

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



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// OCTOBER 2015 ISSUE

A WORD FROM OUR PRESIDENT AND OUR SECRETARY GENERAL

Welcome to the October issue of the EPF newsletter.

Dear colleagues and friends,

Many of you will have heard that our dear colleague, EPF Board Member, Pedro Montellano passed away this month. This was a great shock and we would like to thank all of you for your tributes and thoughts that we have conveyed to Pedro's family. As a beacon for mental health and in his numerous roles driving patient advocacy, he will be sadly missed. To honour his memory, we will dedicate a special session at our AGM early next year.

Illustrating his unstinting work, Pedro is part of our Patient Empowerment Campaign [video](#) which we launched a few days ago. We invite you to watch it and share it to help us raise awareness about patient empowerment and the #PatientsprescribE campaign.

This month EPF was present at two important events: The WHO Regional Committee for Europe where we discussed walking the talk on patient centredness and sustainable health workforces. At the European Health Forum Gastein we had the opportunity to showcase the Patient Empowerment Campaign during our workshop. We are pleased to report on these events in this newsletter.

Our membership activities feature strongly in this issue of our newsletter. Read about the EPF training seminar on strategic communication with ten of our members that was organised under the Capacity Building programme. The Pancyprian Federation of Patients' Associations and Friends is a guest on our blog this month and the Pulmonary Hypertension Association Europe shares important information on their organ donation and transplantation campaign.

From our project portfolio we share some important developments from two of our projects: the European Patients' Academy on Therapeutic Innovation (EUPATI) and the PISCE Platform of experts.

Finally, we are also pleased to introduce you to the new EPF Youth Group Board who was elected during the 5th EPF Youth Group Annual Meeting last month, and to welcome Stefano Tironi from Italy, who joined EPF's Secretariat as Assistant to the Secretary General and Finance.

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'.



IN MEMORY OF PEDRO MONTELLANO



It is with great sadness that we commemorate the memory of EPF Board Member Pedro Montellano, who passed away this month. We say goodbye to a great patient advocate, colleague and friend.

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"AT AGE 26, I AM ABLE TO SHAPE MY OWN THERAPY"



Laurence Woollard is a 26-year old professional with severe Haemophilia 'A' and he is also a Youth Ambassador for our member the European Haemophilia Consortium (EHC). In our blog, he explains how by being equal partners with his health professionals enables him to manage his own treatment and adapt it to his own needs.

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EUPATI TRAINING COURSE: SECOND FACE-TO-FACE TRAINING

THE OFFICIAL PATIENT EMPOWERMENT CAMPAIGN VIDEO!



We are delighted to share with you the official Patient Empowerment campaign video! In the video, patients share their views on why patient empowerment is important, and explain why we need to act now to make patient empowerment a reality.

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5TH EPF YOUTH GROUP ANNUAL MEETING



On 18-20 of September, the EPF Youth Group gathered in Bucharest, Romania for the 5th Youth Group Annual meeting. 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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BUILDING OUR MEMBERS' COMMUNICATIONS CAPACITY

WATCH OUR PATIENT EMPOWERMENT CAMPAIGN VIDEO!

UPCOMING EVENTS

29/10/2015 | [SmartCare site visit Greece](#)

Athens, Greece

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 Attiki region.

EPF attendance:

Walter Atzori

30/10/2015 | [Health Technology Assesment sans frontières](#)

Paris, France

This conference organised by the French National Authority for Health (HAS) and the European Commission, will be dedicated to Health Technology Assesment (HTA) and the benefits of European cooperation in this field.

EPF attendance:

Valentina Strammiello

4 - 5/11/2015 | [DIA Biosimilar Conference 2015](#)

London, UK

This conference organised by the Develop Innovative Advance (DIA) will provide an update on the current status for biosimilars in EU and internationally.

EPF speaker:

Marco Greco

5 - 6/11/2015 | [Ensuring financially sustainable healthcare in Europe](#)

The Hague, Netherlands

The 11th Conference of the European Healthcare Fraud and Corruption Network (EHFCN) focused on countering fraud, waste and corruption, aims to evaluate the actual level of fraud resilience in public /private health insurance.

EPF speaker:

Laurène Souchet

9/11/2015 | [eHealth in Norway Conference](#)

Oslo, Norway

This conference will bring together public and private players to create a common



The second face to face training event part of the EUPATI Patient Expert Course took place on 14-18 September 2015. Over 45 patient advocates from more than 20 European countries gathered in Spain, Barcelona for a week of intensive training on medicines research and development.

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EPF ATTENDS THE EUROPEAN HEALTH FORUM GASTEIN 2015



As in previous years, EPF had a strong presence at the 2015 forum. EPF team members were involved as speakers or contributors in several sessions while, on the third day, EPF held a workshop focused on patient empowerment as a vital element of high-quality, sustainable, equitable and cost-effective health systems.

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LACK OF PATIENT INVOLVEMENT IN THE COUNCIL POSITION ON MEDICAL DEVICES



How can patient organisations use communications strategically to support their advocacy work? The training module on strategic communications that EPF organised on 21-23 September 2015 aimed to answer to this question.

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MY EXPERIENCE AT THE EUROPEAN HEALTH FORUM GASTEIN



This year two members of the EPF Secretariat attended the European Health Forum Gastein 2015 as Young Gasteiners. EPF Policy Officer Laurène Souchet and EPF Membership Officer Camille Bullot had the opportunity to participate in several sessions, share EPF work and exchange with other Young Gasteiners.

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EPF PRESENT AT THE WHO REGIONAL COMMITTEE FOR EUROPE

national forum for digitisation of healthcare and strategic health information technology in Norway.

EPF speaker:
Walter Atzori

[7 - 11/11/2015 | ISPOR 18th Annual European Congress](#)

Milan, Italy

The theme of the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) conference is "Impacting Health Decision Making with Outcomes Research: Closing the Gap," and it will be centered on the use of outcomes assessment in decision making.

EPF speaker:
Nicola Bedlington

[17/11/2015 | The Diabetes Literacy Conference](#)

Brussels, Belgium

The Diabetes Literacy Consortium will host its final event focused on "Strengthening Diabetes Self-Management for All in Europe", where key research outcomes will be presented.

EPF speaker:
Kaisa Immonen-Charalambous

[18/11/2015 | 3rd European Health Literacy Conference](#)

Brussels, Belgium

This conference organised by Health Literacy Europe, the Intervention Research on Health Literacy in the Ageing Population (IROHLA) Consortium and the University Medical Center Groningen (UMCG) focuses on health literacy during the life course, from various perspectives.

EPF speaker:
Kaisa Immonen-Charalambous

[24 - 25/11/2015 | EPF Regional Advocacy Seminar 2015](#)

Lund, Sweden

This year's EPF Regional Advocacy Seminar is focused on "Strengthening the patient's perspective in EU policy-making and research" and its aim is to provide patients' organisations with tools to advocate effectively at European and national level.

EPF speaker:
Anders Olason



On 5th October, the Council formally adopted their position on medical devices and in vitro diagnostics medical devices, which were partially released in June. In the review of this legislation a key stake from the patients' perspective was to ensure more patient involvement in the governance of medical devices, however, this still remains scarce.

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The World Health Organisation (WHO) 65th Regional Committee for Europe took place on 14 – 17 September in Vilnius. Health ministers and high-level representatives took part in this session to discuss key health issues at Pan European level.

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MEMBERS IN THE SPOTLIGHT

PHA EUROPE CAMPAIGN ON ORGAN DONATION AND TRANSPLANTATION



Organ transplantation is vital for the treatment and quality of life of patients living with a wide variety of conditions, such as the ones affecting the liver, kidneys, heart, lungs, pancreas, small bowel and eyes. Our member, the Pulmonary Hypertension Association Europe (PHA Europe) is taking the lead in a campaign to improve organ donation and transplantation across the EU. EPF fully supports this initiative and encourages everyone to get involved.

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OUR MEMBERS IN THE SPOTLIGHT: PANCYPRIAN FEDERATION OF PATIENTS' ASSOCIATIONS AND FRIENDS



This month our Cypriot member, the Pancyprian Federation of Patients' Associations and Friends, is in the spotlight. Despina Roussou, Communications Executive, provides an overview of her organisation in five short answers.

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SECOND WORKING CONFERENCE OF THE PISCE PLATFORM OF EXPERTS



The PISCE Platform of Experts - a group set up to lead work on the promotion of self-care in minor conditions in the EU – met for its 2nd working conference on 15-16 September 2015 in Utrecht, The Netherlands.

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