

European Patients' Forum eNewsletter

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



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A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

Welcome to 2nd issue of the EPF newsletter – and thank you very much to all of you who sent positive and constructive comments on our new-look communications!

In this pre- summer issue we are happy to share with you some updates on current projects and policy priorities. We are delighted to report that our Youth Project 'EMPATHY' has been awarded EU funding. Our policy advisory group held a very exciting meeting in early June. We have also had the opportunity to participate in several conferences and events to present the patients standpoint on issues such as the future of the Innovative Medicines Initiative, Health Research and the direction of HORIZON 2020- the next framework programme on Research and Innovation. We hope you find this issue informative and useful – do not hesitate to contact the EPF team if you need more info.

Warmest Greetings and our best wishes for a lovely summer

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

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

SUCCESSFUL PROJECT APPLICATION: EMPATHY



"EMPATHY: Europe meets Young Patients": this is the name of the new project that EPF will be running as from August. The application submitted in February 2012 under the Youth in Action Programme 2012 Call has been successful.

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EPF ADVOCATES A PATIENT PERSPECTIVE ON THE "HEALTH FOR GROWTH" PROPOSAL

KICK-OFF OF THE JOINT ACTION ON PATIENT SAFETY AND QUALITY OF CARE



The "Patient Safety and Quality of Care" or "PaSQ" Joint Action (JA) has officially started with the kick-off conference in Denmark, 24-25 May. This three-year Joint Action is led by the French Haute Autorité de Santé (HAS) and EPF will be actively involved in several key work packages.

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EPF RESPONSE TO CHRONIC DISEASES CONSULTATION STRESSES PATIENTS' CENTRAL ROLE

UPCOMING EVENTS

19 & 20/06/2012 | [Artic Light eHealth Conference](#)

Lulea, Sweden

Leading politicians, business leaders, operators and public sector officials from all over Europe will convene to discuss the healthcare of the future

EPF Attendance:
Walter Atzori - Speaker

21/06/2012 | [SANOFI Patient meeting on clinical trials](#)

Paris, France

The meeting will focus on the Clinical Trials Directive

EPF Attendance:
Kaisa Immonen-Charalambous - Speaker

21/06/2012 | [Revision of the EU Transparency Directive](#)

Brussels, Belgium

Breakfast meeting
Market Access for Innovatives Medicines

EPF attendance:
Nicola Bedlington

27/06/2012 | [Pharmaceuticals pricing](#)

Brussels, Belgium



The [European Commission's proposal](#) for a health programme 2014-2020, titled "Health for Growth", was published on 9 November 2011. EPF was vocal in giving feedback in the run-up to the publication of this proposal, both independently and jointly with the European Public Health Association (EPHA). The proposal is currently awaiting its first reading in the Parliament, with Françoise Grossetête MEP (EPP, France) as the rapporteur.

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INTERQUALITY: SMARTER FINANCING, IMPROVED QUALITY FOR PATIENTS



How to spend money efficiently in healthcare? The InterQuality project partners held a meeting on 24-25 May in Italy to pave the way of the answer. Started in December 2010 and led by the Medical University of Warsaw, the project intends to develop scientifically validated tools to help decision-makers choose the right financing mechanisms in different areas of healthcare systems. The meeting was the occasion to evaluate the results until now and to focus on theoretical deliverables.

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THREE WORKING GROUPS TO EMPOWER EPF POLICY ADVISORY



The Commission launched a reflection process on chronic diseases in early November 2011. It followed a request by the Council in its Conclusions on "Innovative approaches for chronic diseases in public health and healthcare systems", adopted on 7 December 2010. The reflection process aims to produce an EU strategy on chronic diseases, focusing on the sustainability of health systems. The process is likely to conclude during the first part of 2013.

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RENEWING HEALTH: EPF TO EXPLORE THE PERSPECTIVE OF TELEMEDECINE END USERS



As co-manager of the [Renewing Health User Advisory Board](#) EPF was co-organiser of the second meeting with users of the telemedicine services piloted in the context of the RENEWING HeALTH project. The purpose of [RENEWING HeALTH](#) is to implement multi-site randomised controlled trials for evaluating telemedicine services for patients suffering from three of the most common chronic conditions: diabetes, cardiovascular diseases and Chronic Obstructive Pulmonary Disease (COPD). The ultimate goal is to demonstrate that telemedicine-based services can improve quality of life, enable patient empowerment while optimising the use of resources in healthcare provision.

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EUPATI: AN IMI RECENTLY-LAUNCHED PATIENT ACADEMY

Lunch debate at European Parliament on pharmaceuticals pricing

EPF attendance:
Kaisa Immonen-Charalambous

[28/06/2012 | TOPRA meeting on pharmacovigilance](#)

Brussels, Belgium

TOPRA is the global organisation for Regulatory Affairs professionals and for those who have an interest in Regulatory Affairs in the healthcare sector. This meeting will focus on the EU Pharmacovigilance legislation

EPF attendance:
Kaisa Immonen-Charalambous - Speaker

[28 & 29/06/2012 | High-level Science for Policy Consultation Event](#)

Brussels, Belgium

EPF President will lead the discussion about "What needs to improve from the perspective of third-parties and interest groups?"

EPF attendance:
Anders Olauson - discussion lead role

[03/07/2012 | Platform on ethics & transparency](#)

Brussels, Belgium

Drafting Group meeting about the Platform on Ethics & transparency

EPF attendance:
Kaisa Immonen-Charalambous

[05/07/2012 | EFPIA 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 attendance:
Kaisa Immonen-Charalambous, Nicola Bedlington

[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 !



GROUP



The [Policy Advisory Group \(PAG\)](#) met on 4 June 2012 in EPF offices. Set up in 2009, the Group has become an invaluable advisory body for the EPF Board and Secretariat. Among other topics of interest, the Group in its pre-summer meeting confirmed the launch of three pilot working groups on specific themes, to which all interested EPF members can contribute.

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A EUROPEAN COUNCIL FOR HEALTH RESEARCH INCLUDING A PATIENT PERSPECTIVE?



EPF Executive Director, Nicola Bedlington, gave a presentation on the importance of patient involvement at the Conference "Future of Health Research and Health Innovation – the need for strategic action" on 23 May. The meeting set out to examine the need for a pan European strategic platform for health research in the framework for the next EU research programme HORIZON 2020.

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PLATFORM ON TRANSPARENCY AND ETHICS: THE GUIDING PRINCIPLES ARE ON-GOING



EPF Executive Director, Nicola Bedlington, introduced the project EUPATI - European Patients' Academy on Therapeutic Innovation - at the IMI Stakeholder Forum on 30 May. It was an example of a recently-launched project funded by the [Innovative Medicines Initiative \(IMI\)](#).

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NOW IT IS THE TIME FOR ACTIVE CITIZENSHIP!



Active Citizenship Network celebrated the 6th European Patients' Rights Day in Brussels, with a conference entitled "Active Ageing citizens at the centre of EU health policy", on 15-16 May 2012. The conference was fully focused on the European topic of the year "Active Ageing and Solidarity between Generations". EPF board member Philip Chircop and Nicola Bedlington represented EPF at this event.

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DISCOVER EPF PROJECTS & INITIATIVES



FIND MORE ABOUT EPF POLICY WORK



WHO ARE EPF MEMBERS ?





EPF Executive Director, Nicola Bedlington, attended the Platform on Transparency and Ethics on 4 June 2012. The aim of the meeting was to agree a terms of reference for the EU Platform on Transparency and Ethics. The participants also reviewed a draft document on Guiding principles on Transparency and Ethics in the Pharmaceutical Sector.

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