

# Annual Report 2023



**A strong patients' voice**  
*to drive better health in Europe*





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*2023 was unique, as it marked the year in which EPF turned 20. Now, over two decades after its founding, EPF is the only cross-disease umbrella patient organisation at European level. We remain more committed than ever to continue the important work with our communities in the years to come.*

**Marco Greco**, EPF President

**A strong patients' voice to drive better health in Europe**

# A word from our President

You are about to read the 2023 European Patients' Forum (EPF) annual report. As EPF President, I am more than proud to write an introduction summarising this overview of our efforts to make the patients' voice heard in all areas of European health policy.

At EPF, we envision a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems. Our work in 2023, as part of our Strategic Plan 2021-2026, reflects that ongoing journey.

2023 was unique, as it marked the year in which EPF turned 20. Now, over two decades after its founding, EPF is the only cross-disease umbrella patient organisation at European level. We remain more committed than ever to continue the important work with our communities in the years to come.

This report showcases EPF's policy, advocacy, capacity building, projects, and communications work streams. We report on our advocacy work to ensure patient-centric EU policies such as the revision of the pharmaceutical legislation or the enactment of EU data and digital health laws. We provide an overview of some of the main activities and highlights of EPF's EU projects in 2023. We report on capacity building through STYPA, EPF's AI work, the Youth Group and more. And not least, we share insights on the increasingly growing community surrounding EPF.

Our achievements reflect, as always, the dedication, passion, and hard work of our Secretariat, Board, Members, partners, and supporters. We look forward to continuing our collaborations in advancing patient and patient organisation involvement in health policy, research, and practice.

Thank you for your continued support throughout the years, and we hope that this report provides an insightful overview of our achievements in 2023.

**Marco Greco**, EPF President

# 2023 at a glance

## March

Meeting with the European Commission Vice-President **Margaritis Schinas** and Commissioner for Health and Food Safety **Stella Kyriakides**

Official launch Master's degree **International Patient Advocacy Management**

Joint statement released on the EHDS **Patient Engagement Resource Centre** launched as part of EATRIS-Plus Spring **Data Saves Lives Bootcamp**

## May

**IMMUcan** General Assembly  
**Youth Group Spring Meeting**  
European Public Health Week

## February

Advocacy 101 training course launch

EPF Youth Group's project's final event "**Let's Get Provocative!**"

Validation of the **H2O Patient Agreement**

Registrations opened for the Master's Degree **International Patient Advocacy Management**

## April

Reaction to the **Pharmaceutical Legislation Revision**

Anniversary event and AGM (new **EPF Board Members elected**)

**Patient Engagement Platform** for EU-PEARL launch

**EU-PEARL** comes to an end

## June

**PEOF** (in person), in Baveno

**HTAi** Annual Meeting in Adelaide

# July

Launch of **survey results AI/Patient Organisations STYPA 2023** (face-to-face in Riga)

# October

**Youth Group** Fall Meeting

Launch of "**AI in Healthcare**" **position paper**

Closing webinar **STYPA 2023**

Kick-off meeting HEU-EFS in Milan

First issue of **EUCAPA newsletter released**

SANT hearing on **PERISCOPE ends**

# September

**PERISCOPE** Final Conference

World Patient Safety Day

**European Health Forum Gastein**

# November

**Gravitate Health** face-to-face meeting in Madrid

**Data Saves Lives Toolkit** 2.0 published

**European Anti-microbial Awareness Day**

**EATRIS 10th-anniversary** meeting in The Hague

# December

**DSL x EHDEN** Bootcamp

**HTA Capacity Building** simulation workshop

'It's Time We Talk about Patient Engagement' webinar with **EATRIS**

**EATRIS-Plus** ends

# Strategic plan 2021-2026

Our Strategic Plan 2021-2026 reflects the current European health and social policy environment: it shows 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 in the next five years. 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.

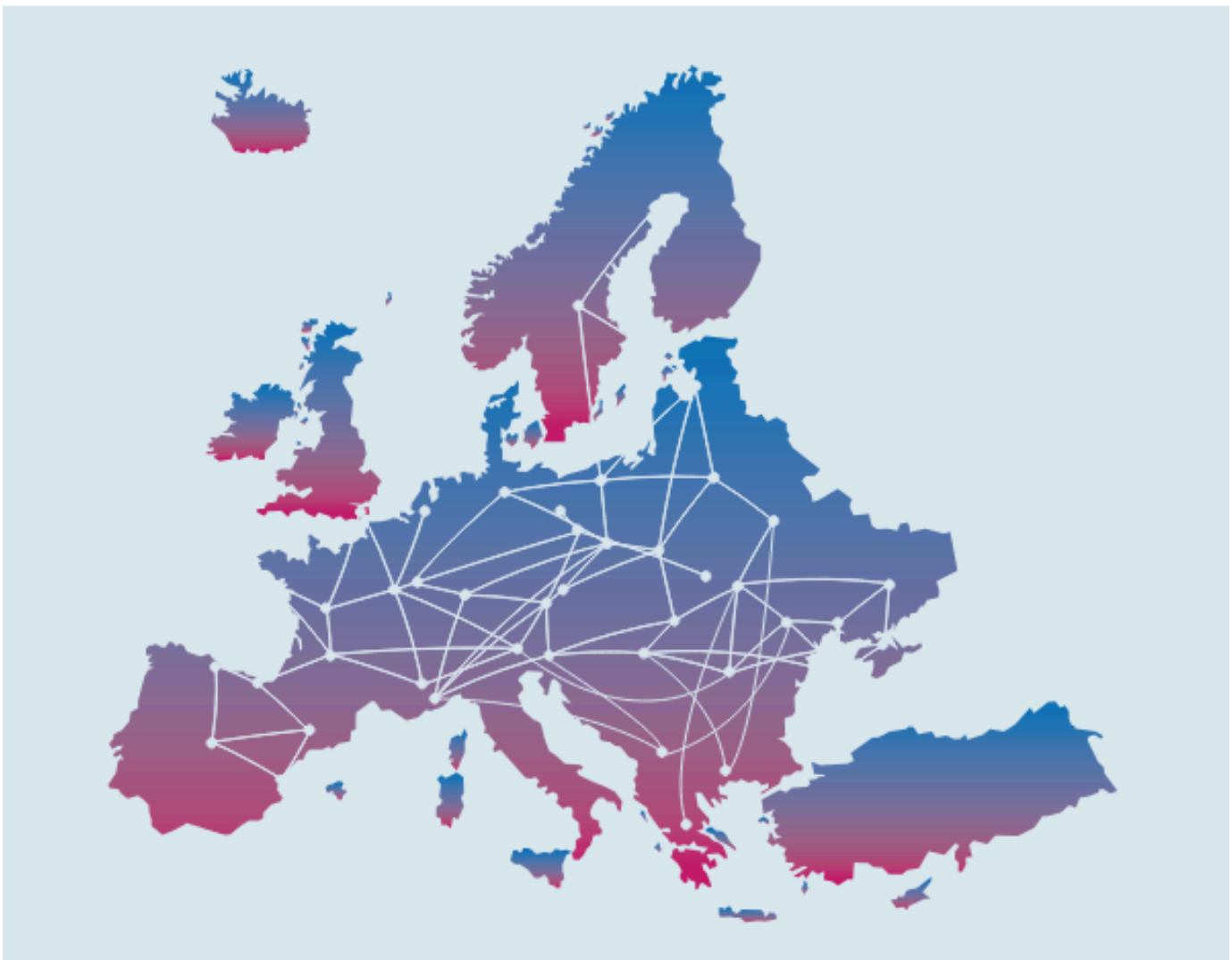
**OUR MISSION** is to advance the interests of patients and patient communities by strengthening their collective impact across Europe through effective advocacy, education, empowerment, and partnership.



# Our Members

Our members are the backbone of our work: their perspective brings an irreplaceable added value to our policy and advocacy activities. In 2023, EPF counts **79 member organisations**, representing **21 countries** and an estimated **150 million patients** across Europe.

Find an overview of our current membership [here](#).



# 2023 Activity Report

## Policy

EPF acts as an intermediary between the patient community and EU policymakers to shape an EU health agenda that meets the needs of patients and translates into patient-centred national policies. 2023 was a particularly important year to convey the patient perspective across policy dossiers. In particular, the European Commission finally published the long-awaited proposal on the review of the pharmaceutical legislation in April and the negotiations on the European Health Data Space (EHDS) reached their final phase. From shaping our positions with our members to participating in panel discussions and exchanging views with decision-makers and other stakeholders, we actively advocated for laws and policies that put patients at the centre.

We also continued building partnerships with key international actors and representing EPF and our community at high level forums. This included the European Medicines' Agency (EMA) Patient and Consumer Working Party (PCWP). We also joined the World Health Organization's (WHO) Novel Medicines Platform and participated in the first meeting of the Transparency Working Group in November.

We highlighted the importance of patient involvement in healthcare systems' reform at two other milestone WHO meetings, namely the 73rd session of the WHO Regional Committee for Europe in Astana and the Tallinn Charter 15th Anniversary Health Systems Conference. Finally, we also continued our collaboration with the Organisation for Economic Cooperation and Development (OECD), in particular through our involvement in the Patient-Reported Indicator Surveys (PaRIS).

Finally, 2023 marked the beginning of our preparations for the 2024 elections campaign, centred around our Manifesto calling for early and meaningful involvement of patient organisations in policy development, health research, and healthcare practice. Here is an overview of our work on the different policy dossiers.

### 7 MAIN AREAS OF WORK

**1. The Pharmaceutical Legislation**

**2. Medical Devices**

**3. Sustainable funding for patient organisations**

**4. Patient access to safe healthcare**

**5. Antimicrobial Resistance**

**6. Pandemic preparedness**

**7. Digital Health**





# Patient involvement throughout the healthcare continuum, from medical products development to health policy-making

## The Pharmaceutical Legislation

The review of the pharmaceutical legislation is a once-in-a-generation opportunity to make the EU regulatory framework for the authorisation of medicines more patient-centred. Following the thorough examination of the proposal and close collaboration with our members, EPF published its [recommendations](#) for a patient-centred revision of the legislation, advocating specifically for medicines that meet patients' needs, improved patient access to medicines, and increased patient involvement in the regulatory process. We established ad-hoc taskforces to support the development of two position papers on specific aspects of the review that are crucial to the communities we represent: [defining unmet medical needs in collaboration with patients](#) and [safeguarding access to medicines for paediatric patients](#). In collaboration with the capacity-building team, we also activated our membership around the issue of medicines shortages through a webinar and a survey.

Throughout the year, we conveyed our position in various forums, including at the European Health Forum in Gastein in September and at a hearing of the European Parliament's Health Sub-Committee (SANT) in October.

## Medical Devices

In 2023, EPF continued to follow the implementation of the medical devices regulation and react to [ongoing developments](#). EPF is also engaged to the extent possible in the Commission's effort to review the regulatory governance and impact of the new regulatory framework on innovation. EPF further conveys the patient voice as an observer at the Medical Devices Coordination Group (MDCG) and is part of two MDCG subgroups, namely on Clinical Investigations and Evaluation (CIE) and on Post-Market Surveillance and Vigilance (PMSV).

## Sustainable funding for patient organisations

A sustainable funding scheme is essential to ensure that patient organisations can play their role in shaping public health policies. As the largest EU Health Programme ever implemented, the EU4Health programme represents a unique opportunity to build stronger, more resilient, and patient-centred health systems but also to promote patient organisations' meaningful involvement through a sustainable, accessible, and transparent funding scheme. In 2023, EPF provided [recommendations](#) on the priorities of the EU4Health 2024 work programme. EPF is also collaborating with other civil society organisations to keep this issue high on the EU agenda through the [EU4Health Civil Society Alliance](#) in particular, which we co-lead, and through [Civil Society Europe](#).

## Patient access to safe healthcare

Patient safety remains a strategic priority for EPF and a key aspect of equitable and patient-centred healthcare systems. In 2023, we emphasised the role of patients in improving quality of care at the Meeting of the WHO European National Focal Points Networks on Quality of Care and Patient Safety. We also stepped up our engagement on antimicrobial resistance, which threatens patients' access to safe care, and continued to engage in ongoing debates on crisis preparedness and response.



## Antimicrobial Resistance

In 2023, EPF continued its participation in various alliances and partnerships on antimicrobial resistance (AMR), such as the [AMR Stakeholder Network](#), the [AMR Patient Group](#), and the [Global AMR R&D Hub](#). EPF further conveyed the patient voice in the European Commission's [AMR One Health Network](#), including a presentation on the key role of patient organisations in the fight against AMR. At international level, we also joined the [AMR Multi-Stakeholder Partnership Platform](#) created by the Quadripartite, as part of our efforts to build new partnerships and engage in global debates ahead of the 2024 UN General Assembly High Level Meeting on AMR. Like every year, we coordinated with the [European Centre for Disease Prevention and Control](#) to mark European Antibiotics Awareness Day and published a [statement](#) on the role of patients in combatting AMR. These activities will pave the way for further engagement on AMR in 2024.

## Pandemic preparedness

The results of the survey EPF conducted as part of the [PERISCOPE project](#) on the impacts of the COVID-19 pandemic on chronic diseases patients informed EPF's contributions to the work of the Health Emergency Preparedness and Response (HERA). In 2023, EPF joined the three working groups of HERA's Civil Society Forum (CFS) and worked with other organisations to develop recommendations on HERA's mandate and priorities. In view of the delays and challenges patients faced to access their usual care during the pandemic, the need for integrating continuity of care as part of pandemic preparedness plans remains a priority for EPF. In December, EPF was invited to convey the patient perspective on medicines' shortages at the annual HERA conference.

## Digital Health

In 2023, a significant milestone was achieved in the area of digital health for EPF with the finalisation of EPF's first ever position paper on Artificial Intelligence (AI) in healthcare in which we explore the applications, benefits, and challenges associated with AI in healthcare from a patient perspective. The paper also includes key recommendations for a responsible deployment of AI solutions, such as respecting human dignity and addressing data quality and integrity. The considerations and recommendations presented in the position paper are based on a survey conducted by EPF in spring 2023, targeting patient organisations and individual patient advocates, and the expertise provided by EPF's Digital Health Working Group, EPF's members, and Secretariat. Thanks to the insights gained through the paper, EPF provided feedback to the EMA reflection paper on AI in medicines development and has participated in the discussions with relevant stakeholders at the EMA's workshop on AI in medicines lifecycle. Our work on AI has also allowed us to start an informal collaboration with OECD on this topic, thereby extending the impact of EPF's work beyond the European context.

With regards to the European Health Data Space (EHDS), EPF has actively engaged with policymakers and stakeholders to promote our recommendations for a patient-centric legislation on the access, exchange and re-use of health data. Our efforts resulted in the inclusion of the majority of our recommendations in the European Parliament's position with the aim of strengthening the access and portability of patients' personal health data, providing for the possibility of opting out of sharing health data for secondary use, and stressing the need for adequate funding for digital health literacy. Lastly, we represented EPF and our community at important policy forums, such as the WHO Symposium on the Future of Digital Health Systems in the European Region, the Expert Summit on European Electronic Health Record Exchange Format in the European Commission and at the EMA's multi-stakeholder workshop on Real-World Data (RWD) and Real-World Evidence (RWE) for regulatory decision-making.



# Projects

EPF's project portfolio acts as a cross-cutting platform underpinning our advocacy, education, and communication pillars. Our aim is to maintain a relevant and impactful portfolio, which is strongly aligned with our key values, [strategic goals](#), and priority topics to the patient community and provides a framework for member organisations to join forces with EPF and increase their direct participation, collaboratively ensuring meaningful patient involvement in projects.

## CORE-MD



[CORE-MD](#) aims to review methodologies for the clinical evaluation of high-risk medical devices and make concrete recommendations to inform future regulatory guidance. Recommendations from the CORE-MD consortium are being submitted to the Working Group on Clinical Investigation and Evaluation of the European Commission.

**EPF's role:** contributor

### Recent updates

In 2023, we recruited 23 patients and carers of patients with different profiles and from different disease areas to participate in consultations to assess patients' experiences with high-risk medical devices and the utility of Patient-Reported Outcome Measures (PROMs). Following recruitment, we launched two consecutive online surveys. The aim is to conclude the consultation with two online focus groups in January 2024 and deliver a report on the approach and results, meeting the agreed timeline.

## EATRIS-Plus



[EATRIS-Plus](#) undertakes the challenge to bridge the gap between the generation of scientific knowledge in academic groups and its adoption at healthcare level, with a specific focus on biomarker validation for personalised medicine. EATRIS- Plus enables EATRIS to effectively shape the operational processes of translational medicine and advance in personalised medicine.

**EPF's role:** lead on the work on stakeholder engagement

### Recent updates

2023 marked the end of the Horizon 2020 project, EATRIS-Plus. The [Patient Engagement Resource Centre](#) (PERC), one of the main outputs of the project, was launched in March and aims to provide researchers with guidance and tools to involve patients effectively. It mainly targets researchers, but patients can also access and promote it.



To further support the EATRIS network and researchers in a shift towards more person-centric preclinical research, together with EATG (European AIDS Treatment Group), EPF took a step forward by providing tailored capacity building on Patient Engagement to the Latvian and Spanish nodes. The overarching objectives were, on the one hand, to test the usefulness and ease of the PERC and, on the other hand, to help both nodes move forward to the implementation phase.

Among other promotional efforts, EPF and EATG organised webinars on patient engagement in preclinical research targeting the patient community (November) and researchers (December). The second event was co-organised with EATRIS and [EU-LIFE-Alliance](#) in order to reach a wider researchers' community.



The objective of the [EHDEN](#) (European Health Data & Evidence Network) consortium is to provide all the necessary services that enable a distributed European data network to perform fast, scalable, and highly reproducible research, while respecting privacy regulations, local data provenance, and governance. This will include services and tools to perform data standardisation, analytical pipelines, tools to share study results, and tools for stakeholder engagement and training. The project is particularly timely due to the entry into force of the GDPR legislation.

**EPF's role:** outreach WP but also involved in topics including PROs, personalised medicine, ethical aspects, and trainings

## Recent updates

In December 2023, the third Data Saves Lives Ambassador Training Bootcamp was held in Brussels, Belgium, in partnership with the European Health Data & Evidence Network (EHDEN). The bootcamp centred on the process of establishing community-led patient registries. The ultimate aim was to empower participants with insights into the steps involved and the pivotal role of patient groups in shaping registry design for community benefit.



[EUCAPA](#) will ensure that patients and patient organisations have the necessary knowledge of the Health Technology Assessment (HTA) process to be meaningfully involved in HTA (both scientific consultations and assessments), as foreseen by the new Regulation on HTA (EU) 2021/2282 that will start assessing health technologies in January 2025. After undergoing the training programmes, patient experts will have acquired the necessary skills, knowledge, and understanding of HTA that will allow them to constructively participate and present their lived experience in assessing health technologies.

**EPF's role:** communicating and disseminating project results to a wider audience to promote awareness and uptake



## Recent updates

The project's kick-off meeting was held in Hall in Tirol, Austria, in March 2023. In 2023, EPF submitted several deliverables – a comprehensive communications and dissemination plan, the EUCAPA website and the project's first informative leaflet. Moreover, EPF is running EUCAPA's social media channels and creating quarterly newsletters, including video content, to promote EUCAPA's training on HTA and to raise awareness about the upcoming Regulation on HTA.



**EU-PEARL** has the ambition of transforming the current siloed approach to single-compound clinical trials into a cross-company collaborative, multi-compound Integrated Research Platform (IRP) that will centre the clinical study on patients and not on molecules. Patient-centric data and knowledge sharing will accelerate the conduct and reduce the costs of clinical trials, improving societal access to timely and affordable medicines. It will establish the IRP as a sustainable and scalable European and global solution.

**EPF's role:** task leader on the Patient Engagement Platform

## Recent updates

The EU-PEARL project reached its finale in April 2023, highlighting achievements in enhancing clinical development. A notable outcome is the **Platform for Patient and Community Engagement in Platform Trials (PACEPT)**, embedding tools such as explanatory leaflets and informative videos that explain the value and benefits of platform trials for patients.



The **Gravitate Health** mission is to equip and empower citizens as users with digital tools that make them confident, active, and responsive in their patient journey, specifically encouraging safe use of medicines for improved adherence, better health outcomes and higher quality of life. This project's ambition is to provide a key piece to advancing this vision, the Gravitate Health Lens or G-lens, to provide personalised, focused content from trusted health information sources to the user and demonstrate its benefits for access to and understanding of information, and adherence through the patient journey.

**EPF's role:** co-leading role of WP on stakeholder engagement, empowerment, and education

## Recent updates

The User Advisory Group took part in the evaluation of Gravitate Health mobile application MVP1 and MVP2 testing. The findings from the MVP1 testing were further included in a second stage of



evaluation with a focus on usability, accessibility, and user satisfaction. In early December, a feedback session/workshop call was organized together with the UAG members testing the app to gather their final input.

In September 2023, EPF drafted 10 recommendations for respecting the patient voice when delivering Digital Health Tools (DHTs) and our user advisory group members were actively involved in reviewing the draft.

In December 2023, EPF hosted the first webinar of a three-part series (GRH 101) targeting its members that were introduced to this project's fundamentals. The focus in this session was on digital health literacy and the pivotal role of digital information tools in patient empowerment, with a specific emphasis on electronic product information.

## HEALTH OUTCOMES OBSERVATORY - H2O



The IMI project, [Health Outcomes Observatories \(H2O\)](#), is the first-ever attempt to collect and incorporate patient outcomes into healthcare decision making – at an individual and population level – across multiple jurisdictions in Europe. The project will set up independent organisations – the Observatories – in four European countries initially, and these organisations will provide information for patients and their healthcare providers for use in clinical care. The benefits of this project will transform patient-reported information in healthcare and drive better outcomes for patients.

**EPF's role:** lead on patient engagement and education, through the set up of three Patient Advisory Boards (PABs), organised by disease areas

### Recent updates

In 2023, EPF engaged with the three Patient Advisory Boards (diabetes, IBD and oncology) to design, develop, translate and disseminate educational material about H2O, in collaboration with other partners. Additionally, EPF hosted a face-to-face event in Brussels for members of the PAB to give their feedback on the H2O Patient Agreement and ultimately validate the document. Some of the Dutch-speaking patient advisors also supported the Dutch translation of the Patient Agreement.

In June 2023, EPF organised and hosted a session at the Patient Engagement Open Forum (PEOF) featuring H2O. This interactive workshop featured two members of the PAB as speakers.

End of 2023, EPF looked forward to becoming a founding member of the H2O Pan European Observatory (PEO), an independent entity that serves as forum of consensus among all stakeholders (patient organisations, clinicians, regulators, industry and society), aiming to safeguard the mission of the IMI H2O project by ensuring consistency and high quality of measuring outcomes that matter in clinical practice.



The ambition of the IHI-project **HEU-EFS** is to create a harmonised framework for conducting Early Feasibility Studies (EFS) in the EU (European Union). EFS are small-scale research studies or tests done in the very early stages of developing a medical device or treatment to see if it is practical, safe, and worth pursuing further. EFS helps assess whether an idea or concept has potential before investing more time and resources into full-scale development and testing. Currently, there are no standardised procedural rules or guidance frameworks for carrying out EFS in the EU – a gap that the HEU-EFS project aims to fill. This also supports efforts by EU regulators to promote a stricter process for the generation of clinical evidence before medical devices can enter the market and be used by patients.

**EPF's role:** lead on patient engagement through the set up and management of a Patient Advisory Group (PAG) composed of individuals with different profiles and covering different disease areas

### Recent updates

The project was launched in October 2023, and the kick-off meeting took place in Milan on 30-31 October 2023. We have started preparing the recruitment of the Patient Advisory Group. Moreover, we have also started drafting Terms of Reference outlining the role and responsibilities of Patient Engagement Ambassadors who are technical experts within the consortium supporting the active involvement of the Patient Advisory Group throughout the project.

The mission of the IHI project, IDERHA (Integration of Heterogeneous Data and Evidence towards Regulatory and HTA Acceptance) is to address the key obstacles to achieving appropriate access, sharing, use and reuse of lung cancer data. The project's ambition is to enhance innovation in EU health care by providing a directly scalable platform for a seamless integration or linkage of diverse real world data at scale to support healthcare professionals, patients and researchers with new capabilities to improve patients' outcomes.

Additionally, IDERHA's mission is to develop policy recommendations for appropriate data sharing to enable heterogeneous health data for research, development and regulatory & HTA decision-making.

**EPF's role:** co-leading role of patient engagement activities together with our member organisation LuCE.

### RECENT UPDATES

The project kicked-off in April 2023. EPF has started preparing the patient engagement strategy and the recruitment of the Patient Advisory Board (PAB) in October 2023.



**IMMUcan** proposes an inclusive and integrated European immuno-oncology platform of data resources and frameworks, where common pre-competitive aspects of immuno-oncology development can be shared by numerous interested parties.

**EPF's role:** lead on dissemination and communication

### Recent updates

EPF continues to promote IMMUCan activities across the project social channels. In February 2023, EPF launched a tendering process to select a design agency to support its work on brand ID, digital content, and other multi-media assets. Early in May, EPF took part in the European Society for Medical Oncology meeting in Madrid whilst in December, we coordinated a social media campaign at ESMO Immuno-Oncology Congress in Geneva.

As part of our communication activity, EPF released a communications deliverable (infographic) in mid-November.



Promoting a trusted mHealth label in Europe: the uptake of technical specifications for quality and reliability of health and wellness apps. The objective of **Label2Enable** is threefold:

- **Trust:** Label2Enable will co-create the missing trust elements, i.e. an EU certification scheme and consistent assessments.
- **Use:** Label2Enable will engage in social policy experimentation and stakeholder engagement to enable all patients, citizens, and carers to (consider to) use healthcare apps.
- **Adoption:** Label2Enable will engage in experimentation, promotion, and appreciative inquiry to find a business model for an efficient certification process; increase adoption of the TS and mHealth label by healthcare systems and authorities; create a sustainable entity that maintains the scheme and promotes the TS.

**EPF's role:** EPF leads a work package that creates a user testing and advisory group

### Recent updates

In May 2023, EPF, together with the University of Amsterdam, we conducted the first series of focus groups to identify the digital health app users' communication needs. The User Advisory Group members were actively involved in the two-stage co-creation process, where the aim was to develop communication prototypes by means of co-creation with target groups e.g., patients, citizens, caregivers and to test whether the communication prototypes support understanding and informed decision making among users with lower levels of health literacy.





In 2023, EPF ran two webinars for its members. In the first webinar of the series, participants were introduced to the fundamentals of quality labelling for digital health apps in the European Union. The focus was on the concept of the label, existing types of EU labelling, ISO standards, and the significance of quality labelling for patients and healthcare professionals (HCPs). The second webinar, held in October 2023, provided EPF members with a behind-the-scenes look at the Label2Enable project, where the focus was on the evaluation criteria and the process of developing the label.

## PERISCOPE

The overarching objectives of **PERISCOPE** are to map and analyse the impacts of the COVID-19 outbreak, develop solutions and guidance for policymakers and health authorities on how to mitigate the impact of the outbreak, and to enhance Europe's preparedness for future similar events, and reflect on the future multi-level governance in the health as well as other domains.

In pursuing this objective, PERISCOPE sheds new light on the unintended and indirect consequences of the outbreak and the related government responses, with the intention to enhance evidence-based policymaking by collecting an unprecedented amount of data and information on the social, economic, and behavioral consequences of the current pandemic.

**EPF's role:** a horizontal role to contribute specifically to workstreams on socioeconomic impact of the COVID-19 pandemic, policy recommendations, and training for patients with chronic conditions

### Recent updates

As PERISCOPE concluded its three-year investigation into the socio-economic and behavioral impacts of COVID-19, the project unveiled key findings in its final conference in September. EPF played a vital role in the project, consulting patient organisations on the impact of the pandemic. In 2023, due to these consultations, EPF helped deliver the Analytical report on the impact of Covid-19 pandemic and the repercussions on the welfare of patients with chronic diseases.

## PROPHET

The **PROPHET** project is focused on defining a European Roadmap towards Personalised Prevention, the so-called Strategic Research and Innovation Agenda (SRIA). The aim of the SRIA is to support the implementation of innovative, sustainable, and effective personalised programmes in the EU to prevent common chronic diseases. The project has a strong policy-driven component which is strategically linked with ICPeMed, the international consortium on Personalised Medicine.

**EPF's role:** contribute to the development and implementation of the Strategic Research Agenda, stakeholder engagement and capacity building

### Recent updates

The Annual Meeting of the consortium took place in Valencia in October 2023. As part of the Work Package on communication and dissemination, we have started preparing a podcast interview with the project coordinator of PROPHET, which will be finalised and released in 2024.



## STRATEGIC PARTNERSHIPS

### HTA 360° Project

2023 saw the conclusion of “Patient Involvement in HTA in Europe”, an **HTAi** project with EPF and **EUPATI**:

- The project aimed at assessing the status of patient involvement in HTA across Europe.
- We presented our preliminary findings at the HTAi Annual Meeting in Adelaide, Australia and released the results in October 2023. Overall, the study identified some enablers for Meaningful Patient involvement in HTA, such as:
  - Patient involvement on the organisational level can help to create and apply processes in a way that they are feasible and relevant
  - Good preparation, early alerts, cross-stakeholder collaboration can help to maximise the level of involvement
  - Evaluation and feedback mechanisms can help to improve quality, consistency, and effectiveness of patient involvement

### PEOF - Patient Engagement Open Forum

As in previous years, in 2023 PEOF was a series of events co-led by EPF, PFMD and EUPATI. The initiative included both online and physical sessions. The in-person event took place in June, in Italy. EPF provided strategic support for the overall programme which covered a wide range of topics such as HTA, digital health and health data under the overarching theme of Patient Engagement.



# Capacity Building

In 2023 the EPF Capacity Building team delivered the 7th edition of the Skills Training for Young Patient Advocates, thematic webinars, the 1st edition of the Master's in International Patient Advocacy Management, while finalising the EPF Youth Group (YG) sexual health and well-being project and starting the Youth involvement in patient organisations project, as well as conducting the yearly face to face Spring and Fall YG meetings.

The team also maintained ongoing activities such as the Advocacy 101 Online course for young patients and the AI Knowledge Hub. Below you can find detailed information on each of the above-mentioned activities.

## AI KNOWLEDGE HUB

Following EPF's successful application for the [NEF EU AI Fund](#), EPF established the [AI Knowledge Hub](#) on the EPF website, where patients are able to learn more about Artificial Intelligence in healthcare.

The different sections of the Hub include:

- Information about the European Artificial Intelligence Fund;
- EPF's work on AI, including initiatives, such as the Understanding AI Webinar Series, and previously published policy and capacity building resources;
- External resources including key papers, reports, policy and legislative files, key events and capacity building activities.



## Thematic webinars

Throughout 2023 EPF delivered thematic webinars, in its mission to raise health literacy among patient organisations in Europe.

"[EPF Webinar on shortages – the new EMA mandate](#)". In June, EPF conducted a webinar focusing on the European Medicines Agency's new mandate, what patients should be aware of, how it will strengthen the EU's role in addressing shortages, and its expected impacts on improving patients' access to medicines. The participants had the opportunity to hear from: Siofradh McMahon, Supply and Availability of Medicines and Devices at the EMA, Marko Korenjak, President of the European Liver Patients' Association and the Pharmacovigilance Risk Assessment Committee at EMA and Claudia Louati, Head of Policy at EPF.

Overall, the webinar was a success, with 73 registrants and live engagement from the audience. The recording is available in EPF's Youtube channel.

"[The review of the EU pharmaceutical legislation from a patient perspective](#)" – on 31.05.2023 EPF conducted this webinar with the purpose of providing an in-depth overview of the main proposed changes from the European Commission, which will affect the patient community. In total 85 people registered for the webinar and were invited to ask questions and raise their concerns live during the event.



## DATA SAVES LIVES

**Data Saves Lives (DSL)** is a multi-stakeholder initiative led by the European Patients' Forum (EPF) and the European Institute for Innovation through Health Data (i-HD). Our aim is to raise wider patient and public awareness about the importance of health data, improve understanding of how it is used, and establish a trusted environment for dialogue on this issue.

Building on the success of the Artificial Intelligence Boot camp in Lisbon, DSL held its second face-to-face bootcamp with 20 patient organisations representatives in December 2023—an insightful Bootcamp focused on patient registries. In collaboration with the IMI project EHDEN, the Bootcamp facilitated discussion with 10 patient advocates about where to start when it comes to building community-led patient registries.

In 2023, Data Saves Lives also released its updated **toolkit**. This resource equips patient organisations with the information and materials they need to have a positive dialogue with their communities about health data and to potentially launch their own health data initiatives.

Data Saves Lives has expanded its reach to Germany and Netherlands. Germany was the first national branch of DataSavesLives, providing patient organisations with a platform to access necessary **resources** in German. For Netherlands, we initiated the national branch by focusing firstly on the toolkit adaptation into Dutch.

## Health Technology Assessment

Following the successful negotiation for a regulation on HTA collaboration, the work to draft the implementing acts started, and so also EPF worked to ensure readiness of the patient community.

In December 2023 we organised an HTA Simulation Workshop, a dynamic learning experience for patients and patient representatives from the European, national and local level and covering several disease areas. The intention was to shed light on how patient involvement will be orchestrated within the HTAR framework and identify potential needs and bottlenecks. A report will follow in 2024.



## The Skills Training Course for Young Patient Advocates (STYPA) 7th Edition

In 2023, EPF held the seventh edition of STYPA in The Mercure Hotel, Riga. The training course consisted of face-to-face training, which was held in person from 13th to 16th July and also webinars held before and after the training. The 29 participants came from all over Europe. A wide range of disease areas and conditions were also represented, such as ADHD, celiac disease, IBD, diabetes, allergies, MS, breast cancer, scleroderma. The topic chosen for the training this year was shortages of medicines, a hot topic in the patient community. Participants were introduced to the topic in a welcome webinar, as well as by completing the Advocacy 101 course. During first day of the training in Riga, participants began with a welcome talk from EPF President Marco Greco, before speaking about their expectations, and delving into the topic of shortages with session, led by Claudia Louati (EPF) and Baiba Ziemele (LPOT).

The second day was devoted to the Agora process, in which representatives from EFPIA, EMA, and Medicines for Europe were in conversation with the participants, giving them their perspective on why there are shortages and what can be done about them. The final day saw participants working on their personal advocacy project. Following the in-person training, there was a series of three webinars, in which the participants delved deeper into topics such as communications and leadership.

The purpose of the training in 2023 was to support the advocacy skills of young patients and support them in developing their knowledge of the subject and how to communicate with relevant stakeholders. The skills that they learnt on the training could also be transferrable to other topics they may need to advocate on in the future.

During the course, the participants had the opportunity to pose questions to relevant stakeholders and learn the best ways to communicate their issues through the development of an advocacy project, which was followed up during the later webinars.

During these webinars, the participants had a chance to build on skills developed during the in-person training, and to further develop their advocacy projects.



## EPF Youth Group in 2023

The Youth Group (YG) currently consists of 9 young patients, coming from all over Europe and representing different chronic conditions. They have been an active part of EPF for years and didn't fail to deliver young patient-centred content in 2023. Some of their key achievements this year include:

- Finalising and continuing the dissemination of the “Sexual Health and Well-Being” project. The final webinar “Let's get provocative! – EPF Youth Group discusses sexual stigmas” of this project was held in February 2023. The webinar brought together medical professionals and young patients coming from all over Europe. The Group continued to share the impactful work they did on this project throughout 2023, mainly their [series of short videos](#). The videos were shared on the YG [Facebook](#) page, [Instagram](#) and [Twitter](#) and on the [EPF YouTube channel](#).
- Focusing on the “Youth Involvement in Patient Organisations (PO)” project. The aim of the project is to promote youth involvement in PO, by educating PO leaders on how to better do that within their own organisations. The YG has already collected data from PO on the challenges and needs for the better involvement of young patients in PO. Following this insightful feedback, the EPF YG will create an online course for patient organisation leaders in 2024.
- The successful completion of the Spring and Fall Youth Group meetings, where YG members gathered to discuss and advance on their focus topics and plan future projects. During the meetings, the YG focused on developing in detail the concept, content and timeline of their current and future projects.
- We held an open call for recruiting new members and welcomed two new YG members in 2023. The two new members represent the European Federation of Allergy and Airways Diseases Patients' Associations (EFA) and FH Europe.
- Representing the young patients' perspective in various events throughout the year – the EPF Annual General Meeting, EPF's 20th Anniversary event, STYPA 2023, IEEPO event on practical steps towards humanising healthcare, [ERN RARE-LIVER transition to care workshop](#), [Data Saves Lives](#) bootcamp on AI in healthcare, the GlobalSkin and IFPA online event on youth involvement in organisations, [EMSP Young Patient's Network Festival](#), the International Epilepsy Congress and various others.

## “ADVOCACY 101” FOR YOUNG PATIENTS

### Online Course

In 2023, EPF continued to offer its online patient advocacy training course: [Advocacy 101](#). The online course aims to strengthen the advocacy knowledge and capacity of young patients in a flexible and accessible way. The entire training is online, and participants have access to videos, interactive activities, exercises, bite-sized informational content and a library of advocacy resources. The content provides participants with the key elements to help them start their journey into patient advocacy.

During the year, 150 people registered for the course.



## Master's in International Patient Advocacy Management

EPF is proud of partnering with [Cattolica University](#) (Patient Advocacy Lab, of the Graduate School of Economics and Management of Healthcare Organizations (ALTEMS), of the Graduate School of Psychology Agostino Gemelli (ASAG), of the Faculty of Economics and of the Faculty of Medicine "A. Gemelli", in collaboration with EngageMinds Hub - Consumer, Food & Health Engagement Research Center of Università Cattolica and the Foundation Policlinico universitario "Agostino Gemelli" IRCCS).

The II level University Master Course lasts one academic year (first edition March 2023 to May 2024) for 60 credits in total, equal to 1500 hours of lessons and study.

The course provides the students with the management skills required for a successful coordination and development of the activities of patients' organizations in the healthcare sector.

The lectures span from healthcare management, European Legislation on health, Patient Involvement, fundraising, strategic communication, planning and bookkeeping, stakeholder management and more. See [here](#) the full programme.

During the 2023-2024 edition there was a total of 10 students, from Turkey, Malta, Italy, North Macedonia, USA, UK, Slovenia, and Belgium. They represented different disease areas – neuromuscular disorders, mental health, liver disease, multiple sclerosis, digestive cancer, and lymphoma. Two participants came from the private sector.

50% of the students attended more than 90% of the lectures and 40% of the students attended more than 80% of the lectures in the syllabus.

## Empowering Western Balkans Patient Organisations: A Comprehensive Needs Assessment

As part of EPF's strategy to strengthen patient groups across Europe, we conducted a comprehensive needs assessment in six Western Balkans countries: Serbia, Montenegro, Bosnia, Albania, Kosovo, and North Macedonia. We understood that the patient landscape in this region is different from the EU model, so we aimed to learn more about the healthcare system and put patient experiences first, aligning with EPF's values.

Our journey began with thorough research and connecting with patient organisations in these countries through our membership network. We then hosted one Zoom meeting, lasting two hours, with 12 Serbian organisations, during which we introduced EPF and listened to the specific needs and concerns of patient organisations. For the other countries we organised individual calls with the organisations.



# Communications

## 2023: A Million Moments of Impact

For 2023, EPF has remarkable communications highlights to share.

In April, we launched the #EPF20 Campaign to mark the 20th anniversary of EPF. The campaign surged across social media platforms, achieving over 1.000.000 impressions in just two days.

Later, in November, we proudly reached another milestone, by building a community of over 10.000 followers on LinkedIn.

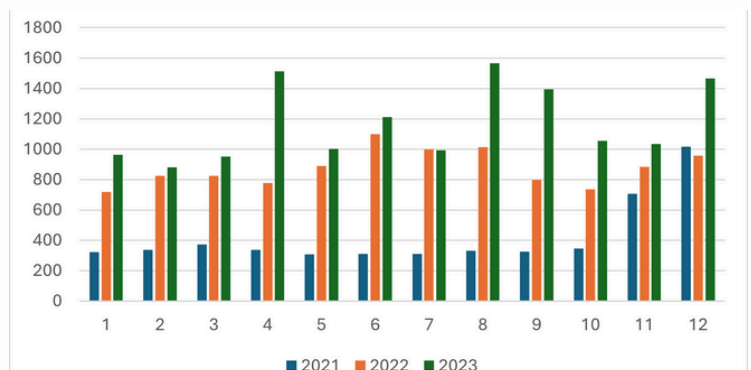
These achievements highlight EPF's unique capacity, with the support of our members, to leverage communication for impactful, cross-border change within diverse healthcare systems.



### The Patient Perspective: Growing Opening Rate

We also take note of the remarkable growth of EPF's monthly newsletter, the Patient Perspective. Compared to 2022, we recorded an increase of 20% in the average number of opens of each issue.

As we look forward to 2024, the Communications team is geared up for the EU Elections Campaign 2024, determined to drive meaningful engagement and advocacy within our community and beyond.





# EPF 20: Anniversary Year

## 20 Years Stronger: EPF's 20th Anniversary Event – The Path of Patient Advocacy: Past, Present, and Future

In April 2023, the European Patients' Forum (EPF) celebrated 20 years of building a strong patient voice across Europe. The anniversary event brought together EPF members, partners, key figures from its two-decade history, and staff members.

EPF's activity throughout its 20 years of existence has seen and triggered profound transformation in the role of patients and patient organisations in healthcare policy and practice. EPF has a track record of highly effective advocacy campaigns on policy and unique multi-stakeholder collaborations that brought the patient perspective to the design of health policies over the years.

The 20th Anniversary Policy Event looked back over these two decades, explored learnings, and built on these to inform and inspire a dialogue with participants about the future direction for the patients' voice and patients' advocacy in Europe. The event resulted in a vision for what the patient movement could achieve in 10 years: the EPF Manifesto - towards a truly participatory, democratic and impactful involvement of patient organisations. The Patient Organisations' Manifesto lies at the heart of the EPF EU elections advocacy campaign launched at the end of 2023.

This was the largest ever structured discussion to determine a roadmap and a manifesto for the overall patient movement in Europe in a multistakeholder format. It aimed to bring key past and current stakeholders that have helped to shape EPF into the impactful organisation it has become, and, crucially, the next generation of young patient leaders to help carve out the future.

Keep reading and find a report of the event [here](#).



# Financial Overview

Extract from the Auditor's Report for the financial year started on the 1st of January 2023 and ended on the 31st December 2023 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, 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 2023, and of its results for the financial year then ended, in accordance with the accounting legislation applicable in Belgium."*

## Auditors:

L&S Reviseurs D'Enteprises  
Kortmansstraat 2a  
1731 Zelik

## External Accounting Support:

Countable BV  
Kantooradres, Heirweg 53  
9270 Kalken



# Financial Statement

Financial statements 2023

31/12/2023 YTD ACTUAL

<b>OPERATING INCOME</b>	<b>€ 2.380.722,41</b>
Membership fees	€ 28.850,00
Forum Work Plan	€ 630.000,00
Capacity Building program	€ 355.734,53
Sponsorship	€ 403.375,39
Honorarium	€ 12.922,40
Data Saves Lives	€ 110.000,00
Artificial Intelligence	€ 55.929,96
PEOF	€ 25.458,00
Project Access to Medicine	€ -6.000,00
Project HTA360	€ 5.635,96
Project COMPARE	€ -15.000,76
Project Core-MD	€ 23.887,38
Project EUCAPA	€ 23.816,76
Project EHDEN	€ 106.954,50
Project EU-PEARL	€ 117.364,39
Project EATRIS+	€ 51.577,85
Project IMMUCAN	€ 29.114,40
Project PROPHET	€ 18.890,54
Project IDERHA	€ 12.075,48
Project Gravitare Health	€ 63.423,70
Project H2O	€ 77.055,65
Project Periscope	€ 37.876,84
Project Immuniverse	€ 0,00
Project Label to Enable	€ 56.407,99
Project HEU EFS	€ 10.901,90
Refund of expenses	€ 135.408,72
VAT to claim pro rata	€ 7.748,75
Other income and refunds	€ 1.312,08
<b>OPERATING CHARGES</b>	<b>€ -2.317.520,44</b>
<b>STAFF COSTS</b>	<b>€ -1.475.469,87</b>
Gross remuneration	€ -1.048.493,79
ONSS contributions	€ -241.309,47
Other staff costs (holiday pay, insurance, meal vouchers, other	€ -185.666,61
<b>SUBCONTRACTING</b>	<b>€ -182.610,17</b>
<b>GENERAL COSTS</b>	<b>€ -659.440,40</b>
Buildingcosts	€ -151.549,96
Office costs	€ -79.113,65
Fees	€ -142.931,89
Insurances	€ -6.472,95
Travel	€ -110.174,42
Meetings	€ -160.159,57
Communication	€ -6.526,91
Others	€ -2.511,05
<b>OPERATING RESULT</b>	<b>€ 63.201,97</b>
<b>DEPRECIATIONS</b>	<b>€ -25.157,51</b>
Addition the legal reserves	€ -24.724,62
Estimated taxes	€ -272,65
<b>BANK RESULT</b>	<b>€ -1.021,68</b>
<b>TOTAL RESULT</b>	<b>€ 12.025,51</b>

# Acknowledgements of funds 1/3

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 2023	% of total income
<b>TOTAL European Commission support to projects 2023</b>	<b>€ 619.982,58</b>	
Core MD	€ 23.887,38	1,1%
ComparEU	€ -15.000,76	-0,7%
EATRIS +	€ 51.577,85	2,3%
EHDEN	€ 106.954,50	4,8%
EU-PEARL	€ 117.364,39	5,2%
Gravitate Health	€ 63.423,70	2,8%
H2O	€ 77.055,65	3,4%
HTA360	€ 5.635,96	0,3%
IMMUCAN	€ 29.114,40	1,3%
LABEL To ENABLE	€ 56.407,99	2,5%
PERISCOPE	€ 37.876,84	1,7%
EUCAPA	€ 23.816,76	1,1%
IDERHA	€ 12.075,48	0,5%
PROPHET	€ 18.890,54	0,8%
HEU EFS	€ 10.901,90	0,5%
Access to Medicine	- € 6.000	
<b>Membership income</b>		
Membership fees	€ 28.850,00	1,3%

EPF wishes to thank the following donors for their support:

	Contribution to Operations	% of total income
<b>Operational &amp; Engagement - work plan 2023</b>	<b>€ 640.000,00</b>	
Abbvie SA	€ 35.000,00	1,6%
Amgen Inc	€ 25.000,00	1,1%
Baxter World Trade SPRL	€ 10.000,00	0,4%
Boehringer Ingelheim International	€ 35.000,00	1,6%
Bosch Health Campus	€ 10.000,00	0,4%
Bristol Myers Squibb	€ 60.000,00	2,7%
Chiesi Farmaceutici S.p.A	€ 25.000,00	1,1%
Edwards Lifesciences SA	€ 25.000,00	1,1%
EFPIA	€ 25.000,00	1,1%
F. Hoffmann-La Roche Ltd	€ 60.000,00	2,7%
GlaxoSmithKline	€ 30.000,00	1,3%
Horizon Therapeutics	€ 35.000,00	1,6%
Intuitive Surgical Sàrl	€ 10.000,00	0,4%
Medecines for Europe	€ 20.000,00	0,9%
Novartis Pharma AG	€ 80.000,00	3,6%
NV Janssen Pharmaceutical	€ 50.000,00	2,2%
Pfizer INC	€ 40.000,00	1,8%
Sanofi-Aventis Group	€ 50.000,00	2,2%
UCB Biopharma SPRL	€ 15.000,00	0,7%

# Acknowledgements of funds 2/3

## Capacity Building Programme 2023 - HTA - Artificial Intelligence - PEOF - DSL

€ 581.942,53

	Contribution to the CBP and others	% of total income
<b>Capacity Building Programme</b>		
Daiichi Sankyo Europe GmbH	€ 30.000,00	1,3%
GlaxoSmithKline	€ 30.000,00	1,3%
Horizon Therapeutics	€ 40.000,00	1,8%
Institut La Conference Hippocrate	€ 20.000,00	0,9%
Merck Sharp & Dohme Corp.	€ 54.323,52	2,4%
Novavax GmbH	€ 15.000,00	0,7%
Novocure Inc	€ 40.411,01	1,8%
Novo Nordisk Denmark A/S	€ 26.000,00	1,2%
Takeda Pharmaceuticals International	€ 20.000,00	0,9%
<b>HTA Capacity Building Simulation Workshop</b>		
Astellas Pharma Europe Ltd.	€ 10.000,00	0,4%
Msd Belgium Bv	€ 30.000,00	1,3%
Novartis Pharma AG	€ 10.000,00	0,4%
Pfizer INC	€ 20.000,00	0,9%
Takeda Pharmaceuticals International	€ 10.000,00	0,4%
<b>Artificial Intelligence</b>		
European Artificial Intelligence & Society Fund	€ 83.250,00	3,7%
<b>PEOF</b>		
The Synergist Asbl	€ 25.458,00	1,1%
<b>DSL</b>		
Aisbl Medtech Europe	€ 10.000,00	0,4%
EFPIA	€ 50.000,00	2,2%
F. Hoffmann-La Roche Ltd	€ 25.000,00	1,1%
Novartis Pharma AG	€ 5.000,00	0,2%
Takeda Pharmaceuticals International	€ 20.000,00	0,9%
Netherlands Patients' Federation	€ 7.500,00	0,3%

# Acknowledgements of funds 3/3

<b>EPF 20th Anniversary event 2023</b>	<b>€ 378.375,39</b>	
Aisbl Medical Nutrition International Industry	€ 10.000,00	0,4%
Baxter World Trade SPRL	€ 10.000,00	0,4%
Boehringer Ingelheim International	€ 10.000,00	0,4%
Bosch Health Campus	€ 10.000,00	0,4%
EFPIA	€ 10.000,00	0,4%
F. Hoffmann-La Roche Ltd	€ 25.000,00	1,1%
Galapagos NV	€ 20.000,00	0,9%
Grünenthal GmbH	€ 5.000,00	0,2%
H. Lundbeck A/S	€ 10.000,00	0,4%
Horizon Therapeutics	€ 15.000,00	0,7%
Intuitive Surgical Sàrl	€ 10.000,00	0,4%
IQVIA Ltd	€ 10.000,00	0,4%
Merck	€ 40.000,00	1,8%
Merck Sharp & Dohme Corp.	€ 19.375,39	0,9%
Novartis Pharma AG	€ 20.000,00	0,9%
Novavax GmbH	€ 20.000,00	0,9%
NV Janssen Pharmaceutica	€ 20.000,00	0,9%
Pfizer INC	€ 10.000,00	0,4%
Servier Affaires Medicales	€ 20.000,00	0,9%
Takeda Pharmaceuticals International	€ 40.000,00	1,8%
UCB Biopharma SPRL	€ 10.000,00	0,4%
Vertex Pharmaceuticals (Europe)	€ 14.000,00	0,6%
Viartis	€ 20.000,00	0,9%
<b>Other income (including reserves)</b>	<b>€ 21.983,23</b>	
Other Income	€ 21.983,23	1,0%

# SECRETARIAT AND GOVERNANCE

A snapshot of the EPF team on 31 December 2023

Anca Toma - Executive Director

Anne Rensma - Communications Officer

Bianca Pop - Project Assistant

Borislava Ananieva - Youth Strategy and Capacity Building Officer

Claudia Louati - Head of Policy

Davide Durante - Communications Assistant

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

Ingrid Weindorfer - Project Officer

Julie Spony - Policy Officer

Klaudia Cymer - Operations Assistant

Laura Henderson - Capacity Building Assistant

Milana Trucl - Policy Officer - Digital Health

Nicola Bedlington - Special Advisor

Ruth Tchapanian - 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 2023: Erika Landvik, Estefania Guzman Cordero, Hannes Jarke, Juan Jose Fernandez Romero, Julie Thill, Lyudmil Ninov, Martina Continisio, Sibel Yamaner, Yevheniia Zhyla.



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