

The European Patients' Forum newsletter – September 2018

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## Hello there,

Welcome to the first autumn edition of the EPF newsletter!

The second half of 2018 is setting out to be as busy and exciting for our community as the first.

The highlights of this month are a comprehensive update on [what is happening around Brexit](#) and why it should be of interest to patient organisations in the EU, as well as our take on the latest news on the legislative proposal on [Health Technology Assessment](#). EUPATI, the European Patient Academy on Therapeutic Innovation, has published a very timely [guidance on patient involvement in HTA](#).

Our PARADIGM team has been discussing the value of [patient engagement as a de-risking strategy](#) in medicines research and development at a major life science conference. We are also again participating in the [European Health Parliament](#) to draw policy-makers' attention to the value of EU health policy.

EPF members' activities featured in this issue are a [survey by EFNA](#) that discovered the main challenges faced by young patients living with brain disorders, and a white paper published by [France Assos Santé](#) together with several other French civil society organisations on medicines prices, therapeutic value and access.

The [Youth Group](#) introduces its newest member, Martin Mastrotto from Pau, in France.

We are also delighted to introduce [two new team members](#) at our Brussels secretariat.

Enjoy the reading!

Marco Greco, EPF President

Nicola Bedlington, EPF Secretary General



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## Policy Updates

**FEATURE ARTICLE:** [Is your patient organisation concerned about Brexit? It should be! →](#)

Brexit is a daily topic of discussion in the “Brussels bubble”. But

perhaps surprisingly, its seriousness for the remaining 27 EU Member States has gone relatively unnoticed.

### **HTA: Improvements in Parliament but Still More Work to do →**

Over the summer there have been interesting developments on the Commission's legislative proposal for collaboration on Health Technology Assessment at EU level.

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## **Projects**

### **Patient Engagement as a de-risking element of medicine development →**

The Nordic Life Science Days (NLS Days), the largest Nordic partnering conference dedicated to the life science industry, took place in Stockholm on 10-12 September.

### **The 4th edition of the European Health Parliament is ready to kick off →**

Four years ago the European Health Parliament (EHP) initiative launched. On 27 September 2018 the 4th edition will kick off with an informal meeting where the partners and 60 new "parliamentarians" will meet and set the scene.

### **EUPATI Guidance on Patient Involvement in HTA published in Peer-Reviewed Journal →**

The EPF-led European Patient Academy on Therapeutic Innovation (set up by the IMI-EUPATI project in 2012-2017), developed guidance documents for patient involvement in key areas of medicines research and development.

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## **EPF Members & Youth Group**

### **French civil society adds its voice to the debate on medicine prices →**

On 20 June, France Assos Santé and 7 other major French civil

society organisations published a White Paper on medicines prices, therapeutic value and access to medicines.

### **EFNA working with Young Europeans with Neurological Conditions→**

The European Federation of Neurological Associations (EFNA) launched a survey on access and stigma among top concerns of young patients.

### **Meet the newest member of the EPF Youth Group! →**

Martin Mastrotto is joining the EPF Youth Group as an EFCCA YG representative to keep advocating for all patients' rights.

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## **Events**



### **HTAi Patient and Citizens Interest Group Meeting**

*3 - 5 October 2018 / Stockholm, Sweden*

EPF speaker: Valentina Strammiello

### **European Health Forum Gastein**

*3 - 5 October 2018 / Gastein, Austria*

EPF speaker: Nicola Bedlington

EPF attendance: Katie Gallagher

### **EPF - Medicines for Europe Dialogue**

*8 October 2018 / Brussels, Belgium*

EPF speaker: Nicola Bedlington

### **Launch of the EPF European Elections Campaign 2019**

*9 October 2018 / Brussels, Belgium*

## Universal Access to Health Conference

9 October 2018 / Brussels, Belgium

EPF speaker: Nicola Bedlington

EPF attendance: Katie Gallagher

## Cloud in Health Advisory Council

10 October 2018 / Leeds, UK

EPF speaker: Nicola Bedlington

## Patient Advocate's Seminar

20 - 21 October 2018 / Brussels, Belgium

EPF speaker: Elena Balestra

## IMI Stakeholder Forum 2018

24 October 2018 / Brussels, Belgium

EPF speaker: Nicola Bedlington

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## EPF Team

### Hello Julien & Camilla! →

After the summer break, EPF has expanded the secretariat. Two new members joined: Julien Richard, the new Communications Manager, and Camilla Habre, the new Project Officer.

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## Publications



### EPF Transparency Guidelines →

What are the actual rules that a patient organisation should respect, and what are the processes to implement and monitor them in your organisation? This publication tries to answer these and other questions, and it provides



information and resources to guide you in fostering transparency within your own organisation.



### **Employment and Chronic Conditions - EPF's initiatives →**

Have a look at the latest initiatives we've developed for the inclusion of people living with a chronic disease in the workplace.

## Stay in touch

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