EPF European Patients Forum

IMPACT REPORT

2022

Our 5-year roadmap

As we approached the end of our last seven year strategic plan (2014–2020), EPF engaged with our members to lead the development of a new strategic plan. **The EPF Strategic Plan (2021–2026)** guides our work for the next five years. It is the basis for a renewed approach towards advocacy, research participation, fundraising, a more vibrant communication plan and an enhanced project engagement strategy. EPF continuously expands 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 core strategic goals are:

Goal 1

Shaping a New European Agenda for Patients

Goal 2

Meaningful Patient Involvement in Co-Creating Better Health Policy, Practice, Research and Education

Goal 3

Digital Transformation that Delivers for Patients

Goal 4

Accessing the Healthcare We Need with No Discrimination

Goal 5

Strengthening Patient Communities Across Europe

Resilience in the face of an ever-changing society

While the challenges of 2020 were enough to put unprecedented strain on healthcare ecosystems across the globe, 2021 saw the world struggling with loss, uncertainty and trying to adapt to the new pandemic reality. Last year showed us how fragile the existing healthcare systems are and, at the same time, it deepened the gap in terms of access to medical services.

For us, at EPF, this meant intensifying our efforts to bring the patients' voice to the public conversation and embed it into the decision making process. While the COVID-19 pandemic response remained a top priority in the European health agenda, we focused our work on digital health, and we also engaged in extensive work on Artificial Intelligence, through both policy input and capacity building.

We are particularly proud to share the story of the 2021 EPF Congress – our second patient driven European Congress, focused on the digital transformation of healthcare. The four day virtual event generated solid background towards making meaningful patient involvement an integral part of health systems. The 2022 in-person edition of the Congress continues the conversation on digital transformation, bringing forward patient-centred solutions and in depth exploration of digital health challenges.

In 2021, our advocacy work focused on patient involvement across all levels of policy making, while empowering patients to speak their minds when it comes to the decisions that directly impact their quality of life. Following the joint efforts of the EU4Health Initiative, the European Commission confirmed the reinstatement of operating grants under the EU4Health Work Programme 2022. We welcomed the creation of the Health Emergency Preparedness and Response Authority (HERA), while underlining that HERA should serve the needs of patients and prioritise public health objectives. In a wider context we continued our work on access to healthcare and we actively engaged in follow-up advocacy on the Commission's Pharmaceutical Strategy for Europe.

Through a strategic approach in terms of involvement in European projects, across all projects we currently have in our portfolio, EPF managed to meaningfully engage patients in research work, patient advisory boards, education, while also raising awareness on topics such as health data, health technology assessment, or personalised medicine.

While having in mind the current challenges patients are facing, we are also building up the next generations of patient advocates and strengthening patient communities across Europe, through our Capacity Building Programme. The 2021 online Summer Training Course for Young Patient Advocates (STYPA) and the work of the Youth Group support young patient advocates to gain a voice of their own, while maximizing their leadership potential. Through the launch of the AI Knowledge Hub, doubled by the capacity building module on fundraising and engagement, we capacitated our members in becoming reliable partners in the face of change.

Looking back, it's safe to say we navigated through the ups and downs of 2021 by standing together and by learning to become more resilient.

We thank you for your untiring support to EPF and hope you will continue to work alongside us for the benefit of patients all across Europe.

Marco Greco
President, European Patients' Forum

Shaping a new European agenda for patients

In 2021 we witnessed the ongoing and far reaching impact of COVID-19 on society, healthcare systems, and patients' communities. As such, EPF actively engaged with its members, stakeholders and policymakers, to bring the patients' voice into policy and legislative initiatives, reflecting the immediate needs of the pandemic response, but also having in mind the sustainable development of health systems.

#SaveEUHealthNGOs Campaign

The EU4Health Civil Society Alliance campaigned since its launch in 2017 for a strong EU health policy. Following the adoption of the Eu4Health Programme in 2021, the alliance noted that the operating grants for health NGO's were removed.

The alliance mounted a campaign for their reintroduction, with the support of 20 health NGOs 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.

EPF will continue the dialogue with the Commission for securing a long term solution for the long-term viability of health NGOs.

Tweet

Stella Kyriakides
@SKyrlakidesEU

Civil society make an invaluable contribution to 🇪🇺 policy making and are key for building a strong European #HealthUnion.

#EU4Health is both a response to #COVID19 and a funding plan for the future.

As such, we will make sure that operating grants for NGOs are maintained.

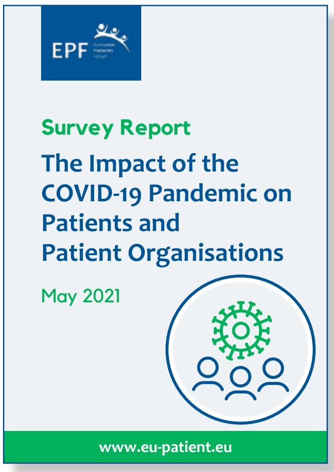
European Commission 🇪🇺 and EU Health

4:11 PM · Oct 25, 2021 · Twitter for iPhone

Statement on HERA

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. In June 2022, EPF was confirmed as a member of the HERA Civil Society Advisory Forum.

Survey report on the impact of the COVID-19 pandemic



EPF

Survey Report

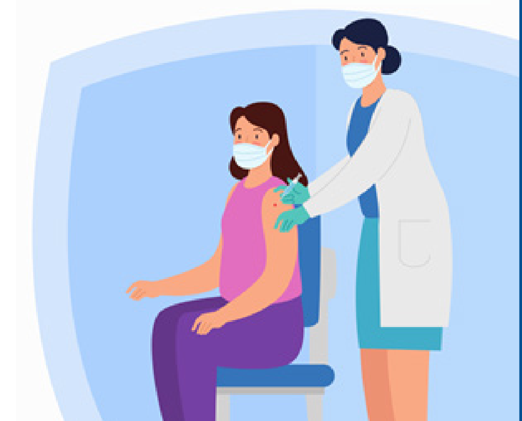
The Impact of the COVID-19 Pandemic on Patients and Patient Organisations

May 2021

www.eu-patient.eu

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.

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.



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

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 2021.

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.

Additionally, via the *Data Saves Lives* initiative, EPF has continued its ongoing work into fostering a trusted environment for multi-stakeholder dialogue on the responsible use and good practices of health data and digital health across Europe.

June 2021

Virtual Meeting of the EPF Working Group on Digital Health

August 2021

Response to the European Commission feedback consultation on artificial intelligence (AI) ethical and legal requirements

November 2021

The 2021 EPF Congress offered rich insights on the EHDS debate

February 2021
Statement on the EU’s Beating Cancer Plan

EPF issued a statement calling for a plan that works for patients and can lead to benefits for patients with other chronic diseases.

We called for:

- ✓ Further action on redressing inequalities on access to treatment
- ✓ Better opportunities for cross-border treatment including access to clinical trials across borders
- ✓ Recognition of health literacy as a vital patient empowerment dimension not only in prevention but across the patient journey

July 2021
Joint meeting of the PCWP and the US FDA’s Patient Engagement Collaborative

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 where its representative was a co-chair.

Our contributions:

- ✓ Activities around the revision of the ICH guidance on clinical trials, big data, and artificial intelligence
- ✓ Ideas & experiences exchange about patient involvement

Meaningful patient involvement:

Co-creating better health policy, practice, research and education

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.

89 responses from individual patients, patient advocates, patient organisations

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

The Medical Devices Regulation (MDR)	In Vitro Diagnostic Medical Devices Regulation (IVDR)	EU Clinical Trials Regulation
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.	EPF has closely followed and informed members of delays in the implementation of the Regulation. 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'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. Via our projects, the EU-PEARL project (aimed at delivering a more efficient and patient friendly adaptive trials platform), EPF has been engaging patients throughout to design solutions that meet their needs.

Involving patients in co-creating better health policy, practice, research and education

In 2021, the Patient Engagement Open Forum (PEOF) 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.

Patient Engagement open forum Into Reality

16 online sessions

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 2021. The three PABs are comprised of representatives of the three project disease areas and the PAB member's experience and expertise are embedded into the project processes and outcomes.

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 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 where we discussed patient involvement with Open Science, bringing patient issues to the forefront.

In 2021, EPF facilitated several meetings with the Patient Advisory Group (PAG) to advance on the Patient Engagement Platform (PEP) and secure Patient Engagement (PE) 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.

Projects ending in 2022

PERMIT
PERsonalised Medicine Trials

prefer.
PATIENT PREFERENCES

COMPAR-EU

EHDEN Patient Academy

In 2021, EPF hosted the inaugural season of the *#PERISCOPEMonthlyTalks* mini-series on our *podcast network*. 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.

over 350 downloads

42 average listeners

In 2021, EPF invested its 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.

6 projects and initiatives have EPF led Patient Advisory Groups

These include: EU-PEARL, COMPAR-EU, Health Outcomes Observatory (H2O), Gravitate Health, EATRIS Plus, and Data Saves Lives.

Digital transformation that delivers for patients

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**.

The virtual event **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. Its goal was 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.

12 advisory board members

2021 EPF Congress

470 registrants

14 programme committee members

152 AVG number of participants per session

50 speakers

4 virtual days

The Congress speakers

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

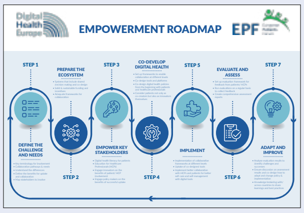
Jan-Philipp Beck
CEO of EIT Health

Digital Health Europe

DigitalHealthEurope came to an end in September 2021. The project results were well received by both wider public and external evaluators. At the final conference on 28–30 September 2021, *EPF led a session* on Patient Centred Health and Care.

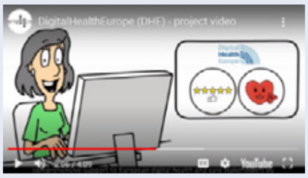
DigitalHealthEurope provided comprehensive, centralised support to the digital transformation of health and care priorities of the Digital Single Market.

EPF’s key achievements



Developing a *Patient Empowerment Roadmap*

Writing a *White Paper on boosting active cooperation between patients and healthcare professionals*, formally outlining our recommendations



Delivering a general audience video on the project’s key achievements

Launch of AI Knowledge Hub with EU AI Fund & the Understanding AI Webinar Series with Members

The overall objective of the webinar series is to shed light on AI in healthcare. The series particularly focusses on the possible advantages but also risks and pending questions for patients, while exploring specific implications for the healthcare sector.

- The AI Knowledge Hub is a place where EPF’s work on AI, as well as key publications, are stored for the benefits of its members and community at large.
- *“AI in Healthcare: From Science Fiction to Reality”* : AI in healthcare and presenting an overview of the NEF European AI Fund.
- *EPF #AI in Healthcare: Ethics and Implications*: ethical challenges raised by the deployment of artificial intelligence in healthcare patient-reported outcomes (PROs) in health research

Data Saves Lives

The *Data Saves Lives* project, launched in 2019, continued raising awareness among patients about the importance of health data.

Key stats:

- 1 Congress session – launching the first version of the Data Saves Lives toolkit
- 10 blog posts
- 1 tweet chat
- 1 webinar Developing more meaningful health interventions through the use of patient-reported outcomes (PROs) in health research
- 1 DSLCoffeeMorning chat

Accessing the healthcare we need with no discrimination

Patients’ access to cross-border healthcare

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. Also, the EPF Universal Access Working Group met virtually in April to discuss ongoing work.

EPF’s work on the Cross-Border Healthcare Directive

January 2021 – The European Commission undertook an evaluation of the functioning of the Cross-Border Healthcare Directive

February 2021 – EPF provided input to the public consultation

March 2021 – EPF participated in evaluation meetings and organised a webinar jointly with the Commission for our membership in March

Pharmaceutical Strategy

EPF actively engaged in follow-up advocacy on the Commission’s **Pharmaceutical Strategy for Europe**, adopted in November 2020. EPF proposed amendments on the European Parliament’s draft report on the Pharmaceutical Strategy, several of which were included in the final report. Additionally, EPF responded to the public consultations launched for this purpose, having in mind the patients’ perspective.

As part of the implementation of the Strategy, the European Commission is 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.

The Pharmaceutical Strategy also included **an extension of the mandates of the EMA and the ECDC**. EPF responded to the *European Commission’s public consultation on a strengthened role for the agency*. EPF contributed to the *European Commission’s public consultation on a reinforced mandate of the ECDC*, highlighting the need to include chronic diseases.

EU legislative review & amendments proposals

WHO Regional Office for Europe’s consultation on access to medicines

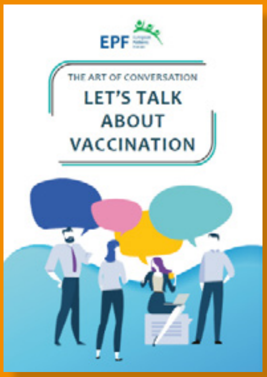
Participating in the OECD PaRIS project’s International Patient Advisory Board

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.

Let’s Talk About Vaccination

January 2021 – Launch of the “Let’s talk about vaccination” guide

July 2021 – Issue of a *statement* on the importance of vaccination of healthcare professionals for patients



October 2021 – EPF-led tender project “VAC-PACT” came to an end

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**.

Patient Safety

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.

Nutrition

On **nutrition**:

✓ We 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 set the ground for further work on good practices to involve patients in nutritional guideline development.

✓ We 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.

The Youth Group

In 2021, the Youth Group:

- Launched the *Sexual Health and Well-Being Project*.
- Held the **Spring and Fall Youth Group Meetings online**
- Provided a new youth representative for the EPF Board – Erin Davis

As part of the Sexual Health and Well-Being Project, the Youth Group:

- Conducted a survey
- Produced an article (interview with Moira Tzitzika a psychologist and psychosexologist certified from the European Society of Sexual Medicine
- Published a podcast episode dedicated to the project

europeanpatients'forum
Youth Group

Strengthening patient communities across Europe

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.

24 participants

26 patient organisations

6 thematic webinars

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:

100% 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).

85.6% of the participants declare to **feel considerably more confident about their fundraising skills (8+, in a scale from 1 to 10)**.

100% of respondents declare they have **improved their level of experience in conducting engagement activities as a result of the learning journey** (7+, in a scale from 1 to 10).

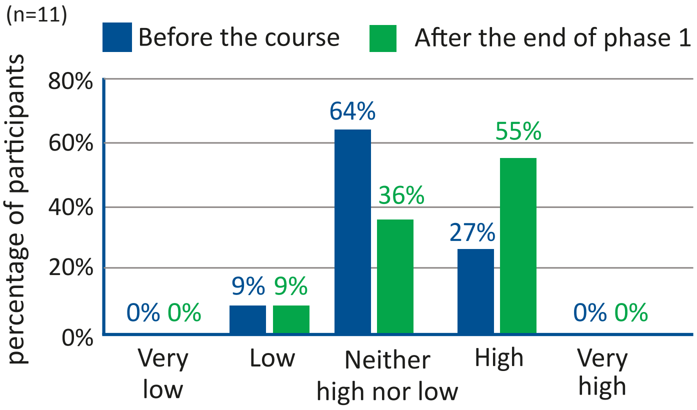
78.5% have declared **feeling more confident about their engagement skills** (8+, in a scale from 1 to 10).

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

The Summer Training Course for Young Patient Advocates (STYPA) 2021 took place online, 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 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 in constant touch with the trainers and EPF staff.

How do you rate your power and leadership abilities as an advocate?



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

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.

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

33
participants

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

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

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

New additions

2021 saw some interesting achievements and wonderful additions to the organisation

EU Patients Podcast – Season 1

- 24 episodes
- 28 countries tuned in
- 1500+ downloads in Season 1

The EU Patients' Podcast

New projects

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.

CORE-MD
Coordinating Research and Evidence for Medical Devices

New members

FH Europe
The European FH Patient Network

EUROPA UOMO
The Voice of Men with Prostate Cancer in Europe

Global HEART Hub
The Alliance of Heart Patient Organisations

International Alliance of Dermatology Patient Organizations
GLOBALSKIN.ORG

So far in 2022:

EPF Congress 2022

2022 EPF Congress

Anca Toma joins as Executive Director as of March 2022

Launch of the 101 online self- learning course on Advocacy for young patients advocates

New members

World Alliance of Pituitary Organizations

napo

SOSTE

Launch of the Master with Cattolica University on International Patient Advocacy

UNIVERSITÀ CATTOLICA del Sacro Cuore
ALTEMS
ALTA SCUOLA DI ECONOMIA E MANAGEMENT DEI SISTEMI SANITARI

Looking forward to 2023…

EPF's 20 Year Anniversary

The patients' voice has never been more important than right now.

We will continue to work with our partners – healthcare professionals, policy-makers, public health NGOs, industry, researchers, regulators and many others – in our mission to empower patients to take an active role in improving healthcare. Whether near or far, working remotely or at the office, our doors and inboxes are always open.

Join us in making an impact for sustainable and equitable patient-centred health systems of the future!

#WeAreEPF

The European Patients' Forum (EPF) is an umbrella organisation of patient organisations across Europe and across disease areas. Our 78 members include disease-specific patient groups active at EU level and national coalitions of patients.

EPF European Patients Forum

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