

EPF 2017 Annual Report

Driving Better Health for Patients in Europe



European Patients' Forum • Chaussée d'Etterbeek, 180 • 1040 Brussels • Belgium
Office Phone Number: +32 (0) 2 280 23 34 • Email: info@eu-patient.eu • www.eu-patient.eu

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE

Contents

1. Foreword.....	3
2. 2017 at a glance	4
3. Patient Access	6
HIGHLIGHT – 2017 CAMPAIGN ON ACCESS TO HEALTHCARE	6
The campaign – why universal access to healthcare?	8
The high-level meetings.....	8
The roadmap.....	9
4. Patient Empowerment.....	16
HIGHLIGHT – EUPATI.....	18
The course.....	18
The outreach.....	19
The future	19
5. Alliance Building.....	21
6. A Vibrant Network	23
National coalition meeting 2017.....	24
Capacity Building Programme.....	25
EPF summer Training Course for Young Patient Advocates	27
The Youth Group	28
7. List of Members	29
8. Accounts and Audit report.....	33
9. Financials.....	35
10. Secretariat & Governance.....	39
11. What’s coming in 2018	42

1. Foreword

Welcome to the EPF Annual Report for 2017. Much was achieved this year in our two core policy pillars – patient empowerment and patient access – and our expanding project portfolio. Our membership grew, and exciting new developments took place to strengthen our communities.

Seven new member organisations joined EPF and we welcomed them at our biggest AGM ever! Alongside this meeting, we convened many leaders from our membership to discuss our Strategic Plan 2014-2020 at mid-term, and reflect on how we move forward, together.

Our year-long **campaign on access** was a great example of the unity we see within EPF. Resulting in a powerful Roadmap for action in the journey towards 2030, it focused on Universal Health Coverage for All, and inter alia, the importance of health in the **Sustainable Development Goals**, and the importance of those goals in a EU context. In parallel, we continued to play a leadership role in the **Patient Access Partnership (PACT)**, with a new emphasis on forging national partnerships to address equitable access.

Building on our previous campaign on **patient empowerment**, EPF continued to call for efforts to recognise this as a core component of quality, sustainable health system of the future. New strategic relationships with OECD on patient relevant outcome measures and WHO on health systems' strengthening reflect important progress in this area. The role of digital health was also in the spotlight in 2017.

The **European Patient Academy on Therapeutic Innovation (EUPATI)** ended in February 2017 as an IMI project, and has been successfully integrated as an EPF programme – highlighting the crucial importance of patient education in the therapeutic innovation process. Much preparatory work took place on a sister project PARADIGM, on patient engagement in the life cycle of medicines which will start in 2018.

Our **Capacity Building Programme** continued to flourish – with dedicated activities in five countries and the very first meeting of over 30 national patient coalitions in Brussels. We were also especially proud to organise, with our **Youth Group**, the first **Summer Training Programme for Young Patient Advocates** which, given its success, will become an annual event as part of our commitment to support a new generation of patient leaders.

We faced some new challenges too – not least profound concerns regarding the **future of health collaboration at EU level post 2020**. EPF is playing a driving role, together with public health community and the health industry to ensure that health is integral to the future of Europe. As we move forward, we will count on the support of all our members and allies to get this right. **Brexit** also loomed large in 2017, and again, we are collaborating with all key players to ensure that patient safety and access is prioritised in the negotiations.

As we enter 2018, we see increasingly the value of the collective, united powerful patient voice during these times of uncertainty, but also hope and optimism. We take this opportunity to thank sincerely all of you who have helped us fulfil our role in 2017, and continue to believe in EPF.

EPF President Marco Greco & EPF Secretary General Nicola Bedlington

2. 2017 at a glance

January	February
<ul style="list-style-type: none"> - Launch of Roadmap for Action on Patient Empowerment - EUPATI becomes an EPF Project - Adapt Smart Annual General Assembly - EPF at the OECD Health Policy Forum 	<ul style="list-style-type: none"> - EPF Access Campaign Kick-Off Meeting - Joint Action CHRODIS: Final Conference
March	April
<ul style="list-style-type: none"> - Pisce Project Final Conference - Launch of First Capacity-Building Module in Poland - EPF Youth Group Annual Spring Meeting - Launch of EPF Breakfast Briefings - EPF participates in workshop on Patient Empowerment in the Swedish Health System - EMA PCWP and Workshop on Personalised Medicine 	<ul style="list-style-type: none"> - EPF AGM and Elections: New Board - New EU Regulations on Medical Devices and on In Vitro Diagnostic - EUPATI's new Partnership in Brazil - EPF speaks about Patient Safety at International Forum on Quality and Safety in Healthcare
May	June
<ul style="list-style-type: none"> - Announcement of the five Champion MEPs of the Access Campaign - eHealth Week - EPF at EFGCP Workshop taking forward the Lay Summaries of Clinical Trials - OECD PaRIS Initiative (PROMs and PREMs) 	<ul style="list-style-type: none"> - #EU4Health: Letter to Juncker - First General Meeting of EUPATI Network of National Platforms - DG Grow Stakeholder Workshop on Biosimilar Medicines - OECD Consultation Meeting on Access to Medicines
July	August
<ul style="list-style-type: none"> - EPF Summer Training for Young Patient Advocates - EPF contributes to the Observatory Summer School for Public Health Professionals 	<ul style="list-style-type: none"> - 3rd Module of Capacity-Building Programme in Bulgaria
September	October
<ul style="list-style-type: none"> - EPF Youth Group Annual Fall Meeting - CHRODIS+ Kick-Off Meeting - EPF Factsheet on Clinical Trials - EMA PCWP and Workshop on Antimicrobial Resistance 	<ul style="list-style-type: none"> - PRO STEP Final Conference - EPF becomes Member of SDG Watch Europe - EPF National Coalitions Meeting - Launch 3rd edition of the European Health Parliament

	<ul style="list-style-type: none"> - EPF gets involved in the World Antibiotic Awareness Week - European Health Forum Gastein - OECD Health Quality Indicators Meeting
November	December
<ul style="list-style-type: none"> - Publication of EPF Report on the Added Value of Patient Organisations - EPF Statement on the 2017 Country-Specific Recommendations on Health and Long-term Care and the European Semester Process - Launch EPF Youth Group Video on Non-Discrimination - EMA PCWP and EMA/DIA Meeting on the EU Pharmacovigilance System - OECD PaRIS Task Force Meeting 	<ul style="list-style-type: none"> - EPF Roundtable on Cross-Border Healthcare - Closing meeting of EPF Access Campaign - Publication of EPF Roadmap to Achieve Universal Health Coverage

EPF 2017 COMMUNICATIONS AT A GLANCE

8,052 likes on Facebook (+667)

7,206 followers on Twitter (+3,476)

720 LinkedIn followers

1.9 million impressions on social media

3,500 EPF newsletter's subscribers

45,900 visitors on the website

3 factsheets

2 videos



3. Patient Access

Patients' access to equitable, high-quality, patient-centred health and related care is a long-standing priority for EPF and its membership and is at the heart of the **vision** of the organisation.

With this vision in mind, EPF strives to **eliminate disparities and barriers** related to access and **address standards of care and health inequalities** within the EU.



EPF in a nutshell. AGM delegate reviewing our new brochure

Access to healthcare is a **basic human right** and one of the fundamental principles of European health systems, yet research provides evidence of the systematic failure of European health systems for many patients currently living within the region, particularly people in situations of precarity, poverty, social isolation, exclusion or vulnerability.

As demonstrated by [EPF's 2016 survey on access to healthcare](#) among other sources, **persistent inequities and growing health inequalities** in the region undermine such

values and carry a significant personal as well as societal cost. This was the spring board for our 2017 campaign.

HIGHLIGHT – 2017 CAMPAIGN ON ACCESS TO HEALTHCARE



Universal Health Coverage
For All.
#Access2030

At a time when implementing the United Nations Sustainable Development Agenda is a priority for world leaders, EPF dedicated its [2017 campaign to Universal Health Coverage](#), a sub target of the United

Nations Sustainable Development Goal (UN SDG) on ensuring healthy lives and promoting well-being for all at all ages. The resulting outcome of the campaign – a [Roadmap to achieving universal health coverage for all by 2030](#) – aims to contribute to European and national strategies for the implementation of the 2030 Agenda for sustainable development.

With input from **EPF's Working Group on Access**, which met three times in 2017, we implemented the following activities:

A campaign driven by members: EPF Campaign on Access to Healthcare and related advocacy tools, including a toolkit for EPF members and a petition which was signed by 571 signatories.

Strong political resonance: two high-level meetings on access to healthcare, in the context of EPF's campaign in the European Parliament, Commissioner Andriukaitis attended the final event, five MEPs championed the campaign.

Development of awareness-raising materials: two factsheets – one on the EPF campaign and the second which illustrates a snap shot of the Roadmap.

Articulating our vision: developed a Roadmap entitled 'Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030' – translated into numerous languages.

Advocating for health in all policies: developed a Statement on the 2017 country specific recommendations on health and long-term care and the European Semester Process.



Supporters of our campaign at the AGM

THE CAMPAIGN – WHY UNIVERSAL ACCESS TO HEALTHCARE?

The campaign's aim was two-fold. The first objective was to **raise awareness of the unequal experiences that patients face** when accessing health and related care in the EU.

The second was to **contribute to making universal access a reality for all EU patients by 2030**, through defining and promoting **recommended actions**, which decision makers and stakeholders should consider and commit to in order to ensure the health UN SDG is achieved by 2030.



“WE CAN'T AFFORD TO LEAVE ANYONE BEHIND. WITHOUT EQUALITY IN HEALTHCARE, WE CANNOT OBTAIN LONGER-TERM SUSTAINABLE DEVELOPMENT.”

KATHARINE WHEELER, LUPUS

THE HIGH-LEVEL MEETINGS

In the context of our campaign, we organised **two high-level meetings** in the European Parliament, which were supported by five MEPs who championed the campaign and its messages.

The first took place in February with objective of launching the campaign and raising awareness of the health inequalities within the EU and the many unmet needs as well as unacceptable barriers to healthcare that patients face in the EU.

“MEMBER STATES HAVE RESPONDED TO THE CRISIS BY BUTCHERING THE HEALTH BUDGET, ADDING AN ADDITIONAL LAYER OF BURDEN TO PATIENTS AND HOUSEHOLDS.”

JUAN FUERTES, PHA EUROPE AND EPF BOARD MEMBER



The second high-level meeting, took place in December and was the opportunity to launch the result of the EPF campaign, a Roadmap entitled ‘Taking Action – A Roadmap to Achieving Universal Health Coverage for All by 2030’.

THE ROADMAP

The [Roadmap](#) identifies the challenges that need to be addressed and proposes political steps and actions that EU decision-makers and Member States need to take in order to achieve universal health coverage for all patients in the EU by 2030.



“WHILE UNIVERSAL HEALTH COVERAGE IS A WELL-RECOGNISED GOAL FOR ALL HEALTHCARE SYSTEMS IN THE EU, THIS BASIC RIGHT IS NOT YET A REALITY FOR ALL PATIENTS IN THE EU, AND FOR THIS REASON, SUCH A ROADMAP IS NEEDED.”

STANIMIR HAZARDHIEV (NPO)

This Roadmap was developed in dialogue with **EPF’s membership** and the **wider health community**, based on an inclusive working process. Also, we organised numerous activities for our members in the context of the campaign, such as a [breakfast briefing](#), workshops at the National Patient Coalitions meeting or presentations about the campaign at members’ events upon request from members.

Policy Dossiers

Access to Medicines

Access to medicines was high on the EU agenda in 2017, given the focus of the previous Dutch Presidency. Having developed a position paper “Value and pricing of innovative medicines” in 2016, we continued to engage on the debates and a decision was made to update and revise the position paper in 2018 to reflect recent developments in this sphere. During the year EPF participated in several high-level discussions around this topic, including the OECD’s stakeholder consultation and meeting on access to medicines and the Fair Pricing Forum, jointly organised by the WHO and the Dutch government.

Generic and biosimilar medicines form an important part of access to medicines and EPF continued to work closely with DG GROW on promoting their access and uptake, as well as providing unbiased, reliable information to patients on biosimilars. Translations of our co-produced information document on biosimilars (2016) were started in 2017 for all EU languages, and EPF provided patient reviews to ensure accuracy of those translations.

We continued as a partner in the ADAPT SMART project exploring adaptive pathways, in order to ensure the patient perspective is central and that patients' safety remains a paramount criterion.

Cross-border Healthcare

In December, we organised a [European Roundtable](#) in Brussels with the involvement of patient organisations, national and European policymakers and particularly National Contact Points, to review progress and highlight gaps and challenges. The outcomes complemented our previous findings and will feed into our future advocacy on the implementation of the Directive, as the Commission will be preparing its next status report in 2018.



Based on input received during the Roundtable, we developed a **proposal for the collection of patient feedback** that can be used to develop concrete tools to ensure a the patient's experience is captured for future monitoring.

European Cross-border Healthcare Roundtable in Brussels. 4 December 2017.

Patient Safety and Quality of Care

Following our 2016 conference, with the involvement of an ad hoc year-long task force, EPF developed **recommendations for 'core competencies' for patients and families** to empower them in patient safety. This document addresses a key gap in implementation of the 2009 Council Recommendation on patient safety, and can serve as inspiration for professionals and policymakers as to patients' involvement and empowerment in this challenging area.

We produced a Breakfast Briefing in anticipation of **European Antibiotic Awareness Day**, where we invited an [European Centre for Disease Prevention and Control \(ECDC\)](#) expert to explain in simple, lay-friendly terms what resistance is, what the implications are for patients and public health, and what patients and our organisations can do to combat resistance. EPF also shaped the agenda of an European Medicines' Agency (EMA) information session on antimicrobial resistance, held in September with the collaboration of the European Commission, the WHO, the ECDC, veterinary health and healthcare professionals' as well as patients and consumers' organisations.

We contributed to an OECD proposal for a study regarding **healthcare professionals' competences** for patient-centred care.

Based on our [2016 patient survey](#) and other previous work, we developed a [position paper on quality of care](#), outlining the priorities of patients.

We commenced a **collaboration with the OECD on healthcare quality indicators**, in the framework of the new PaRIS Initiative launched in January 2017, which aims to develop indicators for patient-reported outcome measures (PROMs) and the patient experience (PREMs) to enable cross-country comparisons. EPF participated in several meetings of the healthcare quality indicators (HCQI) group and is a key partner in the newly established PaRIS Task Force, with the objective of ensuring the patient perspective is embedded throughout.

Social Inclusion and Non-discrimination

Following EPF's 2016 position paper on equal treatment for patients in employment, in 2017, EPF set up a temporary **task force on discrimination in the workplace** and on the employment market. The task force developed three **materials to promote better inclusion of patients with chronic and long-term conditions in the workplace**.

In the context of EPF's efforts in promoting the inclusion of vulnerable groups' perspective within patients' organisations, EPF has put together a [collection of good practices for cooperation of patient organisations with organisations representing underserved groups](#). The identified lack of such practices gives even more importance to the role EPF and its members have to play in promoting such collaboration, facilitating the exchange of good practices and implementing EPF's 2016 [roadmap](#) on inclusion of vulnerable groups.

Health Technology Assessment (HTA)

During 2017, the political debate on HTA has revitalised this policy dossier as the European Commission was preparing to publish a **legislative proposal for strengthening the EU cooperation on HTA**: [EPF responded to the public consultation](#) in early 2017 and has taken active part in the discussions organised both at EU level through the Stakeholder Forum organised by [EUnetHTA Joint Action 3](#); and at international level through the HTA International (HTAi) and ISPOR (International Society for Pharmacoeconomics and Outcomes) annual meetings.

In 2017 EPF has joined the newly established **HTA Network Patient and Consumer Stakeholder Pool** (part of EUnetHTA), whose purpose is to debate HTA policy developments and bring the patients and consumers perspective to the HTA Network. Most of the discussions were naturally directed to influence the legislative initiative on HTA collaboration and ensure the inclusion of patient and civil society perspectives in the legal framework.

Beside collaborating with external stakeholders, EPF has worked to support the membership gain deeper knowledge of HTA, through tools adapted to different levels of understanding of HTA. herefore, face to face sessions were complemented by [breakfast briefings](#) and informative articles.

The Patient Access Partnership (PACT)

In addition to EPF's access campaign activities, EPF played a leadership role in [Patient Access Partnership \(PACT\)](#). In 2017, PACT held two **country stakeholder meetings** entitled 'Patient-Centred Roundtable on Working Together for Accessible Health' under the auspices of the respective Ministries of Health – the first one in [Lithuania](#), together with the Lithuanian Cancer Patient Coalition (POLA) and the second one in [Romania](#) with the Coalition of Organisations of Patients with Chronic Diseases in Romania (COPAC), a member of EPF. The meetings gathered national level policy-makers and the healthcare community with the aim of increasing cooperation between them to improve access to quality healthcare for patients.

As in previous years, PACT supported the [MEP Interest Group on Patient Access to Healthcare](#) in organising two events at the European Parliament. The first meeting addressed the role of [healthcare in future scenarios for the EU](#) and put forward views on how to strengthen and improve it. This led to a follow-up initiative with more than 80 Members of the European Parliament supporting a statement calling for continued EU action in the field of health and enhanced cooperation between EU Member States – a statement which triggered positive feedback from President Juncker.

The [second event](#) was dedicated to the '[State of Health in the EU](#)' – a recent initiative of the European Commission and OECD which goal is to improve the evidence for more meaningful health policies in EU Member States.

PACT also supported the EPF's campaign on access and participated in the development of the Roadmap as a member of the EPF internal access working group.



Country stakeholder meetings in Romania (top), Lithuania (middle) and "State of the EU" event at the European Parliament (bottom).

Medical Devices and In Vitro Diagnostics Regulations

In 2017, EPF contributed significant efforts to engaging in and strengthening the **Patient Medtech Dialogue** by organising **two Patient-Medtech Dialogue workshops** together with Medtech Europe, which took place in June, with over 30 participants each. Participants included members of EPF and members of MedTech Europe. The first workshop was on the new [medical device and in-vitro diagnostics regulations](#) and the second was on [Patients' Access to Health Technologies](#).

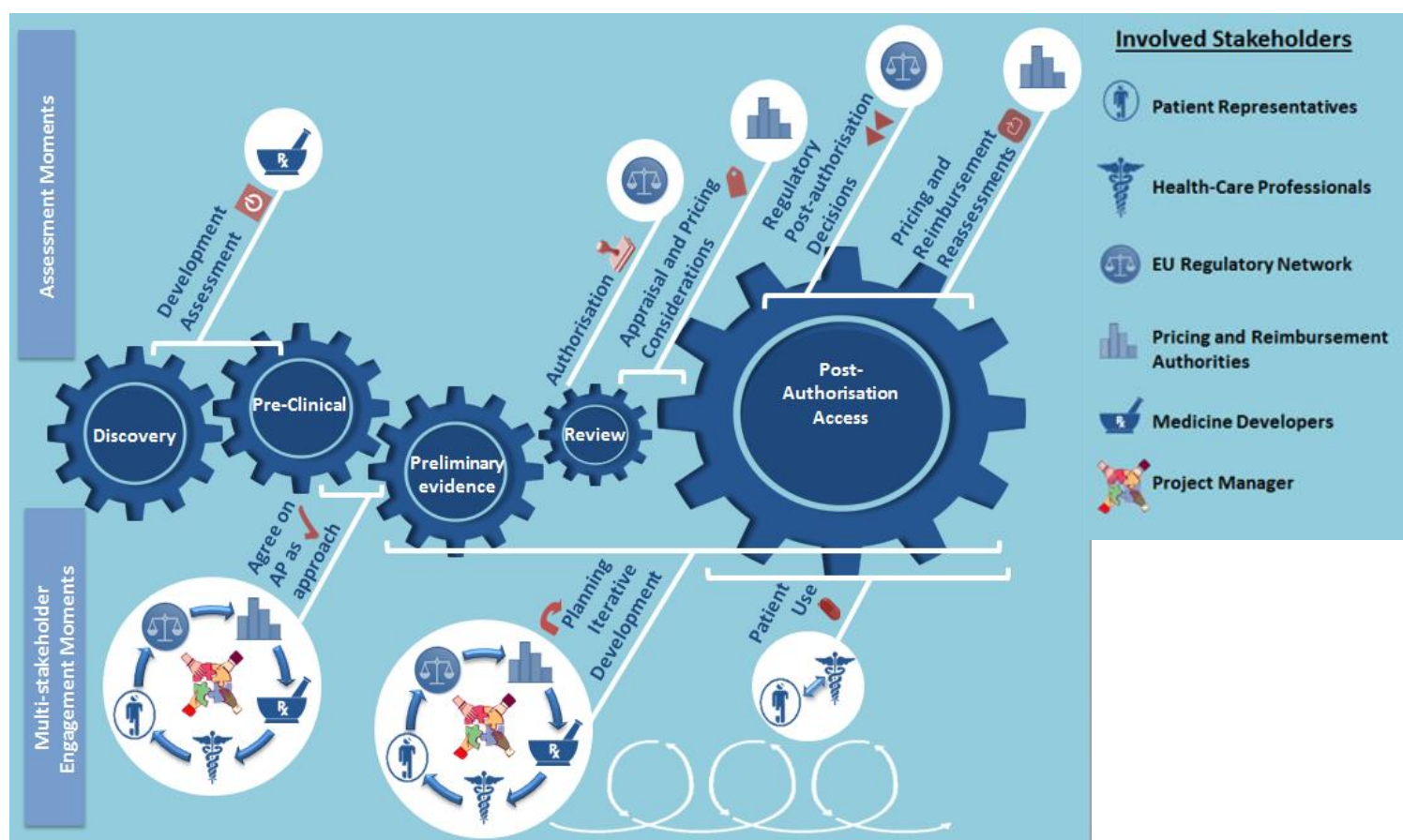
EPF also contributed the patient perspective to the work of the **EFGCP** (European Forum for Good Clinical Practice) **Medical Technology Stakeholder Alliance** and **EUDAMED task force** which in 2017 developed a proposal for the Summary of Safety and Clinical Performance (SSCP).

Related Projects

Adapt Smart (2015- 2018)

“Accelerated Development of Appropriate Patient Therapies: a Sustainable, Multi-Stakeholder Approach from Research to Treatment-Outcomes” (ADAPT-SMART) is a coordination and support action (CSA) funded by IMI 2. It aims to define the right parameters for the use of Medicines Adaptive Pathways to Patients (MAPPs), such as the right balance of benefits and risks and how to manage different levels of uncertainty. EPF contributes a patient perspective on appropriate use, patients’ perceptions of risk and uncertainties, communications, and ethical and legal issues.

www.adaptsmart.eu



EU Joint Action on Chronic Diseases and promoting healthy ageing across the life-cycle (CHRODIS) (2014-2017) and CHRODIS Plus (2017-2020)

CHRODIS aimed at promoting and facilitating the exchange of good practices between European countries and regions on health promotion, prevention and management of chronic conditions, multi-morbidity and diabetes. The project was completed in the first quarter of 2017 and was followed by a second Joint Action called CHRODIS Plus focused on implementing the previously identified good practices for chronic diseases.

EPF is involved in work streams related to dissemination and to the implementation of pilots on quality of care, management of multi-morbidity and employment for people living with chronic diseases. We work at ensuring that the pilots' design and implementation process take into account patients' views.

www.chrodis.eu

4. Patient Empowerment

Patient empowerment is one of the key elements of patient-centred healthcare, and one of EPF's Strategic Goals. It can be seen as both a pre-requisite for and an outcome of patient-centred healthcare; EPF defines it as a “**process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important**”. We also see it as a relational concept where the environment a patient finds themselves in plays a critical role, and a collective concept relating to the empowerment of the community of patients. The EPF thematic campaign of 2015-16 produced two key advocacy tools: the Patient's Charter on Patient Empowerment and a Roadmap for Action.

Working Group on Patient Empowerment

EPF continued to work with our members in the Working Group on patient empowerment, developing a [Toolkit to support patient organisations](#) in their advocacy on patient empowerment. Building on the Charter and Roadmap, we continued outreach and advocacy activities on patient empowerment, including meetings with organisations representing various healthcare professionals to explore possibilities for action in areas such as patient-centred skills development.

Policy Dossiers

Health Literacy and Information to Patients

We continued to work with an **informal coalition of stakeholders** to promote health literacy as a policy priority, again co-organising the highly popular joint session at European Health Forum Gastein 2017. The session gathered a full room and health literacy was mentioned in the 2017 outcomes document of the Forum. Moreover, Council conclusions on digital health of 28/11/2017 mentioned health literacy as the requirement in the design and implementation of digital tools in order to avoid exacerbating health inequalities, and the potential of digital tools as aids to enhancing health literacy.

We continued our close collaboration with the **European Medicines Agency**, being active in the Patient and Consumer Working Party (PCWP), disseminating information to patient communities and participating in relevant EMA activities. In 2017 the Commission finally published its report on the readability of package information leaflets – which has long been a source of frustration for patients – thus opening the way for concrete action to make medicines information truly user-centred.

EPF also contributed to a task group of the PCWP that formalised the involvement of young patients in the Agency, the task groups on visibility of patient involvement and impact, as well as dedicated information workshops on antimicrobial resistance and personalised medicine, a meeting on pharmacovigilance and dialogue with the EMA Biosimilars Working Party.

Information to patients on Food and Nutrition

In June, EPF co-organised an **EU patient groups conference on nutrition**, together with the Patients network for medical research and health (EGAN) and the European nutrition for health alliance (ENHA). In the context of the optimal nutritional care for all (ONCA) campaign, the meeting worked towards a renewed patient agenda on nutrition for 2018 and onwards. Following interest from EPF's members on this topic and EPF's previous work, EPF developed a **position statement on information to patients on food and nutrition**.

Clinical Trials

EPF continued to engage with the implementation of the EU Clinical Trials Regulation, specifically concerning transparency and patient information. We co-organised an event with the European Forum for Good Clinical Practice (EFGCP) to take forward the implementation of **lay summaries** of clinical trial results, following the EU guidance adopted in 2017 with EPF's contribution. EPF will continue to be part of a stakeholder group coordinated by the EFGCP, working on practical issues for the implementation of good quality lay summaries, in 2018 and beyond. The first lay summaries are likely to only be available on an EU web portal after 2020, but the patient community should be prepared for this new and important source of information.

We also issued a **policy factsheet** explaining in simple and visual terms what clinical trials are, why it matters to patients, what the patient's priorities are, and what role the EU plays. [This document](#) can be used by lay people, as well as patient organisations and advocates to support communication and convey effective messages in meetings with policy makers and other stakeholders.

Digital Health, Big Data and Personalised Medicine

Following on from EPF's 2016 position paper on eHealth, we organised a **webinar on eHealth** for our members in April. The webinar, provided a good overview of the EU eHealth policy framework as well as a concrete example of an application led by patients for patients, furthering the knowledge and collaboration between EPF members on this subject.

In 2017, EPF relayed **patients' expectations** of digital health care, the importance of **patient involvement** and the **patient perspective** on the reuse of health data for health research purposes and related privacy and data security concerns to many discussions, conferences and fora on digital health and the collection and sharing of health data. To name few, EPF was involved in the EU Cloud in Health Council, The European Institute for Innovation through Health Data (iHD) annual

conference and Hospital network workshop and delivered a keynote speech at the 2017 i2b2 European Academic User's Group, organised by the Assistance Publique – Hôpitaux de Paris (AP-HP).

Through our participation in the **eHealth stakeholder group**, EPF presented its position on eHealth to kick-off meeting of the Multi Annual Work Programme 2018-2021 subgroup of the Member State-led eHealth Network and contributed to the position of the eHealth stakeholder subgroup on citizens health and data.

In the context of the **Estonian Presidency** and its priority related to the digital society and the free movement of data, EPF contributed the patients' perspective to the digital health society declaration. Furthermore, EPF spoke at the Tallinn Digital Health Summit and at the closing conference of the Presidency.

We continued to follow developments in personalised medicine and participated in the annual conference of the European Alliance, where we spoke about the importance of adopting a public health perspective.

HIGHLIGHT – EUPATI

The five-year IMI EUPATI project ended in January 2017 and a “new” EUPATI programme began under the management of EPF, continuing as a public-private partnership, with a focus on core activities including the **Patient Expert Training Course**.

As an EPF programme, EUPATI continues to flourish and to expand the growing network of empowered patient experts.

Nicola Bedlington, EPF Secretary General

THE COURSE

The third cycle of the course launched in September 2017, with 60 trainees who will be working their way through eLearning on drug discovery, non-clinical and clinical development, regulation, and HTA before meeting each other and EUPATI's diverse faculty for two face-to-face trainings in Madrid in 2018.



On 28 June, the **EUPATI National Platforms (ENPs)** took part in their AGM meeting in Berlin, which was organised and hosted by IPPOSI, the patient organisation umbrella and host of EUPATI Ireland. On the following day, a **Train the Trainer capacity-building event** for 44 EUPATI alumni and future trainers learnt how to transform the tools provided by EUPATI into training tools on a disease specific or national level in order to increase the capacity for patient involvement in their communities.

THE OUTREACH

EUPATI continued to attract global attention with new partnerships with patient organisations and academia in Brazil to adapt the programme for their own needs. Although EUPATI's focus will remain on the EU, the EUPATI team will support the Brazilians with preparations for a potential launch of the EUPATI Course in Brazil and the implementation of the Toolbox in Brazilian Portuguese in the near future.

THE FUTURE

And as we approach the half way point in our 3 year bridging phase, the **EUPATI Futures Team** will be working diligently to deliver a sustainability proposal for the future of EUPATI for the coming years.

The transition from IMI-project to EPF-led programme has gone smoothly and in 2018 and beyond, EUPATI will continue to maintain its mission to increase the capacity and capability of patients to understand and contribute to medicines research and development and also improve the availability of objective, reliable, and patient-friendly information for the general public.

EUPATI IN NUMBERS

60 trainees from **28**
countries for 2017/2018

7 educational webinars

96 EUPATI Fellows

408,000 users on the EUPATI
website

3,300 mailing list members

2,496 Facebook fans

4,714 Twitter followers



Related Projects

Pisce and PRO STEP (2014 and 2016)

EPF was involved in two tender studies in the area of self-care and self-management, a critical life-skill and aspect of patient empowerment. The two studies tendered by DG Sante formed a continuum with the earlier tender on patient empowerment, EMPATHIE, and are part of a general effort to explore how self-management can be more embedded into EU health systems.

We worked as a partner in the [PISCE study](#) on self-care for minor and self-limiting conditions, which was concluded in 2017. The study outcomes and recommendations are available online at www.selfcare.eu

The [PRO STEP study](#) on self-management in chronic conditions, where EPF was the overall leader of the consortium, was a two-year project started in 2016. The action set up a platform of experts in self-care and related fields, and developed strategies to support patients' self-care and chronic disease self-management. Experts focused on identifying barriers, policies, communication tools to enable self-management as well as innovative approaches and potential scenarios for future actions at EU level. In October, EPF successfully organised the PRO STEP final conference, and some dissemination tools have been produced to disseminate the key project results.

PREFER (2016-2021)

EPF joined the consortium of IMI project, PREFER in October 2016. The main objective of the project is to strengthen patient-centric decision making on benefit-risk assessment throughout the life cycle of medicinal products (a term which, in the context of this proposal, also includes medical devices) by developing evidence-based recommendations to guide industry, Regulatory Authorities, HTA bodies, reimbursement agencies, academia, and health care professionals on how and when patient-preference studies should be performed and the results used to support and inform decision making.

EPF is part of the Patient Advisory Group together with ECPC (lead of the PAG) and IAPO, a body with an horizontal consultative role.

5. Alliance Building

Europe needs more, not less health

What should the European Union focus on in the coming years? We are calling for more health! Indeed, we believe that health is one of the areas where European collaboration has immense added value. To draw attention on the importance of health collaboration, EPF, together with the European Public Health Alliance (EPHA) launched the **#EU4HEALTH Campaign**.

The Campaign defends the idea that EU health policies bring the EU closer to its citizens, by protecting patients and consumers against cross-border threats and improving people's health.

What do we want? Calling for an EU action on health that fosters cross-country collaboration, complements the action of Member States and supports them in addressing the unprecedented challenges the EU is facing, the #EU4HEALTH campaign demands an EU action on health supported by a robust EU Health Programme and the leadership of a dedicated Directorate in the European Commission.

The campaign will be pursued in 2018 to make sure health is included in the future budget of the European Union.

"Healthcare is complex and no single government can manage alone. Cross-country solidarity and co-operation is essential as countries face common health, economic, and demographic challenges"

- Stanimir Hasurdjiev, PACT Secretary General and EPF Board Member

#EU4HEALTH AT A GLANCE

234 civil society and health-related organisations support the campaign

3 – the number of letters we sent to EU Officials (President Juncker, Vice-President Timmermans).

70% - of EU citizens want the EU to do more for health, according to a recent [Eurobarometer survey](#).

Patient organisations: the untapped potential of healthcare systems!

Patient organisations represent and voice the situation of a specific population that would otherwise not be represented. Yet, the scope and the role of patient organisations are still very often misunderstood. With this in mind, we commissioned a report to highlight the value of patient organisations as legitimate stakeholders in health-related policies.

This significant report reveals that patient organisations have long ago overstepped their initial role as self-help organisations, where individual patients share experiences of a specific disease.

If **peer support** remains one of the core missions of patient organisations, the report identifies three further areas where patient organisations undertake activities:

- **policy and advocacy,**
- **capacity-building and education,**
- **and research and development.**

“Patient organisations have a lot of influence and their outreach work is very influential. There is a lot of commitment, which their power and dynamism stems from.

- Sirpa Pietikäinen, Finnish MEP.

6. A Vibrant Network

Our vision for the communication with members is that EPF should be a participative forum, a place where members come naturally to share and improve their own strategies and look for contacts, experience and tips. To this end, in 2017, we increased opportunities for members to meet – both online and offline.

In April, EPF members met in Brussels for our second **Leadership Meeting**. Our patient leaders reflected on the role and responsibilities of patient organisations within the European health policy today. Patient leaders agreed on the necessity to advance on the implementation of the pieces of legislation that are already on the table and to continue promoting an enabling environment, through initiatives such as the Patient Empowerment Campaign, or our common work on patient access. The meeting was an opportunity to undertake a mid-term review of our strategic plan (2014-2020) EPF also developed **Guidance on transparency** for members to monitor the respect of EPF membership criteria by its members and to ensure the highest possible standards for our network.



Focus on: BREAKFAST BRIEFING

Earlier this year, EPF decided to propose an innovative way of communicating with members: the EPF Breakfast Briefings. These video podcasts are intended to help members to get the latest updates on European health policy and to receive practical advice to improve their organisation and skills.

What are the EPF Breakfast Briefings?

One-hour discussions recorded and streamed live on EPF YouTube channel. The topic of each Breakfast Briefing is selected according feedback and requests from members. Members can also ask questions and send comments online, during the recording.

What has been done so far?

We had 8 Breakfast Briefings in 2017. Topics ranged from EPF campaign on Access to Healthcare, Transparency & Ethics for Patient Organisations, Relationship with the European Parliament, European Solidarity Corps, HTA, Antimicrobial resistance, EU4Health Campaign, and the Report on Added value of Patient Organisations.

Because a coffee is worth a thousand emails, in 2017, 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 weekly basis that ensures EPF members keep up with the latest news from Europe on what really matters for patients. We sent 47 Weekly Insiders in 2017.

NATIONAL COALITION MEETING 2017

On 16-17 October, more than 30 representatives of national patient coalitions from 28 countries across Europe gathered together in Brussels for the first EPF National Coalitions Meeting. This was the first time such a meeting of national coalitions took place. The aim was to grow synergies between national coalitions and to learn how to advocate effectively at all levels, for better outcomes for patients in Europe.

Shaped around a very interactive [programme](#), the meeting focused on three main objectives:

- building and developing the participants' knowledge of the European Union;
- learning how to get involved in a European advocacy campaign;
- finding a common approach for advocacy for EPF and the national coalitions.

“National coalitions of patient organisations play a crucial role in the national context; they are the eyes and ears of the patient community and that’s why their presence is vital for EPF. They provide us with expertise in country-specific situations and spread our messages to the national and regional levels. A common advocacy strategy between EPF and national coalitions of patients will help us achieve our shared goal of a strong patient voice in every Member States”

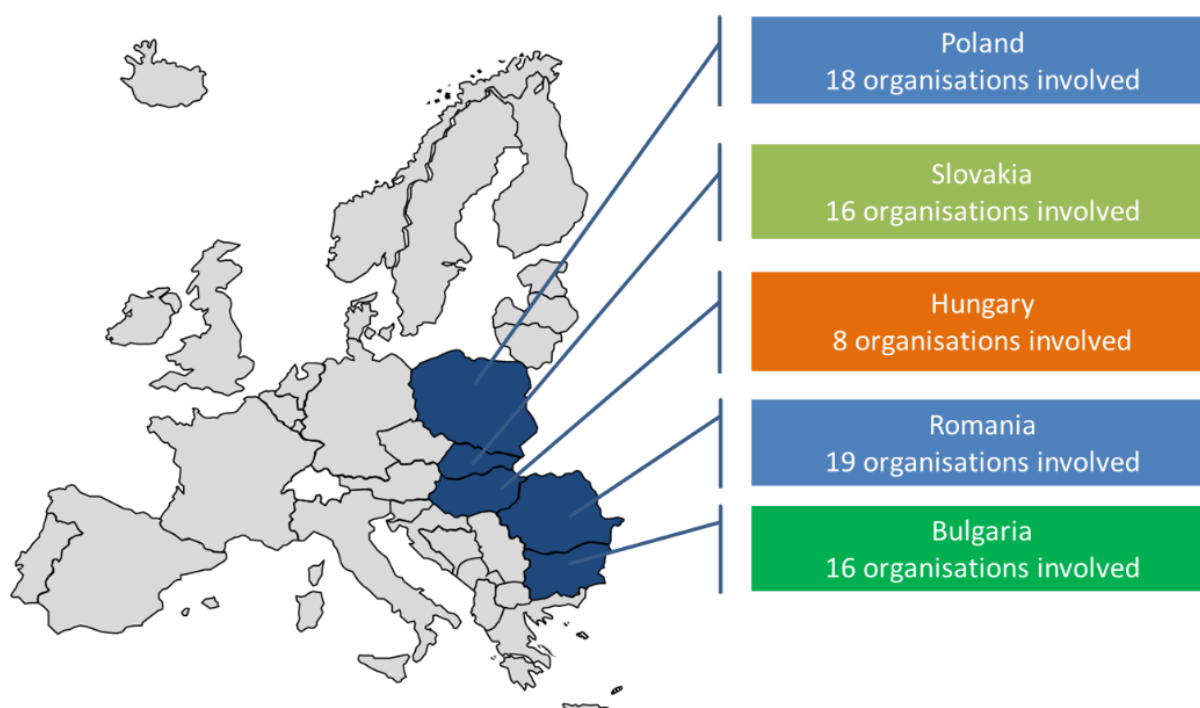
- Radu Ganescu COPAC President and EPF Board Member



In a spirit of openness and knowledge-sharing, representatives of national coalitions of patients shared **best practices in setting up and managing national coalitions**. They also could take part in interactive sessions on advocacy tools, advocacy campaigns and effective leadership. Patient representatives took the floor proposing examples of the DOs and DON'Ts in advocacy (in terms of communication with members, mailing procedures, social engagement tools, and survey processes) and shared many ideas to translate European level campaigns into the different national contexts.

CAPACITY BUILDING PROGRAMME

2017 saw the successful implementation of all training offered in the frame of the EPF Capacity Building Programme. In total, around 70 organisations from four countries participated in activities ranging from: assessments, face-to-face trainings, coaching and individual projects which contributes in building professional and sustainable patient organisations across the EU.



Bulgaria: the training module on Fundraising was successfully completed in summer 2017, including the additional training and coaching. Also, EPF translated its Fundraising toolkit into [Bulgarian](#). During the course of this very practical module, organisations had to engage in a large number of fundraising activities: this contributed to enhance the organisations' entrepreneurial spirit. Beyond the intended outcomes of the training, the module also improved the collaborative culture of the community. Working together within the module also led them to the realisation of the great potential and added value of implementing joint projects and partnerships.

Hungary: extension of the training module on Strategic Communication completed in October 2017 and finalisation of a situational analysis on the healthcare sector in Hungary. Thanks to this training, the Hungarian Celiac Society launched in early November a new, modern, easy to navigate [website](#).

The Hungarian Federation of Rare and Congenital Diseases (HUFERDIS) organised a campaign to raise awareness of the challenges and difficult life conditions faced by Hungarian rare disease patients and their families, and to inform about the possibility of calling HUFERDIS helpline. Thanks to the campaign the number of phone calls increase of 80% in few months. At the same time, the organisation also worked on a communication campaign called "the rare disease of the month".



The communications campaign on rare diseases by HUFERDIS, the Hungarian Federation of Rare and Congenital Diseases.

The module proved to be highly useful for all the participating organisations, who highlighted the importance and value of being able to share experiences with fellow patient organisations.

Poland: the first module of the capacity building programme on Strategic Planning was launched in spring 2017 and completed in November 2017. Thanks to the tailored approach of EPF Capacity Building Programme, the participating organisations could maximise the value of the module focusing on what it was most needed for their organisations. Some of them focused on the creation of a strategic plan and or implementation plan, membership recruitment and members' activation, team building/ internal communications, negotiations skills, strategic communications.

Romania: the revision of the mid-term planning was concluded in March and the training on Strategic Communications was completed in September 2017. As a result of the training the National Coalition of Patients in Romania, COPAC, revised their communication plan. In 2017, they successfully organised the second edition of the COPAC Gala, celebrating and assigning prizes to projects in the health field that distinguish themselves for a specific attention to patients.

We also coached another organisation, the National Union of Patients of HIV on kicking off their campaign [“Are you HIV Negative? Test yourself and be sure”](#) as well as an anti-stigma campaign dedicated to high school students.

The Association for Patient with Multiple Sclerosis revamped its communication strategy supporting the opening of new branches and organising a series of events (MS Patient's Organisation Ethic Code workshop, MS Summer school, National Seminar MS 2017) with the aim of increasing their visibility. Amongst other things, their hard work helped them in obtaining a new agreement with the Romanian Health Minister for better future cooperation.

Western Balkans: a situational analysis was conducted in spring 2017. Key take aways:

- Overall, healthcare financing is poorly organised, vulnerable to external financial risks, and unsustainable;
- Improvements in the quality of Balkan healthcare service delivery systems move slowly;

- Corruption is widespread in most of the region;
- The Laws on the Protection of Patients' Rights are not fully implemented;
- POs acknowledge the need for organisational capacity building support, although it seems there is a greater interest in technical and thematic issues;
- Overall, patients' sphere of influence is weak;
- Patients involved in this research very much appreciate the possibility of having regional cooperation among patients' groups across the Western Balkan countries.

EPF SUMMER TRAINING COURSE FOR YOUNG PATIENT ADVOCATES

As part of our work in supporting young patients who are the future of patient advocacy, EPF strengthened our youth-related activities in 2017 with the first edition of the **EPF Summer Training Course for Young Patient Advocates**.

The Summer Training focused on **overcoming discrimination** and offered a **tailored high-quality training to young patient advocates** or representatives of young patient advocates with the motivation to learn more about advocacy and maximise their leadership potential.

The first edition of this newly branded EPF programme was a success and helped to strengthen the bonds within this very unique, motivated, and inspiring community of young patient advocates.



The participants to the Summer Training Course for Young Patient Advocates in Vienna.

THE YOUTH GROUP

The **EPF Youth Group**, who were all participants in the Summer Training, also elected a new Youth Group Board at their annual meeting held in October in Leuven, Belgium. **Andreas Christodoulou**, a 27 year old from Cyprus who represents the Pancyprian Federation of Patient Associations and Friends, was elected as President.



EPF 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.

An enthusiastic EPF Youth Group in Leuven, Belgium.

7. List of Members

EPF membership consists of 74 members: 53 Full members, 19 Associate members, and 2 provisional members. The membership is composed of 47 pan-European umbrellas and 20 organisations active at national levels, representing 19 countries.

A growing network



Members voting at EPF AGM 2017

In 2017, the EPF family was delighted to welcome **seven new members**:

Full Membership:

- [BAG Selbsthilfe](#), the Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives in Germany.
- [ECHDO](#) – European Congenital Heart Disease Organisation, an umbrella association representing associations of patients with congenital heart disease (CHD).
- [Swedish Disability Rights Federation \(Sweden\)](#) – representing the Swedish disability movement towards policy-makers and national authorities.
- [NCDP](#) – the National Council of Disabled People, an umbrella organisation representing the disability and chronic diseases' patient's movement in Greece.

Associate Membership:

- [AGORA](#), an umbrella organisation for national and regional organisations representing patients with Rheumatic and Musculoskeletal Diseases in southern Europe.
- [LUCE](#) - Lung Cancer Europe, representing lung cancer patients, their families and survivors at a European level.

Provisional Membership:

- [Plataforma de Organizaciones de Pacientes](#), which brings together the main groups that represent patients, people with chronic diseases and symptoms in Spain.

The EPF membership now counts 74 members, strengthening the patient movement and its representativeness at the EU level!

Full members (53)

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) JOINED IN 2017!

BEMOSZ - Hungarian Alliance of Patients' Organisations (Hungary)

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) JOINED IN 2017!

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)

EIA - European Infertility Alliance (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)
 FPP - Federation of Polish Patients (Poland)
 FRANCE ASSOS SANTE / La voix des usagers (France)
 GAMIAN Europe - Global Alliance of Mental Illness Advocacy Networks (Europe)
Swedish Disability Rights Federation (Sweden) JOINED IN 2017!
 IDF Europe - International Diabetes Federation European Region (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) JOINED IN 2017!
 NPO - National Patients' Organisation of Bulgaria (Bulgaria)
 National Voices (United Kingdom)
 Pancyprian Federation of Patients Associations and Friends (Cyprus)
 PE.Pso.POF – Pan-European Psoriasis Patients' Organisations Forum (Europe)
 PHA Europe - Pulmonary Hypertension Association Europe (Europe)
 Retina International (Europe)
 SUSTENTO - The Latvian Umbrella Body for Disability Organization (Latvia)

Associate Members (19)

AGORA - (Southern Europe) JOINED IN 2017!

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)
 ECPP - European Coalition of Positive People (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)

HOPA - Hungarian Osteoporosis Patient Association (Hungary)

IBE – International Bureau for Epilepsy (International*)

LuCE- Lung Cancer Europe (Europe) JOINED IN 2017!

MRCG - Medical Research Charities Group (Ireland)

MHE-SME - Mental Health 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 (2)

APO – Alliance of Patient Organisations (FYROM)

Plataforma de Organizaciones de Pacientes (Spain) JOINED IN 2017!

*International organisations who do not have a formally constituted branch in Europe but are active in the European region may join EPF.

8. Accounts and Audit report

CONTRACTUAL AUDITOR'S REPORT TO THE BOARD OF DIRECTORS OF THE ASBL OF EUROPEAN PATIENT'S FORUM ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED DECEMBER 31, 2017

We report to you on the performance of our mandate as contractual auditor of the Luxembourg Not-for-Profit Organisation "European Patient's Forum (EPF)" (the "Organisation"). As contractual auditor we have to report to the Board of Directors of the Association.

This report was prepared solely for the information and use of the Board of Directors and is not intended to be and should not be used by anyone other without our prior written approval.

This report contains our opinion on the financial statements as December 31, 2017, composed of a balance sheet and an income statement as well as notes to the accounts.

We have reviewed the accompanying financial statements of the EUROPEAN PATIENT'S FORUM ASBL, which show a balance sheet total of 1.629.228 EUR and a result of profit for the year of 98.831 EUR.

Responsibility of the Executive Committee of the Organisation for the financial statements

The Executive Committee of the Organisation is responsible for the preparation and fair presentation of these financial statements in accordance with in Belgium applicable accounting standards, and for such internal control as they determines is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

Responsibility of the auditor

Our responsibility is to express an opinion on these annual accounts based on our audit. We conducted our audit in accordance with International Standards on Auditing ISRE 2400. Those standards require that we comply with the ethical requirements and plan and perform the control to obtain reasonable assurance about whether the annual accounts are free from material misstatement.

Our responsibility is to express a conclusion on the accompanying financial statements. We conducted our review in accordance with International Standard on Review Engagements (ISRE) 2400, *Engagements to Review Historical Financial Statements*. ISRE 2400 requires us to conclude whether anything has come to our attention that causes us to believe that the financial statements, taken as a whole, are not prepared in all material respects in accordance with in Belgium applicable accounting standards. This Standard also requires us to comply with relevant ethical requirements.

A review of financial statements in accordance with ISRE 2400 revised is a limited assurance engagement. The practitioner performs procedures, primarily consisting of making inquiries of management and others within the entity, as appropriate, and applying analytical procedures, and evaluates the evidence obtained. A review also requires the implementation of additional procedures if brought to our knowledge elements lead us to believe that the annual accounts taken together can contain material misstatements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

The procedures performed in a review are substantially less than those performed in an audit conducted in accordance with International Standards on Auditing. Accordingly, we do not express an audit opinion on these financial statements.

Conclusion

With the exception that at the date of our report, valuation rules are absent from the annual accounts, 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, 2017, in Belgium applicable accounting standards.

RSM Interaudit CVBA-SC SCRL
Chaussée de Waterloo 1151,
B-1180 Brussels
interaudit@rsmbelgium.be
VAT BE 0436.391.122 – RLP Brussels

9. Financials

BALANCE SHEET AS AT 31 DECEMBER 2017

ASSETS	2017	2016
I Current Assets		
Accounts receivable	€ 822,369.00	€ 811,277.00
Short Term investment	-	-
Cash in bank and deposit	€ 718,788.00	€ 852,994.00
Prepaid expenses	€ 16,416.00	€ 38,614.00
Total current assets	€ 1,557,573.00	€ 1,702,885.00
II Fixed assets		
Leasehold	€ 18,112.00	€ 40,402.00
Furniture, ICT equipment and software	€ 53,493.00	€ 18,730.00
Guarantees (rent and social security)	€ 50.00	€ 50.00
Total fixed assets	€ 71,655.00	€ 59,182.00
TOTAL ASSETS	€ 1,629,228.00	€ 1,762,067.00
LIABILITIES		
I Current Liabilities		
Accounts payable	€ 174,985.00	€ 141,057.00
Deferred income	€ 750,041.00	€ 452,165.00
Income to be allocated to project partners	€ 10,116.00	€ 553,405.00
Total current liabilities	€ 935,142.00	€ 1,146,627.00
II Reserves		
Funds brought forward	€ 585,507.00	€ 505,507.00
Surplus or deficit for the year	€ 98,831.00	€ 80,000.00
Total reserves	€ 684,338.00	€ 585,507.00
Provisions	€ 9,748.00	€ 29,933.00
TOTAL LIABILITIES	€ 1,629,228.00	€ 1,762,067.00

INCOME AND EXPENDITURE

INCOME	2017	2016
Funding from Public Sector	€ 1,172,461.04	€ 1,191,096.87
Operational Work Programme (CHAFFA Operating Grant 80%)	€ 766,777.40	€ 731,835.98
EC projects	€ 293,276.29	€ 149,507.36
EUPATI (EC contribution)	€ 112,407.35	€ 309,753.53
Funding from the private sector	€ 948,886.12	€ 657,159.25
Operational Work Programme (co-funding of Chafea's Operating Grant, 19%)	€ 173,455.00	€ 172,450.00
Co-funding to EPF projects	€ 29,939.09	€ 37,577.93
Project developments and other costs	€ 254,328.67	€ 104,361.09
Capacity Building Programme	€ 337,753.00	€ 237,786.76
Contribution to EPF Campaigns	€ 0.00	€ 42,273.73
EFPIA contribution within EUPATI	€ 0.00	€ 62,709.74
EUPATI Programme	€ 153,410.36	
Foundations	0	€ 20,000.00
Bosh Foundation grant for the Empowerment Campaign	€ 0.00	€ 20,000.00
Membership fees	€ 21,800.00	€ 17,950.00
Operational Work Programme (co-funding of CHAFFA's Operating Grant 1%)	€ 18,239.35	€ 12,000.00
Contribution to EU projects	€ 3,560.65	€ 5,950.00
Interests and other income	€ 32,112.88	€ 30,516.86
Total Income	€ 2,175,260.04	€ 1,916,722.98
EXPENDITURES	2017	2016
Staff Costs (including EUPATI staff)	€ 1,047,185.99	€ 1,033,791.00
Office and admin costs	€ 204,101.18	€ 197,888.72
Depreciation	€ 15,814.46	€ 15,168.53
Travel and subsistence (EPF staff)	€ 52,676.70	€ 67,325.56
Events	€ 743,190.03	€ 500,511.08
Annual General Meeting	€ 49,726.30	€ 74,022.50
Regional Advocacy Seminar	€ 26,682.19	€ 33,730.55
Youth meetings	€ 21,431.59	€ 17,985.76
Thematic Working Group Meetings (Access, Empowerment, Patient safety Working groups...)	€ 31,502.77	€ 9,183.58
Capacity Building Programme (delivery of training modules)	€ 121,316.95	€ 106,364.18
Cross-border healthcare regional events and conference	€ 48,537.82	€ 65,639.35
Other costs linked to operations, project developments	€ 443,992.41	€ 193,585.16
Campaigns (Empowerment, Access)	€ 12,331.32	€ 20,415.26
Bank and Financial Charges	€ 1,129.52	€ 1,622.83
TOTAL Expenditure	€ 2,076,429.20	€ 1,836,722.98
Surplus or deficit of the Year Operating Grant		
Total Surplus or deficit of the Year	€ 98,830.84	€ 80,000.00

2017 ACCOUNTS AND ACKNOWLEDGEMENTS

EPF wishes to thank the European Commission for its support in 2017 in relation to EPF's role in the following projects

	EC Contribution used in 2017	% of total income
Adapt Smart	28,018.87 €	1.3%
Joint Action CHRODIS	4,926.37 €	0.2%
Joint Action CHRODIS +	2,274.58 €	0.1%
ProStep	246,587.64 €	11.3%
Prefer	6,810.83 €	0.3%
PISCE Self Care Tender	4,658.00 €	0.2%
TOTAL European Commission support to projects	293,276.29 €	13.5%

EPF wishes to thank the following donors for their support:

	Contribution to the OG	% of total income
Operational work programme	958,471.75 €	
European Commission	766,777.40 €	35.2%
AbbVie	11,000.00 €	0.5%
Baxter	10,000.00 €	0.5%
Eli Lilly	15,000.00 €	0.7%
GSK	30,000.00 €	1.4%
Janssen	35,000.00 €	1.6%
Novartis	12,455.00 €	0.6%
Pfizer	25,000.00 €	1.1%
Sandoz	15,000.00 €	0.7%
Teva	20,000.00 €	0.9%
Membership	18,239.35 €	0.8%
Capacity Building Programme	291,000.00 €	
Association SLK	16,000.00 €	0.7%
Amgen	5,000.00 €	0.2%
Novo-nordisk	20,000.00 €	0.9%
Takeda	20,000.00 €	0.9%
Sanofi	25,000.00 €	1.1%
CSL	10,000.00 €	0.5%
Celgene	30,000.00 €	1.4%
GSK	30,000.00 €	1.4%
Novartis	30,000.00 €	1.4%
Pfizer	25,000.00 €	1.1%
Hoffman-Roche	30,000.00 €	1.4%
Vertex	30,000.00 €	1.4%
Teva	20,000.00 €	0.9%

Patient Academy on Therapeutic Innovation “EUPATI Programme”	153,410.36 €	
Industry consortium (AbbVie, Amgen, AstraZeneca UK, Bayer, Boehringer Ingelheim, Bristol-Myers Squibb, F. Hoffmann-La Roche, GSK, Janssen, MSD, Novartis, Novonordisk, Pfizer, Shire, Takeda, UCB, VFA)	153,410.36 €	7.1%
The European Patients’ Academy on Therapeutic Innovation Public Private Partnership (EUPATI-IMI)	112,407.35 €	
Innovative Medicine Initiative (IMI JU) contribution	112,407.35 €	5.2%
Project Development/Portfolio	264,300.00 €	
Abbvie	14,000.00 €	0.6%
Amgen	35,000.00 €	1.6%
Bayer	17,500.00 €	0.8%
EFPIA	12,000.00 €	0.6%
Grunentahl	10,000.00 €	0.5%
Hoffmann Roche	20,000.00 €	0.9%
Janssen	15,000.00 €	0.7%
Merck	40,000.00 €	1.8%
Merck	10,800.00 €	0.5%
Pfizer	5,000.00 €	0.2%
Servier	10,000.00 €	0.5%
UCB	50,000.00 €	2.3%
sanofi	25,000.00 €	1.1%
Membership and other income	35,546.87 €	1.6%
Total Income	2,108,412.62 €	
Accrual and deferrals	66,847.42 €	
Total Income net of adjustments	2,175,260.04 €	100.0%

10. Secretariat & Governance

Meet our board

- **President**, Marco Greco, *European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)*, **re-elected!**
- **Vice President**, Brian West, *European AIDS Treatment Group (EATG)*, **re-elected!**
- **Treasurer**, Radu Costin Ganescu, *Coalition of organisations for patients with chronic conditions of Romania (COPAC)*
- **Board Members:**
 - o Stanimir Hasurdjiev, *Bulgarian National Patients' Organization (NPO)*
 - o Hilkka Karkkainen, *GAMIAN-Europe*, **new board member!**
 - o Susanna Palkonen, *European Federation of Allergy and Airways Diseases Patients Associations (EFA)*
 - o Dominik Tomek, *Association for the Protection of Patients' Rights, Slovak Republic (AOPP)*
 - o Juan Fuertes, *Pulmonary Hypertension Europe (PHA Europe)*
 - o Michal Rataj, *European Alliance of Neuromuscular Disorders Associations (EAMDA)*
- **Honorary President**
 - o Anders Olauson, *Eurordis*

Former board members: Robert Johnstone, *National Voices (UK)*



EPF Secretariat

- **Kostas Aligiannis**, Policy Officer → **Welcome!**
 - Support Policy and Advocacy Work
- **Elena Balestra**, Membership & Capacity-Building Officer → **Welcome!**
 - Capacity-Building Programme, Membership engagement and growth
- **Nicola Bedlington**, Secretary General
 - Leadership, Direction & Guidance
 - High-Level Representation & Liaison with Partners
- **Camille Bullot**, Director of Operations & Engagement
 - Coordination of Operations
 - EPF representation
- **Danielle Flores**, Project Officer
 - EUPATI, EPF Youth Group and Projects Coordination
- **Katie Gallagher**, Policy Adviser
 - Policy & Advocacy
 - Strategy on Access
- **Zilvinas Galvenas**, IT Coordinator
 - IT Management and Planning
- **Sara Gayerre**, Communications Assistant
 - EPF Thematic Campaigns, Social Media
- **Kaisa Immonen**, Director of Policy
 - Strategic & Policy Agenda
 - EU Institutions & Stakeholders
- **Matthew May** → **Welcome!**
 - Coordination of EUPATI
- **Lyudmil Ninov**, Project Officer → **Welcome!**
 - Summer Training for Young Patient Advocates
 - Project support
- **Valentina Strammiello**, Programme Manager
 - Project coordination and development
 - Health Technology Assessment
- **Stefano Tironi**, Financial Manager
 - Financial matters
 - Grants management
- **Ruth Tchapanian**, Office Coordinator → **Welcome!**
 - Office and Information Management
 - Management Support
- **Anna Trzcinska**, Events Officer → **Welcome!**
 - EPF Meetings, Events and Travel Management
- **Matthew Attard**, Youth Trainee

Goodbye, thank you and all the best:

- **Walter Atzori**, Director of Programmes & Operations
- **Selena Imerovic**, Capacity-Building Officer
- **Véronique Tarasovici**, Office & Events Manager
- **Laurent Louette**, Communications Officer

We are constantly learning, growing and changing

In line with our commitment to learn and develop as an organisation, EPF called for an independent consultant to run the external evaluation of the delivery of our work programme for 2017.

Focusing on our actions regarding membership engagement and involvement, the EPF Access Campaign and EPF's influence on partners and stakeholders, the external evaluator assessed the quality and consistency of EPF's activities in 2017.

The evaluator gathered information through online surveys and by speaking to EPF staff and external stakeholders.

Key Findings of the external evaluator

EPF addresses topics that matter for patients. This year's member survey indicated that members recognise that EPF is pursuing objectives and activities that are important for its members and that it is addressing policy issues that are also on the agenda of its members.

EPF a constructive, competent and reliable partner. External stakeholders emphasised that EPF's unique selling proposition is its representativeness and its uniqueness in bringing the patient perspective to the table. They see EPF as constructive, competent, reliable partners with a good network, with in-depth knowledge of a broad range of issues, and a growing influence on the health debate at European level.

The Access Roadmap constitutes an excellent example of EPF's work: it demonstrates the expertise, professionalism and hard work of the EPF staff, as well as its potential to network and activate relevant 'people in high places'.

Improving further

When asked for recommendations on how Interviewees who did come up with suggestions indicated that the quality of the work and the relevance of the organisation could be further enhanced by:

- Paying specific attention to the **interests and concerns of individual members**;
- **Involving members** in the development of European projects;
- Developing **(good) practice examples** that illustrate the variety of circumstances in which its members and their constituencies are living;
- Demonstrating that **EPF is and remains sufficiently distant from industry**.

We will do everything that is in our power to take these recommendations on board.

11. What's coming in 2018

Access – follow up to our campaign

Following EPF's 2017 campaign on Universal Access to Healthcare to All, we will promote the Roadmap on taking action to achieve Universal Health Coverage for All by 2030 and raise awareness of the health target within the UN Sustainable Development Goals.

Digital Health

We will work on relating to patient-centred digital healthcare solutions and services; access to, collection and sharing of and use/reuse of patients' health data; and electronic health records, with a focus on ethical sharing, patients' privacy and respect for patients' choices and preferences.

PARADIGM, a major project on patient engagement

We will launch together with a consortium of patient organisations, academic institutions, SMEs and industry players an IMI project on patient engagement. EPF will be at the steering wheel, as co-leader of the project.

Capacity building on leadership and governance

We will take a step further in the development of our capacity building programme. The redesigned programme will integrate offline and online learning offers and will focus on strengthening the expertise and advocacy skills of patient organisations.

2019 European elections campaign

We will prepare and launch our 2019 European Elections campaign, focusing on what matters to patient and highlighting the EU added value of health cooperation.

Combating vaccines hesitancy

EPF will launch an initiative that will contribute to transform vaccine hesitancy in vaccine confidence in patients with chronic diseases. We will coordinate the production of a toolkit for national advocacy groups to use.

Thank you for joining us in 2017, the journey continues in 2018!