

European Patients' Forum eNewsletter

A strong patient's voice to drive better health in Europe



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// APRIL ISSUE

A WORD FROM THE EPF PRESIDENT AND EPF DIRECTOR

Health inequalities and investing in health - a new wave of consciousness



As you know, addressing health inequalities is a core priority for EPF and our membership. We are working closely with members and allies in countries in crisis to address fundamental problems linked to access to healthcare and to medicines.

The very first European conference on health inequalities from the patient's perspective took place in Sofia last year in September, driven by the National Patients Association there and supported by EPF. This marked the start of an ongoing initiative to create substantive change for patients.

This will be followed up with a meeting in the European Parliament in June this year and a event in autumn in Poland, led by our member organisation FPP. More details to follow in the next EPF newsletter. This activity will complement similar initiatives in Gastein and under the Lithuanian EU Presidency.

All of this is part of the wave of consciousness throughout Europe that it is unacceptable and unjust that patients are denied access to the medicines and care we need. The recently adopted Social Investment Package, and the staff working document on 'investing in health' adopted by the Commission a few weeks ago will certainly provide a framework to advance this agenda.

EPF Board Members were very pleased to meet both Commissioner Borg and Director General Paola Testori- Coggi in early April. Together we had the opportunity to discuss the Package and the role and contribution of patients in achieving modern, responsive and sustainable health systems.

We hope you enjoy this issue of the Newsletter.

Anders Olauson, EPF President

Nicola Bedlington, EPF Executive Director



EPF THREE-DAY KEY EVENTS ARE FAST APPROACHING!



We are getting closer to our Conference *Towards Active Patients' Involvement In Healthcare* and our 10th anniversary celebration on 23 May in Dublin with Commissioner Tonio Borg as our special guest. Our Annual General Meeting will precede this event and a conference on nutrition will follow on 24 May. Please do register as soon as possible!

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PATIENTS VOICE THEIR POSITION ON MEDICAL DEVICES



Medical devices are of crucial importance for patients with chronic diseases. They can contribute to their life expectancy and quality of life. EPF releases our position paper to ensure the EU hears the recommendations of patients while reviewing the framework on Medical Devices.

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WATCH THE PROJECT CHAIN OF TRUST ON VIDEO!



The 2-year project Chain of TRUST ended in Brussels on 24 January with a closing conference. The project was about end users' confidence and trust towards telehealth services. Two videos trace the main project's findings and their potential impact on EU policies and users.

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COMMISSION REVISES THE TRANSPARENCY DIRECTIVE PROPOSAL



The European commission released a redrafted legislative proposal for the Transparency Directive (COM (2013) 168 final/2) on 20 March. The legislative proposal was originally published in March 2012 but a significant majority in the Council had blocked it. EPF took a stand on the first Commission's proposal on 1 October 2012.

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UPCOMING EVENTS

23/04/2013 | [HMA Human Medicines Stakeholders meeting](#)

County Kildare, Ireland

Event organised by the Heads of Medicines Agencies (HMA) under the Irish Presidency

EPF attendance:

Avril Daily, member of EPF Board

03 to 05/05/2013 | [Chronic Myeloid Leukemia \(CML\) Horizons 2013](#)

Prague, Czech Republic

This is the 11th international conference for organisations representing people that includes topics of importance to the CML patient community and provides a unique opportunity for participants to share experiences and best practice

EPF speaker:

Nicola Bedlington

16/05/2013 | [International Compliance Conference](#)

Warsaw, Poland

Our Director will speak on the Policy Debate Panel

EPF speaker:

Nicola Bedlington

22/05/2013 | [EPF Annual General Meeting](#)

Dublin, Ireland

EPF members will elect four new members in the Board and will take important decisions on the budget, on membership requests and on important documents agreements.

EPF attendance:

EPF Secretariat, Board & Members

23/05/2013 | [10th Anniversary Conference Towards active patients' involvement in healthcare](#)

Dublin, Ireland

EPF will celebrate its 10th Anniversary in 2013 and will mark this important milestone with a Conference under the Irish EU Presidency on 23 May featuring the European theme Year of Citizens and the Month of the Brain awareness.

EPF attendance:

EPF Secretariat, Board & Members

24/05/2013 | [Conference on Effective Health Care Requires Good Nutritional Care](#)

CLINICAL TRIALS: 731 AMENDMENTS TABLED BY MEPS



MEPs have tabled 731 amendments on the draft report of Glenis Willmott MEP (S&D, UK) regarding the European Commission’s legislative proposal for Clinical Trials. EPF will now analyse the amendments to take our recommendations forward.

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PATIENT INVOLVEMENT A WEAK AREA IN PATIENT SAFETY



EPF participated in the first 2013 meeting of the Patient Safety and Quality of Care Working Group (PSQC WG) on 8 March. The agenda concentrated on defining a work plan for the group for the next two years. The focus was on the European Commission’s report on the implementation of the Council recommendation of 2009 and input of group members following the last meeting in 2012.

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THE HEALTH LITERACY BLUEPRINT FROM THE PATIENTS’ PERSPECTIVE

EUROPE MEETS YOUNG PATIENTS IN JULY



The EMPATHY project or “Europe meets Young Patients” is now entering its implementation phase. The project consists of a four-day seminar that will take place in Brussels on 8-11 July. The EPF Youth Group is organising the event with the support of EPF.

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WORLD HEALTH DAY 2013 CAMPAIGNS ON HIGH BLOOD PRESSURE



Every year, the World Health Organization selects a priority area of global public health concern as the theme for World Health Day (WHD). The 2013 WHD took place on 7 April and was on controlling high blood pressure, a condition which affects more than one in three adults worldwide.

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A STRONG PATIENTS' MOVEMENT IN SLOVAKIA

Dublin, Ireland

EPF will partner with the Patient Network for Medical Research and Health (EGAN), the Irish Patients’ Association in cooperation with the Irish EU Presidency, the European Nutrition for Health Alliance (ENHA) and the Irish Society for Clinical Nutrition & Metabolism (IrSPEN) for the organisation of this conference on the added value of appropriate nutritional care for effective disease pathways.

*EPF attendance:
EPF Secretariat, Board & Members*

LOOK AT EPF NEWS ! 

DISCOVER EPF PROJECTS & INITIATIVES 

FIND MORE ABOUT EPF POLICY WORK 

WHO ARE EPF MEMBERS ? 



CSR Europe launched the first-ever Blueprint for Business Action on Health Literacy on 27 March 2013 in Brussels, Belgium. Our Director Nicola Bedlington attended the event, outlining the patients' perspective in terms of enabling patients with chronic conditions to participate in the labour market.

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EPF Director Nicola Bedlington led a workshop and participated in a national conference in Slovakia on 20 March 2013. The event explored how the Slovakian Patients' community could become more knowledgeable and influential in their work at national and European levels. Cooperation with EPF was also at the heart of discussions.

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FOCUS ON RESEARCH PRIORITIES AND INVESTING IN HEALTH



EPF attended the meeting of the EU Health Policy Forum on 9 April. The forum meets twice a year in Brussels and this time it focused on health investments and recent policy updates. EPF is part of this forum to ensure the EU's health strategy responds to patients' concerns.

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GOOD BYE ÖZGÜN ÜNVER!



Our Research and Project Officer Özgün Ünver left EPF in end of March. She joined our organisation in April 2011 and was working on our different projects: EMPATHY, InterQuality, SUSTAINS. . We thank her for everything she has done for us and wish her all the best for the future. Stay in touch!

[READ MORE »](#)

**A STRONG PATIENTS' VOICE,
TO DRIVE BETTER HEALTH IN EUROPE**



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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.

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