

The European Patients' Forum newsletter – November 2018

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Hello there,

2018 is coming to its end and we are still busy and excited with important actions related to our policy, projects and patient community work.

We are delighted to share with you the highlights of this month. It is important that guidelines reach patients: this is why we have worked on a [paper on clinical nutritional guidelines and summaries for patients](#). Vaccination is another topic that deserves our attention

and, as part of the initiative launched earlier in 2018, we held a pilot workshop with the patient community in Bucharest.

Patient organisations have a role to play in fighting antibiotic resistance as they can help raise awareness of the issue and improve people's health literacy on this topic. The survey on Electronic Health Records is available now in five new languages: take this opportunity to share with us your perspectives and experiences on electronic health records!

EUPATI, the European Patient Academy on Therapeutic Innovation, has published an important guidance on patient involvement in regulatory processes. Furthermore, we are happy to announce the closing event of STYPA 2018, the Summer Training Course for Young Patient Advocates.

EPF members' activities featured in this newsletter regards the EPF-Medicines for Europe dialogue that took place in 8 October 2018 and we have summarised it for you.

Last but not least, the Youth Group discusses the issues of employment for young patients.

We are also delighted to introduce two new team members at our Brussels secretariat.

Enjoy the reading and see you in December for the wrap-up newsletter of 2018!

Marco Greco, EPF President

Nicola Bedlington, EPF Secretary General



Policy Update

Patient Organisations Have Co-Signed a Joint Statement on HTA

→

15 European patient organisations have co-signed a Joint Statement to draw the attention of Member States' representatives to the need of adequately involving patients in joint consultations on HTA.

EPF paper on clinical nutrition guidelines and summaries for patients →

EPF together with our member organisation the Patients Network for Medical Research and Health (EGAN) set up an EU patient task force on information to patients on nutrition.

The importance of vaccination for patients →

When a patient with a chronic condition catches an infectious disease, it can be more dangerous and difficult to manage because of the increased risks of complications, problems with treatment interactions and adverse effects. Many infectious diseases are, however, preventable through vaccination.

Patient organisations have a role to play in fighting antibiotic resistance →

Ever since antibiotics were invented, the “race” has been on between bacteria and science, with bacteria becoming resistant to existing medicines, and science trying to come up with new medicines.

Survey on EHR – five new languages available →

EPF has launched a survey to gain knowledge on patients' and patient organisations' perspectives and experiences on electronic health records (EHR). After a first version in English, new versions in five languages have now been published to help further dissemination.

ISPOR Europe 2018 Conference highlights the importance of meaningful patient engagement →

EPF attended the International Society on Pharmacoeconomics and Outcomes Research (ISPOR) Europe 2018 Conference in Barcelona on 10-14 November.

Projects

[Closing event of the Summer Training Course for Young Patient Advocates →](#)

EPF believes young patients are the future of patient advocacy. This is why have we continued to strengthen our youth-related activities in 2018 as well, with the second edition of the EPF Summer Training Course for Young Patient Advocates – Leadership Programme (STYPA).

[Peer-Reviewed EUPATI Guidance on Patient Involvement in Regulatory Processes published in Frontiers in Medicine →](#)

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

EPF Members & Youth Group

[EPF - Medicines for Europe dialogue 2018 →](#)

On 8 October, EPF met with Medicines for Europe for the annual dialogue between our members. Patient representatives from all over Europe met with representatives of the generics, biosimilars and value-added medicines industry to exchange perspectives and discuss how to optimize efforts for better access to high-quality medicines for patients.

[The issues of employment for young patients →](#)

From 12 to 14 October, the EPF Youth Group gathered in Sofia, Bulgaria for its second annual meeting, in order to put in practice the 2018-2019 YG Action Plan. This new Action Plan focuses on the challenges and obstacles young people with chronic conditions face when looking for jobs.

Resources

[New recorded webinars available →](#)

EPF is happy to share with you three new recorded webinars
Transparent Funding in Patient Organisations, on Making Patient
Engagement Happen, PFMD* and shaping the Patient Engagement
Management Suite, and on Blockchain in Healthcare.

Events



Meeting on care pathways and integrated care in asthma and allergies

3 - 4 December 2018 / Paris, France

EPF speaker: Kaisa Immonen

The Future of Healthcare in Cyprus Conference

3 December 2018 / Nicosia, Cyprus

EPF speaker: Andreas Christodoulou (Youth Group President)

EU Patient Task Force on Nutrition

4 December 2018 / Brussels, Belgium

EPF attendance: Katie Gallagher

EFPIA Think Tank

5 December 2018 / Brussels, Belgium

EPF attendance: Nicola Bedlington

Value-Based Healthcare in the Digital Era

18 December 2018 / Paris, France

EPF attendance: Nicola Bedlington

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