

# European Patients' Forum eNewsletter

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



// JANUARY ISSUE

## A WORD FROM EPF PRESIDENT AND EPF DIRECTOR

2013 marks the 10th anniversary of the European Patients' Forum. The EPF Board and Secretariat are preparing the celebratory event under the auspices of the Irish EU Presidency this May in Dublin alongside our Annual General Meeting and the registration process will start soon!

In this January issue we report on two major e-Health events: the EPF seminar for our membership and the closing conference of the Chain of Trust project. We also share with you our thoughts on the adoption of the IMCO report on the Professional Qualifications Directive, and work in progress on our advocacy work on the needs and rights of older patients, medical devices and clinical trials legislation. Read about the latest developments on the European Union Network for Patient Safety and Quality of Care, the launch of an empowerment survey as part of the SUSTAINS project and the establishment of a steering group for the Patients-MedTech Dialogue.

Finally, this issue describes a brand new project on hospital-based Health Technology Assessment, of which EPF is part.

We hope you enjoy this issue.

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



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

SAVE THE DATE FOR OUR 10TH ANNIVERSARY CONFERENCE AND ANNUAL GENERAL MEETING!



EPF will celebrate our 10th Anniversary in 2013. We will mark this important milestone with a Conference under the auspices of the Irish EU Presidency on 23 May, preceded by our Annual General Meeting on 22 May 2013.

CHAIN OF TRUST PROJECT: CLOSING MEETING AND NEW HORIZONS



The 2-year project Chain of TRUST ended in Brussels on the 24th of January with a conference that convened a multi-stakeholder audience. The project results compiled in a [final report](#) provoked interesting debates amongst participants.

## UPCOMING EVENTS

**29-30/01/2013** | [Virtual Future: what are the ethical dimensions of using emerging technologies in clinical trials and research?](#)

### Brussels, Belgium

Annual conference of the European Forum for Good Clinical Practice. Ethics of emerging technologies in clinical care, trials and research

*EPF attendance:*  
Kaisa Immonen - Charalambous

**30-31/01/2012** | [Workshop on 'the Future of Public Health Research'](#)

### Brussels, Belgium

Workshop to explore public health priorities in Horizon 2020

*EPF attendance:*  
Nicola Bedlington, Liuska Sanna, Marta Dimitrova

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### E-HEALTH AT A GLANCE WITH THE EPF SEMINAR



70 patient leaders from all across Europe attended the seminar EPF organised on e-Health on 23 January in Brussels. This event was an excellent opportunity to explore advances and the 'state of the art' on patient involvement in this area at both policy and operational level. It clearly emerged from the discussions that patients do want to be more involved in e-Health policies as well as in the design, implementation, and assessment of this innovative type of services.

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### EPF PREPARES RECOMMENDATIONS ON THE RIGHTS AND NEEDS OF OLDER PATIENTS



EPF is preparing a position paper on the rights and needs of older patients, due to be released in February after a full consultation with our membership. The statement will build on our [work since 2010 on this theme](#), including our input in the [Innovation Partnership on Active and Healthy Ageing](#) and our [flagship conference](#) in Warsaw in July 2011.

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### EPF INTERNAL WORKSHOP ON CLINICAL TRIALS REGULATION

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### EPF WELCOMES THE ADOPTION OF THE REPORT ON PROFESSIONAL QUALIFICATIONS DIRECTIVE



EPF welcomes the report adopted in the Internal Market and Consumer Protection Committee (IMCO) on 23 January about professional qualifications as a step forward for patient's safety and quality of care in Europe. The report, drafted by MEP Bernadette Vergnaud (Socialist & Democrats, France), takes on board important points for which EPF advocated.

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### EPF PREPARES A POSITION STATEMENT ON MEDICAL DEVICES



EPF is currently consulting its membership to prepare a formal position statement on [Medical Devices](#). We will provide compelling patient evidence in this debate of vital importance for the patient community.

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### SUSTAINS PROJECT: PATIENT EMPOWERMENT SURVEY

[20/02/2013 | SUSTAINS PSC 3](#)

#### Brussels, Belgium

Project Steering Committee (PSC) meetings are internal consortium-only meetings where decisions on project implementation are made and as such do not need to be communicated externally.

*EPF speaker:*  
Walter Atzori  
*EPF attendance:*  
Özgün Ünver

[25/02/2013 | Conference on 'Health and Social care in digital age'](#)

#### Edinburgh, Scotland

The objective of the conference is to come up with a vision and establish some principles as we move to a new eHealth Patient Strategy and the Bill in Parliament on integrating Health and Social care.

*EPF speaker:*  
Nicola Bedlington

[26/02/2013 | Meeting on the Medical devices Directive](#)

#### Brussels, Belgium

Meeting in the European Parliament

*EPF speaker:*  
Nicola Bedlington

[27/02/2013 | EPF Board Meeting](#)

#### Brussels, Belgium

The EPF Board Members meet five times a year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work programme.

*EPF attendance:*  
Board Members

[28/02/2013 | Mobile World Congress](#)

#### Barcelona, Spain

The congress will focus on the impact mobile will have on the world and EPF will be particularly interested in eHealth discussions.

*EPF speaker & attendance:*  
Liuska Sanna

[20-21/03/2013 | Save the Date! Innovation and Patient access to Personalised Medicines](#)

#### Dublin, Ireland

Major conference organised by the European Alliance of Personalised Medicines. The meeting will bring together researchers, patients, physicians, regulators and politicians, to explore the current barriers and how they can be dismantled.



In the context of EPF's membership consultation process on the European Commission's legislative proposal on [Clinical Trials](#), an internal workshop was organised on 13 December at EPF offices, bringing together representatives of EPF's member organisations and Commission officials who have worked on the proposal. The second round consultation has now ended and EPF will prepare a final position by the end of February.

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EPF PLAYS A KEY ROLE IN PATIENT SAFETY AND QUALITY OF CARE



The second coordination meeting of the [Joint Action, "European Union Network on Patient Safety and Quality of Care" \(PasQ\)](#) took place on 14-15 January in Berlin. EPF is a stakeholder partner in this three-year Joint Action and plays an [active role](#) in all of the core work packages, as well as dissemination.

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NEW STEPS REGARDING THE PATIENT-MEDTECH DIALOGUE

Representatives from EPF and EUCOMED will join forces in a steering group to implement proposals and recommendations from the regular Patient-Medtech dialogue meetings

AVAILABLE SOON



EPF will soon launch a survey in the framework of the [Sustains Project](#). The objective is to measure changes in patient empowerment among those that will be using the services developed and deployed through the project to provide patients' access to Electronic Health Records (EHR).

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ADOPT HEALTH TECHNOLOGY ASSESSMENT AT HOSPITAL



EPF has recently joined the Advisory Board of a new European project on HTA: [AdHopHTA](#) - Adopting Hospital Based Health Technology Assessment (HTA). It aims at strengthening the use and impact of high quality HTA-results in hospital settings. Different tools will be developed to support this objective.

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LOOK AT EPF NEWS ! 

DISCOVER EPF PROJECTS & INITIATIVES 

FIND MORE ABOUT EPF POLICY WORK 

WHO ARE EPF MEMBERS ? 

that have taken place over the last 2 years. This decision emerges following the latest highly successful meeting on 21 November 2012.

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## 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 2 280 23 34  
Email : [info@eu-patient.eu](mailto:info@eu-patient.eu)  
[www.eu-patient.eu](http://www.eu-patient.eu)



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