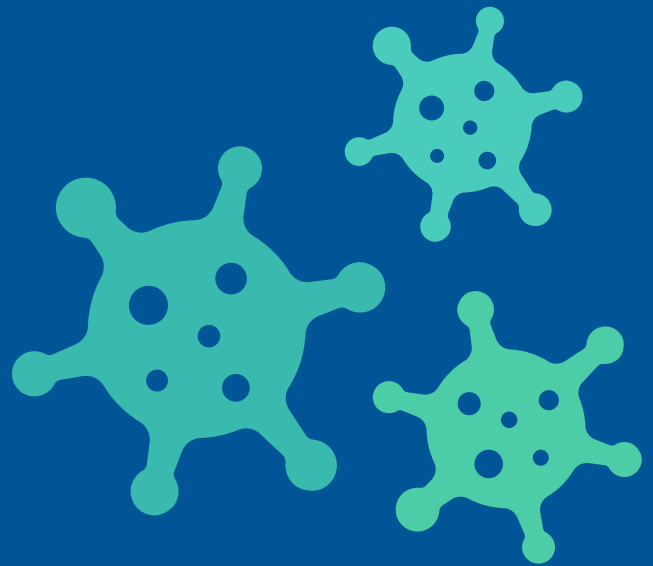




ANNUAL REPORT 2020



**A Strong Patients'
Voice to Drive
Better Health in
Europe**

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A Word from the President

2020 was no ordinary year. The sudden emergence of the **COVID-19** pandemic has changed our world and will have a deep and lasting impact on our societies and particularly on healthcare systems. Many of our objectives and plans were adapted to meet the difficulties and uncertainties presented by the tumultuous period. EPF proved to be a resilient organisation, and this Annual Report outlines the incredible work and achievements made in the areas of empowering and enhancing the patient voice and our cross-cutting activities in 2020 aimed at creating equitable, person-centered, accessible, and sustainable healthcare systems.

Our **Policy** team added patient advocacy on responses to the pandemic as a priority new topic in 2020, with activities ranging from access to medicines, medicines shortages to digital health. Engagement with the EU digital health strategy was a major focus, specifically big data and artificial intelligence, as we invited members to participate in a discussion regarding principles for “patient-centred digital health.” Our on-going work on vaccination confidence for patients and their communities accelerated as COVID-19 vaccines strategy took central stage at the EU level. Moreover, a tremendous effort was undertaken to ensure patient involvement in the EU4Health Programme and European Health Union.

In 2020, our **project portfolio** further expanded with six projects spread across the thematic clusters of Research and Medicines Development, Patient Engagement, Health Systems and Digital Health and Health Data. We concluded our work on the Joint Action CHRODIS Plus project and PARADIGM, our flagship project on Patient Engagement, and we started several exciting projects including PERISCOPE, which investigates the broad socio-economic and behavioral impacts of the COVID-19 pandemic.

Our **Capacity Building Programme** moved into the virtual realm but nevertheless delivered exceptional materials including another successful module on Empowering Leadership and Positive Governance and another 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.

A big reason for our success is, of course, **our members**. They played a fundamental role this past year, outlining the main challenges for patients with chronic conditions during the pandemic such as treatment delay, discontinuation, general lack of clarity, and the strong need for patient involvement when developing solutions. We will continue to advance their interests by strengthening our collective impact across Europe through effective advocacy, education, empowerment, and partnership.

These extraordinary circumstances have reminded us of the value of solidarity, cooperation, and diversity to overcome the biggest health crisis in modern times. Thanks to the continued hard work of our members and board, supported by the EPF Secretariat, patients and patient organisations now have a bigger voice and a vital seat at the table when it comes to co-designing health systems in Europe.

Sincerely,

A handwritten signature in black ink, appearing to read 'Marco Greco', written in a cursive style.

Marco Greco
President
European Patients' Forum

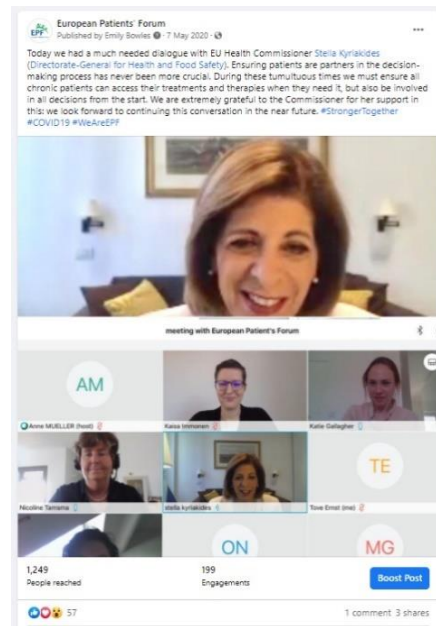


2020 at a Glance

January	VAC-PACT meeting with DG Sante Data Saves Lives (DSL) Core Group Meeting
February	EPF Board Meeting Data Saves Lives (DSL) Board Meeting Central/Eastern Europe Workshop Planning DigitalHealthEurope (DHE) Workshops
March	Launch of EPF's Capacity Building Module on Leadership & Governance
April	EPF Board Meeting PARADIGM Prefer Workshop EHDEN Workshop SAPHIRE Workshop EPF Annual General Meeting (AGM) EHDEN General Assembly
May	Data Saves Lives (DSL) Editorial Board Meeting COMPAR-EU Meeting EPF Youth Group Meeting
June	EPF Industry Roundtable EU-Pearl Workshop EPF Youth Group Spring Meeting 3 rd Patient Engagement Open Forum (PEOF)
July	WEBINAR: Launch of EPF's position paper on 'The Value and Pricing of Innovative Medicines' Summer Training for Young Patient Advocates (STYPA)
September	EPF/EURORDIS WEBINAR: Lessons learnt from COVID-19 pandemic and future of HTA collaboration at EU Level EPF Board Meeting Capacity Building Leadership Seminar 1
October	Digital Health Europe Workshop on Patient Empowerment Roadmap EPF Extraordinary General Meeting (EGM) Capacity Building Leadership Seminar 2 Capacity Building Leadership Seminar 3 Capacity Building Alumni Webinar COMPAR-EU meeting EPF Youth Group Fall Meeting
November	Patient Advocates Seminar (PAS) Data Saves Lives (DSL) Workshop Capacity Building Leadership Module Webinar EPF Board Meeting
December	EUPATI Open Classroom – Launch Event

By the Numbers....

- 153** events organised by EPF in 2020
- 103** events attended by EPF
- 80** participants at our first ever online AGM, the most in EPF history!
- 60** participants at our first ever virtual Industry Roundtable
- 41** Team Meetings among the Secretariat
- 6** Board Meetings held during 2020
- 3** new patient organisations approved as Full Members at AGM 2020
- 1** new Strategic Plan



Platform	Followers	Impressions	Engagement Rate
Facebook	9683 +1000	532K	5.26%
Twitter	11.2K +1420	1.9 million	1.46%
LinkedIn	3400 +1046	123K	6.25%
YouTube	230 +43	41K	0.58%

EPF European Patients Forum

Social Platform Growth & Engagement 2020
as of 31 December 2020

Strategic Plan 2021-2026

As we approached the end of our last seven-year strategic plan (2014-2020), EPF initiated a debate 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-centered, 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-centered, 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



Policy & Advocacy

The sudden emergence of the COVID-19 pandemic changed our world and will have a deep and lasting impact on our societies and particularly on healthcare systems. In 2020, EPF added patient advocacy on responses to the pandemic as a new topic in the 2020 work plan. Activities ranging from access to medicines, medicines shortages and prices to digital health and vaccination were linked to this.

Working towards the reduction of health inequalities by promoting sustainable and patient-centred universal access to healthcare

While the COVID-19 pandemic pushed all meetings into the virtual realm, EPF continued its work with its members online, including the **Universal Access Working Group (WG)**. Given the new and urgent priorities presented by the COVID-19 pandemic, EPF published a statement in April 2020, [“Now is the Time to Protect Patients and Safeguard Access to Care”](#) in close collaboration with the Access WG. Statements on the European Semester 2020 country-specific recommendations (CSRs) were integrated into our [statement on the EU4Health Programme](#), given the Commission’s plans to reorientate the European Semester process. These activities strongly refocused our advocacy on the new EU4Health programme and related initiatives, as well as the impact of COVID-19.



In the context of political priorities on ensuring access to affordable medicines and new Pharmaceutical Strategy for Europe, EPF launched its **position paper “The Value and Pricing of Innovative Medicines”** in July 2020 through an interactive webinar with MEPs Kateřina Konečná (GUE-NGL/CZ), Tomislav Sokol (EPP/HR) and Tiemo Wölken (S&D/DE) that also featured a keynote speech from EU Commissioner for Health and Food Safety, Stella Kyriakides.

This paper contributes EPF’s perspective as a cross-disease umbrella patient organisation to the EU-level and international debate on prices and value of innovative medicines, building on our [core principles of 2016](#). You can find our event report [here](#).



In July 2020, EPF welcomed the ambitious and timely **European Programme of Work (EPW) of the World Health Organisation (WHO)** and its determination to address health inequalities and to leave no one behind. We believe that the empowerment and meaningful involvement of patients and

communities – i.e., the people the health systems aim to serve – at all levels will be critical to the shaping and the delivery of the EPW, but the concept is not entirely elaborated in the document. EPF [responded to the consultation](#) commenting on each of three priorities and how EPF can contribute to making the Regional Office collaborate more effectively and efficiently.

Demonstrating the impacts towards equal access of healthcare during the COVID-19 pandemic, **EPF issued four (4) statements:**

- [“On the COVID-19 Pandemic”](#),
- [“Now is the Time to Protect Patients and Safeguard Access to Care”](#),
- [“The EU needs to Guarantee the Delivery and Supply of Cross-Border Medical products during the COVID-19 Outbreak”](#),
- [“Patients’ safety must take precedence in EU coronavirus vaccination deals”](#).

EPF also published an [Open Memo to the health industry](#) in April 2020 outlining the main challenges for patients with chronic diseases and our expectations on the role and responsibilities of industry, receiving [responses from Health Industry representatives](#): EFPIA, Medicines for Europe, MedTech Europe, AESGP, EUCOPE, COCIR, and EUROPABIO.

EPF also issued a **patient survey** on the [Impact of COVID-19 on patients and patient organisations](#). This survey is part of EPF’s continued efforts to gather COVID-19 related experiences and insights from the patient community. With the results, EPF intends to produce a comprehensive report which will serve as a strong evidence base for our policy and advocacy work. The analysed results were immediately used to inform EPF’s key asks in view of the EU4Health programme negotiations.



On **Nutrition**, EPF continued its engagement through its cluster working on nutrition participating in the ONCA Conference and speaking at the EU4NUTRITION LIVE event co-organised by the European Nutrition for Health Alliance (ENHA) and its partners. On 1 October, EPF Board Member Michal Rataj spoke on our behalf at the European Nutrition Health Alliance’s event ‘EU4Nutrition’ in a workshop on the place of nutrition and nutritional care in European health policies. This was an opportunity to raise EPF’s key recommendations crucial to advancing European nutrition and health policy in the context of the Farm to Fork Strategy of the European Commission.

In October, [EPF co-signed a letter together with the European Chronic Disease Alliance](#) and others on **mandatory front-of-pack nutrition labelling**. The German Presidency is preparing Council conclusions on this in anticipation of the Commission’s proposal expected by end 2022. Several member states call for a voluntary system, which raises important concerns from a health standpoint. One of the key recommendations of our [position](#) on information to patients on food and nutrition (2018) is the introduction of a mandatory front-of-pack labelling scheme and European harmonisation.

Ensuring that patient-centredness is evaluated as a part of healthcare quality

In 2020, EPF continued its collaboration with the **Organisation for Economic Co-operation and Development (OECD)** by participating in the [OECD PaRIS project](#) international patient advisory board and contributing to the virtual meeting of the OECD HCQO working group. We continued our engagement on antibiotic resistance through membership of the stakeholder group on Anti-Microbial Resistance led by the European Public Health Alliance (EPHA).


Monitoring and supporting the implementation of EU legislation on Clinical Trials, medical devices; Contributing to the future of HTA

In 2020, European policymakers recognised that health relies on a transparent, high quality and effective EU cooperation. As a result, EPF continued its contribution of the patient perspective to international networks and meetings focusing on **Health Technology Assessment (HTA)**.

Health Technology Assessment (HTA)




Why an HTA initiative?

EPF 

A long lasting cooperation: projects, joint actions

<p>ACHIEVEMENTS</p> <ul style="list-style-type: none"> • Trust between HTA bodies • Capacity building • Development of joint tools (e.g. EUnetHTA Core Model, POP EVIDENT databases) • Piloting joint work (e.g. early dialogues, joint assessments) 	<p>LIMITATIONS</p> <ul style="list-style-type: none"> • Low uptake of joint work ⇒ duplication of work • Differences in the procedural framework and administrative capacities of Member States • Differences in national methodologies • No sustainability of current cooperation model
-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

EPF 

On 9 September, EPF, EURORDIS and MEP Tiemo Wölken co-hosted an online event [“Lessons learnt from the COVID-19 pandemic and the future of HTA collaboration at EU level”](#) to relaunch a constructive debate and boost HTA cooperation at European level to effectively respond to the needs of national health systems and patients across Europe, in the context of COVID-19 response and beyond. The event was well attended and encouraged the uptake of patient involvement in the HTA decision-making process.

On 22 April 2020, the European Council approved the European Commission’s proposal to postpone the application of the **Medical Devices Regulation** to prioritise the fight against coronavirus. Considering this situation, EPF issued a [statement](#) welcoming the postponement by one year to 26 May 2021, in order to alleviate pressure on key actors and ensure effective implementation of the regulation and the changes that patients need. As a result of the postponement, our joint webinar with the Commission is delayed until Spring 2021.

EPF was set to develop its patient perspective on **biosimilars and generic medicines** by engaging membership in a dialogue to formulate a common position and fact sheet however it has been postponed due to the impact of COVID-19. On **medicine shortages**, we focused on contributing to the European Parliament’s [own-initiative report](#) on the topic. Most of EPF’s proposals were taken on board in the report.

COLLABORATION WITH:



As a result of the COVID-19 pandemic, EPF’s collaboration with the **European Medicines Agency (EMA)**, **European Centre for Disease Prevention and Control (ECDC)** and **European Union Agency for Fundamental Rights (FRA)** increased significantly. EPF continued to co-chair the Patients’ and Consumers’ Working Party (PCWP) and participated in three (3) virtual meetings for the in March, June and November. EPF President Marco Greco currently sits on the Management Board of the EMA.

EPF also contributed to themed virtual meetings held in 2021 including: Good clinical practice workshop with Patients' and Consumers' (PCWP) and Healthcare Professionals' (HCPWP) Working Parties (June); Workshop on the application of the General Data Protection Regulation (GDPR) in health and Secondary Use of Data for Medicines and Public Health Purposes (September); and a Workshop on benefit-risk of medicines used during pregnancy and breastfeeding (September). In September, we responded to a public consultation on the EMA/HMA network strategy, while EPF’s Director of Policy Kaisa Immonen was nominated as patient representative on the **EMA’s COVID-19 task force (ETF)**. One patient representative and one alternate, as well as HCP representatives were invited to attend meetings starting from early October.

In September 2020, EPF released its [response to the European Commission's consultation on the EU Pharmaceutical Strategy](#). We highlighted our belief that embedding meaningful patient involvement in everything that affects the patients' own access to medicines and care, will be key in tackling medicines shortages, and in evaluating medicines appropriately.



Contribution to the future of Health Policy in the EU post-2020



Drawing conclusions from the current COVID-19 pandemic, the European Commission presented an ambitious, stand-alone health programme in May 2020, called **EU4Health**. It aims to demonstrate a higher priority to health and to help health systems get prepared to cope with epidemics and other unforeseeable health threats. With a budget of €9.4billion for the period 2021-2027, EU4Health will be the **largest European health programme ever**.

With the EU4Health programme, EPF strongly supports the increased investment in health at European level. This is an important recognition of the **need to invest in Europe’s health**. EPF began its advocacy work, issuing a statement proposing for [a progressive and patient-centred EU4Health Programme](#). EPF directly engaged with the European Parliament on the EU4Health Programme report, sharing amendments and voting suggestions. EPF is happy to announce that several of its [proposed amendments](#) were adopted by Members of the European Parliament following direct engagement while the approved regulation of the EU4Health Programme included many [crucial principles for EPF](#).

EU4health

Civil Society Alliance

Launched jointly by EPF and the European Public Health Alliance (EPHA), 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.

In 2020, we issued several statements related to the European Health Union and the future of health:

- [COVID-19 has shown EU action on health is more urgently needed than ever](#)
- [EU health organisations react to cuts in EU health programme amidst ongoing COVID-19 crisis: the time to invest in a healthy future is now](#)
- [How To Harvest Long-Term Health Benefits Of The EU4Health Programme?](#)
- [No Dreams For A European Health Union Without A Triple WWW Eu4health Programme](#)
- [An Inclusive EU4Health Programme To Better Meet The Needs Of People In Europe](#)



On 7 January, the new Commissioner for Health and Food Safety Stella Kyriakides invited EPF for a meeting around **Europe’s Beating Cancer Plan**. EPF welcomed the roadmap on Europe’s Beating Cancer Plan and more generally the ambitious approach taken by the European Commission in tackling cancer.

[Our response to the Beating Cancer Plan Public Consultaion](#) was developed in a consultative process together with our members and highlights several issues which are not addressed in the public consultation questionnaire, but which in our view warrant inclusion in the plan. Europe’s Beating Cancer Plan was officially launched in February 2021.

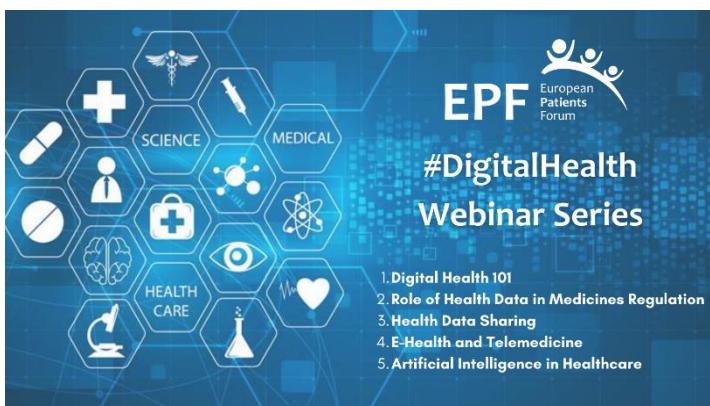
EPF began impactful engagement with the **European Parliament’s internal engagement strategy**, which will be further refined in 2021. The Policy team has started to implement tools and procedures planned in the strategy (e.g. evaluation of amendments work). Overall, we continued showcase and promote the patient voice via participation in European and international conferences, ad hoc and permanent working groups, thematic events, and other fora where this brings added value and impact for the organization.

Cross-Cutting Activities

Digital Health

Health is an area where Europe can undoubtedly benefit from during the data and Artificial Intelligence revolution. The COVID-19 pandemic has demonstrated how accurate and quickly accessible data is fundamental in the management of cross-border public health emergencies. Nevertheless, the road to fully exploit the potential benefits of data and AI in health is only partially built, still extremely fragmented and not yet developed with patients' views at the centre. In 2020, EPF worked on several cross-cutting initiatives and publications addressing some of the most important updates in this field.

In 2020, EPF responded to two key public consultations on the [European Commission's Data Strategy](#) and its [White Paper on Artificial Intelligence](#). Building on these responses, we launched a first [survey on AI](#), developed with the support of the **Digital Health Working Group**, that explored perceptions and basic knowledge on the topic in the patient community. To support this initiative, EPF has also published an [EU Policy Briefing](#) on Big Data and Artificial Intelligence plus a [summary report](#) from our recent survey on Electronic Health Records. The first results were presented at the European Patients Innovation Summit at the end of October.



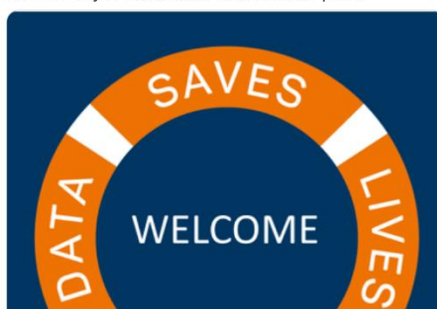
#DigitalHealth Webinar Series

EPF's Capacity Building, Projects and Policy team collaborated on a **five-part webinar series on digital health** with the objective of building the knowledge of our members on the topic and giving them the possibility to interact with experts and other patient organisations. The aim of the series was to provide reliable, easy to digest information on the different aspects of digital health.

Watch the [#DigitalHealth Webinar Series](#)



Welcome to today's tweet chat, exploring how we can improve [#healthdata](#) literacy among patient communities. To follow this chat live, just search the hashtag [#DSLChat](#) and include it in any questions or comments you have to be visible to our panel

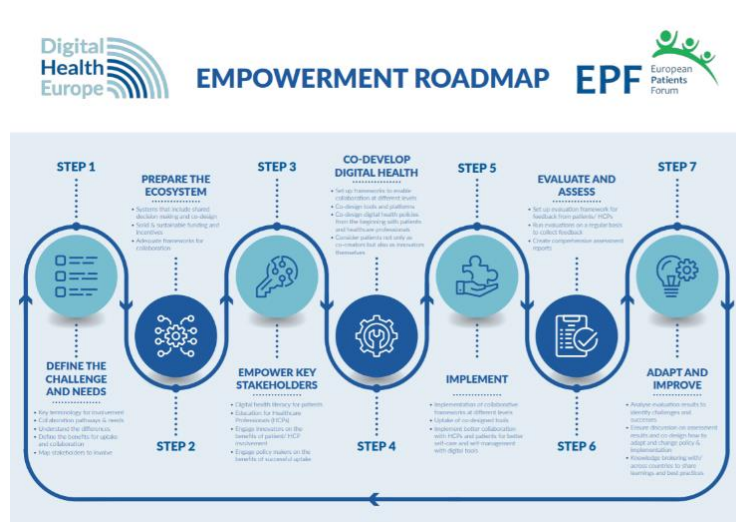


EPF further consolidated the **DataSavesLives** website/portal sharing relevant information and best practice examples about the use of health data and generating easy-to-use materials about the basic concept related to data sharing, the data journey and the safeguards in place.

2020 highlights:

- Grew social media presence to 1,037 followers with a reach of 88,000 people
- Organised 2 Tweet Chats, 2 Webinars and 1 Workshop
- Updated Website copy and image updates
- Contributed monthly blog series published on website

In October 2020, EPF hosted a two-day multi-stakeholder online workshop on **Digital Tools for Patient Empowerment and Person-Centred Care** for Digital Health Europe. The workshop was a mix of plenary and breakout sessions for all participants can contribute their views and shape the discussion. Over the course of the two days, the workshop engaged patient leaders and other health stakeholders with an interest in digital tools that have a potential to boost patient empowerment and person-centred care, and fostered collaboration between patients and healthcare professionals.



Participants discussed the key recommendations of the [EPF Empowerment Roadmap](#) for more successful collaboration between patients and health systems, validated the in-depth analyses developed by EPF, and helped to further identify barriers and enablers to the procurement, adoption, trust and integration of digital health solutions.

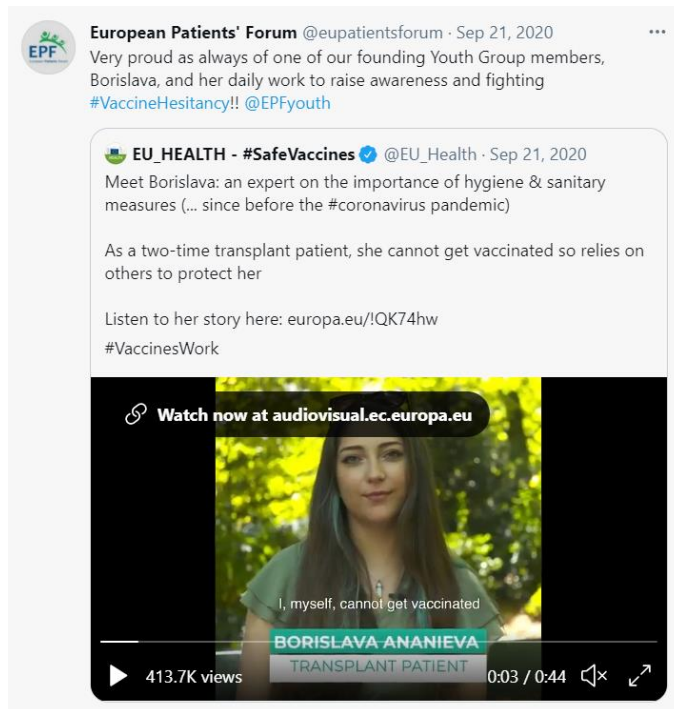
EPF continued to engage regularly in key events and stakeholder platforms dedicated to digital health (e.g. the eHealth Stakeholder group), promoting the positions included in the above-mentioned documents. The strengthening of EPF’s voice in the digital health policy debate resulted in increased opportunities for stronger collaboration and consultation in digital health.

Vaccination

On 27 August, we published a statement explaining EPF’s positioning relating to current concerns around COVID-19 vaccines development, entitled [“Patients’ safety must take precedence in EU coronavirus vaccination deals”](#). In our statement, we ask for transparent and clear information about the conditions of contracts made with pharmaceutical companies, both from the Commission and from national authorities. In addition, we suggest an additional compensation mechanism at European level to protect patients in case of serious adverse reactions that may only become apparent after the vaccines are already on the market.

We shared our statement with Commissioner for Health Stella Kyriakides and were invited to meet Sandra Gallina, who is the lead negotiator for the European Commission’s vaccine strategy. The virtual meeting was initiated on the basis of our statement on vaccines development and safety, but it also served as a general introduction of President Marco Greco and EPF to Ms Gallina and her team and set the scene for ongoing dialogue with Ms. Gallina and her team.

The **patient guide to vaccination**, titled [“Let’s Talk About Vaccination: The Art of Conversation”](#) developed as part of [EPF’s initiative on vaccination](#), was finalised, reviewed by an independent external scientific expert, and designed into a leaflet. The patient guide will be launched in early 2021 via a webinar primarily targeting our membership. Our **factsheet on vaccination** was also [translated into Italian](#), to satisfy several of our member organisations.



As a patient representative on the European Medicines Agency’s COVID-19 Task Force (ETF), EPF focused on supporting public communication around regulatory evaluation and approval of vaccines for COVID-19. This complements the wealth of information on our [COVID-19 Resource Point](#) and communication channels.

Our Youth Strategy and Capacity Building Assistant Borislava Ananieva collaborated with DG SANTE to [raise awareness about and fight vaccine hesitancy](#).

In January 2020, EPF also kicked off an important pilot project funded through a tender from the European Commission. The **VAC-PACT pilot project**, which EPF is leading with a small consortium, focuses on vaccination information and confidence especially for patients with chronic conditions and their carers. The project will develop an advanced toolkit in hybrid online and printed formats, including interactive tools. During the year, we developed a first draft of the advanced toolkit, which will be evaluated and refined in virtual workshops in early 2021. The project includes two advisory boards which have met virtually this year. VAC-PACT is set to deliver its results and a final report at the end of August 2021.

Projects

EPF has developed a strategic approach to our involvement in projects, which carefully defines our criteria for engagement. EPF’s current project portfolio, and prospective project involvement act as a cross-cutting platform which underpins our advocacy, education and communication pillars.



CHRODIS PLUS

Joint Action (JA) CHRODIS PLUS aims to support Member States through cross-national initiatives identified in JA-CHRODIS to reduce the burden of chronic conditions, while ensuring health system sustainability and responsiveness. EPF has been in the heart of the project by co-designing key project deliverables and outputs. In 2020, EPF put significant efforts in producing various types of materials, promoting project outcomes on social media, outlined below and supporting the preparation and delivery of the Final Conference.

Finally, On 27 October 2020, **CHRODIS PLUS** held its closing [conference on Chronic Diseases](#), bringing the project to a successful close. One of the main objectives of the Final Conference was focused on how the [good practices and tools](#) implemented by the project can be tailored to various settings across Europe. EPF actively took part in the implementation phase of the project methodology and assessed the patient involvement throughout this process.

[EPF participated](#) to provide the **patients’ unique experience**, emphasising the importance of empowerment and the creation of supportive work environments. EPF worked together with partners to develop and pilot the [CHRODIS-PLUS Workbox on Employment and Chronic Conditions](#), which supports EU member states and their workplaces in creating working conditions that foster wellbeing, health, and work ability; prevent the development of chronic diseases; and help individuals with chronic health problems to continue working.

Key materials produced by EPF in 2020:

QCR video and leaflet



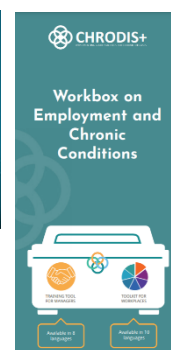
click on the image



Training Tool for Managers and Toolkit for Workplaces video and booklet



click on the image



Guide for the implementation of JA CHRODIS Recommendations and Criteria (QCR) to improve the quality of care for people with chronic diseases, together with a **layman version** and **shortened version of this Guide**



COMPAR-EU COMPAR EU

COMPAR-EU aims to identify, compare, and rank the most effective and cost-effective **self-management interventions (SMIs)** for adults in Europe living with one of the following four chronic conditions: **type 2 diabetes, obesity, chronic obstructive pulmonary disease, and heart failure**. In 2020, EPF has successfully continued working closely with the **COMPAR-EU Patient Panel (PP)** – a group of **12 patient representatives** from **8 different countries endorsed by EPF members**. Their role is to “translate” core outputs into lay language and ensure that the patient perspective is embedded in project outputs. In order to guarantee that patients are meaningfully involved in the project, EPF is hosting monthly webinars and two workshops per year with these patients – processes which would contribute to the validation of the project outcomes. Lastly, in 2020, EPF contributed to the design and development of the final product of the project – the Interactive IT platform aimed at main stakeholders of the health and care ecosystem.



PERISCOPE (Pan-European Response To The Impacts Of Covid-19 And Future Pandemics)

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; 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. EPF contributes to workstreams on the socioeconomic impact of COVID-19 pandemic, policy recommendations, training for patients with chronic conditions and outreach.



PARADIGM

In November 2020, the **Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM)** project ended. PARADIGM, which was **co-led by EPF**, aimed to **make patient engagement in medicines development easier** for all. The project brought together 34 partners from patient organisations, competent authorities, academics, NGOs, companies, hospitals, industry, and others.

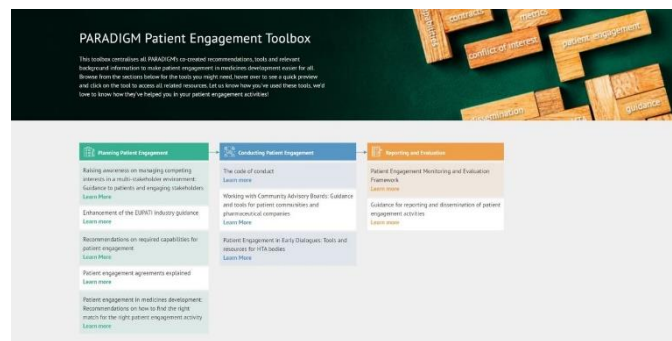
Among its major 2020 achievements, PARADIGM delivered its third **Patient Engagement Open Forum (PEOF2020)**, which took place for the first time in a fully virtual setting, with –ironic but true– the overarching theme “Into Reality”. The Forum aimed to provide a holistic perspective of patient engagement, the landscape and actors, and foster collaboration and co-creation while breaking down fragmentation that are often present in-patient engagement work.



The event was co-organised with **PFMD** and **EUPATI** and consisted of 17 sessions distributed in a time span between June and September. All in all, PEOF 2020 reached the unprecedented number of 1500 registered participants. We are pleased to announce that the PEOF will continue in 2021, and beyond, with EPF joining PFMD and EUPATI as a co-organiser.

Two main outputs of the project were released in 2020:

1. [The Patient Engagement Toolbox](#), which centralises the project recommendations,
2. [The Monitoring and Evaluation Framework with metrics](#) which connects the dots between metrics to understand how patient engagement translates into impact and why initiatives fail or succeed.



For more explanation on how PARADIGM can be factored in the bigger picture, please read [this letter](#) from Magda Chlebus at EFPIA, and EPF’s Nicola Belington and Mathieu Boudes.



PREFER

An IMI project on Patient-Preference Studies, **PREFER** aims to strengthen patient-centric decision making on benefit-risk assessment throughout the life cycle 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 health care professionals on how and when patient-preference studies should be performed and the results used to support

and inform decision making. EPF is part of the Patient Advisory Group together with ECPC (lead of the PAG), Muscular Dystrophy UK and IAPO. 2020 marked another year of collaboration between PREFER and PARADIGM, as patient representatives from both projects were invited to look into Patient-Preference Studies to share knowledge and experiences on patient engagement and patient preference research.

eatris+ EATRIS Plus

A project led by EATRIS, **EATRIS-Plus** contributes to effectively shape the operational processes of translational medicine and advance in personalised medicine. The primary objective is to strengthen EATRIS-ERIC’s long-term sustainability by maturing key aspects of the infrastructure, including the quality of scientific services towards industry and academia, as well as the engagement towards a broader range of stakeholders, including patients, other infrastructures, and policy makers. EPF leads on the work on Stakeholder Engagement activities, including patient engagement, to drive patient empowerment at the heart of EATRIS operations. Over the first year of work, EPF has been working to set up the Patient Advisory Committee (PAC).



EUPATI

In 2020, major changes were introduced in the core activity of **EUPATI**, the Expert Patient Training Programme. The objectives of the Ensuring the future of EUPATI beyond 2020 Project (**EFOEUPATI**) focused on consolidation of the key pillars of the EUPATI programme: The **Patient Expert Training Course**, the multilingual public **Toolbox**, and the **EUPATI**

National Platforms Network. This implied defining and implementing a business model for short and long-term sustainability and implementing the infrastructure required for the key activities of EUPATI to grow and prosper. The **EUPATI Reload** application, funded by EIT Health, was also successfully submitted for 2021.

2020 saw the establishment of a new EUPATI Foundation based in the Netherlands, as well the development of a new governance structure. These aspects resulted in subsequent changes in the administration and will allow for the full implementation of the sustainability plan. Two national platforms were launched in Japan and Scotland with a total of 23 active national platforms. The redesigned [EUPATI homepage and Toolbox](#) now hosts **four million users** and provides services in **13 languages**. A 6-pillar sustainability plan was launched including the **EUPATI Open Classroom**, the new on-demand platform for patient education and the EUPATIconnect Matchmaking tool was conceptualised. Overall, EUPATI’s efforts resulted in greater collaboration amongst regional groups, an increase of knowledge exchange and sharing through innovative materials and improved local patient training initiatives.





EHDEN

In 2020, EPF’s major role was to review the communication plan and initial toolsets given the new context of COVID-19. As part of this communications and dissemination plan, EPF developed scripts for introducing EHDEN concepts to patients’ understanding. As an ongoing action, EPF also coordinates and disseminates EHDEN project activities on DataSavesLives and EPF platforms. Since the start of 2020, EPF also actively contributed to the creation and review of Value Proposition for Patients and the full sustainability plan. EPF also contributed to the development of educational and training material for the developed analytical tools.



DigitalHealthEurope

The project aims to provide comprehensive support to the Digital Health and Care Innovation initiative in the context of the Digital Single Market Strategy. EPF’s role is through managing a collaboration panel between citizens/patients and healthcare providers to come up with an **empowerment roadmap** for larger scale healthcare ecosystems to become more successful at engaging with patients and caregivers and a White Paper report, providing recommendations on ways to boost active cooperation between patients and health and care providers.



Data Saves Lives

DataSavesLives

In 2018, the [DataSavesLives initiative](#) was formally launched. Data Saves Lives worked to raise wider patient and public awareness about the importance of health data. It was crucial to improve the understanding of how health data is used to establish a trusted environment for dialogue. DSL has a crucial role to play in stimulating structured and meaningful discourse with its multi stakeholder health data community on societal questions about the uses of health data, with a view to enhance understanding, trust and cooperation.



PharmaLedger
BLOCKCHAIN ENABLED HEALTHCARE

PharmaLedger

PharmaLedger will use 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.

PharmaLedger aims to create a framework to digitalise the healthcare industry. In 2020, EPF contributed to **outreach activities to inform the patient community about the potential of**

blockchain, and provided feedback on use cases, such as the ones on e-consent, e-leaflet, dynamic permission, patients' enrolment in clinical trials.



Health Outcomes Observatory (H2O)

H2O is a strategic partnership between the public and private sectors to create a robust data governance and infrastructure model to collect and incorporate patient outcomes at scale into healthcare decision making at an individual and population level. The H2O approach gives patients ultimate control of their health data and ensures that only they exercise this control. In October, the project had its **virtual Kick Off meeting** and EPF presented the plan on patient engagement. EPF will contribute a strong patient perspective by bringing on board **three patient advisory boards (diabetes, IBD & oncology)** as the cornerstone of our contribution to the project. Together with the expertise of these patients, we will ensure that there is a strong patient perspective, and that patients are consulted throughout. The project is funded by the Innovative Medicines Initiative (IMI) mechanism, a large, far-reaching public-private partnership between the European Union and the life sciences industry to support research and innovation in life-science.



GRAVITATE Health

This project started at the end of 2020. **Gravitate Health** is a project that aims to equip and empower citizens with digital information tools that make them confident, active, and responsive in their patient journey, specifically by encouraging the safe use of medicines, reducing risks, and for better health outcomes and improved quality of life.

EPF contributes as co-lead of the work on Capacity Building and Multi-Stakeholder Engagement, particularly in tasks that contribute to digital health literacy for patients, citizens and healthcare professionals. We are hoping to achieve the goals of these tasks at the beginning by setting up a User Advisory Group that will consist of patient, healthcare professional and citizen/consumer representatives.

We will also contribute across other workstreams, in particular those related to identifying user needs, developing educational materials for the G-Lens, interoperability and accessibility; and proof of concept, sustainability plans, communication and dissemination activities.



IMMUCan

This past year, EPF drafted and implemented the actions in a project communications plan for IMMUCan. As part of this plan, EPF developed a **patient portal** housed in the overall project website, with messaging targeted to patient audiences, and a patient information **leaflet** in lay language which available on the patient portal of the website, and which will be translated. EPF also coordinates and disseminates a quarterly **project newsletter**; the third edition was published in July 2020, and the fourth edition was published in March 2021. EPF's efforts this year have centred on building a **social channel presence** across LinkedIn, Twitter and Facebook, with a particular focus on making the content accessible to non-expert users.



PERMIT

PERMIT project (PERsonalised Medicine Trials) is another Horizon 2020 project where EPF plays a central role ensuring the patient voice is present throughout key workshops, milestones and deliverables. Launched in January 2020, PERMIT project aims to develop recommendations for robust and reproducible personalised medicine research. Last year, EPF has been actively involved in tasks related to the literature gap analysis and helping in identifying needs and disparities in terms of standardised methodology and data generation, management, analysis, and interpretation. PERMIT aims to improve personalised medicines research by establishing recommendations. These recommendations will ensure the scientific excellence, validity, robustness and reproducibility of results generated by personalised medicine programmes.



EU PEARL

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.

EPF leads on the creation of a patient-led patient engagement platform with buy-in of the pharmaceutical industry and other stakeholders like academia and governmental bodies. The platform will follow the principles for good patient engagement set out in PARADIGM and EUPATI Guidance.

In 2020, EPF worked to set up and launch a Patient Advisory Group. EPF also contributed to the project's patient-centricity through the patient engagement trainings for EU-PEARL partners, as well as the integration of the patient perspective in relevant workshops.



IMMUNIVERSE

Immune-mediated diseases (IMIDs) are an increasing medical burden in industrialized countries worldwide. IMIDs are characterized by an enormous heterogeneity with regard to disease outcome and response to targeted therapies, which currently cannot be adequately anticipated to tailor individual patient management.

ImmUniverse aims to tackle these unmet 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.

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.

There are three main types of Capacity Building Programme activities, which were all conducted in online 2020. The **EPF Patient Advocates Seminar** was postponed for Q1 2021.

1. EPF Capacity Building Module on Empowering Leadership and Positive Governance (online)

The module aimed at strengthening patient organisations by enhancing their leaders' leadership skills and consequently enabling positive governance in their organisation. The overall objective was to support patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners in the national and European health policy environment.

Over 100 applications were received for the 25 available spots with participants from **12 countries** around Europe including Estonia, Bulgaria, Romania, Belgium, Switzerland, Malta, Finland, Hungary.

Evaluation following the training clearly shows a positive change in all participants.



2. EPF #DigitalHealth Webinar Series



[Watch the #DigitalHealth Webinar series](#)

Collaboration with EPF Policy and Projects teams to provide members and member organisations with patient-friendly, comprehensive information on key topics, surrounding digital health, in a series of webinars.

Five (5) webinars in total with **over 270 people registered** for all the webinars.

3. Summer Training Course for Young Patient Advocates (STYPA)

SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES

Shaping the future of Patient Advocacy

The Summer Training Course for Young Patients Advocates (STYPA) – Leadership Programme is an exciting and unique opportunity offering a tailored high-quality training to young patient advocates or representatives, who have the motivation to learn more about advocacy and maximise their leadership potentials in a real environment.

STYPA2020 looked at how **patient advocacy** was evolving and facing emerging challenges and opportunities, and highlighted the importance of keeping a **strong ethical approach**. Through the training course, EPF raised **awareness among the new generation of young patient advocates on current challenges, obstacles, opportunities and share good practices for ethical patient advocacy in complex environments**. More than 35 young patient advocates, aged 18-30 years old, successfully graduated the course. Overall, the participant evaluation indicates a substantial growth in their leadership confidence, patient representation and advocacy abilities.

STYPA2020 participants

38 young patients

18 countries represented

30 chronic diseases represented

including: multiple sclerosis, epilepsy, cystic fibrosis, rare diseases, spina bifida and hydrocephalus and many others

STYPA2020 TESTIMONIALS



For me, STYPA was life changing. I met so many new friends and amazing people, but most of all learned many things that I am now using in my everyday life, and in my patient advocacy work. Overall, it has opened a lot of new doors for me and presented me with a wide range of new possibilities.



CORNELIA FLOOD
STYPA 2020 graduate



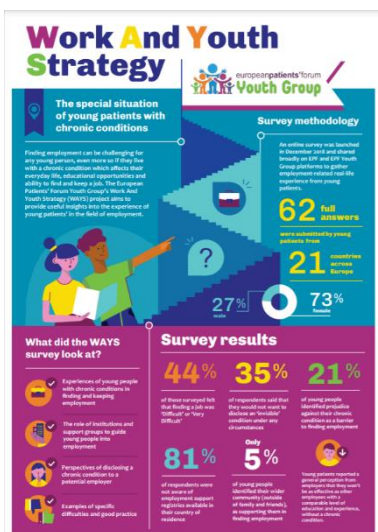
STYPA 2020 was a great opportunity for me to meet several players active in public health across the EU who actually represent their condition and provide their valuable experience. People need more education about chronic diagnosis and young people need support, which makes STYPA the perfect starting point for patient advocacy.



MARIJANA PERICA
STYPA 2020 graduate

Youth Group

In 2020, EPF continued its mission to prepare the next generation of patient advocates through its [Youth Group](#). For the first time ever, as per the new EPF Constitution, a seat on the Board reserved for a representative of the EPF Youth Group was appointed to **Jana Popova**. Three (3) new members were accepted into the Youth Group, representing cerebral palsy, epilepsy and Coarctation of the aorta and asthma.



The **EPF Work and Youth Strategy (WAYS)** aims to gather the opinions of young patients across the EU, to voice their struggles, but also their successes when it comes to employment. WAYS has become a strategic project of the Youth Group, the first in its kind, with three Youth Group presidents, several alumni and current Youth Group members leaving their marks on its development. In 2020, the Youth Group published the [WAYS Report](#) through an [interactive webinar](#) and provided an [accessible factsheet](#), as well as a [video](#) for all participants. All planned deliverables were achieved with over 50 participants at the live webinar launch.

Despite the pandemic, all Youth Group members attended and actively participated virtually in both the **annual Spring and Fall meetings**, which help shape and plan the upcoming projects and activities the Group will take up in the coming year. Youth Group members also took an active role in communications providing **16 articles** to EPF's monthly newsletter, The Patient Perspective.

EPF Youth Group Members in 2020

- Ivett Jakab, President (Hungary)
- Anastasia Seeman, Vice President (Cyprus)
- Marcus Ward (Ireland)
- Jana Popova (Bulgaria)
- Sally Hatton (UK)
- Nikola Kumovic (Serbia)
- Erato Markantoni (Cyprus) ***NEW***
- Erin Davies (UK) ***NEW***
- Marleen Kötzt (Germany/Spain) ***NEW***
- MarLou Schenk (Netherlands)



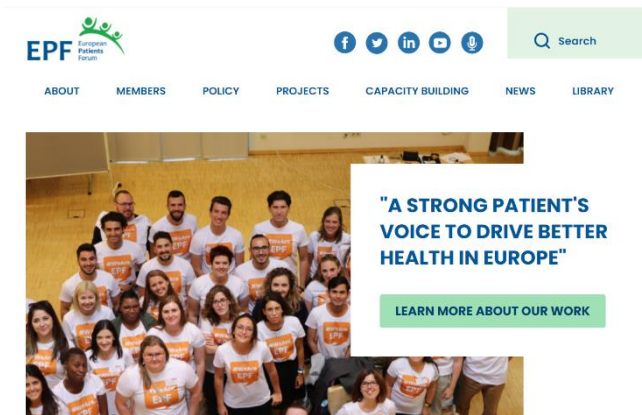
Communications

In 2020, 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.



As a response to the pandemic and our members’ requests, we launched the [COVID-19 Resource Point](#). We collaborated with Prof. Jean-Michel Dogné, Head of the Department of Pharmacy at the University of Namur, expert at the European Medicines Agency (EMA) and member of WHO’s Global Vaccine Advisory Committee for advice. Based on his recommendations, as well as input from our members, we began sharing credible figures, research articles and reports on COVID-19 and its effects on the patient and medical community on a weekly basis.

To provide greater accessibility and readability, we launched a **refresh of our website** in August 2020. Fresh with cooler colours, greater navigation and search features, the “new” website was a response to past requests from our membership and stakeholders from previous years.



In December 2020, we launched the first episode of the [EU Patients’ Podcast](#). The objective is to feature our members, policymakers, and key stakeholders in conversation with EPF Secretariat on various issues relating to patient advocacy and empowerment. This podcast provides another important avenue for the patient voice to be heard.



Newsletter Stats

- 12 editions of The Patient Perspective
- 4644 subscribers to Newsletter (+644)
- 32.6% Average Open Rate
- 10.3% Average Click-Through Rate



New episodes available on:



or wherever you get your podcasts!

Membership



Our members are the backbone of our work: their perspective brings a fundamental added value to our policy and advocacy activities.

We currently represent **75 patient organisations**:

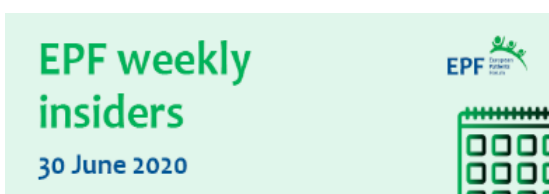
- 57 Full members
- 17 Associate members,
- 1 provisional member.

Out of 75 members, **50 pan-European umbrellas** and **25 organisations** are active at national levels, representing **19 countries**.

Towards a wider Europe. Our ambition is to become a reference point for the EU, European organisations and other stakeholders such as WHO Europe, healthcare professionals and health minded organisations seeking patients’ and patient groups’ opinions. We have adopted a new Constitution, **now enabling organisations based in the wider Europe to become members of EPF.**

In 2020, **three (3) patient organisations** joined EPF as Full Members:

- **Digestive Cancers Europe (DiCE)** (transitioned from Associate Members)
- **Greek Patients’ Association *NEW***
- **Lung Cancer Europe (LuCE)** (transitioned from Associate Members)



In 2020, EPF continued to offer its members the opportunity to chat informally with the EPF Secretariat. We kept our members informed through our **Weekly Insiders’ mailing**, sent on a weekly basis (50 times per year) that ensures EPF members keep up with the latest news from Europe on what really matters for patients.

List of EPF Members (as of 31 December 2021)

Full Members (57)

1. **Alzheimer Europe** (Europe)
2. **AMD** - Age Related Macular Degeneration Alliance International (International*)
3. **AOECS** - Association of European Coeliac Societies (Europe)
4. **AOPP** - Association for the Protection of Patients' Rights (Slovak Republic)
5. **BAG Selbsthilfe** - Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (Germany)
6. **BEMOSZ** - Hungarian Alliance of Patients' Organisations (Hungary)
7. **CF Europe**- Cystic Fibrosis Europe (Europe)
8. **COPAC** - Coalition of Patients' Organizations with Chronic Diseases (Romania)
9. **DE** – Dystonia Europe (Europe)
10. **DiCE** - Digestive Cancers Europe (Europe)
11. **EAMDA** - European Alliance of neuro-Muscular Disorders Association (Europe)
12. **EATG** - European Aids Treatment Group (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. **ECHDO** - European Congenital Heart Disease Organisation (Europe)
17. **EFHPA** - European Federation of Homeopathic Patients' Associations (Europe)
18. **EGAN** - Patients Network for Medical Research and Health (Europe)
19. **EHA** - European Headache Alliance (Europe)
20. **EHC** - European Haemophilia Consortium (Europe)
21. **EHLTF** - European Heart and Lung Transplant Federation (Europe)
22. **EKPF** - European Kidney Patients' Federation (Europe)
23. **ELPA** - European Liver Patients Organization (Europe)
24. **EMSP** - European Multiple Sclerosis Platform (Europe)
25. **ENUSP** - European Network of (ex)Users and Survivors of Psychiatry (Europe)
26. **EPDA** - European Parkinson's Disease Association (Europe)
27. **EPIK** - Estonian Chamber of Disabled People (Estonia)
28. **EUFAMI** - European Federation of Associations of Families of People with Mental Illness
29. **EUROPA DONNA** - The European Breast Cancer Coalition (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. **GPA** - Greek Patients Association (Greece)
38. **Swedish Disability Rights Federation** (Sweden)
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. **NCDP** - National Confederation of Disabled People (Greece)
50. **NPO** - National Patients' Organisation of Bulgaria (Bulgaria)
51. **National Voices** (United Kingdom)
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. **WDO** - World Duchenne Organisation (International*)
57. **SUSTENTO** - The Latvian Umbrella Body for Disability Organization (Latvia)

Associate Members (17)

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

Provisional Members (1)

75. **APO** – Alliance of Patient Organisations (FYROM)

** 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 2020, the Youth Group could nominate a representative as a Board member. We would like to sincerely thank Gabriela Tanasan and Cor Oosterwijk for their service to our Board during the last two years.

In 2020, the EPF Board Members were:

President - Marco Greco

Vice President/Treasurer - Radu Costin Ganescu (COPAC)

***Elisabeth Kasilingam became Acting Executive Director in November 2020*

- Dimitrios Athanasiou (World Duchenne Organisation)
- Hilikka Karkkainen (GAMIAN Europe)
- Marzena Nelken (Federation of Polish Patients)
- Michal Rataj (European Alliance of Neuromuscular Disorders Associations)
- Brian West (European AIDS Treatment Group) ***NEW***
- Jana Popova (EPF Youth Group) ***NEW***

Honourary Chairman – Anders Olauson

Ethics Committee

In 2020, EPF introduced the **Ethics Committee**, as per Art. 30 of the EPF Constitution. The role of the Ethics Committee members include 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 first-ever elected 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)

Extraordinary General Meeting (EGM)

In October 2020, we held an Extraordinary General Meeting (EGM) with our members in order to **approve the EPF 2021-2026 Strategic Plan**, receive an update on the European Health Programme as well as hear a proposal for a change to the EPF Constitution to allow **EPF to hold online General Meetings**, as a result of the pandemic.

The Strategic Plan and the proposal to hold online General Meetings (where necessary) was unanimously approved by our members.

Secretariat

In 2020, EPF said goodbye and good luck to Kostas Aligiannis, Adriana Pereira, Matthew May, Usman Khan, Anna Trzcinska, Zuzanna Skowronek, Camilla Habre, Mathieu Boudes...

...and welcomed Dante Di Iulio, Isabelle Manneh, Estefania Cordero, Maria Duterte in her new role, Desislava Ekzarova, Michele Calabrò, Lamprini Bikou and Elisabeth Kasilingam.

The EPF Secretariat as of 31 December 2020:

- **Borislava Ananieva** - Youth Strategy and Capacity Building Assistant
- **Brendan Togher** - Finance and Administration Manager
- **Dante Di Iulio** - Communications Manager
- **Desislava Ekzarova** - Membership and Governance Officer
- **Elena Balestra** - Head of Governance, Membership and Capacity Building
- **Elisabeth Kasilingam** - Acting Executive Director
- **Estefania Guzman Cordero** - Project Communications Officer
- **Gözde Susuzlu Briggs** - Project Coordinator
- **Isabelle Ellen Manneh** - Vaccination Initiative Coordinator
- **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

‘Extract from the Auditor’s Report to the Board of Members on the Financial Statements for the year ended 31 December 2020’

This audit is performed for the purpose of expressing an opinion to the EPF Board of Members as to whether the financial statements give a true and fair view of the association assets, liabilities, financial position and surplus or deficit, in accordance with the financial reporting framework applicable in Belgium. The balance sheet total of the financial statements as of the 31 December 2020 given is 2.811.070 euros, and there is a surplus of 28.363 euros. Based on our review, nothing has come to our attention that causes us to believe that these financial statements do not present fairly, in all material respects the equity, financial position and results of the Association as at December 31, 2020, in Belgium applicable accounting standards and in accordance with ISRE 2400.

Auditors: RSM Interaudit CVBA-SC SCRL, Chaussée de Waterloo 1151, 1180 Brussels

Accounting support: CFA, Rue de l’Industrie 11, 1000 Brussels

Income and Expenditure (as of 31 December 2020)

INCOME	2020	2019
Funding from Public Sector	€ 707,179.48	€ 470,122.54
EC projects	€ 707,179.48	€ 470,122.54
Funding from the private sector	€ 1,433,980.54	€ 2,127,573.11
Operation and Engagement	€ 679,450.29	€ 767,981.10
Capacity Building Programme	€ 321,767.70	€ 520,655.26
Co-funding to EPF projects	€ 8,049.71	€ 7,018.90
Contribution to EPF Campaigns	€ 0.00	€ 20,000.00
Contribution CONGRESS	€ 1,387.00	€ 428,500.00
PARADIGM	€ 109,520.83	€ 145,395.81
EFO EUPATI	€ 20,000.00	€ 0.00
EUPATI Programme	€ 293,805.01	€ 238,022.04
Membership fees	€ 18,900.00	€ 25,770.00
Contribution to Work Plan (Operations, Capacity Building and project development)	€ 18,900.00	€ 20,150.00
Contribution CONGRESS	€ 0.00	€ 5,620.00
Interest and other income	€ 53,833.21	€ 148,847.77
TOTAL INCOME	€ 2,213,893.23	€ 2,772,313.42

EXPENDITURES	2020	2019
Staff Costs (all projects, all campaigns)	€ 1,322,645.30	€ 1,293,982.23
Office backstopping and admin costs	€ 360,412.08	€ 300,950.72
Depreciation	€ 23,495.25	€ 25,623.71
Travel and subsistence (EPF staff)	€ 5,364.89	€ 45,159.49
Activities (other direct costs)	€ 473,321.93	€ 894,850.69
Annual General Meeting & Board Meetings	€ 10,921.18	€ 57,249.80
Summer Training & Youth Group meetings	€ 18,180.03	€ 66,144.45
Thematic Working Group Meetings/ Initiatives (Nutrition, Vaccines, Digital Health, Data Saves Lives, EHP, PAS)	€ 60,260.18	€ 150,504.87
Capacity Building Programme (delivery of training modules)	€ 17,521.45	€ 48,219.30
Congress 2019 /2021	€ 1,387.00	€ 302,086.21
Other costs linked to operations, project portfolio	€ 365,052.09	€ 270,646.06
Campaigns (direct costs)	-	€ 13,188.29
European Elections	€ -	€ 13,188.29
Bank and Financial Charges	€ 291.02	€ 1,567.39
TOTAL EXPENDITURE	€2,185,530.47	€ 2,575,322.52
TOTAL Surplus or deficit of the Year	€ 28,362.76	€ 196,990.90

Balance Sheet

ASSETS	2020	2019
I Current Assets		
Accounts receivable	€ 1,082,905	€ 139,038
Cash in bank and deposit	€ 1,647,982	€ 2,450,766
Pre-paid expenses	€ 19,479	€ 17,059
Total current assets	€ 2,750,366	€ 2,606,863
II Fixed assets		
Furniture, Fixtures and Fittings	€ 46,270	€ 51,893
IT equipment and software	€ 14,385	€ 15,627
Guarantees (rent and social security)	€ 50	€ 50
Total fixed assets	€ 60,704	€ 67,570
TOTAL ASSETS	€ 2,811,070	€ 2,674,434

LIABILITIES	2020		2019	
I Current Liabilities				
Accounts payable	€	142,369	€	208,206
Deferred income	€	1,563,377	€	1,337,460
Income to be allocated to project partners	€	-	€	-
Total current liabilities	€	1,705,747	€	1,545,666
II Reserves				
Funds brought forward	€	762,821	€	565,815
Social Reserve	€	300,000	€	300,000
Surplus or deficit for the year	€	28,363	€	196,991
Total reserves	€	1,091,184	€	1,062,806
Provisions	€	14,139	€	65,961
TOTAL LIABILITIES	€	2,811,070	€	2,674,434

Acknowledgement of Funds

EPF wishes to thank the European Commission /European Agencies

for their support in 2020 in relation to EPF's role in the following projects

	Public Contribution 2020	% of total income
TOTAL European Commission support to projects 2020	€ 494,674.93	
CHRODIS +	€ 32,198.85	1.4%
ComparEU	€ 35,441.74	1.5%
DigitalHealthEurope	€ 62,635.75	2.7%
EATRIS +	€ 11,262.66	0.5%
EFO EUPATI	€ 92,968.58	4.0%
EHDEN	€ 23,753.40	1.0%
EUPATI Reloaded (EIT)	€ 50,000.00	2.2%
EU-PEARL	€ 30,641.48	1.3%
Gravitate Health	€ 5,768.54	0.2%
H2O	€ 6,610.90	0.3%
IMMUCAN	€ 19,408.57	0.8%
Pharmaledger	€ 5,822.88	0.3%
PERISCOPE	€ 1,675.83	0.1%
PERMIT	€ 10,886.01	0.5%
PREFER	€ 2,799.79	0.1%
VAC-PACT	€ 102,799.98	4.4%

EPF wishes to thank the following donors for their support:

	Contribution to Operations	% of total income
Operational & Engagement - work plan 2020/ Project Development 2020	€ 706,400.00	
AbbVie	€ 5,000.00	1.5%
Amgen	€ 35,000.00	1.5%
Astellas	€ 15,000.00	0.6%
BMS	€ 50,000.00	2.2%
CSL Behring	€ 10,000.00	0.4%
Edwards Lifescience SA	€ 25,000.00	1.1%
Grunenthal	€ 5,000.00	0.2%
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	€ 67,500.00	2.9%
Novartis Pharma AG	€ 100,000.00	4.3%
Pfizer SANV	€ 25,000.00	1.1%
Philips	€ 10,000.00	0.4%
F. Hoffman-La Roche	€ 50,000.00	2.2%
Sanofi Aventis	€ 50,000.00	2.2%
Takeda	€ 30,000.00	1.3%
UCB	€ 25,000.00	1.1%
Vertex	€ 10,000.00	0.4%
Membership	€ 18,900.00	0.8%
Capacity Building Programme 2020	€ 400,375.68	
	Contribution to the CBP	% of total income
Alexion	€ 13,800.00	0.6%
Astellas	€ 15,000.00	0.6%
Baxter	€ 10,000.00	0.4%
EFPIA (DSL)	€ 151,575.68	6.5%
EIT Health (DSL)	€ 25,000.00	1.1%
ENHA (ILC)	€ 10,000.00	0.4%
Gilead Sciences Europe	€ 25,000.00	1.1%
GSK	€ 30,000.00	1.3%
Kyowa Kirin	€ 35,000.00	1.5%
LEO Pharma	€ 15,000.00	0.6%
Medtech (DSL)	€ 10,000.00	0.4%
MSD	€ 20,000.00	0.9%
Pfizer Inc	€ 25,000.00	1.1%

Servier	€ 15,000.00	0.6%
Congress 2021	€ 30,000.00	
	Contribution to CGS	% of total income
Fresenius-Kabi	€ 10,000.00	0.4%
Novo Nordisk	€ 20,000.00	0.9%
Patients Active in Research and Dialogue for an Improved Generation of Medicine "PARADIGM"	€ 322,025.38	
		% of total income
Innovative Medicines Initiative (IMI JU) PARADIGM EC Funding	€ 212,504.55	9.2%
Industry cash contribution (Amgen, Lundbeck, MSD, Pfizer, VFA)	€ 109,520.83	4.7%
Patient Academy on Therapeutic Innovation "EUPATI Programme"	€ 293,805.01	
		% of total income
Industry consortium (AbbVie, Amgen, AstraZeneca UK, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, DIA, F. Hoffmann-La Roche, GSK, Janssen, LEO Pharma, Merck, MSD, Novartis, Novo Nordisk, Pfizer, Shire, UCB, Takeda, VFA)	€ 293,805.01	12.7%
EFOEUPATI	€ 20,000.00	
		% of total income
Industry cash contribution (Novartis)	€ 20,000.00	0.9%
Other income (including reserves)	€ 53,833.21	2.3%
Total Income	€ 2,321,114.21	
Accrual and deferrals	-€ 107,220.98	
Total Income net of adjustments	€ 2,213,893.23	

EPF Funding Transparency (Jan - Dec 2020)	
Overall proportion of Industry and non-industry income	Private: 66.4% Public: 33.6%
Percentage of the highest contribution from a single Industry Donor	EFPIA 6.5%
Percentage of the highest contribution from a single Industry Company	Novartis 4.3%