

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// MAY 2015 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

We would like to wish you a very warm welcome to this issue of our newsletter. This month was particularly important for the European Patients' Forum as we held our Annual General Meeting – AGM - followed by a major conference on patient empowerment.

We were really delighted to meet our member organisations and share with them our collective achievements of the last year, but also how we move forward – this year and beyond. We elected new Board Members and welcomed one new Belgian member which makes our membership now composed of 65 organisations.

We were particularly proud that we have linked our AGM with our flagship conference on patient empowerment to launch our big campaign on this issue. Driving patient empowerment in all its forms is the lifeblood of EPF, and this is a unique and unprecedented opportunity to advance on this – to get the political support needed, and to get things done on the ground!

We hope this campaign will represent the beginning of a new era with political buy-in for patient empowerment at all levels. This is inherent to ensuring patient centred, sustainable health systems - and real impact benefitting our constituency, our people - patients, those around them, communities and society at large.

If this sounds ambitious or ground-breaking - this is because it is. We ask every single one of you, dear readers, to use your time to embrace this unique opportunity not to simply ruminate over the huge challenges facing patients and our health systems today but to work together to orchestrate real change.

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'.



NEW BOARD, NEW MEMBER!



The EPF 2015 Annual General Meeting took place in Brussels on 19 May, just before our Patient Empowerment Conference. This year again, we provided our members with the opportunity to meet, exchange and celebrate their being part of the European Patients' Movement and welcome new members and faces to our community.

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"NOW IS THE TIME TO WIN THE ARGUMENT FOR PATIENT EMPOWERMENT"



We invited Emma Eatwell to deliver a speech at our Annual General Assembly on 19 May, on the eve of the launch of our 'Patient Empowerment' campaign. She leads Hanover Communications' healthcare practice in Brussels and provided to us with a very pertinent analysis of the European context in which we are launching our campaign.

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TOWARDS AN OFFICIAL RECOGNITION OF THE PATIENTS' RIGHTS DAY?

CAMPAIGN "PATIENTS PRESCRIBE" ON PATIENT EMPOWERMENT



On 20-21 May 2015, over 150 patient leaders, health professionals, NGO representatives, researchers and policy-makers gathered in Brussels to explore the role of patient empowerment in building high-quality equitable, sustainable health systems in Europe. This conference marked the official launch of our one-year campaign on this topic.

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PATIENT EMPOWERMENT FROM THE PERSPECTIVE OF A YOUNG PERSON



Aneela Ahmed is a British member of EPF Youth Group, coming from National Voices. She was diagnosed with diabetes at the age of 16. Patient empowerment has a real significance for her, from her understanding of her condition to the relationship with healthcare professionals.

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EPF PERSPECTIVE ON UNIVERSAL ACCESS TO HEALTHCARE

CALL FOR TENDERS

UPCOMING EVENTS

Today | [Are Europeans developing more allergies?](#)

Brussels, Belgium

The event organised by our member EFA will focus on the results of the project MeDALL project "Mechanisms of the Development of ALLergy".

29/05/2015 | [EFGCP Multi-Stakeholder Workshop](#)

Brussels, Belgium

The European Forum for Good Clinical Practise (EFGCP) is organising this workshop to discuss how to communicate clinical trial results to meet patients needs.

EPF speaker:

Kaisa Immonen-Charalambous

29 - 31/05/2015 | [5th National Patients' Organisation Congress](#)

Sofia, Bulgaria

In this year's annual conference, our member, the National Patient Organisation of Bulgaria (NPO) will promote their new Partnership for Health and explore opportunities for improving access to treatment and quality health care for Bulgarian patients.

2/06/2015 | [Health Literacy Seminar \(HEALIT4EU\)](#)

Brussels, Belgium

This seminar will discuss the outcomes of a study on "sound evidence for a better understanding of health literacy in the European Union" (HEALIT4EU), financed by the Public Health Programme.

EPF attendance:

Kaisa Immonen-Charalambous

2-3/06/2015 | [3rd European Alliance for Personalised Medicine Annual Conference](#)

Brussels, Belgium

This two-day gathering will reflect on the work programmes developed since the Alliance's formation and will develop recommendations to strengthen Luxembourg's Council Conclusions on Personalised Medicine.

EPF speaker:



The Active Citizenship Network (ACN) organised a conference in the European Parliament on 12 May 2015 to call for the institutionalisation of Patients' Rights Day. EPF supports continued efforts by ACN as it complements our work, together with our members, on advancing patients' rights.

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COLLABORATION BETWEEN PATIENTS AND INFORMAL CARERS



EPF is delighted to announce that we have signed a cooperation agreement with Eurocarers, the European network representing informal carers and their organisations. This demonstrates our mutual willingness to further enhance our collaboration in advancing the interests of European patients and informal carers.

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On 5 May EPF co-organised a roundtable with European Generics Association (EGA), Doctors of the World, and the International Association of Mutual Benefit Societies (AIM) on Universal Access to health. One year after the EU elections, we asked MEPs how to advance Universal access in the new EU political landscape.

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YOUNG PATIENTS AT YO! FEST



On 6 May 2015 the EPF Youth Group participated in the Esplanade of European Parliament at the Yo!Fest, a yearly youth event organised by the European Youth Forum. Two members of the group represented EPF at the event: Polis Stavrou of Cyprus and Marlou Schenk of The Netherlands.

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Nicola Bedlington

3/06/2015 | [SmartCare site visit](#)

Odense, Denmark

As part of the SmartCare program on the deployment of integrated health and social care for older patients supported by Information Communication technology (ICT), EPF will attend the site visit to Odense in Denmark region.

EPF attendance:
Walter Atzori

3-4/06/2015 | [EMA Patients' and Consumers' Working Party](#)

London, UK

The European Medicines Agency's (EMA) Patients' and Consumers' Working Party (PCWP) will meet to provide recommendations to EMA, on matters of interest to patients in relation to medicinal products.

EPF attendance:
Kaisa Immonen-Charalambous

5/06/2015 | [Big data: what does it really mean for patients?](#)

Luxembourg

This EFPIA-EPF Patient Think Tank Debate will look at the opportunities afforded by the use of Big Data and its potential impact on patients as well as at some of the challenges raised by its use

EPF attendance:
Laurène Souchet

8/06/2015 | [EC Expert Group on Patient safety & quality of care](#)

Brussels, Belgium

The European Commission's (EC) Expert Group on Patient Safety and Quality of Care brings together stakeholders and representatives from the EU member states to assist in developing the EU patient safety and quality agenda.

EPF attendance:
Kaisa Immonen-Charalambous

9-10/06/2015 | [21st EGA Annual Conference](#)

Berlin, Germany

During this conference, the European Generic medicines Association (EGA), will discuss health equality and sustainable access to medicines for all European patients, as well as the need for a strong industrial manufacturing base.

MEMBERS IN THE SPOTLIGHT

ROMANIA CELEBRATED THE PATIENTS' WEEK

"TAME YOUR WOLF, TAME YOUR LUPUS"



Our member, the Romanian Coalition of Patient Organisations for Chronic Diseases (COPAC) held for the sixth time, the Romanian "Patients Week" in Bucharest from 17 to 24 April 2015. Every year our Romanian member dedicates a one week event to its own membership to discuss patients' rights.

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Lupus is an autoimmune connective tissue disease which attacks one or more organs. With variable systemic reactions and complex manifestations, lupus raises significant social challenges in terms of family and employment. So far, there are only few treatment options beyond the basic anti-malarial, corticosteroids and immune-suppressants; all aimed at keeping lupus at bay.

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MEMBER OF THE MONTH : BAPD



Our membership is our compass. We are delighted to feature one of our 65 member organisations every month on our blog. This time, we interviewed Plamen Taushanov of the Bulgarian Association for Patients' Defence (BAPD), who provides an overview of his organisation in five short answers.

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EPF speaker:
Nicola Bedlington

11/06/2015 | [EFPIA Think Tank meeting](#)

Brussels, Belgium

The European Federation of Pharmaceutical Industries and Associations (EFPIA) Think-Tank serves as a forum for both Efpia members and European patients' organisations.

EPF speaker:
Nicola Bedlington

14/06/2015 | [World Blood Donor Day](#)

Worldwide

This year, the World Health Organisation (WHO) focuses this day on thanking blood donors and encouraging more people all over the world to donate blood with the theme "Thank you for saving my life".

15/06/2015 | [European Haemophilia Consortium Round Table of Stakeholders](#)

Brussels, Belgium

Our member, the European Haemophilia Consortium (EHC) will hold it's 25th round table on 'Tenders and Procurement of Coagulation Factor Concentrates' to discuss findings of their 2014 European survey of 38 countries.

15/06/2015 | [IMI Stakeholder Forum 2015](#)

Brussels, Belgium

Every year, the Innovative Medicines Initiative (IMI) Stakeholder Forum gathers to discuss their latest activities and plans.

EPF speaker:
Anders Olauson

29-30/06/2015 | [Universal health: Investing in Health and Wellbeing for All](#)

Riga, Latvia

The aim of this conference, is to identify strategies to harness citizen participation to create efficient, equitable European health systems.

EPF speaker:
Anders Olauson

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TO DRIVE BETTER HEALTH IN EUROPE**



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This e-newsletter arises from the 2015 Health programme, which has received funding from the European Union, in the framework of the Health Programme.

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