Subscribe | Past Issues | Translate ▾ | RSS

The European Patients' Forum newsletter – July 2019

View this email in your browser

European
Patients
Forum

Dear reader,

The EPF Secretariat has been busy drawing together projects, policy updates and other activities before the summer break.

This month's highlights include the third edition of the EPF Summer Training Course for Young Patient Advocates, which was a tremendous success. The whole team is very proud of what we achieved and with the feedback received so far.

We are also very proud of our Youth Group for continuing to play an active role in STYPA, and beyond!

To mark the appointment of Ursula von der Leyen as President of the European Commission, we were very pleased to have been able to make a joint statement with colleagues from the European Health Management Association, European Public Health Alliance, European Public Health Association and the Association of Schools of Public Health in the European Region. EPF joined these prominent health NGOs in making a strong statement calling for prioritisation of health in the new Commission.

The opportunities offered by a new Commission and Parliament feature prominently in the thinking of the EPF Board and Secretariat. At EPF we are focussed on developing and expanding our network of partners working across the health spectrum, so as to be able to fully represent the patient voice over the next mandate. This will include follow-up on the #europeforpatients campaign in the new European Parliament, as well as coordination of further #EU4Health activities.

We are also very happy to announce that the report of the Multistakeholder Roundtable on Inclusion of People with Chronic Conditions in the Workplace and Combatting Discrimination is out, and available for your download.

Last but not least, we are sharing updates on EUPATI, COMPAR-EU, and our recently launched DigitalHealthEurope – a project aimed at identifying digital tools for better patient empowerment.

The EPF Newsletter will be back in September; in the meantime, enjoy the summer and a well-deserved break!

Happy reading!

Usman Khan, EPF Executive Director

Summer Training Course for Young Patient Advocates 2019

Becoming #Advocates4Health →
Another year, another success! The third annual edition of the Summer Training Course for Young Patient Advocates took place on 7-10 July in Vienna 2019, with the theme “Shaping the Future of Patient Advocacy”.

EPF Congress Update

Places for EPF Congress are going fast… make sure you secure yours in time!

In order to meet future challenges, healthcare must urgently shift from a fragmented disease-focus to a person-centred, integrated, participatory approach. Patient involvement is an underused resource in the development of innovative, patient-centred healthcare design and delivery at all levels. It has enormous potential for improving healthcare effectiveness, efficiency and long-term sustainability. However, this is not yet a reality in Europe.

The EPF Congress – developed by representatives of the patient community themselves – will start a process towards real and lasting change in attitudes, knowledge and resources, moving forward policies and practices that will really empower patients.

- *How can co-designing healthcare services and systems with those who use it be successful?*
- *How does patient involvement can contribute to the best value for money in healthcare?*
- *Why must partnership with patients become the norm in health research?*
- *How can patients and their families be empowered to improve patient safety?*

We will discuss these and many more questions, supported by our excellent speakers, and we need your expertise and participation to help us co-create solutions and make this event even more meaningful! Take a look at our **programme** for information about topics and speakers.

We are happy to answer any questions you may have in the meantime.

Seating is limited: **register today** if you have not already done so!

Meet **Zoltán Albert Aszalós** from Semmelweiss University, our second Master of Ceremonies! Take a look at this introductory **video** and find out why he agreed to join us and what he is most looking forward to about the Congress.

Last week, we asked **Dr. Miklós Szócska** a few questions about his role as Congress ambassador and his thoughts on patient involvement. **Here is what he replied**.

We are delighted to welcome patient **Freek Spinnewijn** as one of our speakers for EPF Congress 2019! Discover his biography and more speakers **here**.

Policy Update

Joint call: Recipes for a Healthier Europe by the new Commission President-elect? →

Ursula von der Leyen's medical background has a huge potential, European patient, academic and public health NGOs say. We call on Ms von der Leyen to include a senior level health commissioner in her team, with a strong mandate, and to ensure that one of the Vice-Presidents of the Commission has overall responsibility for mainstreaming health across the whole of the Commission.

Roundtable report: “Inclusion of People with Chronic Conditions in the Workplace and Combatting Discrimination” →

The “Multi-Stakeholder Roundtable on the Inclusion of People with Chronic Conditions in the Workplace and Combatting Discrimination” took place on 21 May 2019. The event brought together 29 stakeholders across the spectrum of employment and social protection, with speakers comprising patients, policy makers, business representatives and researchers.

EPF initiative on vaccination: progress on shaping the Patient’s Guide →

Our work on the importance of vaccination for patients with chronic conditions is progressing. As readers will know, EPF started an initiative in 2018 specifically aiming to provide information and resources for patient organisations to support their advocacy on vaccination. Many of our member organisations are either active, or wish to be more active, on this topic, but we learned there was a gap in provision of resources focusing specifically on chronic conditions.

EPF responds to public consultation on EMA Strategy →

At the end of June, EPF submitted a response to the European Medicines Agency’s consultation on its strategic priorities for the next years, ”Regulatory Science to 2025”. The EPF response, submitted via online questionnaire, will be published by the EMA. In the meantime you can read it on our website.

Projects

EUPATI Update: Patient involvement in medical technology research and development →

EPF and MedTech Europe organised the fifth dialogue between the MedTech industry and patient groups represented by EPF in Brussels on 28 June 2019. The agenda covered the new regulations applicable to the MedTech sector, the lifecycle of products developed and manufactured in this sector, and – very importantly – the possibilities and modalities of patient involvement and education in MedTech research and development.

COMPAR-EU and EPF 2019 – read what's next for this year →
COMPAR-EU is a multimethod, inter-disciplinary project that will contribute to bridging the gap between current knowledge and practice of self-management interventions. COMPAR-EU, which began in January 2018, aims to identify, compare, and rank the most effective and cost-effective self-management interventions for adults in Europe living with type 2 diabetes, obesity, chronic obstructive pulmonary disease, and heart failure.

Digital tools for citizen empowerment and for person-centred care with a particular focus on the interaction between citizens and healthcare providers →
We are pleased to remind you that as of May 2019 EPF has formally kicked off with its activities and tasks in the DigitalHealthEurope project, funded by the European Union's Horizon 2020 Research and Innovation programme.

EPF Members & Youth Group

World Pulmonary Hypertension Day – photo contest →
The pulmonary hypertension community celebrates World Pulmonary Hypertension Day (WPHD) on 5 May. Many events are organized on or around this date, and hundreds and hundreds of photos were taken.

New results of the EURORDIS Rare Barometer survey on patients' preference on rare disease data sharing and protection published →
EURORDIS-Rare Diseases Europe has announced the results of the first multi-country survey on rare disease data sharing and protection, published in the Orphanet Journal of Rare Diseases by EURORDIS and the School of Social Sciences of Cardiff University. Over 2,000

rare disease patients, family members and carers from 66 countries representing 600+ diseases responded to the survey through the Rare Barometer Voices.

European Kidney Forum 2019 – Event report →

On 25 June 2019, in Brussels, Belgium the European Kidney Health Alliance (EKHA) conducted their European Kidney Forum Policy Roundtable on Organ Donation and Transplantation in Europe with the theme “Are we meeting the needs of patients?”. The event saw representatives from largescale pharma companies, NGOs, industry, hospitals, transplantation centers, universities, the EU Commission, doctor committees, national executive agencies and many more.

Events

2nd Open Forum on Patient Engagement

Organised by EUPATI, PARADIGM and PFMD

18-19 September 2019 / Brussels, Belgium

EPF Congress 2019

12-14 November 2019 / Brussels, Belgium

Stay in touch

www.eu-patient.eu

Twitter Facebook LinkedIn YouTube