





# FOREWORD

It is with immense pride that we introduce to you the EPF Annual Report of 2013. This was a very special year for EPF for many reasons, in particular because **we celebrated our 10<sup>th</sup> Anniversary**: 10 years of advancing the rights of patients across the European Union. This report is also special as we will share with you our key 2013 achievements as well as some of the highlights from the past 10 years.

Our Annual General Meeting and Anniversary Conference in Dublin brought together many patient leaders and allies to celebrate EPF and, equally importantly, to contemplate our future with the **adoption of a new Strategic Plan for the next EU Programming Period 2014- 2020** and a new visual identity for EPF that reflects our evolution and growth.

2013 also saw **major advances in our Capacity Building Programme** and the start of a strong collaboration in the Balkans which includes patients' coalitions from EU Candidate Countries, through our Regional Advocacy Seminar in Zagreb in October 2013.

We held **two intensive meetings on eHealth**: one that marked the close of our project 'Chain of Trust', and one working closely with our members on the patients' perspective on eHealth.

“ 2013 has been a rich and rewarding year

On the policy side, **extensive work took place on our priority dossiers - clinical trials, medical devices, data protection and professional qualifications**. The year closed with the **first in a series of regional conferences held on the Directive on Patients' Rights in Cross-Border Healthcare** which took place in Brussels. As a result of the conference, **patient**

**leaders from Belgium, France, Germany, Luxembourg and the Netherlands have created an informal network to support and monitor the implementation of the Directive**. Three further regional conferences will take place throughout Europe in 2014.

On 1 October, **EPF launched our campaign for the European Parliament Elections in 2014** with the support of Commissioner Borg and key health champions in the European Parliament. We were the first organisation to publish our Manifesto in all EU languages. With the slogan **“Patients + Participation = Our Vote for a Healthier Europe”**, our partnership work throughout the autumn on the campaign with our members has laid the foundation for intensive campaigning during 2014 to ensure that our elected representatives in the European Parliament fully understand why and how to include the patients' perspective in their work.

In November, **we were a key partner in the Lithuanian EU Presidency Conference on the Sustainability of Health Systems**. The ensuing Vilnius Declaration and Council Conclusions provide a strong framework for cooperation on access in its widest context and sustainability. 2013 has also seen much **foundation work for the creation of a multi-stakeholder Access Partnership**.

2013 has been a rich and rewarding year and first and foremost we would like to once again thank our members who have worked together unceasingly to ensure a strong and united patients' voice in all that we do. We would also like to thank our powerful networks of allies and supporters, who share our vision and values as an organisation.



EPF President  
**Anders Olason**



EPF Executive Director  
**Nicola Bedlington**

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# EXECUTIVE SUMMARY

In our Work Plan 2013, EPF identified **three objectives** that relate to the **strategic goals** of our organisation:

## OBJECTIVE 1

To reinforce the capacity of the **patient community** actors to effectively **contribute to the health debate**.  
(Contributing to Strategic Goals 1-5)

## OBJECTIVE 2

To **strengthen** the **influence and impact** of the **patient perspective** in health-related policy and decision-making.  
(Contributing to Strategic Goals 1-3)

## OBJECTIVE 3

To **feed** the collected **patients' evidence from projects into policy**.  
(Contributing to Strategic Goals 1-5)

EPF celebrated 10 years of patients' advocacy with a major conference in May 2013 following our Annual General Meeting (AGM). This represented a timely opportunity for us to take stock of the past ten years and explore how to move forward with the adoption of a new Strategic Plan which will run from 2014 to 2020 and coincide with the new EU programming period.

## REINFORCING CAPACITY

### Stronger ties with the Western Balkans

Our **Regional Advocacy Seminar** was held in October 2013 in Zagreb, Croatia and brought together many patient leaders from the Western Balkans region, including Turkey. The meeting initiated a very strong and sustainable collaboration between EPF and our members and potential future members in this region.



### New members approved!

Our AGM approved several **new membership requests**. We welcomed two new Full Members: the **International Osteoporosis Foundation (IOF)** and the **Pulmonary Hypertension Association Europe (PHA Europe)**. We also accepted three new Associate Members: the **Association of Medical Research Charities (AMRC)**, the **European Federation of Neurological Associations (EFNA)** and the **Medical Research Charities Group (MRCG)**. A new Provisional Member from Italy, the **Association for People**

**with Rheumatic Diseases (APMAR)**, has also broadened our membership. We worked both in countries where national coalitions exist and where such structures are still in their infancy to foster EU collaboration through EPF.

### Spotlight on younger patients

We have continued our focus on **younger patients** with two key meetings of our Youth Group in 2013, complementing the highly-successful, EU-funded project EMPATHY, which culminated in a four-day seminar in Brussels.

### Representing EPF at 78 EU events

We continued to work towards forging alliances with European health stakeholders. We voiced patients' interests through representative work at **78 different EU events on health policy issues**. We also continued our strong involvement in the European Medicines Agency, the European Health Policy Forum, European Health Forum Gastein and many other health platforms, as described throughout this report and p. 38.

## STRENGTHENING OUR POLICY IMPACT

Our policy priorities in 2013 addressed a number of broad areas that reflect our vision as an organisation, including patient-centred, sustainable health systems; patient-centred innovation; tackling health inequalities from a patients' perspective and ensuring equitable access to high-quality, safe healthcare. More specifically, intensive and very effective work took place on complex dossiers such as clinical trials, medical devices, data protection, and professional qualifications.

We continued our work on promoting effective implementation of legislation through updated tools and our first Regional Conference on the Cross-Border Healthcare Directive.

We advanced our reflection on core topics such as empowerment, health literacy, patient involvement and the patients' role in sustainability of health and social systems.

We also explored new topics with our members and developed a briefing paper on stigma and discrimination, which now forms one of EPF's strategic goals.

## FEEDING PROJECT AND PATIENT EVIDENCE INTO POLICY

Thanks to our **Chain of Trust Project** and our eHealth Seminar, we disseminated evidence-based messages on patients' engagement in eHealth and how this can be enhanced throughout our network.

Our 2013 Patient Evidence Workshop focused on shaping the patients' contribution to EU-level policy in patient safety, particularly as it pertains to patient involvement.



We also finalised our **position paper on the rights and needs of older patients** based on case studies and input from the membership. This document complements our work within the European Innovation Partnership on Active and Healthy Ageing and explores further efforts to uphold older patients' rights in the EU.

EPF and our members devoted much energy in 2013 to prepare an **advocacy campaign for the 2014 EU Elections**. This was launched on 1 October and entitled "Patients + Participation = Our Vote For a Healthier Europe".

During 2013, EPF continued to improve our **communication strategy** with a strong emphasis on social media and the change of our logo. We launched a new Weekly Digest for our members to facilitate ongoing contact with them. Much emphasis was also placed on our membership's role in driving the EPF Manifesto and European Parliament Elections Campaign in their own contexts and countries.

We engaged in a comprehensive **internal and external evaluation strategy**, which will help us learn from the 2013 Work Plan achievements and challenges and feed this vital knowledge into our future work.

POLICY IMPACT  
REINFORCING  
CAPACITY



*EMPATHY Seminar,  
8-11 July 2013,  
Brussels, Belgium*



*Regional Advocacy Seminar,  
28-29 October 2013, Zagreb, Croatia*



## 2. WHO WE ARE<sup>1</sup>

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 patient community drives **policies and programmes** that affect patients' lives and bring changes that **empower them to be equal citizens** in the EU.

EPF is an **umbrella organisation** that works with patients' groups on public health and health advocacy across Europe. Our members represent specific chronic-disease organisations at the EU level or are national patient coalitions of patient organisations.

Our 5 strategic goals as defined in the 2014-2020 Strategic Plan:

1. The content of this section comes from the EPF Strategic Plan 2014-2020 that was agreed upon in May 2013 at our Annual General Meeting.

### GOAL 1 HEALTH LITERACY

To promote access for patients and their informal carers to information and education that enables them to make informed choices about their health.

### GOAL 2 HEALTH ACCESS AND QUALITY

To contribute to improvements in health systems that enable equitable access to sustainable and high-quality healthcare that is designed and delivered to meet patients' and informal carers' needs at all levels of care, embracing innovation in all its forms.

### GOAL 3 PATIENT INVOLVEMENT

To advance meaningful patient involvement in the development and implementation of health-related policies, programmes and projects in the EU.

### GOAL 4 PATIENT EMPOWERMENT

To promote the development and implementation of policies, strategies and healthcare services that empower patients to be involved in the decision-making and management of their conditions according to their preferences, whilst raising awareness about their rights and responsibilities.

### GOAL 5 SUSTAINABLE PATIENT ORGANISATIONS

To support the development, growth and capacity-building of inclusive, effective, sustainable, and representative patient organisations, and to foster cooperation and synergies between them.

### GOAL 6 NON-DISCRIMINATION

To promote the development of EU and national policies that tackle discrimination faced by patients in health and social care, as well as in domains like education and employment.



## OUR VALUES



### PATIENT-CENTRED

We are driven by a rights-based, patient-centred approach to health and social care policies that affect patients and their informal carers in the EU.



### NON-DISCRIMINATION

We promote patients' rights for all patients regardless of health status, age, sex, ethnic origin, political belief, religious convictions, marital status, economic status, sexual orientation, gender identity or any other factor that could lead to discrimination.



### HEALTH EQUITY

We believe every patient should have equitable access to patient-centred, high-quality health and social care, and we strive to fight the disparities existing within the EU in relation to access to and standards of care for chronic diseases and lifelong conditions.



### HEALTH IN ALL POLICIES

We promote a 'health in all policies' approach to ensure the multiple vulnerabilities of patients and the physical and psychological impact of their conditions are properly addressed, including inability to work, direct and indirect costs of illness, loss of income and risk of poverty, social exclusion, discrimination and stigma.



### EMPOWERING PATIENTS

We advance the empowerment of patients and their informal carers by fostering positive attitudes and the development of support policies and programmes that enable them to make informed choices and have their place in society as equal citizens.



### CONSULTATIVE

We bring a unique patients' perspective by enabling all our member organisations to contribute their distinctive expertise and wealth of knowledge to influence the programmes and policies that will impact patients across the EU.



### INDEPENDENT AND TRANSPARENT

We are an independent organisation, transparent in all our operations - financial, policy, and communications.



### INCLUSIVE

We are an open and inclusive organisation that strives to ensure that our work reflects the needs of all patients and their informal carers, including those who are under-represented.



### 3.

# OUR CAMPAIGN FOR THE 2014 EU ELECTIONS



On 1 October 2013, we launched our campaign entitled “Patients + Participation = Our Vote for a Healthier Europe” ahead of the 2014 European elections. The invaluable presence from Health Commissioner Tonio Borg and MEP Dagmar Roth-Behrendt (S&D, Germany) at this launch event made it a resounding success, which was hopefully the first of many in this campaign.

The 2014 elections will be a **big milestone for patients in Europe**. Every five years, European voters get the opportunity to voice what is important to them in the European elections. This time, we know from our members throughout Europe that **the challenges patient constituencies are facing are still enormous**. Fundamental inequalities and lack of access prevail, even more as our population ages and in the wake of the economic crisis.

Our efforts to influence regulation and set policies that are patient friendly at the European Commission and at the European Parliament have been vital in getting us to where we are today. **This campaign is our tool to advocate at the EU level for patients’ rights and to bring about positive change for those with unmet medical needs in Europe**. It represents an opportunity for us to be heard by candidates and to help them in setting the priorities for the new parliamentary mandate.

*“I fully agree with you that patients’ views matter and that empowered patients are an asset”* said Health Commissioner Borg about our campaign.

With our campaign, we want to create a sense of urgency and true imperative to address the fundamental roadblocks to patients’ access to proper healthcare. We demonstrate how patients can be part of the solution to make health systems more effective and quality-oriented.

**The patients’ perspective matters**, as we ‘live’ our condition every day; we therefore know what works for us and what does not. We want to be full partners in the management of our conditions, according to our individual capacities and situations, and we need to be fully supported to be able to do so. When empowered, we can be involved in designing more effective healthcare and in research to deliver better and new treatments. In other words, **we can contribute to a healthier Europe** as outlined in our Manifesto.

When we cast our vote, we will be confident and assured that we are voting for a healthier Europe, where patients are seen as a part of the solution towards high-quality, sustainable and cost-effective healthcare. **Our vote will reflect the kind of society we want for us and for our future-and health is absolutely central to this.**

More information about the campaign:  
[www.eu-patient.eu/whatwedo/EPFCampaign2014Elections](http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections)

Support our campaign by filling in your details on our online form:  
[www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/I-support-EPF-Campaign](http://www.eu-patient.eu/whatwedo/EPFCampaign2014Elections/I-support-EPF-Campaign)



# 4.

# EPF CAPACITY BUILDING PROGRAMME



**The EPF Capacity Building Programme was launched in 2012 to support the development of organisational capacities and advocacy skills of EPF’s national and European members. We took stock of the progress made with an initial assessment of the outcomes in July 2013.**

Romanian and Hungarian organisations joined the programme in 2012, and **seven Slovakian and ten Bulgarian organisations began the programme at the end of 2013.** The organisations are part of EPF’s national-level members and include the Association for the Protection of Patients’ Rights in Slovakia, the Bulgarian Confederation Health Protection (KZZ) and National Patient Organisation (NPO).

In this initial phase **the organisations will undergo a process to develop their strategic plans and will benefit from a comprehensive organisational capacity assessment exercise** to shape the next phases of the programme.

In drawing from the outcomes of the first phase, **20 patient organisations from Romania and Hungary started the second phase at the end of 2013.** Much more implementation-oriented, this phase consists of providing training related to operational planning. **We will assist in developing the first annual plan,** which will implement the Strategic Plan developed and agreed on for each organisation in the previous phase of the programme.

With other European organisations, we will continue working with Fertility Europe to support them in the development of their strategic plan. **A training module on fundraising will be implemented in summer 2014, and it will be open to all full, European-level EPF members.**



*“Fundraising was identified as a primary urgent need for all organisations. This training module will combine methodological knowledge and practical skill building, as well as concrete support.”* said Liuska Sanna, EPF Capacity Building Programme Manager.

In August, we released a short, one-minute video to explain the fundamentals of the programme.

 [www.youtube.com/user/eupatient](http://www.youtube.com/user/eupatient)



The programme initially provided for the 2012-2014 period is set to continue after 2014. We will evaluate the outcomes of the programme after 3 years of implementation to see how to mainstream the programme long-term.

 [www.eu-patient.eu/whatwedo/Capacity-Building-programme](http://www.eu-patient.eu/whatwedo/Capacity-Building-programme)

### Duration

36 months (January 2012 – December 2014; set to continue in 2014+)

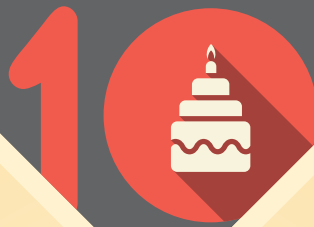
### Status

Running, EPF-led project

### Funding

The Capacity Building Programme is financed by the Medtronic Foundation (2012) and unrestricted grants from industry partners.

# 5. 10 SPECIAL YEARS



## FLASHBACK TIMELINE FROM 2003 TO 2013

2003

### OUR MEMBERS: THE STARTING POINT

Realising we needed a strong European voice to collectively represent patients on common healthcare issues, **13 patient organisations** created EPF. A powerful Constitution was created based on representativeness, legitimacy, independence, accountability and transparency.



2004

### ALLIANCE BUILDING: LAYING THE FOUNDATIONS



EPF organised our **first annual conference** entitled "Driving better health in Europe". This was the first occasion for patient groups to build alliances and lay the foundations for patients' advocacy on cross-cutting issues.

2005

### FIRST COMMITMENTS AND POLICY FOCUS

EPF organised our second annual conference entitled "Health education and compliance" and engaged in crucial policy areas such as **information to patients, patient empowerment, patient safety and quality of care.**



2006

### THE PHARMACEUTICAL FORUM & THE ESTABLISHMENT OF THE SECRETARIAT

EPF represented patient organisations in the Steering Group of the **Pharmaceutical Forum**, a high-level political platform for discussion set up in 2006 by Commission Vice-President Günter Verheugen and Commissioner Markos Kyprianou. The aim was to enhance the pharmaceutical industry's contribution to social and public health objectives. EPF was active in the **three expert working groups**: Relative Effectiveness, Pricing and Reimbursement and Information to Patients.

A permanent secretariat was established in Brussels. Our first annual report documented the collective achievements and challenges of previous years.



2012

## BUILDING CAPACITY AND TRANSMISSION OF KNOWLEDGE

We shared knowledge and learning through our Capacity Building Programme and the European Patients' Academy on Therapeutic Innovation (EUPATI). The aim is to reinforce patient groups' capacities to inform and advocate in order to enable them to become effective actors in driving positive change in all issues affecting patients at both the national and European levels.



2011

## POLICY IMPACT AND NEW TOPICS

We strengthened our policy impact in both EU and national health contexts, particularly through our work on cross-border healthcare and clinical trials. We also extended our activity to new policy topics, such as personalised medicine and the rights of older patients.



2010

## YOUNG PATIENTS, THE VOICE OF THE FUTURE

The 2010 EPF Regional Advocacy Seminar put the spotlight on **young patients**. The Youth Group was established afterwards as the backbone of the EPF Youth Strategy to explore how young patients' needs can be better recognised by patient organisations through their effective involvement and empowerment.



2009

## OUR PATIENT MANIFESTO: HIGH VISIBILITY IN THE EUROPEAN PARLIAMENT

EPF reaped the benefits of the **one-year elections' campaign "150 Million Reasons to Act"** and our **Patient Manifesto**. Many MEPs expressed their commitment to support our mission.



2008

## A FIRST PROJECT, NEW CHALLENGES ON THE HORIZON

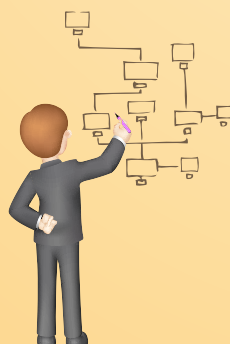
EPF led our first **EU-funded project: Value+**. This marked the start of our involvement in European projects to gather evidence-based information from patients to substantiate our policy work.



2007

## THE STRATEGIC PLAN: A SIGNIFICANT LANDMARK

EPF developed our **first Strategic Plan** (see p. 16) in order to grow and work effectively during the coming **five years**. EPF put our vision of healthcare, mission, values and goals into words and action.





## REFLECTING ON LESSONS LEARNED AND THINKING ABOUT THE FUTURE

We celebrated our 10<sup>th</sup> Anniversary with a major conference in Dublin under the Irish EU Presidency and welcomed Health Commissioner Tonio Borg and Irish Minister for Equity, Kathleen Lynch, as special guests. Featuring the 2013 European Year of Citizens dedicated to the rights that come with EU citizenship, the event highlighted how these rights relate to patients. As May was the European Month of the Brain, the conference championed for neurological disorders in close collaboration with the European Federation of Neurological Associations (EFNA) and the Neurological Alliance of Ireland (NAI).

This celebration also coincided with our change of logo to demonstrate our evolution as an organisation with an ever-expanding membership and widening mandate. The new logo visualises three different and dynamic figures who come together to shape a forum. Together, they are empowered to become the active players that make the voice of European patients heard widely and strongly. All of them are equally included in this forum to demonstrate the need for equal access to healthcare, regardless of diversity of background.

In 2014, EPF continues preparations for the next EU programming period with our new 2014-2020 Strategic Plan developed with our members.



*“EPF is entering an exciting new era, where we can build on past achievements and our track record with our members and allies, to engineer positive change for patients in every part of the European Union”* concluded our President Anders Olauson and our Executive Director Nicola Bedlington.



EPF 10<sup>th</sup> Anniversary  
Celebration Conference,  
23 May 2013, Dublin, Ireland





# ACHIEVEMENTS WITHIN THE 2007-2012 STRATEGIC PLAN

Our 2007-2012 Strategic Plan had five key goals; five key areas where EPF enjoyed significant success. These have been documented extensively in previous annual reports and on our website. The following are a few highlights:

## GOAL 1



**Equal access to information and healthcare: to promote equal access to the best-quality information and healthcare for EU patients, their carers and their families.**

We held a major **health literacy conference** in 2008 in Brussels, Belgium, that provided the framework for our policy and actions in this area (see p.24). This was the first speaking engagement of the newly-appointed Commissioner Androulla Vassiliou.

**Health inequalities dominated the agenda** during 2007-2012, with existing inequalities exacerbated by the economic crisis in many parts of Europe. (see p. 32)

We collaborated very closely with our national member organisations-particularly from Central and Eastern Europe-to make the case for a multi-stakeholder approach to access, which has led to the **Access Partnership** (see p. 32).

## GOAL 2



**Meaningful patient involvement: to ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.**

Our flagship project, 'Value +' set the scene for strong evidence and tools for **meaningful patient involvement in EU health projects and policy**. DG Research integrated patient involvement as a criterion for key health projects. (see p. 37)

In partnership with academia and industry, EPF designed and led the '**European Patient Academy on Therapeutic Innovation**' (EUPATI), which aims to facilitate more and **improved patient involvement in the entire medicines research and development process**. (see p. 23)

**Intensive work took place surrounding patient safety and quality of care** through our involvement in two major projects and our ongoing contribution to the Commission's Working Group. (see p. 30)

## GOAL 3



**Patients' perspective: to ensure a patients' perspective, including issues around human rights and quality of life, is heard in developments at EU level on health economics and health efficacy (health, wealth and equity).**

During this legislative period, we have been successful in **influencing positive EU legislation affecting patients**; core dossiers where we were able to make a strong case on behalf of patients are: **cross-border healthcare, pharmacovigilance, falsified medicines, clinical trials, medical devices, data protection and the Transparency Directive**. (see p. 18-37)



## GOAL 4



### Sustainability of patient organisations: to encourage inclusive, effective and sustainable representative patient organisations

Our **Capacity Building Programme** (see p. 11) helped to strengthen the **role and potential of our members** in shaping EU policy and ensuring patient-centred transposition of legislation.

We have also worked very hard during the preparations of the new EU programming period to ensure **opportunities for patient organisations** to be resourced in respect to their unique contributions.

## GOAL 5



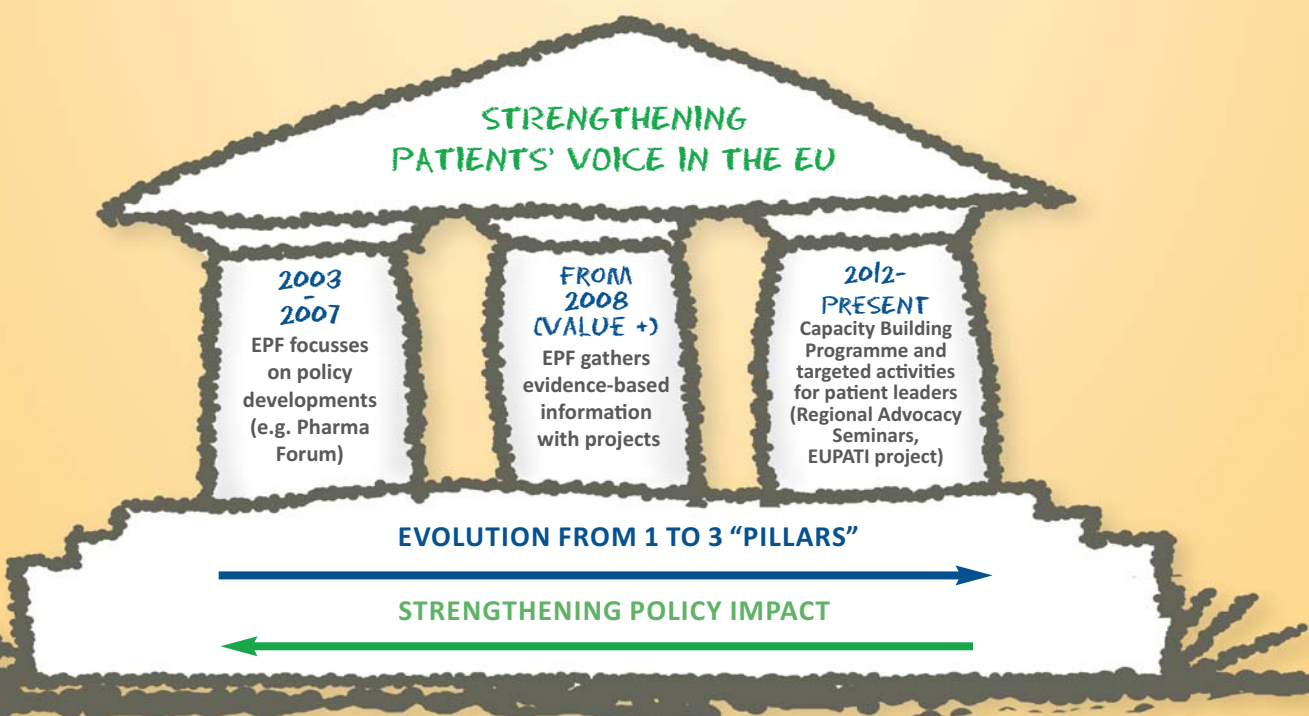
### Unity across the EU Patients' Movement: to nurture and promote solidarity and unity across the EU Patients' Movement.

Much emphasis was placed on **engaging with our members in their own contexts**, through our Regional Advocacy Seminars and our thematic conferences (see p. 6). In certain countries, we were invited to support the **creation and strengthening of national coalitions**.

## OUR EVOLUTION FROM ONE TO THREE PILLARS

EPF evolved from being focused exclusively on policy influence in Brussels – our original 'raison d'être' - to **developing a wide range of projects** to provide the evidence base for our policy positions and communications.

A third pillar of work emerged from our **capacity building activities**, which were developed through our annual Regional Advocacy Seminars and with an explicit request from our members to support their abilities to contribute to, engage in and benefit from being part of the European Patients' Movement.



6.

# 10 MAJOR POLICY-AREA ACHIEVEMENTS SUPPORTED BY EU PROJECTS



1

## CROSS-BORDER HEALTHCARE: FROM LEGISLATION TO IMPLEMENTATION

The organisation, management, financing and delivery of healthcare are the responsibility of the EU member states.<sup>2</sup> However, several judgments of the European Court of Justice confirm that patients have, in certain cases, the right to access healthcare products and services in other member states than their own, with the cost being borne by their respective health system.

To provide legal certainty, in 2008, the European Commission adopted a proposal for a Directive on the application of patients' rights in cross-border healthcare. Directive 2011/24/EU was published in the EU's Official Journal on 9 March 2011 and set to enter into practice on 25 October 2013.

2007

The Commission launched a consultation with all stakeholders involved in the health service sector to explore measures for developing the Community Framework for Safe, High-Quality and Efficient Health Services. EPF developed a first response with our members that highlighted the principles of equitable access, safety and quality of care, continuity of care and provision of clear information to patients.

2010

The Commission adopted a proposal for the Directive in 2008, but it went through a lengthy negotiation process with the European Parliament and Council with failure to reach agreement during several EU Presidencies. A compromise was finally agreed upon under the Belgian EU Presidency in the second half of 2010.

On the eve of the negotiations' conclusion, EPF organised a High-Level Roundtable under the Belgian EU Presidency's patronage to explore the draft Directive in its wider context. Mr. John Dalli, European Commissioner for Health and Consumers, delivered a keynote speech.

2011

EPF welcomed the draft Directive on Cross-Border Healthcare, adopted on 19 January 2011 by the European Parliament. We were intensively involved in the revision process, having worked closely with the Commission, the EU presidencies and especially MEPs throughout the first and the second readings to ensure that a patients' perspective was well-reflected in the parliamentary position. We focused particularly on equity of access and the provision of information to patients concerning their rights under the new legislation. Although the final document was less ambitious than EPF's vision, it nevertheless marked a milestone for European patients.

2012

EPF developed a toolkit for patient organisations to support their involvement at the national level and ensure that policy transposition would take patients' needs into account. This toolkit was comprehensively updated in 2013 to account for developments on implementing this legislation in the EU member states.

2. Article 168, Treaty on the Functioning of the European Union

## EPF'S POSITION

EPF sees in the **Cross-Border Healthcare Directive** the potential to reduce access-related inequalities for patients in healthcare. The Directive created a legal framework establishing the patients' right to seek healthcare in another member state and to be reimbursed. We believe that **many aspects of the Directive can be built upon to achieve better-quality care for all patients** - such as stronger European cooperation in the crucial areas of quality and safety, Health Technology Assessment (HTA), eHealth and rare diseases. We strive to closely monitor the implementation of the Directive by raising awareness in patient communities across the EU on the new legislation and supporting patient organisations' involvement at the national level.

 [www.eu-patient.eu/whatwedo/Policy/Patients-Mobility](http://www.eu-patient.eu/whatwedo/Policy/Patients-Mobility)

2013

As much depends on how the Directive is transposed by member states, **EPF has decided to organise a set of conferences on this topic** to encourage national patient organisations to make full use of the opportunities it provides.

Around 40 patient-organisation representatives from The Netherlands, Luxemburg, Germany, France and Belgium attended the first conference on 9-11 December 2013 in Brussels, Belgium. Further events will be organised in 2014 in other EU countries.

With this conference, EPF, together with participating patient communities, have taken the first steps towards promoting stronger awareness of this landmark Directive and its implications for patients. We have also created a **network of patient leaders** who are committed to disseminating information to their peers and working together with the National Contact Points in their member states to support effective implementation.

During the next two years, EPF and its members will monitor the impact of the legislation closely from a patients' perspective and ensure that the grassroots patients' experience inform the **European Commission's first progress report**, which is due in October 2015.

## CROSS-BORDER HEALTHCARE CONFERENCE



*EPF First Cross-Border Healthcare Conference, 9-11 December 2013, Brussels, Belgium*



# 2

## PATIENT INVOLVEMENT IN PHARMACOVIGILANCE: FROM PLAN TO ACTION



**Pharmacovigilance is a system designed to monitor the safety of medicines after they have been authorised to be used or sold in specific areas or the entire EU. It plays an important role in public health and the protection of patient safety.**

Before being authorised and made available to patients, medicines are tested in clinical trials. However, trials are necessarily limited in time and number, and patients involved in them are selected according to certain criteria. Thus, **trials are based in an ‘artificial’ environment**; they are not representative of real-life use. Once on the market, medicines are used by a far greater number of people and in different circumstances. Furthermore, **some side effects emerge only after a prolonged period of use**. For this reason, it is crucial to continue monitoring and collecting as much information as possible on how medicines work in real-life settings.

the final legislation as it shows promise in many respects. It is embedded with the principle of **patient empowerment**, notably through the implementation of direct patient reporting of suspected adverse reactions throughout the European Union and giving the public access to more information on safety of authorised medicines through the creation of national medicines websites and the Eudravigilance database.

**EPF continues to participate in the implementation process of the legislation through stakeholder forums** regularly held at the European Medicines Agency (EMA). The objective is to raise awareness and promote the exchange of ideas, concerns and opinions.

2008  
2010

The EU **Pharmacovigilance Directive** adopted in 2010 found its roots in the 2008 European Commission (EC)’s communication on the future of the pharmaceutical sector and the so-called “Pharmaceutical Package” of legislative proposals. This proposal on pharmacovigilance, where MEP Linda McAvan (S&D, UK) was rapporteur, **aimed to better protect patients by strengthening the EU’s system for monitoring the safety of medicines**.

EPF, in consultation with our membership, was closely involved in the drafting of this legislation. We welcomed

2012

EPF developed **guidance for patient organisations** to provide an overview of the different aspects of the new EU pharmacovigilance legislation that are of importance for patients. Our recommendations for a **patient-centred implementation** aimed at encouraging the development of a strong, open and transparent pharmacovigilance system that ensures the confidence of patients, health professionals and regulators alike throughout the EU.

### PHARMACOVIGILANCE IN FIGURES

Adverse reactions are the **5<sup>th</sup> largest cause** of in-hospital deaths

Only **10% to 25%** of all adverse reactions are reported

PHARMACO-  
VIGILANCE

## EPF'S POSITION

One essential pillar of pharmacovigilance is the reporting of side effects of medicines (or adverse drug reactions) by patients. **Reporting is crucial:** adverse drug reactions are estimated as the fifth largest cause of in-hospital deaths. **Moreover, patient reporting further provides knowledge that is crucial for the safe use of a medicine;** if new risks are discovered, a range of actions can be taken by competent authorities to ensure patient safety. However, both patients and healthcare professionals are currently underreporting medication side effects: only an estimated 10% to 25% of all adverse reactions are reported.<sup>3</sup>

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

2013

On 28 February 2013, EPF was proud to see one of our board members, Marco Greco, appointed as an alternate member on the new **Pharmacovigilance Risk Assessment Committee (PRAC)** of the EMA. The Directive requires this committee to include two patient representatives.



*"It is not only important to represent patients in such committees; it is symbolic. It means that patients' advocacy has now reached a new dimension. This is the recognition of many years of work of many persons, many volunteers. Our voice is heard and listened to, but in the right places",* said Marco Greco.

Through these resources, we hope to contribute to building a patient-safety culture where all actors – including patients – work together and which encourages openness and transparency around adverse events to better prevent them.



3. Source: European Commission  
([http://ec.europa.eu/health/files/pharmacovigilance/qa\\_pharmacovigilance\\_2011\\_en.pdf](http://ec.europa.eu/health/files/pharmacovigilance/qa_pharmacovigilance_2011_en.pdf))



# 3

## EMPOWERED PATIENTS ARE AN ASSET TO SOCIETY

Empowerment can be seen as a process through which patients gain control over their lives, thereby increasing their capacity to act on issues that they themselves define as important.

At the individual level, empowerment aims to equip patients and their families with the capacity to participate in their own health-related decisions to the individual extent that they wish. At the collective level, patient organisations advocate for patients’ needs and concerns and seek involvement at the policy level to shape a more patient-centred healthcare system.

Ultimately, empowerment aims to realise the vision of patients as “co-producers” of health and as integral actors in the health system.

To achieve this, **there is a need to support patients**, inter-alia through high-quality information and health literacy and equip health professionals with the necessary skills to work in partnership with patients and to make health systems more patient-friendly.

Empowerment has been a major, cross-cutting theme in all our work since our creation. Our advocacy activities have been mainly focused on chronic-disease management, as we focus closely on this area at both the EU level and on a global scale.

2011

EPF continued to play an active role in the development of the partnership through participation in the high-level steering group that drafted the **Strategic Implementation Plan (SIP)**.

Following the SIP’s adoption in 2011, EPF—and several of our member organisations—became involved in the **EIP-AHA implementation** in key thematic action areas, such as adherence and health literacy, integrated care, nutrition and the governance and monitoring of the partnership.

EPF also developed a robust response to the **Commission’s public consultation on chronic disease** in preparation for its reflection process.

2010

In December 2010, the decision to launch a **pilot European Innovation Partnership on Active and Healthy Ageing (EIP-AHA)** was adopted. EPF has been very closely involved in the partnership from the outset, resulting in a strong contribution to the Commission’s public consultation in 2011.

2013

### ENOPE

On 26 November 2013, EPF formally joined the **European Network on Patient Empowerment (ENOPE)**, which promotes patient empowerment in Europe.



*“EPF welcomes the chance to collaborate with this network, which shares our fundamental philosophy that patients are a valuable resource for health systems,”* said our Senior Policy Advisor Kaisa Immonen-Charalambous.



[www.enope.eu](http://www.enope.eu)

### OLDER PATIENTS’ NEEDS AND RIGHTS

We developed a position paper on **older patients’ needs and rights** to make recommendations for EU institutions, member states and stakeholders to further cooperate and work towards achieving the changes that are needed to meet the needs of older patients and uphold their rights across Europe. This document complements our work within the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA).



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

2013

PROJECTS

## JOINT ACTION ON CHRONIC DISEASE

NEW IN 2013!

Member states identified a joint action under the 2013 health programme as the next step forward in the EU Chronic Disease Reflection process. We became a partner in the new Joint Action on Chronic Disease, named CHRODIS-JA, which will commence in early 2014.

PROJECTS

## PROJECT: EMPATHiE

NEW IN 2013!

EPF, as part of a consortium of experts, participated in the EMPATHiE tender “EMpowering PATients in the management of chronic diseases”.

The tender, which is still in progress, sought to achieve a common understanding of the concept of patient empowerment and to identify good practices, success factors and barriers to chronic disease management. EPF leads Work Package 4, which will define scenarios for European collaboration in this area. This mapping assessment will help shape the future development of EU policies for patient-centred healthcare, particularly in the context of the EU ‘Reflection process on chronic disease’.



[www.eu-patient.eu/whatwedo/Projects/Associated-Partner/EMPATHiE](http://www.eu-patient.eu/whatwedo/Projects/Associated-Partner/EMPATHiE)

PROJECTS

## PROJECT: EUPATI, THE “EUROPEAN PATIENT ACADEMY ON THERAPEUTIC INNOVATION (2012-2017)<sup>4</sup>

ONGOING

The European Patient Academy’s annual conference was held in Rome, Italy, on 19 April 2013. It was an opportunity, 14 months after the launch of this EPF-led EU project, to hear about plans currently under way and to look ahead at future challenges.

To enable patients to play a full part in the medicines research and development (R&D) process, the academy focuses on three areas of training and education:

1. A certificate-level course delivered in English for **100** patient leaders across Europe.
2. An online education toolbox and an Internet library will be developed for **12,000** patient advocates in seven languages – English, German, Spanish, Polish, French, Italian and Russian.
3. A multilingual Internet platform for lay patients and the general public explaining specific aspects of the medicines’ development process, reaching a minimum of **100,000** people with an interest in health.



[www.patientacademy.eu](http://www.patientacademy.eu)



PROJECTS

## PROJECT: EMPATHY (2012-2013)<sup>5</sup>

COMPLETED

The EMPATHY “Europe Meets Young Patients” project consisted of a four-day seminar organised by the EPF Youth Group with the support of the EPF Secretariat and took place in Brussels on 8-11 July. The young patients, aged 15 to 25, spoke up about their needs to European policy-makers and stakeholder actors. EPF dedicated a special edition of our newsletter to this project in August 2013.



Andrew Zammit McKeon, 23, Malta, Maltese Diabetes Association: “The EMPATHY seminar was the opportunity to discuss and identify issues that young patients face regardless of their nationality or their condition. It also showed to older patient leaders and stakeholders what issues are truly affecting us as young patients.”

4. Funding programme: Innovative Medicines Initiative (IMI), a public-private partnership between the European Commission and EFPIA

5. Funding programme: Youth in Action Programme

# 4

## HEALTH LITERACY & INFORMATION TO PATIENTS: VITAL FOR EMPOWERMENT



Health literacy<sup>6</sup> is more than the ability to read and comprehend written medical information and instruction. It encompasses access, comprehension and evaluation of health information, as well as the relation of the information to oneself and one's health and the ability to transform health information into appropriate action.

Health literacy is both a means and an outcome, with the fundamental aim of empowering people to take control of their well-being in everyday life. From a patients' perspective, the knowledge and competence gained through health literacy leads to the strength and empowerment necessary to well manage a disease and its impacts on quality of life.

2005

The **High Level Pharmaceutical Forum**, launched in 2005, maintained focus on its working groups surrounding information to patients regarding disease and treatment options. In this framework, **EPF participated with a working group of experts** from member states, stakeholders and three representatives of the European Parliament to find ways to improve the quality of information to patients. **One of the main outcomes of this forum was the 2008 adoption of quality principles for information to patients, which has since formed EPF's point of reference for information to patients, regardless of the source.**

2008

A **public consultation on the key elements of a legislative proposal on information to patients** was launched by the Commission in February 2008. In our response, we stated that *"all patients, regardless of their condition or background, have a fundamental and legitimate human right to access quality information about their health, medical conditions and the availability of treatments- including knowledge of the best available management of their disease"*. We also outlined our commitment to health literacy: *"It is vital that community action continues to support the development of health literacy for patients to ensure that patients are not only informed, but are also empowered"*.

The Commission adopted **two other legislative proposals as part of the 'Pharmaceutical Package'** in December 2008 (see also p. 20, the legislative proposal on pharmacovigilance and p. 30 the legislative proposal on falsified medicines). The overall objective was to harmonise current practices across the EU and ensure that all EU citizens have equal access to reliable and quality information on existing medicines.

This legislative process formed a major focus of our advocacy work in the following years as we published a number of

**position statements and proposals for amendments to improve the directive**, which was perceived as too narrow in focus. We welcomed the shift in focus to patients' rights following the **report of MEP Christopher Fjellner** (EPP, Sweden), and the move of this dossier from DG Enterprise to DG SANCO. We also continued to call for a comprehensive EU strategy on information to patients, including health literacy, and focused on the needs of patients.

Regrettably, despite the improvements achieved, the dossier languished in the Council with no resolution. Some aspects have fortunately been taken on in other legislation, such as the **Pharmacovigilance Directive**.

2008  
2009

EPF, supported by leading health professionals' organisations, conducted a campaign in the European Parliament for a written declaration on health literacy. It called for the creation of a new health literacy network involving all member states and stakeholders, as well as further research in this area to identify its role in healthcare and health outcomes.

**"Health-literate patients: can they really make a difference?"** was one of the key questions raised during the European Patients' Forum's Spring Conference dedicated to this theme on 8–9 April 2008 in Brussels. The conclusions drawn there still shape our advocacy work.

Health literacy was also a key aspect of our manifesto campaign **"150 million reasons to act"** surrounding the 2009 European Parliament elections.

2011

On 12-13 July 2011, EPF held a **flagship conference on the "Rights and Needs of Older Patients"** in Warsaw under the EU Polish Presidency, which included a session on health literacy for older patients.

6. Sorensen K et al. (2012)



## EPF'S POSITION

**Health literacy** is a topic close to EPF's heart and a cross-cutting issue for us as it is essential for equity, quality and efficiency of patient-centred healthcare systems.

Patients need accessible, reliable and understandable health-related information to make genuinely-informed decisions about their health and treatment. Information is a key aspect of health literacy. Health literacy, in turn, is a key dimension of empowerment, as it helps to well manage a disease and its impacts on quality of life.

Health literacy also has a critical relevance for health inequalities (see p. 32). Health literate people are more discerning about their health, make more informed choices and decisions, are more likely to seek earlier diagnosis and recover faster.

 [www.eu-patient.eu/whatwedo/Policy/Health-Literacy](http://www.eu-patient.eu/whatwedo/Policy/Health-Literacy)

 [www.eu-patient.eu/whatwedo/Policy/Information-to-Patients](http://www.eu-patient.eu/whatwedo/Policy/Information-to-Patients)

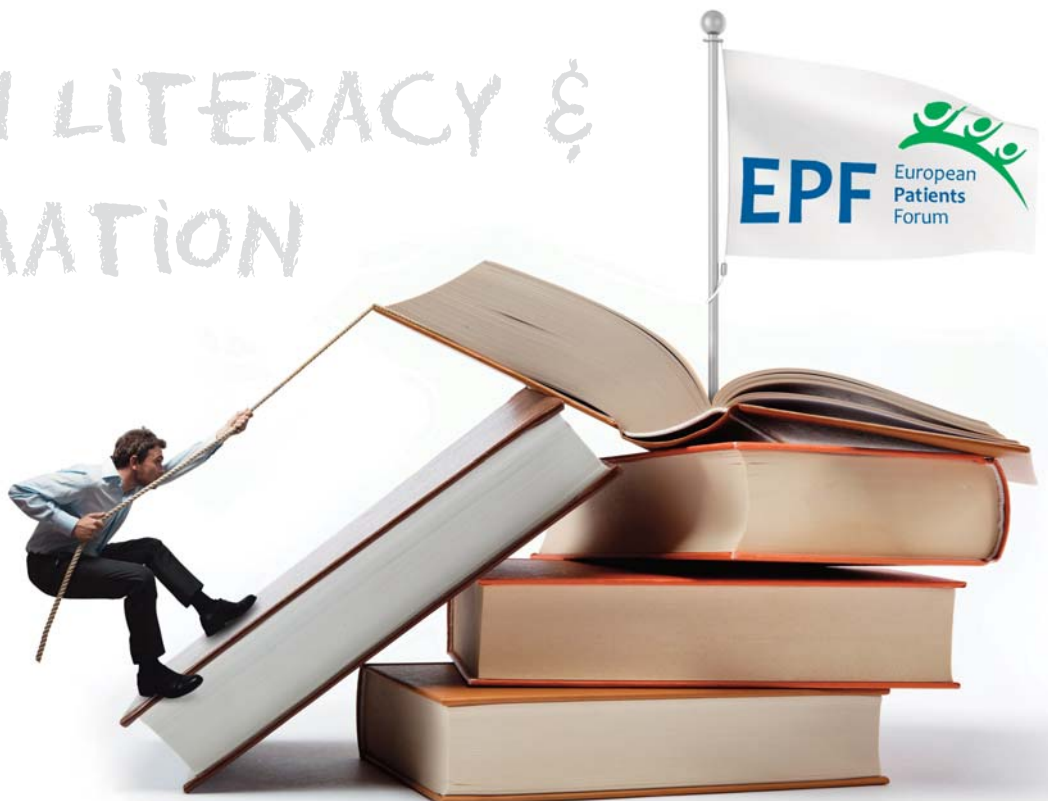
2013

During 2013, EPF focused work on **informal collaboration with other stakeholders** on health literacy.

We developed a **joint consensus paper** on how to advance health literacy in Europe that was launched on 4 October at the European Health Forum in Gastein, Austria, and subsequently presented to Health Commissioner Tonio Borg. The consensus paper was accompanied by a number of **recommendations for action** to be taken at the European level, including a comprehensive mapping exercise on health literacy.



HEALTH LITERACY &  
INFORMATION



# 5

## PATIENTS AS EQUAL PARTNERS IN RESEARCH



Clinical trials are an essential tool for developing new-and better-medicines and treatments to respond to unmet medical needs.

The main legislative instrument laying down the requirements for the conduct of clinical trials in the EU is the Clinical Trials Directive (2001/20/EC) which is complemented by the Good Clinical Practice Directive (2005/28/EC) and various other guidelines. In July 2012, the European Commission presented its legislative proposal for a regulation that will replace the Clinical Trials Directive.

2009  
2011

EPF responded to the **two European Commission public consultations** and reiterated our key principles: **more patient involvement in trial design and assessment, access to high-quality information, meaningful informed consent and equitable access to treatment.**

We welcomed the launch of the **EU Clinical Trial Register**, in line with our call for greater transparency around clinical research. The online register gives public access to information on clinical trials for certain authorised medicines and allows the public to search for information on clinical trials authorised to be carried out outside the EU if these trials are part of a paediatric investigation plan. We will continue to support the EMA through the **Patients' and Consumers' Working Party** to ensure that the register further meets the practical needs of patients.

2012

EPF contributed to the **reflection paper of the European Medicines Agency (EMA) on the application of Ethical and Good Clinical Practice (GCP) standards in third-country trials.** The goal was to address the increasing globalisation of clinical research in the context of the EU marketing authorisation applications.

We organised an internal **Patient Evidence Workshop** with our members in December 2012 to discuss specific aspects of the proposed new clinical trials regulation.



EQUAL  
PARTNERS

## EPF'S POSITION ON CLINICAL TRIALS

The effectiveness of the clinical trials regulatory framework ultimately impacts patients' access to new therapies throughout the EU. It is therefore of fundamental importance for our members.

**Our objective is to ensure that the new legislative framework at the EU level is effective, proportionate, and patient-centred.** We believe the **review of the legislative framework** presents an opportunity for reform towards more patient involvement throughout the research process, greater trust and public confidence in medical research and improved participation rates.



[www.eu-patient.eu/whatwedo/Policy/Clinical-Trials](http://www.eu-patient.eu/whatwedo/Policy/Clinical-Trials)

2013

The **Trilogue negotiations** on the Clinical Trials Regulation concluded on 20 December 2013, when member states adopted a common position. EPF has published a statement on the compromise text, and a position paper will be circulated in 2014 on the new legislation.

We were very pleased with the improved provisions for transparency of all clinical trial results, whether positive or negative. From the outset, **EPF has called for the publication of all clinical trial results in a timely manner**, regardless of outcome. This is why we strongly supported the position of the rapporteur, MEP Glenis Willmott (S&D, UK), on transparency and joined the **All Trials Campaign** in 2013. Ensuring that results are promptly published after a research project is concluded, according to our members, is as important as the trial's approval in the first place.

+ AllTrials

However, **sharing patient-level data is a complex issue**. This requires thorough reflection on potential consequences to ensure sharing serves both scientific and public interests while also affording appropriate protection to trial participants. EPF welcomed the recent initiative by the EMA to open a **public discussion on how to best share data from clinical trials**.

## DATA PROTECTION

**In 2013, we also liaised with MEPs to provide recommendations surrounding the LIBE committee vote on Data Protection.**

We have been involved in the legislative process since 2012 to ensure the **right balance** between ensuring confidentiality for sensitive data and allowing for their availability and sharing for public health, healthcare and research purposes is reached. We promoted the right of patients to access their own data and receive transparent information on how these data are used.



*"Patients, as owners of their health and genetic information, have a fundamental right to participate in decision-making regarding the processing and protecting of their personal data; it is their health and their privacy that is at stake",* said Nicola Bedlington, EPF Executive Director.

# 6

## PATIENTS' VOICE TAKEN ON BOARD IN THE MEDICAL DEVICES REVIEW PROCESS



Medical devices include any apparatus, software, material or other article used for the diagnosis, prevention, monitoring, treatment or alleviation of disease, injury or disability. There are approximately 500,000 different devices currently on the market, covering a wide spectrum from simple bandages to x-ray machines and pacemakers.

Medical devices are of crucial, and often vital, importance for patients with chronic disease; they can contribute majorly to life expectancy and quality of life for patients. Before being placed on the market and reaching patients, medical devices undergo a conformity assessment to ensure they are safe and efficient.

2009

EPF and our members have been involved in the exploratory process on the **future of the medical device sector**. The process began in 2009 by mapping the existing public health and industrial challenges in the sector and investigating possible topics of reflection at the European level-such as the balance between patients' needs and financial sustainability. EPF, in collaboration with the EU consumer organisation, BEUC, presented a **discussion paper on information to patients** on this topic.

The aim of this dialogue was to exchange perspectives on the topic of common interests, such as patient safety or patient-centred healthcare, and to build mutual understanding. EPF also participated in the **High-Level Conference on medical devices** organised by the European Commission.

2012

In 2012, the European Commission issued **two proposals for regulations to modernise the current conformity framework** in order to improve safety and traceability of devices and ensure greater transparency towards patients and the general public. In Vitro Diagnostics, a specific type of device which includes all tests performed on patients to provide a diagnosis, either in a laboratory or through self-testing, are regulated separately.

2011

EPF launched the **Patient-MedTech Dialogue** in partnership with Eucomed. This was the first ever structured meeting of the medical technology industry with various patient organisations, including disease-specific organisations and national coalitions.

## MEDICAL DEVICES



## EPF'S POSITION

**Safer medical devices:** from EPF's perspective, future regulations should aim at achieving a high level of patient safety and quality of care.

**Improving transparency and information to patients:** EPF believes that more transparency towards the public is necessary to empower patients and ensure public trust and confidence in the safety of medical devices. Patients have a fundamental and legitimate right to access information on all aspects of their health and their treatments.

**Patient involvement:** EPF calls for meaningful patient involvement, individually and collectively, in the development process for medical devices. At the EU level, EPF calls for both direct involvement of patients in key decision-making bodies and scientific committees, and the setting up of a dedicated group for patients and consumers.



[www.eu-patient.eu/whatwedo/Policy/Medical-Devices](http://www.eu-patient.eu/whatwedo/Policy/Medical-Devices)

2013

## Medical Devices

Our longstanding work in this area, the publication of our position in April for Medical Devices, and our liaising with MEPs throughout the legislative process has enabled us to have some of our key demands taken on board by the European Parliament in plenary in October.

Key measures adopted by the European Parliament include: better information to patients on medical devices, assurance they are involved in decision-making about medical devices, and provisions to ensure patients can report incidents directly, which will improve the safety of devices.



*"The result of this vote is an important milestone towards safer medical devices for patients in Europe. The adopted text shows a strong commitment to transparency towards the public, and ensures that the patients' voice will be heard in all important parts of the process, from clinical investigations to vigilance. We call on the EU institutions to stay the course in the next phase of the legislative process",* said Nicola Bedlington.

The Council is due to adopt its position in 2014.

## In Vitro Diagnostic Medical Devices

EPF also released a position paper in September 2013 on In Vitro Diagnostic (IVD) medical devices, where MEP Peter Liese (EPP, Germany) was rapporteur, focusing on demanding improved information for patients. We also asked for better regulation of genetic tests sold directly to consumers, to ensure they are clinically valid and that patients receive adequate information to understand the implication of the test and its results.

## Memorandum of Understanding with Eucomed

EPF signed a Memorandum of Understanding (MoU) with Eucomed, the European medical technology industry association, in March 2013. We agreed to work jointly on developing patient-centred healthcare models and exchange views on EU legislation that affects our membership. The collaboration is based on the ethical principles of transparency and independence, and the third objective of the MoU is to develop a common approach towards ethical and transparent relationships between patient organisations and the medical technology industry. We have started work towards concrete outcomes, such as a checklist defining a patient-centred company.

# 7

## PATIENT SAFETY AT THE HEART OF OUR WORK



Patient safety and quality of care are at the heart of our work and included in five of our six core strategic goals. We integrate and prioritise patient safety in all our work - such as our legislative work on EU Directives on pharmacovigilance, falsified medicines, medical devices and professional qualifications - as it is fundamental to all aspects of healthcare that patients receive.

**2006** EPF participated in the **European Commission Working Group for Patient Safety (later re-named Patient Safety and Quality of Care)**, which advises the High-Level Group in developing the EU patient safety and quality agenda.

**2008** EPF responded to the **Commission's consultation on patient safety**, the aim of which was to gather information about general patient safety issues and concerns in preparation for the Council Recommendation.

EPF also responded to the European Commission's consultation on the third legislative proposal published in 2008 as part of the **"Pharmaceutical Package"** on Falsified Medicines. The aim was to strengthen EU legislation to better protect EU citizens from the serious threats posed by **fake medicines** and protect the legal distribution chain from the infiltration of fake medicines.

**2009** EPF contributed to the drafting of the **Commission Communication and Council Recommendation on patient safety**. The resulting Recommendation included a specific section on the empowerment of and information provided to patients and citizens, with specific actions to be taken at the national level.

Our response to the 2008 **European Commission's Green Paper on the European Workforce for Health** was an important milestone. It was the first time we provided a patient perspective on future needs in terms of the health workforce, as well as suggestions on how to face future challenges like the shortage of the health workforce combined with an ageing population.

**European Network for Patient Safety project (2008-2010)** EPF was an associate partner in the European Network for Patient Safety, EUNetPas, from 2008 to 2010 to encourage and enhance collaboration in the field of patient safety.

**2011 2012** EPF published a **position statement** on the review of the **Professional Qualifications Directive** in 2012, after having **responded to the Commission's consultation** in March 2011. We also issued a joint statement with the European Public Health Alliance (EPHA) to assert that safety and quality of care must remain the highest priority in healthcare review and to highlight the importance of maintaining existing minimum training requirements for healthcare professionals.

At the core of our position on patient safety is our strong belief that patients **play a key role in identifying health-care service needs**, including what appropriate skills and competences are needed for high-quality healthcare. **As patients, we live with our conditions every day, and thus become 'experts by experience'**. We should be involved in the development of training schemes for healthcare professionals.

PATIENT SAFETY

2013



EPF conducted a **member survey on patient safety** to gauge the extent of awareness of the existing Council Recommendation, as well as the activity levels of patient organisations in various member states.

This was followed by our annual **Patient Evidence Workshop** in November, which focused exclusively on patient safety this year. The results of these exchanges will feed into our continued work in this area, including the contribution of a patient perspective in the EC's second implementation report, due to be published in April 2014, and for which a public consultation was launched in late 2013.



We were invited to the **EC Working Group on the Health Workforce**, which showed patients' input on healthcare professionals' skills is increasingly valued and taken into account by decision makers.

The Internal Market and Consumer Protection Committee of the European Parliament (IMCO) adopted on 10 July the final text of the **Professional Qualifications Directive**, after the European Parliament and the Council reached a political agreement.

We have stressed that the language competences of migrating healthcare professionals need to be assessed more carefully and that clear provisions are needed to allow competent authorities to systematically check language skills of healthcare professionals.

EPF welcomed this draft Directive as a step forward for patients' safety.

 [www.eu-patient.eu/whatwedo/Policy/Patients-Safety](http://www.eu-patient.eu/whatwedo/Policy/Patients-Safety)



PROJECTS

ONGOING

 PaSQ European Union Network for Patient Safety and Quality of Care

### European Union Network on Patient Safety and Quality of Care – PaSQ Joint Action (2012-2015)

The Joint Action is a 'natural' continuation of the EUNetPas project as it aims to create a permanent platform for future cooperation between member states in the area of patient safety and quality of care.

As an associate partner, one of EPF's tasks is to identify and evaluate good practices to improve safety and quality of care that involve patients and their organisations, as well as ensure meaningful patient involvement is embedded into the permanent network.

# 8

## EQUITABLE ACCESS TO HIGH-QUALITY HEALTHCARE



“Health inequalities are preventable and unfair differences in health status between groups, populations or individuals. They exist because of unequal distributions of social, environmental and economic conditions within societies that determine the risk of people getting ill, their ability to prevent sickness, or opportunities to access the right treatments.”<sup>7</sup>

2009

The European Commission launched a public consultation as part of the EU Health Strategy, “**Together for Health**”. EPF developed a response framed around our vision of high-quality, equitable healthcare and our strategic goals on equity, empowerment and inclusion.

Based on the public consultation, the Commission published a **Communication titled “Solidarity in health: reducing health inequalities in the EU”**. From our perspective, the text was not satisfactory as it made no reference to the particular needs of patients or the importance of health literacy.

2011

EPF achieved recognition in the European Parliament via **the report of MEP Edite Estrela (S&D, Portugal) on reducing health inequalities in the EU (2010/2089 (INI))** which stated that *“patients with chronic diseases form a specific group suffering in-equalities in diagnosis and care, social and other support services, and disadvantages including financial, employment and social discrimination, whose needs should be addressed”*.

2012

On 20-21 September, the first Conference on “**Health inequalities in the New Member States**” was held in Sofia, Bulgaria organised by our member NPO in collaboration with EPF.

In our response to the European Commission’s **stakeholder consultation on the reflection process on chronic diseases**, EPF strongly highlighted health inequalities as an essential aspect to be tackled.

We welcomed the Commission’s proposal in October on the so-called “**Transparency Directive**” as a step forward for more transparent and effective processes on pricing and reimbursement of medicines. **However, further steps are still needed to improve patients’ access to therapies.**

EQUITABLE ACCESS TO HEALTHCARE



Conference on “Equity of Access to Quality Healthcare”, 26 June 2013, Brussels, Belgium



7. Source: glossary of the European Portal For Action on Health Inequalities



## EPF'S POSITION

EPF supports the principle of 'equity and health in all policies', and our core value of equitable access to high-quality healthcare for all patients informs our policy work on health inequalities. As a representative organisation of patients of chronic illness and their families, we focus on chronic disease as a factor leading to health and social inequalities and patient-centred disease management as a crucial part of the continuum encompassing prevention and health promotion.

In our view, patient empowerment and health literacy are among the fundamental aspects of tackling health inequalities, and we will continue to incorporate these aspects in our work in this area and the wider perspective on chronic disease.

In 2013, we created a video on the project: [www.youtube.com/user/eupatient](http://www.youtube.com/user/eupatient)



[www.eu-patient.eu/whatwedo/Policy/Health-inequalities](http://www.eu-patient.eu/whatwedo/Policy/Health-inequalities)



# 2013

The second **Conference on Health Inequalities**, organised by NPO and EPF at the European Parliament on 26 June 2013, produced high-impact results. MEP Andrey Kovatchev (ALDE, Bulgaria) decided to set up an interest group of MEPs to address health inequalities and promote equal access. The meeting also laid the foundations for the establishment of an EU partnership on patient access and equity.

The "**Consensus Meeting on Access and Equity for Patients**", organised by our member organisation, the Federation of Polish Patients (FPP) on 3 December 2013 in Warsaw, Poland, continued the dialogue surrounding this multi-stakeholder platform on access.



*"Access to high-quality healthcare is a fundamental citizen's right. However, patient leaders are very aware that disparities in access exist and are even more pronounced due to the economic crisis and austerity measures"* said Stanimir Hasurdjiev, EPF Board Member from the National Patients' Organization (NPO), Bulgaria.

EPF also released our 2014-2020 Strategic Plan, where we added a new goal of non-discrimination. We aim to promote the development of EU and national policies that address prejudice faced by patients in health and social care, as well as in domains like education and employment.



[www.eu-patient.eu/whatwedo/Policy/Health-inequalities](http://www.eu-patient.eu/whatwedo/Policy/Health-inequalities)

PROJECTS

NEW IN 2013!



### We Care project (2013-2015)<sup>8</sup>

In September, EPF was proud to announce our participation in the consortium titled **We Care – "Towards a Sustainable and Affordable Healthcare"**. This two-year European project will investigate how quality healthcare services can be preserved in the EU while ensuring their viability in terms of costs.

PROJECTS

ONGOING



### InterQuality project (2010-2014)<sup>9</sup>

Spend not more, but smarter! **The InterQuality project** explores the effects of financing systems based on the quality of healthcare. It aims ultimately to provide models for member states to choose the right financing mechanisms in different areas of the healthcare system, according to their own needs and possibilities.

8, 9. Co-funded by the 7<sup>th</sup> Research Framework Programme (FP7)



# ALL FORMS OF INNOVATION IN HEALTH MUST BE USER-DRIVEN



EPF considers innovation as a key priority, because we believe that, when properly designed and deployed, it carries a huge potential for improving the quality of health services for patients while simultaneously serving the needs of health professional groups.

Too much innovation has been technology-driven rather than user-driven. We firmly believe that eHealth can deliver its promise of making healthcare systems more effective and equitable only if the needs of patients are at its core.

2011

EPF responded to the European Commission’s proposal for the 2014-2020 health programme titled “**Health for Growth**”, where MEP Françoise Grossetête (EPP, France) was rapporteur, both independently and jointly with the European Public Health Association (EPHA). The future **EU health programme** will provide a framework for the annual work plans of the Commission and the actions prioritised in the field of health.

2012

EPF contributed to the establishment of the **framework of the Horizon 2020 programme** through the European Health Policy Forum’s (EUHPF)’s position paper on the Commission proposals.

The **EU Task Force of High-Level Advisors on eHealth**, where EPF President Anders Olauson represents us, has recommended making use of information technologies already existing in order to reorganise healthcare in the report “**My data, my decisions**”.

2013

In November, the European Commission appointed **15 groups of independent experts to advise on priorities for Horizon 2020**, the EU research and innovation programme covering the next seven years. Our president, Anders Olauson, will represent the patients’ perspective in the “**Health, demographic change and wellbeing**” group.

On 23 January, 70 patient leaders from all across Europe attended the **seminar EPF organised on eHealth in Brussels**. This event was an excellent opportunity to explore advances and the ‘state of the art’ conditions on patient involvement in this area at both the policy and operational levels. This clearly emerged from the discussions on patients wanting to be more involved in eHealth policies, including the design, implementation, and assessment of these innovative types of services.



*“There won’t be a day we wake and all is eHealth. Like the stethoscope, it took centuries for it to become a tool for every doctor. But ICT should grow to make ehealth mainstream in healthcare”,* said Mr. Robert Madelin, Director General of DG Connect.

In February, the European Commission adopted its Social Investment Package for growth and cohesion, where investment in health was set as a priority. On the eve of an informal meeting of ministers of health on 4-5 March, we called on the Council to commit to investing in health, in people and in reducing health inequalities throughout Europe.

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

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


Numerous eHealth-related projects have taken place over the past few years:

**PROJECTS** **COMPLETED**




The EPF-led **Chain of TRUST project** (2011-2013)<sup>10</sup> ended with a conference in Brussels on 24 January 2013 that included a multi-stakeholder audience. The project produced a thorough assessment of main end users' perspective of telehealth services across Europe to see whether and how views have evolved since the initial deployment of such services. The project findings led to a set of recommendations that were included in the project's final report.

**PROJECTS** **ONGOING**



The **SUSTAINS project** (2012 -2014)<sup>13</sup> aims to develop services providing patients access to Electronic Health Records (EHR) in 11 European regions and a set of eHealth services associated with the EHR. EPF coordinated the implementation of user-requirement focus groups in 2013, which resulted in developing a set of recommendations addressed to regional partners in charge of developing those services. This year, we also coordinated the collection of baseline data for the assessment of the impact of patient-accessible HER on patient empowerment. This assessment will continue in 2014.

**PROJECTS** **COMPLETED**




The **Renewing Health project** (2010-2013)<sup>11</sup>, where EPF acted as co-manager of the User Advisory Board, came to an end in December 2013 with various workshops organised to share the project's results. This multi-site pilot project evaluated telemedicine services for patients with three of the most common chronic conditions: diabetes, cardiovascular diseases and Chronic Obstructive Pulmonary Disease (COPD).

**PROJECTS** **ONGOING**



The 2011- 2014 EU **eHealth Governance Initiative** (eHGI)<sup>14</sup> is an initiative designed to establish a platform enabling cooperation on eHealth between EU member states and stakeholders. EPF is a member of the Executive Committee and is co-leader of the Work Package dedicated to Trust and Acceptability.

**PROJECTS** **NEW IN 2013!**



The **SmartCare project** (2013-2016)<sup>12</sup> takes the deployment of integrated health and social care for older patients supported by Information Communication Technology (ICT) to an unprecedented level. The project uses ICT to integrate both health and social care to tailor these services to individual patient needs. As a member of the User Advisory Board, EPF will ensure the project considers the interests of older patients, drawing especially on our work with this patient group (see p.22).

**PROJECTS** **COMPLETED**



The **CALLIOPE project**, "CALL for InterOPERability"(2008-2011)<sup>15</sup>, was a thematic network with a focus on eHealth interoperability. It created a structured and open forum to support the implementation of interoperable eHealth infrastructures and services across Europe.

10. Funded under: the EU Public Health Programme

11, 12, 13, 15. Co-funded under: the Competitiveness and Innovation Framework Programme (CIP) under the Information and Communication Technologies (ICT) Policy Support Programme (PSP) of the European Commission (EC)

14. Funded under: JA under the EU Public Health Programme and a Thematic Network under ICT strand

# 10

## A MODEL TO INVOLVE PATIENTS



We patients, as healthcare users, need to be involved in designing more effective healthcare systems and in research in order to deliver new and better treatments. Meaningful patient involvement needs, however, to be supported through resources, tools and models.

### Patient Involvement in Health Technology Assessment (HTA)

**Health Technology Assessment (HTA)** is the systematic evaluation of properties, effects, and impacts of health technology. It covers medical, social, economic, and ethical issues.

This multidisciplinary tool should ideally involve the patients' perspective, as it has proved to be crucial to the success of HTA. However, we are still far from achieving meaningful patient involvement in HTA despite the good groundwork already done by patient organisations.

2010

EPF organised a seminar on HTA on 20 May and realised that patient organisations clearly needed support to be meaningfully involved in HTA processes.

2010  
2012

EPF initiated a research project in 2010 on this topic with three main stakeholders:

1. **HTA agencies (1<sup>st</sup> phase):** very few targeted agencies involve and integrate patients' perspectives in their work. Apart from financial resource constraints, main challenges are perceived to be lack of capacity, time and good methodologies to involve patients. The question concerning the exact stage of HTA where patient engagement is needed or is most useful was debated with the general acknowledgement being that it should be from the onset.
2. **HTA appraisal committees and decision-makers (2<sup>nd</sup> phase):** this research clearly illustrated the need for EPF to continue advocating for patient involvement in HTA. This group admits to not always involving patients – or not doing so in a systematic, comprehensive and meaningful way-despite that they consider it as beneficial.
3. **Patient organisations (3<sup>rd</sup> phase):** this phase confirmed that patient groups are poorly involved in both aspects of HTA and decision-making in the stages when decisions are made about treatment scoping or prioritisation. Without this early involvement, there is a serious risk that treatments will not conform to patients' needs, and that crucial needs will remain unmet.



HEALTH  
TECHNOLOGY  
ASSESSMENT

2013

Three reports emerged from our 2010-2012 research initiative – one per stakeholder group – as well as an integrated report offering an overview of the current situation in Europe in terms of patient involvement in HTA. It clearly showed the need to develop a methodology in this area and to build the capacity of those involved.

In response, EPF will establish a **Model for Patients' Involvement in HTA**, based on the model developed and validated for Value+, which can be applied in other contexts.

 [www.eu-patient.eu/whatwedo/Policy/Health-Technology-Assessment](http://www.eu-patient.eu/whatwedo/Policy/Health-Technology-Assessment)

PROJECTS

COMPLETED

**Value + project (2008-2010)**

**Value+ “Promoting Patients’ Involvement in EU supported health-related Projects”<sup>16</sup>** was a flagship project led by EPF. The basic premise is that patients’ meaningful involvement enhances health project results, which can contribute more effectively to policies towards patient-centred, equitable healthcare throughout the EU. Value+ helped to increase the capacity of patient organisations through a **resource kit** on ways to be involved as equal partners, on principles around consultation and how to use and disseminate project outcomes in the most efficient ways.

One step further, Value + provided a model with effective strategies to project leaders and policy recommendations for decision-makers to involve patients in EU Health projects.

 [www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/ValuePlus](http://www.eu-patient.eu/whatwedo/Projects/EPF-led-EU-Projects/ValuePlus)



FLAGSHIP PROJECT

**OTHER HTA-RELATED PROJECTS**

PROJECTS

ONGOING



**AdHopHTA Project (2012-2015)**

EPF has joined the Advisory Board of the European project **AdHopHTA – Adopting Hospital Based Health Technology Assessment (HTA)** to ensure the patients’ perspective is considered and **strengthened during the project’s lifecycle. It aims at strengthening the use and impact of high-quality HTA results in hospital settings.** Although several hospital-based HTA initiatives have emerged of late in Europe, they have yet to be examined systematically. Small, hospital-based HTA units produce valuable knowledge that is not easily accessible or transferrable to other EU hospitals due to a lack of coordination between them. AdHopHTA aims to produce **a handbook on best practices, a deployment toolkit and a (pilot) repository on hospital-based HTA products.** This will ultimately facilitate the transfer of knowledge in this area and improve the efficiency of ones already existing.

PROJECTS

ONGOING



**EUnetHTA Project**, collaboration and Joint Action (2006-2015)

The **EUnetHTA Project (2006-2008)** was established to create an effective and sustainable network for HTA across Europe. The EUnetHTA Collaboration followed in 2009 to lay the foundations of collaboration in the form of a **Joint Action (JA)**. The first phase of this JA ran from 2010 to 2012, and the second phase started in 2012 and is set to run until 2015.

The EUNetHTA Joint Action 2 will provide the European Commission and the member states with a general strategy, principles and an implementation proposal for a strong collaboration in the framework of the Cross-Border Healthcare Directive.

EPF is a member of the Stakeholder Forum created as part of the governance structure of the EUnetHTA JA, and which consists of organisations representing four stakeholder groups – patients/consumers, industry, payers and healthcare providers.

# 7. 10 YEARS OF PARTNERSHIP & COOPERATION



EPF places a strong emphasis on forging alliances and good working relations with European organisations with which we have a common agenda.



## COOPERATION WITH HEALTH STAKEHOLDERS

- We continued our good relationship with our sister organisation at the international level, the **International Alliance of Patients' Organizations (IAPO)** in line with our Memorandum of Understanding (MoU) signed in 2007 and collaborated as a speaker at their Global Patients' Congress and on various policy themes such as pharmacovigilance, anti-counterfeiting, clinical trials, etc.
- EPF has been a member of the **European Health Policy Forum** since 2006. The European Health Policy Forum is composed of key health stakeholders at the EU level to exchange information and give feedback to the Commission on health-related policy.
- We have interacted with the **World Health Organisation – European Regional Office** on issues such as patient safety since 2010.
- We joined the **European Network on Patient Empowerment (ENOPE)** by signing a MoU with them in 2013.
- We signed a MoU with the **European Society for Quality of Care (ESQH)** in 2011.
- We jointly campaigned (see p.30) with the **European Public Health Alliance (EPHA)** on the Public Health Programme. We also collaborated with them closely in the framework of the Lithuania EU Presidency Conference on the Sustainability of Health Systems.
- We have worked with the **European Consumers' Organisation (BEUC)**

- We collaborate closely with **EUROCARERS**, regularly attending their interest group meetings. EUROCARERS were also part of our advisory board for the Chain of Trust project.



## COOPERATION WITH EU INSTITUTIONS AND AGENCIES

- We have worked with **DG SANCO** as a member of the Working Group on Patient Safety and Quality of Care (see p. 30) since 2006 to provide advice to the Council Working Party on Public Health Issues in developing the EU patient safety and quality agenda. We are also participating in the Working Group on Health Workforce and represented in the Medical Devices Expert Group.
- We were involved with **DG Enterprise** as a member from 2010 to 2013 in the European Commission's Platform on Access to Medicines<sup>17</sup>; we were represented in the Steering Group, as well as in the six working groups through representatives of our member organisations.
- We are also represented in the **DG Enterprise** Platform on Ethics and Transparency and have contributed towards the new Guiding Principles for working with the pharmaceutical industry and health professionals.
- EPF initiated collaboration with the **European Union Agency for Fundamental Rights (FRA)** in 2011 as a member of their platform to complement our work on anti-discrimination.

17. [http://ec.europa.eu/enterprise/sectors/healthcare/competitiveness/process\\_on\\_corporate\\_responsibility/platform\\_access/index\\_en.htm](http://ec.europa.eu/enterprise/sectors/healthcare/competitiveness/process_on_corporate_responsibility/platform_access/index_en.htm)

- EPF was represented at the High-Level Steering Group of the European Innovation Partnership (see p.22).
- We were a member of the EU Task Force of High-Level Advisors on eHealth to prepare a specific report on the future of eHealth (see p.34).
- Our close involvement with the **European Medicines Agency (EMA)** includes our representation in the Patient and Consumer Working Party since 2006 to provide recommendations to EMA human scientific committees on all matters of interest to patients in relation to medicinal products. EPF was also member of the EMA's Working Group on Clinical Trials in Third Countries (see p.26) and EMA's Working Group on the EuraVigilance Medicines Safety Database in 2011-2012. In 2013, patients were also represented on the Agency's Pharmacovigilance Risk Assessment Committee (PRAC) for the first time. (see p. 20)
- 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**.
- EPF has worked together with the **European Federation of Nurses (EFN)** since 2011 to look at how both organisations can support their national members in obtaining European Structural Fund monies to translate EU health policies and orientations into practice.
- We are working in partnership with **the European Health Management Association (EHMA)**, **the European Hospital and Healthcare Federation (HOPE)**, and **the European Union of Medical Specialists (UEMS)**.
- We are also involved, together with some of these health stakeholders, in key high-level EU health committees and working parties and as associate partners in European projects such as the EuNetPas (see p.30), Chain of Trust (see p.35), joint action PaSQ (see p.31), joint action on chronic diseases and the EMPATHIE tender on patient empowerment (see p.23).



## COOPERATION WITH HEALTH PROFESSIONALS

- The respective boards of the **European Standing Committee of Doctors (CPME)** and EPF met in September 2007 to explore how we could best work together in relation to the new patient – doctor relationship. We agreed on a set of joint principles and work closely on key EU policy issues – particularly on issues around health literacy. We are also involved together in key high-level EU health committees and working parties and were associate partners in the EuNetPas (see p.30), and Chain of Trust (see p.35) projects.
- EPF also cooperates with the **Royal College of Physicians** in relation to their ongoing work in patient involvement and health literacy and their European activities.
- In 2008, EPF agreed with the **Pharmaceutical Group of the European Union (PGEU)** to have an ongoing dialogue on the issues linked to pharmacists' role in the provision of patient-centred healthcare. We had a joint action on medicine adherence in 2011.
- EPF has been a member of the **European Federation of Pharmaceutical Industries and Associations (EFPIA) Think-Tank** since 2003. This quarterly event is the occasion for patient organisations and the pharmaceutical industry to engage in dialogue on EU issues in the area of health and innovative medical research.
- EPF has also continued the bi-annual Patient-Medtech dialogue established in partnership with the medical devices industry association, **EUROMED**, in 2011. From this meeting of patients' association representatives and the MedTech industry emerged the Memorandum of Understanding in 2013 (see p. 29). EPF also liaises with the European Diagnostic Manufacturers Association (EDMA).
- We established a regular information exchange with **GSMA-Europe**, the European interest group of the international wireless operators association.
- We strengthened our work with **COCIR, the European Coordination Committee of the Radiological Electromedical and Healthcare IT Industry**.



## COOPERATION WITH INDUSTRY



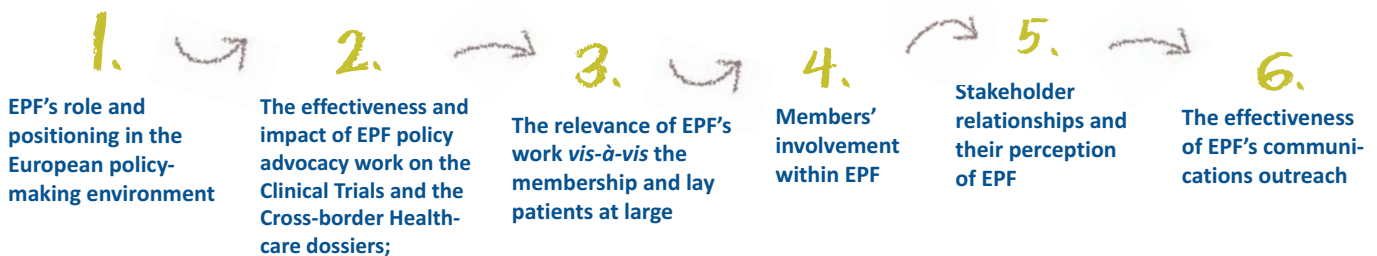
# 8. LET'S EVALUATE 2013!



*EPF Regional Advocacy Seminar,  
28-29 October 2013, Zagreb, Croatia*

EPF is committed to assessing the quality and impact of our activities. We therefore evaluated our 2013 activities to assess whether they have produced intended outcomes as defined in our Annual Work Programme.<sup>18</sup> The internal evaluation focused on assessing our core programme covered by the Operating Grant and also other activities such as the eHealth Seminar, the 10<sup>th</sup> Anniversary Conference and the first Regional Conference on Cross-Border Healthcare.<sup>19</sup>

This year, we have complemented our internal evaluation by an external one led by Cabinet DN Consultancy, selected following an open tender process. It assessed six areas:



The evaluation showed that EPF has been largely successful in meeting almost all Key Performance Indicators that were set for this year's Work Programme.

## POLICY-MAKING ENVIRONMENT

The policy advocacy work constituted the core part of the EPF 2013 Work Programme, and EPF has largely met all the objectives defined in the evaluation plan. There have been some deviations, but these have not affected the outcome of EPF advocacy work to any significant extent.

The external evaluation looked more specifically at EPF's impact on the Clinical Trials Regulation and on the Cross-Border Healthcare Directive, two of the key policy dossiers EPF has been engaged with over the past five years. EPF advocacy work did make an impact on these two policy

dossiers and has been one of the main driving forces behind the integration of some key patient-centred provisions in the final legislative texts.

## EVENT & CAMPAIGN ORGANISATION

The evaluation also showed that EPF has been quite successful at meeting all key performance indicators for all the events and meetings organised in the framework of the 2013 Work Programme.

- The **VI Regional Advocacy Seminar** proved very successful in terms of meeting participants' expectations, increasing their knowledge on the topics concerned, and generating high interest and enthusiasm among patient organisations from across the region.

18. Partly funded under: the Operating Grant in the framework of the EU Public Health Programme.

19. EU-funded projects and the Capacity Building Programme have their own monitoring and evaluation strategies and plans in place.



- The **meetings of the Policy Advisory Group (PAG)** have proved useful in terms of informing the development of policy positions in some key areas such as patient safety, clinical trials and medical devices, as well as discrimination, which was a totally new area for EPF.
- The **2013 Annual General Meeting (2013)**, held in Dublin in May 2013, was assessed quite positively by EPF members, who nonetheless called on the Secretariat and Board to make some effort in order to allow for more interactive discussions and active participation of all members in future AGMs.
- **The Patient Evidence Workshop (PEW)** seemed to have been less successful in terms of contributing to the objectives of the 2013 Work Programme. The PEW focused on shaping patients' contribution to EU-level policy in patient safety. Low attendance has been identified as one factor that contributed to making this event less impactful than expected. EPF needs to reflect on how to ensure and support adequate participation in our events and meetings and/or set more realistic participation targets, especially when targeting countries where EPF has no members or when the subject is complex for or relatively new to its intended audience.

The evaluation also showed that the EPF Campaign for the 2014 EU Elections launched in October 2013 is well on track, but more effort needs to be put into getting the commitment from decision-makers, as well as the active support from patient organisations- especially at the national level.

## EPF COMMUNICATIONS

EPF produced **12 newsletters**, including one 2013 annual review, and **disseminated them to 3,316 individuals** (2012: 2,416) in 2013. The **EPF website has been visited 39,214 times** (2012:30,430) by **24,976 unique visitors** (2012:18,951) in 2013. The **EPF blog has been visited 924 times** (2012: 436) by **774 unique visitors** (2012:356) in 2013. The **EPF Facebook page reached 2,046 'likes'** (2012:200) in 2013. The EPF **Twitter account was followed by 724 followers** (2012: 250) in 2013. The EPF video "EPF from 2003 to 2013" was seen **505 times** and the EPF video "EPF change of logo" **301 times** on YouTube while last year's video "The EPF Board on video" had compiled **157 views**.

## RELATIONS WITH OUR MEMBERS

The overall results of the external evaluation show that EPF's positioning and way of working are more than satisfactory for our members as well as for the external stakeholders who were reached through semi-structured qualitative interviews. It also emerged that EPF delivers tangible results in terms of ensuring that EU health-related legislation takes into account the views and interests of patients.

Few improvements *vis-à-vis* previous years have been noted in respect to members' participation in policy consultations launched by the EPF Secretariat. This area remains a weakness EPF will focus on in the years to come to further strengthen the credibility of our policy work, as well as the ownership of that work among all members.

Another area requiring improvement is the Youth Group which needs to be further integrated into the activities-as well as the governance structure-of EPF, as envisaged in the Youth Strategy. Moreover, additional effort needs to be put into increasing the membership of the group with a view of covering disease and geographic areas that are currently under-represented.



To read the entire report, please visit:  
[www.eu-patient.eu/whatwedo](http://www.eu-patient.eu/whatwedo)



EPF Patient Evidence Workshop, 21 November 2013, Brussels, Belgium



EPF Regional Advocacy Seminar, 28-29 October 2013, Zagreb, Croatia

# 9. SECRETARIAT AND GOVERNANCE

## EPF BOARD

EPF is administered by a **Board of Members**, elected at the Annual General Meeting for a term of two years, which meets five times yearly to provide political leadership, ensure the good running of the Secretariat and oversee the implementation of the Annual Work Programme.

RE-ELECTED IN 2013

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



CONTINUED MANDATE

**Philip Chircop**, Malta Health Network (MHN)



CONTINUED MANDATE

**Avril Daly**, Retina Europe



RE-ELECTED IN 2013

**Marco Greco**, European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA)



ELECTED IN 2013

**Stanimir Hasurdjiev**, Bulgarian National Patients Organisation (NPO)



RE-ELECTED IN 2013

**Robert Andrew Johnstone**, National Voices



STEPPED DOWN IN 2013

**Maria Navarro** from the Spanish Patients' Forum stepped down in 2013.



THANK YOU!

CONTINUED MANDATE

PRESIDENT  
**Anders Olason**, Eurordis



CONTINUED MANDATE  
VICE-PRESIDENT

**Susanna Palkonen**, European Federation of Allergy and Airways Disease Patients Associations (EFA)



CONTINUED MANDATE  
TREASURER

**Tomasz Szelaowski**, Federation of Polish Patients (FPP)



## EPF POLICY ADVISORY GROUP

The EPF Policy Advisory Group (PAG) was set up in 2009 to advise the EPF Board and Secretariat on policy priorities, emerging issues and complex issues that require detailed and in-depth discussion. It complements the membership consultation process and is open to all members. In 2013, the PAG comprised the following members designated by EPF member organisations:

- **Gunta Anca**, SUSTENTO - Umbrella Body For Disability Organization (Latvia)
- **Ian Banks**, EMHF - European Men's Health Forum (Europe)
- **Robert Johnstone**, National Voices (UK)
- **Alastair Kent/Nick Meade** (alternate), EGAN - European Genetic Alliances Network (Europe)
- **Flaminia Macchia**, EURORDIS
- **Hanna Milczarek**, FPP - Federation of Polish Patients (Poland)
- **Rod Mitchell**, EFCCA – European Federation of Crohn's and Ulcerative Colitis Associations
- **Maria Navarro/Guadalupe Morales** (alternate), Spanish Patients' Forum (Spain)
- **Raluca Nica**, GAMIAN - Global Alliance of Mental Illness Advocacy Networks (Europe)
- **Sophie Peresson**, IDF Europe - International Diabetes Federation (Europe)
- **Becky Purvis**, AMRC - Association of Medical Research Charities (Europe)
- **Roberta Savli**, EFA - European Federation of Allergy and Airways Disease Patients Associations (Europe)
- **Hildrun Sundseth**, EIWH - European Institute of Women's Health (Europe)
- **Anthia Zammit**, MHN – Malta Health Network (Malta)

NEW IN 2013!

## EPF SECRETARIAT

The EPF Secretariat, overseen by the Executive Director, executes the Annual Work Programme and works to support and inform the members.



## EPF YOUTH GROUP

The Youth Group is the backbone of the EPF Youth Strategy. It is the reference group where the needs and expectations of the young patient community are formulated and communicated to EPF and its members. Nominated by our members, 11 young patients' representatives between the ages of 15 and 25 – each with different conditions – compose the Youth Group.

- **Aneela Ahmed**, National Voices (UK)
- **Borislava Ananieva**, ELPA - European Liver Patients Association (Europe)
- **Martha Carabott**, MHN - Malta Health Network (Malta)
- **Marta Dimitrova**, NPO - National Patient Organisation (Bulgaria)
- **Claire Hunt**, EFCCA - European Federation of Crohn's and Ulcerative Colitis Associations (Europe)
- **Cristina Iscu Lacatusu**, COPAC - Coalition of Patient Organisations with Chronic Diseases (Romania)
- **Marek Marszalek**, FPP - Federation of Polish Patients (Poland)
- **Yolita Pavlova**, KZZ - Confederation Health Protections (Bulgaria)
- **Marlou Schenk**, EGAN - European Genetic Alliances Network EGAN/ Fabry Support and Information Group (Netherlands)
- **Policarpos Stavrou**, IDF Europe - International Diabetes Federation (Europe)
- **Simas Stoncius**, LPOAT - Council of Representatives of Patients' Organisations (Lithuania)



# 10. EPF MEMBERS



## AN EVER GROWING EPF MEMBERSHIP – TOGETHER FOR PATIENTS' RIGHTS

### • 2003 – Getting started

In 2003, EPF is created by 13 organisations committed to cooperation on cross-cutting issues affecting all patients.

### • 2006 – Opening to national coalitions

EPF modifies its status to allow national coalitions to join.

### • 2013 – A large community

EPF has grown steadily to become a large community which now includes more than 60 members.

Through our network, we represent the interests of an estimated 150 million patients across the European Union.

## WHAT'S NEXT? A GLANCE AT THE FUTURE

Our members are our compass. One of EPF's main concerns is **ensuring that we optimally serve the needs of our members**. To this end, EPF is constantly looking for innovative ways to engage our members and provide them with support in their work and activities. In 2014, EPF plans to present a new membership strategy which will propose solutions for the **consolidation and broadening of EPF membership**. Developed in alignment with the EPF Strategy 2014-2020, this document aims at taking on the three following challenges:

## 1. MAKE IT SMARTER! MORE SYNERGIES WITH OUR MEMBERS' WORK

EPF acknowledges the breadth of our members' expertise and knowledge. We also understand that different organisations with different needs and skills will need different support. We want to explore further the complementarity between the work EPF undertakes in a specifically-EU context and in EPF members' work.

## 2. MAKE IT VIBRANT! A PLACE TO EXCHANGE

We want to effectively involve members in "growing" EPF and our member organisations through well-structured consultation and sharing of information, know-how and good practice. EPF should be a privileged interlocutor for all patient organisations and the place where members come and **look for and share information, experience, tips and contacts**.

## 3. MAKE IT LOUD! ADDING MORE VOICES TO THE CONVERSATION

It is the sum of individual commitments that makes a **difference and benefits patients' rights**. In order to make sure our work represents the full variety of patients' views in Europe, EPF is **looking at broadening our network and involving potential new members** in joint policy initiatives or projects.

## EXTENDING THE MEMBERSHIP

EPF is proud to see our membership has grown to 60 members!

In 2013, EPF welcomed 6 new members:

### • Full Members

- **IOF** - International Osteoporosis Federation (International\*)
- **PHA Europe** - Pulmonary Hypertension Association Europe (Europe)

### • Associate Members

- **AMRC** - Association of Medical Research Charities (Europe)
- **EFNA** - European Federation of Neurological Associations (Europe)
- **MRCG** - Medical Research Charities Group (Europe)

### • Provisional Member

- **APMAR** - Association for People with Rheumatic Diseases / Associazione Persone con Malattie Reumatiche Onlus (Italy)

## FULL MEMBERS (43)

Full EPF Members include:

- Pan-European disease-specific patients' organisations and
- National coalitions of patient organisations which represent at least 10 different disease groups

EPF Full Members are organisations who fulfil criteria relating to legitimacy, representation, democracy, accountability and transparency.

- **Alzheimer Europe** (Europe)
- **AMDIAI** - Age Related Macular Degeneration Alliance International (International\*)
- **AOECS** - Association of European Coeliac Societies (Europe)
- **AOPP** - Association for the Protection of Patients' Rights / *Asociația na ochranu prav pacientov SR* (Slovak Republic)
- **CEAPIR** - European Kidney Patients' Federation (Europe)
- **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)
- **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)
- **EHLTF** - European Heart and Lung Transplant Federation (Europe)
- **EIA** - European Infertility Alliance (Europe)
- **EPIK** - Estonian Chamber of Disabled People / *Eesti Puuetega Inimeste Koda* (Estonia)
- **EUROPA DONNA** - The European Breast Cancer Coalition (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)
- **EUFAMI** - European Federation of Associations of Families of People with Mental Illness (Europe)
- **EUROPSO** - European Umbrella Organisation for Psoriasis Movements (Europe)
- **EURORDIS** - European Organisation for Rare Diseases (Europe)
- **Fertility Europe** (Europe)
- **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\*)** **WELCOME!**
- **IPOPI** - International Patient Organisation for Primary Immunodeficiencies (International\*)
- **KZZ** - Confederation Health Protections (Bulgaria)
- **LPOAT** - Council of Representatives of Patient Organisations of Lithuania / *Lietuvos Pacientų Organizacijų Atstovų Taryba* (Lithuania)
- **LUPUS Europe** (Europe)

\* Organisations who do not have a formally-constituted branch in Europe but are active in the European region.

- **MHN** - Malta Health Network (Malta)
- **National Voices** (United Kingdom)
- **NPO** - National Patient Organisation of Bulgaria / Национална пациентска организация (Bulgaria)
- **Panyprian Federation of Patients Associations and Friends** (Cyprus)
- **PE.Pso.POF** - Pan-European Psoriasis Patient Organisations Forum (Europe)
- **PHA Europe - Pulmonary Hypertension Association Europe (Europe)** WELCOME!
- **Retina Europe** (Europe)
- **Spanish Patients' Forum / Foro Español de Pacientes** (Spain)
- **SUSTENTO** - The Latvian Umbrella Body for Disability Organization / Latvijas Cilvēku ar īpašām vajadzībām sadarbības organizācija (Latvia)

## ASSOCIATE MEMBERS (13)

All other interested organisations operating on a European level that include patient organisations as members but do not meet the Full Membership criteria can participate in the European Patients' Forum as Associate Members.

- **AMRC - Association of Medical Research Charities (Europe)** WELCOME!
- **APAI** - International Association for Autoimmune Pathologies / *Associazione Patologie Autoimmuni Internazionale* (International\*)
- **BAPD** - Bulgarian Association for Patients Defense / Българска Асоциация за Закрила 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)
- **EFNA - European Federation of Neurological Associations (Europe)** WELCOME!
- **EIWH** - European Institute of Women's Health (Europe)
- **EMHF** - European Men's Health Forum (Europe)
- **HOPA** - Hungarian Osteoporosis Patient Association (Hungary)
- **MRCG - Medical Research Charities Group (Europe)** WELCOME!
- **MHE-SME** - Mental Health Europe (Europe)

## PROVISIONAL MEMBERS (4)

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

- **APMAR - Association for People with Rheumatic Diseases / Associazione Persone con Malattie Reumatiche Onlus (Italy)** WELCOME!
- **EuropaColon** (Europe)
- **ENFA** - European Network of Fibromyalgia Associations (Europe)
- **WFIP** - World Federation of Incontinent Patients (Europe)



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

\* Organisations who do not have a formally-constituted branch in Europe but are active in the European region.

# CONTRACTUAL AUDITOR'S REPORT ON THE FINANCIAL STATEMENTS FOR THE YEAR ENDED DECEMBER 31, 2013

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, 2013, composed of a balance sheet and an income statement as well as notes to the accounts.

## Unqualified opinion on the financial statements

We have audited the financial statements for the year ended December 31, 2013, which were prepared by you in accordance with the financial reporting framework adopted by the Executive Committee. This financial reporting framework is intended to be a presentation in conformity with the accounting principles generally accepted in Belgium.

The financial statements show a Assets Total of **1.992.603 Eur** and a deficit for the year of **330 Eur**.

(...) In our opinion, the financial statements for the year ended December 31, 2013 give a true and fair view of the Organisation financial position and the results of its operations in accordance with the financial reporting framework as adopted by the Executive Committee.

## Additional comments and information

The Organisation compliance with the Law for non-for-profit associations and its articles of association is the responsibility of the Executive Committee.

Our responsibility is to include in our report the following additional comments and information, which do not modify the scope of our opinion on the special purpose financial statements:

- The financial statements are presented in accordance with the format of the official Belgium financial statements.
- The accounting policies applied when preparing these special purpose financial statements are in line with those as applied in prior periods.
- Without prejudice to formal aspects of minor importance, the accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.
- We do not have to report any transactions undertaken or decisions taken in violation of the Organisation articles of association (the "EPF Constitution") or the Law for not-for-profit associations.
- This report was prepared solely for the information and use of the Board of Directors and is not intended to be and should not be used by anyone other without our prior written approval.

Zaventem, February 17<sup>th</sup>, 2014

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

## BALANCE SHEET AS AT DECEMBER 31<sup>ST</sup> 2013

ASSETS	2013 (€)	2012 (€)
<b>I Current Assets</b>		
Accounts receivable	508,471.97	338,620.51
Short term investments	-	201,240.00
Cash in bank and deposit	1,370,648.04	1,082,117.39
Prepaid expenses	22,281.59	16,665.53
<i>Total current assets</i>	<i>1,901,401.60</i>	<i>1,638,643.43</i>
<b>II Fixed Assets</b>		
Leasehold	52,510.68	55,947.95
Furniture, ICT equipment and software	26,750.97	30,900.24
Guarantees (rent and social security)	11,939.67	11,733.04
<i>Total fixed assets</i>	<i>91,201.32</i>	<i>98,581.23</i>
<b>TOTAL ASSETS</b>	<b>1,992,602.92</b>	<b>1,737,224.66</b>
<b>LIABILITIES</b>		
<b>I Current liabilities</b>		
Accounts payable	128,029.09	132,506.82
Deferred income	1,353,468.06	1,054,324.52
Income to be allocated to projects' partners	116,585.63	155,542.80
<i>Total current liabilities</i>	<i>1,598,082.78</i>	<i>1,342,374.14</i>
<b>II Reserves</b>		
Funds brought forward	394,850.52	403,927.04
Surplus or deficit for the year	-330.38	-9,076.52
<i>Total reserves</i>	<i>394,520.14</i>	<i>394,850.52</i>
<b>TOTAL LIABILITIES</b>	<b>1,992,602.92</b>	<b>1,737,224.66</b>



## INCOME AND EXPENDITURE AS AT 31<sup>TH</sup> DECEMBER 2013

INCOME	2013 (€)	2012 (€)
<b>Funding from the public sector:<sup>21</sup></b>		
Operational work programme (EAHC operating grant co-funding 79%)	568,488.00	562,012.21
EC projects	188,780.55	129,220.81
EUPATI (through IMI JU)	174,290.91	105,129.19
Sub-total	931,559.46	796,362.21
<b>Funding from the private sector:<sup>22</sup></b>		
Operational work programme (co-funding of EAHC's operating grant 19.3%)	139,250.00	130,000.00
EPF projects and Capacity Building Programme	210,447.63	82,587.65
EC projects	132,277.06	100,046.01
EUPATI	47,517.77	62,045.37
Sub-total	529,492.46	374,679.03
Membership Fees	12,100.00	8,850.00
Interest and Other Income	25,606.09	6,701.21
<b>TOTAL INCOME</b>	<b>1,498,758.01</b>	<b>1,186,592.45</b>
<b>EXPENDITURE</b>		
Staff and consultants fees	877,803.55	726,489.87
Office costs	162,265.05	162,571.20
Depreciation	15,257.01	13,099.10
Travel and subsistence	94,944.74	72,503.18
<b>Events:</b>		
Annual General Meeting	47,330.62	50,649.29
Regional Advocacy Seminar	32,702.11	43,594.18
Youth meeting	8,484.51	6,468.44
Patient Evidence Workshop	3,180.43	2,128.96
Other events and workshops (EPF 10 <sup>th</sup> Anniversary Seminar, eHealth Seminar, Chain of Trust, Capacity Building Programme workshops, EMPATHY, Regional Cross Border Healthcare, etc)	187,779.65	61,681.66
Communications	68,365.82	55,155.55
Bank and financial charges	974.90	1,327.54
<b>TOTAL EXPENDITURE</b>	<b>1,499,088.39</b>	<b>1,195,668.97</b>
<b>SURPLUS OR DEFICIT OF THE YEAR</b>	<b>-330.38</b>	<b>-9,076.52</b>

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

## ACKNOWLEDGEMENT OF FINANCIAL SUPPORT

### EPF WISHES TO THANK THE FOLLOWING DONORS FOR THEIR SUPPORT:

		% of total income
<b>Operational work programme</b>		
European Commission (Executive Agency for Health and Consumers)	568,488.00	44.0%
GSK	30,000.00	2.3%
Janssen	30,000.00	2.3%
MSD	30,000.00	2.3%
Novartis	30,000.00	2.3%
Pfizer	19,250.00	1.5%
<b>Project portfolio and Capacity Building Programme</b>		
Abbvie	25,000.00	1.9%
AMGEN	35,000.00	2.7%
Baxter World Trade	10,000.00	0.8%
CSL Behring Biotherapies	10,000.00	0.8%
Gilead	15,000.00	1.2%
GSK (50,000€ advance on 2014 activities)	50,000.00	3.9%
Hoffmann-La Roche	35,000.00	2.7%
Laboratoires Servier (10,000€ committed in 2013 to cover 2014 activities)	20,000.00	1.5%
Novartis (20,000€ paid in 2013 to cover 2012 activities)	50,000.00	3.9%
Philips	10,000.00	0.8%
Sanofi-Aventis	40,000.00	3.1%
Sanofi-Pasteur MSD	20,000.00	1.5%
<b>The European Patients' Academy on Therapeutic Innovation Public Private Partnership (EUPATI)</b>		
Innovative Medicine Initiative (IMI JU) contribution	105,125.19	8.1%
Industry consortium (UCB, Amgen, Genzyme, VFA, AZ, Novonordisk, Bayer, Merck, Janssen, GSK, Chiesi, Hoffmann, Lilly, Novartis, Esteve)	47,517.77	3.7%
<i>Note: the income provided represents EPF's share in the consortium's contributions to the project only.</i>		
<b>EPF wishes to thank the European Commission for its support in 2013 in relation to EPF's role in the following projects:</b>		
We Care	21,723.35	1.7%
Chain of Trust	34,559.36	2.7%
SmartCare	18,691.73	1.4%
<b>Memberships and other income</b>	<b>37,706.09</b>	<b>2.9%</b>
<b>Total income</b>	<b>1,293,061.49</b>	<b>100.0%</b>
Accruals and deferrals <sup>23</sup>	205,696.52	
<b>Total income net of adjustments</b>	<b>1,498,758.01</b>	

23. 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 2013, this method had the effect of an increase of total income by € 205,696,52.



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*Disclaimer: the content of this report reflects the author's views exclusively and the Executive Agency is not responsible for any use that may be made of the information contained therein.*