

# EPF 2019 Annual Report

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Driving Better Health for Patients in Europe



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# Foreword

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This Annual Report outlines the work and achievements made in the areas of empowering and enhancing the patient voice in a number of different ways. It also covers our cross-cutting activities aimed at strengthening our collective impact to ensure that all patients in Europe have access to high-quality and related care.

The success of our work is down to our members' engagement, by bringing issues that matter to patients to our attention: their input always makes us stronger, and we will continue to strive to meet their needs, by enabling them to benefit from and also contribute to our collective patients' voice.

One of our highlights has undoubtedly been our campaign for the European Parliament elections – we actively conveyed our ambition and determination to all EU leaders, asking them to sign our manifesto and commit to ensuring health and patients' rights are high on the EU health policy agenda post 2020.

The renewal of the European Commission and Parliament represent an opportunity to embed the patient voice even more firmly in EU policy over the new mandate extending to 2024. To this end, we look forward to building on our Campaign outcomes to achieve an even stronger collaboration with key Commission directorates and the Parliament.

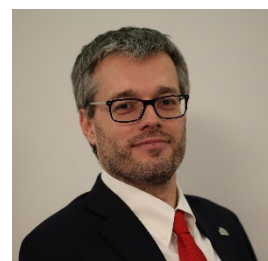
We are also proud to showcase another success story: the EPF Congress, the first ever European Congress on patient involvement driven by the patient community. We could not be happier with the turnout and fruitful outcome of the many lively discussions, as well as the inspiring and often moving stories heard over these three days. We must now look to the future: a lot of groundwork towards making meaningful patient involvement an integral part of health systems has been done, and EPF will take forward key outcomes of the Congress in different ways over the next months.

In 2019 we intensified our work on vaccination from the perspective of patients, extending our work on information resources while also winning an important EU tender for a pilot project; and on digital health and health data, where we kicked off two projects (EHDEN and Digital Health Europe) and a multi-stakeholder initiative (Data Saves Lives). The three initiatives contribute to the need to act on such topics from a patient perspective.

We have also strengthened our work on Capacity Building, with yet another successful module on Empowering Leadership and Positive Governance and another edition of our Summer Training Course for Young Patient Advocates (STYP). Our Youth Group members are increasingly active on the national and EU level, getting involved in local activism, EU-wide initiatives such as the European Health Parliament, and also taking active part in coaching/ mentoring young patients to embark on the journey to advocacy (e.g., during STYP).

Ideas are being shared, challenges and opportunities are being identified to advance patient-centred health across Europe. As demonstrated at our Congress patient involvement is a well-known concept, however it is still far from being a reality. There is a lot of work to do, but we can do it if we are in this together

EPF President **Marco Greco**



# 2019 Key Events

January	February
<p>Kick off meetings: EHDEN, Digital Health Europe</p> <p>Kick-off of new multistakeholder initiative on lay summaries of clinical trial results</p> <p>EPF contributes to EESC public hearing on Digital Health Literacy</p>	<p>EPF webinar “How patient organisations can benefit from pro bono legal support?”</p> <p>Capacity Building Leadership module kick-off</p> <p>PACT meeting “EU collaboration in health for better EU collaboration in health for better access: Taking stock and looking to the future (MEP Interest Group on Access to Healthcare and PACT meeting)</p> <p>EPF Manifesto on Vaccination published</p> <p>OECD PRIMs Working Group meeting</p> <p>DG Santé meeting on ethical and legal issues and stakeholder relations of European Reference Networks</p> <p>EPF Cluster on Nutrition coordination meeting</p>
March	April
<p>Meeting: EPF Digital Health Working Group</p> <p>Event: “Fighting Discrimination at Work” MEP Interest Group on Brain, Mind and Pain</p> <p>EPF Universal Access to Healthcare Working Group web meeting</p> <p>AGM of the STAMP Working Group on access to medicines</p>	<p>European Health Parliament Final Plenary session</p> <p>European Parliament event "on shortages of essential medicines</p> <p>EPF Youth Group Annual Spring Meeting</p> <p>Kick-Off Meeting - Stakeholder Dialogue Platform on Pricing of Medicinal Products (EURIPID)</p> <p>EPF AGM and Leadership meeting</p>
May	June
<p>CIOMS Working Group XI on Patient Involvement in Development and Safe Use of Medicines</p> <p>EPF Webinar on MDR/IVDR transition period for EPF members</p> <p>JA CHRODIS+ General Assembly and Conference</p> <p>EPF Multi-stakeholder meeting on employment and non-discrimination</p> <p>EPF vaccination initiative: patient group meeting</p> <p>EPF-COPAC vaccination workshop, Cluj, Romania</p>	<p>HTAI Annual Meeting</p> <p>Patient Medtech dialogue workshop: “Patient involvement in the lifecycle of medical devices”</p> <p>EPF Industry roundtable</p> <p>OECD conference on health systems performance</p> <p>OECD Health Quality and Outcomes WG meeting</p> <p>EMA PCWP virtual meeting</p>
July	August
<p>EPF Summer Training for Young Patient Advocates (STYPAs)</p> <p>PACT Conference “EU cooperation in health: 'The future of health in the EU: United we stand strong'”</p> <p>Mental Health Europe-led meeting on transparency of financial interests of healthcare professionals</p> <p>EU4HEALTH meeting co-led by EPF and EPHA</p> <p>EPF webinar on “Patient Involvement in Clinical Nutrition Guidelines”</p>	<p>EPF meeting with EIT Health on patient involvement in innovation</p>
September	October
<p>EU Patient Group Cluster web meeting on Nutrition</p> <p>EPF Capacity Building Face-to-Face meeting</p> <p>2<sup>nd</sup> PARADIGM Open Forum on Patient Engagement</p> <p>Data Saves Lives Community Meeting</p> <p>EPF Digital Health Working Group</p>	<p>European Health Forum Gastein</p> <p>EPF-Medicines for Europe Dialogue</p> <p>Universal access to healthcare multi-stakeholder event</p> <p>COMPARE-EU project AGM</p>

Global Vaccination Summit EURIPID Stakeholder Platform meeting EMA PCWP meeting	EC-EPF Webinar on the application of the medical device regulation EPF Digital Health working group EPF-BAG Selbsthilfe vaccination workshop, Berlin CIOMS WG XI meeting
November	December
EPF Congress PACT relaunch of MEP interest group on access OECD PaRIS Working Group meeting OECD HCQO Working Group meeting ECDC high-level meeting on antibiotic resistance EMA meeting with eligible patient organisations CHRODIS PLUS EU Policy Dialogue on Employment and Chronic Conditions in the European Parliament	EPF Universal Access to Healthcare Working Group web meeting EPF meeting with DG Sante on cross-border healthcare EPF speaks at Symposium on Value for patients: the path forward in healthcare Joint Action on medical devices final conference

## 2019 EPF Communications at a glance

**9094** *followers on Facebook*



**9864** *followers on Twitter*

**2549** *LinkedIn followers*



**1120K** *impressions on Twitter*

**1219** *EPF newsletter subscribers*



**13** *Videos*



**European Patients' Forum** @eupatientsforum · Nov 14, 2019

Our motivation and capacity to bring what matters to patients to the EU agenda and to all healthcare systems has never been stronger, and together we will succeed. 🙌 A big thank you to everybody for being part of [#EPFCongress19](#) in person and virtually! [#ForPatientsWithPatients](#)

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**Meaningful patient involvement** is an underused resource in the development of innovative, patient-centred healthcare design and delivery. Yet developments at a European level remain piecemeal and limited in reach.

## *Nothing for patients without patients* (EPF President Marco Greco)

EPF Congress, the very first European Congress on patient involvement organised by patients for patients, aimed at bringing about a narrative of real and lasting change in attitudes, knowledge and resources for participants.



The Congress saw the attendance of over **300 delegates**, including patient advocates, healthcare professionals, health NGOs, academics, members from industry and national institutions. Real-life stories on **self-management**, case studies showing the **added value of patients' insights**, and the importance of embedding patient involvement in **medical education** were among the topics discussed.



*Plenary Session: Opening Remarks (in the picture David Lega, MEP)*

The parallel sessions offered an opportunity to look at specific issues related to patient involvement with a more in-depth perspective.

**High-level speakers** included **David Lega**, MEP, **Hans Kluge** (WHO Europe Regional Director), **Vytenis Andriukaitis** (Former Commissioner for Health and Food Safety), and **Anne Bucher** (Director General for Health and Food Safety).

EPF will reflect on all the outcomes in the coming months and ensure there is follow-up, which may take the form of a second congress.

You may find more pictures [here](#), a short video [here](#) and our Congress report is also available for your download [here](#).

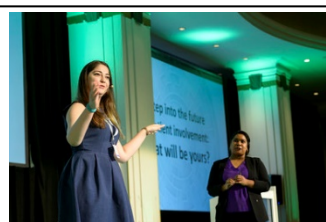
EPF  
Congress

Advancing meaningful  
patient involvement

Summary report

### NUMBERS AT A GLANCE

+1	Report
+ 80%	App downloads
+ 147K	Twitter impressions
+ 1000	Web streaming views
+ 5	Media mentions
+ 2	Videos



# Policy and Advocacy



#europeforpatients

## HIGHLIGHT

### 2019 EU Elections Campaign

#### Putting What Matters to Patients at the Heart of EU Policy

*This year EPF called on political leaders of the EU, Parliament candidates and the future Commission, to take action and ensure health is an EU policy priority in the 2019 mandate.*

Our manifesto outlined the following five priorities:

- Patients' **access to the healthcare** they need **with no discrimination**
- Patient empowerment, to be supported by new, comprehensive and **up-to-date legislation on patients' rights**
- Europe's future **digital health tools** and systems to be **patient-driven**
- Patients to be involved as equal and fully-resourced **partners in driving better research**
- Patient organisations' **involvement in decision-making**, both at EU and national level



#### ABOUT THE MANIFESTO

Translated into **8 EU languages** and gathered a total of **60 signatures** from MEP Candidates. In addition **5 patient videos** were created to lend a human face to each policy priority.







## PARTNERSHIP: EU4HEALTH

Launched jointly by EPF and the European Public Health Alliance (EPHA), EU4Health brings together organisations that share the vision of a Europe where all people are as healthy as they can be throughout their lives. The 7 key asks to the European Commission were outlined in a joint statement released in April 2019. The partnership will continue its active advocacy towards the new EU Institutions

### 1. EPF calls for a strong EU health agenda and serious attention to universal health coverage within sustainable health systems

EPF continues to advocate for truly universal access to healthcare, including medicines, as one of our core priorities. Supported by the **universal access to healthcare working group**, in its [reaction to the 2019 European Semester country specific recommendations](#) published in June, EPF promoted recommendations set out in its Roadmap to achieving universal health coverage and emphasised that health must be made a political priority both at European and national levels to enhance healthcare access and sustainability.

EPF's **position on the value and price of innovative medicines** underwent further revision during the year and is due to be launched in the first half of 2020. We continued to advocate for equitable access to and patient-focused information on **biosimilar medicines**, participating in several meetings around this topic. EPF was also invited to participate in the stakeholder forum of EURIPID, the EU-funded collaboration between Member States that aims to increase **transparency** in medicines pricing. The group held its two first meetings during the year.

In response to the anticipated European Commission **Reflection paper: Towards a sustainable Europe by 2030**, published in January 2019, in the context of the 2030 Sustainable Development Agenda and Future of Europe debate, EPF coordinated the publication of an [immediate reaction to the reflection paper](#), supported by **EU4Health**. As a member of **SDG Watch Europe**, EPF also actively contributed to the alliance's reaction to the paper. EPF was also active in the activities of the **Patient Access Partnership** and preparations for the '[Future of Health in the EU](#)' conference it organised in July.

### 2. EPF ensures patient insight into the European regulatory framework on medical devices

In the ongoing **implementation of the EU Medical Devices Regulation**, EPF was involved in two working groups facilitated by the European Commission – one on clinical investigation and evaluation and the other on post market surveillance and vigilance. In this context, EPF responded to a consultation on the **new manufacturer incident report**, a document issued and updated regularly which was developed to facilitate information exchange on safety monitoring.



To support our members' understanding of the new regulatory framework on medical devices and ongoing implementation activities, EPF organised a **webinar** in May 2019 highlighting progress but also concerns. EPF also had preparatory discussions with the European Commission to assess the information needs of European patients with respect to the new regulation and will organise a large outreach webinar in 2020 on what concretely will change for patients once the new medical device regulation, also explaining new safety and quality assurance modalities.

In collaboration with doctors – the European Society of Cardiology and the Biomed Alliance - these concerns and in particular the need for investment to ensure that the regulation is effectively implemented on time (May 2020) was shared with EU health ministers prior to the June 2019 Council meeting as well as the permanent representations in Brussels in an [Open Letter](#).

2019 also marked an important revision and consultation with our members of our 2016 **position on the value and price of innovative medicines**, due to be published in the first half of 2020.

### 3. HTA (Health Technology Assessment)

Under the Romanian and Finnish Presidencies, 2019 saw the continuation of negotiations among Member States on the legislative proposal on HTA collaboration at European level. EPF continued to closely monitor and actively contributed to debates such as the HTA Network Stakeholder Pool hosted by the European Commission and the EUnetHTA Stakeholder Forum (respectively in January and April 2019). EPF also contributed to discussions on the potential that real-world data may bring to decision making in HTA and the impact of the **EU Medical Devices Regulation** on the future of HTA in medical devices. EPF participates in HTA debates also through HTAi, the dedicated global society, where EPF's Senior Programme Manager Valentina Strammiello holds the role of vice-chair of the Patient and Citizen Involvement Interest Group (PCIG). In 2019 we actively participated at the **HTAi Annual Meeting**, and contributed to discussions focussing on the future of **HTA in Europe post 2020** and best practices in setting up **HTA systems in low middle income countries**, and worked to promote **patient involvement in HTA**.

### 4. EPF active on medicines development, RESEARCH, regulation and safe use

EPF continued as an active member of the **Patient and Consumer Working Party** of the European Medicines Agency. In 2019 the PCWP adopted a new mandate and working procedures. Due to the relocation of EMA to Amsterdam as a consequence of Brexit, fewer meetings were held, but the PCWP still managed to address topics from antibiotics to vaccination.

EPF responded to two important consultations: on the [EMA's Strategy on Regulatory Science to 2025](#), outlining the Agency's priorities for the coming years, where our position makes clear the need for structured and systematic involvement of patients in the implementation of every goal; and the EMA's proposed key principles for **electronic product information**, where EPF stressed that the electronic information should be



Key Principles for EU Electronic Product Information on Medicines  
EPF Response to the EMA Consultation

**Principle 1: Definition of "ePPI" (Electronic Product Information)**  
Proposed definition: "ePPI is a structured, accessible product information for medicines (i.e. SPCs, PI and labeling) in an electronic format created using the common EU electronic standard, ePPI is subject to electronic handling and allows dissemination via the web and other media, and/or print."  
EPF agrees with this definition.

**Principle 2: Common EU electronic standard**  
EPF supports the definition of a common EU electronic standard for ePPI. As stated in the key principles (see 1.1.1.1), a common standard is essential to ensure that patient information is consistent and used in different parts of the EU.

**Principle 3: Supporting access to information**  
EPF supports the objective as part of a comprehensive strategy to ensure all patients across the EU have access to medicines information. EPF considers that medicines information is essential information to a comprehensive patient engagement that enables health literacy, shared decision making and effective self-management. Additionally, patient data and more generally data for health information science, with medicines information is the most high. According to the 2016 Framework, the EU response aims to "enable information science and other areas and ensure that they are distinguished from low quality information sources, i.e. Web 2.0 sites".

Medicine product information – particularly the package insert – is a key and essential source of information available to patients on the medicines they take. It is particularly important to ensure the availability of up-to-date information on all changes, whether regarding safety, benefit/risk, dosing or other factors that patients need to know and, ideally, act upon.

Information on medicines must be released and available through authoritative, public sources such as the EMA and the national competent authorities. We agree that the development of ePPI by public authorities (or expert bodies as part of public-private partnerships) is necessary and other, possibly commercial, bodies doing this need, subject to the rules and national authorities, should ensure that ePPI will be developed with patient health and patient safety as the primary goal, and is critical to ensure patient and public trust.

Please also see below, under "Other comments".

seen as one part of a comprehensive strategy to ensure comprehensive, high-quality, up-to-date, understandable information on medicines for patients.

EPF President Marco Greco, who has contributed as patient representative to the work of the Pharmacovigilance Risk Advisory Committee for six years, was elected to the Agency's Management Board in June 2019. Our Director of Policy Kaisa Immonen, who has been co-chairing the group since 2016, was re-elected as co-chair for a second three-year term.

For the second year, EPF participated in the [CIOMS Working Group XI on Patient Involvement in Development and Safe Use of Medicines](#), which is working on a comprehensive global guide to support patients' involvement across medicines development, regulation and safety monitoring.

#### PROJECT: PREFER - PATIENT PREFERENCES IN BENEFIT-RISK ASSESSMENT DURING THE DRUG LIFE CYCLE

An IMI2 RIA (Research and Innovation Action), PREFER carried out the following activities in 2019: the launch of **three core clinical patient preference case studies** in three disease areas: **Lung cancer, rheumatoid arthritis and neuromuscular disorders**. In addition, both academic and industry partners have added studies to the [PREFER portfolio](#) that will help us cover different disease areas, methods and research questions. Results will be gathered in 2020.

EPF continues to monitor the new **EU Clinical Trials Regulation**, and this year has been developing together with a multi-stakeholder working group a new **guidance document for implementing the "lay summaries" of clinical trial results**. We continue to address patients' involvement in clinical research also through several projects.

As stated in [our position](#) on the **EU Clinical Trials Regulation**, it is of vital importance for patients to be partners in the research and development of new therapies, starting from the earliest stages and focusing on patients' needs and preferences. This topic was prominently discussed at the EPF Congress, and we also addressed it concretely through our involvement in several EU-funded projects, amongst them our flagship IMI project, PARADIGM.



#### PROJECT: EU PEARL

Launched in November 2019, EU-PEARL aims to revolutionise the way we do clinical trials by making them more efficient and patient friendly.

**In 2020** EPF will contribute to the governance aspects of this project. The rationale for EPF contribution relies on the need to bring the **patient perspective** on aspects related to ethics, legal and non-technical aspects of the platform governance, sustainability and multi-stakeholder collaboration, and building on the role EPF plays both in PARADIGM and EHDEN. EPF will also lead on the patient engagement task and on delivering a **patient engagement platform**, which will be completed at the end of the project.



#### PROJECT: IMMUCAN (INTEGRATED IMMUNOPROFILING OF LARGE ADAPTIVE CANCER PATIENTS COHORTS)

Launched in March 2019, IMMUCan aims at identifying potential predictive biomarkers for immunotherapy, towards an inclusive and integrated European immuno-oncology platform. EPF is co-leading the dissemination and communication activities of the project. In 2019 this involved co-creating the IMMUCAN **social media channels**, an **internal project newsletter**, a **dissemination strategy** and a **leaflet**.

EPF also created an **online guide for patients** to understand the project and their involvement before signing the consent form



## PARADIGM

(Patients active in research and dialogue for an improved generation of medicines)

The mission of this IMI-funded project (March 2018 - August 2020) is to participate in the **co-creation of a sustainable ecosystem** that allows **systematic, meaningful and ethical patient engagement in medicines R&D**. PARADIGM is a public-private partnership co-led by EPF and EFPIA.

*“PARADIGM will be remembered as a driver for bringing patient engagement in medicines R&D to the next level, but also as a project that united stakeholders that have merged and are now moving in the same direction.”*

**Mathieu Boudes, PARADIGM Coordinator**

## Activities

- Development of a [framework to monitor and evaluate the impact of patient activities](#)
- Peer reviewed article: [Evaluating the "return on patient engagement initiatives" in medicines research and development: A literature review.](#)
- Video: [Mathieu Boudes, PARADIGM Coordinator explains what is PARADIGM at the DIA Global meeting 2019](#)

[Event highlights](#) and  
[video](#)



## Patient Engagement Open Forum

Co-organised by PARADIGM, [PFMD](#), and [EUPATI](#) in September 2019 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 and silos that are often present in patient engagement work.

<b>200+</b> Attendees	<b>140+</b> Organisations	<b>1,000+</b> Livestream views
<b>7</b> Interactive sessions	<b>100,000+</b> Social media exposure	<b>Events hashtags</b> <b>#PEOF2019 &amp; #PatientEngagement</b> trended in Belgium for two days

The 2-day agenda offered a deep dive into some ongoing patient engagement work done by many collaborative initiatives. Topics ranged **from tools and recommendations for effective patient engagement, methods for monitoring and evaluation of impact and outcomes in patient engagement activities, and fair market compensation for patient input to interactive sessions on assessing good practices in patient engagement and more.**

The European Patients' Academy on Therapeutic Innovation (EUPATI) has concluded its bridging-period and first year of the [IMI-EFOEUPATI \(Ensuring the Future of EUPATI\)](#).

[illegible]

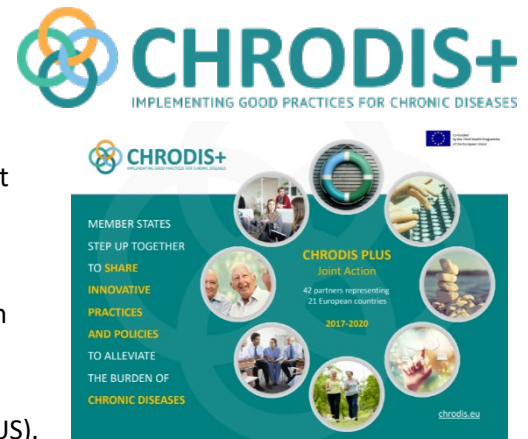
- Development of a five-pillar sustainability model, supporting the strategic objectives for 2020 – 2025.
- Graduation of 53 new EUPATI fellows and the launch of the 4<sup>th</sup> cycle of the EUPATI Patient Expert Training Course with 60 participants.
- Launch of [EUPATI Fundamentals](#), training on patient engagement for professionals from pharmaceutical industry and academia.

More information on the EUPATI 2019 highlights can be found [here](#).

## 5. EPF promotes better inclusion of people with chronic conditions in the workplace

Building on [existing positions and materials](#) on the topic, EPF gathered different stakeholders together in a [multi-stakeholder meeting](#) which took place in May to discuss challenges but also methods and tools to improve inclusion in the labour market for people with chronic conditions and combat discrimination, debating the need for collaboration between stakeholders from different sectors and a societal mindset change.

On a political front, EPF shared patients' experience and recommendations for improved inclusion and non-discrimination in employment in a [policy dialogue on employment and chronic conditions](#) held in the European Parliament in November and organised by the EU Joint Action on Chronic Diseases (CHRODIS PLUS).



To complement EPF's evidence base on this topic, EPF's youth group conducted a **survey on work and youth** (WAYS project) in 2018/2019, which aimed to provide useful insights into the experience of young patients' in the field of employment. Preliminary results were presented in a poster at the General Assembly of the Joint Action on Chronic Diseases and at the EPF Multi-stakeholder meeting on employment and non-discrimination mentioned above. A complete report of survey findings is expected to be published early 2020. A factsheet and a video with the main survey outputs will also follow.

## 6. EPF strives to shape digital innovation that prioritises patients' needs

EPF worked on digital health on two fronts: policy advocacy, and through our involvement in several projects. In 2019, two new EU projects kicked off: the IMI 2 projects **European Health Data & Evidence Network (EHDEN)**, and **Digital Health Europe**. 2019 also saw the launch of a new ["Data Saves Lives" Platform](#). With the support of the **EPF digital health working group**, in 2019 we worked on a **briefing on digital health** for our members, to be published early 2020. Similarly, findings of the survey conducted on **electronic health records** were analysed and a **report** will also be published in early 2020. Patient-driven digital health also featured as one of

### PROJECT: CHRODIS+ JOINT ACTION

(JA CHRODIS +) 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**.

In 2019, EPF co-organized and visited 5 pilot sites (in Croatia, Greece, Finland, Serbia and Slovenia), contributing to the overall aim to foster high-quality care for people with chronic diseases in Europe. Within the framework of increasing **patient involvement**, these visits aimed at **disseminating and communicating** activities that included national stakeholders and **presenting a midterm analysis** of the implementation of the pilots.

Furthermore, **EPF** contributed to the **conduction and revision of the CHRODIS + Toolbox on Employment & Chronic Conditions** and **actively collaborated with other project partners in the dissemination and communication stream** through social media and other promotional activities.

#### Additional activities

CHRODIS+ Conference (May 2019)



the five priorities of [our European Elections Manifesto](#), to be taken forward with the new EU Institutions from 2020 onwards.

In 2020, EPF will focus its advocacy activities in this field on artificial intelligence – one of the Commission’s priority areas – as well as real-world data and evidence. The latter links closely to the strategic objectives of the European Medicines Agency. We will continue to follow and engage with the European **Commission’s digital health strategy**. We will work with our working group and our members on patients’ principles on digital health to inform our advocacy. EPF was invited again to be a member of the European Commission’s **eHealth Stakeholder Group** that is relaunching in 2020.



### PROJECT: DIGITAL HEALTH EUROPE

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 - on boosting active cooperation between patients and health and care providers.



### PROJECT: EUROPEAN HEALTH DATA & EVIDENCE NETWORK (EHDEN)

An IMI2 project, **EHDEN**, aims to generate reliable evidence from health data at scale in Europe. This is achieved by developing a federated network of data partners. The project trains and certifies SMEs (Small medium enterprises) that will provide support to standardize data to a common data model known as [OMOP](#)

Last year EPF led the production of the first version of the **value proposition for patients and patient organisations**.

# #DataSavesLives



### DATA SAVES LIVES INITIATIVE

Lead by EPF Data Saves Lives is a multi-stakeholder initiative with the aim of raising wider patient and public awareness about the importance of health data, improving understanding of how it is used and establishing a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe.

#### 2019 activities:

- Implementation and launch of the **DSL website** by the support of a digital agency and the content partner at the EPF Congress
- Creation of a **“health data community”** with a first meeting made of ~50 key leaders from the EU health data environment
- Setting up the **governance** of the initiative (Advisory Board, Editorial Board, Comms sub-group)

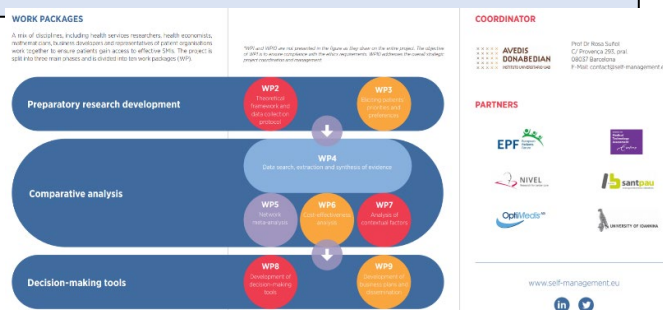


## PROJECT: COMPAR-EU (COMPARING THE EFFECTIVENESS AND COST EFFECTIVENESS OF SELF-MANAGEMENT INTERVENTIONS IN FOUR HIGH PRIORITY CHRONIC CONDITIONS IN EUROPE)

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**.

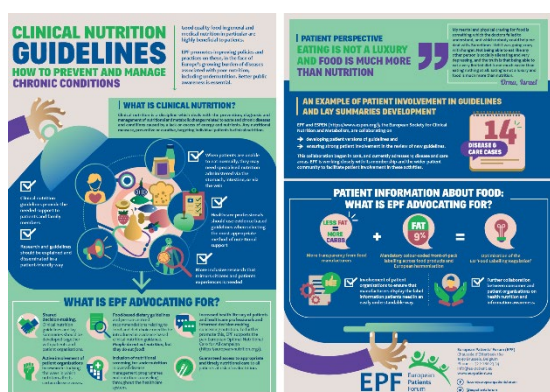
In 2019, EPF has successfully set up the **COMPAR-EU Patient Panel (PP)** – a group of **15 EPF member representatives** from **8 different countries** to “translate” core outputs into lay language and ensure that the patient perspective is embedded in project outputs. Currently, the PP has 15 members representing 8 countries.

Furthermore, **EPF actively collaborated with the other project partners in the dissemination and communication stream through various social media channels and other promotional activities.**



## 7. Patient Involvement in Clinical Nutrition

In past years, EPF has made significant progress raising awareness of the role of nutrition and diet in managing chronic and long-term conditions. In 2019, EPF focused its efforts on the application of **meaningful patient involvement in clinical nutrition**.



Our actions and effective involvement in the multi-stakeholder **European Nutrition Health Alliance** have contributed to improving the receptiveness and willingness of the clinical nutrition sector to involve patients. Promisingly, at the end of 2019, the ENHA board of trustees welcomed Ms Tunde Koltai, a **new trustee representing patients** – a milestone in better involving patients and meeting their needs in this field.

In July, EPF organised a webinar to inform patients on the benefit and value of patient involvement in developing clinical nutrition guidelines and lay summaries. Following this webinar, through a call for interest facilitated by EPF, patient representatives will be involved in the development of **clinical guidelines for 14 disease and care areas** developed by the European Society for Clinical Nutrition and Metabolism (ESPEN) in coming years. In 2018- 2019, patient representatives were involved in the development of two new clinical guidelines, one on home enteral nutrition and the other on home parenteral nutrition. Both guidelines will be published in 2020. The first lay version of a clinical guideline (on Inflammatory



bowel disease) is also underway. Lay summaries of guidelines on cancer, liver and neurology are also planned for 2020-2021.

In consultation with EPF's cluster of members working on nutrition, in November 2019, EPF published a [factsheet](#), summarising our position and key advocacy messages about information to patients on food and nutrition and the need for summaries of clinical nutrition guidelines for patients. Through the factsheet, EPF's main advocacy messages and guidance were shared at the [2019 Optimal Nutritional Care for All Conference](#) which was hosted in the UK.

## 8. Patient safety and quality of healthcare

We continued our focus on the **empowerment of patients and families as partners in patient safety**, with a dedicated working session during the EPF Congress on this topic. Our collaboration with the OECD – which collects international data on healthcare quality – on patient involvement in safety and quality continued to develop; EPF was a member of the **OECD PaRIS working group** developing a new international survey of patient-reported outcomes and experiences, in 2017-19, and was this year invited to participate in an international advisory board for the project as it kicks off; we also gained a standing invitation to the OECD's **Healthcare Quality and Outcomes working group**. Finally, we have given feedback on a new draft survey the OECD is developing on **patients' experience of safety incidents** in healthcare settings.

This year we again supported the **European Antibiotic Awareness Week** in collaboration with the ECDC, the EU agency responsible for monitoring levels of antibiotic resistance. We were invited to participate in the Stakeholder Forum of the EU Joint Action on antibiotic resistance, EU-JAMRAI.

The **EPF vaccination initiative** continued in 2019, with the development of a **Patient's Guide** to be published in 2020, and **two national workshops** with patient communities in Romania (Cluj) and Germany (Berlin) as well as close monitoring of the EU policy response to vaccines hesitancy, which is one of the Commission's top priorities. The patient community's important advocacy role is recognised by the European Commission and EPF was invited to attend the high-level Global Vaccination Summit, co-organised by the WHO and EU, in September. In summer-autumn 2019 we submitted a successful proposal for a **European pilot project on vaccination confidence** for patients and their communities, which will kick off in early 2020.

## 9. Health literacy and information for patients

Health literacy is embedded in all of EPF's work and a critical priority that we will also pursue next year, including engagement with a new initiative from the WHO European Regional office to embed health literacy in health systems. In 2019 specific activities included our information and communication on the topics of vaccination and antibiotics, our contributions to the EMA's meetings on electronic medicines information, but also a workshop we attended at the **European Health Forum Gastein** on health literacy as a disruptor and patient empowerment agent. We also continue our participation in a multi-stakeholder working group developing new guidance on how to convey the **results of clinical trials** ("lay summaries") in a patient-friendly way, which is due to conclude just in time for the new EU Clinical Trials Regulation to start being applied.

# Project Overview

**EHDEN** aims to make the large-scale analysis of reliable health data in Europe into a reality by creating a centralised data-sharing model.

**PREFER** aims to assess when and how patient preferences on benefits and risks should be incorporated into decisions on medicinal products.

**EUPATI** focuses on **education and training** to increase the capacity and capability of patients to understand and contribute to medicines research and development

**EU-PEARL** aims to revolutionise the way we do **clinical trials** by making them more efficient and patient friendly.

**PARADIGM**'s mission is to provide a unique framework that enables structured, effective, meaningful, ethical, innovative, and sustainable patient engagement (PE) and demonstrates the 'return on the engagement' for all players.

**EU-JAV Joint Action On Vaccination** aims at spurring **long-lasting European cooperation** against vaccine-preventable diseases and therefore **improve population health**.

## Digital Health Europe

Aims to boost innovation and advance the Digital Single Market priorities for the digital transformation of health and care (DTHC) via a number of different actions.

**CHRODIS +** Is a Joint Action that 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**

**Data Saves Lives** is a multi-stakeholder initiative that aims to raise wider patient and public awareness about the importance of health data, and establish a trusted environment for multi-stakeholder dialogue

**COMPAR-EU** aims to identify, compare, and rank the most effective and cost-effective **self-management interventions (SMIs)** for adults in Europe living with: **type 2 diabetes, obesity, chronic obstructive pulmonary disease, or heart failure**.

**IMMUCAN** aims at identifying potential predictive biomarkers for immunotherapy, towards an inclusive and integrated European immuno-oncology platform

**EU-JAMRAI, Joint Action on Antibiotic Resistance** fosters synergies among EU Member States by developing and implementing effective One Health policies to fight the rising threat of AMR and reduce healthcare associated infections



# Capacity Building

The Capacity Building Programme was designed in 2012 to respond to needs and concerns which have been identified by our membership during previous activities of EPF. As such, it supports patient organisations to strengthen their role as equal players in the healthcare environment.

Out of the [three main types](#) of Capacity Building Programme activities, in 2019 EPF held the following two:

## EPF Capacity Building Programme: Enabling Leadership and Positive Governance

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

This year EPF received **more than 100 applications** for the 24 available places. The selected participants, meeting specific criteria, come from **more than 10 different countries** and represent a balanced mix of European, national and local patient organisations. For the second time, EPF included **three participants from organisations in the Western Balkans**.

**24 participants**  
**18 countries**



*"We created a special picture with words which says everything necessary for patient leaders and effective management of patient organizations. I keep this picture on my desk and it is my everyday inspiration to go ahead!" (A participant)*



### IN NUMBERS

**24** Patient Organisation leaders  
**6** trainers and coaches  
**+ 10** countries: **2** face-to-face trainings  
**6** months of online coaching  
**1** [toolkit](#)

*"The course allowed me to see the bigger picture as well as all of the every day small things which make a difference to the team and the cause. It helped me focus my energy and heart on those small things that help create the bigger picture" (A participant).*



# Summer Training Course for Young Patients Advocates (STYPA) - Leadership Programme

Summer Training Course for Young Patient Advocates

## Shaping the Future of Patient Advocacy



5-8 July 2019 | Vienna, Austria

Following on from previous years, the final phase of the training, held from 7-10 July in Vienna, focused on **shaping the future of patient advocacy** with regard to **ethics and transparency**, how it is evolving and is evolving in terms of emerging challenges and opportunities, and the importance of keeping a strong ethical approach.

This three-day experience offered a **tailored high-quality training** to young patient advocates or representatives of young patient advocates with motivation to learn more about advocacy and maximise their leadership potential. Following on from previous years, this edition was a success and helped to strengthen the bonds within this diverse, motivated, and inspiring community of young patient advocates

### STYPA19 PARTICIPANTS

- **37** young patient advocates were a part of STYPA 2019.
- Participants from **18** different EU member states.
- Representing around **30** different chronic conditions, keeping in mind that many of the participants are struggling with a few chronic conditions at once.



*“Sometimes you lose hope. I had, partially. It can be your own personal life - or it can be because of what’s happening around the world. Then you go to Vienna and get thrown into a room of mostly new faces. And after three days you step out of that room - out of that experience - like a new person. I’m both amazed and kind of afraid of the personal development that has happened these past few days. What can I accomplish if I set my mind to? What can we accomplish together? What happens if we trust the process, embraces the difficulties and chooses to have the courage to step out of our comfort zone?”*

*I will keep this experience in my heart for a long time to come. Not for the things we have been discussing, not because of the messages from the speakers. But because of the atmosphere - the love, kindness and vulnerability.*

*Thank you for helping me become a better version of me.”*

**(A STYPA19 participant)**



# EPF Youth Group

Various Youth Group members were speakers and panellists at conferences throughout the year, raising awareness about the special needs of young patients and increasing the visibility of their activities with EPF. The Youth Group have also been actively contributing to the **EPF monthly newsletter**: in 2019 they published **10** articles, including event reports, opinion pieces and blogs.



The Youth Group also elected a new Youth Group Board. Members **Borislava Ananieva**, and **Yvett**



**GOODBYE** 😞

**Jakab** were elected as President and Vice President respectively. We were sad to say goodbye to President **Andreas Christodoulou** and Vice-President **Yolita Pavlova** who reached the end of their mandate, but also thankful for their commitment and leadership over the past two years. We wish them all the best, and many successful years as patient advocates!



**HELLO!** 😊



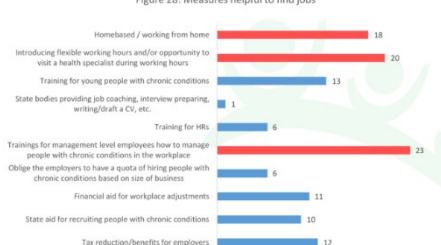
EPF strengthened our youth-related activities in 2019 with the third edition of the EPF's Summer Training Course for Young Patient Advocates (**STYP**A). On this occasion the Youth Group took on a prominent role by assisting the trainers in leading several group activities, chairing a panel of speakers, leading presentations, and more.

This year the Youth Group launched research, and completed surveys towards **Work and Youth Strategy (WAYS)**, a one-year internally funded EPF project. The research arises from the need to examine the current challenges young patients face in the employment sector, given that more

and more young people with chronic conditions face discrimination at work on a daily basis, not to mention difficulty in finding employment. In 2020 the Youth Group will finalise the **project report** and develop more material, including a factsheet with recommendations and a video. Stay tuned!

What measures are needed to increase employment among young patients?

Figure 28: Measures helpful to find jobs



## KEY 2019 ACTIVITIES

**EPF Youth Group Spring Meeting** (April)  
Antwerp, Belgium.

**EPF Youth Group Fall Meeting**  
(September), Budapest, Hungary

**EPF Congress** (November)

**STYP**A (May- October)

**WAYS project research** (ongoing)  
10 Monthly Engagement calls (January – December)



# Membership

---

EPF membership consists of 74 members: 54 Full members, 19 Associate members, and 1 provisional member.

Out of 74 members 50 pan-European umbrellas and 24 organisations are active at national levels, representing 19 countries.

In 2019, the EPF family was delighted to welcome 4 new members:

## Full Membership:

- [World Duchenne Organisation](#), a worldwide organization dedicated to finding a cure and viable treatments for DMD, to promoting good standards of care, and to inform parents around the globe.
- [Cystic Fibrosis Europe](#), a European organisation striving for a longer and better life for people with cystic fibrosis.
- [Federation of European Scleroderma Associations](#) (FESCA), an umbrella group which supports its member organizations representing scleroderma.

## Associate Membership:

[Patiëntenfederatie Nederland](#), the national coalition for Dutch patients.



### MEMBERSHIP IN NUMBERS

- Number of members: **74**
- Number of countries: **19**
- EPF Events: **4 webinars, 2 Capacity-Building Modules + Hackathon** (within the [framework of EPF Congress](#))
- National events: **8**

In 2019, EPF continued to offer its members the opportunity to chat informally with the EPF Secretariat, in Brussels or over Skype, during the “**Weekly Coffees with EPF**”. Finally, we kept our members informed through our **Weekly Insiders’ mailing**, sent on a weekly basis that ensures EPF members keep up with the latest news from Europe on what really matters for patients. For the first two quarters of 2019 the Weekly Insiders included a special section on the European Elections, containing updates on our **#europeforpatients** campaign.

## Full members (54)

Alzheimer Europe (Europe)  
AMD - Age Related Macular Degeneration Alliance International (International\*)  
AOECS - Association of European Coeliac Societies (Europe)  
AOPP - Association for the Protection of Patients' Rights (Slovak Republic)  
BAG Selbsthilfe - Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (Germany)  
BEMOSZ - Hungarian Alliance of Patients' Organisations (Hungary)  
CF Europe- Cystic Fibrosis Europe (Europe)  
COPAC - Coalition of Patients' Organizations with Chronic Diseases (Romania)  
DE – Dystonia Europe (Europe)  
EAMDA - European Alliance of neuro-Muscular Disorders Association (Europe)  
EATG - European Aids Treatment Group (Europe)  
EFA - European Federation of Allergy and Airways Diseases Patients' Associations (Europe)  
EFAPH - European Federation of Associations of Patients with Haemochromatosis (Europe)  
EFCCA - European Federation of Crohn's and Ulcerative Colitis Associations (Europe)  
ECHDO- European Congenital Heart Disease Organisation (Europe)  
EFHPA - European Federation of Homeopathic Patients' Associations (Europe)  
EGAN - Patients Network for Medical Research and Health (Europe)  
EHA - European Headache Alliance (Europe)  
EHC - European Haemophilia Consortium (Europe)  
EHLTF - European Heart and Lung Transplant Federation (Europe)  
EKPF - European Kidney Patients' Federation (Europe)  
ELPA - European Liver Patients Organization (Europe)  
EMSP - European Multiple Sclerosis Platform (Europe)  
ENUSP - European Network of (ex)Users and Survivors of Psychiatry (Europe)  
EPDA - European Parkinson's Disease Association (Europe)  
EPIK - Estonian Chamber of Disabled People (Estonia)  
EUFAMI - European Federation of Associations of Families of People with Mental Illness (Europe)  
EUROPA DONNA - The European Breast Cancer Coalition (Europe)  
EUROPSO - European Umbrella Organisation for Psoriasis Movements (Europe)  
EURORDIS - European Organisation for Rare Diseases (Europe)  
FE - Fertility Europe (Europe)  
FEP - Spanish Patients' Forum (Spain)  
FESCA- Federation of European Scleroderma Associations (Europe)  
FPP - Federation of Polish Patients (Poland)  
GAMIAN Europe - Global Alliance of Mental Illness Advocacy Networks (Europe)  
Swedish Disability Rights Federation (Sweden)  
IDF Europe - International Diabetes Federation (Europe)  
IF – International Federation for Spina Bifida and Hydrocephalus (International\*)  
IOF - International Osteoporosis Federation (International\*)  
IPOPI - International Patient Organisation for Primary Immunodeficiencies (International\*)  
KUZ - Coalition of Associations in Healthcare (Croatia)  
KZZ - Confederation Health Protections (Bulgaria)  
LPOAT - Council of Representatives of Patients' organizations of Lithuania (Lithuania)  
LUPUS Europe (Europe)



MHN - Malta Health Network (Malta)  
 NCDP - National Confederation of Disabled People (Greece)  
 NPO - National Patients' Organisation of Bulgaria (Bulgaria)  
 National Voices (United Kingdom)  
 Pancyprrian Federation of Patients Associations and Friends (Cyprus)  
 PHA Europe - Pulmonary Hypertension Association Europe (Europe)  
 Plataforma de Organizaciones de Pacientes (Spain)  
 Retina International (Europe)  
 WDO- World Duchenne Organisation (International\*)  
 SUSTENTO - The Latvian Umbrella Body for Disability Organization (Latvia)

## Provisional members (19)

AGORA - (Southern Europe)  
 AMRC - Association of Medical Research Charities (United Kingdom)  
 BAPD - Bulgarian Association for Patients Defence (Bulgaria)  
 Debra International - Organisation of people with Epidermolysis Bullosa (Europe)  
 ECO - European Cleft Association (Europe)  
 EuropaColon (Europe)  
 EFNA - European Federation of Neurological Associations (Europe)  
 EIWH - European Institute of Women's Health (Europe)  
 EMHF - European Men's Health Forum (Europe)  
 ENFA - European Network of Fibromyalgia Associations (Europe)  
 IBE – International Bureau for Epilepsy (International\*)  
 LuCE- Lung Cancer Europe (Europe)  
 MRCG - Medical Research Charities Group (Ireland)  
 MHE-SME - Mental Health Europe (Europe)  
 Netherlands' Patients Federation (The Netherlands)  
 SAFE-Stroke Alliance for Europe (Europe)  
 The ALLIANCE - Health and Social Care Alliance Scotland (Scotland)  
 VPP - Flemish Patients' Platform (Belgium)  
 WFIP - World Federation of Incontinent Patients (International\*)

## Provisional members (1)

APO – Alliance of Patient Organisations (FYROM)

# Governance and Secretariat

## EPF Board

- **President**, Marco Greco, *European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)*, **re-elected!**

- **Vice President**, Radu Costin Ganescu, *Coalition of organisations for patients with chronic conditions of Romania (COPAC)* **re-elected and new position!**

- **Treasurer**, Elisabeth Kasilingam, *European Multiple Sclerosis Platform (EMSP)* – **new position!**



- **Board Members:**

Hilkka Karkkainen, *GAMIAN-Europe* – **re-elected!**

Marzena Nelken, *Federation of Polish Patients (FPP)*

Dimitrios Athanasiou, *World Duchenne Organisation (WDO)* – **new Board Member!**

Gabriela Tanasan, *European Network of (ex)users and survivors of psychiatry (ENUSP)*

Cornelius Oosterzijk, *Rare Diseases Europe (EURORDIS)*

Michal Rataj, *European Alliance of Neuromuscular Disorders Associations (EAMDA)*

**Honorary President:** Anders Olauson, *Rare Diseases Europe (EURORDIS)*

**Former Board Member:** Stanimir Hasardzhiev, *Bulgarian National Patient Organisation (NPO)*

## 1. EPF Constitutional Reform

EPF initiated a Constitutional reform process in 2018 which was finalised in 2019 with the approval of the new [EPF Constitution](#) at the EPF 2019 Annual General Assembly.

What are the main changes?

- EPF opens its membership to legitimate patients' organisations based in Europe, not only in the EU.
- EPF Youth group is listed in the Constitution as one of the permanent Supporting Committee.
- EPF created the EPF Ethics Committee to support the EPF Board.
- One of the nine elected Board members will be a youth group member.

In 2019 EPF Secretariat has been given the mandate from the EPF membership to close the registered office in Luxemburg as well as the operating office in Belgium and to move the EPF registered office to Belgium. EPF Secretariat thanks to the pro-bono legal support offered by the legal firm Dechert LLP via the Thomson Reuters' Programme [Trust Law](#) has finalised the paper work in 2020.

## EPF Secretariat

- **Kostas Aligiannis**, Policy Officer
  - o Policy and Advocacy
- **Borislava Ananieva**, EPF Youth Group Trainee
  - o Youth Group activity support and development of Youth Strategy – **welcome!**
- **Elena Balestra**, Membership & Capacity-Building Manager
  - o Capacity-Building Programme, membership engagement and growth
- **Nicola Bedlington**, EPF Special Advisor
  - o Advisory and strategic guidance
  - o Leadership of EUPATI, PARADIGM and Data Saves Lives
- **Mathieu Boudes**, PARADIGM Coordinator
  - o Coordinating the PARADIGM consortium
- **Emily Bowles**, Communications Officer
  - o Communications support and management - **welcome!**
- **Camilla Habre**, Project Officer
  - o EUPATI and project coordination
- **Katie Gallagher**, Policy Adviser
  - o Policy & Advocacy
- **Zilvinas Galvenas**, IT Coordinator
  - o IT management and planning
- **Kaisa Immonen**, Director of Policy
  - o Strategic and policy agenda
  - o EU institutions and stakeholders
- **Usman Khan**, Executive Director
  - o Leadership, direction and guidance
- **Matthew May**, EUPATI coordinator
  - o Coordination of the operational teams and financial management
- **Lyudmil Ninov**, Project Officer
  - o EPF Youth Group, STYPA and project support
- **Adriana Pereira**, Team Assistant
  - o Admin, finance assistance and support with daily team operations
- **Zuzanna Skowronek**, Events Officer and Operations Assistant
  - o EPF meetings, events and travel
  - o Operations and admin assistance
- **Valentina Strammiello**, Senior Programme Manager
  - o Project coordination and development
- **Gözde Susuzlu**, Data Saves Lives Coordinator
  - o Management of Data Saves Lives portal
- **Brendan Togher**, Finance and Admin Manager
  - o Financial matters
- **Ruth Tchapanian**, Grants and Office Coordinator
  - o Office, information and grants management
- **Anna Trzcinska**, Events Officer
  - o EPF meetings, events and travel management



**Goodbye, thank you and all the best:**

- o **Julien Richard**, Communications Manager
- o **Tanja El-Nemr**, Policy Adviser
- o **Josef Cutajar**, Communications Trainee

# Financials

## 10. Extract from the Contractual Auditor's Report to the Board of Members of the ASBL of European Patients' Forum on the Financial Statements for the year ended 31 December 2019

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 2019 given is 2.674.434 euros, and there is a surplus of 196.991 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, 2019, in Belgium applicable accounting standards and in accordance with ISRE 2400.

**RSM Interaudit CVBA-SC SCRL**, Chaussée de Waterloo 1151, B-1180 Brussels

Please contact [info@eu-patient.eu](mailto:info@eu-patient.eu) to request a copy of the full report.

## 11. Income and Expenditure

INCOME	2019	2018
<b>Funding from Public Sector</b>	<b>€ 470,122.54 €</b>	<b>512,670.36</b>
EC projects	€ 470,122.54	€ 512,670.36
<b>Funding from the private sector</b>	<b>€ 2,127,573.11 €</b>	<b>1,562,732.33</b>
Operation and Engagement	€ 807,981.10	€ 782,371.91
Capacity Building Programme	€ 480,655.26	€ 378,403.03
Co-funding to EPF projects	€ 7,018.90	€ 4,960.99
Project development and other costs	€ 0.00	€ 54,833.14
Contribution to EPF Campaigns	€ 20,000.00	€ 41,000.00
Contribution CONGRESS	€ 428,500.00	€ 0.00
PARADIGM	€ 145,395.81	€ 81,453.51
EUPATI Programme	€ 238,022.04	€ 219,709.75
<b>Membership fees</b>	<b>€ 25,770.00 €</b>	<b>20,450.00</b>
Contribution to Work Plan (Operations, Capacity Building and project development)	€ 20,150.00	€ 20,450.00
Contribution CONGRESS	€ 5,620.00	€ 0.00
<b>Interest and other income</b>	<b>€ 148,847.77</b>	<b>€ 31,445.16</b>

<b>TOTAL INCOME</b>	<b>€ 2,772,313.42</b>	<b>€ 2,127,297.85</b>
<b>EXPENDITURES</b>	<b>2019</b>	<b>2018</b>
<b>Staff Costs</b> (all projects, all campaigns)	€ 1,293,982.23	€ 1,041,099.29
<b>Office and admin costs</b>	€ 300,950.72	€ 270,531.29
<b>Depreciation</b>	€ 25,623.71	€ 24,087.88
<b>Travel and subsistence</b> (EPF staff)	€ 45,159.49	€ 39,112.17
<b>Events</b> (direct costs)	€ 894,850.69	€ 541,850.85
Annual General Meeting & Board Meetings	€ 57,249.80	€ 53,927.56
Patient Advocacy Seminar	€ -	€ 23,768.32
Summer Training & Youth Group meetings	€ 66,144.45	€ 57,412.77
Thematic Working Group Meetings/ Initiatives (Universal Access, Nutrition, Vaccines, Digital Health, Data Saves Lives, Incentives)	€ 150,504.87	€ 40,777.59
Capacity Building Programme (delivery of training modules)	€ 48,219.30	€ 47,918.26
Congress 2019	€ 302,086.21	€ 9,473.43
Other costs linked to operations, project portfolio	€ 270,646.06	€ 308,572.92
<b>Campaigns</b> (direct costs)	€ 13,188.29	€ 27,293.92
European Elections	€ 13,188.29	€ 27,293.92
<b>Bank and Financial Charges</b>	€ 1,567.39	€ 1,845.00
<b>TOTAL EXPENDITURE</b>	<b>€ 2,575,322.52</b>	<b>€ 1,945,820.40</b>
<b>TOTAL Surplus or deficit of the Year</b>	<b>€ 196,990.90</b>	<b>€ 181,477.45</b>

## 12. Balance Sheet

<b>ASSETS</b>	<b>2019</b>	<b>2018</b>
<b>I Current Assets</b>		
Accounts receivable	€ 139,038	€ 546,512
Cash in bank and deposit	€ 2,450,766	€ 1,523,927
Pre-paid expenses	€ 17,059	€ 14,121
<b>Total current assets</b>	<b>€ 2,606,863</b>	<b>€ 2,084,560</b>
<b>II Fixed assets</b>		
Leasehold	€ 15,627	€ 16,870
Furniture, IT equipment and software	€ 51,893	€ 44,990
Guarantees (rent and social security)	€ 50	€ 38,170
<b>Total fixed assets</b>	<b>€ 67,570</b>	<b>€ 100,030</b>
<b>TOTAL ASSETS</b>	<b>€ 2,674,434</b>	<b>€ 2,184,590</b>
<b>LIABILITIES</b>	<b>2019</b>	<b>2018</b>

I Current Liabilities				
Accounts payable	€	208,206	€	587,080
Deferred income	€	1,337,460	€	660,488
Income to be allocated to project partners	€	-	€	5,246
<b>Total current liabilities</b>	<b>€</b>	<b>1,545,666</b>	<b>€</b>	<b>1,252,814</b>
II Reserves				
Funds brought forward	€	565,815	€	384,338
Social Reserve	€	300,000	€	300,000
Surplus or deficit for the year	€	196,991	€	181,477
<b>Total reserves</b>	<b>€</b>	<b>1,062,806</b>	<b>€</b>	<b>865,815</b>
Provisions	€	65,961	€	65,961
<b>TOTAL LIABILITIES</b>	<b>€</b>	<b>2,674,434</b>	<b>€</b>	<b>2,184,590</b>

### 13. Acknowledgement of funds

EPF wishes to thank the European Commission for its support in 2019 in relation to EPF's role in the following projects			
	EC Contribution used in 2019		% of total income
<b>TOTAL European Commission support to projects 2019</b>	<b>€</b>	<b>188,009.61</b>	
CHRODIS +	€	25,190.75	0.9%
ComparEU	€	31,468.16	1.1%
DigitalHealthEurope	€	24,273.65	0.9%
EFO EUPATI	€	82,853.30	3.0%
EHDEN	€	13,402.80	0.5%
EU-PEARL	€	1,316.32	0.0%
IMMUCAN	€	5,914.48	0.2%
PREFER	€	3,590.15	0.1%
EPF wishes to thank the following donors for their support:			
	Contribution to the Operations		% of total income
<b>Operational &amp; Engagement - work plan 2019/ Project Development 2019</b>	<b>€</b>	<b>855,150.00</b>	
European Commission	€	-	0.0%
AbbVie	€	35,000.00	1.3%
Amgen	€	35,000.00	1.3%
Celgene	€	30,000.00	1.1%
CSL Behring	€	10,000.00	0.4%
Edwards Lifescience SA	€	25,000.00	0.9%
Eli Lilly	€	15,000.00	0.5%
Gilead Sciences Europe	€	40,000.00	1.4%
Grunenthal	€	5,000.00	0.2%
GSK	€	30,000.00	1.1%
Janssen	€	50,000.00	1.8%
Medicines for Europe	€	20,000.00	0.7%
MSD	€	80,000.00	2.9%
Novartis Pharma AG	€	100,000.00	3.6%
Pfizer Inc	€	25,000.00	0.9%
Philips	€	10,000.00	0.4%
F. Hoffman-La Roche	€	50,000.00	1.8%
Sanofi Aventis	€	50,000.00	1.8%
Servier	€	10,000.00	0.4%
Takeda	€	40,000.00	1.4%

Teva	€	110,000.00	4.0%
UCB	€	25,000.00	0.9%
Vertex	€	40,000.00	1.4%
Membership	€	20,150.00	0.7%
<b>Capacity Building Programme 2019</b>		<b>€ 480,655.26</b>	
	Contribution to the CBP		% of total income
Alexion	€	14,000.00	0.5%
Amgen	€	5,000.00	0.2%
Baxter	€	10,000.00	0.4%
Biogen	€	20,000.00	0.7%
EFPIA (DSL)	€	136,655.26	4.9%
EFPIA/ Vaccines Europe	€	65,000.00	2.3%
EIT Health (DSL)	€	20,000.00	0.7%
ENHA	€	10,000.00	0.4%
GSK	€	30,000.00	1.1%
Kyowa Kirin	€	10,000.00	0.4%
LEO Pharma	€	15,000.00	0.5%
Medtech (DSL)	€	10,000.00	0.4%
Merck	€	35,000.00	1.3%
MNI (Medical Nutrition International)	€	20,000.00	0.7%
Novo-nordisk	€	30,000.00	1.1%
Pfizer Inc	€	25,000.00	0.9%
Teva	€	25,000.00	0.9%
<b>Patients Active in Research and Dialogue for an Improved Generation of Medicine "PARADIGM"</b>		<b>€ 427,508.74</b>	
			% of total income
Innovative Medicines Initiative (IMI JU) PARADIGM Funding	€	282,112.93	10.2%
Industry cash contribution (Amgen, Lundbeck, MSD, Pfizer, VFA)	€	145,395.81	5.2%
<b>Patient Academy on Therapeutic Innovation "EUPATI Programme" 2017-2019</b>		<b>€ 238,022.04</b>	
			% of total income
Industry consortium 2017-2019 (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)	€	238,022.04	8.6%
<b>CONGRESS 2019</b>		<b>€ 541,110.00</b>	
AbbVie	€	20,000.00	0.7%
Alexion	€	13,500.00	0.5%
Baxter	€	10,000.00	0.4%
Bayer	€	10,000.00	0.4%
BMS	€	25,000.00	0.9%
Boehringer	€	20,000.00	0.7%
Celgene	€	25,000.00	0.9%
EFPIA	€	50,000.00	1.8%
EIT Health	€	20,000.00	0.7%
Fresenius Kabi	€	10,000.00	0.4%
Janssen	€	40,000.00	1.4%
Kyowa Kirin	€	10,000.00	0.4%
LEO Pharma	€	10,000.00	0.4%
Merck	€	40,000.00	1.4%
MYLAN	€	10,000.00	0.4%
Novartis Pharma AG	€	40,000.00	1.4%
Novo Nordisk	€	25,000.00	0.9%
F. Hoffman-La Roche	€	10,000.00	0.4%
Servier	€	15,000.00	0.5%
Takeda	€	15,000.00	0.5%
UCB	€	10,000.00	0.4%



Participation Fees	€ 106,990.00	3.9%
Membership	€ 5,620.00	0.2%
Other income	€ 41,857.77	1.5%
<b>TOTAL INCOME 2019</b>	<b>€ 2,772,313.42</b>	