



The Patient Perspective

November 2021



Reflections

Time flies when you're having fun. We can't believe we're nearing the end of 2021.

Our **Policy** team has had a whirlwind month, collecting views on the ongoing revision of the general pharmaceutical legislation while continuing its strong advocacy work in Digital Health, particularly on EHDS and AI.

Our **Projects** team has a lot of interesting announcements revolving around the Gravitare Health project, CORE-MD and Data Saves Lives.

Our **Youth Group** continues its work on Sexual Health and Well-Being with a new article below and stay tuned for their upcoming podcast on the project.

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 taking place in December.

Stay safe, bundle up and enjoy those Black Friday deals!



News From the Secretariat

updates from the inside

The EU Patients' Podcast - New Episodes Available!

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

- **Fertility Week with Satu Rautakallio-Hokkanen of Fertility Europe**
- **PERISCOPE Monthly Talks #8 - COVID Data Atlas with Enea Parimbelli**

The podcast will finish Season 1 with its final episode launching on 7 December.

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New episodes available on:



or wherever you get your podcasts!

Continuing the Conversation on Digital Transformation

Join us from 21-22 April 2022 as we follow-up from our 2021 Congress and continue the conversation in a more intimate and focused setting.

PRE-REGISTER FOR 2022 at epfcongress.eu



Continuing the *conversation*
on digital **transformation**

#EPFCongress2022

APRIL 21 - 22, 2022



Policy and Advocacy Corner

*discussing the most relevant patient-centered
policy and advocacy issues*

Our Policy Activities in November

November has been a busy month for EPF's Policy Team, as we approach the end of the year and many advocacy activities will come to a halt during the Christmas period.

For a couple of weeks now, the team's major priority has been inducting and welcoming its new Policy Assistant, **Julie Spony**! She is a French national with a rich and diverse background working for EU institutions and in several policy fields. She is gradually landing in the healthcare policy "realm". She will provide cross-policy assistance to the team and participate in external meetings and events as needed.

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pharmaceutical legislation. This input will be used for drafting EPF's final response to this consultation. The EU's pharmaceutical legislation is a very important topic for the patient community, as it touches upon topics such as access to medicines, pricing, shortages, and more. In the same vein, on 24 November the European Parliament voted in Plenary its own report on the Pharmaceutical Strategy for Europe, to which the EPF provided several inputs while it was being drafted.

Moreover, the Policy Team continued its strong advocacy work in Digital Health, in particular on the European Health Data Space (EHDS) and Artificial Intelligence (AI). EPF presented its **position** on the EHDS twice, at a Visegrad 4 seminar, and then at the **Digital Health Society Summit**. The team have also promoted its work on AI during a dedicated organised by the **European Policy Center**. Lastly, the team continue on its AI work supported by the European NEF Fund on AI. More info on the latter is available **online**.

Finally, on 22 November, a team Member spoke at the **Global Heart Hub Unite Summit** on the impact of the COVID-19 pandemic on patients and patient organisations. The results are clear: patients and patient organisations have experienced many and severe challenges due to the ongoing pandemic, treatments have been delayed, communication has not always been clear, funding opportunities for organisations have decreased, and more. The full Survey Report, as well as an infographic summarising its key conclusions and recommendations, are all available **online**.



Call for Patient Advisors for the CORE-MD Project

EPF is pleased to announce a call for patient advisors for **CORE-MD**, a project focusing on translating expert evidence on high-risk medical devices into advice for EU policy makers.

We are searching for 10 **people living with high-risk medical devices**, such as cardiovascular devices, orthopaedic devices, or diabetic medical devices, among others. The advisors may also be carers of people with such devices, or individuals soon to have a high-risk medical device inserted.

The patient advisors will inform the work of the project by participating in 2-3 rounds of surveys and a focus group meeting that will aim to **capture patients' experiences and reports on measures that matter to them** in their specific situation. These experiences and preferences will be taken into account when formulating the advice for EU policy makers, and ensures that patient experiences and priorities are integrated into the project from the start.

The call is open until 1 January 2022.

[Learn more about this call, CORE-MD, and the role of EPF >>](#)
[Access the application form >>>](#)



CORE-MD

*Coordinating Research and Evidence
for Medical Devices*

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

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(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 closes on **6 December 2021**.

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



Registrations open for the December PEOF 2021

Registrations are open for the final edition of the 2021 Patient Engagement Open Forum (PEOF). The next PEOF will take place on **7 and 9 December 2021**.

The final edition of the year will feature sessions on **engaging young patients** and their parents in **medical devices**, making **digital health governance accessible**, and a closing session on the **evolving landscape of patient engagement** followed by an opportunity to shape the agenda for PEOF 2022.

PEOF is co-organized by PFMD, EUPATI and European Patients' Forum.

Register now to contribute to the ongoing projects and become a part of the journey towards stronger patient engagement!

[Register for the December 2021 PEOF >>>](#)

Launch of the Data Saves Lives Toolkit

At the **EPF Congress 2021** session on Patient Empowerment Data & Digital Health Literacy, the **Data Saves Lives** (DSL) initiative announced the publication of its awaited toolkit.

The toolkit was shaped over one year of consultations, a workshop event in December 2020 and through listening to the needs and gaps identified by national and international patient organisations as well as health influencers.

The DSL toolkit aims to equip patient groups and health influencers with the information and materials they need to have a **positive dialogue with their communities about health data**, as well as potentially launch their own health data initiatives. It includes guidance on how to explain *how* data saves lives, a risk assessment tool on engaging in digital health initiatives, template webinar agendas and surveys, and many more resources.

Watch this space for the upcoming boot camp workshop calls next year on how to use the toolkit!

[Access the toolkit >>>](#)

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Youth Group
initiatives, stories and events from our most budding members

Sexual Health and Well-Being of Young People with Chronic Conditions

We asked psychologist and certified psychosexologist Moira Tzitzika to answer some of the most pressing questions on sexual health and well-being of young people with chronic conditions. [Read her answers>>>](#)

europaenpatients'forum
Youth Group

SEXUAL HEALTH AND WELL-BEING OF YOUNG PEOPLE WITH CHRONIC CONDITIONS

by: Moira Tzitzika, PhDc



Youth Group at the #EPFCongress2021

President of the EPF Youth Group, Ivett Jakab discusses her role as co-host of the event and how the Youth Group participated over the four virtual days. [Read more>>>](#)

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Healthy the needs
A couple of minutes to meet your needs

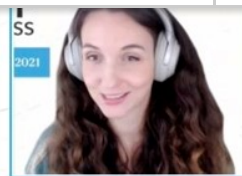
DAY 2 - MIND

This is a "1-minute" relaxation technique you can practice (almost) whenever and wherever you feel like.



Seat yourself comfortable, put both feet flat on the floor, about a foot apart. Keep your arms on the side or in your lap, with your chin parallel to the floor. Close your eyes if it feels comfortable.

- 1) Take a slow, deep breath. Breathe out slowly, saying "Relax" to yourself as you exhale. Do this three times.
- 2) (Inhale) Clench your fists and (exhale) relax.
- 3) (Inhale) Tighten your feet and toes (exhale) relax.
- 4) (Inhale) Raise your shoulders (exhale) relax.
- 5) (Inhale) Tilt your head to the right. Feel the stretch (exhale) return your head to the upright position.
- 6) (Inhale) Tilt your head left (exhale) straighten your head.
- 7) On the final inhale, picture yourself relaxed and refreshed. Breathe out slowly. Open your eyes. It is that simple - and that fast. :)



2021 EPF Congress

#EPFCongress2021



Member Focus

highlights from our member organisations



How has the pandemic affected the mental health of clinicians and patients?

Through its new survey developed in collaboration with the European Psychiatric Association, GAMIAN Europe seeks to answer these questions. The survey is aimed at clinicians who provided mental health services during this challenging time, as well as people with pre-existing or recently diagnosed mental health conditions. Fill it out by **December 20!**

Take the Survey>>>

GAMIAN Europe is part of the **Mind@Work**



Resolution on Persons Living with a Rare Disease and their Families Adopted by UN Third Committee

On 15 November 2021, the **UN Resolution on "Addressing the challenges of persons living with a rare disease and their families"** was

unanimously adopted by the Third Committee of the UN. The text recognises the over 300 million persons living with a rare disease (PLWRD), their families and loved ones and calls for action from the United Nations Member States. This is an important milestone that Rare Diseases International, EURORDIS and the NGO Committee for Rare Diseases have played a crucial role in securing, and is a step towards adoption by the United Nations General Assembly in December.



How's your quality of life after Prostate Cancer? EUROPA UOMO is calling for prostate cancer patients to participate in their recent survey.

Take the Survey>>>



As part of EFNA's Training Initiatives for Neurology Advocates [TINA] programme, a new **series of e-learning modules** is launched today, on the theme of EU Funding. The EU provides funding for a broad range of projects and programmes covering almost all areas. EFNA's e-learning modules are free to access, though registration is required. Participants will be able to

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awareness of **mental health in the workplace** by collecting the stories of young adults about how they manage with work mentally. The stories collected will be developed into a co-created **documentary podcast series** and shared on social media to create wider discussion.

[Share your Story>>>](#)

The European Parliament's Committee on Employment and Social Affairs has recently decided to draft an Own-Initiative report entitled '**Mental Health in the digital world of work**'. The MEP Alliance for Mental Health and the Coalition for Mental Health and Wellbeing co-organised a virtual kick-off meeting aiming at gathering experts' thoughts on the issues that should be addressed by the report. The meeting, attended by six experts, was chaired by MEP and Rapporteur Maria Walsh.

[Read the Report>>>](#)



Plan & Create for Social Media Success

This **free interactive course**, developed by EURORDIS' Open Academy, aims to help patient organisations to plan and create for social media success. It will introduce you to the topic, helping you to set objectives, select the most suitable channels and elaborate campaign and content strategies.

[Enrol in the Course>>>](#)



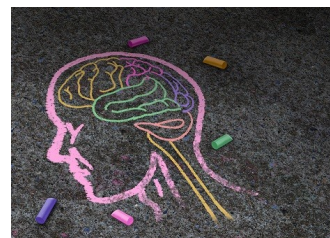
Have you seen the EURORDIS Photo Award is back?

Submissions are now open for you to share your favourite photos of life with a rare disease and be in the chance of winning!

[Submit your photo now>>>](#)

following each module.

[Learn More & Register>>>](#)



"Dementia risk communication. A user manual for Brain Health Services"

Alzheimer Europe has co-authored a new paper, published in the journal Alzheimer's Research & Therapy which provides an overview of perspectives on communicating dementia risk from an ethical, clinical, and societal viewpoint; insights gained from memory clinical practice; available evidence on the impact of disclosing APOE and Alzheimer's disease biomarker test results gathered from clinical trials and observational studies; the value of established registries in light of BHS; and practical recommendations regarding effective strategies for communicating about dementia risk.

[Read the Paper>>>](#)



Inside the Bubble

updates, stories and events around EU healthcare

WHO backs jabbing kids but calls for vaccine equity first

The World Health Organization has given a green light to the vaccination of children with coronavirus jabs that are approved for this age group, but said that the global sharing of vaccines should come first. The WHO said that countries should consider the "individual and population benefits" of vaccinating children and adolescents "in their specific

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Austria becomes first Western country to resort to mandatory coronavirus vaccination

Austria has become the first Western democracy to resort to mandatory vaccination in response to a record-breaking surge in infections that has flooded its hospitals with critical COVID-19 patients. That makes Austria the first European country — and one of the first in the world — to impose compulsory coronavirus vaccination.

COVID-19 deaths in European region on course to exceed 2M by March, warns WHO

Over two million people in the European region are expected to have died from COVID-19 by March 2022, according to estimates from the World Health Organization's Europe office. COVID-19 is today also the leading cause of death in Europe and Central Asia, according to the Institute for Health Metrics and Evaluation, which does modeling for the WHO. What's needed to tackle rising cases and deaths is a "vaccine plus" approach, said Hans Kluge, WHO regional director for Europe.

WHO COVID-19 tech pool agrees first deal

The first licensing agreement between the World Health Organization's COVID-19 technology sharing pool and the Medicines Patent Pool was signed to utilize antibody technology developed by the Spanish National Research Council (CSIC). The deal comes 18 months after the WHO first launched its COVID-19 Technology Access Pool (C-TAP), and will help facilitate the manufacture and commercialization of the Spanish research council's serological tests worldwide. The technology developed by the CSIC has produced four different tests, one of which could potentially identify whether people have developed an immune response to COVID-19 through infection, as opposed to vaccination.

Good health is not something we can buy. However, it can be an extremely valuable savings account.

Anne Wilson Schaeff



Calendar of Events

1 December

World AIDS Day

[visit our website](#)

BMJ Patient access to health records: What are the technical and organisational challenges to implementation?

[contact us](#)

Duchenne Patient Academy

7-9 December
Patient Engagement Open Forum (PEOF)

9 December

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14 November
World Diabetes Day

24 December
Christmas Eve

25 December
Christmas Day

31 December
New Year's Eve

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