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The Patient Perspective

October 2021



Reflections

Apologies for the week late newsletter but we had our hands tied with the EPF Congress 2021.

Having said that, the **EPF Congress 2021** was a smashing success with over 450 registrants across 42 countries attending over the four virtual days. There's more information below in our brief event recap but stay tuned for the full Event Report in the coming weeks and the recorded sessions to be uploaded on our Youtube Page.

You can **PRE-REGISTER here** for our follow-up Congress 2022 to continue the conversation on digital transformation.

Besides the Congress, our **Policy** team has been extremely busy with the EU4Health Programme, as our co-led #SaveEUHealthNGOs yielded some great results, resulting in the restoration of Operating Grants. More on that below along with other important policy news.

Our **Projects** team has a lot of interesting announcements revolving around the Gravitare Health project, EU PEARL and H2O. Our Youth Group is on the lookout for new members, so if you know any 18-29 year olds looking to improve the lives of young European patients, find out below.

Don't forget to check our **Calendar of Events** at the bottom to see the special days and events from us and our member organisations.

Stay safe and enjoy the weekend!



News From the Secretariat

updates from the inside

EPF Congress 2021 - RECAP

Education, co-creation, opportunity but most importantly, TRUST. According to EPF's President Marco Greco, these are the main takeaways of the EPF Congress 2021 on the digital transformation of healthcare, held virtually from 26 to 29 October 2021.

[Read our brief recap>>>](#)

Digital transformation of healthcare

Virtual event
OCT 26-29, 2021

Julie Spony joins the EPF Policy Team

We would like to extend a warm welcome to the newest member of the Policy Team, Julie Spony. She will be joining as the new "Policy Assistant" from mid-November. She is a French national, and has worked at the European Parliament and the European Commission.



The EU Patients' Podcast - New Episodes Available!

In October, we put out a few new podcast episodes. Have a listen:

- **#21 - Patient Health Data with The BMJ's Emma Doble (EPF Congress 2021)**

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- **#23 - Fertility Week with Satu Rautakallio-Hokkanen of Fertility Europe**
- **PERISCOPE Monthly Talks #7 - Health Inequalities with Prof. Giuseppe Costa**



New episodes available on:



or wherever you get your podcasts!



Policy and Advocacy Corner

discussing the most relevant patient-centered policy and advocacy issues

Our Policy Activities in September

We also continued working on the topic of **cross-border healthcare**. We are looking at **the extent to which patients' rights and patient mobility are granted by the current European legislative framework**. For that, we attended a workshop organised by the European Commission (**DG Sante**) in cooperation with the Association of European Border Regions (**AEBR**) on patient mobility in selected EU cross border regions. Among the workshop's conclusions, the most important is probably the following: to better understand cross-border healthcare in Europe we need better data. For example, data gaps are a result of a diversity of approaches while collecting them. In addition, optimising the impact of existing EU patients mobility mechanisms on the beneficiary target groups (i.e., cross-border patients) depends on design-led processes. Finally, a recommendation was given to National Contact Points, who should continue engaging with patients but at the same time, should look into how to provide better and more tailored information.

EPF also continued fulfilling its **speaking commitments** with other organisations - both virtually and in person. We consider that these meetings allow us to amplify the patient community's voice and give our opinion on certain topics. For example, we participated in a panel discussion at the **launch event of the Oath to Society for clinical and hospital pharmacists** created by the European Association of Hospital Pharmacists (**EAHP**) and the European Society of Clinical Pharmacy (**ESCP**). During this event, we talked about the patients' perception of hospitals and clinical pharmacists as valuable and trusted healthcare professionals. On a different topic, we intervened in an event organised by the Federation of European Academies of Medicine (**FEAM**) to talk about the new **European Health Emergency Preparedness and Response Authority (HERA)**.

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protect public health. We believe the HERA is essential to ensure better EU preparedness and response in terms of medical countermeasures to serious cross border health threats. However, if it is to serve patients and public health, it should be an independent public authority with a clear mandate driven by the public interest.


Operating Grants Maintained under EU4Health Programme

We are glad to announce that on 25 October, Commissioner Kyriakides **declared** that **Operating Grants for health NGOs will be maintained under the EU4Health Programme**. This announcement is a welcome positive step forward following months of strong **advocacy campaign** co-led by EPF, EURORDIS, Alzheimer Europe and EPHA, with the support of over 20+ health NGOs, key **stakeholders**, and **over 50 Members of the European Parliament**. Commissioner Kyriakides also announced that the Operating Grants will be at least at the level of the previous Health Programme (3rd) and that more details will be shared around mid-November. EPF, together with the other health NGOs, will follow and directly engage in the next steps to make sure that the details and framework of the EU4Health Operating grants - including for instance scope and eligibility criteria – will be in line with the ambitious nature of the EU4Health programme and the EU Health Union plans, providing health NGOs with adequate support to act as recognised partners of the EU. Particular focus will be given to timeline and the urgency of the matter, especially considering the current Operating grants gap due to their exclusion from the 2021 EU4Health Work Programme. You can read more about this topic [here](#).



Stella Kyriakides ✓
@SKyriakidesEU

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Civil society make an invaluable contribution to  policy making and are key for building a strong European [#HealthUnion](#).

[#EU4Health](#) is both a response to [#COVID19](#) and a funding plan for the future.

As such, we will make sure that operating grants for NGOs are maintained.





briefings on EPF's ongoing projects

2nd Call for interest – Gravitate Health Project searching for User Advisory Group Members

EPF is pleased to announce the 2nd call for representatives for a User Advisory Group (UAG) for the [Gravitate Health Project](#).

The UAG **reviews and advises on the Gravitate Health activities from a user perspective**, and identifies mechanisms for meaningful patient and public involvement and input throughout the project. We believe multi-stakeholder engagement at the heart of Gravitate Health activities will be key to the success of this project.

We are searching for **Patient, Citizen/Consumer and Healthcare Professional representatives** from a diverse range of age groups, genders and geographical origins. The call is open **from 8 November 2021 to 6 December 2021**.

[Learn more about the call >>>](#)



PEOF October session materials – now on demand

Resources for the [Patient Engagement Open Forum \(PEOF\)](#) 2021 sessions held on 6 & 7 October 2021 are now available for download and re-play.

At the October PEOF sessions, the European Patients' Forum organised a session on [what patients want from electronic medicine leaflets](#) – the session slide show and recording are also available online.

PEOF is co-organized by [PFMD](#), [EUPATI](#) & [European Patients' Forum](#) as a series of virtual events in a multi-stakeholder environment to advance the efforts towards stronger patient engagement. Stay tuned for the next session.

[Access the materials for all sessions here >>>](#)

4th EU PEARL General Assembly Meeting

The fourth General Assembly Meeting (GAM) for the [EU-PEARL project](#) took place on 13 and 14 October under the banner 'Overcoming disease challenges together to build a common EU-PEARL network.' This GAM focused on the condition-specific project areas (known as work-packages).

Over the course of two days, participants discussed platform trials and their set-up, shared best-practices and collaborations on clinical networks, data sharing in global trials, and looked forward to the next 6 months ahead.

The [EU-PEARL](#) team has also prepared a video to summarise the 3rd GAM, which was held over the summer under the banner 'Inspire, Engage, Enable and Transform'.

[Watch the video here >>>](#)

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3rd General Assembly for H2O: Powering Health Data

On 4 and 5 October, the **Health Outcomes Observatory (H2O)** project held its third project General Assembly (GA) under the banner 'Powering Health Data.' The GA was an important milestone in marking the considerable progress made towards creating the foundation of the H2O project: creating a standardised language for patient reported outcomes so that patients have better discussions with their doctors.

The GA was held over two days, with one day being open to the public. Project partners shared their progress on several key activities including the launch of a consultation to create standardised language, a data storage governance model and infrastructure, among others. On the public day, several panels were held with participants to hear their feedback on topics **central to H2O**.

Read more about the H2O GA
[>>>](#)



COMPAR-EU Annual Meeting – Hybrid!

On 21 and 22 October, the **COMPAR-EU project** held its first in-person consortium meeting in Hamburg. The European Patients' Forum (EPF) attended virtually.

This year's annual meeting focused on the results of the project's network meta-analysis, the online project platform, and much more. The EPF team presented its work on the COMPAR-EU **lay summaries**, and its work over the last months with the **patient panel**.

COMPAR-EU is a Horizon project which aims to compare the effectiveness of self-management interventions in 4 chronic conditions. To learn more about the project, and the role of the European Patients' Forum, head to our **dedicated project page**.

Stay tuned for further updates on this meeting!



Youth Group

initiatives, stories and events from our most budding members

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the lives of young patients in Europe for the better.

Apply here → <https://bit.ly/joinepfyouth>



EPF Youth Group

We're looking for
New Members!

Together we can change the lives
of **young patients in Europe**

 europeanpatients'forum
Youth Group

Progress during STYPA 2021

STYPA 2021 began in May 2021, and it has been a very fulfilling experience so far. Youth Group Vice-President Anastasia Semaan takes us through her journey as a STYPA Team Leader during 2021. [Read about it here>>>](#)



Member Focus

highlights from our member organisations



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Alzheimer Europe has published a new edition of its **"Dementia in Europe"** policy magazine, in an electronic format. It highlights our efforts and those of our member associations to make dementia a European priority, and provides updates on the latest national- and European-level policy developments in the dementia field.

[Download the latest edition>>>](#)

Reducing health inequalities' **NOVEMBER 19TH, 2021. 10.00 – 13.00hrs**

The annual conference of the MEP Interest Group on Brain, Mind and Pain will explore best practices in reducing health inequalities for those living with neurological disorders and chronic pain conditions. High level stakeholders will discuss how we can advance meaningful policies and interventions to address the drivers of this health inequity, before we take a practical look at examples of best practice that can be scaled up and applied to these disease areas.

[Register Now>>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

Lilly withdraws EU application for coronavirus antibody license

Lilly has withdrawn its application for a rolling review of its COVID-19 antibody therapy with the European Medicines Agency, citing a lack of demand for its treatment to generate the required data.

UK approves first pill to treat COVID-19

MSD won U.K. authorization for its new antiviral coronavirus treatment, the first such approval for an oral medicine to treat adults suffering mild-to-moderate cases of COVID-19. A recent study found that molnupiravir halved the risk of hospitalization or death among at-risk people if it is given early in their infection. MHRA called the treatment "safe and effective."

EU to accept NHS COVID pass as proof of vaccination

The European Commission announced today that the British NHS COVID pass will be accepted as full proof of vaccination, equivalent to the EU's current certificates. This measure will allow NHS COVID pass-holders to prove their vaccination status when traveling, visiting bars or restaurants, and entering any other places one needs to show vaccination.

Commission bans 23 chemicals in cosmetic products

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ranked in the top category of hazardous chemicals toxicity classes according to EU legislation, with the ability to cause cancers, genetic mutations and damage to reproductive processes.

Keep your vitality. A life without health is like a river without water

Maxime Lagacé



Calendar of Events

1 November

All Saints Day

[visit our website](#)

11 November

Armistice Day

[contact us](#)

14 November

World Diabetes Day

18-24 November

World Antibiotic Awareness Week

19 November

EFNA's 'Turning principles into action: best practice in reducing health inequalities'

20 November

Capacity Building Module on Fundraising and Engagement 2021 Closing Event

25 November

Capacity Building Alumni Event

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