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The Patient Perspective

September 2022

EPF European Patients Forum

Reflections

Welcome to our September Patient Perspective newsletter!

We really can't believe September is over! It was such an intense month that we lost track of time. No wonder - with so many events happening all across Europe, about meaningful patient engagement and healthcare improvement.

We welcome some good news coming from the European Commission, who confirmed its support for the civil society through operating grants from the EU4Health programme.

In terms of EPF news, we've been busy with welcoming our Board Members to our office this month, meeting with FDA representatives, and we've welcomed a new addition to our team. We ended the month with a very constructive way, with some of our team members attending the European Healthcare Forum Gastein 2022. They've shared some takeaways from the conference, so make sure to continue reading below.

It's been a productive month for our members, who shared with us exciting updates on their activities. Make sure to read more details under the Member Focus section.

Our schedules will be busy in October too. First stop: **PEOF 2022**, in Barcelona.

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Keep an eye out for the newest EPF updates on our social media channels!

The EPF Team

updates from the inside

EPF Board Meeting

It was such a pleasure to have EPF's Board members joining us between the 23rd and 24th of September, for a very productive and insightful meeting.

With five Board members, including EPF President Marco Greco, on-site, with the others joining remotely, this was a great opportunity for the team to update the Board on all our activities, but also to get input from Board members regarding future EPF projects.

We hope to see you all again soon!

Team EPF at The European Health Forum Gastein 2022

Our colleagues: **Anca Toma**, **Kaisa Immonen**, **Julie Spony**, and **Juan Fernandez Romero** have attended the event in person. This year, The European Health Forum Gastein took place between 26 - 29 September, in Austria.

Under the patronage of the Austrian Federal President, Alexander Van der Bellen, the EHFG has celebrated its 25th anniversary this year and took stock of the substantial accomplishments in public health over the last quarter century.

Our colleagues joined meaningful debates around the challenges for building a more equitable and sustainable future of healthcare, discussing topics such as ethical dilemmas during health emergencies, European Pharmaceutical Strategy, and improving health equity.

Some of our key takeaways:

- Health inequalities are influenced by social determinants. It’s a snowball effect, and every little disaster leads to a bigger disaster. There is nothing more unequal than the equal treatment of unequal people.
- We need to work together to rebuild health systems so they deliver good health for all people. This is a monumental work that Europe cannot afford not to undertake, and soon.
- Health systems must involve patients and citizens in genuine and equal partnerships to make sure the scarce resources are invested smartly in things that matter and will make a difference.

Our partnership 🇪🇺 civil society is essential in making our #HealthUnion priorities a reality.

I was delighted to meet representatives of health CSOs today and to confirm our continued support through operating grants from the #EU4Health programme.

EU Health - #HealthUnion and European Commission 🇪🇺

We are pleased to see the European Commission was open for dialogue and, through EU Commisioner Stella Kyriakides, voiced their support to civil society, through operating grants from the EU4Health programme.

Earlier in September 2022, EPF, together with other civil soiciety organisations, had endorsed a **joint statement** on the inclusion of operating grants as a financing mechanism to provide a strong foundation for the contribution of health NGOs as part of the 2023 Work Programme and beyond.

Expanding our horizons: EPF Secretariat meets with FDA

On 13 September EPF's Executive Director Anca Toma and team members welcomed a delegation from the US Food and Drug Administrative Agency (FDA) into our offices, including Deputy Commissioner for Policy, Legislation, and International Affairs, Andi Lipstein Fristedt, members of her staff, and FDA representatives to the EU and the EMA.

The FDA were keen to meet with key stakeholder organisations on their visit to Brussels. In the meeting we shared EPF's current priorities and views of the changing EU policy landscape, including the European Health Data Space and the upcoming revision of the EU's pharmaceutical legislation, and discussed the importance of patient involvement. FDA shared information about their patient engagement and international activities.

EPF has connected with the FDA also as part of our activities at the EMA: a dialogue was set up in 2021 between the Patient and Consumer Working Party and the FDA's Patient Engagement Collective (PEC). Two virtual meetings have taken place, with information shared about the ways in which the two agencies work with patients and patient organisations. FDA representatives were particularly interested in hearing about how EPF works with young patients, and the work done in the PCWP to engage with them.

Medicines development is global, and there is certainly huge potential for collaboration between the EU and US regulatory agencies when it comes to embedding patient involvement in medicines research, development and authorisation.

Meet Anne Rensma: EPF's new Communications Officer

Communications Officer. In this role, she is responsible for developing and delivering content and communication on EPF’s work and activities.

Over the years, Anne has gathered experience working in communications, content management, and editing. She holds a bachelor’s degree in French from Utrecht University in the Netherlands and continued her postgraduate studies in the same place, obtaining a master’s degree in Gender Studies.

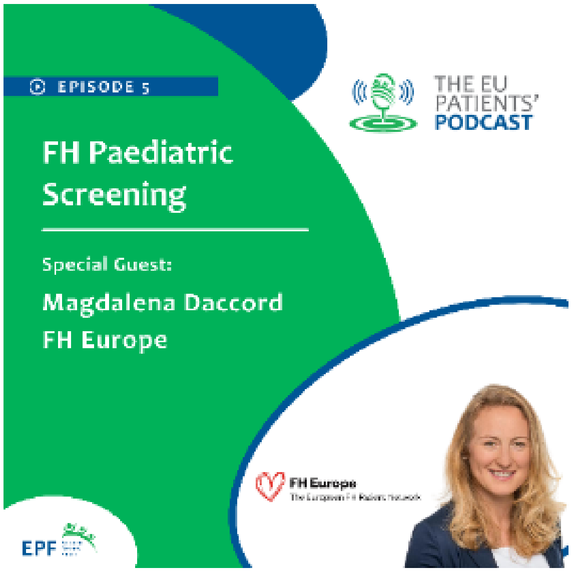
MUST READ: Patient Involvement in the Development, Regulation and Safe Use of Medicines

The **Council for International Organizations of Medical Sciences** (CIOMS): New report on Patient Involvement in the Development, Regulation and Safe Use of Medicines

The report provides a comprehensive overview of the current knowledge about the use.

It summarizes existing initiatives, gives many examples and recommendations, and addresses the remaining challenges and practice gaps.

The publication is available **here.**



New Podcast Episode featuring **FH Europe** | OUT NOW

In the latest EPF podcast episode, we've invited Magdalena Daccord from **FH Europe**, to talk about the huge benefits of paediatric screening, FH Europe's latest achievements and much more.

Tune in to this episode of the **EU Patients' Podcast** to find out how screening for FH can considerably reduce the risk for early cardiovascular disease.

Listen to the **full episode here**!

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europeanpatients'forum
Youth Group

Youth Group Updates & What to Look Forward To....

And just like that summer is (almost) over...which means: the EPF Youth Group is back in action. After enjoying some time off to rest and recoup (taking note from our previously written **newsletter article on advocacy life balance**), we have a jam packed start to the new year.

For one, our sexual and wellbeing project videos, which we filmed during our last face-to-face meeting in Brussels, are ready to be released and to say we are excited is an understatement. There is often a misconception that people living with a chronic illness do not or cannot have sexual relationships, and we think it is important to shatter this stigma by normalising talking about our experiences with sex and well-being. A huge thank you to everyone who shared their stories for the videos and who helped in making them happen, we appreciate your support! Now, the ball is in your court - *no pun intended*.

We are also looking forward to our next EPF Youth Group meeting in Brussels in the next couple of months to start tying up the **sex project** and make progress with the newly named Youth Collaboration project: another hugely important one, which aims to support patient organisations to increase and improve their young patient involvement.

Here are a few words from our EPF Youth Group President Anastasia and Vice President Cornelia on what they are looking forward to this year:

"*What I am most looking forward to in this upcoming year, as the Youth Group President, is to develop a deeper understanding about our members and why they are part of our team. We are so fortunate as a youth group to be made up by patient advocates from different backgrounds and representing different disease areas, that I believe it is important to understand further, 'why' they joined and what topics and domain areas do they currently want to explore whilst in the group (as this might have changed from when they first joined). I am looking forward to closing this stage of the sexual health and wellbeing project and highlighting what still needs to be addressed by young patients, but also what we recommend regarding the action that still needs to be taken by members of society. I am also looking forward to developing the networking that we have with other youth groups and to draw attention to the projects and action that is being done all around us by young patients, and ensure that their voices are acknowledged within their organizations. Most importantly I am looking forward to continuing for our youth group to represent the young patient perspective at different events and on different platforms. In addition to what was highlighted above about what we are looking forward to within the EPF Youth Group, we have additional announcements for what we have coming up including, but not limited to:*

1. Supporting EPF in the deciding of the topic around STYPA 2023
2. Continuing to represent the young patient perspective on different platforms, which currently includes:

- *Attending the 'Patient Organization Workshop on Transitional Care', in Vienna, which is being hosted by ESPGHAN and UEG*
- *Attending and presenting within the session hosted by PEOF in Barcelona titled 'Taking Action to Engage Pediatric and Young Patients in Innovative Clinical Trials'*

3. Brainstorming our new and upcoming Youth Group Project, as a team."
- Anastasia Semaan - EPF Youth Group President

"As the project about Sexual Health and Wellbeing is slowly coming to an end, several project opportunities are available that we will need to brainstorm and prioritize. I think next year will be very interesting but also challenging and rewarding. I believe young patients' involvement and voice need to have better coverage and visibility, which is what we are trying to do, by finding ways to encourage young patients to own their mind and body."
- Cornelia Păuna - EPF Youth Group Vice President

Projects Portal

briefings on EPF's ongoing projects

Save the Date – COMPAR-EU Final Conference Advocacy Event

This advocacy conference marks the culmination of **5 years of interdisciplinary work** to identify, compare, and rank the most effective and cost-effective self-management interventions for adults in Europe living with high-priority chronic conditions.

The aim is to gather ~70 stakeholders to exchange experiences and expertise on self-management (SM) best practices, share the lessons learned from the implementation of SM policies, and discuss how to best integrate and incorporate the project's findings across various settings. Other topics, like the **Self-Management Europe Initiative**, project lay-language materials, and self-management policy implementation practices will also feature in the programme.

The conference will take place in Brussels, and will feature patient representatives from across Europe, EU policy makers, other EU health stakeholder organisations, COMPAR-EU project partners, and national public health representatives.

Key information:
📅 15 & 16 November, 2022
📍 Brussels, Belgium
📩 On site attendance via invitation only
🔗 Livestream link to follow

Background: Learn more about the **COMPAR-EU** project, **EPF's involvement, and the value for patients.**

NEW 📢 launch of the 3rd lay-language course on the EHDEN Academy

EHDEN (European Health Data & Evidence Network) and the European Patients' Forum have launched the third course for non-experts as part of the EHDEN Academy course offering.

This introductory course is designed to familiarise non-experts with the basic concepts around the benefits of health data sharing, what are the possible risks, and how data is being protected. This MOOC-style course uses animated content and examples to illustrate what data sharing benefits may be for the individual and for society, data governance principles and GDPR, and how privacy works in a federated network.

Course 3 builds on the concepts explored in Courses 1 and 2, and sets the stage for a further module.

Academy, or **at this link.**

Call for Interest – Label2Enable User Advisory Group

On 15 September 2022, as part of its role in **the Label2Enable project,** the European Patients' Forum launched a call for representatives for a User Advisory Group (UAG).

The UAG will ensure that the needs, experiences, and feedback of patients, citizens, and carers are integrated into all aspects of the design of the label, and into its implementation and promotion.

We are searching for Patient, Citizen/Consumer and Carer representatives from a diverse range of age groups, genders, disease areas, and geographical origins.

The **call is open from 15 September to 15 October**. **Learn more about the project,** the contributions of the User Advisory Group, and **how to apply at this link >>**

On 15 September 2022, the **EATRIS-Plus project** published an interview **with Patient Advisory Committee (PAC)** member, Zoë Elliott.

Zoë shares with us the journey that led her to becoming involved in patient advocacy, and her involvement in the EATRIS-Plus PAC.

The interview further explores patient attitudes and experiences with health data sharing, and what organizations like EATRIS (and other research infrastructures) can do to help make data sharing a reality. Together with Zoë, themes around the concerns of the patient community on health data sharing are also explored, as well as how sharing data can ultimately benefit future generations of people living with health conditions.

Read the interview here >>

Member Focus

highlights from our member organisations

EFCCA
European Federation of Crohn's & Ulcerative Colitis Associations

Investigating innovative treatment options

Addressing Gender Equity in Neurological Care (Oct 4)

Ulcerative Colitis Associations (EFCCA)has announced that four European research projects, in which EFCCA is a project partner, have been selected under the Horizon Europe programme.

These projects aim to improve treatment options and the quality of life for people with Crohn's Disease or Ulcerative Colitis (collectively known as Inflammatory Bowel Disease or IBD). From developing predictive biomarkers enabling more personalised medicines, investigating mechanisms that will allow us to better understand the health-to-chronic inflammation transition occurring in patients for improved disease prevention and prediction to transforming the treatment of ileal Crohn's disease (CD) by developing a first-in-class oral RNA-based therapy.

For more information please visit **EFCCA's website**.

CET

WHERE: Microsoft Teams Webinar (**registration required**)

Despite the higher prevalence rate in women than in men of many neurological disorders (e.g. multiple sclerosis, migraine, Alzheimer's disease), gender stereotypes can have a negative impact, leading to under-diagnosis, misdiagnosis and delayed treatment. Furthermore, while women experience neurological disorders differently to men (symptomatic profile, pace of progression and effectiveness of medication), women are often excluded from research. In addition to the experience of the patient, the majority of informal caregiving roles are occupied by women who are also burdened by the gender divide.

In 2022, EFNA conducted a large-scale survey- 'Assessing diagnosis and care pathways of people living with neurological disorders in Europe'. During this event the survey results will be launched with a focus on the gender differences that have been uncovered.

During the event, leading experts and key stakeholders will share their views, with time for audience questions.

Registration is available **here >>>**

EURORDIS
RARE DISEASES EUROPE

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parkinson's europe

To celebrate its 30th anniversary year, the European Parkinson's Disease Association has changed its name to Parkinson's Europe which, it hopes, will better reflect its work and mission.

The EPDA was founded in 1992 and has been campaigning for thirty years to support people with Parkinson's and their families to gain access to the highest standards of treatment, support and care they need to live a full and comfortable life. Nothing in their mission has changed but, as President Veronica Clark describes, it was time for a new name to reflect a changing new landscape.

Veronica said: "Our name has served us well for the past 30 years, but we have realised that to have more impact on new stakeholders and audiences we need to have a name that will immediately communicate who we are and what we do. Our new name is no longer an acronym and when people see 'Parkinson's Europe', it is our hope that our messages will be better received."

The new name does not signify a change in the organisation's vision or strategic direction. Indeed, as part of its current work programme, the organisation has recently been working alongside people with Parkinson's, their caregivers and health care professionals to gain insight into their wishes and ambitions for the future. This research will be published shortly in the form of a Parkinson's manifesto for Europe.

The organisation is proud to have achieved many things in its thirty year history including: launching the very first World Parkinson's Day; carrying out far-reaching surveys like the Global Parkinson's Survey; the European Standards of Care Consensus Statement setting out the gold standard for the optimal management of Parkinson's; and launching the first lifestyle online magazine for the Parkinson's community, ***Parkinson's Life*** .

As the only European Parkinson's umbrella organisation, the organisation reflects a membership representing over 120,000 people with Parkinson's in nearly 30 countries across Europe, who advocate for more than 1.2 million people with Parkinson's.

You can find more information on www.parkinsonseurope.org – or sign up to one of their newsletters **here** .

21 September marked World Alzheimer’s Day, a day dedicated to raising awareness of Alzheimer’s and other types of dementia, as well as challenging the stigma surrounding dementia.

This year, to mark this important day, **Alzheimer Europe** is proud to collaborate on a new initiative called “What Makes You, You?”.

The initiative is a collaborative effort between Roche, the European Working Group of People with Dementia (EWGPWD) and Alzheimer Europe. It aims to help create a world where people living with diseases that affect the brain, like Alzheimer’s, can live life to the fullest and stresses the importance of looking beyond a person’s diagnosis and of valuing them for who they are.

Short videos (approximately three minutes each) have been created, featuring three members of the EWGPWD who are living with Alzheimer’s disease, together with some of their family members. Each tells the story of who they are, in their words.

The videos are available on **Alzheimer Europe's Youtube channel.**

Alzheimer Europe is delighted to have worked on this initiative in collaboration with Roche. Alzheimer Europe also expresses their gratitude to Bernd, Hilde, Helen, Janni and Stefan for sharing their stories to help raise awareness, combat stigma and create a world where people with dementia can continue to be who they are, this World Alzheimer’s Day and every day.

Rare Disease Week

Rare Disease Week is back! Commencing 6 February 2023 in Brussels, attendees will enjoy interactive training, meetings with policymakers, and networking events. The week's activities will focus on enabling rare disease organisations to influence EU-level policymaking.

Apply here to attend by Wednesday 5 October.

Learning opportunity - Calling patient advocates!

EURORDIS invites patient advocates to Barcelona to join their Open Academy Schools on health care, research and medicines development.

Apply now!

GAMIAN-Europe launched the campaign **#BreakingSuicideStigma** on the 10th of September on **World Suicide Prevention Day.**

Mental health patients shared their experiences of suicide ideation, slogans and a toolkit were put together to raise awareness about this important topic.

Watch the video **here.**

GAMIAN-Europe's **My HeART** project came to an end and with over **55 contestants** taking part in the contest, it has been a success! A huge congratulations to the winners from three mental health organisations: **Kaarin Poppe (Ups & Downs), Muriel Treille (ADHD, ASC & LD Belgium)** and **Arvide Nilsson (Riksförbundet Balans).**

If you wish to meet the artists and learn about their stories, join the workshop on the 5th of October at 15.000 CET.

Registration is open **here**

Atopic Eczema Consensus Europe – launch of the report

Following one year of in-depth discussions around the reality of Atopic Dermatitis/Eczema (AD/E), patients and doctors from across Europe launch today their consensus on the struggle of AD/E patients in Europe. 'The Burden of Atopic Eczema / Dermatitis - European Consensus Report 2022', published by the European Federation of Allergy and Airways Diseases Patients' Associations (EFA), provides guidance and impetus to advance atopic eczema care.

Read the press release.

Download the report.

European Lung Health Group: New policy briefing on respiratory medicine

The European Lung Health Group published a policy briefing on increasing access to medicines for rare disease patients and children with respiratory diseases, as part of its **Breathe Vision for 2030**.

Read the policy briefing.

You are invited to the 10th edition of the World Spina Bifida and Hydrocephalus Day

The International Federation for Spina Bifida and Hydrocephalus warmly invites persons

Parliament on the 25th of October at 11.00 CET.

The meeting will focus on **the potential for EU-level action on mental health** and will have the participation of **MEP Thomas Zdechovsky and MEP Maria Walsh**.

If you are interested in taking part in the meeting register **here**.

parties to celebrate **the 10th edition of the World Spina Bifida and Hydrocephalus Day** (WSBHD) on the topic of "Elevate Your Voice" on October 25 2022. Various activities will take place around the WSBHD22 throughout the month of October.

All events, materials, information and latest updates are available on **here.**

"In the midst of winter, I found there was, within me, an invincible summer."
Albert Camus

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