

European Patients' Forum eNewsletter

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



A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

Welcome to the July issue of the EPF Newsletter with much information on forthcoming events in autumn, including our EPF Regional Advocacy Seminar and news on progress regarding our capacity building programme. Our next issue will include an update on our youth group, our plans for the European Health Policy Forum Gastein, and our strategic planning working group.

It promises to be very a very productive autumn. Policy news includes an update on the Transparency Directive, Data Protection and Professional Qualifications Directive. We report on EPF's contribution to the first patients' Conference on Nutrition, and our recent joint work with the European Men's Health Forum on Gender and Health Through Life. We hope you enjoy this issue, that you have a happy and relaxing summer, and we look forward to seeing many of you after the break.

Warmest Greetings

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



UPCOMING EVENTS

21 & 22/08/2012 | [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 Attendance:

*Nicola Bedlington, chairing
Liuska Sanna, leading WP6*

25 & 26/10/2012 | [2012 EPF Regional Advocacy Seminar](#)

Lisbon, Portugal

Save the date for the 5th EPF Regional Advocacy Seminar ! This year's theme: "Fundraising: Resourcing Patient Organisations for a Strong Patient Movement"

LOOK AT EPF NEWS !



FIFTH EPF REGIONAL ADVOCACY SEMINAR



The Fifth EPF Regional Advocacy Seminar will take place in Lisbon, Portugal on 25-26 October 2012. The seminar is organised in collaboration with Associação Protectora dos Diabéticos de Portugal (Diabetes Association of Portugal).

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EPF TO CONTRIBUTE TO THE REVISION OF THE EU TRANSPARENCY DIRECTIVE

EPF TO EMPOWER ITS MEMBERS' CAPACITY AND ADVOCACY SKILLS



The European Patients' Forum (EPF) Capacity Building Programme (2012-2014) for patient organisations is launched! 30 patient organisations from Bulgaria, Hungary, and Romania and eight pan-European disease-specific patient organisations will start take part in the pilot part of the programme in the second part of 2012.

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EPF ADVOCATES A PATIENT PERSPECTIVE ON DATA PROTECTION



The European Commission recently published a proposal to revise the so-called "Transparency Directive" ([Council Directive 89/105/EEC](#)). It sets rules for the administrative procedures relating to pricing and reimbursement decisions at national level. While EU legislation provides a harmonised framework for the authorisation of medicinal products, Member States remain responsible for setting national pricing policies and conditions for reimbursement, in the context of national health insurance systems.

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EPF TAKES A STAND ON THE PROFESSIONAL QUALIFICATIONS DIRECTIVE



Professional Qualifications have a direct impact on patient safety and are of great concern for the patient community. Ensuring that healthcare professionals have the right training, and are fit to practice when they move from one EU Member State to another is of crucial importance for safety and quality of care. This is the reason why EPF released in June [its position statement](#) on the European Commission's proposal to review the [Directive 2005/36/EC](#).

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HEALTH AND THE LIFE CONTINUUM FROM A GENDER PERSPECTIVE



Protection of personal data matters to patients. Patients' health and genetic data are sensitive information which requires a high level of protection to ensure they are not unnecessarily disclosed. At the same time, the smooth sharing of these data is absolutely crucial for the good functioning of healthcare services, patient safety, and to advancing research. For this reason, EPF is preparing a position paper with its membership to advocate a patients' perspective on the proposal for a [regulation](#) on personal data protection.

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FIRST CONFERENCE ON THE PATIENTS' PERSPECTIVE ON NUTRITION



Patients have particular – and diverse - needs as regard nutrition, which are currently unmet across the EU. The conference 'EU Patient groups & the relevance of nutrition' held on 4 July in Brussels successfully brought together patients groups from various disease areas, and various stakeholders working on health and nutrition. They identified common priorities and recommendations, and discussed the way forward to continue working together.

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EPF TO SET THE SCENE FOR DISCUSSION ON PATIENT INVOLVEMENT IN HTA

DISCOVER EPF PROJECTS & INITIATIVES



FIND MORE ABOUT EPF POLICY WORK



WHO ARE EPF MEMBERS ?





EPF was proud to partner with the European Men's Health Forum (EMHF), the European Cancer Patient Coalition (ECPC), and Men's Health Society (MHS), to organise a landmark conference on Gender and Health Through Life on 14-15 June in Copenhagen, Denmark. The conference was supported by the Danish Ministry of Gender Equality and was attended by over 270 participants from over 30 countries. The European Institute for Women's Health, the European Public Health Alliance and Mental Health Europe all participated actively. Please [click here](#) for a copy of the programme.

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EHEALTH: FROM AMBITIONS TO ACTIONS



The [Arctic Light e-Health Conference \(ALEC\) 2012](#) took place in Luleå, Sweden on 19-20 June. Leading politicians, business leaders, operators and public sector officials from all over Europe convened to discuss the healthcare of the future. This year the theme was "From Policy to Action". Participants looked at how we handle the increasing numbers of patients with chronic illnesses, and on the issues raised by the introduction of e-health services.

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EPF TO VOICE PATIENTS AT EFPIA THINK TANK EVENT



EPF Programme Manager Liuska Sanna presented the preliminary results of the [EPF Health Technology Assessment \(HTA\) Survey](#) in the [2012 HTA International Conference](#) on 21 June in Bilbao, Spain. Results of our HTA Survey set the scene for the discussion on existing patient involvement in HTA and whether training and education needs were being taken into account.

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EUROPEAN PATIENTS' ACADEMY - JOIN THE EUPATI NETWORK!



After a successful kick-off of the European Patients' Academy on Therapeutic Innovation (EUPATI) in February 2012, the EPF-led project consortium is busy taking the first steps. This 5-year project will develop educational material, training courses and a public information to educate patients and the lay public about medicines development processes.

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Nicola Bedlington and Kaisa Immonen-Charalambous participated in the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patients' Think Tank on 5th July 2012. This event is the occasion for Patients' organisations and the pharmaceutical to have a dialogue on EU policy issues in the area of health and innovative medical research.

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

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