

# European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// MARCH 2015 ISSUE

## A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

*On 19th March, we attended the EU Health Policy Forum as one of its members. Set up in 2001, this Forum brings together umbrella organisations in the health sector and patients' groups in order to ensure that the European Commission's health policy is responsive to public concerns.*

*As its current five-year mandate has now come to an end, the renewed Health Policy Forum will evolve from a consultative body into a multilateral communication mechanism with an internet platform, regular meetings, a biannual Summit and an annual Health Award for the best practice granted to NGOs in Member States.*



*We are really looking forward to taking part in this new way of sharing ideas and good practices with public health stakeholders. We will make sure we provide the perspective of European Patients on various topics of interest to the public health community in this new space.*

*We are delighted to share with you in this issue with you our two new position papers on adherence to medicines and on the lay summaries of the clinical trials regulation. We also present to you some positive developments for the patients' community through the tender PISCE on self-management, our series of mini-workshops on cross-border healthcare and some highlights from our Spanish and French members.*

*Enjoy the reading!*

*Warmest greetings,*

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

A handwritten signature in blue ink, appearing to be 'A. Olauson'.

A handwritten signature in blue ink, appearing to be 'N. Bedlington'.

## EPF PUBLISHES POSITION PAPER ON "ADHERENCE AND CONCORDANCE"



EPF released in March 2015 a position paper on adherence and concordance. With this document, we aim to clarify the terminology of adherence from the patients' perspective. We also position this topic firmly in the context of patient-centred healthcare, patient empowerment, shared decision-making, information and health literacy.

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## EPF PUBLISHES STATEMENT ON THE COMMUNICATION OF CLINICAL TRIAL RESULTS



Transparency about the results of clinical trials is one of the key achievements of the new EU clinical trials regulation that entered into force in June 2014. EPF just released a position statement on the standards for communication on the lay summary to complement our previous paper on the publication of the trial results and the EU database.

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## CROSSING BORDERS FOR HEALTHCARE IN SPAIN, POLAND AND BULGARIA



EPF continues to raise awareness on the Cross-Border Healthcare Directive and to monitor its implementation across Europe. This month we organised mini-workshops in Madrid, Warsaw and Sofia, in close cooperation with our members bringing together patient leaders, National Contact Points and the European Commission.

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## EPF CONTRIBUTES SIX AMENDMENTS TO "SAFER HEALTHCARE IN EUROPE" REPORT



Following the European Commission's evaluation report on the implementation of the Council Recommendation on patient safety, MEP Piernicola Pedicini (EFD, Italy) issued an own-initiative report "Safer healthcare in Europe: improving patient safety and fighting antimicrobial resistance."

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## UPCOMING EVENTS

**Today | [Patient MedTech Dialogue](#)**

### **Brussels, Belgium**

This bi-annual event provides a constructive platform of exchange between patients' organisations and the MedTech industry.

*EPF attendance:*  
*Nicola Bedlington*

**Today | [Policy Roundtable on Seasonal Influenza Vaccination](#)**

### **Brussels, Belgium**

This policy roundtable aims to bring together European policy-makers and stakeholders active in the public health area to take stock of the situation of seasonal influenza in Europe and explore possible ways forward to address the burden of the disease.

*EPF attendance:*  
*Cristina Padeanu*

**30/3/2015 | [EPF Access Working Group](#)**

### **Brussels, Belgium**

The EPF working group on access contributes to shaping our vision and activities in this area from the patients' perspective.

*EPF speaker:*  
*Laurène Souchet*

**29-2/3-4/2015 | [EUPATI Patient Expert Training Course](#)**

### **Barcelona, Spain**

This is the first of two face-to-face training events for the current cycles of the EUPATI Expert Training Course. Course trainees will participate in 5 days of interactive lectures, group sessions and networking with other patient advocates.

*EPF attendance:*  
*Walter Atzori*

**7/4/2015 | [World Health Day 2015](#)**

### **Worldwide**

To celebrate this day, the World Health Organisation (WHO) focuses on food safety improvement together with the UN Food and Agriculture Organization (FAO).

**9/4/2015 | [United4Health User Advisory Board Meeting \(PDF\)](#)**

**Brussels, Belgium**

# MEMBERS IN THE SPOTLIGHT

## OUR MEMBERS IN THE SPOTLIGHT: LE CISS



Our membership is our compass. We are delighted to feature one of our 64 member organisation every month on our blog. This time, we interviewed Marc Morel, Executive Director of our French member, the Inter-Association Collective on Health (CISS), who provides an overview of his organisation in five short answers.

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## HAPPY 10TH ANNIVERSARY TO THE SPANISH PATIENTS' FORUM!



On 17 March we were in Madrid to celebrate the 10th anniversary of our member, the Spanish Patients' Forum. We congratulate them on the road traveled so far, and wish them a lot of success for the years to come!

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## PISCE: EPF JOINS THE PLATFORM OF EXPERTS OF THE SELF-CARE TENDER



The PISCE Platform of Experts – a group set up to lead work on the promotion of self-care in the EU – met for the first time on 1-2 March 2015 in Utrecht, in The Netherlands. The European Commission confirmed patients' representatives from EPF's membership and secretariat as members of this Platform.

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## 20 YEARS OF PROGRESS IN MEDICINES REGULATORY SCIENCE



EPF President Anders Olauson attended the European Medicines Agency (EMA)'s 20th anniversary conference on 18 March. Entitled 'Science, Medicines, Health: Patients at the heart of future innovation', the event captured changes and progress in medicines regulatory science over the past 20 years.

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Meeting of the Advisory Board of the United4Health project, which seeks to share the understanding that in order for telehealth solutions to work it is essential that healthcare providers adopt innovative health and care service models.

*EPF attendance:*  
*Walter Atzori*

**13-15/4/2015 | [27th DIA EuroMeeting](#)**

### **Paris, France**

The 27th DIA EuroMeeting will focus on "Advancing Innovation to combat the Global Burden of disease: A call to action".

*EPF speaker:*  
*Nicola Bedlington*

**14-15/4/2015 | [WE CARE Conference](#)**

### **Gothenburg, Sweden**

This final conference of the WE CARE project will enable the completion of our research plan for sustainable, high quality and cost effective Healthcare. Outcomes of this final meeting include understanding and influencing future calls within Horizon2020 which is the EU's major research fund.

*EPF speaker:*  
*Valentina Strammiello*

**20-23/4/2015 | [EUPATI Annual General Meeting](#)**

### **Dublin, Ireland**

This is the Annual General Meeting of our project EUPATI, the European Academy for Therapeutic Innovation. It will be followed by a workshop on the current and future strategy for the implementation of EUPATI at the national level in each of the 12 participating countries and beyond.

*EPF attendance:*  
*Nicola Bedlington*

**21/4/2015 | [EPF mini-workshop on Cross-border Healthcare](#)**

### **Dublin, Ireland**

EPF continues to raise awareness on the Cross-Border Healthcare Directive and to monitor its implementation across Europe. This time Irish and British Patient Organisations will learn more about the implementation of the Directive in their countries.

*EPF speaker:*  
*Camille Bullo*

**21/4/2015 | [Patient- MedTech Task](#)**

## WHAT THE EU SHOULD START, STOP OR DO DIFFERENTLY?



Our Secretary General Nicola Bedlington attended on 3 March the Friends of Europe's roundtable discussion 'Adapting EU health policy to an evolving Europe'. We are a member of the Health Working Group that has generated 21 recommendations on what the EU should 'Start', 'Stop' or 'Do differently' during this new mandate to improve the health of Europe's citizens.

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## [Force Meeting](#)

### **Brussels, Belgium**

Representatives from patient organisations and the MedTech industry will discuss the implementation and dissemination of the patient-centred companies checklist that was developed last year.

*EPF attendance:*  
*Laurène Souchet*

**23/4/2015** | [EEPF mini-workshop on Cross-border Healthcare](#)

### **Bucharest, Romania**

EPF continues to raise awareness on the Cross-Border Healthcare Directive and to monitor its implementation across Europe. This time Romanian Patient Organisations will learn more about the implementation of the Directive in their country.

*EPF attendance:*  
*Camille Bulot*

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TO DRIVE BETTER HEALTH IN EUROPE**

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