



CAMPAIGN UPDATES

Dear readers,

Let's start the April issue of the Patient Perspective by taking a look at the EU policy agenda for the next few years. A quick view reveals why, as stated by our Executive Director, Anca Toma, *"there has never been a more important, more decisive, more crucial year in the history of health in Europe"*. From the negotiations of the **EU's pharmaceutical legislation** to the implementation of **the European Health Data Space** and agreement on the EU budget for 2028-2035, Members of the European Parliament will have a great impact on the future healthcare landscape for all European citizens.

With so much at stake, the European Patients' Forum (EPF) launched a campaign to elevate the patients' voice in this election and promote better involvement of patients and patient organisations in health policy. With just over a month to go before **the European elections (6-9 June 2024)**, it's time to take stock of the EPF's election campaign.

Our campaign, centred around the **Patients' Organisations Manifesto** adopted at EPF's 20th anniversary, already received endorsements from several current Members of the European Parliament and candidates. The signatories are policy-makers active in the field of healthcare and come from different countries and political parties.

On the communications side, supportive MEPs participated in **interviews, videos**, and **social media cards** to help convey EPF's messages to a wider audience and promote the debate around patient involvement as part of the campaign. The **#Vote4Patients** campaign has almost exceeded **1 million impressions** on social media. Given the importance of these elections, the communications team also collaborated with the European Parliament secretariat on the **#UseYourVote campaign**, which encourages - beyond healthcare - all citizens to take part in the elections.

Our members are essential in getting our messages across to patients and to the wider community in every country. Our members' circle organised mid-February gave us the opportunity to launch the campaign and present the tools our members can use to amplify our collective advocacy efforts. Some members have booked calls or advocacy training sessions with the EPF secretariat, while others are helping us by distributing the toolkits to

[Subscribe](#)[Past Issues](#)[Translate ▼](#)

If you haven't already done so, you can support the EPF and its members' campaign for greater involvement of patient organisations [here](#)!



#VOTE4PATIENTS

MEP
TOMISLAV SOKOL

On the latest episode of the EU Patients Podcast, MEP Tomislav Sokol joins our campaign, highlighting the role patient organisations play in shaping healthcare policy decisions. [Listen to the full episode here.](#)



#VOTE4PATIENTS

MEP
KATEŘINA KONEČNÁ

In the words of MEP Kateřina Konečná, patient organisations have to play a central role in shaping healthcare. [Watch the full recording here.](#)



#VOTE4PATIENTS

MEP
RADKA MAXOVÁ

"Patients' input, as regards the reform of the healthcare system in the EU is priceless, as it is them who have practical understanding and life experience of our healthcare systems", says MEP Radka Maxová. [Have a look at her full testimonial.](#)



#VOTE4PATIENTS

MEP
TILLY METZ

MEP Tilly Metz was interviewed by our colleague, Yann Heyer. She values patient organisations as vital partners, as they are complementing the efforts of policy makers and healthcare providers. [Join their conversation here.](#)



#VOTE4PATIENTS

MEP
STELIOS KYPOUROPOULOS

MEP Stelios Kypourouopoulos believes in a strong patients' voice: "Patients are still active, let them speak for themselves".

SECRETARIAT NEWS



EPF IS PART OF THE CRITICAL MEDICINES ALLIANCE

Nikos Dedes, EPF Board member, at the launch of the Critical Medicines Alliance: "Shortages are not an industrial issue; they are a public health issue with an industrial and manufacturing component". [More about the Alliance here.](#)

[Subscribe](#)[Past Issues](#)[Translate ▼](#)

EPF RECEIVES OPERATING GRANT

EPF has received an operating grant under the EU4Health Programme to advance patient advocacy across Europe. [Read more here.](#)



AGM 2024

On 13 and 14 April, EPF hosted a capacity-building workshop tailored for members, on the opportunities, perspectives, and challenges of AI use in healthcare, followed the day after by the Annual General Meeting (AGM). [Catch up on both events by following this link.](#)



PROVISIONAL AGREEMENT ON THE EHDS

During the plenary meeting on the 25 April 2024, the European Parliament voted the provisional agreement on the European Health Data Space with 445 votes in favour. EHDS is one of the key pillars of the strong European Health Union as it provides the essential framework for the exchange of health data to support healthcare delivery, and facilitate research, innovation, regulatory decisions, and policy making. [Go through our opinion.](#)



REACTION TO THE EUROPEAN PARLIAMENT'S POSITION ON THE REVISION OF THE EU PHARMACEUTICAL LEGISLATION

EPF welcomes the European Parliament's adoption of the reports on the Directive and the Regulation, formalising the Parliament's official position on the revision of the EU pharmaceutical legislation. [Explore our reaction.](#)



FEEDBACK ON THE IMPLEMENTING ACT ON JOINT CLINICAL ASSESSMENTS OF MEDICINAL PRODUCTS

We welcome the publication of the draft Implementing Act on Joint Clinical Assessments (JCA) of medicinal products, which sets out the rules for patient involvement in the context



Just a few more spots available for STYPA 2024! With the applications closing on May 1st, **make sure you don't miss out and register now!**

YOUTH GROUP UPDATES



Being a part of the EPF Youth Group has been such a fulfilling experience, and especially since having an active role on the EPF board. I am looking forward to working with the amazing new Vice President Marleen and all of our members to further our current Youth Group projects and further develop connections within the patient community, ensuring that our voices are not being silenced. Through our welcoming and inclusive environment, strong communication, collaboration and utilising the knowledge and lived experiences of all of our members, each from their own patient backgrounds, I know we will continue to make an impact on the wider patient community - Anastasia, Youth Group President



I joined the youth group during the height of the pandemic. Thanks to a wonderful board, we were able to grow as a team even without meeting in person. Now, I believe it's my time to give back to the group and help especially new members to feel welcomed. I am very grateful for the trust and opportunity of being the new vice president and excited for the journey ahead. - Marleen, Youth Group Vice-President

The Fresh Faces of the Newly Elected EPF Youth Group Board Members

By: Marleen Sorensen & Anastasia Semaan

During the EPF Youth Group Spring Meeting in March, one of our goals which we achieved was holding elections for the new and now current youth group board, including electing the new president and vice president. It was amazing to see the commitment and dedication of our members who put themselves up for these roles. We are very thrilled to

all we will accomplish together as a team.

Ensure that you follow us on our social media platforms, including [Facebook](#), [X](#), [Instagram](#) and [LinkedIn](#) to find out more about our current projects and the progress being made within the EPF Youth Group and within the Youth Group Board, or regarding how you can get involved and support our team.

PROJECTS PORTAL



IDERHA hosts their first Annual Public Meeting at the Fraunhofer Forum, in Berlin

On 15 April 2024, IDERHA hosted their first Annual Public Forum at the [Fraunhofer Forum, in Berlin](#).

Seizing the opportunity to go through the latest achievements and challenges about this project, the members of the consortium will discuss:

- The use of AI across the care pathway
- The technical challenges when integrating healthcare data to drive innovation and research
- How to shape policies to meet the needs of the future

[Subscribe](#)[Past Issues](#)[Translate ▼](#)

the [Patient Advisory Board](#) and the next plans for this year.

Follow our social media channels for updates!

IDERHA (Integration of Heterogeneous Data and Evidence towards Regulatory and HTA Acceptance) is a European public-private partnership launched in April 2023. This initiative aims to build a scalable platform for a seamless integration or linkage of diverse real world data at scale to support healthcare professionals, patients and researchers with new capabilities to improve patients' outcomes. The consortium aims to achieve this by providing better treatment and disease management, enabling personalised care, bolstering research innovation based on the development of common standards and practices.

Follow [this link](#) to learn more.

MEMBER FOCUS



COPAC Announces New Project | SHIFT HUB - Smart Health Innovation & Future Technologies Hub

The Coalition of Patients Organisation with Chronic Disease from Romania is proud to be a partner within a dynamic consortium comprising 12 entities spanning 7 countries. Together, they are spearheading the project SHIFT HUB project - Smart Health Innovation & Future Technologies Hub, funded by Horizon Europe scheme. The project aims to bring together different stakeholders along the healthcare value chain, including patients, healthcare professionals, technology providers, knowledge and infrastructure providers, innovation intermediaries, financial intermediaries, and public authorities.

COPAC invites fellow patient associations, coalitions, and federations from national and European level to join SHIFT-HUB community. By doing so you will gain access to the online services of the consortium and external stakeholders. Learn more about the project by visiting the [website](#) or follow us the project's work on [LinkedIn](#).

Subscribe

Past Issues

Translate ▼



EFA community is now represented in the newly launched European Critical Medicines Alliance

EFA has been elected to become a member of the newly launched European Critical Medicines Alliance, a European Commission initiative to address, reduce and react against medicine shortages in the EU which are far too often a daily challenge for allergy, food allergy, atopic eczema, asthma and COPD patients in Europe, despite the prevalence and impact of these diseases. [Read more on EFA website](#)



Support the #KeepBreathing campaign on social media: new filter!

We need to keep breathing and you can show your support today. The yellow lungs of the #KeepBreathing campaign are now featured in a filter on social media. Whether at an event or your workplace, use this opportunity to get set, shoot and share directly on your smartphone!

The [#KeepBreathing campaign](#) is a joint advocacy effort of the European Lung Health Group (ELHG), nine European level patient and healthcare professional organisations, gathering 179 national associations in 36 countries together for better lung health policy in Europe. Visit the [breathevision.eu](#) and learn more!



In a move that supports the established approach of patient-centered healthcare in European research, [GAMIAN-Europe](#), as a project's communication leader, is actively working on the **development of the TRUSTING Users Board (TRUSB)**, within



[GAMIAN-Europe](#) is excited to share the continuous success of its **Vibrant Mind Travelling Exhibition** within the **Vibrant Mind Project**. This initiative is dedicated to empowering individuals with mental health conditions through the transformative power

[Subscribe](#)[Past Issues](#)[Translate ▼](#)

early intervention in psychosis. **To learn more or become a member of the Board, click [here](#).**

7th. This time the project will be accompanied by different workshops. If you are not registered yet, you can join with a click [here](#).



Updates from **Fertility Europe**

On March 22 - 23, Fertility Europe held its annual Spring Meeting, this time in Warsaw, Poland. As always, it was an exceptional event, bringing together individuals dedicated to Fertility Europe's mission.

The ExCo meeting

It started with a face-to-face (a rare occasion!) ExCo meeting where many important issues were discussed and a lot of crucial decisions were made in preparation for the upcoming members' meeting as well as for the future, including preparations for Fertility Europe's 15th anniversary.

Together for Fertility

It was followed by the host-country association Nasz Bocian's special event "Together for Fertility" marking the completion of a joint project of three FE members: Roda of Croatia, Zachatie of Bulgaria and Nasz Bocian of Poland. It provided a unique opportunity for the attendees all to delve deeper into the organisation's joint initiatives and impacts.

Members' meeting

The next day started early in the morning welcoming 32 delegates representing Fertility Europe member associations from across Europe. Throughout the gathering, the participants engaged in a series of productive meetings, covering various topics essential to Fertility Europe and their membership's mission and objectives. These sessions were marked by robust discussions and collaborative efforts aimed at advancing the organisation's goals.



Global Heart Hub | Job Opportunities

Global Heart Hub, the international alliance of 100+ heart patient organisations, is seeking to hire for two positions:

- **[Patient and Stakeholder Engagement Manager \(Remote\)](#)**
- **[Senior Communications Specialist \(Remote\)](#)**



Updates from European AIDS Treatment Group

EACS endorses EATG's Belong project on inclusion of people living with HIV in non-HIV clinical trials

The European AIDS Clinical Society (EACS) has endorsed the European AIDS Treatment Group's (EATG) Belong project, advocating for regulatory authorities in Europe to adopt clinical guidelines that include people living with HIV in trials relating to other health conditions that affect people living with HIV.

SCOPE project: Amplifying Community Voices for Prevention (2022-2023) – Newsletter

For two fruitful years, SCOPE worked in close collaboration with community representatives including gay and other men having sex with men, transgender and gender-diverse people, migrants, women and people who use drugs to facilitate cross-learning, awareness-raising, networking, community monitoring of the implementation of combination prevention, production and adaptation of targeted information materials and policy advocacy.

This is a review of what we achieved together in SCOPE.

EATG presents on community engagement in R&D at BioIntegraSaude 2024 conference

On April 9, Rocco Pignata and Fiona Greenhalgh, EATG Programme Officers and Project Coordinators, presented and discussed how to coordinate patient and community engagement at BioIntegraSaúde 2024 conference (Vigo, Galicia).

EVENTS

CORE Knowledge Hub Meeting # 1 | The HIV, Viral Hepatitis and STIs Testing and Diagnostics Landscape: An Update

{WORLD AIDS DAY 2024 – SAVE THE DATE} CORE Local Multi-Stakeholders' Meeting | Improving Health Outcomes of Most Affected Populations: The Response to HIV, VH, STIs & TB in Poland and the European Region

NEW PROJECT

Ageing with HIV – The Glasgow Manifesto: A Platform for Change

ENDORSEMENTS

Future Members of the European Parliament:
Take Control to Ensure Access to Medicines
Correlation: **Drug Policy Manifesto for the 2024 European Parliament Elections**



[Subscribe](#)[Past Issues](#)[Translate ▼](#)

WFIPP is pleased to announce that the World Continence Week (WCW) toolkit for 2024 is now available online ([Resources Archive – WFIPP.org](#)). Included in this toolkit are the various WCW2024 posters! All created to help you promote World Continence Week 2024 across the globe. World Continence Week (WCW) is an annual initiative devised and managed by WFIPP, intended to raise awareness of bladder & bowel issues, chronic pelvic pain and other debilitating conditions which impact greatly on the lives of patients, families and carers.

[contact us](#)[visit our website](#)[view this email in your browser](#)

Copyright © 2024 European Patients Forum, All rights reserved.

You are receiving this email because you opted in at our website www.eu-patient.eu

Our mailing address is:

European Patients' Forum
Chaussée d'Etterbeek, 180
Brussels 1040
Belgium

[Add us to your address book](#)

Want to change how you receive these emails?
[You can update your preferences or unsubscribe from this list.](#)

This email was sent to <<Email Address>>

[why did I get this?](#) [unsubscribe from this list](#) [update subscription preferences](#)
European Patients' Forum · Chaussée d'Etterbeek, 180 · Brussels 1040 · Belgium