



THE **EPF** European Patients Forum

PATIENT PERSPECTIVE

MARCH 2025

Dear reader,

This month, EPF launched the “We Are Here”, campaign, calling for patient voices to actively shape healthcare systems. For over two decades, EPF has connected policymakers with Europeans living with chronic conditions, advocating for fair, inclusive, and accessible healthcare. However, healthcare is increasingly sidelined in EU priorities, evidenced by a 20% budget cut to the EU4Health Programme in 2024 and delays in the 2025 Work Programme, causing uncertainty for civil society organisations.

EPF emphasizes health as a vital investment rather than an expense. The EU4Health Civil Society Alliance event on 26 March 2026, hosted by MEPs Tilly Metz, Stine Bosse, Vytenis Andriukaitis, and Andras Kulja MD, drew over 150 participants, showing strong cross-party support for prioritising health in the upcoming Multiannual Financial Framework (MFF). As MFF negotiations approach, EPF reiterates our call for health to be a central pillar of the EU budget, for stable and sustainable funding for health NGOs, and for the meaningful involvement of civil society organisations from the start.

The European Commission’s Critical Medicines Act proposal is promising, particularly regarding joint procurement and supplier diversification, yet lacks structured patient involvement and transparency on procurement processes and public funding. Redirecting EU4Health and Horizon Europe funds risks undermining essential health initiatives. EPF stresses the importance of robust healthcare systems for Europe’s security and competitiveness.

The Critical Medicines Alliance’s report highlights the necessity of transparent, patient-centred approaches to medicine shortages, advocating patient engagement throughout procurement and assessment processes. Amid revisions to EU pharmaceutical legislation, EPF and EURORDIS urge Member States to maintain robust patient representation within the European Medicines Agency, warning that weakening patient involvement could reverse decades of progress.

EPF remains committed to building a comprehensive, patient-centred framework to ensure equitable access to medicines across Europe. As we reflect on past achievements and confront new challenges, EPF remains resolutely “Here”, making sure every patient’s voice shapes the future of European health.

SECRETARIAT NEWS

UNLOCKING EUROPE'S FUTURE: PRIORITISING HEALTH UNDER THE NEXT MULTIANNUAL FINANCIAL FRAMEWORK



On 26 March 2025, the EU4Health Civil Society Alliance recently brought together over 150 participants, both in person and online, for a discussion focused on the role of health within the upcoming Multiannual Financial Framework (MFF). Hosted by MEPs Tilly Metz, Stine Bosse, Vytenis Andriukaitis, and Dr Andras Kulja, the event demonstrated robust cross-party commitment to prioritising health in the EU budget. [Read more details.](#)

STATEMENT ON THE EUROPEAN COMMISSION'S PROPOSAL FOR THE CRITICAL MEDICINES ACT

EPF supports the European Commission's proposed Critical Medicines Act as a significant step toward enhancing medicine security, availability, and accessibility for all EU patients, but highlights gaps that need addressing for full effectiveness. [Read our full statement here.](#)

EPF LAUNCHES "WE ARE HERE": A CALL FOR A PATIENT-CENTRED FUTURE FOR HEALTH

Health is not an expense; it is an investment. A society that neglects its people's health is a society that is failing its future. [Read more about EPF's new campaign.](#)

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CALL TO PROTECT AND STRENGTHEN MEANINGFUL PATIENT INVOLVEMENT IN EMA DECISION-MAKING

EPF and EURORDIS - Rare Diseases Europe (EURORDIS) are urging EU Member States to uphold strong and meaningful patient involvement in the European Medicines Agency's (EMA) regulatory decision-making. [Explore the joint statement.](#)



In November 2024, Data Saves Lives (DSL) celebrated its five-year anniversary event in Brussels. The two-day event provided an opportunity to reflect on the DSL journey of empowering health communities through data literacy. It brought together key stakeholders to discuss the progress made and explore the future of health data sharing in healthcare. The full event report is out, [read more here.](#)

MEMBER FOCUS



Updates from EATG

- [World TB Day, 24 March: TB CAB Weekly Newsletter special edition](#)
- [DoxyPEP: Info note](#)

Webinars and events

- [Community Breakfast Club at CROI 2025](#)
- [EATG Women Converse | The silent heroine: Olimbi's extraordinary HIV activism in Albania](#)
- [Belong | Inclusion of Women and Transgender People in Clinical Trials: Advancing Equity in Research](#)

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From 28 to 30 March 2025, Europa Donna will host 80 dedicated advocates and experts from 34 countries in Milan for the Europa Donna Advocacy Training Course. The event will feature distinguished speakers and discussions will focus on key topics such as breast cancer prevention, early detection, treatment options, research advancements, and evidence-based advocacy. Collaboration between scientists and patient advocates will be central to the event, aiming to drive meaningful change for individuals affected by breast cancer.



On 26 March, Fertility Europe hosted the "FActs! Fertility Awareness Matters: Tackling the Knowledge Gap for European Youth" event at the European Parliament, aiming to empower youth with essential fertility knowledge. The event presented findings from a study of 3,803 gameplay responses across Bulgaria, Finland, Norway, Poland, and Portugal, highlighting critical gaps in young Europeans' understanding of reproductive health and fertility. Recognising the real-life impacts of these gaps, Fertility Europe concluded the event with a Call to Action, urging policymakers to integrate fertility awareness into Comprehensive Sexuality Education (CSE). [More details are available here.](#)

PROJECTS PORTAL



Why is patient involvement important when developing digital health technologies?

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the Patient Advisory Group. [Listen to the episode here.](#)



The H2O project seeks to establish patient-centered health outcomes observatories at both the pan-European and national levels. Its primary objective is to amplify the patient voice within healthcare systems by providing tools that allow patients to report their health outcomes in a standardised manner, while having full control over their personal health data and access permissions.

To further this goal, the European Patients' Forum (EPF), in collaboration with the Data Saves Lives initiative, H2O national observatories, and other project consortium partners, co-organized three Patient Engagement events in Austria, Germany, and Spain. [Explore the event here.](#)



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