EPF European Patients Forum

Annual Report

2024

A strong patients' voice
to drive better health in Europe

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Introduction

In 2024, the European Patients' Forum (EPF) stood at the forefront of advocating for a truly patient-centred healthcare system across Europe. This year, EPF channelled its efforts to amplify the patient voice during the European Elections, strengthened strategic partnerships, and delivered tangible outcomes across its key thematic areas: **Patient Safety, Patient Equity, Data & Digital Health,** and **Community Building**.

This report captures the impact of EPF's work in 2024, following the roadmap set in the Work Plan and based on the measurable outcomes. Throughout 2024, EPF has demonstrated its unique role as the umbrella organisation uniting Europe's patient voice, translating shared challenges into strategic advocacy for shaping health policies, capacity building, and community engagement.

Strategic plan 2021-2026

Our Strategic Plan 2021-2026 reflects the challenges and opportunities for EPF as an umbrella of patient organisations active across Europe.

This plan describes **who we are, what we stand for, and what we want to achieve**. Patients and the patient community remain key actors and contributors in creating equitable, person-centred, accessible, and sustainable healthcare systems in Europe. This plan outlines our proactive role and impact.

OUR VISION is a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise.

OUR MISSION is to advance the interests of patients and patient communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.

Our Members

Our members are the backbone of our work: their perspective brings an irreplaceable added value to our policy and advocacy activities. In 2024, EPF counts **79 member organisations**, representing **21 countries** and an estimated **150 million patients** across Europe.

Find an overview of our current membership **here** (or on page 38 of this report).

A word from our President Marco Greco

2024 reminded us why the patient voice matters more than ever. As Europe stood at a turning point, with new leadership on the horizon and major health policy reforms underway, the European Patients' Forum continued to do what it does best: bring the lived experiences of patients to the heart of decision-making.

From the European Elections to high-level debates on health policy topics, EPF was there, speaking up, sharing real stories, and shaping change.

What made this year particularly meaningful was how much of our work was driven by people: by patient communities who contributed their time, expertise, and energy. Whether it was a youth advocate completing their first training, a member organisation co-developing a toolkit, or a PAG member representing their community in an EU project, the impact of patient engagement has never been clearer.

At EPF, we talk often about values like inclusion, transparency, and equity. In 2024, we turned those values into action. We launched tools, held dialogues, joined forces with global and European institutions, and created space for patients to lead.
To all our members, partners, staff, and friends: thank you for your trust, your voice, and your belief in the power of patient advocacy.

Cross-Cutting Activities: Foundations of Impact

Delivering on our strategic mission through leadership, engagement, and visibility

1. Parliamentary Elections Campaign 2024: #Vote4Patients

The 2024 EU elections provided an important opportunity for the patient community to make its voice heard by current and future policymakers.

In February 2024, EPF launched its European Election Campaign 2024, focused on elevating the voice of patients in the EU healthcare landscape. **#Vote4Patients** aimed to ensure that the significant challenges faced by patients are given central attention by candidates and, ultimately, by the European Parliament. The campaign was guided by the **Patient Organisations' Manifesto**, which was first introduced during EPF's 20th Anniversary event in 2023. The Manifesto expressed our community's vision for European patient advocacy and served as a roadmap for the broader patient movement in Europe.

EPF engaged its membership in disseminating its manifesto and building the patient community's capacity for political engagement at national level.

Key outcomes:

- **The campaign** closed with 2.5 million social media impressions, 646 posts, and significant engagement, demonstrating broad support for a patient-inclusive EU health agenda.
- **EPF's Elections Campaign toolkit** supported patient organisations in building national-level advocacy capacity.

2. High-Level Policy Event: Towards a patient-centred EU mandate: Health policy with and for patients

The High-Level Policy Event *“Towards a patient-centred EU mandate: Health policy with and for patients”* took place on October 16th, 2024, in Brussels, Belgium. The event marked a step towards enhancing patient representation in healthcare policymaking, reaffirming the commitment to prioritise the voices of patients in every aspect of health policy development.

The event aimed to conclude EPF’s EU elections campaign by bringing together decision-makers, newly elected Members of the European Parliament and EPF members in a conversation about the consolidation of patient involvement in health policy in the new EU mandate.

It gathered **140 on-site participants** and featured **including high-level guest speakers**, receiving extensive coverage across Brussels-based and European media outlets.

> **The voice of patients must be heard if we are to build the resilient, people-centred healthcare systems we seek.**
>
> Stella Kyriakides, European Commissioner for Health and Food Safety

Key highlights (Read the full report of the event here)

- **Strong Institutional Endorsement:** European Commissioner Stella Kyriakides and WHO Europe Director Hans Kluge reaffirmed the importance of patient involvement in shaping EU health policies and the European Health Union.
- **Systemic Integration of Patient Voices:** Discussions emphasised how patient engagement is becoming embedded across the therapeutic and healthcare continuum, from drug development to Health Technology Assessment (HTA) and digital health literacy initiatives.
- **Legislative Momentum:** MEPs discussed actionable policy changes, including mechanisms for equitable access to medicines, improved transparency, and stronger roles for patients in EU-level health decision-making.
- **Challenges of the Patient Movement:** Panellists addressed key barriers such as insufficient funding, the need for training and support, and the importance of youth involvement and combating misinformation in digital spaces.

Patient Safety

Building safe, patient-centred systems through advocacy and collaboration

Ensuring safety in healthcare is a fundamental patient right. In 2024, EPF led impactful initiatives in two key domains: **Antimicrobial Resistance (AMR)** and the **Medical Devices Regulatory Framework (MDRF)**, to safeguard patients and support more effective, accountable, and inclusive systems of care. Through both our policy and advocacy efforts, as well as our involvement in EU projects, we raised awareness, influenced EU-level debates, and empowered patient communities to engage meaningfully in shaping safety standards and regulatory practices.

1. Amplifying Patient Advocacy on Antimicrobial Resistance (AMR)

Antimicrobial Resistance remains a critical global health threat. EPF positioned patients at the heart of the response, combining policy advocacy, awareness raising, and community mobilisation through a campaign under the theme #UnderstandingAMR.

2024 Achievements at a Glance

- **Three high-impact webinars** (June, August, September), offering a platform for dialogue between patients and policymakers
- **Public speaking engagements at premier events, including:**
  - WHO Novel Medicines Platform
  - European Commission AMR One Health Network
  - Belgian Presidency Conference on AMR
- **Over ten bilateral meetings** with key decision-makers, including EU Member States, WHO, and the European Commission
- **Launch of the AMR Toolkit for Members**, including messaging templates, factsheets, and a policy briefing
- **Publication of a joint statement with The AMR Narrative** after the UN High-Level Meeting on AMR
- **Creation of a dedicated AMR Info Point** on EPF’s website, housing comprehensive resources on AMR.

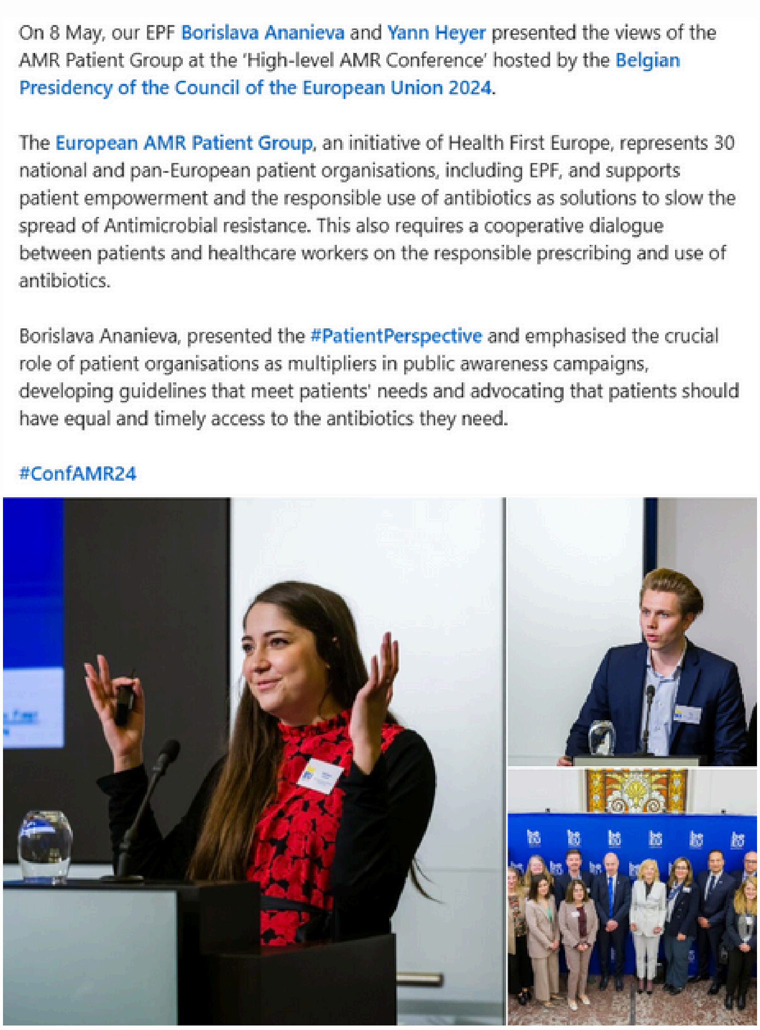
In 2024, EPF implemented a **robust, multi-layered advocacy and awareness campaign on antimicrobial resistance (AMR)**, emphasising its implications for patient safety. Central to the campaign was a dedicated AMR Info Point webpage, which attracted over 1,200 visits and hosted key advocacy materials. A wide-reaching communications effort followed, with two podcast episodes, three webinars, videos, press releases, news items, and targeted social media outreach under the #UnderstandingAMR campaign.

To build capacity among its members, EPF developed and disseminated a communication toolkit and finalised the syllabus for an AMR advocacy course, to be launched in 2025. The webinar series attracted more than 600 registrants and facilitated engagement on how patients can effectively influence AMR policy.

At the EU level, EPF published policy briefs, engaged in over ten high-level meetings with key decision-makers including MEPs, WHO representatives, and national authorities, and presented the patient perspective at major events such as the High-Level AMR Conference under the Belgian EU Presidency.

EPF also supported **national-level advocacy** by providing members with background materials, messaging templates, and practical guidance.

Globally, **EPF strengthened partnerships** with organisations like The AMR Narrative, ReACT, and Cancer Patients Europe, actively participating in platforms such as the WHO Novel Medicines Platform and the Global AMR R&D Hub. This culminated in a joint policy statement issued after the UN High-Level Meeting on AMR, reinforcing the recognition of AMR as a patient-centred challenge requiring urgent, coordinated action across sectors and borders.



On 8 May, our EPF Borislava Ananieva and Yann Heyer presented the views of the AMR Patient Group at the 'High-level AMR Conference' hosted by the Belgian Presidency of the Council of the European Union 2024.

The European AMR Patient Group, an initiative of Health First Europe, represents 30 national and pan-European patient organisations, including EPF, and supports patient empowerment and the responsible use of antibiotics as solutions to slow the spread of Antimicrobial resistance. This also requires a cooperative dialogue between patients and healthcare workers on the responsible prescribing and use of antibiotics.

Borislava Ananieva, presented the #PatientPerspective and emphasised the crucial role of patient organisations as multipliers in public awareness campaigns, developing guidelines that meet patients' needs and advocating that patients should have equal and timely access to the antibiotics they need.

#ConfAMR24

WEBINAR SERIES

Amplifying patient advocacy on Antimicrobial Resistance (AMR)

Register

1 Webinar 1: Patient Advocacy on AMR in the EU: where do we begin?

Date & Time: 20 June 2024, 3 - 4pm CEST

Platform: Zoom

Language: English

“Call for greater involvement of patient organisations to address AMR”

2. Medical Devices Regulation: Advocating for Safe, Accessible Technologies

2024 Achievements at a Glance

- **Participation in all plenary meetings of the Medical Devices Coordination Group** (MDCG) and most working group meetings (e.g., Clinical Evaluation, Post-Market Surveillance)
- **Delivery of a members' circle webinar** in June, followed by a targeted survey on the MDR experience
- **Publication of two policy statements:** one highlighting implementation concerns, and another calling for impact assessment if a possible revision
- **Active input to consultations and bilateral meetings** with national and EU-level authorities, including Dutch and Irish NCAs, the European Commission, and the European Parliament
- **Publication of a report** with the findings of a survey on the implementation challenges of the EU Medical Devices Regulation and the in vitro Diagnostic Medical Devices Regulation.

Six years after adoption, the implementation of the EU's Medical Devices and *in vitro* Diagnostics Regulations (MDR/IVDR) continues to face challenges. EPF advanced its strategic objective to promote patient access to safe medical devices in the EU by **actively supporting and monitoring the implementation of the Medical Devices Regulatory Framework (MDRF)**.

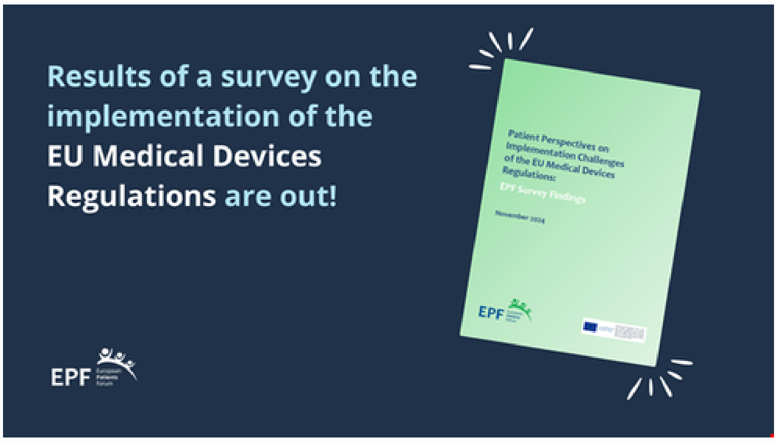
As a core part of this effort, EPF participated in all plenary and working group meetings of the **Medical Device Coordination Group (MDCG)**, including sessions focused on post-market surveillance, clinical investigations, and orphan devices. Insights from these engagements were regularly disseminated to members through direct communications and updates in EPF's Insiders newsletter.

EPF also strengthened member engagement through a **dedicated webinar** in June, attended by 25 organisations, and a follow-up **survey capturing patient experiences with the MDR**. While the creation of an ad hoc working group was postponed due to limited demand, bilateral exchanges and contributions via the Universal Access Working Group ensured continued member input.

On the advocacy front, EPF published a **comprehensive policy paper** based on member consultations, providing concrete examples and recommendations from a patient perspective. This was shared widely with EU institutions, including the Council, the European Commission, and MEPs. Two additional statements addressed the rollout of the MDR/IVDR and called for a thorough impact analysis of a possible regulatory revision.

EPF also held multiple **high-level meetings with national and EU authorities**, such as the Dutch National Competent Authority and the Irish HPRA, and maintained regular dialogue with the European Commission and Parliament to ensure patient views were considered in ongoing MDR discussions and the October 2024 EP plenary debate.

Feedback on joint scientific consultations on medical devices



Results of a survey on the implementation of the EU Medical Devices Regulations are out!

PROJECTS

Coordinating Research and Evidence for Medical Devices (CORE-MD)

The project ended in March 2024. Based on the findings from a Delphi study with patients conducted in late 2023 to early 2024, EPF co-authored a deliverable on Patient Reported Outcome Measurements (PROMs) which was published on the CORE-MD project website.

EPF reviewed several project deliverables on final results and recommendations for the European Commission, one of which was an Ethical Charter. The team also co-authored a scientific paper based on CORE-MD results which reviews and recommends key methodologies for clinical investigations for medical devices, with the aim of harmonising investigation approaches and certification of devices across Europe.

Harmonised Approach to Early Feasibility Studies for Medical Devices in the European Union (HEU-EFS)

In early 2024, EPF launched a call to establish a Patient Advisory Group (PAG), successfully recruiting 11 patients and informal carers from diverse backgrounds. Since then, PAG members have actively contributed to project activities, including consortium meetings, work package sessions, training events, the Annual Project Meeting (October 2024, Milan), and mid-term reviews (April 2024, March & April 2025).

To support their engagement, EPF and project partners developed and delivered training materials and videos on Early Feasibility Studies (EFS) and the EU regulatory framework.

In mid-2024, the “Patient Engagement Ambassadors”, the project’s work package leaders, were appointed and collaborated with EPF to create tailored Patient Engagement Plans outlining PAG contributions across the project. Multiple consultations were conducted to gather PAG input, including surveys (November 2024 to March 2025) and focus groups. Further consultations are planned for 2025.

EPF co-organised a workshop at the PEOF event in Baveno (May 2024) and facilitated patient representation at high-level events.

PAG feedback has contributed to several key project deliverables, addressing topics such as the regulatory landscape, eligibility for EFS, gaps in patient involvement, digital health technologies, and engagement with national competent authorities.

IMMUcan

IMMUcan completed patient recruitment, enrolling over 2600 patients. The work of the project was showcased through eight poster presentations at leading international scientific conferences. The core project team also welcomed four new partners: Novigenix SA, AstraZeneca, Institut Gustave Roussy, and Cliniques Universitaires Saint-Luc. In addition, the team started new collaborations with the UroCCR kidney cancer network and the Nirvana study to share materials and data. At the same time, the project teams have been working to complete data preparation and carry out advanced analyses to move the project forward.

EPF supported the project efforts by disseminating key milestones and achievements, by leveraging the project’s social media channels as well as providing lay language articles and posts to explain the work carried out in the project.

Health Outcomes Observatory (H2O)

EPF participated in several key engagement events, including co-organising the Vienna (March 2024) and Berlin (November 2024) workshops, which brought together patients, healthcare professionals, and partner organisations to discuss the role of initiatives like H2O in transforming care delivery. Outcomes included the creation of a practical guide for National Observatories and collaborative discussions on infrastructure development in Germany.

Throughout the year, Patient Advisory Board (PAB) meetings played a vital role in shaping the project. Notable activities included:

- IBD PAB discussions on dashboard development and research priorities (June 2024), supported by a research prioritisation survey (September 2024);
- Insights Center feedback on tool mock-ups to improve data use for decision-making (July 2024);
- Finalisation of PROMs screening questions for diabetes outcome sets through the Diabetes PAB (July 2024).

EPF also supports the Pan-European Health Outcome Observatory (PEO), launched in 2024 as a legacy of H2O. Serving as a multi-stakeholder forum for digital outcome alignment, PEO includes EPF representation on its board, reinforcing the central role of patients in shaping meaningful healthcare metrics across Europe.

PROPHET
a PeRsOnalized Prevention roadmap
for the future HEalThcare

PROPHET

Together with consortium partners, EPF organised interviews and several focus groups with patients and patient organisation representatives, to learn about and develop best practices for patient engagement for personalised prevention. The results were presented in a project deliverable and a scientific paper, which will be published in the BMC Public Health Journal.

EPF developed a strategy to organise capacity building activities on personalised prevention for patient communities in 2026.

EPF drafted and revised several iterations of the main project outputs, the Strategic Innovation and Research Agenda (SRIA) and the companion Roadmap for implementation of the SRIA. In terms of dissemination, EPF produced and published a **podcast episode** on the project with the project coordinator at Università Cattolica del Sacro Cuore (UCSC) in Rome.

Patient Equity

Working toward fair, inclusive, and patient-centred access to healthcare across Europe

At the core of EPF’s mission is the belief that every patient deserves equitable access to quality healthcare, irrespective of their condition, location, or socioeconomic status. In 2024, EPF advanced this mission through strategic advocacy on pharmaceutical legislation, health technology assessment (HTA), and national-level policy engagement.

Policy and Advocacy

1. Pharmaceutical Strategy

The European Commission’s proposal to review the general pharmaceutical legislation represents **a unique opportunity to ensure a more patient-centred regulatory system** at EU level and address inequalities in access to medicines across the EU within the remit of the legislation.

2024 Achievements at a Glance

- **Held 10+ meetings** with key policymakers, including rapporteurs from the European Parliament, Council health attachés, and the European Commission
- **Published three major policy statements:**
  - A response to the European Parliament’s position on the revision
  - A statement on improving access through the pharma legislation
  - An opinion piece on the role of patient experience data in defining unmet medical need
- **Developed and disseminated an advocacy toolkit** for EPF members offering tailored messaging, visuals, and policy asks
- **Participated in high-level events and roundtables, including:**
  - DIA Europe (March 2024)
  - ISPOR Europe (November 2024)
  - RAPS Euroconvergence and POLITICO Summit
  - Committee of the Regions debates on medicine shortages
- **Actively involved** in the Belgian NEED project and the EU Court of Auditors' inquiry on medicine availability

EPF delivered a **comprehensive advocacy and capacity-building programme** to empower patient organisations and strengthen the patient voice in the ongoing revision of EU Pharmaceutical legislation. A key milestone was the publication of an Advocacy Toolkit, complemented by two webinars, in March and May, and targeted bilateral engagements with members. These efforts enhanced understanding and enabled active participation in shaping legislative changes.

EPF **maintained strong momentum in policy engagement**, holding more than 10 meetings with key stakeholders including rapporteurs of the pharmaceutical review, newly elected MEPs, Member State representatives, and the EU Court of Auditors. EPF's position paper was continually updated and widely disseminated, while four high-impact public statements addressed crucial legislative milestones, from patients' access to medicines and advertising regulations to unmet medical needs and the value of patient experience data.

EPF also **ensured patient representation at high-level forums**, participating in panels at major events such as DIA Europe, ISPOR, RAPS Euroconvergence, the POLITICO Healthcare Summit, and a Committee of the Regions debate. Internally, the Working Group on Access to Healthcare held six meetings, with expert input from the European Commission, Belgian KCE, and WHO Europe.

Finally, EPF **extended its advocacy** to to the WHO European Region Novel Medicines Platform, where it helped develop transparency initiatives and participated as a speaker at the Consensus Building Meeting in July 2024.

These achievements significantly reinforced the role of patients as stakeholders in shaping a more transparent, equitable, and responsive pharmaceutical landscape in the EU.

2. Health Technology Assessment (HTA)

With the new HTA Regulation set to take effect in January 2025, **2024 was a critical preparation year**. EPF focused on building capacity within its membership and advocating for meaningful patient involvement in the design and implementation of joint clinical assessments at EU level.

2024 Achievements at a Glance

- **Coordinated five submissions** to the European Commission's draft Implementing Acts
- Published four statements articulating the importance of patient involvement in HTA
- **Organised a consensus-building** to model EU-level HTA implementation and identify real-world bottlenecks
- **Maintained the HTA Info Hub**, an online resource on EPF website, containing tools, and policy updates
- **Participated in multi-stakeholder events** such as DIA, HTAi 2024, and ISPOR Europe to align perspectives with other key actors
- **Launched a Coordination Plan for a Patients' Stakeholder Group** to improve communication and advocacy across patient communities

EPF made **significant progress in supporting and structuring patient involvement** in the implementation of the EU HTA Regulation.

Throughout the year, EPF organised **three dedicated meetings** with patient organisations in the HTA Stakeholder Network, complemented by bilateral exchanges with the European Commission (DG SANTE), industry representatives, and clinicians during HTA-focused events. EPF actively participated in multi-stakeholder platforms and international events, such as DIA Europe, HTAi 2024, ISPOR Europe, and the European Access Academy, contributing to discussions on aligning stakeholder efforts in preparation for the regulation's rollout.

To support informed advocacy, EPF submitted written responses to five draft implementing acts, addressing topics such as joint clinical assessments, scientific consultations, conflict of interest policies, and cooperation with the EMA. These contributions were developed through internal consultations with members and are publicly available via the HTA Info Hub, which also hosts media content and statements.

EPF also **strengthened communication between patient organisations** through the development of a shared Teams-based coordination tool, featuring a calendar, key documents, and internal discussion space. Currently, 41 external patient representatives are active on the platform.

Two major consensus-building activities further deepened patient input into HTAR processes. A Delphi consensus-building exercise, carried out in collaboration with EAMDA and Open Health.

PROJECTS

European Digital Health Technology Assessment framework co-created by all stakeholders along the value chain (EDiHTA)

The project was launched at the beginning of 2024, and it aims to allow the assessment of different Digital Health Technologies (DHTs), such as telemedicine, mApps and AI, at different Technology Readiness Levels (TRL), territorial levels and from the perspective of beneficiaries and providers of healthcare.

The Patient Advisory Group (PAG) was established in August 2024, which includes 15 Patient Advisers. PAG members were selected following a call for patient experts. Profiles were selected based on their disease, geographical origin, age, gender, level of expertise, and engagement with digital health technologies, with the ultimate goal to ensure diverse perspectives. While the role of the PAG is to inform the development of the EDIHTA framework through the implementation of the project, a first opportunity for engagement was offered by the planned focus groups discussions.

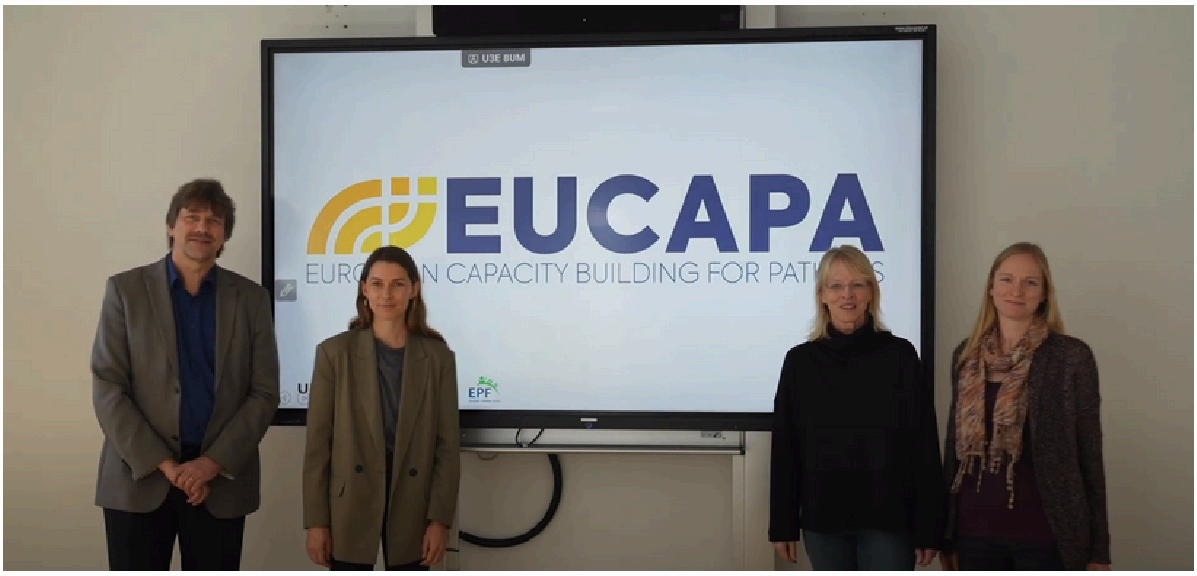
EPF organised a meeting with patient advocates, to test the design of upcoming focus group sessions. The aim was to assess the clarity of presentations, the subtopics to be discussed, and to set expectations for future sessions. The team provided an overview of key concepts, such as Health Technology Assessment, the value of patient involvement, and the project's objectives.

Following the pilot, the Patient Advisory Group (PAG) was split into two smaller groups for more focused discussions. The first group, consisting of six members, discussed Artificial Intelligence (AI) and telemedicine, evaluating their pros and cons from a patient perspective. The second group, with nine members, focused on mobile health apps and digital medical devices, also analysing their pros and cons from a patient perspective. The findings provided a comprehensive perspective on patient expectations, perceived needs, barriers and enablers towards the uptake of digital health technologies.

European Capacity Building for Patients (EUCAPA)

In 2024, over 100 people registered for the EUCAPA online introductory training, and took part in seven fast-track trainings, and three 3-day extended trainings in March, June and October. During this period, three newsletters (February, April, July) were sent out to over 100 subscribers. The project continued its #HTAInEurope series on real examples of the implementation of the HTA regulation in Estonia and Czechia.

EUCAPA partners also promoted the project during meetings, workshops, and conferences - including DIA Europe 2024, HTAi 2024 Annual Meeting, and HTA Stakeholder Network.



Data & Digital Health

Ensuring digital innovation serves people, not systems

In 2024, EPF took several steps to ensure that digital transformation in healthcare was developed with and for patients. Through sustained advocacy, stakeholder collaboration, and capacity-building resources, EPF shaped the emerging European Health Data Space (EHDS) and related AI and digital policies with a focus on trust, transparency, and inclusion.

Policy and Advocacy

1. Continued advocacy on patient-centred EU digital policies, including artificial intelligence

As the EU moved toward the adoption of the EHDS regulation, EPF worked to make sure patients' voices were embedded in its design and implementation. From governance frameworks to data access rights, EPF engaged with policymakers to advocate for a democratic, inclusive, and patient-governed approach.

2024 Achievements at a Glance

- **Engaged directly with policymakers and Permanent Representations** involved in the EHDS negotiations
- **Actively contributed** to TEHDAS 2, eHealth Stakeholder Group, and WHO Europe's SPI-DDH initiative
- **Delivered two toolkits on the EHDS:**
  - One for patient organisations to guide them through institutional processes and rights
  - One for patients, explaining EHDS impacts and opportunities in lay language
- **Published two position papers** marking milestones in the EHDS legislative process
- **Maintained a strong presence at strategic conferences, including:**
  - DIA Europe and HMA/EMA Big Data Stakeholder Forum
  - EIT Health Summit, EUPHA Conference
  - Hungarian Presidency seminar on AI in Healthcare

In 2024, EPF significantly advanced its engagement in digital health and data governance, ensuring the patient voice was central in European policy and practice. **The Digital Health Working Group**, composed of 20 members, met four times (three virtual meetings and one in person) to coordinate member contributions and shape EPF's digital health agenda. Through this forum, EPF co-signed key multi-stakeholder publications, including PFMD's Digital Roadmap and EIT Health's report on the European Health Data Space (EHDS) implementation.

A major milestone was the delivery of **two toolkits on the EHDS**, one tailored for individual patients and another for patient organisations, both completed in December 2024. These resources were co-created with members to support greater understanding of the EHDS framework and its implications.

EPF maintained **active involvement in EU-level policy dialogues**, participating in both 2024 meetings of the eHealth Stakeholder Group, and submitting feedback on major consultations covering AI, data strategies, and digital healthcare models. Direct advocacy efforts included meetings with key rapporteurs on EHDS, Permanent Representations, the European Commission, EMA, WHO Europe, and national stakeholders via platforms such as TEHDAS 2 and the SPI-DDH initiative.

EPF also published **two major position statements** in 2024, including a contribution to the Eurohealth journal and a detailed analysis of the final EHDS legislative text, issued in early 2025. Throughout the year, EPF was invited to present its views at over five high-profile events, including DIA Europe, the EIT Health Summit, the HMA/EMA Big Data Stakeholder Forum, the EUPHA Conference, and a Hungarian Presidency seminar on AI in healthcare.

On the global stage, EPF strengthened strategic collaborations through participation in the WHO SPI-DDH, the OECD expert group on AI, and the EMA/HMA network, with representation in the Network Data Steering Group (NDSG). These initiatives reinforced EPF’s leadership in shaping digital health policy that respects patient rights, promotes equitable access, and fosters trust across health systems.

Capacity Building and Membership

Data Saves Lives (DSL) 5th Anniversary Event

Now in its fifth year, Data Saves Lives continued to grow in both reach and influence. **2024 marked the anniversary of this multi-stakeholder initiative**, and EPF took this opportunity to expand community engagement, strengthen health data literacy, and promote responsible data use.

In November 2024, 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 event welcomed over 130 participants, primarily from patient organisations, along with EU and International representatives, health professionals, industry representatives, and university representatives.

Read the event report **here**.

DSL Achievements at a Glance

- **Organised a DSL Anniversary Event** with over 130 participants
- **Delivered a successful social media campaign**, achieving over half a million impressions across all platforms
- **Translated the DSL toolkit** into six European languages
- **Presented DSL at major forums, including:**
    - SHIFT Hub event (Bucharest)
    - European Data Protection Congress
    - Euronews Health Summit
    - Flemish Government's Data Conference

In 2024, EPF continued to build momentum around DSL, driving engagement through a robust communications strategy and targeted outreach. The campaign achieved strong visibility across digital platforms, with over 40 DSL-related posts on EPF's social media channels generating 18,000+ impressions, and 133 posts on DSL's own channels reaching an additional 19,000+ impressions. A major milestone was the #DSL5 campaign, which celebrated five years of impact through 205 posts and achieved a remarkable 567,223 impressions across all platforms.

Through three blog publications, the DSL narrative highlighted patient-centric health data applications and real-world use cases, while more blog contributions are in development. The DSL website was regularly updated with new content, including blog posts, events, and news, and efforts to upload translated toolkits continued throughout the year.

A significant achievement in 2024 was the translation of the DSL Toolkit into six European languages, enhancing accessibility and supporting national-level dissemination.

DSL had a strong presence at high-level conferences and panels, contributing to discussions at events such as the Euronews Health Summit, the Flemish Government's data conference, the European Digital HealthTech Conference, and the European Data Protection Congress. Training sessions were another key component of the year's activities, with EPF delivering a tailored data and AI training, including DSL content.

Gravitate Health

EPF participated in a range of events to communicate and disseminate information about the Gravitate Health project, including the PEOF online webinar, HIMSS, DIA, and the PEOF face-to-face event in 2024, with additional participation planned for 2025.

In summer 2024, EPF developed a Civil Society Engagement Plan for 2025–2026 to guide future engagement activities, including upcoming User Advisory Group (UAG) meetings and dissemination opportunities, aiming to reach a broader audience as the project approaches its conclusion in 2026.

EPF held monthly meetings with the UAG to test and provide feedback on different versions of the G-Lens solution. Results from these sessions were presented to the UAG, along with updates on how their input was integrated. EPF also organised three dedicated UAG sessions covering topics such as sustainability, reliable health education sources, and personalisation.

To ensure clear, consistent communication, and long-term engagement, EPF began developing a Frequently Asked Questions (FAQ) document about Gravitate Health and the G-Lens, which will serve as a resource for external stakeholders and support project sustainability beyond its formal end.

Electronic Health Data in a European Network (EHDEN)

In 2024, the European Health Data and Evidence Network (EHDEN) concluded its six-year initiative aimed at transforming the use of real-world health data across Europe.

A significant development in its final year was the establishment of the EHDEN Foundation, a legal entity incorporated in the Netherlands, designed to ensure the project's sustainability and continued impact beyond its initial funding period. EPF is not part of this new Foundation.

Throughout the EHDEN project, EPF played a key role in promoting patient involvement. In 2024, EPF continued to focus on patient education, data and digital health awareness and community. Additionally, EPF collaborated with EHDEN to support the Data Saves Lives initiative, aiming to enhance patient engagement and understanding of health data usage.

Label2Enable

Label2Enable came to an end on 30th June 2024. Throughout the year, EPF continued its work, with a particular focus on engaging with the User Advisory Board (UAB) and the User Advisory Group (UAG). The UAB convened ad-hoc meetings to provide guidance on the project’s strategic activities, including overseeing key tasks and deliverables such as the development of the certification scheme. The UAG, which was composed of a diverse group representing various age ranges, genders, and geographic backgrounds, participated in bi-monthly online meetings. During these sessions, members were introduced to the Label2Enable initiative and provided valuable feedback on the Patient, Citizen, and Carer Survey.

The final group call, bringing together members from both the UAG and UAB, took place on 20th June 2024. This meeting marked the conclusion of their active involvement in the project.

Integration of Heterogeneous Data and Evidence towards Regulatory and HTA Acceptance (IDERHA)

The IDERHA Public Forum took place in April 2024, where representatives from EPF and three members of the Patient Advisory Board actively participated onsite. They played a key role in the discussions surrounding the critical issues of data sensitivity, access, and sharing within the healthcare sector. Their contributions emphasised the importance of safeguarding patient privacy while ensuring that data is used effectively to improve healthcare outcomes. The discussions covered a range of topics, including the application of AI throughout the care pathway, the technical challenges of integrating healthcare data effectively to foster innovation and research, and the ongoing efforts to shape policies that address the evolving needs of the future.

The Integrated Data Access Governance Council (IDAGC) was established in 2024, to advance policy development within the broader health data landscape. As a key initiative supported by EPF, the IDAGC’s primary role is to offer expert guidance and strategic advice. The IDAGC is co-chaired by EPF and the Danish Medicines Agency.

We also led a session at the Patient Engagement Open Forum, discussing how IDERHA engages patients in policy development, and we contributed with the patients’ perspective.

EPF organised seven sessions with the PAB in which they were onboard with the project and provided feedback on the Hygiaso solution, as well as on the Data Governance Framework and DPIA Guidance Framework.

Community

Empowering the patient movement through connection, capacity, and leadership

At the heart of EPF's mission is its vibrant, diverse, and growing community of patient organisations. In 2024, EPF invested heavily in building the capacity of its members, supporting young advocates, and ensuring meaningful involvement in both EU-level health policy and local patient advocacy efforts.

1. Strengthening the EPF Membership

In 2024, **EPF's membership grew stronger** in both size and engagement. The organisation welcomed new member organisations, bringing new perspectives and energy to its cross-disease, cross-border network. Throughout the year, EPF prioritised horizontal collaboration, capacity-sharing, and ongoing outreach.

Key Outputs:

- **Hosted four Member Circles**, focusing on priority topics: AMR, medical devices, EU elections, and patient participation in projects
- **Conducted 50+ one-on-one meetings** with member organisations to understand needs, support engagement, and co-develop initiatives
- **Surveyed member expertise** and updated the monitoring tool to better capture strengths across the network
- **Engaged national coalitions and supported the development of the Barometer** on Patient Involvement through targeted consultations

EPF also continued to support emerging patient coalitions across Europe - including in neighbouring regions such as the Western Balkans - to **foster more inclusive representation** and amplify the voice of underserved patient communities.

2. Youth Engagement: Investing in the Next Generation

europeanpatients'forum
Youth Group

EPF's Youth Group (YG) continued to be a cornerstone of our community-building strategy, championing **fresh perspectives and youth-led innovation**.

2024 Youth Group Activities at a Glance

- **Held two strategic meetings** (Spring and Autumn) to advance the YG work plan, onboard new members, and build cohesion
- **Led the second phase of the Youth Involvement in Patient Organisations project, including:**
  - A new online course on youth engagement
  - A template for creating a Youth Strategy
  - A “Top Tips” fact sheet for involving young people in governance and advocacy
- **Continued to disseminate resources** from the Youth Group’s 2023 project on Sexual Health and Wellbeing, including articles, podcasts, and videos
- **Hosted a webinar in partnership with EMSA and EPSA**, promoting dialogue between young patients and medical/pharmacy students on communication with healthcare providers

In 2024, EPF delivered on its commitment to youth engagement through a **dynamic programme of activities led by the EPF Youth Group**. Two in-person group meetings were held in Brussels: the Spring Meeting (March) and the Fall Meeting (October), providing valuable opportunities for young patient advocates to shape EPF’s youth agenda and connect with peers. Youth Group members also contributed regularly to EPF's newsletters throughout the year, highlighting their perspectives and experiences.

Building on this, **EPF Youth Group developed new tools** aimed at fostering youth involvement in patient organisations. This included a course syllabus, a template for creating a Youth Strategy, and a “Top Tips” factsheet to support organisations in meaningfully involving young people. These resources were co-created with EPF’s capacity-building team and will be made available through EPF’s learning platform.

The Youth Group also worked to **amplify its project on sexual health and well-being**, first launched in 2023, by redistributing materials through social media, including short videos and a recorded webinar. These resources were further promoted by EPF members during public speaking engagements. The group capped the year with a high-impact webinar in December 2024, titled *“Sexual Health and Wellbeing: Empowering Young Patients with Open Discussion”*, co-hosted with the International Diabetes Federation Europe, EPSA, and EMSA. The session attracted 50 registrants and 31 attendees, creating an inclusive space for dialogue on communication between young patients and healthcare providers.

SKILLs TRAINING FOR YOUNG PATIENT ADVOCATES (STYPA)

In 2024, EPF dedicated its annual Skills Training for Young Patient Advocates (STYPA) to the critical topic of **Antimicrobial Resistance (AMR)**, recognising it as a major threat to patient safety and public health. Despite its significance, awareness of AMR remains limited. Patients are often uninformed about resistant bacteria, healthcare-associated infections, and the importance of preventive measures such as hygiene, vaccination, and appropriate medicine disposal.

Against this backdrop, STYPA 2024 aimed to strengthen health literacy and empower young patients to become informed advocates on AMR. The training programme was designed to:

- Increase awareness of AMR among young patients and the wider healthcare community;
- Highlight the specific vulnerabilities of patients with chronic conditions to AMR-related risks;
- Provide advocacy skills and accurate knowledge to support ethical and transparent patient advocacy on AMR;
- Encourage continued engagement in local and national advocacy efforts, with support from EPF;
- Involve participants in EPF’s broader AMR communication and policy campaigns, helping to disseminate key messages within their communities.

101 COURSE ON PATIENT ADVOCACY FOR YOUNG PATIENT ADVOCATES

Throughout 2024, EPF continued to work on the main objective of the “Advocacy 101” course, by providing young patients around Europe with an easy to understand, accessible, online course on the basics of patient advocacy which they can take at their own pace. In the course, young patients receive an in-depth knowledge of representative skills, learn how to engage in awareness and advocacy actions, discover the difference between advocacy, lobbying and being a patient representative and various more important topics. In 2024, **88 individuals registered** for the course. Ongoing support was provided through a dedicated contact email, and the course platform was actively maintained.

MASTER'S PROGRAMME ON INTERNATIONAL PATIENT ADVOCACY

In 2024, EPF continued to support the organisation of the International Master’s Degree Programme on Patient Advocacy, the first ever recognised of its kind, in partnership with Cattolica University of Rome. The first edition of the master was concluded in May 2024 and the second edition kicked off in February 2024. EPF along with the University, worked on improving the curriculum, selecting the participants, and delivering lectures.

European & Global Cooperation

Engagement in the HERA Civil Society Forum and the Critical Medicines Alliance

EPF played a **key role in shaping EU policy on crisis preparedness and access to medicines** through its active engagement in the HERA Civil Society Forum (CSF) and the Critical Medicines Alliance (CMA). EPF attended all four meetings of the HERA Advisory Forum and CSF, presenting its EU elections campaign and policy priorities during the first session and its contributions to the CMA at the second. EPF also participated in six CMA Working Group meetings between June and December, covering areas such as HERA review and health threats.

EPF also **represented the patient perspective in both CMA working groups and the Steering Board**, ensuring continued patient involvement in key decisions. EPF provided substantive input on key CMA documents, including recommendations on contingency stocks, public procurement criteria, and the CMA's strategic plan outline.

In terms of visibility and advocacy, EPF Board Member Nikos Dedes spoke at the CMA high-level launch event in April 2024, while the Executive Director, Anca Toma, participated in a HERA interview addressing medicine shortages from a patient perspective. Additionally, EPF contributed to the public consultation on the future of HERA with a dedicated position paper, reinforcing the importance of sustained, structured patient engagement in EU-level crisis preparedness efforts.

Engagement with the European Medicines Agency

EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Throughout 2024, EPF maintained a **strong and consistent presence in EMA activities**, ensuring the patient voice remained central to regulatory discussions. EPF participated in all Patients' and Consumers' Working Party (PCWP) meetings and engaged in additional ad-hoc webinars and national-level dialogues, including sessions hosted by the Portuguese NCA (INCLUIR) and AIFA on Good Clinical Practice.

To **enhance transparency and member involvement**, EPF regularly disseminated EMA updates and meeting outcomes through its Insiders newsletter and direct communications. These included summaries of PCWP meetings, alerts for public consultations, and calls for expert input on regulatory topics, such as the QRD template survey.

EPF also contributed to several **strategic EMA initiatives**, reflecting its expertise in patient engagement. Key contributions included:

- Active participation in the ACT-EU Multi-Stakeholder Platform (MSP);
- Feedback on EMA policies, including those on conflict of interest, the CTIS platform, and the Network Strategy to 2028;
- Support in nominating patient speakers and experts for EMA committees and advisory roles.

EPF **joined multiple focused working groups**, such as the subgroup on implementing Good Practice Guidance on preventing medicine shortages, the drafting group for the reflection paper on patient experience data, and a joint communications campaign on shortages, set to launch in 2025.

- The EU NTC 10-year anniversary (30 May),
- The public workshop on Advancing Regulatory Science Research (18 November),
- And the CHESSMEN Multistakeholder Workshop (27 November).

Engagement with the OECD

EPF **continued to contribute actively to the OECD's health systems and quality of care agenda**, ensuring the integration of patient perspectives in international policy dialogues. EPF participated in the Health Care Quality and Outcomes (HCQO) Working Party meeting in May, and maintained ongoing involvement in the international PaRIS Advisory Panel, helping shape the OECD's work on person-centred healthcare.

A key area of contribution was the **Patient-Reported Indicators Surveys (PaRIS) project**, where EPF played a central role in gathering patient insights. This included coordinating the collection of patient stories for inclusion in the OECD's upcoming flagship report, expected in February 2025. EPF also supported the OECD's efforts to enhance the use of Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) by contributing to a PROMs-focused survey and participating in the PRIMs working group.

Collaboration with WHO Europe

World Health Organization

EPF **strengthened its strategic collaboration with the WHO European Regional Office**, aligning with the objectives of the European Programme of Work and amplifying patient voices in key policy discussions. EPF held several strategic meetings with WHO representatives, contributing both to the organisation’s Non-State Actor (NSA) engagement strategy and the planning of WHO-led events. Notably, EPF attended the WHO Regional Committee in October 2024 and co-led a joint statement on behalf of 12 organisations in support of the NSA Engagement Plan.

EPF contributed to multiple WHO Europe initiatives, including:

- The WHO Meeting on the Ecosystem of Health Decision-Making (Milan, October 2024),
- The WHO Primary Care Talk Show (online, March 2024),
- And active involvement in the Strategic Partners’ Initiative for Data and Digital Health (SPI-DDH), particularly in the healthcare and prevention working group.

EPF also l**ed and supported joint dissemination campaigns**, including the promotion of World Patient Safety Day and the public sharing of EPF’s statement on the NSA Engagement Plan.

Further engagement took place through **EPF’s participation in the WHO Europe Access to Novel Medicines Platform (NMP)**. EPF attended two working group meetings on Transparency and two plenary sessions, including the Consensus Building Meeting in July, where EPF spoke during the opening panel. EPF contributed to the development of concept notes and future planning documents, reinforcing its role in shaping fair, transparent, and patient-inclusive approaches to access to innovative medicines.

Communications, Visibility & Reputation

Making the patient voice seen, heard, and trusted across Europe

Strategic communicatiosn is not just a support function at EPF — it is a core driver of the organisation's impact. In 2024, EPF significantly expanded its visibility, credibility, and engagement across multiple platforms and audiences, positioning itself as a trusted, go-to voice for patient advocacy in Europe.

1. A Year of Digital Growth and Strategic Messaging

EPF's communications team focused on amplifying patient stories, increasing transparency, and supporting policy and project work with **strong outreach**. Messaging was aligned with the organisation's overarching values: **trust, empowerment, and equity.**

Key Metrics:

- **600+ social media posts** across LinkedIn, X, Facebook, and Instagram, with a notable increase in reach and engagement on platforms like Instagram
- **2.5 million impressions** generated by the flagship #Vote4Patients campaign ahead of the European Elections
- **10 podcast episodes** published, including features on member initiatives and EU-level projects
- **48 news items, 4 press releases, and 12 Patient Perspective newsletters,** achieving an impressive 36.6% open rate, well above sector benchmarks

THE EPF European Patients Forum
WEEKLY INSIDERS


"A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE"

European Patients' Forum

We are the leading voice of patient organisations in Europe.

Hospitals and Health Care · Brussels · 13K followers · 11-50 employees

THE EPF European Patients Forum
PATIENT PERSPECTIVE

THE EU PATIENTS' PODCAST

2. Strengthening EPF's Reputation in the Policy Ecosystem

2024 marked an evolution in EPF’s profile as a **highly credible actor within the EU health policy landscape**. The organisation’s communications efforts helped shape perceptions among policymakers, regulators, researchers, and the media.

Key Achievements:

- **Media presence increased by 10%**, with EPF featured in high-impact EU-level outlets and national media
- **Frequent spokesperson roles** at major conferences, summits, and expert panels
- **Strengthened ties with member organisations’ communications teams**, resulting in collaborative storytelling and cross-promotion

EPF’s transparent, well-researched, and people-centred communication approach helped elevate the organisation’s voice.

3. Communication as Support to Members

Beyond outward messaging, EPF also used communications as a means to cooperate with its member organisations. Through toolkits and content co-creation, EPF supported its members in amplifying their own visibility and public influence.

Key Achievements:

- **1 podcast episode and 12+ posts** spotlighting member organisations
- **Continuous support for member-led campaigns** through shared media assets, cross-posting, and newsletter features

Conclusion & Outlook

2024 was a year of **strategic relevance, operational excellence, and tangible progress** for the European Patients' Forum. Guided by the principle of patient involvement, EPF successfully translated its Work Plan into real-world results, from influencing legislation and amplifying advocacy, to empowering communities and strengthening patient-led innovation.

Across its thematic priorities, EPF delivered its commitments with rigour and creativity. EPF also reinforced its role as a bridge between institutions and citizens and **a trusted voice representing the lived experience of millions of patients across Europe.**

Looking Ahead: 2025 and Beyond

As we move into 2025, EPF will **enter a new cycle of influence and action**, aligned with the continued implementation of its Strategic Plan 2021-2026. We will also continue to support our members as they navigate changing political, digital, and healthcare landscapes, offering tools, knowledge, and solidarity to keep the patient voice strong and visible.

Financial Overview

Extract from the Auditor's Report for the financial year started on the 1st of January 2024 and ended on the 31st of December 2024 of the association European Patients Forum (EPF)

''In our opinion, in accordance with the provisions of the standard concerning the contractual audit of SME's and small (international) non-profit organisations and foundations, the attached financial statements give a true and fair view of the assets and financial situation of the association European Patients' Forum (EPF) as of 31st December 2024, and of its results for the financial year then ended, in accordance with the accounting legislation applicable in Belgium.''

Auditors:

L&S Reviseurs D’Entreprises
Kortmansstraat 2a
1731 Zelik

External Accounting Support:

Dénombrable BV
Kantooradres, Heirweg 53
9270 Kalken

Financial Statements

Financial Statement 2024	**31/12/2024 YTD ACTUAL**
OPERATING INCOME	**2.653.429,02**
Membership fees	25.000,00
Forum Work Plan	710.000,00
Capacity Building program	60.000,00
Sponsorship	494.500,00
Honorarium	14.101,62
Data Saves Lives	2.826,78
Artificial Intelligence	9.299,63
PEOF	25.458,00
Project Access to Medicine	6.000,00
Operating Grant	638.638,09
Project EDiTHA	40.389,51
Project Core-MD	25.995,29
Project EUCAPA	13.138,74
Project EHDEN	15.762,78
Project IMMUCAN	26.417,44
Project PROPHET	28.141,14
Project IDERHA	59.707,40
Project Gravitate Health	65.691,40
Project H2O	100.610,15
Project Immuniverse	377,47
Project Label to Enable	39.196,93
Project HEU EFS	66.802,09
Refund of expenses	176.103,21
VAT to claim pro rata	9.271,35
OPERATING CHARGES	**-2.408.495,04**
STAFF COSTS	**-1.647.558,16**
Gross remuneration	-1.160.303,30
ONSS contributions	-277.066,89
Other staff costs (Holiday pay, Insurances, Meal vouchers, Others)	-210.187,97
SUBCONTRACTING	**-33.715,91**
GENERAL COSTS	**-727.220,97**
Building costs	-134.974,15
Office costs	-97.621,52
Fees	-154.217,51
Insurances	-7.797,54
Travel	-107.969,76
Meetings	-194.386,25
Communication	-26.504,84
Others	-3.749,40
OPERATING RESULT	**244.933,98**
DEPRECIATIONS	**-26.033,58**
Provision for legal fees	-27.974,96
Provision for liabilities and charges	-63.863,81
BANK RESULT	**1869,71**
TOTAL RESULT	**128.931,34**

Acknowledgements of funds 1/2

Membership income	25000	
Membership fees	25000	0,9%
EPF wishes to thank the European Commission / European Agencies for their support in 2023 in relation to EPF's role in the following projects		
	Public Contribution 2024	% of total income
TOTAL European Commission support to projects 2024	**1.126.868,43**	
Operating Grant	638.638,09	24,1%
Access to Medicine	6.000,00	0,2%
EDiTHA	40.389,51	1,5%
Core-MD	25.995,29	1,0%
EUCAPA	13.138,74	0,5%
EHDEN	15.762,78	0,6%
IMMUCAN	26.417,44	1,0%
PROPHET	28.141,14	1,1%
IDERHA	59.707,40	2,3%
Gravitate Health	65.691,40	2,5%
H2O	100.610,15	3,8%
Immuniverse	377,47	0,0%
Label to Enable	39.196,93	1,5%
HEU EFS	66.802,09	2,5%
EPF wishes to thank the following donors for their support:		
	Contribution to Operations	% of total income
Operational & Engagement - work plan & Capacity Building Programme 2024	**660.000,00**	
Amgen (Europe) GmbH	55.000,00	2,1%
AstraZeneca UK Limited	20.000,00	0,8%
BRISTOL MYERS SQUIBB	40.000,00	1,5%
CSL Behring GmbH	10.000,00	0,4%
Daiichi Sankyo Europe GmbH	30.000,00	1,1%
F. Hoffmann-La Roche Ltd	60.000,00	2,3%
Gilead Sciences Europe Ltd.	35.000,00	1,3%
GlaxoSmithKline	60.000,00	2,3%
MEDICINES FOR EUROPE AISBL	20.000,00	0,8%
Merck Healthcare KGaA	40.000,00	1,5%
Novartis Pharma AG	80.000,00	3,0%
NV Janssen Pharmaceutica	50.000,00	1,9%
Pfizer Inc.	40.000,00	1,5%
Sanofi Pasteur S.A	25.000,00	0,9%
Shionogi B.V.	20.000,00	0,8%
Takeda Pharmaceuticals Interna	60.000,00	2,3%
Ucb Biopharma Srl	15.000,00	0,6%

Acknowledgements of funds 2/2

STYPA - DSL EVENT - ELECTIONS CAMPAIGN & POLICY EVENT - PEOF	**644.059,62**	
	Contribution to the CBP and others	% of total income
STYPA	**110.000,00**	
Msd Belgium Bv	30.000,00	1,1%
SERVIER AFFAIRES MEDICALES	50.000,00	1,9%
AOP Orphan Pharmaceuticals Gmb	10.000,00	0,4%
VERTEX PHARMACEUTICALS (EUROPE	20.000,00	0,8%
PEOF	**25.458,00**	
The Synergist Asbl	25.458,00	1,0%
DATA SAVES LIVES EVENT	**131.000,00**	
Amgen (Europe) GmbH	15.000,00	0,6%
Boehringer Ingelheim Internati	5.000,00	0,2%
F. Hoffmann-La Roche Ltd	35.000,00	1,3%
Grünenthal Gmbh	5.000,00	0,2%
Intuitive Surgical Sàrl	10.000,00	0,4%
IQVIA Ltd	5.000,00	0,2%
Msd Belgium Bv	500,00	0,0%
OPEN APPLICATIONS CONSULTING L	500,00	0,0%
OPEN APPLICATIONS CONSULTING L	5.000,00	0,2%
Pfizer Inc.	20.000,00	0,8%
SERVIER AFFAIRES MEDICALES	30.000,00	1,1%
ELECTIONS CAMPAIGN AND POLICY EVENT	**363.500,00**	
Abbvie Sa	23.500,00	0,9%
Amgen (Europe) GmbH	20.000,00	0,8%
Boehringer Ingelheim Internati	15.000,00	0,6%
Bosch Health Campus	120.000,00	4,5%
Daiichi Sankyo Europe GmbH	10.000,00	0,4%
ENT E FEDERATION EUROPEENNE D'ASSOC	10.000,00	0,4%
F. Hoffmann-La Roche Ltd	15.000,00	0,6%
Intuitive Surgical Sàrl	10.000,00	0,4%
Novartis Pharma AG	20.000,00	0,8%
Novo Nordisk Denmark A/S	10.000,00	0,4%
Novocure Inc	10.000,00	0,4%
NV Janssen Pharmaceutica	20.000,00	0,8%
Pfizer Inc.	20.000,00	0,8%
SERVIER AFFAIRES MEDICALES	30.000,00	1,1%
Takeda Pharmaceuticals Interna	20.000,00	0,8%
VERTEX PHARMACEUTICALS (EUROPE	10.000,00	0,4%
Other income	**14.101,62**	
Honorarium	14.101,62	0,5%

SECRETARIAT AND GOVERNANCE

A snapshot of the EPF team on 31 December 2024

Anca Toma - Executive Director

Bianca Pop - Project Assistant

Borislava Ananieva - Youth Strategy and Capacity Building Officer

Claudia Louati - Head of Policy

Dalila Lopes - Communications Officer

Djilo Tchatchouang - Finance Officer

Elena Balestra - Head of Governance, Membership and Capacity Building

Eric Moris - Director of Operations

Estefanía Callejas De Luca - Membership and Governance Officer

Flavia Topan - Communications Manager

Gözde Susuzlu Briggs - Senior Projects Manager

Julie Spony - Policy Officer

Klaudia Cymer - Operations Assistant

Laura Henderson - Capacity Building Assistant

Milana Trucl - Policy Officer - Digital Health

Ruth Tchaparian - Senior Operations and Grants Manager

Sylvie Vandereyd - Office Manager

Valentina Strammiello - Head of Programmes

Yann Heyer - Policy Officer

Yasemin Zeisl - Project Coordinator

Zilvinas Gavenas - IT Manager

With thanks to colleagues active in 2024: Anna Rensma, Davide Durante, Ingrid Weindorfer, Nicola Bedlington

SECRETARIAT AND GOVERNANCE

The EPF Board on 31 December 2024

Marco Greco - President

Elisabeth Kasilingam - Vice President

Radu Costin Ganescu - Treasurer

Elena Moya - Board Member

Isabel Proano Gomez - Board Member

Andreas Christodoulou - Board Member

Nikos Dedes - Board Member

Konstantina Boumaki - Board Member

Pedro Carrascal Rueda - Board Member

The EPF Ethics Committee on 31 December 2024

Dimitrios Athanasiou

Dominik Tomek

Michal Rataj

Vasilis Karatzias

Veronica Rubio

EPF Members

EPF Members on 31 December 2024

- **Full Members**
- Alzheimer Europe (Europe)
- AOECS - Association of European Coeliac Societies (Europe)
- AOPP - Association for the Protection of Patients' Rights (Slovak Republic)
- BAG Selbsthilfe - Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (Germany)
- CF Europe - Cystic Fibrosis Europe (Europe)
- COPAC - Coalition of Patients' Organisations with Chronic Diseases (Romania)
- CyFPA: Pancyprian Federation of Patients Associations and Friends (Cyprus)
- DE - Dystonia Europe (Europe)
- Digestive Cancers Europe (Europe)
- EAMDA - European Alliance of Neuromuscular Disorders Associations (Europe)
- EATG - European Aids Treatment Group (Europe)
- ECHDO – European Congenital Heart Disease Organisation (Europe)
- EFA - European Federation of Allergy and Airways Diseases Patients' Associations (Europe)
- EFAPH - European Federation of Associations of Patients with Haemochromatosis (Europe)
- EFCCA - European Federation of Crohn's and Ulcerative Colitis Associations (Europe)
- EFHPA - European Federation of Homeopathic Patients' Associations (Europe)
- EGAN - Patients Network for Medical Research and Health (Europe)
- EHC - European Haemophilia Consortium (Europe)
- EHLTF - European Heart and Lung Transplant Federation (Europe)
- EKPF - European Kidney Patients' Federation (Europe)
- ELPA - European Liver Patients’ Association (Europe)
- EMHA - European Migraine and Headache Alliance (Europe)
- EMSP - European Multiple Sclerosis Platform (Europe)
- ENUSP - European Network of (ex)users and survivors of psychiatry (ENUSP) (Europe)
- EPIK - Estonian Chamber of Disabled People (Estonia)

- EUFAMI - European Federation of Associations of Families of People with Mental Illness (Europe)
- EUROPA DONNA - European Breast Cancer Coalition (Europe)
- EUROPA UOMO - The European Prostate Cancer Coalition (Europe)
- EUROPSO - European Umbrella Organisation for Psoriasis Movements (Europe)
- EURORDIS - European Organisation for Rare Diseases (Europe)
- FE - Fertility Europe (Europe)
- FEP - Spanish Patients' Forum (Spain)
- FESCA- Federation of European Scleroderma Associations (Europe)
- FPP - Federation of Polish Patients (Poland)
- GAMIAN-Europe - Global Alliance of Mental Illness Advocacy Networks (Europe)
- Global Heart Hub - The Alliance of Heart Patient Organisations (Europe)
- Greek Patients Association (Greece)
- HAPO - Hungarian Alliance of Patients' Organisations (Hungary)
- IDF Europe - International Diabetes Federation European Region (Europe)
- IF - International Federation for Spina Bifida and Hydrocephalus (International*)
- IOF - International Osteoporosis Foundation (International*)
- IPOPI - International Patient Organisation for Primary Immunodeficiencies (International*)
- KUZ - Coalition of Association in Healthcare (Croatia)
- KZZ - Confederation of Health Protections (Bulgaria)
- LPOAT - Council of Representatives of Patients’ organisations (Lithuania)
- LUCE - Lung Cancer Europe (Europe)
- LUPUS Europe (Europe)
- MHN - Malta Health Network (Malta)
- NAPO - National Association of Patients' Organizations (Czech Republic)
- NCDP – National Confederation of Disabled People (Greece)
- NPO - National Patients' Organisation (Bulgaria)
- Parkinson's Europe (Europe)
- PHA Europe - Pulmonary Hypertension Association Europe (Europe)
- Plataforma de Organizaciones de Patientes (Spain)
- RI - Retina International (Europe)
- SOSTE - Finnish Federation for Social Affairs and Health (Finland)
- Sjögren Europe (Europe)
- SUSTENTO - The Latvian Umbrella Body For Disability Organization (Latvia)

- Swedish Disability Rights Federation (Sweden)
- World Duchenne Organization (International*)
- ZOPS - Patient Organisations Association of Slovenia (Slovenia)

Associate Members

- AGORA (Southern Europe)
- BAPD - Bulgarian Association for Patients Defence (Bulgaria)
- DEBRA International - Global Network of Epidermolysis Bullosa Support Groups (Europe)
- ECO - European Cleft Organisation (Europe)
- EFNA - European Federation of Neurological Associations (Europe)
- EIWH - European Institute of Women's Health (Europe)
- ENFA - European Network of Fibromyalgia Associations (Europe)
- FH Europe Foundation (Europe)
- Global Skin - International Alliance of Dermatology Patient Organisations (International*)
- Health and Social Care Alliance Scotland - The Alliance (Scotland)
- IBE - International Bureau for Epilepsy (International*)
- LPOT - Latvian Network of Patient Organizations (Latvia)
- Mental Health Europe (MHE-SME) (Europe)
- Patiëntenfederatie Nederland - National Coalition of Dutch Patients (The Netherlands)
- SAFE - Stroke Alliance for Europe (Europe)
- VPP - Flemish Patients' Platform (Belgium)
- WFIPP - World Federation of Incontinence and Pelvic Problems (WFIPP) (International*)

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