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THE EPF European Patients Forum
PATIENT PERSPECTIVE
APRIL 2023

EDITORIAL

Dear reader,

This April, we are coming to you with a festive issue of the Patient Perspective newsletter - EPF turns 20 this year, and we marked this momentous milestone with a celebratory event.

As you may know, yesterday, 28 April 2023, members, partners, and friends gathered in Brussels to celebrate the 20th anniversary of the European Patients' Forum. The event focused on the past, present, and future of patient advocacy in Europe with four plenary sessions and six breakout sessions. The morning sessions looked back on the past 20 years and in the afternoon, we shifted our attention to the future! In particular, we took this approach to reflect on developing effective policy and advocacy campaigns, capacity building in the patient community, and shaping the stakeholder and research environment.

To conclude the day, we proudly presented the Patient Organisations' Manifesto, which was a result of the co-creation done during the afternoon sessions by all stakeholders who attended the event. This document will feed our advocacy work for the upcoming 2024 election campaign. Keep close - you will certainly hear more from us on this topic!

Did you join us in Brussels yesterday? Or did you tune in on social media? We were happy and grateful to have you with us! And it's not over just yet – throughout 2023, we celebrate our anniversary year in various ways. Have you listened to our anniversary podcast series, for example, featuring **Marco Greco** and **Nicola Bedlington**? Share your thoughts and reflections with us throughout the entirety of 2023, using the hashtag **#EPF20**!

On the morning of 29 April, the EPF members have met for the Annual General Meeting. Read some highlights below!

Until next month, get regular updates by following our social media channels!

Next to news regarding our anniversary activities, April 2023 also saw the publication of the revision of pharmaceutical legislation. This is a once-in-a-generation opportunity to that better address unmet medical needs. More information on the revision and on EPF's reaction can be found below in this letter.

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Happy reading!

The EPF team

POLICY CORNER

April in Review

April concludes with the publication of the highly-anticipated proposal of the European Commission on the **revision of the pharmaceutical legislation**, originally scheduled for adoption in the final quarter of 2022. The revision includes a new directive and a new regulation that constitute the EU regulatory framework for all medicines (including those for rare diseases and children). In addition to this reform, the Commission proposes a **Council Recommendation** to step up the fight against antimicrobial resistance. The proposal on the revision of the pharma legislation, as technical and politically sensitive as everyone expected it to be, is now in the hands of the European Parliament and the Council for a first reading.

Following a first analysis, EPF issued a **statement** welcoming the long-awaited revision of the pharmaceutical legislation and expressing its support for patient involvement in the Committee for Medicinal Products for Human Use, which assesses applications for marketing authorisation at EU level. Further efforts to involve patients and their representatives in the development and evaluation of medicines are needed, including the definition of unmet medical needs – one of the key concepts of this review. A thorough review of the proposal by our policy team and consultation with our members will lead to amendments and a position in the coming months.

In the area of digital health, the focus has once again been on the European Health Data Space (EHDS) Regulation. In mid-April, the European Parliament published over 2000 amendments to the draft report by MEPs Tomislav Sokol (EPP) and Annalisa Tardino (ID). The amendments include patient-centred provisions on consent mechanisms, patient involvement in the governance and decision-making structures, digital health literacy and improvement of Electronic Health Records. However, several amendments tend to water down the potential of the Regulation and include provisions that, if approved, would make the final text less patient-centric. The team will continue its advocacy efforts to ensure that patients' voice is taken seriously and that patients are part of the discussion.

To conclude, an important reminder for all patient advocates and patient organisations interested in AI: **our survey** aiming to assess awareness and perceptions of risks and benefits linked to AI in healthcare is open until the 21st of May!

SECRETARIAT NEWS

News from our latest AGM (29 April 2023)

Following the 20th Anniversary Event, EPF members met on the 29th of April for the Annual General Meeting.

The elections for Board Members and members for the Ethics Committee were high on the agenda, among other topics, such as the approval of the 2022 Annual Report and financial results and the approval of the 2023 work plan and budget.

We are proud to be introducing the new members of the Ethics Committee:

- Dimitrios Athanasiou – World Duchenne Organization
- Dominik Tomek - Association for patient's rights protection in Slovakia
- Michal Rataj - EAMDA - European Alliance of Neuromuscular Disorders Association
- Pedro Carrascal - Spanish Platform of Patient Organisations
- Veronica Rubio - Association of European Coeliac Societies

And we are equally proud to present the newly (re)elected Board Members:

- Andreas Christodoulou – Cyprus Federation of Patients' Associations
- Marco Greco – European Liver Patients' Association
- Nikos Dedes – Greek Patients Association
- Radu Costin Ganescu - Coalition of Organisations of Patients with Chronic Diseases in Romania (COPAC)
- Konstantina Boumaki – EPF Youth Group

We thank them for their dedication to support our vision. We look forward to working with

At the same time, we thank the Board Members who ended their mandates. We are grateful for your valuable advice and your service.

Publication of EUnetHTA 21 guidelines for patient interaction in HTA

Earlier this month, the European Network for Health Technology Assessment (EUnetHTA) 21 published its **guidelines** for interaction with patient representatives, health professionals and other experts. The guidelines will inform the European Commission's work on the implementation of the Regulation on Health Technology Assessment (HTA) until 2025 before it becomes formally applicable.

While we welcome the emphasis on the value of meaningful involvement of patients and patient organisations, we would like to reiterate that patients and patient organisations should not be seen as two mutually exclusive entities.

Individual patients with "collective experiential knowledge" are often members and representatives of patient organisations, while patient organisations as stakeholder representatives act in the interests of patients, and not of a specific organisation.

In relation to this, the framework applied to determine conflicts of interest will exclude many patients who are members of patient organisations whose total budget is more than 40% funded by industry. This does not reflect the reality that many patient organisations are privately funded but remain independent due to the diversity of their funding sources. Similarly, there is a lack of clarity on what constitutes a conflict of interest for patient organisations, leading to a lack of predictability in engagement.

The ability of patients to contribute may also depend on compensation for costs and time invested. Financial compensation will be needed, as well as for patient organisations. Preparing well-informed feedback on joint clinical evaluations and selecting patients as external experts will require a significant investment in human resources and time.

Finally, it would be of the utmost importance for the Commission and the Member States to adopt a flexible approach in the implementation of the Regulation and to be able to make adjustments when assessing the progress made.

20 YEARS OF EPF: Looking back with key figures from EPF history

The latest podcast episode of the anniversary series features Marco Greco, EPF President.

Join us in this inspiring conversation as we dive into EPF's impactful work and mission to strengthen the voice of the patient community across Europe. Let's reflect on the past two decades of patient advocacy and look forward to the future!

Listen to the podcast **here.**

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europeanpatients'forum
Youth Group

Busy March for the Youth Group

By: Bianka Tomózer

March was full of opportunities for the Youth Group, many of our members have attended events that have allowed them to broaden their knowledge and present their youth perspective.
Our Youth Group Vice-President Cornelia Păuna attended the Data Saves Lives 2023 Bootcamp in Lisbon, Portugal. The Bootcamp's focus was on AI and how we can involve this technology to our healthcare.
You can read Cornelia Păuna's personal experience **here**.

Our Youth Group President Anastasia Semaan and our Youth Group alumni members Bhagirathi Shah and Ivett Jakab participated in the ERN RARE-LIVER Transition of Care Workshop. During the workshop interesting topics were discussed like, the transition process from paediatric to adult healthcare, transitional care, networking etc.
You can read Anastasia's personal experience **here**.

Our Youth Group member Konstantina Boumaki attended #IEEPO2023 event and participated in two panels discussing practical steps towards Humanising Healthcare. The event's aim was to explore practical steps towards Humanising Healthcare.
You can read Konstantina's personal experience **here**.

As the Annual General Meeting (AGM) and the EPF 20th Anniversary events are fast approaching in April, and the Spring Meeting of the Youth Group is coming up in May, we would surely benefit from our members' experience of these events and overview the knowledge they gained from them. We encourage you, as a reader to follow our social media platforms, to be informed about our engagement in utilising our young patient voice.

Follow the EPF Youth Group here:

PROJECTS PORTAL

EU-PEARL Project comes to an end!

The final event of the EU-PEARL project has taken place on the 25th of April, 2023, at the Le Plaza Hotel in Brussels, Belgium. The event showcased the learnings drawn from the project and the work done for enhancing clinical development and care by developing sustainable and replicable Integrated Research Platforms (IRPs) that allow collaborative adaptive platform trials to thrive.

Funded under the Innovative Medicines Initiative 2 Programme, the EU-PEARL consortium has been working since 2019 to achieve the project's mission of simplifying and standardising clinical trial platforms to make them more patient-friendly and efficient.

Making clinical trials more efficient and patient friendly can improve the process so that individuals find the clinical trial that matches their needs, that companies enrol enough patients, and eventually, that new treatments are evaluated in better ways.

To further bolster the project's commitment to patient centricity at the heart of Innovative Research Platforms, the project also developed the Platform for Patient and Community Engagement in Platform Trials (PaCEPT) which is a **Repository for Patient and Community Engagement.**

Head to **www.eu-pearl.eu** to find out more about EU-PEARL's results, explore

MEMBER FOCUS

Coming soon from **GAMIAN-Europe**

On **World Schizophrenia Awareness Day** (May 24th) at 11.00 CET, GAMIAN-Europe and the European Psychiatric Association (EPA) are holding the online event*: "Living with schizophrenia: hearing the different perspectives".* The webinar will present the findings of a two-year project focused on strengthening and improving the therapeutic relationship between patients with schizophrenia and their psychiatrists. Read more **here**.

GAMIAN-Europe is currently working on a project called **"The Vibrant Mind"** which explores the link between art and mental health through a pan-European exhibition. This year-long initiative includes exhibitions, events, and digital resources to showcase artists' work and promote awareness. The project aims to expand its reach and inclusivity by

Updates from EATG

EATG and APH launch the **online training platform STEP-UP MOOC**

RBDCOV: HIPRA's booster vaccine against COVID-19, BIMERVAX®, receives **EMA's positive opinion**.

EATG shares response to the European Commission consultation on the proposal for a Council **Recommendation on vaccine-preventable cancers**

EATRIS+: **The Patient Engagement Resource Centre (PERC) has been launched**.

EVENTS:
From the **EU Health Policy Platform Annual Meeting** – Stakeholders' Dialogue: Joint Statements, Study results and discussion

This week the Coordination Team of the EU HIV/AIDS, VH, and TB Civil Society Forum attended the annual meeting of the EU Health Policy Platform **#EUHPP** in Luxembourg.

Durning this meeting we presented the Joint Statement on the standards of care and stigma, discrimination and criminalisation of key populations.

EATG pointed out that we have to stop saying it's impossible to measure stigma and that we need more data to act, since we now have good baseline data from the ECDC-led HIV-related stigma survey. It is time to act to address stigma & discrimination faced by people living with HIV and the people most affected by HIV, TB and hepatitis.

In addition, the UN Sustainable Development Goals are good indicators of how countries are doing regarding infectious diseases. In this frame, they need to prioritise making services easily accessible, safe and welcoming for people most affected.

The Joint Statement will be available for endorsements in the coming days – **check this space**.

BELONG: Why people living with HIV must be included in non-HIV clinical trials – **A Virtual Roundtable Discussion**

iCOPe HIV: HIV and Ageing: Setting Global Priorities – **Virtual Meetings**

European Mental Health Week 2023 will take place between the 22nd and 28th of May

The awareness week is led by **Mental Health Europe** (MHE) and this year it will focus on mentally healthy communities.

This is the fourth edition of the pan-European awareness campaign and events will be held by organisations, public authorities, and individuals across Europe, both online and in-person. Mental Health Europe will be hosting a policy event at the European Parliament in Brussels on May 24th, in collaboration with the European Parliament Coalition for Mental Health and Wellbeing. The goal of this year's EMHW is to increase understanding and learning about mental health in our communities, schools, workplaces, and at home so that everyone can thrive and flourish at every stage of life.

Director of Mental Health Europe, Claudia Marinetti said 'The concept of European Mental Health Week builds on the long-standing global tradition of celebrating Mental Health Awareness month in May. The 2023 European Year of Skills focuses on vocational skills, education and digital skills. We have the opportunity this year to mainstream mental health across all of our communities and focus on the knowledge and skills that are needed to understand and take care of communities' mental health."

European Mental Health Week is an awareness event to promote the mental wellbeing of millions of people in Europe, protect the rights of people with lived experience of mental health problems and raise awareness to end mental health stigma and discrimination.

If you are interested in hosting an event for European Mental Health Week, get in touch: info@mhe-sme.org

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