Annual Report
2010

europeanpatients'forum

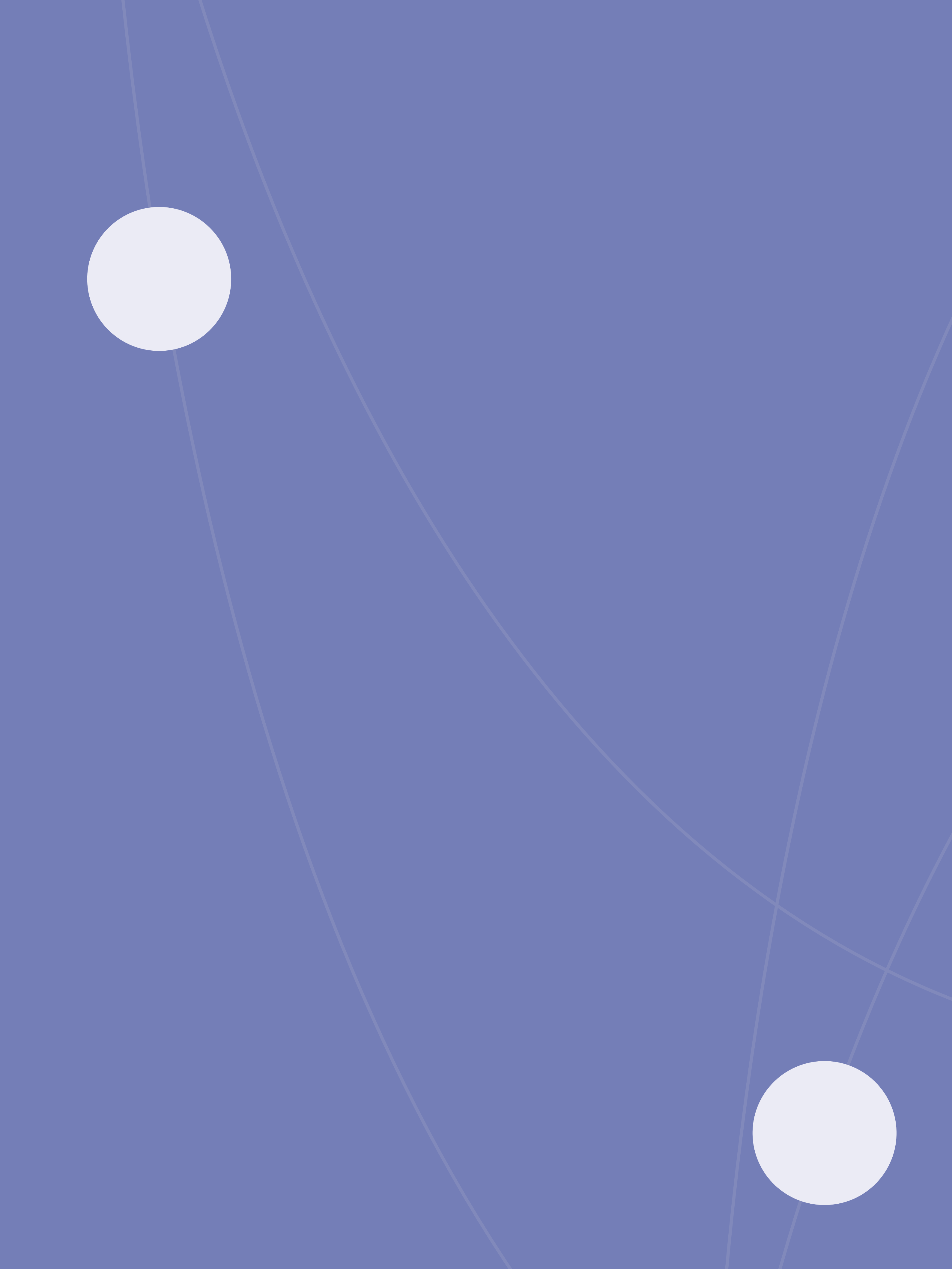


Table of Contents

Introduction and executive summary

We are delighted to report, on behalf of the EPF board, that 2010 was another very dynamic and productive year for EPF, where the impact of our work was very much in evidence. We hope this Annual Report will give you a brief overview of what we achieved and also some of the challenges we have faced as a growing organization.

For more detailed information please visit the EPF website at www.eu-patient.eu or contact the secretariat at info@eu-patient.eu

EPF identified four objectives in our work plan for 2010 that relate to the strategic goals of our organisation:

- **Building Capacity** within the governance structures, the secretariat, and through reinforcing and extending the membership, and diversifying/solidifying funding (GOAL 1-5)
- **Strengthening Our Policy Impact** (GOAL 1-3)
- **Developing Project and Patients' Evidence and Expertise** to feed into policy (GOAL 1-3)
- **Building Powerful and Effective Communications** and **Partnerships** (GOAL 1-5)

EPF organised six significant meetings during the course of 2010. Our Annual General Meeting in Brussels in May elected new board members, and adopted important changes to the EPF Constitution to ensure EPF remains exclusively and essentially a patients' organisation, whilst collaborating closely with the whole spectrum of EU health stakeholders and allies who share our vision.

Linked to the AGM, our Health Technology Assessment (HTA) Seminar brought together some of the best experts across the European Union to discuss the importance of patients' involvement in HTA processes and to develop strategies with the EPF membership to ensure this happens in practice, systematically across the EU.

In June, in the framework of the Open Health Policy Forum, EPF coordinated a workshop on Cohesion Policy and Structural Funds, reflecting our concern that health and a strong patients' perspective becomes and remains a strong component in this key policy and funding area.

In September EPF, together with PGEU, the European organisation representing community pharmacists, held an event in the European Parliament in Brussels on the eve of the vote on Pharmacovigilance legislation, which focussed on important new provisions on direct patient reporting.

In October, our Annual Regional Advocacy Seminar took place in Budapest, Hungary. A major emphasis of the event was young patients' involvement in patients' organisations and youth/health policy. The Hungarian Secretary of State for Health made an important intervention on the forthcoming Hungarian Presidency. A specific workshop involving young patient representatives in Budapest developed the framework for EPF's new Youth Strategy.

On 1st December, during the Trialogue negotiations on the Draft Directive on Patients' Rights in Cross Border Healthcare (CBCH), EPF held a high level roundtable event under the patronage of the Belgian EU Presidency to examine the deal-breakers from the perspective of patients. Commissioner Dalli, three leading MEPs and high level representatives from the Belgian EU Presidency led the discussions.

Our flagship project 'Value+' on the meaningful involvement of patients in EU health projects and policies came to an end in January 2010 with the launch of the Value+ Model on meaningful patient involvement and a number of other resources for patients and the broader healthcare community. Much energy has been devoted in 2010 to maximising the political and practical impact of these tools, particularly with DG Research in the context of the Seventh Framework Programme (FP7) for Research, Development and Innovation, the Innovative Medicines Initiative and DG Information Society and Media, on eHealth.

2010 saw some very welcome developments in relation to EPF's policy priorities. Significant progress was made on dossiers such as Patients' Rights relating to Cross Border Healthcare, Patient Safety and Quality of Care, eHealth, and Health Inequalities. A major priority for us was to continue to provide input to the EU Pharmaceutical Package of proposals on Counterfeiting, Pharmacovigilance and Information to Patients and this report describes how far we came in 2010. Policy work in the areas of Health Technology Assessment, Personalised Medicines, Non-discrimination, Medical Devices and Clinical Trials were also high on our agenda throughout 2010 and will be upscaled in 2011 in the light of Commission focus on these themes.

The EPF Annual General Meeting outcomes reflected once again the huge importance of eHealth for EPF and our membership. During 2010 EPF was actively involved in the development of a Joint Action and Thematic Network on eHealth Governance, the eHealth User Stakeholder Group, the launch of the Renewing Health Project and preparing our own EU funded telehealth project 'Chain of Trust' that will be launched at the beginning of 2011.

Preparatory work also took place in relation to the FP7 funded project 'InterQuality' in which EPF is an associate partner that focuses on investigating funding schemes and incentive systems affecting the quality, effectiveness and equity of access to health care and develop effective models of healthcare financing . EPF will provide the patients' perspective on this highly timely, universally important project.

During the latter part of 2010, EPF coordinated a patient-led consortium in the submission of a proposal to the Third Call under the Innovative Medicines Initiative – Fostering Patients Awareness in Pharmaceutical Research.

Six new members were formally approved at the AGM, two more recommended for membership by the board, and we have membership requests from several others in process.

An evaluation survey took place with the EPF Membership in order to ensure EPF delivers the best we can for our member organisations and their patient representatives – and that they are able to contribute effectively their knowledge, experience and network to our collective work.

EPF representation in major EU level health Forums, Consultative Committees and Working Groups doubled in 2010, thanks in no small part to the Value+ outcomes. 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 European Medicine Agency (EMA) Management Board, the EMA Patient and Consumer Working Party and ad hoc EMA related activities. We also provided key advice to the Commission regarding the European Innovation Partnership on Active and Healthy Ageing and Innovation and Research.

EPF has participated once again, as speaker, chair or moderator in very many EU health meetings in 2010, 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 new income from the Commission for projects initiated in 2010 and new applications submitted in 2010 in the areas of public health, research, the Innovative Medicines Initiative 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.

We would like to thank sincerely 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 towards the next EU Programming period, and the EU strategy for the next decade EUROPE 2020 takes shape, 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 measurable progress in achieving patient-centred equitable healthcare throughout the European Union, and our contribution towards smart, sustainable and inclusive growth.

Anders Olauson
EPF PresidentEPF

Nicola Bedlington
Executive Director

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 2010

This non-exhaustive summary is based on the performance indicators and targets identified in the EPF work plan for 2010 for selected activities, to give a flavour of our work and impact.

EQUAL ACCESS FOR PATIENTS

Performance Indicator: *The degree to which EPF is able to influence the European Parliament and Council to support our proposals on information to patients.*

Our target was to ensure, alongside the current legislative proposal, to harness explicit support for a comprehensive information to patients strategy and Health Literacy. This was achieved through extensive advocacy work in the European Parliament (EP). The rapporteur Christofer Fjellner reflected this in his report to the EP that was adopted with a significant majority.

The Commission is now working on next steps with regard to the proposal and we will continue to dialogue with all three Institutions on this issue.

Performance Indicator: *The degree to which EPF is able to influence the European Commission (EC) and Member States (MS) represented in the Patient Safety and Quality of Care Working Group in ensuring a patient-centred and equitable approach in the discussions around Quality of healthcare.*

This has been achieved – the new forthcoming Joint Action on Quality of Care and Patient Safety has embedded patient involvement as a core concept and this will be evident in all of the work packages. EPF's central role in this new Joint Action has been welcomed.

INVOLVEMENT OF PATIENTS

Performance Indicator: *Analysis of the impact and added value of the Value+ deliverables, to ensure in the long term that meaningful patient involvement is systematically built in to calls for proposals for EU funded health projects, and that EPF tools are referenced.*

This has been achieved in relation to FP7 Health Research Calls for Proposals, where the following wording has been integrated in the text: 'The early involvement of patients and their advocacy groups in the planning, implementation, and monitoring of a clinical trial is considered important so that patients' needs are appropriately considered.' A specific link to Value+ resources is included in this text.

Continued efforts are needed in relation to the European Public Health Programme and calls relating to Information Society and Structural Funds.

Performance Indicator: *To be recognised as a key partner, alongside health stakeholders in determining civil society's input in EU health policy.*

This has been achieved in 2010. EPF has been extremely effective in the revised European Union Health Policy Forum (EUHPF), with the inclusion of EPF comments in all EUHPF positions and initiatives. EPF also played a very active role in the Open Health Forum.

PATIENTS' PERSPECTIVE

Performance Indicator: *The degree of uptake of the EPF Manifesto '150 Million Reasons To Act' in the new Commission.*

We now have a core group of trusted officials in DG SANCO, RESEARCH, ENTERPRISE, and INFORMATION SOCIETY. The new Commissioner for Health and Consumers, and the new Director General of DG SANCO have demonstrated strong support for the goals of EPF and our role as the interlocutor for cross-cutting issues affecting all patients.

SUSTAINABLE PATIENT ORGANISATIONS

Performance Indicator: *Perceived effectiveness of EPF's new outreach strategy and membership guide based on independent feedback by patient leaders of new EPF members, and direct commitment from health ministers in countries where newly formed umbrella platforms have emerged, to support their EU work.*

It is evident from the membership survey and from discussions we have engaged in with MEPs and national ministries that our efforts to support national patient coalitions are reaping dividends. There remains, however, significant work to ensure national coalition representation within EPF from all 27 countries of the EU.

Performance Indicator: *To demonstrate the importance of EPF as a credible, indispensable civil dialogue partner for all the EU Institutions, through a successful application for operational funding through the EU Public Health Programme.*

EPF made application for operation funding in 2010 for 2011. This was not successful, however, a great deal of discussion took place at the highest level on this issue and the criteria have been changed for the next call for proposals to enable us to meet the criteria in future.

Our dialogue with all of the Institutions was up-scaled in 2010, partly due to the impact of the Value+ outcomes.

PATIENT UNITY

Performance Indicator: *The expansion of EPF's membership by the end of 2010 by extending representation to a total of 46 members*

This was achieved – EPF welcomed six additional members taking the membership to 46. Several other patient organisations have applied or are in the process of applying to become part of EPF.

Performance Indicator: *The perceived success and impact of the Autumn Regional Advocacy Meeting taking place in Budapest, Hungary, through the extent of participation by 50 patient leaders from the region in subsequent EPF work on EU health policy issues.*

This was achieved – an extremely productive and intensive meeting gave both experienced and young patient leaders the opportunity to share their skills and knowledge. The seminar resulted in extensive networking and the foundations for a very strong youth group and strategy within EPF.

EPF GOVERNANCE

Membership

During 2010, EPF's membership grew to 46 members.

At the Annual General Meeting in May the following members were endorsed as full members following recommendation from the EPF board:

- Association of European Coeliac Societies (AOECS)
- European Parkinson's Disease Association (EPDA)
- Federation of Patients and Consumer Organisations in the Netherlands (NPCF)
- Fertility Europe
- Malta Health Network (MHN)
- The Coalition of Patients' Organizations with Chronic Diseases from Romania (COPAC)

The European Institute of Women's Health became an Associate member.

Two organisations were recommended by the board to become full members to be endorsed at the next Annual General Assembly:

- The Association for the Protection of Patients Rights in Slovakia
- The European Umbrella Organisation for the Psoriasis Movements 'EUROPSO'.

An additional five organisations, it is anticipated, will submit requests for membership in the very near future.

The EPF Board

In accordance with the EPF statutes and by-laws, Mike O'Donovan, Anders Olauson and Susanna Palkonen ended their two-year mandates as members of the Board. Anders Olauson and Susanna Palkonen stood for re-election with the new nominated candidates.

Anders Olauson thanked Mike O'Donovan very much for his enormous and valuable contributions to EPF as treasurer of EPF since 2006.

Panos Englezos withdrew his membership within EPF board and he was also thanked warmly for the contribution he had brought to EPF during his mandate.

Vida Augustiniene, Guadalupe Morales, Maria Navarro and Timo Nerkko are half way through their mandate.

Philip Chircop, Avril Daly, and Tomasz Szelagowski were elected as new board members.

Anders Olauson and Susanna Palkonen were re-elected and the board members elected them as President and Vice President respectively. Timo Nerkko was elected by the board as treasurer.

EPF Capacity Building and Development of the EPF Secretariat

The EPF Secretariat welcomed new team members in 2010 and said good bye to some close colleagues too.

Roxana Radulescu, Senior Policy Advisor, left EPF in May 2010 and was replaced by Kaisa Immonen-Charalambous. Kia Megas, Communication Officer, left EPF in December 2010 and a replacement will be sought in early 2011.

Zilvinas Gavenas continued to work with EPF as IT consultant/Webmaster. Liuska Sanna, who joined the team as Project Officer in January 2008, was promoted and began her role as Programme Manager in mid-2010. Nicola Bedlington continued as EPF Executive Director.

Our two interns Sabine Lobnig and Yves Brand, who worked with EPF in 2009/2010 on communications and policy, respectively, were replaced by Walter Atzori and Magdalena Machalska, who focused on programme and policy communications. A Research Secondee, Abinaya Rajan, joined us in October 2010.

Veronique Tarasovici joined EPF as Office manager in March 2010.

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 2009 accounts and these were presented at the Annual General Meeting in May 2010. These were then posted on the EPF website.

EPF policy orientation in 2010

EPF's work with the EU Institutions and Health Stakeholders in Brussels

EPF has been an active partner with the European Commission and the European Parliament on key policy dossiers in the course of 2010. We have also carried out important work with Member States' governments with a view of the EU Presidencies in 2011, and contributed to the work of the European Medicines Agency and a number of health-related forums, working groups and think-tanks.

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

Key achievements in 2010

Some of the key areas where EPF has achieved concrete results and successes this year towards our strategic goals include the following:

- **Cross-border healthcare:** EPF's close cooperation with key MEPs helped shape the Parliament's position, which was very strongly centred on patients' rights and the principles of equitable access, safety and quality. The final compromise agreed with Council is less ambitious but retains many aspects of EPF's position.
- **Information to patients:** our work with the rapporteur and shadows helped transform this legislative proposal from a rather narrow, commercially focused one into a more ambitious vision centred on the equal right of all patients to access good quality, comprehensive information on the medicines they take.
- **Pharmacovigilance:** EPF successfully called for greater patient involvement in medication safety, particularly the possibility for patients to report suspected adverse events directly to the authorities. This is included in the final legislative text and will now become EU law.
- **Patient involvement in healthcare:** EPF's sustained efforts in the recent years to promote patient empowerment and involvement are reflected in the goals of the Joint Action in Patient Safety and Quality of Care, which include specifically the promotion of patient empowerment and involvement in Member States.

Main policy areas for 2010

Patients' Rights in Cross-Border Healthcare

The proposal for a Directive on the application of patients' rights in cross-border healthcare was one of EPF's core policy dossiers since the Commission's original proposal published in 2008. During 2009 EPF had successfully campaigned to include many patient-centred amendments in the European Parliament's first reading position adopted in April of that year.

The Council remained very divided on the proposal, having blocked its progress in December 2009. Political agreement was finally reached at the end of the Spanish EU Presidency, in June 2010 and a common position adopted in September. The Council position rejected most of the amendments of the Parliament.

EPF continued working closely with the new Parliament rapporteur appointed for the second reading, French MEP Françoise Grossetête, and the shadow rapporteurs. As a result, her recommendation for the second reading drafted in October strongly reflected EPF's key messages.

Following intense negotiations, the EU Institutions finally reached agreement on 21 December 2010, thus avoiding a conciliation procedure and possible failure of the legislative proposal. The text was endorsed by the Parliament on 18 January and is pending formal adoption by the Council. The compromise is less ambitious than EPF and the Parliament would have hoped for, however it does create a legal framework codifying patients' rights into EU law. EPF believes that many aspects of the Directive can be built upon, particularly the basis it sets for European cooperation in the areas of quality, safety, Health Technology Assessment, eHealth and rare diseases.

In 2011 EPF will work with its member organisations to support the transposition of the Directive into national legislation and ensure the patients' voice is heard in that process.

EPF High-Level Roundtable on Cross-Border Healthcare

EPF has established a tradition of holding high-level events under the patronage of the EU Presidency, as exemplified by the Value+ conference in 2009. On 1 December 2010, on the eve of the negotiations between the EU Institutions, EPF organised a High-Level Roundtable on Cross-Border Healthcare at the Solvay Library in Brussels, under the official patronage of the Belgian EU Presidency. The keynote speech was given by the European Commissioner for Health and Consumers, Mr John Dalli, and the participants included key decision-makers and opinion-formers such as representatives of the Commission, the Parliament, several EU Member States, and leading stakeholder organisations. The event sent a strong message from a patients' perspective on key aspects of the proposed draft Directive, setting it in the wider context of equity, quality and safety of healthcare. A summary statement and a full report of the event were widely disseminated afterwards.

The EU Pharmaceutical Package

During 2010 EPF continued its advocacy work with the EU Institutions on the so-called "Pharmaceutical package", which includes legislative proposals on information to patients on prescription medicines, anti-counterfeiting, and pharmacovigilance. The Secretariat worked closely with the European Parliament through the rapporteurs, shadow rapporteurs, the secretariat of the relevant committees, and the coordinators of political groupings, to ensure that the patients' views were taken into account. EPF's work with the Parliament has been very effective, with much of our positions being reflected in the reports adopted by the Parliament.

Pharmacovigilance

Of the three proposals, the legislative process on pharmacovigilance reached its conclusion in September 2010, and the new legislation came into force in the beginning of January 2011. We are pleased that the final result reflects EPF's input to a great extent, including enhanced warnings for products under intensive monitoring; provisions for patients to report adverse events directly to their national authorities; and a forthcoming review of the user-friendliness of the product packaging and patient information leaflet. On 15 September 2010, EPF co-organised a lunch seminar in the European Parliament with PGEU (the EU community pharmacists' organisation), exploring the new rules and highlighting the opportunities for patients and health professionals to work together for better patient safety.

'*Working with EPF has been of immense value to PGEU – it has given us a comprehensive insight into the concerns of Europe's patients and the objectives of the patients' movement, something we believe no health professional can afford to ignore. EPF's thorough professionalism also makes the experience a pleasure.*", PGEU

Anti-Counterfeiting

On the anti-counterfeiting legislative proposal, EPF highlighted the need to tackle sales, including Internet-based sales, and called for patients' organisations' involvement in awareness initiatives targeted to the general public. We also called for mandatory safety features all medicines listed in a restricted list of products and that this list should be conceived and developed by the Commission and Member States in consultation with stakeholders. The report prepared by MEP Marisa Matias reflected to a great extent EPF's input. Unfortunately, the progress of this dossier was delayed in the autumn of 2010 due to difficulties in the negotiations between the Parliament and the Council, which at the end of January 2011 were not yet fully resolved. EPF continues to follow the dossier closely.

Information to Patients

The legislative proposal on information to patients and the public on prescription medicines proved quite controversial, and attracted divergent views both within and outside the Parliament. EPF achieved a very good collaboration with the rapporteur, Swedish MEP Christofer Fjellner, who really took on board the patients' perspective. In fact, his report managed to shift the focus of the proposal on the patients' right to access information – a substantial improvement over the Commission's rather limited original proposal.

Given the difficulty in achieving consensus in the Parliament on this dossier, EPF was broadly happy with the first reading position, adopted in the plenary session on 24 November with a strong majority. There is still some room for improvement in the current proposal to make it really work for patients, but that result bodes well for the next phase in the legislative process in 2011, where the Commission is required to put forward a revised proposal to the Council and Parliament. EPF will continue its work with all three Institutions and our members, to ensure that the new proposal reflects patients' needs and preferences within a broader EU strategy on health literacy.

Health Literacy

During 2010 EPF continued to follow up on the outcomes of the Spring Conference 2008 on Health Literacy, with the aim of making this a real priority at EU level and initiating a comprehensive strategy with adequate resourcing. Stronger political momentum has been created this year to promote health literacy by several interlinked initiatives: the legislative proposals on information to patients and counterfeit medicines, the new draft legislation on pharmacovigilance and cross-border healthcare, the Commission's Communication on health inequalities, and continuing work in the area of eHealth. In our involvement in all of these policy areas EPF has continued to include our key messages on health literacy. Notably, on the information to patients' dossier, the rapporteur Mr Fjellner has echoed our call and asked for the Commission to submit a separate proposal on an EU-wide strategy on information to patients and health literacy.

We will continue our strategic campaign work on this topic in 2011, particularly in the context of the next stage of the information to patients proposal and preparatory work on the next EU health programming period.

Tackling Health Inequalities from the Patients' Perspective

The reduction of health inequalities is a major pillar of the EU Health Strategy, "Together for Health". Following the adoption of the Commission's Communication "Solidarity in health: reducing health inequalities in Europe" in 2009, EPF has continued to present a patients' viewpoint on health inequalities, linking it with our work on health literacy, in an effort to provide a complementary perspective to the emphasis on prevention which has dominated the political debate.

EPF provided specific input to the European Parliament's non-legislative report on health inequalities, drafted by Portuguese MEP Edite Estrela in November 2010, and some of our proposed amendments were tabled by MEPs for the plenary vote scheduled for early 2011.

Health inequalities were also strongly present in our work on EU Cohesion Policy and Structural Funds during 2010. The Commission has stated that it will support Member States in actions on tackling inequalities through Structural Fund monies (see on the next page).

Health and Cohesion Policy

Throughout 2010 EPF has played an active role in the Cohesion Policy area, particularly in the context of the debate around the fifth reform of the Structural Funds for the 2014–2020 programming period. EPF has made an important contribution towards raising awareness of the importance of including health among the list of future Structural Funds' eligible investment priorities, but also towards ensuring that such investment is aligned with needs and requirements of local healthcare systems and provides an effective contribution in terms of health gains for all citizens and patients. A key milestone in this respect was the EPF's organisation of a workshop on this topic in the context of the 2010 EU Open Health Forum (see box below).

Building upon the results of the work done in this area in 2010, EPF will continue to advocate for the

Workshop: Positioning Health at the Centre of the 2014-2020 Cohesion Policy

On June 30th EPF organised a workshop around the overall theme "Positioning Health at the Centre of the Post-2013 Cohesion Policy" in the framework of the 2010 Open Health Forum. The workshop looked at reconsidering the role of "Health" as a key element for supporting economic, social and territorial cohesion across Europe and exploring ways to integrate Health into sustainable regional development frameworks through the Structural Funds in the 2014-2020 programming period.

One of the main lessons we have learnt in this workshop is that using Structural Funds to invest in Health does not necessarily lead to health gains. Health investments have the most impact when they are effectively integrated into a regional master plan and strategically geared towards the needs of local citizens and patients.

The workshop also recalled the importance for national authorities to consider setting up a specific operational programme for health, but also to take action to effectively integrate health considerations in all other sectoral operational programmes (health mainstreaming) through health assessment of all programmes.

The workshop was a valuable contribution to the emerging debate on the future of the Cohesion Policy, by stimulating the effective exchange of views on how to turn Cohesion Policy into one of the most important drivers for reducing health inequalities between and within countries and regions and ensuring a more sustainable approach to healthcare services provision throughout the EU.

A full report on this workshop is available on the EPF website.

inclusion of health as a priority for Structural Funds spending. To this end we will seek cooperation with other health stakeholders at EU level and the active engagement of national patient organisations whose contribution and commitment will be crucial in ensuring the uptake of health in future national and regional operational programmes implementing the EU Cohesion Policy.

Patient Safety and Quality of Care

Patient safety and quality of care is at the heart of EPF's work and one of the priority areas in our Five-Year Strategic Plan adopted in 2007. We are active through our participation in the Commission's Working Group on Patient Safety and Quality of Care, as partner in a proposed Joint Action, as well as other relevant initiatives and projects.

Working Group on Patient Safety and Quality of Care

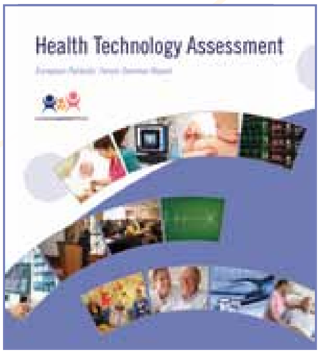
Since the adoption of the Commission Communication and Council Recommendation on patient safety in 2009, the Commission working group on patient safety finished its mandate, and a new working group was set up. The new working group advises the Council's Working Party on Public Health at senior level on patient safety, but with increasing focus on the quality of healthcare. EPF continues to represent a patients' perspective in this new working group. During the year, we contributed notably to a Commission draft reflection paper on "Quality of Healthcare: Policy Actions at EU Level", which outlines some specific objectives for improving the quality of healthcare in the EU. EPF emphasised the need for a patient-centred approach and for patients' meaningful involvement in safety and quality policies, as well as the importance of patients' health literacy. We were pleased that these aspects were included in the paper.

As a result of the draft reflection paper, the Commission and Member States decided to set up a proposal for a Joint Action to promote cooperation among Member States and stakeholders for improved patient safety and quality across the EU. EPF was invited as a partner in this Joint Action that, if successful, aims to start at the end of 2011. (See section on projects below.)

EPF also furthered cooperation with the WHO European regional office, in the context of an initiative on patient safety and patient empowerment. The first meeting for this initiative took place in November 2010.

Health Technology Assessment

EPF organised a highly successful seminar on Health Technology Assessment for its members and patient group allies in May 2010. The report from this meeting was widely circulated, and EPF followed up with a survey with HTA agencies to determine good practice in patients' meaningful involvement in HTA practices, to support our members' advocacy work in this arena. The survey will address also patient organisations and decision-makers in 2011 to ultimately produce a state of the art of patient involvement in HTA in Europe and a tool to support and strengthen this involvement.



EPF has also been actively involved in the EUnetHTA project focussing on Member State collaboration in HTA, through the Stakeholder Forum. Plans are underway to get involved in a new Joint Action on HTA where patient involvement will be a core component. The adoption of the cross-border healthcare Directive, that includes an article on HTA and the importance of stakeholder involvement in HTA processes provides new impetus in this arena.

Clinical Trials

The effectiveness of clinical trials throughout the EU is of fundamental importance for EPF and its members. EPF is working closely with the EU institutions and other relevant stakeholders to achieve patient-centred EU legislation on clinical trials.

Review of the EU Clinical Trials Directive

In January 2010, based on a member consultation in late 2009, EPF responded to the Commission's public consultation on the impact and functioning of the Clinical Trials Directive (2001/20/EC). Our response focused on the key patient issues that did not feature in the consultation paper but should, in our view, be included in the review of the Directive, namely:

- Ensuring meaningful patient involvement across all aspects of clinical trials, so that they are centred on patients;
- Giving patients access to quality information regarding clinical trials;
- Transparency concerning the results of clinical trials (even failed trials);
- Meaningful informed consent especially regarding patients from the mental health arena.

Following the consultation, the Commission published a Roadmap for the review of the Directive, which was given increased impetus by the adoption of the EU Pharmacovigilance legislation at the end of 2010. In 2011, EPF will continue to work with the Commission to ensure that the review of the Directive puts patients at the centre and resolves some of the acknowledged loopholes and hurdles of the current text.

Working Group on Clinical Trials in Third Countries

Since March 2009, EPF has participated in a working group at the European Medicines Agency on clinical trials in third countries. The aim of this working group is to develop practical proposals for guidance regarding ethical standards required for clinical trials conducted outside the EU submitted in the context of EU marketing authorisation.

EPF contributed to the drafting of a reflection paper on "the ethical and GCP aspects of clinical trials conducted in third countries for evaluation in marketing authorisation applications for medicines for human use, submitted to the EMA", working closely with the two other patient organisations, International Alliance of Patients' Organizations (IAPO) and European Aids Treatment Group (EATG). Patient groups' concerns centred on the need for comprehensive information to patients and their families participating in the clinical trials, meaningful informed consent, the transparency of clinical trials procedures, and effective sanctions to combat unethical research. The draft paper was put to a public consultation in September, to which EPF contributed feedback from a consultation of our membership and the EPF Policy Advisory Group. EPF also participated in a workshop at EMA to discuss the results of the consultation and the next steps.

The working group will continue its work in 2011 with a view to finalising the EMA guidance and proceeding to its practical implementation, and EPF will continue to represent the interests of patients in this process.

Medical Devices Exploratory Exercise

During the late 2009, EPF participated in an exploratory exercise set up by the European Commission on the future of the medical devices sector, with three main work areas:

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

The final meetings took place in January 2010, and the process ended formally with the publication of a report with recommendations for future directions for medical devices in Europe, both from a competitiveness and public health perspective. EPF contributed core issues of importance to patients, particularly linked to information, quality and safety, to the report. Based on this, the Commission in the course of the year prepared a "roadmap" document for the recast of the EU legislation governing medical devices and in vitro diagnostic medical devices. This will be led by DG SANCO and expected to be adopted in early 2012. EPF will continue to be closely involved in this process during the course of 2011.

Ageing and the Needs of Older Patients

In the latter part of 2010, the EPF Board approved the development of a strategy for the needs of older patients as a complement to EPF's new youth strategy, with the aim of enhancing intergenerational solidarity in the patients' movement. Specific anchor-points at EU level are provided by the adoption in December 2010 of a pilot European Innovation Partnership on Healthy and Active Ageing, and the decision to adopt the year 2012 as the European theme year for active ageing.

We initiated our work in this arena with a member consultation during December 2010 and January 2011, resulting in a strong patients' contribution to the Commission's consultation on the Innovation Partnership. EPF will continue this work in 2011 by taking an active role in the Innovation Partnership and through a planned high-level conference under the Polish EU Presidency centred on older patients with chronic diseases.

Platform on Access to Medicines in Europe

On 23 September 2010, the Commission (DG Enterprise) launched an Initiative on Corporate Responsibility in the Field of Pharmaceuticals, as a follow-up activity to the Pharmaceutical Forum (2005–2008). The initiative focuses on the entry on to the market of medicines after the granting of EU marketing authorisation, and aims to adopt a balanced approach to address both societal and industrial challenges. The work will be done through three independent "platforms": ethics and transparency; access to medicines in developing countries; and access to medicines in Europe.

The first platform to be launched was the Platform on Access to Medicines in Europe, in which EPF was invited to participate as a stakeholder organisation. The Platform aims to enhance fair and timely access to medicines within the existing legislative and regulatory framework. In practice, it will work through a number of projects. EPF is a member of the Steering Group, which includes representatives of the EU and European Free Trade Association (EFTA), Member States and stakeholder organisations, and has an overall coordinating role. For each specific project, we invited expressions of interest among our membership as we believe patient representation in each project is fundamentally important. Two coordination meetings of the Steering Group took place in late 2010, but the much of the work will be done during the next two years until the end of 2012.

DG SANCO Data Partnership

EPF participated in a workshop organised by DG SANCO on 17 March 2010, in a follow-up of an internal reflection process of the Directorate-General in 2009 known as the "Data strategy project". The objective of the Data Strategy is to ensure that DG SANCO uses the most efficient processes and the best possible quality of evidence, throughout its policy-making and for its impact assessments. The participants exchanged views on data-related challenges, such as the different capacities of stakeholders to produce, collect and access data, the need to respect confidentiality, the need for clear quality indicators, transparency, and other views.

Although there was no further progress on the part of the Commission this year, EPF will follow the initiative and prepare a response to an eventual public consultation with our members, reflecting the best options from a patient organisation's perspective for easier access and use of data for future initiatives.

Cooperation with the European Medicines Agency

EPF continued to provide active input to the work of the European Medicines Agency (EMA), notably through the direct involvement of Susanna Palkonen, EPF's Vice President, in the Patients' and Consumers' Working Party of the Committee on Human Medicinal Products (CHMP/PCWP) and through the EPF patient representative on the EMA Management Board, Mike O'Donovan.

EPF is also a regular invitee to ad hoc working groups on specific topics, such as the working group on third country clinical trials (see clinical trials, above) and the new working group on the Eudravigilance database (below). We also continued to contribute to the quality review of documents aimed at patients and consumers (product information leaflets). In 2010 EPF identified three new patient representatives among our membership to take part in the annual training of patient experts, which took place in London in December. The training enables patients and patient organisation representatives to contribute to the Agency's work.

EMA Road Map to 2015

In April 2010 EPF contributed to a public consultation on the EMA Road Map to 2015, titled "the Agency's Contribution to Science, Medicines and Health", setting out the Agency's long term strategy while taking into consideration the main drivers for change and future challenges.

Implementation of the EMA Access Policy regarding the Eudravigilance database

Eudravigilance is the centralised European database of adverse drug reactions. The role of this database is significantly strengthened as a result of the new EU Pharmacovigilance legislation adopted in December 2010, and it will become the single repository of data concerning adverse reactions across the EU.

The EMA is currently in the process of implementing an Access Policy with the aim to make the information contained in Eudravigilance accessible to the public, including patients and consumers. The policy was finalised in April 2010, and a "Eudravigilance Users Group" with patients, consumers and healthcare professionals was established to prepare the practical implementation of this policy. EPF represents the interests of patients in the group. We believe it is vital to ensure that access to Eudravigilance meets the real-life needs of patients, and that appropriate guidance is made available to enable patients and their families to interpret the information in the database. If properly implemented, this will be a key resource for all patients' representatives. EPF will continue participating in the working group during 2011.

European Commission high-level groups, working groups and platforms

Participation in working groups and discussion platforms provides an important regular opportunity for EPF to put forward a patient-centred perspective in the developments in various policy areas, and to reinforce our key messages on topical issues.

In 2010, EPF continued its active contribution to a number of Commission working groups, such as the Patient Safety and Quality of Healthcare working group (see patient safety, above), the e-Health Users Stakeholders Group, and the editorial board of the EU Health Portal. EPF also continues to participate in the European Union Health Policy Forum (EUHPF), which meets twice yearly. We also participated in a number of health-related think tanks and advisory panels, including stakeholders groups linked to the Innovative Medicines Initiative, the European Federation of Pharmaceutical Industry Associations (EFPIA) patients' think tank, the EUROPABIO patient's advisory group, and the Centre for Health, Ethics and Society (CHES). The EPF President is a member of a high-level group for health research within the Seventh Framework Programme on research and development, set up by the Commissioner for Research.

Political work with the European Commission and European Parliament

The new Commission

2010 saw significant changes in EU politics, with the entry into force of the Lisbon Treaty at the end of 2009, a new European Commission (Barroso II), and changes in high-level Commission posts. In addition, the European Parliament is relatively new, having been elected in June 2009.

EPF has established a fruitful dialogue and constructive working relations with the new European Commissioner for Health and Consumers, Mr John Dalli, who has committed himself to "putting patients and consumers first" and to make a case for health in all policies among his colleagues in the Commission. Close contact has also been established with the new SANCO Director General, Mrs Paola Testori-Coggi.

EPF has used the Manifesto "150 Million Reasons to Act" to support our work with the new Commission, both at college level and with the new hierarchies and key players in the relevant Directorates General. EPF was given the opportunity to present alongside Commissioners and Health Ministers at several political meetings, enabling us to stress our vision of high quality patient-centred healthcare at the highest levels.

One of our overriding policy goals is to promote the involvement of patients' organisations in EU health-related projects and programmes, and we have continued to work with a range of Commission Directorates, including Health (SANCO), Research (RDT), Information Society (INFSO), Regional Development (REGIO), and Enterprise (ENTR), in the spirit of "Health In All Policies" (health mainstreaming).

In particular, our sustained work with DG Research has been fruitful: patient involvement now becomes a criterion in some new calls for proposals under the 7th Framework Programme.

EPF was also invited to provide a patients' perspective in a workshop on personalised medicine at the European Health Forum Gastein in October. Personalised medicine is likely to become a major focus of EU health policy in the near future, and so it is particularly important that a patients' perspective is incorporated from the outset.

EPF will continue to work proactively with DG Research and SANCO in this arena during 2011 and will contribute to a major conference around this theme to be organised by DG Research.

"In 2010, EPF has been a particularly active stakeholder in the preparation and running of EU actions on health, for instance on eHealth and HTA cooperation. EPF helps us by providing the Commission with an overall patients' organisations' view and facilitates the communication with more disease-specific patients representatives"
- Senior Commission Official

The European Parliament

During 2010, EPF continued to reinforce relations with key MEPs already established as "patients' champions" – notably through our work in 2009 on the Health Literacy written declaration and the EPF Patients' Manifesto – but also reaching out to new MEPs. Over 100 MEPs are committed to the work of EPF in the European Parliament.

We have chosen not to set up an interest group or 'intergroup' in the Parliament, but rather aim to secure a strong on-going relationship with highly committed MEPs from across the political groupings, to enable us to be highly effective in our advocacy on specific health-related policy issues. We continue to use the EPF Manifesto "150 Million Reasons to Act" as a tool to ensure as much political support as possible from MEP's for a patients' perspective in EU health policy developments.

" EPF is highly present at very many of the Forums I am also involved in, leading the fight for patients' rights and patient centred, equitable health care". Antonyia Parvanova, MEP

The Council and EU Presidencies

EPF aims to establish a close relationship with each upcoming EU Presidency, and we have liaised closely in 2010 with Spain and Belgium, which held the Presidency in the first and second half of the year respectively. We attended a number of high-level health meetings and conferences to reinforce the visibility of patients, and contributed input from a patients' perspective in relation to key health policy initiatives addressed by the Presidencies. Our Patients' Manifesto continues to be an important tool in this dialogue.

In 2010, EPF participated among others in the Spanish Presidency's conferences on eHealth and patient safety, and Belgian Presidency conferences on chronic diseases and innovation as we organised our own high-level event on cross-border healthcare under the patronage of the Belgian presidency. Also, we established links with Hungary and Poland, which are holding the Presidency in 2011, with a view in particular towards promoting the rights of older patients through a major conference under the Polish presidency.

The EPF Policy Advisory Group

The Policy Advisory Group met twice in 2010, in April and in September. The group was set up in 2009 to advise the EPF Board and Secretariat on policy topics prioritised by EPF's Annual General Meeting which, because of their complex, controversial and/or highly political nature require detailed and in-depth discussion and input from members.

The Policy Advisory Group contributes to EPF's member consultation procedure, particularly in the formulation of a first draft, identifying key issues and indicating areas where member input is crucial. The group also occasionally contributes expert knowledge on specific issues where it is not possible to undertake a full member consultation due to time limitations, and identifies emerging policy issues that are of importance to EPF's member organisations.

The Policy Advisory Group currently has 11 members, who are elected representatives or staff members of EPF member organisations that have a particular expertise in the policy areas EPF is working on. In 2010, the Policy Advisory Group discussed and provided input on the following topics:

- the Commission's draft reflection paper on Patient Safety and Quality of Care;
- the legislative proposals of the "pharmaceutical package";
- funding opportunities for patient organisations and ways of building up on the achievements of the Value+ project;
- the EMA public consultation on the draft reflection paper on third country clinical trials; personalised medicine; and
- EU Structural Funds and cohesion policy.

Harnessing the Patients' Evidence Base

Key achievements in 2010:

- Strengthened patient perspective in the area of eHealth, telemedicine and telehealth as well as evidence on patients' needs that EPF can feed into policy work
- Increased awareness and understanding amongst health stakeholders of the concept of meaningful patient involvement particularly in the research area
- Initial developments around the establishment of an EPF Youth Strategy
- Improved advocacy capacity of and networking between patient organisations in a number of Member States and stronger links between them and EPF established.

Renewing Health

2010 has seen the launch of a new project called "RENEWING HeALTH" in which EPF is participating as associated partner. RENEWING HeALTH aims at implementing 26 large scale real-life pilots in nine European regions for the validation and subsequent evaluation of telemedicine services for the remote management and monitoring of patients suffering from diabetes, Chronic Obstructive Pulmunary Disease (COPD) and cardiovascular diseases (CVD), using a patient-centred approach and a common rigorous assessment methodology called MAST.

EPF is involved together with the European Health Telematics Association (EHTEL) in the management of the project's User Advisory Board (UAB), whose primary mission is to operate as a standing advisory committee for the consortium to advise and provide ongoing feed-back on the needs of current and future users of the piloted telemedicine services (i.e. mainly patients and healthcare professionals, but also health authorities).

A major achievement in 2010 was the establishment of this UAB with a broader membership than initially expected consisting of 15 pan-European organisations representing different groups of telemedicine users, including representatives of the leading pan-European patient organisations representing patients with the three abovementioned diseases. The UAB met twice in the second part of 2010.

Another important milestone was the production of the "User Requirements" document, providing for a collection of needs and requirements of users of telemedicine services as identified in the literature. This document will serve not only as a reference framework for the representation of user needs and requirements by the UAB and the assessment of the extent to which have such requirements been taken care of in the various pilot sites, but also for providing recommendations for the revision of the assessment methodology at the end of the project.

In 2011 EPF will work to bring the UAB closer to the patients involved in the pilots by means of meetings with local users and holding a regional meeting of the UAB in one of the pilot sites. The goal is to validate and refine the "User Requirements" document on the basis of evidence and feedback from the users involved in the various pilot sites.

Regional Advocacy Seminar

EPF held its third regional advocacy seminar in Budapest, Hungary on 25-27 October 2010. Co-hosted by the Hungarian Osteoporosis Patient Association (HOPA) this seminar involved 50 patient leaders from Hungary, Czech Republic, Estonia, Lithuania, Bulgaria, Romania, Poland, Italy, Greece and Portugal.

EPF 2010 advocacy seminar's overall theme was the promotion of the involvement of young patients in patient organisations in order for them to become strong patient advocates. The key feature of this seminar was the participation of an equal number of senior and youth representatives aged between 15 and 25 years.

The seminar had three major objectives, namely a) promoting stronger participation of young patients within patient organisations, b) strengthening capacity building for patient organisations' leaders on how to work and get involved in EU-level policy-making, particularly by working together in national coalitions, c) brainstorming on an EPF Youth Strategy to be launched in 2011 with the youth representatives.

The seminar has been very successful in enhancing participants' communication and advocacy skills to influence policies that affect their lives but also the lives of their communities, but also in raising the awareness about benefits of involving young patients in patient organisations.

The key challenge for 2011 will be to capitalise on the outcomes of this seminar by developing and implementing a Youth Strategy whose purpose should be to enable EPF to recognise, understand and thus meet young patients' needs and expectations. Through this strategy EPF will try to ensure that a youth perspective is strategically integrated in our future work plans and, in the longer run, that young patient representatives are given effective representation in the EPF governance structure.

Value+ Project Follow-up

In early 2010 we completed the project Value+ 'Promoting Patients' Involvement in EU-Supported Health-Related Projects'. Value+ aimed to exchange information, experiences and good practice among patients' organisations and other key stakeholders to encourage the meaningful involvement of patients' organisations in EU-supported health projects at EU and national level. The results of the projects have been widely disseminated to a broad health-related audience through the project flagship deliverables: (1) a Resource Kit for patient organisations to facilitate patient involvement in future projects, (2) a Handbook for project leaders and promoters, (3) Policy recommendations for policy makers.

A very important development in relation to the impact of Value+ is represented by the close cooperation that EPF has established with DG Research with regard to the promotion of patient involvement in the research field. Following recommendations of the project the Framework Programme Work Plan 2011 has included an explicit mention on the need to involve patient organisations in relation to clinical trials projects. EPF has liaised with the FP7 National Contact Points (NCPs) to raise their awareness on the concept of and available tools for fostering meaning patient involvement and we made interventions and set up a stand in the FP7 Health Research Info Day held in Brussels on 8th June 2010. Further cooperation has taken place in the NCPs meeting in the autumn and it will continue at their networking meeting in March 2011. More activities are envisaged and being explored with DG Research.

CALLIOPE Project

CALLIOPE has been set up by the EU-funded Thematic Network «CALLIOPE - Creating a European coordination network for eHealth interoperability implementation». The project launched on June 2008 has seen its completion. The main goal of the CALLIOPE Network was to produce value for decision makers for national eHealth implementations.

The Network has established a successful collaborative platform for many actors in eHealth interoperability in Europe and EPF has been involved from the onset to integrate a patient perspective. The project main achievements have been the creation of a good cooperation mechanism between the network members that include Member States and eHealth stakeholder organisations and building an eHealth Interoperability roadmapping process.

eHealth Joint Action and Thematic Network

eHealth has seen major progress in 2010 in the development of a Joint Action and of a Thematic Network to support the eHealth governance established by Member States. The main purpose of this initiative is to contribute to the European e-Health Governance Initiative by supporting cooperation between Member States at the decision makers and political governance levels including their relationship with the e-Health Stakeholders Groups.

EPF has been involved in the development of this initiative which will be launched in early 2011 and we will be playing an active role in most of the working areas related to the legal framework, semantic and interoperability issues, roadmapping and mainstreaming and developing trust amongst eHealth users.

Chain of Trust

An important achievement of this year was the co-funding from the Public Health Programme of the project 'Chain of Trust' that EPF developed, in cooperation with partners from the health professional field and interested members. The project focuses on building confidence and acceptance of telehealth solutions among patients and health professionals. The project will be launched in early 2011.

RESPECT Project

EPF had continued its participation to a research project called 'RESPECT' - Relating Expectations and Needs to the Participation and Empowerment of Children in Clinical Trials, under the Seventh Framework Programme for Research and Development. The project explores the expectations and needs of children and their families in relation to clinical trials for new drugs in Europe and how this should be translated into empowering and motivating participants in future clinical trials research.

In 2010 EPF has consolidated the findings of a survey with patient organisations and has held a workshop to explore the expectations of patients and parents. As a result of this work we have undertaken developing a model of empowerment for participants to paediatric clinical trials that will be finalised in early 2011.

EUNetPaS

EUNetPaS
European Union Network for Patient Safety

The European Network for Patient Safety (EUNetPaS) project, in which EPF was an associate partner, came to an end this year. The project was funded by the EU Health Programme 2007 call. It was coordinated by the French National Authority for Health (HAS) . The project started in February 2008 for a duration of 30 months.

The aim of EUNetPas was to establish an umbrella network of all 27 EU Member States, international organisations, and stakeholders in the field of healthcare to enhance collaboration in the field of patient safety. The achievements of this project included a number of resources and practical tools, including a tool to measure patient safety culture, guidelines for education and training, a virtual library of European reporting and learning systems and recommendations on medication safety. National Patient Safety Platforms were established in 13 EU Member States.

EPF worked closely with our partners in work package 2 and contributed to the preparation of a Guidelines document on "Education and training in patient safety", which aims to support healthcare providers at national and local levels to design, establish and evaluate training interventions in patient safety. EPF was also involved in the evaluation of the project.

We were pleased to see the progress that was achieved by the project; however, the experience also demonstrated the enormous differences in the level of patient engagement across Europe: in many Member States there is little involvement, and little knowledge about ways to be involved. For this reason we were delighted to be invited as partners in a forthcoming Joint Action, that will continue the work of EUNetPas and includes as a specific objective the promotion of patient involvement and empowerment.

Joint Action on Patient Safety and Quality of Care

Building on the achievements of the EUNetPas project, a plan was put forward in 2010 for a Joint Action in Patient Safety and Quality of Healthcare. EPF was invited to participate as a stakeholder organisation. This Joint Action has a triple objective: to implement the Council Recommendation on patient safety and create a sustainable platform for cooperation between Member States; to initiate cooperation in the area of quality; and to facilitate the exchange of good practices in patient involvement and empowerment. We are particularly pleased that the council has recognised the importance of patient engagement in safety and quality initiatives.

Preparatory work started during the second half of 2010 between the Commission, Member States and stakeholders, with a view to submitting the proposal in the 2011 call under the Public Health Programme. If successful, the Joint Action will begin its work at the end of 2011 or in early in 2012 and is expected to last three years. If realised the Joint Action will provide an important platform for EPF to voice the perspective of patients and for the promotion of concrete measures towards greater patient empowerment and involvement in healthcare across the EU, both at individual and collective levels.

EPF – GROWING THE EPF MEMBERSHIP AND RESPONDING TO THEIR NEEDS

EPF's membership grew from 42 to 46 members in 2010. 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 2011.

An EPF Membership Guide has been produced to support current and potential new members and is available on the EPF website.

Following a decision at the Annual General Meeting, EPF also organised an in-depth membership survey during the autumn, in order to glean a better understanding from our members on what they need and want from EPF, and how they can best contribute. We have fed the outcomes of this survey into our work plan for 2010 and our communication strategy.

EPF – WORKING IN PARTNERSHIP

EPF Alliance Building and Representation at external meetings during 2010

EPF was represented by its board and Secretariat as speakers, moderators or chairs at over 60 European health-related meetings during 2010. 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:

- DIA (Drug Information Association) 22nd Annual Eurometeeting, Monaco, February 2010
- IAPO Global Patients' Congress, Istanbul, February 2010 – Presentation of Value+
- High-level eHealth Conference under the Spanish Presidency, Barcelona, March 2010

- European Patients' Rights Day, European Parliament, Brussels, April 2010
- Innovation in Healthcare from Research to Market Brussels, May 2010
- International Patient Safety Conference, Madrid, June 2010
- FP7 Open Information Day, Brussels June 2010
- Global Health Conference, Brussels June 2010
- Innovative Medicines Initiative Stakeholder Meeting Brussels, June 2010
- Open Health Forum, Brussels, June 2010
- Women's Health – Seminar on Gender and Health Brussels, July 2010
- Belgian Ministerial Conference – Innovation and Solidarity Conference Brussels, September 2010
- European Health Forum Gastein, Bad Hofgastein, 6-9 October 2010
- Power of embedded mHealth Solutions GSMA Europe, Brussels, October 2010
- Microsoft Government Leaders Conference, London, October 2010
- Belgian Presidency Ministerial Conference "Innovative Approaches to Chronic Illness", Brussels, October 2010
- "Health network in Europe: the ENRICH experience ", Brussels, October 2010
- EPPOSI Workshop, Patient involvement in HTA, Brussels, November 2010
- EHTEL–AER–EUREGHA Annual Symposium "E-health in the regions: Acting for Citizens' Health", Committee of the Regions Brussels, November 2010,
- "Challenges in European RTD Health Programmes", Regione Lazio Representation, Brussels
- December 2010 EMA Topra Conference, London, December 2010
- EMA Scientific Conference, London December 2010.

EPF ALLIANCE BUILDING

In 2010, EPF continued to place much importance in fostering alliances and good working relations with European organisations with which we have a common agenda. These include the European Public Health Alliance (EPHA) – we attended EPHA's AGM and an EPHA representative participated in our seminar in Budapest, the European Standing Committee of Doctors (CPME), the European Federation of Nurses' Associations (EFN), the Pharmaceutical Group of the European Union (PGEU), European Hospital and Healthcare Federation (HOPE), 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 partnering with EPF in our new EU funded project 'CHAIN OF TRUST'

We also continue our close relationship with our sister organisation at international level, the International Alliance of Patients' 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 led a session at the IAPO Global Patients' Congress in Istanbul in February 2010 on Value+ and meaningful patient involvement.

In 2010, we have strengthened our relationship with consortia such as CONTINUA in relation to eHealth, and Federations such as EDMA, COCIR and EUCOMED in relation to medical devices. We are also starting to work with GSMA-Europe, the European interest group of the international wireless operators association. EPF was invited to participate and speak in a number of events organised by GSMA Europe around mobile Health solutions for the remote management and monitoring of patients.

In 2010 we have started to cooperate with major pan-European networks of regions and health authorities such as EUREGHA the European association of regional and local health authorities, 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 also continued our dialogue with pharmaceutical companies on an individual basis, in accordance with our Code of Ethics, and through EFPIA the European Federation of Pharmaceutical Industries and Associations.

"Just like policy-makers, pharmaceutical companies need to do a better job at including the perspective of patients. EPF has steadfastly challenged our company to improve how we conduct research and develop medicines, and they've gained our respect by engaging in candid and open dialogue, while building credible alliances with a variety of different groups. Over the years, EPF has raised the standards of excellence for patient advocacy in Europe, and we're proud to be one of their partners." An EPF sustainable partner.

EPF KNOWLEDGE MANAGEMENT AND COMMUNICATIONS in 2010

Our new website, launched in February 2010, is easier to navigate, more accessible, more up to date, and reflects the dynamism of our growing organisation. It has been very positively received by EPF members and external audiences alike. The website complies with the Health on the Net Code of Conduct (HONcode) for medical and health websites. EPF Website

Displaying: Clicks from: All Visits with more than: 0.00%

New EPF Website has an external Website analysis system. According to the latest data EPF Website has an average 700 hits a day. Every visitor spends approximately 3-4 mins online and visits at least 5 different sections of the Website.

Most popular sections are About EPF, Initiatives and Policy, EPF mailing, Members.

Website has been visited from more than 70 countries, which speak more than 30 different languages: Belgium (25%), UK (10%), France, Netherlands, Germany, Italy, Poland. As well as the USA, Australia, India.

Most of the visitors are forwarded to EPF website using the Google search results, as well as various online articles, linked EPF Members' websites or other external documents.

Collected visitors' data is also being used to improve our present website. Like screen resolutions, internet browsers or internet connection speed are taken into account when EPF upgrades website functionalities.

Because of the trained staff, respective website sections on the new website are updated more frequently.

www.eu-patient.eu

EPF continues to produce and distribute its EPF Mailing every six weeks. The mailing is sent out to more than 3000 individuals which include our members and the EU health policy community as a whole. The Mailing includes policy and project updates, events and conferences and a new section added in 2010 on member news. It is also available on the website. According to our membership survey the Mailing is an extremely useful tool, but further efforts should be made to make it as accessible as possible.

The EPF Mailing has proved also to be a very effective external communication tool, relaying EPF's perspective and our on-going campaign and advocacy work on key health dossiers.

In 2010, EPF continued to build a close relationship with relevant media to enhance and promote EPF's activities and position, using our expanded media contact list comprising EU, international medical, healthcare IT and national medical and health reporters.

EPF also undertook extensive media work around the events we organised in 2010 with increasing resonance in EU and national health-related press.

In 2009, the EPF Membership Guide was launched 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 is an on-line tool and was updated in 2010.

Regarding social media, the board has agreed a step-by-step approach: we will use our new e-platform of young patients as a testing ground to establish the degree to which EPF engages in social media in the future, balancing the importance of this growing communications medium with resource implications. During 2010, EPF also extended its video streaming of key events and YouTube links.

DIVERSIFICATION AND SUSTAINABILITY OF OUR FUNDING BASE 2010

EPF is highly committed 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 organisations' annual turnover.
EPF received significant income from Commission funded projects in 2010, such as RESPECT, RENEWING HEALTH. We also received confirmation that the CHAIN OF TRUST, an EPF coordinated project was approved and will commence in 2011. Another important research project in which EPF is an associate partner was also approved: INTERQUALITY will begin in 2011 although significant preparatory work took place in 2010.

During the course of 2010 EPF allocated considerable resources to apply for Commission funding for projects that contribute to our policy objectives, through the Public Health Programme, information society, research, and the Innovative Medicines Initiative.

We have been extensively involved in the preparation for a Joint Action/Thematic Network on eHealth Governance – a project involving the EU member states and other stakeholders that will also begin in 2011. Preparatory work has also taken place on Joint Action on Quality of Care and Patient Safety following up the EUNETPAS project that ended in 2010.
We have worked actively with the Commission in relation to encouraging more involvement of patients in Structural Funds projects linked to health.

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.
EPF will continue to work constructively 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.
Unrestricted grants from a range of pharmaceutical companies or pharmaceutical federations continue to make up part of EPF's resources, using the EFPIA Code of Practice for working with patients' organisations.

EPF has also reached out successfully to other corporate partners working in the area of eHealth and has established a relationship with Philips Healthcare and Microsoft.
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 2010 to discuss with all our funders the progress and successes in relation to EPF's work plan 2010 and our plans for 2011 and beyond.
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.
EPF is committed to sound financial management and we continue to aim to establish reserves equalling six months' operational budget.

EPF Board Members

Anders Olauson – EPF President
Susanna Palkonen – European Federation of Allergies and Airways diseases Association – EPF Vice President
Timo Nerkko - European Kidney Patients' Federation – EPF Treasurer
Philip Chircop - Malta Health Network – Board Member
Avril Daily - Retina Europe – Board Member
Tomasz Szelagowski - Federation of Polish Patients – Board Member
Maria D. Navarro – Spanish Patients' Froum – Board Member
Vida Augustinienė – Lithuanian Diabetes Association – Board Member
Guadalupe Morales – GAMIAN Europe – Board Member

EPF secretariat Team

Nicola Bedlington – Director
Kaisa Immonen Charalambous – Policy Officer
Liuska Sanna – Programme Manager
Walter Atzori – Junior Programme Officer
Zilvinas Gavenas – IT/Web consultant
Véronique Tarasovici – Office Manager
Magdalena Machalska – Policy Assistant

EPF Member List

Full Members

Age Related Macular Degeneration (AMD) Alliance International
Alzheimer Europe
Association of European Coeliac Societies - AOECS
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 Associations of Families of People with Mental Illness - 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
European Parkinson's Disease Association - EPDA
EURORDIS - European Organisation for Rare Diseases
Federation of Patients and Consumer Organisations in the Netherlands - NPCF
Federation of Polish Patients - FPP
Fertility Europe
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
Malta Health Network - MHN
National Voices
Pancyprian Federation Of Patients Associations and Friends
Retina Europe
SUSTENTO - The Latvian Umbrella Body For Disability Organization
The Coalition of Patients' Organizations with Chronic Diseases from Romania – COPAC

Associate Members

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

Provisional Members

European Forum for Psoriasis Patients' Association in Europe

Provisional Members to be approved at the 2011 AGM

Association for the Protection of Patients' Rights (Slovak Republic)
European Umbrella Organisation for Psoriasis Movements - EUROPSO

Account and Audit report

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 2010

We have audited the financial statements of European Patients' Forum ("the Organization") for the year ended 31 December 2010, which show a balance sheet total of **€463.125** and a loss for the year of **€14.800**.

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 Organization.

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 reasonable basis for our opinion.

In our opinion, the financial statements for the year ended 31 December 2010 give a fair view of the Organization'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 21st, 2011

FIDINTER BVBA
Represented by F. Léonard, Director

EPF Account

Balance sheet as of December 31, 2010

	2010	2009
ASSETS		
I Fixed Assets		
Computer's equipment	€ 0,00	€ 0,00
Guarantee to Axa and Securex	€ 11.014,00	€ 10.876,00
II Current Assets		
Accounts receivable	€ 36.690,00	€ 64.125,00
Cash in bank and deposit	€ 405.223,00	€ 482.761,00
Accruals	€ 10.198,00	€ 5.823,00
TOTAL ASSETS	**€ 463.125,00**	**€ 563.585,00**

	2010	2009
LIABILITIES		
I Capital and reserves		
Funds brought forward	€ 353.037,00	€ 280.782,00
Surplus or deficit for the year	-€ 14.800,00	€ 72.255,00
II Debts		
Payment received in advance	€ 32.457,00	€ 0,00
Accounts payable	€ 42.431,00	€ 123.888,00
Income to be received	€ 50.000,00	€ 86.660,00
TOTAL LIABILITIES	**€ 463.125,00**	**€ 563.585,00**

Income and Expenditure - December 31, 2010

	2010	2009
INCOME		
Membership Fees	€ 8.642,00	€ 7.250,00
Unrestricted Grants	€ 420.000,00	€ 342.858,11
Spring Conference (HTA Seminar)	€ 100.000,00	€ 0,00
Autumn Seminar	€ 26.660,00	€ 40.000,00
Commission Projects	€ 65.072,95	€ 122.779,49
Other Projects	€ 40.000,00	€ 158.516,85
Interest - Other Income	€ 16.062,58	€ 6.006,55
TOTAL INCOME	**€ 676.437,53**	**€ 677.411,00**

EXPENDITURE		
Staff and Fees	-€382.413,50	-€ 301.387,51
Office costs	-€75.943,64	-€ 64.502,58
Travel	-€50.396,29	-€ 40.599,57
Events (Spring Conference HTA Seminar)	-€88.869,34	€ 0,00
Events (Autumn Seminar)	-€57.535,16	-€ 42.155,92
Commission projects	-€97.428,41	-€ 153.967,18
Swedish Conference	€ 0,00	-€ 107.251,35
Other Projects	-€33.669,01	-€ 25.034,88
Communications	-€15.785,90	-€ 17.359,05
Bank fees and Holiday Pay Provision	€ 2.089,95	-€ 5.709,81
TOTAL EXPENDITURES	**-€ 799.951,30**	**-€ 757.967,85**
SECRETARIAT INCOME*	**€ 108.713,68**	**€ 152.811,38**
SURPLUS OR DEFICIT OF THE YEAR	**-€ 14.800,09**	**€ 72.254,53**

* About the secretariat income :

The secretariat income is composed of :

Respect	€ 20.000,00
Eunet Pas	€ 7.000,00
Renewing Health	€ 41.713,68
Seminar	€ 5.000,00
Spring Conference (HTA Seminar)	€ 20.000,00
High Level Roundtable CBHC	€ 15.000,00

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 2010 :

Astra Zeneca	€ 50.000,00*
	€ 25.000,00
Novartis	€ 50.000,00
CSL Behring	€ 10.000,00
Baxter	€ 15.000,00
Msd	€ 30.000,00
Amgen	€ 25.000,00
Pfizer	€ 50.000,00
GSK	€ 40.000,00
Eli Lilly	€ 25.000,00
Philips	€ 20.000,00
Pasteur Sanofi	€ 10.000,00
GE Health Care	€ 10.000,00

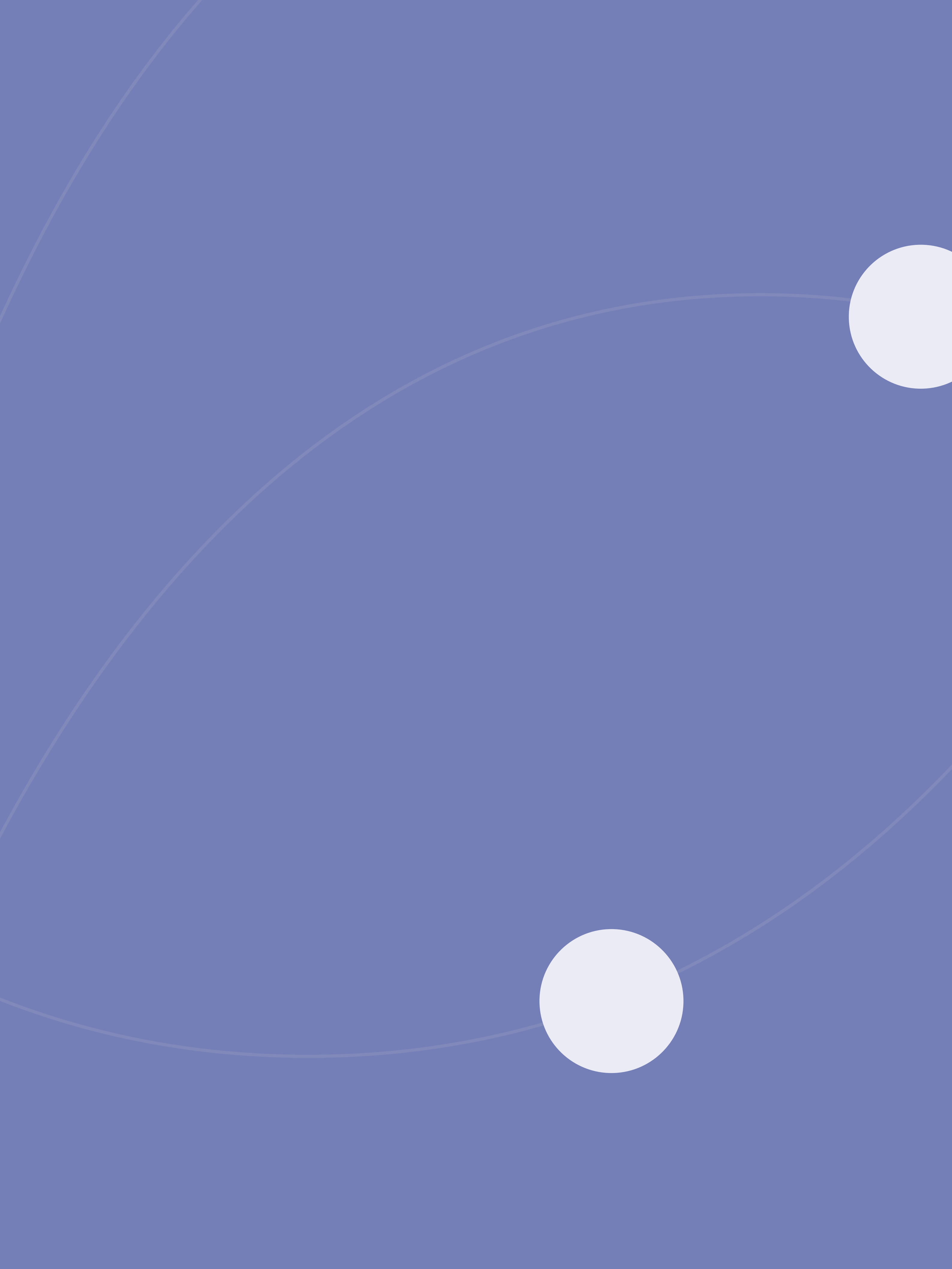
*2009 amount received in 2010

EPF wishes to thank the following sponsors for their support in the form of unrestricted grants to EPF's events in 2010 :

HTA seminar (Spring conference annual General Meeting)	
GSK	€ 30.000,00
Pfizer	€ 30.000,00
Amgen	€ 10.000,00
Novartis	€ 30.000,00
Autumn Seminar	
Medtronic Foundation	€ 26.660,00
High Level Roundtable CBHC	
Hoffman Laroche	€ 20.000,00
Johnson & Johnson	€ 20.000,00

EPF wishes to thank the European Commission for their support in 2010 in relation to EPF's role in the following projects :

RESPECT	€ 16.088,96
Renewing Health	€ 48.983,99



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