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The European Patients' Forum Newsletter – May 2019

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## EPF Newsletter - May 2019

A video player interface for a trailer. The background is a photograph of a man with glasses and a dark suit over a white shirt, sitting in an orange chair. A large black play button is centered over the image. On the left, a blue speech bubble contains the text 'Getting involved'. On the right, a green speech bubble contains the number '19'. At the bottom of the video frame, a dark grey bar contains the text 'Why attend the EPF Congress 2019? Watch and share the trailer!'.

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## EPF Congress 2019

We are pleased to announce that our official [EPF Congress trailer](#) is now available for your viewing: help us share it and spread the word far and wide!

We would like to remind you that registration is open and available [via this link](#).

Are you interested in benefiting from a travel grant? EPF [offers 10 travel grants](#) covering registration fee, accommodation, travel costs, as well as attendance to the gala dinner.

Want to display some content during the exhibition? [Apply for a table top today](#) and become one of our exhibitors!

More details, preliminary programme and speakers' information are available on our [Congress website](#), however if you would like to receive more updates and speakers' interviews we strongly encourage you to subscribe to our [dedicated Congress newsletter](#)!

[Register here](#)

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## EU Elections 2019

[EPF calls on the newly elected mandate to ensure health is an EU policy priority and that patients' rights are implemented across the EU →](#)

Between 23 and 26 May 2019, European citizens and patients took to the polls to cast their votes for the next European mandate. EPF is very pleased to see that 13 (confirmed) of the 60 candidates that endorsed and showed support for our #europeforpatients campaign and take the opportunity to offer our most sincere congratulations to everyone. We look forward to working together in the future to ensure

issues that matter to patients are at the heart of EU health policies.

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## Policy Update

### [Vaccination workshop for Patients with Chronic Conditions in Romania →](#)

On 24 May, EPF co-organised a workshop on vaccination for patients together with COPAC, the Romanian national patients' umbrella organisation. This workshop was the second one organised in Romania, following the first event held on 1 November 2018 in Bucharest. It is part of an initiative by the European Patients' Forum to enhance vaccination uptake among persons with chronic conditions.

### [One year to go to restore the trust and confidence of patients and the public in the regulation of medical devices in the EU →](#)

Sunday 26 May marked the 365-day countdown to the application of the new EU Regulation on medical devices. To mark this critical milestone, earlier this month, EPF organised a webinar for its members, European and national patient organisations which aimed to present an update on the status quo, highlighting progress that had been made so far but also concerns and next steps for the coming year in terms of ensuring the optimal operationalisation of the new regulatory system.

### [EPF calls for effective implementation to ensure patient safety →](#)

In advance of the June Health Council, EPF calls for Member States to free up investment and increase the capacities of the Commission and national competent authorities to speed up the designation of notified bodies to ensure access to medical technologies and patients' safety come May 2020.

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## Projects

### [EUPATI – activities for 2020-2025 →](#)

The European Patients' Academy (EUPATI) is about to embark on a new journey. This upcoming phase in 2020 marks exciting new developments for EUPATI run under the auspices of EPF. This Public Private Partnership (PPP) has transformed the knowledge and impact achieved over the past 8 years in order to offer more meaningful patient education and engagement in the future.

### **[Summer Training Course for Young Patient Advocates 2019 →](#)**

The final countdown has begun: 45 days to go to the 3rd edition of the Summer Training Course for Young Patient Advocates! This year's aim will be to investigate how patient advocacy is evolving and facing emerging challenges and opportunities while keeping a strong ethical approach.

### **[CHRODIS+ Project visits Slovenia, Finland, Croatia, Greece and Serbia →](#)**

In March and April, the EPF Secretariat visited five pilot sites in different EU countries as part of the CHRODIS + project on fostering high-quality care for people with chronic diseases in Europe: Novo Mesto (Slovenia), Helsinki (Finland), Zagreb (Croatia), Thessaloniki (Greece) and Belgrade (Serbia).

### **[New website for IMI project EHDEN →](#)**

EPF is pleased to be part of the EHDEN (Electronic Health Data and Evidence Network) project that was launched as a Public-Private Partnership (PPP) under the framework of the Innovative Medicines Initiative (IMI), with eleven public partners, led by Erasmus Medical Centre, Rotterdam NL, and eleven pharmaceutical partners, led by Janssen Pharmaceutica, Belgium, working together as a consortium.

### **[The Innovative Medicines Initiative \(IMI\) launches a pool of patient experts →](#)**

IMI plans to create a pool of patient experts to strengthen the role and voice of patients in IMI activities at both strategic and operational levels. Patients (and family members and carers) who wish to be part of the pool should submit an Expression of Interest via the IMI website. Deadline for submitting expressions of interest is 16 July 2019. IMI will

hold a webinar for people interested in joining the pool on Tuesday 18 June.

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## EPF Members

### [Introducing the Netherlands Patient Federation →](#)

We are delighted to welcome Patiëntenfederatie Nederland to our EPF family! The Netherlands Patients Federation represents more than 200 patient organisations across diseases. We asked them a few questions in order to get to know them better.

### [Ageing with HIV →](#)

The Ageing with HIV project by our member the European Aids Treatment Group (EATG) sheds light on challenges that emerge from the increasing number of people living longer with HIV, facing new and poorly understood issues that still require further research and policy dialogue.

### [New tool facilitates better diagnosis of Parkinson's disease in clinical settings →](#)

The European Parkinson's Disease Association (EPDA) has launched the Parkinson's Disease Composite Scale (PDCS) in clinical settings in Belgium, Ireland, Italy, Portugal and Spain. The PDCS is a newly-developed tool for healthcare professionals – particularly Parkinson's specialist neurologists – to help them measure the severity of both motor and non-motor symptoms experienced by people with Parkinson's in a timely way.

### [Career opportunity - IDF Europe Regional Manager →](#)

The International Diabetes Federation European Region (IDF Europe) is looking to hire a Regional Manager to be based in the IDF European Region Office in Brussels, Belgium. The Regional Manager will be accountable to the Regional Board through the Regional Chair of IDF Europe.

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## Events



### **EFPIA Think Tank**

Organised by the European Federation of Pharmaceutical Industries and Associations (EFPIA)

*5 June 2019 / Brussels, Belgium*

EPF attendance: Nicola Bedlington

### **HTAi Annual Meeting**

Organised by HTA International

*16-19 June 2019 / Cologne, Germany*

EPF speaker: Valentina Strammiello

### **EHMA Annual Conference 2019: Health management 2.0**

Organised by the European Health Management Association (EHMA)

*17-19 June 2019 / Espoo, Finland*

EPF speaker: Kaisa Immonen

### **EUFAMI Family Congress**

Organised by EUFAMI in collaboration with FinFami

*19-20 September 2019 / Helsinki, Finland*

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