



THE **EPF** European Patients Forum
PATIENT PERSPECTIVE
DECEMBER 2023



Reflections

Welcome to our December Patient Perspective newsletter!

As we approach the conclusion of 2023, we find ourselves reflecting on a year marked by significant milestones, impactful advocacy, and rewarding achievements. We celebrated the **20-year anniversary of our collective journey**, a pivotal moment prompting us to take stock of EPF's accomplishments and the collaborative efforts of our dedicated members and community.

Throughout the year, our efforts ranged from advocating on crucial legislation shaping the EU public health landscape to spearheading patient voice representation in various projects. We have actively worked towards building capacity for effective patient advocacy across our diverse community, highlighting the central role of patients as active partners in health systems.

Our members and allies, representing the voice of patients in Europe, are the backbone of our strength. Their dedication motivates us give our best every day. Our commitment remains steadfast — to enhance patient involvement, drive a meaningful digital transformation, and advocate for equitable access to healthcare across Europe.

During this festive season, the EPF Secretariat wishes you a joyful holiday break. May your time be filled with warmth, joy, and cherished moments with loved ones. Wishing you good health and all the best for the new year.

See you in 2024!

The EPF team

HAPPY
HOLIDAYSWishing you a joyous
holiday season!

Policy and Advocacy Corner

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

2023 in Review

The policy team went through some transitions this year, with two new team members, Claudia Louati and Yann Heyer, joining Julie Spony and Milana Trucl. As a team, we are proud to continuously advocate for more patient-centred EU policies and to have brought the patient perspective in so many dossiers! As the year draws to a close, the policy team looks back on an extremely busy but rewarding year, with many important developments for the patient community. Here is a snapshot!

A digital transformation that delivers for patients

The digital transformation can bring many benefits to care, but its challenges also have to be addressed to ensure patients' trust – our October 2023 [paper](#) on Artificial Intelligence (AI) in healthcare highlights some key recommendations in this regard. We are using the paper as a key advocacy tool as we engage with EU institutions and agencies on this topic. Thanks to all who helped shape our input! On the legislative front, while 2022 marked the development of the [EPF position](#) on the European Health Data Space (EHDS), in 2023 we were able to shape this initiative to better address patients' needs. On 13 December, the European Parliament adopted its position on the EHDS, reflecting many of our calls to strengthen the portability of patients' health data, empower patients to control their data, and promote digital health literacy. As the trilogue negotiations start with the Council, we are hopeful a patient-centred EHDS will soon be ready for implementation!

Patients' access to the healthcare they need

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authorisation of medicinal products. After going through thousands of pages, and in collaboration with its members, EPF has published its **recommendations** for a patient-centred revision of the legislation, including fairer access across Europe. We have also focused on three aspects of the review that are crucial to the communities we represent: **defining unmet medical needs in collaboration with patients, safeguarding access to medicines for paediatric patients**, and shortages. In October, our Executive Director Anca Toma highlighted the impact of shortages on patients and the need to involve patients in policy solutions at a hearing of the European Parliament's Health Committee (SANT). Beyond pharmaceuticals, we have also engaged in the debates on the **implementation** of the medical devices regulation and on **access to healthcare during the pandemic** in the context of the Periscope project. As a member of the Civil Society Forum of the EU's Health Emergency Preparedness and Response (HERA), we are calling for the inclusion of continuity of care in times of crisis as part of discussions on crisis preparedness and response.

A new European agenda for patients: building policy partnerships

From representing EPF at the European Medicines Agency (EMA) to engaging with international organisations on various topics, we are building partnerships to elevate the patients' voice. Along with our partners of the EU4Health Civil Society Alliance, we continued to advocate for **more sustainable funding for health-focused civil society organisations**. Another area where partnerships play a key role, along with continued awareness-raising and education, is antimicrobial resistance (AMR). The impact of AMR on patients with chronic conditions is often overlooked, even though they are particularly vulnerable. Like last year, EPF was actively engaged in **Antimicrobial Awareness Week** in 2023. We plan to step up our engagement on this issue next year, so stay tuned!

2024 promises to be an exciting year for the policy team, with many policy dossiers still on the agenda before the European elections in June and priorities for the new mandate currently in the making. We cannot wait to get back to work and highlight the importance of patient involvement in the political debates. But first, we need some rest!



News From the Secretariat

updates from the inside

EPF European Patients Forum

EPF's Reaction to European Parliament's adoption of the **EHDS** report

EHDS | EPF's reaction to European Parliament's adoption of the EHDS report

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We believe that the Parliament's report improves the Commission's proposal to empower European patients and citizens to access and control their personal healthcare data in an electronic format and facilitate secure sharing for research and altruistic purposes.

We particularly welcome the changes to Article 33 which include an opt-out mechanism for sharing health data for secondary use. We suggest that health data access bodies provide an accessible and easily understandable mechanism for natural persons to express their objection against all or part of their personal electronic health data being processed for some or all purposes for secondary use listed in Article 34, with the exception of public health emergencies and regulatory purposes.

Read the full statement [here](#).



INTERVIEW | Claudia Louati on the revision of the EU's pharmaceutical legislation

Claudia Louati joined an episode of Karger's The Waiting Room Podcast, to discuss the the ins and outs of the pharmaceutical legislation.

Listen to the [full episode here](#).



What the EPF Youth Group has Accomplished in 2023...

By: Blaz Urbanc and Anastasia Semaan

The year 2023 has been a remarkable period for us, on behalf of the European Patients' Forum (EPF) Youth Group (YG). It has been a beacon of advocacy and raising awareness of actions for young patients. Throughout the year, our members have been dedicated to the landscape of advocacy, by attending and actively contributing to several events, workshops, conferences, and informal discussions. The common thread weaving through our collective activities and individual contributions is the commitment to advocating the voices and rights of young patients. Each step taken by the EPF Youth Group and each of our members individually, is a step forward in the journey towards a more inclusive and empathetic healthcare system. One where the needs and perspectives of young patients are not just heard, but are playing an active integral role in shaping the future of patient

- We finalised our "Sexual Health and Wellbeing Project" and hosted a webinar with key speakers including a nurse and a sexologist, and together with our EPF Board Representative Konstantina, a round table discussion was held. The key conclusions of our project were reflected on, as well discussions about areas regarding patient sexual health and wellbeing that needed more patient and practitioner voice.
- Throughout the spring and fall meeting, as a YG we were engaged in analysing and finalising our "Patient Involvement in Patient Organisations" Project, by finalising our concept note and setting our short and long-term goals. During these in-person meetings, our members also reflected on their current projects, celebrated their achievements, and set goals for the future.
- Cornelia Păuna (Vice President) attended the GlobalSkin and IFPA online event on "Youth Involvement within Organisations".
- Anastasia Semaan (President), alongside YG alumni Bhagirathi Shah and Ivett Jakab, presented at the ERN Rare-Liver Transition of Care Workshop in Ghent, Belgium.
- Konstantina Boumaki (EPF YG Board Representative) participated in the IEEPO panel discussions on "Humanising Healthcare" in Basel, Switzerland.
- Cornelia Păuna (Vice President) attended the Data Saves Lives 2023 Bootcamp in Lisbon, Portugal, focusing on AI in healthcare.
- EPF celebrated its 20th Anniversary Event, with Marleen Sorensen, Konstantina Boumaki and Anastasia Semaan engaging in discussion panels throughout the event, and by opening and closing the whole celebration.
- April was also marked with the election of Konstantina Boumaki as the new YG Board Representative, during the AGM, where we too actively participated and presented our accomplishments. Since then, Konstantina has represented the young patient voice throughout the EPF Board Meetings.
- We recruited three new members, Anna Revilla Bruñol, Aedan Kaal and Eimear O'Rourke who recently joined our Youth Group family. We have met them virtually during our monthly TCs, and we will hopefully be meeting them in-person during the Spring Meeting.
- We were sad to say goodbye to two of our YG members, Leonie and Erin, but we are looking forward to seeing what they do next as advocates, and we wish them the best of luck.
- IDF Europe Youth Leadership Lab 2023 - our Youth Group coordinator Borislava Ananieva attended and presented our YG and activities.
- 4 of our YG members completed the STYPA 2023 Program, including Cornelia, Konstantina, Leonie and Anna (prior to joining the YG).
- We also wrote and submitted monthly articles as a part of the EPF Newsletter, and have been consistently posting throughout our social media platforms.

As we reflect on the year's accomplishments, one of them being our Sex Health and Wellbeing Project Roundtable Webinar where expertises were invited, we are reminded of the power of collective effort and the impact of dedicated individuals. "Alone we can do so little; together we can do so much." – Helen Keller. These words resonate with the spirit of the YG's endeavours throughout 2023, which we strive to continue throughout 2024, whilst continuing to represent the young patient voice and perspective. To find out more about what we are achieving in 2024 continue to follow us on our social media channels on [Facebook](#), [Twitter](#) and [Instagram](#). If you have any questions, reach out to us through the following email address: youthgroup@eu-patient.eu.

As the festive season approaches, we spread our warmest wishes for a Merry Christmas and a Happy New Year. May the coming year 2024 be filled with joy, health, and continued success in all our collaborative efforts for a better world.

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Projects Portal

briefings on EPF's ongoing projects



EHDEN x DATA SAVES LIVES Bootcamp

Data Saves Lives and **EHDEN** teamed up earlier this month to organise a Patient Registries Bootcamp, where 10 patient advocates debated the crucial topic of building community-led patient registries.

Together, we explored the intricacies of launching patient registries, addressing challenges ranging from the technical requirements of GDPR compliance to the implications of the proposed EHDS legislation.

Here are some key takeaways from the enriching discussions:

✦ **Empowering Patient Involvement:** The consensus among our experts is clear—patients and caregivers should take the lead in registry development from the outset. By identifying the type of data needed and leveraging their community expertise, patient groups play an integral role throughout the entire process.

✦ **The Power of Collaboration:** Building a registry is undeniably complex, but our discussions emphasized that collaboration is the linchpin of success. Challenges, whether in selecting partners or securing funding, are part of the journey. However, the burden shouldn't solely rest on the community. Diverse data collection approaches, such as forming networks with existing registries, can be explored to enhance outcomes.

✦ **Community-Centric Development:** Generating insights and meaningful learnings from data is a time-consuming process. It is imperative to involve the community throughout the journey and share developments with them to foster trust. Transparency and inclusivity in the process ensure that the community remains engaged and informed.

highlights from our member organisations



WAD 2023 | Stigma-Free: We call for stigma-free integrated services

This World AIDS Day, in the frame of our ongoing Stigma-Free campaign, we launched a **video of interviews** from HIV experts stressing why we must focus the HIV response on ending stigma and discrimination and alleviate their impact on the mental health and wellness of communities affected by HIV.

Belong: "What We Wanted was What We Needed" – A Model of Inclusive Community Advocacy: The Sitges Meetings

EATG is publishing **"What We Wanted was What We Needed" – A Model of Inclusive Community Advocacy: The Sitges Meetings**. This case study was conducted within the framework of the **Belong project**, advocating for the inclusion of people living with HIV in non-HIV clinical trials, and documents experiences, results, and lessons learned from the Sitges meetings.

BLOGS

A call to action for collective activism against gender-based violence by Nicoletta Policek

We can't end HIV unless we end the war on drugs by Magdalena Bartnik

SCOPE: Study Trip from Stronger Together (North Macedonia) to GAT (Portugal)

SCOPE: Study Trip from NGO Cohort (Ukraine) to New Generation NGO (Armenia)

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