# European Patients' Forum Newsletter A strong patients' voice to drive better health in Europe



#### // JUNE 2015 ISSUE

#### A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Last month EPF embarked on a <u>one-year campaign on patient empowerment</u> and we are delighted to see the support that this is receiving from many health stakeholders who participated in our launch conference and who want to involve and engage their networks on patient empowerment.

A very clear signal emerged from this event and our previous work on this on the need and indeed the appetite for a European strategy on patient empowerment. We all know that this is not uppermost on the political agenda and our work over the next year will hopefully stimulate fresh commitment as well as fresh ideas on how to move forward.

The launch conference marked a powerful start to the campaign. We can make patient empowerment a reality only if we work together. Readers can also take immediate action to support patient empowerment by filling the <u>online pledge</u> and sharing this link through your networks; keeping the discussions alive on <u>Twitter</u> using #PatientsprescribE hashtag; including the campaign messages through your events and representation work. More information on how to engage in the campaign is available <u>here</u> and please contact EPF Secretariat at <u>communications@eu-patient.eu</u> if you have questions.

Patient empowerment features strongly in other key articles in this issue of the newsletter. Read about the upcoming EU conference we are organising on cross-border healthcare; our reaction regarding the Council vote on medical devices last Friday; and a reflection on discrimination faced by patients at school or at work. We are also very proud to feature our second patient safety focus of the year dedicated to healthcare-associated infections with MEP Pedicini as invited guest on our blog and some highlights from our members

Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Secretary General





MEDICAL DEVICES: VOTE IN THE COUNCIL



#### **UPCOMING EVENTS**

29 - 30/06/2015 | Universal health: Investing in Health and Wellbeing for All

#### Riga, Latvia

EPF together with the European Generic medicines Association (EGA), the European Public Health Alliance (EPHA) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) is organising this conference to identify strategies to harness citizen participation to create efficient, equitable European health systems.

After series of national and regional events organised in 2013-2015 EPF is organising a European conference on cross-border healthcare on 2 July in Brussels, Belgium. Patient leaders from across the EU and National Contact Points (NCPs) will meet to discuss on the implementation of the Directive, focusing specifically on the role of NCPs.

EPF welcomes the fact that the Council has reached partial agreement on the medical devices regulation on 19 June. However some key shortcomings need to be addressed in the trilogue to ensure the final Regulation provides for safer medical devices in the EU.

EPF speaker: Anders Olauson

### **30/06/2015** | <u>European Gender Medicine final conference</u>

#### Brussels, Belgium

This conference will introduce the "Roadmap for a gender-sensitive approach to biomedicine and healthcare research in Europe" and will discuss the inclusion of sex and gender at all levels of the healthcare process.

EPF attendance: Laurène Souchet

# **30/06/2015** | Economics of prevention and improved Public Health

#### Brussels, Belgium

This workshop organised by the Slovenian Business and Research Association (SBRA) and the Knowledge Economy Network (KEN) aims to produce practical recommendations towards public health based on common sense and viable approaches.

*EPF attendance: Laurène Souchet* 

### 1/07/2015 | Adapting an EU Health Policy to an evolving Europe

#### Brussels, Belgium

During this meeting, Friends of Europe (FoE) will present their report "Adapting EU health policy to an evolving Europe: What the EU should 'Start', 'Stop' or 'Do Differently'.

EPF attendance: Cynthia Bonsignore

1/07/2015 | Edelman Trust Barometer: Health, Trust & Innovation

#### Brussels, Belgium

The aim of this meeting is to offer unique insights on trust in healthcare and its implications on regulation and innovation.

EPF attendance: Camille Bullot

**1/07/2015** | Health Literacy in Europe: Empowering patients

#### Brussels, Belgium

This workshop organised by the European Parliament Science and Technology Options Assessement (STOA) will examine how technology can contribute to improving health literacy.

EPF speaker:

#### READ MORE »





People with chronic and long-term conditions face a variety of obstacles, including stigma and discrimination, at school or at work. These issues can potentially affect a large share of the population in the EU given that 1 in 4 people of working age (15 to 64) lives with long-standing health problems that restrict their daily activities.

#### READ MORE »

EPF CONTRIBUTES TO A JOINT EVENT ON LAY SUMMARIES OF CLINICAL TRIALS



As the new Clinical Trials Regulation is now in its implementation phase, the European Forum for Good Clinical Practice (EFGCP) organised a one-day workshop on 29 May in Brussels to take stock of the current situation on lay summaries. This event was organised in partnership with EPF and some of our members' representatives for AIDS (EATG) and Medical research (EGAN).

READ MORE »

#### READ MORE »

### PATIENT SAFETY FOCUS





Patient Safety will be the focus in four issues of our newsletter

MEP PEDICINI: "PATIENTS PLAY A PIVOTAL ROLE IN THE PREVENTION OF HAI"



MEP Piernicola Pedicini (EFDD, Italy) was the rapporteur in the

this year. We want to raise awareness on the importance of this topic which, if not properly addressed, can affect the lives of millions of people. This month, we focus on healthcareassociated infections.

report on Safer healthcare in Europe. We asked him for his views healthcare-associated infections (HAIs) for our focus on patient safety of this month.

READ MORE »

READ MORE »

### "YOU HAVE TO SEE THE BRIGHT SIDE, ALWAYS!"



Cristian is a member of the EPF Youth Group and is living with HIV/AIDS. Through two movies, he provides an insight of the two mains issues he faces in his life: the treatment and discrimination. Despite his young age, this young Romanian is a strong patient representative, well committed to fight for patients' rights.

MORE PATIENT INVOLVEMENT NEEDED IN HEALTH TECHNOLOGY ASSESSMENT



'EUnetHTA' or European Network on Health Technology Assessment (HTA) was established to create an effective and sustainable network on this issue across Europe. On 28-29 May the consortium of the EUnetHTA Joint Action (JA) gathered in Copenhagen, Denmark, for their last plenary assembly.

READ MORE »

READ MORE »

### MEMBERS IN THE SPOTLIGHT

### FIVE QUESTIONS TO THE FLEMISH PATIENTS PLATFORM



Our membership is our compass. We are delighted to feature one of our 65 member

#### THE FIGHT AGAINST BREAST CANCER IN THE EU



Representatives of EUROPA DONNA, the European Breast Cancer Coalition, held an information event on 18-21 May to give Members of the Kaisa Immonen-Charalambous

#### 1/07/2015 | Digital Health Revolution?

#### Brussels, Belgium

During this event, POLITICO will gather together healthcare professionals from the public and private sectors to examine the opportunities and challenges facing the widespread deployment of digital health care in Europe.

EPF speaker: Nicola Bedlington

### **1/07/2015** | Workshop on access to medicine

#### Brussels, Belgium

This workshop organised by the Socialists and Democrats (S&D) will gather experts and stakeholders to discuss the substantial disparities between countries as regards access to medicines in the EU.

*EPF attendance:* Laurène Souchet

#### **2/07/2015** | EPF EU conference on crossborder healthcare

#### Brussels, Belgium

EPF will bring together National Contact Points (NCPs) patients' organisations and stakeholders to discuss the implementation of the Cross-Border Healthcare Directive.

EPF speaker: Nicola Bedlington

## **6/07/2015** | <u>mHealth - Meeting on health</u> and wellbeing apps

#### Brussels, Belgium

Organised by the European Commission, this meeting aims to develop a common guidance for assessing the quality of health and wellbeing apps, and present a first draft of the Code of Conduct on privacy and security of the apps.

EPF attendance: Walter Atzori

**8/07/2015** | Making access to personalised medicine a reality for patients

#### Luxembourg

This conference organised by the Ministry of health of Luxembourg will concentrate on how to address obstacles to the integration of personalised medicine into Europe's healthcare systems; identify best practices; outline the potential benefits on public health and impact on policymaking in the FU.

organisations every month on our blog. This time, we interviewed Ilse Weeghmans of the Flemish Patients Platform (VPP), our brand new member just approved at our last Annual General Meeting, who provides an overview of his organisation in five short answers.

European Parliament 10 good reasons to sign the Written Declaration on the Fight Against Breast Cancer in the EU before 27 July 2015. EPF fully supports this Declaration and encourages all MEPs and allies to sign

READ MORE »

READ MORE »

EPF speaker: Kaisa Immonen Charalambous

#### 7 - 10/07/2015 | The Aspen Forum at Expo

#### Milan, Italy

Aspen, a non-profit organisation working on promoting enlishtened leadership, is organising this gathering to feature the innovations in food security, nutrition, global health and sustainability in the challenge of Expo: Feeding the Planet.

EPF speaker: Nicola Bedlington

#### **26/7 - 1/8 /2015 |** <u>Integrated Care:</u> moving beyond the rhetoric

#### Venice, Italy

The Observatory Venice Summer School 2015 is a one-week intensive course aimed at senior and mid level policy-makers, civil servants and professionals involved in the funding, design nd implementation of innovative integrated delivery models.

EPF speaker: Kaisa Immonen Charalambous

#### 19 - 21/11/2015 | 3rd World Congress on Integrated Care, Mexico City

#### **Mexico City, Mexico**

The International Foundation of Integrated Care (IFIC) calls for abstract submissions for the congress "Co-producing High Quality People-Centered Integrated Care for ALL". Deadline for submissions: 10 July.

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









#### CONTACT US

#### **EUROPEAN PATIENTS' FORUM**

Rue du commerce 31 1000 Brussels **BELGIUM** 

Phone: +32 (0)2 280 23 34 Email: info@eu-patient.eu

www.eu-patient.eu | eu-patient.org/blog





This e-newsletter arises from the 2015 Health programme, which has received funding from the European Union, in the framework of the Health Programme.

Disclaimer: The content of this e-newsletter reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

If you no longer wish to receive emails from EPF, simply send an email to <a href="mailto:mailing@eu-patient.eu">mailing@eu-patient.eu</a> to unsubscribe.

Please note that some links may not work anymore because the articles have moved, do therefore not hesitate to look at the news section where all the articles are archived or contact our <u>Communication Officer</u> for more information.