 2019 Managing Director of the Center for Biomedicine and Medical Technology Mannheim (CBTM), Medical Faculty Mannheim, Heidelberg University
- 2013 - 2019 Vice-Dean for Research, Medical Faculty Mannheim, Heidelberg University

Research interests

Peripheral sensory transduction mechanisms in nociception; Efferent functions of nociceptive afferents on microcirculation and neurogenic inflammation; Mechanisms and assessment of nociceptive and neuropathic pain; Hyperalgesia and pain memory; Cortical representation of pain; Pain processing in patients with psychiatric disorders.

PROF THOMAS R. TÖLLE

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Chronic pain should be regarded as a disease in its own right.

Pain: a disease in its own right

Pain is an elementary and universal symptom of almost all diseases that can affect mankind. In 2001, the European Pain Federation (EFIC) declared: "Acute pain, such as that following surgery, constitutes a signal to a conscious brain about the presence of noxious stimuli and/or ongoing tissue damage..., and (this) is reasonably classified as a symptom of underlying tissue damage or disease. However, in many patients pain persists long after its usefulness as an alarm signal has passed, and indeed, often long after the tissue damage has healed. Chronic pain in these patients is probably not directly related to their initial injury or disease condition, but rather to the secondary changes including ones that occur in the pain detection system".

Regardless of the medical views on the bio-psycho-social backgrounds of chronic pain in the current literature, and having in mind that pain is a horizontal problem affecting all medical disciplines, for the purpose of policy-, budget- and resource allocation chronic pain should be regarded as a disease in its own right. While acute pain by definition is a brief and self-limiting process, chronic pain comes to dominate the life of the patients concerned with it and often also family, friends and caregivers. Chronic and recurrent pain is a specific healthcare problem, leading to typical co-morbidity, such as sleep disturbances, anxiety, depression and low self-esteem and often sets the stage for the emergence of a set of physical and psychosocial changes adding to the individual and societal impact of pain.

In order to meet the challenges caused by the societal impact of pain we will need to implement individualized health care delivery systems. This can be very simple support for some patients, while for other patients it might need an intensive multimodal approach. Although in recent years the topic of pain and pain management has moved into the consciousness of the media and drew more attention from politics, we must forcefully strive for an overall European strategy. Now, with the growing knowledge about the societal impact of pain, the health policy needs to act and address pain prevention and management as a key health policy focus of the EU.

Thomas Tölle is a Professor of Neurology at the Technische Universität München, Germany. He is a neurologist and psychologist by training. He was formerly also appointed as Professor of Medical Psychology and Neurobiology at the Ludwig-Maximilians-University in Munich. He set up an interdisciplinary research group for clinical and experimental research into pain, focusing primarily on the neurobiological mechanisms of neuronal plasticity, pharmacological treatment and central imaging with fMRI and PET. His research and clinical interests also include the prevention and treatment of chronic neuropathic pain and he is spokesman and runs the headoffice of the German Research Network for Neuropathic Pain (DFNS). Prof. Tölle has authored many peer reviewed publications and lectures on many aspects of pain medicine all over the world, served as the president of the German IASP chapter and will chair the scientific program committee for the EFIC European Pain Congress in 2017 in Copenhagen.

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RIANNE VAN BOEKEL RN MSc

Pain Nursing Consultant

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Pain should be a quality indicator of Health Care. Every country may want to start this project. In the Netherlands we managed to create an indicator set in hospitals containing pain assessment, digital documentation of pain data and pain consultation as a start.

Diagnosis and treatment of all kinds of pain must contain the multidimensional factors that influence pain and its perception. Chronic pain has always started somehow as acute pain. Optimal diagnosis and treatment of acute pain in order to prevent the transformation to chronic pain (if possible) is therefore very important. Investments in pain education for patients and professionals are necessary, as well as adequate research on those topics that are most important for helping patients. Quality indicators should be a reflection of care, education and research if possible.

Rianne van Boekel is the chairman of the Dutch Society of Pain Nurses who has been working on a new Quality Indicator PAIN in hospitals, an assignment given to the Society by the Dutch Health Care Inspectorate. She is also one of the board members of Dutch Pain Society and advises on several organizational and substantial pain issues. Rianne works in the Radboud University Medical Center in Nijmegen as a clinical pain nursing consultant and as the hospital wide "Theme leader" for early recognition and treatment of pain. She almost finished her PhD studies concerning acute postoperative pain management. Pain education for nurses is also an important topic for her, she set up and coordinates a two-year postgraduate pain education for nurses.

JOOP VAN GRIENSVEN

President

Pain Alliance Europe



As president of Pain Alliance Europe I'm excited to be a small part of this 2017 SIP program.

Excited as the program tackles a lot of topics which eventually will improve the quality of life of people with chronic pain in Europe. Something all of us at PAE have been striving for since we began.

Personally it is an honor to have the opportunity to express the feelings of the chronic pain patients at this event, being the voice of people with chronic pain in Europe. I know I'm just one of them, one of the over 100 million chronic pain patients.

For me, the best possible care for people with chronic pain is to start by believing them. If that isn't happening, all that we are trying to do to improve the environment for the chronic pain patient will not have any effect. Believe the patient, believe his story, believe his possibilities, believe and honor his wishes in reaching goals.

If we could agree on that, the personal story of each individual chronic pain patient will lead any follow up. If we could get rid of our stigmatic image of the chronic pain patient. If we could consider to see the chronic pain patient as a normal, thinking human being. We need to be able to do that, all of us: society at large, healthcare professionals, researchers, policymakers, politicians, industry, social security insurance companies, all the stakeholders present at SIP.

Yes, then we could attain a society in which we still have chronic pain but it will be manageable and the patients will still have an independent life according to their wishes and options. We would have a society which doesn't forget about people who have a problem.

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We would have a society in which we accept everyone just as he is, without any prejudice.



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It is our social obligation to guide patients with chronic pain towards realistic participation and professional reintegration. Successful RTW needs facilitating measures: tailor-made support, intensive coaching (also in the workplace) and communication between all involved parties.

PETER VAN WAMBEKE

Specialist

Physical and Rehabilitation Medicine (PRM) of the University Hospitals Leuven

Workable work for patients with chronic pain: a randomized trial.

The prevalence of chronic pain in Europe is estimated at 19% and for Belgium even at 23% (Breivik, 2006). About 80% of the people with chronic pain are within the labour active age. Of those still at work (full time and part time: 44%), ¼ experience a clear impact of pain on employment.

According data of the National Institute of Health and Disability Insurance (NIHDI) of Belgium Musculoskeletal Disorders (MSD) is one of the major causes of work incapacity (about 50.000 new cases of long term sickness absence each year), with pain as one of the most important complaints. The chance to return to work (RTW) after 1 year of work incapacity is less than 20%.

Taking into account the huge cost for society of long term work incapacity on the one hand and the motivators for patients with chronic pain who stay at or return to work (e.g. work as income, value, responsibility) (de Vries, 2011) on the other hand, it should be our social obligation to guide patients with chronic pain towards realistic participation and if possible (adapted) RTW. RTW seems possible using facilitating measures: tailor-made support, intensive coaching (also in the workplace) and communication between all involved parties.

With the financial support of the NIHDI and in close cooperation with external employment services, the Leuven Center for Algology and Pain Management started in 2017 a project for 3 years: workable work for patients with chronic pain. Patients with chronic non-malignant pain who have followed a Multidisciplinary Pain Education Program (MPEP) within the pain center are eligible for this randomized trial if they are less than 3 years on sickness leave and still have an employment contract. A tailored work related cognitive behavioural therapy module will be compared with care as usual in terms of sustainable RTW.

Peter Van Wambeke is a specialist in Physical and Rehabilitation Medicine (PRM) of the University Hospitals Leuven. He is specialized in spine disorders, manual therapy, pain management and rehabilitation. Since several years he works in the multidisciplinary pain center where he is coordinating the rehabilitation programs with specific interest in participation. He is a former board member of the Belgian Pain Society (BPS) and a current board member of the Royal Belgian Society of Physical and Rehabilitation Medicine (RBSPRM) and of the Spine Society of Belgium (SSBe).

DR ELISABETTA VAUDANO DVM PHD

Principal Scientific Manager

Innovative Medicines Initiative

Pain and particularly chronic pain is a major health care challenge. Approximately 20% of the world's population has an on-going pain problem, many of whom are poorly served with currently available treatment modalities. Better translational tools and novel and more efficient and effective clinical trials are urgently needed if the promise of innovative treatments to pain patients has to be delivered.

The Innovative Medicines Initiative (IMI) is working to improve health by speeding up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need. It does this by facilitating collaboration between the key players involved in healthcare research, including universities, the pharmaceutical and other industries, small and medium-sized enterprises (SMEs), patient organisations, and medicines regulators. IMI is a partnership between the European Union (represented by the European Commission) and the European pharmaceutical industry (represented by EFPIA, the European Federation of Pharmaceutical Industries and Associations).

Pain and in particular chronic pain has been an area of focus for IMI from its very beginning with the implementation of the EUROPAIN project. In IMI2 recognition of the continuing high need for improving understanding, treatment and management of pain and that the magnitude and complexity of these goals require complementary expertise and multi-disciplinary approaches which are best assured by public-private partnerships between industry, small/medium-sized enterprises, academia, healthcare professionals (HCPs), patients and regulators has led to the creation of the strategic Pain Group a satellite to the IMI2 Strategic Governance Group Neurodegeneration in July 2015. The Pain group is responsible to define Call proposals addressing a broad spectrum of relevant pre-competitive themes in pain and it has already generated two topics, one of which is aimed to deliver an ambitious pain platform, while more are in the pipeline.

The EUROPAIN project has now concluded successfully its activities. The IMI2 pain strategy, including the first projects already implemented or in the making, and provide some insights on what is in the pipeline for the future will be presented.

Italian born Elisabetta Vaudano is responsible of the Neuroscience area at the Innovative Medicines Initiative (IMI), the largest European Public Private partnership in Health Sciences with a total budget of more than 5 billion EUR. Elisabetta is a doctor in veterinary medicine, holds a PhD in neuroscience and an MSc in Laboratory Animal Science. Elisabetta started her career as scientist in Academia working in the field of neuronal degeneration, regeneration and plasticity in Italy, UK, Sweden and Denmark. Elisabetta moved to industry in 2000, when she joined Lundbeck as group leader of their Parkinson's disease in vivo Neuroprotection Group. In 2004 she became Head of Pharmacology and CNS Biology at ENKAM Pharmaceuticals (SME). Elisabetta joined IMI in 2010.



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The effective management of pain is an increasing concern in the medical arena, and in the broader economic and political environment. The only way to tackle effectively this challenge is to join forces in an open collaborative way involving all stakeholders, both from the public and private sectors, and keeping the patients in the centre.

V



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Pain management addresses the quality of life for so many patients. It deserves systematic and systemwide action.

DR CHRISTOF VEIT

Institutsleiter

IQTIG

After studying medicine in Freiburg, Breisgau, London and Boston and a practical year at the Städtische Klinikum Karlsruhe, Veit received the license in 1984. After his doctorate in 1985 he worked as an assistant physician in further education in the Urological Department and the Surgical Department of the General Hospital Altona.

From 1990 to 1992 he was Deputy Head of the Department of Information and Communication Technology of the General Hospital Altona, which he helped with. From 1992, he was head of the EQS (External Quality Assurance) Hamburg office until 2007. After obtaining the qualification certificate "Medical Quality Management" in accordance with the curriculum of the Federal Chamber of Physicians in 2002, he became the first auditor for this additional designation at the Hamburg Medical Association.

From 1996 to 2008, Veit was Managing Director of quant-GmbH. This service company of the Hamburgische Krankenhausgesellschaft and the Hamburg hospitals for the BQS Institute for Quality & Patient Safety in Düsseldorf and for a large part of the state offices of the external quality assurance was merged with the BQS Institute in 2008. From 2007 onwards, he headed the business of the BQS Institute until he was appointed Head of the recently established Institute for Quality Assurance and Transparency in Health Care (IQTIG) in January 2015

CHRISTOPHER VELLA

Healthcare professional and Bioethicist

MA Bioethics & Medical Law (Lon), Dip.Dent.Tech, SRDT, LBIDST, FRSA.



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It is a great pleasure and honour for me to be present for this SIP symposium. Even though SIP Malta has been around for less than a year, it does not mean that we are newcomers on the scene. The vast majority of the stakeholders that make up SIP Malta, are veterans when it comes to pain. Our stakeholders are the testimony that highlights the importance of having a holistic and inclusive policy when it comes to tackling pain. SIP Malta has brought together individuals and organisations from diverse backgrounds; academics, health care professionals, patient organisations, those involved in policy making, those from the public sector, those that come from the private sector and political representatives just to name a few.

Christopher Vella is a healthcare professional and bioethicist within the private sector who has been involved with medical ethics, policy and management. For the past 12 years he has been involved in setting up and running his own private laboratory, whilst also pursuing his passion for medical ethics and law by providing consultation services and policy compliancy audits and reviews in the private sector. In 2013 he was appointed as a government appointed member on the Council for the Professions Complimentary to Medicine (CPCM), a position he still occupies to this day. He graduated as a Dental Technologist in 2005, and MA in medical law and ethics in 2014, and is now involved with the Malta Health Network as an advisor, where he represents it in the Policy Advisory Group of the European Patients Forum.

Hopefully the momentum which we have gathered this year will continue across the years to come, even because our current projects will definitely lay out a solid basis upon which to continue expanding our understanding of the current local situations so as to be better positioned so as to propose the most ideal pain policies for the ultimate benefit of all those directly affected; us as a society!



SABINE VERHEYEN

Member of the European Parliament, Germany

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I consider pain treatment as extremely important because untreated pain can cause first and foremost great distress to the patients.

Sabine Verheyen has been a Member of the European Parliament for the German Christian Democrats (CDU) since 2009. She is Coordinator for the European People's Party (EPP) in the European Parliament's Culture and Education Committee and a substitute member in the Internal Market and Consumer Protection Committee. She focuses in particular on media policy, intellectual property and copyright and digital agenda issues. She is co-rapporteur for the Audio-Visual Media Services Directive and has been a Member of the European Parliament's annual delegation to the Internet Governance Forum since 2009. As former mayor of Aachen (1999 to 2009) she focuses additionally on issues that are of relevance to the local authorities, such as eGovernment and accessibility. She has been a member of the Euregio Council since 1999, a member of the council of WDR, the West German public broadcaster, from 2003 and has been a substitute member from 2009- 2016. She is furthermore a member and part of the Steering Committee of the European Internet Foundation. Sabine Verheyen studied architecture at FH Aachen University of Applied Sciences.

It (pain) does not only have a big impact on our health but also on our society and our labour market. It is therefore crucial to raise awareness of these problems, to further encourage targeted training for doctors and nursing staff and to exchange best practices within and among countries and their healthcare systems to tackle challenges and find the best solutions.



V



MICHAEL VON FISENNE

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It is important to maintain the dialogue of pain and its impact on society with all stakeholders in order to make a sustainable change throughout Europe.

Treatment of pain especially chronic pain remains challenging. There are many hurdles to overcome and awareness is still low. Many patients suffering from pain feel alone and helpless. Poorly controlled pain is not only an individual burden but also a global public health issue. Societal costs due to pain are huge. During the last few years I have moderated a lot of meetings dealing with the impact of pain and I realized that continuous communication, exchange of experiences and sharing of best practices are necessary to find solutions and trigger changes in policies in order to conquer this burden.

The Societal Impact of Pain (SIP) is a unique platform, bringing multiple stakeholders like patients, healthcare providers, politicians, payers and others together. It is my conviction that we have a good chance to make progress when we unite forces for the sake of both patients and society.

Michael von Fisenne holds a Master of Science in Biology from the University RWTH Aachen, Germany. He has been working at Grünenthal in the department of Corporate Communications since 2011 and is responsible for live-communication.

MARIANO VOTTA

Director of European Affairs

Active Citizenship Network

Mr Votta graduated in Political Science at University of Rome, Italy. He attended a postgraduate course in European Public Relations and another in Corporate Social Responsibility. He has more than 15-years experience working in the field of protection of citizens' rights, stakeholder engagement, communication and civic information. In 2011 – 2012, he worked as consultant for the United Nations Development Programme in Colombia to assert a new governance in the management of Public Services and Health. Since June 2013, he has been working as Director of Active Citizenship Network, the European interface of the Italian civic organization Cittadinanzattiva, and is also responsible for European Policy and international relations.

In 2015 he took the initiative to encourage and promote the MEPs Interest Group focused on patients' rights called "European Patients' Rights and Cross-border Healthcare" inside the EU Parliament.



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**Making the invisible
visible on chronic pain**

V



DR JOHANNES WACKER

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Challenges for peri-operative pain management include inadequate treatment or severe complications like opioid-related respiratory depression. Organisation and staffing may be more important to improve quality than individual techniques. Pain scores should be used as part of overall outcome measures.

Pain related patient safety and quality in the perioperative setting

Perioperative pain means additional suffering for patients and a challenge for healthcare providers. Patient safety considerations focus on how professionals can eliminate or reduce adverse events that are caused by the process of healthcare, and not by the patient's underlying health condition.

Inadequately treated postoperative pain remains a problem without measurable improvement. Yet, the treatment of pain also creates risks. Opioids are important to treat moderate and severe pain. Their risks include respiratory depression and longterm opioid dependence. By overprescribing, postoperative opioid treatment may contribute to opioid misuse. About 78 opioid overdose deaths occur in the US every day!¹ In the perioperative setting, staffing may have an important impact on pain treatment practice. Recent multiplication of surgical productivity have often not come along with increase in nursing staff. Lower nurse-to-patient staffing ratio and nurses' level of education correlate with higher patient mortality.²

Freedom of pain is one of multiple important outcomes in the perioperative setting besides functional recovery, satisfaction, overall quality of life, and the avoidance of morbidity and mortality. Value-based healthcare should prioritise outcomes that matter to patients.³ Hence, they must be individually prioritised together with patients. Looking at pain indicators in isolation can be misleading. However, pain indicators are an important part of overall outcome assessment.

Clinicians and health care stakeholders can contribute to improving the situation. Opioid-based pain treatment should be as short as possible. Risks should be discussed with patients. The US based Anesthesia Patient Safety Foundation recommends to monitor all patients on postoperative opioids: If oxygen is added, by ventilation monitoring (e.g., capnography), if not, by pulse oximetry. The 2010 Helsinki Declaration on Patient Safety in Anaesthesiology⁴ recommends the use of protocols for managing "postoperative care including pain relief" and may help to implement them.

Dr. Wacker has completed his Anaesthesiology training in Switzerland. He has trained as Clinical and Research Fellow in Cardiac Anaesthesia & Intensive Care at Toronto General Hospital, Canada. He has been a Consultant Anaesthesiologist at the University Hospital Zurich, from 2001-2009, and at the Hirslanden Clinic in Zurich since 2009. He currently serves as Chair of the Patient Safety and Quality Committee of the European Society of Anaesthesiology. Dr. Wacker is a member of the Data and Quality Committee of the Swiss Society for Anaesthesiology and Reanimation. He is Associate Lecturer in Patient Safety at the University of Zurich.

References: 1. Kharasch ED, Anesthesiology. 2016;124(4):960-965; 2. Porter ME, NEJM, 2016;374(6):504-506; 3. Aiken LH, Lancet 2014;383(9931):1824-1830; 4. Mellin-Olsen J, Eur J Anaesth 2010;27(7):592-597

DONNA WALSH

Executive Director

EFNA

Donna Walsh is the Executive Director of the European Federation of Neurological Associations (EFNA).

Donna's background is in journalism but she began her career working in patient advocacy on a national platform as Information and Communications Officer at the Migraine Association of Ireland. This led to her first involvement at the European level via the European Headache Alliance – where she worked as Coordinator for a number of years. She then moved on to take up her current position within EFNA in 2012.

Since then she has been actively involved as EFNA stepped up its advocacy activities at the Brussels Institutions which culminated in February 2015 with the launch of the MEP Interest Group on Brain, Mind and Pain.

Donna also oversees EFNA's other workstreams in the areas of awareness, empowerment and engagement. This includes EFNA's Training Initiatives for Neurology Advocates and their Together Under the Umbrella awareness campaign.

Donna represents EFNA externally – amongst others – at the European Brain Council, European Academy of Neurology (Liaison Committee), European Society of Radiology (Patient Advisory Group) and within SIP.



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EFNA endorses the SIP initiative as there is a clear alignment between the policy outcomes we aim to achieve through the MEP Interest Group on Brain, Mind and Pain and those being pursued by this platform.





DR CHRIS WELLS

President

European Pain Federation EFIC®

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Since 2011, the European Pain Federation EFIC® has worked, together with European and national policy makers, on the “Road Map for Action” outlining how to effectively address the societal impact of pain at policy level. Five years later, we are seeing some concrete results!

The EU roadmap to action

Dr Chris Wells is President of the European Pain Federation EFIC®. This is the largest multi-disciplinary professional organisation in the field of pain science and medicine in the world. It comprises the 37 European Chapters of the National Pain Societies of IASP® (International Association for the Study of Pain). Established in 1993, EFIC’s constituent Chapters represent Pain Societies from 36 countries and more than 20.000 healthcare professionals across Europe, who study pain and treat patients suffering from pain.

Dr Wells has just retired from clinical practice in the management and treatment of pain in Liverpool and the North West of England.

Born in Durban, South Africa on 5th October 1947 of one Welsh and one English parent, Chris Wells trained in Liverpool, graduated in 1970 and then worked in Canada for 4 years. He did further training in anaesthesia and then pain medicine; specialising solely in pain medicine from 1982. He was Director of the Pain Research Institute in Liverpool from 1983 to 1994.

Dr Wells pioneered drug delivery systems in the UK and also Pain Management Programmes in Europe, setting up the first continuously running programme in Liverpool in 1983. His clinical interests include assessment and management of back pain and neuropathic pain.

Dr Wells has been an active Council member of the British Pain Society, Chair of the Scientific Committee from 1995 to 1999 and Secretary from 1999 to 2002. He has organised 4 Pain Society meetings and was made an Honorary Member of the British Pain Society in 2008. He gave the Pain Society’s Annual Lecture in 2008 on “Back to the Future: A Review of Pain

Management Past and Present”.

He has given the British Pain Society lecture, and also the EFIC lecture in memory of David Niv. He has been an invited lecturer at plenary sessions and workshops throughout the world.

He has been a Board member and Treasurer of the World Society of Pain Clinicians and a Board member of the World Institute of Pain. He is a Founder Examiner for the WIP Fellowship of Interventional Pain Practice.

Dr Wells was a Founder Member of NeuPSIG, setting up the group with Ed Charlton in 1999. He was Treasurer of NeuPSIG from 2001 to 2010, and was made the second Honorary Member of this group. He co-organised their 3 successful meetings in Madrid (2004), Berlin (2007) and Athens (2010), Charing this last meeting.

Dr Wells has been active in the European Pain Federation EFIC® for 13 years. He was Secretary of EFIC® from 2002 to 2005, and Chair of the Bye-laws Committee from 2005 to 2008; he became President Elect of EFIC® in June 2011 and President in June 2014. He lectures throughout Europe and the rest of the world on pain and its management, and is actively involved at these meetings to reshape the face of pain management through research, evidence based medicine, education and innovation. He has initiated a multidisciplinary core curriculum in Europe, leading to a Diploma in Pain Medicine for all medical doctors.

He is a member of the current NICE Guideline Development Group on low back pain and sciatica. He has just been selected as a Citizen of Honour by the Liverpool City Council.

He is the author of 3 books and over 150 articles.

DR WOLFGANG WIESMAYR

Head of HOSPICE Upper Austria

Praxis Dr. Wiesmayr Wolfgang, Hospice Upper Austria, Palliativteam
Salzkammergut

It is necessary to have free access to pain medication (even the newly developed) without barriers to treat patients in their last phase of their life!

- Born in Austria 1957, two children (30+31), widower, studied medicine, psychology, political affairs
- General Practitioner for 35 years, specialized in palliative care, special pain treatment and geriatrics
- Chairman of Hospice/Palliative care in Upper Austria (1,5 Mio)
- Head of a mobile palliative care team for 250.000 people in a rural area
- Responsible for Palliative Care in the Medical Association
- Member of HOSPICE AUSTRIA
- University lecturer



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**Accompanying dying
patients and their
families at home with-
out suffering from pain**



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Pain specialists must be involved in cancer treatment at an earlier stage. Interprofessional communication between oncologists, palliative specialist and pain specialists must be improved.

Due to advances in oncologic therapies, 5-year survival rates increased to nearly 70%.

However, chronic pain arises in his population frequently as an undesirable effect after oncologic surgery, chemotherapy or radiotherapy. Tumours are capable to initiate an escalation of pain via tissue processes. Also genetic variables may lead to elevated pain levels in several types of tumours. Significant predictors for chronic pain are nerve damage ('neuropathic pain'), higher pain levels at the beginning of the disease, and demographic variables. Further on, also psychosocial factors are associated with chronic cancer pain. Whereas the impact of these variables is well known in chronic non-cancer pain, the association of psychodynamic mechanisms with chronic cancer often is neglected.

The rate of chronic cancer pain amounts to 20% of cancer survivors and approximately 40% of cancer patients suffer from pain during the course of their oncologic treatment. Overall, the numbers of cancer patients with an insufficient pain therapy in western countries reaches 50%. Multifarious reasons for this under treatment are: problems related to the health care system, such as deficiencies in education resp. training in pain medicine, problems related health care professionals, problems related to patients, such as concerns about opioids, and communicative barriers of both physicians and patients. Many physicians reveal deficiencies in pain assessment, e.g. problems in diagnosing nerve pain in cancer patients. Otherwise, many patients with chronic cancer pain feel reserved to attend palliative specialists, because in contrast to the palliative population, cancer survivors show no need for palliative medicine. The relevance of an adequate pain control is underlined by the fact that an adequate pain therapy at an early stage of a cancer disease shows a positive effect on both quality of life and survival rates. Therefore, an early integration of pain specialists in the curative cancer treatment is compulsory. However, a differentiation of cancer pain according to different stages should be made, because patients' needs differ in the 'palliative' and 'non-palliative' situation.

In summary

- early integration of pain specialists at an early stage of a cancer resp. its oncologic treatment
- educational programmes on pain medicine in academic institutions and medical capacities
- investigation on epidemiology, diagnosis, and treatment of chronic cancer pain are warranted.

Stefan Wirz, PhD, MD, is Chair of the Special Interest Group Cancer Pain of the IASP (International Association for the Study of Pain), speaker of the Working Group Cancer Pain of the German Pain Society and has been involved in the German Guideline Program in Oncology. He completed his PhD thesis on pain and symptom control in cancer pain, published many publications on this topic, and is speaker at national and international congress.

PROF ANTHONY WOOLF

Clinical Director, Clinical Research Network South West Peninsula, NIHR

Bone and Joint Research Group



Professor Anthony Woolf is Honorary Professor of Rheumatology, University of Exeter Medical School, and Plymouth Peninsula Medical and Dental College, and Clinical Director of the NHS National Institute of Health Research Clinical Research Network Southwest Peninsula.

He is and has been involved in various initiatives at a national, European and global level to raise awareness and priority for musculoskeletal health and identify solutions. He coordinated the WHO Report on the Burden of Musculoskeletal conditions at the Start of the New Millennium; lead the European Bone and Joint Health Strategies project; is co-lead of the Musculoskeletal Expert Group of the Global Burden of Disease Study and has lead the European Musculoskeletal Surveillance and Information Network – an initiative supported by the European Community.

He is immediate past Chair of the Global Alliance for Musculoskeletal Health of the Bone and Joint Decade, and is Chair of the Arthritis and Musculoskeletal Alliance (UK). He is editor-in-chief of Best Practice and Research Clinical Rheumatology.

He advises the WHO on various relevant issues, in particular disability, ageing, and noncommunicable diseases. He works with WHO, the European Commission and policy makers in the UK to ensure they consider musculoskeletal health in all policies – health, social and employment. He has most recently successfully advised WHO Europe on including musculoskeletal health in the Noncommunicable Action Plan that was adopted by all 53 member countries in September 2016. He is now working with WHO Europe on its implementation.

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Musculoskeletal health is commonly impacted by pain and musculoskeletal conditions are the major cause of disability world wide with a great economic impact through health and social care and workloss. Actions are needed to address this burden.



EU CIVIC PRIZE ON CHRONIC PAIN

In 2015, Active Citizenship Network (ACN) started a research-project the **“European Civic Prize on Chronic Pain - Collecting Good Practices”** with the aim to give evidence on existing good practices in several European countries in terms of struggle against pain.

The establishment of a “European Civic Prize on Chronic Pain”, based on the selection of the practices presented by different healthcare stakeholders (patients’ associations, health professionals, private and public hospitals, universities, etc.) provides an occasion for demonstrating what this community can offer in terms of good practice and experiences which are useful in raising awareness about the condition, enhancing the body of knowledge of positive cases and success, and strengthening commitment to this topic.

Aims of the project

1. To raise awareness among institutions about the need to identify chronic pain as a priority in health policies and programs at EU and national levels;
2. To encourage the exchange of experiences between professionals and patients’ associations;
3. To create a body of evidence that can be used to support the expansion of programs tailored to the care and treatment of patients with chronic pain;
4. To raise awareness about the technological advances and their impact on the care and treatment of chronic pain – how to improve the lives of those with chronic pain.

It is a recognition of ongoing excellences and, after a lot of important national experiences, the FIRST EUROPEAN new award: “EU Civic Prize on Chronic Pain”.

The project collected 30 Good practices experiences on chronic pain (cancer & no cancer- related) from 11 different countries: (Malta 2; UK 6; Spain 8; Portugal 2; Ireland 1; Italy 6; Germany 1; Denmark 1; Finland 1; Netherlands 1; Russia 1). All the received Good Practices have been collected and published within a report. This work will start the creation of a network of best practice practitioners, able to provide information, advice and practical help to each other.

On February 28 2017, a jury composed by international experts in chronic pain (from universities, healthcare professionals and providers’ organizations, civic and patients’ associations etc.) has selected the 4 winners of the prize, one for each requested category:

Patients' empowerment

Good practices concerning: providing information, creating information campaigns, supporting and capacity-building for individual patients with chronic pain, as well as their relatives, including their social, psychological, and other impacts. This also includes partnerships between patients' organisations and other stakeholders (health professionals, public institutions, media, healthcare industry, etc.) to empower patient and civic organizations so that patients can understand their rights and make informed choices

Innovation (legislative and technological)

Good practices concerning: laws, technologies, apps, etc.

Clinical practices

Good practices concerning: pain management (prevention, diagnosis, treatment and monitoring), dedicated units, therapeutic pathways, clinical records, ways of measuring pain, etc. It will be especially valuable if these involve patients

Professional education

Undergraduate and postgraduate education for healthcare professionals, training courses in the hospitals/clinics, updating general practitioners, etc.

The final event of the Prize will be celebrated during the Societal Impact of Pain (SIP) 2017 symposium that will be held in Malta on 8-9 June 2017, during the Maltese Presidency of the EU Council.



<http://www.activecitizenship.net/patients-rights/projects/204-european-civic-prize-on-chronic-pain-collecting-good-practices.html>

For more information, please contact Daniela Quaggia: d.quaggia@activecitizenship.net

Active Citizenship Network is responsible for the scientific design and contents of this Project, that shall be realized with the financial and non-financial support of





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GOOD PRACTICE NUMBER 1
04/2015 – 05/2016

Category:
Clinical practices

**Newly developed
application for chronic
low back pain Innovation**

JAKE FENECH

Undergraduate Student

University of Malta, Faculty of Health Sciences

Objectives

1. To design a patient-centered smartphone application serving as a pain assessment tool with the main function of recording and tracking pain.
2. To create a functional application that is feasible for both the patient and the health care professional.
3. To scientifically evaluate the validity, reliability and usability of the application.

Outcome

After testing the application and comparing it to the NRS, it was found to be a valid and reliable tool as all the participants showed a positive attitude towards the usability of the application. The researcher acknowledges that generalizations should not be made and though the application worked in these restricted circumstances, results may vary with other conditions. The researcher also recognizes that the application is still in its prototypical stage so further developments would be required. Nonetheless, the results obtained show a great potential and a satisfactory proof-of-concept. Ultimately, the aim of creating a smartphone based application that is valid, reliable and usable was reached. Hence, within these restricted parameters, the presented hypothesis of no statistical difference between the application and the NRS can be supported.

Information about Good Practice Applicant

She is a physiotherapy student currently in her final year of studies to graduate as a physiotherapist. As part of her final year, she performed a study on chronic pain patients with satisfactory results.

SUSAN CHILDS

Consultant Clinical Psychologist

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GOOD PRACTICE NUMBER 2
01/2015 - 08/2016

Category:
**Empowerment,
Innovation,
Clinical practices,
Professional education**

A one stop multidisciplinary pain clinic for Survivors Of Torture

Objectives

A. To identify Survivor of Torture (SoT) patients in a timely manner and offer direct access into appropriate services for SoT, thereby reducing risk of vicarious retraumatisation. B. The one stop format of this assessment clinic aims to reduce unnecessary retraumatising by having multiple appointments with different health care professionals. C. To offer SoT clinics during quieter periods in the outpatient department insuring less chance of psychological distress. D. To offer a medications review clinic to minimise risk of accidental/intentional overdose and contraindication issues. E. To educate SoT patients about pain medications and counter possible cultural beliefs about Western medication being stronger, or "the bigger the dose the better the effect." F. To offer a pain physician and psychological assessment in a safe and culturally sensitive environment so that SoT patients have a clear pathway to investigations and treatments and time to understand what these involve reducing vicarious retraumatisation. G. To help SoT patients understand better why chronic pain is different from acute pain and that the central nervous system is involved. H. To look how much central sensitization plays a role in the presentation of their symptoms. I. To offer matched investigations and treatments to the patient's needs and identified life values and goals. J. To develop a new compassion focused therapy group to introduce and practice pain management strategies. K. To offer SoT patients the opportunity to work with defined staff members to allow a relationship of trust to develop. L. Swift referral to psychiatric services for patients who have severe mental health issues.

Outcome

This group of patients would typically avoid attending psychology appointments; as though they feared their pain and suffering would be explained away by mental illness. They might present with uncontrolled psychological illness/symptoms. They decided that the easiest way forward is to offer a combined appointment. Little is currently known about the impact of chronic pain on survivors of torture in the UK and they have started trying to understand the presentation issues more fully for this vulnerable patient group. Outcomes collected to date include: 1. Survivors of torture now attend more frequently to the pain clinic than before the specialist SoT clinic began (evidenced by attendance rate / DNA's). Previously nonattendance (DNA) rates were higher than for other pain patients. 2. Telephone interviews with 6 SoT patients who attended when the service was first created indicate higher patient satisfaction and knowledge of what treatments were offered. 3. Survivors of torture are facilitated access to physiotherapy and pain management sessions with a psychologist (evidenced by attendance rate / DNA's). 4. Clinicians have gained a better understanding of this patient group and their beliefs and the impact of their pain upon their lives and self-efficacy. (As evidenced by the Brief Pain Inventory (English & Arabic)). Additionally they are collecting audit data to observe SoT patient mood levels on using the PHQ9, GAD7 & BPI, + newly developed pain sensitivity scale (PSQ) & meds.

Information about Good Practice Applicant

She is the joint project leader with Dr. Bianca Kuehler (Specialty Pain Doctor). They observed that survivors of torture did not attend scheduled pain management psychology sessions well and realised that they needed a more holistic approach to accessing pain management advice and interventions. Dr. Susan Childs, Clin Psych D., is a Consultant Clinical Psychologist who works in a major London based NHS Trust and provides the lead for the therapies arm of their pain management services. She has specialised in Chronic Pain since her doctorate in 1999 and has written and provided both 1:1 and group services for a number of trusts.

Dr Bianca Kuehler, is a Speciality Doctor in Pain Management. She initially qualified in Germany as an Anaesthetist in 1993. In 1997 she began to focus on acute and chronic pain. After moving to the UK she obtained a Diploma in Occupational Health. She has worked over the past few years to provide outstanding multidisciplinary services in the treatment of chronic and acute pain.



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GOOD PRACTICE NUMBER 3
01/2011 - 12/2017

Category:
Clinical practices

Physical activity in women with fibromyalgia: effects on pain, health status, and quality of life.

MANUEL DELGADO FERNÁNDEZ

Professor (with a Chair)

Department of Physical Education and Sport, University of Granada, Granada, Spain

Objectives

Overall aim: To determine the role of physical activity on the development and treatment of fibromyalgia in female patients. Specific aims: 1. To analyse the levels and patterns of physical activity and sedentary behaviours (objectively measured by accelerometry), functional capacity, pain, overall health status and quality of life of 300 Spanish women with fibromyalgia aged 35-65 years; cross-sectional study. 2. To track the levels and patterns of physical activity and sedentary behaviours (objectively measured by accelerometry), functional capacity, pain, overall health status and quality of life of 300 Spanish women with fibromyalgia aged 35-65 years over a 2-year period; 2-year follow-up study. 3. To determine the effect of two types of exercise training interventions (water and land-based aerobic strength training vs. a control group) on pain (primary aim), health and quality of life (secondary aim) in women (n=180) aged 35-65 years with fibromyalgia; Intervention (randomised controlled trial) study.

Outcome

The main variables of the study were: body composition by bioelectrical impedance analyses (InBody R20, Biospace, Seoul, South Korea). Physical fitness by standardised performance based tests (e.g., the back scratch, arm curl, and 6 minutes' walk tests). Fibromyalgia impact and quality of life by the Fibromyalgia Impact Questionnaire (FIQ) and Short Form Health Survey 36 (SF36). Sleep quality and fatigue by the Pittsburgh Sleep Quality Index and Multidimensional Fatigue Inventory. Tenderness by a physical examination with a standard pressure algometer (FKP 20; Wagner Instruments, Greenwich, CT, USA) at 18 tender points according to the American College of Rheumatology (ACR). Pain by subscales of the FIQ (pain), SF36 (bodily pain), and the ACR questionnaire for the modified 2010 preliminary criteria (widespread pain index), and visual analogue scales. Physical activity and sedentary behaviors with triaxial GT3X+ accelerometers (Actigraph, Pensacola, FL, USA) over 7 consecutive days. Cognitive performance by the Paced Auditory Serial Addition Task and Rey Auditory Verbal Learning Test to measure working memory and declarative memory. The alAndalus Project is unique because of the inclusion of subjective assessments (e.g., patient reported outcomes) and objective measurements (e.g., performance based tests). To avoid patients' flare-ups, the assessments were distributed over 3 consecutive days.

Information about Good Practice Applicant

Manuel Delgado Fernández is Professor (with a Chair) at the Department of Physical Education and Sport, Faculty of Sport Sciences, University of Granada, Granada, Spain (since April, 2012). Manuel got his BSc and PhD in Biomedical Research at University of Granada in 1988 and 1991, respectively. Then he started to work at University of Granada as an Assistant Professor in 1991. Since 2014, he is the director of the MSc in Research in Sport Sciences at University of Granada. In 2012, he was awarded as an Excellent Teacher with a score of 97 out of 100. He has been supervisor of 27 PhD thesis. He is currently supervising 8 thesis. From 2004 to 2015, he was the Director of the Research Group "Physical Activity, Sport, and Ergonomics for Quality of Life". From 2016, he is the Director of a new Research Group named "Physical Activity for Health Promotion". He is author of more than 150 scientific papers in peer reviewed journals (81 in PUBMED), 8 books, 40 books chapters, and Editor of 5 books. He has participated in 25 Research Projects; 14 as the Principal Investigator. He has been invited as Speaker in 25 conferences; 15 of them were international. He has been author of more than 175 communications in conferences; more than 120 were international. The National Board of Sport and Physical Activity Professionals awarded his professional labour. Manuel Delgado Fernández is the project leader of the good practices presented here.

GERTRUDE BUTTIGIEG

Honorary Secretary

Malta Health Network (MHN)

Objectives

On a local level MHN brings together patient groups who suffer from chronic pain as part of their condition or secondary to their condition. The past campaigns indicated a need for more training and resources to be made available locally for patients, for public in general and professionals. Thanks to collaboration with other entities including Societal Impact of Pain (SIP) and ISAL Foundation, over the past years MHN has distributed copies of the Pain Tool Kit Booklet in English and this was gladly accepted however patients and professionals asked for material in Maltese language. The main objectives of the projects are

- To train and educate patients on ways of dealing with chronic pain – currently there are too many patients who are not sufficiently informed on how to deal with chronic pain affordably
- To facilitate the cooperation of NGOs representing patients and professionals in the field of chronic pain leading toward raising awareness on self-help and empowerment.
- To have information in Maltese available as a publication and also some information in electronic format on MHN website.
- To offer training to professionals and patients on pain management.

Outcome

Having information for patients and professionals available aims at having a positive impact on the quality of life of patients with chronic pain and of their families. Information is also beneficial for the general public to educate people who are currently non-patients to look after their health and also be more understanding of people with chronic pain. Having better trained professionals will possibly have a positive impact on the service they offer to patients. Empowering patients to take the responsibility of their care. Training sessions for patients (about 40 people attended the 2 sessions) and professionals (30 in one session) were attended with enthusiasm and from the feedback forms collected after the sessions the content resulted very interesting and relevant to daily life. Feedbacks were also very positive about the impact on patients and indicated that such sessions were very helpful and should be repeated at different places to reach out more people. Professionals had the same positive comments and indicated that having booklets and reference material for use in their professional practice has been extremely useful indeed. MHN has also raised awareness amongst the Ministry of Health and the Health Promotion Department and they asked to carry out similar sessions in the future - this is a work in progress and through them MHN hopes to reach a much wider audience.

Information about Good Practice Applicant

Gertrude Buttigieg is Honorary Secretary of the Malta Health Network. Ms. Buttigieg has been Secretary to the MHN on a voluntary basis since 2007, she has led or coordinated various projects for MHN including Patients' Rights, awareness on the Patients' Rights in the Cross Border Directive and raising awareness on Chronic Pain. She has represented MHN as a participant and speaker in several local and European events.



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GOOD PRACTICE NUMBER 4
02/2016 - 02/2017

Category:
Empowerment

**Relieving the
Suffering of Chronic
Pain Patients**



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GOOD PRACTICE NUMBER 5
11/2013 - 08/2016

Category:
Professional education

**RCN Pain Knowledge
and Skills Framework
for the Nursing Team**

FELICIA COX

Chair, Royal College of Nursing Pain and Palliative Care Forum

Royal College of Nursing

Objectives

The Royal College of Nursing (RCN) Knowledge and Skills Framework for Nurses (KSF) is a 52-page document produced as a national initiative funded by the RCN. It aims to provide a framework that supports the development of competence in managing pain for the entire nursing team; from unregistered care assistants to registered nurse consultants. The framework contains the eight aspects of care identified at a roundtable discussion of nursing experts from the RCN Pain and Palliative Care Forum held in November 2013. It has been designed to be used alongside local competency documents and illustrates Benner's vision of individual nurse's migration from novice to expert (Benner 1984). There is clear progression in the knowledge, practice and experience of nursing staff working within the framework. Firstly the career framework (Skills for Health 2010) is mapped against both Benner's levels of performance (novice, advanced beginner, competent, proficient, expert). These two, in turn, are mapped against levels of education across the spectrum from the care certificate through to doctoral studies. Content has been split to meet the specific needs of unregistered (care support workers) and registered members (Registered Nurses) of the nursing team. Each staff group has their own framework summary based on Benner's 1984 novice to expert levels of practice mapped against levels one to eight of the Skills for Health Career Framework (SFH 2010). The document also supports the Pain Patient Pathway Recommendations; to prioritise, raise awareness and educate about chronic pain. Prior to the publication of this document, there were no nationally agreed standards, competencies or frameworks for pain management nursing in the UK or Europe. It is available to download from <https://www.rcn.org.uk/professionaldevelopment/publications/pub004984>.

Outcome

The KSF was launched simultaneously across the four countries (England, Wales, Scotland and Northern Ireland) of the United Kingdom and in Europe at the 2015 EFIC meeting in Vienna. As there are some differences in nursing care and pain management provision, representatives across the four countries all contributed to the development and launch of the document. No formal evaluation of the impact of the KSF has yet been undertaken as the launch was only conducted in late 2015. An electronic survey of all UK acute and chronic pain services (n=214) in early 2017 is planned to establish the dissemination, implementation and local impact. It is intended to undertake qualitative exploration of the impact of the framework by early adopters using focus groups in mid-2017. This work will build on the National Pain Audit Report 2010-2012 (British Pain Society www.nationalpainaudit.org) which indicated that 'specialty interest groups in each profession should provide guidance on which competency and skills are required in order to meet patients' needs and to support commissioners and providers in identifying more clearly what skills are commissioned from particular services' (BPS 2012 p.8). It is anticipated that the document will standardise roles and responsibilities, and by mapping education against experience this should provide specialist nurses with support for their practice and to develop and expand services to meet local and regional service user (patient) needs.

Information about Good Practice Applicant

Felicia Cox MSc RN is a specialist pain management nurse who is the current Chair of the Royal College of Nursing Pain and Palliative Care Forum. She is the lead for this innovative and extensive project which has developed a national knowledge and skills framework which aims to empower nurses to assess and manage pain more effectively. Felicia is the Editor of the British Journal of Pain for the British Pain Society (BPS) and was awarded Honorary Membership in 2015. She has published extensively on the assessment, management and impact of both acute and chronic pain.

MARIA TERESA SILVEIRA DIAS FLORDELIMA

Coordinator of the Program and Consultant for Pain Strategies

Regional Health Directorate

Objectives

Since 2009 ADDCA has organised a Program for Acute Pain, Chronic Pain and Delivery Pain, applying national and international guidelines. Priorities were: education of professionals and public information (campaigns, partnerships, patient associations). The Objectives were well defined: to develop regional policies to organise structures for pain control in hospitals; to educate professionals before and after the graduation; to coordinate the care systems to ensure timely access to the right support; to find funding for pain research; to improve treatment of pain; to reduce the prevalence of pain; to reduce major physiological, psychological, economic, and social consequences for patients, their families, and society; to promote better quality of life; to reduce costs of pain patients. Activities planned: 1 – pain courses for physicians, nurses, other healthcare technicians, nursing students; 2 – post graduation trainings for physicians; 3 – thematic courses related with pain, such as palliative care, teamwork, burnout, giving bad news; 4 – organisation of conferences, workshops; 5 – commemoration and information in national days and international days about pain and palliative care; 6 – articles and interviews in papers and TV.

Outcome

The three hospitals organised Multidisciplinary Pain Units, Acute Pain Units, Pain in Delivery, to meet the human rights of those in pain. Professionals are aware about pain evaluation and treatment, pain impact, drugs, etc. They refer more patients to Pain Units; they are able to prescribe opioids. Citizens know the burden of pain, its impact, and what should be done in terms of policy interventions to reduce these problems; they changed to healthy life styles and improved Life Quality. Public knows the impact of chronic pain. The indicators who were programmed: education of all physicians about national guidelines and all nurses about pain evaluation as the 5th vital sign; number of those who attended the courses; number of nursing students and number of hours to teach pain; number of physicians who attended post-graduate courses about pain; number of courses (2-4 hours, 2 days); number of workshops (4 hours); number of first consultations for chronic pain patients (increased From 400 to >500); number of surgical patients with analgesic techniques (>80%); number of deliveries with epidural analgesia (>60%); waiting times for chronic pain consultations; opioid consumption.

Information about Good Practice Applicant

Leader of Regional Pain Control Program 2009 - 2013 and Chronic Pain Strategies 2014 - 2016 Physician, specialist in Anesthesiology 1981, Pain Medicine 2004, Health Service Management 2003, Master in Palliative Care 2014. Advanced Studies Course on Biomedical Ethics at the end of human life, Bereavement and counselling Courses. Since 1997 pioneer in the fight against pain and implementation of palliative care in the Autonomic Region of Azores (Portuguese Islands) and pioneer in prevention of suffering since 2001, when started the first Pain Consultation in Azores. Member of the Palliative Care Teams of the Divino Espírito Santo Hospital, Ponta Delgada 2010 to 2016. Coordinator of Multidisciplinary Pain Unit 2001 to 2016. Consultant of Azorean Chronic Pain Patients Association (ADDCA), Coordinator of the Social Network of Volunteers in Community in Seniors Association of São Miguel (ASSM). Visiting Professor at the Azorean University since 1983 and Teacher for Anesthesiology, Pain, Palliative Care in Hospital, Regional Health Directorate, Basic courses of National Palliative Care Association, Specific courses for Volunteers. Member of the Bioethics Research Group, Azores Center (CEB Açores) and other professional Associations: International Association for the Study of Pain (IASP) and Special Interested Groups on Pain in Older Persons and Pain Education; European Association for Palliative Care (EAPC); European Union of Medical Specialists.



Portugal
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GOOD PRACTICE NUMBER 6
01/2009 - 12/2016

Category:
Professional education

**Regional Pain Control
Program**



Italy
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GOOD PRACTICE NUMBER 7
10/2016

Category:
Empowerment

**Hundred Cities
Against Pain**

ELISA AMAUDO

Collaborator

Fondazione ISAL

Objectives

The aim of the Day – celebrated in 2016 on 1st October– is to sensitise and inform people about pain, to recognise chronic pain as a preventable and treatable disease, to support healthcare efforts to prevent and manage chronic pain, to promote fundraising for research, to involve media in pain fighting. Hundred Cities Against Pain is also supported by the Web campaign #Zeropain16, a campaign that brings together people from all over the world and that during the International Day share their selfies and comments to say “No!” to chronic pain. ISAL Foundation strives also for creating a supportive social network which can link up chronic pain’s suffering patients all over the world and for raising awareness about this global public health issue. 135 Italian cities, including hospitals and local associations and 16 European cities are involved in the event.

Outcome

ISAL Foundation promoted the development of a national network of physicians and pain patients working together to improve the knowledge of pain treatment centers, therapeutic options and possibility of cure. Its main success is related to the increase of cities participating to the event year after year.

Information about Good Practice Applicant

She holds a PhD in Science, Technology and Humanities obtained with a thesis in Philosophy of Medicine on the acknowledgment of chronic pain as a disease. She has been working for Fondazione ISAL for 2 years. She cooperates with other members of the Foundation in the organisation of the events and she also maintains the relations with foreign institutions and associations. In addition to this, she participates in the Foundation’s research projects.

ELISA AMAUDO

Collaborator

Fondazione ISAL

Objectives

The School was founded in 1993 as the first Italian Institute for the Study of Pain and its treatment. The mission of the School is to train medical experts in the field of pain therapy in order to create a network of evidence-based competences.

Outcome

Since its foundation, the School has entitled about 500 physicians to the practice of pain therapy and promoted several specialistic seminars and developed a network of professors who operate towards a widespread diffusion of the knowledge in the field. The Italian Ministry of Health has recognised the School as provider of ECM credits for medical education.

Information about Good Practice Applicant

Hold a PhD in Science, Technology and Humanities obtained with a dissertation on pain as a disease. I have been working in Fondazione ISAL for 2 years cooperating in the organisation of the events and in the communication area. I participate to the Foundation's research and manage international relations.



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GOOD PRACTICE NUMBER 8

Since 1993

Category:
Professional education

ISAL School of
Algological Sciences



Ireland
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GOOD PRACTICE NUMBER 9
09/2015 - 12/2018

Category:
**Empowerment,
Innovation**

**"What's Under the
Hat?" campaign**

JANE WHELAN

General manager

European Headache Alliance

Objectives

The European Headache Alliance (EHA) devised an innovative pan-European public awareness campaign to raise awareness across Europe of the extreme effects of headache disorders and the number of people affected (over 88 million). The 'What's Under the Hat?' campaign was devised by EHA in conjunction with its members to address the key issues they reported: 1. The lack of public compassion for headache sufferers; 2. The need to make the invisible visible; 3. The lack of a platform to give those living with headache disorders a voice. The lack of recognition and 'branding' of headache disorders was deemed key to address these issues. By devising the 'What's Under the Hat?' campaign, EHA aimed to:

- Increase awareness and understanding of the real severity and impact of headache disorders
 - Empower those living with a headache disorder to access better information and support
 - Provide platform to give those living with a disorder a voice. People living with a headache disorder were asked to share their headache story by:
 - Sharing a photo of them wearing a hat on Facebook or twitter with the hashtag #underthehat
 - Creating a short video to post on YouTube tagging it with Underthehat
 - Writing a blog post to share online
- The campaign aims to empower people living with a headache disorder to seek support and advice, speak up and educate others on headache disorders.

Outcome

The toolkit created gave patient groups materials and branding to adapt and use to support their work on a national level. Most organisations used the hashtag #UndertheHat with several other created in other languages: e.g. #ponteunsombrero. The campaign online generated stories and photographs of people living with headache disorders, their families and friends. Stories shared empowered and encouraged others to post and share on Facebook and twitter. Most stories focused on the impact and burden of living with a headache disorders on day to day life, with those suffering sharing their feelings of frustration, anger and resignation. Increased posting and sharing was noted around the launch date on European Migraine Day of Action (12th September) and again for Cluster Headache Day (21st March). Facebook posts and tweets with photos were shared with the hashtag #underthehat however many people shared their photo in a private Facebook group e.g. closed cluster headache Facebook groups, indicating how many people are not willing to share their disorder publicly. However other people felt empowered and encouraged to share their photo and story publicly and welcomed the initiative. Many reported feeling isolated and that the campaign was needed to let other people know: 1) about the impact and severity of their disorder on their daily life 2) of the available treatment options and support groups available in their country.

Information about Good Practice Applicant

Project submitted on behalf of the European Headache Alliance, a nonprofit, patient umbrella group which was launched in 2006. Since then, the Alliance has grown to represent 25 patient groups from across the continent. EHA was setup to: voice the views and concerns of headache patients across Europe Inform and influence policy makers on headache disorders; work in partnership with other relevant organisations to promote common aims and goals; coordinate the efforts of national advocacy groups in Europe. EHA aims to: promote awareness and understanding of migraine and other primary headache disorders Improve access to appropriate diagnosis and treatment for people affected by a headache disorder.

MARIAN NICHOLSON

Director

Shingles Support Society

Objectives

Patients ask the charity about shingles and post herpetic neuralgia. Shingles is a rash caused by the reactivated chickenpox virus coming back to the skin surface, often many years after chickenpox was first caught. People who have not had chickenpox cannot get shingles. Sometimes something 'triggers' the virus to awaken or reactivate and shingles appears. It can happen at any age, but is more likely to affect older people. About 60 % of 85 year olds will have had shingles. After the shingles has healed, some people are left with pain in the area affected by the shingles. This is called post herpetic neuralgia and is more common in older people. Patients reported that family doctors (GPs) did not know how shingles was transmitted nor did they know how to treat post herpetic neuralgia. This is a neuropathic pain which does not respond to 'ordinary painkillers'. This neuropathic pain varies in intensity from patient to patient, but in the worst cases it can "render the patients' final years an unendurable misery" as one pain doctor told us. Shingles Support Society decided to create an information pack that would supply all the information that a patient with shingles or post herpetic neuralgia will need. It includes four pages of detailed and referenced treatment information for the GP, written by pain specialist (consultant in anaesthesia), as well as leaflets on other aspects of shingles and post herpetic neuralgia.

Outcome

The information pack on shingles and post herpetic neuralgia allows the patient to ask the GP for pain treatments which have not been considered. These may correctly treat the pain. If the patient is lucky enough to respond well, normal life can resume. Even when the patient only gets partial relief, this can sometimes be enough to allow the patient to leave the house, partake in social events and even resume work. The pack also includes a full explanation of what shingles is and how it is not infectious in social situation, two pages of self-help suggestions, two pages on the use of TENS machines, two pages of contact details given by patients who are happy to talk/email other patients.

Information about Good Practice Applicant

She is the director of the shingles support society. Since 1989, the Shingles Support Society responds to questions about shingles (Herpes Zoster): its infectivity, its treatment, what self-help can do.



United Kingdom
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GOOD PRACTICE NUMBER 10
11/2014 - 11/2016

Category:
**Empowerment,
Professional education**

**Shingles & PHN
information pack**



Spain
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GOOD PRACTICE NUMBER 11
10/2016

Category:
Empowerment,
Clinical practices

Patients' School

GEMMA FERNANDEZ BOSCH

President

Asociacion Sine Dolore

Objectives

The main objective of the patient school is to educate, raise awareness and improve the quality of life of patients with pain. Also, to make familiar to the chronic pain problem. The school consists of small talks given by pain specialists. One of its characteristics is that the doctor speaks in plain language, easy to understand.

Outcome

The biggest impact is that many of the participants understand their problem or their family member's problem. Helping to improve the quality of life of the person affected by pain. It is a very important annual activity because there are many people who require medical attention and cannot access it. Thanks to these annual meetings, doctors can be contacted and personally advised, since the most important of the talks is the interaction between doctor and the patient. That is, the patient can ask the doctor about his problem and the doctor helps him with the best answer.

Information about Good Practice Applicant

Gemma is the president of the association, together with the team of Sine dolore she carries out the activities.

ELISE HOUDAYER

Researcher

Ospedale San Raffaele

Objectives

Chronic pain is a highly disabling condition severely degrading people's quality of life. Low back pain, as well as trigeminal neuralgia, is a common condition of chronic neuropathic pain. Pharmacological therapies are effective only in a minority of patients and alternative treatments have to be developed to relieve patients' pain. Apart from the devastating symptoms patients may experience such as spontaneous burning feeling, sensation of "pins and needles" or continuous crushing pain, neuropathic pain can also lead to severe anxiety or depression disorders. The chronicity of pain acting on mood can also lead to a distortion of patient's own body perception. Since clinical evaluation of pain is based on the subjective reports of patients, a "distortion of self" can lead to incorrect pain rating leading to incorrect treatment. This project aims thus at defining an innovative neuro-rehabilitative strategy helping patients to regain a correct somatotopic sensibility using a multimodal approach. The project combines highly technological rehabilitation tools (virtual reality) with neuropsychological support. Importantly, the patient is placed in the core of a multidisciplinary team composed of neurologists, neuropsychologists, neurophysiologists, neurosurgeons and physiotherapists, all working in close interactions to provide patients with a personalized rehabilitative strategy. Psychological effects of pain in each patient were first measured using a detailed neuropsychological evaluation. Then, the multidisciplinary team defines a neuro-rehabilitative plan based on virtual reality rehabilitation combined with psychological support. The virtual reality setting reinforces patients' feedback in a multisensory point of view (visual, auditory and proprioceptive) and has the advantage of increasing patients' compliance and motivation. The setting also permits remote communication with patients' home from the hospital, allowing close follow-ups after hospital-based rehabilitation.

Outcome

This multimodal approach to chronic pain treatment had so far the great benefit of improving patients' quality of life, assessed by appropriate scales, and of reducing chronic drug abuse. This treatment offers each patient a complete neuropsychological evaluation, a psychological support, and an innovative and efficient neuro-rehabilitative treatment which is also associated with a better compliance of patients compared to standard rehabilitation. Moreover, a remote control communication platform was developed to allow close follow-ups of patients when they end their rehabilitative period, directly from their homes.

Information about Good Practice Applicant

Elise Houdayer (PhD) is a passionate 36 y.o. Neuroscience researcher (H index 16) specialised in the study and treatment of cognitive and sensorimotor disorders using neurophysiological tools such as noninvasive brain stimulation (transcranial magnetic stimulation – TMS, or transcranial direct current stimulation), neurorehabilitation based on computer generated 3D environments and high density electroencephalography. During her PhD she collaborated with neurosurgeons on the study and treatment of neuropathic pain and published 2 papers (1 in second and 1 in last author) on the effect of motor cortex stimulation on pain and brain activity in patients with sensory differentiation. Recently, she won a grant of the Italian Multiple Sclerosis Foundation (FISM) for a project aiming at using repetitive TMS to reduce chronic neuropathic pain in multiple sclerosis patients. Elise is a communicative, empathic person who always sought patient's contact and collaborative interactions within or between groups. This reflects on her publications (for example, during her 3 years of PhD she published 4 papers in first author and 11 papers in coauthor). Same efforts were pursued on publication and congress attendance during her postdoctoral fellowships, demonstrating a real interest toward the constant innovations in her field. Elise is also a dedicated teacher and mentor. She is thus a highly specialized, motivated and empathic researcher who perfectly endorses her role of project leader.



Italy
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GOOD PRACTICE NUMBER 12
09/2016 - 09/2018

Category:
Innovation,
Clinical practices

**Nonpharmacological
treatment of chronic
pain: a multimodal
approach.**



Germany
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GOOD PRACTICE NUMBER 13
05/2015 - 02/2016

Category:
**Empowerment,
Innovation**

**Tele-medical support
for patients with
chronic pain**

DR WIENFRIED MEISSNER

Chair

Jena University Hospital, Pain Unit

Objectives

Aim of this study was to assess acceptance and feasibility of a telemedicine support after chronic pain patients have passed a comprehensive multimodal pain management programme. In addition, effects on pain intensity, perception of impairments and well-being were analysed as secondary outcome parameters. After the end of their standard therapy, the intervention group (n=23, from 05/2015 to 02/2016) of patients from the interdisciplinary outpatient pain clinic received text messages (SMS) over a 4-week period. There were 2 SMS categories: Treatment SMS (based on standard therapy topics) and Feedback SMS (questions about impairments in daily life, well-being, dealing with pain, average pain intensity). Secondary outcome parameters were compared to the historical patient group.

Outcome

93.5 % of all Feedback SMS were answered. 76 % of respondents assessed getting the text messages as (very) helpful, no one as bothering. Almost 74 % were willing to get further Feedback SMS, 90 % would appreciate further Treatment SMS. Regarding secondary outcome parameters, no statistically significant differences could be observed.

Information about Good Practice Applicant

Chair of Pain Unit, Dep. of Anesthesiology and Intensive Care, Chair of Palliative Care Dep., Jena University Hospital Professor Patient Care, Research, Teaching.

SERENA MINGOLLA

APMAR Communication Officer

APMAR - National Association of People with Rheumatic and Rare Diseases

Objectives

The project "A pain to listen - un dolore da ascoltare" is a multidisciplinary and multifactorial project addressed to women with Fibromyalgia. Fibromyalgia pain has no boundaries. People describe the pain as deep muscular aching, throbbing, shooting, stabbing, or intense burning. Quite often, the pain and stiffness are worse in the morning, and muscle groups which are used repetitively may hurt more. In addition, the severity of regional pains (particularly those in the head, neck, shoulders and lower back) are a strong predictor of a person's overall pain rating. Pain in every muscle and the profound exhaustion are not symptoms that people can see, but they are real and may be devastating for the person with fibromyalgia. Although the invisible nature of the condition causes credibility dilemmas for patients. Despite recent gains in understanding this condition, the lack of an easy "gauge" for chronic pain makes it difficult for people to grasp how fibromyalgia may cause so many symptoms and seriously jeopardize every aspect of a person's quality of life. The project "A pain to listen - dolore da ascoltare" includes: psychological support to women suffering from Fibromyalgia, self-help groups where women talk, meet, discuss the pain and jointly organise events and other projects; information, through the creation of brochures and different kind of materials; an info point managed by APMAR and a toll-free number that provides information and immediate help for women feeling lonely. The project aims at improving the quality of life of women with Fibromyalgia. It has the main following objectives: provide information about Fibromyalgia, raise public awareness, collect useful data for research development, give support to the person, reinforcing third sector, provide mediation of the recognition process and bioenergy structuring activities and exercises classes tailored to symptoms (stiffness and fatigue) useful to boost endurance.

Outcome

Main outcomes were: psychological and physical well-being of women with Fibromyalgia syndrome were enhanced by social support. Chronic pain, depression, self-efficacy, helplessness, mood disturbance, health status, impact of FMS, were improved. Psychologists involved in the project observed a decrease of alexithymia and depression, greater security and openness in relations. Women started processing and overcoming the sense of loneliness and isolation, increasing knowledge and therefore awareness, acceptance of the disease. Regression analyses indicated that the created social support networks were associated with greater levels of self-efficacy for pain and symptom management, while the perceived quality of social support was associated with lower levels of depression, helplessness, mood disturbance, impact of Fibromyalgia, higher levels of self-efficacy for function and symptom management, as well as overall psychological well-being.

Information about Good Practice Applicant

Serena Mingolla is Director of Morfologie, the journal of APMAR - National Association of People with Rheumatic and Rare Diseases. As volunteer and communication expert, she helped draft the present good practice, raise awareness for the project and involve participants. The project leader is Antonella Celano, President of APMAR.



Italy
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GOOD PRACTICE NUMBER 14
01/2015 - 12/2016

Category:
Empowerment

A pain to listen



United Kingdom
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GOOD PRACTICE NUMBER 15
Since 05/2016

Category:
**Empowerment,
Innovation.**
Professional education

**Empowering people to
self-manage their pain**

PETE MOORE

Author and Trainer

Pain Toolkit

Objectives

To make the learning pain self-management more interesting and fun for patients and the healthcare professionals

Outcome

Participants (both patients and healthcare professionals) get feedback from the Pain Toolkit Quiz. Which questions they got right and which ones they didn't. They can also go return to the quiz to increase their score and knowledge.

Information about Good Practice Applicant

Author and Trainer of the Pain Toolkit Quiz <http://quiz.paintoolkit.org>

JUDY BIRCH

CoFounder

Pelvic Pain Support Network (PPSN)

Objectives

The British Medical Journal (BMJ) and others have published articles over many years that emphasise the need for and the importance of patient involvement in medical education. Surveys and feedback from health professionals regarding input on chronic pain into the curriculum have highlighted the general lack of such content. Of all health professional groups, physiotherapists appear to have the most input on chronic pain into their training. The objective of this work is to give trainee health professionals – both nurses and doctors the opportunity to hear firsthand, as part of the taught curriculum, about the personal experience of people with long term pain regarding their encounters with health professionals. These sessions are delivered by patients who are also experienced teachers, and are thus taught from a firsthand “Patient Experience” perspective rather than as abstract “Case Studies”. This method of delivery gives students the opportunity to ask questions, to delve deeper and to clarify the whole picture from the patient perspective. These ‘Patient Teacher’ sessions were introduced in the School of Healthcare (SHC), University of Leeds (UoL), BSc(H) Nursing (adult) Programme in 2009 and in 2016 for Medical Students at the UoL and the University of Southampton (UoS).

Outcome

For the BSc(H) Nursing (adult) programme, qualitative feedback via the module evaluation process has been collated since 2009. This data is reviewed via the SHC Programme Leader, Director of Education and Head of School and made available to the wider University and all SHC staff. In addition, the PPSN ‘Patient Teachers’ have obtained and evaluated qualitative and quantitative feedback on a short rating questionnaires from all of the ‘Patient Teacher’ sessions since 2009. It is clear that the students highly value this input. Students say that they have no input on ‘Patient pain experience’ anywhere else in the curriculum nor do they have any input on chronic pelvic pain. They report that the impact it makes will benefit them in their subsequent roles as practitioners. Since the introduction of the SHC ‘Patient Teachers’ sessions, at least one student elects to focus their assessment on Chronic Pelvic Pain. This raises the individual students awareness of chronic pelvic pain issues and management strategies and ultimately may contribute to clinical practice chronic pain awareness and discussions. The sessions for doctors in their 4th year of training started at Leeds and Southampton in 2016. The groups so far have responded positively with observations such as “Why is not there a multidisciplinary approach to chronic pain as there is for cancer and other conditions ?” and “it is so important to have the patient perspective alongside the “medical model” .

Information about Good Practice Applicant

Judy Birch is the Co-Founder of the Pelvic Pain Support Network and a qualified teacher. She is the coordinator of this project and has planned and delivered the content in collaboration with the School of Healthcare at the University of Leeds and the University of Southampton. Her role is voluntary.



United Kingdom
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GOOD PRACTICE NUMBER 16
11/2009 - 12/2016

Category:
**Empowerment,
Innovation,
Clinical practices,
Professional education**

**Patients as Teachers
in Health Professional
Education**



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GOOD PRACTICE NUMBER 17
12/2016

Category:
Empowerment

Christmas party

GEMMA FERNANDEZ BOSCH

President

Asociación Sine Dolore

Objectives

The Christmas appetizer is an event which brings together patients with their families and medical staff. There is a festive atmosphere, which let patients forget their troubles for a moment. This is also another way to make visible the invisible, as governments authorities participate too and so they indirectly endorsing the fight against pain.

Outcome

The Christmas appetizer involves also patients' families and local/national authorities so that they can really see that the pain affects people regardless of age, social classes, etc. Pain is between us every day. A very important step for the association is to involve also patients' families as most of the time patients feel lonely and their pain misunderstood. Our mission is to fight patients' loneliness and facilitate their quality of life and well-being.

Information about Good Practice Applicant

She is the president of the Sine Dolore association, which struggles every day to make "visible the invisible: pain".

GEMMA FERNANDEZ BOSCH

President

Asociación Sine Dolore

Objectives

The Gala Sine Dolore is an activity open to everybody. Through music we want to make the invisible visible: through culture and the musical notes people are made aware of chronic pain and at the same time they join the fight against pain.

Outcome

The Gala is celebrated in the Main Theater of Mahon. It is an emblematic place as it is one of the oldest buildings in Europe. It can accommodate about 800 people, therefore message conveyed by the Gala reaches 800 people. Artists who perform for free delight the public with high-level musical performances. The message is clear: they all fight against pain, they want to make it visible, raise awareness of this problem as chronic pain

Information about Good Practice Applicant

She is the president of the association whose mission is to fight against pain.



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foundation.org

GOOD PRACTICE NUMBER 18
05/2016

Category:
Empowerment

Gala Sine Dolore



Italy
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GOOD PRACTICE NUMBER 19
02/2016 - 12/2017

Category:
Clinical practices

Allenarsi per la salute

LUCA DI BLASIO

Research fellowship

Department of Medicine and Aging Science „G.d’Annunzio“ University of ChietiPescara

Objectives

The main objectives of the projects are: 1. to characterise the health status of breast cancer survivors and to study the correlates and determinants of their health status; 2. to prevent/treat the negative side effects of breast cancer treatments (i.e. fatigue, arthralgia, myalgia, shoulder and upper limb functions and ROM impairments, insomnia, anxiety, depression, obesity and cardio-metabolic diseases onset) through both physical exercise practice and nutritional education; 3. to offer individual counseling about the proper lifestyle to adopt to prevent/treat the negative side effects of breast cancer treatments. The objective number 1 is reached through a multidisciplinary evaluation by a senologist, a cardiologist, an endocrinologist, a sports medicine specialist, a psychologist, a nutritionist, a kinanthropometrist and a physical exercise specialist. In order to optimise the objectives number 2 and number 3, the eligible participants selected were trained for three months, for 3 hours per week, under the supervision of three physical exercise specialists and then had a personal counseling with both a physical exercise specialist and a nutritionist.

Outcome

Basal characterisation of the considered breast cancer survivors (BCS) revealed that they had high daily salivary cortisol, high daily carbohydrates and saturated fat intake, and high daily pain. On the contrary, they had low daily salivary DHEAS, low quantity and quality of nocturnal sleeping, low aerobic fitness, low daily fiber intake, and low self-reported health. High daily salivary cortisol has been shown negatively correlated with sleeping quality and quantity and with self-reported health. On the contrary, it has been shown positively correlated with self-reported pain. After three months of supervised physical exercise practice, participants reduced daily salivary cortisol and pain. On the other hand, they increased sleeping quality and quantity, self-reported health, and daily salivary DHEAS that has been shown correlated with the variation of self-reported pain: a greater DHEAS increase was related to a greater pain reduction. Results also indicate the presence of a dose-response relationship: greater physical exercise adherence brought greater positive results.

Information about Good Practice Applicant

Andrea Di Blasio is an Italian PhD. working at the “Department of Medicine and Aging Sciences” of the “G. d’Annunzio” University of ChietiPescara. His research activity is about 1. the study of the relationships among physical activity, physical exercise and health, with a special focus on female health and chronic non-communicable diseases; 2. the study of the effects of exercise on female health and chronic non-communicable diseases, with a special focus on its effect on breast cancer treatments and side effects. He attended several specialistic courses to increase his skills in the field of public health, kinanthropometry, physical activity analyses and both physical exercise planning and periodisation in health and diseases. The project presented is a multidisciplinary project merging University and Hospital competences. The leader of the University group is Prof. Giorgio Napolitano, while the leader of the Hospital group is Prof. Ettore Cianchetti. Luca Di Blasio is the coordinator of the operative group, i.e. the group providing for participants screening and physical exercise practice.

PIM GIEL

President

Happy Motion

Objectives

Pain Together is an initiative of Happy Motion foundation. The main aim of the project are: acknowledge and recognise chronic pain; promote cooperation between regular and complementary therapists; promote own management by patients.

For the achievement of these goals, Pain Together used the most efficient means of communication to attract attention: movies! An essential support of the project Pain Together, among other things, came from the documentary "To be crazy" in which six pain patients are followed for one year and a half. All six are seeking solutions to combat the pain, or - at the very least - to facilitate handling of the pain and thus to improve their quality of life.

Outcome

Results achieved: seven movies, two conferences, a book published, education trajectory, nationwide campaign Week Pain, country presentations and discussion meetings, (digital) media campaigns.

Information about Good Practice Applicant

Pim Giel (1959) worked 30 years in health care; nursing, aged care, intensive care, anesthesia, as a teacher and as an independent innovation manager. He knows the problems so from the inside. He decided to combine his experience in the care of his passion for making documentaries. He is now a fulltime director/ producer and he made the last few years dozens of commissioned films about care: two documentaries about dementia (My Head In Your Hands and Ger, my head into his own hands) and a documentary about chronic pain (In order to be crazy). With his own foundation Happy Motion he aims to deal with serious topics from a positive angle, challenging manner and with the experience to bring central image and link it to an (educational) event, conference or symposium. He gives throughout the country (often with patients and experts from his films) presentations about his vision care. Where his film is a reason for encounter, dialogue and moving discussions in the hall between patients, caregivers and healthcare professionals.



The Netherlands
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GOOD PRACTICE NUMBER 20
09/2016 - 10/2016

Category:
Empowerment

Pijn Samen
(Pain Together)



Italy
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GOOD PRACTICE NUMBER 21
04/2016 - 03/2017

Category:
Empowerment

At lessons from the expert patients (EP) : advices for the physicians to improve their care of cluster headache (CH) patients

PAOLO ROSSI

Chief

Alleanza Cefalalgici Cluster

Objectives

Cluster headache (CH) is an excruciating form of primary headache characterised by recurrent unilateral, short lasting attacks of very severe headaches and most commonly appearing in clusters, that is active periods separated by pain-free remission periods. Despite the diagnosis of CH is very simple, and rapid and effective treatments for alleviating CH pain induced sufferings are available, data from literature have documented that CH is largely under-recognised, undertreated and underestimated. Barriers to a proper care for CH are strictly connected to its low prevalence. In fact, as for other rare or infrequent disorders CH is not adequately known, apart from few specialists, and - as a consequence - CH patients' needs are largely unmet. As for other rare or infrequent disorders, a precious but untapped resource is represented by the expert patients. The aim of this project was to collect a list of recommendations from CH expert patients (EP) for the physicians engaged in the CH management, with the purpose to improve their ability in taking care of CH patients.

Outcome

77% of the EP' advices could be grouped in 7 main recommendations: 1) Prescribe the correct medication at the right dose and in the right quantities; 2) Consider few clinical clues to make the diagnosis: it is very simple! And educate other doctors; 3) Provide good information and be able to correct the misleading ones; 4) Take the patient seriously, listen to him to recognise his suffering and that CH is a valid medical disorder that can have a significant impact on the person, and support him (care, not cure); 5) Be sensitive to the CH consequences on the patient's significant ones and provide, if necessary, family and carer's consultations; 6) Suggest patient to not conceal and to be active in patients' support; 7) Allow quick access for ECH patients to headache specialists. These commandments have been used as guidelines to propose pragmatic patient-centred changes in health care services dedicated to CH patients. The following actions were started: to encourage the national and international associations focused on headaches to multiply the initiatives to educate the physicians about this disorder; to call upon the EU parliament and the Member States to remove the barriers to the access to effective treatments and to acknowledge that CH is a highly disabling disorder; to invite the headache specialists to refer to the patient associations their CH patients; to encourage the physicians to create facilitated pathways to allow a quick access to headache specialists.

Information about Good Practice Applicant

Paolo Rossi is the Project Leader of the following good practice. He is also Vice President of European Headache Alliance, Chief of Alleanza Cefalalgici Cluster, Chief of the Headache Clinic INI Grottaferrata Research Associate University Centre for Adaptive Disorders and Headache (UCADH), Pavia, Italy.

In addition to that, he is Professor of Clinical Neurology at the Nursing School of the Tor Vergata University in Rome, assistant at the Neuro-Rehabilitation Unit, INI Grottaferrata. Main research areas: headache, pain medicine, clinical neurophysiology, integrative and alternative medicine. Other scientific activities: he is member of the Scientific and Editorial Committee and Reviewer for more than 20 international scientific journals, including Frontier in Neurology, BMJopen, BMCneurology, Complementary and Alternative medicine, Complementary therapies in medicine. He has written more than 70 Medline articles.

ROSARIO RODRIGUEZ GONZALEZ

President

National Fibromyalgia and Chronic Pain Confederation

Objectives

Fibromyalgia is a chronic rheumatologic disease that affects several systems of the human body and its functions, being represented by innumerable symptoms. Although in recent years the rate of people affected by this disease has been increasing and the visibility of this disease has grown, these patients must face great problems to which, today, is not yet being given a solution. Some of the main problems are: it is a chronic disease with great variability in its symptoms; it affects the biological, psychological and social sphere of patients; there are not too many research teams working on it.

That is why National Fibromyalgia and Chronic Pain Confederation has set up a helpline for people affected by fibromyalgia and their families. It is the most agile and efficient way of working to meet the existing needs, posing the following objectives:

- Provide an information service and specialised help on fibromyalgia, on the existing healthcare resources and patient associations, among others, aimed at people suffering from these diseases or at people who are suspected of suffering from them.
- Advise the family members of people with fibromyalgia about the disease, treatment and how to adequately support their relatives.
- To create a protocol of psychological first aid, to branch patients affected by fibromyalgia in need of immediate attention to professionals collaborating with associations federated to National Fibromyalgia and Chronic Pain Confederation.

Outcome

The results of the project have been satisfactory. Although it is imperative to be aware that it has been a pioneering project throughout the Spanish territory, people have gradually become acquainted with it and with the helpline number, 901 760 997. At first, we have taken into account the calls received, which have been progressively proportioned as the months passed by. This seems very positive since it is a sign of real acceptance. The number of calls is increasing and this means that the service helps a greater number of patients. Another positive result has been the great users' satisfaction with regard to the helpline service, which was high regardless of whether they were directly affected by the disease, or the relatives of someone suffering from fibromyalgia.

Information about Good Practice Applicant

The National Fibromyalgia and Chronic Pain Confederation has conducted a project of addressed to patients with fibromyalgia and their relatives. This group of patients is socially forgotten, because fibromyalgia is not an accepted disease in society. In many cases these patients need information and answers to their doubts. Usually, doctors tell them they suffer from a chronic illness and give them a diagnose, but no other information. Patients get scared by this news. The National Fibromyalgia and Chronic Pain Confederation wants to help patients and offer them a useful, fast and effective service. To serve this purpose, they have established a helpline service so that anyone interested can access, regardless of their place of residence. Patients will always be assisted by a specialised professional. Concrete doubts will be solved. Psychological assistance will be given to patients, since they require it. This has been a pioneering project in Spain and has obtained some fantastic results.



Spain
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GOOD PRACTICE NUMBER 22
01/2016 - 12/2016

Category:
Innovation

Helpline of care for fibromyalgia patients and their families



Spain
accionpsoriasis4@gmail.com

GOOD PRACTICE NUMBER 23
Since May 2014

Category:
**Empowerment,
Innovation**

Elearning. Online educational platform for patients with psoriasis and psoriatic arthritis

ALFONSO SANTIAGO

Director

Acción Psoriasis (Spanish Psoriasis and Psoriatic Arthritis Patients Association)

Objectives

It has been found that the management of the disease depends on several factors, such as knowledge of the disease, adherence to treatment, doctor-patient relationship, personal characteristics, emotional state and attitude of patients, among others. For this reasons, it is important to give people affected by psoriasis tools to improve the management and evolution of the disease. In the same way, it is of vital importance that patients have an adequate knowledge of their therapeutic options. Indeed, the empowered patient coexists better with his illness. For these reasons, Acción Psoriasis launched the Online ELearning course. Training patients and increasing their knowledge about their disease leads to an improvement in the control and management of the disease itself. Furthermore, empowerment of patients provides resources and tools to live better with the pathology and improves their quality of life.

Primary objective: to establish a network of expert psoriasis and psoriatic arthritis patients. Secondary objectives: 1. To test the level of knowledge about the disease at baseline. 2. an e-learning platform for psoriasis and psoriatic arthritis patients and their relatives. 3. Assess the level of benefit for each subject of the training.

Outcome

For patients: the psoriasis and psoriatic arthritis patient who becomes aware and takes an active role with the pathology learns and educates, improving at the same time the health outcomes and adherence. He also helps other patients by providing information and support. 2. For healthcare providers: the expert and informed patient manages the disease in a better way, has a better health, takes the treatment better and makes easier the communication and relationship with the health care provider saving time and efforts. 3. For public institutions: the expert patient saves money of his public health system as he does not waste resources; at the same time, he optimises the management of his disease by using less medications and fewer visits to healthcare providers which joined the online platform. 4. For civic organisations: Psoriasis Action aims to improve the lives of patients with psoriasis and psoriatic arthritis. This activity improves quality of life of these patients working both directly with the patient and his family and also to improve the patient's condition in the health system and society in general. The online educational platform is within the Psoriasis Action website so the patient and family can easily find other resources of the association offered on this website.

Information about Good Practice Applicant

Santiago Alfonso is director of Acción Psoriasis and the project leader of the described best practice.

GUSTAVO NORTE

Anesthesiology resident

Chronic Pain Unit, Anesthesiology Department, Centro Hospitalar e Universitário de Coimbra

Objectives

Main objective: implementation of compressive therapy in patients with chronic pain related to leg ulcer. Specific objectives: specific training for the implementation of compressive therapy by nurses of the chronic pain unit; elaboration of a procedure protocol for the use of compressive therapy in selected patients of the chronic pain unit; reduction of pain using compressive therapy as an adjuvant technique in patients with leg ulcer without significant arterial pathology; promotion of leg ulcer healing and prevention of its recurrence using compressive therapy. The success of compressive therapy is reliant on the patients' self-care at home. During their consultation with the nurses, patients are provided with essential information (oral and written) in, ligature care, alarm signs of ischemia, daily registry of pain and pharmacologic management, specific footwear, promotion of physical exercise and specific feeding habits. All patients are also provided with a pack of four ligatures, two of them are applied during the consultation as they need specific management, while the other two are stored at the patient's home. They need to be washed, dried and packed properly according to nurses' indication. Ischemia of lower leg is a possible complication of compressive therapy. Patients are informed of ischemia signs and how to proceed in that case. Patients are encouraged to fill out a daily registry of pain using a numerical scale to better evaluate pain in different situations and thus optimising pain control with systemic analgesics, which are prescribed in a specific range by the medical doctor. This pain registry also helps the medical doctor to understand the patient's pain range and adapt the prescription to his needs. Daily physical exercise (specially walking and mobilisation of tibiotarsal joint) and regular intake of proteins, iron, vitamins and other nutrients are encouraged to improve and fasten ulcer healing. A guide about how to exercise and which foods to eat is provided through a flyer and also during the consultation with the nurse.

Outcome

Between May 2011 and April 2014, 52 patients with leg ulcer were referred to the chronic pain unit, 12 of whom were excluded by significant arterial pathology. Of the 40 remaining patients, 11 were undergoing compressive therapy in another hospital, and 10 had no criteria to perform the treatment or refused. We found that 90% of 19 patients submitted to treatment, presented pain reduction by 50% during the 4th week of treatment and 80% of patients were pain-free after 8 weeks of treatment. The systemic analgesics consumption was reduced in 20% of patients. Ulcer healing was achieved during the 12th week in 45% of patients while this occurred in 32% patients in the 24th week. The remaining patients were admitted to treatment before the 12-week time and the average time to ulcer healing was 16 weeks. With regard to the follow-up after ulcer healing, all patients were observed after 15 days, a month, three months, six months, and annually after treatment discharge. Ulcer relapse occurred in 59% of patients, and it was associated with incorrect use of compression socks, wider ulcer and issues such as venous thromboembolism.

Information about Good Practice Applicant

Gustavo Norte is an anesthesiology resident, now finishing his second year of training. His special interest in chronic pain has led him to perform chronic pain rotations which consists in clinical activities and research work. He is the main researcher of this project.



Portugal
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GOOD PRACTICE NUMBER 24
05/2011 - 12/2018

Category:
**Empowerment,
Innovation,
Clinical practices**

**Compressive therapy
in patients with chronic
pain related to leg ulcer**



Denmark
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GOOD PRACTICE NUMBER 25
Since 03/2017

Category:
**Empowerment,
Innovation**

**SmerteLinjen
(The pain line)**

LARS BYE MØLLER

Vice president

FAKS The Association For Chronic Pain Patients

Objectives

One of the initial reasons for starting a telephone helpline was to take some of the pressure off from people calling and asking FAKS for personal help in the patient organisation. Also the idea was to pursue a more professional and organised approach to guide people living with chronic pain and their relatives. Main goals: providing free information and support to people suffering from chronic pain and their relatives; recognition of the pain people experience and helping them to navigate the healthcare system, the social system and their own lives; guiding people towards the right treatment as soon as possible and empowering people to take responsibility for their own lives. Secondary goal: in addition to offer guidance, FAKS also hoped for the telephone helpline to help spread and increase the awareness of chronic pain among citizens and professionals.

Outcome

Statistics and data: first of all being able to track the call rate is important not only to see if our effort is effective, but also in order to provide leverage for future fundraising. Second, FAKS tried to know more about our callers in order to adapt our advice with the right content and knowledge (sex, age, residency, marital status, income basis, caller group patient, relative, health professional, other, subject, where did you hear about the pain line).

Information about Good Practice Applicant

Lars Bye Møller is vice president of The Association For Chronic Pain Patients (FAKS) which is a Danish nondiagnosis specific patient organisation. After the SIP 2012 in Copenhagen he also took part in the foundation of a Danish interest organisation "SmerteDanmark" (Pain Denmark) where he was vice president for four years. Together the two organisations founded the telephone helpline SmerteLinjen (The pain line). Today, he is member of the steering committee managing the telephone helpline "SmerteLinjen". Besides taking part in lot of the organisational tasks, and political work, he is also an eager photographer and videographer. This comes in handy when trying to portray and make chronic pain visible and the work of the organisation through social media. Last but not least important, he himself lives with chronic pain due to fibromyalgia. After several years spent learning how to navigate the healthcare system and by coincidence being referred to an interdisciplinary pain clinic, he finally saw some improvement. He now uses his position to undertake various patient empowerment initiatives and increase the awareness of chronic pain and put it on the political agenda.

ANNA GISS

Board member, advocate

Suomen Kipu ry

Objectives

Teaching from personal experiences, that is it. Anna Giss holds advocacy speeches in nursing schools, and wherever people happen to reach her out from. She tells people what it is like to live her life, how does pain affect her, what difficulties she has come across with, how could the nursing staff help her, what is there to think about when they have a patient like her. During these lessons, she always let people ask her any questions. By asking questions they really want to know, they will get the answers they are looking for. Her main goal with these advocacy speeches is that other pain patients could benefit from these lessons. If a nursing student attends her lectures and then comes across with a patient with similar kind of conditions, he or she might remember how to act, what to ask, and what not to do, based on her lecture. She also posts photographs on Instagram that reflects her battles with her health condition, but also her everyday life. The account name is: @lusikoitakiitos. With over 800 followers she has lots of people from the spoonie community (chronically ill people who identify as a spoonie, the name coming from the spoon theory). Photos really say more than words: some of her photos are cruel, some poetic. She also has her own pain and health related blog: www.lily.fi/blogit/lusikoitakiitos She also writes some advices and information to people, who are in similar situations. These all together makes her a great pain advocate.

Outcome

The teachers who have asked her to give speeches, have told many times how innovative the students were after they had had the chance to ask Anna Gill things. Now the students have a piece in their memory on how to act, if a person suffering from pain comes for their patient. She has also been contacted after my appearances in the media. People told her how they have found power in themselves, but some other people have also studied her conditions a bit more and have offered some help. The impact might also be that a chronic pain patient who has stayed in the bed under the covers way too long, can read the blog or see her on TV or in a magazine, and think: "oh the hell with it. If that young girl does it, so do I." When she gives her advocacy speeches, there are usually roughly 35 nursing students plus two or three teachers. She goes to the University of applied sciences of Tampere about ten times a year, that means she has educated about 350 nursing students every year for a couple of years now. In the last month there have been at least 1,4k individual visitors on her blog.

Information about Good Practice Applicant

She is a 28 year old student from Finland. She has studied German language and culture, teaching, nursing and social services, but most important: she has learned from her personal experiences in life. She has gone through a short training programme after which she has worked as an "experience advocate". In the near future she has to retire because of her four chronic pain conditions, but she is not giving up on volunteer work. Pain is her everyday life, involving Thoracic Outlet Syndrome, Complex Regional Pain Syndrome, chronic complex migraine and bulging disc with radiculopathy. She is very outspoken and have done advocacy in the media, and through her own ways.



Finland
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GOOD PRACTICE NUMBER 26

Since 11/2014

Category:
**Empowerment,
Innovation,
Clinical practices,
Professional education**

Experience advocate



Spain
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com

GOOD PRACTICE NUMBER 27
05/2016 - 01/2017

Category:
Empowerment,
Professional education

Sinedolore World Park

GEMMA FERNANDEZ BOSCH

President

Asociacion Sinedolore

Objectives

Menorca is the least known island of the Balearic Islands, which since the beginnings of mankind has been related to pain. In its history, apart from the great amount of talaiotic wealth, there is the Hospital of the Island of the King, a place where the pain was visible during the wars, as thousands of soldiers of different nationalities were brought here. Also, there is the Island of Lazareto, where Leprosy patients used to be isolated. The history of Menorca day by day was involved in advancing to improve the quality of life, alleviate suffering, that is why Sinedolore is born: to fight against pain and make it visible. The main objective of this event is to make visible the invisible, that is pain. 20% of population suffers from this invisible evil. Sinedolore's mission is to raise awareness about this great problem. This is why the island of Menorca for four days becomes celebrates the struggle against pain. Menorca is a place that in itself has a great quality of life, its tranquility and its environment is ideal for this project.

Outcome

The greatest result is that anyone who is on the island, has been able to understand the problem of pain. During these days, many doctors from different parts of the world give informative, explanatory talks about how to alleviate suffering, how to understand the patient, what possible treatments there are, latest research etc. The biggest impact is that people who come to Menorca from other places find an island totally dedicated to the fight against pain.

First of all, what is essential is the help of all the Menorcan entities. This initiative is possible thanks to the collaboration of the municipalities of the island, private companies and employers, associations, hotels and restaurants, including the support of the military and the church. Being all involved is much easier and cheaper. Using free public spaces it is possible to hold conferences for anyone who wants to participate. Sports activities are also done in sporting clubs. During these days, also military museums and diocesan museums are free. We also have the collaboration of the press, which facilitates the activities that take place during the days of the park, as well as programmes spread in hotels and shops on the island.

Information about Good Practice Applicant

The association Sine Dolore is an entity that fights against pain, to make visible this evil that is neither seen nor can be measured. They are volunteers and with the few resources they have they always try to benefit society at the maximum.

ROSARIO RODRIGUEZ GONZALEZ

President

Alba Andaluca

Objectives

The general aim was to offer patients affected by fibromyalgia a total knowledge of the different aspects of the illness, ways to face it and ways of taking care of themselves. The specific goal was to provide with knowledge about the existent techniques and resources to fight the illness in order to improve the quality of their lives. A better treatment of the pain caused by fibromyalgia involves raising awareness among patients of their joint responsibility about their state of health and having to overcome the stereotypes which label patients as passive receptor of care. Indeed, it was necessary to switch to a model where the patient is key to reach a good state of health. For that purpose, empowering the patient and motivating him was fundamental too.

Outcome

Patients have been provided with knowledge about the illness in more than 55% cases, and also with a set of specific strategies and skills to learn how to have and maintain a positive attitude about their health. The guidebook has changed into a tool that supplies information for the family and people around the patient, improving the understanding about the illness and inducing to a better acceptance of it. The guidebook works as a tool addressed to the medical personnel to be well informed about the illness and be able to provide patients with a better service. The handbook has been well received by different Spanish organisations. Thanks to the dissemination of the guidebook, the illness was made visible to more people, and society was provided with general information in a more accessible format.

Information about Good Practice Applicant

The ALBA Andaluca Federation was born in 2007 as an associative entity for Fibromyalgia, Chronic Pain and Multiple Chemical Sensitivity patients, as these pathologies are considered barely known as chronic illnesses that have an important repercussion. Nowadays, the presence of this entity in Andaluca has a growing trend, with a total of 66 member associations, representing a collective of 13,000 patients. There has currently been a slight advancement in the field of knowledge of chronic pain and fibromyalgia, but it can be said that it is still widely unknown in society. Although unfortunately it lacks a cure, the life of patients can still be improved, through the own acceptance that they have a chronic illness and that as a consequence they have to follow a series of steps. That is why, the challenge posed by this project was to create an informative guide aimed at patients diagnosed with fibromyalgia. So far, there is not a guide, manual or publication by a public or private institution directed towards patients to shed light to the helpless situation which they face.



Spain
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GOOD PRACTICE NUMBER 28
01/2016 - 05/2016

Category:
Empowerment

**Informative guide for
fibromyalgia patients**



Russia
danilov@intermeda.ru

GOOD PRACTICE NUMBER 29
01/2014 - 01/2017

Category:
Empowerment,
Professional education

Patient education for
headache management

ALEXEY DANILOV

Head of the centre

Russia Headache Society

Objectives

Russia Headache Society, in collaboration with the department of Neurology, I.M. Sechenov First Moscow State Medical University, has developed an educational project for doctors, patients and citizens in general, based on the European recommendations for headache management. According to the International Headache Society, the effectiveness of proper headache treatment can be up to 95%.

However, more than 70% of patients are not satisfied with their treatment(s), due to the lack of awareness about the causes and mechanisms underlying the headache, and misconceptions about the treatment. The aims of the school are the dissemination of knowledge about headache and learning techniques of pain self-management.

Outcome

The screening tool ID Migraine; Algorithm of diagnostics Migraine triggers; Algorithm of migraine treatment; website PAININFO.RU; headache schools for patients, brochures for patients; clinical study on efficacy of patient education; educational seminars for doctors.

Information about Good Practice Applicant

Alexey Danilov (Moscow, Russia) project leader and professor at the Department of Neurology of the I.M. Sechenov First Moscow State Medical University. He is also executive director of the Interdisciplinary Medicine Association (Moscow, Russia), head of an awareness raising project "Brain ecology", coordinator of an Internet portal for doctors and patients "PAIN", co-organiser of two international education schools: «Brain and pain: biopsychosocial approach to pain management» and «Brain ecology». A.B. Danilov is a member of Russian and International Association on pain studies.

SIMON EVANS

Chief Executive

Migraine Action UK

Objectives

The treatment and management of headache disorders is poor across the UK. Anecdotally, we had heard it was worse in Wales with patients expected to travel significant distances to access services, and with NICE guidance not being followed in Cardiff (the major population centre). Goals: Undertake research to ascertain the facts, and compare services across the UK; develop a simple plan to influence politicians at the Welsh Assembly Change policy.

Outcome

Secured funding through a partnership with Allergan Engaged a political consultancy; undertook research with people with migraine. Undertook research proving services in Wales were worse than in England, and that one health board was ignoring NICE guidance; ran an event at the Welsh Assembly, presenting findings and securing the attendance of politicians from four main political parties; secured change in policy at Cardiff and Vale University Health Board; received an invitation to speak at the Cross Party Neurological Conditions Group at the Welsh Assembly, and developed long-term relationships. Due to the enormous success of the event, the Vale Health Board has agreed to introduce Botox for migraine.

Information about Good Practice Applicant

Simon Evans, the Chief Executive of Migraine Action, speak to a migraine sufferer from North Wales, who has suffered migraines for many years.

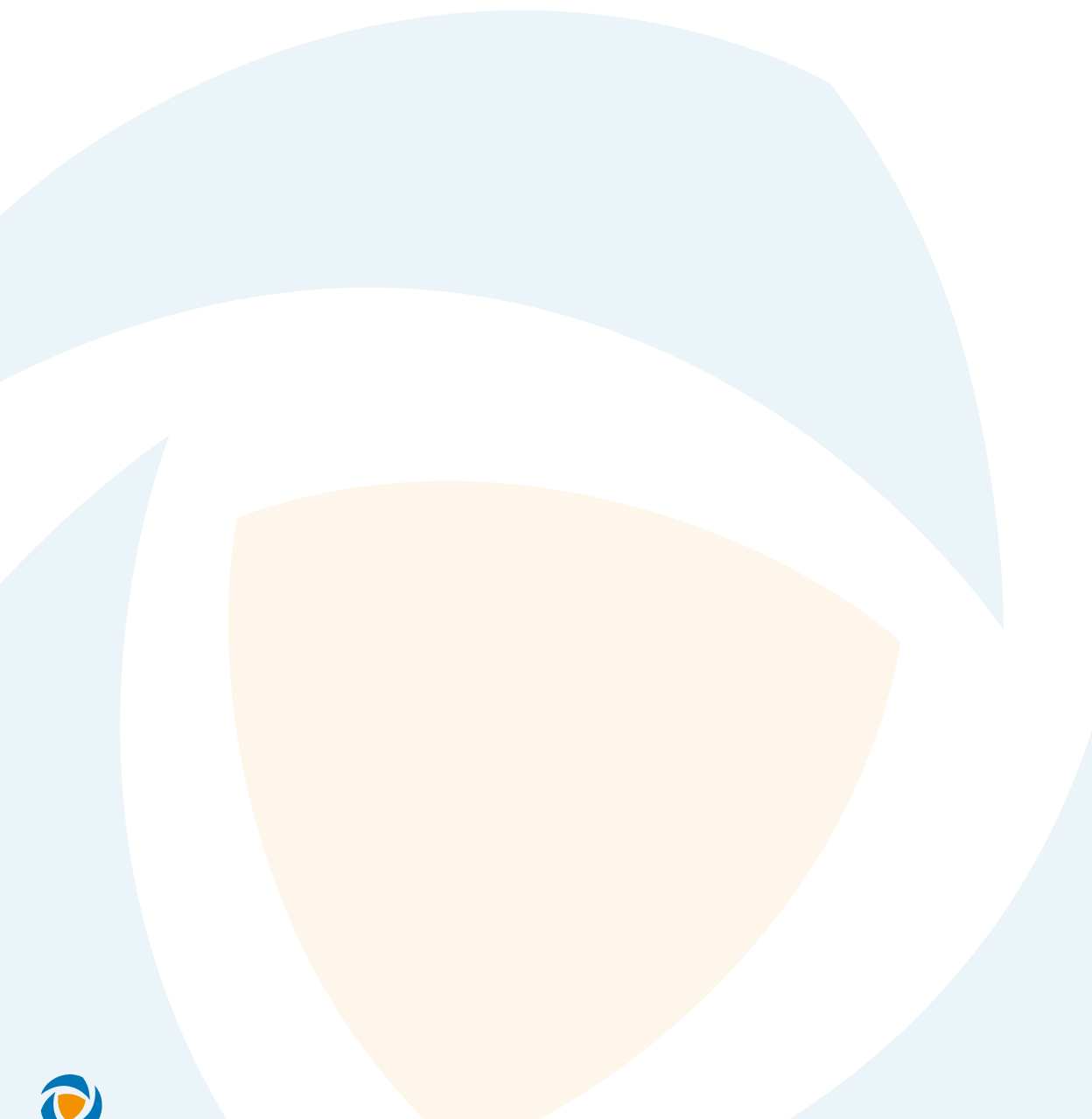


United Kingdom
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GOOD PRACTICE NUMBER 30
03/2015 - 01/2017

Category:
Empowerment

**The Needs of Migraine
Sufferers Across
Wales**





MALTA
EU2017



SIP
Societal Impact of Pain

ENDORISING ORGANISATIONS

Since the start of the SIP platform the scientific objectives of the SIP symposia and events have been endorsed by the following organisations, listed in alphabetical order:

Please contact sip-platform@grunenthal.com if your organisation wants to be added to the list of endorser on the website <https://www.sip-platform.eu> or if the contact details or logos have changed.

-  **European Pain Federation EFIC®**
www.efic.org
-  **Grünenthal GmbH**
www.grunenthal.com
-  **Pain Alliance Europe (PAE)**
www.pae-eu.eu
-  **Cittadinanzattiva**
<http://www.cittadinanzattiva.it/>
-  **Malta Health Network**
www.maltahealthnetwork.org
-  **No Pain Foundation**
www.nopainfoundation.org
-  **Academia de Ciencias Médicas de Bilbao**
www.acmbilbao.org
-  **ACTHealthy Lab, ALGEA Group University of Cyprus**
www.algea.com.cy
-  **Action on Pain**
www.action-on-pain.co.uk/
-  **AGE Platform Europe**
www.age-platform.eu


- | | | |
|--|---|------------|
| <p>Agencia de Calidad Sanitaria de Andalucía
www.juntadeandalucia.es/agenciadecalidadsanitaria</p> |  <p>Agencia de Calidad Sanitaria de Andalucía
CONSEJERÍA DE IGUALDAD, SALUD Y POLÍTICAS SOCIALES</p> | <p>11.</p> |
| <p>Albanian Pain Association
www.health-pain.al/</p> |  <p>A.P.A.
ALBANIAN PAIN ASSOCIATION</p> | <p>12.</p> |
| <p>ALGOS. Recerca en dolor
algos-dpsico.urv.cat/es/</p> |  <p>algos:</p> | <p>13.</p> |
| <p>Allianz Chronischer Schmerz Österreich –
Alliance Chronic Pain Austria
www.schmerz-allianz.at</p> |  <p>Allianz
Chronischer Schmerz
Österreich</p> | <p>14.</p> |
| <p>ALPADOC – Association Luxembourgeoise
des Patients à Douleurs Chroniques
www.alpadoc.lu</p> |  <p>ALPADOC
Association Luxembourgeoise des
Patients à Douleurs Chroniques</p> | <p>15.</p> |
| <p>Alvleeskliervereniging Nederland AVKV
www.alvleeskliervereniging.nl/ik-ben-patient.aspx</p> |  <p>Alvleeskliervereniging
Nederland</p> | <p>16.</p> |
| <p>Arthritis and Rheumatism Association
of Malta
www.aramalta.com</p> |  <p>aram
Arthritis and Rheumatism
Association Malta</p> | <p>17.</p> |
| <p>ASL 4 Teramo
fabiana.dantonio@aslteramo.it</p> |  <p>AUSL 4
TERAMO
Il meglio è nel tuo territorio</p> | <p>18.</p> |
| <p>Asociación Andaluza del Dolor
www.asociacionandaluzadeldolor.es/</p> |  <p>ASOCIACION ANDALUZA DEL DOLOR</p> | <p>19.</p> |
| <p>Asociación Corunesa de Fibromialgia
y Síndrome de Fatiga Crónica (ACOFIFA)
www.acofifa.org</p> |  <p>acofifa</p> | <p>20.</p> |








21.  **Asociación de Fibromialgia y Síndrome de Fatiga Crónica de la Comunidad de Madrid (AFINSYFACRO)**
www.afinsyfacro.es/
22.  **Asociación española de enfermería de anestesia-reanimación y terapia del dolor (aseedar-td)**
www.aseedar-td.org
23.  **Asociación Nacional de Enfermería Comunitaria (AEC)**
www.enfermeriacomunitaria.org
24.  **Asociación Profesional de Salud (PHA)**
www.pha-ks.com
25.  **Associação de Doentes de Dor Crónica Açores (ADDCA)**
addcacores@iol.pt, addcadirecao@iol.pt
26.  **Associação Portuguesa de Cuidados Paliativos - Núcleo Regional dos Açores**
www.apcp.com.pt
27.  **Associação Portuguesa de Cuidados Paliativos**
www.apcp.com.pt
28.  **Associação Portuguesa para o Estudo da Dor (APED)**
www.aped-dor.org
29.  **Asociación Extremena de Fibromialgia (afibro ex)**
www.afibroex.com/
30.  **Association for Pain Therapy Bosnia and Herzegovina**
www.apt-bh.ba

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|--|--|------------|
| <p>Association française de la cystite interstitielle
(AFCI)
www.asso-afci.org</p> |  | <p>31.</p> |
| <p>Association Francophone pour Vaincre les Douleurs
(AFVD)
www.association-afvd.com</p> |  | <p>32.</p> |
| <p>Associazione Italiana per lo Studio del Dolore (AISD)
www.aisd.it</p> |  | <p>33.</p> |
| <p>Associazione Sammarinese per lo Studio del Dolore
www.assd-rsm.org</p> |  | <p>34.</p> |
| <p>BackCare, The Charity for Back and Neck Pain
www.backcare.org.uk/</p> |  | <p>35.</p> |
| <p>Belgian Back Society
www.belgianbacksociety.be</p> |  | <p>36.</p> |
| <p>Belgian Pain Society
www.belgianpainsociety.org</p> |  | <p>37.</p> |
| <p>Berufsverband der Ärzte und Psychologischen
Psychotherapeuten in der Schmerz- und Palliativmedizin
in Deutschland e.V.
www.bv-schmerz.de</p> |  | <p>38.</p> |
| <p>Berufsverband Deutscher Anästhesisten e.V. BDA
www.bda.de</p> |  | <p>39.</p> |
| <p>Bijniervereniging NVACP
www.nvacp.nl</p> |  | <p>40.</p> |

41.  **Bildungswerk Aachen: Servicestelle Hospizarbeit für die Städte Region Aachen**
www.servicestelle-hospizarbeit.de
42.  **Brain, Mind and Pain (MEP Interest Group)**
www.brainmindpain.eu
43.  **Brigada de Sanidad del Ejército de Tierra Ejército Español**
fconben@et.mde.es
44.  **British Pain Society**
www.britishpainsociety.org
45.  **Bulgarian Association for Study and Treatment of Pain (BASTP)**
www.rtb-mu.com/anestsoc
46.  **Bürger Initiative Gesundheit e.V.**
www.buerger-initiative-gesundheit.de
47.  **Catedra de Dolor Infantil, Universitat Rovira i Virgili**
www.catedradeldolor.com
48.  **CEADE Coordinadora Española de Asociaciones de Espondilitis**
www.espondilitis.es
49.  **Center for Palliative Medicine, Medical Ethics and Communication Skills**
www.mef.unizg.hr
50.  **CHANGE PAIN Initiative**
www.change-pain.com/





- Chronic Pain Ireland**
www.chronicpain.ie/
-  **Chronic Pain Ireland** 51.
- Chronic Pain Policy Coalition CPPC**
www.policyconnect.org.uk
-  52.
- CLA - Cercle Luxembourgeois d'Algologie
Zithaklinik (Clinique de la douleur)**
www.douleurs.lu
-  53.
cercle luxembourgeois d'algologie
- Colegio Oficial de Medicos de Caceres**
www.comeca.org
-  54.
ILUSTRE COLEGIO
OFICIAL DE MEDICOS
DE CACERES
- Collectif Doloplus**
www.doloplus.com/
-  55.
EHELLE
Doloplus
- Conartritis (Coodinadora Nacional de Artritis)**
www.conartritis.org/
-  56.
conartritis
COORDINADORA NACIONAL DE ARTRITIS
- Consejo Andaluz de Colegios Farmaceuticos**
www.cacof.es
-  57.
Consejo Andaluz de Colegios Oficiales
de Farmacéuticos
- COST Action TD1005 - Pain Assessment in
Patients with Impaired Cognition, especially Dementia**
www.cost-td1005.net
-  58.
COST
EUROPEAN COOPERATION
IN SCIENCE AND TECHNOLOGY
- Croatian Association for the Treatment of Pain
(CATP)**
www.hdlb.org
-  59.
HDLB
HRVATSKA DRUŠTVO ZA LJEČENJE BOLEŠTAVI I NEKVALIFIKACIJSKI ZBOR
THE CROATIAN PAIN SOCIETY - CROATIAN MEDICAL ASSOCIATION
- Cystitis & Overactive Bladder Foundation COB**
www.cobfoundation.org
-  60.
The
Cystitis
& Overactive
Bladder
FOUNDATION

61.  **Deutsche Gesellschaft zum Studium des Schmerzes e.V.
DGSS**
www.dgss.org/
62.  **Deutscher Forschungsverbund Neuropathischer
Schmerz**
dfns@lrz.tum.de
63.  **Deutsche Gesellschaft für Anästhesiologie und
Intensivmedizin (DGAI)**
www.dgai.de
64.  **Deutsche Gesellschaft für Neurologie**
www.dgn.org
65.  **Deutsche Gesellschaft für Orthopädie und
Orthopädische Chirurgie e.V. (DGOOC)**
www.dgoc.de
66.  **Deutsche Gesellschaft für Psychologische
Schmerztherapie und -forschung (DGPSF)**
www.dgpsf.de
67.  **Deutsche Gesellschaft für Schmerztherapie e.V.
(DGS)**
www.dgschmerztherapie.de/
68.  **Deutsche Kinder Palliativ Stiftung**
www.palliativ-portal.de/
69.  **Deutsche Palliativ Stiftung**
www.PalliativStiftung.de/
70.  **Deutsche Schmerzgesellschaft e.V.**
Sektion der International Association for the Study of Pain (IASP)
www.dgss.org

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| <p>Deutsche Schmerzliga e.V.
www.schmerzliga.de/</p> |  | 71. |
| <p>Deutsche Seniorenliga e.V.
www.deutsche-seniorenliga.de/</p> |  | 72. |
| <p>Deutsche Wachkoma Gesellschaft
www.schaedel-hirnpatienten.de</p> |  | 73. |
| <p>Deutscher Orthopäden-Verband e.V. (DOV)
www.dov-online.de</p> |  | 74. |
| <p>DGVP e.V. für Gesundheit Deutsche Gesellschaft für Versicherte und Patienten
www.dgvp.de</p> |  | 75. |
| <p>Direcao Regional de Saude - Plano Regional de Saude 2014-16
www.azores.gov.pt</p> |  | 76. |
| <p>Douleurs sans Frontières
www.douleur.org</p> |  | 77. |
| <p>Dutch Pain Society
www.dutchpainsociety.nl</p> |  | 78. |
| <p>Dwarslaesie Organisatie Nederland
www.dwarslaesie.nl</p> |  | 79. |
| <p>Endometriosis Association of Ireland
www.endometriosis.ie</p> |  | 80. |

81.  **Gobierno de Canarias**
Escuela de Servicios Sanitarios
y Sociales de Canarias
**Escuela Canaria de Salud y Servicios Sociales
(ESSSCAN)**
www.essscan.es
82.  **EESTI VALU SELTS**
Estonian Pain Society
www.valu.ee
83.  **EURAG**
ÖSTERREICH
EURAG Österreich
www.dgvp.de
84.  **ean**
European Academy of Neurology EAN
www.eaneurology.org
85.  **EAF**
European ADPKD Forum
European ADPKD Forum EAF
[www.pkdinternational.org/
eaf_adpkd_forum_policy_report_2015/](http://www.pkdinternational.org/eaf_adpkd_forum_policy_report_2015/)
86.  **EAPC**
ONLUS
**European Association for Palliative Care
EAPC**
www.eapcnet.eu
87.  **EBC**
European Brain Council
European Brain Council
www.europeanbraincouncil.org/
88.  **EUROPEAN
CANCER
PATIENT
COALITION**
**European Cancer Patient Coalition
(ECPC)**
www.ecpc.org
89.  **ECNP**
neuroscience applied
European College of Neuropsychopharmacology
www.ecnp.eu
90.  **E.C.H.O.**
EUROPEAN CONFEDERATION OF CARE HOME ORGANISATIONS
**European Confederation of Care Home Organisations
ECHO**
www.echo-eu.com

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| <p>European Digital Peer Patient Alliance EUDiPPA
Facebook: /EUDIPPA/</p> |  | <p>91.</p> |
| <p>European Federation of National Associations
of Orthopaedics and Traumatology (EFORT)
www.efort.org/</p> |  | <p>92.</p> |
| <p>European Federation of Neurological Associations
(EFNA)
www.efna.net</p> |  | <p>93.</p> |
| <p>European Headache Alliance
www.e-h-a.eu</p> |  | <p>94.</p> |
| <p>European League Against Pain EULAP
www.eulap.org</p> |  | <p>95.</p> |
| <p>European Network of Fibromyalgia Associations
www.enfa-europe.eu/</p> |  | <p>96.</p> |
| <p>European Patient Forum EPF
www.eu-patient.eu</p> |  | <p>97.</p> |
| <p>European Platform for Patients' Organisations,
Science and Industry (EPPOSI)
www.epposi.org/</p> |  | <p>98.</p> |
| <p>European Society for Regional Anaesthesia
& Pain Therapy (ESRA)
www.esraeurope.org</p> |  | <p>99.</p> |
| <p>European Society of Physical and Rehabilitation
Medicine
www.esprm.net/</p> |  | <p>100.</p> |

101.  **Federación de Asociaciones de Enfermería Comunitaria y Atención Primaria (FAECAP)**
www.faecap.com
102.  **Federalno Ministravo Zdravstva**
www.fmoh.gov.ba
103.  **Federdolore-Società Italiana dei Clinici del Dolore**
www.federdolore.it
104.  **fibromyalgi förbundet**
Fibromyalgia Association of Sweden
www.fibromyalgi.se
105.  **Fibromyalgie en Samenleving (F.E.S.) - De Nationale Vereniging voor Fibromyalgiepatiënten**
www.fesinfo.nl
106.  **fit for work global**
Fit for Work Global Alliance
www.fitforworkeurope.eu
107.  **Focus Fibromyalgia Belgium ASBL**
www.focusfibromyalgie.be
108.  **Fondazione IRCCS Istituto Nazionale dei Tumori**
Fondazione IRCCS Istituto Nazionale dei Tumori
www.istitutotumori.mi.it
109.  **Fondazione ISAL**
Fondazione ISAL
www.fondazioneisal.it
110.  **FONDAZIONEISTUD**
Fondazione ISTUD
www.fondazioneistud.it

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| <p>Fondazione Paolo Procacci
www.fondazioneprocacci.org/</p> |  | 111. |
| <p>Foreningen Af Kroniske Smertepatienter (FAKS)
www.faks.dk</p> |  | 112. |
| <p>Foro Español de Pacientes (FES)
www.webpacientes.org/fep</p> |  | 113. |
| <p>Foundation Pijn-Hoop
www.pijn-hoop.nl/</p> |  | 114. |
| <p>Fundació Acadèmia de Ciències Mèdiques i de la Salut de Catalunya i de Balears
www.academia.cat</p> |  | 115. |
| <p>Fundacio Salut i Envel·liment UAB
www.salut-envelliment.uab.cat</p> |  | 116. |
| <p>Fundación Afectados y Afectadas Fibromialgia y Síndrome Fatiga Crónica
www.fundacionfatiga.org/</p> |  | 117. |
| <p>Fundación para la Investigación en Salud (Fuinsa)
www.fuinsa.org/</p> |  | 118. |
| <p>Fundación Signo
www.fundacionsigno.com</p> |  | 119. |
| <p>Fundacja Chustka
www.fundacjachustka.pl</p> |  | 120. |

121.  **Funde Salud**
www.fundesalud.es
122.  **Fundolor (Fundacion de la comunidad valenciana para el estudio y tratamiento del dolor)**
www.fundolor.org
123.  **Generalitat Valenciana - Conselleria De Sanitat**
www.san.gva.es
124.  **Geriatric Medicine Society e.V.**
www.geriatric-medicine.org
125.  **German Maltese Medical Society**
www.germanmaltesecircle.org/gmms.htm
126.  **Getidor: Grupo de Estudio, Trabajo e Investigación del Dolor Crónico en Rehabilitación**
xoan.miguens.udc.mais@gmail.com
127.  **Gobierno de Cantabria, Consejería de Sanidad y Servicios Sociales**
leon_c@cantabria.es; hoyos_e@cantabria.es
128.  **Health First Europe Secretariat**
www.healthfirsteurope.org
129.  **Hellenic Society of Algology**
www.algologia.gr
130.  **Hellenic Society of Palliative and Symptomatic Care of Cancer and non Cancer patients**
www.grpalliative.org/

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| <p>Hereditaire Multiple Exostosen -
Multiple Osteochondromen HME-MO
www.hme-mo.nl</p> |  | 131. |
| <p>Herescon gmbh
www.herescon.com</p> |  | 132. |
| <p>Hrvatsko Drustvo Palijativnu Medicinu HLZ
www.palijativa.com</p> |  | 133. |
| <p>Institut Català d'Oncologia
www.ico.gencat.cat</p> |  | 134. |
| <p>Institut national d'assurance maladie-invalidité
www.riziv.fgov.be</p> |  | 135. |
| <p>Institute for Research in Operative Medicine
(IFOM)
www.uni-wh.de/ifom</p> |  | 136. |
| <p>Instituto Aragonès de Ciencias de la Salud
www.iacs.aragon.es</p> |  | 137. |
| <p>Instituto de Estudios de Ciencias de la
Salud de Castilla y León
www.iecsyl.com</p> |  | 138. |
| <p>Instituto Mediterráneo de Dolor y Anestesia
Regional (IMEDAR)
www.imedar.com</p> |  | 139. |
| <p>Instituto para el estudio y tratamiento integral
de Dolor (IETID)
www.ietd.es</p> |  | 140. |

141.  **International Alliance of Patients' Organizations (IAPO)**
www.patientsorganizations.org
142.  **International Association for Hospice and Palliative Care**
www.hospicecare.com
143.  **International Headache Society**
International Headache Society
www.ihs-headache.org
144.  **International Painful Bladder Foundation (IPBF)**
www.painful-bladder.org
145.  **IPO Porto**
carocha321@hotmail.com
146.  **Irish Pain Society**
www.irishpainsociety.com
147.  **Israel Pain Association**
www.ipa.org.il
148.  **Italian Presidency of the Council of Ministers**
149.  **Junta de Andalucía - Consejería de Salud y Bienestar Social**
www.juntadeandalucia.es/organismos/saludybienestarsocial.html
150.  **L'Association Française de Lutte Anti-Rhumatismale**
francoisealliotlaunois@gmail.com

- Latvian Association for Study of Pain - LASP**
www.sapes.lv  151.
- LeukaNET e.V.**
www.leuka.net/  152.
- Lietuvos Skausmo Draugija**
www.skausmomedicina.it  153.
- Lifting the Burden**
www.l-t-b.org/  154.
- Liga Portuguesa Contra as Doencas Reumaticas**
www.lpcdr.org.pt  155.
- Liga Reumatológica Catalana**
www.ligareumatologica.org  156.
- Liga Reumatologica Espanola**
www.lire.es  157.
- Liga Reumatológica Gallega (LRG)**
www.ligagalega.org  158.
- Malta Association of Physiotherapists**
www.physiomalta.com  159.
- ME/ CVS-Stichting Nederlands**
www.mecvs.nl  160.

161.  **MedAix Training GmbH / MedAix Laurensberg GmbH**
www.medaix.de
162.  **Medicinska fakulteta Univerze v Mariboru**
www.mf.uni-mb.si/index.php/en
163.  **Metges de Residències Geriàtriques del Vallès**
josep.sanchez.aldeguer@uab.cat
164.  **Moldovan Society for the Study and Management of Pain**
www.neverpain.org
165.  **Multinational Interstitial Cystitis Association (MICA)**
www.mica-online.org
166.  **Myeloma Euronet Romania**
www.myeloma.ro/
167.  **National Association of Patients with Rheumatoid Arthritis (ANDAR)**
www.andar-reuma.pt
168.  **National Council for Palliative Care (NCPC)**
www.ncpc.org.uk
169.  **Nederlands Interstitial Cystitis Patients Organization (ICP)**
www.icpatienten.nl/
170.  **Nederlandse Vereniging van Hoofdpijnpatiënten**
www.hoofdpijnpatienten.nl

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|---|---|------|
| <p>Nederlandse Vereniging van Patienten met Sternocostoclaviculaire Hyperostose (SCCH)
www.scch.nl</p> | The logo consists of a stylized red and white 'M' shape with a yellow and red graphic element in the center. | 171. |
| <p>Nederlandse Vereniging van Rugpatiënten "de Wervelkolom"
www.nvvr.nl</p> | The logo features a yellow and black graphic of a spine with the text 'NVVR "de Wervelkolom"' below it. | 172. |
| <p>Neil Betteridge Associates
neil@neilbetteridge.me.uk</p> | The logo shows a stylized 'NB' in blue and green, with 'NEIL BETTERIDGE ASSOCIATES' written below. | 173. |
| <p>Neurologiskt Handikappades Riksforbund
www.nhr.se</p> | The logo features a red ladybug icon and the text 'NEUROLOGISKT HANDIKAPPADES RIKSFÖRBUND'. | 174. |
| <p>Norsk Revmatikerforbund
https://www.revmatiker.no</p> | The logo is the acronym 'NRF' in large, bold, blue letters. | 175. |
| <p>OSAKIDETZA - Departamento de la Salud del Gobierno Vasco
www.osakidetza.euskadi.net</p> | The logo is a stylized blue and white 'O' shape with a cross-like element, and the text 'Osakidetza' below. | 176. |
| <p>Osservatorio Italiano Cure Palliative (OICP)
www.oicp.org</p> | The logo is a diamond shape with 'Osservatorio Italiano' at the top, 'Cure Palliative' at the bottom, and 'OICP' in the center. | 177. |
| <p>Osteoporose Vereniging
www.osteoporosevereniging.nl</p> | The logo features a map of the Netherlands and the text 'Osteoporose Patiënten Vereniging'. | 178. |
| <p>Österreichische Gesellschaft für Geriatrie und Gerontologie ÖGGG
www.geriatrie-online.at</p> | The logo shows a stylized tree with colorful dots and the text 'ÖGGG Altern Mitten im Leben'. | 179. |
| <p>Österreichische Schmerzgesellschaft
www.oesg.at/</p> | The logo is a red and white circular emblem with the text 'ÖSTERREICHISCHE SCHMERZGESELLSCHAFT' and 'ÖSG'. | 180. |



Österreichisches Rotes Kreuz
www.roteskreuz.at



Pain Alliance of Northern Ireland
Twitter: @PainAllianceNI



Pain Association Scotland
www.chronicpaininfo.org



Pain Concern
www.painconcern.org.uk/



Pain Nursing Magazine – Italian Online Journal
www.painnursing.it



PAIN OUT - improvement in postoperative PAIN
www.pain-out.eu



Pain Research Forum
www.painresearchforum.org



PAIN South Africa (PAINSA)
www.painsa.co.za



Pain Toolkit
www.paintoolkit.org



Pain UK
www.painuk.org

- Painaustralia**
www.painaustralia.org.au/
- painaustralia™**
working to prevent and manage pain 191.
- Paliativos Andalucia**
www.paliativosandalucia.com
- SACPA**
paliativos andalucia 192.
- Palliactief**
www.palliactief.nl/
- palliactief**
Nederlandse vereniging voor professionele palliatieve zorg 193.
- Palliatives Netzwerk für die Region Aachen e.V.**
www.servicestelle-hospizarbeit.de/
- Palliatives Netzwerk**
für die Region Aachen e.V. 194.
- Patienten Vereniging Voor Neurostimulatie (PVVN)**
www.pvvn.nl
- PVNVN**
www.pvvn.nl 195.
- Patientenschutzorganisation Deutsche Hospiz Stiftung**
www.patientenschuetzer.de
- Patientenschutzorganisation**
Deutsche Hospiz Stiftung 196.
- Patientenvereniging CRPS**
www.posttraumatischedystrofie.nl
- Patiëntenvereniging**
CRPS
Complex Regional Pain Syndrome 197.
- Pelvic Pain Support Network**
www.pelvicpain.org.uk/
- pelvic pain**
SUPPORT NETWORK 198.
- Personskadeförbundet RTP**
www.rtp.se
- PERSONSKADE**
FÖRBUNDET RTP 199.
- Pijn Platform Nederland (PPN)**
www.pijnplatform.nl/
- PIJNPLATFORM**
NEDERLAND 200.

201. **PLATAFORMA SinDOLOR**

Plataforma SinDOLOR
www.plataformasindolor.com/
202. 
Polskie Stowarzyszenie Pomocy Chorym na Szpiczaka
www.szpiczak.org.pl
203. 
Polskie Towarzystwo Badania Bolu
www.ptbb.pl/
204. 
Portuguese League Against Rheumatic Diseases (LPCDR)
www.lpcdr.org.pt
205. 
Presidenza della Regione Abruzzo
www.regione.abruzzo.it/
206. 
Prikkelbare Darm Syndroom Belangenvereniging
www.pdsb.nl
207. 
Programa de Prevenció i Atenció a la Cronicitat
www.canalsalut.gencat.cat
208. 
Red Espanola para Defensa de los Enfermedades FM Sfc y Sqm
www.facebook.com/Red-Espa%3%B1ola-de-FM-SFCSQM-366279756915804/
209. 
Romanian Association for the Study of Pain (RASP)
www.arsd.ro
210. 
RSI-Vereniging
www.rsi-vereniging.nl

- Russian Association for the Study of Pain (RASP)**
www.painrussia.ru
- 
- 211.
- Russian Headache Research Society**
www.headache-society.ru
- 
- 212.
- Samenwerkingsverband Pijnpatiënten naar een stem**
www.pijnpatientennaar1stem.nl
- 
- 213.
- Sant Joan de Deu Hospital**
www.hsjdbcn.org
- 
- 214.
- SARquavitae**
www.sarquavitae.es
- 
- 215.
- SchmerzNetzNRW eG**
www.schmerznetznrw.org
- 
- 216.
- Schweizer Gesellschaft zum Studium des Schmerzes**
www.pain.ch/
- 
- 217.
- Schweizerische Kopfwehgesellschaft SKG**
www.headache.ch
- 
- 218.
- Shingles Support Society**
www.herpes.org.uk/shingles-support-society
- 
- 219.
- SINE DOLORE – Asociación Española de Pacientes Contra el Dolor**
www.sinedolore.org
- 
- 220.

221.



**SLOVENSKÁ SPOLOČNOSŤ PRE
ŠTÚDIUM A LIEČBU BOLESTI**

www.pain.sk/

222.



Slovensko združenje za lajšanje bolečine

www.szzb.si/

223.



**Sociedad Andaluza de Geriatria y Gerontología
(SAGG)**

www.sagg.org

224.



**Sociedad Andaluza de Medicina Fisica y Rehabilitacion
SAMFYRE**

www.samfyre.net/

225.



Sociedad Aragonesa del Dolor

www.sociedadaragonesadeldolor.sedolor.es

226.



Sociedad Aragonesa de Cuidados Paliativos

www.cusirar.org

227.



Sociedad Asturiana de Medicina Fisica y Rehabilitación

www.samefyr.com

228.



Sociedad Canaria del Dolor (SCD) - Canarian

www.socadolor.org/es/

229.



Sociedad Castellano Leonesa de Dolor

www.sociedaddocyl.wordpress.com

230.



**Sociedad Castellano Leonesa de Rehabilitacion
y Medicina Fisica**









rehacyl@gmail.com

- Sociedad Castellano Manchega del Dolor (SCDM)**
www.sociedadcastellanomanchegadeldolor.sedolor.es/
- 
- 231.
- Sociedad de Acupuntura Medica de Espana (SAME)**
www.same-acupuntura.org
- 
- 232.
- Sociedad Espanola De Calidad Asistencial**
www.calidadasistencial.es
- 
- 233.
- Sociedad Española de Cuidados Paliativos (SECPAL)**
www.secpal.com
- 
- 234.
- Sociedad Espanola de Directivos de Atención Primaria (SEDAP)**
www.sedap.es
- 
- 235.
- Sociedad Española de Directivos de la Salud (Sedisa)**
www.sedisa.net/
- 
- 236.
- Sociedad Española de Disfunción Craneomandibular y Dolor Orofacial**
www.sedcydo.com
- 
- 237.
- Sociedad Española de Fisioterapia y Dolor (SEFID)**
www.sites.google.com/site/sefidsp/Home
- 
- 238.
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- Sociedad Gallega del dolor y Cuidados Paliativos**
www.sociedadgallegadeldolor.sedolor.es  254.
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- Sociedad Valenciana de Medicina Paliativa (SVMP)**
www.svmpaliativa.org  260.

261.  **Sociedad Valenciana Terapéutica del Dolor (SOVTED)**
pallares_jor@gva.es
262.  **Sociedade Portuguesa de Medicina Física e Reabilitação (SPMFR)**
www.spmfr.org
263.  **Societa Italiana di Medicina Generale e delle Cure Primarie (SIMG)**
www.simg.it
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www.sirn.net
265.  **Societat Catalana de Gestió Sanitària (SCGS)**
www.academia.cat/gestiosanitaria
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webs.academia.cat/societats/oncologia/
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webs.academia.cat/societats/curespal

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www.pacientesatm.com  272.
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<http://www.mentalhealthcommissioner.gov.mt/>  279.
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The Work Foundation
www.theworkfoundation.com



Trigeminal Neuralgia Association
www.tna.org.uk/



Udruženje za Istraživanje i Tretman Bola Srbije (UITBS)
www.uitbs.org.rs/



Ukrainian Association for the Study of Pain (UASP)
www.pain.in.ua/



ULSS7 del Veneto
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Univerzitet u Zagrebu - Akademija Dramatičnog Umjetništva
www.adu.hr



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Vereniging van Ehlers-Danos Patiënten
www.ehlers-danos.nl



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Vlaamse Liga voor Fibromyalgie-Patiënten vzw
www.fibromyalgie.be/



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Vlaamse Pijnliga
www.vlaamsepijnliga.be



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Whiplash Stichting Nederland
www.whiplashstichting.nl



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WIP Foundation
www.wipfoundation.org/



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World Federation for Incontinent Patients
(WFIP)
www.wfip.org/



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World Federation of Societies of
Anaesthesiologists (WFSA)
www.wfsahq.org/



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www.w-h-a.org/
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www.worldinstituteofpain.org/
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www2.kenes.com/wspc-soc/pages/home.aspx
304.  **XUNTA DE GALICIA**
CONSELLERÍA DE SANIDADE **Xunta de Galicia - Consellería de Sanidade**
www.sergas.es
305.  **Young Against Pain (YAP)**
www.simpar.eu/simpar/progettoyap/



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Email: info@excelsior.com.net

- 2 Casino Maltese**
Republic Street 247, Valletta, Malta
<http://www.thecasinomaltese.com>

- 3 Osborne Hotel**
South Street 50, Valletta, Malta
Tel.: +356 21243656
<http://www.osbornehotel.com>

- 4 British Hotel**
Battery Street 40, Valletta, Malta
<http://www.britishhotel.com>
E-Mail: info@britishhotel.com

- 5 La Falconeria Hotel**
Malta Street 62, Valletta, Malta
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