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SAVE THE DATE EPF Congress 2025



Shaping the Future of Healthcare: Join Us at the EPF Congress!

26-27 NOVEMBER 2025 | DOUBLETREE BY HILTON, BRUSSELS

In today's evolving political landscape, discussions at both European and national levels are shaping long-term strategies across economic, social, and political spheres. Yet, one critical element remains missing: a patient-driven definition of what high-quality healthcare should look like in the medium and long term.

At the EPF Congress 2025, we are stepping up to fill this gap. Through our extensive network and expertise, we will showcase best practices from across the healthcare ecosystem and present a bold, cohesive vision for the future of patient-centred care.

This will be a transformative opportunity to shape the healthcare system patients truly need and deserve. More details to come soon!

SECRETARIAT NEWS



POLICY PRIORITIES FOR THE NEW EU MANDATE

As we prepare to tackle current and future cross-border health challenges, the European Health Union must step up its coordination efforts to pave the way for greater access to high-quality healthcare for all. From equitable access to healthcare and medical products

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THE JOURNEY TOWARDS THE EU HTA REGULATION

In January 2025, the HTA Regulation began its implementation phase. Valentina Strammiello, EPF Director of Strategic Initiatives, who has been working on the topic since 2015, shared some of her reflections on the journey so far.



NEW SEASON 2025: HEALTH FORWARD

EPF has published a report with patient-centred proposals for the new mandate, addressing healthcare access, medicine shortages, and EU health funding. **In this episode of the EU Patients' Podcast**, EPF Head of Policy Claudia Louati joins us to discuss key challenges and solutions from the report.



ANTIMICROBIAL RESISTANCE PATIENT TESTIMONIALS

In our **latest policy paper**, we highlight patients and stakeholders' experiences with Antimicrobial Resistance (AMR) issues shared during the **three webinars** we organised in collaboration with **The AMR Narrative**.



STYPA 2025 IS OPEN FOR APPLICATIONS

The Skills Training for Young Patient Advocates (STYPA) is back for 2025! This year's topic will be dedicated to digital health and Artificial Intelligence in healthcare. If you are a patient between 18 and 30, **find out more and apply here.**

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HEALTHCARE INNOVATION

Our colleague, Flavia Topan, Communications Manager at EPF, is conducting a doctoral research, to better understand how communication strategies influence the adoption of innovation in healthcare. The focus is on ensuring that advancements not only reach healthcare settings but are also implemented effectively, benefiting patients and professionals alike. The survey will be open until 21st February 2025 and it lasts less than 10 minutes to complete. **Take the survey today** and share it with your networks!

PROJECTS PORTAL

This month, we witnessed the successful launch of three exciting new projects. Below, you'll find brief details about each initiative. Stay tuned for further updates on EPF's involvement in all of them!

PROACT EU-Response: PROACT EU-Response's overarching objective is to prepare Europe for future pandemics by strengthening upon existing networks of experts and civil society focused on clinical therapeutic platform trials within hospital inpatient settings across Europe.

READI: Central to READI's approach is a sustainable, patient-focused digital platform to improve access to clinical study information, tools, and resources while fostering collaboration. READI will test its tools in four clinical studies, addressing challenges such as mistrust and lack of information.

ENKORE: The project's main objective is to develop an eco-design framework that facilitates the creation of medical devices and packaging that are both safe and environmentally responsible - reducing carbon footprints and optimising resource use.

YOUTH GROUP UPDATES

A Reflection of 2024 for the EPF Youth and Looking into 2025

Anastasia Semaan

The year 2024 was a very busy and impactful year for the EPF Youth Group, where we had the opportunities to take part in a range of events and represent the young patient perspective, but also opportunities that allowed us to develop and grow as evolving patient advocates. One of the most significant progresses that we have made this year is in our current project, which is our *Involving Young People in Patient Organisations Project*. In 2024, we set clear goals and targets for what we want to be included in our online course that we are developing for leaders of patient organisations to take part in, to support them in better involving young patients. Throughout the year we have been working to develop the content that we are planning to release within the course and how we hope for it to be structured, with an impactful flow. In 2025 we are hoping to launch the online course and spend time in encouraging patient organisation leaders to take part and provide us with feedback.

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MEMBER FOCUS



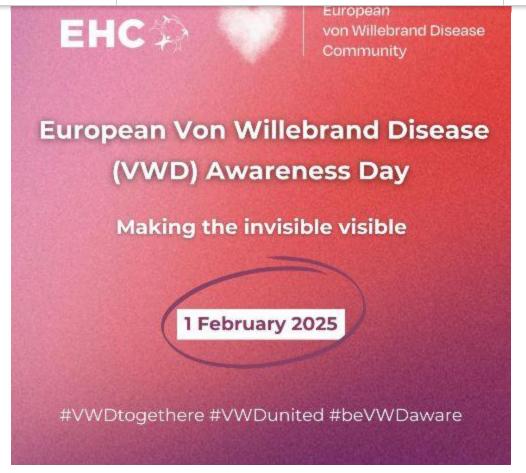
Colorectal Cancer (CRC) is on the rise, and it's affecting younger people more than ever. Many still believe CRC is only a concern for older adults, but the latest European health data proves otherwise—cases are decreasing among those over 70 while rising alarmingly in people under 50. It's time to take action.

That's why #ECCAM2025—European Colorectal Cancer Awareness Month—is more critical than ever. Launched by **Digestive Cancers Europe** (DiCE) in 2008, ECCAM is dedicated to raising awareness, promoting early detection, and driving life-saving conversations. This year, they're going social-first, ensuring that essential CRC information reaches younger audiences like never before.

Join DiCE on 27 February 2025, at 10 AM CET, for the official #ECCAM2025 launch event. Your voice matters. Don't miss out—be part of the movement! \$\varphi\$ #ColorectalCancer #GetChecked

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On 1 February, the **European Haemophilia Consortium** (EHC) marks European VWD Awareness Day, dedicated to increasing awareness of Von Willebrand Disease (VWD) within the bleeding disorders community and beyond. This year, we are placing a special focus on the impact of VWD in women and girls.

To highlight this important day, the EHC YouTube channel (@EHCTVChannel) will premiere the first 10 video recordings from the ongoing educational series, "Topic on Focus on VWD". This initiative, developed in collaboration with ERN-EuroBloodNet, explores the unique aspects of VWD from both clinical and patient perspectives.

EHC invites us to join in spreading awareness! Whether you post, repost, or engage in the conversation, don't forget to tag the EHC and use the official hashtags of the European VWD Community.

Together, we can make a difference! #VWDawareness #EHC #BleedingDisorders #VonWillebrand

Parkinson's Europe has released its bold new strategy to improve lives for people living with Parkinson's, their families and caregivers across Europe.

To ensure it truly represented the needs of the Parkinson's community in Europe, the strategy was created in collaboration with people living with Parkinson's, as well as

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in 2022, which was based on input from 1,000 people in 35 countries.

The result is a strategy with three new strategic pillars designed to keep the organisation focused on its most important goals over the next three years:

- 1. Defining the impact of Parkinson's in Europe (Data & Innovation)
- 2. Helping the European Parkinson's community grow stronger together (Empowerment)
- 3. Ensuring the voice of the European Parkinson's community is heard (Awareness & Visibility)

You can read more about Parkinson's Europe's new strategy here.





This January, **Europa Donna** participated in two major EU-funded initiatives shaping the future of breast cancer care.

DEFINITIVE Consortium Meeting (Barcelona)

The DEFINITIVE project is validating a minimally invasive diagnostic tool for HER2+ breast cancer, which affects 390,000 women annually. Europa Donna plays a key role as a Work Package Leader, ensuring patient involvement remains central and aligned with the NIHR's principles for impactful cancer research.

PATH FOR YOUNG Kickoff Meeting (Paris)

This project focuses on improving care for premenopausal women with hormone receptorpositive breast cancer. Building on the OPTIMA trial, PATH FOR YOUNG aims to redefine treatment pathways and empower patient voices by: Subscribe Past Issues

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• Developing a digital learning platform for patients and healthcare providers

Both projects highlight Europa Donna's commitment to advancing breast cancer care and prioritizing the quality of life for patients across Europe

Be Seen and Be Heard: Projects by the Malta Health Network

In 2023 and 2024 **Malta Health Network** (MHN) worked on increasing visibility, facilitating their ability to promote the Maltese patients' perspectives and importance to policymakers and stakeholders. This is an integral requirement for a healthy and respectful healthcare environment.

The two projects mainly focused on promoting the concepts of patient empowerment, self-management, and patient professional communication.

The first project **To Be Seen, to Be Heard** consisted of a series of videos targeting both patients and professionals, and the research for this project mainly came from focus groups conducted with these two groups. The videos are freely available on social media including YouTube, Facebook and MHN website, and everyone is encouraged to share and disseminate them using either the Maltese or English versions. All videos are with subtitles for ease of accessibility.

The second project **Up to You** was a follow-up for which, upon request, the promoted material in the videos was transformed into a **booklet format**. The leaflet and PDF version are available for free so that both patients and professionals can have a copy.



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