

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



// OCTOBER ISSUE

A WORD FROM EPF PRESIDENT AND DIRECTOR

A warm welcome to the October issue of the EPF Newsletter.

We are delighted to share with you that our EU election campaign "Patients + Participation = Our Vote for A Healthier Europe" was officially launched on 1 October, with the support of Commissioner Borg, and Health champion in the European Parliament Dagmar Roth Behrendt, MEP. Read more in the article below and please do support or campaign actively!

A key feature in the last month was, of course, the European Health Forum Gastein – which was a very rewarding event – a particular highlight was a special session on non-discrimination in health. While fair treatment is a basic right in the EU, the EU framework for tackling discrimination does not include discrimination on the grounds of health status. Yet many patients face discrimination and stigma in various areas of their life, including healthcare, financial services, education, and employment.

Non-discrimination is among our core values at EPF. We are committed to promoting the rights of all patients and challenging discrimination. This is the reason why we have adopted non-discrimination as one of our 2014-2020 [strategic goals](#). We are also developing a briefing paper to define with our membership the priorities for future work in this area.

In this issue we are also excited to share the some updates, on our work in Gastein, developments in health literacy, the implementation of the Cross-Border Directive, our project on Patient Safety and Quality of Care, our Youth Group, etc.

Warmest greetings for a pleasant and inspiring autumn – we look forward to working with you!

Anders Olauson, EPF President and Nicola Bedlington, EPF Director



EPF CAMPAIGN FOR THE 2014 EU ELECTIONS

BLOG: WHY SHOULD PATIENTS CARE ABOUT THE EU?

UPCOMING EVENTS

28, 29/10/2013 | [EPF 6th Regional Advocacy Seminar](#)

Zagreb, Croatia

The event is open to patients organisations' leaders from Croatia, Serbia, Montenegro, Macedonia and Turkey (the EU acceding and candidates countries) and will look at the link between policy-making at EU and member state level and advocacy skills for patient advocates.

EPF attendance:



On 1 October 2013, we launched our campaign entitled "Patients + Participation = Our Vote For a Healthier Europe" ahead of the 2014 European elections. The invaluable presence and support from Health Commissioner Tonio Borg and MEP Dagmar Roth-Behrendt (S&D, Germany) made this event a resounding success, hopefully to be followed by many others.

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SPECIAL REPORT FROM EPF IN GASTEIN



On 2-4 October 2013, the health policy community gathered in Austria for the 16th annual Gastein European Health Policy Forum (EHFG). The focus was on how Europe can build resilient and innovative healthcare systems with the dramatic mark left on health, healthcare systems and therefore patients by the crisis.

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PATIENTS' RIGHTS IN CROSS-BORDER HEALTHCARE SOON IMPLEMENTED

Alastair Kent, President of the Patients Network for Medical Research and Health (EGAN), talks about patients and the EU on the occasion of the EPF Campaign for the 2014 EU Elections. He believes that patient advocacy at the EU level has been an effective tool in bringing about positive change for those with unmet medical needs in Europe.

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SHAPING A HEALTH LITERATE EUROPE



A new consensus paper on how to advance health literacy in Europe was launched on 4 October at the European Health Forum in Gastein, Austria. EPF contributed a patients' perspective to this joint document, developed by a broad policy coalition composed of the Standing Committee of European Doctors (CPME), the Maastricht University and MSD.

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POSITIVE DUTCH DECISION ON POMPE AND FABRY DISEASE TREATMENTS

EPF secretariat

[04/11/2013 | EC working group on patient safety and quality of care](#)

Brussels, Belgium

The working group will focus on reporting and learning systems, education and training of health professionals

EPF attendance:

Kaisa Immonen-Charalambous

[05/11/2013 | Joint ACCA-Hanover event on eHealth](#)

Brussels, Belgium

Entitled "Towards improving patient safety, increasing clinical accountability and addressing information governance", the event co-organised by ACCA (the Association of Chartered Certified Accountants) and Hanover aims to feed into the eHealth Action Plan 2012-2020 debate and underline the importance of sharing of good eHealth practice in Europe.

EPF speaker:

Nicola Bedlington

[06/11/2013 | PALANTE Project-mid Term Workshop](#)

Sofia, Bulgaria

The PALANTE midterm conference discusses the challenges and opportunities for implementing eHealth solutions in Europe's regions, caused by shifting relationships between health professionals and patients, trust and accessibility of new devices and systems, and involvement of all stakeholders in the implementation process.

EPF speaker:

Walter Atzori

[06/11/2013 | 6th 'Patients-MedTech Dialogue'](#)

Brussels, Belgium

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

EPF speaker:

Nicola Bedlington

[08/11/2013 | International Day of Radiology](#)

The European Society of Radiology (ESR), the Radiological Society of North America (RSNA) and the American College of Radiology (ACR) will celebrate the second International Day of Radiology (IDoR 2013) with radiological societies the world over.



The EU Directive 2011/24/EU on patients' rights in cross-border healthcare will enter into application on 25 October 2013. EPF has developed a set of recommendations to guide the national authorities and bodies to ensure that this Directive brings tangible benefits for patients and healthcare.

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PASQ PROJECT: FOCUS ON PATIENT INVOLVEMENT AND EMPOWERMENT



The European Union Network for Patient Safety and Quality of Care (PaSQ Project) partners met on 30 September and 1 October 2013 in Bratislava, Slovakia. Discussions focussed on feasible actions to ensure the sustainability of the project.

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BLOG: PATIENTS ORGANISATIONS AND CLINICAL RESEARCH



EPF speaker:
Nicola Bedlington

[13/11/2013 | Meeting of the International Medical Device Regulators Forum](#)

Brussels, Belgium

The meeting will be titled "Innovation for Safety: achievements and challenges " and will aim at gathering the point of views and specific challenges every stakeholder is facing when ensuring quality and safety of Medical Devices.

EPF speaker:
Nicola Bedlington

[14, 15/11/2013 | Event on Scientific Support to Public Health](#)

Brussels, Belgium

The Joint Research Centre of the European Commission is launching an initiative on "Scientific Support for Public Health: existing actions, new challenges and European added value".

EPF speaker:
Nicola Bedlington

[15, 17/11/2013 | 16th EULAR Autumn Conference for People with Arthritis/Rheumatism in Europe \(PARE\)](#)

Reykjavik , Iceland

The EULAR Autumn Conference is an annual meeting of people with arthritis/rheumatism in Europe organised by the EULAR PARE Standing Committee. The main goals of the conference are education, specialised training and networking.

EPF speaker:
Walter Atzori, Claire Hunt (EPF Youth Group)

[19, 20/11/2013 | Lithuanian Health Forum 2013](#)

Vilnius, Lithuania

EPF will partner this annual Conference, which will be held under the Lithuanian Presidency of the Council of the European Union, especially in one of the sessions on patients' engagement and empowerment

EPF attendance:
Anders Olason (Moderator of the parallel session on "Effects of health inequalities")

[21/11/2013 | EPF Patient evidence workshop](#)

Brussels, Belgium

The event is open to EPF member organisations and focuses on shaping EPF

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3RD ANNUAL MEETING OF THE EPF YOUTH GROUP



The EPF Youth Group met for its 3rd annual meeting in Blagoevgrad, Bulgaria, from 26 to 29 September. The group followed up on the positive outcomes emerging from the EMPATHY seminar, drafted policy recommendations and elected the new youth board.

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LIMITED RESOURCES VERSUS PATIENTS' NEED: HOW TO PRIORITIZE?



Our Senior Policy Adviser contributed to the Careum Congress blog with an article titled "Patient organisations are driving change in clinical research". The Careum congress event will take place on 17-18 March 2014 in Basel, Switzerland and will explore ways to engage patients in future healthcare systems.

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Key health stakeholders throughout Europe are invited to complete an online survey on their preferences on specific policy objectives (e.g. equitable access to medicines) and on their assessment of major reimbursement policies for medicines.

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contributions to EU-level actions in the Patient Safety area, emphasizing on patient involvement in patient safety.

EPF attendance:
Kaisa Immonen-Charalambous, Cristina Padeanu

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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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



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