

# ANNUAL REPORT 2021

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

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## A word from the President

*"We are EPF"* – has been our motto guiding us through the ups and downs of 2021, with a strong accent on the word: WE. The idea of community, of a common and joint fight in a critical year has been essential. If in 2020 the COVID-19 crisis has highlighted the critical importance of proactive patient engagement in shaping health policy at national and European levels, 2021 has been the year we tested the patient-centred solutions brought forward by the pandemic in the last two years.

This Annual Report highlights the impact of our policy and advocacy work during these trying times, as well as our collaborative projects and capacity-building – all of which were achieved by working closely with our members as well as with our many partners. We would like to thank all of you for your untiring support to EPF.

In 2021 our team fully committed to having patient advocacy as a priority topic while the COVID-19 pandemic remained high in the EU health agenda and influenced many of the health policies that were being discussed and implemented. A key element of our policy work has been the focus on digital health, and we also engaged in extensive work on Artificial Intelligence, both through policy inputs and capacity building.

Our Capacity Building Programme moved into the virtual realm but delivered exceptional materials including another successful Patient Advocates Seminar and a new edition of our Summer Training Course for Young Patient Advocates (STYPA), in addition to various other learning programmes. Our Youth Group members were increasingly active on the national and EU level, getting involved in local activism, in EU-wide initiatives such as the European Health Parliament, and taking an active role in mentoring young patients to embark on their first journey to advocacy.

Our projects portfolio continued to expand in 2021 and now consists of fifteen projects spread across the thematic clusters of Research and Medicines Development, Patient Engagement, Health Systems and Digital Health and Health Data. In 2021, we concluded our work on Digital Health Europe, while we started new projects such as CORE-MD, the first formalised group of stakeholders in Europe working together to identify ways to enable the scientific, fair, and systematic evaluation of medical devices.

We are particularly proud to showcase the success story of the EPF Congress 2021, our second European Congress, dedicated to the digital transformation of healthcare and fully driven by the patient community. We could not be happier with the turnout of the many lively discussions, as well as the inspiring and often moving stories heard over the four-day virtual event. Last year's event generated a lot of groundwork towards making meaningful patient involvement an integral part of

health systems, and EPF will implement these key outcomes in its work over the next months, including with a new edition of the EPF Congress coming in 2022.

These accomplishments reflect the solid expertise, reputation, unity and credibility of our organisation and trusted network of members and partners. As the leading voice of patient organisations in Europe, we thank you for your support and hope very much that you will continue to work with us for the benefit of Europe's patients.



**Marco Greco**  
**President, European Patients' Forum**



## 2021 at a Glance

<b>January</b>	EGM
	Shot callers: a virtual event on COVID-19 vaccines
	EPF Digital Health Working Group virtual meeting
	Launch of EPF's Let's Talk About Vaccination – guide for patients
	European Commission stakeholder webinar on EU4HEALTH
	EU4Health Civil Society Alliance virtual meeting
	DSL Webinar
	VAC-PACT virtual regional workshop 1: Central-Eastern Europe
	VAC-PACT virtual regional workshop 2: Southern Europe
	Lessons Learned from COVID-19: Unleashing the Potential of Digital Solutions in Chronic Disease Management (EPF speaker)
	All Policies for a Healthy Europe coalition meeting
	Gravitate Health UAG induction meeting
	Virtual OECD Workshop: Supporting Health Innovation with Fair Information Practice Principles (EPF speaker)
	Partners' meeting: European Alliance for Value in Health
DHE Multi Stakeholder Workshop	
<b>February</b>	EU-JAMRAI Joint Action on AMR – final conference
	Commission's eHealth Stakeholder Group virtual meeting
	Masters of Digital online event (EPF speaker)
	EU Health Coalition virtual members' meeting
<b>March</b>	European Commission's Expert Group on Health Systems Performance Assessment: focus group on patient vignettes as a data collection tool
	EMA Patient and Consumer Working Party joint meeting with Healthcare Professionals' Working Party
	Finnish Ministry of Health and SOSTE webinar on European Health Union (EPF speaker)
	OECD PaRIS virtual meeting
	EPF webinar for members on cross-border healthcare in collaboration with DG Sante
	EU Health Policy Platform annual meeting
	DIA Europe annual conference (EPF speakers)
	VAC-PACT virtual regional workshop 3: Northern Europe
	DSL Tweet chat
<b>April</b>	DSL Webinar
	PEOF
	AGM
	OECD working group on patient-reported safety indicators (PRIMs)
	WHO Fair Pricing Forum – virtual meeting

	EPF Working Group on Universal Access to Healthcare virtual meeting
	OECD PaRIS International Advisory Group virtual meeting
	Joint HMA/EMA Workshop on Artificial Intelligence in Medicines Regulation
	Portuguese EU Presidency's 3A Conference (EPF speaker)
	COMPAR-EU Patient Panel workshop 1
	EPF information session on the implementation of the EU Medical Devices Regulation for members (with the European Commission)
	EU4Nutrition event (EPF speaker)
	Portuguese Presidency conference on access to medicines (EPF speaker)
<b>May</b>	EU4Health Civil Society Alliance Virtual Meeting
	EPF Digital Health Working Group Virtual Meeting
	European Commission medicines shortages virtual focus group
	OECD Healthcare Quality and Outcomes working party virtual meeting
	EURIPID (European medicine price database) virtual stakeholder meeting
	Webinar on partnerships for empowerment – in collaboration with CEMPAC
	EU Nutrition and Health Alliance meeting
	AI webinar 1
<b>June</b>	DSL Toolkit pilot launch workshop
	EMA Patient and Consumer Working Party joint meeting with Healthcare Professionals' Working Party
	EPF industry roundtable
	CIOMS Working Group XI editorial meeting
	WHO Non-State Actors virtual consultation meeting
	Equinet – European network of equality bodies virtual meeting (EPF speaker)
	European Commission workshop on EHDS, part 1
	AMR stakeholder group meeting
	EU Medical Devices Coordination Group meetings
	European Commission HTA Network meeting
	EPF Shot Callers webinar, part 2
	PEOF
	DSL Tweet chat
	Gravitate Health UAG training
	Portuguese Presidency high-level conference on digital health – Portugal eHealth Summit (EPF speaker)
<b>July</b>	EMA PCWP and FDA patient engagement committee joint meeting
	European Commission workshop on EHDS, part 2
	DSL Webinar
<b>September</b>	DSL Tweet chat
	EMA Patient and Consumer Working Party joint meeting with Healthcare Professionals' Working Party
	European Commission workshop on cross-border healthcare

	OECD Healthcare Quality and Outcomes working party virtual meeting
	Good Lay Summary Practice working meeting
	European Health Forum Gastein – virtual workshops and meetings
	Consultation webinar – EU4HEALTH work programme 2022
	ASPHER 2021 conference (EPF speaker)
	Meeting with Commission re: IVDR implementation
	COMPAR-EU Patient Panel workshop 2
<b>October</b>	EPF Digital Health Working Group Virtual Meeting
	Good Lay Summary Practice partners’ meeting
	BMJ Webinar series on access to electronic health records (EPF speaker)
	EU Health Coalition strategy meeting
	EAHP “Oath to Society” even (EPF speaker)
	FEAM forum meeting to discuss EU HERA
	EPF Congress
<b>November</b>	EU4Health CSA Virtual Meeting
	Science for Health conference (EPF speaker)
	EMA PCWP annual meeting with eligible organisations
	PERMIT workshop on ethical issues in personalised medicine research
	TEHDAS joint action on digital health - stakeholder forum
	ECHA Alliance Digital Health Summit (EPF speaker)
	CHES and Health in all Policies event – Unlocking potential of artificial intelligence in healthcare (EPF speaker)
	Commission’s eHealth Stakeholder Group
	EU Medical Devices Coordination Group meetings
	Global Heart Hub event (EPF speaker)
	RWE4DECISIONS event “Towards establishing an EU real-world evidence generation action plan for better healthcare systems & patient outcomes2
	DSL Tweet chat
<b>December</b>	DSL Webinar
	EMA Big Data Stakeholder Forum (EPF speaker)
	EU Medical Devices Coordination Group meetings
	Partner meeting of thematic stakeholder network “Integrated Nutrition Cancer Care”
	Meeting of the MEP’s interest group on access to care and PACT
	EPF-ONCA webinar on patient involvement in nutritional care
	PEOF

## Strategic Plan 2021-2026

As we approached the end of our last seven-year strategic plan (2014-2020), EPF initiated a dialogue with our members that led to the development of a new strategic plan. The **EPF Strategic Plan (2021- 2026)** will guide our work for the next five years. It will be the basis for a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan and an enhanced project engagement strategy. EPF will expand its project portfolio, while carefully refining criteria for involvement.

This [Strategic Plan 2021-2026](#) reflects the latest changes in the European health and social policy environment and 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. Amidst the ongoing COVID-19 pandemic, patients and the patient community are, more than ever before, key actors and contributors in creating equitable, person-centred, accessible, and sustainable healthcare systems in Europe. We hope that 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 patients’ 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





## EPF Congress 2021: The Digital Transformation of Healthcare

From 26 to 29 October 2021, the European Patients’ Forum virtually convened experts, professionals, and patients to tackle the topic of digitalised healthcare for the second **EPF Congress**.

# Digital transformation of healthcare

Virtual event  
OCT 26-29, 2021

Following the success of the first Congress held in 2019, EPF held a **four-day virtual event that explored the digital transformation of healthcare** and reflected on our engagement in EU policies focusing on digital health, and the experience of the COVID-19 pandemic. The objective of the event is to put the spotlight on policy-making

initiatives, connecting meaningful patient involvement to one of the headlines priorities of the European Commission – the EU data strategy and European Health Data Space and initiatives on artificial intelligence.

2021 EPF Congress



**SOCIAL MEDIA STATISTICS**

#3 TWITTER TRENDING TOPIC IN BELGIUM

4.6 MILLION POST IMPRESSIONS ON TWITTER

350K VIEWS ON VIDEOS

The Congress saw the attendance of over **450 participants**, including patient advocates, healthcare professionals, health NGOs, academics, members from industry and national institutions, that during the four days of the event participated in a lively discussion around the topics of the digital transformation of healthcare, the EU data strategy and European

Health Data Space and initiatives on artificial intelligence, and the experience of the COVID-19 pandemic.

**High-level speakers** included **Hans Kluge** (WHO Europe Regional Director), **Dipak Kalra** (President of The European Institute for Innovation through Health Data), **Tessa Richards** (Senior Editor at the BMJ), **Anca Petre**, (CEO of 23 Consulting), **Signe Ratso**, (European Commission DG RTD Deputy DG for Open Innovation), **Jan-Philipp Beck** (CEO of EIT Health), among many others.



The rich and dynamic discourse and exchange of ideas inspired by the EPF Congress 2021 generated a lot of groundwork around the theme of patient-driven digital solutions, and EPF will make sure to implement these key outcomes in our work over the next months, including with a **new edition of the EPF Congress coming in 2022**.

## Policy & Advocacy

The year 2021 was characterised by the far-reaching impact of the ongoing COVID-19 pandemic on societies, healthcare systems, patients and patients’ communities, but also on the European health and social policy environment. EPF proactively engaged with our members, stakeholders and policymakers to channel the patients’ voice into policy and legislative developments, reflecting the immediate needs of the pandemic response and the importance of strengthening our health systems.

### Shaping the future of EU health policy

Launched jointly by EPF and EPHA, the **EU4Health Civil Society Alliance** brings together organisations that share the vision of a Europe where all people are as healthy as they can be throughout their lives. Since 2017, the



alliance campaigned vigorously for a strong EU health policy and an ambitious EU health programme. Following the adoption of the new programme in 2021, called EU4Health, the alliance welcomed the programme but noted that **operating grants for health NGOs** were removed. The alliance mounted a campaign for their reintroduction, with the support of more than 20 health NGOs including several EPF member organisations, and 56 Members of the European Parliament.



In October, EU Health Commissioner Stella Kyriakides confirmed the reinstatement of operating grants under the EU4Health Work Programme 2022, with increased funding. EPF will continue the dialogue with the Commission with the aim of securing a longer-term solution with more favourable eligibility criteria.

In early 2021, EPF responded to a public consultation on the role of the new EU health “agency” set up as part of the “European Health Union” legislative package: the **Health Emergency Preparedness and Response Authority (HERA)**. In September, EPF and EPHA issued a joint statement stressing that HERA should serve the needs of patients and prioritise public health objectives.

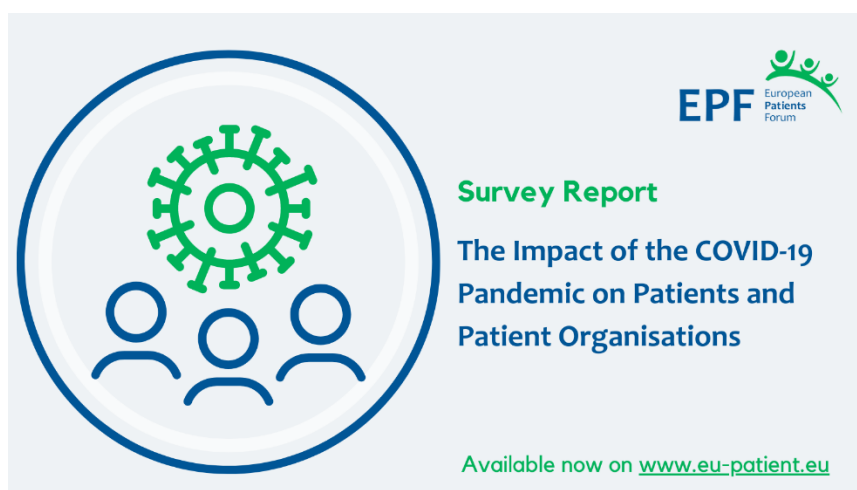


Following the presentation of the **EU's Beating Cancer Plan** by the European Commission in February 2021, EPF issued a statement calling for a plan that works for patients and can lead to benefits for patients with other chronic diseases. We welcomed the overall approach and called for further action on redressing inequalities on access to treatment, better opportunities for cross-border treatment including access to clinical trials across borders, and recognition of health literacy as a vital patient empowerment dimension not only in prevention but across the patient journey.

EPF's strong collaboration with the **European Medicines Agency** continued. EPF President Marco Greco currently represents patients on the Management Board of the EMA. EPF continues to participate actively in the Patient and Consumer Working Party, and contributed to activities around the revision of the ICH guidance on clinical trials, big data, and artificial intelligence. In July, EPF participated in the first joint meeting of the PCWP and the US FDA's Patient Engagement Collaborative to exchange ideas and experiences about patient involvement.

## Bringing a patient perspective on responses to the COVID-19 pandemic

In May 2021, EPF published the [results](#) of its **survey on the impact of the COVID-19 pandemic** on patients and patient organisations. The survey findings support our advocacy activities relating to COVID-19, the strengthening of health systems and the digital transformation of healthcare. A second edition is planned in 2022 to capture longer-term impacts on patient organisations.



EPF organised, in collaboration with the EMA, a series of virtual meetings under the title "Shot Callers," in January and June, giving patient representatives an opportunity to ask questions regarding COVID-19 and the development of vaccines.

Since October 2020 EPF continued to be represented as civil society member in the EMA's **COVID-19 task force (ETF)**. The task force supported the scientific evaluation and marketing authorisation of new vaccines and therapeutics for the prevention and treatment of COVID-19.

## Monitoring and supporting the implementation of EU legislation on medical devices and clinical trials

In 2020, the European Commission decided to postpone the application of the **Medical Devices Regulation (MDR)** until 27 April 2021. Throughout 2021, EPF monitored and disseminated information to its members on the state of play of the MDR. We also monitored the implementation of the Regulation through participation in the Medical Device Coordination Group (MDCG) sub-groups on clinical studies and post-market vigilance. Similarly, EPF has closely followed and informed members of delays in the implementation of the **In Vitro Diagnostic Medical Devices Regulation (IVDR)**. In December 2021, EU institutions agreed on the progressive roll-out of the IVDR to prevent supply disruptions. The transition period depends on the type of device, with higher-risk devices delayed until 2025-2026 and lower-risk devices until 2027.

EPF also continued to monitor the implementation of the **EU Clinical Trials Regulation** and informed members accordingly. The Regulation entered into force in 2014, but was applied from 22 January 2022, after a delay of almost six years. EPF's work in 2021 has focused on collaboration regarding the preparation of lay summaries of clinical trial results – a key requirement under the CTR – with a focus on patient involvement.

## Promoting patient involvement in research and professional education

In early 2021, EPF conducted an online survey on **patient involvement in continuing professional education**, which collected 89 responses from individual patients, patient advocates or family members and patients' organisations. Results were published in the first part of 2022 and will serve as a basis for further dialogue with healthcare professionals' organisations regarding future actions.

In parallel, EPF engaged with academic stakeholders on patient involvement in research.

## Advocating for meaningful involvement of patients in shaping the future of digital health

Following an [information webinar](#) jointly organised with the European Commission on 21 May and internal consultation with its members, EPF submitted its [public consultation response](#) and [accompanying position statement](#) to the upcoming European Health Data Space (EHDS) proposal on 26 July. This initiative has the potential to have positive impacts on digital health and ultimately improve the lives of patients, but only if it is shaped and implemented with patients at the centre. EPF conveyed its key messages on the EHDS at several

webinars and interinstitutional meetings. In November, the 2021 EPF Congress delved into the digital transformation of healthcare and provided EPF with additional insights on the EHDS debate.

In August, EPF submitted a [response](#) to the European Commission feedback consultation on artificial intelligence (AI) ethical and legal requirements. Building on its previous work and the support of the Network of European Foundations (NEF) European AI Fund, EPF has engaged in extensive work on the topic, through policy input and capacity-building. A position statement on AI is due in 2022 following further member engagement at the 2021 and 2022 EPF Congress.

The EPF Working Group on Digital Health met virtually in June, with the agenda focused on discussion of EPF's position on the planned European Health Data Space. The group was also actively engaged in shaping the programme of the EPF Congress 2022, which replaced the regular autumn meeting. In view of these intensive working engagements, the planned revision of the group's membership and terms of reference was postponed to 2022.

## Access to healthcare, including medicines, patient safety and quality of care

In 2021 EPF engaged actively in follow-up advocacy on the Commission's **Pharmaceutical Strategy for Europe**, adopted in November 2020. In April 2021, EPF proposed amendments on the European Parliament's draft report on the Pharmaceutical Strategy, based on [our priorities](#) and [previous position statements](#). The [final report](#), adopted in plenary in November, includes several of EPF's amendments.

As part of the implementation of the Strategy, the European Commission is currently evaluating the EU's **general pharmaceutical legislation** and assessing the impacts of possible changes. In December 2021, EPF responded to the public consultation launched for this purpose, setting out our priorities. The Pharmaceutical Strategy also included **an extension of the mandates of the EMA and the ECDC**. In January, EPF responded to the [European Commission's public consultation on a strengthened role for the agency](#). In October, the EU institutions reached an agreement on the EMA's role, which includes new structures for monitoring and mitigating shortages, and more rapid approval of therapies in public health crises. EPF also contributed to the [European Commission's public consultation on a reinforced mandate of the ECDC](#), highlighting the need to include chronic diseases. Final agreement by the EU institutions on this is expected in 2022. In parallel to the EU legislative review, we also participated in the WHO Regional Office for Europe's consultation on access to medicines.

In a wider context, we continued our work on **access to healthcare**. EPF participated in a meeting organised by the Commission to discuss methods of collecting data on patients' access barriers and give feedback on certain proposed new methods. The EPF Universal Access Working Group met virtually in April to discuss ongoing work. Due to ongoing pandemic restrictions, the revision of the group's membership and terms of reference has been postponed to 2022.

In January 2021, the European Commission undertook an evaluation of the functioning of **the Cross-Border Healthcare Directive**. Based on our extensive previous work on this topic and after further consultation with the

membership, EPF [provided input](#) to the public consultation in February. We also participated in evaluation meetings and organised a webinar jointly with the Commission for our membership in March. The Commission published its evaluation report in February 2022.

EPF continued to collaborate with **the Organisation for Economic Co-operation and Development (OECD)** by participating in the [OECD PaRIS project's](#) International Patient Advisory Board and attending the virtual meetings of the OECD Healthcare Quality and Outcomes working group. EPF also actively contributed to a working group on patient-reported incidence measures in patient safety.



In the context of declining vaccination coverage, the spread of hesitancy and the re-emergence of vaccine-preventable diseases in some parts of Europe, EPF continued to be actively involved in advocating for the importance of **vaccination for patients with chronic conditions**. In January, EPF launched the guide titled [“Let’s Talk About Vaccination”](#), co-developed with patient advocates, to fill awareness and information gaps and support the vaccination advocacy efforts of patient organisations. In July, EPF issued a [statement on the importance of vaccination of healthcare professionals for patients](#). In parallel, the EPF-led tender project “VAC-PACT” was finalised in October.

In the area of **patient safety**, in 2021 we focused on disseminating information on **antimicrobial resistance (AMR)** to our members. We also endorsed a [joint statement with 18 other organisations](#) on the importance of tackling AMR within the new Pharmaceutical Strategy for Europe.

On **nutrition**, EPF continued our collaboration with the [European Society for Clinical Nutrition and Metabolism \(ESPEN\)](#), promoting the development and dissemination of lay-language nutritional guidelines for patients living with chronic diseases. We also set the ground for further work on good practices to involve patients in nutritional guideline development. In September, EPF co-signed a [letter with three other health NGOs](#) to reiterate the importance of a mandatory harmonised and understandable EU front-of-pack nutrition labelling system.

## Projects



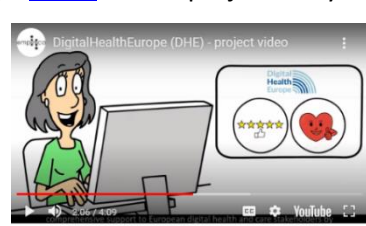
In 2020, EPF developed a strategic approach to its involvement in European projects and a plan for membership engagement. In 2021, this plan took shape – our member, the [European AIDS Treatment Group \(EATG\)](#), has been working in partnership with EPF on two IMI-projects: EU-PEARL and EATRIS-PLUS as a linked third-party. EATG has worked closely with EPF in the patient engagement activities and has been responsible for coordinating the Patient Advisory Group within EU Pearl, and the Patient Advisory Committee in EATRIS-PLUS.



### DIGITALHEALTHEUROPE

[DigitalHealthEurope](#) came to an end in September 2021. The project results were well received by both wider public and external evaluators. As [co-leader of the work](#) on establishing and managing a collaboration panel between citizens and patients, and healthcare providers, EPF is particularly proud of the key achievements that will further inform our work in Digital Health. At the final conference on 28-30 September 2021, [EPF led a session](#) on Patient Centred Health and Care, where participants shared the youth perspective, developer and patient organisation view on the full uptake to digital health solutions.

DigitalHealthEurope provided comprehensive, centralised support to the digital transformation of health and care priorities of the Digital Single Market. The project aimed to support the large-scale deployment of digital solutions for person-centred integrated care by identifying, analysing, and facilitating the replication of highly impactful best practices. EPF's key achievements for the project include:

<p>Developing a <a href="#">Patient Empowerment Roadmap</a> to outline the road to better collaboration with healthcare professionals and the health systems towards better uptake of digital health in Europe.</p> 	<p>Writing a <a href="#">White Paper on boosting active cooperation between patients and healthcare professionals</a>, formally outlining our recommendations.</p> 
<p>Producing a <a href="#">video</a> on the project's key achievements</p> 	





## COMPAR-EU

[COMPAR-EU](#) aims to identify, compare, and rank the most (cost) effective self-management interventions for adults in Europe living with one of the four high-priority chronic conditions. In 2021, EPF's continued the lay language "translation" of key deliverables that focus on cost-effectiveness and contextual factors of self-management interventions.

EPF also continues to coordinate a Patient Panel of 14 patients and patient representatives who provide their views on key aspects of the Project and are advocates for the four disease areas of the Project. To guarantee that patients are meaningfully involved in the project, EPF has hosted 7 webinars and 2 workshops with the patient representatives – meetings that contributed to the validation of the project outcomes, co-design and patient centricity. Some key topics discussed during these events were: reimbursement of drugs; relationship with healthcare professionals; differences among healthcare systems across Europe.

COMPAR-EU will end in December 2022.



## CORE-MD

Coordinating Research and Evidence  
for Medical Devices

## CORE-MD

[CORE-MD](#) is a new project which began in 2021. It is the first formalised group of stakeholders in Europe working together to identify ways to enable the scientific, fair, and systematic evaluation of medical devices. EPF has also reviewed and edited the first project publication, published in the *European Heart Journal - Quality of Care and Clinical Outcomes*.



## Data Saves Lives

## DATA SAVES LIVES

[Data Saves Lives](#) is a multi-stakeholder initiative, led by EPF, aimed at raising patient/public awareness about the importance of health data, improving the understanding of how it is used and establishing a trusted environment to discuss responsible use and good practices across Europe. In 2021, [Data Saves Lives](#) held "[The tweet chat](#)" focused on the work of #datasaveslives hashtag and power of social media in our campaign. Crucially, DSL also launched the [first version of its toolkit](#) in a dedicated session at the EPF Congress. The toolkit is created to equip patient groups and health influencers with the materials they need to have a positive dialogue with their communities about health data and to potentially launch their own health data initiatives.



## EATRIS-PLUS

A project led by [EATRIS](#), EATRIS-PLUS contributes to effectively shape the operational processes of translational medicine and advances in personalised medicine in Europe. In 2021, EPF invested our capacity in initiating the EATRIS-PLUS network to the concept of

Patient Engagement in Research. This effort resulted in the organisation of a satellite session at the [EATRIS-PLUS summer school](#), with its insights being published online. We also prepared and conducted workshops for EATRIS national nodes examining their specific needs and situations. The Patient Advisory Committee contributed with testimonials on the value of Patient Engagement.



## EU-PEARL

[EU-PEARL](#) aims to make clinical trials more efficient and patient friendly, by standardising and simplifying trial platforms to make it easier to enrol enough patients. In 2021, EPF facilitated several meetings with the Patient Advisory Group (PAG) to advance on the Patient Engagement Platform (PEP) and secure Patient Engagement across all part of the project.

A project-wide event, labelled ‘Patient Engagement Day,’ was successfully conducted in November 2021. This event, will become a regular part of the EU-PEARL schedule to increase PE across the project. An external presentation at the [Patient Engagement Open Forum on PE in platform trials](#) took place in December 2021, and the session materials and recordings are now available online.



## EHDEN

[EHDEN](#) aims to respond to the current challenges in generating insights and evidence from real-world clinical data at scale. In 2021, EPF launched its [first EHDEN course](#) for non-expert users as part of its EHDEN Academy course offering. The course is designed to equip non-expert readers with the tools and knowledge to understand the concepts of health data, federated networks, and data privacy. EPF hosted 3 podcasts in the series on “All About EHDEN” on the topics of [Real World Data and Real World Evidence](#), [Federated Networks](#), and the [launch of the academy course](#). Additionally, we drafted a [guest blog](#) on the role of patients in RWE/RWD on the EHDEN website and were guests in the Voice of [EHDEN podcast](#) on patient involvement with Open Science.



## GRAVITATE HEALTH

Gravitate Health aims to equip and empower citizens with digital information tools that empower them in their patient journey, and encourage the safe use of medicines to reduce risks, and improve health outcomes and quality of life. In 2021, the Gravitate Health [User Advisory Group](#) focused its trainings on deep-dive online workshops (2 workshops already) about the Gravitate lens (G-lens) wireframes, personas and scenario mapping. The G-lens platform focuses (but does not conceal or filter) on approved electronic product information (ePI) content, and offers a route for patients to access trustworthy, up-to-date information that better meet their individual needs.

The Group has a dedicated section on the GH website with the pictures and bios of members. In late 2021, EPF opened a [“second call for interest”](#) to recruit new members to the User Advisory Group.



## HEALTH OUTCOMES OBSERVATORY (H2O)

The Health Outcomes Observatory (H2O) project will aim to set-up patient-centric pan-European and national observatories to amplify the patient voice in their own healthcare and in healthcare systems. In H2O, EPF brings the patient perspective across the project. In order to do so, EPF has [established three Patient Advisory Boards \(PABs\)](#), and held two workshops for each disease area (diabetes, IBD & oncology) throughout the year. The three PABs are comprised of representatives of the three disease areas and their experience and expertise are embedded into the project processes and outcomes. EPF Secretariat attended the Steering Committee Face-To-Face Meeting in Vienna in November 2021 as an opportunity to advocate for patient engagement in different workstreams and make impactful contribution to the project.



## IMMUCAN

IMMUCan aims to study the tumour microenvironment in a bid to gain a deeper understanding of how the immune system and cancer cells interact at the molecular level. In 2021, EPF focused on improving IMMUCan's visibility across the project media channels and website. IMMUCan channels improved their performance in terms of followers and impressions, with the launch of several [awareness day campaigns](#) coinciding with the project's main indications.



## PERISCOPE

[PERISCOPE](#) investigates the broad socio-economic and behavioural impacts of COVID-19, to make Europe more resilient and prepared for future large-scale risk. In 2021, EPF hosted the inaugural season of the [#PERISCOPEMonthlyTalks](#) mini-series on our [podcast network](#). The objective of the podcast is to provide an accessible platform to translate the project efforts to a general audience in lay-language. Over 8 episodes, we hosted researchers, scientists, and project partners to discuss their initiatives during the ongoing pandemic and provide evidence to prevent future large-scale risks. The podcast was downloaded over 350 times and listened to by an average of 42 listeners per episode.



## PERMIT

[PERMIT](#) aims to improve personalised medicines research by establishing recommendations, developed over a series of workshops held with experts. EPF, together with project partners, held a virtual workshop on Ethics in Clinical Trials on 19 November 2021. The workshop gathered patient representatives, healthcare professionals, and academics to discuss the topic of

ethics in Personalised Medicine – the outcomes of this discussion will inform the project report on the final ethical recommendations.

PERMIT will end in June 2022.



**PharmaLedger**  
BLOCKCHAIN ENABLED HEALTHCARE

## PHARMALEDGER

PharmaLedger aims to drive the early-adoption of blockchain-based technology to build a complete solution for improving the quality of healthcare and explore how blockchain technology can help tackle real-world health challenges. In 2021, EPF recruited [8 patients and 2 coordinators](#) that will work on the project collaboration platform, which will provide knowledge and understanding of the role and benefits of blockchain in healthcare. A scoping exercise was held to investigate where and how PE can be implemented. Patient Advisors received training in using the collaboration platform to increase cooperation across working groups.

EPF contributed to design and co-organised [two webinars](#) on the e-product information stream. Some aspects outside the scope of PharmaLedger which were raised by patients, were presented at a [PEOF interactive session](#) to raise awareness and reach out to relevant stakeholders.



## PREFER

The [PREFER project](#) aims to assess when and how patient preferences on benefits and risks should be incorporated into decisions on medicinal products. With the project coming to an end in May 2022, in 2021 EPF contributed to the review of several deliverables and joined an editorial committee in charge for wrapping up PREFER set of recommendations.



## PEOF

A legacy from the IMI project [PARADIGM](#), the [Patient Engagement Open Forum](#) is a joint initiative from EPF, Patient Focused Medicine Development (PFMD) and the EUPATI Foundation. PEOF aims to collaborate in a multi-stakeholder context, to turn patient engagement into reality. The Forum provides a holistic perspective of patient engagement, the landscape and actors, and fosters collaboration and co-creation while breaking down fragmentation that are often present in patient engagement work. In 2021 the initiative was able to run 16 online sessions on different aspects of Patient Engagement including Digital Health, Youth and Paediatric, Platform Trials, just to name a few topics.

## Capacity Building Programme



The Capacity Building Programme was launched in 2012 as a response to the needs and concerns identified by our members during various EPF activities. As such, it supports patient organisations in strengthening their role as equal players in the healthcare environment.

### The Capacity Building Module on Fundraising and Engagement

In 2021, EPF had the pleasure of accepting **24 participants representing 26 patient organisations from a variety of countries across Europe** for the CB Fundraising and Engagement Module.

The participants had the opportunity to attend 6 thematic webinars: 3 dedicated to fundraising and 3 dedicated to engagement. After the first phase participants selected a specific project they wanted to work on and joined online coaching group sessions with a dedicated trainer. Towards the end of the module, participants had the opportunity to share their learning journey and best practices with others.

Within this module EPF had the opportunity to organize an **Alumni webinar**. The main objective of this online event was to provide opportunity for **participants of previous capacity building modules to reconnect**. The event focussed on exchanging good practice and experience on topic of interest, mapping steps for future collaboration and peer learning.

Following the module, according to the feedback forms, most of the participants felt more confident and resourceful in their fundraising roles. Some interesting statistics include:

<p><b>100%</b> of the respondents in the final evaluation survey report high numbers as their level of experience in fundraising after the program (7+, in a scale from 1 to 10).</p>	<p><b>85,6 %</b> of the participants declare to <b>feel considerably more confident about their fundraising skills (8+, in a scale from 1 to 10).</b></p>
<p><b>100%</b> of respondents declare they have <b>improved their level of experience in conducting engagement activities as a result of the learning journey (7+, in a scale from 1 to 10).</b></p>	<p><b>78.5%</b> have declared <b>feeling more confident about their engagement skills (8+, in a scale from 1 to 10).</b></p>

Overall, the participants enhanced their fundraising and engagement knowledge and increased cooperation between patient organisations across the participating countries, as well as developed new skills, while working on their individual projects.

## Understanding AI Webinar Series

Following EPF’s successful application for the [NEF European 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 particularly focus on the possible advantages but also risks and pending questions for patients, while exploring specific implications for the healthcare sector.



In 2021 EPF broadcasted two webinars:

- [“AI in Healthcare: From Science Fiction to Reality”](#) focusing on the concept of AI in healthcare and presenting an overview of the NEF European AI Fund.
- [EPF #AI in Healthcare: Ethics and Implications](#) focusing on the ethical challenges that the deployment of artificial intelligence in healthcare is bringing.

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.

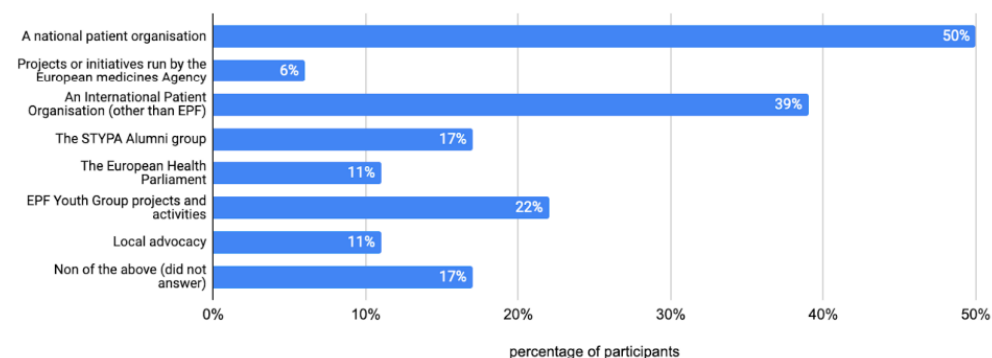
## The Summer Training Course for Young Patient Advocates (5th edition)



This year EPF conducted the second fully virtual [STYPA](#) with 33 **young patient advocates accepted, from a variety of different European countries, representing different disease communities** (many of them living with multiple conditions). The purpose of the training is to support young patient advocates through a high-quality tailored course, while maximizing their leadership potential in real environment settings.

STYPA 2021 allowed the participants the opportunity to participate in a combined training, consisting of two phases. **In the first phase the participants work on a designated online platform, while participating in whole group online hangouts. During the second phase the participants go through a peer led coaching, while**

Which of the following things have you become more involved in as a result of STYPA?  
(n=18)



**tackling team challenges and applying their new learnings by completing real world advocacy tasks.** The young patients were able to attend various online events, such as whole group webinars, team leaders' meetings, team hangouts, while being constantly in touch

through the dedicated WhatsApp groups and the having the ability for individual support by the trainers and EPF staff.

Overall, STYPA 2021 has been another successful edition with great feedback from participants.

### Some of the things learnt during STYPA that participants found most valuable.

*I learned that people in STYPA faces nearly the same issues and they are very dedicated to become advocates. Will a lot of work, emotional help and determination we can make a lot of progress.*

*How to approach the patients with right attitude and questions*

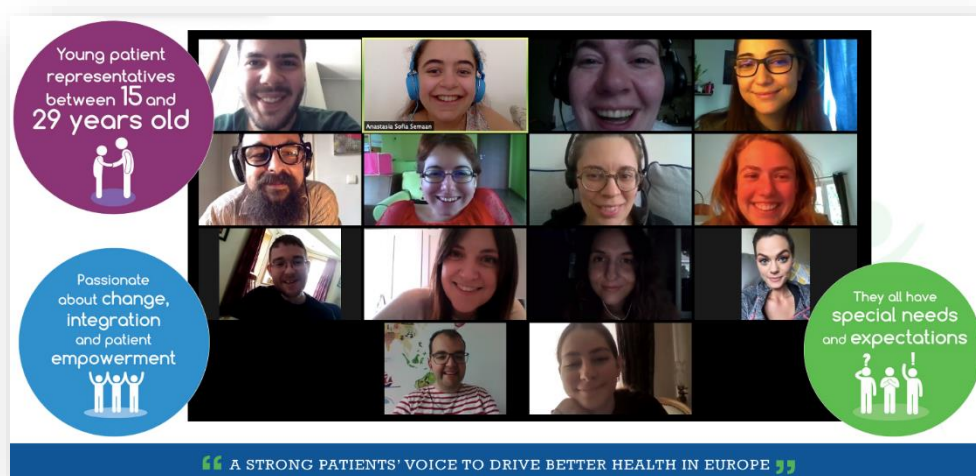
*Go with my fears, do not let them stop me. Failure is part of the process- kind of a success and do not take it personally, steps by steps method is good enough*

*That it is okay to be uncertain and to change course*

*I made friends at first, then I empower my advocacy skills to become a better version of my self like a human being, patient and patient advocate.*

## Youth Group

The Youth Group (YG) has been an active part of EPF for years and didn't fail to deliver young patient centred content in 2021. Some of their key achievements this year include:



- Launching [the Sexual Health and Well-Being Project](#). In 2021 the EPF Youth Group (YG) reached out to the wider young patient community, through a survey, asking them what the key topics are, concerning their sexual health and well-being that they would like to know more about and how they would like to see that information presented.





In the table below we can see the comparison of the top voted topics by young people both with and without a chronic condition.

No.	Topic related to sexual health and well-being	With chronic condition	Without chronic condition
1	Mental Health (body confidence, self-esteem issues)	72.68%	77.22%
2	Relationships/Communication with your partner (or potential partners)	63.4%	73.42%
3	The effect of your health condition and/or treatment on sexual functioning (Medicinal side effect that may impact sexual health)	44.33%	40.51%

Following a great success of the survey with more than 300 answers, the YG has since:

- Published [an article](#), interviewing Mrs. Moira Tzitzika a psychologist and psychosexologist certified from the European Society of Sexual Medicine. As chronic illness can have many negative effects on a relationship and sexual satisfaction of both patients and partners, the article proved to be of great interest to the young patient community.
- Published a [podcast episode](#) dedicated to the project.
- Launched 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. The survey is still collecting responses.
- Executed the **Spring and Fall Youth Group Meetings**, online, where all the YG members gather to discuss and advance on their focus topics and plan future projects.
- Elected a new youth representative for the EPF Board position at the 2021 AGM. Erin Davies will ensure the Youth Group voice is heard in all key matters until 2023.
- **Tailored training for all members of the EPF Youth Group.** The EPF Staff has so far held policy and social media trainings for the young patient advocates, which were recorded and will be used for future references. The trainings will continue with more topics including projects, funding, and other relevant topics. EPF YG also participated in a training on project management dedicated to further shape the sexual health and wellbeing project.

## Communications

In 2021, EPF’s Communications continued to provide organisational support to the three main pillars of the organisation while providing consistent branding and messaging across all our channels.

# SOCIAL MEDIA STATISTICS

2021

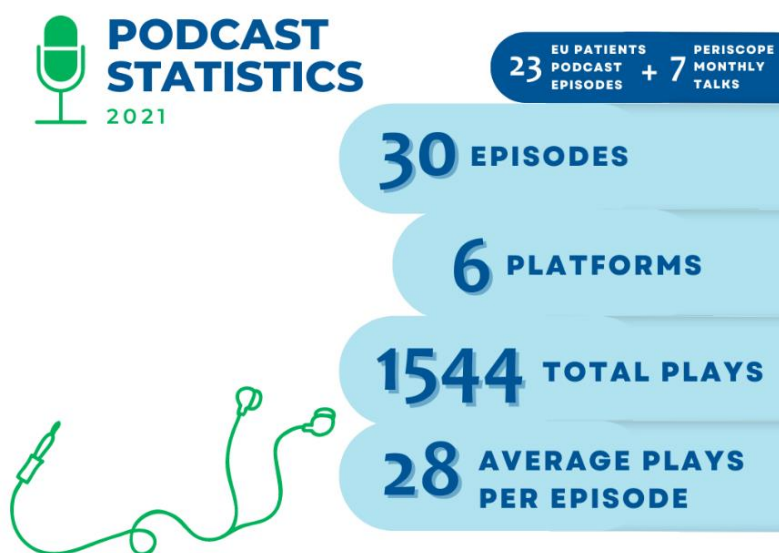


To promote all EPF activities to a wider audience, we continued our effort to promote EPF’s and its members’ activities, using a lay language voice on the social media channels of **Facebook**, **Twitter**, and **LinkedIn**.

With the release and authorisation of several COVID-19 vaccines during the first months of 2021, EPF decided to use its expertise and leverage its network to host an informative session with high-level experts to provide crucial answers regarding the vaccines for COVID-19 vaccines. The event “**Shot Callers: A Virtual Event on COVID-19 Vaccines**” was held on 28 January 2021, featuring EPF President Marco Greco, Prof. Jean-Michel Dogne, Committee Member of WHO Global Advisory Board on Vaccine Safety and Dr Guido Rasi, former

Executive Director of European Medicines Agency (EMA). The discussion was moderated by EPF Special Advisor Nicola Bedlington. This event was followed by a second edition on 16 June 2021 to tackle some of the questions on the European vaccination campaign, COVID-19 variants and vaccine misinformation.

From the conversation sparked during the event, we collected the most relevant answers from our speakers in a video, shared on our social media channel and available on our YouTube channel as well.



In 2021 released 23 new episodes of the **EU Patients' Podcast**, plus 7 episodes of the Periscope Monthly Talk, focused on the Periscope project. Firstly, launched in December 2020, the podcast has the objective to feature our members, policymakers, and key stakeholders in conversation with the EPF Secretariat on various issues relating to patient advocacy and empowerment.

This podcast provides another important avenue for the patient voice to be heard.

## List of EPF Members (as of 31 December 2021)

### Full Members (58)

1. **Alzheimer Europe** (Europe)
2. **AOECS** - Association of European Coeliac Societies (Europe)
3. **AOPP** - Association for the Protection of Patients' Rights (Slovak Republic)
4. **BAG Selbsthilfe** - Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (Germany)
5. **BEMOSZ** - Hungarian Alliance of Patients' Organisations (Hungary)
6. **CF Europe**- Cystic Fibrosis Europe (Europe)
7. **COPAC** - Coalition of Patients' Organizations with Chronic Diseases (Romania)
8. **DE** – Dystonia Europe (Europe)
9. **DiCE** - Digestive Cancers Europe (Europe)
10. **EAMDA** - European Alliance of neuro-Muscular Disorders Association (Europe)
11. **EATG** - European Aids Treatment Group (Europe)
12. **ECHDO** - European Congenital Heart Disease Organisation (Europe)
13. **EFA** - European Federation of Allergy and Airways Diseases Patients' Associations (Europe)
14. **EFAPH** - European Federation of Associations of Patients with Haemochromatosis (Europe)
15. **EFCCA** - European Federation of Crohn's and Ulcerative Colitis Associations (Europe)
16. **EFHPA** - European Federation of Homeopathic Patients' Associations (Europe)
17. **EGAN** - Patients Network for Medical Research and Health (Europe)
18. **EHC** - European Haemophilia Consortium (Europe)
19. **EHLTF** - European Heart and Lung Transplant Federation (Europe)
20. **EKPF** - European Kidney Patients' Federation (Europe)
21. **ELPA** - European Liver Patients Organization (Europe)
22. **EMHA** - European Migraine and Headache Alliance (Europe)
23. **EMSP** - European Multiple Sclerosis Platform (Europe)
24. **ENUSP** - European Network of (ex)Users and Survivors of Psychiatry (Europe)
25. **EPDA** - European Parkinson's Disease Association (Europe)
26. **EPIK** - Estonian Chamber of Disabled People (Estonia)
27. **EUFAMI** - European Federation of Associations of Families of People with Mental Illness
28. **EUROPA DONNA** - The European Breast Cancer Coalition (Europe)
29. **EUROPA UOMO** – The voice of Men with Prostate Cancer in Europe
30. **EUROPSO** - European Umbrella Organisation for Psoriasis Movements (Europe)
31. **EURORDIS** - European Organisation for Rare Diseases (Europe)
32. **FE** - Fertility Europe (Europe)
33. **FEP** - Spanish Patients' Forum (Spain)
34. **FESCA** - Federation of European Scleroderma Associations (Europe)
35. **FPP** - Federation of Polish Patients (Poland)
36. **GAMIAN Europe** - Global Alliance of Mental Illness Advocacy Networks (Europe)
37. **Global Heart Hub** – The Alliance of Heart Patient Organisations
38. **GPA** - Greek Patients Association (Greece)
39. **IDF Europe** - International Diabetes Federation (Europe)

40. **IF** – International Federation for Spina Bifida and Hydrocephalus (International\*)
41. **IOF** - International Osteoporosis Federation (International\*)
42. **IPOPI** - International Patient Organisation for Primary Immunodeficiencies (International\*)
43. **KUZ** - Coalition of Associations in Healthcare (Croatia)
44. **KZZ** - Confederation Health Protections (Bulgaria)
45. **LPOAT** - Council of Representatives of Patients' organizations of Lithuania (Lithuania)
46. **LuCE**- Lung Cancer Europe (Europe)
47. **LUPUS Europe** (Europe)
48. **MHN** - Malta Health Network (Malta)
49. **National Voices** (United Kingdom)
50. **NCDP** - National Confederation of Disabled People (Greece)
51. **NPO** - National Patients' Organisation of Bulgaria (Bulgaria)
52. **Pancyprian Federation of Patients Associations and Friends** (Cyprus)
53. **PHA Europe** - Pulmonary Hypertension Association Europe (Europe)
54. **Plataforma de Organizaciones de Pacientes** (Spain)
55. **Retina International** (Europe)
56. **SUSTENTO** The Latvian Umbrella Body for Disability Organization (Latvia)
57. **Swedish Disability Rights Federation** (Sweden)
58. **WDO** - World Duchenne Organisation (International\*)

## Associate Members (17)

59. **AGORA** - (Southern Europe)
60. **AMRC** - Association of Medical Research Charities (United Kingdom)
61. **BAPD** - Bulgarian Association for Patients Defence (Bulgaria)
62. **Debra International** - Organisation of people with Epidermolysis Bullosa (Europe)
63. **ECO** - European Cleft Association (Europe)
64. **EFNA** - European Federation of Neurological Associations (Europe)
65. **EIWH** - European Institute of Women's Health (Europe)
66. **ENFA** - European Network of Fibromyalgia Associations (Europe)
67. **FH Europe** – The Familial Hypercholesterolaemia Network
68. **Global Skin** – The International Alliance of Dermatology Patient Organisations
69. **Health Research Charities Ireland** (Ireland)
70. **IBE** – International Bureau for Epilepsy (International\*)
71. **MHE-SME** - Mental Health Europe (Europe)
72. **Netherlands' Patients Federation** (The Netherlands)
73. **SAFE**-Stroke Alliance for Europe (Europe)
74. **The ALLIANCE** - Health and Social Care Alliance Scotland (Scotland)
75. **VPP** - Flemish Patients' Platform (Belgium)
76. **WFIP** - World Federation of Incontinent Patients (International\*)

## Provisional Members (3)

77. **APO** – Alliance of Patient Organisations (FYROM)
78. **SOSTE** - Finnish Federation for Social Affairs and Health
79. **WAPO** - World Alliance of Pituitary Organizations

*\* International organisations who do not have a formally constituted branch in Europe but are active in the European region may become Full members.*

## Governance & Secretariat

### EPF Board Members

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. In 2021, the Youth Group nominates a representative as a Board member. We would like to sincerely thank Hilikka Karkkainen and Jana Popova for their service to our Board during the last years.

In 2021, the EPF Board Members were:

- **President** - Marco Greco
- **Vice President** - Brian West (European AIDS Treatment Group)
- **Treasurer** - Radu Costin Ganescu (COPAC)
  
- Dimitrios Athanasiou (World Duchenne Organisation) **\*NEW\***
- Marzena Nelken (Federation of Polish Patients)
- Michal Rataj (European Alliance of Neuromuscular Disorders Associations)
- Erin Davies (EPF Youth Group) **\*NEW\***
- Manuel Arellano (Plataforma de Organizaciones de Patientes) **\*NEW\***

### Ethics Committee

In 2021, the **Ethics Committee** continued to fulfil its role and functions. The role of the Ethics Committee members includes issuing opinions or advice upon written request from the Board; recommending appropriate handling of conflict of interests and providing general advice on wider ethical issues that EPF needs to address, in the context of legislation or practice.

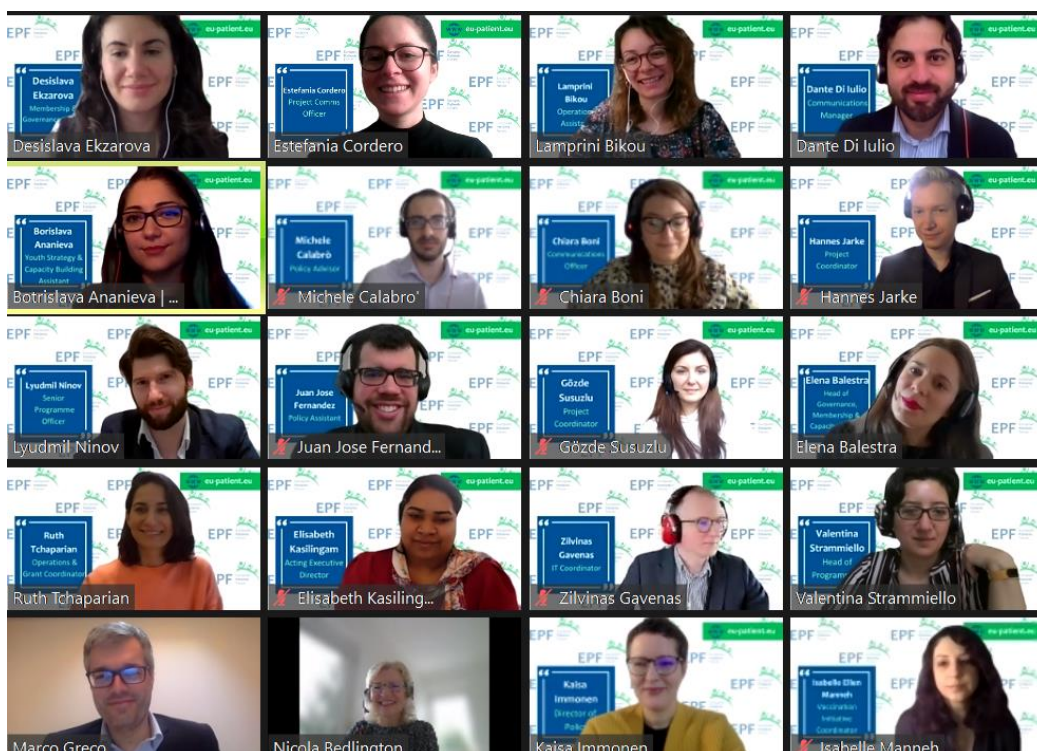
**The officials of the EPF Ethics Committee are:**

- Amanda Bok (European Haemophilia Consortium),
- Anita Arsovska (Stroke Alliance for Europe),
- Birgit Dembski (BAG Selbsthilfe),
- Stella de Sabata (International Diabetes Federation European Region)
- Mateja Krzan (European Network of Fibromyalgia Associations)

## Secretariat

In 2021, EPF said goodbye and good luck to Brendan Togher, Desislava Ekzarova, Isabelle Ellen Manneh...

...and welcomed Chiara Boni, Eric Moris, Hannes Jarke, Ingrid Weindorfer, Juan Jose Fernandez Romero, Julie Spony, and Martina Continisio.



*(Our team during the 2021 AGM)*

## The EPF Secretariat as of 31 December 2021:

- **Borislava Ananieva** - Youth Strategy and Capacity Building Assistant
- **Chiara Boni** – Communications Officer
- **Dante Di Iulio** - Communications Manager
- **Elena Balestra** - Head of Governance, Membership and Capacity Building
- **Elisabeth Kasilingam** - Acting Executive Director
- **Eric Moris** – Director of Operations
- **Estefania Guzman Cordero** - Project Communications Officer
- **Gözde Susuzlu Briggs** - Project Coordinator
- **Hannes Jarke** - Project Coordinator
- **Ingrid Weindorfer** – Project Assistant
- **Juan Jose Fernandez Romero** – Policy Officer
- **Julie Spony** – Policy Assistant
- **Kaisa Immonen** - Director of Policy
- **Katie Gallagher** - Senior Policy Advisor
- **Lamprini Bikou** - Operations Assistant
- **Lyudmil Ninov** - Senior Programme Officer
- **Michele Calabrò** - Policy Advisor
- **Nicola Bedlington** - Special Advisor
- **Ruth Tchapanian** - Operations and Grants Coordinator
- **Valentina Strammiello** - Head of Programmes
- **Zilvinas Gavenas** - IT Coordinator



## Financials

### Income and Expenditure as at 31 December 2021

<b>INCOME</b>	<b>2021</b>	<b>2020</b>
<b>Funding from Public Sector</b>	€ 780,689.02	€ 707,179.48
EC projects	€ 780,689.02	€ 707,179.48
<b>Funding from the private sector</b>	€ 1,220,153.92	€ 1,433,980.54
Operation and Engagement	€ 717,000.00	€ 679,450.29
Capacity Building Programme	€ 179,000.00	€ 321,767.70
Co-funding to EPF projects DSL-PEOF +AI	€ 178,776.10	€ 8,049.71
Contribution to EPF Campaigns	€ 0.00	€ 0.00
Contribution CONGRESS	€ 145,377.82	€ 1,387.00
PARADIGM	€ 0.00	€ 109,520.83
EFO EUPATI	€ 0.00	€ 20,000.00
EUPATI Programme	€ 0.00	€ 293,805.01
<b>Membership fees</b>	€ 22,351.43	€ 18,900.00
Contribution to Work Plan (Operations, Capacity Building and project development)	€ 22,351.43	€ 18,900.00
Contribution CONGRESS	€ 0.00	€ 0.00
<b>Interest and other income</b>	€ 9,704.71	€ 53,833.21
<b>TOTAL INCOME</b>	<b>€ 2,032,899.08</b>	<b>€ 2,213,893.23</b>

EXPENDITURES	2021		2020	
Staff Costs (all projects, all campaigns)	€	987,710.15	€	1,322,645.30
Office backstopping and admin costs	€	372,744.02	€	360,412.08
Depreciation	€	22,431.98	€	23,495.25
Travel and subsistence (EPF staff)	€	2,647.81	€	5,364.89
Activities (other direct costs)	€	527,482.47	€	473,321.93
Annual General Meeting & Board Meetings	€	-	€	10,921.18
Summer Training & Youth Group meetings	€	12,502.27	€	18,180.03
Thematic Working Group Meetings/ Initiatives (Data Save Lives - PEOF - AI)	€	116,459.54	€	60,260.18
Capacity Building Programme (delivery of training modules)	€	29,526.13	€	17,521.45
Congress 2019 /2021	€	105,679.94	€	1,387.00
Other costs linked to operations, project portfolio	€	263,314.59	€	365,052.09
Campaigns (direct costs)	€	-	€	-
European Elections	€	-	€	-
Bank and Financial Charges	€	4,400.59	€	291.02
<b>TOTAL EXPENDITURE</b>	€	<b>1,917,417.02</b>	€	<b>2,185,530.47</b>
<b>TOTAL Surplus or deficit of the Year</b>	€	<b>115,482.05</b>	€	<b>28,362.76</b>

## Balance Sheet

ASSETS	2021		2020	
<b>I Current Assets</b>				
Accounts receivable	€	514.695	€	1.082.905
Cash in bank and deposit	€	1.938.605	€	1.647.982
Pre-paid expenses	€	19.737	€	19.479
<b>Total current assets</b>	€	<b>2.473.037</b>	€	<b>2.750.366</b>
<b>II Fixed assets</b>				
Furniture, Fixtures and Fittings	€	45.115	€	46.270
IT equipment and software	€	13.142	€	14.385
Guarantees (rent and social security)	€	50	€	50
<b>Total fixed assets</b>	€	<b>58.307</b>	€	<b>60.704</b>
<b>TOTAL ASSETS</b>	€	<b>2.531.344</b>	€	<b>2.811.070</b>

<b>LIABILITIES</b>		<b>2021</b>	<b>2020</b>
<b>I Current Liabilities</b>			
Accounts payable	€	385,567	€ 142,369
Deferred income	€	939,111	€ 1,563,377
Income to be allocated to project partners	€	-	€ -
<b>Total current liabilities</b>	<b>€</b>	<b>1,324,678</b>	<b>€ 1,705,747</b>
<b>II Reserves</b>			
Funds brought forward	€	791,184	€ 762,821
Social Reserve	€	300,000	€ 300,000
Surplus or deficit for the year	€	115,482	€ 28,363
<b>Total reserves</b>	<b>€</b>	<b>1,206,666</b>	<b>€ 1,091,184</b>
Provisions	€	-	€ 14,139
<b>TOTAL LIABILITIES</b>	<b>€</b>	<b>2,531,344</b>	<b>€ 2,811,070</b>

## Acknowledgment of funds

<b>EPF wishes to thank the European Commission /European Agencies for their support in 2021 in relation to EPF's role in the following projects</b>		
	Public Contribution 2021	% of total income
<b>TOTAL European Commission support to projects 2021</b>	<b>€ 780,689.02</b>	
Core MD	€ 6,691.20	0.3%
ComparEU	€ 55,385.14	2.4%
DigitalHealthEurope	€ 36,348.09	1.6%
EATRIS +	€ 52,343.71	2.3%
EHDEN	€ 26,421.96	1.2%
EU-PEARL	€ 41,723.00	1.8%
Gravitate Health	€ 35,867.48	1.6%
H2O	€ 51,827.53	2.3%
IMMUCAN	€ 14,666.06	0.6%
IMMUNIVERSE	€ 725.93	0.0%
Pharmaledger	€ 37,323.50	1.6%
PERISCOPE	€ 12,035.68	0.5%
PERMIT	€ 10,175.38	0.4%
PREFER	€ 4,654.36	0.2%
VAC-PACT	€ 394,500.02	17.2%

EPF wishes to thank the following donors for their support:		
	Contribution to Operations	% of total income
<b>Operational &amp; Engagement - Work Plan 2021/ Project Development 2021</b>	<b>€ 774.351,43</b>	
AbbVie	€ 35.000,00	1,5%
Amgen	€ 35.000,00	1,5%
Astellas	€ 20.000,00	0,9%
BMS	€ 50.000,00	2,2%
CSL Behring	€ 10.000,00	0,4%
Chiesi	€ 25.000,00	1,1%
Edwards Lifescience SA	€ 25.000,00	1,1%
Gilead	€ 40.000,00	1,7%
GSK	€ 30.000,00	1,3%
Janssen	€ 50.000,00	2,2%
Leo Pharma	€ 10.000,00	0,4%
Medicines for Europe	€ 20.000,00	0,9%
Merck	€ 35.000,00	1,5%
MSD	€ 50.000,00	2,2%
Novartis	€ 100.000,00	4,3%
Pfizer	€ 25.000,00	1,1%
Philips	€ 10.000,00	0,4%
F. Hoffman-La Roche	€ 50.000,00	2,2%
Sanofi	€ 50.000,00	2,2%
Takeda	€ 40.000,00	1,7%
UCB	€ 25.000,00	1,1%
Vertex	€ 17.000,00	0,7%
Membership	€ 22.351,43	1,0%

<b>Capacity Building Programme 2021 - DSL - PEOF -Artificial Intelligence</b>	<b>€ 372.681,00</b>	
	Contribution to the CBP and others	% of total income
Alexion	€ 14.000,00	0,6%
Astellas	€ 10.000,00	0,4%
Baxter	€ 15.000,00	0,6%
EFPIA (DSL)	€ 153.608,02	6,6%
EHNA	€ 10.000,00	0,4%
Fresenius Kabi	€ 5.000,00	0,2%
GSK	€ 30.000,00	1,3%
Kyowa Kirin	€ 20.000,00	0,9%
Leo Pharma	€ 15.000,00	0,6%
Medtech Europe (DSL)	€ 10.000,00	0,4%
MSD	€ 20.000,00	0,9%
Servier	€ 5.000,00	0,2%
The Synergist ( PEOF )	€ 20.072,98	0,9%
European AI Fund	€ 45.000,00	1,9%

<b>Congress 2021</b>	<b>€</b>	<b>385.800,00</b>	
	Contribution to CGS		% of total income
Alexion	€	10.000,00	0,4%
BMS	€	25.000,00	1,1%
Biogen	€	5.000,00	0,2%
Robert Bosch Stiftung	€	30.000,00	1,3%
CHIESI	€	40.000,00	1,7%
EFPIA	€	50.000,00	2,2%
EATRIS	€	500,00	0,0%
F. Hoffman-La Roche	€	30.000,00	1,3%
Grunenthal	€	5.000,00	0,2%
Galapagos	€	15.000,00	0,6%
Janssen	€	40.000,00	1,7%
Janssen JC General Services	€	150,00	0,0%
Kyowa Kirin	€	10.000,00	0,4%
Merck	€	40.000,00	1,7%
Medizinische Universitat Wien	€	150,00	0,0%
Novartis	€	40.000,00	1,7%
Servier	€	10.000,00	0,4%
Vertex	€	15.000,00	0,6%
Viartis	€	20.000,00	0,9%
<b>Other income (including reserves)</b>	<b>€</b>	<b>9.704,71</b>	
			% of total income
Other Income	€	9.704,71	0,4%
<b>Total Income</b>	<b>€</b>	<b>2.323.226,16</b>	
Accrual and deferrals	-€	287.004,91	
<b>Total income net of adjustments</b>	<b>€</b>	<b>2.036.221,25</b>	

<b>EPF Funding Transparency (Jan - Dec 2022)</b>	
Overall proportion of Industry and non-industry income	Private: 66,00% Public: 34,00 %
Percentage of the highest contribution from a single Industry Donor	EFPIA 6.7%
Percentage of the highest contribution from a single Industry Company	Novartis 4.36%