

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// SEPTEMBER ISSUE

A WORD FROM EPF PRESIDENT AND SECRETARY GENERAL

A very warm welcome to the September issue of the EPF Newsletter.

As we go to press, preparations are well underway for the Commissioner – designates' Hearings in the European Parliament in early October. In this issue we highlight the core priorities from our perspective. Together with fellow public health NGOs we have also highlighted our concern over Mr Juncker's decision to move the pharmaceutical dossier from DG SANCO to DG Enterprise.

We are pleased to include a number of exciting updates surrounding key events this autumn, including outcomes from the 5th Healthcare Forum held in Krynica Zdroj, Poland on 2-4 September and the second annual conference of the European Alliance for Personalised Medicines on 9-10 September.

We continue to keep you updated on the EMPATHiE tender on patient empowerment- the final report will be released by the end of this month.

We are also delighted to report on developments within the EPF Youth Group, which is seeking to take concrete steps to build awareness of the needs of young patients in Europe. Also aimed at raising public awareness of patients, the European Parkinson's Disease Association's "Step Forward for Parkinson's" campaign, came to a climax last weekend at their European Unity Walk in Luxembourg.

We hope you enjoy the newsletter. Best wishes for a dynamic and creative autumn – we look forward to our continued work with you!

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



**COMMISSIONERS' HEARINGS:
ASK YOUR QUESTION!**

**EPF JOINS OTHER HEALTH NGOS
IN LETTER ON THE PHARMA
PORTFOLIO OF PRESIDENT-ELECT
JUNCKER**

UPCOMING EVENTS

26/09/2014 | [EPF Policy Advisory Group Meeting](#)

Brussels, Belgium

The Policy Advisory Group meets four times a year to advise the EPF Board and Secretariat on policy topics prioritised by EPF's annual general meeting and issues which, because of their complex, controversial and/or highly political nature, require detailed and in-depth discussion.

*EPF speaker:
Kaisa Immonen-Charalambous*

Each Member State has now appointed a candidate to be part of the next European Commission for the period 2014-2019. EPF takes the opportunity of the upcoming hearing of the Health Commissioner designate to encourage reform towards a healthier Europe through policies that reflect patients' real life needs.

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TENDER STUDY ON PATIENT EMPOWERMENT SOON FINALISED



The final report of the EMPATHiE tender "EMpowering PATients in the management of chronic diseases" will be released by the end of this month. The tender aimed to achieve a common understanding of the concept of patient empowerment and identify good practices, success factors and barriers.

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"HEALTH IS NOT SIMPLY ABOUT ECONOMICS, BUT ABOUT PEOPLE"

EPF and the public health community in Europe sent an open letter to Mr Juncker, President-elect of the European Commission, expressing astonishment and concern regarding his decision to move the competence for medicinal products and health technologies from the Commissioner in charge of Health to the Commissioner in charge of internal market and industry.

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EPF YOUTH GROUP PLANS FOR THE FUTURE



The EPF Youth Group met for their 4th Annual Meeting on 13-16 September in Brussels. The young patient representatives discussed their plans for 2015-2017 and identified three main thematic areas for further discussion: discrimination, transition to adult care and capacity development.

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A STEP FORWARD FOR PARKINSON'S DISEASE!

[1-3/09/2014 | 17th European Health Forum Gastein](#)

Gastein, Austria

The EHFG is the leading health policy event in the EU and takes place annually. It provides a major platform for decision-makers in various fields of public health & health care.

[6-8/09/2014 | Cross-Border Healthcare Regional Conference IV](#)

Tallinn, Estonia

Patient organisations' representatives from representatives from Denmark, Estonia, Finland, Latvia, Lithuania and Sweden will learn and share experiences about how the Directive works for patients and how they can contribute a strong patient's perspective. This is the 4th Regional Conference organised by EPF, further conferences will take place in 2015 with the remaining countries.

*EPF speaker:
EPF Secretariat*

[3/10/2014 | SUSTAINS Final Workshop](#)

Brussels, Belgium

This is the final event of the project aimed at sharing the preliminary results of the project with the external audience. It will be organised in the framework of the 11th European Week of Regions and Cities

*EPF attendance:
Walter Atzori*

[13-15/10/2014 | TOPRA Annual Symposium 2014](#)

Brussels, Belgium

TOPRA's Annual Symposia - on pharmaceuticals, veterinary medicines and medical devices - comprise the key event on the European healthcare regulatory calendar. It provides the largest forum for regulatory professionals to meet up and discuss current regulatory issues and debate future plans for regulation.

*EPF speaker:
Nicola Bedlington*

[15/10/2014 | Patient-MedTech Dialogue Meeting](#)

La Hulpe, Belgium

The European MedTech Forum is the largest health and medical technology industry conference in Europe. The Patient-MedTech

On 2-4 September, Nicola Bedlington attended the 5th Healthcare Forum of the 24th Economic Forum, a meeting of political business leaders in Central and Eastern Europe, in Krynica Zdroj, Poland. The event was an opportunity to evaluate and debate on new perspectives in health across Europe.

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SETTING THE EU HEALTH AGENDA WITH PERSONALISED MEDICINES



Nicola Bedlington participated in the European Alliance for Personalised Medicine (EAPM)'s second annual conference on 9-10 September 2014. This year's conference aimed at setting the EU health agenda by showing how personalised medicine has the potential to change healthcare for the better.

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Only 12% of patients with Parkinson's disease are referred to a specialist for their diagnosis in the EU. On 20 September, the European Parkinson's Disease Association organised the European Unity Walk to raise awareness for effective, equal treatment for Parkinson's patients.

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Dialogue provides a constructive platform of exchange between patients' organisations and the MedTech industry.

EPF attendance:
EPF Board

16 - 17/10/2014 | [EFPIA/PhRMA Healthcare Summit](#)

Brussels, Belgium

The gathering of around 150 representatives from patient organisations and the pharmaceutical industry will provide a unique opportunity to explore themes of empowering patients and citizens to becoming more involved in EU health policy decisions.

EPF attendance:
Anders Olason

16 - 17/10/2014 | [Open Roundtable on the 'Ethics of Citizen Involvement and Health'](#)

Brussels, Belgium

High level public Roundtable of the European Group on Ethics in Science and New Technologies with the purpose of promoting dialogue, and gaining expert input to further the Group's reflection.

EPF attendance:
Kaisa Immonen-Charalambous

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



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