

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// NOVEMBER 2016 ISSUE

Welcome to the latest issue of our Newsletter

Our campaign on **Access to Healthcare** is taking shape: in this publication we share details on the **areas of actions** that are the backbone of our campaign policy work. We will also present the **logo** and visual identity as well as the hashtag **#Access2030** that will single out and maximise outreach on social media.

At the beginning of November, EPF organised a major conference on patient safety in Brussels. The event helped pinpoint the current barriers to meaningful patient involvement in patient safety and spotlight the necessary next steps towards a better and safer healthcare for all patients in Europe.

Discrimination in the **workplace** is very close to our heart. Under the auspices of the Slovak Presidency of the EU, EPF took part in the **Fit for Work Global Alliance Summit** focusing on early intervention as a solution to improve patient quality of life. The take-home message comes very much in line with our call to actors from the relevant sectors to be involved in implementing an equal treatment strategy, as stated in our recent position paper and our work on sustainable health systems.

In the same area, EPF is preparing a response to the EU consultation on the **European Pillar of Social Rights**, giving us the opportunity to reinforce our work and position on the field of employment and social policies.

The Directive on **Cross-Border Healthcare** is far from fulfilling its original objective of clarifying patients' rights. EPF's extensive work on the topic was presented at a European Commission **conference** late October, underlining outstanding challenges for a better implementation of the Directive.

Some major updates regarding the **EUPATI** project! First of all, some information on the final conference of the programme that will take place in December in Brussels, then we'll expand on the future plans, notably the inclusion of EUPATI as a dedicated programme under the auspices of EPF, maintaining the spirit of a Public Private Partnership.

We share some recent stories from our members, namely the **Written Declaration supported by EFNA**, on access to employment for those affected by neurological disorders, and an update on an interesting research project led by Parkinson UK, a member of our member the **European Parkinson Disease Association**.

We're delighted to share with you updates from our **Youth Group**, that took part in two international meetings, advancing young patients' advocacy in Europe.

Finally, a warm farewell to Laurène Souchet, our Policy Adviser who will leave the EPF Secretariat this December. Many thanks to Laurène for her dedication and expertise over the last 6 years. We wish her all the best in her new endeavours and will certainly miss her.

Enjoy the read!

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



EPF CAMPAIGN ON UNIVERSAL HEALTH COVERAGE - #ACCESS2030



Just a few weeks before the official start of our campaign on Universal Health Coverage! Time to uncover the main policy focuses of the campaign, as well as the official logo and hashtag.

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NO PATIENT SAFETY WITHOUT PATIENT INVOLVEMENT - EPF CONFERENCE



On 8 and 9 November, patients and healthcare professionals' representatives from all over Europe got together in Brussels to discuss challenges of patient safety. The debate focused on how patient and family involvement can improve this crucial matter for patients in Europe.

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[SEE OUR VIDEOS ON OUR YOUTUBE PAGE](#)

UPCOMING EVENTS

5-6/12/2016 | [EMA Workshop: Measuring Impact of Pharmacovigilance Activities](#)

London

EPF attendance:
Kaisa Immonen

5-8/12/2016 | [European Summit on Digital Innovation for Active and Healthy Agein](#)

EPF attendance:
Laurène Souchet

6/12/2016 | [Alzheimer's Association Academy](#)

Brussels

EPF speaker:
Camille Bullo

8/12/2016 | [COCIR eHealth Summi](#)

Brussels

EPF attendance:
Camille Bullo

17-18/01/2017 | [Adaptsmart annual meeting](#)

London

EPF attendance:
Valentina Strammiello

EARLY INTERVENTION KEY TO QUALITY OF LIFE AND SUSTAINABLE HEALTH SYSTEMS



Fit for Work Global Alliance, the Work Foundation, Asociácia na ochranu práv pacientov and the European Patients' Forum organised on 9 and 10 November in Bratislava an International Summit on Early Intervention Solutions for Chronic Conditions, gathering over 80 delegates from all over Europe.

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CROSS-BORDER HEALTHCARE: STILL A LONG WAY TO GO



On 24 October 2016, EPF was invited to speak at the European Commission's multi-stakeholder conference titled "Towards amplified awareness of EU rights to cross-border care".

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PATIENTS' RIGHTS AND SAFETY ON THE MENU OF EPF WORKING GROUPS



Two internal EPF Working Groups gave the opportunity to our members to focus on patients' rights and safety, fuelling our future advocacy work in these fields.

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REVIEWING THE QUALITY PRINCIPLES FOR INFO TO PATIENTS



EPF wants to review the current status of the "core quality principles" for information to patients and assess their usefulness to stakeholders and to patients. Be quick! The survey closes in two weeks: Deadline 15 December.

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EUROPEAN PILLAR OF SOCIAL RIGHTS: PATIENTS' CONCERNS MATTER!



In March 2016, the European Commission launched a consultation on a European Pillar of Social Rights, focusing on needs and challenges in employment and social policies. The European Commission proposed a first preliminary outline of the principles. And EPF is ready to respond.

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EUPATI: FINAL CONFERENCE AND NEXT STEPS IN SIGHT




Following the graduation ceremony of the patients' experts, the EUPATI programme will see its Final Conference entitled "All Aboard to a Better Health Future" taking place on 14 December in Brussels. Before entering a whole new phase in 2017...

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MEMBER IN THE SPOTLIGHT

NEUROLOGICAL PATIENTS' STRUGGLE TO GET BACK TO WORK

CHRODIS: IMPROVE THE MULTIMORBIDITY CARE MODEL



Join me to #MakeWorkWork
ACCESS TO EMPLOYMENT FOR THOSE AFFECTED BY NEUROLOGICAL DISORDERS AND CHRONIC PAIN CONDITIONS

A Written Declaration on "Access to Employment for those affected by Neurological Disorders and Chronic Pain Conditions" was launched in the European Parliament in late October. It will remain open for signature by MEPs until January 24th 2017.

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Experts from the Joint Action CHRODIS (Chronic Diseases and Promoting Healthy Ageing across the Life Cycle) identified two important tweaks to improve the multimorbidity care model.

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(BLOG) INVOLVING PATIENTS - DOES IT REALLY MAKE A DIFFERENCE?



Parkinson's UK, the British member of the European Parkinson Diseases Association (EPDA - EPF member) have been running a research project to measure the impact of patient involvement in the different phases of scientific research. Read the interesting results on our blog.

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(BLOG) ANTIMICROBIAL RESISTANCE - A VERY PERSONAL STORY



Antimicrobial Resistance, the resistance to some antibiotic drugs is a very hot topic currently raging - and rightly so - in view of its alarming proportions. Mary Lynne Von Poelgeest-Pomfret, from the World Federation of Incontinent Patients shares on our blog her very personal and touching story.

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(BLOG) EPF YOUTH GROUP BRINGS USEFUL INSIGHTS TO CHILD CARE MODELS



(BLOG) TRANSITION TO ADULT CARE - ROLE OF THE PHARMACISTS



The Models of Child Care Appraised (MOCHA) project held its General Assembly meeting in Rome on the 20 October 2016. The EPF Youth Group Chair, Aneela Ahmed tells us about her experience as a participant.

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Transition to adult care involves a wide range of stakeholders from hospital and health managers, health professionals, pharmacists, young patients and their families. The European Pharmaceutical Students Associations explains the crucial role of pharmacists in that regard.

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