

# European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// APRIL 2016 ISSUE

## A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

*Welcome to the April issue of the EPF newsletter.*

*A very rich publication this month, with many updates on EPF and our members' activities! Let's start with a **save-the-date** for a high level policy roundtable in the European Parliament in the framework of our campaign on **Patient Empowerment: pencil in the 22nd of June** in your diaries! We will discuss how we move forward with the conclusions of the campaign and implement the Charter and Roadmap.*

*EPF was again very active in **meetings**, with participation in panel debates in the European Parliament about the **value of health**; in a Brussels workshop on ethical review in **clinical trials**; at DIA Europe in Hamburg, to discuss **innovation** in medicines and in Vienna to explore **patient involvement in radiology** settings.*

*Earlier this month, EPF published two important **papers**: a preliminary statement on the **pricing and reimbursement** of innovative medicines, and a position statement on the implementation of the **Cross-Border Healthcare Directive**. These papers reaffirm our vision of equitable access to high quality healthcare systems, and are very timely with the current EU level debates led by the Dutch EU Council Presidency and the European Commission.*

*Some updates as well regarding our **Capacity Building Programme**! The fundraising module set up for patients' organisations in **Hungary** is now officially completed and we are already seeing impressive results from participating organisations. On 7 April 2016, the World Health Day put diabetes in the spotlight, the Joint Action **CHRODIS**, in which EPF is a partner, issued a policy briefing on National Diabetes Plans.*

*In the framework of **EUPATI**, the European Patient Academy on Therapeutic Innovation, 50 trainees convened in Barcelona for a week long face to face meeting, as part of the EUPATI training course.*

*We are very proud to open our blog to our members and friends. This month, we propose you no less than 4 entries to discover the work and activities of our members! You will read an interview of one of our brand new members elected at our AGM in March, the **International Federation of Spina Bifida and Hydrocephalus (IF)**, as well as an invitation to a conference organised by **EURORDIS**, the European rare diseases organisation. The **EPF Youth Group** also features in good place, with reports of two recent meetings about their roundtable to transition to adult care, and their annual spring meeting, that both took place in Brussels.*

*Warmest greetings,*

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

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**SAVE THE DATE - PATIENT EMPOWERMENT CAMPAIGN CLOSING EVENT**



The European Patients' Forum (EPF) will organise a high-level policy roundtable on Wednesday 22 June 2016 at the European Parliament in Brussels to mark the end of the Patient Empowerment Campaign.

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**"INVOLVE PATIENTS TO IMPROVE THE QUALITY OF CARE" - EUROPEAN CONGRESS OF RADIOLOGY**



Patients and professionals met in a dedicated session of the European Congress of Radiology (ECR) held in Vienna on the 5th of March to discuss best ways of implementing a patient-centred approach in clinical radiology.

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**WATCH OUR PATIENT EMPOWERMENT CAMPAIGN VIDEO!**

**UPCOMING EVENTS**

**20-21/5/2016** | [European Youth Event 2016](#)

**Strasbourg, France**

In the framework of the European Youth Event 2016, the EPF and the European Multiple Sclerosis Platform Youth Groups will jointly organise a workshop on access to employment for young people with chronic conditions.

*EPF speaker:*  
*Valentina Strammiello*

**19 - 23/5/2016** | [EUPATI Face-to-Face Training Event](#)

**Brussels, Belgium**

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*

**MEASURING PATIENT-CENTRED HEALTH OUTCOMES: AN INDISPENSABLE TOOL TO IMPROVE HEALTH SYSTEMS**



On 15 March, MEPs, the European Commission and different stakeholders met to discuss how the effectiveness and quality of health care can be measured and how measuring health outcomes can improve health systems in Europe.

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**VALUE OF PATIENT INVOLVEMENT IN INNOVATION**



On 19 March, EPF Secretary General Nicola Bedlington took part in DIA Europe open plenary panel discussion about the value of patient involvement in medicines' innovation.

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**CLINICAL TRIALS - EPF ASKS FOR MORE SYSTEMATIC PATIENT INVOLVEMENT IN ETHICS REVIEWS**

**AN IMPORTANT WEEK FOR THE DEBATES ON PRICING AND REIMBURSEMENT OF INNOVATIVE MEDICINES**



On 13 April, EPF contributed to a workshop organised by the EFGCP (European Forum for Good Clinical Practice) on "How to Ensure Optimal Ethical Review within the New Clinical Trials Regulation?"

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The week of 18 April saw important updates on the topic of pricing and reimbursement models for medicines. EPF published a preliminary report presenting the key concerns from patients' perspective ahead of the informal meeting of Health Ministers in Amsterdam to discuss patients access to innovative medicines.

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### CROSS-BORDER HEALTHCARE - EPF PAPER ON STATE OF THE IMPLEMENTATION



EPF publishes a position statement on the implementation of the cross-border healthcare Directive. Based on feedback from its members, the paper portrays a very patchy situation all over Europe.

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### CAPACITY BUILDING PROGRAMME - FUNDRAISING MODULE IN HUNGARY



The fundraising module in the framework of our capacity building programme in Hungary finished in early 2016 with very positive feedback from participants. Attendees welcomed the new approach, which led to the development of practical tools and activities that will be used to further the work of their organisations.

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### HUGE SUCCESS FOR EUPATI FACE-TO-FACE TRAINING!

### WORLD HEALTH DAY AND DIABETES - JA CHRODIS ACTIVITIES



The first face-to-face training for the second cohort of EUPATI trainees was held in Barcelona on 18-22 April 2016.

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Diabetes constitutes a major risk factor for health and a burden for the sustainability of health systems. The World Health Organisation focused their 2016 World Health Day on Diabetes and on this occasion, the Joint Action on Chronic Diseases (CHRODIS) published a policy briefing on National Diabetes Plan.

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## MEMBER IN THE SPOTLIGHT

[BLOG] 5 QUESTIONS TO... THE INTERNATIONAL FEDERATION OF SPINA BIFIDA AND HYDROCEPHALUS (IF)



EPF is proud of its members' and their work. We are delighted to feature one of our 67 member organisations on our blog and share their successes and achievements. This month we interviewed Jana Moravcova, Advocacy Officer at the International Federation of Spina Bifida and Hydrocephalus (IF), just elected as EPF member in March!

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[BLOG] EPF YOUTH GROUP ANNUAL SPRING MEETING

YOUNG PATIENTS ARE YOUNG PEOPLE

On 19 and 20 March, the EPF Youth Group gathered in Brussels for its two-day Spring Meeting to discuss key issues, such as capacity development, preparatory work for the Roundtable on Transition to Adult Care and for the Youth Group's participation at the European Youth Event in May 2016 (#EYE2016).

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## [BLOG] EPF YOUTH GROUP ROUNDTABLE ON TRANSITION TO ADULT CARE



On 21 March, the Youth Group conducted a roundtable on transition from paediatric to adult care, attended by representatives of patient organisations, health groups, as well as healthcare professionals and delegates of Member States.

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## [BLOG] EUROPEAN CONFERENCE ON RARE DISEASES & ORPHAN PRODUCTS



On 26 to 28 May, our member EURORDIS is organizing the eighth edition of the European Conference on Rare Diseases & Orphan Products (ECRD) in Edinburgh, UK. Rare diseases stakeholders from across Europe will get together and discuss crucial themes for the sector.

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TO DRIVE BETTER HEALTH IN EUROPE**

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This e-newsletter arises from the 2016 Health programme, which has received funding from the European Union, in the framework of the Health Programme.

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