



The Patient Perspective

April 2022



Reflections

Welcome to our April Patient Perspective newsletter!

Here's a recap of what we have been up to in the last month:

This month we have quite a few news from our Secretariat. Firstly, we held our **Annual General Meeting (AGM)** on 23 April. Below, we share all the highlights from our latest AGM, including our newly elected Board members and the newest EPF members.

The **EPF Youth Group** has a new President and Vice President. They share some thoughts with us below.

The registration for the EPF Congress 2022 is now open! You can find more information on the registration details and the new preliminary programme below.

Our **Policy team** published a report on the survey on continuing professional education. You will find more info on the findings, including a handy infographic, below. The team has also participated in a workshop presenting the results of the study commissioned by the European Commission to support the evaluation and impact assessment of the general pharmaceutical legislation.

The **Projects team** has been busy with the launch of the 2d course for non-experts on the EHDEN Academy and they are organising webinar to better understand how patients perceive their involvement in the Health Technology Assessment (HTA) process. They also have a few updates on the Data Saves Lives initiative, EATRIS+, and the Health Outcomes Observatory (H2O) projects.

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 May.

We are deeply concerned by the situation that has been unfolding in Ukraine in the last few weeks. As a European patient organisation, we are particularly concerned about the situation of people living with chronic diseases, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. For this reason we are working with our members to collect and amplify any initiatives our members launched to support the patient community in Ukraine and neighboring countries. A resource page is now available on our website, and we have highlighted a few initiatives in this newsletter.



Annual General Meeting

EPF AGM 2022 - Recap

EPF Members have gathered online on 23 April, 2022, for the 19th Annual General Meeting. During this event, EPF's board members, together with the Secretariat, reported on 2021 activities and gave an overview on the current and upcoming work for 2022. The event also saw the election of new board members, the approval of two new full member organisations and one associate member organisation.

[Read the full recap on our website>>>](#)

WELCOME ON BOARD!

EPF IS PROUD TO HAVE **WAPO**, **SOSTE**
AND **NAPO** AS NEW MEMBERS!



SOSTE



Continuing the *conversation* on digital transformation

DOUBLETREE BY HILTON
BRUSSELS

23 - 24 JUNE 2022

REGISTER NOW FOR THE EPF CONGRESS 2022

The European Patients' Forum is pleased to announce the **EPF Congress 2022 – Continuing the conversation on digital transformation** will be held on **23 and 24 June 2022** in a live-streamed format.

This unique event will take place at the **DoubleTree by Hilton**, set in a prime location in the heart of Brussels, Belgium, with the option of participate online for those who wish to join us remotely.

Registration is now open for the in-person event. You can also join us virtually, for free. Please note that only the plenary sessions will be live-streamed, and you will have access to all EPF 2022 Congress content for "on-demand" viewing after the event.

[Register now for the #EPFCongress2022>>>](#)

[Take a look at our preliminary programme >>>](#)



Flavia Topan is EPF's new Communications Manager

Flavia joined EPF team in April 2022. As Communications Manager, she is responsible for developing EPF's communication strategy and to manage the delivery of EPF's communication and PR activities.

Before joining EPF, Flavia handled communication & PR activities for both public and private hospitals in Romania, and also worked together with national patients' associations on various communication and patient education projects.

WE'RE HIRING!

**BE OUR NEW
HEAD OF GOVERNANCE,
MEMBERSHIP AND
CAPACITY BUILDING**

Send your cover letter, CV and references to
recruitment@eu-patient.eu

EPF European Patients Forum

The advertisement is a white rectangular box with a blue border. It features the EPF logo on the left, which consists of the letters 'EPF' in a bold, blue, sans-serif font, followed by the text 'European Patients Forum' in a smaller, blue, sans-serif font. To the right of the logo is a green graphic of three stylized human figures. The main text is in a large, bold, blue, sans-serif font, and the contact information is in a smaller, blue, sans-serif font.

We are hiring a new Head of Governance, Membership and Capacity Building!

EPF is looking for a new Head of Governance, Membership and Capacity Building to ensure the inclusiveness and representation of all EPF Members in the daily functioning of the EPF secretariat and to oversee the learning offer of EPF.

If you know someone who is passionate about patients' rights in Europe, let them know about this unmissable opportunity!

[Read the full job description>>>](#)



LAST CHANCE to apply to STYPA 2022!

We have extended the deadline for application for the new edition of the Summer Training Course for Young Patient Advocates (STYPA) to **8 May!**

STYPA is a European Patients' Forum (EPF) training dedicated to young patient advocates (18-30 years old).

We are back this year with a new edition of STYPA that will focus on the delicate topic of sexual health and well-being for young people with chronic conditions. STYPA 2022 will include:

- Introduction webinar - June 2022.
- The face-to-face meeting of STYPA will be held on 14,15,16 and 17 July 2022, in Strasbourg, France.
- Follow up workshop webinars - September and October 2022.
- Closing webinar - November 2022.

[More info on our website>>>](#)



Policy and Advocacy Corner

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

April was a busy month for the Policy Team, where, in addition to our policy work, EPF held our Annual General Meeting on 23 April and continued to prepare for the EPF 2022 Congress, which will take place on 23 and 24 June.

This month we published our [report](#) on the **survey on continuing professional education** and an [infographic](#) on the main findings. The survey shows that, despite inherent shortcomings of current patient involvement in CPE activities, there is a willingness in the patient community to advance patient participation in CPE activities. The patients interviewed value building a relationship with their healthcare professionals, as they feel that when this happens, their needs are better met. Patient involvement in CPE activities should be encouraged and be part of the continuing education of health professionals throughout their careers.

In addition, the Policy Team participated in a workshop presenting the results of the study commissioned by the European Commission to support **the evaluation and impact assessment of the general pharmaceutical legislation**. EPF had already taken part in such a workshop to discuss the evaluation process findings in January and further participated in a bilateral interview with the consultancy hired by the Commission. The Policy Team echoed key messages to advance patient-centred legislation.

Finally, the Policy Team participated in the first engagement meeting on **the Value-Based Taxonomy initiative** led by the [European Alliance for Value in Health](#), of which EPF is a member. This initiative aims to develop a clear and robust taxonomy for value-based healthcare (VBHC) as the different interpretations and usage of VBHC terms lead to misalignment and impede progress.



Projects Portal

briefings on EPF's ongoing projects

🚩 **Launch of the 2d course for non-experts on the EHDEN Academy**

On 26 April 2022, [EHDEN](#) (European Health Data & Evidence Network) and the European Patients' Forum launched the second course for non-experts as part of its EHDEN Academy course offering.

This introductory course is designed to **familiarise non-experts with the basics of how data is managed across large systems, and the benefits of doing this on a large scale**. The key concepts covered include what are federated data networks and related concepts, as well as the [OMOP](#) common data model.

This course uses animated content and examples to illustrate how the EHDEN project aims to apply these structures to maximise the value of health data and ultimately improve patient treatment and outcomes. Course 2 builds on the concepts explored in Course 1. You can access the course, plus many other free training materials at the [EHDEN Academy](#) Or [>> Watch the course here](#)



Have your say! Help us learn how patients perceive involvement in HTA processes

On **12 May, 12:30 CEST**, EPF and **360 HTA Patient Involvement** partners will hold the project's first webinar to better understand how patients perceive their involvement in the Health Technology Assessment (HTA) process. The **360° HTA PATIENT INVOLVEMENT** project aims to understand and update our knowledge on how the differences in implementation of processes can affect the perceived effectiveness of the patient involvement.

This brief information session will provide an **overview of how we aim to do this** and promote a **survey which will help us understand how patients are involved in HTA** at the moment, and how to better involve them in the future. This survey will form a knowledge base to identify best practices can support better patient engagement in HTA in the future, both in Europe and beyond. [>> Learn more and register here](#)



How do Patients Perceive their Involvement in HTA Processes?

 12 May 2022
12:30 CEST

  

Making Meaningful Patient Engagement in Translational Research the New Normal – EATRIS-Plus at PEOF 2022

On 14 April, **EATRIS** and the European Patients' Forum (EPF) **co-hosted a session** at the **Patient Engagement Open Forum**. The event aimed at building on important learnings from initiatives like IMI **PARADIGM** and **PFMD**, to explore with patients, funders and researchers how to normalise patient engagement (PE) practices in research, in EATRIS and beyond. It also aimed to present a new toolkit being developed as part of the

In the framework of **EATRIS-Plus** (a **Horizon 2020** project), EATRIS and EPF formed a multistakeholder taskforce in February 2022 **to develop a toolkit on patient engagement in translational research**. The taskforce includes **members of the project Patient Advisory Committee**, patients and patient organisation representatives, academic researchers, research managers, as well as university patient engagement officers.

[>> Read on to learn more about the aims of the toolkit, and the take-aways from the PEOF session](#)

Data Saves Lives marks 2000 followers 🌟

THANK YOU for being part of the **#DataSavesLives** journey to **raise awareness about importance of health data** & understanding of how its used, & establishing a trusted environment for multi-stakeholder dialogue about responsible use & good practices in Europe. [>> Explore more about Data Saves Lives](#)

2000
FOLLOWERS

📅 COMPAR-EU event in May

The **COMPAR-EU project** has just announced two exciting **workshops taking place on 17 and 19 May 2022** to explore the market opportunities for self management tools.

The workshops will explore, among others, what are the opportunities for implementation and the barriers to use self-management decision tools? Attendees can expect to learn about new innovations, self-management tools, and state-of-the-art research developed by the COMPAR-EU consortium. [>> Register here](#)

📅 Save the date for H2O's virtual public days in May

On 10 and 11 May, the **Health Outcomes Observatory (H2O)** project is hosting virtual open days! Join H2O for this exciting **event focused on Patient Reported Outcomes** and their collection

Interesting event 🤖 newest edition of HealthTech for Patients

HealthTech For Care, which aims to promote and support access to care for patients, invites you to the second edition of **HealthTech For Patients** on

at an unprecedented scale. Live panels and talks from known experts in the field of patient reported outcomes and the European healthcare data landscape will cover the why, the how and the who of making this goal a reality. >> [Detailed agenda and registration here](#)

19 May, 1pm to 4pm CET, in a digital event accessible for all. This event will give the opportunity to patients to express their needs and introduce them to innovations in healthcare in order to improve access to care. >> [Register here](#)



Youth Group

initiatives, stories and events from our most budding members



Anastasia Semaan

NEW YOUTH GROUP PRESIDENT

Cornelia Pauna

NEW YOUTH GROUP VICE PRESIDENT



Newly Elected YG President and Vice President

At the beginning of April, the EPF Youth Group held elections to elect a new President and Vice President. We are very happy to announce that after the votes of our members Cornelia Pauna is the new youth group Vice President and Anastasia Semaan is the new youth group President. We are looking forward to seeing what they continue to accomplish as a group.

Here are a few words from our newly elected Youth Group Board members:

"I feel that being part of the Youth Group my voice became stronger, and I believe we have something important to say. I believe that nowadays, when an infinite amount of information is coming right back at us, we easily tend to be ignorant. Thus, it's important to stand up so that our voices can be heard. The projects that the group is having are of interest for me, especially the Sexual Health and Wellbeing project. Same world bombarded with information I was just talking about, is lacking information on this topic. I wish when I was younger someone would have told me: "Own your body, own your illness."

All these transformations that I have gone through in the last couple of years made me

want to be more engaged in the group and maybe a part in the transformation of other patients. I hope to find their way, just like I did (as I still do). I have time and a voice in my head saying "use it right". Time is a precious concept that everybody talks about and as a safe investor would say: "Invest in your best bet!". This is my bet."

- Cornelia Pauna, new YG Vice President

"Being a part of the youth group is a chance for every young patient or patient advocate to have their voice heard and acknowledged and for change to happen within each of our communities. As President I want to ensure each of our members' voices are heard and represented in as many ways as possible, especially regarding the roles each of them hold in the youth group and throughout the progress that we make in active projects, to then allow us all to represent the young person perspective on multiple platforms. Working closely with the EPF youth group board representative and supporting them in the gap that they bridge between our youth group and EPF, especially regarding representing our progress that we make to the EPF board, is also crucial for our success and progress as a group. Through communication, collaboration and coordination can we not only address any areas of concern that we ever have in the legalities of the running and structure of our youth group but continue to be strong advocates for patients and change. Ultimately for change to happen, we as a group need to raise awareness about areas that we feel need to be adjusted and collaborate to not only raise awareness about any unfairness or concerns of young patients, but to act against them. I have loved working with the group as a whole and with each member individually and learning from each of them, and I am looking forward to continuing to do so as the President."

- Anastasia Semaan, new YG President



Ukraine crisis

Our members' initiatives to support the patient community in Ukraine

The European Patients' Forum stands in solidarity with the people in Ukraine, who are facing an aggressive military invasion in violation of international law since 24 February 2022. As a European patient organisation, we are particularly concerned about **the situation of people living with chronic diseases**, who are vulnerable to disruptions in healthcare services, medical treatment and medicines caused by war. Patients with chronic diseases, especially those with multiple conditions and severe illness, are less likely to have the means to flee the conflict and access humanitarian aid.

EPF is working with its members to understand the needs and challenges to support policy decision-makers to address those needs. We are currently **collecting all the initiatives, projects, events** they have envisioned to support the patient community in Ukraine, a few of which are reported here below, and that can also be found on this [resource page on our website](#).



Alzheimer Europe has a new online resources page to help support people with dementia and carers, during the ongoing war in Ukraine.

You can access [Alzheimer Europe's resource page here](#).



European
AIDS Treatment
Group

EATG published a statement in solidarity with people living in Ukraine and those displaced by the war, that can be accessed [here](#).

They also created a [resource page](#) with information for donations targeted to people living with HIV and key affected populations in Ukraine.

In addition, EATG contributed to a piece published by POLITICO, that can be found [here](#). Furthermore, they are in close contact with partner organisations and individuals in Ukraine and they are liaising with international organisations as well as pharma industry to ensure continuity of services and access to medicines.



**WORLD
DUCHENNE
ORGANIZATION**
UPPMD

The **World Duchenne Organization** set up a donation page to contribute the DMD Emergency Fund to aid families with Duchenne and Becker muscular dystrophy affected by the Ukrainian conflict. You can find it [here](#).

They are currently working on creating a documentary about people living with a neuromuscular disease that are affected by the Ukrainian war, as their community manager Nicoletta Madia travelled to the Czech Republic and other countries to interview refugees, patient organisations, and volunteers.

A trailer of a documentary titled 'Help has no borders' on the emergency in Ukraine is available [here](#).

This activity is part of the **DMD Emergency Program**. A life feed with all the updates can be found [here](#).



Member Focus

highlights from our member organisations

VIRTUAL EVENT: 12 MAY 2022, 14.00-16.30 CET

PATIENT INVOLVEMENT IN BRAIN HEALTH: SAFEGUARDING THE FUTURE OF BRAIN HEALTH FOR PATIENTS

REGISTER NOW: brainhealth.heysummit.com



Patient involvement in Brain Health: Safeguarding the future of Brain Health for patients **May 12th, 2022, 14.00 – 16.30hrs CET**

To safeguard the future of brain health for patients it is imperative that all stakeholders ensure the priorities, needs and expertise of those living with brain health disorders are considered and included in all policy developments.

Three leading European patient groups - EFNA, Alzheimer Europe and GAMIAN Europe - have come together to organise a virtual meeting on this topic.

This meeting will emphasise the importance of engaging the patient community in the ongoing discussions on brain health at European level. United, the brain health patient voice of Europe call on all stakeholders to be accountable for patient involvement and shared decision making.

[Register here>>>](#)

Alzheimer Europe reacts to Biogen withdrawing its marketing authorisation application for Alzheimer's disease treatment aducanumab

On 22 April 2022, Biogen announced that it had notified the European Medicines Agency (EMA) about the withdrawal of its marketing authorisation application for aducanumab for the treatment of early Alzheimer's disease.

With the last approval of an Alzheimer's medicine by the EMA dating back to 2002, people living in Europe affected by Alzheimer's disease have been waiting to gain access to better treatments for 20 years. It will therefore be disappointing news for them to hear that there was insufficient scientific evidence for the EMA to support the authorisation of aducanumab, and that the wait for innovative, disease modifying treatments will have to continue in Europe.

Alzheimer Europe will continue to monitor clinical trial developments with great interest and notes the welcome announcement by Biogen about the launch of a phase IV trial of aducanumab in May 2022. The organisation hopes that this trial and ongoing trials by other companies will lead to positive results and to the approval by the EMA of the first new treatment against Alzheimer's disease in over 20 years.

[Read the full statement on Alzheimer Europe's website >>>>](#)



EFA's AGM and the European Lung Health Group policy briefing on "Improving lung health through the future European Health Data Space (EDHS)"

EFA's Annual General Meeting was held online on 31 March. During the session we were excited to welcome three new full member organisations: Samtök lungnasjúklinga /Icelandic Lung Association (SLS), COPD Patients' Society of Turkey/KOAH Hastalari Derneği and Slovak Association of Allergic and Asthmatic Patients/Slovenská asociácia alergologických a astmatických pacientov (SAAAP). This makes EFA's membership expand to 45 members in 26 countries!

The European Lung Health Group (an informal group of European level patient groups and healthcare professionals) launched its policy briefing on "Improving lung health through the future European Health Data Space (EDHS)". The brief highlights the opportunities the EDHS brings for patients with lung disease and healthcare providers, with concrete demands to make these benefits a reality. The virtual event was co-hosted by MEPs Sara Cerdas (S&D – Portugal) and Manuel Pizarro (S&D – Portugal) and brought together 236 participants.

[Read the European Lung Health Group policy briefing>>>](#)

THE STROKE PATIENT
VOICE IN EUROPE

Stroke
Prevention.info



WORLD
DUCHENNE
ORGANIZATION
UPPMD

1 in 5 Europeans have high blood pressure

We support the Stroke Alliance for Europe (SAFE) on European Stroke Awareness Day (Tuesday 10 May) to raise awareness of #StrokePrevention.

High blood pressure is one of 10 key modifiable risk factors of stroke.

According to recent statistics from **Eurostat** (European Commission research), 1 in 5 Europeans have high blood pressure – the highest levels were recorded in Croatia, Latvia and Hungary.

The majority of strokes can be prevented by changing lifestyle and behaviours. SAFE's Vice President Professor Anita Arsovska said:

"The majority of strokes can be prevented by changing lifestyle and behaviours. Our **stroke prevention website** has been updated with all the latest facts and information to help people reduce their risk of stroke and is available in six languages (English, French, Polish, Portuguese, Russian, Spanish)."

[More info on SAFE's stroke prevention website>>>](#)



EUROPA DONNA has a new website

3rd International Muscle-Bone Interaction in Duchenne Muscular Dystrophy Symposium: Moving beyond the 2018 international standards of care for osteoporosis management

This online symposium, organised in collaboration between the World Duchenne Organization and the International Conference on Children's Bone Health, will be held on November 3 and 14, 17:00-20:00 GMT. The event is aimed to clinicians and scientists who want to gain a deeper understanding of the impact of DMD on the growing skeleton and on endocrine outcomes. Patient advocates are also welcome.

The scientific programme is designed to address the following main aims:

1. Highlight the minimum standards of care for bone and endocrine management as laid out in the 2018 international standards of care consensus with particular focus on practical aspects of implementation in the clinic;
2. Share results of clinical research to support current management of osteoporosis in DMD;
3. Showcase new clinical and translational research to consider the path forward to prevent fractures and related bone morbidity in DMD.

[More info and event registration>>>](#)



Two job opportunities from EHC and the EHC Think Tank

The European Haemophilia Consortium (EHC) is looking for an Operations Director (full-time) and a Digital Media Officer (part-time) to join its Brussels-based team.

[Read the full job](#)

EUROPA DONNA has just launched a major update of its website which now covers the entire breast cancer pathway from prevention to diagnosis and metastatic breast cancer.

You can still find all of the information related to their history, mission, work, policies, statements and publications as well as new and updated information on Screening and Early Detection, Breast Cancer Treatment and Genetics/Genomics.

[Come check it out!>>>](#)



New EURORDIS' Rare Barometer survey on diagnosis for people with rare diseases

The EURORDIS survey programme Rare Barometer has launched a global survey on the journey to diagnosis for people living with a rare disease! The survey is open to people living with a rare disease and their family members from any country in the world and is translated in 26 languages.

[Share the survey with your network today!>>>](#)

European Conference on Rare Diseases 2022

Registrations to attend the European Conference on Rare Diseases are open! Sign up to join online the largest, patient-led rare disease policy conference.

[More info and registration>>>](#)

EURORDIS webinar: #30millionreasons for Europe to take action on rare diseases

Join us on 31 May 2022 to hear from us about how you, alongside 2000 people, have helped us in our call for a European Action Plan on rare diseases, how we have used these reasons and what we are doing next in preparation of the European Conference on Rare Diseases at the end

The EHC Think Tank explores a range of complex issues to drive healthcare systems change and improve patients' quality of life. At three workshops, participants worked on identifying the challenges concerning registries, organisation of care and patient agency respectively. The EHC Think Tank has published the outcomes from the three workshops in The Journal of Haemophilia Practices under their new thematic category: System Change.

[Read them online here>>>](#)



HIV and opioid dependency treatment for people displaced by the war in Ukraine

On 21 April, NGOs working with and representing the interests of communities of people living with and affected by HIV, tuberculosis, viral hepatitis and drug dependence in Europe addressed a letter to governments in the EU and EU institutions. The organisations report on the great will of various partners to accommodate the needs of people escaping the war but also major obstacles, especially regarding access to opioid agonist therapy. Therefore, the NGOs call governments in the EU and EU institutions to implement a set of urgent measures.

[Read the full letter>>>](#)

EATG launches new reports on HIV and HCV testing

EATG has launched a set of reports aiming to strengthen community leadership for access to HIV and HCV testing in Europe and Central Asia.

[Access the reports>>>](#)

Happy 30th Birthday, EATG!

This year the European AIDS Treatment Group (EATG) turns thirty. For their thirty years, they take the opportunity to reflect on their wins and losses as well as on their future challenges, recover from what



Inside the Bubble

updates, stories and events around EU healthcare

EU ends emergency phase of coronavirus pandemic

The EU declared an end on Wednesday to the coronavirus emergency as pressures on hospitals recede and countries drop restrictions. "We are entering a new phase of the pandemic, as we move from emergency mode to a more sustainable management of COVID-19," said European Commission President Ursula von der Leyen. "Yet, we must remain vigilant. Infection numbers are still high in the EU and many people are still dying from COVID-19 worldwide." In more than two years, the pandemic has claimed more than a million lives in the EU, putting health systems under huge strain, forcing governments to impose travel restrictions, and galvanizing a massive research and logistics effort to get populations vaccinated.

Mystery hepatitis in children first found in UK reported in five more countries

Following the reports of cases of acute hepatitis of unknown origin by the UK Health Security Agency, additional cases in children have been reported in Denmark, Ireland, the Netherlands, and Spain.

In addition, nine cases of acute hepatitis among children between 1 and 6 years old in the state of Alabama in the United States who also tested positive for adenovirus have been reported.

Investigations are ongoing in all countries reporting cases. At present, the exact cause of hepatitis in these children remains unknown. The incident team in the United Kingdom, where most of the cases have occurred to date, consider that an infective cause is most likely based on the clinical and epidemiological features of the cases under investigation.

Pfizer, BioNTech seek emergency use authorization for COVID boosters for kids 5-11

Pfizer and BioNTech submitted to the U.S. Food and Drug Administration on Tuesday their application for a booster dose of its pediatric COVID-19 vaccine to be given to children ages 5-11, the companies said. The companies said earlier this month that Phase II and III clinical trial data showed that a third dose administered to that age group about six months after the second shot boosts neutralizing titers against both the original coronavirus strain and the Omicron variant, a subvariant of which is now linked to most U.S. infections. No new safety concerns were detected among trial participants, the companies said.

There are two ways to live: as if nothing is a miracle, or as if everything is a miracle.

Albert Einstein



Calendar of Events

5 May

Global Hand Hygiene Day

[visit our website](#)

9 - 13 May

European Mental Health Awareness Week 2022

[contact us](#)

10-11 May

H2O Public Day 2022

12 May

260 HTA Patient Involvement event

17-19 May

COMPAR-EU workshops

19 May

HealthTech for Patients

16-20 May

European Public Health Week

[view this email in your browser](#)



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