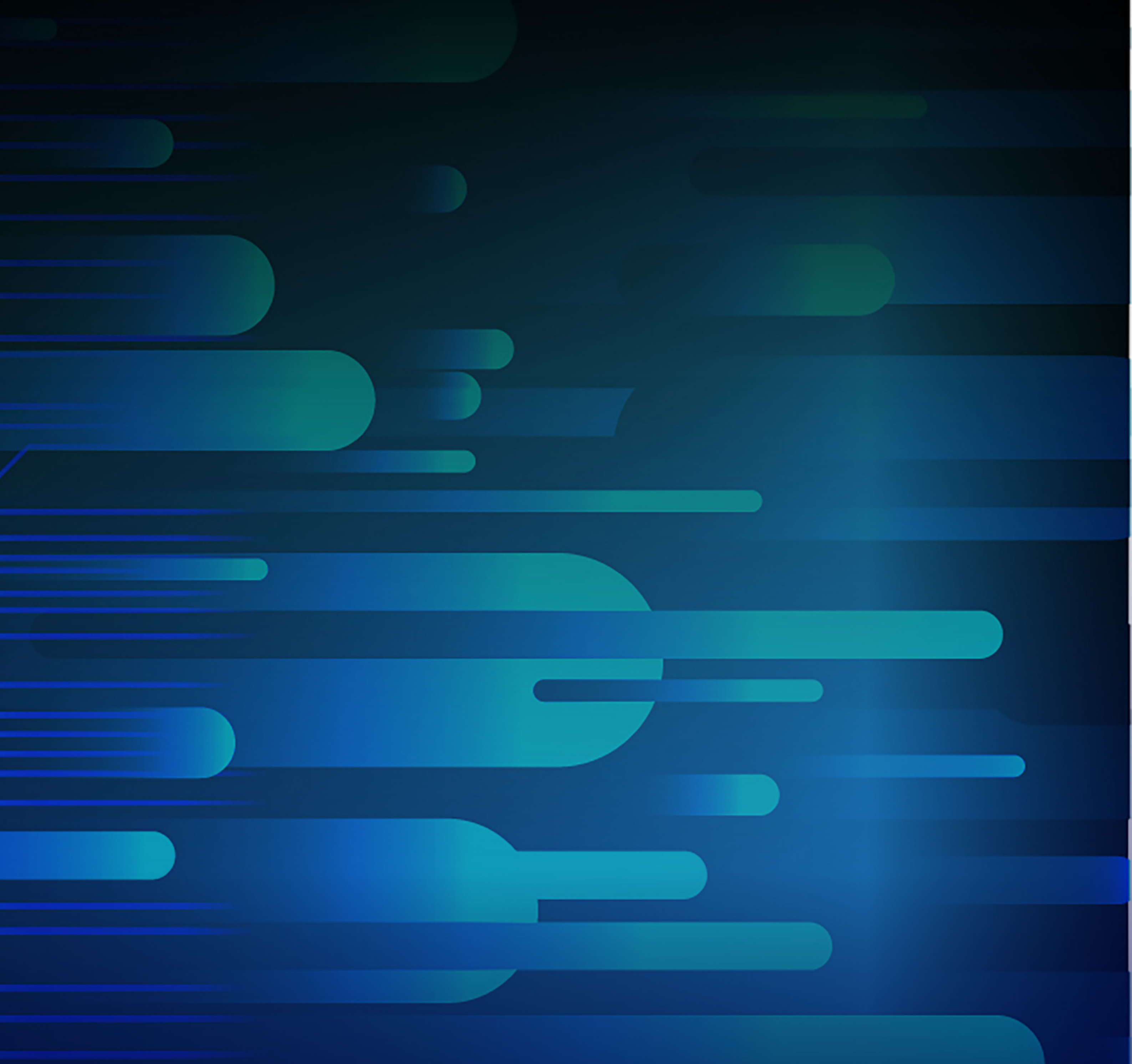

European Patients' Forum

ANNUAL REPORT

2022

www.eu-patient.eu

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

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A WORD FROM OUR PRESIDENT

I am pleased to present to you the annual report for the European Patients' Forum, representing our ongoing efforts to make the patients' voice heard in all areas of European health policy. As the President of EPF, I am proud that we achieved numerous milestones in working towards our vision of creating a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise. Our report highlights the work we have undertaken in various areas, including policy advocacy, capacity building, projects, and communications. We strived to increase our reach, engage with more stakeholders, and collaborate with other organisations to achieve our objectives. Our achievements are a reflection of the dedication, passion, and hard work of our staff, board, members, partners, and supporters.

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

MARCO GRECO
EPF PRESIDENT

2022 AT A GLANCE

JANUARY

9EPF WEBINAR ON PATIENT INVOLVEMENT IN NUTRITIONAL CARE

FEBRUARY

9: EPF WEBINAR ON THE EU’S BLOOD, TISSUES AND CELLS LEGISLATIVE

MARCH

25: PARTNERS' MEETING INTRODUCING NEW GENERAL DIRECTOR

APRIL

12-14: PEOF ONLINE
23: EPF AGM

MAY

9-11: EATRIS-PLUS PROJECT MEETING

27-29: YOUTH GROUP SPRING MEETING

JUNE

23-24: EPF CONGRESS

29: EUROPEAN HEALTH PARLIAMENT FINAL PLENARY

JULY

6: PARTNERS ROUNDTABLE

14-17: STYPA 2022

SEPTEMBER

26-29: EUROPEN HEALTH FORUM GASTEIN

OCTOBER

3-4: PEOF IN-PERSON

17-18: H2O GENERAL ASSEMBLY

28: AI WEBINAR

NOVEMBER

15-16: COMPAR-EU FINAL CONFERENCE

18: AI WEBINAR

22: PEOF ONLINE

29-30: PHARMALEDGER CLOSING EVENT

DECEMBER

1: H2O'S "LAUNCHING H2O'S OBSERVATORIES"

2: AI WEBINAR

STRATEGIC PLAN 2021-2026

Our Strategic Plan 2021-2026 is a reflection of the most up-to-date changes in the European health and social policy environment. This translates to the new challenges and opportunities for EPF as an umbrella of patient organisations active across Europe. Overall, 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-centered, accessible, and sustainable healthcare systems in Europe. This plan outlines our proactive role and potential 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 FIVE (5) CORE STRATEGIC GOALS ARE:

1. Shaping a new European agenda for patients
2. Meaningful patient involvement in co-creating better health policy, practice, research and education
3. Digital transformation that delivers for patients
4. Accessing the healthcare we need with no discrimination
5. Strengthening patient communities across Europe

OUR MEMBERS

Our members are the backbone of our work: their perspective brings an irreplaceable added value to our policy and advocacy activities. We currently represent 77 patient organisations representing 19 countries and an estimated 150 million patients across Europe.

Find an overview of our current membership here.

2022 AT THE SECRETARIAT

On the eve of our anniversary year, 2022 was without a shadow of a doubt a very busy, interesting, and moving period in EPF history. In the following section, the Secretariat teams share their highlights. These are the ins and outs of our policy, projects, communications, and capacity building teams.

POLICY

EPF acts as an intermediary between the patient community and EU policymakers by providing a crucial cross-disease perspective based on issues that have a direct impact on patients' lives - in a national and regional context. 2022 was no different. This is how our policy and advocacy work is conducted.

2022 was a big year policy and advocacy-wise. The EPF policy team focused on digital health, access to healthcare (including the ongoing revision of the EU’s pharmaceutical legislation), renewing the membership and the Terms of Reference of its two Working Groups (on Digital Health and Universal Access to Healthcare), patient involvement in research and professional education, and the continuing impact of COVID-19 across the patient community.

Next to this, we continued our engagement in high-level European and international health policy events and meetings. This included joint work with other Brussels-based organisations, such as, for example, our efforts in the context of the EU4Health Civil Society Alliance (co-led by EPF, together with the European Public Health Alliance), the AMR Patient Group (led by Health First Europe), and the Alliance Meeting for the Digitalisation of Medication Management (led by the European Health Management Association).

High-level EU health advocacy

Next to responding to the stakeholders' consultation on the future 2023 EU4Health work programme and beyond, we continued our joint advocacy within the EU4Health Civil Society Alliance on operating grants, including a joint statement in September 2022. Operating grants were successfully renewed for 2023, and although EPF could not apply, we were pleased that this instrument remained available for some of our members.

EPF was also active in the European Medicines Agency (EMA) and co-chairing the Patients and Consumers' Working Party until June 2022.

The response to the COVID-19 pandemic

From August to September 2022, we conducted our second survey on the impact of the COVID-19 pandemic on patients and patient organisations, as part of the EU project PERISCOPE. The survey had an excellent response rate. 847 individual patients living with chronic diseases responded, and 76 patient organisations. The results will be published in 2023 and will inform EPF's policy and advocacy work.

Digital Health

Concerning the European Health Data Space: following member consultations from June to November, EPF released a position statement on the European Commission's proposal on 28 November, with 19 proposed amendments. EPF's recommendations put patients at the heart of the EHDS initiative and focus on trust, transparency, meaningful patient involvement, security, and data protection. The statement and suggested amendments guided EPF's advocacy strategy and shaped the interactions with the co-legislators during the last months of 2022.

On the topic of artificial intelligence, 2022 was dedicated to building knowledge of the patient community and capacity-building activities. We contributed to and disseminated the research findings of our two AI Fund-supported reports on the challenges and opportunities of AI from a patient perspective and on the mapping of EU policy frameworks. In addition, we organized three webinars on the topics of EU Legislation on AI, AI in Medicines Innovation, and Patients, Healthcare Professionals, and AI. The membership and Terms of Reference of the Digital Health Working Group were renewed and the first meeting was held in December 2022.

Access to healthcare

The EU revision of the pharmaceutical legislation occupied much of our year, preparing for its publication, originally scheduled for December 2022. This included participation in the stakeholders' public consultation published by the European Commission, stakeholders' workshops organised by the Technopolis Group (under the framework of a study they received from the European Commission), and internal consultation with our members on the key topics of this revision.

In 2022, antimicrobial resistance played a major role in our activities: in addition to our continued collaboration with the European Centre for Disease Prevention and Control on the occasion of European Antibiotics Awareness Day in November 2022, we have issued a statement on the five key points we would like to see included in the next proposal for a Council Recommendation on AMR.

We monitored the implementation of the Medical Devices Regulation and In-Vitro Diagnostics Medical Devices and, in light of the emerging reports of disruptions in the availability of many medical devices in the EU, in December, we issued a reaction to the proposed amendments to the new Regulation, followed by a call for action highlighting our concerns. The membership and the Terms of Reference of the Universal Access Working Group were renewed, and the first meeting was held in December 2022.

Patient involvement in health professionals’ education

We published the survey report on continuing professional education (CPE) in March 2022, which demonstrates that, despite the shortcomings inherent in current patient participation in CPE, there is a willingness to continue enhancing and fostering patients’ participation in these activities.

Health in the European Semester 2022

EPF published an analysis report of the health-related aspects of the Commission’s 2022 European Semester process and explained its major elements, timeline, and relevance to the patient community represented by EPF. As part of the European Semester process, the European Commission issues a series of Country Reports (CRs), with a detailed analysis of the situation of each Member State regarding fiscal, economic and social policies. The EPF report provides a summary of the CRs for each Member State, with a focus on health and the United Nations Sustainable Development Goals.

Legislative initiative resolution with recommendations to the European Commission on a Statute for European Cross-Border Associations and non-profit organisations

The European Commission published a call for evidence and public consultation (the latter was answered by EPF) on a proposal for a legislative initiative on cross-border activities of associations. It includes two legislative proposals: a regulation to create the legal form of the European Association and a directive harmonising minimum standards for non-profit organisations. EPF welcomed both and joined other civil society organisations via the Civil Society Europe network in issuing a position statement supporting the creation of a new legal form for associations, allowing recognition in all Member States to fully benefit from the single market as well as to adopt common minimum standards based on fundamental rights.

Policy's important dates in 2022

27 January, 29 June and 14 July 2022 – Some EPF staff members mentored the Working Groups of the 7th edition of the European Health Parliament (organised by Johnson&Johnson), and/or participated in the drafting of its final recommendations. The European Health Parliament is a movement connecting and empowering the next generation of European health leaders to rethink EU health policies. Each year the EHP convenes a diverse group of 60 young professionals representing all healthcare sectors. Participants work together for six months to develop policy recommendations that address today's most pressing European health issues, which are picked in cooperation with the European Commission.

9 February 2022 – EPF organised a Members-only webinar titled "The evaluation of the EU's Blood, Tissues and Cells Directives – what is at stake for the patient community?". The purpose of this webinar was to explain to the patient community the ongoing work being carried out by the European Commission evaluating the "Blood, Tissues and Cells legislation" to identify issues of importance to patient organisations and potential engagement needs and opportunities for EPF and its Members.

26-29 September 2022 – European Health Forum Gastein in Badhof Gastein (Austria) took place. EPF provided the patient perspective in various panels on pandemic control, the EU pharmaceutical strategy and health equity.

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 to 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.

EPF's role: eliciting patients’ priorities and preferences

COMPAR-EU (Comparing effectiveness of self-management interventions in 4 high priority chronic diseases in Europe) aims to identify, compare, and rank the most effective and cost-effective self-management interventions (SMIs) for adults in Europe within four high-priority chronic conditions: Type-2 Diabetes (T2DM), obesity, chronic obstructive pulmonary disease (COPD), and heart failure.

RECENT UPDATES

The project has ended in December 2022, a final conference was held in November in Brussels. Together with the Patient Panel, lay summaries and communication materials were produced and translated in multiple languages, available here.

CORE-MD

Coordinating Research and Evidence
for Medical Devices

EPF's role: contributor

CORE-MD will propose how to generate evidence using innovative methodologies like randomised registry trials and how to assess artificial intelligence algorithms that are incorporated within devices. Recommendations from the CORE–MD consortium will be submitted to the Working Group on Clinical Investigation and Evaluation of the European Commission.

RECENT UPDATES

We are completing an extensive form for ethical approval for the DELPHI, which we hope to obtain from the Institutional Review Board at our partner institution, the University of Gothenburg. We plan to recruit patients once we obtain approval and hope to conduct the DELPHI starting in 2023, meeting the current timeline.

eatris+

EPF's role: lead on the work on stakeholder engagement (principally WP5)

With EATRIS-Plus, EATRIS 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 will enable EATRIS to effectively shape the operational processes of translational medicine and advance in personalised medicine.

RECENT UPDATES

The taskforce for patient engagement kicked off and met multiple times, including in-person. We prepared a session for PEOF. EATRIS and EPF have developed a joint communication strategy (led by EPF) to raise awareness on the need for early involvement of the patient, including in translational research, and perform joint advocacy on key issues such as how to support and leverage the increasing patient mobility in Europe, along with their increasing agency over their own data as well as the need for more patient-directed academic research. The communication strategy plan has been completed. The first campaign was published on 15 September 2022

EHDEN
EUROPEAN HEALTH DATA & EVIDENCE NETWORK

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

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.

RECENT UPDATES

EPF promoted the third EHDEN Academy course, focusing on the benefits, possible risks, and protections on responsible use of health data. EPF also launched a fourth course that is focusing on patient reported outcomes (PROS) for patients. This fourth episode is co-created with H2O project partners and Patient Advisory Boards representatives. It expands on the first three courses produced by EPF.

EU-PEARL
EU PATIENT-CENTRIC
CLINICAL TRIAL PLATFORMS

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

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.

RECENT UPDATES

We identified the benefits for patients of platform trials and materials to be created for Patient Engagement Platform (PEP). We held a second public "Patient and Community Engagement Day" online, informing interested participants about what platform trials are and how patients can benefit. We also hosted a panel discussion on informed consent in platform trials. Patient advisors contributed substantially to the work in disease-specific work packages, including input on Master Protocol Templates and published scientific papers. EPF led a joint advocacy/awareness raising campaign, ahead of the end of the project. The campaigns plan was submitted in late July, and work began to publish the first campaign item to mark World Mental Health Day.

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

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 (not concealed or filtered) 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.

RECENT UPDATES

The User Advisory Group continued to meet regularly to also find new ways to engage with the other project activities. The deliverable toolkit has gotten approval from the Commission. This was EPF's first deliverable. A face-to-face General Assembly took place in Oslo at the end of June. As co-lead of the WP on Stakeholder Engagement, EPF contributed to the overall coordination of the WP and to the agenda design for the General Assembly that took place in December 2022 in Athens.

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

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 each of the 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, if successful, will transform the use of patient-reported information in healthcare and will, as a result, drive better outcomes for patients.

RECENT UPDATES

In addition to focusing on patient engagement, we need to focus on healthcare team engagement, designing and developing training materials for patients and healthcare professionals (together with other partners). These training materials should include patients and healthcare professionals (the whole care team) - some stakeholder-specific, some mixed groups. Additionally, the training materials that EPF is developing are on the importance of PRO/PROMs, while other H2O partners will be developing disease-specific content.

EPF's role: lead on dissemination and communication

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

RECENT UPDATES

EPF continues to promote (as WP co-lead) IMMUcan activities across the project social channels. The much-awaited amendment request has been approved. For EPF this had significant time implications, as we needed to launch a tendering process to select a design agency to support our work on brand ID, digital content, and other multi-media assets.

IMMUniverse

EPF's role: production of a communication tool for the patient community

IMMUniverse aims to tackle unmet (IMID) needs and to understand the role of the crosstalk between tissue microenvironment and immune cells in disease progression and response to therapy of two different IMIDs: ulcerative colitis and atopic dermatitis.

RECENT UPDATES

EPF’s involvement in project activities is limited. EPF is supporting the patient recruitment search (via social media and our newsletters) of the IMMUNIVERSE study.

LABEL2 ENABLE

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

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:

1. Trust: Label2Enable will co-create the missing trust elements, i.e. an EU certification scheme and consistent assessments.
2. Use: Label2Enable will engage in social policy experimentation and stakeholder engagement to enable all patients, citizens, and carers to (consider to) use healthcare apps.
3. 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

RECENT UPDATES

EPF created the initial user advisory board. The board members reviewed the survey on “Trust about digital health solutions/apps”. It was translated into around 25 languages and was disseminated to EPF members.

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

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 affected by the outbreak. 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 behavioural consequences of the current pandemic.

RECENT UPDATES

EPF delivered the second edition of its COVID-19 survey to patients and patient organisations. This survey is aimed at individual patients living with chronic diseases, and at patient organisations (with two separate sections, one for each). The questions are tailored to the needs of PERISCOPE's WP1 (socio-economic impact of COVID-19 on patients) and to the report that partners would produce as the final deliverable. So far, we have collected nearly 847 responses from individual patients and 76 from patient organisations.

EPF's role: contribute to the project’s patient advocacy and engagement

PharmaLedger uses block-chain technology to create a platform for the healthcare sector that integrates the supply chain, clinical trials, and health data as case studies. The project aims to drive the early-adoption of blockchain-based technology by working together with partners to build a complete solution for improving the quality of healthcare, and explore how blockchain technology can help us tackle real-world health challenges.

RECENT UPDATES

The final meeting took place in November. EPF voted yes to the creation of the “PharmaLedger Association” as a follow-up NGO to sustain developments from the project and serve as a conduit to develop future health and care apps based on blockchain technology.

EPF's role: EPF was part of the Patient Advisory Group together with ECPC (lead of the PAG), Muscular Dystrophy UK, and IAPO

The main objective of PREFER was to strengthen patient-centric decisionmaking on benefit-risk assessment throughout the lifecycle of medicinal products (a term which, in the context of this proposal, also includes medical devices) by developing evidence-based recommendations to guide industry, Regulatory Authorities, HTA bodies, reimbursement agencies, academia, and healthcare professionals on how and when patient-preference studies should be performed and the results used to support and inform decisionmaking.

RECENT UPDATES

The project was completed in May 2022. A report was submitted in July. One of the main legacies left by the PREFER project is the Qualification obtained by the European Medicines Agency.

EPF's role: mainly to contribute to development and implementation of the Strategic Research Agenda and stakeholder engagement and Capacity Building

The PROPHET project is focused on defining a European Roadmap towards Personalised Prevention. It is not a research project, it is more a policy-driven action to be strategically linked with ICPerMed, the international consortium on Personalised Medicine.

RECENT UPDATES

Kick-off meeting took place in Rome, Italy, between 21-23 September.

STRATEGIC PARTNERSHIPS

Health Technology Assessment

Following the successful negotiation for a regulation on HTA collaboration, the work to draft the implementing acts started. Together with EURORDIS and UMIT University we have successfully submitted a successful project proposal to support capacity building for Patient Involvement in HTA under the EU4Health programme. The project, titled EUCAPA, started in 2023.

Other updates

HTAi 360, an EPF-EUPATI project with EFPIA:

- The project aims at assessing the status of patient involvement in HTA across Europe.
- We have presented on our work at HTAi in Utrecht in June.
- In 2022, we have conducted a survey and disseminated it in multiple languages. We have gathered 150 complete responses.
- We are aiming to make the survey and the anonymous dataset publicly available, so it can be used by patient organisations and researchers in the future – a repository has been set up and will be made public once the report is finished.

PEOF - Patient Engagement Open Forum:

The 2022 edition of PEOF took place in throughout the year, with online sessions taking place in April, June, and November, and an in-person session in the first week of October. EPF has provided strategic support for the overall programme. At the face-to-face session, EPF actively contributed to three sessions including one on preclinical research and one on HTA.

CAPACITY BUILDING

The Capacity Building Programme was designed to respond to needs and concerns identified by our members. It supports patient organisations in strengthening their role as equal players in the healthcare environment.

“ADVOCACY 101” FOR YOUNG PATIENTS - ONLINE COURSE

The overall aim of this online course is to build and strengthen the advocacy knowledge and capacities of young patients, in a flexible and accessible way. The entire training is available on a dedicated online platform. Once on the platform, participants have access to videos, interactive activities, exercises, bite-sized informational content, and a library of advocacy resources. The content provides participants will key elements to help them start their journey into patient advocacy.

Most importantly – the young patients are able to take this course entirely at their own pace, while having quick contact with an EPF staff member and the opportunity to receive a certificate following the successful completion of the course. The course was launched in November 2022 – so far we’ve had 10 young patients, who have graduated. EPF will make sure to disseminate widely this great opportunity and support young patients all over Europe in the beginning of their advocacy journey.

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), in collaboration with EngageMinds Hub and the Foundation Policlinico universitario “Agostino Gemelli” IRCCS).

The II level University Master Course lasts one academic year for 60 credits in total. The course provides the student with the management skills required for a successful coordination and development of the activities of patients' organisations in the healthcare sector.

The lessons span from Healthcare management, European Legislation on Health, Patient Involvement, fundraising, strategic communication, planning and bookkeeping, stakeholder management, and more. In 2022, the Scientific Committee was created and gathered twice.

THE SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES (STYPA) - 6TH EDITION

In 2022, EPF conducted the sixth edition of STYPA held in the European Youth Centre, in Strasbourg, France. This year, STYPA was back to its original structure having both online and face-to-face modules. The topic was "Sexual Health and Well-Being for Young Patients". The training continued for 3 days and brought together 38 young patient advocates, coming from different European countries such as: Italy, Georgia, Romania, Spain, Bosnia & Herzegovina, Greece, Croatia, Cyprus, Belgium, Germany, the UK, Turkey, Sweden, Portugal, Poland, Czech Republic, Slovenia, Switzerland, Bulgaria, Ireland, Serbia, Albania, and others. The young patients represented different disease areas and chronic conditions (many of them living with multiple conditions) such as: MS, Ulcerative Colitis, Thyroid cancer, IBD, Autism Spectrum Disorder, Pulmonary Hypertension, ADHD, Asthma, Addisons Disease, Ehlers Danlos Syndrome, Diabetes Type 1, HIV/AIDS, Psoriatic arthritis, Breast & Ovarian cancer, Lupus, Polycystic Ovarian Syndrome, Hashimoto, Kidney Transplant, Haemophilia Type A, Epilepsy, Endometriosis, Friedreich's Ataxia, and others.

The purpose and nature of the STYPA 2022 programme was to support and build the capacity of young patient advocates or representatives of young patient advocates who are motivated to learn more about sexual health and well-being as well support them in developing communication principles for their peers on young patients and their sexual health.

Throughout the course, the participants had the opportunity to take part in workshops and various educational activities focusing on the importance of communication with healthcare providers, partners, and potential partners on this topic.

STYPA 2022 combined the on-site training in Strasbourg, France from 14 to 17 July, 2022, with a series of webinars and an online launch event. The course lasted from July to October 2022 and contained a number of elements. The participants attended online webinars where they worked hard to develop the communication principles which were then presented during a public online event, attended by 18 different stakeholders.

At the beginning of the in-person course, each participant received a STYPA 2022 t-shirt and by the end, they all received a certificate for the successful completion of the course.

After the training, a podcast was recorded with two participants of STYPA 2022 – Amaranta Mora and Ozla Nuh, who discussed the main takeaways of the programme. The podcast was moderated by Martina Continisio, EPF's Membership and Governance Officer, and Anne Rensma, EPF's Communications Officer.

UNDERSTANDING AI: WEBINAR SERIES

Following EPF's successful application for the NEF EU AI Fund, EPF launched the Understanding AI webinar series for its members. The overall objective of the webinar series is to shed light on AI in healthcare. The series' particular focus is on the possible advantages but also risks and pending questions for patients, while exploring specific implications for the healthcare sector.

Starting in 2021, EPF broadcasted two webinars: "AI in Healthcare: From Science Fiction to Reality" and "AI in Healthcare: Ethics and Implications". Following that, in 2022, EPF continued the series with another three webinars:

- "EU Legislation on AI" - The third webinar in our AI series addressed interesting and important reflections on EU legislation regarding artificial intelligence and the healthcare sector and its implications for patients and patient organisations.
- "AI in Medicines Innovation" - This webinar covered topics such as pre-clinical research, clinical trials, regulatory approval, and medicines safety monitoring. It reflected on how the use of AI could improve or accelerate medicines development and what the implications may be for patients.
- "Patients, Healthcare Professionals and AI" – In the last webinar of the series our speakers dived deeper into informing patients on AI use, shared decision-making and AI, the challenges of the use of AI in healthcare provision, and the risk and mitigation approaches for making AI efficient (including some examples on how AI can improve clinical decisions).

Overall, the webinar series was a great success, with more than 320 participants registering for the series.

EPF has also launched the AI knowledge hub where its work on AI as well as key publications are stored for the benefits of its members and the patient community at large.

EPF YOUTH GROUP

The Youth Group (YG) currently consists of 10 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 2022. Some of their key achievements this year include:

- The Sexual Health and Well-Being Project. After consulting the wider young patient community back in 2021 about the key topics surrounding sexual health they would like to discuss, the EPF YG has been actively publishing more and more content on the project, starting with publishing an article, interviewing Moira Tzitzika – a psychologist and psychosexologist certified from the European Society of Sexual Medicine. Following the article, the Group recorded a podcast episode, diving deeper into the results of the survey and interests of the wider young patient community. The YG reached out to the young patient community again to ask them to share fully anonymously their stories related to their condition and their sexual health. After collecting many interesting stories, the Group shared them through a series of short videos. The videos were then shared on the YG Facebook page, Instagram and Twitter and on the EPF YouTube channel. The project was finalised with a final online event on Zoom in February 9th 2023 open to all stakeholders.
- Picked up work on the Young Patients' Involvement in Patient Organizations (POS) survey. The aim of the survey is to understand from the source what are the barriers, concerns, and needs for the better involvement of young patients in patient organizations. After the survey collects a sufficient amount of responses, the EPF Youth Group will focus on providing, throughout 2023, "10 tips to better involve young patients in patient organizations".
- The successful Spring and Fall Youth Group Meetings, where all the YG members gathered to discuss and advance on their focus topics and plan future projects.
- Representing the young patients' perspective in various events throughout the year – the EPF 2022 Congress, the COMPAR-EU Project Advocacy Conference, the PEOF conference, Data Saves Lives' event, and various others.

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.

RECENT UPDATES

DSL Germany is approved by the Ministry of Health. DSL helped with a workshop at the F2F EPF Congress. The outcomes fed into the 2.0 version of the toolkit. DSL has also held its first F2F bootcamp with 20 patient organisation representatives in October 2022.

COMMUNICATIONS

2022 was the year almost 4000 people joined our overall social media following. We are so pleased to see so many getting involved in our mission to advance patient empowerment. We started several social media periodicals in 2022, including a weekly recap post that highlights speaking and policy engagements and a dedicated section to share our members' updates, celebratory moments, and key happenings. We ongoingly worked on improving the website SEO-wise and in terms of usability (UX/UI).

The European Patients' Podcast welcomed twelve inspiring guests this year, sharing important and topically relevant stories with us on, i.e., AMR, young patients and sexual wellbeing, Rare Disease Day, and much more. We also welcomed a number of expert speakers from our membership network.

In June, EPF's 2022 Congress took place, in which we continued the conversation on digital transformation with over 300 registrants, of which 150 people joined us onsite. During this two-day event that ran from the afternoon of 23 June to the following afternoon on the 24th, #EPFCongress2022 became the number two most trending hashtag on Twitter, testifying of our participants' engagement and solidifying our communications efforts in the lead-up to the congress. Afterwards, we created a post-congress video with highlighted speakers, built a short-running social media campaign around the recordings of the plenary sessions, and published an in-depth report.

We are happy to report that the press consistently finds its way towards us and that, last year, we continued to maintain high visibility of our policy and advocacy efforts on established media platforms. Some highlights include a long-read article featuring Anca Toma in Politici de Sănătate, a quote in the French political reporter Contexte, and several mentions in POLITICO's Morning Healthcare updates.

EPF CONGRESS 2022

Back in 2019, we decided to organise EPF's first ever European Congress. It created an unprecedented space for dialogue and growth, putting the patients in their rightful place – at the centre of the healthcare ecosystem. One of the key ideas that came to life following the 2019 Congress was that patients are (and should be treated as) partners in knowledge – for physicians and political factors alike. Our plans for organising another in person Congress edition were detoured, when the COVID19 pandemic struck in 2020.

In 2021, we held a full online Congress edition, having in mind to organise a face-to-face follow-up event. The online edition of the Congress brought forth a paradigm shift. Patients had moved from passive recipients of treatment to partners in knowledge and, as we saw in 2021, they became more and more involved in the decision-making process for matters that concern them: health data sharing, equal access to medical services, and shaping the healthcare system future generations need. We set our attention towards creating a call for action on patient-driven digital health, compiling all the knowledge, insight, and experience we gather from the patients, experts, and the many more who attended the two congress editions, which set off 2022's congress on "Continuing the conversation on digital transformation".

More on the 2022 edition of the EPF Congress can be found in the congress report here.

FINANCIAL OVERVIEW

Extract from the Auditor’s Report to the Board of Members on the Financial Statements for the year ended 31 December 2022

"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 and the shared legally reserved tasks of SME's and small (international) non-profit organisations and, the attached financial statements give a true and fair view of the assets and the financial situation of the association European Patients' Forum (EPF) as of 31 December 2022, 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

Accounting:
Les Comptables et Fiscalistes Associés
Rue de L’Industrie 11 bte 16
1000 Bruxelles

Income and expenditures

Income and Expenditure as at 31 December 2022

INCOME		**2022**		**2021**
Funding from Public Sector	**€**	**701,899.48**	**€**	**780,689.02**
EC projects		€ 701,899.48		€ 780,689.02
Funding from the private sector	**€**	**1,630,740.77**	**€**	**1,220,153.92**
Operation and Engagement		€ 769,902.24		€ 717,000.00
Capacity Building Programme		€ 196,000.00		€ 179,000.00
Co-funding to EPF projects DSL-PEOF +AI+Access to Med		€ 290,303.35		€ 178,776.10
Contribution CONGRESS		€ 374,535.18		€ 145,377.82
Membership fees	**€**	**23,300.00**	**€**	**22,351.43**
Contribution to Work Plan (Operations, Capacity Building and project development)		€ 23,300.00		€ 22,351.43
Interest and other income		**€ 14,966.75**		**€ 9,704.71**
TOTAL INCOME		**€ 2,370,907.00**		**€ 2,032,899.08**
EXPENDITURES		**2022**		**2021**
Staff Costs (all projects, all campaigns)	**€**	**1,396,283.01**	**€**	**987,710.15**
Office and admin costs	**€**	**381,672.67**	**€**	**372,744.02**
Depreciation	**€**	**23,419.09**	**€**	**22,431.98**
Travel and subsistence (EPF staff)	**€**	**4,452.72**	**€**	**2,647.81**
Activities (other direct costs)	**€**	**566,934.03**	**€**	**527,482.47**
Summer Training & Youth Group meetings	€	64,989.38	€	12,502.27
Thematic Working Group Meetings/ Initiatives (Data Save Lives - PEOF - AI)	€	190,073.90	€	116,459.54
Capacity Building Programme (delivery of training modules)	€	3,393.52	€	29,526.13
Congress	€	146,820.59	€	105,679.94
Other costs linked to operations, project portfolio	€	161,656.64	€	263,314.59
Bank and Financial Charges	**€**	**4,769.67**	**€**	**4,400.59**
TOTAL EXPENDITURE	**€**	**2,377,531.19**	**€**	**1,917,417.02**
TOTAL Surplus or deficit of the Year	**€**	**-6,624.19**	**€**	**115,482.05**

Balance sheet

Balance Sheets as at 31 December 2022

ASSETS		2022		2021
I Current Assets				
Accounts receivable	€	83,965	€	514,695
Cash in bank and deposit	€	1,817,743	€	1,938,605
Pre-paid expenses	€	8,297	€	19,737
Total current assets	**€**	**1,910,005**	**€**	**2,473,037**
II Fixed assets				
IT Equipment and softwares	€	57,127	€	45,115
Furniture, Fixtures and Fittings	€	11,899	€	13,142
Guarantees (rent and social security)	€	50	€	50
Total fixed assets	**€**	**69,076**	**€**	**58,307**
TOTAL ASSETS	**€**	**1,979,082**	**€**	**2,531,344**

LIABILITIES		2022		2021
I Current Liabilities				
Accounts payable	€	347,350	€	385,567
Deferred income	€	431,690	€	939,111
Total current liabilities	**€**	**779,040**	**€**	**1,324,678**
II Reserves				
Funds brought forward	€	791,666	€	791,184
Social Reserve	€	415,000	€	300,000
Surplus or deficit for the year	-€	6,624	€	115,482
Total reserves	**€**	**1,200,042**	**€**	**1,206,666**
TOTAL LIABILITIES	**€**	**1,979,082**	**€**	**2,531,344**

Acknowledgements of funds

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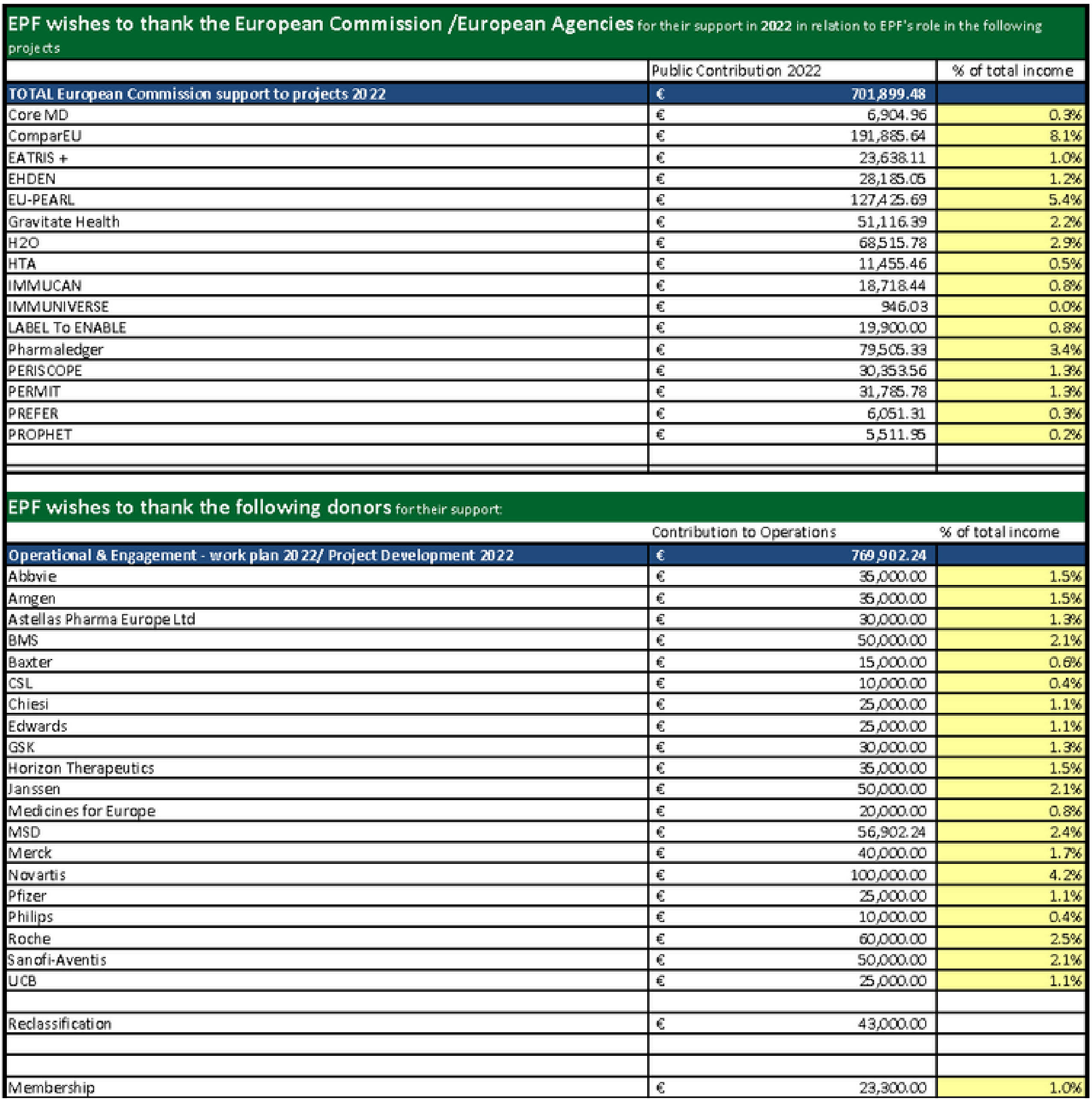


EPF wishes to thank the European Commission /European Agencies for their support in **2022** in relation to EPF's role in the following projects

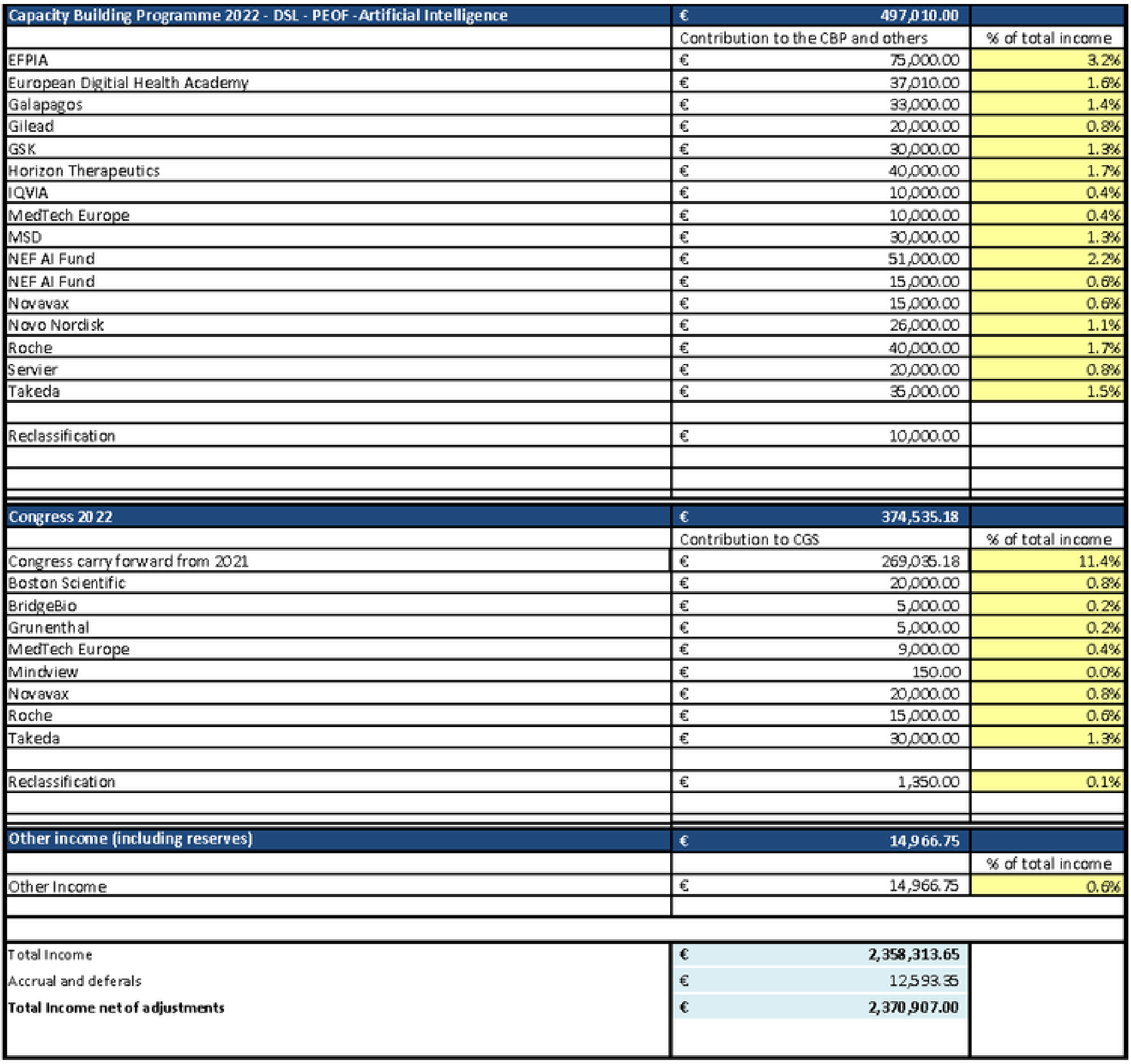
	Public Contribution 2022		% of total income
TOTAL European Commission support to projects 2022	**€**	**701,899.48**	
Core MD	€	6,904.96	0.3%
ComparEU	€	191,885.64	8.1%
EATRIS +	€	23,638.11	1.0%
EHDEN	€	28,185.05	1.2%
EU-PEARL	€	127,425.69	5.4%
Gravitate Health	€	51,116.39	2.2%
H2O	€	68,515.78	2.9%
HTA	€	11,455.46	0.5%
IMMUCAN	€	18,718.44	0.8%
IMMUNIVERSE	€	946.03	0.0%
LABEL To ENABLE	€	19,900.00	0.8%
Pharmaledger	€	79,505.33	3.4%
PERISCOPE	€	30,353.56	1.3%
PERMIT	€	31,785.78	1.3%
PREFER	€	6,051.31	0.3%
PROPHET	€	5,511.95	0.2%

EPF wishes to thank the following donors for their support:

	Contribution to Operations		% of total income
Operational & Engagement - work plan 2022/ Project Development 2022	**€**	**769,902.24**	
Abbvie	€	35,000.00	1.5%
Amgen	€	35,000.00	1.5%
Astellas Pharma Europe Ltd	€	30,000.00	1.3%
BMS	€	50,000.00	2.1%
Baxter	€	15,000.00	0.6%
CSL	€	10,000.00	0.4%
Chiesi	€	25,000.00	1.1%
Edwards	€	25,000.00	1.1%
GSK	€	30,000.00	1.3%
Horizon Therapeutics	€	35,000.00	1.5%
Janssen	€	50,000.00	2.1%
Medicines for Europe	€	20,000.00	0.8%
MSD	€	56,902.24	2.4%
Merck	€	40,000.00	1.7%
Novartis	€	100,000.00	4.2%
Pfizer	€	25,000.00	1.1%
Philips	€	10,000.00	0.4%
Roche	€	60,000.00	2.5%
Sanofi-Aventis	€	50,000.00	2.1%
UCB	€	25,000.00	1.1%
Reclassification	€	43,000.00	
Membership	€	23,300.00	1.0%

Acknowledgements of funds

2/2



Capacity Building Programme 2022 - DSL - PEOF -Artificial Intelligence	**€**	**497,010.00**	
	Contribution to the CBP and others		% of total income
EFPIA	€	75,000.00	3.2%
European Digitial Health Academy	€	37,010.00	1.6%
Galapagos	€	33,000.00	1.4%
Gilead	€	20,000.00	0.8%
GSK	€	30,000.00	1.3%
Horizon Therapeutics	€	40,000.00	1.7%
IQVIA	€	10,000.00	0.4%
MedTech Europe	€	10,000.00	0.4%
MSD	€	30,000.00	1.3%
NEF AI Fund	€	51,000.00	2.2%
NEF AI Fund	€	15,000.00	0.6%
Novavax	€	15,000.00	0.6%
Novo Nordisk	€	26,000.00	1.1%
Roche	€	40,000.00	1.7%
Servier	€	20,000.00	0.8%
Takeda	€	35,000.00	1.5%
Reclassification	€	10,000.00	
Congress 2022	**€**	**374,535.18**	
	Contribution to CGS		% of total income
Congress carry forward from 2021	€	269,035.18	11.4%
Boston Scientific	€	20,000.00	0.8%
BridgeBio	€	5,000.00	0.2%
Grunenthal	€	5,000.00	0.2%
MedTech Europe	€	9,000.00	0.4%
Mindview	€	150.00	0.0%
Novavax	€	20,000.00	0.8%
Roche	€	15,000.00	0.6%
Takeda	€	30,000.00	1.3%
Reclassification	€	1,350.00	0.1%
Other income (including reserves)	**€**	**14,966.75**	
			% of total income
Other Income	€	14,966.75	0.6%
Total Income	**€**	**2,358,313.65**	
Accrual and deferals	€	12,593.35	
Total Income net of adjustments	**€**	**2,370,907.00**	

SECRETARIAT AND GOVERNANCE

A snapshot of the EPF team on 31 December 2022

Anca Toma - Executive Director
Anne Rensma - Communications Officer
Borislava Ananieva - Youth Strategy and Capacity Building Assistant
Elena Balestra - Head of Governance, Membership and Capacity Building
Eric Moris - Director of Operations
Erika Landvik - Finance Manager
Estefania Guzman Cordero - Communications and Outreach Officer
Flavia Topan - Communications Manager
Gözde Susuzlu Briggs - Project Coordinator
Hannes Jarke - Project Coordinator
Ingrid Weindorfer - Project Assistant
Juan Jose Fernandez Romero - Policy Officer
Julie Spony - Policy Officer
Julie Thill - Operations and Events Assistant
Kaisa Immonen - Director of Policy
Lyudmil Ninov - Senior Programme Officer
Martina Continisio - Membership and Governance Officer
Milana Trucl - Policy Officer
Nicola Bedlington - Special Advisor
Ruth Tchaparian - Operations and Grants Coordinator
Valentina Strammiello - Head of Programmes
Zilvinas Gavenas - IT Coordinator

With thanks to colleagues active in 2022: Mercedes Serrra, Lamprini Bikou, Chiara Boni, Michele Calabro, Dante Di Iulio, and our Interim Execcutive Director Elisabeth Kasilingam.

EPF's Board and Ethics committee

EPF is administered by a Board of Members elected by the Annual General Meeting for a term of two years. The Board meets five times a year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the annual work programme.

President - Marco Greco
Vice President - Brian West
Treasurer - Radu Costin Ganescu

Board Members

Dimitrios Athanasiou
Elena Moya
Isabel Proano Gomez
Manuel Arellano
Erin Davies
Elisabeth Kasilingam

With thanks to the Board members until April 2022, Marzena Nelken and Michal Rataj.

Ethics Committee

Amanda Bok
Anita Arsovska
Birgit Dembski
Stella de Sabata
Mateja Krzan