

# European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



// SEPTEMBER 2016 ISSUE



After what we hope was a relaxing summer break for all of you, it is our pleasure to welcome you back, with this 50th issue of the EPF newsletter, the *rentrée* issue!

As you may remember from our last newsletter, EPF is organising a public conference on Patient Safety in the coming weeks. Entitled 'Patient & Family Empowerment for Better Patient Safety', the event will take place on the 08th and 09th of November in Brussels. The conference will address how empowered patients and carers can improve safety of healthcare as a whole. You will find further details and registration information below.

While summer continues to shimmer in Brussels, some important policy dossiers already resurfaced! EPF participated in late August to the European Commission public consultation on **lay summaries of clinical trials**, where we were represented at two events from the **European Medicines Agency (EMA)** in London.

EPF keeps its dedicated focus on **access to healthcare** with our online **survey**, gathering feedback from across diseases and Member States. Share your thoughts with us! The survey is open until the 31st of October.

The **EUPATI** project is still going strong! The second face-to-face training for patients took place recently in Barcelona. Once again a very productive get-together for expert patients from all over Europe. We will share more information in our next issue regarding sustainability plans for EUPATI.

Our **Capacity Building Programme** is central to EPF's strategic objective to develop solid and sustainable patient organisations. In September we organised a **training workshop** on transparency and ethics, a crucial matter for the credibility of patient organisations in Europe. You will also find an **overview** of the Capacity Building Programme so far, with an overview of our activities in 2017.

Tomorrow is around the corner, and at EPF we truly believe in the future European patients advocates! Our **Youth Group** gathered for its autumn Meeting in Utrecht, the Netherlands. The young leaders reported on their recent activities and prepared planning for 2017. It was the first meeting for Laura, a new member from Belgium! Read below her portrait, and discover why indeed you can just call her Laura.

We open this month our blog to the '**European Federation of Homeopathic Patients Associations (EFHPA)**', our member, taking on our small questionnaire, introducing themselves and their objectives.

Finally, a warm welcome to our **new colleague** Selena Imerovic Hodzic, who joined our Brussels team as Project and Capacity Building Officer!

Warmest greetings,

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

A handwritten signature in blue ink, appearing to be 'M Greco'.

A handwritten signature in blue ink, appearing to be 'N Bedlington'.



## EPF CONFERENCE: HOW PATIENTS' AND FAMILIES' INVOLVEMENT CAN IMPROVE PATIENT SAFETY



On the 08th and 09th of November, EPF will organise a 2-day conference on patient safety, in Brussels. The event aims at exploring how the involvement of patients and their families could improve the current worrying figures on patient safety and health-related adverse events.

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## HOW SOCIAL MEDIA IMPACT MEDICINES-RELATED BEHAVIOUR: EMA WORKSHOP



Earlier this month, the European Medicines Agency (EMA) organised a workshop on social media, ancillary to the joint PCWP-HCPWP meetings. EPF was represented at both events.

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## EUPATI: SECOND FACE-TO-FACE TRAINING BARCELONA



## CLINICAL TRIALS: RESPONSE TO PUBLIC CONSULTATION ON LAY SUMMARIES



EPF participated in the European Commission's public consultation on a guideline for drafting lay summary of clinical trials results for lay persons. Welcoming these much-needed guidance, EPF provided the patient's perspective.

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## LET'S TALK ABOUT ACCESS: TAKE ON OUR NEW SURVEY!



In August, EPF launched a survey on access to healthcare in the EU. Designed by patients and patient representatives from within our membership, the questionnaire aims to gather experiences of patients across diseases and Member States.

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## OVERVIEW OF THE CAPACITY BUILDING PROGRAMME (CBP) IN 2016/2017



## WATCH OUR PATIENT EMPOWERMENT CAMPAIGN VIDEO!

### UPCOMING EVENTS

**29/9/2016** | [Lupus Europe Convention 2016](#)

#### Würzburg, Germany

The theme for this year's convention is "Treatment".

*EPF speaker:*  
Camille Bullo

**13-14/10/2016** | [PUTTING THE NEUROLOGY PATIENT PERSPECTIVE AT THE HEART OF RESEARCH AND BEYOND](#)

#### Dublin, Ireland

The pan-European workshop, held annually as part of EFNA's Training Initiatives for Neurology Advocates [TINA], has been designed to equip and empower neurology patient advocates with the information and skills needed to influence decision-making during the Research & Development [R&D] process, and beyond – in areas such as pricing, access and reimbursement. With a focus on patient reported outcome measures and patient based evidence, the course will explore why the engagement and involvement of patient advocates from the neurology sector is particularly important, and how this can be achieved.

*EPF speaker:*  
Camille Bullo

**18/10/2016** | [Fórum MAIS PARTICIPAÇÃO, melhor saúde](#)

#### Lisbon, Portugal

Final conference of our project MAIS PARTICIPAÇÃO, melhor saúde and launch of the Portuguese Charter for Public Participation in Health

*EPF speaker:*  
Camille Bullo

**17-18/10/2016** | [Patients Association of Kosovo](#)

#### Pristina, Kosovo

Two day conference on the successes and challenges of patients rights advocacy in Kosovo.

*EPF speaker:*  
Selena Imerovic

**20/10/2016** | "Value of health" seminar organised by Fipra

#### Brussels

*EPF attendance:*  
Kaisa Immonen

More than 50 patient advocates gathered in Barcelona, Spain, for five days of discussions and coaching on the different phases of a medicine's life cycle, in the framework of the European Patients' Academy on Therapeutic Innovation (EUPATI) project.

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Year after year, the Capacity building approach proves to be an important element underpinning our commitment to empower patients and patient organisations. Now is a good time to reflect on past achievements and look towards the next milestones.

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[medication errors](#)

**London**

*EPF attendance:  
Kaisa Immonen*

## MEMBER IN THE SPOTLIGHT

(BLOG) 5 QUESTIONS TO EUROPEAN FEDERATION OF HOMEOPATHIC PATIENTS' ASSOCIATIONS - EFHPA



We're happy to open our blog to our members! This month, we put the EFHPA to our now classic 5 Questions interview.

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(BLOG) EPF TRAINING ON TRANSPARENCY & ETHICS: "REPUTATION IS ESSENTIAL CURRENCY FOR ADVOCACY, PROTECT IT!"



Because of sensitivities around healthcare issues and the complex environment in which they evolve, ethics and transparency are an absolute priority for patient organisations. But how do you ensure your organisation meets the highest degree of integrity and accountability?

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(BLOG) HELLO, I AM LAURA!



Read below the story of Laura, a young Belgian patient with asthma. She tells about her daily challenges and aspiration for life and as a new member of the EPF Youth Group.

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(BLOG) EPF YOUTH GROUP ANNUAL EVENT



The 2016 annual Youth Group Meeting was held over the weekend of 9-11 September in Utrecht, the Netherlands. EPF staff Valentina Strammiello and Danielle Flores organised the meeting and attended as representatives of the Secretariat.

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

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