A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the May issue of the EPF newsletter.

The stage is set for the closing event of our Patient Empowerment Campaign! We are delighted to let you know that MEPs Karin Kadenbach (S&D, Austria), Andrey Kovatchev (EPP, Bulgaria) and Roberta Metsola (EPP, Malta) will co-host the policy roundtable. Taking place at the European Parliament on the 22/06, the meeting will present the results of the campaign and reflect on the follow-up towards real implementation of patient empowerment. Wait no longer and register, we are waiting for you!

New publications in store: two important policy papers from EPF! A statement outlining our vision on informed consent in clinical trials, in time for the implementation of the Clinical Trials Directive; and a policy paper on patient safety, where we highlight our position on this central theme for patients.

We also report in this issue on an interactive event organised by the Danish Permanent Representation, where experts discussed new avenues to improve the complex process of Health Technology Assessment. EPF was also represented at a meeting of WHO Europe in Copenhagen to discuss the topic of patient-centred healthcare services.

After four years of tough negotiations within the EU institutions, the General Data Protection Regulation has been finally adopted and published! We tell you more on EPF’s work on this very important topic for scientific research and patients’ rights.

Some updates as well regarding our Capacity Building Programme! As the coalition building module set up for patients’ organisations in Poland will soon be open, we are happy to share some information on the programmes planned for these activities.

A couple of news as well on the projects EPF is involved in: we will hear about the first impressions following the Delphi panels of the Joint Action CHRODIS; while you will know more about the final conference of the SMARTCARE project, in Trieste, Italy.

As always, our blog hosts many entries from our members and external partners! It is a pleasure to feature an interview of our member the International Bureau of Epilepsy (IBE), with updates on their achievements and objectives. From the EPF Youth Group, Thomas, aka the Chronic Adventurer will tell us more about his recent running adventures to raise awareness of Crohn’s disease and his association EFCCA.

Finally, we will receive an update from the European Health Parliament (EHP) on their soon-to-be published recommendations on prevention and self-care. Those will be officially presented at the EHP plenary session of June the 29th, where EPF will have a stand showcasing the results of the Patient Empowerment Campaign.

Warmest greetings,

Marco Greco, EPF President and Nicola Bedlington, EPF Secretary General
The Patient Empowerment Campaign is entering its final weeks! After a year of advocating for patient empowerment, EPF is organising a high-level policy roundtable on the 22nd of June to present the campaign’s results and to discuss further steps at policy level. We shall also organise an exhibition in the European Parliament to celebrate the campaign and what it stands for.

READ MORE »

EPF Director of Policy Kaisa Immonen participated in an event organised by the Danish permanent representation, on 16 March 2016, on the topic of Relative Effectiveness Assessment (REA) at time of launch.

READ MORE »

On 2-3 May 2016 EPF participated in a consultation meeting of the WHO European Region’s “Framework for action on Integrated Health Services Delivery”, in Copenhagen.

READ MORE »

EPF has published a position paper calling for patient-centred implementation of the new EU Clinical Trials Regulation. Focusing on informed consent and information to patients, the paper outlines our vision from a patient’s perspective.

READ MORE »

UPCOMING EVENTS

26/5/2016 | 10th SEMI Brussels Forum

Brussels, Belgium
The theme of this half-day conference is cooperation across the value chain for the electronics manufacturing industry and we will focus our first session on the area of active and healthy ageing.

EPF speaker: Camille Bullot

31/5/2016 | European Patients' Forum & Medicines for Europe Seminar

Brussels, Belgium
Building on increased collaboration and ongoing initiatives over the last several months the European Patients Forum and Medicines for Europe are setting up their first structured dialogue between members.

EPF speaker: Nicola Bedlington

31/5/2016 | Launch of interest group of biomedical engineering

Brussels, Belgium
The new Interest Group on Biomedical Engineering will fill this void and work to ensure the needs of the biomedical engineering community are adequately reflected in policy. We intend to give biomedical engineers and medical researchers a voice in Brussels.

EPF attendance: Laurene Souchet

1-2/6/2016 | Personalised medicine conference 2016

Brussels, Belgium
The conference will explore personalised medicine through a research policy lens. It will also introduce a new collaboration among health research funding and policy making organisations called the International Consortium for Personalised Medicine (IC PerMed).
EPF has recently developed a briefing paper on Patient Safety. The document highlights the importance of patients' empowerment and involvement in improving safety, and some of the remaining challenges.

READ MORE »

On 27 April the Data Protection Regulation was officially adopted after four years of debates between the EU institutions. From May 2018, it will be directly applicable in all Member States.

READ MORE »

Following the completion of the Delphi-style panels of the Joint Action CHRODIS, a pannelist reflects on the main take-away messages of these assessment activities.

READ MORE »

The final conference of SmartCare will take place on 6 July 2016 in Trieste, Italy. Time reflect on the results observed so far!

READ MORE »

After months of preparation, we are...
pleased to announce that Poland is the sixth country to join our Capacity Building Programme.

86% of all deaths in the EU. Only 3% of health budgets are devoted on prevetion activities. Time for a change, calls the European Health Parliament.

**READ MORE »**

Every month we put the spotlight on one of our members. Today, we are delighted to put the International Bureau for Epilepsy to our now famous short questionnaire!

This month we tell you the fascinating story of Thomas, a young patient living with Crohn's Disease. As soon as he heard about his diagnosis, Thomas turned into the Chronic Adventurer, running around the UK to raise awareness about his condition.

**READ MORE »**

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

**CONTACT US**

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

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

This e-newsletter arises from the 2016 Health programme, which has received funding from the European Union, in the framework of the Health Programme.

Disclaimer: The content of this e-newsletter reflects only the author’s views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

If you no longer wish to receive emails from EPF, simply send an email to mailing@eu-patient.eu to unsubscribe.

Please note that some links may not work anymore because the articles have moved, do therefore not hesitate to look at the news section where all the articles are archived or contact communications@eu-patient.eu for more information.