

The European Patients' Forum newsletter – June 2019

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Dear colleagues,

This is my first chance to introduce myself as the new Executive Director at the European Patients Forum. I am honoured to be taking on the mantle from Nicola Bedlington and very much look forward to working with Marco Greco, the EPF Board, the fantastic Secretariat Team here in Brussels and not least you our stakeholders.

In my first weeks I have been struck by the good will communicated to me as I have travelled around to meet with patient representatives, patient

organisations and those across the European health system. I have also felt a common belief and commitment amongst those to whom I have spoken to ensuring that the patient voice becomes integral to all aspects of health and social care. Much progress has been made and as EPF Director I know that this platform provides a starting point not an end point and that much work needs to be done to support the development of the patient voice at an individual and organisational level as well as ensuring that time and space is given for that voice to be fully integrated into all aspects of health and social care.

Facilitating effective communication must be core to our efforts, and as such I am very pleased that EPF has such a wide range of engagement platforms. Our newsletter is an important vehicle for reaching out to our network and I hope you enjoy this edition.

Among our key highlights, I am pleased to inform you that the [EPF 2019 Summary Report](#) is now out and available on our website! The report outlines the work and achievements made in the areas of empowering and enhancing the patient voice in a number of different ways. It also covers our cross-cutting activities aimed at strengthening our collective impact to ensure that all patients in Europe have access to high-quality and related care continues.

This month has seen plenty of Congress preparation and more updates on speakers, sponsors. Our programme is shaping up, and is almost complete! We are committed to having a diverse audience at our patient led event, so with limited availability please ensure you [register](#) as soon as possible to avoid disappointment.

Happy reading!

Usman Khan, EPF Executive Director



**EPF Congress 2019**



A few months to go, and yet many new highlights for EPF Congress 2019!

- Meet **Mair Elliott**, young patient advocate and one of our two Masters of Ceremonies! Take a look at this introductory and find out why she agreed to join us and which part of the Congress she is most looking forward to!
- Last week, we asked **Susanna Palkonen** patient representative and EPF Board Member to detail some initial thoughts on the Congress by answering a few questions. Find out what she replied !
- We are delighted to welcome patient representative **Cees Smit** as one of our keynote speakers for EPF Congress 2019! Drawing on his broad expertise and long experience, he will speak on the topic “Why patient involvement?” Read his full biography.

Want to stay in the loop with EPF Congress updates? Subscribe to our monthly Congress newsletter and visit our website at [www.epfcongress.eu](http://www.epfcongress.eu) for more information about our programme and speakers.

If you have not registered yet, please make sure you do so. [Click here for more details.](#)

## Policy Update

### [EPF President selected as patient representative to EMA's Management Board](#) →

EPF welcomes the official announcement and confirmation that our President Dr Marco Greco has recently been appointed as one of two civil society representatives to the European Medicines Agency's (EMA) Management Board. This [follows a decision of the Council of the European Union](#) on 6 June 2019. The appointment is for a three-year term starting on 15 June 2019.

Marco has a long track record of working with the Agency, as a member of the Patient and Consumer Working Party (PCWP), and for six years, serving as a patient representative on the Pharmacovigilance Risk Assessment Committee (PRAC) – a first for the Agency. Read his reaction [here](#).

### [Country-specific recommendations 2019: EPF calls for a strong EU health agenda](#) →

On 5 June 2019, the European Commission published its proposals for Country Specific Recommendations (CSRs) as part of the European Union's yearly European Semester cycle, which monitors the EU Member States' economic and fiscal progress. In a reaction released shortly after this publication, EPF is pleased to note that the Commission's recommendations recognise the need to ensure accessibility and affordability of healthcare for all as part of efforts to enhance health systems' cost-effectiveness and sustainability. For more information, read EPF's full analysis and call for a strong EU health agenda [here](#).

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## Projects

### [EUPATI Fundamentals – Training on Patient Engagement for Academy and Pharmaceutical professionals available!](#) →

The European Patients' Academy on Therapeutic Innovation (EUPATI)

is the EPF-led programme providing education and training to increase the capacity of patient advocates to understand and contribute to medicines research and development, and to improve the availability of medical information for the health interested public.

Following the success in patient training, EUPATI is now providing education on patient engagement for professionals working in academia and the pharmaceutical industry, to ensure the acceleration of effective patient engagement in Europe. The next training is planned on 21 November 2019 at EPF offices in Brussels.

For more information and to register please visit this [page](#).

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## EPF Members & Youth Group

### [Introducing Cystic Fibrosis Europe →](#)

We are delighted to welcome Cystic Fibrosis Europe (CF-Europe) to our EPF family! CF-Europe represents persons with CF and their families in Europe. It was founded at the European CF Conference in Belfast in 2003. Currently, national CF Associations from 39 European countries are members of CF Europe. We asked them a few questions in order to get to know them better.

### [Nordic Meeting for Primary Immunodeficiency: the shortage of immunoglobulins is a global problem →](#)

EPF Youth Group member Magdalena Dörögrip attended the *workshop on the supply of immunoglobulins* that was organised by the Swedish patient organisation [PIO](#) (Primär Immunbristorganisationen). This workshop gave doctors, nurses, pharmaceutical representatives and patient's a chance to tell their view of this problem.

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## Other news

### [Rising inequalities and harassment as fundamental rights protection falters →](#)

Many people across the EU risk being left behind, as growing

intolerance and attacks on people's fundamental rights continue to erode the considerable progress achieved to date, finds FRA's Fundamental Rights Report 2019.

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## Events



### **Conference on EU cooperation in health: “The future of health in the EU: United we stand strong”**

Organised by the Patient Access Partnership (PACT)

*11-12 July 2019 / Brussels, Belgium*

### **EPF Congress 2019**

*12-14 November 2019 / Brussels, Belgium*

## Stay in touch

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