

“A STRONG  
PATIENTS’  
VOICE  
TO DRIVE  
BETTER  
HEALTH IN  
EUROPE”



**EUROPEAN PATIENTS’ FORUM**  
ANNUAL REPORT 2011



europeanpatients'forum



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# introduction

## WELCOME TO THE EPF ANNUAL REPORT FOR 2011



This year has been, in many ways, a year of transformation for EPF. We are evolving as an organisation, responding to new and different demands from our membership and the EU political environment.

As this report portrays, EPF's "raison d'être" is our policy influence in an EU health context, supported by our projects and partnerships. Alongside this, however, we are increasingly engaged in capacity-building work to bring EPF even closer to our members, building on the outcomes of our flagship project, Value+.

In 2011, we have undertaken significant work to promote meaningful patient involvement in the next EU Programming period 2014-2020.

2011 marked the adoption of key health dossiers in which EPF has played a critical advocacy role. We will continue to invest in these by working with our national members and their governments in relation to effective patient-centred transposition and implementation.

We were proud to launch our youth strategy in 2011. We also initiated intensive work on the needs and rights of older patients, in the framework of the European Innovation Partnership on Active and Healthy Ageing, and our own major conference under the EU Polish Presidency in July 2011.

eHealth in all its guises continues to be a core priority for EPF. We believe it is absolutely central to our vision of high quality, patient-centred, equitable healthcare. We welcome

strongly the significant political focus on eHealth, and this report describes our advances in this arena in 2011.

2011 was an important year of achievement for EPF, thanks to the unstinting commitment of our strong and vibrant members, and our valued partners. For the first time, EPF was awarded an operating grant from the EU Public Health Programme, enabling us to step up a gear in delivering for patients. We also led a major Consortium to a successful proposal to the Innovative Medicines Initiative for a European Patients' Academy on Therapeutic Innovation (EUPATI), which will guarantee a stronger role for patients in pharmaceutical research, through patient-led knowledge building and networking.

New times and new challenges – our warmest thanks go to all of you.



**Anders OLAUSON**

| EPF President



**Nicola BEDLINGTON**

| EPF Executive Director

# strategic goals, mission statement and values

## EPF'S VISION

Our vision is **high quality, patient-centred, equitable healthcare** 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:

### 1. Equal access for patients:

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

### 2. Patient involvement:

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

### 3. Patients' perspective:

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

### 4. Sustainable patient organisations:

To encourage inclusive, effective and sustainable representative patient organisations.

### 5. Patient unity:

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

## 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, carers and their families.

### ➔ Empowering of patients:

We foster the empowerment of patients, carers and their 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 to be able 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:

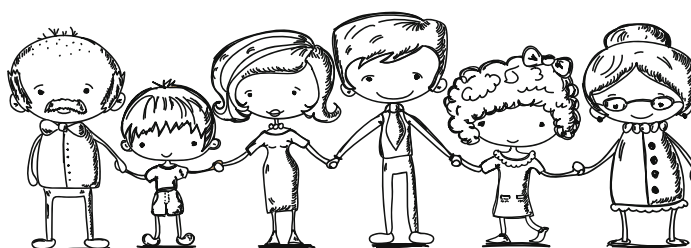
We are an independent organisation, transparent in all our operations (financial, policy, communications).

### ➔ Inclusive:

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

### ➔ Equitable:

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



# Key EPF achievements in 2011

**EPF IDENTIFIED FOUR OBJECTIVES IN OUR WORK PLAN 2011 THAT RELATE TO THE STRATEGIC GOALS OF OUR ORGANISATION:**

1. **BUILDING CAPACITY** WITHIN THE GOVERNANCE STRUCTURES, THE SECRETARIAT, AND THROUGH REINFORCING AND EXTENDING THE MEMBERSHIP, AND DIVERSIFYING/SOLIDIFYING FUNDING (GOALS 1-5)
2. **STRENGTHENING OUR POLICY IMPACT** (GOALS 1-3)
3. **DEVELOPING PROJECTS AND PATIENTS' EVIDENCE TO FEED INTO POLICY** (GOALS 1-3)
4. **BUILDING POWERFUL AND EFFECTIVE COMMUNICATIONS AND PARTNERSHIP** (GOALS 1-5)

2011 marked a turning point for EPF. For the first time we were successful in our application for operational funding from the EU Public Health Programme for 2012. This support will enable EPF to fulfil even more effectively the expectations of our growing membership.

## BUILDING CAPACITY

The foundations for a major Capacity Building Programme were set in 2011 and will allow us to strengthen the organisational and advocacy skills of selected member organisations, on their request. This will build on the outcomes of the Value+ project.

We proudly reached a milestone with the launch of the Youth Strategy and the establishment of the EPF Youth Group. We aspire to work with young patient leaders, creating appropriate tools and the environment to articulate their specific needs and expectations.

We are pleased that our Regional Advocacy Seminar held in September was an unreserved success. We paved the way for mutual understanding and trust-building between 65 health professional representatives and patient leaders from Bulgaria, Estonia, Hungary and Romania.

EPF continued to place much emphasis on growing and reinforcing our membership; on forging alliances and good working relations with European organisations working on health; and on enhancing EPF's visibility through representation work as the voice of patients

at EU level in order to present the patients' perspective on EU health policy issues.

## STRENGTHENING OUR POLICY IMPACT

2011 offered good opportunities for EPF to consolidate our policy influence in an EU health context. We added significant value to the EU legislative process regarding therapies and treatments – Clinical Trials, Medicine Devices, Transparency, Corporate Responsibility in the field of Pharmaceuticals, Personalised Medicine and Adherence therapies – but also positively influenced planning around the EU Health Programme 2014-2020, the EU Research Framework Programme, the EU reflection process on chronic disease and on the EU Directive on professional qualifications. Our objective was to ensure that health policy and programmes at EU level reflect our vision of patient-centred, equitable healthcare.

EPF put a strong focus on ageing in 2011. We committed ourselves to playing an active role in the Innovation Partnership on Active and Healthy Ageing. This was also the purpose of our conference in Warsaw, which will lead to a position paper on the rights and needs of older patients.



We extended our activity to new policy strands, notably with our work on old and young patients, but also for other vulnerable groups such as migrants, including undocumented people, ethnic minorities, refugees and asylum seekers though our work with the Fundamental Rights Agency (FRA). We explored discrimination on the grounds of illness and addressed health inequalities from the perspective of patients. Accessible and high quality healthcare was also a main policy thrust in 2011, with good results on cross-border healthcare, information to patients, health literacy and Quality of Care and Patient Safety.

## DEVELOPING PROJECTS AND PATIENTS' EVIDENCE

eHealth continued to be a core priority for EPF in 2011. We completed the first year of the 'Chain of Trust' project, which aims to improve available knowledge among patients and health professionals with regard to telehealth. The RENEWING HEALTH project entered its second phase with the recruitment and training of patients, as well as the finalisation of protocols and the launch of the large-scale real-life test beds in nine European regions. We strongly welcomed the political focus on eHealth with the eHealth Governance Initiative.

2011 saw the completion of the literature review for the InterQuality project, which will provide the basis for this 5-year project. The RESPECT project ended in 2011, and we hope our investment in it will contribute long-term to increasing the safety of treatments for children and young people.

We continued the policy work started in autumn 2009 on Health Technology Assessment (HTA), through our continued involvement in EUnetHTA in the form of the new Joint Action launched in 2011, the wide dissemination of EPF's resources

on Health Technology Assessment, and a series of surveys on patient/patient organisations' involvement in HTA.

During 2011 we also prepared the ground for new challenging projects. With EUPATI, we will try to guarantee a stronger role for patients in pharmaceutical research through education and information. With SUSTAINS, we hope to contribute to a new paradigm in healthcare where the passive patient becomes an active player in his/her own health. The Joint Action on Patient Safety and Quality of Care will also kick-off in 2012, fostering more cooperation between Member states in this area.

## EVALUATION AND COMMUNICATION

At the end of this annual report, we share a non-exhaustive summary based on the performance indicators and targets identified in the 2011 EPF Work Plan. It will provide you with a flavour of the impact of our work. We also share an evaluation of our communication work, to give you an overview of our efforts to date and our plan to extend these in 2012 through a brand-new communication strategy.

# EPF Prepared for a major capacity programme

**IN RECENT YEARS, EPF HAS IMPLEMENTED SEVERAL CAPACITY-BUILDING ACTIVITIES WITH AND FOR PATIENT ORGANISATIONS IN THE FORM OF: AN ANNUAL REGIONAL ADVOCACY SEMINAR; WORKSHOPS LINKED TO THE EPF ANNUAL GENERAL MEETING AND THE ANNUAL SPRING CONFERENCE; PRODUCTION OF TOOLKITS AND GUIDELINES; AND AD-HOC ADVICE IN RESPONSE TO MEMBERS' REQUESTS. THESE ACTIVITIES HAVE ALWAYS BEEN EXTREMELY WELL RECEIVED BY PARTICIPANTS, WHICH UNDERLINES THE NEED TO CONTINUE THEM.**



## Focus

Capacity Building is defined as a process of enhancing an organisation's activities in order to fulfil our mission.

The goal is to tackle problems related to policy and methods of development, while considering the potential, limits and needs of the people of the country concerned.

In 2011, an initial needs assessment was made by consulting EPF members and a preliminary plan was developed. It became very clear that there is a large variation in skill-levels between patient organisations.

EPF drew the following conclusions:

- National specificities require a more focused country approach;
- Some limitations in terms of impact and sustainability have to be taken into account (e.g. the number of people and organisations that can be involved, language barriers, difficulties in following up);
- Capacity building activities must address more than just advocacy and policy-related skills. Patient organisations have expressed a series of needs that are not strictly linked to the type of issues that European or regional level events would address; e.g. fundraising, project writing, management of volunteers, etc.

The message we received from numerous patient organisations is clear: they cannot advocate effectively if they do not have a minimum structure behind them that can support advocacy work. Being able to fundraise, to be involved in projects, to run the basics

of an organisation, to mobilise volunteers efficiently, to manage a budget – these are key elements that an organisation needs to have in place in order to operate effectively.

The Capacity Building programme will be launched in early 2012. EPF aims in the long term to improve the advocacy capacity of patient organisations by first of all strengthening their organisational skills and some key elements that an organisation needs to have in place to operate effectively. Ultimately, patient organisations will be in a position to contribute even more strongly to healthcare policy and decision-making.



# EPF to Diversify and Solidify its Funding Base

- EPF IS HIGHLY COMMITTED TO AND ACTIVE IN DIVERSIFYING ITS FUNDING SOURCES.
- EPF'S FUNDING BASE IS THREE-FOLD: MEMBERSHIP FEES, EU FUNDING AND UNRESTRICTED FUNDING FROM SPONSORS.
- EPF HAS A MEMBERSHIP FEE STRUCTURE BASED ON THE ANNUAL TURNOVER OF MEMBER ORGANISATIONS.

## EU FUNDING

EPF received a significant proportion of its income from Commission-funded projects in 2011: **'Chain of Trust'** (funded by the Public Health Programme), **InterQuality** (funded by the Seventh Framework Programme (FP7) for research and innovation), **RESPECT** (also funded by the FP7), **RENEWING HeALTH** (funded by the Competitiveness and Innovation Programme-ICT Policy Support Programme), **eHealth Governance Initiative** (Joint Action under the Public Health Programme and Thematic Network under the Competitiveness and Innovation Programme-ICT strand).

In 2011, EPF was successful for the first time in applying for operational funding from the EU Public Health Programme for 2012. As EPF grows as a European non-governmental organisation that delivers important input to the EU health policy debate, it is important and appropriate that a significant proportion of EPF's funding comes from the European Commission.

## UNRESTRICTED FUNDING

Unrestricted grants from a range of companies and foundations continue to make up part of EPF's resources. These grants primarily co-finance our portfolio of projects, in line with funding partners' Codes of Practice for working with patient organisations. Our own Code of Ethics and Framework for working with funding partners, which were revised in 2008 and adopted unanimously by the AGM in 2009, also ensure that EPF's relationship with sustainable funding partners meets the highest standards of transparency and independence. A new funding model has been put in place to ensure strict adherence to European Commission regulations.

This diversity of funding composed of institutional, corporate and membership funds is crucial to the healthy development of EPF as a vibrant and dynamic organisation.

*Details of all of these projects are found elsewhere in this report.*



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## NEW PROJECTS DUE TO START IN 2012:

- EPF is consortium-leader of the EUPATI project, funded by the Innovative Medicines Initiative. A tremendous amount of preparatory work took place with the 29-member Consortium to ensure the project could be launched on 1 February 2012.
  - We are also a key partner in the SUSTAINS project, starting in January 2012; EPF has a key role in two work packages (WP), "Evaluation and Deployment Planning" (WP3) and "User Requirements" (WP4).
  - Further preparatory work was also done on the Joint Action on Patient Safety and Quality of Care, following on from the EUNetPAS project which ended in 2010. This Action will start in 2012.
-

# the EPF secretariat and governance



## THE EPF SECRETARIAT



**Nicola BEDLINGTON**  
| EPF Executive Director



**Walter ATZORI**  
| Senior Programme Officer



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



**Liuska SANNA**  
| Programme Manager



**Véronique TARASOVICI**  
| Office Manager



**Zilvinas GAVENAS**  
| IT and Webmaster

Welcome  
**TO THE EPF  
SECRETARIAT!**



**Laurène SOUCHET**  
| Policy Officer



**Özgün ÜNVER**  
| Research Officer



**Abinaya RAJAN**  
| Intern until March 2011,  
focusing on HTA surveys



**Gayathree DUCCESCHI**  
| Programme Officer  
until December 2011



**Eda ÖZDEK**  
| Assistant to Office Manager  
until December 2011

Good bye,  
**STAY IN TOUCH  
AND ALL THE BEST!**

## THE EPF BOARD :

In accordance with the EPF statutes and by-laws, **Vida Augustiniene, Guadalupe Morales, Maria Navarro** and **Timo Nerkko** ended their two-year mandates as members of the Board. **Vida Augustiniene** and **Maria Navarro** were re-elected. **Tomasz Szelagowski** was elected by the Board as Treasurer. **Anders Olauson, Susanna Palkonen, Tomasz Szelagowski, Avril Daly** and **Philip Chircop** are halfway through their mandate.

**Anders Olauson** thanked Guadalupe and Timo very much for their contributions to EPF.

**Marco Greco** and **Robert Johnstone** were elected as new Board members.



**ANDERS OLAUSON**  
| *President*



**Susanna PALKONEN**  
| *Vice President*



**Tomasz SZELAGOWSKI**  
| *Treasurer*

## THE BOARD

## BOARD MEMBERS



**Philip CHIRCOP**



**Avril DAILY**



**Maria D. NAVARRO**



**Vida AUGUSTINIENĖ**



**Marco GRECO**



**Robert ANDREW JOHNSTONE**



### Marco Greco

is Chairman of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) since 2008. He was the founder of the EFCCA Youth Group, and its leader from 2003 to 2007. He is currently a practising attorney at the Milan law firm of Brambilla, Invernizzi & Greco, focusing on litigation, commerce and consumers' protection legislation. He obtained a PhD in Law and Religion (religious freedom and discrimination and canon law) from Università Cattolica del Sacro Cuore in Milan, after a period of research spent at George Washington University School of Law, in Washington D.C. (USA). His main area of research focused on the relationship between law and religion in the healthcare system.



### Robert Andrew Johnstone

is Chairman of Access Matters, a pan-disability consultancy working on the premise that encouraging accessible environments and culture enhances the workplace for employees and improves service delivery to customers. Robert, a wheelchair user, is an informed and committed patient advocate with a strong interest in international policy issues. He is active as a Board member of National Voices, and as National Voices' representative to and Board member of the International Alliance of Patient Organisations.



# reinforcing and extending the membership

**EPF IS PROUD TO SEE THAT ITS MEMBERSHIP HAS GROWN TO 51 MEMBERS.**

## FULL MEMBERS

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

*The Federation Of Patients and Consumers Organisations in the Netherlands - NPCF withdrew membership of EPF*





*New members in 2011!*

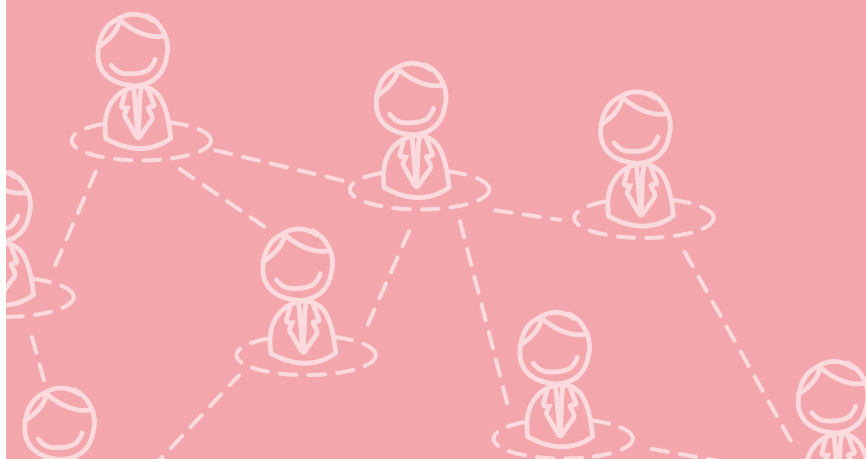
**THE FOLLOWING ORGANISATIONS WERE ENDORSED AS FULL MEMBERS AT THE ANNUAL GENERAL MEETING IN APRIL 2011, ON THE RECOMMENDATION OF THE EPF BOARD:**

- Association for the Protection of Patients' Rights (Slovak Republic)
- Confederation Health Protections - KZZ
- European Forum for Psoriasis Patient's Associations in Europe - PE.Pso.POF
- European Headache Alliance & Migraine Association of Ireland - EHA
- European Liver Patients Organisation - ELPA
- European Umbrella Organisation for Psoriasis Movements - EUROPSO
- National Patients' Organisation of Bulgaria - NPO

*Associate members:*

**OTHER INTERESTED ORGANISATIONS OPERATING ON A EUROPEAN LEVEL THAT INCLUDE PATIENTS ORGANISATIONS AS MEMBERS ARE ASSOCIATE MEMBERS OF EPF:**

- Associazione Patologie Autoimmuni Internazionale - APAI
- European Alliance of Genetic Support Groups
- European Cleft Organisation - ECO
- European Coalition of Positive People - ECPP
- European Institute of Women's Health
- European Men's Health Forum
- Hungarian Osteoporosis Patient Association - HOPA
- Mental Health Europe
- Organisation of people with epidermolysis bullosa - Debra Europe
- Pan European Psoriasis Organisation Forum



# YOUTH STRATEGY AND ESTABLISHMENT OF THE YOUTH GROUP

## EPF INVOLVES AND EMPOWERS YOUNG PATIENTS

The 2010 Regional Advocacy Seminar dedicated to the involvement of young patients in patient organisations inspired EPF Youth Strategy. "The needs and expectations of young patients do not necessarily match those of adult patients. Being a patient inevitably impacts on every aspect of one person's life and, for a chronically ill youngster, it has important repercussions on his/her growth process," explained Nicola Bedlington, EPF's Director, after the adoption of the strategy at the 2011 Annual General Meeting.

Through the Youth Strategy, EPF would like to provide young patients with appropriate tools and avenues through which their specific needs and expectations can be put forward. This would contribute to strengthening

their representatives' skills and self-confidence while reinforcing their representation in patient organisations. EPF also intends to be the driving force of better cooperation between young patients and adult patient advocates. Ultimately, this should lead to health policies that are more responsive to young patients' needs.

Next steps include the development of a European project aimed at fostering better recognition of young patient needs in EU-policy making and the integration of the youth group into our governance structure, as well as our main advisory body (PAG).

"The experience gained is invaluable and broadens my perspective in life. It is a great opportunity to meet other people from different nations who also have a medical condition. I'm happy to contribute to my own organisation and to help other youth patients in any way I can."

| Andrew Zammit McKeon, member of the EPF Youth Group.



## EPF YOUTH GROUP

### WHO ARE THEY?

Nominated by EPF members, the Youth Group is composed of 11 young patient representatives between 15 and 25 years of age with different chronic conditions.

### WHAT IS THEIR ROLE?

The Youth Group is the backbone of the EPF Youth Strategy. It plays an important role in the implementation of the 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.

The Youth Group held its first Annual Congress in Brussels on 19-21 August 2011.



# regional advocacy seminar 2011, BUCHAREST

## EPF FOSTERS COOPERATION BETWEEN PATIENT AND HEALTH PROFESSIONAL ORGANISATIONS



Co-hosted by the Coalition of Patients' Organisations with Chronic Diseases in Romania (COPAC), the fourth EPF Autumn Regional Advocacy Seminar was held in Bucharest, Romania on 27-28 October 2011. Besides 40 patient leaders, we hosted 15 healthcare professionals (general practitioners, specialist doctors, nurses, and pharmacists) from Romania, Bulgaria, Hungary and Estonia. This is the first time representatives of national health professionals' organisations participated at the Regional Advocacy Seminar along with patient leaders.

The overarching theme of the seminar was to promote the cooperation between patient and health professional organisations.

### THERE WERE THREE MAJOR OBJECTIVES:

- To strengthen patient organisations' capacity in order to become more empowered actors in the national and European health policy area

- To raise knowledge and awareness among national patient and professional organisations on how to get involved and cooperate in the transposition and implementation of key EU health-related policies
- To enhance mutual understanding and build trust between patient and health professional organisation.

The participants were pleased with the seminar and concluded that their awareness of opportunities for better patient-professional cooperation had increased. They explored the benefits of trust-based patient-professional cooperation and came up with concrete ideas and plans for enhancing it in national health policy-making. Most patient and health professional representatives reported that they had become more willing to cooperate with one another.

## EPF / alliance BUILDING

**IN 2011, EPF CONTINUED TO PLACE A LOT OF EMPHASIS ON FORGING ALLIANCES AND GOOD WORKING RELATIONS WITH EUROPEAN ORGANISATIONS WITH WHICH WE HAVE A COMMON AGENDA.**



### THESE INCLUDE:

- European Public Health Alliance (EPHA) – campaigning jointly on the new Public Health Programme;
- European Standing Committee of Doctors (CPME) – participating in meetings in Warsaw in November to revisit our joint principles;
- European Federation of Nurses' Associations (EFN) – contributing to their 40th Anniversary Publication;
- Pharmaceutical Group of the European Union (PGEU) – collaborating closely on medicine concordance issues and European Hospital and Healthcare Federation (HOPE).

### WE ALSO HAVE VALUED RELATIONSHIPS WITH:

- the European Union of Medical Specialists (UEMS)
- the European Health Management Association (EHMA)
- the European Consumers' Organisation (BEUC)
- EUROCARERS
- ...and many more.

Several of these organisations are partners with EPF in the EU-funded 'Chain of Trust' project.

We also continued our close relationship with our sister organisation at the international level, the International Alliance of Patients' Organisations (IAPO), in line with our Memorandum of Understanding, and worked closely on core policy themes which included pharmacovigilance, anti-counterfeiting and clinical trials. IAPO representatives

were present at several of our external meetings and EPF will be involved in the IAPO Global Patients' Congress and in IAPO's next biannual Congress in London in 2012.

In 2011, we strengthened our work with organisations such as EDMA, COCIR and EUCOMED, setting up a regular dialogue meeting twice a year with representatives of the medical devices sector. We also established a regular information exchange with GSMA-Europe, the European interest group of the international wireless operators association.

We also continued our 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. EPF was also involved in the launch and follow-up of the Committee of the Regions—DG SANCO "Technical Platform for Co-operation on Health".

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).

In 2011 we became a member of the European Fundamental Rights Platform (see section on healthcare for vulnerable groups). We also signed a Memorandum of Understanding with the European Society for Quality of Care (ESQH) and we are exploring potential collaboration with EPPOSI in its mission to be a health innovation think tank.

# EPF / Working in Partnership



**ONCE AGAIN, EPF WAS REPRESENTED BY ITS BOARD AND SECRETARIAT AS SPEAKERS, MODERATORS OR CHAIRS IN VERY MANY EUROPEAN HEALTH-RELATED MEETINGS DURING 2011.**

**THE PURPOSE OF THIS INVESTMENT WAS 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. THE EPF MAILING FEATURES REPORTS ON ALL OF THESE MEETINGS.**

## **HIGHLIGHTS INCLUDE PRESENTATIONS AT:**

- ⊕ OECD Workshop "Building a smarter health and wellness future", 17-18 February, Washington
- ⊕ 4th European Forum of Healthcare Deciders, London School of Economics, 17-18 February, London
- ⊕ FP7 National Contact Points Networking meeting, 8 March, Brussels
- ⊕ Medical Devices Congress, 22-23 March, Brussels
- ⊕ BioVision, the World Life Sciences Forum, 27-29 March, Lyon
- ⊕ Innovation in Healthcare, 30-31 March, Brussels
- ⊕ International Forum on Quality and Safety in Healthcare, 5-8 April 2011, Amsterdam
- ⊕ European Patients' Rights Day, 11-12 April 2012, Brussels
- ⊕ Pharmacovigilance Legislation Meeting, EMA, 15 April, London
- ⊕ eHealth week, 9-13 May, Budapest
- ⊕ European Perspectives on Personalised Medicine Conference, 12-13 May, Brussels
- ⊕ EFGCP workshop on the Clinical Trials Directive, 7 July, Brussels
- ⊕ Task Force of high-level advisors on eHealth, 16 September, Tallinn
- ⊕ European Innovation Partnership on Active & Healthy Ageing, 17 September, Brussels
- ⊕ European Commission Research Advisory Board, 9 November, Brussels
- ⊕ ABC Project European Forum on Patient Adherence to Medication, 8 December, Brussels
- ⊕ Pan-European Workshop on Medical uptake of Mobile Health solutions, 5 December, Brussels
- ⊕ EUneHTA Conference, 8-9 December, Gdansk
- ⊕ Meeting of the Steering Group on Access to Medicines in Europe, December 15, Warsaw



# therapies

## REVISION OF THE EU CLINICAL TRIALS REGULATORY FRAMEWORK

During 2011, EPF contributed to the planned revision of the EU clinical trials regulatory framework. The objective was to ensure that regulation at EU level is effective, proportionate, and more patient-centred.

The European Commission completed its second public consultation in May 2011, to which EPF again gave a strong input. We submitted comments on the Commission's proposals, as well as a statement reiterating and expanding on the key principles that had already been voiced in our response to the first public consultation: more patient involvement in trials design and assessment; access to high-quality information; meaningful informed consent; and equitable access to treatment.

In July, EPF held bilateral discussions with the Commission to exchange views on the revision. The dossier was discussed again in the Policy Advisory Group in September, and in a patients' evidence workshop in November.

## PATIENTS' EVIDENCE WORKSHOP

EPF organised a patients' evidence workshop in Brussels on 21 November 2011. Representatives of EPF's member organisations met to discuss the direction of the review of the EU clinical trials legislation. They had the opportunity to ask questions and convey their views to European Commission officials who attended part of the meeting and gave an overview of the Commission's approach.

## REVISION OF THE MEDICAL DEVICES DIRECTIVES

In 2011 EPF was closely involved in the discussion process to prepare the forthcoming revision of the EU legislation on Medical Devices. Placing patient safety at the centre of the revision is a key priority for EPF; Director Nicola Bedlington gave the patients' views on safety and medical technology at the High-level conference on medical devices in March.

Other core issues for patients include better information and meaningful patient involvement throughout the process, from innovation to vigilance activities. In this respect, a key milestone was the adoption of the Council Conclusions on innovation in the medical device sector in June, which reflects a strong patient perspective and takes into account expectations of the patient community.

EPF and EUCOMED, the European MedTech industry association, established the first-ever structured dialogue between patient organisations and Medical Technology industries to exchange views on the role of medical technology and explore common healthcare challenges.

DG SANCO is expected to issue its proposal for a Regulation in the second quarter of 2012, and EPF will then consult its full membership. Building on our continuous work on this dossier since 2008, EPF will continue its strong dialogue with stakeholders and EU institutions throughout 2012, to ensure the legislative process results in a patient-centred framework for medical devices in Europe.





## REVIEW OF THE EU TRANSPARENCY DIRECTIVE

### FOSTERING TIMELY AND TRANSPARENT PRICING AND REIMBURSEMENT DECISION ACROSS THE EU

EPF actively participated in the debate for the review of the so-called Transparency Directive (Council Directive 89/105/EEC) which harmonizes certain aspects of national procedures for pricing and reimbursement decisions for medicines across EU Member States, including through setting strict time limits for Member States to adopt pricing and reimbursement decisions. The central issue for patients is that these timeframes should under no circumstances be extended, as this would worsen existing inequalities and delays in access to medicines across the EU. In addition, effective means to enforce these limits are needed to ensure all Member States are complying with these provisions.

The other essential issue is the modernisation of the concept of transparency, which should encompass transparency to patients and the public regarding the procedures and criteria on which decisions are taken, the responsible bodies and pricing decisions.

EPF raised these issues in its contribution to the Commission's consultation in May 2011. The European Commission is expected to issue its proposal in early 2012. EPF will consult its membership and work with partners and institutions to ensure the reopening of the Directive results in strengthening good governance, accountability, timeliness and transparency in decision-making for price and reimbursement.

### EPF INVOLVEMENT WITH THE EUROPEAN MEDICINES AGENCY

EPF continued to be actively involved in the work of the EMA, notably through the Patients and Consumers

Working Party (PCWP), which met four times. One of the meetings focused on improving the EMA patient training strategy, developing patient-friendly information on EMA and medicines regulation, and increasing the visibility of patient involvement in EMA.

EPF was also involved in a number of specific activities: the working group on the EudraVigilance medicines safety database, which in July finalised the Access Policy to grant more access to stakeholders; and the working group on ethics and good clinical practice in third-country clinical trials, where we achieved the inclusion of a patients' perspective in the draft reflection paper endorsed by the EMA MB on 15 December.

Two new EPF patient representatives received training in medicines regulation and in the review of EMA documents at the annual training workshop on 30 November, and are now included in the group of reviewers coordinated by the EPF Secretariat.

EPF representatives also attended two special stakeholder forums on the implementation of the new EU pharmacovigilance legislation, where we stressed the importance of the new rules for patients and the need to have training on pharmacovigilance and to implement direct patient reporting in a way that captures the special richness of patient experiences.

The terms of the patient representatives on the Management Board came to a close in 2011, and EPF put forward Mike O'Donovan for a second term. We also put forward a patient representative for the new Pharmacovigilance Risk Assessment Committee (PRAC), set up as a result of the new pharmacovigilance legislation.





## COMMISSION INITIATIVE ON CORPORATE RESPONSIBILITY IN THE FIELD OF PHARMACEUTICALS

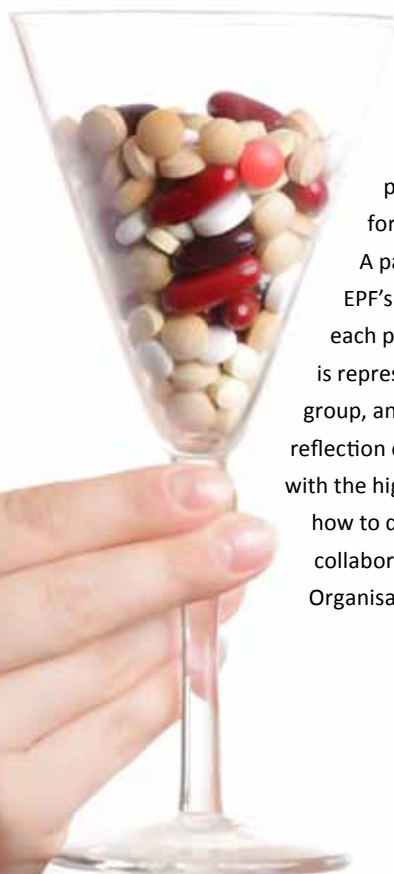
EPF represented the patients' perspective in the Commission Initiative on Corporate Responsibility in the Field of pharmaceuticals led by DG Enterprise. The focus of this initiative is to improve access to medicines and innovation across Europe. Our key principles were: access to high-quality information; equity in access; the importance of quality of life; patients' empowerment, and the need for patient input into the whole chain, from definition of medical needs through to approval, prioritisation and reimbursement.

The Initiative comprises three main platforms:

The Platform on Access to Medicines was the first to be launched in 2010. The aim is to improve access to medicines following their market authorisation. In practice, it works through five projects which focus on specific topics: access to orphan medicines; access to

biosimilars; managed entry agreements for innovative medicines; facilitating medicines supply in small markets; and promoting good governance for non-prescription drugs.

A patient representative from EPF's membership participates in each project. The EPF Secretariat is represented on the steering group, and is undertaking a broader reflection on how to identify areas with the highest medical needs and how to define innovation, working in collaboration with the World Health Organisation.



The Platform on Transparency and Ethics focuses on adherence to rules and duties, focusing particularly on relations of industry with patient organisations, health professionals and Member States' competent authorities. EPF participates on the steering group of this Platform, as well as co-chairing the working group on patient organisations together with the Commission. The Platform aims to develop a comprehensive charter of good practices to identify the roles and responsibilities of industry and the stakeholder groups, in order to create the highest possible standards in the sector.

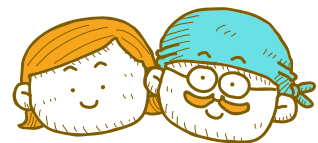
The third Platform focuses on Africa. EPF is not involved in this Platform directly, but we work closely with the International Alliance of Patients' Organisations (IAPO), which represents patients on this platform, to ensure coordination with our work in the other platforms.

## PERSONALISED MEDICINE

Personalised medicine has emerged since 2010 as a topic of interest, based on discussions within the EPF Policy Advisory Group and following EPF's involvement in a workshop on the topic organised by the European Commission's Directorate-General for Research and Innovation.

In 2011, EPF developed this topic further through background research and participation in various events. EPF's key message is that patients need to be fully engaged from the very start of the process of developing innovative treatments in order to be able to identify real unmet medical needs up to the very final stage.

Doing so, EPF will ensure that treatments will be available to all on an equitable basis. The involvement of patient groups will be key in developing a patient-centred future regulatory framework at EU level. EPF aims to develop a formal policy paper on personalised medicine in 2012.



## ADHERENCE AND CONCORDANCE

Non-adherence to therapies costs the EU millions of euros annually – not just in costs to health systems, but in terms of personal cost to patients' health. EPF believes that improving adherence has the potential to improve the quality of chronic disease care, as well as the overall quality and cost-effectiveness of European healthcare systems.

In 2011, EPF joined forces with the European umbrella organisations representing doctors, community pharmacists and the pharmaceutical industry, to raise awareness on this vital topic. We held a joint seminar at the European Parliament on 21 September to highlight the scope of this problem. The key message that emerged clearly from the speeches and discussions was

that a coordinated multi-stakeholder and patient-centred approach – involving patients, their carers/families, health professionals, industry, and the public – is needed to address this major issue in order to improve patient safety and provide patients with high-quality healthcare which responds to their needs.

Christos Sotirelis, a patient from the UK speaking for EPF, highlighted the need to really put the patient at the centre and adopt a “concordance” approach, where the health professional and patient work as equals in a genuine partnership.

“Adherence support and concordance are key components of good quality care. We believe that concordance in healthcare decision-making will lead to higher adherence by the patient. We need to empower patients and educate health professionals in order to create such an environment and promote meaningful dialogue.”

| **Christos SOTIRELIS**



# innovation



## INNOVATION PARTNERSHIP ON HEALTHY AND ACTIVE AGEING

Early in the year, EPF gave a strong input into the European Commission's public consultation on healthy and active ageing. We committed ourselves to playing an active role in the Partnership to ensure that it results in concrete actions that benefit older patients with chronic diseases.

EPF was represented on the High-Level Steering Group of the first-ever "European Innovation Partnership". This is a novel concept designed to address societal challenges through linking research and innovation in order to turn them into concrete actions.

The theme selected for first Innovation Partnership was healthy ageing. This theme fits in well with EPF's core values of equity, inclusiveness and empowerment, and our focus on the importance of patients' meaningful involvement in delivering healthcare innovation.

EPF was able to contribute a strong patients' perspective to shaping the Strategic Innovation Plan of the Partnership.

It seeks to address bottlenecks and weaknesses in the way of innovation in healthcare to achieve a "triple win" for Europe:

- Enabling EU citizens to lead healthy, active and independent lives until old age
- Improving the sustainability and efficiency of social and health systems
- Developing markets for innovative products and services, thus creating new opportunities for European businesses.

The overarching goal is, by 2020, to increase the average healthy life years (HLY) in the European Union by two years.

The Steering Group adopted the Strategic Implementation Plan (SIP) on 7 November 2011, which sets out the vision for a new paradigm of ageing, a vision for "healthy and active" ageing, and the key action areas that will be addressed by the Partnership.

## Focus



At the **European Health Forum Gastein**, in October, EPF co-organised a workshop "Ageing in action: a renewed focus on the rights and needs of older patients". Despite being on the last day of the Forum, the session was a very well-attended, showing that there is great interest on this topic. The session placed older patients' rights and needs in the context of the Innovation Partnership and presented views from a variety of stakeholders – older patients themselves, health professionals, policy makers, older people's advocates and industry. EPF also participated in a plenary session panel on the Innovation Partnership, where again we had the opportunity to express key points of our vision of how we want to move forward on healthy ageing.

In August, EPF participated in the World Demographic and Ageing Conference, in St Gallen, where we presented our work on the rights and needs of older patients, including the outcomes of the Warsaw conference, and our contribution to the European Innovation Partnership on Active and Healthy Ageing.



## PATIENTS' MEANINGFUL INVOLVEMENT IN RESEARCH

Encouraged by the outcomes of the Value+ project, EPF engaged in promoting in a concrete way the principle of meaningful patient involvement in EU-funded health research projects.

Evidence from Value+ that explored patient involvement in a whole range of EU-funded programmes, including FP6 and FP7, highlighted that patient involvement was clearly weaker in research projects than in other types of projects, especially those focused on clinical trials, studies or development of technologies and devices.

Through constructive and supportive collaboration with officials at DG Research, we engaged for the second year in some activities to promote patient involvement in the light of 2011 FP7 Health Research Calls:

- Ensuring that the principle of meaningful patient involvement is clearly reflected and integrated in the 2012 FP7 Work Programme and in the support activities done by FP7 NCP
- Raising awareness among prospective FP7 applicants from non-patient organisations and supporting them on the importance of applying a more patient-centred approach in designing and implementing research projects and engaging patient organisations as partners
- Supporting patient organisations in getting involved in future FP7 health-related projects

EPF had a stand at the FP7 Health Research Info Day held in Brussels on June 2011 and distributed copies of the Value+ Handbook, one of the core deliverables developed during the Value+ project, providing detailed information for project coordinators, leaders and promoters on how to involve patient and patient organisations in health-related projects.

We also co-hosted a workshop on patient involvement for the NCPs organized in cooperation with the HEALTH-NCP-NET and the PatientPartner project (PP) (<http://patientpartner-europe.eu>). The main objective of the meeting was to provide support to National Contact Points to enable them to actively promote the involvement of patient organisations in FP7 projects.



# Health in an eu context

## EU HEALTH PROGRAMME 2014-2020

On 9 November 2011, the European Commission adopted proposals for the new Health Programme 2014-2020, entitled “Health for Growth”. EPF contributed to the development phase of the programme, giving input through the European Health Policy Forum, ahead of the launch of the Commission’s multi-annual financial framework in June. We then went on to develop a joint statement with the European Public Health Alliance (EPHA), as well as liaising with key officials in the European Commission directly.

EPF also argued for: patient-centred chronic disease management coupled with effective prevention to address chronic diseases and demographic ageing; making health inequalities an urgent priority, including equity of access to high-quality medical and other care; and for health literacy and patient empowerment as a crucial strategy for tackling health inequalities and realising high-quality healthcare of the future.

## EU RESEARCH FRAMEWORK PROGRAMME

EPF gave input to the Commission’s consultation on a Green Paper “From Challenges to Opportunities: Towards a Common Strategic Framework for EU Research and

Innovation Funding”, through a statement arguing that investment in both biomedical and public health research is essential for realising the EU2020 vision for smart, sustainable and inclusive growth. We stressed that research should be centred on patients’ needs, and the key to achieving this is to build in their meaningful involvement from the onset. We also asked for easier involvement of patient organisations in research, through simpler rules, less bureaucracy, and adequate funding.

## EU REFLECTION PROCESS ON CHRONIC DISEASES

The Commission launched a reflection process on chronic diseases in early November 2011. It follows a request by the Council in its Conclusions on “Innovative approaches for chronic diseases in public health and healthcare systems”, adopted on 7 December 2010. EPF, as a member of the European Health Policy Forum, contributed to the Forum response. We stressed particularly the role of health systems, equity of access, quality of care, patient involvement and patients’ empowerment as a crucial element of high-quality, sustainable strategy on chronic diseases.





In 2012, EPF will develop a comprehensive response with our membership. The reflection process aims to produce an EU strategy on chronic diseases; the process is likely to conclude in the first part of 2013.

## MODERNISATION OF THE EU DIRECTIVE ON PROFESSIONAL QUALIFICATIONS

Ensuring that healthcare professionals have the right training and are fit to practice when they move from one Member State to another is crucial for patient safety and quality of care. This is why, throughout 2011, EPF actively contributed to the debate on the modernisation of Directive 2005/36/EC.

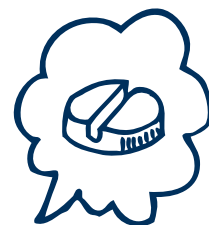
This Directive establishes the rules for mutual recognition of qualifications for health professionals who want to provide their services in another Member State. EPF collaborated with allies' organisations EPHA and BEUC through joint statements, to put questions of safety and quality of care at the centre of the review, and to prevent the downgrading of requirements for professionals' mobility.

EPF also contributed views to the two European Commission consultations in March and September. Our input focused on core areas of interest for patients: involvement of patients in healthcare professionals' education and training, language and communication skills, and measures to ensure that mobile healthcare professionals are fit to practice and have complied with continuous professional developments requirements when they wish to move to another Member State.

The European Commission issued its legislative proposal in December 2011. In 2012, EPF will continue to provide a patient's perspective on this dossier, and on the skills and competence to equip the health workforce with the right skills to face healthcare challenges.



# accessible and high quality healthcare



## CROSS-BORDER HEALTHCARE

The adoption by the Council on 28 February 2011 of Directive 2011/24/EU on the application of patients' rights in cross-border healthcare was a major achievement. EPF had a long and intense involvement in the drafting of this Directive, as we see the potential to reduce health inequalities for patients in access to healthcare.

Though the final Directive was less ambitious than EPF's vision, it nevertheless marked a milestone for European patients. It created a legal framework for the patient's right to seek healthcare in another Member State and to be reimbursed. It also provided a legal basis for enhanced European cooperation in key areas of healthcare – including quality and safety, HTA and eHealth, and rare diseases.

In 2011, EPF continued to liaise with the European Commission and relevant stakeholders on the implementation of the Directive. We were particularly focused on the provision of information to patients concerning their rights under the new legislation. We also developed guidance for patient organisations to support their involvement at national level, to ensure that transposition and the implementation process take patients' needs into account.

## INFORMATION TO PATIENTS AND HEALTH LITERACY

Access to high-quality information to patients has been a policy priority since EPF was established in 2003.

The European Commission's legislative proposals on information to patients on prescription medicines, published in 2008 as part of the EU "pharmaceutical package", formed an important part of our work in this area. EPF worked closely with the European Parliament during the first reading, and our input

was clearly reflected in the Parliament's position of November 2010, which achieved above all a shift in focus onto the patients' rights and needs. Following this first reading, the European Commission published its amended proposals in October 2011. EPF consulted its membership on the new proposals. However, they continued to face opposition in the Council.

The legislative proposal will be a priority for EPF during 2012. However, EPF believes there is a need for a **broader EU information strategy on health** for patients and citizens, which encompasses information on diseases and conditions, available therapy options, and health literacy programmes across the EU.

## HEALTH LITERACY

For EPF, information to patients is a key tool for improving health literacy. Health literacy in turn is key to empowering patients and equipping them with the knowledge and skills to take an active and equal role in managing their health and healthcare – an essential element in sustainable, high-quality, patient-centred chronic disease management.

In 2011, EPF continued to highlight the importance of health literacy and patients' empowerment, particularly in the context of the Innovation Partnership, the reflection process on chronic diseases, work on health inequalities and patient safety/quality of care, as well as adherence to therapies.

## QUALITY OF CARE AND PATIENT SAFETY

Patient safety and quality of care is at the heart of EPF's work, being one of the priorities in our Strategic Plan. In 2011, EPF participated actively in the Commission's Working Group meetings, launched our own survey on the implementation of the Council Recommendation on patient safety, and contributed as a partner to the development of the Joint Action on Patient Safety and Quality of Care. We also worked with WHO on an initiative around patient safety and patients' rights, and presented the patient perspective at several events.

### COMMISSION WORKING GROUP

The Commission working group met twice in 2011, in January and September. The main focus was the implementation of the Council Recommendation, on which the Commission is due to publish a progress report in 2012. The Recommendation includes a number

of specific provisions concerning empowerment and involvement of patients, and EPF considered it important to gather feedback from the perspective of patient organisations as to the extent to which these provisions are being implemented in Member States. We developed an online survey to gauge our members' views, the results of which will be published in 2012.

### WHO INITIATIVE ON PATIENT SAFETY

EPF participated in a World Health Organisation (WHO) EURO-coordinated working group on patients' rights and patient safety. The group seeks to identify means to improve safety by enhancing patients' empowerment and health literacy, focusing initially on blood transfusions, prevention of hospital infections through hand hygiene, and patient handovers. A report will be produced in 2012.







# inclusive and equitable healthcare

## HEALTH INEQUALITIES AND ANTI-DISCRIMINATION

Non-discrimination is among EPF's core values. We combat discrimination on the grounds of illness and address health inequalities from the perspective of patients.

### HEALTH INEQUALITIES

Following up on the Commission's Communication "Solidarity in Health", EPF supports the principle of "equity and health in all policies" and integrates health inequalities as a cross-cutting issue in all our policy work. In 2011, EPF achieved recognition in the European Parliament report of Edite Estrela, MEP that "patients with chronic diseases form a specific group suffering inequalities in diagnosis and care, social and other support services, and disadvantages including financial, employment, and social discrimination, whose needs should be addressed". Moreover, the European Parliament called for equitable access to healthcare for older patients as a priority. In our view, patient empowerment and health literacy are fundamental aspects of tackling health inequalities among patients with chronic diseases and their families and we will continue our work on this.

### ANTI-DISCRIMINATION

In 2011, EPF initiated collaboration with the European Union Agency for Fundamental Rights (FRA). It will complement our work on discrimination in relation to the EU anti-discrimination legislation framework. EPF also contributed to the Commission's public consultation on a possible successor instrument to the EU's Employment and Social Solidarity Programme (PROGRESS). This instrument plays a role in tackling discrimination towards patients and in implementing the "Health in all policies" principle. We recommended that PROGRESS should include tools to address discrimination against patients with chronic diseases, including in employment, and that funding from this programme should be available for patient organisations that actively focus on discrimination against patients.

## NEEDS AND RIGHTS OF OLDER/YOUNG PATIENTS

EPF's core values include non-discrimination and inclusivity. We strive to ensure that our work reflects the needs and views of potentially underrepresented patient groups. In this rationale it was appropriate to initiate actions around the rights and needs of older as well as young patients.

We committed ourselves to playing an active role in the Innovation Partnership on Healthy and Active Ageing Partnership to ensure that it results in concrete actions that benefit older patients with chronic diseases (see page 22). This was the focus of our conference in Warsaw, held on 12-13 July 2011 under the Polish EU Presidency. The outcomes of the conference fed into our work and will lead to the development of a position paper in on the rights and needs of older patients in 2012.

EPF wants to also put young patients at the centre of the healthcare debate. This is the reason why we have implemented the Youth Strategy and nominated a Youth Group (see page 14).

### HEALTHCARE FOR VULNERABLE GROUPS

In 2011, EPF developed a relationship with the Fundamental Rights Agency (FRA) based in Vienna. The FRA is an advisory body of the European Commission; its mission is to help ensure that the fundamental rights of people living in the EU are protected. It does this by collecting evidence about the situation of fundamental rights across the European Union and providing evidence-based advice on how to improve the situation. The FRA also informs people about their fundamental rights. It is conducting a research project on multiple discriminations in healthcare, for which EPF gave input based on previous consultations on health inequalities. We joined the FRA's Fundamental Rights Platform (FRP). This is another avenue for EPF to be involved in EU anti-discrimination policy, to raise our concerns on health inequalities and discrimination faced by patients and to suggest potential measures for equal treatment in healthcare and health-related discrimination in other fields such as the work-place, insurance.

# EPF POLICY ADVISORY GROUP

## THE EPF POLICY ADVISORY GROUP MET TWICE IN BRUSSELS DURING 2011.

Since its inception in 2009, the Policy Advisory Group has become an invaluable advisory body for the EPF Board and Secretariat. In view of the increased and complex workload of members, the EPF Board decided in 2011 to clarify the Group's role within the EPF policy-making process, and to strengthen the link with the general membership. The responsibility areas of its members could also be made more specific to enable member organisations to focus their input on areas of particular interest and widen participation further. A revised structure and process were developed, and a call for interest on policy topics circulated. The new process will be implemented in 2012.

EPF would like to thank all the members of the Policy Advisory Group for their tireless work and wholehearted commitment.

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### THE POLICY ADVISORY GROUP AT A GLANCE:



#### WHO?

Currently 11 members, nominated by EPF member organisations.



#### WHY?

In response to growing demand on EPF – growing membership, increasing complexity of health policy at EU level.



#### WHEN?

Created by the Annual General Meeting in 2009, they meet twice a year in Brussels.



#### WHAT?

It supports the policy work of the EPF Secretariat and Board and complements the EPF member consultation process.

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## eHealth



## Focus: eHealth, Telehealth vs. telemedicine

The World Health Organisation defines eHealth as the combined use of electronic communication and information technology in the health sector. Telehealth is that subset of eHealth that includes the delivery of health-related services and information via telecommunications technologies. Telehealth encompasses preventative, promotional and curative aspects and is in turn an expansion of the term telemedicine, which focuses more narrowly on the curative aspect.

## CHAIN OF TRUST

## EPF HIGHLIGHTS THE NEEDS OF MAIN END-USERS OF TELEHEALTH SERVICES

What do end-users know about telehealth? Do they use telehealth services? What would they like to improve? What are the barriers? Despite wide acknowledgment of the potential benefit of telehealth services, their use remains limited and contains wide disparities across and within European countries.



With the start of the Chain of Trust project in January 2011, EPF (as consortium leader) and the other associated partners<sup>1</sup> aim to tackle this issue. For the first time ever, a project assesses the perspective of the main end-users of telehealth services, i.e. patients, doctors, nurses and pharmacists, across the EU.

“We strongly believe that such a project will contribute to our vision of high quality, patient-centred, equitable healthcare for all EU patients.”

| Liuska Sanna, EPF Programme Manager and coordinator of the Chain of Trust project.

In 2011, Chain of Trust's main focus was on delivering the project's first objective, which was to improve available knowledge among patients and health professionals with regard to telehealth services. We gathered knowledge of the needs, expectations and perceptions of telehealth among patients and health professionals. To this end, a state-of-the-art literature review was undertaken and its findings were validated through an online survey to which some 6,500 patients and health professionals responded. The survey was followed by a series of national workshops organised with the support of local patients' and professional organisations in six different European countries: Greece, Latvia, the Netherlands, Norway, Poland and Portugal.

The key findings of these activities, together with the outcomes of four European focus groups that will be implemented in early 2012, will be presented in an intermediate public deliverable that is expected to be released in April 2012.

➡ [www.chainoftrust.eu](http://www.chainoftrust.eu)



1. - The associated partners are the Standing Committee of European Doctors (CPME), the European Federation of Nurses Associations (EFN), the Pharmaceutical Group of the European Union (PGEU), the Norwegian Centre for Telemedicine and Integrated Care (NST), the Latvian Umbrella Body of Disability Organisations (SUSTENTO), and Thalassaemia International Federation (TIF).





## EPF'S EFFORTS TO INCLUDE PATIENT'S PERSPECTIVE IN TELEMEDICINE

RENEWING HeALTH = REgions of Europe Working Together for HeALTH

2011 was the second year of the RENEWING HeALTH project. While the first year was dedicated to the preparation of the clinical protocols and the specification of the assessment technology, the focus of last year was on the recruitment and training of patients, the

“RENEWING HeALTH is an excellent opportunity to gather much-needed scientific and evidence-based information on the benefits of telemedicine for patients. This is not only in terms of clinical outcomes, but also in terms of patient experiences, and the impact of telemedicine on quality of life and patient empowerment.”

| Walter Atzori, EPF Senior Programme Officer responsible for EPF role in the RENEWING HeALTH project

finalisation of the protocols and the launch of the large-scale real-life test beds in nine European regions. The purpose of RENEWING HeALTH is to implement multi-site randomised controlled trials for evaluating telemedicine services for patients suffering from three of the most common chronic conditions: diabetes, cardiovascular diseases and Chronic Obstructive Pulmonary Disease (COPD). The ultimate goal is to demonstrate that telemedicine-based services can improve quality of life, enable patient empowerment while optimising the use of resources in healthcare provision. EPF is involved in the management of the User Advisory Board (UAB) that operates as a standing advisory committee mandated to feed the perspective of telemedicine users into the project. A key achievement of the User Advisory Board in 2011 was the publication of the first version of the “User Requirements” document and a set of recommendations for the assessment of users’ perception of the piloted telemedicine services. A second version of the User Requirements is due to be released in early 2012.

Although the project will not deliver results before mid-2013, EPF is working to make sure the end-users’ perspective is properly integrated and assessed throughout the entire life-cycle of the project.

www.renewinghealth.eu

## eHEALTH GOVERNANCE INITIATIVE

### A EUROPEAN eHEALTH ENVIRONMENT FOR THE BENEFIT OF EUROPEAN PATIENTS

The EU eHealth Governance Initiative (eHGI) is a political initiative aimed at establishing a platform to enable cooperation on eHealth between EU Member States and stakeholders. In other words, the purpose 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. The WP’s general objective is to provide stakeholders’ representatives with the means and the opportunities to discuss and identify possible ways to enhance eHealth users’ trust and acceptability. It also aims to make proposals to EU Member States, representatives as well as to the European Commission,

“The eHGI will support the setup of a European eHealth environment for the benefit of European. It is therefore of the utmost importance that EPF is fully involved in this process.”

| Liuska Sanna, EPF Programme Manager

as appropriate, on how the needs of end-users should be best taken into account in the development of European and national eHealth strategies.

As part of the activities envisaged in its Work Package, EPF provided input to a document underlining the various elements of trust and acceptability in relation to targeted domains. EPF has also contributed to the proposal of recommendations for a common EU framework on electronic identity (eID) management. It will be delivered in early 2012 and will be presented at the 2012 eHealth week in Copenhagen (7-9 May)

# InterQuality

## MEDICAL SERVICES: SMARTER FINANCING, IMPROVED QUALITY FOR PATIENTS



Spending more on healthcare often does not result in improving quality, effectiveness and accessibility to health services. Healthcare financing reforms in Europe have encountered

various technical and political difficulties in tackling this issue.

The InterQuality project, started in December 2010 and led by the Medical University of Warsaw, intends to develop scientifically validated tools to help decision-makers choose the right financing mechanisms in different areas of healthcare systems.

Policy recommendations will be produced to help national governments to improve the quality of their healthcare, at the same time ensuring the sustainability of the health system. Ultimately, this would impact positively on patients' access to high quality healthcare services.

2011 was a year of literature review in order to analyse and compare financing systems in different countries. As one of the nine associate partners, EPF leads the dissemination of the project's progress and results in close cooperation with CPME, and has developed this year a strategy for the coming years. As for the next steps, we are also responsible for the development of communication strategy guidelines on the implementation of innovative healthcare financing models. Finally, we will also play a key role in organising the project's final conference in late 2013.

➡ [www.interqualityproject.eu/](http://www.interqualityproject.eu/)



# RESPECT



RESPECT  
patient needs

## CHILDREN TO TEST MEDICINES THEY WILL TAKE

Begun in 2008, the RESPECT project ended in August 2011. A comprehensive report was published at the end of the process, containing the findings and recommendations produced during the project lifecycle

“There will be more collaboration and engagement of stakeholders to empower the role of children/parents in decision process while safeguarding safety, rights and well-being of children.”

| Annagrazia Altavilla, speaking at the Dissemination Meeting of May 2011

This project grew from the observation that over 50 percent of medicinal products used to treat children may not have been tested or authorised for their use. This left health care professionals with no alternative but to use medicines «off-label». They had to judge the suitability and the correct dose of these medicines themselves in the absence of paediatric labelling information. This posed significant risks of inefficacy and/or adverse reactions for children.

RESPECT has provided an important contribution to improving the way paediatric trials are designed and run. As an associate partner, EPF helped to identify the needs of children and their families in relation to trial outcomes. We ran surveys with EPF members and other patient organisations and also organised a workshop bringing together parents, patient representatives and young people with different degrees of experience of clinical trials.

Overall, the project contributed to increasing the safety of treatments for children, with more medicines being tested on them. More importantly, it made children and parents partners in research instead of mere subjects.

➡ [www.patientneeds.eu](http://www.patientneeds.eu)

# Health technology assessment

## EUNETHTA JOINT ACTION

In 2011, EPF engaged in bringing the patient's perspective to the EUNETHTA Joint Action project through its membership in the project's Stakeholder Forum. The project's vision is “to contribute to the generation of Health Technology Assessment (HTAs) in order to encourage new health technologies to be adopted and obsolete technologies abandoned in a well-informed and robust manner. (...)” Making HTA more efficient can support more consistent and rapid decisions relating to the treatments available to patients.

## EPF RESEARCH ON EU PATIENT INVOLVEMENT IN HEALTH TECHNOLOGY ASSESSMENT (HTA)

Health Technology Assessment (HTA) is a multidisciplinary tool that ideally should involve patient perspectives. However, in reality there is still a long way to go in achieving meaningful patient involvement in HTA. Despite doing some good groundwork, patients' organisations are still struggling to gain a foothold in the HTA process, as was highlighted in EPF's HTA Seminar held in May 2010.

EPF has therefore made patient involvement in HTA the subject of research since November 2010. There was a dual objective: to understand the involvement of lay patients, informal carers and patient organisations in all the EU member states, but also to use this knowledge to contribute to informing HTA research, policy and practice.

EPF's HTA research was broken down into three stages. Firstly, a survey was conducted in February 2011 with 40 HTA agencies and/or national bodies responsible for HTA from 22 European countries. Secondly, in late 2011, the HTA survey focused on healthcare decision-makers. The final phase, launched in September, involved a consultation with patient organisations. The surveys have come to an end and a first report is available on EPF website. The second and third reports are on-going and will be finalised in 2012.

# Projects starting in 2012

## EUPATI – EUROPEAN PATIENTS ACADEMY ON THERAPEUTIC INNOVATION



### EDUCATING PATIENTS ON PHARMACEUTICAL RESEARCH

EPF will lead a consortium of 29 organisations involved in the “European Patients’ Academy on Therapeutic Innovation” (EUPATI). This major five-year project will create better education/information tools for patients on pharmaceutical research. Our Expression of Interest was accepted by the Commission in early 2011. We invested significant time last year in developing the full project proposal and completing rigorous external evaluation and negotiation processes.

In 2012, our efforts will bear fruit with the launch of the project. The Academy will educate patient representatives and the lay public on personalised and predictive medicine, the design and conduct of clinical trials, drug safety and risk/benefit assessment, pharmaco-economics, as well as patient involvement in drug development and regulatory processes. EUPATI will

provide educational material in six European languages targeting eleven European countries.

Well-informed patients and carers have a key role to play in the implementation of patient-centred clinical research strategies, approval processes, access to treatments and treatment optimisation. With appropriate training, patient advocates can become accepted partners in scientific, ethical and regulatory committees, which can speed up and improve clinical trials, drug development and access strategies.

To improve the availability of both patient-centred information as well as educated patient experts, EUPATI will develop scientifically reliable, objective and comprehensive information on therapeutic innovation by:

- establishing certificate training courses to create ‘expert advocates’ on therapeutic innovation;
- developing a “toolkit” of educational multi-media material to be re-used by patient organisations for educational purposes;
- developing an Internet-based library of up-to-date and unbiased information on medicinal development for patients and the public.

EUPATI is funded by the Innovative Medicines Initiative (IMI), a public-private partnership between the European Commission and EFPIA. It will fund the EPF-led consortium that comprises 29 leading pan-European patient organisations, academic and not-for-profit organisations as well as EFPIA member companies. It features excellence across disease areas in state-of-the-art, high-quality, and objective education to patients about therapeutic innovation. It will foster collaboration between patients’ organisations, academic institutions, regulatory bodies, ethics committees and the industry. A Regulatory Advisory Panel led by regulatory authorities as well as a Project Advisory Board composed of high-level experts with long-standing credibility in patient involvement and pharmaceutical R&D will ensure the objectivity, transparency and independence of EUPATI’s educational content, adhering to the highest quality standards on information to patients.







## **SUSTAINS** **PATIENTS TO BECOME ACTIVE** **HEALTH PLAYERS**

In 2011, EPF was involved in the preparation of a proposal for a project called "SUSTAINS" (Support Users To Access INformation and Services).

Submitted in June 2011, the proposal was approved by the European Commission and the project will officially launch on 1 January 2012.

By developing and deploying a basket of services providing patients with access to their Electronic Health Records (EHR), SUSTAINS will contribute to the achievement of a new paradigm in healthcare: the passive patient becomes an active player in the management of his/her own health. The services proposed have been distilled from the experience of European regions which have already pioneered such

*"We have a lot of expectations with this project. We believe that, thanks to access to EHR, patients will be better informed about their health. They will be able to make more conscious decisions about treatment and lifestyles in collaboration with the healthcare professionals looking after them."*

**|Walter Atzori, EPF Senior Programme Officer**

access.

EPF plays a key role in this project, especially in two Work Packages (WP). In the context of WP4 "User Requirements", EPF is responsible for the work to identify patient requirements in an attempt to ensure that SUSTAINS services are as close as possible to real users' needs. As for WP3 "Evaluation and Deployment Planning", EPF is leading the work on patient empowerment evaluation aimed at assessing the change in patient empowerment before and after using the services.

## **JOINT ACTION ON PATIENT** **SAFETY AND QUALITY OF CARE**

The development of the proposal for a Joint Action on Patient Safety and Quality of Care progressed throughout 2011 and was successful. This three-year Joint Action is envisaged to begin in the first half of 2012. The overall aim is to create a permanent platform for future cooperation between Member States in the area of patient safety and quality of care. The specific objectives are:

- to support Member States in the implementation of the Council Recommendation on patient safety
- to initiate cooperation on quality of healthcare
- to facilitate the sharing of good practices in patient involvement.

The Action is led by the French health authority, HAS (Haute Autorité de santé), and EPF is an associate partner together with other EU-level stakeholders representing doctors, nurses, dentists, health and hospital managers as well as international organisations.

EPF will be actively involved in several key work packages of the Joint Action.



# let's evaluate 2011...

**THIS NON-EXHAUSTIVE SUMMARY IS BASED ON THE PERFORMANCE INDICATORS AND TARGETS IDENTIFIED IN THE EPF WORK PLAN FOR 2011 FOR SELECTED ACTIVITIES, TO GIVE A FLAVOUR OF OUR WORK AND ITS IMPACT.**

## ➡ OBJECTIVE 1: BUILDING CAPACITY

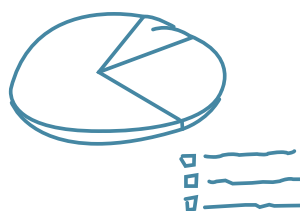
The indicators selected for this objective were:



- ➡ The expansion of EPF's membership. The target was to increase to EPF membership to 50 members. This was achieved at the end of 2011, as EPF has 51 full and associate members.
- ➡ The perceived success and impact of the Regional Advocacy Seminar. The target here was increased cooperation with patient organisations at national level in the region and specific conclusions on the patient/health professionals' relationship, relayed back to European umbrella bodies. Analysis of the evaluation forms, informal feedback and follow-up indicate unequivocally this was a highly successful event with very strong immediate and long-term impact.

## ➡ OBJECTIVE 2: POLICY IMPACT

The indicators selected for this objective were:



- ➡ EPF is recognised as an effective key partner in the political dialogue in determining civil society's input in EU health policy.
- The target was the Inclusion of EPF comments in EC, EP and Council positions and initiatives. This was achieved in many core areas – the policy section of this annual report outlines the specific impact of our work.
- ➡ The perceived success and impact of the Polish Conference that was documented through evaluation forms and policy follow-up. The target was for the Polish EU Presidency to integrate the outcomes of the conference on ageing into its work, the European Year on Active Ageing and Inter-generational solidarity and the European Innovation Partnership on Active and Healthy Ageing. This was achieved, with high-level political representation at the event and follow-up with the national and European officials specifically concerned.



### ➡ OBJECTIVE 3: PROJECT AND PATIENTS' EVIDENCE AND EXPERTISE

The indicators selected for this objective were:



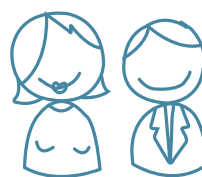
- ➡ The degree of success of project funding applications and of projects already running. Our target was

successful programme applications following Value+ and a successful EU operational grant application. This was achieved. For an overview of successful applications please go to page 09 (Diversification of funding). Significant progress was made in all of the projects EPF was involved in, particularly Chain of Trust which successfully completed its first year of operation.

- ➡ The degree of influence on the new EU Health Programme, the EU Framework Programme for Research and Innovation (Horizon 2020) and Structural Funds programmes to enable better access to funds for patient organisations. The target was the inclusion of mechanisms facilitating the participation of patient organisation in strategic documents and specific calls linked to these programmes. As this work is still in progress, it is premature to assess our success in this area, but we have been relatively pleased with the main direction and scope of the new EU Health Programme, and the research framework programme proposals on Horizon 2020.

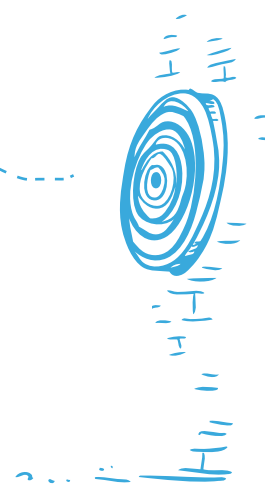
### ➡ OBJECTIVE 4: PARTNERSHIPS

The indicator selected for this objective was:



- ➡ Established cooperation with the European Older People's Platform – AGE. The target was participation of AGE in the EU Presidency Conference

on the needs and rights of Older Patients and collaboration on the European Year on Healthy Ageing 2012. This was achieved, and EPF and AGE have worked closely on the European Innovation Partnership on Active and Healthy Ageing. The AGE President also participated in our workshop on Active and Healthy Ageing in Gastein.



# EPF 2011 communications in figures.



## WEBSITE<sup>2</sup>

Our website has been **visited 22,249 times** by **13,400 absolute unique visitors** (first-time visitors to the site), which means that new visitors come back to [www.eu-patient.eu](http://www.eu-patient.eu) on average 1.66 times.

There were **97,934 pageviews**, with an average of **4.40 pages viewed** per visit and **2.46 minutes** spent on the website.

People from **126 different countries** accessed our website.

**The top 10:** Belgium, United Kingdom, India, United States, France, Germany, the Netherlands, Poland, Romania, Spain.

**57%** of our users arrived at our website through a **search tool** such as Google or Yahoo, **27.3%** of our users typed our address [www.eu-patient.eu](http://www.eu-patient.eu) **directly** and the remaining **15.7%** accessed our site indirectly through an **external link** on sites like eurobrussels.com, ispor.org, facebook.com, ec-europa.eu, efcca.org, renewinghealth.eu or interqualityproject.eu.

The visitor data we collected in 2011 will serve as a reference-point and tool for improving our website in 2012. The Communication Officer and the Webmaster will work together to facilitate better navigation and access to content, at the same time ensuring that the information is refreshed regularly and made more digestible.

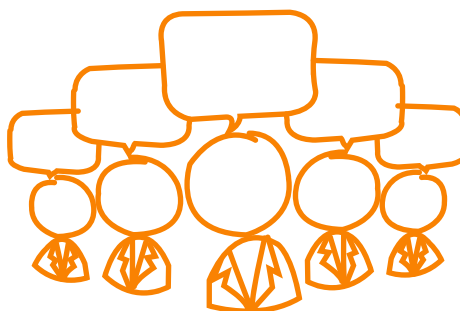
## MAILING

EPF continued to produce and distribute its mailing every six weeks. More than 3,000 individuals, including our membership and the EU health community, receive regular reports of events and updates on policies and projects.

The mailing will undergo a change in 2012. We will release a monthly e-newsletter with fresh news and ensure a regular update on our website.

## OUR COMMUNICATIONS EFFORTS WILL BE EXTENDED IN 2012:

- Reinforcement of our identity
- Regular updates of our website
- A dynamic presence in social media
- A monthly e-newsletter with the latest news
- More contacts with journalists thanks to regular press releases
- Concise and accessible leaflet introducing EPF in general
- Online videos posted on YouTube



2. - Website statistics are extracted from the Google Analytics tool, from January 1, 2011 until January 1, 2012



# account and audit report

## EUROPEAN PATIENTS' FORUM NON-FOR-PROFIT ORGANISATION.

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

### REPORT FOR THE YEAR ENDED 31 DECEMBER 2011

We have audited the financial statements of European Patients' Forum ("the Organisation") for the year ended 31 December 2011, which show a balance sheet total of €2.475.989 and a surplus for the year of €65.690.

### 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 test 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.

In our opinion, the financial statements for the year ended 31 December 2011 give a fair view of the Organisation's assets, liabilities, financial position and results of operations.

### ADDITIONAL REMARKS

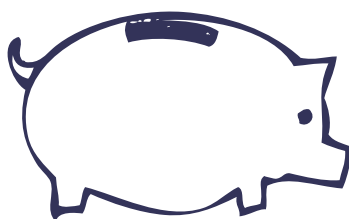
The accounting records were maintained in accordance with the legal and regulatory requirements applicable in Belgium.

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, March the 14th, 2012

**FIDINTER BVBA**

| Represented by F. Léonard, Director



## BALANCE SHEET AS OF DECEMBER 31st 2011

	2011	2010
<b>ASSETS</b>		
<b>I Fixed Assets</b>		
Computer's equipment	€ 0,00	€ 0,00
Guarantee to Axa and Securex	€ 11.154,00	€ 11.014,00
<b>II Current Assets</b>		
Accounts receivable	€ 102.891,00	€ 36.690,00
Cash in bank and deposit *	€ 2.351.679,00	€ 405.223,00
Accruals	€ 10.265,00	€ 10.198,00
<b>TOTAL ASSETS</b>	<b>€ 2.475.989,00</b>	<b>€ 463.125,00</b>
<b>LIABILITIES</b>		
<b>I Capital and reserves</b>		
Funds brought forward	€ 338.237,00	€ 353.037,00
Surplus or deficit for the year	€ 65.690,00	- € 14.800,00
<b>II Debts</b>		
Payment received in advance	€ 0,00	€ 32.457,00
Accounts payable	€ 77.818,00	€ 42.431,00
Income to be carried over *	€ 712.528,72	€ 50.000,00
Income to be allocated to project partners *	€ 1.281.715,28	€ 0,00
<b>TOTAL LIABILITIES</b>	<b>€ 2.475.989,00</b>	<b>€ 463.125,00</b>

\* Includes the 2012 EUPATI pre-financing received on 27 Dec 2011 (€ 1,680,000)

## INCOME AND EXPENDITURE - DECEMBER 31st 2011

	2011	2010
<b>INCOME</b>		
Membership Fees	10.950,00	8.642,00
Unrestricted Grants	430.000,00	420.000,00
Annual General Meeting	60.000,00	100.000,00
Regional Advocacy Seminar	45.000,00	26.660,00
Commission Projects	137.445,57	65.072,95
Conference on Rights and Needs of Older Patients	100.000,00	-
Other Projects	-	40.000,00
Interest - Other Income	5.920,28	16.062,58
<b>TOTAL INCOME</b>	<b>789.315,85</b>	<b>676.437,53</b>
<b>EXPENDITURE</b>		
Staff and Fees	-423.114,22	-382.413,50
Office costs	-74.134,70	-75.943,64
Travel	-56.433,48	-50.396,29
Events ( Annual General Meeting)	-62.543,02	-88.869,34

	2011	2010
<b>EXPENDITURE</b>		
Events ( Regional Advocacy Seminar )	-41.886,93	-57.535,16
Commission projects	-185.888,54	-97.428,41
Conference on Rights and Needs of Older Patients	-65.449,93	-
Other Projects	-3.652,73	-33.669,01
Communications	-12.352,34	-15.785,90
Bank fees and Holiday Pay Provision	-6.279,16	2.089,95
<b>TOTAL EXPENDITURES</b>	<b>-931.735,05</b>	<b>-799.951,30</b>
<b>SECRETARIAT INCOME*</b>	<b>208.109,56</b>	<b>108.713,68</b>
<b>SURPLUS OR DEFICIT OF THE YEAR</b>	<b>65.690,36</b>	<b>-14.800,09</b>
* The secretariat income is composed of :		
Respect :		€ 17.099,56
Interquality :		€ 46.773,34
Chain Of Trust :		€ 44.491,21
Renewing Health :		€ 54.745,45
Regional Advocacy Seminar :		€ 5.000,00
Annual General Meeting :		€ 20.000,00
Conference on Rights and Needs of Older Patients :		€ 20.000,00

## ACKNOWLEDGEMENT OF FINANCIAL SUPPORT :

		% of total income
<b>EPF WISHES TO THANK THE FOLLOWING SPONSORS FOR THEIR SUPPORT IN THE FORM OF UNRESTRICTED GRANTS TO EPF'S OPERATIONAL PROGRAMME 2011 :</b>		
AMGEN	€ 25.000,00	3,2%
AztraZeneca (1)	€ 50.000,00	6,3%
Baxter	€ 10.000,00	1,3%
CSL Behring	€ 10.000,00	1,3%
GILEAD (2)	€ 15.000,00	1,9%
GSK (3)	€ 41.932,89	5,3%
Janssen Pharmaceutica	€ 10.000,00	1,3%
Microsoft	€ 20.000,00	2,5%
MSD	€ 30.000,00	3,8%
Novartis	€ 50.000,00	6,3%
Pfizer	€ 50.000,00	6,3%
Philips (4)	€ 20.000,00	2,5%
Phrma	€ 40.000,00	5,1%
Sanofi Aventis	€ 25.000,00	3,2%
Sanofi Pasteur MSD	€ 20.000,00	2,5%
Les Laboratoires Servier	€ 10.000,00	1,3%
Shire	€ 5.000,00	0,6%
(1) 2011 contribution received in 2012		
(2) A contribution of € 45,000 was received from GILEAD in 2011 of which € 30,000 related to 2010 and € 15,000 to 2011		
(3) GSK gave honoraria of €1000 and travel of €932,39 to support the attendance of EPF Executive Director at GSK's April and November European Health Advisory Board meetings		
(4) 2011 contribution received in 2010		
<b>EPF WISHES TO THANK THE FOLLOWING SPONSORS FOR THEIR SUPPORT IN THE FORM OF UNRESTRICTED GRANTS TO EPF'S EVENTS IN 2011 :</b>		
<b>Annual General Meeting</b>		
Eli Lilly	€ 20.000,00	2,5%
Hoffmann La Roche	€ 20.000,00	2,5%
Janssen Pharmaceutica	€ 20.000,00	2,5%
<b>Regional Advocacy Seminar</b>		
Medtronic Foundation	€ 30.000,00	3,8%
SANOFI AVENTIS	€ 15.000,00	1,9%
<b>Conference on Rights and Needs of Older Patients</b>		
AMGEN	€ 10.000,00	1,3%
GSK *	€ 30.000,00	3,8%
Novartis	€ 30.000,00	3,8%
Pfizer	€ 30.000,00	3,8%
* 2011 Contribution paid in 2010		
<b>EPF WISHES TO THANK THE EUROPEAN COMMISSION FOR ITS SUPPORT IN 2011 IN RELATION TO EPF'S ROLE IN THE FOLLOWING PROJECTS :</b>		
RESPECT *	€ 16.311,00	2,1%
RENEWING HEALTH *	€ 27.163,92	3,4%
InterQuality	€ 48.094,00	6,1%
Chain of Trust	€ 41.376,65	5,2%
eHealth Governance Initiative	€ 4.500,00	0,6%
* 2011 contribution to be received in 2012		



## EUROPEAN PATIENTS' FORUM

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



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

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