

# EPF Annual Report

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## 2015

# Driving Better Health for Patients in Europe



## 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.

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# Foreword



**Supporting patients to become empowered and actively involved at all levels has become an inherent part of EPF's strategy.**

*Anders Olauson*  
EPF President

2015 was another significant year for EPF and our membership. Our flagship initiative, the EPF Patient Empowerment Campaign was launched successfully in May 2015 with a ground-breaking conference. EPF has been delighted by the feedback, enthusiasm and uptake of the campaign both at European and at national level, among policy makers and the health community alike. The concept of Patient Empowerment is central to EPF's work and we will continue to strive to make it integral to European and national policies on health and social care.

Building on EPF 2014-2020 Strategic Plan, we clustered our activities around three thematic areas: patient empowerment, access to healthcare and sustainable patient organisations.

In concert with our campaign, much has been achieved elsewhere regarding **Patient Empowerment**. Our internal dedicated working group met twice and agreed on a definition of patient empowerment from patients' perspective. We also contributed to related policy dossiers, such as clinical trials, health literacy, pharmaceuticals and health technology assessment.

**Equitable Access to Healthcare** is the other pivotal element of our work. 2015 saw the foundation of the European Parliament Interest Group on Patient Access to Healthcare. Together with the Patient Access Partnership (PACT), we were proud to receive a large and cross-party support from many MEPs. The two well-attended meetings organised in 2015 demonstrated the importance of patient access for European and national strategies. On the policy side, our access pillar was reinforced by activities on discrimination, cross-border healthcare, and quality and safety of care.

An important part of our work focuses on projects. In 2015, we were delighted to continue our leadership or collaboration in 12 highly diverse and rewarding European projects which contribute a vital evidence base to our work.

Our vibrant network of **Members** is our raison d'être. Their diversity and commitment is our strength and we will continue to strive to meet their needs to enable them to both benefit from and contribute to a collective patients' voice.

And our wider trusted network of fellow stakeholders across the spectrum of healthcare has once again proven the true value of sustained collaboration on the issues that really matter to patients and citizens.

Together we can drive better health for European patients,



**Anders Olauson**  
EPF President



**Nicola Bedlington**  
EPF Secretary General



# 2015 at a glance

190

EPF events' representation



1.812

EPF twitter campaign  
#PatientprescribE usage



2.703

Followers on Twitter



4.300

Readers subscribed to  
EPF Newsletter



5.194

Likes on Facebook



32.227

EPF video campaign  
views



## DECEMBER

- EPF Membership Guide
- EPF Factsheets
- Position Paper on Equal Treatment in Education and the Workplace

## JANUARY

Launch of EP Interest Group on  
Access to Healthcare

## FEBRUARY

First Members' Spotlight in  
EPF Newsletter

## MARCH

- Position paper on Clinical Trials' Results Publication
- EUPATI Training Course 1
- Meeting Working Group Access
- EPF Youth Group meeting

## APRIL

- Patient Empowerment Working Group
- Consensus Definition of Patient Empowerment

## MAY

- Patient Empowerment Campaign Kick-Off Conference
- Roundtable on Access to Healthcare
- EPF Annual General Meeting

## JUNE

- EP Interest Group on Access to Healthcare Meeting
- Latvian Presidency High-Level Conference

## JULY

- Event on Health Literacy, European Parliament
- Conference on Cross-Border Healthcare

## AUGUST

Launch of the Riga Roadmap

## SEPTEMBER

- EUPATI Training Course 2
- AdaptSmart Kick-Off Meeting
- Social Media Training Module
- EPF Youth Group elections

## OCTOBER

- Meeting Working Group Access
- EPF response to EP resolution on health and safety at work

## NOVEMBER

- Patient Empowerment Working Group
- EP Interest Group on Access to Healthcare Meeting
- EPF Recommendations on Medical Devices Regulation Proposal
- Regional Advocacy Seminar
- EPF response to consultation on access to healthcare

# Patient Empowerment

Patient-centred chronic disease management with focus on patient empowerment is a key priority for EPF. With input from our working group on empowerment, EPF published in 2015 a briefing with a consensus definition of patient empowerment and other related concepts, such as patient involvement and health literacy.



**Engaged patients can change the quality of their health and influence future healthcare delivery.**

*Vytenis Andriukaitis,  
European Commissioner  
for Health and Food Safety*

**The time is right to make patient empowerment known and understood in every part of Europe.**

*Anders Olauson,  
EPF President*

**What we need now is more political commitment at all levels to create the conditions where everyone can be empowered.**

*Nicola Bedington  
EPF Secretary General*

## HIGH LEVEL CONFERENCE & CAMPAIGN

In 2015, EPF launched a one year campaign on Patient Empowerment to promote understanding of patient empowerment among political decision-makers and health stakeholders. The objective is also to promote the development and implementation of policies, strategies and healthcare/social services that empower patients in the decision-making and management of their condition.

The campaign kicked off with a conference on 20-21 May which gathered over 150 high-level participants to explore the role of patient empowerment in building high-quality equitable, sustainable health systems in Europe. Healthcare experts and patients joined forces to present the evidence-base on patient empowerment based on their personal experiences and research in the field. We also took our campaign to the Gastein Health Forum where we held a lunch seminar dedicated to “empowerment in practice”. With the tagline “Patients prescribe E5 for sustainable health systems” this campaign underlines that patients are active people who can, if adequately supported, contribute to the sustainability of healthcare systems.

This campaign would not have been a success without the help of our members and partners. We are grateful for their invaluable support. They are the driving force of this campaign and with their help, we were able to deliver our messages and raise awareness about patient empowerment at EU and national level.

## PATIENT EMPOWERMENT WORKING GROUP

The patient empowerment working group met twice this year, in April and November. The group mainly contributed to the development and implementation of the empowerment campaign, by reviewing the draft Charter and Roadmap and providing advice on campaign reach-out and participation. Given the forthcoming publication of a European Commission mapping study on patients’ rights, the group agreed to discuss the topic in 2016.

They also decided to start developing a toolkit on patient empowerment based on the Charter being developed as part of the EPF campaign. The group consists of 14 members, and following Martin Georgiev’s departure from NPO<sup>1</sup>, Guadalupe Morales took on the role of the third steering group member alongside Tunde Koltai and Irene Oldfather. The group also welcomed two new members, Momchil Baev (NPO) and Mario Sel (IF)<sup>2</sup>.



*Patients prescribe E<sup>5</sup> for Sustainable Health Systems*

<sup>1</sup> National Patients’ Organisation in Bulgaria

<sup>2</sup> The International Federation for Spina Bifida and Hydrocephalus

# What is patient empowerment about ?

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.

1.

## EDUCATION

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

4.

## EXPERIENCE

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

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.



#PatientsprescribE

# Policy Dossiers



## CLINICAL TRIALS

This year, EPF concentrated its efforts on ensuring the **transparency and patient-friendliness** of clinical trials' results. The new EU regulation requires that the results of all trials must be posted on a European database, together with a lay summary. EPF published a position statement in early 2015, highlighting some gaps in the Regulation and calling for EU guidelines to ensure the quality of these summaries.

We were pleased to see that our call was answered, and a process was indeed set in place. EPF participated in a working group that prepared the draft guidance. We also developed a draft position paper on the implementation of **informed consent** under the Regulation, which will be adopted in early 2016. We explored patient involvement in ethics review through a webinar organised by the project EUPATI, which highlighted the need for a shift of mind-set in some ethics committees.



## HEALTH LITERACY

EPF continued our fruitful participation in an informal **stakeholder coalition** comprising health professionals (CPME and PGEU), researchers (Maastricht University) and industry (MSD). Our work focused on awareness-raising among policymakers. In May, EPF contributed to an event at the European Parliament STOA (Science and Technology Options Assessment) on technology and empowerment, to discuss the implications of new technologies for health literacy and the need to look at the citizens' role in health generally.

We also attended the launch of the European Commission's mapping study on health literacy, set up following the request of our informal group. Finally EPF presented the patient perspective on health literacy and EPF's empowerment campaign at the 3rd European Health Literacy Conference, which took place in Brussels in November 2015.



## PHARMACEUTICALS

EPF continues its long-standing collaboration with the **European Medicines Agency (EMA)**, through Susanna Palkonen (EPF Vice President) as member of the working party with patients and consumers (PCWP), Kaisa Immonen-Charalambous (EPF Director of Policy) as her substitute, and Marco Greco (EPF Treasurer) as member of the pharmacovigilance working party (PRAC).

This year we participated in the first of future annual meetings dedicated to biosimilar medicines, organised by the European Commission DG GROW. The meeting identified several action areas from the patient perspective, including simple, user-friendly and relevant information and a need to update existing information materials in 2016.



# Projects

## JA CHRODIS

'EU Joint Action on Chronic Diseases and Promoting Healthy Ageing across the Life Cycle' or JA-CHRODIS paves the way for better health policies across Europe to lessen the burden of chronic diseases. The project looks at identifying good practices in health promotion and prevention, and management of chronic conditions. EPF, as associated partner, contributed to gathering patients' views in the management of chronic conditions, multi-morbidity and helped disseminate information about CHRODIS findings. Work in 2015 has also paved the way for the setting up of a platform of knowledge exchange in 2016 where stakeholders will be able to share good practices on chronic disease management and have them evaluated.



## PISCE AND PROSTEP

Self-care is gaining considerable attention in the healthcare field. Patients are gradually taking a more active role in their own healthcare. EPF is involved in two pilot studies in this area: the PISCE tender on the promotion of self-care in minor conditions, which started in 2014; and a new tender "PRO-STEP" on self-care in chronic conditions where EPF is the overall leader of the consortium and work package leader on dissemination. Both actions will set up platforms of experts in self-care and related fields, and develop strategies to support patients' self-care and chronic disease self-management.



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

2015 has been an exciting year for EUPATI, with the project entering its fourth year of implementation. Funded by the Innovative Medicines Initiative (IMI), EUPATI aims to provide scientifically reliable, objective and comprehensive information to patients on medicines research and development.

In 2015 much effort was put into developing educational material geared towards patient advocates compiled in the multi-lingual "EUPATI Toolbox", which was successfully launched on 27 January 2016. The Toolbox hosts patient-friendly, ready-to-use educational material on medicines' research and development in seven different European languages.

EPF continued its delivery of patient expert-level training courses, via the EUPATI Expert Training Course. The course is a blend of independent e-learning and face-to-face training events over a 14-month period offering expertise in medicines R&D.

By the end of 2015, more than 40 patient advocates completed the first course that was launched in autumn 2014. As part of this training, two interactive face-to-face events took place in Barcelona in 2015 where participants had the opportunity to apply concepts acquired within the e-learning. The second course was launched in October 2015 with another 60 patient advocates on board. Major developments have taken place at national level with more platforms taking off the ground this year, namely in Romania, Slovakia, Denmark, and Greece. EPF's leadership worked very hard to implement the project's sustainability strategy. With the plan for a post 2017 EUPATI laid out, efforts are now directed towards securing resources to continue to run the core elements of the project in the future.



# Patient Access

Every patient should have equitable access to patient-centred high-quality health and social care. In 2015 we continued our fight against the disparities existing within the EU in relation to access to and quality of care for chronic diseases and long term conditions.

## ACCESS WORKING GROUP

In 2015, the European Patients' Forum launched its working group on access to healthcare. 11 patient representatives nominated by EPF members meet twice a year to shape EPF's vision and activities on access. The aim of the group is to put patients' access to healthcare higher on the political agenda.

Throughout 2015, the group developed a **definition of access** from the patients' perspective, to help pave the way towards more patient-centred indicators at EU level. Looking ahead, the group started developing EPF's campaign on access (to be launched in 2017), and contributed to building up a survey for patients to be carried out in 2016 aiming at outlining a clear picture on access to healthcare in the EU.



Picture on the right:  
MEP Interest Group  
on Patient Access,  
Brussels, January  
2015

## PATIENT ACCESS PARTNERSHIP - PACT

EPF was a founder member of the Patient Access Partnership (PACT) and contributed to setting up the European Parliament Interest Group on Patient Access to Healthcare. Officially launched on 27 January, this informal group aims at providing a platform for discussion and concrete actions to improve access of EU citizens.

The 5 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) demonstrate a strong and **cross-party support** for access to healthcare.

The group was very active in 2015. In June a meeting gathering key healthcare stakeholders discussed the opportunity to create synergies between the different EU agendas related to access to healthcare. The group also met in November to reflect on the opinion on access to healthcare drafted by the European Commission's Expert Panel on Effective Ways of Investing in Health. At the Latvian Presidency high level conference on "*Universal Health: Investing in Health and Wellbeing for All*", the PACT was acknowledged as the most tangible follow up to the Vilnius Declaration<sup>3</sup>. PACT also co-organised a session on facing the challenge of multi-morbidity at the European Health Forum Gastein in October, featuring 3 patients on its agenda.

The PACT developed a **questionnaire on access**, and preliminary results showed that perspectives on the level of access vary a lot according to the countries. The survey also indicated that the 5 A's definition of access (affordability, adequacy, accessibility, availability, appropriateness) could become a valid tool to develop standard indicators.

<sup>3</sup> The Vilnius Declaration is a joint call for action following the Lithuanian Presidency of the Council, in November 2013. It aims to ensure European health systems are people-centred, sustainable and inclusive and that they deliver good health for all.

# Policy Dossiers

## ACCESS TO HEALTHCARE

While universal access is a well-recognised objective for healthcare systems in the EU, it is not yet a reality for all patients in the EU. On 5 May, EPF co-organised a roundtable with the EGA<sup>4</sup>, Doctors of the World, and AIM<sup>5</sup> on Universal Access to Health, asking MEPs to develop Universal access in the new EU political landscape.

On 6 November EPF provided comments to the Expert Panel on Effective Ways for Investing in Health opinion on “Access to Health Services in the European Union”. While welcoming the opinion’s main recommendations, EPF underlined that measures supporting patient-centred healthcare need to play a vital role in policies to improve patient access to high quality healthcare.

## QUALITY AND SAFETY OF CARE

Access and quality of care are closely linked and need to go hand-in-hand for EU patients. With the proposal for a Regulation on medical devices in its final stage, EPF updated its **recommendations on medical devices**. The safety and quality of these products is paramount for patients. Once adopted, the Regulation could provide better scrutiny over high risk devices, improved post market surveillance, the possibility for patients to report directly adverse events, and transparency of clinical investigations.

However, the Regulation still lacks the acknowledgment of patients as experts on medical devices. EPF has advocated firmly for meaningful patient involvement in medical devices’ assessment and this will remain a priority in 2016.

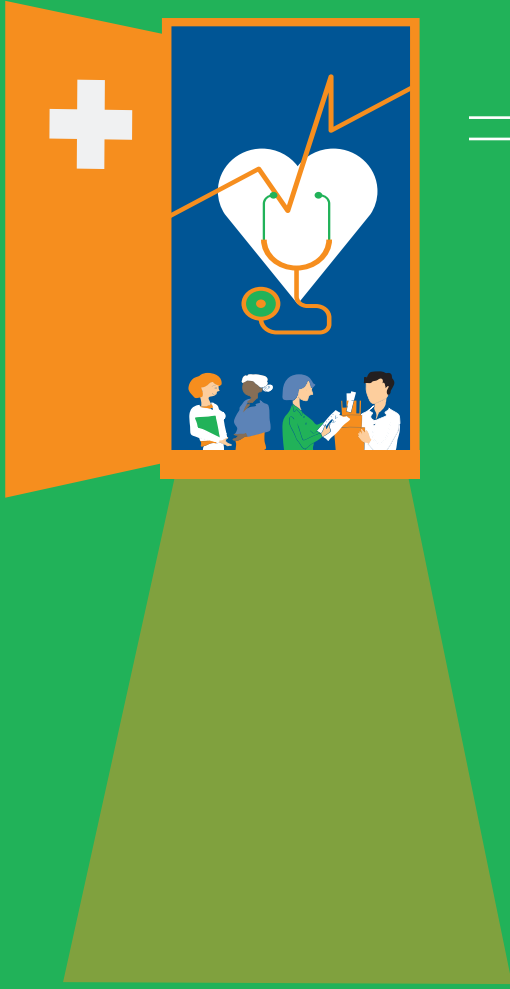
In 2015, an informal EPF Working Group on Health Technology Assessment (HTA) was set up, involving an increasing number of member representatives with an interest or expertise in HTA. The group facilitates EPF’s contribution to fora such as the HTA Network and EUnetHTA Stakeholder Forum, HTA International (HTAi) and ISPOR<sup>6</sup>.

Together with MedTech Europe, EPF organised a meeting of the Patient MedTech dialogue. Participants focused on HTA, including the challenges for medical devices, and the value of patient involvement in HTA.

EPF has been closely involved in EU level policy discussions through our participation in three meetings of the European Commission’s Expert Group on Patient Safety & Quality of Care. The topics discussed by the group in 2015 included health professionals’ training, the cost of unsafe care, and standardisation.

EPF started to explore connections with the EU debates on health systems performance (HSPA) and the European semester process. In June 2015 we co-developed the “Riga Roadmap” following the Latvian Presidency’s high-level health conference, which contains a number of recommendations around access, equity, quality and participation.

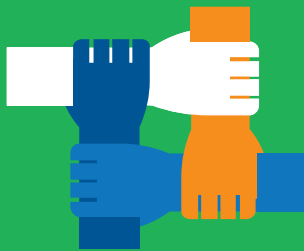
We also developed a membership survey to better understand how patients perceive “quality” in healthcare. The report due at the end of 2016 will include recommendations that will enable us to give robust input into EU-level debates on healthcare quality.



<sup>4</sup> European Generic and Biosimilar Medicines Association

<sup>5</sup> International Association of Mutual Benefit Societies

<sup>6</sup> International Society for Pharmacoeconomics and Outcomes Research



## TACKLING DISCRIMINATION

In 2015 EPF continued to work towards its strategic goal to tackle the multiple facets of discrimination encountered by patients. Following our position paper of 2014 which focused on **discrimination** in healthcare, EPF addressed in 2015 the issues that patients meet in **education and at the workplace**. Building on discussion with Eurofound<sup>7</sup>, and the Empathy project with young patients, we delivered comprehensive recommendations for the EU to make workplaces and education more patient-friendly and inclusive.

EPF also provided input into the European Parliament Resolution on the EU Strategic Framework on Health and Safety at Work 2014-2020 adopted in October 2015. The report urges the Commission to consider the increasing group of professionally active patients with chronic conditions, and asks Member States to support sensible adaptations of the workplace.



**We have the experience, we have the capacity and we have the knowledge to lead the discussion on what is best for the patients, whom we represent (...). Cross-border healthcare is a fundamental right, because without access to healthcare you cannot have full citizenship.**

*Marco Greco,  
EPF Board Member*

## CROSS-BORDER HEALTHCARE

In July 2015, EPF concluded our series of regional and national workshops<sup>8</sup> with a conference in Brussels bringing together National Contact Points and patient representatives from across the EU. We presented the outcomes from our regional events, and were invited to share these with the European Commission's network of National Contact Points in December.

The EU Health Commissioner, Dr Vytenis Andriukaitis passed on a message of strong support to the patient community and emphasised the importance of feedback about patients' experiences. Later in the autumn, EPF developed a position paper on the Commission's implementation report highlighting three areas of concern from the patient perspective: **equity of access; quality and safety; and health systems' transparency and information for patients.**



Picture above: Cross-Border Healthcare Conference, Brussels, July 15

<sup>7</sup> European Foundation for the Improvement of Living and Working Conditions

<sup>8</sup> In 2015, our workshops took place in Croatia (27/01), Spain (16/03), Poland (19/03), Bulgaria (21/03), Ireland (21/04), Romania (23/04)



# Projects

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

The Joint Action “European Network for Patient Safety and Quality” (PASQ) agreed to extend its work until early 2017. This will bridge the gap until a decision is made for a permanent platform at European level. EPF is committed to contributing to a permanent structure to continue the collaboration with member states and stakeholders around patient safety.



## WE CARE

This 2-year project aimed to investigate viable solutions for sustainable and affordable healthcare systems. EPF contributed the patient perspective to the core deliverables: a Strategy Plan and R&D Roadmap for innovative solutions. Findings show that person-centredness is central to both achieving high quality and sustainable healthcare services and that patient involvement is an essential part of the solution for cost-effective planning.

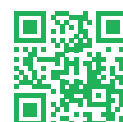


## EUnetHTA JOINT ACTION 2

The EUnetHTA collaboration was established to create an effective and sustainable network for HTA across Europe. The Joint Action 2 aimed to develop a general strategy, principles and an implementation proposal for a sustainable European HTA collaboration. EPF represented the patient community in the Stakeholder Forum on transversal topics such as ethics or methodology and disseminated consultations on specific diseases to appropriate patient organisations. Initial planning took place with regard to the next Joint Action, in which EPF alongside sister patient groups are advocating and systematic and structured approach to patient engagement.



eunetha



## AdHopHTA

EPF was a member of the Advisory Board of the AdHopHTA project, “Adopting Hospital Based Health Technology Assessment (HTA)”, which aimed to strengthen the use and impact of high quality HTA-results in hospital settings. A toolkit, database and handbook were developed to support this objective.



AdHopHTA  
Adopting Hospital Based  
Health Technology Assessment





### 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. It will identify gaps, barriers, and critical points of transition with relevant stakeholders. EPF contributes a patient perspective on critical aspects such as appropriate use, patients’ perceptions of risk and uncertainties, communications, and ethical issues.



### SMARTCARE

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 is primarily to contribute a patient perspective to this project as a member of the User Advisory Board (UAB).

In 2015 the UAB undertook a series of site visits to evaluate the user experience and involvement. Regions visited were Friuli Venezia Giulia (Italy), South Karelia (Finland), South Denmark, Scotland, and Attica (Greece).

Drawing on the outcomes of these visits the UAB will produce a report outlining evidence-based recommendations on how to promote a user-centred approach to integrated care design and delivery.



Picture above: SmartCare visit, Trieste, March 15

# A Vibrant Patients' Movement

Communication and daily exchanges with our members is close to EPF's heart. In 2015, we invested much time to make this happen as effectively as possible.



## OUR MEMBERS – OUR COMPASS

EPF is proud of our members' work. Since February 2015, we share their successes and achievements in a dedicated section of our newsletter called "Our members in the Spotlight". This gives EPF members the opportunity to introduce their organisation to the patients' community by answering to five short questions or share important information on their activities.

This year we also tested an innovative format of meetings, the "Patient Comms' Network", bringing together Communications Officers from our member organisations, to work together on ensuring our profile and visibility across the EU institutions.

Because a coffee is worth a thousand emails, EPF continued to offer its members the opportunity to have an informal chat during the "Weekly virtual coffees with EPF". In Brussels or over Skype, this bilateral exchange gives EPF the chance to collect fresh and first-hand information about what our members are doing, enabling us to connect their needs and priorities with what is going on at EU level.

We kept our members updated through our **Weekly Insiders' mailing**. This short but informative email is sent on a weekly basis to ensure EPF members keep up with the latest news from Europe on what really matters for patients: upcoming events, policy developments, EPF consultations, funding opportunities. The feedback from our members has been tremendous!

In 2015 we also published a new Membership guide: with all you need to know to become a member of EPF and to optimise the benefit of your membership.

## CAPACITY BUILDING PROGRAMMES AT EU & NATIONAL LEVEL

2015 showed real advances within the EPF Capacity Building Programme (CBP). New training modules have been launched in participating countries and for our European members. An evaluation was carried out and will prove helpful to strengthen the programme activities and impact.

The CBP aims to support the development of organisational and advocacy skills of national and European patient organisations. In 2015 training modules on fundraising and communication were rolled-out in Bulgaria, Hungary, Romania and Slovakia, and a training module was organised for European members. In Cyprus, we facilitated the development of the first strategic and operational plan of our Cypriot member, the Pancyprian Federation of Patients Associations and Friends.

“  
It is always nice to exchange experiences and help each other out, because we are all trying to achieve great things for our organisations.”

Lore Dupont,  
Flemish Patients' Platform



In March and April an evaluation of the strategic and operational planning modules was carried out. The feedback received paved the way for developing training modules on communication and fundraising. Future training modules will promote a more hands-on practical approach to the training, allowing participants to put into practice the knowledge acquired during the training.

### **SOCIAL MEDIA IS NOT GEEK'S STUFF**

Regarding our training for European organisations, we opted for a resolutely practical module in 2015, with a focus on strategic communications.

Most EPF members are faced with the challenge of building and managing a community of member organisations spread across Europe. Online platforms can be of great help – that is, if you know how to use them!

During a three-day training session, 12 participants worked tirelessly to develop their own project, a social media strategy or the development of an upcoming policy campaign.

Choosing the tool most adapted to the audience, and anticipating the evolution of the platform were some of the key learnings for the participants, who agreed upon the following conclusion: Social media is not geek's stuff!

### **REGIONAL ADVOCACY SEMINAR**

**Stronger ties with the Nordic Countries: some work to accomplish together!**

Our Regional Advocacy Seminar was held on 24-25 November 2015 in Lund, Sweden, and brought together patient leaders from Denmark, Finland, Iceland, Norway and Sweden. The seminar looked specifically at how to strengthen patient involvement in research and policy.

The window of opportunities for patients' involvement in research has never been greater. Raising the awareness of such opportunities and empowering patients with knowledge and confidence in their own expertise are central for patients to make a meaningful contribution in research and policy.

This interactive meeting also allowed for extensive networking between patient leaders from the Nordic countries, initiating a strong and sustainable collaboration between EPF and patient organisations. The full report on the seminar is available on the EPF website.



Picture above: Regional Advocacy Seminar, Lund, November 15



## NATIONAL COALITION BUILDING

National coalitions of patient organisations play a crucial role: they are best placed to monitor, understand and react to the health policies in their respective countries. They are a **vital partner** for EPF. Their expertise on country-specific situations and cascading our messages at national and regional levels is essential.

Supporting the constitution of national coalitions brings great political added value, both for the targeted countries and EPF. Their input supports an effective advocacy, towards a more coordinated and sophisticated work with the Council.

One of the challenges in rallying national coalitions to our movement is the absence, in some countries, of a national alliance of patients' organisations. This is, for example, the case in Slovenia, Portugal or Italy. For this reason, national coalition building is one of our foci in terms of development and growth.

From December 2014 onwards, EPF has undertaken some work to facilitate the creation of a national coalition in Italy, by bringing together about 15 patient organisations together. It is slow and tenacious work but we believe it is crucial and central to EPF's remit to share its experience in countries where a united patient movement is still under development.



**46**  
Weekly Insiders'



**71%**  
opening/total  
membership  
(Weekly Insiders')



**19**  
Weekly Coffees  
with EPF



**1**  
New member



**9**  
Members' events  
attended/spoke



**It's been a fantastic year for the Youth Group. Our members have been very active in strengthening the voice of young patients and we are increasingly gaining recognition within the public health sphere.**

*Polis Stavrou,  
EPF Youth Group,  
International Diabetes  
Federation.*

## EPF YOUTH GROUP

2015 was a truly exceptional year for the EPF Youth Group, with a full programme of activities and appearances that raised the group's profile and provided opportunities for networking, brand development, and capacity building. The Youth Group held their biannual meetings in March (Brussels, Belgium) and September (Bucharest, Romania). Elections were held in September and Aneela Ahmed was elected president, with Cristina Iscu Lacatusu and Polis Stavrou elected as Board Members. With these meetings, the group deals with governance issues while continuing work related to their 2015-2017 work plan, which focuses on discrimination, transition to adult care, and capacity development.

In addition to the biannual group meetings, the Youth Group participated in YO!Fest 2015 in May. YO!Fest is a major youth event sponsored by the European Parliament, and the Youth Group had a stand with games and information to raise awareness about chronic conditions from the perspective of young people.

In July, member Cristian Traicu represented the Youth Group at the EPF Cross-border Healthcare Conference in Brussels. In August, President Aneela Ahmed was featured on BBC News, discussing mental health issues for young patients. Member Martha Carabott was awarded the Coeliac Youth of Europe (CYE) Golden Cookie Award in September for her successful organisation of the Coeliac Youth Summer Camp. In October, member Lembe Kullamaa participated in a patient event at the Estonian Parliament to help parliamentarians experience daily life with rheumatic diseases.

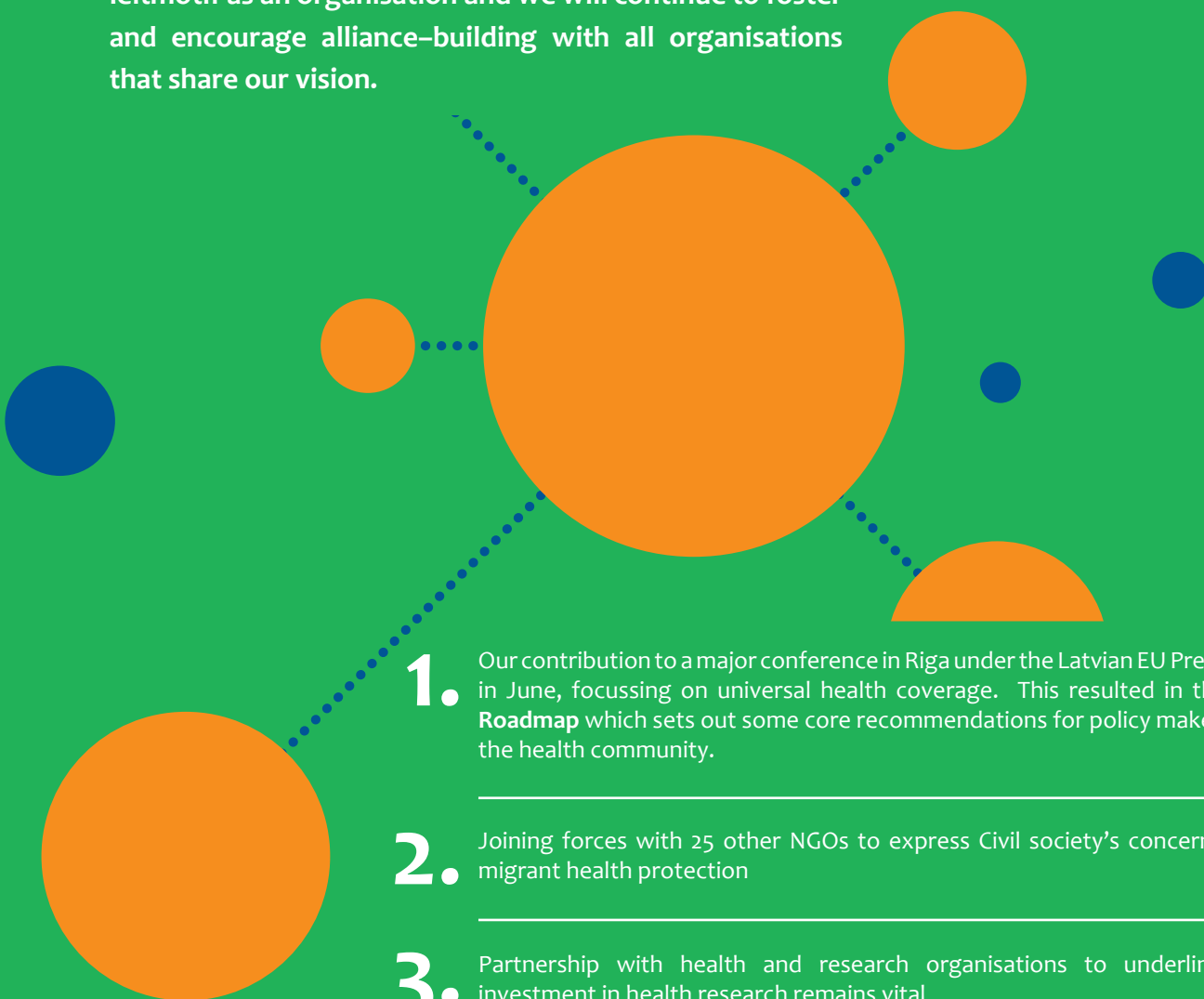
The group finished the year by welcoming new member Anna Zaghi from Italy. Recruitment for the Youth Group is a continuing priority, as the group seeks to find new members from unrepresented Member States. After a year of phenomenal growth and success, the EPF Youth Group is ready for even more new challenges and opportunities in 2016!



Picture above: EPF Youth Group, Annual Meeting, Bucharest, September 15

# Alliance Building

During 2015, EPF continued to consolidate and grow our partnerships with many different organisations both within the EU health sector, and beyond, in the spirit of health in all policies. Partnership continues to be our leitmotif as an organisation and we will continue to foster and encourage alliance-building with all organisations that share our vision.



1. Our contribution to a major conference in Riga under the Latvian EU Presidency in June, focussing on universal health coverage. This resulted in the **Riga Roadmap** which sets out some core recommendations for policy makers, and the health community.

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2. Joining forces with 25 other NGOs to express Civil society's concern about migrant health protection

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3. Partnership with health and research organisations to underline why investment in health research remains vital

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4. Enhanced cooperation with **WHO** by attending the 65th Regional Committee for Europe (September, Vilnius), presenting our perspective on making progress towards a sustainable health workforce in the WHO Europe Region, and introducing priorities for health systems strengthening in the WHO Europe Region. This was followed up by a high level experts meeting on large scale health systems transformation in Madrid in December.

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5. The launch of the Patient Access Partnership, PACT and interest group on access to healthcare took place in January 2015. 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.

# Secretariat & Governance

## Meet our Board



**Anders Olason**  
President  
Eurordis



**Susanna Palkonen**  
Vice President  
European Federation of Allergy  
and Airways Diseases Patients  
Associations



**Marco Greco**  
Interim Treasurer  
European Federation of  
Crohn's and Ulcerative  
Colitis Associations



**Stanimir Hasurdjiev**  
Bulgarian National Patients'  
Organization



**Robert Andrew Johnstone**  
National Voices



**Radu Costin Ganescu**  
Coalition of  
Organisations for  
Patients with Chronic  
Conditions of Romania



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



**Brian West**  
European AIDS Treatment  
Group

## FORMER BOARD MEMBERS

**Vida Augustiniene**  
Council of Representatives  
of Patients' Organisations of  
Lithuania

**Pedro Montelano**  
GAMIAN Europe



# EPF Secretariat



**New position**

**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



**New position**

**Camille Bullo**  
**Membership and Stakeholders Relations Manager**  
Membership Engagement & Growth, Capacity-Building Modules, Cooperation with EPF Partners



**New position**

**Danielle Flores**  
**Junior Project Officer**  
EUPATI, Youth Group, Projects Coordination



**Zilvinas Galvenas**  
**IT Manager**  
IT Coordination, Servers Maintenance, Web Solutions



**New position**

**Kaisa Immonen-Charalambous**  
**Director of Policy**  
Strategic & Policy Agenda, EU Institutions & Stakeholders, Patient Empowerment, Patient Safety, Quality of Care & Cross-Border Healthcare



**New position**

**Laurène Souchet**  
**Policy Adviser**  
Policy & Advocacy, Strategy on Access, Policy Advisory Group & Working Group on Access



**Valentina Stramiello**  
**Programme Officer**  
Horizon 2020, Health Technology Assessment, Youth Group



**Welcome!**

**Valentina Stylianou**  
**Communications Assistant**  
Patient Empowerment Campaign, Social Media, Content



**Véronique Tarasovici**  
**Office and Events Manager**  
HR, Events, Finance task force



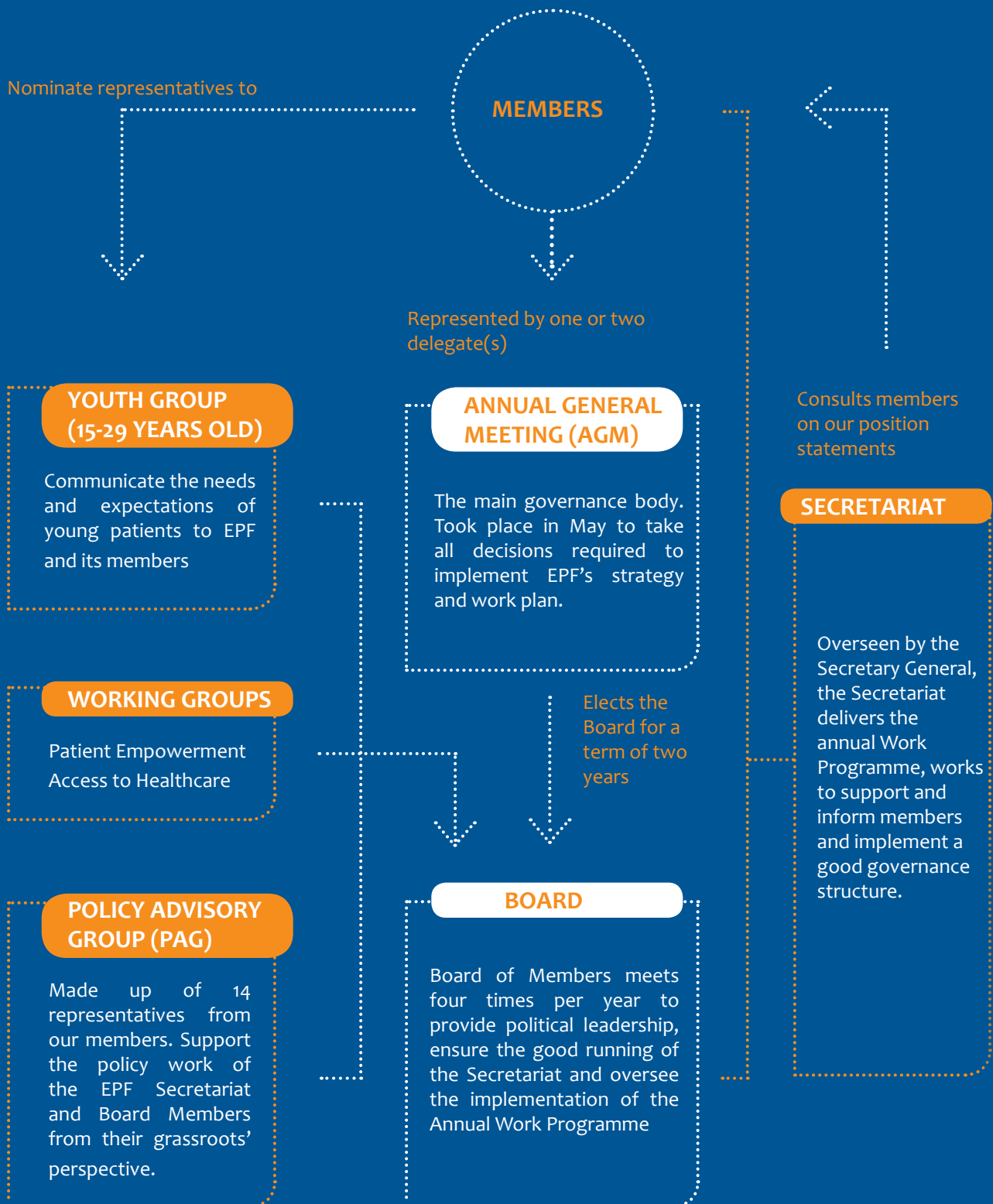
**Welcome!**

**Stefano Tironi**  
**Finance Officer and Assistant to the Secretary General**  
Financial matters, Assistant to Secretary General, EUPATI & PACT

## GOOD BYE, THANK YOU AND ALL THE BEST

Cynthia Bonsignore (Communications Officer), Stefania Laferte (Assistant to the Secretary General and Office Manager), Cristina Padeanu (Project Officer), Liuska Sanna (Programme Manager), Anke Seidler (Head of Office).

# Governance



The report is available on our website



## COMMITMENT TO LEARNING – EVALUATION

Inherent to its commitment to learn and progress as an organisation, EPF called for an independent consultant to run the **external evaluation** of the delivery of its work programme for 2015.

Focusing on EPF's activities in Cross-border Healthcare, its Working Group Empowerment, the Youth Group and finally the Regional Advocacy Seminars, the evaluator assessed the quality and consistency of EPF's actions in 2015. The overall conclusions of the report state the successful delivery of the EPF work programme for 2015. It appeared from the interviews run by the evaluator that the work undertaken by EPF is much appreciated by the participants. The report also underlines the high level of supervision and follow-up of the individual actions.

To further improve the delivery of the work programme, the evaluator recommends EPF to better communicate on the results of its actions' follow-up, as well as fine-tuning the information provided to patient representatives when attending an EPF event for the first time. It was also recommended to enhance the national capacity building experiences, and to mainstream the unique vision of the Youth Group in EPF activities. Besides the external evaluation of its work programme for 2015, EPF has voluntarily run an **internal assessment** of its activities related to the Capacity Building Programme of its national members.

The findings show that most participating organisations have achieved some important milestones in the development of their organisational capacity. These are likely to benefit not only representatives and participating organisations but also partner organisations and coalition members in the long-term.

It was recommended that EPF should take into consideration the capacity and resources of the participating organisations to strike a better balance between achieving meaningful results and what is realistic for the organisations. This would not only contribute to increase quantitative and qualitative input during the training but also strengthen the implementation of the activities.



# Accounts & Audit Report

## **CONTRACTUAL AUDITOR'S REPORT TO THE BOARD OF DIRECTORS OF THE ASBL OF EUROPEAN PATIENTS' FORUM ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED DECEMBER 31, 2015**

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

This report contains our opinion on the financial statements as December 31, 2015, 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 Patients' Forum ASBL, which show a balance sheet total of **1.524.677 EUR** and a result of profit for the year of **112.886 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, 2015, in Belgium applicable accounting standards.

**Registered Auditors Represented by Jean-François 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



# Financials

## Income & Expenditure

INCOME	2015 (€)	2014 (€)
<b>Funding from Public Sector</b>	<b>1,087,670.21</b>	<b>1,047,894.54</b>
Operational Work Programme (Chafea Operating Grant 80%)	728,212.00	653,966.00
EU projects	97,060.59	164,180.54
EUPATI (IMI JU contribution)	262,397.62	229,748.00
<b>Funding from the private sector</b>	<b>705,331.95</b>	<b>502,035.06</b>
Operational Work Programme (co-funding of Chafea's Operating Grant, 19%)	171,000.00	156,500.00
Co-funding to EPF projects	49,595.65	145,815.06
Project developments and other costs	248,011.24	-
Capacity Building Programme	141,282.34	120,943.00
Contribution to EPF Campaigns	34,586.61	-
EFPIA contribution within EUPATI	60,856.11	78,777.00
<b>Foundations</b>	<b>125,000.00</b>	<b>-</b>
R. Bosch Foundation grant for the Empowerment Campaign	125,000.00	-
<b>Membership fees</b>	<b>15,132.31</b>	<b>14,650.00</b>
Operational Work Programme (co-funding of Chafea's Operating Grant 1%)	11,000.00	11,000.00
Contribution to EU projects	4,132.31	3,650.00
<b>Interests and other income</b>	<b>18,070.02</b>	<b>29,182.21</b>
<b>Total Incomes</b>	<b>1,951,204.49</b>	<b>1,593,783.24</b>
EXPENDITURES	2015 (€)	2014 (€)
Staff Costs (including EUPATI staff)	966,587.13	975,018.51
Office and admin costs	176,220.78	169,334.61
Depreciation	14,239.39	18,898.00
Travel and subsistence (EPF staff)	58,645.98	53,816.67
<b>Events</b>	<b>512,051.69</b>	<b>271,183.77</b>
Annual General Meeting (AGM)	41,664.34	61,574.14
Regional Advocacy Seminar (RAS)	35,909.49	-
Youth meetings	13,759.07	8,265.46
Patient evidence workshop	-	12,227.24
Capacity Building Programme (delivery of training modules)	105,773.27	108,356.75
Cross-border healthcare regional events and conference	79,089.36	80,760.18
<b>Other costs linked to operations &amp; development of new projects</b>	<b>235,856.16</b>	<b>-</b>
<b>EPF Campaigns</b>	<b>112,841.21</b>	<b>106,186.38</b>
<b>Bank and Financial Charges</b>	<b>645.55</b>	<b>1,195.95</b>
<b>TOTAL Expenditure</b>	<b>1,841,231.73</b>	<b>1,595,633.89</b>
<b>Surplus or deficit of the Year Operating Grant</b>	<b>- 2,913.91</b>	<b>- 1,900.65</b>
<b>Total Surplus or deficit of the Year</b>	<b>112,886.67</b>	<b>- 1,900.65</b>

# 2015 Accounts & Acknowledgment

EPF wishes to thank the European Commission for its support in 2015 in relation to EPF's role in the following projects		
	EC Contribution used in 2015	% of total income
Adapt Smart	11,693.07 €	0.6%
Joint Action CHRODIS	19,600.00 €	1.1%
Joint Action PASQ	18,680.02 €	1.0%
SmartCare	6,551.93 €	0.4%
We Care	18,934.51 €	1.0%
PISCE Self Care Tender	21,601.06 €	1.2%
<b>TOTAL European Commission support to projects</b>	<b>97,060.59 €</b>	<b>5.2%</b>
EPF wishes to thank the following donors for their support:		
	Contribution to the OG	% of total income
<b>Operational work programme</b>	<b>910,312.00 €</b>	
European Commission	728,212.00 €	39.1%
Almirall	20,000.00 €	1.1%
Baxter	10,000.00 €	0.5%
Gilead	20,000.00 €	1.1%
GSK	30,000.00 €	1.6%
MSD	16,100.00 €	0.9%
Pfizer	20,000.00 €	1.1%
F. Hoffmann-La Roche	15,000.00 €	0.8%
Sanofi Pasteur MSD	20,000.00 €	1.1%
TEVA	20,000.00 €	1.1%
Membership	11,000.00 €	0.6%
<b>Capacity Building Programme</b>	<b>165,000.00 €</b>	
Biogen Idec	20,000.00 €	1.1%
GSK	30,000.00 €	1.6%
Janssen	30,000.00 €	1.6%
Lilly	15,000.00 €	0.8%
Novartis	35,000.00 €	1.9%
Philips	25,000.00 €	1.3%
Sandoz	10,000.00 €	0.5%
<b>Empowerment Campaign</b>	<b>170,000.00 €</b>	
Amgen	15,000.00 €	0.8%
Bosch Foundation	125,000.00 €	6.7%
GSK	30,000.00 €	1.6%
<b>Project Portfolio</b>	<b>173,900.00 €</b>	
Abbvie	25,000.00 €	1.3%
Amgen	35,000.00 €	1.9%
CSL Behring	10,000.00 €	0.5%
Grünenthal	10,000.00 €	0.5%
Hospira Benelux BVBA	25,000.00 €	1.3%
MSD	13,900.00 €	0.7%
Sanofi-Aventis	40,000.00 €	2.1%
Servier	10,000.00 €	0.5%
Shire	5,000.00 €	0.3%
<b>The European Patients' Academy on Therapeutic Innovation Public Private Partnership (EUPATI)</b>	<b>323,253.73 €</b>	
Innovative Medicine Initiative (IMI JU) contribution	262,397.62 €	14.1%
Industry consortium (Hoffman L a Roche, Genzyme, Boehringer, VFA, GSK, AMGEN, ESTVE, Novonordis, Pfizer, S.A. Eli Lilly, Novartis, Astra Zeneca, Bayer, UCB, CHIESI, Janssen, Merck)	60,856.11 €	3.3%
<b>Memberships and other income</b>	<b>€ 22,202.33</b>	<b>1.2%</b>
Total Income	1,861,728.65 €	100.0%
Accrual and deferrals	89,475.84 €	
<b>Total Income net of adjustments</b>	<b>1,951,204.49 €</b>	

# Membership

## 47

Full Members

## 16

Associate Members

### 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)  
 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)  
 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)  
 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)

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## ASSOCIATE MEMBERS

AMRC - Association of Medical Research Charities  
(United Kingdom)

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)

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)

New Member

WFIP - World Federation of Incontinent Patients  
(International)\*

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









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