

# European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// FEBRUARY 2016 ISSUE

## A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the February issue of the EPF newsletter.

We are delighted to share with you **two new videos**. The first one encapsulates the finest quotes from the Kick-Off Conference of our Patient Empowerment Campaign. Many speakers, but a single common message: patient empowerment is crucial both for patients and healthcare systems!

In our second video we aim at building stronger ties with MEPs, by inviting them to meet our patients' experts, and ultimately to drive better healthcare together.

On the policy side, three important updates: the development of a **Charter on Patient Empowerment**, an essential 'product' of our campaign; a survey on patients' perception of **quality in healthcare**; and an introduction to our position paper on **informed consent** in clinical **trials**.

In this newsletter you will also find a report of the **EPF Leadership Meeting**. We were pleased to gather 27 patients' leaders from 21 organisations to discuss challenges and opportunities for patients' associations.

EPF is proud of our members and their work and we will continue to feature one of our 65 member organisations every month. In February we focus on the European Federation of Neurological Associations (EFNA) and their brand new campaign **'Together under the Umbrella'**, to raise awareness about brain disorders and the importance of collaboration.

Our **capacity building programme** is central to our goal of creating sustainable patients' organisations. This month we share updates from the Pancyprian Federation of Families and Friends (Cyprus).

We are glad to share with you feedback from two key meetings in which EPF was involved: the JA **Chrodis General Assembly**, and the **ISPOR congress** in Milan.

And finally we are very proud to announce the EPF Youth Group's **Roundtable on Transition to Adult Care**, a topic very close to the heart of our young ambassadors!

Warmest greetings,

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

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

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



### 13 SPEAKERS, ONE MESSAGE: MAKE PATIENT EMPOWERMENT A REALITY



At our high-level conference on patient empowerment in May 2015, speakers with different backgrounds, and experiences gathered and underlined their genuine commitment: to make patient empowerment a reality. The new video from our Patient Empowerment Campaign spotlights this.

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### EPF SURVEYS PATIENTS ON THEIR PERCEPTION ON QUALITY IN HEALTHCARE



EPF developed a membership study in 2015 on "Patients' Perceptions of Quality in Healthcare". The survey aims to explore the key dimensions of quality identified in literature from a patient perspective, with the aim of developing policy recommendations on quality of care.

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### EPF LEADERSHIP MEETING

### PATIENT EMPOWERMENT CHARTER: 10 FUNDAMENTAL PRINCIPLES



An important milestone of the Patient Empowerment Campaign is the delivery of a Charter encapsulating the 'cardinal rules' of patient empowerment. The document outlines "what really matters" to patients.

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### CLINICAL TRIALS - EPF TO RELEASE POSITION PAPER ON INFORMED CONSENT



EPF is consulting our members on a position paper that will provide recommendations for patient-centred implementation of the provisions of the new EU Clinical Trials Regulation (Regulation 536/2014). The survey focuses on informed consent and information to patients.

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### SUPPORTING MEMBER'S CAPACITY IN CYPRUS

### **WATCH OUR PATIENT EMPOWERMENT CAMPAIGN VIDEO!**

#### UPCOMING EVENTS

**29/2/2016** | [LGBTI Health Awareness Raising Meeting](#)

##### **Vienna, Austria**

This meeting aims to bring duty bearers (policy makers and health professionals) and rights holders closer together to raise awareness of and jointly address the health inequalities that lesbian, gay, bisexual, transgender and intersex (LGBTI) people face in their everyday lives.

*EPF attendance:*  
*Nicola Bedlington*

**1 - 2/3/2016** | [EFGCP Annual Conference 2016](#)

##### **Brussels, Belgium**

At its 2016 annual conference, the European Forum for Good Clinical Practice will explore how medicines and devices can be developed swiftly but safely for patient benefit on a sound evidence base within the current and changing regulatory European frameworks.

*EPF speaker:*  
*Robert Andrew Johnstone*

**16/3/2016** | [Conference "Relative Effectiveness Assessment - at time of launch"](#)

##### **Brussels, Belgium**

This conference organised by the Permanent Representation Of Denmark To The European Union, will focus on Relative Effectiveness Assessment (REA) in Europe.

*EPF speaker:*  
*Nicola Bedlington*

**21/3/2016** | [EPF Roundtable on Transition to Adult Care](#)

##### **Brussels, Belgium**

EPF will organise this roundtable to discuss challenges, potential pitfalls, and possible solutions to adult care transition with healthcare professionals, patient organisations and other health stakeholders.

*EPF speaker:*  
*Valentina Strammello*

**21 - 23/3/2016** | [EPF Annual General Meeting](#)



On 4th February 2016, 27 patient leaders from 21 different patient organisations (EPF members) met in Brussels for the first EPF Leadership Meeting.

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Cyprus was the latest country to join the EPF Capacity Building Programme (CBP). Major changes in the healthcare system and the need to ensure the representation of patients' interests prompted the Pancyprian Federation of Families and Friends (the Federation) to seek support to develop its first strategic and operational plan.

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### Brussels, Belgium

The EPF Annual General Meeting provides EPF members with the opportunity to meet, celebrate their involvement in the European Patients' Movement and elect the new members in the EPF Board.

**19 - 23/3/2016** | [EUPATI Face-to-Face Training Event](#)

### Barcelona, Spain

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*

### PATIENT INVOLVEMENT MATTERS FOR HEALTH ECONOMICS



The International Society for Pharmacoeconomics and Outcomes Research (ISPOR) announced in December that its board of Directors has approved the creation of a special category for Patient Representatives.

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### EU JA CHRODIS GENERAL ASSEMBLY: ACHIEVEMENTS & NEXT STEPS

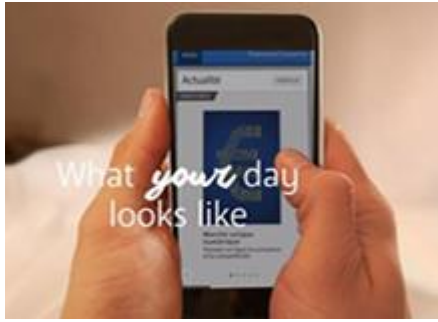


On 4-5 February, partners of the Joint Action CHRODIS met in Madrid for the 2nd Annual Meeting of the project and the 3rd Stakeholder Forum. EPF Programme Officer Valentina Strammiello and EPF Policy Adviser Laurène Souchet participated in the event as EPF is a partner in this CHRODIS.

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### GIVE US A HAND: EPF NEW VIDEO FOR STRONGER TIES WITH MEPS

### EPF YOUTH GROUP ROUNDTABLE ON TRANSITION TO ADULT CARE



On the 12th of February, EPF published our new video to support our policy actions. The small clip aims at binding stronger ties with MEPs by inviting them to meet our patients' experts.

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The EPF Youth Group will be hosting a Roundtable on Transition to Adult Care on 21 March in Brussels. The objectives will be to raise awareness of the challenges and potential pitfalls that young patients face when transitioning to adult care, to contribute to building a safe support network and to highlight best healthcare practices for the transition process.

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## MEMBER IN THE SPOTLIGHT

EFNA CAMPAIGN: 1 IN 3 EUROPEANS FIT UNDER THE UMBRELLA – DO YOU?

**WE'RE GETTING TOGETHER  
#UNDERTHEUMBRELLA  
FOR BRAIN DISORDERS,  
ARE YOU?**

[www.undertheumbrella.eu](http://www.undertheumbrella.eu) | [@UderUmbrellaU](https://twitter.com/UderUmbrellaU)

'Together Under the Umbrella' is the new campaign of our member the European Federation of Neurological Associations (EFNA). It aims to raise awareness on the range and prevalence of brain disorders. Quick! let's get under the umbrella here.

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CALL FOR TENDER - WORKSHOP FACILITATION



The European Patients' Forum (EPF) is inviting applications of professional consultants to design and lead two workshops a role play simulation during the upcoming EPF Regional Advocacy Seminar.

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

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### CONTACT US

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#### EUROPEAN PATIENTS' FORUM

Rue du commerce 31  
1000 Brussels  
BELGIUM

**Phone :** +32 (0)2 280 23 34  
**Email :** [info@eu-patient.eu](mailto:info@eu-patient.eu)  
[www.eu-patient.eu](http://www.eu-patient.eu) | [eu-patient.org/blog](http://eu-patient.org/blog)



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