

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// DECEMBER 2015 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to this special December issue of the EPF newsletter.

As 2015 comes to a close, we are delighted to share with you some of our main achievements, which have contributed to driving better healthcare for all patients in the EU.

Unquestionably, none of those achievements would be possible without our members' valuable contribution and engagement. We wish to express our gratitude to all our member organisations, new and old, for their collective investment and support that drives the European Patients' Movement to be a strong voice for patients in Europe.

Similarly, we are grateful to our many allies and fellow stakeholders who work with us on a daily basis to advance patient-centred, equitable and sustainable health systems in Europe.

There have been some really fantastic and memorable times this year and we are proud to share some of these achievements with you. There have also been challenges – very serious challenges for Europe and, inter alia, the Patients' movement. We count on your on-going commitment, energy and ambition to help address these together.

The EPF Board members and Secretariat are wishing you a restful and happy break with your family and friends for the festive season. We look forward to working with you again in 2016!

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'.



JANUARY

ENSURING EQUITABLE ACCESS TO HEALTHCARE FOR ALL PATIENTS



Access to healthcare was an important priority for EPF in 2015. We began the year with the launch of the European Parliament Interest Group on Access to Healthcare on 27 January.

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FEBRUARY

2015 FOR AND WITH OUR MEMBERS



Communication and daily exchanges with our members is close to EPF's heart. But when you are an umbrella network spread over Europe, how do you ensure that each of your members helps to drive your work, and shapes your activities? In 2015, we invested much time to make this happen as effectively as possible.

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MARCH

EPF PUBLISHES STATEMENT ON THE COMMUNICATION OF CLINICAL TRIALS



The new EU Clinical Trials Regulation, that will be applicable from May 2016, will increase the transparency of clinical trials, including their results, and so-called "lay summaries" of all clinical trials will be publicly available. In March 2015, EPF released a position statement on the standards for communication on the lay

APRIL

BUILDING THE CAPACITY OF PATIENT ORGANISATIONS IN EUROPE



2015 showed real advances within the EPF Capacity Building Programme. Strategic and operational plans were finalised and new training modules have been launched in participating countries and for our European members. An evaluation of the programme was also carried out and its outcomes were used to reflect on

SAVE THE DATES FOR THE 2016 EVENTS!

1 /02/2016 | [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 Bulot

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

Brussels, Belgium

Over the years, the patient movement has evolved considerably, as has the role of patient organisations in European decision-making. Recognising this, 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

03/2016 | [Patient Empowerment Campaign event at the European Parliament](#)

Brussels, Belgium

EPF will organise a high level roundtable meeting at the European Parliament in March to engage Members of the European Parliament in the campaign and discuss with them the first two concrete campaign deliverables: the "Charter of Patient Empowerment" and the "Roadmap to Patient Empowerment".

21/03/2016 | [EPF Roundtable on Transition to Adult Care](#)

Brussels, Belgium

EPF will organise this roundtable to discuss challenges, potential pitfalls, and possible solutions to adult care transition with healthcare professionals, patient organisations and other health stakeholders.

EPF speaker:
Valentina Strammiello

21-23/03/2016 | [EPF Annual General Meeting](#)

Brussels, Belgium

The EPF Annual General Meeting provides EPF members with the opportunity to meet, celebrate their involvement in the European

summary which was adopted as a basis for an EU guideline.

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the training achievements and approaches used, to strengthen the programme activities and impact.

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Patients' Movement and elect the new members in the EPF Board.

EPF speaker:
Anders Olauson

09-11/04/2016 | [7th Global Patients Congress](#)

London, UK

This congress organised by the International Alliance of Patients' Organisations will bring together 200 patient advocates from across the world to share best practice and gain insight into pressing healthcare issues.

EPF speaker:
Anders Olauson

18-22/04/2016 | [EUPATI Face-to-Face Training Event](#)

Barcelona, Spain

During this 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 speaker:
Walter Atzori

20-21/05/2016 | [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

06/2016 | [Patient Empowerment Campaign Exhibition at the European Parliament](#)

Brussels, Belgium

EPF will bring the Patient Empowerment Campaign to the heart of the European institutions by presenting an exhibition in the hall of the European Parliament, to discuss with MEPs and health stakeholders the outcomes of the campaign as well as follow-up actions.

06/2016 | [EPF Regional Advocacy Seminar](#)

Amsterdam, Netherlands

The overall objective of the 8th EPF Regional Advocacy Seminar will be to provide patients' organisations with tools to



NEW BOARD, NEW MEMBERS, NEW CAMPAIGN!



The EPF 2015 Annual General Meeting took place in Brussels on 19 May, just before our Patient Empowerment Conference and the launch of our Patient Empowerment Campaign. This was an opportunity for our members to meet, exchange, celebrate their involvement in the European Patients' Movement and vote for the new EPF Board.

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A ROADMAP TO SUSTAINABLE AND EQUITABLE EU HEALTH SYSTEMS



At the end of June 2015, EPF co-organised a high-level conference under the Latvian Presidency titled "Universal health: Investing in Health and Wellbeing for All". A major outcome of the event was the "Riga roadmap" that calls on EU and national policymakers to develop health systems that embed the principles of prevention, promotion, protection and – importantly – participation.

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LET'S ENSURE CROSS-BORDER HEALTHCARE WORKS FOR PATIENTS ACROSS THE EU



EPF'S ACTIVE ROLE ON EU KEY LEGISLATION THAT IMPACT PATIENTS



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After a series of national and regional events on cross-border healthcare, organised in 2013-2015, EPF held a major European conference on July 2015 to discuss the implementation of the Directive with patient leaders from across the EU and National Contact Points (NCPs).

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In 2015, EPF advocated a patients' perspective on various EU legislative dossiers. These included recommendations on the Medical Devices Regulation, to ensure patients have access to safe quality devices, and actions to ensure the final Data Protection Regulation reaches the right balance for patients and for research.

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advocate effectively at European and national level.

*EPF speaker:
Camille Bullo*

19-23/09/2016 | [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 speaker:
Walter Atzori*

SEPTEMBER

YOUNG PATIENTS ARE YOUNG PEOPLE!



It has been an incredibly busy and successful year for the EPF Youth Group, the highlight of which was the Annual General meeting that took place on 18-20 of September, in Bucharest. This was the opportunity for the Youth group to discuss plans for 2016, do practical exercises on capacity development and run the new Board elections.

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OCTOBER

THE EUROPEAN PATIENTS ACADEMY ON THERAPEUTIC INNOVATION



2015 has been an exciting year for the European Patients Academy on Therapeutic Innovation (EUPATI), with the project entering its fourth year of implementation. In October, the second course of the EUPATI expert training course was launched, with 60 new patient advocates from across 30 different European countries.

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NOVEMBER

NORDIC COUNTRIES: WE HAVE SOME WORK TO ACCOMPLISH TOGETHER

DECEMBER

PATIENT EMPOWERMENT CAMPAIGN



On 24-25 November 2015, 45 patient leaders from Iceland, Norway, Sweden, Denmark and Finland met in Lund for the seventh EPF Regional Advocacy Seminar. This year, the seminar looked specifically at how to strengthen patient involvement in research and policy.

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In 2015 EPF launched a thematic Patient Empowerment Campaign, to build momentum for the real empowerment of patients in Europe. With this campaign EPF aims 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.

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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