

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// SUMMER 2015 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the summer issue of the EPF Newsletter. We hope you had a pleasant and restful summer break.

Patient Empowerment and our campaign 'Patients Prescribe' remain high on our agenda in the autumn. We start with a session on this topic at the 18th European Health Policy Forum Gastein in late September. In November, we continue with the launch of a roadmap for action at the European Parliament.

To help you join the movement on patient empowerment, EPF developed [guidance and support](#). We encourage you to get involved and contribute to the momentum of the campaign.

In this issue of the newsletter, Martha from our Youth Group speaks about patient empowerment from a young person's perspective through her experience of social media. Maria Nyman of Mental Health Europe and Jean George of Alzheimer Europe are guests on our blog this month to share information about the diseases they represent.

The concept of patient empowerment also resonated strongly at the cross-border healthcare conference we organised in early July. Participants agreed on the key role played by patient advocates to make the Directive actually 'work' on the ground. Also in this issue are insights from Romanian and Hungarian patient leaders who started the 3rd phase of our Capacity Building programme. On the policy front, we include articles on our views concerning patients' rights in the partial general approach on Data protection adopted by the Council and about Health Technology Assessment (HTA). EPF is passionate about meaningful patient involvement in HTA and inroads are being made but there is still a long way to go!

Warmest greetings,

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

A handwritten signature in black ink, appearing to be 'A. Olauson'.

A handwritten signature in black ink, appearing to be 'N. Bedlington'.



THE "PATIENTS PRESCRIBE" CAMPAIGN: NEXT STEPS



Just before summer EPF set European policy-makers and health stakeholders an ambitious challenge: to adopt a strategy on patient empowerment at EU-level. With our "Patients Prescribe" Campaign, we want to demonstrate that patients are active citizens who can, if supported, and according to their individual capabilities and situation, make a difference to the sustainability of health care systems.

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IS CROSS-BORDER HEALTHCARE WORKING FOR PATIENTS ACROSS THE EU?



After a series of national and regional events organised in 2013-2015 EPF has organised a major European conference on cross-border healthcare in Brussels, Belgium. Patient leaders from across the EU and National Contact Points (NCPs) agreed that patients – and their representative organisations – play a key role in ensuring the Directive effectively "works".

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"I USE SOCIAL MEDIA TO MAKE INFORMED HEALTH CHOICES"



Martha is a member of the EPF Youth Group from Malta and is living with Coeliac disease, an autoimmune disorder where the ingestion of gluten leads to damage in the small intestine. Like most young people, she uses social media as a tool to find information her health.

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COUNCIL ON DATA PROTECTION: UNCERTAINTIES ON PATIENTS' RIGHTS



The Council adopted a partial general approach on Data protection on 15 June 2015. Following this, a trilogue process with the European Parliament was launched in July in order to come to a final agreement within the next few months. For patients, it is important that the Regulation reaches a balanced approach, protecting their privacy rights, and allowing data processing to continue for healthcare, public health and research purposes.

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UPCOMING EVENTS

02 - 03/09/2015 | [European Public Health Alliance 6th Annual Conference](#)

Brussels, Belgium

During this conference, the European Public Health Alliance (EPHA) will discuss the development of Health in All Policies (HiAP) and policy coherence at the EU level.

EPF speaker:
Nicola Bedlington

10/09/2015 | [Health literacy in the context of risk communication](#)

London, UK

This event, organised under the European Medicines Agency (EMA) 20th anniversary, will focus on 'health literacy in the context of risk communication'.

EPF speaker:
Marco Greco

14 - 15/09/2015 | [EPF Board meeting](#)

Brussels, Belgium

The EPF Board Members meet five times a year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work programme.

EPF attendance:
EPF Board

14 - 17/09/2015 | [65th session of the WHO Regional Committee for Europe](#)

Vilnius, Lithuania

During this session organised by the World Health Organisation (WHO), health ministers, high-level representatives and partner organisations will meet to discuss key technical health issues and set the priorities for health system strengthening for the next years.

EPF speaker:
Nicola Bedlington

14 - 18/09/2015 | [EUPATI Face-to-Face Training Event](#)

Barcelona, Spain

During this second face-to-face training event, the trainees of the European Patients' Academy on Therapeutic Innovation (EUPATI) will participate in 5 days of interactive lectures, group sessions and networking with other patient advocates.

HEALTH TECHNOLOGY ASSESSMENT: HOW PATIENTS CAN BE INVOLVED?



Health technology assessment (HTA) is the systematic evaluation of the properties and effects of a health technology to inform policy at national, regional or hospital level. It is an area that ideally should involve patients' perspectives but in reality there is still a long way to go.

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NEW LOGO FOR ONLINE SHOP SELLING MEDICINES



As from 1 July 2015, all online pharmacies or online shop selling medicines in the EU must display a new logo to show they are operating legally. This logo was introduced through the Falsified Medicines Directive (2011/62/EU) to protect patients from falsified medicines.

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3RD PHASE OF EPF CAPACITY BUILDING PROGRAMME FOR ROMANIA AND HUNGARY



Romanian and Hungarian members have entered the 3rd phase of the EPF Capacity Building Programme. The Programme has also been rolled out in Bulgaria, Slovakia, and Cyprus to build the capacities and advocacy skills of patients' organisations at national and European levels.

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GOODBYE AND STAY IN TOUCH!



Two staff members are leaving EPF this month: Cynthia Bonsignore and Stefania Laferte. We thank them both for their hard work and commitment and wish them all the best for their future.

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MEMBERS IN THE SPOTLIGHT

MENTAL HEALTH EUROPE IN THE SPOTLIGHT

"DEMENTIA IS NOT A NATURAL PART OF GROWING OLD"

EPF attendance:
Walter Atzori

18 - 20/09/2015 | [EPF Youth Group Annual Meeting](#)

Bucharest, Romania

EPF Youth Group, made up of young patient representatives between 15 and 29 years old with different chronic conditions, will meet to discuss the EPF Youth Group Strategy.

EPF attendance:
Valentina Strammello

19 - 20/09/2015 | [6th EUFAMI European Congress](#)

Sofia, Bulgaria

The European Federation of Associations of Families of People with Mental Illness (EUFAMI) will hold its 6th major European Congress under the theme 'When East meet West' emphasising in 'Families at the heart of Europe'.

21/09/2015 | [EFPIA Think Tank meeting](#)

Brussels, Belgium

The European Federation of Pharmaceutical Industries and Associations (EFPIA) Think-Tank serves as a forum for both EFPIA members and European patients' organisations.

EPF attendance:
Nicola Bedlington

21 - 23/09/2015 | [EPF Training Module on Strategic Communication](#)

Brussels, Belgium

The aim of this training is to strengthen the capacity of 10 EPF members in communication, and will focus on the effective use of appropriate media and communication tools to support their advocacy work.

EPF attendance:
Camille Bullo

22/09/2015 | [European Institute for Health High-Level Conference](#)

Brussels, Belgium

The aim of this conference organised by the European Institute for Health's (E.I.H.) is to explore the contribution of the "Global Health" sector to economic growth and job creation in Europe.

EPF speaker:
Robert Andrew Johnstone



22/09/2015 | [Patient MedTech Dialogue](#)

Brussels, Belgium

This biannual event provides a constructive platform of exchange between patients' organisations and the MedTech industry.

*EPF speaker:
Nicola Bedlington*

Our membership is our compass. We are delighted to feature one of our 65 member organisations every month on our blog. This time, we interviewed Maria Nyman, Director of Mental Health Europe (MHE-SME), who provides an overview of her organisation in five short answers.

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The Glasgow Declaration calls for the creation of a European Dementia Strategy, as well as strategies in every European country. EPF supports Alzheimer Europe's (AE) initiative that aims to achieve real change for people living with dementia in Europe. Jean George, AE Executive Director, speaks about this growing public health challenge on our blog.

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**A STRONG PATIENTS' VOICE
TO DRIVE BETTER HEALTH IN EUROPE**

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