

The European Patients' Forum newsletter – April 2019

[View this email in your browser](#)



## AGM 2019: farewell to our Secretary General, Nicola Bedlington and what lies ahead for EPF



On 13-14 April 2019, EPF members gathered in Brussels for EPF's 16th Annual General Meeting. During the event, members of EPF's Board and Secretariat reported on 2018 activities and gave an overview of our current and upcoming work for 2019-2020. The meeting also saw the election of new board members and the approval of four new member organisations.

EPF's Annual General Meeting (AGM) has always played a key role in the democratic and governing process of the organisation. It approves the annual report and the financial report for 2018, and the budget and work plan for 2019. This AGM also saw the election of new Board members and voted to welcome three new members.

It was also our long-standing Secretary General Nicola Bedlington's last AGM after 13 years of leadership. The entire membership and the Board thanked her warmly for being a truly inspirational and dedicated leader and for making EPF the successful organisation it is today: she will be missed. At the same time, the team is looking forward to welcome incoming Executive Director Usman Khan, who will be officially joining the EPF Secretariat on 29 April. [Read more here.](#)

## EPF Congress 2019

[Registration for the first European Congress on patient involvement is now open" →](#)

We are pleased to announce that registration for the first patient community-driven Congress is officially open. This unique event will take place from 12 to 14 November 2019 at the Crowne Plaza Hotel – Le Palace, in the heart of Brussels, Belgium.

---

## European Parliament Elections 2019

[#EuropeForPatients builds momentum and increases its political support →](#)

EPF is campaigning for the 2019 EU elections, to bring patient involvement and access to healthcare at the heart of the EU agenda. Recently, European Commissioner for Health Vytenis Andriukaitis publicly endorsed the five messages we are promoting with our EU elections manifesto.

---

## Policy Update

### [Towards promising opportunities with the new EURIPID collaboration →](#)

On 10 April, EPF participated in the first meeting of the Stakeholder Dialogue Platform of the EURIPID collaboration. The EURIPID collaboration is a “voluntary and strictly non-profit cooperation between mostly European countries on building up and maintaining a database with information on national prices of medicinal products in a standardized format.” It is funded by the European Commission.

### [The 4<sup>th</sup> edition of the European Health Parliament officially comes to a close →](#)

The closing session of the European Health Parliament (EHP) took place on 2 April. It officially brought the edition to a close by presenting the recommendations issued by the group of young EHPers. As part of the overall aim to call on European and national decision makers to take action to improve the health of all citizens, they tabled recommendations for the upcoming European Parliament and Commission in the following five areas: data for healthy societies, health literacy, mental health, value of innovation, and air pollution.

---

## Projects

### [EUPATI Training: tailoring the Expert Training Course according to new demands →](#)

The EUPATI Expert Training Course is a unique opportunity for patients and patient advocates, offering expert-level training in medicines R&D. This pioneering course blends independent e-learning coursework with face-to-face training over a 14-month period.

### [PARADIGM: turning patient engagement into reality one year on →](#)

PARADIGM recently blew out candles for its first anniversary! The IMI-

project has arrived at the crucial time of having to leverage all the background work done last year into actionable outputs to ensure maximum impact in the ecosystem of patient engagement (PE).

---

## EPF Members

### [MEP Interest Group on Brain, Mind and Pain launches its new Book of Evidence →](#)

The Brain, Mind and Pain (BMP) initiative has launched its Book of Evidence (BoE) for the 2019-2024 EU mandate. This document sets a strategic vision on policy action to deliver better care for people with neurological and chronic pain disorders in the EU. It will be used as the core policy document of the MEP Interest Group on Brain, Mind & Pain – which will continue after the upcoming EU elections.

### [Making the Invisible Visible – World IBD Day 2019 →](#)

On 19 May the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) together with its 36 national patient associations and other IBD sister organisations will join efforts to raise awareness of the 10 million people living with IBD worldwide.

### [Share your experience of rare disease treatments via the new Rare Barometer Voices survey →](#)

Is there a treatment for your rare disease? Are you able to access it? EPF member organisation EURORDIS is currently running a Rare Barometer Voices survey on rare disease patients' experience of treatments. This global survey is open to all rare disease patients, family members and carers and is available in 23 languages until 30 April.

---

## EPF Youth Group

### [WAYS project conclusions and upcoming projects →](#)

On 10-12 April the members of the EPF Youth Group gathered in Antwerp (Belgium) to attend their bi-annual 2019 meeting. One of the main outcomes of this meeting was the advancement of the WAYS (Work and Youth Strategy) project.

---

## Events



### ICHOM Conference

2-3 May 2019 – Rotterdam, The Netherlands

EPF Speaker: Nicola Bedlington

### EMSP Annual Conference

10-11 May 2019 – Vilnius, Lithuania

EPF Speaker: Nicola Bedlington

### JA CHRODIS+ General Assembly and Conference

13-15 May 2019 – Budapest, Hungary

EPF Speaker: Valentina Strammiello

### Transforming the Medical Model Symposium

Organised by CEmPaC

16 May 2019 – Berlin, Germany

EPF Speaker: Kaisa Immonen

### COPAC-EPF workshop on vaccination

25 May 2019 – Cluj, Romania

EPF Speaker: Kaisa Immonen

### 2nd Workshop of the EUnetHTA Task Force on HTA and Medical Devices

Organised by the Ludwig Boltzmann Institute for Health Technology Assessment

28 May 2019 – Vienna, Austria

EPF Attendance: Valentina Strammiello

## **27th International Conference on Health Promoting Hospitals and Health Services**

Organised by the Competence Centre for Health Promotion in Hospitals and Health Care Gesundheit Österreich GmbH (Austrian Public Health Institute)

29-31 May 2019 – Warsaw, Poland

EPF Speaker: Lyudmil Ninov

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

Organised by the European Health Management Association

17-19 June 2019 – Espoo, Finland

### Stay in touch

[www.eu-patient.eu](http://www.eu-patient.eu)



[Twitter](#)



[Facebook](#)



[LinkedIn](#)



[YouTube](#)

---

*Copyright © 2019 European Patients' Forum, All rights reserved.*

Want to change how you receive these emails?

You can [update your preferences](#) or [unsubscribe from this list](#).