

INSIDE:
EPF from 2003 to 2013
The timeline leaflet

A STRONG PATIENTS' VOICE TO DRIVE BETTER HEALTH IN EUROPE



EUROPEAN PATIENTS' FORUM
ANNUAL REPORT 2012



Foreword

We are very pleased to present the EPF Annual Report for 2012 outlining our key achievements and milestones.

2012 has been a highly eventful and successful year, with a strong focus on the future and how health policy and healthcare systems are going to be shaped in the decades ahead. We have reiterated the importance of meaningful involvement of patients at all stages to make future healthcare systems patient-centred, quality-oriented and fully sustainable. As we move into 2013, which marks our ten year anniversary, we are proud to see how much our organisation has achieved since 2003 to drive better health for patients in Europe.

This report describes the numerous activities that we have been carrying out in close collaboration with our members. Our involvement in EU projects helped us gather solid patient-related, evidence-based information and fed into our policy work. This work, in turn, allowed us to play a critical advocacy role on key health dossiers, ensuring a strong perspective of patients.

2012 marks the start of a key programme for EPF supporting the capacity of our members and patients' organisations at large through different projects, tools, materials and events.

We have invested a great deal of energy into laying the foundations for a successful Strategic Plan for 2014 - 2020.

As we look forward to 2013 we would like to take this opportunity to thank our member organisations which have contributed so much to the achievements of 2012. We would also like to thank all those people who work with us on a daily basis to help to advance patient-centred, equitable health care in Europe. We live in very challenging times and only by working together will we be able to engineer the changes needed for empowerment, quality and sustainability.

We invite all patient community and health stakeholders to continue to move forward on our common vision of high-quality, patient-centred, equitable healthcare throughout the European Union.

Anders Olauson, EPF President and Nicola Bedlington, EPF Executive Director



Anders OLAUSON
| EPF President



Nicola BEDLINGTON
| EPF Executive Director



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1. WHO WE ARE

The European Patients' Forum (EPF) is an umbrella organisation that works with organisations of patients on public health and health advocacy across Europe. Our members represent specific chronic disease groups at EU level or are national coalitions of patients.

EPF'S VISION

Our vision is **high quality, patient-centred, equitable** healthcare for **all patients** throughout the European Union.

EPF'S MISSION

Our mission is to be the **collective patients' voice** at EU level, manifesting the **solidarity, power and unity** of the EU patients' movement, and to provide a **strong and united patients' voice** to put patients at the **centre** of EU health policy and programmes.

EPF'S FIVE STRATEGIC GOALS :

01

> EQUAL ACCESS FOR PATIENTS

To promote equal access to best quality information and healthcare for EU patients and their carers and families.

04

> SUSTAINABLE PATIENT ORGANISATIONS

To encourage inclusive, effective and sustainable representative patient organisations.

02

> PATIENT INVOLVEMENT

To ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.

05

> PATIENT UNITY

To nurture and promote solidarity and unity across the EU patients' movement. No patient organisation is too small to contribute to our work.

03

> PATIENTS' PERSPECTIVE

To ensure the perspective of the patients, 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).



EPF'S VALUES

➔ Patient-centred

The European Patients' Forum is driven by a rights-based, patient-centred approach to healthcare in Europe.

➔ Non-discriminatory

We combat discrimination on the grounds of illness and address health inequalities from the perspective of patients.

➔ Holistic

We advocate a holistic approach to healthcare issues that includes the social, economic, cultural, environmental and mental health agenda for patients and their carers and families.

➔ Empowering patients

We foster the empowerment of patients and their carers and families by breaking down attitudinal barriers and prejudice regarding patients' place in society as equal citizens.

➔ Consultative

EPF consults and builds consensus within its membership in order to address, from a uniquely patients' perspective, the multitude of EU health policy issues that will directly and indirectly impact on patients across the Member States.

➔ Independent, transparent

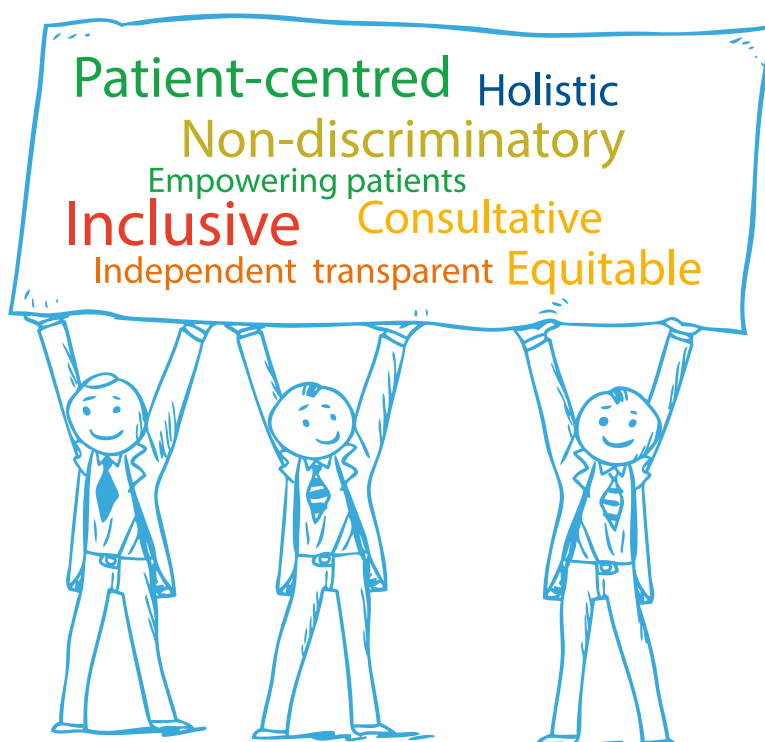
We are an independent organisation, transparent in all our operations (financial, policy, communications).

➔ Inclusive

We are an open and inclusive organisation and strive to ensure that our work also reflects the opinion of potentially marginalised and under-represented patients and their carers and families.

➔ Equitable

Gender equity is an intrinsic part of the patients' rights agenda. EPF is fully committed to gender equality in all aspects of its work.



2. Executive summary 2012

EPF identified four objectives in our 2012 Work Plan that relate to our strategic goals:

- 👉 **OBJECTIVE 1** - Building capacity within the governance structures, the secretariat, and through reinforcing and extending the membership, and diversifying / solidifying funding (GOALS 1-5)
- 👉 **OBJECTIVE 2** - Consolidating our policy impact (GOALS 1-3)
- 👉 **OBJECTIVE 3** - Feeding Project and Patient Evidence into policy (GOALS 1-3)
- 👉 **OBJECTIVE 4** - Building powerful and effective communications and partnerships (GOALS 1-5)

2012 marked a new milestone for EPF as we started to develop a new Strategic Plan for 2014 to 2020. This will be a critically important period for patients in Europe and EPF will do its best to engage in and influence EU and national developments that impact on patients' lives.

CAPACITY BUILDING ACTIVITIES

The EPF Capacity Building Programme for patient organisations was launched and piloted in 2012. This included 20 patient organisations from Hungary and Romania and five pan-European disease-specific patient organisations. The objective of the programme is to strengthen the advocacy capacity of these organisations so that they can achieve their goals more effectively. As a result, they will be able to feed their expertise into the work of EPF and translate this in a national context.

Our Regional Advocacy Seminar held in October was an unreserved success. Patients' organisations from four Mediterranean countries representing 15 diseases came to learn how to enhance their fundraising skills, diversify their funding base and bolster their advocacy capacities.

We welcomed three new provisional members - Europa Colon, the European Network of Fibromyalgia Associations (ENFA) and the World Federation of Incontinent Patients (WFIP), as well as one associate member, the Bulgarian Association for Patients' Defence (BAPD).

We continued to forge strong alliances with other European health organisations and voice patients' interests through our representation work at more than 50 EU events on health policy issues.

OUR POLICY IMPACT

EPF has continued to play a pro-active role in promoting a patient-centred philosophy and agenda throughout 2012.

We have highlighted equitable access to healthcare for all patients across Europe in three priority areas; health inequalities, access to medicines and the revision of the EU Transparency Directive.

We have added significant value to patient empowerment through several activities focusing on information to patients and health literacy and the reflection process on chronic diseases, not to mention our own projects.

Health innovation and research are also key priorities. We have adopted strong positions on data protection and clinical trials and supported the European Innovation Partnership on Active and Healthy Ageing.

We have worked closely with the European Medicines Agency (EMA), to ensure that the perspective of patients is taken into consideration in medicine regulation, and also the European Commission's Platform on Access to Medicines and Platform on Ethics and Transparency.

Safe, high quality healthcare across the EU was another main policy thrust in 2012. This revolved around three areas: our contribution to the new EU Joint Action on Quality of Care and Patient Safety, our contribution to



the Commission's Patient Safety and Quality of Care Working Group, and our consultation and position on medical devices.

Finally, we have monitored the implementation of key EU Directives across Europe and offered resources to our members and patients' organisations at large. These included toolkits on pharmacovigilance and cross-border healthcare which aim to help them understand the implications of the legislation at the national level as well as enabling them to get involved in a meaningful way.

POLICY SHAPED BY EVIDENCE FROM PATIENTS AND PROJECTS

EPF has also been able to translate significant evidence from our projects into our policy work in 2012. We concluded the Chain of Trust project on building trust and confidence between telehealth users with a final report containing the main findings and recommendations. The RENEWING HeALTH project entered its third year and aims to determine whether telemedicine services can work from a patients' point of view. The SUSTAINS project on patient access to their Electronic Health Records (EHR) was also launched in 2012. All of these projects have played an important part in outlining the first draft of our position statement on eHealth that will be reviewed in consultation with our members in 2013.

A position on Health Technology Assessment (HTA) has also been drafted, drawing on findings from our HTA initiative. We continue to monitor this area thanks to our role on the advisory board of the new European project AdHopHTA. The aim is to address the problem of poor use and awareness of hospital-based HTA initiatives. We are also involved in the Stakeholder Forum created as part of the governance structure of the EUnetHTA Joint Actions which objective is to create an effective and sustainable network for HTA across Europe.

Patient safety continued to be a major priority for EPF in 2012. We have relaunched a survey in order to gain an understanding of the awareness and key concerns of patients' organisations regarding patient safety. We are confident that this will allow us to complement the results of the European Commission consultation on patient safety.

2012 marked the start of the European Patient Academy of Therapeutic Innovation (EUPATI) which EPF is coordinating. This innovative patient-led academy prepares the ground for educational material, training courses and a public Internet library to educate patient representatives and the general public on all processes involved in medicines development.

COMMUNICATION AND EVALUATION

EPF has raised the bar on communications in 2012. We have changed our logo to reflect the evolution of our organisation with a new visual identity (see page 46). A range of social media tools have been launched to connect with the patient community to convey the dynamics of our policy, projects and events work, and promote unity across the EU patients' movement. This has coincided with the launch and the revamping of a series of communication tools (newsletter, website, leaflet, video) emerging from our communication strategy.

All of these contribute to a focused effort in ensuring our target audiences are kept abreast of all our activities.

Our strategy includes a comprehensive plan for evaluation of our activities (see page 34) and we have agreed on the tools we are going to use to measure our work plan.

3. A New Strategic Plan For the Next EU Programming Period



EPF has developed a new Strategic Plan for 2014 to 2020, the next EU programming period. Our 2012 Annual General Meeting (AGM) afforded us the opportunity to explore the progress made from the previous strategic plan (2007-2012) with our members, and to prepare the ground for the final document.

Our Strategic Planning process is designed to involve our entire membership at all stages. At the AGM, we ran workshops to help us review our accomplishments since 2007 and identify future challenges.

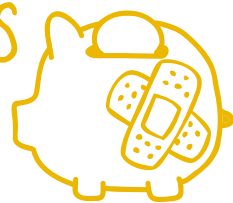
The outcomes of the workshop have been consolidated in a blueprint. A dedicated working group made up of our members plus one delegate from the EPF Youth Group has been set up to develop this planning further.

EPF has identified new challenges for public health services which have been affected profoundly by the economic crisis. We have started to plan for the future on this basis. Our experience and development over the last few years will shape our goals for the next period.

A draft plan will then be circulated to the wider membership for consultation in early 2013. We aim to have the new 2014-2020 Strategic Plan endorsed at our next AGM in Dublin, in May 2013.



4. Health and Patients in Times of Austerity



The current economic crisis has resulted in substantial cuts in healthcare spending across Europe. In response, EPF is striving to shape policies that put the patients at the centre of healthcare developments. We are certain that if we involve patients, the provision of healthcare can be more cost-effective as well as quality-oriented.

A **fundamental shift** is needed in how healthcare is organised and delivered in order to address the challenge of chronic diseases in a sustainable way. Putting patients at the centre of healthcare will be the catalyst for this shift. This cannot be achieved without patient empowerment, however.

An effective **empowerment strategy** starts with promoting **health literacy**. This will equip patients with the knowledge and skills needed to take an active role in managing their health. It will help patients to get better information from health professionals to drive better and more cost-effective health outcomes. EPF believes that there is a need for a strategy on information to patients at EU level. High quality information on health, diseases and therapy options is vital to patient safety and empowerment.

Patients should also be involved in the **innovation process**, whether low tech or high tech solutions, therapeutic or social innovation. This will ensure that resources are invested in the right areas as patients can bring their unique expertise to the

table as an added value to improve the quality of services.

An **integrated approach** is also called for to address chronic diseases throughout the patient journey. The solution needs to incorporate all aspects of social care (including nutrition and mobility) into the healthcare system to help people lead active and healthy lives. This process should focus on the person rather than the disease, and should also support patients and their families in managing their condition.

In order to be successful, the healthcare environment must be founded on a patient-centred healthcare approach. The training of healthcare professionals should include patient self-care and the skills required to maintain patient involvement.

In EPF's vision for the future of healthcare, the patient is no longer considered as 'the problem,' but part of the solution.

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EUROPEAN HEALTH POLICY FORUM GASTEIN

The focus of the 15th edition of the European Health Policy Forum Gastein in October 2012 was on «Crisis and Opportunity - Health in a time of Austerity» This topic is crucial for EPF as the economic crisis and austerity measures are affecting patients and their rights negatively. This ranges from treatment no longer being reimbursed, to patients unable to afford their care and turning to clinics run by NGOs, to situations of shortage of medical devices or medicine.

«Even if there are attempts at change, my feeling is that without empowering and involving patients, we are continuing on the same healthcare model as before and painting a worrying picture for the healthcare of 2050. Patients are part of the solution - I am convinced it is possible to achieve EPF's vision»

| Extract from the panel session address of Anders Olauson, EPF President, at the European Health Policy Forum in Gastein.



5. What We Do to Drive Better Healthcare For Patients in Europe

5.1 STRENGTHENING THE CAPACITY OF PATIENT ORGANISATIONS



EPF CAPACITY BUILDING PROGRAMME

We launched our Capacity Building Programme (2012-2014) for our members and patient organisations in mid-2012. The objective is to strengthen the organisational and advocacy capacity of both the member state and European level patients' organisations. In doing so, we hope to enable them to be more effective in achieving their objectives and aspirations. Their experiences and expertise will feed into the work EPF is carrying out and they will be able to use the outcomes of this collective work at a national level, and/or in a disease-specific context.

EPF is leading the Capacity Building Programme with the support of its national members in the countries participating in the programme. *"This Programme responds to needs and concerns which have been identified by EPF membership during previous activities. With this programme, we aim to strengthen the impact of the work undertaken by our members and their members in turn, which should ultimately contribute to stronger, more effective patient organisations at both national and European level"*, said Liuska Sanna, EPF Programme Manager responsible for the EPF Capacity Building Programme.

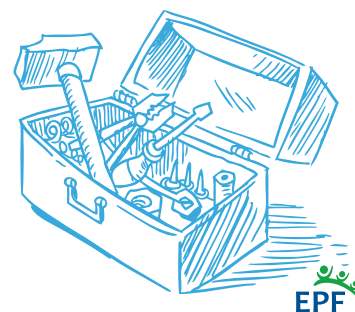
In total 20 patient organisations from Hungary and Romania and five pan-European, disease-specific patient

organisations have come onboard the programme in 2012. The first phase has consisted of completing a strategic planning process and organisational capacity assessment aimed at developing a strategic plan and identifying training needs for each national organisation. Drawing on the outcomes of the first phase of the programme, training modules will be provided to the various organisations in their local languages in 2013 and 2014. Bulgaria, Latvia, Poland and Slovakia will join the programme in 2013.

A comprehensive organisational capacity assessment exercise has been undertaken with the five European patient organisations in 2012. The objective is to assess whether each organisation requires a strategic planning process, or whether there is a coherent Strategic Plan already in place. We have also reached decisions on which training modules are needed in order to help the organisation achieve its goals and aspirations.

EPF SUPPORT FOR EU LEGISLATION IMPLEMENTATION AT NATIONAL LEVEL

In 2012 EPF has supported the implementation of key pieces of EU health legislation on cross-border healthcare and pharmacovigilance. We have developed toolkits for patient organisations to provide them with guidance and implementation recommendations to support the effective dissemination of information to patient communities in EU member states. EPF has also provided patient groups with the information and tools to engage proactively at the national level and ensure that national laws are patient-centred and effective. This policy work complements our broader strategy of supporting our members in participating in the national policy-making process as equal partners in their own right.





EUPATI project: an academy to educate patients on therapeutic innovation



The European Patients' Academy on Therapeutic Innovation (EUPATI) was launched in February 2012. It is an Innovative Medicine Initiative (IMI)-funded project led by EPF to educate patient experts, patient organisations, and the general public on how drug Research & Development (R&D) works.

This consortium of 29 organisations is developing training courses, educational toolkits and a web-based library to provide objective and credible information about drug R&D and how patients can get involved. EUPATI will span seven languages in 12 countries.

In its call for educational material on drug R&D, 306 resources, comprising handbooks, publications, course materials, presentations and guides have been submitted to the Academy. 230 resources have been selected for the first review report, which has now been completed. The report forms the basis for the development of EUPATI's educational content.

The syllabus for the European Patients' Academy's training courses has been drawn up and agreed upon in 2012. The «table of contents» lists about 300 topics that are relevant to fully understanding the end-to-end processes of drug R&D.

Learning outcomes and editorial processes will be defined in the next step. Web-based learning will constitute a major part of the expert-level training courses for patient advocates.

More than 400 individuals are now members of the European Patients' Academy Network, which is open to patients and patient organisations, caregivers, academia, pharmaceutical and biotech companies, journalists and anyone else interested in finding information on drug research and development in lay language.

➤ More information can be found on the project's website: www.patientsacademy.eu



OUR FIFTH REGIONAL ADVOCACY SEMINAR TO RESOURCE PATIENT GROUPS



➤ Regional Advocacy Seminar, October 2012

The Fifth EPF Regional Advocacy Seminar took place in Lisbon, Portugal on 25-26 October 2012. The theme of this year's seminar was "Fundraising: Resourcing Patient Organisations for a strong Patient Movement".

In this climate of crisis and austerity, it is of upmost importance that patients' organisations maintain their capacity and effectiveness to advocate patients' rights. This two day seminar focused on different potential sources of funding as well as on how to diversify funding sources.

Over 50 participants attended from four focus countries, namely Greece, Italy, Portugal, and Spain. These leaders were representatives of national patients' organisations.

➤ The full report on the seminar is available on the EPF website.

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5.2 ACCESSIBLE & INCLUSIVE HEALTHCARE

We promote equal access to the best quality information and healthcare for EU patients and their carers and families as one of our five core strategic goals. We combat discrimination on the grounds of illness but we also strive to ensure our work reflects the opinion of potentially marginalised and underrepresented patients.

INFORMATION TO PATIENTS AND HEALTH LITERACY

Health literacy and information to patients have been a key priority for EPF since our establishment in 2003. The conclusions and recommendations that emerged from our conference on health literacy, in 2008, continue to feed into our policy work in this area today.

In 2012 EPF has consulted its members on the European Commission's revised proposals on information to patients. However we have not published our position on the specific proposals as the draft legislation remained blocked in the Council.

In the second half of the year, we focused on working collaboratively with other stakeholders on health literacy in the context of the new Commission proposal for a health programme "Health for Growth" (see page 30). We have also integrated our position on information to patients in other policy areas we are working on.

We have contributed to a draft concept paper on health literacy which was presented at the European Health Policy Forum Gastein. The intention has been to consolidate the concept, its meaning and implications for different stakeholder groups.

ACCESS TO THERAPIES

National measures on pricing and reimbursement of medicines have a direct impact on patient access to therapies. EPF highlighted this in a position statement on the so-called Transparency Directive (Council Directive 89/105/EEC), which sets rules for administrative procedures relating to pricing and reimbursement decisions at the national level.

Overall, we welcome the Commission's proposal as it marks a step forward for more transparent and effective processes. While member states remain responsible for setting national pricing policies and conditions for reimbursement, the Directive provides a harmonised framework to ensure a timely and transparent decision-making process.

EPF has approved measures for shorter time limits in the decision-making process, with the inclusion of all necessary steps in the time limits for the decisions, including conducting the Health Technology Assessment. We also welcome the provisions that would bring clarity to the assessment process.

We have strongly advocated the inclusion of more genuine transparency and stakeholder involvement in the Directive. We have also highlighted potential inequalities in access to medicines by patients with chronic diseases, and ultimately in the health care systems.





Finally, we have continued our involvement in the European Commission's Platform on Access to Medicines in Europe. We were represented on the Steering Group as well as in the six working groups of this platform through representatives of patients from our member organisations. We would like to express our gratitude to our members who led the work in the working groups, as follows:

- ➡ Working Group on Biosimilars – National Voices
- ➡ Working Group on Orphan Drugs – EURORDIS
- ➡ Working Group on Small Markets – Pan Cyprian Patients' Association
- ➡ Working Group on Managed Entry Agreements – Spanish Patients' Forum
- ➡ Working Group on Non-Prescription Medicines – European Men's Health Forum

EPF has also been represented in the Working Group on Ethics and Transparency and contributed towards new Guiding Principles for working with the Pharmaceutical Industry (see page 21).

The final reports and recommendations of these working groups will be published in 2013.

HEALTH INEQUALITIES

The reduction of health inequalities is a key focus of the EU health strategy "together for health". It is also the priority policy area for EPF in the current financial crisis.

In 2012 EPF has offered its support to a conference in Sofia, Bulgaria, hosted by the Bulgarian National Patients' Organisation (NPO) focusing on health inequalities from the perspective of patients with chronic diseases. It was the first time such a conference was organised by patients' organisations and the outcomes will play an important role in the development of an updated position paper on health inequalities. This will be complemented in 2013 by a survey of our members to gauge the extent of health inequality in terms of access to healthcare, medicines, and other support services. It will also be an opportunity to assess the direct impact of the financial crisis on patient organisations.

EPF has also stressed health inequalities in access to healthcare as a key concern during the reflection process on chronic diseases. EPF participated in a conference on austerity measures in Greece, and met with European Commission officials representing the Task Force for Greece.

Our participation at the European Health Policy Forum Gastein (see page 11) also formed part of a continued effort to safeguard patients' rights and health equity. Our director Nicola Bedlington spoke at the session on "health literacy – the cornerstone of health for the future", focusing on the role of health literacy as a critical factor for change in combating health inequalities. Finally, EPF has addressed health inequalities in our work on health literacy and other relevant areas such as the revision of the EU Transparency Directive.

5



THE RIGHTS AND NEEDS OF OLDER PATIENTS

We released a report in April on the outcomes of the conference on the rights and needs of older patients, co-organised with the Polish Patients' Forum (FPP) in Warsaw on 12-13 July 2011. The goal of the EPF/FPP conference was to exchange experiences and insights with stakeholders at EU and national levels on how to ensure high-quality, patient-centred, equitable care for older patients. We also discussed how to face this challenge while meeting their needs and respecting and improving their rights, quality of life and dignity.

EPF has participated at all levels in the European Innovation Partnership on Active and Healthy Ageing (EIP-AHA) since 2011. In 2012, we have helped to develop an action plan under this Partnership, focusing on adherence to therapies and health literacy. We have

also been involved in partnership with the Patients Network for Medical Research and Health (EGAN), one of our members, in an action to address frailty and malnutrition. EPF will continue to be an active partner in the EIP-AHA in 2013, through participation in these two action groups and our position on the Steering Group.

Based on this work, we have prepared the ground for a position paper on the rights and needs of older patients by conducting a consultation with our members.

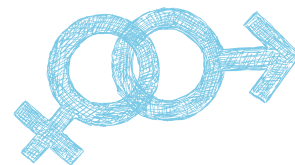
This position will be published in 2013 and will build on:

- ➔ the outcome of the conference
- ➔ our previous input into the Partnership
- ➔ the reflection process on chronic diseases (see page 31).





➔ *Second Annual Youth Meeting,
August 2012*



YOUTH PROJECT: EMPATHY

In its second Annual Youth Meeting in August in Malta, the EPF Youth Group laid the foundations for its work for the months to follow. This year's meeting was the first annual meeting of the Youth Group where it announced its first youth project "EMPATHY: Europe Meets Young Patients". It was also an opportunity to involve young patients in the strategic planning process (see page 10).

The EMPATHY project will organise a four-day seminar in July 2013 in Brussels for young patients, European policy-makers, and stakeholder actors in the fields of health, education, social and youth policy. The intention is to promote a more holistic approach to addressing young patients' needs in EU-level decision-making processes.

Thanks in no small part to this meeting, the young people attending have acquired a better understanding of the project's objectives and their role within it. They have worked tirelessly at raising awareness about the project right up to the end of the year.

GENDER

EPF was proud to partner with the European Men's Health Forum (EMHF), the European Cancer Patient Coalition (ECPC), and the Danish Men's Health Society (MHS), to organise a landmark conference on Gender and Health through Life on 14-15 June 2012 in Copenhagen, Denmark.

EPF Vice President Susanna Palkonen in her speech there, made reference to the EPF Value+ Handbook on Promoting Patients' Involvement in EU supported health-related Projects: *"Gender should definitively be considered in relation to health. Men and women should be treated equally wherever they have common needs. At the same time, their differences should be addressed in an equitable manner."*

EPF will continue to interact with EMHF and the European Institute for Women's Health to support gender health policies. We will strive to include our perspective, representing patients already diagnosed with a chronic disease, and the gender specific research, information, treatment and support that this implies.

NUTRITION



Patients have particular – and diverse - needs as regards nutrition, which are currently not being met throughout the EU. EPF supported the conference 'EU Patient groups & the relevance of nutrition' held on 4 July in Brussels, organised jointly by the Patients Network for Medical Research and Health (EGAN), and the European Health and Nutrition Alliance (ENHA).

The meeting showed that nutrition is an important, though often neglected part of a holistic approach to healthcare. Patient representatives agreed that there is a need to step up collaboration in this field with the signature of a Memorandum of Understanding. They came up with key recommendations encompassing many areas such as care, research, labelling and information and reimbursement of medical nutritional products.

5





5.3 HIGH QUALITY AND SAFE HEALTHCARE

Patient safety and quality of care is at the heart of our work and are included in our five core strategic goals. Reducing the risk of mistakes during treatment and care is of utmost importance. Involving patients in this process, therefore, enhances their safety as they have unique experience and expertise “as patients” and can make a valuable contribution to preventive efforts.



PATIENT SAFETY AND QUALITY OF CARE



Joint Action – European Union Network on Patient Safety and Quality of Care (PASQ)

The “European Union Network on Patient Safety and Quality of Care” or “PaSQ” Joint Action (JA) was officially launched with a kick-off conference in Denmark on 24-25 May 2012. This three-year Joint Action is led by the French Haute Autorité de Santé (HAS). EPF, as an Associate Partner, is actively involved in several core work packages. The overall objectives of the project are to support the implementation of the Council Recommendation on Patient Safety (2009) and to create a permanent platform for future cooperation between member states in the area of patient safety and quality of care.

EPF’s role is particularly important as one of the specific goals of the JA is to promote patient empowerment and involvement in the safety and quality of healthcare they receive. Our tasks within the JA include the identification of existing proven good practices in this area. There is also a focus on identifying strategies for improving the quality of healthcare through patient empowerment and involvement. We are also involved in strengthening network sustainability and effective dissemination.

EPF has drafted a working definition of patient empowerment and involvement for the joint action in 2012. We have led a data collection task force to gather information on good practices in patient safety at the clinical level, as well as good organisational practices in quality management systems. The data was collected in late 2012 and the results will be available in early 2013.

➡ More information about the project is available at the website: www.pasq.eu

EPF has continued its active participation in the European Commission's Patient Safety and Quality of Care Working Group. The group brings together representatives from all 27 EU countries, European Free Trade Association (EFTA) countries, international organisations and stakeholders. We provide advice to the Council Working Party on Public Health Issues at Senior Level in developing the EU patient safety and quality agenda. The group met just the once in 2012, in November, when the Commission presented its progress report on the implementation of the Council Recommendation on Patient Safety. Working areas for the next two years were also discussed. EPF identified patient involvement as a major area of weakness and stressed that further work is needed in this area.

In the first half 2012, EPF rolled out a survey for its members to gauge the perspective of patient groups on the implementation of the Council Recommendation on Patient Safety (2009). The focus was patients' awareness of the EU legislation and their involvement in its implementation at the national level. The survey was relaunched at the end of the year in a simplified format, also taking into account the European Commission's progress report published in November. The results will be available in 2013.

The outcomes of the survey will guide our input into the EC Patient Safety and Quality of Care Working Group and will also complement our contribution to the Patient Safety and Quality of Care Joint Action, which was launched in April 2012.



In June, EPF released a position statement on the European Commission's proposal to review Directive 2005/36/EC governing the recognition of professional qualifications. Ensuring that healthcare professionals have the right training and are fit to practice when they move from one EU Member State to another is of crucial importance for patient safety and quality of care.

Healthcare professionals are the most mobile category among the regulated professions in the EU and this is likely to increase in future. Mobility of the health workforce can help balance shortages and surpluses and promote the exchange of good practices across Europe. But there is also a potential risk to patient safety and of increased health inequalities, if quality standards for healthcare are not assured. EPF has called for several changes to the proposal, to make patient safety a priority over internal market considerations. This includes clearer provisions on checking language competences and verification of healthcare professionals' suitability to practice by the appropriate authorities. The alert mechanism for fraudulent diplomas must be extended to all competent authorities, and the patients must be involved in identifying the future skill requirements of the EU health workforce.

EPF has worked closely with the Committee on the Internal Market and Consumer Protection (IMCO) and the Environment and Public Health Committee (ENVI) of the European Parliament who have taken onboard many of the provisions we have advocated with MEPs. EPF will support the amendments proposed in their report that are in line with our position in the plenary vote on the review of the Professional Qualifications Directive in 2013.





DATA PROTECTION



EPF released its position statement on the European Commission's proposal for a Regulation on personal data protection on 10 December. Patients' fundamental rights to protection of personal data are an important issue in healthcare and research. Our position will ensure the patients' voice is heard in debates on the use of their health and genetic records.

EPF welcomes, in principle, a stronger and more coherent framework for the protection of personal data. Our key concern is to strike the right balance between assuring confidentiality of data on the one hand, and ensuring their availability and dissemination for public health, healthcare and research purposes on the other.

We have strongly recommended that the EU institutions guarantee those individual rights which apply to patients – the right to access one's personal data and the right to transparent information about data processing – be effectively implemented.

In this debate, EPF is also advocating more cooperation between member states to establish minimum security requirements in sharing patients' data. Our aim is to ensure that patients across the EU benefit from an equivalent level of protection of personal data, and to facilitate cross-border healthcare and research.

We will continue to work closely with the EU institutions to achieve this in 2013, particularly the European Parliament, who will discuss and vote on the draft Regulation.



MEDICAL DEVICES

In 2012, EPF has been very active in providing input for the revision process of the EU legislative framework on medical devices, building on our long standing work on this dossier since 2008. The European Commission released two proposals for Regulations on Medical Devices and on In-Vitro Medical Devices in September 2012. The previous March, we had contributed to an earlier draft as part of the Medical Device Expert Group, with the participation of the Policy Advisory Group. In December we invited our entire membership into the debate through a consultation, to develop a position paper to be released in 2013.

The revision of the legal framework on Medical Devices is a major opportunity for the patient community to call for a renewed focus on the safety and quality of medical devices available to patients in Europe. To achieve this, EPF will continue advocating improved clinical evaluation and a strengthened certification and vigilance process.



PATIENT MEDTECH DIALOGUE

EPF has also continued the bi-annual Patient MedTech dialogue established in partnership with the medical devices industry association EUCOMED since 2011. In this year's meeting, representatives of patients' associations and the MedTech industry focused on the themes of patient safety, and patient-centred healthcare. Participants decided to step up the dialogue by appointing a steering group to implement proposals and decisions taken during the twice yearly meetings of the Patients–MedTech Dialogue.

"The topics covered are at heart of EPF's work - it is essential for us to be able to express the patients' perspective to the MedTech industry. We need to raise awareness among our members regarding the nature of the relationship between patients and the MedTech industry to contribute towards patient-centred healthcare, based on our core values on transparency and independence", stated EPF Executive Director Nicola Bedlington.



"We are keen to provide input and ideas on how to achieve better transparency and foster patient involvement in decision-making for these products, which play a vital role in the daily lives of patients in managing their conditions" says EPF Policy Officer Laurène Souchet.

OUR WORK WITH THE EUROPEAN MEDICINES AGENCY

EPF has continued to work closely with the European Medicines Agency (EMA). We have coordinated volunteers to review documents that target patients and the general public alike. We have also disseminated information on medicines to patient communities across the EU and supported the Agency in further developing its framework for patient involvement.

Our close involvement with EMA also includes our representation in the Patients and Consumers Working Party (PCWP) on the Committee for Medicinal Products for Human Use (CH MP) and the EMA Managing Board.

EPF has also promoted the interests of patients through the Agency's Pharmacovigilance Risk Assessment Committee (PRAC-19/07/2012). The European Commission has appointed a member and an alternate in representation of patient organisations. As of 1 March 2013, EPF will be represented by our board member Marco Greco who will act as delegate over a three-year mandate.

We have also participated in a stakeholder workshop and training seminar on the implementation of the new EU pharmacovigilance legislation. In response to this, we have developed a toolkit on this topic to guide patient organisations through the implementation process at the national level (see page 12).

ETHICS AND TRANSPARENCY

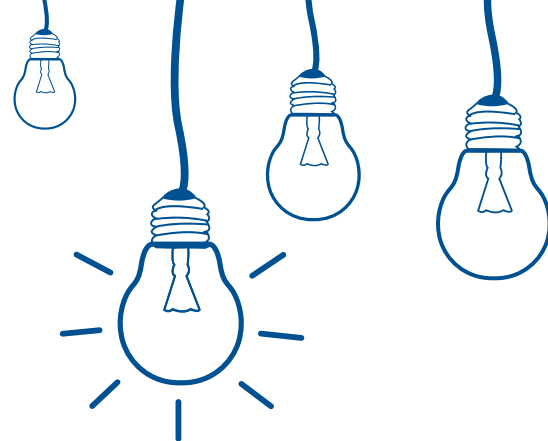
EPF has been involved in the European Commission's "Process on Corporate Responsibility in the Field of Pharmaceuticals" since it began in late 2010. We are represented on the Steering Group, which jointly oversees the Platform on Access to Medicines in Europe and the Platform on Transparency and Ethics.

During 2012, the Platform on Transparency and Ethics has agreed terms of reference and drafted a document containing a set of Guiding Principles on Transparency and Ethics in the pharmaceutical field. The aim of this document is to create an instrument which can be used by different players in the pharmaceutical sector to collaborate in a transparent and ethical way in all EU countries.

We have based our contribution on our long-standing commitment to transparency and independence in all aspects of our work and our experience in applying our Code of Ethics and Framework for working with funding partners.

The final version of the Guiding Principles was agreed by all stakeholders at the steering group meeting in Paphos, in November 2012, and has subsequently been endorsed by the EPF Board.





5.4 INNOVATION AND TECHNOLOGY

Patient-centred innovation and technology is at heart of our work. We are striving to ensure that patients' needs are firmly at the centre of the EU vision of innovation in healthcare, and that the Europe 2020 parallel objectives of "smart growth" and "inclusive growth" will be achieved.

EPF has focused activities in the key areas listed below.

PATIENT-CENTRED INNOVATION

In a Europe where the ratio of older and chronically ill people is rising, we have no choice but to embrace continuous innovation in healthcare systems and services to make sure these growing needs are met. EPF therefore continued to focus on patient-centred innovation, particularly through our role in the European Partnership on Healthy and Active Ageing (see page 16). We continued our involvement in the governance of the partnership and contributed to specific actions on adherence to therapies and frailty/malnutrition.

We have also actively participated in the European commission's "Initiative on Corporate Responsibility in the field of pharmaceuticals". Our contribution has had a particular impact on the Working Group on Innovation and Priority Setting, run in collaboration with the European Commission and World Health Organization (WHO). This first impact resonated in a special meeting on patient involvement in the context of priority setting for biomedical research organised in September. This meeting will be followed-up by a larger one in early 2013. It will explore what recommendations concerning patient involvement could be included in the updated WHO report "Priority medicines for Europe and the World", which will be published in mid-2013.

PERSONALISED MEDICINES

EPF provided a patient perspective in a special session of the European Federation of Pharmaceutical Industries and Associations (EFPIA) Think Tank on personalised medicine. We were also invited to observe the work of the European Alliance for Personalised Medicine, participating in several coordination meetings.

In light of this work and the more up-to-date information it has afforded, we have started to prepare an updated member briefing on personalised medicine. A draft position paper will be finalised in 2013.



CLINICAL TRIALS

Clinical trials have formed a major focal area of EPF's work during 2012. We have developed a position paper in consultation with our members on the European Commission's legislative proposal for a Regulation. The proposal comprises a new provision that requires patient involvement in the assessment of clinical trials. This represents a major achievement in EPF's intensive advocacy work in the last few years. The effectiveness of the clinical trials framework throughout the EU is of fundamental importance for patient safety as it ultimately impacts on the development of new and improved treatments responding to unmet medical needs.

The proposed Regulation will replace the controversial EU Clinical Trials Directive 2001/20/EC. Although the Directive introduced important provisions to protect patients participating in clinical trials, it has been widely perceived as having had an overall detrimental effect on the conduct of clinical trials in Europe.

However, the draft Regulation provides much needed simplification and standardisation of the clinical trials administrative processes. Indeed the legal form of a Regulation has an important harmonising effect as it eliminates the need for transposition into national laws. It will therefore enable the planning and conduct

of clinical trials, including those carried out at a multi-national level, on the basis of a single common regulatory framework, rather than a "patchwork" amalgamation of 27 national frameworks.

In addition, the Commission proposes a more risk-adjusted approach. While continuing to uphold patient safety, this approach aims to tailor the regulatory requirements to the actual risks of a trial. They will differ depending on whether a trial is designed to test a completely new medicine or one that has already been approved, for instance.

We have attended a number of events throughout the year to speak out on key issues for patients, including patient involvement at all stages of the research process, the quality of information and informed consent, and transparency around information on the results of clinical trials.



PATIENT EVIDENCE WORKSHOP

We organised an internal Patient Evidence Workshop with our members in December 2012 to discuss specific aspects of the proposed new clinical trials Regulation. Participants were able to exchange their views with representatives of the European Commission. They discussed the proposed role for patients in clinical trials assessment, the role of ethics review, information to

patients and informed consent, and transparency in information and the results of clinical trials. The outcomes of the workshop were circulated to all EPF members and helped formulate consensus positions on outstanding issues for the EPF position paper.

eHEALTH

We firmly believe at EPF that eHealth can only deliver on its promise of making healthcare systems more effective, efficient and equitable if the needs of patients are at its core.

In 2012 we have built on the knowledge gained in our projects and policy activities to develop a position paper on eHealth. We have highlighted that:

- ☞ Too much innovation in eHealth has been taking place as a result of technology-driven rather than user-driven patterns and processes.
- ☞ The majority of public funding has been invested in large-scale solutions that have failed to address and integrate the user experience sufficiently.
- ☞ Patient involvement in eHealth, thus far, has been very limited and occurs too late in the process which has been affecting patients' confidence in the system.
- ☞ Patients are no-longer passive receivers of services. Instead they become active users who co-manage their health in equal partnership with healthcare professionals.
- ☞ Patients need to be empowered through health literacy, digital literacy and communication skills in order to get involved.
- ☞ Both patients and health professionals will also need to understand and accept how the integration of eHealth in routine healthcare will affect their new roles and responsibilities.



Closing of the Chain of Trust project

2012 ended with the closing of the ambitious Chain of Trust project started in January 2011. The EPF-led EU project looked at assessing the perspective of the main end users (patients, doctors, pharmacists and nurses) of telehealth services across the EU. It focused primarily on exploring how views have evolved, if at all, since the initial deployment of this innovative type of service and what barriers there are to building confidence in and acceptance of it. The paramount objective was to advance the empowerment of patients and health professionals in their understanding and effective use of such services.

The project findings have been compiled in a final report together with recommendations to foster users' acceptance of telehealth. A final conference on 24 January 2013 shared the main project results with the wide range of stakeholders, as well as future strategies to take these forward. These have helped to build evidence for our position statement on eHealth.

"After almost two years of intense work we are really satisfied and proud of the wealth of knowledge on user perspective we have managed to put together through this project. We hope this will make an important contribution towards more user-centred telehealth policies and services", concludes Liuska Sanna, Programme Manager at EPF.

➤ To find out more about the project and to read the final report, you can visit the website:
www.chainoftrust.eu



eHealth : According to the definition used by the World Health Organisation (WHO), eHealth refers generally to the use of electronic communication and information technology (ICT) in the health sector.

telehealth : According to the definition used by the World Health Organisation (WHO), telehealth is a subset of eHealth. It encompasses the use of ICT in relation to the preventative, promotional and curative processes. Telehealth is, in turn, an extension of the term telemedicine, which focuses more narrowly on the curative aspect. Chain of Trust project uses the word "telehealth" to refer to the delivery of healthcare remotely, using information and telecommunications technology and specially-adapted equipment. It allows health professionals to diagnose, treat, care, assess and monitor patients without requiring both individuals to be in the same location physically.



SUSTAINS project

The SUSTAINS project officially started in January 2012. The goal of this three-year project is to develop and deploy a wide range of eHealth services in 11 European regions linked to patients' access to Electronic Health Records (EHR).

Throughout 2012, EPF has been coordinating the implementation of user requirement focus groups aimed at identifying needs, expectations and constraints of patients and healthcare professionals on the envisaged services. Every effort is therefore being made to ensure that these are aligned with the needs and expectations of patients and health professionals as far as possible.

"Involving patients and health professionals through user requirement focus groups has proven to be a very useful exercise for us in understanding how the planned services can be improved to better match users' needs and expectations", said Josu Xabier Llano Hernaiz, from the Directorate General of the Ente Público Osakidetza – the Basque Public Health Service.

Except in very limited cases, there has been widespread agreement among patients and health professionals alike that patient-accessible EHR, if properly designed, can open a window of opportunity for improving the quality of healthcare services. It can ensure the continuity of care and more regular contact between patients and healthcare professionals. Withholding access to EHR to patients is no longer an option. All the participants agreed that granting access to personal health records is even becoming a fundamental right of the patient and constitutes an important step forward in strengthening the role of the patient in the healthcare process.

EPF has also taken a lead in 2012 on the development of methodology and tools for assessing the impact of patient-accessible EHR on patient empowerment.

➤ More information about the project is available at this site: www.sustainsproject.eu



RENEWING HeALTH

The large-scale telemedicine pilot project RENEWING HeALTH entered its third year of implementation in 2012. The purpose of RENEWING HeALTH is to implement multi-site randomised controlled trials for evaluating telemedicine services for patients with three of the most common chronic conditions: diabetes, cardiovascular diseases and Chronic Obstructive Pulmonary Disease (COPD). The ultimate goal is to gather evidence on the use of telemonitoring in real life settings.

EPF participates in this project as co-manager of the User Advisory Board (UAB), which brings together representatives of different categories of user of the services, as part of the project to advise the project team on the real needs of users and to give feedback on the services that have been piloted.

The User Advisory Board (UAB) has been busy finalising the second version of the User Requirement document. This document, which is continuously being reviewed and improved throughout the project lifecycle, provides a reference framework for representing the needs, constraints and expectations of telemedicine end-users. This second version complements the initial literature review carried out in 2010 with the outcomes of two rounds of consultations. The third version will be released in 2013 and will include the outcomes of a series of local meetings with end users of the piloted telemedicine services.

In 2012 the User Advisory Board organised two local meetings with representatives of end users the telemedicine services piloted in two regions, i.e. Veneto (Italy) and Norrbotten (Sweden). These meetings proved to be very successful in enriching the user requirements framework through the hands-on experience of end users involved in the local sites.

➤ More information about the project is available at this site: www.renewinghealth.eu

5



EHEALTH TASK FORCE REPORT

Our President, Anders Olauson, presented the report “Redesigning health in Europe for 2020” at the Danish eHealth Observatory’s Annual Meeting on 9 September. This document is the fruit of the work of the EU Task Force, a High Level Advisory group on eHealth of which our president was a member. In this document, the group identified five levers that could generate the momentum for a fundamental re-organisation of healthcare to make use of already existing information technologies:

- **“My data, my decisions”:** patients are the owners and controllers of their own health data, with the right to make decisions on data access and to be informed about how it will be used.
- **“Liberate the data”:** governments should ensure that health data is accurate, reliable, and up-to-date. It must be collected in a standard way and anonymised before it is made available to anyone that can add value to it in the best interest of the patient.
- **“Connect up everything”:** the digital environment is evolving rapidly with an increasing trend of interaction and sharing. Healthcare therefore needs to take advantage of this in order to provide more integrated and personalised care to patients rather than “standard” interventions.
- **“Revolutionise health”:** by this we mean creating the necessary conditions for patients to be able to make more informed choices about where and how they want to be treated. This will have real impact on resource allocation in health, as funding follows the patient and not the other way round.



- **“Include everyone”:** the needs of the vulnerable communities that are outside the reach of eHealth tools need to be accommodated, otherwise there is a danger that eHealth could ultimately exacerbate existing inequalities rather than reducing them.

On the basis of these five levers, the Task Force has formulated five recommendations for action to support their vision of health in 2020. These have been addressed to policymakers at European and national levels.

“Although key to fostering eHealth uptake, user acceptance is all too often disregarded in discussions on eHealth strategies and policies. EPF is firmly convinced that the only way for these innovative solutions to work effectively is ensuring acceptance by the people who will eventually use them”, said EPF President Anders Olauson.



eHealth Stakeholder Group

The European Commission eHealth Stakeholder Group (eHSG) met twice in 2012. EPF is a member of this group, which comprises expert representatives of European umbrella organisations active in the eHealth sector and is mandated for a period of three years. This group has been set up to contribute to the development of EU policies related to eHealth.

This year, the eHealth Stakeholder Group has assessed the progress made in advancing some key actions of the Digital Agenda for Europe and the eHealth Action Plan, the two policy areas of specific interest for the group.



eHealth Governance Initiative

The EU eHealth Governance Initiative (eHGI) is a political initiative designed to establish a platform to enable cooperation on eHealth between EU member states and stakeholders. In other words, the intention is to implement and deploy interoperability among eHealth services across Europe.

EPF is a member of the Executive Committee and is co-leader of the Work Package (WP) dedicated to Trust and Acceptability.

EPF has contributed to the package of recommendations for a common EU framework on electronic identity (eID) management. The document was published in early 2012 and presented at the 2012 eHealth week in Copenhagen (7-9 May).

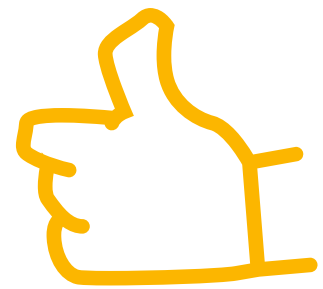
Launch of SmartCare

Another major change patients expect of ICT, is more support for the integration of social care with health, providing seamless services for patients. At EPF, we believe ICT provides a window of opportunity to promote a more holistic approach in designing and delivering health and social services to the patients.

It is for this reason that we have decided to become a member of the User Advisory Board of the new SmartCare project, due to be launched in 2013. This three-year project will take the deployment of ICT-supported integrated health and social care for older patients to an unprecedented level.

5





HEALTH TECHNOLOGY ASSESSMENT (HTA)

Health technology assessment (HTA) acts as 'a bridge' between evidence and policy-making. It seeks to provide health policy-makers with accessible evidence-based information to guide their decisions about the appropriate use of technology and the efficient allocation of resources.

Patients have a genuine interest in this discipline since HTA is instrumental in deciding which treatments and care will be made available. However, there is still a long way to go before patients are involved in this area and EPF has focused on promoting greater and better patient involvement.

EPF's research initiative

EPF has recognised that patient organisations clearly needed support to be involved in HTA processes in a meaningful manner following a seminar on HTA in May 2010. As a follow-up to the event recommendations, we have started conducting primary research in this area. We have managed to collect the views, needs, ideas and expectations of different stakeholders through surveys and discussions to shape the role and scope of patient involvement in HTA processes.

In 2012 EPF has released three consecutive reports emerging from this initiative to help patients gain a foothold in the HTA process. Three reports, three different stakeholder groups: HTA agencies (first stage), HTA appraisal committees/policy makers (second stage) and patient organisations (third stage).

The final step of this initiative will be to incorporate the results of all stages into an integrated report, which is expected for 2013.

The research phase has provided us with enough information to develop a position paper on HTA. Our key message is that patient representation is needed in all stages of HTA right from the outset. Patients have a unique perspective, as they have the knowledge of the disease and how a specific technology impacts their daily lives. Until now, they have been poorly involved in the assessments and appraisals. Without this early involvement there is a serious risk that the treatments made available will not respond to patients' needs.

To achieve this meaningful involvement there is a need, inter alia, for:

- ✔ A legal framework and methodology to provide legitimacy to patient involvement.
- ✔ Tailored educational tools and training to enable them to engage in HTA effectively.
- ✔ Transparency of decisions on health technologies to identify and engage with the relevant decision-making bodies.
- ✔ Considering patients as equal partners at the table.





AdHopHTA

EPF has joined the Advisory Board of a new European HTA project this year: AdHopHTA - Adopting Hospital Based Health Technology Assessment. The mission is to strengthen the use and impact of high quality HTA-results in hospital settings. Different tools will be developed to support this objective.

EPF will ensure the perspective of patients is considered and strengthened during the project lifecycle. We will also make policy recommendations to guarantee a patient-based approach in transferring the lessons learnt and best practices to other hospitals. Lastly, this project will enable us to better understand the decision-making process for adopting innovation at the hospital level and we will use this knowledge for our own development in HTA research.



EUNetHTA

The EUNetHTA Collaboration was launched in November 2008 to implement a sustainable, permanent collaboration for HTA in Europe in the form of a Joint Action. The first phase of the Joint Action has been completed in 2012 and a second phase will run into 2015. This second JA aims to bolster the practical application of tools and approaches to cross-border HTA collaboration.

EPF has been involved in this collaboration from the start. We will be active in the dissemination stage of the JA2, with a focus on training. We are convinced that involvement must go hand in hand with capacity building. HTA is a complex subject that requires tailored educational tools and training. We will also work towards establishing a sustainable structure for HTA in Europe. As a member of the project coordination team, we will focus developing recommendations to move forward on a European HTA Network.



Health technology assessment (HTA) is a multidisciplinary activity that systematically studies the medical, social, economic and ethical implications related to the application of a health technology – a drug, medical device or clinical/surgical procedure.



5.5 OUR WORK TOWARDS THE NEXT EU PROGRAMMING PERIOD

HEALTH FOR GROWTH

In 2012 EPF has continued its engagement in the policy-making process for the next EU programming period (2014-2020). We have worked on the new health programme proposal of the European Commission, entitled “health for growth” in particular.

EPF has suggested a number of amendments to the Commission’s own proposal. Our focus has been primarily on inequalities, patient empowerment and health literacy. We strongly advocated the inclusion of these areas as a priority to help ensure actions are taken at EU level that favour high quality, patient-centred and sustainable health systems.

“We believe a strong recognition of the fundamental European values of solidarity and equity is particularly important in the current financial climate. The concept of “European added value” should include the potential for achieving key social objectives, such as the reduction of health inequalities as well as patients’ and citizens’ empowerment”, said Kaisa Immonen-Charalambous, Senior Policy Adviser for EPF.

The Environment, Public Health and Food Safety (ENVI) Committee took many of our amendments onboard in its June vote. The future EU health programme will provide a framework for the annual work plans of the Commission and the prioritised actions in the field of health. It will therefore have a direct or indirect impact on patient communities across the EU.

HORIZON 2020

EPF has made a contribution this year to the European Health Policy Forum’s (EUHPF) position paper on the Commission proposals establishing the framework of

Horizon 2020. As a member of the EUHPF, we have ensured that this new EU financial programme for research and innovation is a powerful and strategic instrument that is fit for purpose and delivers for citizens and patients Europe-wide.

We recommend establishing an overall European Health Research strategy for 2014-2020 to coordinate the programme through the EUHPF. Such a strategy would offer a long term prospect for innovative and value-added health research at all levels.

We believe a comprehensive approach to Horizon 2020 is necessary to achieve a healthier Europe. When designing research programmes and setting priorities, it is crucial to look not only at innovative solutions but also at public needs, including those of the patient. Research priorities in healthcare should be centred on patients’ medical and social needs.

EPF sees the need for prioritising research into health inequalities. This will include the social determinants of health and promotion of good health, not to mention research into the impact of access to high-quality healthcare on health inequalities and the solutions on the table for ensuring equitable access.

Horizon 2020 must provide a holistic vision. Prevention of disease, promotion of health, and patient-centred disease management are essential and complementary aspects of the same continuum. Projects should address not only the medical but also the social and societal impacts of chronic diseases.

Horizon 2020 needs to focus on patient empowerment and greater involvement in health care, both at individual



The Value+ project contributed to raise awareness about the added-value of involving patients’ organisations in projects, as well as to increase the capacity as patients’ organisations of getting involved in projects as equal partners and of applying for and managing EU supported projects through different project information tools



EU STRATEGY ON CHRONIC DISEASES

and collective levels. Patients must be meaningfully involved throughout the research process, from the “idea” stage to the tried and tested intervention, as they have the unique expertise and experiential knowledge that comes from living with a given condition. With their involvement, the scientific expertise of researchers is integrated with patients’ real-world knowledge, balancing scientific excellence with social and cultural relevance.

“Evidence shows patient involvement in research leads to more relevant results. It also ensures that research results are disseminated effectively and contributes to greater trust and acceptance of research in society. Research in isolation will not help patients. An holistic approach is needed that blends innovation in all its guises, patient empowerment and a robust public health framework”, stated Nicola Bedlington, EPF Executive Director.

EPF calls for the implementation of the recommendations of our flagship project Value+ in all health-related research projects. Meaningful involvement of end-users, including patients with chronic diseases and their representative organisations, must be a key criterion in the assessment of funding applications and the evaluation of projects undertaken. Involvement should be demonstrated throughout the entire research process – starting from priority-setting and defining the research questions, to the implementation of research programmes and their evaluation, and the dissemination of results. Involvement is also key for successful take-up.

The spotlight has very much been on chronic diseases, both at EU level and globally, in 2012. EPF has actively engaged in the chronic diseases reflection process initiated by the Commission. We responded in May 2012 to the European Commission’s stakeholder consultation, having previously contributed to the response of the EU Health Policy Forum.

From our perspective, health systems must involve not only greater attention to prevention and health promotion in order to be sustainable, but also fundamental changes in the way healthcare is delivered. National health systems need to become more efficient and, importantly, genuinely patient-centred.

Chronic disease strategies and reflection on healthcare system sustainability are crucial areas in which patients can and must contribute.

“The patients’ perspective on chronic disease is unique: patients live with their disease, they learn to manage it and to navigate the health system to get the right care. This is why we believe that patients play a key role in identifying unmet service needs. They can point out inefficiencies and waste in the system and ensure that strategies to address chronic disease are effective and sustainable” explained Kaisa Immonen-Charalambous, EPF Senior Policy Adviser.

The ultimate goal of the general reflection process is to produce an EU strategy on chronic diseases, focusing on the sustainability of health systems.



5



Healthcare Financing Mechanisms: InterQuality project

How can we spend money more efficiently in healthcare? Launched in December 2010, the InterQuality project is striving to develop scientifically validated tools to help decision-makers choose the right financing mechanisms in different areas of healthcare systems.



As one of nine associate partners, EPF leads the dissemination of the project’s progress and results in close cooperation with CPME – the Standing Committee of European Doctors. The next step for EPF is the development of communication strategy guidelines on the implementation of innovative healthcare financing models. The final role of EPF will be the organisation of the project’s final conference in mid-2013.



More information about the project is available on the website: www.interqualityproject.eu

6. Alliance Building

6.1 RELATIONS WITH EUROPEAN ORGANISATIONS

In 2012, EPF has continued to place a lot of emphasis on forging alliances and good working relations with the European organisations with whom we have a common agenda.

These include:

- The European Public Health Alliance (EPHA) – campaigning jointly and through the European Health Policy Forum on HORIZON 2020, the new EU Health Programme and on Health Inequalities
- The Standing Committee of European Doctors (CPME), the European Federation of Nurses Associations (EFN) and the Pharmaceutical Group of the European Union (PGEU)

All of these were associate partners in the EPF-led Chain of Trust project (see page 24)

We also maintain valued relationships with:

- The European Hospital and Healthcare Federation (HOPE)
- The European Union of Medical Specialists (UEMS)
- The European Health Management Association (EHMA)
- The European Consumers' Organisation (BEUC)
- The European Association of Hospital Pharmacists (EAHP)
- EUROCARERS
- ...and many more.



We have continued our close relationship with our sister organisation at an international level, the International Alliance of Patients' Organizations (IAPO), in line with our Memorandum of Understanding. We have worked closely on core policy issues and have supported their research work into patient-centred care, encouraging our members to respond to the survey.

In 2012 we have strengthened our work with organisations in the medical devices sector such as EDMA, COCIR and EUCOMED, setting up a dialogue meeting twice a year. We have also established a regular information exchange with GSMA-Europe, the European interest group of the international wireless operators associations.

EPF has continued its collaboration with major pan-European networks of regions and health authorities such as the European Network of Regional and Local Health Authorities (EUREGHA), the Assembly of European Regions (AER) and Health ClusterNET. We have continued our dialogue with pharmaceutical companies on an individual basis, in accordance with our Code of Ethics, and through the European Federation of Pharmaceutical Industries and Associations (EFPIA) with a quarterly patient think tank.

Having initiated a collaboration with the European Union Agency for Fundamental Rights in 2011, in 2012 we became a member of the European Fundamental Rights Platform.

We have signed a Memorandum of Understanding with the European Society for Quality of Care (ESQH) and will do the same in 2013 with EPPOSI, the Health Innovation Think Tank.

6.2 REPRESENTATION WORK

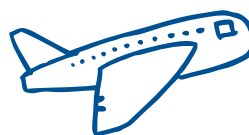
Once again, our board and secretariat members have represented our organisation as speakers, moderators or chairs in numerous European health-related meetings. The purpose of this investment is to enhance the visibility of EPF as the representative voice of patients at EU level, and to present the patients' perspective on EU health policy issues.

A non-exhaustive list of our presentation activities includes:

- The European Union Agency for Fundamental Rights (FRA) Stakeholder Meeting, February 2012, Vienna, Austria
- The European Organisation for Research and Treatment of Cancer (EORTC) 50th Anniversary Conference, March 2012, Brussels, Belgium
- The IAPO Global Patient Congress, March 2012, London, UK
- The Patient-MedTech Dialogues, April & November 2012, Brussels, Belgium
- The IPPOSI Information Day on Health Technology Assessment, April 2012, Dublin, Ireland
- A High-level conference on future EU health systems, May 2012, Brussels, Belgium
- Innovation in Healthcare, May 2012, Brussels, Belgium
- A meeting of the eHealth Task Force, May 2012, Copenhagen, Denmark
- eHealth week, May 2012, Copenhagen, Denmark
- The IMI stakeholder Forum, May 2012, Brussels, Belgium
- The 3rd EU Societal Impact of Pain symposium, May 2012, Copenhagen, Denmark
- The Nordic Conference on cross cooperation on rare diseases, May 2012, Reykjavik, Iceland
- The European Alliance for Personalised Medicine, June 2012, Brussels, Belgium
- The Hospage Conference, June 2012, Berlin, Germany
- The Economist Conference "New responses to non-communicable diseases", October 2012, Geneva Switzerland
- The Patient Link Workshop "High Impact Patient Advocacy", November 2012, Brussels, Belgium
- The Friends of Europe's annual Healthcare Summit, November 2012, Brussels, Belgium
- The EFPIA Patient Think Tank, March & November 2012, Brussels, Belgium
- The DuQue Final Conference, November 2012, Berlin, Germany



➤ EPF President, Anders Olauson, and EPF Executive Director Nicola Bedlington presenting EPF



7. Let's Evaluate 2012

EPF has monitored and evaluated the objectives and activities set out in the 2012 Annual Plan. We have focused on the core programme which has received financial support from an operating grant under the EU Public Health Programme. We have also consulted our members through a working group to review and approve the evaluation plan. A non-exhaustive summary of this evaluation report is provided here and more information is available on our website. This thorough, outcome-orientated approach to evaluation helps EPF to realign its work on an on-going basis and to learn and plan effectively for the future.

OBJECTIVE 1: BUILDING CAPACITY

The evaluation process reveals that:

- The strategic planning process has largely included EPF membership right from the outset. This engagement has proven to be more challenging than was initially expected however.
- EPF has been quite successful in involving the Youth Group in the EPF strategic planning process. By contrast, we have been less successful in involving youth representatives in the EPF Policy Advisory Group and in preparing for the election of a youth board member. This will be addressed actively in 2013.
- EPF has started to strengthen the capacity of its members and patient organisations with no small degree of success :
 - We have developed two policy toolkits to encourage national patient groups to get involved in the transposition and implementation of the pharmacovigilance and cross-border healthcare legislation into national laws (see page 12). The effectiveness of these tools will be assessed in 2013.
 - It is still quite premature to make a thorough assessment of the impact of the Regional Advocacy Seminar (see page 13) in terms of impact on organisations' fundraising strategies and success. However the initial indications tell us that awareness and knowledge of funding opportunities available for patient organisations in the respective countries has very much increased for the large majority of participants as a result of attending the Seminar.
 - EPF's strategy for supporting members has been coupled with the launch of a major three-year Capacity Building Programme (see page 12) this year. The first phase of the Capacity Building Programme will be assessed in 2013.

OBJECTIVE 2: CONSOLIDATING EPF POLICY IMPACT

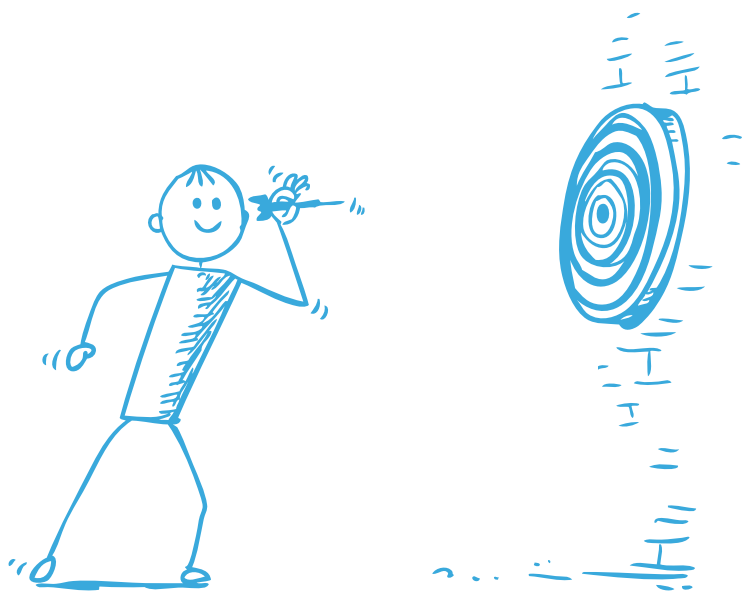
The evaluation process reveals that:

- The policy-related activities and associated deliverables outlined in our 2012 Operational Work Plan (OWP) have, on the whole, been implemented and delivered. There have, however, been a few deviations vis-à-vis the initial plans for certain policy items, namely health inequality and information to patients. This was due to both internal, e.g. a change in strategy and prioritisation within EPF, and external factors, e.g. changes in EU institutions' policy agendas and/or delays in decision-making processes.
- EPF has continued to face some challenges engaging the full membership in the process of drafting policy papers. While some members are extremely active in responding to policy consultations and feeding input and expertise into policy topics, the majority of members only do this occasionally. Two major steps have been taken to overcome this problem. Firstly, we have revised our consultation process and grouped members into target groups according to policy topics that are relevant to them. Secondly we are confident that the above mentioned Capacity Building Programme will enhance our members' participation in policy consultations.
- Assessing the impact of policy advocacy remains a key challenge for all NGOs. Nevertheless several EPF comments and statements have been integrated into the European Commission's, European Parliament's and the European Council's positions and initiatives in areas such as clinical trials, data protection and access to medicines.

OBJECTIVE 3: FEEDING EVIDENCE FROM PROJECTS AND PATIENTS INTO POLICY

The evaluation process reveals that:

- We have focused our Patient Evidence Workshop (see page 23) on clinical trials in order to collect more evidence in this area. This has enabled us to shape our position in relation to some of the key open issues with the new Clinical Trials Regulation.
- The outcomes of the EPF-led Chain of Trust project (see page 24), coupled with the work on telemedicine user requirements, conducted as part of the Renewing Health project, has helped us to put together a preliminary draft paper on eHealth. This will be developed further in 2013, drawing on the results of the SUSTAINS project as well as further evidence from the RENEWING HeALTH pilot sites.
- We have also been able to use the outcomes of our research into EU Patient Involvement in HTA (see page 28) to draft a position paper in this area.



OBJECTIVE 4: BUILDING POWERFUL AND EFFECTIVE COMMUNICATION

The evaluation process reveals that:

- Several steps forward have been made to strengthen and harmonise EPF's visual identity thanks to the adoption of a new communication strategy, the definition of new visual guidelines and the initiation of discussions on the revision of the EPF logo. Efforts towards defining a new visual identity will be finalised in 2013.
- We have revamped our eTools with updated content and layout changes. This includes eight monthly newsletters released from May 2012, improved website content and navigation as well as the production of a video.
- Publications such as our annual reports and leaflets were distributed to target audiences identified in the stakeholder analysis carried out as part of the communication strategy.
- We have also been able to reinforce our 'human side' thanks to social media platforms. This is a medium-term outcome indicator and as such it cannot be assessed at the end of 2012. It can, nevertheless, be highlighted that the starting phase has been quite positive.
- We have managed to build a list of targeted journalists and have achieved satisfactory coverage of our positions and news, but we need to continue to improve our press and media relations.
- We have nurtured cooperation with other stakeholders. This includes strengthening relations with new EU-level health stakeholders and organising joint events with other stakeholders. We are delighted to have relevant stakeholders and policy makers who regularly participate at events organised by EPF.

This evaluation is based on the performance indicators and targets identified in the EPF 2012 Work Plan.

➤ To read the entire report, please visit EPF website www.eu-patient.eu

GOVERNANCE AND SECRETARIAT

THE EPF BOARD

In accordance with the EPF statutes and by-laws, EPF members were re-elected **Anders Olauson**, **Susanna Palkonen**, **Tomasz Szelągowski**, **Avril Daly** and **Philip Chircop** for a two-year mandate. They maintain their previous appointments as Board members and the board have voted in of favour of **Anders Olauson** as President, **Susanna Palkonen** as Vice President and **Tomasz Szelągowski** as Treasurer.

Vida Augustiniene, **Maria Navarro**, **Marco Greco** and **Robert Andrew Johnstone** are midway through their mandate.



Anders OLAUSON
President



Susanna PALKONEN
Vice President



Tomasz SZELĄGOWSKI
Treasurer

BOARD MEMBERS



Vida AUGUSTINIENĖ



Philip CHIRCOP



Avril DAILY



Marco GRECO



Robert Andrew JOHNSTONE



Maria D. NAVARRO

THE EPF SECRETARIAT



Kaisa Immonen-Charalambous
Senior Policy Adviser



Zilvinas GAVENAS
Web / IT Officer



Liuska SANNA
Programme Manager



Cristina PADEANU
New Project Officer



Cynthia BONSIGNORE
New Communication Officer



Nicola BEDLINGTON
EPF Executive Director



Laurène SOUCHET
Policy Officer



Clarissa SPENCER
New Administrative Assistant



Peter WINDEY
New Finance and Operations Manager



Walter ATZORI
Senior Programme Officer



Véronique TARASOVICI
Office Manager



Özgün Ünver
Research Officer



Giulia EVOLVI
Project Officer until June 2012

Good bye,
STAY IN TOUCH
AND ALL THE BEST!



THE EPF POLICY ADVISORY GROUP

The EPF Policy Advisory Group (PAG) was set up in 2009 to advise the EPF Board and Secretariat on policy topics prioritised by EPF's Annual General Meeting. They also debate issues which, because of their complex, controversial and/or highly political nature, require detailed and in-depth discussion.

The group comprises designated representatives by EPF member organisations:

- Robert Johnstone – National Voices
- Hanna Milczarek – Federation of Polish Patients
- Maria Navarro – Spanish Patients' Forum
- Sophie Peresson – International Diabetes Federation Europe
- Rod Mitchell – European Federation of Crohn's and Ulcerative Colitis Associations
- Ian Banks – European Men's Health Forum
- Anthia Zammit – Malta Health Network
- Raluca Nica, Global Alliance of Mental Illness Advocacy Networks (GAMIAN Europe)
- Avril Daly, Fighting Blindness / Retina Europe
- Alastair Kent, European Genetic Alliances Network (EGAN)
- Flaminia Macchia, EURORDIS

- Gunta Anca, Latvian Umbrella Body For Disability Organization (SUSTENTO)
- Hildrun Sundseth, European Institute of Women's Health (EIWH)
- Roberta Savli, European Federation of Allergy and Airways Disease Patients Associations (EFA)

The group met twice in 2012. The major priority of the meetings has been to carry forward the revised structure of the PAG in practical terms, alongside the new strategic planning exercise. Due to the increasing number of policy topics with EPF involvement, the board has decided that the PAG's role within the consultation process should be clarified and strengthened. It has therefore been decided to set up three "pilot" working groups on specific topics reflecting members' interest, but also with a view to plugging some "gaps" to address important but under-recognised issues.

The group has also given advice on critical points about several substantial policy dossiers: the proposed Clinical Trials Regulation, the revision of the Transparency Directive and the Professional Qualifications Directive, and the draft regulations on data protection and medical devices.



THE EPF YOUTH GROUP

The Youth Group is the backbone of the EPF Youth Strategy. It plays an important role in the implementation of this strategy and 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, the Youth Group is composed of 11 young patients' representatives between the ages of 15 and 25, each with different chronic conditions.

In summer 2012, the Youth Group laid the foundations of its work for the following months during its second Annual Youth Meeting. This year's meeting served as the springboard for their first annual meeting as well as the kick-off meeting of the first youth project

"EMPATHY: Europe Meets Young Patients" (see page 17). It has provided an opportunity for them to exchange information and best practices with regard to the ways youth groups operate within various patients' organisations across the EU.

Young people took full advantage of this event to contribute to the EPF Strategic Planning process (see page 10). They have unanimously declared their desire for the young patient's perspective to be considered. They added "Being a patient means going through various stages in life with a number of potential disadvantages associated to having a long term condition which can create discriminatory barriers".



➔ *First Annual Youth Meeting, August 2011*



MEMBERSHIP

EPF is proud to see that its membership has grown to 57 members this year, whether Full, Associate, Provisional or Candidate members.

Full Members

Full EPF Members consist of:

A / Pan-European disease-specific patients' organisations and

B / national coalitions of patients' organisations which represent at least 10 different disease groups.

Full EPF Members are:

- Age Related Macular Degeneration (AMD) Alliance International - International
- Alzheimer Europe - Europe
- Association for the Protection of Patients' Rights - Slovak Republic
- Association Of European Coeliac Societies (AOECS) - Europe
- Collectif Inter associatif Sur la Santé (CISS) - France
- Confederation Health Protections (KZZ) - Bulgaria
- Council of Representatives of Patients' Organisations of Lithuania (LPOAT) - Lithuania
- Estonian Chamber of Disabled People - Estonia
- EUROPA DONNA - The European Breast Cancer Coalition - Europe
- European Alliance of neuro-Muscular Disorders Association (EAMDA) - Europe
- European Federation of Allergy and Airways Diseases Patients' Associations (EFA) - Europe
- European Federation of Associations of Families of People with Mental Illness (EUFAMI) - Europe
- European Federation of Associations of Patients with Haemochromatosis (EFAPH) - Europe
- European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) - Europe
- European Federation of Homeopathic Patients' Associations (EFHPA) - Europe
- European Forum for Psoriasis Patient's Associations in Europe (PE.Pso.POF) - Europe
- European Genetic Alliances Network (EGAN) - Europe
- European Headache Alliance & Migraine Association of Ireland (EHA) - Europe
- European Heart and Lung Transplant Federation (EHLTF) - Europe
- European Infertility Alliance (EIA) – Europe
- European Kidney Patients' Federation (CEAPIR) - Europe
- European Liver Patients Organisation (ELPA) - Europe
- European Multiple Sclerosis Platform (EMSP) - Europe
- European Network of (ex-) Users and Survivors of Psychiatry (ENUSP) - Europe
- European Organisation for Rare Diseases (EURORDIS) – Europe
- European Parkinson's Disease Association (EPDA) - Europe
- European Umbrella Organisation for Psoriasis Movements (EUROPSO) - Europe
- Federation of Polish Patients (FPP) - Poland
- Fertility Europe (FE) - Europe
- Foro Español de Pacientes (Spanish Patients' Forum) - Spain
- Global Alliance of Mental Illness Advocacy Networks (GAMIAN Europe) - Europe
- International Diabetes Federation - Europe
- International Patient Organisation for Primary Immunodeficiencies (IPOPI) - International
- LUPUS Europe - Europe
- Malta Health Network (MHN) - Malta
- National Patients' Organisation of Bulgaria (NPO) - Bulgaria
- National Voices – United Kingdom
- Pancyprrian Federation of Patients Associations and Friends - Cyprus
- Retina Europe - Europe
- The Coalition of Patients' Organizations with Chronic Diseases from Romania (COPAC) - Romania
- The Latvian Umbrella Body for Disability Organization (SUSTENTO) - Latvia



Associate Members

Associate Members of EPF operate on a European level :

- ➔ Associazione Patologie Autoimmuni Internazionale (APAI) –International
- ➔ Bulgarian Association for Patients Defence (BAPD) - Bulgaria
- ➔ European Alliance of Genetic Support Groups -Europe
- ➔ European Cleft Organisation (ECO) -Europe
- ➔ European Coalition of Positive People (ECP) - Europe
- ➔ European Institute of Women's Health - Europe
- ➔ European Men's Health Forum (EMHF) - Europe
- ➔ Hungarian Osteoporosis Patient Association (HOPA) - Hungary
- ➔ Mental Health Europe - Europe
- ➔ Network of national groups working on behalf of people with epidermolysis bullosa (Debra Europe) - Europe
- ➔ Pan European Psoriasis Organization Forum -Europe

Provisional Members

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, then they will be considered for Associate Membership status.

- ➔ EuropaColon - Europe
- ➔ European Network of Fibromyalgia Associations (ENFA) - Europe
- ➔ World Federation of Incontinent Patients (WFIP) - International

Candidate Members

This level of membership is a transitional status for the organisations whose application for Full or Provisional Membership have been approved by the Board but not yet endorsed by the Annual General Meeting.

- ➔ European Federation of Neurological Associations (EFNA) - Europe
- ➔ International Osteoporosis Foundation (IOF) - International



Account and Audit Report



EUROPEAN PATIENTS' FORUM - NON-PROFIT ORGANISATION

Incorporated in the Grand Duchy of Luxembourg with a branch in Belgium.

Registered at the Crossroads Bank with number 0886 909 305.

REPORT FOR THE YEAR ENDED 31 DECEMBER 2012

We have audited the financial statements of European Patients' Forum ("the Organisation") for the year ended 31 December 2012, which show a balance sheet total of **€1,737,224.66** and a deficit of **€9,076.52** for the year.

AUDIT OPINION ON THE FINANCIAL STATEMENTS

Our auditing standards require that we plan and perform our audit to obtain reasonable assurance about whether the financial statements are free of material misstatement. In accordance with those standards, we considered the accounting Organisation.

We received clear answers to our requests for explanation and information. We have examined, on a trial basis, the evidence supporting the amounts included in the financial statements.

We have assessed the accounting policies, the significant accounting estimates made by the Organisation and the overall financial statement presentation. We believe that our audit provides reasonable basis for our opinion.

The financial statements for the year ended 31 December 2012 give a fair view of the Organisation's assets, liabilities, financial position and operating results.

ADDITIONAL REMARKS

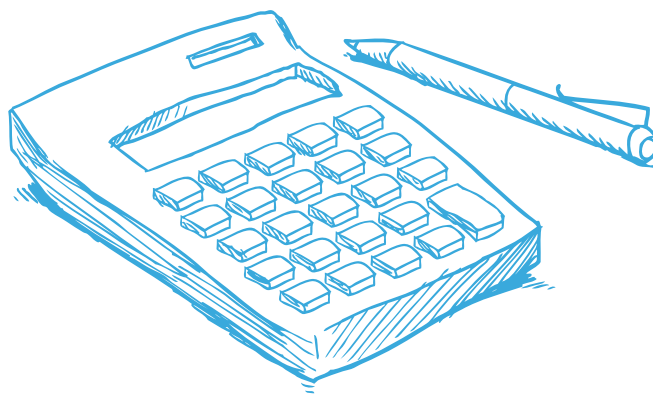
The accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.

The Organisation is registered in the Grand Duchy of Luxembourg. All accounting, legal and regulatory requirements applicable in the Grand Duchy of Luxembourg are beyond the scope of this audit.

— Brussels, February the 19th, 2013

FIDINTER BVBA

| Represented by F. Léonard, Director



BALANCE SHEET AS AT DECEMBER 31ST 2012

	2012	2011
ASSETS		
I Current Assets		
Accounts receivable	€ 338,620.51	€ 102,891.00
Short term investments	€ 201,240.00	€ 200,680.00
Cash in bank and deposit	€ 1,082,117.39	€ 2,150,999.00
Prepaid expenses	€ 16,665.53	€ 10,265.00
Total current assets	€ 1,638,643.43	€ 2,464,835.00
II Fixed Assets		
Leasehold	€ 55,947.95	-
Furniture, ICT equipment and software	€ 30,900.24	-
Guarantees (rent and social security)	€ 11,733.04	€ 11,154.00
Total fixed assets	€ 98,581.23	€ 11,154.00
TOTAL ASSETS	€ 1,737,224.66	€ 2,475,989.00
LIABILITIES		
I Current liabilities		
Accounts payable	€ 132,506.82	€ 77,818.00
Deferred income	€ 1,054,324.52	€ 712,528.72
Income to be allocated to projects' partners	€ 155,542.80	€ 1,281,715.28
Total current liabilities	€ 1,342,374.14	€ 2,072,062.00
II Reserves		
Funds brought forward	€ 403,927.04	€ 338,237.00
Surplus or deficit for the year	€ -9,076.52	€ 65,690.00
Total reserves	€ 394,850.52	€ 403,927.00
TOTAL LIABILITIES	€ 1,737,224.66	€ 2,475,989.00



INCOME AND EXPENDITURE AS AT 31ST DECEMBER 2012

	2012	2011
INCOME		
Membership Fees	€ 8,850.00	€ 10,950.00
Funding from the private sector¹:		
Operational work programme <i>(co-funding of EAHC's operating grant 18,5%)</i>	€ 130,000.00	} € 635,000.00
EPF projects portfolio and capacity building programme	€ 82,587.65	
EC projects	€ 100,046.01	
Eupati	€ 62,045.37	-
Sub-total	€ 374,679.03	€ 635,000.00
Funding from the public sector¹:		
Operational work programme <i>(EAHC operating grant co-funding 80%)</i>	€ 562,012.21	-
EC projects	€ 129,220.81	€ 137,445.57
Eupati (through IMI JU)	€ 105,129.19	-
Sub-total	€ 796,362.21	€ 137,445.57
Interest and Other Income	€ 6,701.21	€ 5,920.28
TOTAL INCOME	€ 1,186,592.45	€ 789,315.85
EXPENDITURE		
Staff and consultants fees	€ 726,489.87	€ 424,903.89
Office costs	€ 162,571.20	€ 74,134.70
Depreciation ²	€ 13,099.10	-
Travel and subsistence	€ 72,503.18	€ 56,433.48
Events:		
Annual General Meeting	€ 50,649.29	€ 62,543.02
Regional Advocacy Seminar	€ 43,594.18	€ 41,886.93
Conference on Rights and Needs of Older Patients	-	€ 65,449.93
Youth meeting	€ 6,468.44	€ 3,652.73
Patient evidence workshop	€ 2,128.96	-
Other events and workshops (eHealth conference, Chain of Trust, etc)	€ 61,681.66	-
Commission projects ²	-	€ 185,888.54
Communications	€ 55,155.55	€ 12,352.34
Bank and financial charges	€ 1,327.54	€ 4,489.49
TOTAL EXPENDITURES	€ 1,195,668.97	€ 931,735.05
SECRETARIAT INCOME²	-	€ 208,109.56
SURPLUS OR DEFICIT OF THE YEAR	€ -9,076.52	€ 65,690.36

¹ Income from pluriannual projects and activities is adjusted with accruals and deferrals according to the level of utilization of resources during the year.

² Deviations from prior year are the effect of changes in the accounting methodology.

ACKNOWLEDGEMENT OF FINANCIAL SUPPORT³

		% of total income
EPF WISHES TO THANK THE FOLLOWING DONORS FOR THEIR SUPPORT:		
Operational work programme		
European Commission (<i>Executive Agency for Health and Consumers</i>)	€ 562,012.21	40.3%
GSK	€ 30,000.00	2.2%
MSD	€ 30,000.00	2.2%
Novartis	€ 30,000.00	2.2%
Pfizer	€ 25,000.00	1.8%
Gilead	€ 15,000.00	1.1%
Project portfolio and capacity building programme		
GSK (<i>30.000€ received in 2011 and 50.000€ advance on 2013 activities</i>)	€ 80,000.00	5.7%
Novartis (<i>20.000€ received in 2013 for the eHealth conference</i>)	€ 50,000.00	3.6%
Sanofi-Aventis	€ 40,000.00	2.9%
AMGEN	€ 35,000.00	2.5%
Janssen Pharma	€ 30,000.00	2.2%
Medtronic Foundation	€ 30,000.00	2.2%
Eli Lilly	€ 20,000.00	1.4%
Sanofi-Pasteur MSD	€ 20,000.00	1.4%
Microsoft Corporation XC	€ 15,276.00	1.1%
Hoffmann-La Roche	€ 15,276.00	1.1%
Baxter World Trade	€ 10,000.00	0.7%
CSL Behring Biotherapies	€ 10,000.00	0.7%
Laboratoires Servier	€ 10,000.00	0.7%
Philips	€ 10,000.00	0.7%
The European Patients' Academy on Therapeutic Innovation Public Private Partnership (EUPATI)		
Innovative Medicine Initiative (IMI JU) contribution	€ 105,129.19	7.5%
Industry consortium (<i>UCB, Amgen, Genzyme, VFA, AZ, Novonordisk, Bayer, Merck, Janssen, GSK, Chiesi, Hoffmann, Lilly, Novartis, Esteve</i>)	€ 62,045.37	4.4%
<i>Note: the income provided represents EPF's share in the consortium's contributions to the project only.</i>		
EPF WISHES TO THANK THE EUROPEAN COMMISSION FOR ITS SUPPORT IN 2012 FOR EPF'S ROLE IN THE FOLLOWING PROJECTS:		
INTERQUALITY	€ 55,488.17	4.0%
Chain of Trust	€ 42,235.42	3.0%
Sustains	€ 25,350.64	1.8%
Joint Action Patient Safety & Quality Care	€ 21,970.24	1.6%
MEMBERSHIPS AND OTHER INCOME	€ 15,551.21	1.1%
TOTAL INCOME	€ 1,395,058.45	100.0%
ACCRUALS AND DEFERRALS³	€ -208,466.00	
TOTAL INCOME NET OF ADJUSTMENTS	€ 1,186,592.45	

³ In accordance with widely accepted accounting principles, any funding received in-year is subject to accrual and deferral adjustments proportionate to the level of resources assigned to pluriannual activities and projects. In 2012, the effect of this method was a reduction in total income by €208.466, of which €142.642 corresponded to private sector donations.



EPF CHANGE OF LOGO

The process of changing the logo started in October 2012. EPF realised the old logo created back in 2003 was no longer reflecting the evolution of our organisation. In ten years, EPF has established itself as a key interlocutor with important stakeholders on health issues. In parallel, the patients' role in healthcare has transformed. They are becoming active and responsible actors in the management of their own health.

BRAINSTORMING SESSION WITH THE BOARD AND SECRETARIAT

The process of changing a logo takes time and is not to be taken lightly. A brainstorming session held in September 2012 with the EPF Board and Secretariat initiated the process. It emerged from this that there was a willingness to have a new logo that conveys EPF's strong values of patients' empowerment, equitable access to healthcare, humanity, professionalism, unity, moving-forward, ethical and credible.

ONLINE SURVEY WITH OUR MEMBERS

Following this brainstorming phase, we encouraged our members to share their thoughts through an online survey. They wanted the values "patient-centeredness", "powerful/strong/empowering/voicing" and "unity/solidarity" to be strongly represented in the logo. In addition they requested a new logo keeping 'people' at the forefront but associated to a strong symbol. Finally the symbol they wished to see associated with the new EPF logo was the forum.

THE NEW LOGO

The new logo mirrors the evolution of our organisation as well as the changing role of patients. It also reflects our key values. The new shape maintains the original style with the three characters and therefore shows our human side while bringing our values to the fore.

It visualises three different and dynamic figures that gather together to shape a forum. All together they are

empowered to become active players that make the voice of European patients heard widely. And all of them are equally included in this forum, representing the need for equal access to healthcare, regardless of their diversity.

The choice of colours is deliberate. Blue is the most prevalent colour in European affairs and represents trust and reliability. Green symbolises nature, healthiness and good fortune. Last but not least, these colours are contrasted enough to be accessible for visually impaired people.

The name "European Patients Forum" is written in full to ensure the understanding of the EPF acronym. Finally the word "patients" is highlighted in bold to recall that patients should be at the centre of policies that affect us.

The identity of EPF is the face of our organisation to the world. It conveys our ideals, motives and objectives — a sense of what we are all about.

Our appearance has evolved with time, but our essence remains: we are a strong patients' voice to drive better health in Europe.

The new logo will be revealed at our 2013 Annual General Meeting and will be used officially as from 3 June 2013. Our communications will be adapted to our new identity and we will keep you informed through our website.



EUROPEAN PATIENTS' FORUM

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➤ www.eu-patient.eu/blog

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📘 www.facebook.com/europeanpatientsforum



This 2012 annual report arises from the EPF 2013 Work Programme, which has received funding from the European Union, as part of the framework of the Health Programme.

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.