

EPF ANNUAL REPORT

2016

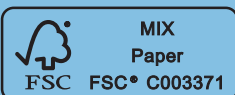
DRIVING BETTER HEALTH FOR  
PATIENTS IN EUROPE





#### QR Codes

Information in this publication can be accessed via QR codes.



---

© EPF asbl, Brussels 2017. All rights reserved.



This annual report arises from the EPF 2017 Work Programme, which has received funding from the European Union, in the framework of the Health Programme. The content of this annual report reflects only the author's views and the Executive Agency is not responsible for any use that may be made of the information contained therein.

# CONTENTS

<b>FOREWORD</b>	5
<b>2016 AT A GLANCE</b>	6
<b>01 PATIENT EMPOWERMENT</b>	7
<b>02 ACCESS AND INEQUALITIES</b>	12
<b>03 A VIBRANT NETWORK</b>	17
<b>04 ALLIANCE BUILDING</b>	21
<b>05 SECRETARIAT AND GOVERNANCE</b>	22
<b>06 ACCOUNTS AND AUDIT REPORT</b>	26
<b>07 FINANCIALS</b>	28
<b>08 MEMBERSHIP</b>	30

## ABOUT EPF

The European Patients' Forum (EPF) is an umbrella organisation that works with patients' groups 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 is that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care.

Our mission is to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU. EPF helps to empower patient organisations through educational seminars, policy initiatives and projects.

We coordinate best practice exchanges between patient organisations at European and national levels. Our programmes also help to strengthen their organisational and advocacy capacity.

**+150** MILLION  
PATIENTS REPRESENTED

---

**67**  
PATIENT  
ORGANISATIONS





The events and uncertainties that characterised 2016 remind us that a strong and united European patient community is crucial, to ensure progressive policies on safe, patient-centred and quality health and social systems in the EU.

Marco Greco  
EPF President



# FOREWORD

2016 was a crucial and memorable year for EPF and our membership. Our major campaign on patient empowerment officially came to an end in June with two high-level policy meetings. The sheer enthusiasm and commitment from both European and national allies, demonstrate the central role of patient empowerment in creating a better, safer, patient-centred and sustainable healthcare.

2016 will also be remembered as the year Marco Greco got elected as EPF President for a two-year mandate at our Annual General Meeting, in March. A patient himself, Marco took over from Anders Olauson, who had been president since 2005. Anders was nominated Honorary President in recognition of his longstanding dedication to EPF. The meeting also saw the election of two new Board members and the mandate renewal of four current members.

In line with our 2014-2020 Strategic Plan, we organise our activities around three thematic areas: patient empowerment, access to healthcare and sustainable patient organisations.

In parallel with the campaign, our work related to **Patient Empowerment** yielded excellent results. The EPF Working Group on Empowerment met twice and developed a preliminary statement on patients' rights and responsibilities. We also contributed to related policy dossiers, such as clinical trials, health literacy, information on medicines, and data protection.

**Equitable Access** to health and social care is central to our vision of healthcare. In 2016, our dedicated working group provided invaluable input to our policy work, including the development of a survey on patients' access to healthcare, and of course contributed greatly to the preparatory work for our campaign on Universal Health Coverage, to be rolled out in 2017. As a founding member of the Patient Access Partnership (PACT), we supported two events of the European Parliament Interest Group on Patient Access to Healthcare, focusing on access to medicines and sustainable health systems. In consultation with our members, we provided extensive policy input on patient safety, cross-border healthcare, quality of care, pricing of innovative medicines, medical devices, and health technology assessment. We have a diverse portfolio of exciting projects all bringing crucial evidence for our advocacy work. In 2016, we continued our leadership or collaboration in eight such projects.

Our vibrant network of **Members** is our raison d'être. Their engagement through their vast constituencies makes us stronger and we will continue to strive to meet their needs to enable them to both benefit from and contribute to our collective patients' voice. During the course of 2016, our wide network of trusted allies helped us advance our work on the issues that really matter to patients and citizens. We are, as ever, extremely grateful for this precious support.

Finally, a short word to express our gratitude to all our members and colleagues for their messages of support and resilience during the tragic events that took place in Brussels last year. On that day, more than ever we felt part of a united community.

Together we can drive better health for European patients,

Marco Greco,  
EPF President

Nicola Bedlington,  
EPF Secretary General

# 2016 AT A GLANCE

## JANUARY



LAUNCH OF THE  
EUPATI TOOLBOX ON  
MEDICINES RESEARCH  
AND DEVELOPMENT

POSITION PAPER ON  
EQUAL TREATMENT  
IN EDUCATION AND  
EMPLOYMENT

## FEBRUARY



EPF LEADERSHIP  
MEETING



JOINT ACTION  
CHRODIS' ANNUAL  
MEETING

## MARCH



EPF AGM AND ELECTION  
OF A NEW BOARD AND  
PRESIDENT



EPF YOUTH GROUP  
ROUNDTABLE ON  
TRANSITION TO  
ADULT CARE

POSITION PAPER ON  
'DEFINING AND  
MEASURING ACCESS  
TO HEALTHCARE:  
THE PATIENTS'  
PERSPECTIVE'



EPF YOUTH  
GROUP ANNUAL  
SPRING MEETING

## APRIL



PRELIMINARY STATEMENT  
ON 'PRICING AND  
REIMBURSEMENT OF  
INNOVATIVE MEDICINES'

POSITION STATEMENT  
ON 'DIRECTIVE ON  
PATIENTS' RIGHTS IN  
CROSS-BORDER  
HEALTHCARE'



FACE-TO-FACE TRAINING  
FOR THE SECOND COHORT  
OF EUPATI TRAINEES

## MAY



BRIEFING PAPER  
ON PATIENT  
SAFETY

POSITION PAPER  
ON CLINICAL  
TRIALS  
REGULATION'

## JUNE

EPF REGIONAL ADVOCACY SEMINAR  
POLICY ROUNDTABLE ON PATIENT EMPOWERMENT  
CLOSING EXHIBITION OF PATIENT EMPOWERMENT CAMPAIGN

## JULY

EPF YOUTH GROUP AT THE  
EUROPEAN YOUTH EVENT



SMARTCARE FINAL  
CONFERENCE

## AUGUST



EPF'S RESPONSE TO THE  
CONSULTATION ON THE  
'SUMMARY OF CLINICAL TRIAL  
RESULTS FOR LAYPERSONS'

## SEPTEMBER



EPF YOUTH GROUP  
ANNUAL EVENT



EUPATI: SECOND  
FACE-TO-FACE TRAINING



EPF TRAINING ON  
TRANSPARENCY &  
ETHICS

## OCTOBER



EPF WORKING GROUP  
ON PATIENT  
EMPOWERMENT



EPF TRAINING ON  
PATIENT SAFETY

## NOVEMBER

EPF WORKING  
GROUP ON ACCESS

EPF CONFERENCE ON  
PATIENT SAFETY

## DECEMBER

EPF POSITION  
PAPER ON  
EHEALTH



EUPATI FINAL  
CONFERENCE AND  
GRADUATION CEREMONY



# 7.385

LIKES ON  
FACEBOOK

# 3.730

FOLLOWERS ON  
TWITTER

# 32.227

EPF VIDEO  
CAMPAIGN VIEWS

# 1.2

 MILLION  
IMPRESSIONS ON  
SOCIAL MEDIA

# 4.000

NEWSLETTER  
SUBSCRIBERS

# 39.211

VISITORS ON  
WEBSITE

# 3

FACTSHEETS

# 1

VIDEO

# 01



Only a shared effort will lead us to achieve patient empowerment and, eventually, to improve patients' lives and the sustainability of our healthcare systems.



**Nicola Bedlington**  
EPF Secretary General

# PATIENT EMPOWERMENT

## PATIENT EMPOWERMENT CAMPAIGN

Patient-centred chronic disease management with focus on patient empowerment is a key priority for EPF.

Having started in May 2015, the Patient Empowerment Campaign officially concluded in June 2016 with two high-level policy events at the European Parliament. The campaign helped promoting the development of policies, strategies and healthcare services that empower patients to be involved in the management of their condition and in health policy that affects their lives.

In March 2016, an EPF delegation met with 12 MEPs from different countries and parties to present the concept of patient empowerment, bring updates on the campaign and ask for commitment in including the concept in the shaping of EU health policy. This strategic step in our approach towards policy makers offered a greater visibility to the campaign and set the basis for further political engagement towards patient empowerment.

To officially draw the curtain on the campaign, EPF organised a high-level roundtable in the European Parliament, in June 2016. The meeting, co-hosted by MEPs Andrey Kovatchev (EPP, Bulgaria), Karin Kadenbach (S&D, Austria) and Roberta Metsola (EPP, Malta) offered the opportunity to share the results and outcomes of the campaign, and to discuss further steps on how to take patient empowerment to the next level with the involved stakeholders.

A highlight of the event was the official presentation of the two campaign policy instruments: the Charter on Patient Empowerment and the Roadmap for Action.

The Charter on Patient Empowerment encapsulates what really matters to patients. Co-developed with EPF members, the Charter defines the fundamental principles of patient empowerment from the patients' perspective. EPF aims to work further with patient communities across the EU to increase visibility and ownership of the Charter and Roadmap, and to engage with a wide range of health stakeholders to ensure concrete commitment and actions to support empowerment.

The Roadmap for Action turns the Charter's principles into eight priority action areas that need to be addressed at different levels in order to apply the principles in policy and practice. This document also builds on the EMPATHIE study (2014), which recommended first and foremost the development of a European strategy on patient empowerment to inform



Charter on Patient  
Empowerment



Roadmap for  
Action



policy, practice and further research. The Roadmap is therefore intended to provide direction and inspiration for action. There is a need to develop a new, much more collaborative mind-set to cut through existing “silos” and develop solutions together – and always with patients and their representative organisations as partners.



Image above: Empowerment Campaign Roundtable, June 2016

Finally, in conjunction with the plenary session of the European Health Parliament at the end of June, EPF held an exhibition stand showcasing the outcomes of the Patient Empowerment Campaign.

The stand provided the latest campaign communication and promotional materials, as well as a photo booth, where many participants had their pictures taken as a proof of their commitment to the campaign, including high-level policy and decision-makers such as Commissioner for Health and Food Safety Vytenis Andriukaitis, the Belgian Minister for Health Maggie De Block, the WHO Europe Director Roberto Bertollini, and many Members of the European Parliament. The campaign is officially over, but EPF will continue advocating for patient empowerment and will make the best use of these tools to take it to the next level.

## PATIENT EMPOWERMENT WORKING GROUP

The EPF Working Group on Patient Empowerment met twice during 2016, in June and October. The group's work plan this year focused on patients' rights and responsibilities, and healthcare quality indicators for patient-centeredness, with for the latter, a guest intervention from an OECD expert. The group also developed a paper on **patients' rights and responsibilities** which will serve as a basis for further reflection with the membership.

A patient safety capacity-building session was held adjacent to the second meeting of the working group with the aim to prepare participants for the conference on patient safety and to have a preliminary discussion on EPF priorities in the area for the next years. In this session, a particular focus was on antimicrobial resistance and healthcare-associated infections, with the contribution of an external speaker from the ECDC.

EPF would like to thank the members of the Empowerment Working Group for its productive and important work in 2016.



EMPATHIE study



Patients prescribe E<sup>s</sup> for Sustainable Health Systems

## WHAT IS PATIENT EMPOWERMENT ABOUT ?

### 1.

#### EDUCATION

Patients can take informed decisions about their health if relevant information is accessible in an easily understandable format.

### 2.

#### EXPERTISE

Patients manage their condition every day so they have a unique expertise on healthcare.

### 3.

#### EQUALITY

Patients need support to become equal partners with health professionals in the management of their condition.

### 4.

#### EXPERIENCE

Individual patients work with patient organisations to represent them, and channel their experience and collective voice.

### 5.

#### ENGAGEMENT

Patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services.

# POLICY DOSSIERS

## EUROPEAN MEDICINES AGENCY (EMA)

We continue to work closely with the EMA to disseminate information to patient communities, contribute to the review of documents, user-test EMA services (such as new web tools) and act as a liaison between the EMA and disease-specific patient representatives where appropriate.

In March, we partnered with the EMA on its first-ever event on the theme of health literacy and how it impacts risk communication. We also participated in several EMA events throughout the year, e.g. on pharmacovigilance, information to the public on medicines, adaptive pathways, and the use of social media.

Our representative was nominated as member of the EMA Pharmacovigilance and Risk Assessment Committee (PRAC) to help integrate patient perspective in safety of medicines.

In November, our Director of Policy, Kaisa Immonen, was elected as co-chair of the EMA Patients & Consumer Working Party, for a three-year mandate. This election reinforces our commitment to the Working Party, where EPF has been represented since 2008.



## CLINICAL TRIALS

EPF continued to engage with the implementation of the new EU Regulation. We published our position paper on informed consent and responded to the European Commission's public consultation on the EU draft guideline on patient-friendly, unbiased lay summaries in August.



## DATA PROTECTION

The new EU Regulation on personal data protection was published in May 2016. In this regard, EPF published a guide for patients and patient organisations to explain what the new EU Regulation on the protection of personal data means for patients.

The guide also outlines how patient organisations can contribute to ensuring that patients' rights to privacy, data sharing, and accessing their health data are implemented in an optimal way.



## HEALTH LITERACY

2016 saw the continuation of our engagement on health literacy: we updated our consensus paper and kept on with outreach activities, for example with the European Commission's DG Education. As EPF, we reviewed the "core quality criteria" on information for patients, developed in 2008 by the High-Level Pharmaceutical Forum, in the form of a stakeholder survey during the second half of the year.

For the second time, EPF worked with the European Commission's DG Grow to co-organise a stakeholder workshop on biosimilar medicines, focusing on the information needs of patients, in June 2016. We also contributed, along with an impressive group of patient representatives from diverse disease areas, to a comprehensive update and re-write of an information document on biosimilars for patients and lay persons.

# PROJECTS

## PISCE AND PRO-STEP

EPF continues to be involved in two pilot studies in the area of self-care and self-management, a significant life-skill aspect of patient empowerment. We participated as a partner in the **PISCE tender** on self-care for minor conditions, which started in 2014 and held its final conference in March 2017. The **PRO-STEP** tender on self-management in chronic conditions, where EPF is the overall leader of the consortium, commenced in 2016 and will conclude in early 2018. Both actions will set up a platform of experts in self-care and related fields, and develop recommendations to support patients' self-care and chronic disease self-management to inform future policy at EU and national levels.

## EU JOINT ACTION ON CHRONIC DISEASES AND PROMOTING HEALTHY AGEING ACROSS THE LIFE-CYCLE (CHRODIS)

CHRODIS aims at promoting and facilitating the exchange of good practices between European countries and regions on health promotion and prevention of chronic conditions, multi-morbidity and diabetes. In 2016, EPF led the production of two policy factsheets on Diabetes and Multi-Morbidity, and took an active role in the definition of quality criteria for good practices, the development of recommendations and of the multi-morbidity care model.

## THE EUROPEAN PATIENTS ACADEMY ON THERAPEUTIC INNOVATION (EUPATI)

2016 was de facto the last year of the EUPATI project. The European Patients' Academy concluded its first phase as a project of IMI in January 2017 to become a programme under the EPF work plan.

During the five-year period 2012-2016, EUPATI provided scientifically reliable and comprehensive information to patients and the general public on medicines research and development (R&D) process.

2016 saw major achievements for EUPATI, such as the roll out of the second Expert Training Course and the finalisation and exploitation of the EUPATI Toolbox, a repository of online resources on medicines R&D geared towards patient advocates and lay patients including more than 200 articles, 400 glossary terms, 55 infographics, 40 presentations, all in more than seven languages. The material is presented under a Creative Commons license, free to use and adapt. By the end of 2016 more than 90,000 individual visitors have used the toolbox.

In December 2016 EUPATI also held its final conference in Brussels. In the framework of this event, EUPATI graduated 96 Expert Patients (now known as EUPATI Fellows) from 31 different countries in 58 disease areas to become future trainers and experts in their patient roles. The EUPATI Fellows reported that their new expertise helped increase their engagement as partners in all stages of medicines development - with the pharmaceutical industry, regulatory authorities, universities and HTA bodies.

# 2014-2016



P  
I  
S  
C  
E

# 2014-2017



# 400

## GLOSSARY TERMS

# 200

## ARTICLES

# 55

## INFOGRAPHICS

# 40

## PRESENTATIONS



# 02



We need transformative measures building on collaboration among stakeholders. Patients are facing unacceptable barriers to healthcare services, resulting in worse health outcomes, and greater human suffering.

Marco Greco,  
EPF President

EPF SURVEY  
ON ACCESS TO  
HEALTHCARE

395  
RESPONDENTS

28  
EU MEMBER STATES



EPF Survey on Access  
to Healthcare

## ACCESS AND INEQUALITIES

Patients' access to equitable, patient-centred high-quality and sustainable health and social care is a long-standing priority for EPF and its membership, and is at the heart of the vision of the organisation. In 2016, EPF continued its work in voicing the disparities and inequalities existing within the EU in relation to access to quality care for chronic diseases and long term conditions.

### ACCESS WORKING GROUP

The EPF Working Group on Access met twice in 2016 and provided beneficial input to our policy work related to this crucial topic for patients in Europe. In 2016, the working group worked towards the development and deployment of a survey on patients' access to healthcare. Published at the end of year, the report from the survey provides important insight on health inequalities and access barriers met by patients with chronic and long-term diseases in the European Union.

Throughout 2016, the working group also contributed to the development of EPF's preparatory work for the 2017 campaign on access and universal health coverage. Under the tagline '*Universal Health Coverage for All*', the campaign is an opportunity to raise awareness about the barriers patients face in accessing healthcare, and to build on current political momentum, including the UN sustainable development goals, to foster more EU cooperation on access to healthcare.

EPF would like to thank the members of the Access Working Group for its productive and important work in 2016.

### PATIENT ACCESS PARTNERSHIP - PACT

EPF is a founding member of the Patient Access Partnership (PACT), a patient-led multi-stakeholder network, and contributed to setting up the European Parliament Interest Group on Patient Access to Healthcare.

The six co-chairs of the group, MEPs Biljana Borzan (S&D, Croatia), Cristian Silviu Buşoi (EPP, Romania), Karin Kadenbach (S&D, Austria), Kateřina Konečná (GUE/NGL, Czech Republic), Andrey Kovatchev (EPP, Bulgaria) and Lieve Wierinck (ALDE, Belgium) demonstrate a strong and cross-party support for access to healthcare.

In June, the group hosted a special event to discuss the European Commission activities on access to medicines, in light of the own-initiative report of the European Parliament on "*EU options for improving access to*





Image above: PACT Partners' Assembly 2016

medicines". The group also met in November to discuss the joint European Commission/ OECD report "Health at a Glance: Europe 2016" which illustrates the Commission's knowledge-building efforts as a resource for Member States in addressing challenges to their health systems.



Image above: EPF Patient Safety Conference, November 2016

In September, the Patient Access Partnership held its first Regional Conference entitled "Cooperation within the region: a way to improve access to quality healthcare in Central and Eastern Europe", in Sofia, Bulgaria. Delegates from more than 25 countries in Europe gathered to discuss challenges and cooperation opportunities for improving access for patients to quality healthcare.

## HIGHLIGHTS: EPF SURVEY ON ACCESS TO HEALTHCARE

### AVAILABILITY

**36.6%**

OF RESPONDENTS  
INDICATE A MODERATE  
EASE OF HEALTHCARE  
SERVICES ACCESS

### AFFORDABILITY

**60.6%**

EXPERIENCED FINANCIAL  
DIFFICULTIES AS A RESULT  
OF HEALTHCARE SPENDING

### ACCESSIBILITY

**72%**

DID NOT EXPERIENCE DELAY  
IN ACCESSING MEDICINES

### ADEQUACY

**54.9%**

WERE SATISFIED WITH THE  
SAFETY OF CARE RECEIVED

### APROPRIATENESS

**46.79%**

FELT NOT STIGMATISED IN THE  
HEALTHCARE ENVIRONMENT

# POLICY DOSSIERS



## PATIENT SAFETY AND QUALITY OF CARE

A major conference entitled “Patient and family empowerment for better patient safety” was held on 8-9 November 2016. This was the first EPF event explicitly linking empowerment and safety, and the rich discussions showed patients want to see a real culture change and that patients and their organisations play a potentially very important role in triggering improvements in safety.

The EPF survey to explore the concept of quality in healthcare from the patient perspective was launched in 2016 and data was collected during the year until 30 September, with the report published in early 2017.



## PRICING AND VALUE OF INNOVATIVE MEDICINES

In June, EPF published a position paper on this important topic, which outlines nine core principles from the patient perspective to inform EU policy. This paper was a prime contribution to the debate around medicine prices, and form the basis of our continued advocacy for access to valuable innovation that is affordable and sustainable for patients and for society.



## CROSS-BORDER HEALTHCARE

Still very much a core priority for EPF, we published our position statement on the implementation of the Cross-Border Healthcare Directive, which shows that the situation is currently very uneven across the EU and patients’ rights are still not applied. We continued to draw on this paper and the extensive work accomplished during our series of regional conferences; we presented the patients’ recommendations for policy and practice in several meetings and conferences to national and EU decision-makers.

Finally, we participated in a survey conducted by our member International Federation for Spina Bifida and Hydrocephalus on the impact of the Directive on persons with disabilities and chronic conditions.



## MEDICAL DEVICES

The new EU Regulations on medical devices and in vitro diagnostic devices were adopted in June 2016, setting new rules to ensure the safety and quality of medical devices in the EU.

EPF has since developed a series of information materials - factsheets and briefings - for patient organisations and for decision makers to foster awareness and help empower patient organisations to participate in the development, safety and quality of medical devices.

Furthermore, during the course of 2016, EPF continued its dialogue with the Medical Technology industry via the Patient-MedTech Dialogue. The dialogue aims to exchange views and information, working towards a Code of Conduct for the MedTech industry.



## ENDING DISCRIMINATION

In 2016, EPF put increased efforts on working with groups that are vulnerable to health inequalities and discrimination. Following the work done by the newly set-up task force on inclusion of vulnerable groups' perspective in patient organisations, a roadmap was published at the end of 2016 aiming to identify and encourage actions to support patient organisations in integrating the perspective of groups vulnerable to social exclusion and discrimination in their activities. This roadmap will also serve as a tool to contribute towards EPF's strategic goals and core values as outlined in our strategic plan 2014-2020.

In 2016, EPF became a partner of the EU Agency for Safety and Health at Work (OSHA) campaign on healthy workplaces for all ages. In this capacity, in November 2016, EPF co-hosted a Slovak Presidency endorsed conference on early intervention in Bratislava with the Fit for Work Global Alliance and AOPP, our member in Slovakia.

EPF also provided a response to the European Commission's consultation for a European Pillar on Social Rights. This is a high-level, cross-cutting initiative, allowing EPF to highlight the importance of applying the principle of health in all policies.



## eHEALTH

In 2016, EPF published a position paper on eHealth. This paper was developed following consultation of the EPF Policy Advisory Group, and draws on the findings of various eHealth-related projects in which EPF has participated in over the last few years.

## HEALTH TECHNOLOGY ASSESSMENT (HTA)

In 2016 the informal EPF Working Group on Health Technology Assessment (HTA) discussed HTA related activities at EU and international level, such as the HTA Network and EUnetHTA, HTA International (HTAi) and ISPOR (International Society for Pharmacoeconomics and Outcomes Research). To help EPF members navigate in the HTA arena, EPF has produced an informative factsheet with key messages and ongoing initiatives.

2016 marked the kick-off of EUnetHTA third Joint-Action and several meetings with EPF to envisage the role in the action for patient organisations. In parallel, meetings with the European Commission were organised in the light of the ongoing initiative on "Strengthening of the EU cooperation on HTA" and in the perspective of a potential involvement in EUnetHTA as well as in the future HTA Network stakeholder pool.

EPF has also been increasingly involved in the HTAi Steering Committee of the Patient and Citizen Involvement Interest Sub Group (PCIG) and has kept an open dialogue on HTA with other stakeholders, including EFPIA and MedTech.

## WHAT IS HEALTH TECHNOLOGY ASSESSMENT (HTA)?

**HTA MEASURES THE ADDED VALUE OF A NEW HEALTH TECHNOLOGY IN COMPARISON TO EXISTING TECHNOLOGIES/CURRENT STANDARD OF CARE**

## WHY DOES IT MATTER TO PATIENTS?



1. Patients are the ultimate users of health technologies, as such they have a crucial role in the assessment process.



2. Decisions made on availability and reimbursement of technologies have an impact on access to high quality healthcare.



3. At European level patients can advocate and promote models for patient involvement among other stakeholders.



4. HTA can prevent financing technologies with limited or no-added value.

# PROJECTS

## EUROPEAN NETWORK FOR PATIENT SAFETY AND QUALITY (PASQ)

The project concluded its work in March 2016, after a no-cost extension from March 2015 for one year. EPF was proud to be a partner in this Joint Action, which produced impressive results:

- an extensive wiki with over 500 good practices for inspiration and learning, including practices for the empowerment and involvement of patients.
- 35 events were organised to exchange information and learnings and build relationships between practitioners across Europe.
- 220 healthcare organisations from 18 European countries participated in the implementation of selected Safe Clinical Practices – the WHO Surgical Safety Checklist, Medication Reconciliation, multimodal intervention to increase hand hygiene compliance, and Paediatric Early Warning Scores.
- a proposal for a sustainable model for collaboration on patient safety and quality of care at European level.

## ADAPT SMART

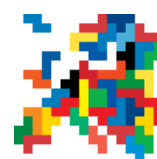
“Accelerated Development of Appropriate Patient Therapies: a Sustainable, Multi-Stakeholder Approach from Research to Treatment-Outcomes” (ADAPT-SMART) is a coordination and support action (CSA) funded by IMI 2. It aims to define the right parameters for the use of Medicine Adaptive Pathways to Patients (MAPPs), such as the right balance of benefits and risks and how to manage different levels of uncertainty.

EPF contributes a patient perspective on critical aspects such as appropriate use, patients’ perceptions of risk and uncertainties, communications, and ethical and legal issues.

## SMART CARE

Launched in early 2013, SmartCare aims to promote a more integrated and effective approach to health and social care provision to older people across Europe, by testing Information and Communication Technology (ICT)-supported integrated care pathways. EPF’s role in this project was primarily to contribute a patient perspective as a member of the User Advisory Board (UAB). The project ended in July 2016 with a final conference in Trieste, Italy, where partners presented the conclusions from their work streams and the guidelines for the implementation of integrated e-care services.

2012-  
2016



2015-  
2017



2013-  
2016





# 03

# A VIBRANT NETWORK

”

Only by getting real recognition of the contribution of patient organisations to the public health debate can we expect a change in funding schemes.



**Anders Olauson,**  
EPF Honorary President

Our vision 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 2016, we increased opportunities for members to meet - both online and offline.

## HOW DO WE PUT FORWARD PATIENTS' INTERESTS IN A EUROPEAN POLICY LANDSCAPE WHERE HEALTHCARE APPEARS NOT TO BE A PRIORITY?

In February, EPF members met in Brussels for our first 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.

## SUSTAINABILITY OF PATIENT ORGANISATIONS WAS ALSO ONE OF OUR HIGHLIGHTS THIS YEAR

Putting forces together is especially important as resourcing their work is a real issue for patient organisations. The lack of awareness of the added-value of patient organisations to the healthcare system was identified as one of the roots of the problem. A working group on sustainable patient organisations, created by EPF in January 2016, was tasked to take forward this issue and to look at innovative ways to support the work of patient organisations.

## EPF CONNECT – LET'S PURSUE THIS DISCUSSION ONLINE!

With the launch of EPF's online platform in March 2016, EPF members have for the first time the opportunity to exchange between our physical meetings. EPF CONNECT was developed around the needs of our members and offers the opportunity to build new collaborations and to access original contents such as training material and presentations.

Because a coffee is worth a thousand emails, in 2016, EPF continued to offer to 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, a short and to-the-point mailing sent on weekly basis that ensures EPF members keep up with the latest news from Europe on what really matters for patients.



Image above: EPF Training on Transparency and Ethics, September 2016

## CAPACITY BUILDING PROGRAMMES AT EU & NATIONAL LEVEL

2016 was again a year of many activities and achievements within the EPF Capacity Building Programme (CBP). Training modules on strategic communication (providing support on presentation and negotiating skills, advocacy, campaigning and media relations) have taken place in Bulgaria, Slovakia and Hungary, while patient representatives from Slovakia and Romania participated in a training module on fundraising.

The programme aims to support the organisational capacity and sustainability of patient organisations. In that view, the Hungarian Federation of People with Rare and Congenital Diseases (HUFERDIS) completed a mid-term review of strategic plans. The exercise provided helpful insights and recommendations on how to grow as a professional and sustainable organisation. The EPF Capacity Building Programme (CBP) has extensively promoted ethical and transparency principles between EU diseases-specific and national coalitions, has supported the development of the concept of Patient Safety through workshops and trainings, and has helped raise the profile of patient organisations as legitimate partners among healthcare policy and decision makers.

Finally, EPF initiated the preparatory work for CBP chapters in Poland and the Western Balkans, with the view to launch a similar set of modules in 2017.

## REPUTATION IS ESSENTIAL CURRENCY FOR ADVOCACY, PROTECT IT!

Ethics and transparency are an absolute priority for patient organisations. But how do you ensure your organisation meets the highest degree of integrity and accountability? This is the question that 11 committed patient organisations aimed to answer during our three-day-training on transparency which took place in September 2016.

The training provided participants with useful and hands-on tips on how to increase their organisation's transparency. Improving your credibility can thus be done through very easy steps such as ensuring a representative membership with solid legitimacy criteria, having a clear governance and management ruling system, or by communicating on your transparency measures on the organisation's website.

When it comes to cooperation with industry, the key principles are independence, mutual respect, and unrestricted funding: "Walk in as equal partners", recommended Noémi Ambrus who facilitated the training. "Ideally, NGOs' funding should come from at least four different funding sources", she added.

**+4**  
MEMBERS

**46**  
WEEKLY COFFEES  
WITH EPF

**103**  
NEW USERS ON EPF  
CONNECT

**8.200**  
INTERACTIONS ON EPF  
CONNECT

**To be solid, a house  
needs good pillars. So do  
patient organisations.  
They have to be built  
on pillars such as  
appropriate policies and  
procedures which will  
ensure transparency and  
accountability.**

**Eleni Zymboulaki,  
Cypriot coalition of patient  
organisations**

Beyond improvements for each individual organisation, the meeting aimed at starting a collective reflection on the accountability of patient organisations: “Supporting Patient organisations’ work on transparency and accountability helps the whole patient movement to advance”, concluded Marko Perovic, from the European Federation of Crohn’s and Ulcerative Colitis Associations.

## REGIONAL ADVOCACY SEMINAR PATIENTS PUT ON THE SHOES OF MEMBERS OF THE PARLIAMENT FOR ONE DAY!

On 6-7 June 2016, 40 patient leaders from Belgium, Germany and the Netherlands met in The Hague (NL) for the 8th edition of the EPF Regional Advocacy Seminar, held under the auspices of the Dutch Presidency of the Council of the EU. This interactive seminar looked specifically at the role patient organisations can play in the European decision-making process, and at the advocacy techniques they have at their disposal to voice their interests.

During the course of the role play simulating the legislative process within the Parliament, participants put on the shoes of Members of the European Parliament, having to decide health priorities for the next five years. They sometimes had to face difficult situations, and to prioritise their political group’s preference over their individual choice. They could also experience the pressure from stakeholders’ groups, including civil society groups and industry representatives.

While the stated goal of this seminar was to strengthen patient organisations’ capacity to become more empowered actors in the national and European health policy arena, the interactive format of the meeting also allowed for extensive networking between patient leaders from the region.



Image above: EPF Regional Advocacy Seminar, June 2016



Seminar Report

## NATIONAL COALITION BUILDING

National coalitions of patient organisations play a crucial role in a national context: they are best placed to monitor, understand and react to as well as to actively influence national health policies of their respective countries. For EPF, they are a vital partner, providing us with expertise on country-specific situations, and cascading our messages from and to the national and regional levels.

Thanks to its experience and its knowledge of the local stakeholders, EPF can support the coalition-building process in countries where there is currently no national coalition of patient organisations. By providing examples from other Member States and acting as a bridge between patient organisations and external stakeholders, we can help facilitate the creation of new platforms. In 2016, we met with Portuguese patient organisations to understand the local context and support their advocacy efforts at national level by bringing EPF’s collective experience.

We also developed a practical step-by-step toolkit for national, regional and local patient organisations who wish to set up a national coalition in countries where it does not yet exist. This toolkit will also constitute a practical reference for existing well-established national coalitions of patient organisations who wish to raise their profile further, especially in terms of strengthening their legitimacy, representativeness, and accountability.

**The support of national and local patient groups is essential to convince decision-makers here in Brussels. They simply know best what is happening on their ground: they can witness and report on the good implementation of directives and regulations adopted at European level.**

**Nicola Bedlington**  
EPF Secretary General



## EPF YOUTH GROUP

Throughout 2016, the EPF Youth Group continued to raise its international profile with an impressive agenda of meetings, special events, and contributions to their own brand development and capacity building. The group has continued to promote the unique views of young patients through social media and through contributions to EPF policy consultations.

In March, the group hosted its first policy roundtable on transition to adult care and was attended by a wide variety of stakeholders from different EU Member States. Around the same time, EPF Youth Group President Aneela Ahmed was also active in the promotion and activities of EPF's Patient Empowerment Campaign and accompanied the delegation of EPF who met with various MEPs in Brussels.

In May EPF Youth Group collaborated with young members of the European Multiple Sclerosis Platform members to hold a session on young patients at the European Youth Event in France.

Over the summer months, members Borislava Annanieva (Bulgaria) and Polycarpus Stavrou (Cyprus) were actively involved in patient youth camps in their countries, while Thomas Hough was busy running international marathons - including the New York Marathon! - to raise awareness of chronic conditions on the international stage.

In September, a new Youth Group Board member, Marlou Schenk, was elected for a two-year mandate. In November, members Anna Zaghi and Yolita Pavlova spoke at the European Pharmaceutical Students Association Autumn Assembly in Romania, and Lembe Kullamaa was a participant in the Patients and Consumers Training Day at European Medicines Agency in London.

In addition to these activities, the Youth Group contributed to the work of the Secretariat in a new and exciting initiative. The first Youth Group traineeship was completed in 2016 by member Laurence Woollard, allowing a member to temporarily work full-time in the EPF Offices to support the work of the Secretariat and act as a direct liaison with the Youth Group. His traineeship was a great success for all parties and EPF will continue to extend this opportunity to new trainees in the coming year.

Recruitment for the Youth Group remains a priority, as the group seeks to find new members from unrepresented Member States and disease areas. After a year of phenomenal growth and accomplishments, the EPF Youth Group is ready to continue expanding their advocacy work and for even more new challenges in 2017!

**11**  
MEMBERS

**10**  
BLOG POSTS

*Image on the left: EPF Youth Group, September 2016*



# 04

# ALLIANCE BUILDING



**EPF PLACES A STRONG  
EMPHASIS ON FORGING  
ALLIANCES AND GOOD  
WORKING RELATIONS WITH  
EUROPEAN ORGANISATIONS  
WITH WHICH WE HAVE A  
COMMON AGENDA**

2016 saw EPF continuing to strengthen and expand our partnerships with various organisations both within the EU health sector and beyond, in the spirit of health in all policies. Partnership and collaboration remain our credo as an organisation and we will seek to continue to foster and encourage alliance-building with all allies that share our vision.

Particular highlights during 2016 include:

- Cooperation with Civil Society Europe and its members on the **added-value of non-governmental organisations, including patient organisations**, in light of the European Parliament Environment and Health Committee Opinion on the Funding of EU NGOs. A crucial collaboration to demonstrate the fundamental significance of patient organisations for patients in general and EU citizens.
- Joining forces with the European Public Health Alliance (EPHA), the European Disability Forum (EDF), the European Federation of National Organisations Working with the Homeless (FEANTSA), the Platform for International Cooperation on Undocumented Migrants (PICUM) and the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA Europe) and with seven EPF members on the drafting of a Roadmap towards the **inclusion of vulnerable groups' perspective within patients' organisations**.
- Partnership with Medicines for Europe, the European Public Health Alliance (EPHA) and the International Association of Mutual Benefits Societies (AIM) on the setting up of the third edition of the "Universal Access to Health" debate, an initiative allowing different stakeholders (industry, insurers, health organisations) to exchange their views on how we can reach universal access to healthcare.
- Participation in the Patient Access Partnership (PACT) and interest group on access to healthcare took place. EPF was instrumental in the creation of the Patient Access Partnership, with the premise that advancing equity of access to quality healthcare should be everyone's business and not one stakeholder is strong enough to tackle this alone. Multi-stakeholder collaboration is vital.



# 05 SECRETARIAT AND GOVERNANCE

## MEET OUR BOARD



**MARCO GRECO**  
**EPF PRESIDENT**

*European Federation of Crohn's and Ulcerative Colitis Associations*



**BRIAN WEST**  
**VICE PRESIDENT**

*European AIDS Treatment Group*



**RADU COSTIN GANESCU**  
**TREASURER**

*Coalition of Organisations for Patients with Chronic Conditions of Romania*



**STANIMIR HASURDJIEV**

*Bulgarian National Patients' Organization*



**ROBERT ANDREW JOHNSTONE**

*Access Matters*



**SUSANNA PALKONEN**

*European Federation of Allergy and Airways Diseases Patients Associations*



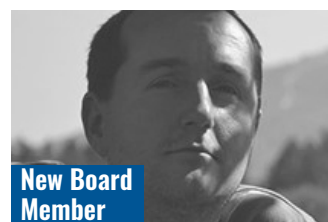
**DOMINIK TOMEK**

*Association for the Protection of Patients' Rights, Slovak Republic*



**JUAN FUERTES**

*Pulmonary Hypertension Europe*



**MICHAL RATAJ**

*European Alliance of Neuromuscular Disorders Associations*

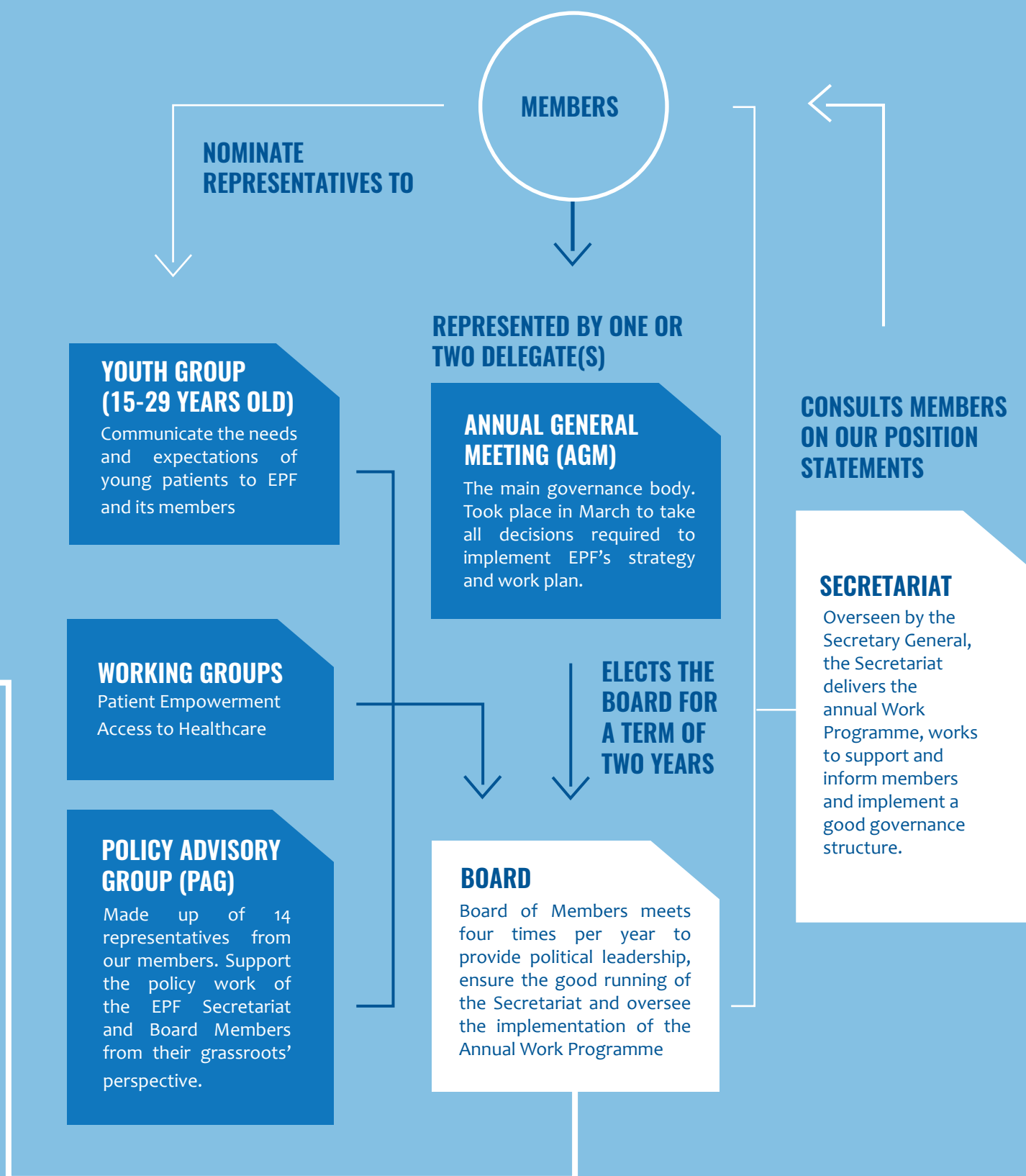


**EPF HONORARY PRESIDENT**

*Anders Olauson, Eurordis*

Anders has been active in EPF since the conception of the association, in 2003. Chairing EPF since 2005, he was instrumental in creating and supporting the patient movement at the European level. In recognition of his time and involvement within EPF, Anders Olauson was awarded the title of Honorary President of EPF by the assembly.

# GOVERNANCE



# EPF SECRETARIAT



## WALTER ATZORI

### *Director of Programmes and Operations*

Capacity Building Programme, EUPATI, Operational & Financial Matters



## NICOLA BEDLINGTON

### *Secretary General*

Leadership, Direction & Guidance, Main Spokesperson, High-Level Representation & Liaison with Partners



## CAMILLE BULLOT

### *Membership and Stakeholders Relations Manager*

Membership Engagement & Growth, Capacity-Building Modules, Cooperation with EPF Partners



## DANIELLE FLORES

### *Junior Project Officer*

EUPATI, Youth Group, Projects Coordination



## KATIE GALLAGHER

### *Policy Adviser*

Policy & Advocacy, Strategy on Access, Policy Advisory Group & Working Group on Access



## ZILVINAS GALVENAS

### *IT Manager*

IT Coordination, Servers Maintenance, Web Solutions



## SARA GAYARRE

### *Communications Assistant*

Patient Empowerment Campaign, Social Media, Content Production



## SELENA IMEROVIC

### *Capacity Building Officer*

Capacity Building Programme, Thematic Workshop, Projects Support



## KAISA IMMONEN

### *Director of Policy*

Strategic & Policy Agenda, EU Institutions & Stakeholders, Patient Empowerment, Patient Safety, Quality of Care & Cross-Border Healthcare





Welcome

## LAURENT LOUETTE

**Communications Officer**

Communications Strategy,  
Press Relationship, Content  
Management



## VALENTINA STRAMMELLO

**Programme Officer**

Project Management, Health  
Technology Assessment, Youth  
Group



## VÉRONIQUE TARASOVICI

**Office and Events Manager**

HR, Events, Finance Task Force



## STEFANO TIRONI

**Finance Officer and Assistant  
to the Secretary General**

Financial Matters, Assistant to  
Secretary General, EUPATI &  
PACT

## GOODBYE AND THANK YOU

- *Laurène Souchet (Policy Adviser)*
- *Valentina Stylianou (Communications Assistant)*

# COMMITMENT TO LEARNING – EVALUATION

In line with its commitment to learn and develop as an organisation, EPF called for an independent consultant to run the external evaluation of the delivery of its work programme for 2016.

Focusing on EPF's actions regarding Patient Safety, the Regional Advocacy Seminar and the Working Group on Access, the external evaluator assessed the quality and consistency of EPF's activities in 2016.

The evaluation report set forth in its overall conclusions the successful delivery of the EPF work programme for 2016. It appeared from the interviews run by the evaluator that the work undertaken by EPF is much appreciated by the participants. The report also stresses the high level of supervision and follow-up of the individual actions, and the impressive quality and consistency of the programme documents.

To further improve the delivery of the work programme, the evaluator recommends EPF to continue looking for innovative approaches towards more interactive trainings and events, as well as further develop contacts with European networks of vulnerable groups. It was also suggested to strengthen capacity of grass-roots organisations, to help small patient organisations address decision-makers.

# 06 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, 2016**

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, 2016, 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 1.762.067 EUR and a result of profit for the year of 80.000 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 determine 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 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, 2016, in Belgium applicable accounting standards.

**RSM INTERAUDIT BVBA-  
SC SCRL, REGISTERED  
AUDITORS REPRESENTED  
BY JEAN-FRANCOIS  
NOBELS**

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

[interaudit@rsmbelgium.be](mailto:interaudit@rsmbelgium.be)

VAT BE 0436.391.122 – RLP  
Brussels

# 07 FINANCIALS

## INCOME AND EXPENDITURE

INCOME	2016(€)	2015(€)
<b>Funding from Public Sector</b>	<b>1,191,096.87</b>	<b>1.087.670,21</b>
Operational Work Programme (Chafea Operating Grant 79%)	731.835,98	728.212,00
EU projects	149.507,36	97.060,59
EUPATI (IMI JU contribution)	309.753,53	262.397,62
<b>Funding from the private sector</b>	<b>657,159.25</b>	<b>705,331.95</b>
Operational Work Programme (co-funding of Chafea's Operating Grant, 19%)	172.450,00	171.000,00
Co-funding to EPF projects	37.577,93	49.595,65
Project developments and other costs	104.361,09	248.011,24
Capacity Building Programme	237.786,76	141.282,34
Contribution to EPF Campaigns	42.273,73	34.586,61
EFPIA contribution within EUPATI	62.709,74	60.856,11
<b>Foundations</b>	<b>20.000,00</b>	<b>125.000,00</b>
R. Bosch Foundation grant for the Empowerment Campaign	20.000,00	125.000,00
<b>Membership fees</b>	<b>17.950,00</b>	<b>15.132,31</b>
Operational Work Programme (co-funding of Chafea's Operating Grant 1%)	12.000,00	11.000,00
Contribution to EU projects	5.950,00	4.132,31
<b>Interests and other income</b>	<b>30.516,86</b>	<b>18.070,02</b>
<b>Total Incomes</b>	<b>1.916.722,98</b>	<b>1.951.204,49</b>
EXPENDITURES	2016 (€)	2015 (€)
Staff Costs (including EUPATI staff)	1.033.791,00	966.587,13
Office and admin costs	197.888,72	176.220,78
Depreciation	15.168,53	14.239,39
Travel and subsistence (EPF staff)	67.325,56	58.645,98
<b>Events</b>	<b>500.511,08</b>	<b>512.051,69</b>
Annual General Meeting (AGM)	74.022,50	41.664,34
Regional Advocacy Seminar (RAS)	33.730,55	35.909,49
Youth meetings	17.985,76	13.759,07
Patient evidence workshop	9.183,58	-
Capacity Building Programme (delivery of training modules)	106.364,18	105.773,27
Cross-border healthcare regional events and conference	65.639,35	79.089,36
<b>Other costs linked to operations &amp; development of new projects</b>	<b>193.585,16</b>	<b>235.856,16</b>
<b>EPF Campaigns</b>	<b>20.415,26</b>	<b>112.841,21</b>
<b>Bank and Financial Charges</b>	<b>1622,83</b>	<b>645,55</b>
<b>TOTAL Expenditure</b>	<b>1.836.722,98</b>	<b>1.841.231,73</b>
<b>Surplus or deficit of the Year Operating Grant</b>	<b>-</b>	<b>- 2.913,91</b>
<b>Total Surplus or deficit of the Year</b>	<b>80.000,00</b>	<b>112.886,67</b>

# 2016 ACCOUNTS AND AKNOWLEDGEMENTS

EPF wishes to thank the European Commission for its support in 2016 in relation to EPF's role in the following projects		
	EC Contribution used in 2016	% of total income
Adapt Smart	24.886,69 €	1,3%
Joint Action CHRODIS	22.059,72 €	1,2%
Joint Action PASQ	2.598,32 €	0,1%
SmartCare	4.600,59 €	0,2%
ProStep	89.345,89 €	4,7%
Prefer	1.594,45 €	0,1%
PISCE Self Care Tender	4.421,70 €	0,2%
<b>TOTAL European Commission support to projects</b>	<b>149.507,36 €</b>	<b>7,9%</b>
EPF wishes to thank the following donors for their support:		
	Contribution to the OG	% of total income
<b>Operational work programme</b>	<b>916.285,98 €</b>	
European Commission	731.835,98 €	38,5%
Almirall	5.000,00 €	0,3%
AbbVie	11.000,00 €	0,6%
Gilead	20.000,00 €	1,1%
GSK	30.000,00 €	1,6%
MSD	30.000,00 €	1,6%
Pfizer	36.450,00 €	1,9%
Novartis	30.000,00 €	1,6%
Sanofi Pasteur MSD	10.000,00 €	0,5%
Membership	12.000,00 €	0,6%
<b>Capacity Building Programme</b>	<b>220.810,08 €</b>	
Association SLK	20.000,00 €	1,1%
Alexion	10.000,00 €	0,5%
Baxter	10.000,00 €	0,5%
Celgene	15.000,00 €	0,8%
GSK	30.000,00 €	1,6%
Janssen	10.810,08 €	0,6%
Eli Lilly	15.000,00 €	0,8%
Novartis	30.000,00 €	1,6%
Pfizer	25.000,00 €	1,3%
Hoffman-Roche	40.000,00 €	2,1%
Vertex	15.000,00 €	0,8%
<b>Empowerment Campaign</b>	<b>53.230,61 €</b>	
Janssen	4.339,00 €	0,2%
Bosch Foundation	20.000,00 €	1,1%
MSD	28.891,61 €	1,5%
<b>Project Portfolio</b>	<b>80.000,00 €</b>	
CSL Behring	10.000,00 €	0,5%
Grunentahl	10.000,00 €	0,5%
Mylan	10.000,00 €	0,5%
Sanofi-Aventis	40.000,00 €	2,1%
Servier	10.000,00 €	0,5%
<b>Project Development</b>	<b>75.100,92 €</b>	
AbbVie	14.000,00 €	0,7%
Janssen	14.850,92 €	0,8%
J&J	10.000,00 €	0,5%
Teva	20.000,00 €	1,1%
Shire	10.000,00 €	0,5%
Pfizer	6.250,00 €	0,3%
<b>The European Patients' Academy on Therapeutic Innovation Public Private Partnership (EUPATI)</b>	<b>372.463,27 €</b>	
Innovative Medicine Initiative (IMI JU) contribution	309.753,53 €	16,3%
Industry consortium (Hoffman La Roche, Genzyme, Boehringer, VFA, GSK, AMGEN, ESTEVE, Novonordis, Pfizer, S.A. Eli Lilly, Novartis, Astra Zeneca, Bayer, UCB, CHIESI, Janssen, Merck)	62.709,74 €	3,3%
<b>Memberships and other income</b>	<b>32.360,23 €</b>	<b>1,7%</b>
Total Income	1.899.758,45 €	100,0%
Accrual and deferrals	16.964,53 €	
<b>Total Income net of adjustments</b>	<b>1.916.722,98 €</b>	

# 08 MEMBERSHIP

47  
FULL MEMBERS

17  
ASSOCIATE MEMBERS

## A GROWING NETWORK

In 2016, the EPF family was delighted to welcome as full members Dystonia Europe (DE) and the International Federation for Spina Bifida and Hydrocephalus (IF), while International Bureau for Epilepsy (IBE) and the Alliance of Patients' Organisations (FYROM) have been elected Associate Members. The EPF membership now counts 67 members, strengthening the patient movement and its representativeness at the EU level!

## FULL MEMBERS

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)

BEMOSZ - Hungarian Alliance of Patients' Organisations (Hungary)

CISS - Collectif inter associatif Sur la Santé (France)

COPAC - Coalition of Patients' Organizations with Chronic Diseases (Romania)

**DE - Dystonia Europe (Europe) New Member**

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)

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)

GAMIAN Europe - Global Alliance of Mental Illness Advocacy Networks (Europe)

IDF Europe - International Diabetes Federation (Europe)

**IF – International Federation for Spina Bifida and Hydrocephalus (International\*)** **New Member**

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)

NPO - National Patients' Organisation of Bulgaria (Bulgaria)

National Voices (United Kingdom)

Pancyprrian 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

AMRC - Association of Medical Research Charities (United Kingdom)

**APO – Alliance of Patient Organisations (FYROM)** **New Member**

BAPD - Bulgarian Association for Patients Defence (Bulgaria)

Debra Europe - 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\*)** **New Member**

MRCC - 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\*)

---

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



**European Patients' Forum**

Rue du Commerce 31

1000 Brussels, Belgium

Phone: + 32 2 280 23 34

Fax: + 32 2 231 14 47

[www.eu-patient.eu](http://www.eu-patient.eu)

[@eupatientsforum](https://twitter.com/eupatientsforum)