



// JANUARY 2016 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the January issue of the EPF newsletter and our warmest wishes for a happy, healthy and fulfilling year ahead – we look forward to sharing it with you!

Dear colleagues and friends,

2016 will indeed be a very exciting year for EPF! At the end of January, our flagship project EUPATI, the European Patient Academy on Therapeutic Innovation will launch its Toolbox in 7 languages – read [more](#) on what fruits this will bring to patients and the research and regulatory community.

In 2016, EPF will continue to address patient empowerment as a pre-requisite to achieve equity in healthcare and advance the concept of patients as “co-producers” of health.

Following the successful launch of our Patient Empowerment Campaign in 2015, EPF will continue to promote the development and implementation of policies, strategies and services that empower patients to be involved in the decision-making and management of their condition. We appeal to our readers and our allies to lean in and get involved in the campaign! Interested in getting more information? It is [just one click away!](#)

Key policy updates are also on the menu! We are pleased to share new policy documents including our comments to the opinion of the Expert Panel on Effective Ways for Investing in Health on Access to Healthcare; EPF’s opinion on the new Data Protection agreement and our position paper on equal treatment in education and in employment.

EPF is proud of our members’ and their outstanding work. In 2016, we will continue to put the spotlight on our 65 member organisations by sharing their successes and achievements in our newsletter. This month we are delighted to feature the International Diabetes Federation (IDF) Europe and the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP).

Last month, EPF was present at two high-level meetings focused on Continuing Professional Development for Doctors, hosted by CPME and sister organisations and health system transformation organised by the World Health Organisation. You can find key highlights of these events in this issue.

EPF Youth Group is excited to welcome a new member in 2016, Anna Zaghi, who shares her story on our blog! And we welcome her warmly too – we know Anna will bring a great deal to the Youth Group as it expands its programme and focusses in 2016 on transition into adult care.

Finally, a warm welcome to Laurent Louette, who joined our Secretariat this January! A Belgian citizen, Laurent is our new Communications Officer and will be responsible for the development of our Communications strategy. Have a look at our team in Brussels [here!](#)

Warmest greetings,

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



THE EUPATI TOOLBOX ON MEDICINES RESEARCH AND DEVELOPMENT IS LIVE!



On 27 January 2016, the European Patients' Academy on Therapeutic Innovation (EUPATI) launched its second 'core product' after the EUPATI Patient Expert Training Course, the EUPATI Toolbox for patient advocates on Medicines Research and Development.

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EPF WELCOMES THE NEW DATA PROTECTION AGREEMENT



On 15 December, the Council and the European Parliament reached a compromise on the Data Protection Regulation. Overall EPF welcomes this agreement which is positive for research and also grants more rights to patients and other data subjects who share their information for research or health related purposes.

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BUILDING THE CAPACITY OF PATIENT ORGANISATIONS IN HUNGARY

EPF'S VERDICT ON THE OPINION OF THE EXPERT PANEL ON EFFECTIVE WAYS OF INVESTING IN HEALTH ON ACCESS TO HEALTHCARE



On 6 November the European Patients' Forum provided comments to the Expert Panel on Effective ways of Investing in Health as part of the consultation on the preliminary opinion on access to healthcare in the European Union.

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EPF CALLS FOR EQUAL TREATMENT FOR PATIENTS IN EDUCATION AND EMPLOYMENT



In January, EPF published a position paper on equal treatment in education and in employment. While some patients have to cease their professional activity due to their health condition, many continue working or wish to do so. However, as acknowledged by a recent study from Eurofound, the participation of people with chronic and long standing conditions in the job market is often problematic across the EU.

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"WE DON'T WANT TO BE JUST PART OF THE PROBLEM - WE WANT TO BE PART OF THE SOLUTION!"

WATCH OUR PATIENT EMPOWERMENT CAMPAIGN VIDEO!

UPCOMING EVENTS

1/2/2016 | [EATG Stakeholders' event](#)

Brussels, Belgium

EPF member, the European AIDS Treatment Group (EATG) will organise this event to share the results of their work with their partners and stakeholders and discuss some of their ideas and projects for the coming years.

EPF attendance:
Camille Bullot

4/2/2016 | [EPF Membership Leadership Meeting](#)

Brussels, Belgium

EPF will organise this meeting to reflect with its members on the respective roles of each organisation in advancing the patient movement, and to share views on how best to coordinate our advocacy efforts in specific areas.

EPF speaker:
Anders Olauson, Nicola Bedlington

4 - 5/2/2016 | [JA-CHRODIS General Assembly](#)

Madrid, Spain

This annual meeting will gather together all partners of the project Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle (CHRODIS) to discuss how to promote the exchange and transfer of good practices in Europe.

EPF attendance:
Valentina Strammiello

11/2/2016 | [Careum Dialog - Choosing the future health systems together](#)

Brussels, Belgium

The objective of this meeting will be to discuss the fundamental shift towards shared decision-making of the healthcare systems in three countries: Switzerland, Germany and Austria focusing on how healthcare professionals and patients can team up to deliver increased benefits for patients.

EPF speaker:
Christoph Lotter, EMSP Vice-President

11/2/2016 | [Wokshop "Ticking the Boxes or Improving Healthcare and Patient Safety?"](#)

Brussels, Belgium



Hungary, alongside Romania, was the first country to undergo and complete Phase I and II of the EPF Capacity Building Programme (CBP). Nine national-level patient organisations are currently participating in the programme and have implemented activities with the support of Civil Support, the local experts delivering the activities in-country.

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Svetlana Bajalica is a physician, a scientist and a breast cancer patient. On our blog, she provides an unusual perspective, from all three points of view, on patient empowerment and data protection.

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The aim of the workshop organised by the European Commission DG SANTE is to discuss ways to optimise Continuing Professional Development of health professionals to improve quality of care and patient safety.

EPF attendance:
Kaisa Immonen-Charalambous

18/2/2016 | ["My PD Journey" Summit 2016](#)

Brussels, Belgium

Led by EPF Member the European Parkinsons Disease Association (EPDA), 'My PD Journey' is a multi-stakeholder project for people with Parkinson's in Europe, which aims to create a sustainable environment that ensures people with Parkinson's receive optimal and timely access to appropriate diagnosis, treatment and care.

EPF attendance:
Camille Bullot

18/2/2016 | [HoNCAB Final Conference](#)

Brussels, Belgium

The final conference of the Support Creation of Pilot Network of Hospitals Related to Payment of Care for Cross Border Patients (HoNCAB) project will be the opportunity to present and discuss the project's main results on the financial and organisational requirements arising from the implementation of the Cross-Border Healthcare Directive.

EPF speaker:
Kaisa Immonen-Charalambous

MEMBERS IN THE SPOTLIGHT

INTERNATIONAL DIABETES FEDERATION EUROPE IN THE SPOTLIGHT



EPF is proud of its members' and their work. We are delighted to feature one of our 65 member organisations every month on our blog and share their successes and achievements. This month we interviewed Prof Sehnaz Karadeniz, Chair of IDF Europe, who provides an overview of her organisation.

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ENUSP'S 6TH EMPOWERMENT SEMINAR IN BRUSSELS



In December 2015, EPF member, the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP) organised a three-day empowerment seminar in Brussels entitled "Strengthening the (ex) user/survivor voice in Europe". With the support of Mental Health Europe, also member of EPF, under the European Commission Rights, Equality and Citizenship Programme, ENUSP was happy to welcome 22 participants from 16 different European countries.

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EPF YOUTH GROUP WELCOMES ANNA!

"CONTINUING PROFESSIONAL DEVELOPMENT FOR DOCTORS - IMPROVING HEALTHCARE"



EPF Youth Group enters 2016 with a new member, Anna Zaghi! Anna is a young Italian who lives with Multiple Sclerosis. On our blog, she speaks about her condition, the European Multiple Sclerosis Platform, and why she joined EPF Youth Group.

EPF collaborates on an ongoing basis with many healthcare professionals' organisations on topics such as eHealth, Cross Border Healthcare, Patient Safety and Patient Empowerment. On 18 December, EPF Secretary General participated in the joint conference on 'Continuing Professional Development for Doctors - Improving Healthcare' in Luxembourg, organised with the support of the Government of the Grand Duchy of Luxembourg and the Luxembourg Presidency of the Council of the European Union.

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EPF PARTICIPATES IN WHO MEETING ON LARGE SCALE IMPLEMENTATION OF HEALTH SYSTEM TRANSFORMATION



Under the leadership of Hans Kluge, Director of the Division of Health Systems and Public Health in WHO Europe, a high level meeting took place in Madrid, Spain in December. Hosted by the Deusto Business School, this meeting convened a number of 'health leaders' from the political and academic arena.

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

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