

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// APRIL 2015 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

April was a busy month for healthcare advocacy. We supported and celebrated the World Health Day on 7 April, the Parkinson's Day on 11 April and the Patients' Rights Day on 18 April. EPF supports the institutionalisation of the Patients' Rights Day, as it complements our work together with our members on advancing patients' rights. We believe that activities surrounding the Day should be driven by patients' organisations and reflect our values, to achieve the best possible momentum. We wish all patients throughout Europe strength and courage in fighting for our rights!

Equitable access to healthcare was again high on our policy agenda this month. We warmly congratulate our member, the National Patient Organisation, which has launched the national version of the Patient Access Partnership in Bulgaria. We also met with some of our members at our Access Working Group to advance our work in this critical area.

Much has happened in our project portfolio this month too. Two projects in which we were partners have ended: SUSTAINS on providing patients' access to Electronic Health Records and WeCare on identifying models for sustainable and affordable healthcare; we are pleased to give a glimpse of the main impacts of this work. We also share some outcomes regarding our projects on patient safety and quality of care (JA PASQ), European Patient Academy (EUPATI) and on integrated ICT care (SmartCare).

Last but not least, we will be launching our campaign on Patient Empowerment on 19-21 May during our AGM and Conference. We want to build the momentum on the empowerment of patients in Europe to contribute towards genuine sustainability of quality health systems and societal 'growth'. We look forward to working with you in Brussels at this important event and during our exciting campaign.

Rendezvous on 19-21 May!

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'.



LET'S CAMPAIGN FOR PATIENT
EMPOWERMENT!

OUR WORKING GROUP TACKLES
THE ACCESS TO HEALTHCARE
ISSUE

**REGISTER TO OUR PATIENT
EMPOWERMENT CONFERENCE**

UPCOMING EVENTS

Today | [AdHopHTA Advisory Committee](#)



On 20-21 May EPF will launch our one-year campaign dedicated to Patient Empowerment with a major conference in Brussels, Belgium. With this campaign, we want to take the European discussions a crucial next step forward towards concrete actions.

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A PATIENT ACCESS PARTNERSHIP IN BULGARIA



The Bulgarian "Health Partnership" was officially launched on 26 March 2015 at the Council of Ministers in Sofia. This initiative from our member, the National Patient Organisation (NPO), falls within the 2020 Objectives for Health 2020 of the Bulgarian Health Ministry and follows the model of the European Patient Access Partnership platform, launched in January 2015.

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FIRST FACE-TO-FACE MEETING FOR EUPATI 'STUDENTS'



In March, the EPF working group on access met for the 3rd time in Brussels. This internal group was launched at our Annual General Meeting in 2014 to support our work on access to healthcare, a longstanding priority and one of our six strategic goals for 2014-2020.

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CLOSE OF SUSTAINS, THE ELECTRONIC HEALTH RECORDS PROJECT



The SUSTAINS project, in which EPF was one of the partners, ended last December. Since then, the various partners have pulled together the main findings and lessons learned. The project has promoted citizens with online access to their Electronic Healthcare Records (EHR), fulfilling one of the key actions of the European Digital Agenda.

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PATIENTS HIGHLIGHTS AT THE WE CARE FINAL CONFERENCE

[meeting](#)

Barcelona, Spain

The AdHopHTA Advisory Committee Meeting will offer the opportunity to present and discuss the content of one of the main outputs: the Handbook with best practices and an accompanying toolkit for high quality hospital-based HTA products. EPF is member of the Advisory Board of this project on Hospital Based Health Technology Assessment in the EU.

EPF attendance:
Valentina Strammello

[Today | Working together for better health outcomes in Europe](#)

Brussels, Belgium

This partners' meeting aims to bring together senior representation of international organisations collaborating with the World Health Organisation (WHO) Regional Office for Europe in the area of health systems and is focused on how their role in improving health and well-being.

EPF speaker:
Nicola Bedlington

[5/05/2015 | Universal Access to Health: One Year after the EU Elections](#)

Brussels, Belgium

We join forces with other European stakeholders including Association Internationale de la Mutualité (AIM), European Generic medicines Association (EGA) and European Public Health Alliance (EPHA) to organise a joint event on "Universal Access to Health".

EPF speaker:
Nicola Bedlington

[5/05/2015 | World Asthma Day](#)

Worldwide

World Asthma Day is an annual event organised by the Global Initiative for Asthma (GINA) and takes place on the first Tuesday in May each year. Its aim is to improve asthma awareness and the lives of people with asthma across the world

[8/05/2015 | World Thalassaemia Day](#)

Worldwide

The World Thalassaemia Day is dedicated to all thalassaemia patients and this year, the Thalassaemia International Federation's theme focuses on "Enhancing partnership towards patient-centred health systems: good health adds life to years!"



The first in-person training of the EUPATI Expert Patient Course took place in Barcelona from 29 March - 2 April 2015. This is the 15 month training programme for patient advocates on medicines' research and development of the project 'European Patients Academy on Therapeutic Innovation' that we have been leading since 2012.

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PASQ PROJECT CONTINUES FOR ONE MORE YEAR!



"The European Union Network for Patient Safety and Quality of Care" or "PaSQ" Joint Action (JA), in which we are a partner, continues for one more year until March 2016. This will contribute to building a stronger network involving representatives of Members States, European stakeholders and international organisations.

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On 14-15 April, EPF President Anders Olauson and Board Member Robert Johnstone attended the WE CARE final conference. This two-year project investigated how quality healthcare services can be preserved and guaranteed in EU countries while ensuring their viability and sustainability.

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SMARTCARE PROJECT: VISIT OF THE TRIESTE SITE



As a member of the SmartCare project's User Advisory Board (UAB), we took part in the site visit of the Muggia area, Trieste region, Italy in March. SmartCare promotes a more integrated and effective approach to providing health and social care to older people across Europe. This region represents a real-life "laboratory" as it is one of the Italian regions with the highest percentage of elderly people.

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MEMBERS IN THE SPOTLIGHT

OUR MEMBERS IN THE SPOTLIGHT: EFA

CELEBRATING THE INTERNATIONAL PARKINSON'S DAY!

[8-10/05/2015 | EPF Youth Group Spring meeting](#)

Brussels, Belgium

EPF Youth Group, made up of young patient representatives between 15 and 29 years old with different chronic conditions, will meet to discuss the EPF Youth Group Strategy.

EPF speaker:
Valentina Strammiello

[12/05/2015 | 9th European Patients' Rights Day](#)

Brussels, Belgium

EPF supports continued efforts by Active Citizenship Network towards the Institutionalisation of the Patients' Rights Day, as it complements our work, together with our members on advancing patients' rights. We will participate in Active Citizenship Network's meeting in Brussels on 12 May, where the Day will also be celebrated.

EPF speaker:
Nicola Bedlington

[14/05/2015 | eHealth week 2015](#)

Riga, Latvia

There will be two main events during the eHealth week 2015. Firstly, the High Level eHealth Conference will be organised by the Latvian Ministry of Health and the Latvian Presidency of the Council of the European Union. Secondly, there will be the World of Health IT Conference & Exhibition, organised by HIMSS Europe.

EPF speaker:
Walter Atzori

[17/05/2015 | World Hypertension Day](#)

Worldwide

Organised by the World Hypertension League, the "World Hypertension Day" is celebrated on 17 May every year to raise awareness on Hypertension.

[19/05/2015 | EPF Annual General Meeting](#)

Brussels, Belgium

At this year's Annual General Meeting, EPF members will have the opportunity to meet, celebrate their being part of the European Patients' Movement and elect the new members in the EPF Board.

[19/05/2015 | EPF Annual General](#)



Our membership is our compass. We are delighted to feature one of our 64 member organisation every month on our blog. This time, we interviewed Isabel Proano of the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), who provides an overview of her organisation in five short answers.

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Parkinson's is a progressive, chronic and complex neurodegenerative disease that has no cure. It affects all aspects of daily living and is the most common neurodegenerative disease after Alzheimer's. The effects of Parkinson's invariably involve the physical, cognitive and psychological domains, and impact across nearly every cultural, social and economic boundary.

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Meeting

Brussels, Belgium

In this year's Annual General Meeting, EPF members will have the opportunity to meet, celebrate their being part of the European Patient's Movement and elect the new members in the EPF Board.

*EPF attendance:
EPF Board & Secretariat*

20-21/05/2015 | [EPF Patient Empowerment Conference](#)

Brussels, Belgium

This conference will mark the official launch of our EPF Patient Empowerment Campaign that takes the European discussions on this topic a crucial next step forward – towards concrete actions at practical and political levels.

*EPF attendance:
EPF Board & Secretariat*

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

Sofia, Bulgaria

Our member, the National Patient Organisation of Bulgaria, organises the 5th edition of its annual congress. This year NPO will take this opportunity to promote the new Partnership for Health (see article) and focus on exploring opportunities for improving access to treatment and quality health care for Bulgarian patients.

THE PATIENTS' PERSPECTIVE AT DIA EUROMEETING



The 27th edition of the Drug Information Association (DIA) EuroMeeting took place in Paris, France, on 13-15 April and was entitled "Development, Innovation, Access and Patient Safety". Patients were very active at the Meeting and four major issues for the European Patients Academy were discussed.

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

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