

A
STRONG
PATIENTS'
VOICE
TO DRIVE
BETTER
HEALTH
IN EUROPE



2014
ANNUAL REPORT





Welcome to the European Patients' Forum 2014 report! We are delighted to present some of our main achievements of the year, which have contributed to driving better healthcare for the European patients' community.

2014 was a year of active engagement for patients. The European Elections were the first to be held under the Lisbon Treaty, which enhances the role of the EU citizen as a political actor in the EU. We, together with many millions of Europeans, made our voices heard in May.

The year also marked a turning point in our work on the implementation of our 2014-2020 Strategic Plan. We have applied a thematic approach to our work, clustering our activities around two themes – patient empowerment and access to healthcare – and consolidated this with the launch of two members' working groups on these topics. Alongside these two content-related themes we will continue our focus on building strong and inclusive patients' organisations, and on capacity building.

On the legislative front, our policy priorities in 2014 addressed a number of key areas that reflect our vision as an organisation, including patient-centred, sustainable health systems; patient-centred innovation; tackling health inequalities from a patient's perspective and ensuring equitable access to high-quality, safe healthcare. More intensive and very effective work took place on complex dossiers such as clinical trials, medical devices, and data protection.

The emphasis in 2014 was very much on our work to promote effective implementation of legislation through our Regional Conferences around the Cross-Border Healthcare Directive.

We are proud that patient leaders from 20 European countries now better understand the details and the scope of this text. We will continue this effort in 2015 with mini-workshops organised in eight countries not covered by the previous events.

Major projects finished this year – Renewing Health, SUSTAINS and InterQuality – with major outcomes for patients. We also launched the EUPATI Expert Training Course, an exciting and unique opportunity offering patients and patients' advocates expert-level training in medical research and development. We reached a key milestone in our Capacity Building Programme with training in fundraising organised for our European members, and with Cyprus being the fifth country to join our Programme in 2014 after Bulgaria, Hungary, Romania and Slovakia.

We would like to take this opportunity to thank all our campaign signers and ambassadors for their unceasing support throughout our campaign and look forward to working with them in the coming years. We wish especially to express our gratitude to the outgoing Health Commissioner Tonio Borg and former MEP Dagmar Roth-Behrendt (S&D, Germany) for their exceptional support throughout our campaign. Finally, we look forward to working together with our health allies throughout Europe.



EPF President
Anders Olason



EPF Secretary General
Nicola Bedlington



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A GLANCE INTO 2014

EPF's operational objectives for 2014 were threefold:

- **OBJECTIVE 1:** Reinforcing the capacity of patient community actors to effectively contribute to the health debate;
- **OBJECTIVE 2:** Strengthening the evidence base, recognition and impact of the patient perspective in health-related policy and decision-making;
- **OBJECTIVE 3:** Reinforcing cross-fertilisation between evidence obtained from projects and policy work.

January

We unveiled our seven-year strategic plan, defining non-discrimination as one of our main goals. This month also marked the official launch of the new Joint Action on Chronic Diseases (see page 19).

February

The Commission Patient Safety and Quality of Care Working Group, of which EPF is a member, met in February to discuss the 2014 agenda. EPF accomplished a great deal in this area this year, with the inclusion of several patients' provisions to the Council of the EU's conclusions, which were adopted in December (see page 16).

August

We reached a key milestone in our Capacity Building Programme with a training session on fundraising for our European members. Cyprus, after an ad-hoc request by our member the Pancyprian Federation of Patients Associations and Friends, was the fifth country to join our Programme in 2014 after Bulgaria, Hungary, Romania and Slovakia (see page 21).

July

Our Patient Academy EUPATI held a major workshop in July, which laid the foundations for expert-level engagement in medical research and development (see page 21) at the beginning of Italy's Presidency of the Council of the European Union.

September

September brought a focus on youth and self-management to EPF. Our Youth Group held its annual meeting (see page 23) and we got involved in the PISCE 16-month project (see page 20).


October

We were active at over 70 different health-related events in 2014, and we were particularly well represented at the 17th Conference of the European Health Forum Gastein (see page 18). We also closed our series of four regional conferences on Cross-Border Healthcare with one last event in Estonia. Patient leaders from 20 European countries now better understand the details and the scope of the Directive (see page 15).

EPF communications at a glance:

 **2935** likes

 **1535** followers & **709** uses of **#patientsvote**

 Website visited **35894** times
136236 page views

 **4017** readers/month

Once again in 2014 an external evaluator was commissioned to evaluate our work, focusing in particular on our initiatives on cross border healthcare and our election campaign.

Ongoing evaluation is intrinsic to our development in order to assess our impact in the wider political dimension and also help us deliver future campaigns that mobilise the patients' community.

March

EPF was a key partner in the European Network on Patient Empowerment (ENOPE) Conference, "The power of patients 3.0." in March (see page 19). Patient empowerment was also at the centre of the EMPATHIE tender "EMpowering PATients in the management of chronic diseases", which ended in September (see page 19).

April

April was a month for projects. With the WeCare project, we played a core advisory role to ensure patients' involvement (see page 17), and we saw the closure of the InterQuality project (see page 17), which investigated the effects of financing systems on the quality of healthcare.

June

Healthy ageing was in the spotlight at the Uppsala Health Summit in June and we took this opportunity to reiterate our position on the rights and needs of older patients. The Clinical Trials Regulation entered into force in June, and we focused on its implementation in the latter part of the year; in particular on transparency measures, and guidelines regarding how to create explanatory summaries for non-experts (see page 13).

May

May was a busy month for the patients' community. We convened with our members at our Annual General Meeting (see page 28) to elect our new Board and five new members, taking our membership to 64 European and national patients' groups (see page 28). Alongside the AGM, we launched two new EPF working groups on patient empowerment (see page 18) and patient access to healthcare (see page 10) respectively.

November

In November we achieved important goals in the field of Medical Devices towards ensuring safer devices and more transparency, as well as sending recommendations to the Council on the Regulation on In Vitro Diagnostics.

December

We were the driving force behind the Patient Access Partnership established formally in late 2014 to tackle the unacceptable inequities facing Europe's patients (see page 11). We closed the year with the launch of the Data Protection campaign, run jointly with various stakeholders (see page 13).

EPF was also involved in the following projects in 2014: SUSTAINS (see page 24), AdoptHTA (see page 25), the eHealth Governance Initiative (see page 24), the second Joint Action of Health Technology Assessment EUnetHTA (see page 25) and Smartcare (see page 25).

OUR VOTE FOR A HEALTHIER EUROPE

On 22-25 May 2014, EU citizens elected the new European Parliament (EP), comprising 751 members (MEPs) to represent their interests for the next five years. For the first time, elected political parties nominated their candidates as “Spitzenkandidaten” for President of the Commission.



As the EP is the only directly elected European Institution, this was a unique opportunity for us

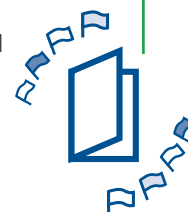
to express what patients expect from EU policy-makers. We encouraged candidates to commit to including the patient perspective in their agendas.

Entitled “Patients + Participation = Our Vote for a Healthier Europe”, our campaign focused on four main areas: patients’ collective engagement, patient empowerment, patient access to healthcare and patient involvement in decision-making and research.



The campaign in figures:

- Out of the **75** candidates who supported our Manifesto, **34** were re-elected and are committed to ensuring that patients have the right place on the European healthcare agenda.
- We developed a Campaign Manifesto that was translated into the **24** EU languages thanks to our members and printed in five language versions.
- The campaign hashtag **#patientsvote** was used **709** times and trended on the screen during the 5 May 2014 Presidential debate.
- EPF produced six campaign videos, one of which was translated into **15** EU languages and a total of **25.666** views were counted for all of them!



**What MEPs
said** about
our campaign



EPF President Anders Olason and MEP Dagmar Roth-Behrendt; EPF Exhibition, European Parliament, March 2014

The campaign from the point of view of **Members of the European Parliament:**



"We have to give patients the opportunity to help improve healthcare systems because it is not only good for patients but also for healthcare."

MEP Karin Kadenbach (S&D, Austria)



"Patients are not passive individuals to whom things happen; they're active people. They are people who are actively – should be actively – engaged within determining their own healthcare."

MEP Jean Lambert (Greens-EFA, UK)

"I have been very active in promoting health and prevention since my first election to the EP (2004). I will continue in the same spirit in the next legislature – for more and better health for all EU citizens."

MEP Alojz Peterle (EPP, Slovenia)

"The opinions and experience of chronic disease patients must become the key ideas in defining policies that are dedicated to them. Patients are the ones who know best what works for them and what doesn't."

MEP Nathalie Griesbeck (ALDE, France)



While the 2014 Elections Campaign has been a success thus far, we look forward to building further on the work we have done to continue establishing a strong patient voice and driving forward better health in Europe over the next five years.



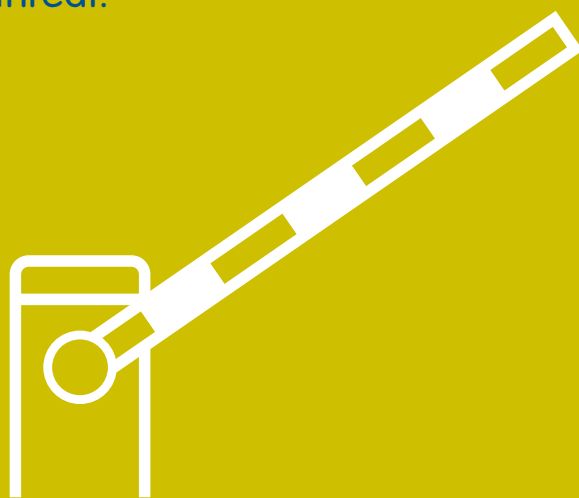
MEP Heinz K. Becker; MEP Nessa Childers; MEP Petru Luhan; Professor Ilona Kickbusch and Philip Chircop; MEP Andrey Kovatchev; EPF Exhibition, European Parliament, March 2014



We wish to warmly thank the informal advisory group involving leading experts from a number of agencies who regularly advise EPF Secretariat on our campaign strategy and support where possible on implementation on a pro bono basis.

BREAKING DOWN ACCESS BARRIERS

The economic crisis has strongly affected our society. It has put health systems under severe pressure while they already have to cope with a growing demand for healthcare due to demographic changes. Access to quality healthcare, whilst being a basic EU citizen's right¹, has never been under such threat.



Access to healthcare is one of the key areas of focus chosen by our members. A working group on access was established in 2014 to shape our activities in this area from the patients' perspective, but it will also build our evidence base on health access and inequalities, and contribute to putting access higher on the political agenda.

EQUAL ACCESS TO HEALTHCARE

Equitable access to high-quality healthcare for all patients is our core value and it informs our policy work on health and social inequalities.

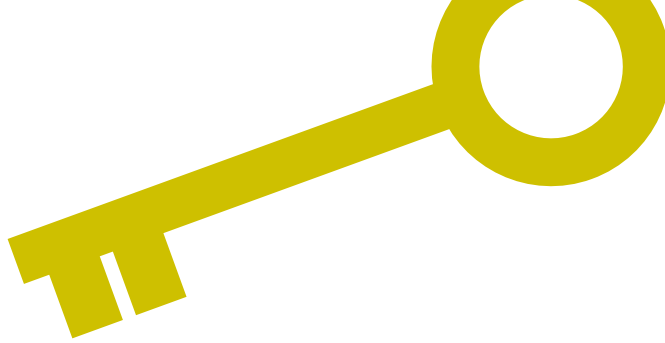
As a representative organisation of patients with chronic illnesses and their families, we focus on chronic disease as a factor leading to these inequalities.

EU Elections Campaign

Equal access to healthcare was one of the four key messages of our campaign's manifesto for the 2014 EU Elections. We asked politicians to break down access barriers, as all patients in the EU deserve equitable access to care.

Ensuring care is available and affordable is also good for the sustainability of health systems.

¹ Charter of Fundamental Rights of the European Union, article 35.



If patients do not get the care they need at the right time, they are at risk of developing more severe illness, reducing their capacity to live a full and productive life and increasing health, social and economic costs.

Universal access

We partnered with EPHA (European Public Health Alliance), EGA (European Generic medicines Association), and AIM (Association International des Mutualités) in April to



address universal access to health as a priority of the forthcoming European Parliament in a joint event. It was hosted by Andrey Kovatchev (EPP, Bulgaria)

and attended by MEP Rebecca Taylor (ALDE, UK) and Angelika Werthmann (ALDE, Austria) who all signed our Manifesto.

Bulgarian public debate

Our Bulgarian member, the National Patients' Organisation (NPO), held a public debate on our 2014 Elections Campaign Manifesto with their national Medical Association in April. Three Bulgarian European Parliament candidates participated in the debate: Antonia Parvanova, Andrey Kovachev and Dragosh Metodiev.

Patient Access Partnership (PACT)

In our campaign we called on EU decision-makers to support an



EU initiative on equitable access to healthcare for all European citizens. Our major focus on health inequalities led us, with our Bulgarian member, NPO, to officially set up the Patient Access Partnership in December. This is an independent patient-led multi-stakeholder partnership that will work on identifying innovative solutions to reduce inequities in access to quality healthcare in Europe.



"The role of patients is not simply to criticise or demand; they have expertise and know the system and the gaps in it. We need to bring all stakeholders together to work on this problem to propose concrete actions with better outcomes for patients."

EPF Board Member
Stanimir Hasurdjiev, NPO



The Partnership's work will be supported at the European Parliament through the MEP Access Interest Group, who will ensure that it is recognised by the European institutions and ranks high on the priority list.

www.eupatientaccess.eu



NON-DISCRIMINATION IN HEALTH

EPF members selected non-discrimination as a critical issue for patients and a core strategic goal for our 2014-2020 Strategic Plan.

Landmark conference

DG SANCO² organised the landmark conference 'Health in Europe, making it fairer' in Brussels in March to address the multiple forms of health and other discrimination faced by patients, as well as the political commitment needed to combat this issue.

"Evidence that there is discrimination in healthcare is compelling and this human rights issue calls for a strong and collective response from the EU."

EPF Board Member **Robert Johnstone**,
National Voices UK

Together with the public health community, we congratulated the previous Health Commissioner Borg on this initiative, which sent a strong message to the Council of Ministers to break the gridlock around the Non-Discrimination Directive that has been blocked since 2008 (see page 26).

Alliance of 10 EU NGOs

EPF, together with nine other European non-governmental organisations, agreed on key demands for the next European Commissioner on Health in September (see page 26). We called on Members of the Environment, Public Health and Food Safety Committee (ENVI Committee) of the European Parliament to take the opportunity of the hearings to convey those demands to the then candidate for the position of Health Commissioner and ensure his commitment to equality in healthcare.

"Healthcare for all" Position paper

We closed the year with a position paper called 'Healthcare for all' released in January 2015. This document, developed in consultation with our members, raises awareness about discrimination patients are still facing today on various grounds, such as age or gender, in healthcare. We provided recommendations to EU decision-makers on how to tackle this challenge effectively.

🔍 www.eu-patient.eu/whatwedo/Policy/Anti-discrimination/

² The European Commission is to revamp DG SANCO, the directorate general dealing with food safety and other regulatory issues in 2015, notably with a name change to DG Santé – the French word for 'health' – and a new role in dealing with food waste.



DATA PROTECTION

In March the European Parliament adopted a first reading position for stricter rules on patient consent for research. If adopted as such, this regulation could harm health research by creating an obligation to seek specific consent from patients when identifiable personal health data is used, with only few possibilities for exemption.

"New treatments are only going to come from medical research and the use of patient data will play a crucial role in this."

Nick Meade of the Patients' Network for Medical Research and Health (EGAN)

EPF joined the 'European Data in Health Research Alliance' that was officially set up in December. This coalition brings together academic, patient and research organisations from across Europe to ensure decision-makers understand the importance of having data protection rules that facilitate research. It also demonstrates that patients and researchers have the same concerns and are united on this question.

www.eu-patient.eu/whatwedo/Policy/Data-Protection/



CLINICAL TRIALS

The new EU Clinical Trials Regulation entered into force on 16 June 2014. EPF welcomed the new law for its many positive aspects, such as the adoption of a single submission through an electronic EU portal, and coordinated assessment for a more streamlined and efficient assessment of trials.

Other important improvements include more specific requirements for informed consent of patients, and greater transparency around trial results. With regard to the involvement of patients in ethics committees, the final text was watered down but we will continue to advocate strongly for patient involvement as Member States now proceed with implementing the Regulation.

In a parallel development, the European Medicines Agency (EMA) adopted its new policy for the release of clinical trial data in October. EPF made a statement to welcome this as a step forward towards greater transparency of the regulatory process on clinical trials.

www.eu-patient.eu/whatwedo/Policy/Clinical-Trials/



MEDICAL DEVICES

In Vitro Diagnostics Medical Devices

In November EPF sent recommendations to the Council on the Regulation on In Vitro Diagnostics Medical Devices.

We asked the Council to keep measures to ensure better information and transparency to patients on in vitro diagnostics devices, as well as measures on clinical performance studies that aim at ensuring better patient involvement in the assessment of the study, particularly in ethics committees.

However we do not support the European Parliament's provisions for mandatory genetic counselling after a genetic condition has been diagnosed. We would welcome instead guidelines, drafted with involvement of healthcare professional societies.

Finally the European Parliament asks for patients to give written consent before a genetic test. EPF believes informed consent is essential but we explained that written consent is not the only valid form of informed consent across Europe.

Medical Devices

In April we welcomed the adoption by the European Parliament of the report on Medical Devices as it ensures safer devices and more transparency, as requested in our 2013 position.

The office of ex-Consumers Affairs

Commissioner Neven Mimica reassured us that patient safety and transparency were well taken into account in the review process.

We urged the Council to give priority to this dossier and ensure patients can benefit from provisions to improve the safety of their devices, availability of information, and a better vigilance system.

MedTech Dialogue

In January, we organised, together with the medical technology (MedTech) industry association, Eucomed, an interactive workshop for an open exchange of views on the EU Medical Devices Directive.

For the first time, we opened a direct dialogue on the IVD Medical Devices Regulation with representatives of the relevant sectors at the 7th MedTech dialogue, which took place in March.

The 8th Patients-MedTech Dialogue meeting, a constructive biannual platform of exchange between patients' organisations and the MedTech industry, took place in October. An important item on the agenda was the release of a patient-centred checklist for companies to better involve patients in the medical devices sector.

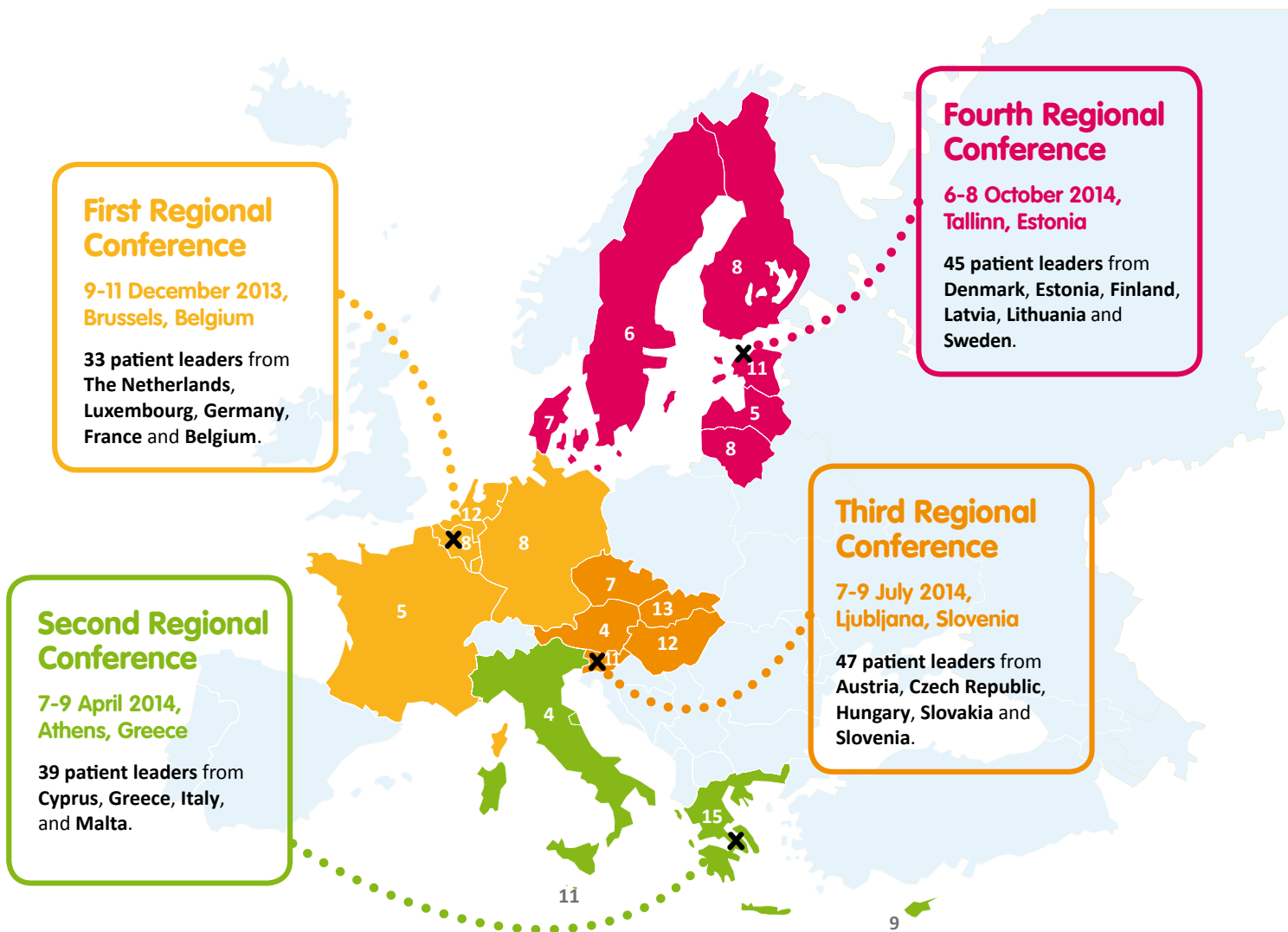
CROSS-BORDER HEALTHCARE

We continued to monitor and support the implementation of the Cross-Border Healthcare Directive with three major regional conferences organised in collaboration with the European Commission. We succeeded in ensuring patient leaders in different regions of Europe are more aware about patients' rights enshrined within this legislation.

As a result of these conferences, we built a network of 134 patient leaders committed to monitoring the implementation of the Directive and its impact on patients, to inform the European Commission's 2015 report.

EPF will continue this work in 2015 with national workshops organised in the eight remaining EU Member States.

www.eu-patient.eu/whatwedo/Policy/Patients-Mobility

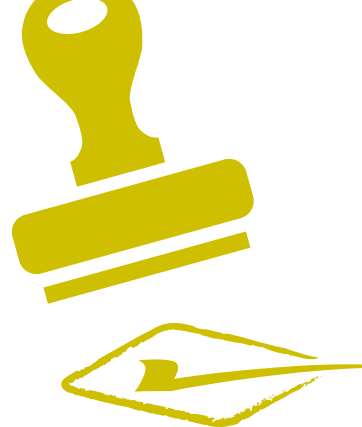


PROMOTING SAFE AND HIGH-QUALITY CARE

EPF accomplished a great deal to promote safe and high-quality holistic care for patients this year.

As a member of the European Commission's Working Group on Patient Safety and Quality of Care, we contributed to the recommendations on reporting and learning systems, and health professionals' education, issued in May. We included specific sections on the role of patients and families, and highlighted the value of patient experience as a learning resource. We also responded to the public consultation on the future EU agenda on patient safety and quality.

In October, the European Commission Expert Panel on Effective Ways of Investing in Health approved the paper "Future EU Agenda on quality of healthcare with a special emphasis on patient safety". EPF contributed to this paper as an external expert and emphasised the importance of patient-centredness as an aspect of quality. Patients' views, preferences and experiences should be used to develop indicators to measure the quality of care.



In December, the Council of the EU adopted conclusions on patient safety and quality of care which EPF welcomed enthusiastically, as we contributed to them through our participation in key high-level meetings during the Italian Presidency. The text encourages national governments and the Commission to promote a patient safety culture, including the participation and empowerment of patients, families and their informal caregivers, as well as patients' organisations.

Nutrition

For many people attaining good nutrition is not a simple question of having good eating habits, especially for some medical conditions that makes it a challenge sometimes.

EPF signed in 2014 a Memorandum of Understanding (MoU) with the European Nutrition for Health Alliance (ENHA) and the European Genetic Alliances Network (EGAN) to express the urgency of these issues for European patients' groups.



PROJECT

ONGOING



Joint Action

April 2012 – March 2016³

This year we also continued our input into the Patient Safety and Quality of Care Joint Action (PaSQ JA), which aims to create a permanent platform for future cooperation between Member States and stakeholders in this area by April 2015.

We provided the patient perspective for the evaluation of the implementation of safe clinical practices in 17 countries. We detailed good practices on the involvement and empowerment of patients. This work will further inform a position paper on patient involvement in patient safety, which we are preparing for 2015. Many of these practices have also been submitted to the PaSQ wiki, a repository of safe practices.

www.pasq.eu

HEALTHCARE FROM THE FINANCIAL SIDE

PROJECT

ONGOING



September 2013 – August 2015⁴

We played a core advisory role in

the series of five workshops organised in 2014 under the We Care project that works

³ The project, funded by the Health Programme of the European Union, was supposed to close in 2015 and was finally granted one more year with no cost extension by the Consumers, Health, Agriculture and Food Executive Agency.

⁴ Funded by the Seventh Framework Programme for Research and Technological Development (FP7).

PROJECT

COMPLETED



December 2010 – April 2014⁴

Starting in December 2010, the InterQuality

project investigated the effects of financing systems on the quality of healthcare. The four-year research project closed in April with the provision of useful input for European countries. It helps them to choose the right financing mechanisms in different areas of their healthcare systems, according to their needs and resources, and to pay not more, but smarter.

www.interqualityproject.eu



EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY

Empowerment was central to our EU Election Campaign's Manifesto as we called on decision-makers to adopt an EU Strategy on this topic, including an action plan on health literacy and high-quality information for patients on all aspects of our care.



Our EP election campaign's prominence and success both at EU level and in the Member States created an ideal backdrop for future actions. The EMPATHIE study (See page 19), in September, provided compelling recommendations for EU action on patient empowerment. We have therefore decided to lead a major campaign and conference in 2015 to take the European discussions a crucial next step forward.

European Health Forum Gastein

The 17th European Health Forum Gastein held in October in Austria was themed "Electing health – The Europe we want!" We took this opportunity to promote our campaign and

reiterate some important messages, specifically on patient empowerment and patient access to quality healthcare, leading a session on this, as well as patient involvement in research and decision-making. We also spoke at a session on personalised medicine, where we represented the patient perspective, and collaborated with our information stakeholder group on a session dedicated to health literacy.

We also highlighted the importance of equality of access to quality care and empowering choice with accessible information in a panel on freedom of choice to care organised by the Austrian Ministry of Health and European Observatory of Health Systems and Policies.



Many patient representatives were present at this important health policy event where we sit on the steering group, and not just in the 'patient-focused' sessions. This was the first time, for instance, that patient representatives took part in the Young Gasteiner programme.

CAREUM Congress/2nd ENOPE Conference

The March Careum Congress entitled "The power of patients 3.0" explored ways to engage patients in future healthcare systems. This event was also the second conference of the European Network on Patient Empowerment (ENOPE), of which EPF is a member. EPF organised a dedicated session on patient involvement and empowerment in research, and collaborated with the International Alliance of Patients' Organizations (IAPO) in a session about patients' organisations.

Patients' Rights Day – 18th April

EPF supports continued efforts by Active Citizenship Network towards the Institutionalisation of the Patients' Rights Day. It complements our work, together with our members on advancing patients' rights. We believe that activities surrounding the Day should be driven by patients' organisations and reflect our values, to achieve the best possible momentum.

EMPOWERING PATIENTS IN CHRONIC DISEASE MANAGEMENT

PROJECT

COMPLETED



EMPATHiE

December 2013 –
September 2014⁵

We played a prominent role in the study 'Empowering patients in the management of chronic diseases' (EMPATHiE). Requested by the European Commission, this research project achieved a common understanding of the concept of patient empowerment and identified good practices, success factors and barriers. EPF led a work package on future scenarios for EU collaboration, which made a number of concrete proposals on key areas: information and health literacy, professional training, self-management with technology and transparency of healthcare quality.

PROJECT

NEW



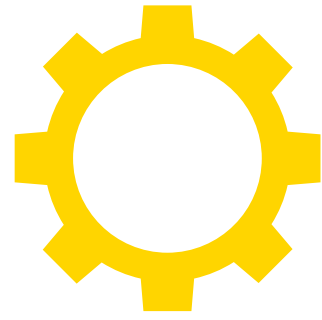
CHRODIS

January 2014 –
March 2017⁶

January marked the official launch of the new Joint Action on Chronic Diseases, named 'EU Joint Action on Chronic Diseases and Promoting Healthy Ageing Across the Life Cycle' or JA-CHRODIS. EPF, as a partner in this collaboration, provides the patient perspective to identify and promote best practices in the management

⁵ Funded by the Executive Agency for Health and Consumers (EAHC), part of the European Commission.

⁶ Co-funded by the Health programme of the European Union.



of chronic conditions, building around the ‘reflection process on chronic diseases’ initiated by the European Commission and member states, in which we have been strongly involved.

www.chrodis.eu

Chronic Disease Summit

EPF participated in the April Chronic Disease Summit organised by the European Commission’s DG SANCO. The event aimed at developing a set of policy recommendations for action on how the medical, social and economic burden of chronic diseases should be tackled in the European Union now and in years to come.

SELF-CARE

PROJECT

PISCE September 2014 – December 2015⁷

Since September, EPF has been involved in a brand new 16-month pilot project on the ‘promotion of Self-Care systems in the European Union’ called PISCE. Self-care is gaining considerable attention in the healthcare field, as patients are gradually taking a new and more active role in their own healthcare.

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This action will create a platform of experts in self-care and develop strategies to support its broader implementation.

BUILDING PATIENTS’ CAPACITY

EPF Capacity Building Programme

The EPF Capacity Building Programme (CBP) is going from strength to strength. Launched in 2012, this EPF-led initiative supports the development of organisational capacities and advocacy skills of our members and their own affiliates.

European members started building knowledge on how to diversify funding and create viable financial structures in August. This training phase will close with the development of a toolkit on this topic in 2015.

“Fundraising is a core issue at the European Parkinson’s Disease Association, but being a European umbrella organisation means we cannot access ‘traditional’ funding channels which are available to national-based patients’ organisations.”

Francesco De Renzis,
Fundraising Officer at EPDA

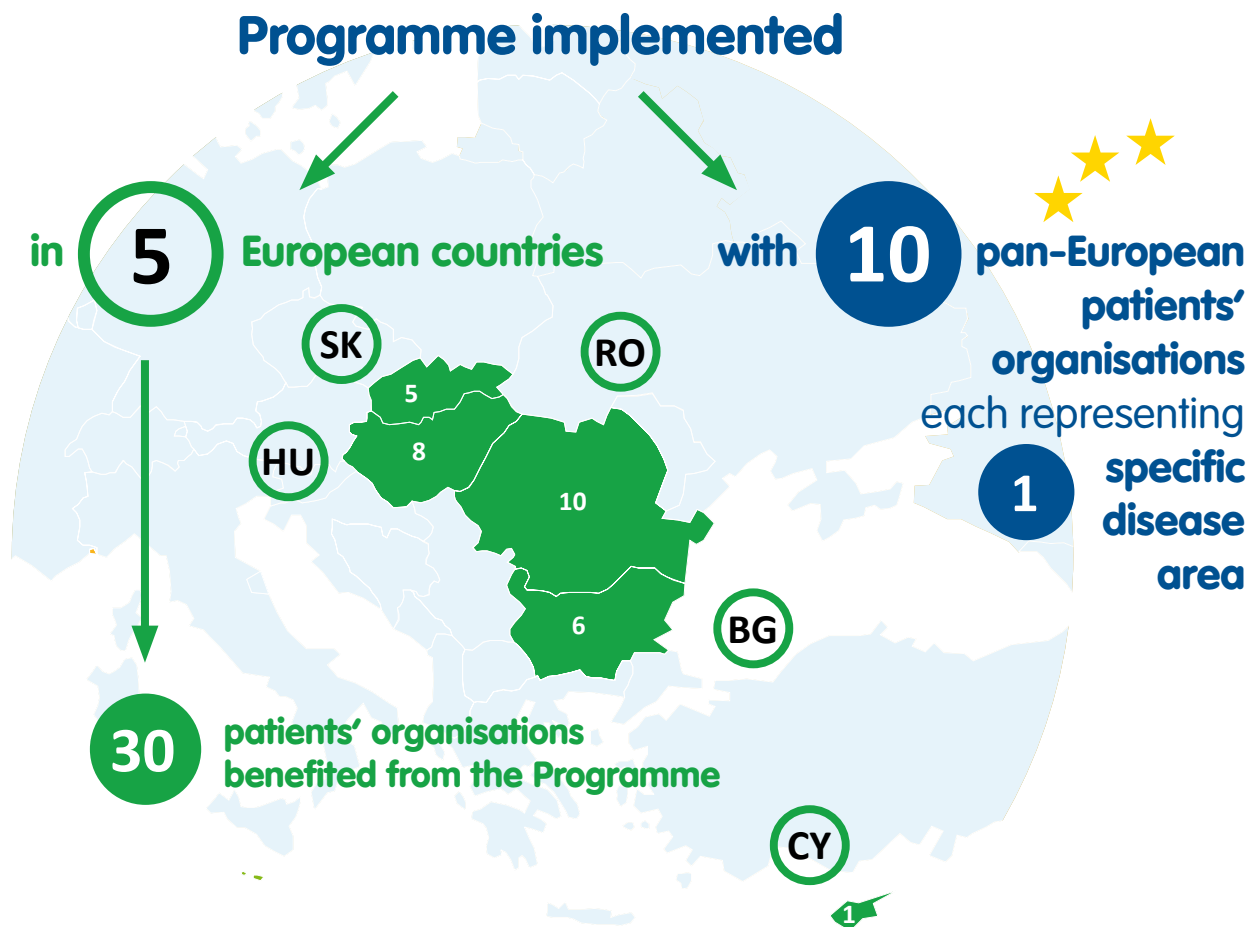
⁷ Tender project (reference: EAH/2013/D2/027) financed by the European Commission’s Directorate-General for health and consumers (DG SANCO).

Slovakia and Bulgaria entered the first phase of the Programme in early 2014. At this stage, they learned about strategic planning and how to assess their organisational capacity.

Romania and Hungary participated in the second phase of the Programme. Much more implementation-oriented, this level addresses operational planning. We undertook an evaluation of the first two phases of the Programme in these two countries and we

prepared for the next phase which will focus on training for fundraising.

We started supporting our Cypriot member (the Pancyprian Federation of Patients Associations and Friends) in November, helping them develop their very first strategic plan as a step towards raising their profile as an equal partner in the national debate around health issues.





"Currently patients in Cyprus face many challenges. With the EPF programme, we strongly believe that the voice of the patients will be heard and that policy-makers will act in order to influence the policies and the strategies for health."

Marios Kouloumas, President of the Pancyprian Federation of Patients Associations and Friends

expert-level training on medicines R&D, specifically tailored for them. The Course consists of a mixture of online and face-to-face education modules over a 15-month period.

"The course makes you understand the very basics of medicine development. Besides being user-friendly, the online format allows me to study whenever I feel like it. For a lot of patients it is hard to follow regular classes, because unexpected hospital visits are part of our life. This course fits around my schedule, instead of the other way around."

Kate Sparkles, The Netherlands

PROJECT

ONGOING



February 2012 –
January 2017⁸

Our European
Patients' Academy on

Therapeutic Innovation (EUPATI) has moved into a particularly exciting phase, with a focus on education, content development and the establishment of National Platforms. This patient-led academy has been set up to develop and deliver educational material, training courses and a public internet library to educate patient advocates and the health-interested public about all processes involved in medicines Research and Development (R&D).

The first round of the EUPATI Expert Training Course started in October as a unique opportunity for patient advocates to receive

EUPATI is preparing for the longer term with the creation of National Platforms in each of the 12 participating countries. Three national teams were created in 2014: UK in March Ireland in September and Spain in November. Events were held to promote National Platform formation in the German-speaking region of Switzerland and in Luxembourg in December.

www.patientsacademy.eu

⁸ Funded by the Innovative Medicines Initiative (IMI), a public private partnership between the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA).



EPF Youth Group, EMPATHY Seminar, Brussels, Belgium, July 2013

EMPOWERMENT OF SPECIFIC GROUPS

Older patients

We promoted our position paper on the needs and rights of older people with chronic diseases at the Uppsala Health Summit in June on "Healthcare for Healthy Ageing". The European Union has given increased attention to this issue over the last few years, notably through the European Innovation Partnership on Active and Healthy Ageing.

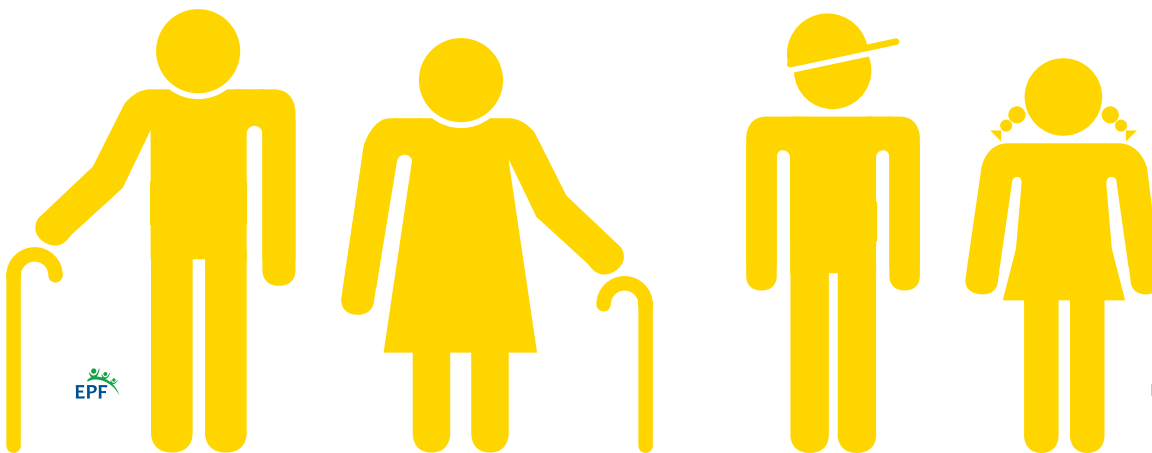
We believe, however, that more actions from decision-makers are necessary to ensure the empowerment of older patients and their full participation in society. Our paper highlights important flaws that have been identified by patients' organisations and provides recommendations for the EU institutions, Member States, and health stakeholders.

www.eu-patient.eu/whatwedo/Policy/Ageing

Youth Group

The EPF Youth Group held its 4th Annual Meeting in September in Brussels. The young patient representatives discussed their plans for 2015-2017 and identified three main thematic areas for further discussion: discrimination, transition to adult care and capacity development.

The group wishes to raise awareness amongst civil society and policy-makers of the implications of living as a young person with chronic conditions that may lead to discrimination. They expect policy-makers to set up a legislative framework that protects them and promotes equal opportunities.





HEALTH IN INFORMATION AND COMMUNICATIONS TECHNOLOGY

EPF has remained engaged in the areas of eHealth and Health Technology Assessment (HTA) through participation in a number of European projects.

EPF has been leading the work related to the identification of user requirements and the assessment of patient empowerment resulting from using the project's services.

Despite its strong focus on Information and Communications Technology (ICT), SUSTAINS has rather become a 'cultural' endeavour. SUSTAINS promotes openness and transparency in handling patients' medical data and acknowledges the changing role of patients in managing their own health. This project has been paving the way in terms of breaking old patterns not only in the relationship between patients and health professionals, but also, and perhaps even more importantly, between patients and the health system as a whole.

The project partners formulated recommendations to all other European regions on how to move forward in the development and deployment of secure online access to their medical health data. These will be available to the public in 2015.

www.sustainsproject.eu

PROJECT

eHealth Governance Initiative eHGI

COMPLETED

February 2011 – September 2014⁹
The eHealth

Governance Initiative (eHGI) is a political initiative that provided the Member States, the European Commission, health authorities, competence centres, user groups, industry and other relevant stakeholders with a European interoperability framework on eHealth policy areas.

PROJECT

sustains

COMPLETED

January 2012 – December 2014¹⁰
The SUSTAINS (Support Users

To Access INformation and Services) project aimed to develop and roll out a wide range of eHealth services linked to patients' access to their Electronic Health Records (EHR) in 11 regions in 9 European countries.

⁹ Jointly funded by the EU Public Health Programme and a Thematic Network under the Competitiveness and Innovation Programme-ICT strand.

¹⁰ Co-funded under the Competitiveness and Innovation Programme of the European Commission.



PROJECT

ONGOING



March 2013 – February 2016¹¹

The SmartCare project

promotes a more integrated and effective approach to providing health and social care to older people across Europe. The project installed several pilot sites all across Europe to test integrated care pathways that are supported by ICT.

“During the site visit we had the opportunity to visit two patients living in a rural area, and meet several health professionals as well as social workers taking care of the social aspects of care delivery. They were very enthusiastic about the services as they see a great window of opportunity there to improve the quality of care while keeping an eye on the sustainability of health and social care services.”

Walter Atzori, EPF Senior Programme Officer

The project’s User Advisory Board, of which we are a member to ensure the perspective of older patients is taken into account, conducted a series of 10 site visits to evaluate the user experience and involvement in the services. We took part in the first site visit in November in the Barbastro area, Aragon region, Spain, where we realised that it is possible to deliver integrated health and social care without necessarily making fundamental changes to the organisation and delivery of care.

www.eu-patient.eu/whatwedo/Projects/SmartCare

¹¹ Co-funded under the Competitiveness and Innovation Programme of the European Commission.

¹² EUnetHTA Joint Action 2 (2012-2015), EUnetHTA Joint Action 1 (2010-2012), EUnetHTA Collaboration (2009), EUnetHTA Project (2006-2008) funded by the EU Health Programme.

¹³ Funded by 7th Framework Research Programme.

PROJECT

ONGOING



eunethta

2012 – 2015¹²

The EUnetHTA Project was established to create an effective and sustainable network for HTA across Europe. After its successful completion, a new collaboration emerged in the form of a Joint Action to implement.

EPF is part of the Stakeholder Forum representing patients among the four stakeholder groups; patients/consumers, industry, payers and healthcare providers.

www.eunethta.eu

PROJECT

ONGOING



AdHopHTA
Adopting Hospital Based
Health Technology Assessment

September 2012 – September 2015¹³

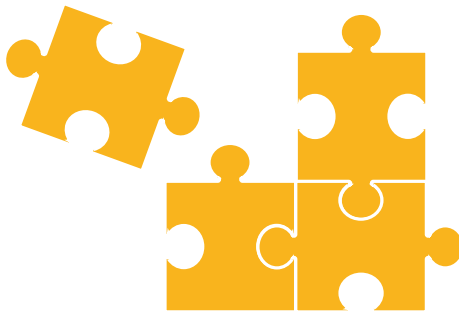
EPF is a member of the Advisory Board of the AdHopHTA project, “Adopting Hospital Based Health Technology Assessment (HTA)”, which aims to strengthen the use and impact of high quality HTA-results in hospital settings. Different tools will be developed to support this objective.

In 2014 AdHopHTA gathered relevant preliminary results that show how HTA units improve hospitals’ efficiency and organisational processes.



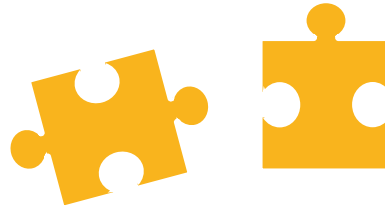
COOPERATION WITH OTHERS

Partnership is EPF's leitmotif and in 2014 we continued our approach of dialogue, cooperation and collaboration with other stakeholders working in our field.



Cooperation with Health Stakeholders

- Together with the wider health community, EPF expressed concerns regarding the changes in the health portfolio of the European Commission. Alongside many other health NGOs, we welcomed President Juncker's decision in October to keep the pharmaceutical portfolio in the Directorate-General for Health and Consumers (DG SANCO).
 - We published a joint press release with the European Public Health Alliance (EPHA) after DG SANCO's landmark conference "Health in Europe, making it fairer" organised in March. We called on the Council of Ministers to break the gridlock and swiftly adopt the Discrimination Directive (see p. 12). Also with EPHA, we joined forces to express our views on the Europe 2020 Strategy in an open letter. We raised issues linked to poverty, education, research, and employment targets.
 - Leading Public Relations & Public Affairs Agencies' Healthcare Consultants provided ongoing support during our 2014 European Elections Campaign (see p. 8) with strategic advice and expertise, and practical material where feasible.
 - We forged alliances with ten NGOs to develop questions for the next Health Commissioner
- (see p.12): the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA), the European Public Health Alliance (EPHA), the Platform for International Cooperation on Undocumented Migrants, the European Network Against Racism, the AGE Platform Europe, the International Planned Parenthood Federation European Network, Transgender Europe, the International Lesbian, Gay, Bisexual, Transgender & Queer Youth & Student Organisation, and European AIDS Treatment Group.
- EPF partnered with the European Network on Patient Empowerment (ENOPE) to organise the 2014 Careum Congress/2nd ENOPE Conference, "The power of patients 3.0. Patients are changing the face of health care" in March (see p. 19).
 - 44 European stakeholder groups expressed support for the EPF Election Campaign in 2014 and we will ensure continuous collaboration in the future.
 - EPF joined the 'European Data in Health Research Alliance' to drive a common campaign on Data Protection to ensure the final regulation allows the vital research that has taken place for many years to continue (see p. 13).
 - We also continued to work closely with the International Alliance of Patients' Organizations (IAPO), the World Health Organisation – European Regional Office, the European Network on Patient Empowerment (ENOPE) (see p. 19), the European Society for Quality of Care (ESQH), the European Health Policy Forum, the European Consumers' Organisation (BEUC), the Chiropractic Patients' Federation Europe (CPFE) and EUROCARERS.



Cooperation with EU institutions and agencies

• DG SANCO

- o Member of the Working Group on Patient Safety and Quality of Care (see p. 16)
- o Member of the Working Group on Health Workforce and represented in the Medical Devices Expert Group.

• DG Research

We were represented on the DG Research Health Advisory board, ensuring a strong patient perspective in the new Horizon 2020 programme, encouraging synergies between the public health programme and health research initiatives.

• European Medicines Agency (EMA)

- o Members of the Patient and Consumer Working Party to provide recommendations to EMA human scientific committees on all matters of interest to patients in relation to medicinal products.
- o Patients' representative at the Pharmacovigilance Risk Assessment Committee (PRAC) We initiated an EU Latvian Presidency event in 2015, to follow up the Vilnius Declaration on Sustainability of Health Systems.

We built alliances with major pan-European networks of regions and health authorities such as the Assembly of European Regions (AER), the European Network of Regional and Local Health Authorities (EUREGHA) and Health ClusterNET.

Cooperation with health professionals

We cooperated regularly with the European Standing Committee of Doctors (CPME), the Royal College of Physicians, the Pharmaceutical Group of the

European Union (PGEU), the European Federation of Nurses (EFN), the European Health Management Association (EHMA), the European Hospital and Healthcare Federation (HOPE), and the European Union of Medical Specialists (UEMS).

Cooperation with industry

As a member of the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think-Tank, we are a member of the Steering Group and participated in 4 meetings in 2014 to engage in dialogue on EU issues in the area of health and innovative medical research.

EPF also continued the bi-annual Patient-Medtech dialogue established in partnership with the medical devices industry association, EUCCOMED (see p. 14).

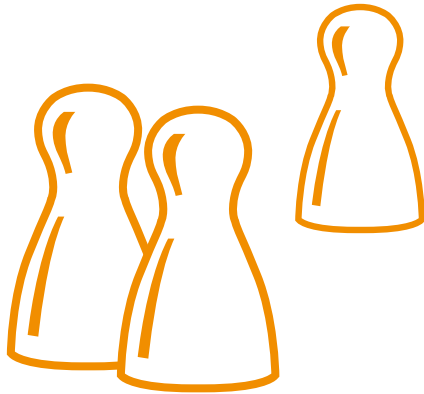
EPF also liaised regularly with the European Diagnostic Manufacturers Association (EDMA), the European interest group of the international wireless operators association (GSMA-Europe), the European Coordination Committee of the Radiological Electromedical and Healthcare IT Industry (COCIR).

www.eu-patient.eu/whatwedo/Cooperation/



OUR MEMBERS, OUR COMPASS

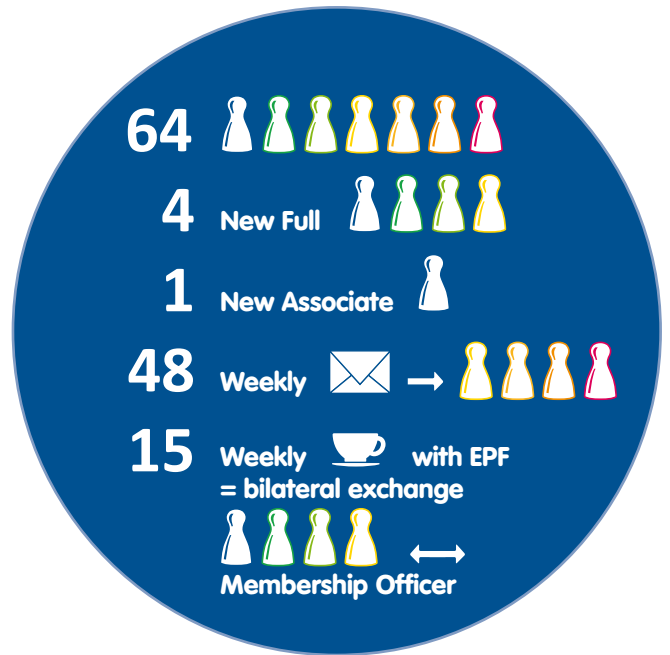
Our members unanimously adopted a new membership strategy in May at our Annual General Meeting (AGM). This document is intended to accompany the implementation of our 2014-2020 Strategic Plan, and to bring EPF closer to its members.



"Being part of EPF means support in the actions we take for patients and gives us the opportunity to work towards achieving our goals alongside other European patients' associations, with the conviction that we all work for the good of the patients."

Maria Dolores Navarro,
Spanish Patients' Forum

We were happy to welcome four new Full Members; the Hungarian Alliance of Patients' Organisations (HAPO), the Croatian Coalition of Associations in Healthcare (CAH), the European Aids Treatment Group (EATG), and the European Haemophilia Consortium (EHC), and one Associate, the Health and Social Care Alliance Scotland, at our AGM. This contributes to the diversity of the diseases we represent (HIV/Aids, Haemophilia) and enlarges our network with new countries (Hungary, Croatia, and Scotland). We are now proud to represent 64 members!





FULL MEMBERS



Our Full Members consist of pan-European disease-specific patients' organisations, present in at least 14 countries, and national coalitions of patients' groups which represent at least 10 different disease groups. They meet the criteria of legitimacy, representation, democracy, accountability and transparency requested by EPF to become members.

- **Alzheimer Europe** (Europe)
- **AMD** – Age Related Macular Degeneration Alliance International (International¹⁴)
- **AOECS** – Association of European Coeliac Societies (Europe)
- **AOPP** – Association for the Protection of Patients' Rights / Asociacia na ochranu prav pacientov SR (Slovak Republic)
- NEW** • **BEMOSZ** – Hungarian Alliance of Patients' Organisations (Hungary)
- **CISS** – Inter-Association Collective on Health / Collectif Interassociatif Sur la Santé (France)
- **COPAC** – Coalition of Patients' Organizations with Chronic Diseases / Coaliția Organizațiilor Pacienților cu Afecțiuni Cronice din România (Romania)
- **EAMDA** – European Alliance of Neuro-Muscular Disorders Association (Europe)

NEW

- **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)

NEW

- **EHC** – European Haemophilia Consortium (Europe)

- **EHLTF** – European Heart and Lung Transplant Federation (Europe)
- **EIA** – European Infertility Alliance (Europe)
- **ELPA** – European Liver Patients' Organisation (Europe)
- **EKPF** – European Kidney Patients' Federation (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 / Eesti Puuetega Inimeste Koda (Estonia)

¹⁴ International organisations who do not have a formally constituted branch in Europe but are active in the European region may become Full Members.



OUR MEMBERS, OUR COMPASS

7

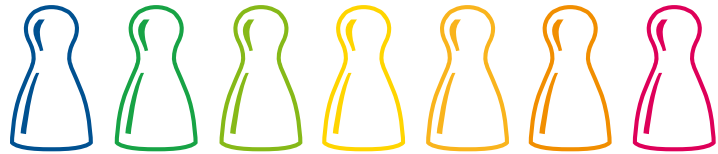
- **EUFAMI** – European Federation of Associations of Families of People with Mental Illness (Europe)
- **EUROPA DONNA** – The European Breast Cancer Coalition (Europe)
- **EUROPSO** – European Umbrella Organisation for Psoriasis Movements (Europe)
- **EURORDIS** – European Organisation for Rare Diseases (Europe)
- **FE** – Fertility Europe (Europe)
- **FEP** – Spanish Patients' Forum / Foro Español de Pacientes (Spain)
- **FPP** – Federation of Polish Patients / Federacja Pacjentów Polskich (Poland)
- **GAMIAN Europe** – Global Alliance of Mental Illness Advocacy Networks (Europe)
- **IDF Europe** – International Diabetes Federation (Europe)
- **IOF** – International Osteoporosis Federation (International)
- **IPOPI** – International Patients' Organisation for Primary Immunodeficiencies (International)
- **KUZ** – Coalition of Associations in Healthcare (Croatia)
- **KZZ** – Confederation Health Protections (Bulgaria)
- **LPOAT** – Council of Representatives of Patients' organisations of Lithuania / Lietuvos Pacientų Organizacijų Atstovų Taryba (Lithuania)
- **LUPUS** Europe (Europe)
- **MHN** – Malta Health Network (Malta)
- **National Voices** (United Kingdom)
- **NPO** – National Patients' Organisation of Bulgaria / Национална пациентска организация (Bulgaria)
- **Panyprian 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 Europe** (Europe)
- **SUSTENTO** – The Latvian Umbrella Body for Disability Organization / Latvijas Cilvēku ar īpašām vajadzībām sadarbības organizācija (Latvia)

"The European Patients' Forum has played a key role in the growth of the Bulgarian patients' movement by providing guidance and training to patients' organisations and facilitating dialogue in the country."

Martin Georgiev and Daniela Shikova,
National Patients' Organisations, Bulgaria


"EPF is like an experienced, old friend, to whom we can turn at any time with any questions or queries to quickly find the optimal solution. Our main goal is common: to support and help chronically ill people, their families and patients' organisations, regardless of where they live in Europe."

Tunde Koltai, Association of European Coeliac Societies



ASSOCIATE MEMBERS

Organisations that operate at a European level and include patients' organisations as members but do not meet the full membership criteria can still join EPF as Associate Members.

- **AMRC** – Association of Medical Research Charities (Europe)
- **APAI** – International Association for Autoimmune Pathologies / Associazione Patologie Autoimmuni Internazionale (International)
- **BAPD** – Bulgarian Association for Patients' Defense / Българска Асоциация за Заскрила на Пациентите (Bulgaria)
- **DEBRA Europe** – Organisation of People with Epidermolysis Bullosa (Europe)
- **EAGS** – European Alliance of Genetic Support Groups (Europe)
- **ECO** – European Cleft Organisation (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 Patients' Association (Hungary)
- **MRCG** – Medical Research Charities Group (Europe)
- **MHE-SME** – Mental Health Europe (Europe)
-  • **The ALLIANCE** – Health and Social Care Alliance Scotland (Scotland)
- **WFIP** – World Federation of Incontinent Patients (International)

"Through educational and capacity building programmes, EPF has also contributed to the development and empowerment of its members. GAMIAN-Europe is proud to be a member of this active, effective and dynamic organisation."

Pedro Montellano, GAMIAN

"As a member of the EPF since it was founded I have watched it steadily grow in confidence and influence on behalf of patients. More to the point it has not subsumed the role of other voluntary organisations but rather augmented and facilitated their work. It is impossible to overstate the effect this has had on policy makers and thus potentially on the lives of people we represent".

Ian Banks, European Men's Health Forum

OUR STRUCTURE

MEMBERS

Nominate representatives to:



Youth Group (15-25 years old)

The EPF Youth Group met for its 4th Annual Meeting in September in Brussels (see page 23).

Represented by one or two delegate(s)



Thematic working groups

We launched two working groups on patient empowerment and access to consolidate our work in these areas. Chaired by a member of the group, they meet and work together supported by the EPF secretariat.



Policy Advisory Group (PAG)

Made up of 14 representatives from our various members, this body met twice this year in June and September to support the policy work of the EPF Secretariat and Board Members from their grassroots' perspective. The Group also complements the broader EPF membership consultation procedure on specific policies that we get involved in.



Annual General Meeting (AGM)

EPF's AGM, the main governance body, took place in May to take all decisions required to implement EPF's strategy and work plan, such as establishing a budget, approval of the audited accounts and of the yearly report of the Board, appointment and discharge of the members of the organisation, the Board and an external and independent auditor, amendment of the constitution and internal rules.

Elect the Board for a term of two years

Consult members on our position statements

Secretariat

Overseen by the Secretary General and Head of Office, the secretariat delivers the annual work programme, works to support and inform members and implement a good governance structure.

Board

EPF is administered by a Board of Members which meets four times per year to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the Annual Work Programme.



BOARD MEMBERS



Continued
mandate

Vida Augustinienė,
Council of
Representatives of
Patients' Organizations
of Lithuania



Interim Treasurer:
Marco Greco, European
Federation of Crohn's
and Ulcerative Colitis
Associations (EFCCA)¹⁵



Stanimir Hasurdjiev,
Bulgarian National
Patients' Organisation
(NPO)



**Robert Andrew
Johnstone**, National
Voices



Re-elected
in 2014

President:
Anders Olauson,
Eurordis



Re-elected
in 2014

Vice-President:
Susanna Palkonen,
European Federation
of Allergy and Airways
Disease Patients'
Associations (EFA)



New Board
Member 2014

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



New Board
Member 2014

Brian Charles West,
European AIDS
Treatment Group (EATG)

Good-Bye, Stay in Touch and All the Best!



Philip Chircop (Malta Health Network) and
Avril Daly (Retina Europe) stepped down in 2014,
and we thank them for their great commitment.

¹⁵ Marco Greco was designated as interim Treasurer in December until our 2015 Annual General Meeting. This decision follows Tomasz Szlagowski's resignation from his position as EPF Treasurer and member of the Board following internal changes within the Polish Patients' Federation.

EPF SECRETARIAT



Senior Programme Officer, **Walter Atzori**



New position

Secretary General, **Nicola Bedlington**



Communications Officer, **Cynthia Bonsignore**



Membership Officer, **Camille Bullot**



Welcome in the team!

Policy & Project Team Administrative Assistant, **Danielle Flores**



IT Officer, **Žilvinas Gavėnas**



Senior Policy Adviser, **Kaisa Immonen-Charalambous**



Welcome in the team!

Assistant to the Secretary General and Office Manager, **Stefania Laferte**



Project Officer, **Cristina Padeanu**



Programme Manager, **Liuska Sanna**



Welcome in the team!

Head of Office, **Anke Seidler**



Policy Officer, **Laurène Souchet**



Project Officer, **Valentina Strammiello**



Office & Event Manager, **Véronique Tarasovici**

Good-Bye, Stay in Touch and All the Best!



Finance and Operations Manager, **Peter Windey**



Part-time Campaign Assistant, **Brooke Aksnes**



Team Administrative Assistant, **Leah Cozens**

CONTRACTUAL AUDITOR'S 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, 2014

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 of December 31, 2014, 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 **1.299.326** EUR and a result of loss for the year of **1.901** 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 Belgian 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.

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, 2014, in Belgian applicable accounting standards.

REGISTERED AUDITORS REPRESENTED BY JEAN-FRANCOIS NOBELS RSM INTERAUDIT CVBA-SCRL

Lozenberg 22 b2 - B 1932 Zaventem
T +32 (0)2 725 50 04 - F +32 (0)2 725 53 41
interaudit@rsm-belgium.be
VAT BE 0436.391.122 - RLP Brussels

Member of Toelen Cats Dupont Koevoets group Offices in Antwerp, Brussels, Charleroi.

ACCOUNTS AND AUDITS REPORTS

BALANCE SHEET AS AT 31 DECEMBER 2014

ASSETS	2014 (€)	2013 (€)
I Current Assets		
Accounts receivable	562.887,00	508.471,97
Short term investments	–	–
Cash in bank and deposit	637.262,00	1.370.648,04
Prepaid expenses	26.870,00	22.281,59
Total current assets	1.227.019,00	1.901.401,60
II Fixed Assets		
Leasehold	48.474,00	52.510,68
Furniture, ICT equipment and software	23.783,00	26.750,97
Guarantees (rent and social security)	50,00	11.939,67
Total fixed assets	72.307,00	91.201,32
TOTAL ASSETS	1.299.326,00	1.992.602,92
LIABILITIES		
I Current Liabilities		
Accounts payable	99.437,00	128.029,09
Deferred income	755.500,00	1.353.468,06
Income to be allocated to projects' partners	51.769,00	116.585,63
Total current liabilities	906.706,00	1.598.082,78
II Reserves		
Funds brought forward	394.521,00	394.850,52
Surplus or deficit for the year	-1.901,00	-330,38
Total reserves	392.620,00	394.520,14
TOTAL LIABILITIES	1.299.326,00	1.992.602,92



INCOME AND EXPENDITURE AS AT 31 DECEMBER 2014

INCOME	2014 (€)	2013 (€)
Funding from the public sector:¹⁶		
Operational work programme (EAHC operating grant co-funding 79%)	653.966,00	568.488,00
EC projects	164.180,54	188.780,55
Eupati (through IMI JU)	229.748,92	174.290,91
Sub-total	1.047.895,46	931.559,46
Funding from the private sector:¹⁶		
Operational work programme (co-funding of EAHC's operating grant 19.3%)	156.500,00	139.250,00
EPF projects and capacity building programme	120.963,51	210.447,63
EC projects	145.815,06	132.277,06
Eupati	78.777,00	47.517,77
Sub-total	502.055,57	529.492,46
Membership Fees	14.650,00	12.100,00
Interest and Other Income	29.182,21	25.606,09
TOTAL INCOME	1.593.783,24	1.498.758,01
EXPENDITURE	2014 (€)	2013 (€)
Staff and consultants fees	975.018,51	877.803,55
Office costs	169.334,61	162.265,05
Depreciation	18.898,00	15.257,01
Travel and subsistence	53.816,67	94.944,74
Events		
Annual General Meeting	61.574,14	47.330,62
Regional Advocacy Seminar	108.356,75	32.702,11
Youth meeting	8.265,46	8.484,51
Patient evidence workshop	12.277,24	3.180,43
Other events and workshops (Capacity Building Programme workshops, Regional Cross Border Healthcare, etc)	80.760,18	187.779,65
Communications	106.186,38	68.365,82
Bank and financial charges	1.195,95	974,90
TOTAL EXPENDITURE	1.595.683,89	1.499.088,39
SURPLUS OR DEFICIT OF THE YEAR	-1.900,65	-330,38

¹⁶ Income from pluriannual projects and activities is adjusted with accruals and deferrals according to the level of utilisation of resources during the year.



2014 ACCOUNTS - ACKNOWLEDGEMENT OF FINANCIAL SUPPORT¹⁷

EPF wishes to thank the European Commission for its support in 2014 in relation to EPF's role in the following projects:

	% of total income	
Renewing Health	3.000,00 €	0,2 %
Sustains	23.681,00 €	1,6 %
JA PASQ	48.560,40 €	3,4 %
JA Chronic Diseases	30.498,60 €	2,1 %
Cross Border Health Care Conference	53.355,71 €	3,7 %
Empathie	36.062,36 €	2,5 %
Interquality	41.566,00 €	2,9 %

EPF wishes to thank the following donors for their support:

Operational work programme

European Commission (Executive Agency for Health and Consumers)	653.966,00 €	45,5%
Baxter World Trade	10.000,00 €	0,7%
GSK	30.000,00 €	2,1%
Janssen	16.500,00 €	1,1%
Merck Sharp & Dohme	30.000,00 €	2,1%
Novartis	30.000,00 €	2,1%
Pfizer	20.000,00 €	1,4%
Sanofi-Aventis	20.000,00 €	1,4%

Note: The donors contribute as follows: European Commission: 80%, industry donors 19,1%, membership fees: 0,9%.

Project portfolio and capacity building programme

Abbvie	25.000,00 €	1,7 %
AMGEN	35.000,00 €	2,4 %
Biogen IDEC International GmbH	20.000,00 €	1,4 %
CSL Behring Biotherapies	10.000,00 €	0,7 %
Gilead	20.000,00 €	1,4 %
GSK	50.000,00 €	3,5 %
Grünenthal GmbH	10.000,00 €	0,7 %
Hoffmann-La Roche	15.000,00 €	1,0 %
Hospira Benelux BVBA	25.000,00 €	1,7 %
Janssen Pharmaceutica	13.500,00 €	0,9 %
Laboratoires Servier	10.000,00 €	0,7 %
Novartis	20.000,00 €	1,4 %
Pfizer	20.000,00 €	1,4 %
S.A. Eli Lilly Benelux N.V	15.000,00 €	1,0 %
Sanofi-Aventis	40.000,00 €	2,8 %
Shire	5.000,00 €	0,3 %

The European Patients' Academy on Therapeutic Innovation Public Private Partnership (EUPATI)

Innovative Medicine Initiative (IMI JU) contribution	171.114,05 €	11,9 %
Industry consortium (Hoffman La Roche, Genzyme, Boehringer, VFA, GSK, AMGEN, ESTVE, Novonordis, S.A. Eli Lilly, Novartis, Astra Zeneca, Bayer, UCB, CHIESI, Janssen, Merck)	78.777,00 €	5,5 %

Note: the income provided represents EPF's share in the consortium's contributions to the project only.

Memberships and other income	43.832,21 €	3,0 %
Total income	1.437.689,26 €	100,0 %
Accruals and deferrals ¹⁷	-80.630,09 €	
Total income net of adjustments	1.357.059,17 €	

¹⁷ In accordance with generally accepted accounting principles, funding received in-year is subject to accrual and deferral adjustments proportionate to the level of resources assigned to pluriannual activities and projects. In 2014, this method had the effect of a decrease of total income by € 80.630,09.

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