

# European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



// JULY 2016 ISSUE



## A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the July issue of the EPF newsletter.

To further celebrate the official end of our **Patient Empowerment** campaign, EPF was invited by the European Health Parliament to hold an exhibition stand in the framework of its final plenary session, on the 29th of June, at the European Parliament. It gave us the perfect opportunity to organise a final informative and promotional event on the Campaign! Many high-level officials and policy-makers paid us a visit, underlining their on-going commitment to patient empowerment. Once again, we would like to convey our gratitude to our supporters for what has been an extremely successful campaign!

**Access to healthcare** is without a doubt on everyone's lips in Brussels, with events proliferating around the capital, and indeed in other capitals in Europe. EPF was invited to represent the patients' perspective in no less than three key meetings in the past two weeks, consolidating our position as a central player in this very important debate. You will read below reports of these intervention, building on our recent paper on Value and Pricing on Innovative Medicines.

A quick update and policy analysis of the recently adopted Regulation on **In Vitro Diagnosis Devices**. We give you our 'read' of this new piece of legislation, carrying important changes for patient safety and quality of care and diagnosis.

Two very interesting surveys are coming to an end this summer: an EPF questionnaire on the perception of patients on **quality of care**; and a multi-stakeholder survey on **cross-border healthcare**! Find our more below on why these matter, and how you can be involved

The **European Medicines Agency (EMA) Patient and Consumers Working Party (PCWP)** is 10 years old! To celebrate this anniversary, the EMA organised a special session at the latest reunion of the PCWP late June. EPF was there to report on this important platform for patient involvement.

As per usual, we give some short updates on three **projects** EPF is involved in: SmartCare, PiSCE and ProStep!

Finally, we open this month our blog to **'Each of Us'**, the campaign from our members Mental Health Europe, raising awareness of mental health related diseases. Join us and see how you can support this initiative!

Warmest greetings and best wishes for peaceful and well-deserved holidays!, the EPF Newsletter will be in your in-box in September,

Warmest greetings,

Marco Greco, EPF President and Nicola Bedlington, EPF Secretary General

Two handwritten signatures in blue ink. The first signature is 'M Greco' and the second is 'N Bedlington'.



PATIENT EMPOWERMENT  
CAMPAIGN: CLOSING EXHIBITION  
FRAMED HIGH-LEVEL

PATIENTS' OPINION: A  
PREREQUISITE TO ANY DEBATE ON  
ACCESS

[WATCH OUR VIDEOS HERE](#)

## COMMITMENTS



In conjunction with the plenary session of the European Health Parliament, EPF held an exhibition stand showcasing the outcomes of the Patient Empowerment Campaign. It was a beautiful opportunity to get commitments from high-level policy-makers and EU officials, and to mark the official end to the campaign!

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## REGULATION ON IN VITRO DIAGNOSTIC MEDICAL DEVICES- EPF'S VERDICT



On May 25, the new Regulation on in vitro diagnostic medical devices was adopted. EPF welcomes the updated legislation, in particular in relation to its stronger provisions for patient safety and information to patients. We can, however, only regret the very limited provisions on patient involvement.

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## EMA CELEBRATES 10 YEARS OF PATIENT INVOLVEMENT



EPF was recently invited to provide its position on access to healthcare in three important meetings in Brussels. Highlighting the patients' perspective, EPF positions itself as a pivotal player in this crucial debate at the EU level.

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## YOUR OPINION MATTERS! TAKE ON OUR NEW SURVEYS



Just a few weeks left to give your thoughts and feedback on two important surveys conducted by EPF and partners: let your voice be heard!

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## SMARTCARE FINAL MEETING – TOWARDS BETTER INTEGRATED CARE



## UPCOMING EVENTS

**2/9/2016** | [Project/Programme Meeting](#)

**Budapest, Hungary**  
Capacity Building training event

*EPF speaker:*  
*Walter Atzori*

**19-21/9/2016** | [EPF Event](#)

**Brussels, Belgium**  
**EPF Training Module on Transparency & Ethics**

This training module aims at reviewing transparency and ethics guidelines for patient organisations, through the exchange and building of good practices. It will also be the opportunity to initiate a collective reflection within EPF on the ways for patient organisations to increase their credibility and strengthen their position on the public health scene.

*EPF speaker:*  
*Camille Bullo*

**19-23/9/2016** | [Project/Programme Meeting](#)

**Barcelona, Spain**  
**EUPATI Face-to-Face Training Event**

During this second face-to-face training event, the second cohort of trainees of the European Patients' Academy on Therapeutic Innovation (EUPATI) will participate in 5 days of interactive lectures, group sessions and networking with other patient advocates.

*EPF attendance:*  
*Walter Atzori*

**28-30/9/2016** | [International Health Event](#)

**Gastein Valley, Austria**  
**EHFG 2016**

The European Health Forum Gastein is the most important health-related event in the European Union and a meeting point for experts from different fields within the health system

*EPF attendance:*  
*Nicola Bedlington*

The year 2016 marks the 10th anniversary of the Patient and Consumer Working Party (PCWP) at the European Medicines Agency (EMA). The PCWP was formalised in 2006, built on a working group of patients' organisations created in 2003. EPF has been represented on the PCWP since 2008.

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EPF Junior Project Officer Danielle Flores attended the SmartCare Final Conference in Trieste, Italy on July 6. This conference was the final meeting of the three year EU project. Time is now to reap the results for a better integrated care!

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## MEMBER IN THE SPOTLIGHT

(BLOG) 'EACH OF US CAMPAIGN' – DEBUNKING MYTHS ABOUT MENTAL HEALTH



1 in 4 adults will experience mental health problems. EPF member Mental Health Europe set up a campaign to end stigma and raise awareness of mental health.

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

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