

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// AUGUST ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

A warm welcome to the August issue of the EPF Newsletter, we hope that you had a pleasant and restful summer break.

This issue includes information on a number of key events coming up this autumn. **The post-European election period** is an important opportunity to ensure new and re-elected MEPs put patients and health on their agenda but also to highlight this at commissioner-designates' hearings in the European Parliament, that are scheduled for late September.

MEP Andrey Kovatchev (EPP, Bulgaria) shares on our blog his willingness to see an informal MEP Interest Group on patient access to healthcare emerging from the previous intensive work on health inequalities. This is also part of our current efforts to build a multi-stakeholder Patient Access Partnership in collaboration with our member, the Bulgarian National Patient Organisation.



We are also delighted to share with you the positive outcomes of our third in a series of four EPF **regional events for patient communities on the Cross-Border Healthcare Directive**, which took place in Ljubljana, Slovenia in July. The fourth and last conference will take place in Tallinn, Estonia, on 6-8 October with patient leaders from Denmark, Estonia, Finland, Latvia, Lithuania and Sweden. Registrations are still open so please do not hesitate to share this among your contacts.

The concepts 'patient centeredness' and 'patient involvement' resonated strongly at the July event of our European Patient Academy, EUPATI. This EPF-led project moves up gear in October with the beginning of its 14-month Patient Expert Programme that will train 50 patient advocates to become specialists in research and development.

We hope you enjoy the reading. Warmest greetings for a productive and inspiring autumn – we look forward to working with you!

Anders Olauson, EPF President and Nicola Bedlington, EPF Director

EUROPEAN PARLIAMENT
ELECTIONS CAMPAIGN'S NEXT
STEPS

MEP KOVATCHEV SPEAKS OUT ON
ACCESS TO HEALTHCARE

**EPF IS HIRING A HEAD OF
BRUSSELS OFFICE**

UPCOMING EVENTS

2-4/09/2014 | [5th Healthcare Forum](#)

Krynica-Zdroj, Poland

The debate during the Healthcare Forum is a great opportunity to not only to evaluate, but also to debate new perspectives that are



While the May elections are no more than a distant memory for many, European leaders have been working hard to shape the landscape of the future Parliament (EP) and Commission (EC). The lists of Parliament Committees were published in early July; some top jobs were defined; the hearings of potential Commissioners are on the horizon; and the possibility of creating an EP Health Intergroup is under discussion.

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EPF collaborates closely with the National Patient Organisation of Bulgaria (NPO) to put in place a multi-stakeholder Partnership on patient access to healthcare. MEP Andrey Kovatchev (EPP, Bulgaria) was very involved from the onset; he explains on our blog why this issue should be a priority for EU institutions and Member States.

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yet to be set in the Polish healthcare system.

EPF speaker:
Nicola Bedlington

9-10/09/2014 | ["Integrating Personalised Medicine into the EU Strategy"](#)

Brussels, Belgium

The European Alliance for Personalised Medicine (EAPM) organises its second annual conference to raise awareness among policy-makers about how personalised medicine has the potential to change healthcare for the better.

EPF speaker:
Nicola Bedlington

14-15/09/2014 | [EPF Youth Group Annual Meeting](#)

Brussels, Belgium

The EPF Youth Group meets once a year to implement the EPF Youth Strategy and was established to become the reference group through which needs and expectations of the young patient community are formulated and communicated to EPF and its members.

EPF attendance:
Valentina Strammiello

15-16/09/2014 | [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

16/09/2014 | [SUSTAINS Steering Committee Meeting](#)

Treviso, Italy

This is the last Steering Committee meeting before the end of the project in December 2014.

EPF speaker:
Walter Atzori

16-17/09/2014 | [EUPATI series of events](#)

Dublin, Ireland

On 16 September, EUPATI will launch its Irish National Platform and its consortium industry will meet. The EUPATI Executive Committee will meet on the 17th.

OUR EUROPEAN MEMBERS TRAINED TO RAISE FUNDS TO BECOME STRONG ADVOCATES



On 26-28 August our training on fundraising took place in Brussels as part of our Capacity Building Programme. Ten of our European Full Members had the opportunity to acquire more expertise and practical tools on how to diversify funding and create a viable financial structure.

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THIRD REGIONAL CONFERENCE ON CROSS-BORDER HEALTHCARE



The third EPF Cross-Border Healthcare Conference took place in Ljubljana, Slovenia, on 7-9 July, as part of a series of four EPF regional events for patient communities on this topic. The fourth and last one will take place in Tallinn, Estonia, on 6-8 October 2014.

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EUPATI REPORT FROM JULY'S EVENT & EXPERT PROGRAMME

SHARING OF CLINICAL TRIALS RESULTS TO INCREASE TRANSPARENCY



The concept of 'Patient-centeredness' is omnipresent today, to the point where patient engagement has been quoted as the 'blockbuster drug of the century'. The European Patient's Academy on Therapeutic Innovation (EUPATI) hosted a workshop on 23 July in Berlin, Germany, to discuss concrete actions that support meaningful patient involvement in Research and Development (R&D).

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REPORT FROM THE EUROPEAN COMMUNICATION SUMMIT'S WORKING GROUP



For the first time, EPF took part in the European Communication Summit on 9-11 July in Brussels, Belgium. Our Communication Officer, Cynthia Bonsignore, spoke at the working group dedicated to health about "Storytelling is the new black: what should communication in the healthcare sector really look to meet patients' needs?"

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As from July, data from clinical trials submitted to the European Medicines Agency must be made available to the public. EPF welcomes this as we have called for the publication of the results of all clinical trials in a timely manner, regardless of the outcomes, since the beginning of our involvement with EU clinical trials legislation.

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BENEFITS AND RISKS DISCUSSED AT THE EFPIA PATIENT THINK TANK IN JULY



The European Federation of Pharmaceutical Industries and Associations (EFPIA) Patients' Think Tank convened on 1 July 2014 in Brussels. A key item on the agenda was benefit-risk. This session started with a background presentation from Yann le Cam, Chief Executive Officer of EURORDIS.

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EPF speaker:
Nicola Bedlington

17/09/2014 | [We CARE Workshop](#)

Brussels, Belgium

The workshop will address the barriers and dilemmas for the adoption of cost containment strategies in the economic, institutional and political environment.

EPF attendance:
Valentina Strammiello

18-19/09/2014 | [PaSQ Coordination Meeting](#)

Rome, Italy

The meeting will aim at updating partners on the achievements in the project and planning of further activities. The PaSQ Joint Action (JA) aims to create a permanent platform for future cooperation between Member States in the area of patient safety and quality of care.

EPF speaker:
Cristina Padeanu

18-19/09/2014 | [EMA Patient Consumer Working Party](#)

London, UK

At this event we will contribute to provide recommendations to the European Medicines Agency and its human scientific committees on all matters of interest to patients in relation to medicinal products.

EPF attendance:
Susanna Palkonen

20/09/2014 | [European Unity Walk 2014](#)

Luxembourg

This annual event is organised by our member, the European Parkinson's Disease Association (EPDA).

21-22/09/2014 | [Conference "Innovative Systems and Health Horizons"](#)

Milan, Italy

The conference will provide an opportunity to develop further the debate on the possible solutions enabling the EU network to promote a better balance between the dual need of a rapid access for patients to innovative medicines and the financial sustainability of the National Health systems.

EPF speaker:
Nicola Bedlington

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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