

# European Patients' Forum Newsletter

## A strong patients' voice to drive better health in Europe



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// SUMMER ISSUE

### A WORD FROM EPF PRESIDENT AND DIRECTOR

Welcome to this summer issue of the EPF Newsletter. We are pleased to share some important **policy updates** including the European Medicines Agency's proposed new policy on release of clinical trials data; and the European Commission's latest report on **health and safety at work**; we also report on the Uppsala Health Summit in Sweden where the spotlight was on healthy ageing and sustainability.

This issue features a report on our Greek regional conference on the **Cross-border Healthcare** Directive held in April. As we go to press our third Regional Conference on Cross Border Healthcare is taking place in Ljubljana, Slovenia (7-9 July) and we will share the outcomes in the August's edition.

There have been some exciting project developments this month: the release of our video closing **InterQuality project** on financing mechanisms in healthcare and the meeting organised in Spain on patient safety practices around quality of care under the **Joint Action on Patient Safety and Quality of Care**.

Finally we are delighted to share some news from our members. The European Federation of Allergy and Airways Diseases Associations' (EFA) organised the very first stakeholder health event in the new European Parliament in June. Luisa Avedano, CEO of the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), shares some thoughts on the way chronic diseases are tackled at the EU level. And we introduce to you one of our new members approved at our last Annual General Meeting: the European Haemophilia Consortium.

We hope you enjoy this newsletter – do not hesitate to contact the EPF team if you need further insights on any of the topics.

We wish you a wonderful, relaxing summer time and look forward to our continued collaboration on your return.  
Warmest greetings,

Anders Olauson, EPF President and Nicola Bedlington, EPF Director



PATIENTS IN HEALTH IN THE  
NEXT MANDATE

NEW POLICY FOR RELEASE OF  
CLINICAL TRIAL DATA

**EPF IS HIRING A  
PROGRAMME OFFICER!**

#### UPCOMING EVENTS

7-9/07/2014 | [Cross-Border Healthcare Regional Conference III](#)



It has been more than a month since the elections and the political landscape of the next legislature takes shape, little by little. EPF is keeping a watchful eye to ensure patients and health is on the agenda of both the newly elected Members of the European Parliament and the future College of Commissioners.

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### HEALTH AND SAFETY AT WORK – NEW STRATEGIC FRAMEWORK



The European Commission's Directorate for Employment, Social Affairs & Inclusion published in June a report and a Communication on an EU Strategic Framework on Health and Safety at Work. This follows a consultation from 2013 where EPF flagged patients' specific needs in the workplace and the need to be further involved in policies on safety and health at work.

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### UPPSALA HEALTH SUMMIT ON HEALTHY AGEING



Our Senior Policy Adviser Kaisa Immonen-Charalambous attended the joint meeting of the Patient and Consumer Working Party and the Health Professionals' Working Party on 3 June 2014 in London, UK. A key item on the agenda was the Agency's proposed new policy for release of clinical trial data.

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### SECOND REGIONAL CONFERENCE ON CROSS-BORDER HEALTHCARE



This Conference was the second in a series of four EPF regional events for patient communities on the Cross-border Healthcare Directive. We have just released a report that captures the priorities and nuances expressed during this meeting. Our third one is currently underway in Ljubljana, Slovenia.

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### INTERQUALITY: PROJECTS' OUTCOMES NOW ON VIDEO!

#### Ljubljana, Slovenia

Patient organisations' representatives from representatives from Austria, Czech Republic, Hungary, Slovakia and Slovenia learn and share experiences about how the Directive works for patients and how they can contribute a strong patient's perspective. This is the third Regional Conference, one last event will be organised by the end of 2014 in another EU country.

[9-11/07/2014 | European Communication Summit 2014](#)

#### Brussels, Belgium

EPF will provide a patients' perspective in the "Health" working group entitled: "Storytelling is the New Black: What should communications in the healthcare sector really look for to meet patients' needs?"

*EPF speaker:*  
*Cynthia Bonsignore*

[21-23/07/2014 | EUPATI meetings](#)

#### Berlin, Germany

The Executive Committee meeting will meet on 21 July, to be followed by a combined meeting with Executive Committee members and Project Advisory Board and Regulatory Advisory Panel. Finally there will be a patient involvement in industry Research & Development meeting on the last day.

*EPF speaker:*  
*Nicola Bedlington*

[26/08/2014 | EPF Training on Fundraising](#)

#### Brussels, Belgium

The Training on Fundraising is delivered within the EPF Capacity Building Programme that was launched in 2012. The objective of the training is to strengthen the capacity of 10 EPF European Full Members in fundraising.

*EPF attendance:*  
*EPF Secretariat*

[14-15/09/2014 | EPF Youth Group Annual Meeting](#)

#### Brussels, Belgium

The EPF Youth Group meets once a year to implement the EPF Youth Strategy and was established to become the reference group though which needs and expectations of the young patient community are formulated and communicated to EPF and its members.

*EPF speaker:*  
*Valentina Strammiello*

[16/09/2014 | EPF Board Meeting](#)



Our Director Nicola Bedlington attended the Uppsala Health Summit on 3-4 June 2014 in Sweden. As member of the Advisory Board, she provided a patients' perspective on this year's theme "Healthcare for Healthy Ageing" where she highlighted the EPF position on the rights and needs of older patients.

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**LEARNING FROM THE EXPERIENCE OF INVOLVING PATIENTS**



The Spanish Ministry of Health, Social Services and Equality organised a European Conference on 12 June 2014 in Madrid, Spain. The aim was to exchange experiences of good organisational and patient safety practices around quality of care. The event was held under the framework of the European Union Network for Patient Safety and Quality of Care (PaSQ).

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**WELCOMING A NEW MEMBER: EUROPEAN HAEMOPHILIA CONSORTIUM**



To get better quality healthcare, we do not need to pay more; we need to pay smarter. This was the rationale behind the InterQuality project – it investigated the effects of financing systems on the quality of healthcare. The knowledge gained from the 4-year research is now compiled in a short video.

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**PATIENT INVOLVEMENT IN EU INNOVATIVE RESEARCH FOR CHRONIC DISEASES**



Patients' representatives from more than 25 European countries participated in the very first stakeholder event of the new European Parliament on 17 June in Brussels, Belgium. Our Membership Officer Camille Bullot attended this debate organised by our member, the European Federation of Allergy and Airways Diseases Associations (EFA).

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**GET YOUR BELLY OUT FOR CROHNS AND COLITIS!**

**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*

[20/09/2014 | Save the date! European Unity Walk 2014 \(EUW 2014\)](#)

**Luxembourg**

This annual event is organised by our member, the European Parkinson's Disease Association (EPDA). The first ever European Unity Walk was held in 2012 and attended by more than 1,000 of the EPDA's friends and supporters from 25 countries across the world – including hundreds of people with Parkinson's and their family members. The success of this event has since inspired eight (and counting) national unity walks by EPDA members across Europe.



Part of our Annual General Meeting in May was devoted to approving new members. We welcomed four new Full Members and one new Associate Member. This month we asked three core questions to Amanda Bok, CEO of the European Haemophilia Consortium (EHC), one of our new Full Members.

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#### PILOT CROSS-BORDER EHEALTH PROJECT SHOWS PROMISE FOR REAL-LIFE IMPACT



The European Patients Smart Open Services (epSOS) project, a pilot programme for cross-border eHealth services, has been operational since April 2012. As demonstrated by the following testimonials, the test run has already enjoyed great success.

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#### EUROSAFE IMAGING CAMPAIGN TOWARDS PATIENT SAFETY



Crohn's disease and ulcerative colitis are both major categories of Inflammatory Bowel Diseases (IBD). The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), member of EPF, represents national patients' organisations to tackle the disease at the EU level. While CEO Luisa Avedano believes prevention is not an appropriate way to tackle this particular condition, a young British model, Bethany Thownsend, made awareness the hobbyhorse of the Crohns disease.

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#### PHARMACISTS AND PATIENTS: COULD WE DO MORE?



The Pharmaceutical Group of the European Union (PGEU) invited our Director Nicola Bedlington to their General Assembly and Symposium on June 16 in Bratislava. This was the opportunity to reflect on the evolution of the relationship between patients and pharmacists and think about new ways of collaboration.

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The European Society of Radiology's (ESR) launched in March 2014 at their Congress in Vienna the EuroSafe Imaging campaign. This campaign aims to ensure the highest quality and safety in the use of imaging procedures in Europe. With patients always put at the centre.

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

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