

Good afternoon everybody!

A warm greetings from Rome, Italy, to the representatives of local and National Authorities, European Commission, leader of patient's organization, stakeholder, media, citizens and patients. It's really a pleasure and a honor for me, as Director of Active Citizenship Network, to participate, even if only by skype, to the official launch of this relevant EU project "PATIENTS' VOICE" in the field of civic activism in the health sector in the northern part of Cyprus.

Please, let me first introduce myself and the civic organization that I represent.

INSTITUTIONAL PRESENTATION

My name is Mariano Votta and I am Director of Active Citizenship Network and Responsible for European Affairs at the Italian NGO Cittadinanzattiva. I am more than 10 years of experience in the field of protection of citizens' rights, stakeholder engagement, communication and civic information. Mine was the idea to encourage and promote the Member of the European Parliament Interest Group "European Patients' Rights & Cross-Border Healthcare" at the European Parliament during 2015.

Active Citizenship Network (ACN) is one of the most widespread and flexible European networks, composed of more than 100 civic, patients' and users' organizations. Established in 2001, it is coordinated by Cittadinanzattiva, an Italian non-profit organization founded in 1978, independent from any political affiliation, trade unions, private companies and public institutions.

The main objectives of ACN are the promotion of civic activism and participation in the political arena, and the protection of citizens' rights; both these goals may be defined the strength and the uniqueness of ACN.

As an international interface of Cittadinanzattiva, ACN focuses on the following two objectives:

- encourage the active participation of citizens in the European policy-making in order to promote the construction of an "European active citizenship", through the citizens' powers and responsibilities in public policies. This includes:
 - recognizing the primary role of citizens and civic organizations in the care of the common good;
 - supporting citizen's participation in policy making at local, national and EU level;
 - involving them in the defence of their fundamental rights as citizens, patients, consumers, passengers, users, savers, etc.
- promote abroad all the successful experiences achieved by Cittadinanzattiva in Italy.

Since its inception, the partnership has been enhanced by the involvement of partners in common projects, political initiatives and actions, all founded on strong co-operation ties.

Together with its partners, ACN operates in several different fields and it is an ideal actor for those public and private subjects that consider relevant the involvement of citizens in their activities.

ACN is an official member of ...

- "Health Policy Forum", the EU platform dealing with health and patient's rights led by the EU Commission-DG Health and Food Safety
- "Active Citizenship Structured Dialogue Group", led by the EU Commission-DG Migration and Home Affairs, the EU platform dealing with civic participation

Over the years, ACN has promoted several political activities such as the drafting of the European Charter of Patients' Rights (2002) and of the European Charter of Active Citizenship (2005-06), the

European Patients' Rights Day, celebrated every year since 2007, and the launch of the Interest Group "European Patients' Rights and Cross-border Healthcare" (2015).

In particular in 2002, Active Citizenship Network (ACN) together with a group of European citizens organizations established a European Charter of Patients' Rights, which includes the following 14 rights: the right to preventive measures; access care; information; consent; free choice; privacy and confidentiality; respect of patients' time; observance of quality standards; safety; innovation; avoidance of unnecessary suffering and pain; personalized treatment; to complain; to receive compensation. All these rights, based on the *Charter of Fundamental Rights* of the European Union, are crucial in matter of European citizens and healthcare services. The majority of these rights are also embodied within the Council conclusions on Common values and principles in EU Health Systems adopted in June 2006.

The reinforcement of these rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country. It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect.

OUR COMMITMENT IN CYPRUS

Why we are here today? Because Active Citizenship Network, in partnership with civic societies and patient organizations, is committed to strengthen the protection of patients' rights in the European framework. And, At the same time, we strongly believe that empowered patients and their organisations are a resource and not a cost: for this reason we have well accepted to cooperate at nation level in Cyprus with the Universal Patients' Rights Association in the framework of the EU Patients' Voice project.

Since 2014 we tried to win the call and for sure I have to congratulate with Universal Patients' Rights Association for the great effort. I am so glad to have a so good cooperation since years with the President Emete Imge and her staff.

As co-applicant, in this project we'll play a consultative role, responsible, among other issue, for a study visit in Italy of a group of leader of Cypriot civic and patient organizations.

To be clear, even if you do not know or nor remember, it's not the first time for my organization to work in Cyprus in partnership with national associations.

We have worked in 2003 developing the project "Seminars on Active Citizenship in Cyprus" realizing "Introductory seminars on active citizenship" in the northern and the southern part of Cyprus.

And last but not least, we have promoted this year "Patients' rights have no borders", an European communication campaign on patients' rights in cross-border healthcare in 14 EU Member States. In Cyprus this initiative is coordinated by the patient organization "Cyprus Alliance for Rare Disorders". Of course, I invite all you for official presentation to the EU Institutions on 3 May 2016 at the European Parliament in Brussels. More details on our websites www.activecitizenship.net and monthly newsletter, both written in English.

PATIENTS' RIGHTS ACROSS THE EUROPEAN UNION

The recognition of Patients' Rights across the European Union is due to an increasing demand from European citizens and the reinforcement of these rights will become effective only with the cooperation and commitment of all the stakeholders in each EU country.

Over the years, the EU Commission, as well as the civic and patient organizations, developed several European assessments in order to produce information on the actual implementation of patients' rights at EU level. In general, the level of awareness regarding the 14 rights mentioned in the European Charter of Patients' Rights is generally unacceptable. The negative evaluation was also confirmed with the assessment realized in 2013-2014 regarding the "Right to avoid unnecessary suffering and pain", whose aim was to bring to the attention the condition of patients suffering with chronic diseases and chronic pain. These negative results send a precise signal to the civic society and to the European Institutions about the work that still needs to be done: it is a difficult challenge which needs to be faced as a joint effort.

We hope, with the initiative that starts today, to cooperate to improve this situation for the Turkish Cypriot community. How we can do it? We strongly believe in the role of citizens' organisations in the empowerment of individual patients and patient organizations.

THE ROLE OF CITIZENS' ORGANISATIONS IN THE EMPOWERMENT OF PATIENTS

The key role of citizens' organisations in the empowerment of individual patients and their families is often underestimated. Patients, first of all with chronic diseases, do not only have to cope with the medical aspects of their condition, but also with the caring, social, relational and psychological aspects of their disease, which often have as much weight as the disease itself on the quality of their lives.

The added-value of citizens' organisations consists in a global approach to patient empowerment, supporting, informing educating and training patients to help them face the many difficulties of their daily lives. This global approach is necessary to make patients strong enough to collaborate with their health care professionals on an equal footing, helping them personalize the plan of care, participating actively in the management of their disease, and using health services more effectively.

They play a decisive role in the development of a modern patient-centred health system! Therefore, we believe the empowerment of patient organizations should be considered as an added value, because they become actual partners in the health policy, sharing with the institutions the responsibility of finding the best balance between the interest of patients and the sustainability of the system. This shall be achieved through the creation of networks and alliances, which allow the identification of common objectives and goals. This includes the development of a global and long-term perspective, which goes beyond the single chronic diseases and reflects the general interest of patients.

Patient empowerment does therefore have two different but complementary dimensions:

1. Improvement of a person's capabilities to effectively self-manage his/her disease;
2. Enhancement of patient groups' capacities to participate efficiently in health policies.

In both cases, citizens' organisations – which include self-help groups, associations of patients with a chronic disease, networks and umbrella organisations - play an essential role. And I know they can play a decisive role in this project.

The key themes to reach these goals are trust, collaboration, and communication.

Trust: is an important asset that patient organizations manage. Trust has been lost among many groups, but the public opinion and the Government trust patient organizations. It is crucial for effective allocation of research assets to build trust among all the stakeholders; it starts with open communication and sharing of information.

Collaboration: it is imperative for patient organizations to strategically align themselves and to speak to policy makers with one voice about their goals and objectives. It is also essential for researchers to work with patients from the outset to understand and address their needs.

Communication: Patients must be asked and all their needs must be considered. For this reason we have decided to title this project PATIENTS' VOICE, and for this reason I kindly ask to the media present to support this initiative.

Thanks you again, I hope to come soon in Cyprus.

Best wishes,
Mariano Votta