

European Patients' Forum eNewsletter

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



// NOVEMBER ISSUE

A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

Welcome to the November's issue of the EPF newsletter. In this issue we are delighted to share with you the outcomes of our Fifth EPF Regional Advocacy Seminar that took place in October. Please save the date of our next major [seminar on eHealth](#) on 23 January. And on 24 January [the closing conference of our Chain Of Trust Project](#) will take place. Read the results of the user requirements focus groups on electronic health records that we organised as part of the SUSTAINS project. We also share some updates on the Cross-Border Healthcare Directive and European Union Network on Patient Safety and Quality of Care (PaSQ) project. Find also reports from the events we attended: the Economist Conference on Non-Communicable Diseases, the World Health Summit, the 3rd Pan- European Conference on Haemoglobinopathies and Rare Anaemias, etc. Finally we are happy to welcome a new staff member within our Secretariat: Cristina Padeanu, from Romania, who will work on the Joint Action PaSQ mentioned above. A warm welcome to Cristina! We hope you enjoy reading this issue.

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Executive Director



A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

HOW CAN WE RESOURCE PATIENT ORGANISATIONS IN TIMES OF AUSTERITY?



The [Fifth EPF Regional Advocacy Seminar](#) took place in Lisbon, Portugal on 25-26 October 2012. The theme of this year's seminar was "Fundraising: Resourcing Patient Organisations for a strong Patient Movement". This was a good opportunity for Patients' Organisations to learn how to diversify their funding in order to maintain their capacity and effectiveness to advocate for patient' rights.

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THE CLOCK IS TICKING ON CROSS-BORDER HEALTHCARE!



On 25-26 October 2012, Kaisa Immonen-Charalambous participated in the [International Conference on Cross-Border Health Care](#), held in Bled, Slovenia. Our Senior Policy Adviser presented EPF's perspective on this [Directive](#). The Directive will be applicable from 25 October 2013 which means that Patients Groups will be able to support transposition at national level.

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UPCOMING EVENTS

21/11/2012 | 4th 'Patients-MedTech Dialogue'

Brussels, Belgium

The focus will be on concrete future collaboration on two strategic topics of joint interest - Patient-centered healthcare models and transparency and interaction with patients.

EPF speaker:
Nicola Bedlington

21/11/2012 | [European Workshop on Risk Management for Patient Safety](#)

Brussels, Belgium

Our senior policy advisor will provide EPF's position on Patient Safety

EPF speaker:
Kaisa Immonen-Charalambous

27/11/2012 | [Friends of Europe's annual Healthcare Summit](#)

Brussels, Belgium

Friends of Europe is an independent think tank for EU policy analysis and debate. This healthcare summit focuses on 'Why health is crucial to European recovery'

CHAIN OF TRUST: THE CLOSING CONFERENCE



A [final conference](#) on 24 January 2013 in Brussels will close [the EPF-led project Chain Of Trust](#) started in January 2011. The main project findings and recommendations will be shared with the wide range of stakeholders as well as future strategies to take these forward. This will also be the occasion to increase your awareness in telehealth services and the user perspective.

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THE EUROPEAN UNION NETWORK ON PATIENT SAFETY AND QUALITY OF CARE IS RUNNING



The second coordination meeting of the new Joint Action, "European Union Network on Patient Safety and Quality of Care" (PasQ) took place on 3-5 October 2012 in Madrid. EPF is a stakeholder partner in this three-year PaSQ Joint Action and we are actively involved in all the main work packages.

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PATIENT LINK WORKSHOP: HIGH IMPACT PATIENT ADVOCACY

PATIENTS IN FAVOUR OF HEALTH RECORDS ACCESS



The [SUSTAINS project](#) is deploying patient-accessible Electronic Health Records (EHR) associated with a basket of related services in 11 European regions. EPF has been coordinating the implementation of user requirement focus groups. This article outlines the SUSTAINS end users' views on the envisaged services in order to ensure these are aligned to the needs and expectations of patients and meet the requirements of health professionals.

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THE ECONOMIST CONFERENCE



Our Director Nicola Bedlington attended the [Economist Conference](#) on 29 October in Geneva, Switzerland. "New Responses to Communicable Diseases: Strengthening Health Systems –Changing Behaviour" was the focus of the event and EPF provided some solutions from the patients' perspective.

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REPORT ON 'EU PATIENT GROUPS & THE RELEVANCE OF NUTRITION'

EPF speaker:
Nicola Bedlington

[28/11/2012 | GSMA Connected Europe event](#)

Brussels, Belgium

The event will explore the potential of a Connected Europe and the role of industry-government partnerships in seizing this opportunity

[28/11/2012 | Patient Advocacy Leaders' Summit](#)

Helsinki, Sweden

Susanna Palkonen, EPF Vice President, will speak about "The European Patient - who are we, what is our role and what does it mean for the Finnish patient?"

EPF speaker:
Susanna Palkonen

[03/12/2012 | EUPATI Executive Committee Meeting](#)

Berlin, Germany

EPF is the project coordinator of EUPATI project and will chair the meeting, and in particular will lead Work Package 6 about Deployment and Quality Assurance. The objective of this WP6 is to implement the EUPATI expert, education and information programmes at European and national levels with three patient audiences, and to monitor and evaluate on an on-going basis the quality and impact of the programmes' delivery

EPF speaker:
Nicola Bedlington

[06/12/2012 | EHTEL Symposium](#)

Brussels, Belgium

The focus is "Fact not fiction: The future of eHealth is already here" - EPF will provide the patients' perspective view to the symposium

EPF speaker:
Walter Atzori

[11/12/2012 | EFPIA Patients Think Tank](#)

Brussels, Belgium

Patients' organisations and the pharmaceutical industry as consumers and producers of pharmaceutical products set up a joint Think-Tank in order to have a dialogue on EU policy issues in the area of health and innovative medical research.

EPF speaker:
Nicola Bedlington

[17/12/2012 | DuQue Final Conference](#)

The DUQuE project ends with this closing conference entitled "Deepening our Understanding of Quality Improvement in Europe". The project was aiming at



Over 60 patient representatives, primarily from the neurological disease arena came together from 15-17 November to participate in the Patient Link Workshop, organised by the Medtronic Foundation. Nicola Bedlington set the scene by giving an overview of the patient involvement in EU-level health policy.

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ACTION PLANS OF HEALTHY AND ACTIVE AGEING



On 6 November Laurène Souchet, EPF Policy Officer, attended the [1st Conference of Partners of the European Innovation Partnership on Active and Healthy Ageing](#). One year after the delivery of the Strategic Implementation Plan where EPF was able to contribute a strong patients' perspective, the six Action Groups presented their action plans to a wider audience. These plans aim to bring the benefits of innovation in the field of active and healthy ageing to Europe's citizens .

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NOVEL SOLUTIONS? YES, BUT ONLY WITH PATIENTS



Patients have particular – and diverse - needs as regard nutrition, which are currently unmet across the EU. [The first conference for EU Patient Groups on nutrition](#) successfully brought together patients groups from various disease areas, and various stakeholders working on health and nutrition. A [report](#) emerges from this conference jointly organised by the European Nutrition Health Alliance, EPF and the European Genetic Alliances' Network (EGAN).

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THE NEED FOR PATIENTS' PERSPECTIVE TO FACE CHRONIC DISEASES



Our Board Member Philip Chircop attended the [3rd Pan- European Conference on Haemoglobinopathies and Rare Anaemias](#) on 26 October in Chyprus. Participants discussed avenues of action to tackle the growing public health burden of chronic and rare diseases in the European region of the W.H.O. Mr. Chircop brought the patients' perspective to the fore.

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THE VALUE OF HEALTH IN PRACTICE IN HUNGARY

providing promising theoretical insights and evidence-based toolkits related to improving the effectiveness of quality improvement systems in hospitals

EPF speaker:
Nicola Bedlington

LOOK AT EPF NEWS !



DISCOVER EPF PROJECTS & INITIATIVES



FIND MORE ABOUT EPF POLICY WORK



WHO ARE EPF MEMBERS ?





The [World Health Summit 2012](#) took place in Berlin, Germany, on 21-25 October. 'Research for Health and Sustainable Development' was the theme, articulating the urgent need of finding novel solutions for non-communicable diseases and conditions of global concern. Our Board Member Tomasz Szelagowski took the opportunity to put patients at the centre of these novel solutions.

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On 9 November a conference entitled "The Value of Health in Practice – from patient perspective" was held at the Ministry of Human Resources (EMMI) in Budapest, Hungary. More than one year of legal preparation of the National Patient Forum (NPF), which is the contact and advisory board of the State Secretariat for Healthcare, is almost completed.

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EPF WELCOMES A NEW PROJECT OFFICER!



In November 2012 Cristina Padeanu joined the Secretariat as project officer. She was previously responsible for health program planning, project writing and coordination, monitoring and advocacy. For EPF Cristina will coordinate the activities of the European Union Network on Patient Safety and Quality of Care (PaSQ) project.

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

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