

# European Patients' Forum Newsletter

## A strong patients' voice to drive better health in Europe



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// JANUARY 2015 ISSUE

## A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the January issue of our newsletter. In this new year 2015 we want to continue to ensure that a strong patients' perspective is integrated into all relevant health-related policies at EU level, and support the implementation of key EU legislation of relevance to patients.

The EPF strategic plan 2014-2020 is built around the new 'thematic approach' in our work. We have reflected this by setting up two working groups with our members to address the overarching priorities in our work: patient empowerment and patient access.

EPF will also lead a major patient empowerment campaign this year that will run until mid-2016, starting with a launch conference on 20-21 May 2015. This campaign will take the European discussions a crucial next step forward – towards concrete actions at practical and political level, led by the patient community in partnership with all relevant stakeholders.

In this issue, we share with you 2015's first successes for the patient community: the launch of two new Interest Groups on equitable access to healthcare and neurological diseases in the European Parliament; the release of our new position paper on discrimination in healthcare; great achievements for our Romanian friends within our Capacity Building Programme; and exciting updates from our EUPATI and SmartCare projects.

We hope you enjoy this issue!

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Secretary General



LAUNCH OF THE MEP ACCESS TO HEALTHCARE INTEREST GROUP

OUR POSITION TO PROMOTE 'HEALTHCARE FOR ALL'

**"SURVEY ON PATIENTS' INFORMATION NEEDS RELATED TO PERSONALISED MEDICINE"**

### UPCOMING EVENTS

24/2/2015 | [Launch Interest Group "Brain, Mind and Pain"](#)

#### Brussels, Belgium

The group – a joint initiative of the European Federation of Neurological Associations and Pain Alliance Europe – will



BRUSSELS, 27 January 2015 - Members of the European Parliament (MEPs) launch the Access to Healthcare Interest Group, a caucus where EPF will provide patients' expertise to tackle health inequalities and enhance proper access to high-quality healthcare for all patients.

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Brussels, January 2015 – EPF released a position paper called “Healthcare for all” to promote the development of EU and national policies that tackle discrimination faced by patients in exercising their right to healthcare. While there are existing principles and laws on this issue, we believe further steps need to be taken to truly tackle stigma across the EU and apply the right to health for all.

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be co-chaired by MEPs Marian Harkin, Jeroen Lenaers and Daciana Octavia Sărbu.

*EPF attendance:*  
Camille Bullot

[10/3/2015 | Workshop on Cross-border healthcare for Polish patients' organisations](#)

**Warsaw, Poland**

This workshop will help to raise awareness about the Cross-Border Healthcare (CBHC) Directive and patients' rights enshrined within this legislation.

*EPF speaker:*  
Camille Bullot

[16/3/2015 | Workshop on Cross-border healthcare for Spanish and Portuguese patients' organisations](#)

**Madrid, Spain**

This workshop will help to raise awareness about the Cross-Border Healthcare (CBHC) Directive and patients' rights enshrined within this legislation. We will ensure to 'unpack' various aspects of the Directive which have wider policy and systems implications of interest to patients (eHealth provision, HTA provision, general provisions on Quality of Care and Patient Safety, specific provisions linked to Rare Diseases, etc)

*EPF speaker:*  
Camille Bullot

[17/3/2015 | Spanish Patients' Forum 10th anniversary](#)

**Madrid, Spain**

Celebration of the Spanish Patients' Forum 10th anniversary in cooperation with EPF: looking at the achievements and challenges ahead.

*EPF speaker:*  
Nicola Bedlington

**PATIENTS CAMPAIGN ON DATA PROTECTION**



EPF has recently joined the European Research Data Alliance to drive a common campaign on Data Protection. We want to ensure the final Regulation allows the vital research that has taken place for many years to continue. Nick Meade of Genetic Alliance UK shares on our blog why he strongly supports the campaign based on a UK example.

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**POSITIVE OUTCOMES OF EPF CAPACITY BUILDING PROGRAMME IN ROMANIA**



Romania was the first country to complete the two first phases of the EPF Capacity Building Programme (CBP). An evaluation was conducted at the end of each stage, consisting of training on strategic and operational planning respectively. It is now time to take stock during the implementation to transfer this learning to the other participative countries.

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**SMARTCARE: VISIT OF THE ARAGON'S PILOT SITE**

**EUPATI: SECOND EXPERT TRAINING COURSE AND LOCAL ACTIVITIES**



As a member of the SmartCare project's User Advisory Board (UAB), we took part in the first site visit in late 2014 in the Barbastro area, Aragon region, Spain. We wanted to get an in-depth understanding of how integrated care services are delivered locally and get feedback from all actors involved: patients, informal carers, health professionals, social workers, and volunteers.

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Our EUPATI project, the European Patient Academy on Therapeutic Innovation, got off to a good start in 2015. On 19 January we launched the second cycle of the EUPATI Patient Expert Training Course. The Academy also starts to expand locally with new national liaison teams created and a major event in sight on 22 April in Dublin, Ireland. Save the dates!

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### MORE PATIENT INVOLVEMENT IN PATIENT SAFETY



Patient safety and quality of care was high on December's agenda. The Council conclusions adopted on 1 December 2014 marked an important milestone in this area while our Senior Policy Adviser Kaisa Immonen-Charalambous attended two important meetings to remind policy-makers of the importance of transparency and patient empowerment in this area.

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### NEW MEP INTEREST GROUP ON BRAIN, MIND AND PAIN

### TOWARDS AN ITALIAN COALITION OF PATIENTS' REPRESENTATIVES



EPF Membership Officer Camille Bullo travelled to Rome, Italy, on 10 December 2014 to meet with Italian Patients' representatives. This is part of our wider membership strategy to ensure representativeness in every country, to be expanded to Scandinavian countries in 2015, but also linked to national level cooperation.

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### BLOG ARTICLE OF A YOUNG PATIENT ON SELF-HELP AND PEER SUPPORT



On Tuesday 24 February, our member, the European Federation of Neurological Associations (EFNA), and Pain Alliance Europe (PAE) will launch a new Interest Group on Brain, Mind and Pain at the European Parliament. The two umbrella organisations want to put neurological and pain conditions high on the European agenda.

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Yolita Pavlova is a member of the EPF Youth Group and a young representative of the Confederation of Health Protection (KZZ) in Bulgaria. She provides on EPF blog her young patient's perspective on self-help and peer support

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### CONTACT US

**EUROPEAN PATIENTS' FORUM**  
Rue du commerce 31  
1000 Brussels  
BELGIUM

**Phone :** +32 (0)2 280 23 34  
**Email :** [info@eu-patient.eu](mailto:info@eu-patient.eu)  
[www.eu-patient.eu](http://www.eu-patient.eu) | [eu-patient.org/blog](http://eu-patient.org/blog)



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