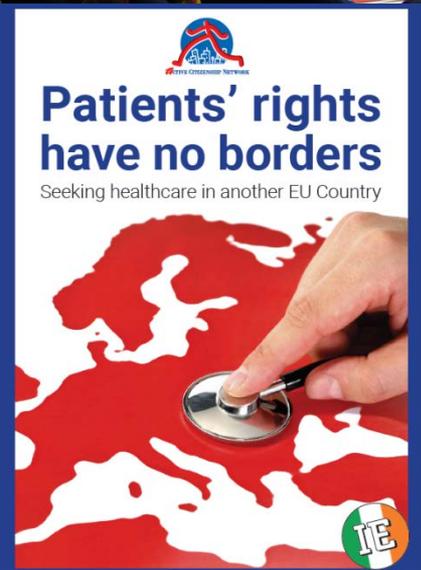


European communication campaign “Patients’ rights have no borders”



Network of 26 organizations in 24 MS

- AT  Lower Austrian Patient and Nursing Advocacy
- BE  Active Citizenship Network
- BG  Patients' Organizations "With You"
- CY  Cyprus Alliance for Rare Disorders
- CZ  Klub pacientů mnohočetný myelom, z.s.
- EL  Greek Alliance for Rare Diseases
- DE  Bürger Initiative Gesundheit e.V.
- DK  Rare Disease Denmark
- FI  Association of Cancer Patients in Finland
- FR  Inter-Association on health (CISS)
- EI  Irish Patients' Association
- ES  Plataforma de Organizaciones de Pacientes
- HR  Croatian Association for the Promotion of Patients' Rights
- HU  Hungarian Federation of People with Rare and Congenital Diseases
- IT  Cittadinanzattiva - Tribunal for patients' rights
- LT  Council of Representatives of Patients' Organizations of Lithuania
- NL  European Patients Empowerment for Customised Solutions
- MT*  Malta Health Network
- PL  Institute for Patients' Rights & Health Education
- PT  Azorean Chronic Pain Patients Association
- RO  Romanian National Alliance for Rare Diseases
- SL  SIBAHE Slovenian Foodbank; Kultlab Celje Society;
Association for justice and control
- SK  Society of Consumer Protection
- UK  Pelvic Pain Support Network





In the last year we have continued to inform, carrying out a subsidiary activity that should concern the Institutions at National level, starting from the National Contact Points, not always very active also due to the lack of public investments.

Please let me thank the informal network that we have built over our multi annual activity: a great example of key initiatives to promote the health as common good.

In particular, together with these associations, after two years of campaigning to raise awareness on cross-border healthcare¹, we have decided to develop our commitment focusing on the European Reference Networks (ERNs) and on patients' rights with rare or complex diseases.

¹<http://www.activecitizenship.net/patients-rights/projects/208-patients-rights-have-no-borders.html>



The Conclusions² of the Council of the European Union on June 2017 under the Maltese Presidency have recognised that European Reference Networks, when fully developed, will represent an opportunity for the dissemination of knowledges and innovative practices in the provision of specialised health services in the field of rare diseases.

The Council has invited the Member States and the Commission to encourage the European Reference Networks, thus to attain their intended objectives of providing better access for patients requiring highly specialized healthcare.

We strongly believe that the more advocacy groups and patients associations would play an active role in terms of raise awareness European citizens about it, facilitating dialogue and exchange of experiences, collection of data & good practices and by removing barriers & obstacles, the more effectively these goals could be reached.

A collaborative approach: challenging borders and geography

European Reference Networks are not meant to be operating in isolation: their impact should be much broader, as they mark a new chapter in European cooperation in the field of healthcare. ERNs could serve as a platform for the development of eHealth tools and could even see greater cooperation on more common chronic illnesses too. They are a clear example of how it is possible to work together to add value for citizens; they are a

² On 16 June 2017, the Maltese Presidency of the Council of the European Union on Employment, Social Policy, Health and Consumer Affairs adopted its conclusions on "[Encouraging Member States-driven Voluntary Cooperation of Health Systems](#)".

