

# EPF Annual Report 2009



# Contents

Introduction and Summary of Key Achievements and Milestones	p.2
EPF's Five Core Strategic Goals	p.4
How Much Progress Did We Make? - Key EPF Achievements in 2009	p.5
EPF Governance in 2009	p.8
EPF Policy Orientation in 2009	p.9
EPF Harnessing the Patients' Evidence and Experience	p.17
EPF Capacity Building and Development of the Secretariat in 2009	p.19
EPF Growing the Membership – initiatives in 2009	p.20
EPF Alliance Building and Representation at External Meetings during 2009	p.21



EPF Knowledge Management and Communications –  
Developments in 2009

p.22

Funding Sources and Diversification –  
Initiatives in 2009

p.23

Annexes

p.24



# Introduction and Summary of Key Achievements and Milestones



*Anders Olsson*

2009 was a successful year for EPF – and also a very challenging one. The economic crisis hit health budgets and patients very hard across the EU. Our EPF Annual Report for 2009 gives you a brief overview of what we achieved and also the hurdles we have faced. For more detailed information please visit the EPF website at [www.eu-patient.eu](http://www.eu-patient.eu) or contact the Secretariat at [info@eu-patient.eu](mailto:info@eu-patient.eu)

EPF identified six objectives in its work plan for 2009:

- Building capacity within the Secretariat; governance structures and our relationship with members
- Strengthening our policy impact
- Harnessing patients' own evidence and experience
- Extending our membership base to ensure that EPF is as representative and inclusive as possible
- Building powerful and effective communications and partnerships
- Diversifying the funding base

2009 was shaped by four very significant EPF events. In March, we co-organised a conference with the European Commission 'The Pharmaceutical Forum – Delivering for Patients'. This was an important 'first' for EPF and reflected our credibility with the Commission, our investment in the Pharmaceutical Forum itself - helping to ensure that the deliverables from that process have the widest possible outreach, and importantly, that unfinished business remains on the political agenda.

Our Annual General Meeting in March attracted the largest number of delegates and observers ever and was a key opportunity for the members to review and define the direction of our policy work and revisit our governance model. It also gave us a chance to learn from patient leaders how the economic crisis was impacting them and how we could best contribute to their lobbying work. The AGM approved the setting up of the EPF policy advisory group to support the board and the Secretariat in the increasingly wide array of EU policy issues on the table.

Another important highlight was our Regional Advocacy Seminar in Bulgaria in September - the 50 patient leaders from that region who attended heralded it as 'a crucial step in EPF's influence and impact at country level'.

Finally, the year ended with our Value+ conference, organised under the patronage of the Swedish EU Presidency. The purpose of the conference was to discuss the outcomes and deliverables of our two-year EU funded Value+ conference focusing on meaningful patient involvement in EU funded health-related projects and policies. The conference marked a milestone in patient involvement and the evidenced- based tools that were produced will generate a measurable shift towards **meaningful patient involvement**, in both EU policy and programme terms.

Our EPF Manifesto Campaign, '150 million reasons to act' reaped dividends, as EPF enjoyed a much more active relationship with the European Parliament both before and after the EP elections. We were delighted with the clear inclusion of our messages in the EP report on cross border healthcare, adopted in the First Reading in April 2009, and also our influence in critical dossiers such as information to patients, pharmacovigilance, anti-counterfeiting and animal testing proposals.



Thanks in no small part to the Manifesto, we have an informal 'core' group of over 100 MEPs across the Groupings who actively support our patient-centred advocacy work in the European Parliament.

In 2009, we also began to address a number of policy dossiers new to us – medical devices, through our input in the Commission's Exploratory Exercise on Medical Devices, clinical trials, through the Commission's review of the Clinical Trials Directive, Health Technology Assessment, through a Stakeholder Group linked to a major Commission project on HTA, and health inequalities through the Commission's consultation on health inequalities.

eHealth continued to be a key priority for EPF, with the submission of a project under the Public Health Programme on building confidence and acceptance in telemedicine solutions, 'Chain of Trust', in close partnership with our EU health professional allies. We have also been very active in other eHealth projects and policies to promote a genuine patient perspective in this area, notably through the eHealth user stakeholder group.

Three new members were formally approved at the AGM, three more recommended for membership by the board, and we have membership requests from several others in process – an EPF Membership Guide was produced in 2009 to facilitate our crucial work and communications with members and prospective members. We have been actively engaged in the European Union Health Policy Forum working closely with Health NGO allies on broader health themes, again ensuring a patient's viewpoint is present.

EPF representation in major EU level health Forums, Consultative Committees and Working Groups has continued to grow. In addition to involvement in the Patient Safety Quality of Care Working Group (which provides input to the High Level Working Group on Health Services and Medical Care), the European Union Health Policy Forum, the Open Health Forum, the Health Systems Working Group, we are involved in the Editorial Board of the Health Portal, and the eHealth users stakeholders group, the EMEA Management Board and the EMEA patient and consumer working party.

EPF has participated once again, as speaker, chair or moderator in over 50 EU health meetings in 2009, presenting EPF and its membership's work and a patients' perspective on EU health policy. EPF has continued its efforts in diversifying its funding sources with continued income from the Commission for four projects initiated in 2008 and new applications submitted in 2009 in the areas of public health, research and information society. EPF has also continued to extend its range of industry sponsors to the broader healthcare environment, in accordance with stringent rules on transparency and independence.

Once again, on behalf of EPF, I would like to thank and congratulate EPF members and our allies in the European Union for your contribution to these achievements and your trust and confidence in EPF.

As we move into the next decade, we need your vision and unity, both to set a patient-centred agenda, and also to ensure ongoing high quality responses to all the EU Institutions on behalf of patients - to ensure high quality, patient-centred equitable healthcare throughout the European Union becomes a reality.

**Anders Olason**  
EPF President

# EPF's Five Core Strategic Goals

EPF developed a five year strategic plan in close consultation with its members and this plan was adopted unanimously at our Annual General Meeting in June 2007. The European Patients' Forum's vision is patient-centred equitable healthcare across the European Union.

Our strategic plan identified five core strategic goals:

## **EQUAL ACCESS FOR PATIENTS**

**GOAL 1:** To promote equal access to best quality information and healthcare for EU patients, their carers and their families.

## **PATIENT INVOLVEMENT**

**GOAL 2:** To ensure meaningful patient involvement in EU health-related policy-making, programmes and projects.

## **PATIENTS' PERSPECTIVE**

**GOAL 3:** 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).

## **SUSTAINABLE PATIENT ORGANISATIONS**

**GOAL 4:** To encourage inclusive, effective and sustainable representative patient organisations.

## **PATIENT UNITY**

**GOAL 5:** To nurture and promote solidarity and unity across the EU patients' movement. No patients' organisation is too small to contribute to our work.

# How Much Progress Did We Make?

## - Key EPF Achievements in 2009

This non-exhaustive summary is based on the performance indicators and targets identified in the EPF work plan for 2009 for selected activities, to give a flavour of our work and impact.

### INVOLVEMENT OF PATIENTS

---

**Performance Indicator:** The impact and added value of the Value+ conference under the patronage of the Swedish Presidency December 2009, and the three main deliverables from the project: the Value+ policy recommendations, handbook for project coordinators, and toolkit for patients and their organisations.

The external evaluation to date, at both political and programme level, from the broad range of stakeholders involved in the Value+ conference has been highly positive. It is premature to assess the longer term impact of the three deliverables but already as a direct result of the Conference, very close work is taking place with DG Research to ensure more meaningful involvement of patients in future research projects. We are confident that this will be replicated in DG Information Society and DG SANCO. Our longer term goal is to ensure that meaningful patient involvement is systematically built in to Calls for Proposals for EU funded health projects, and that EPF tools are referenced.

Feedback by patients and their organisations has been without exception, extremely encouraging indicating a real added and long-term value of the resources produced.

**Performance Indicator:** EPF's effectiveness in the revised European Union Health Policy Forum (EUHPF) that brings together a broad range of Health NGOs to advise the Commission on Health policy.

EPF has been a very active member of the EUHPF in 2009, ensuring a strong patient's perspective in strategic documents, open letters on the economic crisis and to the Swedish Presidency on the EU strategy for Health, and the consultation on the European Commission's strategy for 2020. At the end of 2009, EPF became involved in the steering group planning the next Open Health Policy Forum in June 2010, and is also shaping this agenda. In this regard we are increasingly recognised as a key partner, alongside other health stakeholders in determining civil society's input in EU health policy.

### EQUAL ACCESS FOR PATIENTS

---

**Performance Indicator:** Influence on the legislative process linked to the draft Directive on patients' rights in cross border healthcare.

EPF was very successful in the European Parliament in the lead up to the first reading of the EP report on the Directive. Key demands to make the proposal as inclusive, patient-centred and workable were evident, including a rethink on upfront payments, patient involvement in national information points, and a patient's ombudsman.

We communicated several times to the EU Council and Member States political representatives and health officials with similar messages. Unfortunately, the Council were less enthusiastic regarding the Directive and despite the Swedish EU Presidency efforts to arrive at a compromise, it was rejected in Council in early December. The new Commissioner and the European Parliament will take it up again in 2010.

EPF will continue to campaign vigorously for a proposal that will make a real difference for patients across the EU and commits unequivocally to patient safety and quality of care.

## How Much Progress Did We Make? - Key EPF Achievements in 2009

**Performance Indicator:** The Health Literacy Declaration in the European Parliament and Political Engagement in other Institutions.

EPF was approached by several MEPs to launch a Health Literacy Declaration in the European Parliament, following our work on the EPF Manifesto in late 2008. Although we were aware that the chances of success were limited, particularly given the timing, so close to the European Elections, we decided to pursue this as an awareness raising exercise. Ninety-nine MEPs signed the Declaration, and engaged in dialogue with EPF regarding the importance of Health literacy.

In discussions with MEPs on the information to patients' dossier, it is clear that core messages have been received regarding health literacy. We will be working closely with the new European Commission regarding follow up to commitments on health literacy in the European Health Strategy 'Together for Health'. The Spanish Presidency 2010 has expressed a firm interest in health literacy, in the context of tackling health inequalities, one of their Presidency priorities.

### PATIENTS' PERSPECTIVE

---

**Performance Indicator:** The degree of uptake of the EPF Manifesto '150 million reasons to act'.

EPF launched the EPF Manifesto '150 Million Reasons to Act' in September 2008 and continued campaign work with current and prospective MEPs in the lead up to the elections in June 2009. This resulted in a strong and supportive response from more than 100 MEPs with an active interest in health who expressed their commitment to work with EPF on health-related dossiers from a patient's perspective. Subsequent work with the European Parliament has confirmed this commitment.

At Member State level, there was a large uptake of the Manifesto because of the energy of our national members who in many cases translated the Manifesto into their own languages and undertook direct campaign work with their governments. This bodes well for on-going work with the Member States through the Health Council. Patient organisations in Croatia and Turkey also used the Manifesto with their national governments.

**Performance Indicator:** Evidence in the final text of EPF's contribution to the EU Communication on Tackling Health Inequalities.

Although there was implicit reference to marginalised patients in the Communication, EPF was somewhat disappointed by the lack of direct reference to this constituency and indeed the absence of a specific reference to health literacy, that we considered, in our extensive response, to be a central pillar in tackling health inequalities. We will be working closely with the European Commission and the forthcoming presidencies to address this issue.

### SUSTAINABLE PATIENT ORGANISATIONS

---

**Performance Indicator:** Perceived effectiveness of EPF's new outreach strategy based on independent feedback by patients leaders in the countries concerned.

Through the four events organised, our communications strategy including our membership guide, our support for patient organisations appealing to EPF during the economic crisis, and one to one high level meetings between the EPF president and ministers and secretaries of states, patient leaders have reported greater visibility and greater commitment from Health Ministries to support the work of umbrella platforms.



**Performance Indicator:** A successful application for funding through the EU Public Health Programme.

EPF coordinated a proposal that focused on building confidence, acceptance and eHealth literacy around telemedicine. Key health stakeholder allies joined us in our submission of the 'Chain of Trust' project: a decision on the approval of this project is pending.

#### PATIENT UNITY

---

**Performance Indicator:** The enlargement of the EPF membership to 42 members by the end of 2009.

This was achieved - EPF welcomed officially three new members at the AGM in March and three more organisations have been recommended by the board for membership. These include national platforms from Cyprus, Estonia, Malta, and the Netherlands, Lupus Europe and the European Women's Health Research Network.

**Performance Indicator:** The perceived success and impact of the Autumn Regional Advocacy meeting taking place in Sofia, Bulgaria in September 2009.

The seminar convened 50 patient leaders of patients' organisations from Bulgaria, Romania, Hungary, Slovenia, Greece and Cyprus. The evaluation of this seminar, overseen by an external evaluator demonstrated that this model is really effective in building knowledge and know-how on working at EU level through and with EPF and influencing the EU health policy debate through initiatives at national and regional level. There was a strong commitment on the part of patients' leaders from the region to participate in subsequent EPF work on EU health policy issues. This is affirmed by the number of representatives who also attended the final Value+ conference in Sweden.

# EPF Governance in 2009

The EPF Annual General Meeting in March 2009 welcomed three organisations as new full members:

- Estonia Disability Chamber
- Pan Cypriot Association of Patients
- Lupus Europe

A further three member organisations were accepted by the board during the second half of 2009, to be ratified at the AGM in 2010.

With regard to the board, in accordance with the EPF statutes and by-laws, Christian Saout and Albert Jovell were required to stand down after two years of office. The President thanked all his colleagues very much for their enormous contribution to EPF. It was explained that neither representative would be standing for re-election, because of significant demands on them at national level, however they would be happy to continue to be 'champions' of EPF. Anders Olauson, President, Susanna Palkonen, Vice President, and Mike O'Donovan, Treasurer all continued their mandate.

The Annual General Meeting voted in the following four new board members:

- Vida Augustiniene from the National Patients' Platform in Lithuania
- Guadalupe Morales from Gamian Europe ( a mental health patients organisation)
- Maria Navarro from the Spanish Patients' Forum
- Timo Nerikko from CEAPIR (an organisation representing kidney patients and their families)

All four board members were congratulated and it was highlighted how much the board was looking forward to working with them to guide and direct EPF.

The Annual General Meeting approved unanimously the annual report and accounts for 2008 and the EPF Work Plan and budget for 2009.

# EPF Policy Orientation in 2009 - EPF's Work with the EU Institutions and Health Stakeholders in Brussels

EPF has worked extremely hard to enhance its political impact in 2009 and its capacity to be pro-active and to shape the EU policy agenda. We have been an active partner particularly with the European Commission and the European Parliament. We have also carried out important work with Member State governments, to a great degree before the Health Council meetings.

This section gives an overview of the major initiatives undertaken throughout the year.

## KEY ACCOMPLISHMENT - EPF MANIFESTO "150 MILLION REASONS TO ACT" CAMPAIGN

Much pro-active work took place in the European Parliament and at national level in relation to EPF Patients' Manifesto campaign "150 million reasons to act" and to health literacy, an integral element of the Manifesto. Launched in September 2008 in the European Parliament - where a number of "health friendly" MEPs expressed its support and confirmed its importance, the Manifesto was actively promoted during a one year campaign.

Our main collective message was the need for more commitment to act in three fundamental areas to improve the quality of healthcare delivered across Europe:

- Equal and timely access to safe, effective diagnosis, treatment and support
- Better information and resources for patients to be partners in determining their care – a comprehensive information strategy at EU level
- A genuine patients' voice to be heard in Brussels and throughout the EU

EPF fervently continued the promotion of the Manifesto and requested each of the European Parliament political grouping leaders to note how far the key demands in the EPF Patients' Manifesto are reflected in their Groupings' own Manifesto for the European Parliament elections.

The Secretariat worked closely with EPF's members to further promote the Manifesto, not just in the context of the elections but in particular the focus of the next European Parliament and the new European Commission.

- Copies of the Manifesto were sent out to the entire membership together with a campaign guide
- The Manifesto was translated into French and used at a number of events under the French EU Presidency
- The Manifesto was translated in Lithuanian, Polish, German, Romanian, Latvian, Estonian, Czech and Spanish and promoted in significant campaign work in these countries
- EPF had requests from Croatia and Turkey, where patients' organisations have requested permission to translate and use the document as their own manifesto with their own governments

At the 2009 Annual General Meeting, EPF's President Anders Olauson said, "I can only highlight the vital importance of your engagement - the Manifesto goes back to basics – to what patients across Europe really need. It is central to our vision "high quality, patient-centred, equitable healthcare across the European Union. I am delighted and proud to be able to work alongside all of you on making sure that our Manifesto is visible in the next round of European health policy making".

Our campaign did not stop with the June elections. EPF worked intensively with the new European Parliament to engage both newcomers and past supporters to champion our work on advancing high quality, patient-centered, equitable healthcare across the EU, and to support our contribution to the various health-related legislative proposals that will be on the agenda in the next EP term.



## EPF Policy Orientation in 2009 - EPF's Work with the EU Institutions and Health Stakeholders in Brussels

### WORK WITH THE EUROPEAN PARLIAMENT – SUCCESS IN FOSTERING THE POLITICAL COMMITMENT FOR HEALTH LITERACY

---

A good example and a direct result of the Manifesto was the Written Declaration on Health Literacy 95/2008, launched by MEPs Bulzesc, Maaten and Busoi, calling for wider distribution of quality health information to citizens and patients and further training for health professionals to improve their communication with patients. In March 2009, the Declaration was signed by 99 MEPs. This was a major achievement, which reflected an understanding of the importance of health literacy and a commitment from a significant number of MEPs across the political groupings and European countries. In this process, the Secretariat worked closely with EPF's members operating at national level, as well as with the European patients' organisations members of EPF who contacted directly the MEPs in their national languages.

Enthusiastic support in promoting the Declaration was welcomed from health professional allies such as: the European Federation of Nurses (EFN), the Standing Committee of European Doctors (CPME), the European Union of Specialised Doctors (UEMS), the European organization representing community pharmacists (PGEU), the European Hospital and Healthcare Federation (HOPE) and IFMSA (International Federation of Medical Students Association).

### MAJOR CONFERENCE ON THE OUTCOMES OF PHARMACEUTICAL FORUM – DELIVERING FOR PATIENTS

---

EPF co-organised with the European Commission a major conference on the outcomes of the Pharmaceutical Forum, a three-year process involving the European

Commission, the Member States and representatives from other stakeholders to explore the future of pharmaceuticals and public health in terms of information to patients, pricing and reimbursement and relative effectiveness.

Held on 25 March in Brussels, the conference brought together 130 patients' organisations leaders and other health stakeholders from across the European Union to critically explore the outcomes of the Pharmaceutical Forum and how to use these effectively at a European and local level.

This conference was a key milestone in moving forward on the achievements of the Pharmaceutical Forum and proved once again that EPF was a reliable and credible partner for the European Commission in the policy dialogue on pharmaceuticals. Participants had a unique opportunity to share knowledge on the tangible outcomes of the Forum and to examine in very concrete terms how the conclusions and recommendations of the Pharmaceutical Forum could and should be translated into reality by the whole range of stakeholders in their own organisations and in their own contexts. According to the representative of the European Commission, "patients proved with this event that, in addition to being the beneficiaries of public health systems, they are also the drivers for change in all constituencies. Such commitment from a key member of the Pharmaceutical Forum is needed for Europe".

### ONGOING WORK WITH THE EUROPEAN PARLIAMENT – THE EU PHARMACEUTICAL PACKAGE

---

EPF has been very active in providing a patients' perspective on the so-called "pharmaceutical package" covering three areas:

- Information on prescription medicines: A Directive amending Directive 2001/83 on Human Medicines; - A Regulation amending Regulation 726/2004 on the centralized procedure



- Counterfeit medicines: - A Directive amending Directive 2001/83 on Human Medicines
- Pharmacovigilance: - A Directive amending Directive 2001/83 on Human Medicines; - A Regulation amending Regulation 726/2004 on the centralized procedure

We participated in innumerable internal and external debates on the issues, conducted several consultations with members, held a policy workshop with a cross-section of our members and patient group allies to explore the package itself, develop a strategy for the legislative procedure and to prepare and consolidate EPF's baseline positions on these dossiers.

The Secretariat worked closely and intensively with the European Parliament, both in Brussels and in Strasbourg, particularly through the rapporteurs, shadow rapporteurs and the Secretariat of relevant committees (ENVI, IMCO, ITRE) and the political groupings' coordinators to make sure the patients' views are taken into account.

Our starting point was that we welcomed the objectives of the pharmaceutical package and broadly support the proposals, while expressing concern that a number of elements required re-think and/or clarification in order to make the proposals really work for patients. In the context of the information to patients proposal, we are very clear that this was very narrow in scope, and should in fact be only one, albeit important, part of a much broader comprehensive EU strategy on information to patients that includes health literacy.

With regard to pharmacovigilance, EPF welcomed the warnings for products under intensive monitoring and particularly supported the opportunity for patients and their families to report on suspected adverse effects of medicines. We advocated for the provision of accessible information to patients about the procedures to report and form a real cooperation between regional and national pharmacovigilance centres and patients' organisations in order to enable a meaningful patients' reporting.

In relation to the proposal on combating counterfeit medicines, EPF highlighted the need for consistent information and communications strategies to tackle sales of counterfeit medicines, including the Internet-based sales, and called for patients' organisations' involvement in this process. The two reports prepared by MEP Linda McAvan on pharmacovigilance and MEP Marisa Matias on anti-counterfeiting at the end of December reflected to a great extent EPF's input and our contributions to the debate.

EPF also undertook some robust work with the Council, in particular on the "Information on Prescription Medicines" proposal and urged for continuing the work on this proposal, despite its narrow scope, to place it in the broader context of a comprehensive information to patients strategy.

EPF will monitor closely the legislative journey of the proposals during 2010 and will continue to promote patients' views on these important pieces of legislation.

#### PATIENTS RIGHTS IN CROSS BORDER HEALTHCARE

2009 was a year in which EPF also worked intensively with the European Parliament on the Council on the *Directive on the application of patients' rights in cross-border healthcare*.

Following the reflections and consultations with members and in line with our equity and inclusion principles, EPF held various briefing meetings with the main rapporteurs. After the publication of John Bowis' report, the Secretariat proposed a series of amendments to the relevant MEPs from the Committees involved: Public Health and Environment (ENVI), Women's Rights and Gender Equality (FEMM), Industry, Research and Energy (ITRE), Employment and Social Affairs (EMPL), Economic and Monetary Affairs (ECON), Internal Market and Consumer Protection (IMCO).

## EPF Policy Orientation in 2009 - EPF's Work with the EU Institutions and Health Stakeholders in Brussels

Our key messages referred to the following:

- The need for stronger cooperation between Member States on cross border healthcare
- Include the principles of quality and safety of healthcare
- Alternative solutions to pay healthcare providers directly instead of asking patients to pay upfront for hospital treatment
- Transparent and effective prior authorisation systems, if Member States chose to go for this option
- Mechanisms for patients with rare diseases to access healthcare in another Member States without prior authorization
- Involve patients organisations in provision of information to patients and drafting and adopting guidelines on information to patients
- Involve patients in the proposed European health technology assessment network

The final report adopted on 23 April by the European Parliament included key aspects of interest for the patients' community, reflecting thus EPF's consistent work with the MEPs.

After the summer, EPF continued the advocacy work with the new MEPs, the Swedish EU Presidency, health attachés and Member State representatives to ensure that the patients' views are reflected in the final legal text. In the preparation of the Health Council meeting from 1 December, the Secretariat sent out letters for the Member States' ministers, heads of permanent representations, and health experts from Member States highlighting some core issues for patients and appealing to them, on behalf of patients in their country and on behalf of the European patients' movement to take these perspectives into account during the next few weeks while working on the Council's position on the Directive.

Finally, EPF expressed a strong disappointment at the surprising outcome of the Health Council from 1 December, where Member States were not able to find a political agreement and to move forward the Directive for a second reading in the European Parliament.

Despite this block, EPF continued to engage with the forthcoming Spanish EU Presidency and advocate for ALL patients' fundamental rights to quality healthcare, in their country and abroad. Our conference in Gothenburg was also a key opportunity to discuss with the highly supportive Swedish Health Minister the members and allies on how to move forward on this issue.

### HEALTH INEQUALITIES

---

The European Commission launched early in 2009 a consultation document on Tackling Health Inequalities – this is part of the EU Health Strategy 'Together for Health'. EPF in consultation with its membership developed a response to this, framed around our vision of high quality, patient-centred, equitable healthcare across the European Union and our strategic goals on equity, empowerment and inclusion.

Our response identified the key challenges, and strategies needed at EU level from a patients' perspective. The EPF response also explored opportunities for action by patient organisations in providing quality information targeted at patients vulnerable to social exclusion, and also approaches to ensure patients' organisations are as inclusive and as representative as possible.

Although there was implicit reference to marginalised patients in the Communication, EPF was somewhat disappointed by the lack of direct reference to this constituency and indeed the absence of a specific reference to health literacy, that we considered, in our extensive response, to be a central pillar in tackling health inequalities. We will be working closely with the European Commission and the forthcoming Presidencies to address this issue.



## COMMISSION'S CONSULTATION ON CLINICAL TRIAL DIRECTIVE

---

EPF participated in a Commission meeting on the Clinical Trials Directive Impact Assessment in November, alongside a number of other patient groups. On the basis of this meeting, EPF prepared a memorandum to the membership outlining the issues at stake and inviting comments and experiences to feed into the Commission's Consultation process on the Clinical Trials Directive. We also drew on evidence from the Value+ project, the PatientPartner project which is coordinated by VSOP in the Netherlands, the INVOLVE group in UK, the RESPECT project on the meaningful involvement of young patients in clinical trials and the work we are undertaking with EMEA in relation to Third Country Clinical Trials and the Patients and Consumers Working Party.

Our response focused on the inclusion of key patient issues that did not feature in the consultation paper, namely:

- Ensuring meaningful patient involvement across all aspects of clinical trials. We believe that this will enhance and improve the outcome of clinical trials. This may also increase patients' participation rates in clinical trials
- Giving patients access to quality information regarding clinical trials
- Transparency concerning the results of clinical trials (even if the clinical trials failed or did not achieve the expected results)
- Meaningful informed consent, especially regarding patients from the mental health arena

## HEALTH TECHNOLOGY ASSESSMENT

---

Health Technology Assessment (HTA) has become a priority area at the EU level, primarily as part of a strategy to ensure the sustainability of healthcare systems. Significant work is underway to enhance EU cooperation and good practice in the area of HTA.

The European Commission is funding a Joint Action on HTA, EUnetHTA, that will commence formally in January 2010. This grew in part out of the EUnetHTA project outcomes and the conclusions and recommendations from the Pharmaceutical Forum on Relative Effectiveness.

An EUnetHTA meeting chaired by the European Commission on how to work effectively with stakeholders took place in November 2009 to which EPF attended. The meeting's main purpose was to discuss and develop a draft policy document on how to involve stakeholders in both governance and the implementation of the Joint Action.

EPF promotes the notion that patients, as individual experts, and patient organisations should be involved meaningfully in HTA processes. In general terms, this is happening only in an ad hoc, piecemeal fashion across the Member States, with some reservations in a number of countries on the added value of involving patients.

On the other hand, with some exceptions, there is generally limited knowledge and know how across the broad EU patient community on the science and the policy rationale behind HTA and mechanisms to get involved effectively. To address this challenge, EPF will be organising a seminar on HTA as one of its major activities in 2010 and will also be an active player in the European Commission's activities on HTA.

## MEDICAL DEVICES

---

The EU exploratory process on the future of the medical devices sector began in October 2009 to map the existing public health and industrial challenges in the sector and investigate possible topics of reflection at the European level. This process was an opportunity for industry, users, and consumers of medical devices to share views, experiences and aspirations. Various members of EPF were involved during the entire process.

## EPF Policy Orientation in 2009 - EPF's Work with the EU Institutions and Health Stakeholders in Brussels

The objective was to get an overview of current public health and industrial challenges linked to the medical devices sector.

The process was organised around two **discussion sessions** with representatives of the stakeholders organisations involved and experts. In addition to a plenary session, the participants explored more in depth challenges covered within three distinct work streams.

- **Future challenges and opportunities for medical technologies developments and their impact on public health**
- **Balance between the patients' needs and financial sustainability**
- **Competitiveness and innovation of the medical devices industry**

The final meetings on the Exploratory Process on Medical Devices took place on 22 and 23, January 2010. During December, in preparation for this last meeting, EPF, in collaboration with BEUC, presented a discussion paper about information to patients on medical devices, drawing on the Pharmaceutical Forum process and the quality principles agreed in this context.

EPF was pleased with the process and the concrete outcome of the process which gives a clear framework for future work and greater awareness on the range of concerns and opportunities in the medical devices field. We will continue to pursue this work in 2010.

### EPF INVOLVEMENT – EXAMPLES OF INVOLVEMENT IN COMMISSION HIGH LEVEL GROUPS

---

#### **Working Group on Patient Safety and Quality of Care**

EPF was active in the Patient Safety Working Group set up by the European Commission to advise the High Level Working Group on Health Services and Medical

Care. The group worked to promote further commitment from Member States to identify and share potential solutions to address patient safety and in particular advised the Commission for drafting and elaborating the Recommendation on Patient Safety and Health Care Associated Infections. EPF has contributed to this process and strongly advocated for involving patients and their representatives in patients' safety initiatives. We also pushed for further information and training of patients and their families and carers about patient safety core aspects, while providing the Commission with examples of information and education interventions tailored for patients that were developed in various Member States. These included in particular the "Patient Handbook: A Patient Guide to a Safer Hospital Stay", developed by the Danish Society for Patient Safety, and the "Patient University Project" – run by the University of Barcelona in cooperation with the Spanish Patients' Forum and Joseph Laporte Library – which includes courses and information toolkits for patients about specific chronic diseases and disease self-management.

The Recommendation, highlighting patients' involvement and training for health professionals and patients in patient safety, was adopted by the Health Council in June 2009. Starting in autumn, the Commission moved forward in engaging representatives of Member States and stakeholders, including EPF, in a reflection on quality of healthcare and possible policy actions at EU level. The group became the Patient Safety and Quality of Care Working Group (PSQCWG). The Commission proposed a series of specific objectives and policy options that could contribute to improving the quality of healthcare in the EU, such as: to achieve a common understanding of quality in EU Member States, to propose a collection of comparable data, to promote continuous healthcare quality improvements in all Member States and to establish a culture of mutual learning among Member States.



EPF gave feedback to the Commission outlining the need for a patient-centred approach and for patients' meaningful involvement in policies on safety and quality and the importance of patients' health literacy. Towards the end of the year, EPF worked together with other health stakeholders like the European Society for Quality of Care (ESQH), European Health Management Association (EHMA,) and the Standing Committee of European Doctors (CPME) to prepare a joint response to the Commission on this issues.

#### **Editorial Board Health Portal**

EPF sits on the Editorial Board of the Health-EU Portal, which brings together representatives of EU Member States, NGOs and other parts of the Commission. The Health-EU Portal aims to provide European citizens with easy access to information on public health initiatives and programmes at EU level and with clear and scientific information about measures to protect health and prevent disease.

#### **eHEALTH USERS STAKEHOLDERS GROUP**

---

EPF is a member of the Commission eHealth Users' Stakeholders Group, which is an advisory group of the i2010 Subgroup on eHealth, working under the coordination of the Information Society and Media Directorate-General. The group provides advice on the progress of the eHealth Action plan in Europe. A major focus of the work in 2009 was the Commission Communication on Telemedicine and the eHealth Ministerial Conference "eHealth for Individuals, Society, and Economy" (18-20 February 2009, Prague). Anders Olauson, EPF's President, made a presentation at this conference on key issues of the ethical use of eHealth towards building trust on eHealth solutions. EPF also contributed to the Patients' Charter for eHealth Information Systems, prepared by the European Health Telematics Association (EHTEL).

#### **THE EUROPEAN UNION HEALTH POLICY FORUM**

---

EPF is a member of the European Union Health Policy Forum (EUHPF) that brings together a wide variety of pan-European health NGOs and associations to contribute towards the development of EU health-related policies and actions. One of the important developments in 2007 was a revised mandate for the Forum in light of the new EU Health Strategy. In concert with several other health NGO members, EPF is committed to supporting a stronger, more pro-active and political health policy forum. EPF has been actively involved in a specific working group (STEPS) that developed a strategy and work plan for the European Health Policy Forum.

EPF has been a very active member of the EUHPF in 2009, ensuring a strong patient's perspective in strategic documents, open letters on the economic crisis and to the Swedish Presidency on the EU strategy for Health, and the consultation on the European Commission's strategy for 2020. At the end of 2009, EPF became involved in the steering group planning the next Open Health Policy Forum in June 2010, and is also shaping this agenda. In this regard we are increasingly recognised as a key partner, alongside other health stakeholders in determining civil society's input in EU health policy.

## EPF Policy Orientation in 2009 - EPF's Work with the EU Institutions and Health Stakeholders in Brussels

### COOPERATION WITH THE EUROPEAN MEDICINES AGENCY, EMEA

---

EMEA activities in which EPF was involved included:

- EMEA /CHMP Working Party with Patients' Organisations
- Quality Review of documents (product information)
- Proactive involvement in the preparation of guidelines
- Specific requests from the EMEA scientific committees, working parties and scientific advisory groups

EPF is represented in EMEA consumer and patient working party by Susanna Palkonen, EPF Vice President. Mike O'Donovan, EPF Treasurer, at the end of 2008 was appointed as one of two patient representatives to the EMEA Management Board.

### SEVENTH FRAMEWORK PROGRAMME ON RESEARCH AND DEVELOPMENT (FP7)

---

EPF President Ander Olauson continues to represent patients in a High Level Group set up by the Commissioner for Research to provide overall strategic guidance to developments within FP7. EPF is involved as an associate partner in a project funded under FP7 entitled 'RESPECT' that will explore the meaningful involvement of young patients in clinical trials.

As a direct result of the Value+ project on meaningful patient involvement a much greater understanding and commitment to patient involvement in research projects has been achieved within the European Commission which EPF will continue to develop in 2010.



*The Pharmaceutical Forum Final Conference, March 2009*

# EPF Harnessing the Patients' Evidence and Experience

## THE EPF AUTUMN REGIONAL ADVOCACY SEMINAR

---

On 18-19 September 2009, EPF held its second regional advocacy seminar in conjunction with the Value+ project. Fifty patient leaders of patient organisations from Bulgaria, Romania, Hungary, Slovenia, Greece and Cyprus were hosted in Sofia by the Bulgarian Confederation "Health Protection" (KZZ), one of the members of the Value+ consortium.

The seminar formula was similar to the one adopted in 2008 in Lithuania. Part of the programme focused on providing an overview of the EU policy-making and decision-making processes with contributions from representatives of the European Parliament, the European Commission and patient leaders.

The other main focus was Value+. The project results – almost in their final stages – were shared with participants who also had the opportunity during the workshops to input into two of the resources produced by Value+: the model of meaningful patient involvement in European projects and the policy recommendations. The seminar was supported by an unrestricted educational grant from Medtronic. The full report of the seminar can be found on EPF's website.

## VALUE+

---

2009 has been the final year of EPF's first major EU project Value+ that focuses on meaningful patient involvement in EU health projects.

The aim of the project was to exchange information; experiences and good practice to encourage the meaningful involvement of patient organisations in EU-supported health projects at EU and at national level. After assessing the current status of involvement through a survey, focus groups and workshops, Value+ developed

a set of specific targeted resources: a Toolkit for patient organisations to facilitate their participation in projects; a Handbook for project coordinators, leaders and promoters and policy recommendations for decision-makers.

The project culminated in a major conference under the Swedish EU Presidency where the project results and resources were shared. The conference succeeded in bringing together key health stakeholders to discuss patient involvement in programmes and policy and in setting the scene for a post-Value+ phase.

EPF will concentrate on disseminating the project results during 2010 and in reflecting on the next steps to bring forward Value+ achievements.

Value+ has its own web page where you can access more detailed information: <http://www.eu-patient.eu/Initatives-Policy/Projects/ValuePlus/>

## EUNETPAS

---

EPF was involved as an associate partner in the EUNetPaS (European Union Network for Patient Safety) project, an EU financially supported project, which established an umbrella network of representatives of the 27 EU Member States, health professionals, healthcare and patient organisation) as well as the WHO, OECD and the Council of Europe. The aim is to evaluate, validate and diffuse the new knowledge and good practices garnered within the network on patient safety in order to decrease the risk of preventable harm to patients and to improve the quality of healthcare. In 2009, national patient safety networks were established in 13 Member States, modelled on the EUNetPas platform.

## EPF Harnessing the Patients' Evidence and Experience

### RESPECT

---

RESPECT aims to empower children and adolescents participating in clinical trials, to increase paediatric trials and provide treatments and drugs that are more appropriate and effective for children than those actually provided.

As a first phase, the project focused on assessing the factors motivating or discouraging children and their parents to enroll in clinical trials. This was done through case studies conducted through interviews, focus groups and online surveys. This assessment will be concluded in April 2010 with completion of the surveys and the organisation of a workshop.

More information is available at [www.eu-patient.eu](http://www.eu-patient.eu).

### CALLIOPE

---

EPF continues being involved as a beneficiary in the EC supported project CALLIOPE – “Call for Interoperability: Creating a European coordination network for eHealth interoperability implementation”. CALLIOPE is a Thematic Network composed of Member States' health authorities and by organisations representing networks of physicians, community pharmacists, patients, industry, health insurers and payers.

The main objectives of the project are to:

- Establish a competent, self sustainable mechanism for experience sharing and consensus building for eHealth Interoperability in Europe
- Provide an open forum and “a think tank” for current and emerging challenges in interoperability
- Provide targeted support for activities requiring broad convergence across Europe, such as eHealth projects and the EU Interoperability Recommendation
- Disseminate and create knowledge and understanding of important EU level policy documents supporting interoperability through training and dissemination events

EPF has been very much engaged in the review of the EU Recommendation and in the development of a Roadmap on interoperability meant to pave the path for the deployment of eHealth interoperable solutions across the EU.



*EPF President Anders Olauson and Swedish Minister for Health and Social Affairs, Göran Hägglund, Value+ Conference December 2009*

# EPF Capacity Building and Development of the Secretariat in 2009

## THE EPF SECRETARIAT

---

The EPF Secretariat welcomed three new team members in 2009. Kia Megas joined EPF in October 2009 as communications officer. Sopia Letorey, intern left in May 2008, two new interns Sabine Lobnig and Yves Brand worked with EPF in 2009 on communications and policy respectively.

Zilvinas Gavenas continued to work with EPF as IT consultant/webmaster. Roxana Radulescu who joined the team as full time policy officer in January 2007 began her role as senior policy advisor at the beginning of 2009. Nicola Bedlington continued as EPF executive director and Liuska Sanna as programme officer.

EPF works with an accountancy firm to manage the book-keeping and financial accounts in accordance with Belgian and Luxembourg law. An external auditor audited the 2008 accounts and these were presented at the Annual General Meeting in March 2009. These were then posted on the EPF website.



# EPF Growing the Membership – Initiatives in 2009

EPF's membership grew from 38 to 42 members in 2009. Several national platforms and disease specific organisations have expressed an interest in joining EPF in the near future. The EPF Secretariat is liaising with them with a view to membership in 2010. An EPF Membership Guide has been produced to support current and potential new members.



# EPF Alliance Building and Representation at External Meetings during 2009

## REPRESENTATION AT EXTERNAL EVENTS

---

**EPF was represented by its board and Secretariat as speakers; moderators or chairs at over 50 European health – related meetings during 2009.**

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.

A few highlights include presentations at:

- The European Health Management Association Round-Table on Patient Safety, January, Brussels
- The eHealth conference under the Czech Presidency, February, Prague, key note address on eHealth and ethics
- European Society on Quality of Care, Accelerating Patient Participation April, Rome
- Patients Rights Day April, Strasbourg, on the eve of the adoption of the first reading on the Directive on Patients Rights in Cross Border Healthcare
- World Health Congress, May, Brussels
- Annual Conference of the European Federation of Allergies and Airways Diseases Patients Organisations, June, Rome
- Annual Conference of PGEU (European Pharmacists) June, Stockholm
- Swedish EU Presidency on Relative Effectiveness, July Stockholm
- EU Health Forum Gastein, October, Gastein
- Med-e-Tech Forum, October Brussels
- Patient Safety in intensive care settings, October Vienna
- Planning European Healthcare Revolution - Friends of Europe, December, Brussels

## EPF ALLIANCE BUILDING

---

In 2009, EPF continued to place much importance in continuing to foster alliances and good working relations with European organisations with which we have a common agenda. These include the European Public Health

Alliance (EPHA), the European Standing Committee of Doctors (CPME), the European Federation of Nurses (EFN); the European Pharmacists Organisation (PGEU), the European Hospitals Association (HOPE), the European Health Management Association (EHMA), the European Consumer Association (BEUC) etc.

We also continue our close relationship with our sister organisation at international level, the International Alliance of Patient Organizations, in line with our Memorandum of Understanding and worked closely on core policy themes including pharmacovigilance, anticounterfeiting, and EU financial regulation. IAPO representatives were present at all our external meetings and EPF will lead a session at the IAPO congress in Istanbul in February 2010 on Value+ and meaningful patient involvement.

EPF has also reached out to umbrella organisations representing insurers. A representative of AIM (Association Internationale des Mutualites) attended our Value+ conference and close discussions are now underway regarding a common project on disease management. The EPF Treasurer and Director met ESIP (European Social Insurance Platform) in November to discuss potential areas of cooperation, particularly regarding funding.

In 2009, we strengthened our relationship with consortia such as CONTINUA in relation to eHealth, COCIR and EUCOMED in relation to medical devices.

## PARTICIPATION IN THINK TANKS AND REFLECTION GROUPS OUTSIDE THE COMMISSION

---

EPF is a member of:

- The EFPIA Think Tank with Patients Groups that met four times in 2009 and is a member of its steering group
- The GSK Health advisory board
- EUROPA BIO patient advisory board
- The steering group of the Centre for Health, Ethics and Society (CHES)

# EPF Knowledge Management and Communications – Developments in 2009

**EPF continued to make progress on the development of the new website in 2009. New features now include an enhanced content management system, improved navigation with greater accessibility and upgraded website structure. The new website will be launched in early 2010 and EPF will continue improving and updating content to reflect the dynamism of the organisation.**

EPF continues to produce and distribute its EPF Mailing every six weeks. The mailing is sent out to nearly 2000 individuals which include our members and the health policy community as a whole. The newsletter includes policy and project updates, events and conferences and new to the EPF mailing, a section on member news. It is also available on the website. The EPF Mailing has proved to be a very effective communication tool, relaying EPF's perspective and ongoing campaign and advocacy work on key health dossiers.

EPF achieved an important objective in its communication strategy adopted by the EPF board in 2008 to employ a communication officer. Following an equal opportunities recruitment procedure, Kia Megas joined EPF as communication officer in October 2009, responsible for EPF's internal and external communication.

In 2009, EPF continued to build a close relationship with relevant media to enhance and promote EPF's activities and position. EPF expanded its media contacts to include an additional 320 EU, International Medical, Healthcare IT and National Medical reporters.

EPF reached out to the new Parliament after the 2009 elections. The goal was to enhance our strategic position with MEPs and the EP Committee Secretariat and develop a collaborating working relationship to achieve our goal of equitable, patient-centred, high quality healthcare for all patients throughout the European Union. A targeted welcome letter with EPF resources was sent to all MEPs who expressed support for EPF during the EPF Manifesto Campaign in 2008/2009.

EPF also undertook a media campaign around the Value+ conference in Gothenburg, Sweden in December 2009. Five articles were published in both EU and medical journals. EPF was published in Euractiv, European Hospital, eHealthNews, EUChronicle and the British Medical Journal.

In 2009, the EPF membership guide was developed to give an overview of the services we offer to our potential new members and assist existing members to fully achieve and represent their interests. This will initially be an online tool and will be updated on an annual basis.

# Funding Sources and Diversification – Initiatives in 2009

**EPF is highly committed and active in the diversification of its funding sources. By the end of 2008, EPF's funding base was three-fold: membership fee, EU funding and unrestricted funding from sponsors.**

EPF has a membership fee structure based on the organisations' annual turnover.

Our first EU funded project 'Value+' was a major focus during 2009. We also continued to engage as an associate partner in EUnetPas, a major European project on patient safety, and as an associate partner in a project developed under the Seventh Framework Programme on Research and Development, FP7. This project entitled 'RESPECT' addresses young patients' involvement in clinical trials. We are active in a project called 'CALLIOPE', looking at the interoperability of health systems across the EU. All four projects commenced in early 2008 and continued throughout 2009.

During the course of 2009 EPF allocated considerable resources to apply for Commission funding for projects that contribute to our policy objectives, through Public Health, information society, research, and the Innovative Medicines Initiative. We have also worked actively with the Commission in relation to encouraging more involvement of patients in the structural funds projects linked to health.

At the end of 2009 we were happy to learn that the large scale project in telemedicine 'Renewing Health', in which EPF is an associate partner was approved and will commence in 2010. We await final news on our own project 'Chain of Trust' and a number of other applications are pending decision.

Unrestricted grants from a range of pharmaceutical companies or pharmaceutical federations continue to make up part of EPF's resources. In this regard, we welcomed the EFPIA Code of Practice for working with patients' organisations that was adopted by the EFPIA board in October 2007.

Our own Code of Ethics and Framework, revised in 2008 and adopted unanimously by the AGM in 2009 also ensures that EPF's relationship with sustainable funding partners meets the highest standards of transparency and independence.

A funders' meeting was held in September 2009 to discuss with all our funders progress and successes in relation to EPF's work plan 2009 and our plans for 2010 and beyond.

In resource terms, as EPF grows as a European non-governmental organisation that delivers significant input to the EU policy debate, it is important and appropriate that a significant proportion of EPF's funding comes from the European Commission.

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

The European Commission launched a consultation late last year on a Review of Financial Regulation. The main objective of the review of the Financial Regulation is to simplify the financial rules and procedures applicable to the EU budget. EPF consulted its members and patient group allies concerning the consultation and submitted a response in December. EPF will continue to work vehemently with the European Commission to ensure core funding for patient groups to be able to play their role effectively, based on principles of transparency, independent and diversity of funding sources.

EPF is committed to sound financial management and we continue to aim to establish reserves equaling six months operational budget.

# Annexes

## EPF Board Members

Anders Olauson – EURODIS – EPF President  
Susanna Palkonen – European Federation of Allergies and Airways Diseases Association – EPF Vice President  
Mike O'Donovan – European Multiple Sclerosis Platform – EPF Treasurer  
Panos Englezos – Thalassaemia International Federation – Board Member  
Maria D. Navarro – Spanish Patients' Forum – Board Member  
Vida Augustiniene – Lithuanian Diabetes Association – Board Member  
Guadalupe Morales – GAMIAN Europe – Board Member  
Timo Nerikko – European Kidney Patients' Federation – Board Member

## EPF Secretariat Team

Nicola Bedlington – Director  
Roxanna Radulescu – Senior Policy Advisor  
Liuska Sanna – Programme Officer  
Zilvinas Gavenas – IT/Web Consultant  
Efsthia Megas – Communications Officer  
Veronique Tarasovici - Office Manager  
Magdalena Machalska – Policy Assistant  
Walter Atzori – Assistant Programme Officer

## EPF Member List

### Full Members

- Age Related Macular Degeneration (AMD) Alliance International
- Alzheimer Europe
- Collectif inter associatif Sur la Santé (CISS)
- Council of Representatives of Patients' organizations of Lithuania (LPOAT)
- Estonian Chamber of Disabled People
- EUROPA DONNA - The European Breast Cancer Coalition
- European Alliance of neuro-Muscular Disorders Association – EAMDA
- European Federation of Allergy and Airways Diseases Patients' Associations – EFA
- European Federation of Association of Families of Mentally Ill People – EUFAMI
- European Federation of Associations of Patients with Haemochromatosis

- European Federation of Crohn's and Ulcerative Colitis Associations – EFCCA
- European Federation of Homeopathic Patients' Associations
- European Genetic Alliances Network – EGAN
- European Heart and Lung Transplant Federation
- European Infertility Alliance
- European Kidney Patients' Federation – CEAPIR
- European Multiple Sclerosis Platform
- European Network of (ex)users and survivors of psychiatry (ENUSP)
- EURORDIS - European Organisation for Rare Diseases
- Federation of Polish Patients
- Foro Español de Pacientes
- GAMIAN Europe - Global Alliance of Mental Illness Advocacy Networks
- International Diabetes Federation - Region Europe
- International Patient Organisation for Primary Immunodeficiencies IPOPI
- LUPUS Europe
- National Voices
- Pancyprian Federation Of Patients Associations and Friends
- Retina Europe
- SUSTENTO - The Latvian Umbrella Body For Disability Organization
- Thalassaemia International Federation

#### Associate Members

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

#### Provisional Members

- European Forum for Psoriasis Patient's Associations in Europe

#### Provisional Members to be approved at 2010 AGM

- Federation of Patients and Consumer Organisations in the Netherlands
- Malta Health Network
- European Institute of Women's Health
- Fertility Europe

# Accounts and Audit Reports

## European Patients' Forum Balance sheet as of December 31, 2009

	2009	2008
<b>ASSETS</b>		
<b>I Fixed Assets</b>		
Computer's equipment	0.00 EUR	2,504.90 EUR
Guarantee to Axa and Securex	10.876,00 EUR	10.707,00 EUR
<b>II Current Assets</b>		
Accounts receivable	64.125,00 EUR	1.620,00 EUR
Cash in bank and on deposit	482.761,00 EUR	463.023,00 EUR
Accruals	5.823,00 EUR	7.126,00 EUR
<b>TOTAL ASSETS</b>	<b>563.585,00 EUR</b>	<b>482.476,00 EUR</b>
<b>LIABILITIES</b>		
<b>I Capital and reserves</b>		
Funds brought forward	280.782,00 EUR	221.130,00 EUR
Surplus for the year	72.255,00 EUR	59.652,00 EUR
<b>II Debts</b>		
Payment received in advance	0,00 EUR	0,00 EUR
Accounts payable	123.888,00 EUR	76.297,00 EUR
Income to be received	86.660,00 EUR	125.397,00 EUR
<b>TOTAL LIABILITIES</b>	<b>563.585,00 EUR</b>	<b>482.476,00 EUR</b>

## European Patients' Forum Profit and Loss Account - 31 December 2009

	2009	2008
<b>INCOME</b>		
Membership Fees	7,250.00 EUR	72,52.00 EUR
Corporate Sponsoring	342,858.11 EUR	322,500.00 EUR
Spring Conference	0.00 EUR	109,203.35 EUR
Autumn Seminar	40,000.00 EUR	35,00.00 EUR
Value+	122,779.49 EUR	52,617.51 EUR
Other Projects	158,516.85 EUR	50,646.40 EUR
Interest - Other Income	6,006.55 EUR	12,310.52 EUR
<b>TOTAL INCOME</b>	<b>677,411.00 EUR</b>	<b>589,529.78 EUR</b>
<b>EXPENDITURE</b>		
Staff and Fees	-301,387.51 EUR	-261,551.24 EUR
Office Costs	-64,502.58 EUR	-66,681.64 EUR
Travel	40,599.57 EUR	-27,173.47 EUR
Events (Spring Conference)	-0.00 EUR	-109,227.27 EUR
Events (Autumn Seminar)	-42,155.92 EUR	-29,780.30 EUR
Value+*	-153,967.18 EUR	-88,524.77 EUR
Swedish Conference	-107,251.35 EUR	
Other Projects	-25,034.88 EUR	-50,900.00 EUR
Communications	-17,359.05 EUR	-20,955.57 EUR
Bank Fees and Holiday Pay Provision	-5,709.81 EUR	-11,555.83 EUR
<b>TOTAL EXPENDITURES</b>	<b>-757,967.85 EUR</b>	<b>-666,350.09 EUR</b>
<b>SECRETARIAT INCOME**</b>	<b>152,811.38 EUR</b>	<b>136,471.93 EUR</b>
<b>SURPLUS FOR THE YEAR</b>	<b>72,254.53 EUR</b>	<b>59,651.62 EUR</b>

\*About the Value+ Cost

Please note that 10,000 euros for the translation costs of the Value+ project have been accrued in 2009 according to supporting documents (contracts) provided by the translators and giving a fair estimate of the amount to be paid in 2010.

\*\*About the Secretariat income:

The Secretariat income is composed of:

Value+	99,063.24 EUR
Respect	16,544.77 EUR
Eunetpas	7,367.58 EUR
Swedish Conference	20,170.22 EUR
Autumn Seminar	9,665.57 EUR

## European Patients' Forum Non-for-profit Organization

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

### Report for the year ended 31 December 2008

We have audited the financial statements of European Patients' Forum ("the Organisation") for the year ended 31 December 2009, which show a balance sheet total of **€563,585** and a profit for the year of **€72,255**.

### 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 Organization and the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

In our opinion, the financial statements for the year ended 31 December 2009 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 Organization 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 17th, 2010  
FIDINTER BVBA, represented by F.Léonard, director

# Acknowledgement of Financial Support

**EPF wishes to thank the following sponsors for their support in the form of unrestricted grants to EPF's operational programme 2009:**

Amgen	25,000.00 EUR
Baxter	10,000.00 EUR
Cs Behring	10,000.00 EUR
EFPIA	50,000.00 EUR
Ei Lilly	20,000.00 EUR
GE Healthcare	15,000.00 EUR
GSK	40,000.00 EUR
MSD	50,000.00 EUR
Norartis	50,000.00 EUR
Pfizer	50,000.00 EUR
Pharma	52,858.11 EUR

**EPF wishes to thank the following sponsors for their support in the form of an unrestricted grant for EPF events in 2009:**

## **Value+ Conference**

Amgen	15,000.00 EUR
GSK	40,000.00 EUR
Pfizer	40,000.00 EUR

## **Autumn Regional Advocacy Seminar Bulgaria**

Medtronic Foundation	25,000.00 EUR
----------------------	---------------

**EPF wishes to thank the European Commission for their support in 2009 in relation to EPF's role in the following projects:**

Value+ project (EPF coordinator)	122,779.49 EUR	(total subsidy for project 300,000 EUR)
RESPECT (EPF, Associate Partner)	20,000.00 EUR	
EUnetPAS (EPF, Associate Partner)	10,195.20 EUR	
Commission Conferences	7,925.00 EUR	



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