

PRESS RELEASE

Conference Towards Active Patients' Involvement in Healthcare with a Reflection on Brain Disorders, Self- management and Empowerment

Dublin, 23 May 2013 – The European Patients' Forum (EPF) celebrated its 10th Anniversary with a major conference in Dublin under the EU Irish Presidency and welcomed Commissioner Tonio Borg as a special guest. Featuring the 2013 European Year of Citizens dedicated to the rights that come with EU citizenship, the event translated what this means for patients. As May is the European Month of the Brain, the Conference championed neurological disorders in close collaboration with the European Federation of Neurological Associations (EFNA) and the Neurological Alliance of Ireland (NAI).



The need for a neurological strategy in all countries was one of the core issues emerging from the discussions. Effective partnerships are needed among patients' organisations to tackle serious and long term conditions. Moreover people affected by brain disorders require equitable access to high quality, appropriate, care, treatment and support for full participation and inclusion in society.

This conference represented a timely opportunity for EPF to take stock of the past ten years, and explore how to move forward. The patients' role in healthcare has transformed over years from being passive recipients to becoming active and responsible actors of their own health management.

The discussions were also framed around the patients' role in the triangle from research to policy to practice. Participants shared best practices on active patients' involvement in healthcare and research to be able to replicate them in their own area. Collaboration between the entire patient community across disease areas means, vitally, that we speak with one strong voice towards politicians and the research community. Participants highlighted an urgent need for public-private partnership and cooperative research programmes with a focus on meaningful patient involvement.

Finally the concept of 'self-management' was presented, and we explored strategies to empower patients to take an active role in the management of their chronic condition. EPF will continue to strive for the political commitment needed to pursue this area effectively. We need a different mindset and strong leadership to make this a reality across Europe.

"Brain disorders will affect 1 in 3 citizens and cost the EU economy almost €800 annually. So, this conference and its emphasis on the brain is timely in highlighting that all patients share similar concerns and illustrating the value of sharing expertise from within", said Audrey Craven, President of EFNA.

“This Conference – marking 10 years of EPF – was a huge milestone. It reflected our strong bond with the Irish patient community and through working with EFNA and NAI, it demonstrated our commitment to solidarity and genuine partnership. It was a great springboard for concerted action, and EPF will take forward the recommendations of the meeting in close collaboration with our members and allies”, said EPF Executive Director Nicola Bedlington.

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On the picture:

EPF Board Member Avril Daly and also General Manager of Fighting Blindness , EPF President Anders Olauson, Commissioner Tonio Borg and EFNA President Audrey Craven at the Conference Towards Active Patients’ Participation on 23 May 2013 in Dublin, Ireland.

The **European Patients’ Forum (EPF)** was founded in 2003 to become the collective patients’ voice at EU level, manifesting the solidarity, power and unity of the EU patients’ movement. EPF currently represents 60 member organisations - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organisations. EPF reflects the voice of an estimated 150 million patients affected by various diseases throughout Europe.

www.eu-patient.eu

The **European Federation of Neurological Associations (EFNA)** is a non-profit umbrella organization representing pan-European patient neurology groups. Their slogan: Empowering Patient Neurology Groups reflects the work of EFNA as an organization committed to adding capacity and value to the work of its members.

www.efna.net

The **Neurological Alliance of Ireland (NAI)** is the national umbrella body representing over thirty not for profit organisations working with people with neurological conditions and their families.

www.nai.ie