

# European Patients' Forum Newsletter

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



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// MAY 2016 ISSUE

## 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

A handwritten signature in black ink, appearing to be 'MG', representing Marco Greco.

A handwritten signature in black ink, appearing to be 'NB', representing Nicola Bedlington.



**HIGH-LEVEL POLICY  
ROUNDTABLE: "MAKING  
EMPOWERMENT A REALITY:  
PATIENTS AS PARTNERS"**



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.

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**TIME TO REFLECT ON AVENUES TO  
IMPROVE HTA PROCESSES**



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.

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**WATCH OUR PATIENT  
EMPOWERMENT CAMPAIGN  
VIDEO!**

**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 Bullo*

**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:*  
*Laurène 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).

**WHO MEETING ON PATIENT-  
CENTRED SERVICES**



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.

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**CLINICAL TRIALS INFORMED  
CONSENT PAPER**



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 »](#)

**PATIENT SAFETY BRIEFING PAPER  
– "EVERYONE'S BUSINESS"**



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.

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**DATA PROTECTION REGULATION  
NOW OFFICIALLY PUBLISHED**



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 »](#)

*EPF speaker:*  
*Valentina Strammiello*

[22/6/2016 | Patient Empowerment Campaign - High Level Policy Roundtable](#)

**Brussels, Belgium**

Closing Event of the Patient Empowerment Campaign. A policy roundtable will discuss results of the campaign and concrete implementation into national and european policies

*EPF speaker:*  
*Anders Olauson*

[6 - 7/6/2016 | EPF Regional Advocacy Seminar](#)

**Amsterdam, Netherlands**

The overall objective of the 8th EPF Regional Advocacy Seminar will be to provide patients' organisations with tools to advocate effectively at European and national level.

*EPF speaker:*  
*Nicola Bedlington*

[8/6/2016 | Annual Symposium "How big data can help healthcare delivery and advance pharmacy practice"](#)

**The Hague, Netherlands**

During this second face-to-face training event, the second cohort of 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.

*EPF speaker:*  
*Anders Olauson*

[8 - 10/6/2016 | eHealth week 2016](#)

**Amsterdam, Netherlands**

The sessions of eHealth Week 2016 in Amsterdam will focus on Empowering People, Trust & Standards and Social Innovation & Transition

*EPF speaker:*  
*Laurène Souchet*

[18/6/2016 | International Federation for Spina Bifida and Hydrocephalus European workshop](#)

**Budapest, Hungary**

Annual event for IF members

*EPF speaker:*  
*Camille Bullot*

[20/6/2016 | Stakeholder Event on Biosimilar Medicinal Products](#)

**Brussels, Belgium**

National uptake of biosimilar medicines, policies, information needs of patients and health professionals

*EPF attendance*  
*Kaisa Immonen-Charalambous*

**CHRODIS DELPHI SURVEYS: FIRST IMPRESSIONS**



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.

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**SMARTCARE FINAL CONFERENCE: 6 JULY 2016**



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 »](#)

**CAPACITY BUILDING PROGRAMME  
– POLAND**



After months of preparation, we are

**(BLOG) SELF-CARE A GAME-CHANGER FOR CHRONIC DISEASES PREVENTION – EHP RECOMMENDATIONS**



Chronic diseases are responsible for

pleased to announce that Poland is the sixth country to join our Capacity Building Programme.

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

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[22/6/2016 | FRA Fundamental Rights Forum - eHealth workshop](#)

**Vienna, Austria**

idea lying beyond the FRF is to offer a major platform to reaffirm the commitment to fundamental rights as the foundational value of the European Union. T

*EPF speaker:*  
*Laurène Souchet*

[29/6/2016 | European Health Parliament](#)

**Brussels, Belgium**

Final Plenary Session of the European Health Parliament. Opportunity to discuss recommendations by internal committees and see EPF exhibition on Patient Empowerment!

*EPF speaker:*  
*Nicola Bedlington*

[BLOG] 5 QUESTIONS TO...  
INTERNATIONAL BUREAU FOR  
EPILEPSY



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!

[READ MORE »](#)

[BLOG] MEET THOMAS, THE  
CHRONIC ADVENTURER



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 »](#)

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TO DRIVE BETTER HEALTH IN EUROPE**

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