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EDITORIAL

Prioritising Patient Voices: Ensuring Health Policy Remains a Top EU Focus

As we close out August 2024, the European healthcare landscape continues to evolve. For us, at EPF, it is vital that health remains a priority in the EU agenda. Patients should have a say in policies that affect their health. But currently, most EU and national institutions fall short in guaranteeing early, meaningful and impactful involvement of patient organisations in health policy decision-making.

As our leaders show waning interest in fortifying health policies, patient organisations face the threat of losing support, including public funding, that is vital for civil society. We have recently elected new MEPs who will represent us in the EU for the next five years. Now is the time to make sure they keep health at the top of the EU agenda and guarantee patients to have a meaningful say in any related policy making.

While this is a reminder that progress has been made, the road ahead remains long. As we look forward to the coming months, it is clear that sustained efforts and innovative approaches will be essential in ensuring that all Europeans can enjoy equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise.

SECRETARIAT NEWS



HIGH LEVEL POLICY EVENT
TOWARDS A PATIENT-CENTRED EU MANDATE: HEALTH POLICY WITH AND FOR PATIENTS

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On 16 October 2024, EPF will host the invitation only high-level policy event **"Towards a patient-centred EU mandate: Health policy with and for patients"** in Brussels, bringing together elected MEPs and representatives of our membership in a conversation about how to consolidate patient involvement in policy in the 2024-2029 EU mandate. Find more information [here](#).



LET'S CELEBRATE 5 YEARS OF DSL

Data Saves Lives 5-year Anniversary Event | 26-27 November 2024, Brussels, Belgium

This invitation only event celebrates **Data Saves Lives** (DSL) 's continued commitment to empower and inspire the patient community and facilitates discussions on multistakeholder collaboration on European Health Data Space, AI, Health Technology Assessment (HTA) and other key health data literacy areas. Find more information [here](#).



WEBINAR 2: "HOW DO WE USE OUR VOICES TO REACH A WIDER COMMUNITY FOR AMR?"

Webinar 2: "How do we use our voices to reach a wider community for AMR?"

On August 29th, in collaboration with the **AMR Narrative**, EPF organised the second webinar in the AMR series. In case you have missed it, the **full recording is available here**.



MEMBER FOCUS A CONVERSATION WITH ZOPS

New Episode Alert | The EU Patients' Podcast

ZOPS (Patient Organisations Association of Slovenia) is a national coalition representing over 40 patient organisations in Slovenia, covering 25 different health conditions.

In this episode, we discuss the role of Slovenian patient organisations in creating a unified voice for patients. [Listen to the episode here](#).

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EHDEN 101

EHDEN is changing the way we understand health data. The project tackles the challenges of generating insights and evidence from real-world clinical data at scale.

EPF plays a role in outreach and sustainability, helping coordinate alongside other project partners, the production of educational and training material.

The EDHEN 101 video series is designed to help non-experts explore key topics like real-world data, real-world evidence, patient reported outcomes, federated data networks, and much more.

Ready to expand your knowledge? Head over to YouTube now and [explore the four available videos](#).



Join the **PROPHET Stakeholder Session** and contribute to advancing personalised prevention!

PROPHET aims to develop a European **Strategic Research and Innovation Agenda (SRIA)** for the implementation of personalised prevention approaches focused on stakeholder engagement.

On 1st October 2024 from 13:30 to 17:30, join the PROPHET Stakeholder Session in Stockholm and contribute with your expertise to building the SRIA!

The workshop will include group discussions, presentations, and focus groups, to gather inputs from you on the **SRIA**. The participants will automatically be registered in the **PROPHET Stakeholder Forum**, an ad-hoc platform created for the project's members to easily share information.

Do you want to contribute? Click [here](#)!

MEMBER FOCUS



AIDS Treatment Group

News from EATG

EATG attended the **the 25th International AIDS Conference!** AIDS 2024 that took place in Munich, Germany, and virtually from 22 to 26 July. EATG co-hosted two Networking Zones: The Silver Zone: Celebrating older people living with HIV and 555 Zone: We Won't Be Left Behind! and a booth with great success. **Explore moments from #EATGatAIDS2024 here.**

BLOGS from AIDS 2024

AIDS 2024: Put People First Now, Put People First Right Now!

EATG member **Anton Basenko shares his takeaways from AIDS 2024** in Munich and his speech from the closing ceremony of the conference.

AIDS 2024: A Profound Reminder of the Importance of Community, Collaboration, and Continued Advocacy

EATG member and ombudsperson **Karen Badalyan highlights the best moments from AIDS 2024** in Munich.



EURORDIS | Final call to fill in the Rare Barometer survey

Final call: the Rare Barometer survey closes on September 8th, there's still time to make your voice heard. If you are living with a rare disease, this is your chance to share your experiences—from navigating work and pursuing hobbies to finding social support. Your insights are crucial in shaping future policies and improving understanding for the entire

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The survey is available in 25 languages, ensuring it is accessible to as many people as possible. Every response matters, and by sharing your story, you can help drive positive change and make a real difference in the lives of those affected by rare diseases.

Don't miss out on this opportunity and [fill in the survey here](#).

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