European Patients' Forum Newsletter A strong patients' voice to drive better health in Europe



//JANUARY 2017 ISSUE

Welcome to the latest issue of our Newsletter!

First of all, the whole EPF Secretariat and Board would like to wish you a wonderful and rewarding year, let 2017 be a year of joy and good health!

It is a great pleasure to announce you the official launch of our campaign on **Access to Healthcare**! Our one-year major campaign started earlier this month, with the online publication of dedicated pages on our <u>website</u>, a press release and some posts on social media. Policy-wise, we are organising a **kick-off meeting** on the 27th of February in the European Parliament, where we will describe the five areas for policy action and reflect with participants on the measures needed to really achieve Universal Health Coverage for All by 2030. #Access2030

We are delighted to share with you one of the prime achievements of our recent campaign on Patient Empowerment: The **Roadmap** for Action. The document proposes concrete actions stakeholders across the EU can take to drive positive change. Fruit of the Empowerment Campaign's policy arm, the Roadmap is a substantial piece of work that is a spring board to a new era on patient empowerment.

Some weeks ago, EPF organised a key **conference on patient safety** in Brussels. The report of the meeting is now publically available, compiling the highlights and take-home messages for better and safer healthcare for all patients in Europe- and the role of patients ourselves in achieving this.

January was not short of events! 2017 started with the last executive committee of **EUPATI** in its IMI project configuration, the first steering group meeting for the new EUPATI as an EPF programme, and dedicated workshops and the General Assembly of **ADAPT SMART**.

Some updates on our <u>YouTube</u> channel! Have a look at our **new video** on the special relationship we have with our members, and how important their feedback is for our credibility and work as the voice of patients in the EU.

Lembe Kullamaa from the **EPF Youth Group**, took part in a recent training at the European Medicines Agency (EMA) in London. Read her story on this very informative meeting!

Finally, we are happy to share some stories from our members on our **Blog**. You will read the testimonial from **Lupus Europe**, on how presumption can be detrimental to patients, and the policy manifesto from our French member **Le CISS** at the occasion of the forthcoming Presidential and legislative election in France.

Enjoy the read!

Marco Greco, EPF President and Nicola Bedlington, EPF Secretary General

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EPF CAMPAIGN ON UNIVERSAL ACCESS - KICK-OFF MEETING



The European Patients' Forum (EPF) will organise a policy meeting on Monday 27 February 2017 in Brussels to officially launch the EPF campaign on Access to Healthcare. The opportunity to discuss concrete actions towards Universal Health Coverage for All by 2030.

THE PATIENT EMPOWERMENT CAMPAIGN -LET'S EXPLORE THE EPF'S ROADMAP!



A major milestone of our recent campaign on Patient Empowerment has just been published. The Roadmap for Action proposes concrete actions policymakers, healthcare professionals, and other stakeholders across the EU can take to drive positive change.

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REPORT OF EPF PATIENT SAFETY CONFERENCE NOW AVAILABLE!



In November 2016, EPF organised an international conference on Patient & Family Empowerment for Better Patient Safety. The report of the event, including policy recommendations, is now publically available.

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ADAPT SMART GENERAL ASSEMBLY: PATIENTS' CONCERNS AT THE CENTRE OF THE DEBATES

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EUPATI GRADUATION CEREMONY AND FINAL CONFERENCE



Coming to a close as an IMI-project, the European Patients' Academy on Therapeutic Innovation (EUPATI) programme marked the occasion with a graduation ceremony for 100 expert patients and a final conference drawing conclusions on 5 years of effort by the EUPATI team, patients, and partners.

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YOUNG PATIENT ADVOCATE? OUR NEW INITIATIVE IS JUST FOR YOU!

SEE OUR VIDEOS ON OUR YOUTUBE PAGE

UPCOMING EVENTS

7/02/2017 | Mental Health Europe Meeting

Brussels

Mental Health & Active Ageing: Ensuring opportunities and participation in society at all ages

EPF attendance: Laurent Louette 21-22/02/2017 |EFGCP annual conference

Brussels

Meeting the Ethical Standards under the Clinical Trials Regulation: the Burning Questions (and Answers) for Researchers, Sponsors and Patients EPF newsletter



On 17 and 18 January 2017, the Adapt Smart consortium held its Annual General Assembly at the European Medicines Agency, in London. The twoday event gathered representatives from regulatory bodies, pharmaceutical industry, HTA agencies and patient organisations.



As part of our Capacity Building Programme, EPF has launched a new project: The Summer Training for Young Patient Advocates! An exciting and unique opportunity proposing tailored and high-quality training to young (18-30) patient representatives.

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répercussions sur la santé.

Public health does not usually play in big role in the French political debates. But this year might be different. Our French member LE CISS tells us why in an opinion letter, ahead of the general elections in France.

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(BLOG) A TRAINING DAY AT EUROPEAN MEDICINES AGENCY -EPF YOUTH GROUP



Lembe Kullamaa, Member of EPF Youth

(BLOG) EPF VIDEO – OUR MEMBERS, OUR COMPASS!

EUROPEAN PATIENTS FORUM

The feedback from our members is the backbone of our work. The new EPF video will tell you all about our consultation processes, and how we can support our members growing, for better patient advocacy in the EU.

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(BLOG) PRESUMPTION IS A VERY DANGEROUS THING – PATIENT STORY



Read here the very eye-opening

Group took part in November 2016 in a European Medicines Agency (EMA)'s training directed to patients and consumers. She tells us more about this interesting and useful experience.

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testimonial from Katharine Wheeler, from LUPUS Europe, on the importance of patients' feedback in diagnosis.

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A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



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