

European Patients' Forum Newsletter

A strong patients' voice to drive better health in Europe



//MAY 2017 ISSUE

Welcome to the latest issue of our Newsletter!

Our campaign on **Access to Healthcare** is developing strong momentum within the European Parliament! Read about how the five high-profile MEPs are driving this work as official champions. Each of them will promote our policy work on a particular action area of the campaign and stand up for the achievement of the UN SDG on universal health coverage by 2030.

Very much in line with our campaign, EPF, Medicines for Europe, the European Public Health Alliance, and the European Social Insurance Platform organised a **high-level debate on Universal Access to Health**, to move forward on collaborative approaches to this topic.

Representing EPF at the **eHealth Week** in Malta, our Secretary General Nicola Bedlington shared the perspective of patients to new policy initiatives on eHealth and ageing. EPF is preparing a survey on electronic health records and data sharing to be published later this year in parallel with the European Commission's Communication on Digital Health.

Following the publication of the results from the consultation on **Health Technologies Assessment (HTA)**, EU Health Commissioner Vytenis Andriukaitis confirmed the forthcoming Commission's proposal on a EU HTA collaboration

Meaningful patient engagement in the life cycle of medicines is one of EPF's priorities. We are pleased to welcome a new roadmap from **EUPATI** contributors detailing patient involvement in medicines' development and regulatory processes.

New member of EPF's Board, **Hilkka Kärkkäinen, President of GAMIAN-Europe** puts pen to paper and shares with us her vision for EPF and priorities for the near future.

Elected as full EPF membership in April, our German member, **BAG SELBSTHILFE** features in our 'Under the Spotlight' interview.

This month, our **Blog** has two passionate stories from young patients: Sophie, representing **LUPUS UK** tells us all about her challenges and hopes; while Andreas from the **Pancyprian Federation of Patients Associations**, shares his experiences and learnings as a patient.

Enjoy the reading!

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



MEET THE 5 CHAMPION MEPS OF THE #ACCESS2030 CAMPAIGN!



UNIVERSAL ACCESS TO HEALTH: HOW CAN WE ALL CONTRIBUTE?



[SEE OUR VIDEOS ON OUR YOUTUBE PAGE](#)

UPCOMING EVENTS

01/06/2017 | [Patient-MedTech Dialogue: Workshop on the new Medical Device and In-vitro Diagnostics Regulation](#)

Brussels

During the workshop, participants will have the opportunity to understand and contribute to the patients' and the industry's perspectives and potential concerns about the new legislations. Furthermore,

With the EPF campaign on Access to Healthcare, we want to have a real and meaningful impact on the EU health policy. To make our voice louder, we have identified five high-level champions who will be helping us to raise awareness about the barriers that patients face in accessing healthcare and to place universal health coverage at the centre of the policy debate.

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EHEALTH: MUCH MORE THAN PATIENTS' DATA



On 10-12 May, the annual eHealth Week took place in Malta. Bringing together all major players in the field, including patient organisations, the convention was the opportunity to reflect on new developments and get updates on the coming Commission's paper on the matter.

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EUPATI: GUIDELINES ON PATIENT INVOLVEMENT IN MEDICINES' DEVELOPMENT



Patient involvement in the whole life-cycle of a medicines is a key matter in patient empowerment, but can also bear some challenges and threats. A recent article from various EUPATI contributors proposes some new ideas on how to make it clear and rigorous.

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LET'S KICK LUPUS OUT!

On 27 April, health stakeholders gathered together in Brussels to explore avenues for collaborative contribution and commitment to better access for better health. A joint effort by EPF and other important players, the debate called for contributions from all parties involved, in a more holistic approach.

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HTA: ADVANCING TOWARDS EU COLLABORATION



The results of the recent Health Technology Assessment (HTA) consultation confirmed the need for a sustainable EU collaboration on HTA beyond 2020, echoing EPF's recommendations on stronger and deeper cooperation between Member States. Will this be taken over by the coming Commission's proposal?

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NEW EPF BOARD MEMBER HILKKA KÄRKKÄINEN: MENTAL HEALTH IS AS IMPORTANT AS PHYSICAL HEALTH



Hilkka Kärkkäinen, President of GAMIAN-Europe puts pen to paper and shares with us her vision for EPF and priorities for the near future.

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(BLOG) 5 QUESTIONS TO: BAG SELBSTHILFE, GERMAN NATIONAL COALITION OF PATIENT ORGANISATIONS AND DISABILITY GROUPS

there will be an opportunity to exchange views on relevant elements of the Regulations, including transparency measures and information to patients, clinical evaluation and clinical performance and stakeholder involvement.

EPF speaker:
Nicola Bedlington

[02/06/2017 | Patient-MedTech Dialogue: Workshop on Access to Healthcare and the EPF's campaign](#)

Brussels

During the workshop, participants will have the opportunity to hear the patients' and the industry's perspectives on various themes of Access to Healthcare. Furthermore, there will be an opportunity to exchange views on two of the Campaigns' themes: committing to sustainable investment in health and implementing access to a holistic range of health and social services.

EPF speaker
Nicola Bedlington

[07/06/2017 | How to Create an Ecosystem Which Unlocks the Full Potential of Health Data?](#)

Brussels

The objective of this session is to create some awareness on the benefits of health data for different stakeholders and to discuss the conditions for building a collaborative health data ecosystem in order to realize the full potential of this data.

EPF attendance
Kostas Alianni

[08/06/2017 | Health systems for the future - Making EU health systems resilient and innovative](#)

Brussels

EPF attendance:
Kaisa Immonen

[09/06/2017 | Scientific Panel for Health forum: Health Research in a Connected and Participative Society](#)

Brussels

EPF attendance:
Kostas Alianni

[09/06/2017 | Portugal National Alliance Meeting](#)

Lisbon

EPF attendance:
Camille Bullot

[14/06/2017 | EPF Policy Advisory Group](#)

Brussels

EPF attendance:
Kaisa Immonen

[17-21/06/2017 | HTAi 2017 Annual Meeting](#)

Rome

EPF attendance:
Valentina Stramiello

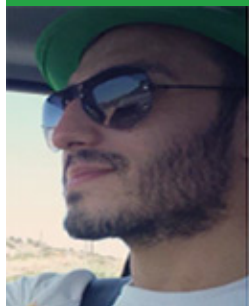
[21/06/2017 | IMPROVING ACCESS, CARE AND DIAGNOSIS FOR RARE DISEASES](#)



The World Lupus Day is celebrated every year on the 10th of May. We take the opportunity to share the call from our member Lupus Europe for more awareness and treatment opportunities. On our blog, you will read the incredible story of Sophie, a UK patient helping school personnel to get to know the disease.

[READ MORE »](#)

(BLOG) OVERCOMING A CHRONIC DISEASE: THE BEST IS YET TO COME



Andreas Christodoulou recently joined the EPF Youth Group, representing the Pancyprian Federation of Patients Associations. Read on our blog his very interesting story about overcoming an invisible yet serious disease.

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Every month we put the spotlight on one of our members. Today, we are delighted to catch up with BAG SELBSTHILFE, the German national coalition of patient organisations and disability groups, who recently joined EPF.

[READ MORE »](#)

Brussels

EPF attendance:
Camille Bullot

18-22/06/2017 | [Chicago DIA 2017 - Driving Insights to Action](#)

Chicago

EPF attendance:
Nicola Bedlington

22/06/2017 | [Value of Treatment Conference](#)

Brussels

EPF attendance:
Kostas Aligiannis

27-28/06/2017 | [EMA Patients' and Consumers' Working Party Meeting](#)

London

EPF attendance:
Kaisa Immonen

27/06/2017 | [The current and future treatment of Alzheimer's dementia](#)

Brussels

EPF attendance:
Katie Gallagher

29/06/2017 | [Conference on Medical Nutrition and Prevention for EU Patient Groups](#)

Brussels

EPF attendance:
Katie Gallagher

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

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CONTACT US

EUROPEAN PATIENTS' FORUM

Rue du commerce 31
1000 Brussels
BELGIUM

Phone : +32 (0)2 280 23 34
Email : info@eu-patient.eu
www.eu-patient.eu | eu-patient.org/blog



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EPF newsletter

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