

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// JANUARY 2014 ISSUE

A WORD FROM OUR PRESIDENT AND OUR DIRECTOR

2014 marks the launch of our strategic planning period with important new and refined goals for our organisation. This [plan](#) provides a clear blueprint of the direction we want to take over the next seven years resulting from the contribution of all our members.

Patients and the patient community are called upon to play a new and different role than in the past and intervene directly in both policy and programmes. We are key actors and contributors to build future health systems that are patient-centred, of high quality and sustainable.

Our first newsletter of 2014 kicks off with exclusive policy updates on older patients, clinical trials and medical devices. As the 2014 European elections draw closer we are also stepping up a gear with our campaign "Patients + Participation = Our Vote For a Healthier Europe".

In this January issue we also share with you future development of EU policies for patient-centred healthcare, particularly in the context of the EU 'Reflection process on chronic disease'. We will represent patients in the new tender consortium on patient empowerment, EMPATHIE, and within the Joint Action on Chronic Disease, CHRODIS-JA.

We hope you enjoy this issue and wish you all the best for a healthy and fulfilling 2014 – we are very much looking forward to working with you.

Warmest greetings,

Anders Olason, EPF President and Nicola Bedlington, EPF Director



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EPF POSITION ON THE RIGHTS AND NEEDS OF OLDER PATIENTS

CLINICAL TRIALS: THE LACK OF PATIENT INVOLVEMENT A BACKWARD STEP

UPCOMING EVENTS

29-31/01/2014 | [PASQ Coordination Meeting](#)

Budapest, Hungary

The "Patient Safety and Quality of Care" or "PaSQ" Joint Action (JA) aims to create a permanent platform for future cooperation between Member States in the area of patient safety and quality of care.

EPF Attendance:

Cristina Padeanu

29-31/01/2014 | [CHRODIS-JA Kick-off](#)



As the general population is ageing, EPF is strongly committed to raising awareness of older patients' needs and rights at EU level. Our position paper complements our work within the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) and explores further efforts needed to uphold older patients' common rights in the EU.

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OUR RECOMMENDATIONS ON MEDICAL DEVICES FOR THE COUNCIL



On 17 December we sent a letter to permanent representations of EU Member States with recommendations on the proposal for a regulation on Medical Devices. These recommendations reiterate our position and support key changes adopted by the European Parliament in October 2013.

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LAUNCH OF THE JOINT ACTION ON CHRONIC DISEASES



The Trilogue negotiations on the clinical trials regulation concluded on 20 December 2013, when Member States adopted a common position. EPF has published a statement on the compromise text, and we will circulate a detailed analysis of the Regulation to our members in the next weeks with the aim of developing a comprehensive position paper.

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STEPPING UP A GEAR ON EPF CAMPAIGN



We are now stepping up a gear with our campaign entitled "Patients + Participation = Our Vote For a Healthier Europe" as the 2014 European elections draw closer. We just released a video featuring various stakeholders who support our campaign.

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EMPOWERING PATIENTS IN THE MANAGEMENT OF CHRONIC DISEASES



Meeting

Madrid, Spain

Launch event of the Joint Action on Chronic Disease which will focus on good practices between European countries and regions in health promotion and prevention of chronic conditions, multi-morbidity and diabetes.

EPF Attendance:

Liuska Sanna

[4-5/01/2014 | ALEC 2014 - Artic Light E-health Conference](#)

Kiruna, Sweden

The Conference will focus on the patient as a knowledgeable and active co-partner in care. Leading politicians, business leaders, operators and public sector officials from all over Europe will convene to discuss the healthcare of the future.

EPF Speaker:

Anders Olsson

[6/02/2014 | Mid-term Conference of the ENGAGED project](#)

Kiruna, Sweden

The Engaged Community for Active and Healthy Ageing will be holding its mid-term event on Thursday 6 February between 8:00 and 11:30am. This interactive session will focus on developing stakeholder-led sustainable mechanisms for sharing innovative solutions for active and healthy ageing, and responding to serious social, societal and organisational challenges.

EPF Speaker: Camille Bulot

[6/02/2014 | EPF Online Webinars](#)

Brussels, Belgium

EPF will lead three successive one-hour webinars with our members to explain our campaign for the 2014 EU Elections and make sure they cascade the messages with their own networks.

EPF Speakers:

*Nicola Bedlington,
Kaisa Immonen-Charalambous
& Cynthia Bonsignore*

[11/02/2014 | EU Committee Briefing Lunch briefing](#)

Brussels, Belgium

EPF Director Nicola Bedlington will introduce the EPF Campaign for the 2014 EU Elections at an EU Committee Briefing organised by the British Chamber of Commerce.

EPF Speaker: Nicola Bedlington

The official launch of the new Joint Action on Chronic Diseases, CHRODIS-JA, will take place on 29-31 January in Madrid, Spain. EPF Programme Manager, Liuska Sanna, will represent EPF as we are an associate partner of this project.

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UP AND RUNNING EPF CAPACITY BUILDING PROGRAMME



The EPF Capacity Building Programme will continue to support our members in 2014. Slovakian and Bulgarian patient organisations initiated the first phase while Romanian and Hungarian groups continued, building on their strategic plans. EPF European-level members will benefit from a training module on fundraising that will be implemented in summer 2014.

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AN INTERNATIONAL SURVEY ON PATIENT INVOLVEMENT IN HTA



If you seek to develop and promote Health Technology Assessment (HTA), we invite you to take part in a survey initiated by the Health Technology Assessment International (HTAi). This study focuses on patient involvement in this area as patients have a unique knowledge and expertise to provide valuable insights to the decision-making processes.

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EPF participates in the EMPATHiE tender "EMpowering PATients in the management of chronic diseases". The tender will try to achieve a common understanding of the concept of patient empowerment and identify good practices, success factors and barriers.

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A PATIENT COURSE TO UNDERSTAND CLINICAL RESEARCH IN CANCER



The European Organisation for Research and Treatment of Cancer (EORTC) is organising a patient course entitled "Understanding Clinical Research in Cancer". This initiative is in the framework of the EUPATI project, the European Patients' Academy on Therapeutic Innovation.

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[13/02/2014 | EC working group Patient Safety and Quality of Care](#)

Brussels, Belgium

Meeting of the sub-group on Education and Training.

EPF Attendance:

Cristina Padeanu

[14/02/2014 | EC working group Patient Safety and Quality of Care](#)

Brussels, Belgium

First meeting of the Commission Patient Safety and Quality of Care Working Group that brings together representatives from all 27 EU countries, EFTA countries, international organisations and EU bodies. The Group assists in developing the EU patient safety and quality agenda.

EPF Attendance:

Kaisa Immonen-Charalambous

[14/02/2014 | EPF Capacity Building Programme - second phase in Hungary](#)

Budapest, Hungary

Romania and Hungary completed the first phase in late 2013 and have now entered the second phase. Hungarian groups will start on 14 February and will receive training to enable them to plan operationally and develop the first annual plan implementing the Strategic Plan developed in the previous phase of the Programme.

EPF Attendance:

Liuska Sanna

[19-20/02/2014 | 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:

EPF Board

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