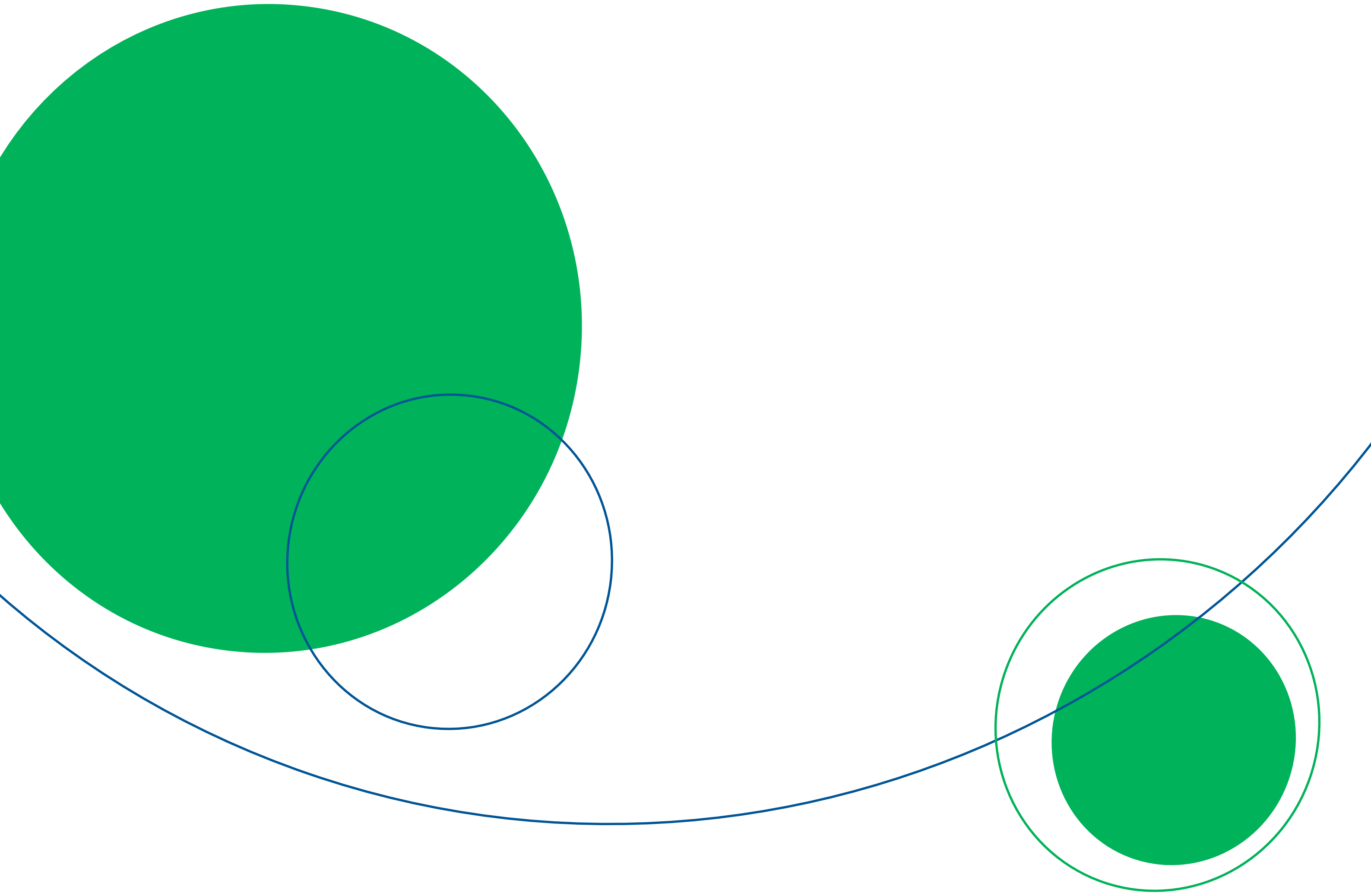
EPF European Patients Forum

EPF 2018 ANNUAL REPORT

DRIVING BETTER HEALTH FOR PATIENTS IN EUROPE



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1. FOREWORD

“2018 has been an important year for EPF, with many achievements we are proud to share with you. Over the last 12 months, EPF has continued to be at the forefront of patient advocacy in Europe, providing a cross-disease perspective and solutions from a wide patient community on issues which have a direct influence on patients' lives.

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

With Europe's healthcare systems facing multiple challenges, and a profound transformation, particularly in terms of equitable access to high-quality care that meets people's real needs – our activities in 2018 advanced the goals of our long-term strategy (2014-2020).

With the continuum of prevention in mind, we also embarked on a new project looking at vaccine confidence in patients with chronic diseases, and intensified our work on nutrition.

The implementation of our financial sustainability strategy with, as ever, maximum attention to transparency, ethics and impact for our members has also been in focus for EPF.

Another key development in 2018 was the revision of our Constitution, to extend our membership base to neighbouring EU countries.

These accomplishments reflect the solid expertise, reputation, unity and credibility of our organisation and trusted network of members and partners. We are ready for another exciting year in 2019, with the European Parliament elections and our first ever Congress being key milestones.

We look forward to our continued work together, and thank you once again!”

Marco Greco
EPF President

Nicola Bedlington
EPF Secretary General

2. MISSION & OBJECTIVES

EPF is the leading voice of patient organisations in public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level, or are national coalitions of patients.

OUR VISION

All patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care.

OUR MISSION

EPF's primary focus is to be the collective influential patient voice in European health and related policies, and a driving force to advance patient empowerment and equitable patient access to care in Europe. For over 15 years, we have helped empower patient communities through educational seminars, policy initiatives and projects; coordinate best practice exchanges between patient organisations at European and national levels, and strengthen their organisational and advocacy capacity.

This broad mission is translated into three core objectives, which are underpinned by cross-cutting activities.

	Policy & Advocacy	Projects: Collecting Evidence	Capacity Building Programme	
Patient Involvement & Empowerment	✔	✔	✔	Campaigns & Comms
Sustainable Healthcare Systems for All	✔	✔	✔	
Effective Research & Regulatory Framework	✔	✔	✔	

Objective 1: Patient involvement and empowerment

EPF seeks to promote a wider understanding and acceptance of patient empowerment, and the concept of meaningful patient involvement – embedding it at all levels of health systems, and encouraging the implementation of good practices that are "patient approved". Embedding health literacy in organisations and systems is an important aspect of patient empowerment, for instance by ensuring that information on complex health topics is communicated in a patient-friendly manner.

Objective 2: Sustainable health systems for all

EPF is working towards a vision by building patients' evidence of what constitutes high-quality, safe, equitable and sustainable healthcare systems from the patient perspective.

Objective 3: Effective and patient-centred research and regulatory frameworks

EPF monitors, supports and reports on the effective implementation of key EU legislation to ensure that the patients' interests are reflected in legislation under development and are effectively implemented.

> *"Advocacy is at the heart of what EPF does. Influencing policy is an important part of advocacy; but it is wider than that. Advocacy also means changing healthcare practice, for example by engaging with academics and healthcare professionals. Advocacy means talking to everyone – from policymakers, regulators, payers, HTA bodies, professionals and managers, to academics, industry and other health NGOs – to make sure they understand the patient perspective and integrate it in their own work."*

Kaisa Immonen, Director of Policy

3. HIGHLIGHTS OF 2018

> *“EPF is a staunch fighter for meaningful patient involvement and empowerment. Incredible changes happen in patients’ health and lives when we feel strong, have the power to speak with our own voice, regain the authority over our own lives, and are encouraged and supported to live independently.”*

Gabriela Tanasan, Board member, ENUSP Representative

JANUARY

- Launch of COMPAR-EU, a project focusing on self-management interventions within four chronic conditions
- Conclusion of the PRO-STEP tender study on the self-management of chronic conditions and wide dissemination of the recommendations

FEBRUARY

- We spoke at the WHO Health Systems Foresight Group
- Publication of materials to promote better inclusion of people with chronic conditions in the workplace
- Publication of a factsheet on Roadmap to Achieve Universal Health Coverage by 2030 in 13 EU languages
- We held an educational workshop on pharmaceutical incentives
- We took part in a joint meeting organised by the European Commission’s task force on Article 50 on prioritising patient safety and public health in Brexit negotiations
- Launch of the capacity building module on empowering leadership and positive governance

MARCH

- We spoke at the ‘Personalised Medicine and the Big Data Challenge’ conference organised by the European Alliance for Personalised Medicine
- We replied to the European Commission’s consultation on EU funds in the area of investment, research & innovation, SMEs and single market, specifically on civil society involvement in priority setting
- Publication of position paper on information to patients on food and nutrition
- We launched our flagship initiative on vaccination
- EUPATI face-to-face training event in Madrid
- We contributed to OECD PaRIS task force and healthcare quality and outomes (HCQO) Expert Group
- Launch of IMI project PARADIGM focusing on patient engagement in medicines development

APRIL

- EPF AGM and Leadership meeting
- Publication of #EU4Health joint statement on the future of health in the EU
- EPF and EPHA call for the next Commission to include a Vice-President for Health trough our joint intiative #EU4Health
- We supported the WHO call on world leaders to commit to concrete steps to advance the Sustainable Development Goals agenda on Universal Health Coverage
- IMI-PARADIGM First Open Forum on Patient Engagement
- We spoke about patient empowerment at the SCiE Self Care Initiative Summit
- We participated in the Patient and Consumer Working Party (PCWP) of the European Medicines Agency (EMA)
- WE contributed to the kick-off meeting of the Council for International Organizations of Medical Sciences’ Working Group XI on patient involvement

MAY

- Publication of our statement on the European Commission’s proposal for the next EU budget
- Publication of our preliminary statement on the European Semester country-specific recommendations
- Publication of our position statement on Health Technology Assessment
- We published our first impact report
- We actively promoted patient engagement and patient education at the DIA Europe 2018 Annual Meeting
- EPF-MedTech Europe held workshops on HTA on medical technologies and on community care
- We contributed to the OECD healthcare quality and outcomes (HCQO) working group
- We participated in the EUnetHTA Stakeholder Forum

JUNE

- We spoke at the Innovative Medicines Initiative (IMI) 10th Anniversary
- We spoke to medical student societies at European Parliament about patients’ involvement in medical education
- We published a statement on HTA calling on EU Member States to put patients first and make progress on negotiations
- We published a statement on the European Commission’s proposal for the next framework programme on research, Horizon Europe
- Publication of EPF’s Transparency Guidelines
- AGM of the EUPATI national platforms

JULY

- We held our 2nd Summer Training for Young Patient Advocates
- We chaired a session on Global Perspectives on Patient Engagement at DIA Global Annual Meeting
- We chaired a session on engaging patients and clinicians on HTA at the event "The way forward for HTA cooperation – the views of stakeholders" organised by the European Commission
- We participated at COMPAR-EU face-to-face meeting
- We participated in an initial meeting of the Spanish Medicines Agency on electronic product information on medicines

AUGUST

- Publication of a collection of initiatives for better inclusion of people with chronic diseases in the workplace

SEPTEMBER

- We spoke at the European Society for Clinical Nutrition and Metabolism Conference
- We spoke at the 12th EMA Stakeholder Forum on the Pharmacovigilance Legislation
- We spoke at the EU Patient Task Force on Nutrition
- We spoke at European Diabetes Patient Advocacy Summit
- We spoke about patients' involvement in research at a conference of Deusto University
- We spoke at the EMA Patients' and Consumers' Working Party
- Publication of informative article on Brexit for EPF members
- EUPATI Guidance on Patient Involvement in HTA published in Peer-Reviewed Journal
- We participated in the kick-off meeting of EU Joint Action on Vaccination (EU-JAV)

OCTOBER

- We published a statement for the European Antibiotic Awareness Day
- We launched our 2019 European Elections Campaign
- Universal Access to Health Conference, co-organised by AIM, EPHA, EPF, ESIP and Medicines for Europe
- We spoke at the IMI Stakeholder Forum 2018
- EUPATI reaches 1 million users
- Peer-Reviewed EUPATI Guidance published in Frontiers in Medicine
- We held our first Patient Advocates' Seminar – "be a lobbyist for a day"
- We participated in a high-level roundtable on digital health with Commissioner Mariya Gabriel
- We participated in the 2nd meeting of the Council for International Organizations of Medical Sciences (CIOMS) Working Group XI on patient involvement
- We spoke at stakeholder meeting of EU-JAMRAI Joint Action on antimicrobial resistance
- We spoke at HTAi Patient and Citizens Interest Group Meeting
- In addition to our role as member of the Advisory Committee at the European Health Forum Gastein, we spoke on innovative medicines, vaccines for all and the value of evidence in outcomes-based healthcare, as well as on personalised medicines and health literacy
- We spoke about patient empowerment at a meeting of the Austrian Presidency with chief medical, nursing and dental officers
- We spoke at the European Institute for Innovation through Health Data (i~HD) annual conference about patient expectations of digital health
- We spoke at the EMA workshop on priorities for digital medicines information

NOVEMBER

- We highlighted the importance of meaningful patient engagement at ISPOR Europe 2018
- We published a position paper on clinical nutrition guidelines and summaries for patients
- We co-signed a joint-statement on HTA on involving patients
- We held our first pilot workshop on vaccination with member COPAC in Bucharest, Romania
- EUPATI publishes a guidance on patient involvement in regulatory processes
- Launch of the IMI project EHDEN on health data and evidence network

DECEMBER

- We announced the first ever European Congress on patient involvement in November 2019
- We participated in a panel session on 'speeding up the digitisation of health care' at a Conference on Value-Based Healthcare in the Digital Era

EPF ACTIVITIES
PROJECTS-RELATED ACTIVITIES
EVENTS WITH MAJOR PARTNERS SUCH AS WHO, OECD, EMA
OTHER IMPORTANT EVENTS

EPF 2018
COMMUNICATIONS AT A GLANCE

> “*Engaging with audiences and disseminating our work in an ever compelling and impactful manner, through telling the stories and sharing the experiences of the communities we represent, are key to helping make a difference for patients and achieving positive change in society.*”

Julien Richard,
Communications Manager

WEBSITE

57,900
visitors on the website (+12,000)

SOCIAL MEDIA

8,293
likes on Facebook (+2.5%)
with a reach of 108,022 people

8,252
followers on Twitter (+13%)
with over 1 million impressions

1,367
followers on LinkedIn (+90%)
with nearly 150,000 impressions

NEWSLETTER

4,650
subscribers to our monthly newsletter

CONTENT PRODUCED

16
videos published

6
press statements

3
recommendations for good practices

3
position papers

3
factsheets produced

1
impact report

4. POLICY & ADVOCACY

Policy and advocacy are at the heart of what EPF does. We follow all policy areas of relevance to patients to influence the EU policy agenda. We develop campaign and advocacy strategies to encourage the EU institutions and other health stakeholders to listen to and incorporate patients' views when developing and implementing policies. We also act as a "bridge" between EU and national developments, channelling our members' input towards EU policy and supporting them in their national advocacy work. Here is an overview of our main policy and advocacy activities in 2018. More details about our policy work can be found at www.eu-patient.eu/whatwedo/Policy.

EPF ACTIVE ON MEDICINES AND MEDICAL DEVICES

In 2018, EPF was again active in bringing a patient perspective into debates on medicines and medical devices at European level.

A dialogue between members of EPF and Medicines for Europe took place in October to discuss the EPF Roadmap on universal health coverage and the role of generics and biosimilars. Another event co-organised with public health NGOs also included Universal Access to Health in the discussion. In September, once again we participated in the 4th stakeholder conference on biosimilar medicines, organised by the European Commission (DG GROW), and in a similar meeting at the European Parliament. We worked on various initiatives on access to medicines, including participation in various conferences to express the patient perspective, and organised an initial educational roundtable for our members to enable better understanding of the role of incentives. Due to many recent developments, we also undertook a revision of our 2016 position paper on the value of medicine pricing, due to be published in the first half of 2019.

In the ongoing implementation of the EU Medical Devices Regulation, EPF contributed to a working group looking at the development of transparent, lay-friendly summaries of the safety and clinical performance of a device (SSCP), which is an activity led by Member States. Our annual Patient-MedTech Dialogue workshops focused on HTA on medical devices, and on community care. In December we published a statement calling for quick and effective implementation of the new and improved EU rules for patient safety and transparency.

At the European Medicines Agency, we continued as a member of the PCWP, and EPF President Marco Greco, contributed as member of PRAC, the pharmacovigilance committee. Our activities included contributed to shaping future electronic product information, and drafting a reflection paper on how to improve patient input in medicines evaluation. EPF also became a member of a new international working group of CIOMS on patient involvement in the safe use of medicines, and participated in activities around the European Antibiotic Awareness Day in October. In addition, we took part in a stakeholder meeting of an EU Joint Action on antimicrobial resistance (EU-JAMRAI) in October.

"THIS IS
WHERE THE VOICE
OF THE PATIENT
COMMUNITY
IS SHAPED."

“Being part of EPF is instrumental for our organisation to amplify its work towards parity of esteem between physical and mental health. We particularily welcomed EPF's support for our Call to Action on empowerment of mental health patients and their self-management of treatment.”

Hilkka Kärkkäinen,
Board Member,
President of GAMIAN-Europe

EPF CALLED FOR A PATIENT-CENTRED EU FRAMEWORK ON HTA

"AN IMPORTANT STEP TOWARDS MORE EQUITABLE ACCESS TO EFFECTIVE HEALTHCARE FOR ALL PATIENTS ACROSS THE EU."

In 2018, we welcomed the publication of a legislative proposal on a future EU framework on health technology assessment (HTA). As our position paper adopted in May explained, this was an important step towards more equitable access to effective healthcare for all patients across the EU. Currently, although new medicines are mostly authorised at EU level, HTA is done at national level, which often results in fragmentation and unequal levels of access.

The proposal was broadly backed by the European Parliament and by many Member States but ran into strong opposition by a minority of countries, mainly because of the requirement for mandatory uptake of the joint work. However we believe common work is vital to support informed healthcare decision-making, more effective investment in technologies (and disinvestment in ineffective or obsolete ones), improving quality and access. Some degree of mandatory uptake is needed to achieve the "EU added value" of common work, and avoid duplication and waste of resources.

EPF continues to call for an effective and patient-centred HTA framework. In 2018, a public statement on the Council deliberations and a joint statement with 14 patient organisations were developed in this regard. Our priorities centre on meaningful patient involvement in the process: it is the only way to ensure assessment results truly take into account the patients' experience with health technologies.

THE IMPORTANCE OF VACCINATION FOR PATIENTS

Because of gaps in vaccination uptake, and the important risks patients with chronic conditions face, EPF started an initiative in 2018 on providing information and supporting patient organisations' advocacy on the importance of vaccination. We started by asking our members questions to get a picture of the needs and gaps in the patient community.

We developed several information resources that together form a toolkit aimed primarily at supporting the advocacy efforts of national patient groups. The tools available include an extensive background report, two factsheets (available in English, Romanian, French and German) and a Power Point overview presentation. A Manifesto on the importance of vaccination for patients encapsulates our call to action.

Additionally, EPF held a pilot workshop with the patient community in Bucharest, Romania, in collaboration with our member organisation COPAC – the Coalition of Patients' Organisations with Chronic Diseases in Romania in November 2018. More than 40 participants representing patients, academia, national institutions and industry identified some of the key needs of patients but also of professionals, ultimately recognising the importance of working together to confront the challenges with success.

This initiative will continue in 2019 with the development of further resources and workshops. EPF is also participating in the stakeholder forum of an EU Joint Action on vaccination (EU-JAV), which started its work in September.

"Access to quality healthcare is a basic human right and should never be withheld in our society. Everyone everywhere should benefit from health services they need without falling into poverty when using them. For this reason, EPF's working group on universal access to healthcare advocates for a future where universal health coverage is a reality in Europe and where "universal" means "for all", without discrimination, leaving no one behind."

Katie Gallagher, Policy Adviser

NEW INITIATIVES IN THE AREA OF DIGITAL HEALTH

2018 laid the groundwork for many promising new initiatives in the area of digital health. Many thoughts and ideas we had around the topic became concrete plans.

EPF welcomed the European Commission's communication on digital health and contributed to the European Parliament's draft motion for a resolution on enabling the digital transformation of heath and care in the Digital Single Market. Our new working group on digital health got off to a successful start, by developing a survey on Electronic Healthcare Records and contributing to a briefing on digital health, which is due to be published in 2019. EPF participated in the Commission's eHealth Stakeholder Group and in many other debates and high-level events and meetings, including a high-level roundtable with European Commissioner for Digital Economy and Society, Mariya Gabriel.

In 2019, two new EU projects will kick off: the IMI project for European Health Data & Evidence Network (EHDEN), and Digital Health Europe. 2019 will also see the launch of a new "Data Saves Lives" Platform, as well as the publication of a briefing on digital health.

"Digital solutions can substantially improve patients' lives. At the same time going digital for the sake of digital is expensive and without added value. We need solutions that digital innovation that prioritises patients' needs by involving them in the inception, development, and deployment."

Kostas Aligiannis
Policy Officer

EPF STRIVES TO MAKE EQUITABLE ACCESS AND UNIVERSAL HEALTH COVERAGE (UHC) A REALITY

While UHC is a well-recognised goal for all healthcare systems in the EU, this basic right is not yet a reality for all patients. As a follow-up to our 2017 Campaign on Access to Healthcare and to the Roadmap to Achieving Universal Health Coverage for all in the context of the 2030 Agenda for Sustainable Development, in 2018 EPF focused its efforts on building awareness and capacity of the patient communities on these topics. The goal was to provide meaningful input to policy discussions in this area. To this end, we developed a factsheet on UHC and the UN SDG on health in September to mark the 3rd anniversary of the adoption of the UN SDGs. Throughout the year, EPF seized many opportunities to repeatedly urge different health actors to take responsibility in implementing the recommendations set out in EPF's Roadmap on UHC. EPF's work on this topic has been guided by a new member-based working group on universal access to healthcare, and we would like to take this opportunity to thank all members for their valuable contributions.

To further support Member States in the implementation of health reforms, in 2017 EPF had recommended that the European Commission link existing funding mechanisms to the country-specific recommendations (CSRs) issued in the context of the European Semester, which allocate existing funding to support the implementation of health-related CSRs. We were pleased to see that the post-2020 European Social Fund plus programme has adopted this approach. In May 2018, health recommendations were attributed to 12 EU countries. EPF welcomed the clear shift towards more social and less financial-oriented recommendations, which is a significant step forward and achievement for EPF as well as other civil society actors. In the context of improving equal access and ensuring the sustainability of health care systems, EPF also contributed to efforts being made to improve the measurement of access to healthcare across Europe. To this end, a framework towards a fairer and more effective measurement of access to healthcare across the EU (based on EPF's five dimensions of access), together with a strategy and roadmap, will be published and proposed to the Commission and Member States.

Finally, as a member of SDG Watch Europe, EPF has urged the EU to take leadership in the implementation of the 2030 Agenda for Sustainable Development. In 2019, the EU will for the first time report on how it is implementing the agenda for sustainable development and what progress has been made. Similarly, 2019 will also be an opportunity for EPF and other civil society actors to call for an improved and more robust monitoring and reporting process.

On the topic of cross-border healthcare, EPF also contributed to the drafting of a European Parliament's own-initiative report, including an invitation to a hearing organised by the European People's Party (EPP), as well as a reply to the Court of Auditors' public consultation.

"EPF WELCOMED THE CLEAR SHIFT TOWARDS MORE SOCIAL AND LESS FINANCIAL-ORIENTED RECOMMENDATIONS."

EPF PROMOTES BETTER INCLUSION OF PEOPLE WITH CHRONIC CONDITIONS IN THE WORKPLACE

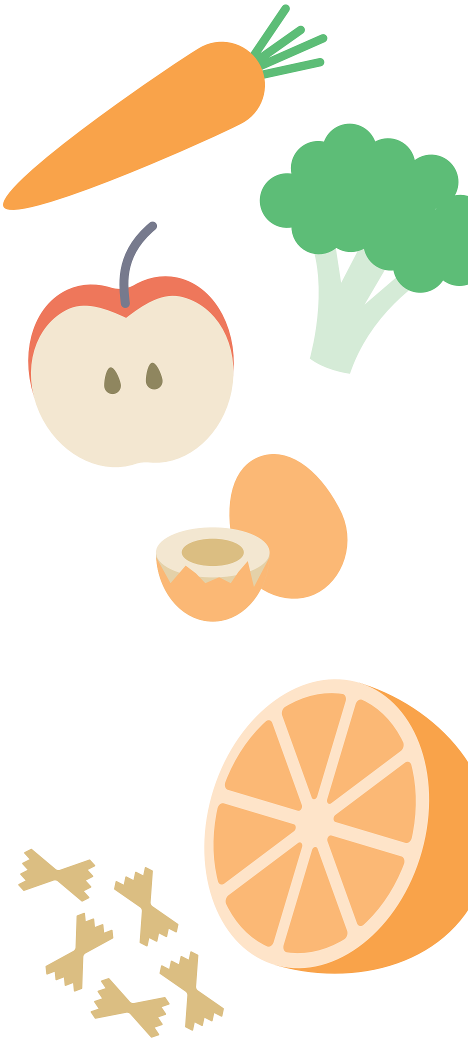
Employment is fundamental to stay connected to the community, maintain skills and continuing to develop professionally. While some people with chronic conditions cannot continue their professional activity due to their health condition, many continue working or wish to do so. In 2018, EPF intensified its advocacy for the development and implementation of policies and initiatives that eliminate discrimination, reduce stigma and promote the inclusion of patients with chronic diseases in healthcare, employment and society at large.

EPF started the year by publishing three materials developed by a task force primarily made up of EPF members: i) a collection of patient organisation initiatives to promote patient-led actions on this topic and take-up of existing materials; ii) recommendations to policy makers on how they can promote better inclusion of people with chronic conditions in the workplace in the context of the European Pillar of Social Rights; and iii) a digital leaflet for employers on how to foster inclusive work places. On a policy front, we actively contributed to the development of the unanimously adopted European Parliament Report and motion for a Resolution on Pathways for the Reintegration of Workers Recovering from Injury and Illness into Quality Employment, of which most of our proposals were adopted. EPF also supported the launch of a new MEP focus group on employment and health.

As a partner of the Joint Action on Chronic Diseases, EPF has been particularly active in the work package on employment, which aims to develop a toolkit and training tool for employers. In 2019, EPF will focus on promoting its recommendation on equal treatment in the workplace to employers and policy-makers by organising a multi-stakeholder meeting on the integration of patients in the work place. We will also combat discrimination in the context of the European Pillar of Social Rights.

> “WE WILL ALSO
> COMBAT DISCRIMINATION
> IN THE CONTEXT
> OF THE EUROPEAN PILLAR
> OF SOCIAL RIGHTS.”

BETTER INFORMATION TO PATIENTS ON FOOD AND NUTRITION



In line with its responsibilities as an agent for public health for our specific constituency, and given the interest of EPF members on this topic, in 2017 and 2018 EPF elevated its strategy in the sphere of information to patients on nutrition. In 2018, EPF has made significant progress in advancing the awareness and application of meaningful patient involvement in clinical nutrition, information for patients, and raising awareness of the role of nutrition and diet in managing long-term conditions. Our actions and effective involvement in the European Nutrition Health Alliance have contributed to improving the receptiveness and willingness of the clinical nutrition sector to involve patients.

In March, EPF published a position statement on information for patients on food and nutrition, which highlights nutrition as an essential component of disease management and gives an overview of the EU legislation related to information for patients on food and nutrition. Our statement highlights the need for summaries of clinical nutrition guidelines for patients, the need for more patient involvement in the development of guidelines, and the importance of health literacy and informed decision-making concerning food and nutrition.

Guided by the EPF-EGAN led EU patient task force on nutrition which was launched earlier in 2018, EPF published a paper on Clinical Nutrition Guidelines and Summaries for Patients in collaboration with EGAN. It includes recommendations primarily intended for scientific societies and guideline developers, which were presented in the opening plenary of the Optimal Nutritional Care for All Conference in November 2018. This work has led to a formal collaboration with the European Society for Clinical Nutrition and Metabolism (ESPEN) with whom we will work in the coming years to develop patient versions of existing guidelines and to ensure strong patient involvement in the review of new guidelines.

SHAPING THE FUTURE EU POLICY FRAMEWORK FOR HEALTH

2018 was an important year in terms of influencing the future shape of major EU programmes – the EU budget, the future EU health programme, and the next framework programme on research. Major decisions are pending finalisation in 2019, which we will continue to follow closely. The new programme for health will be included in a wider framework titled "European Social Fund Plus" (ESF+), which EPF broadly welcomed but worked with the European Parliament to improve the original proposal. The same goes for the new research framework programme, Horizon Europe. It was not an easy battle, but the result was that both texts are now more patient-friendly. Next to a large number of language improvements that address social aspects like inclusion and other relevant concepts (in both programmes), the Steering Bard for Health has been suggested: a structure that will help in coordinating the health strand with other programmes by promoting patients' engagement at a strategic level.

Both ESF+ and Horizon Europe programmes are part of the general EU budget – the multi-annual financial framework (MFF). In addition to our independent advocacy as EPF, we also joined forces with EPHA and other health organisations involved in the #EU4Health campaign to call for increased funding on health. EPF took the lead in calling for a Commission Vice-President for health, a request that many others have taken up since.

Another large policy file in 2018 concerned Brexit, for which EPF was an active partner in an informal coalition of stakeholders. We produced a joint statement highlighting patients' priorities and the primary importance of ensuring safety. We also had meetings with the EU "Article 50 Task Force" as well as with the UK Permanent Representation. We were also involved in the organisation of two events, including one in the European Parliament. At our request, the Commission published a notice to stakeholders on clinical trial preparedness.

In 2019, EPF will continue to be active in the #EU4HEALTH campaign, which will complement our own patient-led campaign for the 2019 elections.

> “WE ALSO CONTINUED OUR WORK WITH THE WORLD HEALTH ORGANISATION ON HEALTH SYSTEMS STRENGTHENING.”

IMPROVING HEALTH SYSTEMS’ PERFORMANCE

In 2018, EPF continued to advocate for better measures to improve the evaluation of health systems’ performance from the perspective of a patient.

We collaborated with the OECD and contributed to the shaping of the PaRIS project as part of a special task force. PaRIS is a partly EU-funded initiative that builds on a mandate from the member countries’ health ministers to develop comparable, cross-country indicators for patient-reported outcome measures (PROMs) for chronic conditions, and measures for assessing patients’ experiences of care (PREMs). EPF has mainly been involved in discussions around generic (non-disease specific) PROMs and advising the OECD on how to engage with patients more widely, once PaRIS gets going in 2019. In addition, EPF has been contributing to the expert group on healthcare quality and outcomes (HQCO) especially on discussions on how to capture patients’ experience of safety in healthcare environments.

We also continued our work with the World Health Organisation on health systems’ strengthening, bringing the perspective of patients and exploring the role of patient empowerment as a concept and as a strategy to contribute to sustainable and quality health systems for the future.

THE #EUROPEFORPATIENTS CAMPAIGN: PUTTING WHAT MATTERS TO PATIENTS AT THE HEART OF THE 2019 EUROPEAN ELECTIONS

The European Patients' Forum launched its 2019 European Parliament election campaign to ensure that what matters to patients is prominent in the upcoming European elections. During a special event on 9 October at our offices in Brussels, we launched our manifesto, which sets out five key demands for the next term of the European Parliament. We are seeking advances in access, patient empowerment, digital health, patient involvement in research, and patient organisations' involvement in health policy. These five keys asks have been translated into five powerful video testimonials of patients and were presented during the launch event.

Among the keynote speakers, two strong patient advocates from the Netherlands and from Denmark talked about their experiences and how they would like to see health cooperation evolve at EU level. Commissioner for Health and Safety, Dr Vytenis Andriukaitis, who closed the event, gave a rousing speech on the importance of the EU for patients, while endorsing EPF's five key messages for the 2019 European elections. EPF Secretary General, Nicola Bedlington, placed a special emphasis on the need to ensure that this campaign goes well beyond Brussels and resonates in all EU countries at local and regional level.

To coincide with the launch event, a dedicated website for the campaign was also launched. This website brings together information about the elections, and includes our manifesto and the five videos. We have also developed a detailed toolkit and website containing key messages and other materials, which can be used by our supporters. Further outreach actions have been planned in the first half of 2019 to help Europe's citizens understand how they can make an impact by voting to ensure the next Parliament and Commission act on the priorities of patients and their families.

> "WE ARE SEEKING ADVANCES IN ACCESS, PATIENT EMPOWERMENT, DIGITAL HEALTH, AND MEANINGFUL INVOLVEMENT OF PATIENTS IN DRIVING BETTER HEALTH POLICY."

Thank you to all our members for their valuable contributions, hard work, and commitment to our working groups!

5. PROJECTS

EPF's participation and leadership in projects strengthens our advocacy work. In 2018, EPF continued to be active in various health-related EU projects as a leader or a partner. We also expanded our project portfolio to build expertise and collect evidence reflecting our policy objectives. More info about our ongoing and finished projects can be found at eu-patient.eu/whatwedo/Projects.

- The EPF-led tender study PRO-STEP on self-management of chronic conditions was successfully completed and recommendations were widely disseminated at national level.
- The IMI project PARADIGM focusing on patient engagement in medicines' development was launched.
- EUPATI continued to expand as an EPF-led Public Private Partnership that educates patient representatives and the lay public about all processes involved in medicines development.
- Joint Action CHRODIS-PLUS (JA CHRODIS +) was launched: it aims to support Member States through cross-national initiatives identified in a previous Joint Action, to reduce the burden of chronic diseases, while assuring health systems sustainability and responsiveness.
- COMPAR-EU moved forward in identifying, comparing, and ranking the most effective and cost-effective self-management interventions (including preventive and management domains) for adults living with four high-priority chronic diseases today.
- The EHDEN project was launched: it aims at setting an interoperable and federated network of databases to improve access to quality health data and increase research results.

> *“In 2018, PARADIGM, under the leadership of EPF and EFPIA, worked on the development of tangible solutions to advancing patient engagement in medicines R&D that are fit for purpose for the community of medicines developers at large. It will slowly but surely support the much-needed cultural change.”*
>
> **Mathieu Boudes**
> PARADIGM Coordinator

A YEAR INTO PARADIGM TO ADVANCE PATIENT ENGAGEMENT IN MEDICINES DEVELOPMENT

Since the launch of the EUPATI project almost a decade ago, the long-term vision at EPF is that patient education, training and empowerment are intrinsically linked with patient engagement during the development of medicines. In line with this strategy, EPF is co-leading the IMI-funded project PARADIGM with EFPIA, in order to create an ecosystem fostering patient engagement in R&D.

The synergy between EUPATI and PARADIGM will result in a nexus that will support the de-risking of medicines R&D in the long term.

With this in mind, the PARADIGM project forms partnerships with all actors in the area of patient engagement in medicines development, including Patient Focused Medicines Development (PFMD), an initiative in which EPF is a founding member.

For the past 11 months, the PARADIGM project worked to understand the needs of all stakeholders when it comes to patient engagement, to develop a framework to evaluate and monitor patient engagement, and to make progress on a sustainability roadmap. More than 500 people responded to our online survey.

In 2019, PARADIGM will have more patient representatives involved, thanks to a pool of patient advisors selected through an open call, who will work with EPF to advance our involvement and leadership on this flagship project.

EUPATI'S MAIN ACHIEVEMENTS IN 2018

2018 has been an exciting year for EUPATI with some major achievements.

EUPATI Toolbox used by more than 1 million people

The EPF-led European Patient Academy on Therapeutic Innovation (set up by the IMI-EUPATI project in 2012-2017) launched a Toolbox in early 2016, which reached more than 1 million users in 2018. The Toolbox provides the "A-Z of medicines research and development" from lab bench to approval, drug safety and other topics. Users can access the Toolbox information in nine languages with three additional languages in progress (Portuguese, Romanian, Swedish).

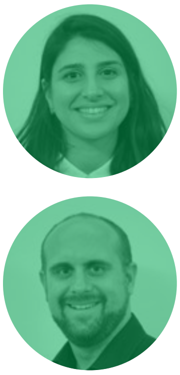
Completion of the Patient Expert Course: more than 50 trainees graduated

The third EUPATI Expert Training Course ended in late November 2018. More than 50 trainees had the chance to learn or increase their understanding of the R&D topic and to contribute in the future as an informed patient advocate. The EUPATI Course aims to train patients, patient representatives and/or carers who will advocate for an effective improvements and solutions in healthcare systems. The applications for the fourth Expert Training Course will be launched during Spring 2019.

Peer-Reviewed EUPATI Guidance published in Frontiers in Medicine

EUPATI published guidance for patient involvement in key areas of medicines research and development:

- Patient Involvement in Ethical Review of Clinical Trials
- Patient Involvement in Medicines Research and Development: Health Technology Assessment
- Patient Involvement in Regulatory Processes
- Guidance for Pharmaceutical Industry-Led Medicines R&D



> *"When EUPATI first launched the toolbox in 2016 with the aim of reaching 100,000 we saw it as a huge mountain to climb. The reality of course was as the world woke up to the necessity and importance of patient engagement, the demand for knowledge exploded, we could never have imagined that we would be now seeing numbers as high as the 120,000+ users we saw per month in the second half of 2018. This is what will drive the Patients' Academy of the future forward and continue to provide education not just to the patient community, but increasingly to all stakeholders to ensure effective and impactful patient involvement in Europe and around the world."*

Camilla Habre
Project Officer
Matthew May
EUPATI Coordinator

SHARING RESULTS OF THE PRO-STEP PROJECT

Completed in January 2018, the PRO-STEP pilot project on self-management of chronic conditions marks a major achievement for EPF. PRO-STEP aimed at putting in place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care. In practice, the project explored the added-value of self-management in chronic diseases and developed a set of key recommendations for policy makers.

The PRO-STEP results identified the need for:

- An EU-wide mission and vision on self-care and self-management.
- A strategic approach at policy level encompassing development of knowledge and skills among relevant healthcare professionals and promotion of changes in societal attitudes.
- An assessment of cost-effectiveness of self-management from a societal perspective.
- Health literacy as a policy priority.
- Investment in communication.
- Support to innovation and digital technology as enablers of improved self-care.
- Further research to fill in gaps and further strengthen the evidence-base.

“The importance of participating in projects has many faces. To me projects are a huge opportunity for mutual exchange with partners. We learn from their expertise and offer them a perspective that can contribute to change their mindsets. In projects, my hidden agenda is always to advocate for appropriate and meaningful patient involvement -hoping it will be mainstreamed in our partners’ daily practices.”

Valentina Strammiello
Senior Project Manager

> “THE PRO-STEP PILOT PROJECT ON SELF-MANAGEMENT OF CHRONIC CONDITIONS MARKS A MAJOR ACHIEVEMENT FOR EPF TO GAIN A DEEPER INSIGHT IN ASPECTS STRONGLY RELATED TO PATIENT EMPOWERMENT.”

6. 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 EPF activities. As such, it supports patient organisations to strengthen their role as equal players in the healthcare environment.

The target group is primarily constituted primarily of representatives of EPF members: pan-European disease-specific organisations and national coalitions of patient organisations, including their members. EPF also targets other patient organisations representatives' who are not affiliated with EPF.

Our vision with our members is that EPF should be a participative forum, a place where they can spontaneously share and improve their own strategies, and look for contacts, experience and tips. To this end, 2018 was again a significant year for the development and implementation of EPF's Capacity Building Programme, further contributing to our mission to support patient organisations, and to strengthen their role as equal players in the healthcare environment. Among the most significant elements of this important work are the launch of our new Capacity Building Module on Empowering Leadership and Positive Governance, as well as the successful execution of our Patients Advocates' Seminar.

> *“With EPF capacity building programme, we want to equip national and European patient organisations with the skills to advocate for patient rights and express their full potential.”*
>
> **Elena Balestra**
> Membership &
> Capacity Building Manager

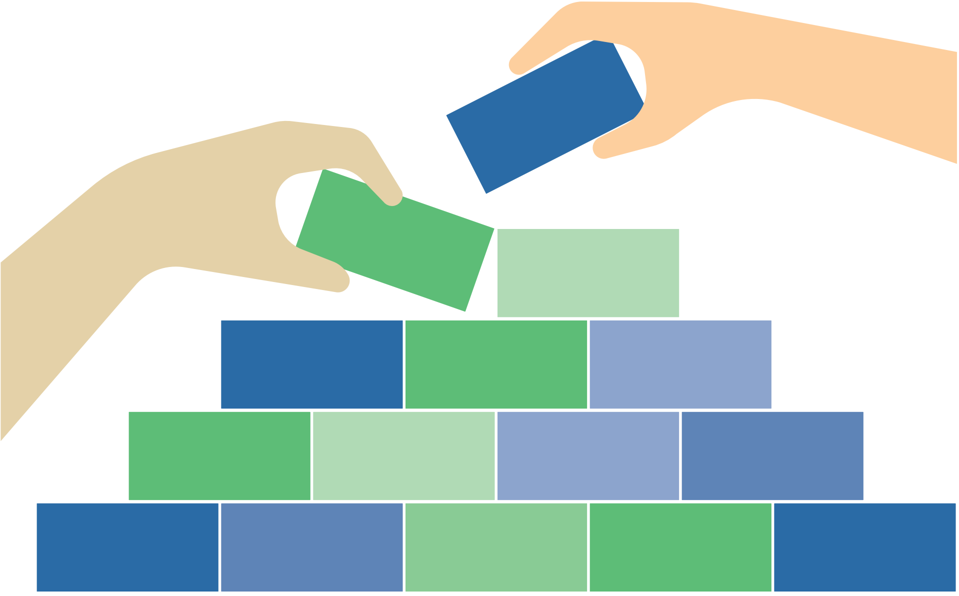
The module – which started in April 2018 and was implemented throughout the year – aims at strengthening patient organisations by enhancing their leaders' leadership skills, and consequently enabling positive governance in their organisation. The overall objective is to support patient organisations in positioning themselves as legitimate stakeholders, strong advocates and reliable partners in the national and European health policy environment – leading to greater impact and positive change within communities.

In this context, one of the main highlights is most certainly the first EPF Patient Advocates' Seminar organised in Brussels on 20-21 October, which brought together 30 representatives of patient organisations from more than 20 countries across Europe. Conducted in a dynamic and engaging atmosphere, the aim was to show how the European legislative process works, and to learn how to advocate effectively at all levels, for better outcomes for patients in Europe.

Our journey doesn't stop here. In 2019, EPF will launch a Capacity Building Module on Empowering Leadership and Positive Organisational Governance.

Read more about our Capacity Building Programme at www.eu-patient.eu/whatwedo/capacity-building-programme.

“THE FIRST EPF PATIENT ADVOCATES' SEMINAR ORGANISED IN BRUSSELS ON 20-21 OCTOBER, WHICH BROUGHT TOGETHER 30 REPRESENTATIVES OF PATIENT ORGANISATIONS FROM MORE THAN 20 COUNTRIES ACROSS EUROPE.”



7. ALLIANCE BUILDING

EPF brings significant added value in strongly advocating for the value of Europe in health and health in Europe. To do so, we believe in engaging in partnerships with diverse actors to address high-level strategic issues such as the future of EU health policy. We collaborate with both EU and international bodies and can point out relevant synergies or gaps.

EPF has an advisory role in various organisations (SIP-Societal Impact of Pain, BBMRI-biobanking association, European Health Policy Forum Gastein) and engagement with relevant stakeholders in the area of healthcare (Health Policy Officers meetings, relations with healthcare student associations, Youth Cancer Forum, Civil Society Europe, the Integrated Care Alliance), academia through our projects, and engagement with the European Commission's Health Policy Platform.

Let's home in two exciting initiatives we are currently involved in:

The Patient Access Partnership (PACT)

"ENSURE EQUAL ACCESS TO QUALITY HEALTHCARE"

Initiated by the National Patients' Organisation of Bulgaria and EPF, the PACT was officially launched in 2014 to tackle the issue of health inequalities from the perspective of patients. This patient-led network brings together the patients, the medical community, the industry and the European policy-makers to ensure equal access to quality healthcare is a priority of the EU institutions too as Member States alone cannot tackle this problem. A genuine involvement of all stakeholders engaged with healthcare is vital to find workable solutions to fit real-life needs.

In 2018, The MEP Interest Group on Access hosted an event on the results of the pilot project 'Towards a fairer and more effective measurement of access to healthcare across the EU', carried-out on behalf of the European Commission (DG SANTE). The meeting provided a platform to present the results to health stakeholders as well as discussing with them the challenges and opportunities for implementation.

This project aims to identify effective ways of measuring access to healthcare whilst developing a conceptual framework and a list of indicators to measure access in the EU. It is a result of the proposal put forward in 2016 by the MEP Interest Group on Access following a close cooperation with the Patient Access Partnership (PACT).

THE EUROPEAN HEALTH PARLIAMENT

The European Health Parliament (EHP) is led by a multi-disciplinary and multi-stakeholder partnership including EPF, Politico, the College of Europe, the MEP group "EU40", Johnson & Johnson, and Porter Novelli as the new communication partner.

EPF joined the EHP in 2017 to ensure that the patient perspective is always part of the debates.

The 2018 edition of the EHP had as overarching topic "We Run 4 Health: Rediscovering Health in Europe", linked to the 2019 European Elections. Its purpose was to stimulate conversations and engage with candidates running for the new European Parliament. Five specific topics were addressed by dedicated committees on data for healthy societies, disease prevention and management, innovation and value, health literacy and self-care, as well as on environmental and human health. After extensive research and outreach into the healthcare community, each committee presented their policy recommendations, which were then passed onto decision-makers at the highest levels.

> *“Youth is all about passion. The EPF Youth Group is here to bring a positive change and strive for integration of young patients’ perspective in EPF advocacy work.”*

Andreas Christodoulou, EPF Youth Group President

8. YOUNG PATIENTS

For more information about the Youth Group and our Youth Strategy, please visit: *eu-patient.eu/About-EPF/whoweare/Youth-Strategy*

The EPF Youth Group represents young patients within the EPF community. This diverse group of motivated young people aims to raise awareness about young patients’ lives and addresses cross-cutting issues, which affect their quality of life.

Creativity, communication and mutual respect are key elements to empower young patients, says the EPF Youth Group. Indeed 2018 was an exciting and promising year, which led to great achievements in the field of young patient empowerment. The members of the Youth Group attended multi-stakeholder conferences and various working groups to talk about discrimination, patient engagement, cross-border healthcare and digital health. With the 2019 European Elections just around the corner, it is now crucial for the Youth Group to focus all its strengths on bringing young patients’ needs on the EU agenda.

In 2019, the Youth Group will advance its work on improving young patients’ employment, particularly through the implementation of the WAYS (Work and Youth Strategy) project.

“DEVELOPING PERSONAL LEADERSHIP SKILLS AND LEARNING HOW TO CAMPAIGN EFFECTIVELY”

SUMMER TRAINING FOR YOUNG PATIENT ADVOCATES

This exciting and unique opportunity offers on yearly basis a tailored high-quality training to young (18-30) patient advocates or representatives of young patient advocates who have the motivation to learn more about advocacy and maximise their leadership potentials in real environment. Our vision for the Summer Training Course – Leadership Programme is to create a platform where young patients’ advocates would empower, inspire and learn from each other.

The 2nd edition of the EPF Summer Training for Young Patient Advocates in 2018 was built on the theme of the previous year on overcoming discrimination and expanded on the concept of inclusion. In total, 39 participants from 23 European countries joined us in Vienna for three days of intensive but inspiring and fun training sessions. The aims of this 2018 edition were ambitious: developing personal leadership skills and learning how to campaign effectively to achieve advocacy goals. Participants were very motivated with strong post-event follow-up engagement.

> *“We were all young. At some point, we were, we are and we will be patients. Tomorrow starts Today. The voice of the youth needs to be heard in order to have a better future for the whole patient community. Because of these reasons, EPF set up the Youth Group almost a decade ago, with the aim to embed the youth perspective into our core values, strategy and workstream. At the same time, for the 3rd time in a row, the Summer Training Course prepares future patient advocates to “enter the real world”, stand their ground and navigate themselves among ever-more-complex environment of various stakeholders, opportunities and challenges. The voice of young patient advocates matters, and it is here to stay.”*

Lyudmil Ninov, Project Officer

9. IN THE PIPELINE

Our journey towards ensuring that all patients with chronic conditions in Europe have access to high-quality, patient-centred health and related care continues and we have some major projects in the horizon. Here is an overview of three upcoming highlights of our work.

#EuropeForPatients

In 2019 we will be campaigning for the European Elections, to put what matters to patients at the heart of the EU health policy and make health a priority in the EU post 2020. To achieve these goals, EPF is mobilising collaborators, member organisations and supporters, so that the five key priorities for health and patients defined at the 2018 AGM by our own members are well promoted throughout our network and made accessible to EU's citizens. Patient advocacy in the European elections is crucial to drive positive change for patients. With 72 member organisations, representing the interests of an estimated 150 million people with chronic diseases, EPF amplifies the voice of a high proportion of voters. Over the next weeks and months, we will be working hard with members and supporters to engage patients and citizens on issues that matter to them and to encourage candidates to adopt the manifesto nationally.

Visit europeforpatients.eu for more information about our campaign.

#EPFCongress19

In 2019, EPF will organise the first ever European Congress on patient involvement, driven by leading representatives of the patient community, and patient experts. The event will provide an exceptional opportunity for dialogue, engagement with a wide range of health players who aspire to make patient involvement a reality. Together, we will explore why this will lead to better outcomes for patients and society, and how we can achieve this in practice across the European Union.

Visite epfcongress.eu and stay informed about this exceptional opportunity for dialogue, engagement with a wide range of health players who aspire to make patient involvement a reality.

#DataSavesLives

EPF believes that research into chronic diseases and their management and treatment is increasingly reliant on data generated by patients, physicians and other healthcare workers. For this reason, it is in the mission of EPF and allied organisations to propose to develop a European Health Data Platform, in the framework of the "Data Saves Lives" multi-stakeholder initiative. The aim of this portal is to build and improve awareness and knowledge, to promote the importance of data in health research to the public, and to create a trusted environment for dialogue about the use of health data.

> *"One of the most important things that EPF does is involving patients and listening to them in order to represent their voices. There is no better way to share thoughts and experience than during the EPF events. Thanks to a valuable input of patients and EPF staff, detailed planning and commitment we have managed to organise various successful events in the 2018."*

Anna Trzcinska
Events Officer

10. LIST OF MEMBERS

Our membership is our raison d'être, our members are the backbone of our work: their feedback bring an inestimable added value to our policy and advocacy activities. With these new members, EPF now represents 72 patient organisations throughout Europe – 53 Full Members, 19 Associate Members, and 1 Provisional Member – making it the strongest cross-disease patients' voice at European level.

In 2018, the EPF family was delighted to welcome 2 new members – one of which (Plataforma de Organizaciones de Pacientes) – has been confirmed as a full member of EPF. Keeping the organisation growing and strengthening our representation by adding the voice of several countries and diseases to EPF's, it is our pleasure to count as new members:

FULL MEMBERSHIP

Plataforma de Organizaciones de Pacientes, which brings together the main groups that represent patients, people with chronic diseases and symptoms in Spain.

ASSOCIATE MEMBERSHIP

SAFE, an umbrella organisation for national and regional organisations representing a range of stroke patient across Europe that were affected by stroke.

FULL MEMBERS (52)

EPF Full Members consist of patient organisations who meet the 5 following criteria:

LEGITIMACY

EPF member organisations should be registered in one of the EU member states.

DEMOCRACY

EPF members should have governing bodies, which are elected by their members, who shall be patients, their carers, or their elected representatives.

REPRESENTATION

EPF pan-European disease-specific organisations should have members of their own in more than half of the EU member states. National platforms should represent at least 10 different disease groups to be accepted as Full members.

ACCOUNTABILITY & CONSULTATION

Statements and opinions should reflect the views and opinions of their memberships, and consultation procedures with those memberships should be put in place.

TRANSPARENCY

EPF members should generally disclose their sources of funding and make their audited financial accounts available.

OUR CURRENT FULL MEMBERS INCLUDE

Alzheimer Europe
AMD • Age Related Macular Degeneration Alliance International
AOECS • Association of European Coeliac Societies
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)
COPAC • Coalition of Patients' Organizations with Chronic Diseases (Romania)
DE • Dystonia Europe
EAMDA • European Alliance of neuro-Muscular Disorders Association
EATG • European Aids Treatment Group
ECHDO • European Congenital Heart Disease Organisation
EFA • European Federation of Allergy and Airways Diseases Patients' Associations
EFAPH • European Federation of Associations of Patients with Haemochromatosis
EFCCA • European Federation of Crohn's and Ulcerative Colitis Associations
EFHPA • European Federation of Homeopathic Patients' Associations
EGAN • Patients Network for Medical Research and Health (Europe)
EHC • European Haemophilia Consortium
EHLTF • European Heart and Lung Transplant Federation
EIA • European Infertility Alliance
EKPF • European Kidney Patients' Federation
ELPA • European Liver Patients Organization
EMHA – European Migraine and Headache Alliance
EMSP • European Multiple Sclerosis Platform
ENUSP • European Network of (ex)Users and Survivors of Psychiatry
EPDA • European Parkinson's Disease Association
EPIK • Estonian Chamber of Disabled People
EUFAMI • European Federation of Associations of Families of People with Mental Illness
EUROPA DONNA • The European Breast Cancer Coalition
EUROPSO • European Umbrella Organisation for Psoriasis Movements
EURORDIS • European Organisation for Rare Diseases
FE • Fertility Europe
FEP • Spanish Patients' Forum
FPP • Federation of Polish Patients
FRANCE ASSOS SANTE • La voix des usagers
GAMIAN Europe • Global Alliance of Mental Illness Advocacy Networks
HAPO • Hungarian Alliance of Patients' Organisation
IDF Europe • International Diabetes Federation
IF • International Federation for Spina Bifida and Hydrocephalus
IOF • International Osteoporosis Federation
IPOPI • International Patient Organisation for Primary Immunodeficiencies
KUZ • Coalition of Associations in Healthcare (Croatia)
KZZ • Confederation Health Protections (Bulgaria)
LPOAT • Council of Representatives of Patients' organizations of Lithuania
LUPUS Europe
MHN • Malta Health Network
National Voices (United Kingdom)
NCDP • National Confederation of Disabled People (Greece)
NPO • National Patients' Organisation of Bulgaria
Pancyprian Federation of Patients Associations and Friends
PHA Europe • Pulmonary Hypertension Association Europe
Plataforma de Organizaciones de Pacientes (Spain)
RI • Retina International
SUSTENTO • The Latvian Umbrella Body for Disability Organization Swedish Disability Rights Federation

ASSOCIATE MEMBERS (19)

Associate members are organisations that represent patients' associations but do not meet the 5 EPF legitimacy criteria. Associate members participate to the EPF activities and policy work but cannot vote during the Annual General Assembly.

MEMBERSHIP

Members are patient organisations, but not solely.

LEGITIMACY

Organisations registered in an EU country or in a candidate country.

REPRESENTATION

Pan-European disease-specific organisations: represent less than 14 countries (but are aiming to expend their membership). National platforms: represent less than 10 diseases (but are aiming to expend their membership).

DEMOCRACY

Governing bodies are elected by the members and include patient representatives, but not solely.

ACCOUNTABILITY & CONSULTATION

Statements and opinions of EPF member organisations should reflect the views and opinions of their memberships and consultation procedures with those memberships should be put in place.

TRANSPARENCY

EPF member organisations should generally disclose their sources of funding and make available their audited financial accounts.

OUR CURRENT ASSOCIATE MEMBERS INCLUDE

AGORA • (Southern Europe)
AMRC • Association of Medical Research Charities (United Kingdom)
BAPD • Bulgarian Association for Patients Defence
DEBRA International • Organisation of people with Epidermolysis Bullosa Support Groups
Digestive Cancers Europe
ECO • European Cleft Organisation
EFNA • European Federation of Neurological Associations
EIWH • European Institute of Women's Health
EMHF • European Men's Health Forum
ENFA • European Network of Fibromyalgia Associations
Health and Social Care Alliance Scotland • The Alliance
HOPA • Hungarian Osteoporosis Patient Association
IBE • International Bureau for Epilepsy
LUCE • Lung Cancer Europe
MRCG • Medical Research Charities Group (Ireland)
MHE-SME • Mental Health Europe
SAFE • Stroke Alliance for Europe
VPP • Flemish Patients' Platform
WFIP • World Federation of Incontinent Patients

PROVISIONAL MEMBERS (1)

This level of membership is a transitional status for the organisations who do not meet the five Full Membership criteria but intend to do so in the foreseeable future. If they do not meet the criteria within two years, then they will be considered for associate membership status.

This level of membership is also reserved for organisations having been approved by the Board but whose membership still need to be confirmed by EPF members at the Annual General Meeting. National platforms of patients' organisations from EU candidate countries that meet full membership status may become provisional members until accession, after which they will become full members.

There is currently one provisional member in EPF's network: APO – Alliance of Patient Organisations (North Macedonia).

> *“Our work would not be the same without our members: in turn we want to show our support. The Weekly Insiders are not only a great way to put our own resources to good use, but to stay in touch with fellow organisations who strive to place the patient and access to healthcare at the heart of EU policy.”*
>
> **Emily Bowles**
> Communications Officer

EPF AND WIDER EUROPE CONSTITUTIONAL REFORM

In 2017, EPF's Annual General Assembly mandated the secretariat to examine a potential constitutional change to encompass the expansion of our membership to the wider European region. This need for change has been accelerated with the developments that have emerged with Brexit and the increase interest in pan European cooperation. This constitutional reform allows organisations based in geographical Europe to become members of EPF. In addition, we will establish an Ethics Committee for EPF and the EPF Youth Section Committee will be entitled to have a representative as EPF Board Member. A Constitutional Reform Committee headed by our President Marco Greco has driven this work and revised Constitution and internal rules will be circulated to our members for adoption at our AGM 2019.

11. SECRETARIAT & GOVERNANCE

> *“ Driving excellence in IT operations and data protection is a daily challenge, key to ensuring team members carry out their roles efficiently, productively and securely. ”*

Žilvinas Gavėnas, IT Coordinator

MEET OUR BOARD

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

PRESIDENT
Marco Greco, European Federation of Crohn’s and Ulcerative Colitis Associations (EFCCA)

VICE PRESIDENT AND TREASURER
Radu Costin Ganescu, Coalition of organisations for patients with chronic conditions of Romania (COPAC)

BOARD MEMBERS
Stanimir Hasurdjiev, Bulgarian National Patients’ Organization (NPO)
Hilkka Karkkainen, GAMIAN-Europe
Elisabeth Kasilingam, European Multiple Sclerosis Platform (EMSP)
Marzena Nelken, Polish PKU and Ars Vivendi
Cor Oosterwijk, Dutch National Patient Alliance for Rare and Genetic Disorders (VSOP)
Michal Rataj, European Alliance of Neuromuscular Disorders Associations (EAMDA)
Gabriela Tanasan, European Network of (Ex-)Users and Survivors of Psychiatry (ENUSP)

> *“ As Office Coordinator and Team Assistant, we work hard to ensure that the secretariat can work in a positive and comfortable environment and that we are compliant with Belgian human resource and administration law, contributing to the overall objectives of EPF. ”*

Ruth Tchaparian, Office Coordinator
Adriana Pereira, Team Assistant

MEET THE EPF SECRETARIAT

The EPF Secretariat is composed of professional and dedicated staff.

Kostas Aligiannis, Policy Officer
- Support Policy and Advocacy Work

Elena Balestra, Membership & Capacity Building Manager
- Capacity-Building Programme, Membership engagement and growth

Nicola Bedlington, Secretary General
- Leadership, Direction & Guidance
- High-Level Representation & Liaison with Partners

Mathieu Boudes, PARADIGM Coordinator *Welcome!*

Emily Bowles, Communications Officer *Welcome!*
- Supporting communications activities
- Managing weekly members newsletter

Katie Gallagher, Policy Adviser
- Policy & Advocacy
- Strategy on Access

Žilvinas Gavėnas, IT Coordinator
- IT Management and Planning

Camilla Habre *Welcome!*
- Coordinating contribution to EUPATI, IMI-EFOEUPATI and IMI-PARADIGM
- Supporting the Project Team in project development

Kaisa Immonen, Director of Policy
- Strategic & Policy Agenda
- EU Institutions & Stakeholders

Matthew May, EUPATI Coordinator

Lyudmil Ninov, Project Officer
- Summer Training for Young Patient Advocates
- Project support

Adriana Pereira, Team Assistant *Welcome!*
- Office and information management

Julien Richard *Welcome!*
- Leading on communication strategy
- Managing key communication tools

Valentina Strammiello, Senior Programme Manager
- Project coordination and development
- Health Technology Assessment

Ruth Tchaparian, Office Coordinator
- Office and Information Management
- Management Support

Brendan Togher, Financial Manager *Welcome!*
- Financial matters
- Grants management

Anna Trzcinska, Events Officer
- EPF Meetings, Events and Travel Management

GOODBYE, THANK YOU AND ALL THE BEST
Camille Bullot, Director of Operations & Engagement
Danielle Flores, Project Officer
Letizia Gambina, Communications Manager
Sara Gayarre, Communications Officer
Stefano Tironi, Financial Manager

12. FINANCIALS

> *"EPF's committed and profession team absorbed the financial hit from the loss of the Operating Grant through diversifying its funding streams whist continuing to deliver valued contributions and quality results for our stakeholders."*

Radu Costin Ganescu, Treasurer
Brendan Togher, Financial Manager

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 2018.

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 2018 given is 2.184.590 euros, and there is a surplus of 181.477 euros.

All transactions, including any known or potential lawsuits or disputes, have been recorded correctly and are reflected in the financial statements. They were appropriately disclosed in the financial statements.

RSM Interaudit CVBA-SC SCRL, Chaussée de Waterloo 1151, B-1180 Brussels
Please contact *info@eu-patient.eu* to request a copy of the full report.

INCOME AND EXPENDITURES AS AT 31 DECEMBER 2018

INCOME	**2018**	**2017**
FUNDING FROM PUBLIC SECTOR	**€ 512,670.36**	**€ 1,172,461.04**
Operational Work Programme (Chafea Operating Grant 80%)	€ 0.00	€ 766,777.40
EC projects	€ 512,670.36	€ 293,276.29
EUPATI (EC contribution)	€ 0.00	€ 112,407.35
FUNDING FROM THE PRIVATE SECTOR	**€ 1,562,732.33**	**€ 948,886.12**
Operational Work Programme (co-funding of Chafea's Operating Grant, 19%)	€ 0.00	€ 173,455.00
Operation and Engagement	€ 782,371.91	€ 0.00
Capacity Building Programme	€ 378,403.03	€ 337,753.00
Co-funding to EPF projects	€ 4,960.99	€ 29,939.09
Project developments and other costs	€ 54,833.14	€ 254,328.67
Contribution to EPF Campaigns	€ 41,000.00	€ 0.00
Contribution CONGRESS	€ 0.00	€ 0.00
PARADIGM	€ 81,453.51	€ 0.00
EUPATI Programme	€ 219,709.75	€ 153,410.36
MEMBERSHIP FEES	**€ 20,450.00**	**€ 21,800.00**
Operational Work Programme (co-funding of Chafea's Operating Grant 1%)	€ 0.00	€ 18,239.35
Contribution to Work Plan (Operations, Capacity Building and project development)	€ 20,450.00	€ 0.00
Contribution to EU projects	€ 0.00	€ 3,560.65
INTEREST AND OTHER INCOME	**€ 31,445.16**	**€ 32,112.88**
TOTAL INCOME	**€ 2,127,297.85**	**€ 2,175,260.04**

EXPENDITURES	**2018**	**2017**
STAFF COSTS (ALL PROJECTS, ALL CAMPAIGNS)	**€ 1,041,099.29**	**€ 1,047,185.99**
OFFICE AND ADMIN COSTS	**€ 270,531.29**	**€ 204,101.18**
DEPRECIATION	**€ 24,087.88**	**€ 15,814.46**
TRAVEL AND SUBSISTENCE (EPF STAFF)	**€ 39,112.17**	**€ 52,676.70**
EVENTS (DIRECT COSTS)	**€ 541,850.85**	**€ 743,190.03**
Annual General Meeting & Board Meetings	€ 53,927.56	€ 49,726.30
Regional Advocacy Seminar	—	€ 26,682.19
Patient Advocacy Seminar	€ 23,768.32	—
Summer Training & Youth Group meetings	€ 57,412.77	€ 21,431.59
Thematic Working Group Meetings	€ 40,777.59	€ 31,502.77
(Access, Empowerment, Nutrition, Vaccines, Digital Health, Data Saves Lives, Incentives)		
Capacity Building Programme (delivery of training modules)	€ 47,918.26	€ 121,316.95
Congress 2019 (preparation)	€ 9,473.43	—
Cross-border healthcare regional events and conference	—	€ 48,537.82
Other costs linked to operations, project portfolio	€ 308,572.92	€ 443,992.41
CAMPAIGNS (DIRECT COSTS)	**€ 27,293.92**	**€ 12,331.32**
Access Campaign Roundtable	—	€ 12,331.32
European Elections	€ 27,293.92	—
BANK AND FINANCIAL CHARGES	**€ 1,845.00**	**€ 1,129.52**
TOTAL EXPENDITURE	**€ 1,945,820.40**	**€ 2,076,429.20**
Access Campaign Roundtable		
TOTAL SURPLUS OR DEFICIT OF THE YEAR	**€ 181,477.45**	**€ 98,830.84**

EPF WISHES TO THANK THE EUROPEAN COMMISSION for its support in 2018 in relation to EPF's role in the following projects

	EC Contribution used in 2018	% of total income
Total European Commission support to projects 2018	**€ 354,554.71**	
Adapt Smart	€ 1,701.37	0.1 %
Chrodis	€ 8,797.99	0.4 %
JA CHRODIS +	€ 19,843.95	0.9 %
Pisce	€ 747.64	0.0 %
ProStep	€ 190,056.47	8.9 %
Prefer	€ 7,564.13	0.4 %
ComparEU	€ 109,520.56	5.1 %
EFO EUPATI	€ 13,031.94	0.6 %
EHDEN	€ 3,290.66	0.2 %

EPF WISHES TO THANK THE FOLLOWING DONORS for their support

	Contribution to the Operations	% of total income
Operational & Engagement – work plan 2018/Project Development 2018	**€ 933,029.40**	
European Commission	—	0.0 %
AbbVie	€ 45,000.00	2.1 %
Amgen	€ 35,000.00	1.6 %
Bayer	€ 10,000.00	0.5 %
BMS	€ 75,000.00	3.5 %
Celgene	€ 15,000.00	0.7 %
CSL Behring	€ 10,000.00	0.5 %
CSL Behring (Congress)	€ 10,000.00	0.5 %
Edwards Lifescience SA	€ 25,000.00	1.2 %
EFPIA	€ 7,500.00	0.4 %
Eli Lilly	€ 15,000.00	0.7 %

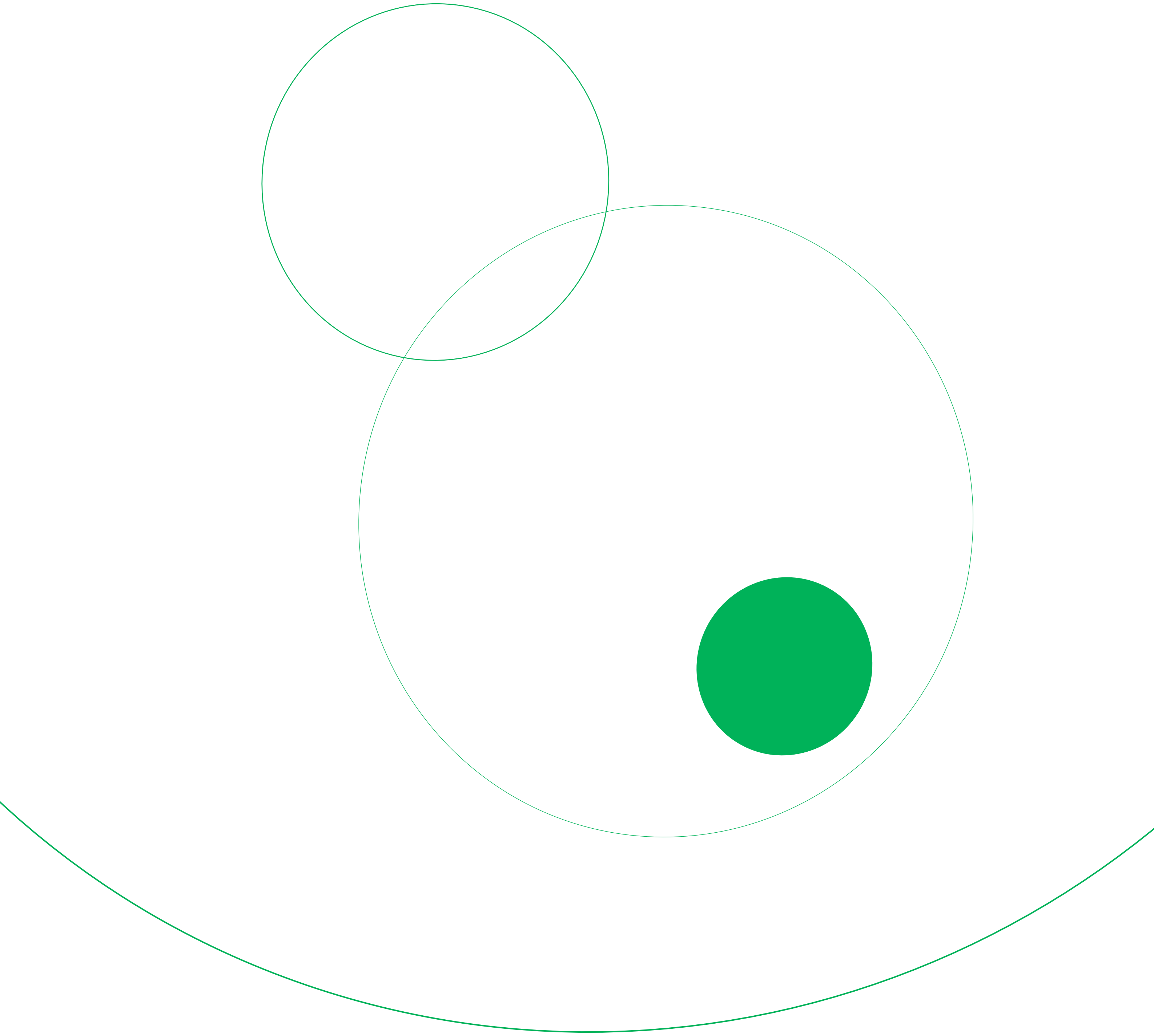
Gilead Sciences Europe	€ 64,034.40	3.0 %
Grunenthal	€ 10,000.00	0.5 %
GSK	€ 30,000.00	1.4 %
Janssen	€ 60,000.00	2.8 %
Medicines for Europe	€ 27,500.00	1.3 %
MSD	€ 100,000.00	4.7 %
Novartis Group	€ 20,000.00	0.9 %
Novartis Pharma AG	€ 32,545.00	1.5 %
Novartis Sandoz	€ 20,000.00	0.9 %
Pfizer Inc	€ 26,000.00	1.2 %
Pfizer SA	€ 30,000.00	1.4 %
F. Hoffman - La Roche	€ 50,000.00	2.4 %
Sanofi Aventis	€ 50,000.00	2.4 %
Servier	€ 15,000.00	0.7 %
Shire	€ 10,000.00	0.5 %
Takeda	€ 40,000.00	1.9 %
UCB	€ 30,000.00	1.4 %
Vertex	€ 50,000.00	2.4 %
Membership	€ 20,450.00	1.0 %
Capacity Building Programme 2018	**€ 378,982.02**	
	Contribution to the CBP	% of total income
Alexion	€ 20,000.00	0.9 %
Amgen	€ 5,000.00	0.2 %
Baxter	€ 10,000.00	0.5 %
Biogen	€ 15,000.00	0.7 %
EFPIA (DSL)	€ 3,982.02	0.2 %
ENHA	€ 10,000.00	0.5 %
GSK	€ 70,000.00	3.3 %
Kyowa Kirin	€ 10,000.00	0.5 %
Merck	€ 30,000.00	1.4 %
Microsoft	€ 30,000.00	1.4 %
MNI (Medical Nutrition International)	€ 20,000.00	0.9 %
Novartis Pharma AG ONCO	€ 30,000.00	1.4 %
Novo Nordisk	€ 30,000.00	1.4 %
Shire	€ 5,000.00	0.2 %
Vaccines Europe/ EFPIA	€ 75,000.00	3.5 %
Vertex	€ 15,000.00	0.7 %
Patients Active in Research and Dialogue for an Improved Generation of Medicine "PARADIGM"	**€ 239,569.16**	
		% of total income
Innovative Medicines Initiative (IMI JU) PARADIGM Funding	€ 158,115.65	7.4 %
Industry cash contribution (Amgen, Lundbeck, MSD, Pfizer, VFA)	€ 81,453.51	3.8 %
Patient Academy on Therapeutic Innovation "EUPATI Programme"	**€ 219,709.75**	
		% of total income
Industry consortium (AbbVie, Amgen, AstraZeneca UK, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, F. Hoffmann-La Roche, GSK, Janssen, MSD, Novartis, Novo Nordisk, Pfizer, Shire, UCB, Takeda, VFA)	€ 219,709.75	10.3%
Other income	€ 31,445.16	1.5%
TOTAL INCOME	**€ 2,157,290.20**	
Accrual and deferrals	€ 29,992.35	
TOTAL INCOME NET OF ADJUSTMENTS	**€ 2,127,297.85**	

BALANCE SHEETS AS AT 31 DECEMBER 2018

ASSETS	**2018**	**2017**
CURRENT ASSETS		
Accounts receivable	€ 546,511.56	€ 822,369
Short Term investment	—	—
Cash in bank and deposit	€ 1,523,926.92	€ 718,788
Pre-paid expenses	€ 14,121.47	€ 16,416
Total current assets	€ 2,084,559.95	€ 1,557,573
FIXED ASSETS		
Leasehold	€ 16,869.80	€ 18,112
Furniture, IT equipment and software	€ 44,990.48	€ 53,493
Guarantees (rent and social security)	€ 38,170.00	€ 50
Total fixed assets	€ 100,030.28	€ 71,655
TOTAL ASSETS	**€ 2,184,590**	**€ 1,629,228**

LIABILITIES		
CURRENT LIABILITIES		
Accounts payable	€ 587,080	€ 174,985
Deferred income	€ 660,488	€ 750,041
Income to be allocated to project partners	€ 5,246	€ 10,116
Total current liabilities	€ 1,252,814	€ 935,142
RESERVES		
Funds brought forward	€ 384,338	€ 585,507€
Social Reserve	€ 300,000	—
Surplus or deficit for the year	€ 181,477	€ 98,831
Total reserves	€ 865,815	€ 684,338
Provisions	€ 65,961	€ 9,748
TOTAL LIABILITIES	**€ 2,184,590**	**€ 1,629,228**

NOTES



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