



MAKING VISIBLE THE INVISIBLE ON HEADACHE PAIN: SHARING SUCCESSFUL EXPERIENCES ACROSS EUROPE

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10:00 - 12:00

ASP A3F38310, European Parliament, Brussels

Mariano Votta's speech – Director Active Citizenship Network

Good morning and thanks a lot for your decision to join us today.

Special thanks to the Member of the European Parliament Sofia Ribeiro, who is hosting the event today. She is also one of the MEP supporters of the Interest Group "European Patients' Rights and Cross-Border Healthcare". As you know, each event organized within the Interest Group is linked to one or more specific patient's rights. Today, the debate is mainly focused on the patient's right to avoid unnecessary suffering and pain (eleventh right in the European Charter of Patient Rights).

Some years ago the "Charter of headache patients' rights" was written following the suggestions of the International Headache Society and the platform - established by Active Citizenship Network - that drafted the already mentioned European Charter of Patients' Rights in 2002. Since then, what has been improved for headache patients? To what extent the commitment of the European Institutions in the fight against pain can help in improving the condition of headache patients? What recommendations, resulting from the collaboration between experienced patients and professionals, can be addressed to policy makers and relevant stakeholders?

Less than one year ago, in occasion of the "Cluster Headache Day 2017", our partner European Headache Alliance together with the European Headache Federation and the endorsement of many associations, mine included, have launched "In the face of pain there are no heroes", an open letter to the members of the European Parliament about ensuring in the whole Europe high quality care, research, equitable employment opportunities, and socio-economic support for Cluster Headache (CH) patients.

Today, starting from a selection of good practices across Europe, and taking into account the important achievement in the field of fight against pain, the aim is to demonstrate what this community can offer in terms of raise awareness about the phenomenon, enhance the body of knowledge of positive cases and success, and strengthen commitment to this topic.

About the relevance to gather and share good practices, thanks to the first edition of the "European Civic Prize on Chronic Pain", Active Citizenship Network gave evidence of existing good practices across European countries in terms of struggle against pain. Among them, several are related to headache. And in the two books you have received you can find much more details about what I can just mention now.

In particular, the winner for the category Patients' Empowerment, awarded last June 8th during the *Societal Impact of Pain Symposium* and in the framework of the Maltese Presidency of the Council of the European Union, is the experience titled "*At lessons from the expert patients: advices for the physicians to improve their care of cluster headache patients*", that today we are glad to host – among others - providing to the promoters the opportunity to better explain us its main features and added value.

Well, just few days later, last June 16th, the Council of the European Union on Employment, Social Policy, Health and Consumer Affairs adopted its conclusions in which the Health Ministers have agreed that it is time to **evaluate access to treatment for patients with chronic pain**. This is a substantial step for pain patients, included for those suffering of headache pain, of course.

Not only, DG Santè has recently opened its EU Health Policy Platform to a group of experts on the subject, while Directorate-General for Research & Innovation has allocated more funds for research dedicated to the topic. About it, I thank the representative of the European Commission that later on will help us to identify not only in which direction the research moves on, but also to clarify if the cooperation among all the stakeholder it's encouraged since the early stage.

Well, immediately after the Conclusions of the Council of the European Union, this initiative, focused on headache, I hope could testify a concrete example to transfer the recent achievement on chronic pain from the European political agenda to the EU culture, and so it could be considered extremely in line with the goals of the EU Institutions and the constituency on pain across Europe.

Last but not least, please let me thank in advance all the panelists for their contributions, and special thanks to my colleague and friend Elena Ruiz de la Torre, President of the European Headache Alliance, who not only has accepted the role of chairing this meeting, but and first of all has decided to be our partner of this initiative, confirming their role of leader in the field.

Elena has great experiences in the field of advocacy, started in her Country as founder and President of the Spanish Patient's organization "Asociación Española de Pacientes con Cefalea" and then developed at EU level not only as President of the European Headache Alliance, but also as responsible of the International affairs of the Spanish board of the National Platform of Chronic Diseases Patient's Organizations.

Thanks again Elena and many thanks to all you for the attention.