

# EPF Annual Report

## 2007





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# Introduction



Anders Olauson

Welcome to the EPF Annual Report for 2007. This report gives you a brief overview of our work during 2007. For more detailed information you are invited to 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 five objectives in its work plan for 2007

- Building capacity within the secretariat; governance structures and our relationship with members
- Strengthening our policy impact
- 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

These were framed around five core strategic goals. Our work plan also identified a series of performance indicators to measure EPF's success in 2007. These are summarized in the next section and serve to demonstrate the enormous progress made in 2007. This has been a defining year for EPF, and I am extremely proud that we have delivered on every front.

- We now have a highly competent and committed secretariat to support us in our work;
- our governance structures are effective – enabling all of our members to really play their part in growing the organization;
- there is clear evidence of our policy impact with on-going high quality input, from a uniquely patients' perspective, in all relevant EU health developments and some exciting new projects on the horizon;
- we have several new member organisations and several more potential members ready to join us in the near future;
- we have developed strong communications to get our messages across both internally and externally;
- we have also extended our funding base with more sustainable corporate partners, and for the first time EU funding from the European Commission.

I would like to take this opportunity to thank and congratulate EPF members and our allies in the European Union for your contribution to these achievements. I look forward to our continued teamwork in the challenges the lie ahead to ensure patients are at the centre of all EU healthcare developments – and patient centred equitable healthcare throughout the European Union becomes a reality.

A handwritten signature in blue ink, appearing to read 'A. Olauson'.

Anders Olauson  
EPF President

# Five Core Strategic Goals for EPF



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 health care 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.

# Summary of Key EPF Achievements and Milestones in 2007

## EQUAL ACCESS FOR PATIENTS

- Information to patients was the top policy theme for EPF in 2007. Three consultations were undertaken with the membership regarding our position on 'Quality Criteria', an information package, and the Commission report on Information to patients on medicinal products. Board and staff members shared EPF views extensively at numerous meetings on the issue throughout the year.
- We have engaged very actively and given concrete input from a patient's perspective in all aspects of the Pharmaceutical Forum. This is reflected in agreed texts and outcomes in 2007. We have been involved in leading one work stream in the Information to Patients working group, and inputting on the added value of stakeholder involvement in the Relative Effectiveness working group. In all of the documents emerging from Pricing and Reimbursement working group, there is evidence of EPF contribution from a Quality of Life / equity of access perspective.
- EPF has also worked with other health NGO stakeholders; led by the European Public Health Alliance to prepare a joint statement on information to patients that has been warmly received by the Commission.
- The concept of patient empowerment and the importance of involving patients in decision-making is an integral part of the European Health Strategy, and several of EPF's proposals for the Strategy have been incorporated, including a reference to health literacy.

## PATIENT INVOLVEMENT

- The EPF project proposal 'VALUE +' on the meaningful involvement of patients in EU health projects was approved under the Public Health Programme Call 2007. This is the first funding EPF has received from the Commission.
- EPF representation in major EU level health Forums, Consultative Committees and Working Group has increased significantly in 2007. In addition to involvement in the Patient Safety Working Group (which provides input to the High Level Working Group on Health Services and Medical Care), the Pharmaceutical Forum and the European Health Policy Forum, we are involved in the Editorial Board of the Health Portal, and the E-health stakeholders group.

## PATIENTS' PERSPECTIVE

- EPF promotes a patients' perspective, including issues around human rights and quality of life in developments at EU level on health economics and health efficacy (health, wealth and equity). A very tangible illustration of this in 2007 was the unanimous endorsement by participants (patients and key health stakeholders) at the EPF Spring Conference for Action Points to move forward on empowerment, information and sustainability, and a mandate given to EPF to move forward with effective follow-up.
- EPF drafted, consulted and agreed the following position papers/statements with the Membership in 2007
  - EPF's response to a Commission consultation on an EU Health Strategy,
  - EPF statement on Animal Testing
  - EPF's response to a Commission Consultation on the Future of Pharmaceuticals for Human Use
  - EPF's response to the Commission Consultation on Health Services
  - Information to Patients (3 consultations on four documents)
  - Pricing and Reimbursement Guiding Principles and Practices



- We also supported the work of EURORDIS re. Advanced Therapies, and the work of IAPO regarding their response to a WHO global strategy on public health and Intellectual Property.
- A Press Release/Mailing was circulated on the following issues
  - The Spring Conference outcomes 'Moving forward together'
  - EPF's position on Health Services
  - EPF cooperation with the EU Permanent Standing Committee for Doctors ( CPME)
  - EP work on ensuring core funding for NGOs remains in Public Health Programme
- EPF has participated as speaker; chair or moderator in over 50 EU health meetings in 2007, presenting EPF's work and the patients' perspective.
- Over 80 MEPs across all EP Groupings have made an explicit commitment to support actively the work of EPF.

### SUSTAINABLE PATIENT ORGANISATIONS

- EPF has been successful in diversifying its funding sources with some income from the Commission through 3 projects in 2008 and 2009, and will apply for annual core funding from the Commission in the framework of the new Public Health Programme.
- The EPF Autumn Advocacy Seminar was very well-received according to feedback from the 40 patient leaders who participated. They valued the exchange of experience and expertise and the opportunity to work closer with EPF.

### PATIENT UNITY

- Linked to the goal to nurture and promote solidarity and unity across the EU patients, the EPF membership was enlarged to 30 members by the end of 2007, and representation was extended in one key disease area previously unrepresented within EPF: diabetes.

- The EPF Annual General Meeting in June 2007 was a very successful meeting, In terms of governance, EPF's accounts and annual report for 2006 were accepted, and the EPF strategic plan was adopted. The 'open space' session for members was seen as particularly valuable, where they could exchange views and experiences from their own organizations. It was agreed that the next AGM should take place in the framework of the Spring Conference, to optimize resources and time.

This Annual Report pinpoints some of the highlights for EPF during 2007. It has been a challenging and extremely rewarding year – that will be remembered as one of both innovation and growth – but also where EPF board and members have been able to consolidate the considerable work undertaken in the early years of EPF and to galvanise the enthusiasm, spirit and ambition of patients' organisations throughout the European Union.

As we look to the future – to 2008 and beyond, we have laid the foundations this year through our vision and our strategic plan, through our cooperation with a whole range of partners and through our commitment to sharing the patient's unique experience, expertise and knowledge in our policy and campaign work.

The Commission's own paper 'Future Challenges' identifies some of the opportunities and barriers facing us all in the years to come. EPF as the representative voice of the European Patients' Movement is ready to embrace these challenges wholeheartedly.

# EPF Governance in 2007

**The EPF Annual General Meeting in June 2007 welcomed four organizations as new full members: the International Diabetes Federation - European Section; the National Platform of Patients' Organisations in France; the Spanish Patients' Forum and the Lithuanian National Platform of Patients' Organisation.**

The AGM also elected two new board members: Albert Jovell, President of the Spanish Patients' Forum and Christian Saout, President of the National Platform of Patients' Organisations in France.

Jean Georges (Alzheimer Europe) stood down as Vice President of EPF and continued as Member of the Board. Susanna Palkonen (European Federation of Allergies and Airways Diseases Patients' Organisation) became EPF's new Vice President. Astrid Sharpantgen stood down as board member and was warmly thanked for her contribution to EPF.

The Annual General Meeting approved unanimously the Annual Report and Accounts for 2006, the EPF Strategic Plan; and the EPF Work Plan and budget for 2007.

An 'Open Space' session took place that explored communication and consultation within and between patients' organizations.

By the end of 2007, a further 3 organisations had submitted formal requests to become full members and were given provisional status until the 2008 AGM.

In December 2007, EPF circulated a questionnaire to its members to establish the number of patient representatives EPF represents directly and indirectly across the European Union. This will help to strengthen our democratic voice in Brussels.

## GOVERNANCE

- Four new member organizations
- Two new board members
- AGM adopts Strategic Plan
- Audited Accounts and Annual Report on Website
- Membership survey on representativeness



# EPF Policy Orientation in 2007



## EPF work with the EU Institutions and Health Stakeholders in Brussels

EPF has worked extremely hard to enhance its political impact in 2007. This section gives an overview of the major initiatives undertaken throughout the year.

### THE EPF SPRING CONFERENCE 'EMPOWERMENT: SUSTAINABILITY: INFORMATION'

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The EPF Spring Conference took place on 20-21 March in Brussels. This third EPF Conference brought together more than 120 participants representing a wide range of patient organizations and other stakeholders involved in healthcare policy at European and national level. At the end of the conference, participants endorsed recommendations for concrete actions for EPF to take forward at EU level in partnership with other stakeholders in advancing policy in the areas of empowerment; sustainability and information.

The full conference report is available on the EPF website.

### THE PHARMACEUTICAL FORUM

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The High Level Pharmaceutical Forum was established by the Commission Vice President Verheugen and Commissioner Kyprianou (Commissioner for Health) in 2005 to examine the competitiveness of the European-based pharmaceutical industry and related public health issues.

EPF has been actively involved in all three working groups of the Pharmaceutical Forum (Relative Effectiveness; Pricing and Reimbursement; and Information to Patients) represented by the EPF President and board or former board members, and supported by the EPF Director.

Some progress has taken place during the course of 2007 particularly since the High Level Ministerial Forum in June 2007 where EPF President Anders Olauson represented EPF.

During the High Level Forum a series of conclusions were adopted that provided the work plans for the following year's work. EPF was represented at subsequent meetings of the Pharmaceutical Forum where the focus was taking forward a work plan in each of the three core areas. There have been interesting developments in the area of information to patients, where EPF is represented by Susanna Palkonen, EPF Vice President. Four work streams were agreed: developing a strategy in relation to information to patients in specific healthcare settings (community pharmacists, hospitals, and primary health care settings); exploring methodology around the application of quality principles on information to patients; and partnership in developing ITP pilots at national level; and development of an overall strategy on information to patients. Given the fundamental importance of all these areas – EPF committed to be as active as possible in contributing to each from a patients' perspective. The Joint Statement on Information to Patients, coordinated by the European Public Health Alliance (EPHA) and signed by 21 health organisations including EPF was well received by the Commission. The Statement makes the case for in-depth analysis and research based on existing materials and sources, exploration of good practice examples of public private partnerships in relation to ITP, strategies to optimise the impact of EMEA networks and Eudrapharm, promoting health literacy and using the structural funds to the maximum extent possible. The signatory organisations will meet in early 2008 to examine how to advance on these actions in concrete terms and EPF is very pleased to contribute to this work.

With regard to developments in relation to Pricing and Reimbursement, where EPF is represented by Christoph Thalheim, the working group agreed to fine-tune the guiding principles on pricing and reimbursement, following pilot work with volunteer Member States and companies, and evaluation of their impact on cost-containment, access to patients and reward for innovation. Further debates will take place on the value of innovation, with a survey across the European Union on good practice; and continued exchanges of information around pricing. EPF will continue to input on all of these areas from the perspective of patients. In 2008, the Pricing and Reimbursement working group will explore in further depth trade and distribution, including the themes of parallel trade and trade and distribution margins.

The 'Relative Effectiveness' working group, where EPF was represented in 2007 by Jean Georges pursued work in relation to the development of principles to establish good practice for relative effectiveness assessments and a tool box; to explore the availability of data by using real life examples, and the development of networking and collaboration. EPF has joined a sub-group on networking and our contribution will be in relation to the added value of involving stakeholder groups, including patients, in post Pharmaceutical Forum developments.

- ▶ European Commission website:  
[http://ec.europa.eu/health/ph\\_overview/other\\_policies/pharma\\_forum\\_en.htm](http://ec.europa.eu/health/ph_overview/other_policies/pharma_forum_en.htm)

### EUROPEAN COMMISSION CONSULTATION ON THE FUTURE OF PHARMACEUTICALS FOR HUMAN USE

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EPF submitted its response to the Commission Consultation Paper on the Future of Pharmaceuticals for Human Use in mid October 2007. We also had the opportunity to present the key challenges on the future of pharmaceuticals, as identified by the EPF membership at a parallel session devoted to pharmaceuticals at the European Health Forum Gastein.

### EUROPEAN COMMISSION NEW HEALTH STRATEGY (2008-2013)

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The European Commission DG SANCO published the white paper "Together for health": a Strategic approach for the EU 2008-2013 in Autumn 2007. The White Paper followed the consultation at the beginning of 2007 and identified three key challenges: population ageing; threats to health and new technologies and sets strategic objectives and actions for the EC and Member States. There are four fundamental principles pinpointed: (1) a strategy based on shared values; (2) health is the greatest wealth; (3) health in all policies (HIAP); (4) strengthening the EU's Voice in global health. EPF welcomed the strategy. Many of the points that EPF raised in the response to the consultation have been taken on board. EPF highlighted the need to recognise families and carers' crucial contribution to the health care and social systems. There is an explicit recognition of citizens' and patients' rights as a key starting point for Community health policies. The fundamental importance of health literacy was also recognized in the White Paper.

EPF is looking forward to working with the EU Institutions and other health stakeholders in taking forward the strategy.



## EUROPEAN COMMISSION DIRECTIVE ON CROSS-BORDER HEALTHCARE

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The draft Directive ensuring the protection of basic rights for patients travelling to other EU Member States in receiving medical treatment was due to be launched by the Commission in late 2007, following a public consultation. It was however delayed for political reasons.

EPF's response to the consultation on regarding community action on health services highlighted that:

- Patients want to benefit from high quality healthcare as close to home and as quickly as possible. Their access to high quality, timely and accurate information, in their own language, is critical.
- In relation to patients' cross-border mobility, it is important to examine accessibility to healthcare, equity issues, patient safety, cost implications, patients' mental health and well-being.
- The way forward is a policy mix including a legally binding instrument, a political "tool" (e.g. a Patients' Charter) and robust and effective management systems. In areas of error, or negligence, EU action should explore an additional safety net for redress at EU level through a structure such as an Ombudsman system for patients.

## INFORMATION TO PATIENTS

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Three consultations came from the Commission during the course of 2007 on quality principles in relation to information to patients, a European Information model using diabetes as an example; and a report prepared by the Commission. A legislative proposal will be made by the end of 2008 in relation to article 88A of Directive 2001/83/EC, which called on the Commission to submit a report in 2007 and 'if appropriate, put forward proposals setting out an information strategy to ensure good quality, reliable and non promotional information on medicinal products and other treatments and shall address the question of the information source's liability'.

This proposal will be developed on the basis of an impact assessment from an economic, environmental, public health and social perspective.

EPF worked with the membership extensively on our response to these consultations and these responses form part of a series of EPF documents on the issue of information to patients that are available on the EPF website.

## ANIMAL TESTING

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In mid 2007, EPF developed a brief statement on animal testing in cooperation with other organizations such as the European Genetic Alliance Network that is a member of EPF. This is readiness for a revision of animal testing legislation that will take place during 2008.

### OTHER COMMISSION HIGH LEVEL GROUPS

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#### **Patient Safety Working Group**

EPF is a member of the Patient Safety Working Group of the European Commission's High Level Working Group on Health Services and Medical Care, which works to promote further commitment from Member States to identify and share potential solutions to address patient safety.

EPF became involved as an associate partner in the EUNetPaS (European Union Network for Patient Safety) project, a EU financially supported project, which has established an umbrella network of representatives of the 27 EU Member States, health professionals, health care 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.

#### **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.

### E-HEALTH STAKEHOLDERS GROUP

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EPF is a member of the Commission e-Health Users' Stakeholders Group, which is an advisory group of the i2010 Subgroup on e-Health, working under the coordination of the Information Society and Media Directorate-General.

The group provides advice for the progress on the eHealth Action plan in Europe. In 2007 the group has worked mainly on the European Commission Recommendation on e-Health Interoperability and the Commission Working Document on processing personal data related to electronic health records.

### THE EUROPEAN HEALTH POLICY FORUM

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EPF is a member of the European Health Policy Forum. One of the important developments in 2007 was a revised mandate for the Forum in the light of the new EU Health Strategy. In concert with several other health NGO members EPF would support a stronger, more pro-active and political health policy forum in the future.



## COOPERATION WITH THE EUROPEAN MEDICINES AGENCY EMEA

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EMA activities in which EPF is involved includes

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

EPF is represented in EMEA by Christoph Thalheim, and EPF board member Jean Georges is represented in the EMEA management committee.

One key event in 2007 was a brainstorming meeting held in September on EMEA's provision of information to its stakeholders, and current communication tools and information practices. The EMEA website includes information on all centrally authorized medicines for use in EU countries. Participants raised the need to provide easier access to such information for health professionals and patients.

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

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The EPF President continues to represent EPF in a High Level Group set up by the Commissioner for Research to provide overall strategic guidance to developments within FP7.

EPF will be 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. This project is due to start in 2008.

## COOPERATION WITH THE WORLD HEALTH ORGANIZATION

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EPF provided input on a WHO Regional Office for Europe document on "National health system quality and safety strategies: guidance for WHO Europe members states". The guide offers a detailed description of various national quality and safety strategies and methodologies related to this. While appreciating the high quality of the guide, EPF recommended that it should explicitly outline the need for member states to provide adequate resources for patients organisations in order to enable them to participate meaningfully by: giving feed-back about quality, identifying gaps and needs, contributing to choosing priority for actions, and supporting public health interventions.

## COOPERATION WITH OECD

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EPF participated in a meeting set up by the OECD Business and Industry Committee (BIAC), on the area of ICT and health; EPF presented the patients' perspective on e-health based on discussions with our membership. There is a clear need to accelerate progress in this area, particularly in relation to interoperability issues across the Member States.

# EPF – Capacity Building and Development of the Secretariat in 2007

## THE EPF SECRETARIAT

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The EPF Secretariat grew in 2007. Roxana Radulescu joined the team as full time policy officer in January 2007. Our stagiaire Nicolas Pradalié left the Secretariat in September to go the College of Bruges and we were joined by a new stagiaire; Elisabeth Kasilingam in October 2007. Zilvinas Gavenas continued to work with us as IT consultant/ Webmaster in a 75 % post. Amanda Casey supported EPF in our conference and seminar coordination during 2007.

Nicola Bedlington continued as EPF Executive Director in an 80% post.

EPF engaged in an equal opportunities recruitment process for a new post of programme officer Liuska Sanna, who joined us in January 2008.

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 2006 accounts and these were presented to the Annual General Meeting in June. These were then posted on the EPF website.

At the end of 2007, new accessible offices premises were chosen and EPF will move in early 2008. The office includes meeting space and a temporary office facility for member organizations visiting Brussels

## THE EPF AUTUMN ADVOCACY SEMINAR

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Over 40 leaders of patient organisations from 20 different EU countries attended the EPF Autumn Advocacy Seminar in November 2007. It gave some important insights into what really concerns patients throughout the European Union and how EPF can and should respond. The support of high level speakers and significant numbers of MEPs enriched the experience of all those attended. The workshop sessions on the final day on effective campaigning and communications proved to be huge practical benefit and gave delegates a clear focus for on-going representational work.

The Seminar was organized by EPF and was supported by an unrestricted educational grant from EFPIA.

## VALUE +

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In 2007, EPF was awarded EU funding for the first time. A major EU project that focuses on meaningful patient involvement in EU health projects 'VALUE +' will commence in 2008 and last for two years. Coordinated by EPF, 'VALUE' + will involve 7 other partners. The aim of the project is to exchange information; experiences and good practice among patients' organizations to encourage the meaningful involvement of patients' organizations in EU-supported health projects at EU and at National level. The project will develop a set of specific targeted resources: a resource kit for patients organizations to facilitate their input in projects; a handbook for project leaders, promoters and evaluators; and policy recommendations for decision-makers. The project will culminate in a major Conference that will take place in Stockholm in 2009 under the Swedish EU Presidency.

# EPF – Growing the Membership – Initiatives in 2007



**EPF's membership grew from 23 to 30 members in 2007. The most significant area of growth is in relation to national platforms of patient organizations. Such 'umbrella' platforms composed of national patients' associations from France, Lithuania, Poland and Spain became full members.**

In terms of disease areas, EPF was delighted to welcome the International Diabetes Federation – European Section, the European Federation of Associations of Patients with Haemochromatosis (EFAPH), and Thalassemia International Federation.

We were also very pleased to receive a request for EPF membership from Mental Health Europe, which we are confident will help to ensure that the mental health dimension will remain high on our agenda.

Several national platforms and disease specific organizations have expressed an interest in joining EPF in the near future. The EPF Secretariat is liaising with them with a view to membership in 2008.

# EPF Alliance Building and Representation at External Meetings during 2007

## 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 2007. 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 Internal Mailing features reports of all of these meetings;

A few highlights include:

- European Voice Health Conference 'Diagnosing our Future' – representation on a panel exploring 'future perspectives', March 2007
- Chair of a parallel session on 'Pharmaceuticals and the EU – looking back and forth, European Health Forum Gastein 10th Anniversary, October 2007
- PGEU Annual General Meeting – representation on a panel on 'Information to Patients', Vienna, June 2007
- European Heart Network Patients Seminar; presentation of the work of EPF and opportunities for involvement... June 2007
- The Health Strategy Round Table, Lisbon, July 2007
- European Patient Safety Research Conference – under the EU Portuguese Presidency, Porto, September 2007
- OECD meeting on ICT and Health, Paris, November 2007, presentation of EPF's position on Information Communication Technology (ICT) and Health

- European Health Compliance Packaging Council Conference, Copenhagen, November 2007 – presentation on EU Healthcare developments and EPF's advocacy role.
- European Parliamentary Meeting on Information to Patients, December 2007 – Presentation of EPF's perspective on information to patients

## Alliance Building

In 2007, EPF placed 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; the European Pharmacists Organisation (PGEU), the European Hospitals Association (HOPE), the European Health Management Association (EHMA), the European Consumer Association (BEUC) etc.

The following are some specific examples of this work.

- EPF President attended the General Assembly of the International Alliance of Patients' Organisations in New York in March to finalise our Memorandum of Understanding with the IAPO board. Since then we have attended each others' respective meetings and supported our respective policy documents and position papers.
- In September, the EPF board and director held a creative workshop with the executive committee and Secretary General of CPME. The day resulted in a firm commitment for EPF and CPME to work together more closely and to agree a set of principles to take this forward. EPF President said of the day 'This is, in a way, a historic development – the start of a very exciting cooperation that will bring dividends for both our organizations and our members'. The joint principles will be adopted at our respective Annual General Assemblies in 2008.





- EPF worked closely with the European Public Health Alliance as part of a Stakeholder Consultation Group on Information to Patients. The aim of the group is to coordinate action with other health and consumer organizations for a common advocacy strategy to maintain public health concern in the debate on information to patients. The group prepared a joint statement on information to patients: the Way Forward which was very well received by the European Commission in the framework of the Pharmaceutical Forum.

#### Participation in Think Tanks and Reflection Group

EPF is a member of the EFPIA Think Tank with Patients Groups that met 5 times in 2007 and a member of its steering group; we are also member of the GSK Patient Advisory Committee and are a member of the new steering group of the Centre for Health, Ethics and Society (CHES).



# EPF Knowledge Management and Communications – Developments in 2007

**EPF has continued to invest in the EPF Website as our central communication tool. Much work has taken place to ensure that the website is accessible and is as up to date as possible.**

In 2007 we produced the EPF brochure that explains, at a glance; the EPF and what we stand for.

EPF continues to produce its 'EPF Internal Mailing' every six weeks, which gives a regular overview of the campaign; policy and representation work in which EPF is engaged and reports on EU health policy developments of interest to EPF members and allies.

We now have extensive internal, external and media mailing lists that are updated on a regular basis.

EPF is working on a variety of topics in line with our strategic plan and work plan. For some key working areas we produced fact sheets in 2007 on the current status of discussion at EU level. These include: the Pharmaceutical Forum; Health Services; Information to Patients; the EU health strategy; the EU Public Health Programme; and Patient safety.

We also produced briefings on specific themes for our member organizations.

EPF has drafted a number of articles and features for health related magazines and journals across the European Union. We featured in the European Voice's Special Report on Patients Rights in December 2007.

During the course of 2007 several policy briefings and press releases went to our external and media contacts highlighting news on the website and announcing the launch of position papers and policy statements.

The EPF board adopted an external communications strategy at its meeting in December 2007 to bring together the various actions undertaken on an ongoing basis and to maximize impact.

# Funding Sources and Diversification – Initiatives to the end 2007

**By the end of 2007, EPF's funding base was three-fold.**

This year, EPF introduced its new membership fee structure based on organisations' annual turnover.

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

Our own Code of Conduct ensures that EPF's relationship with sustainable funding partners meets the highest standards of transparency and independence.

A funders' meeting was held in September 2007 to discuss with all our funders progress and successes in relation to EPF's work plan 2007 and our plans for 2008 and beyond.

The EPF board and secretariat devoted significant energy to preparing a proposal in the framework of the European Public Health Programme and were extremely pleased to learn that the European Public Health Agency accepted the project 'VALUE +'. We also engaged 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. All three projects will commence in early 2008.

Alongside other NGOs, EPF also campaigned successfully for the inclusion of core funding for representative patients' organizations in relation to the new Public Health Programme to begin in 2008, and will respond to a Call for Proposals scheduled for February 2008.

In resource terms, this means as EPF grows as an organization, it is likely that a proportion of EPF's funding will come 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.

EPF is committed to sound financial management and we aim to establish reserves equaling 6 months operational budget.

# EPF member organisations list

## EPF Board Members

Anders Olauson - EURORDIS - EPF President

Susanna Palkonen - European Federation of Allergies and Airways Diseases Association - EPF Vice President

Mike O'Donovan - European Multiple Sclerosis Platform - EPF Treasurer

Jean Georges - Alzheimer Europe - Board Member

Albert Jovell - Spanish Patients' Forum - Board Member

Christian Saout - CISS ( Patients' Forum, France) - Board Member

## Full members

Organization	Representative	Address	Contacts
Alzheimer Europe	Jean Georges	145, route de Thionville L-2611 Luxembourg	Tel: +352-29 79 70 Fax: +352-29 79 72 info@alzheimer-europe.org www.alzheimer-europe.org
Collectif inter associatif Sur la Santé (CISS) Joined in 2007	Christian Saout	5 rue du Général Bertrand 75007 Paris	Tel: + 33 1 40 56 01 49 Fax: + 33 1 47 34 93 27 secretariat@leciss.org president@leciss.org www.leciss.org
Council of Representatives of Patients' organizations of Lithuania (LPOAT) Joined in 2007	Vida Augustinien_	Gedimino av. 28/2 – 404 Lithuania	LT 01104 Vilnius Tel: + 37 05 26 20 783 Fax: + 37 05 26 10 639 info@dia.lt info@pacentutaryba.lt www.pacentutaryba.lt
Euro Ataxia - European Federation of Hereditary Ataxias	Dagmar Kroebel	Haagwindelaan, 6 B-3090 Overijse Belgium	Tel: +32 2 657 15 10 Fax: +32 2 657 61 76 dk.euro-ataxia@skynet.be www.euro-ataxia.org
EUROPA DONNA - The European Breast Cancer Coalition	Susan Knox	Via G. Previati 12 I-20149 MILAN ITALY	Tel: +39 02 8907 9660 Fax: +39 02 8907 9664 europadonna@mclink.it www.cancereurope.org/europadonna

European Alliance of neuro-Muscular Disorders Association - EAMDA	Dr. Peter Streng	Lt. Gen. Van Heutszlaan 6 3743 JN BAARN The Netherlands	Tel: +31 (0)35 5480 480 Fax: +31 (0)35 5480 499 peter.streng@vsn.nl www.vsn.nl
European Federation of Association of Families of Mentally Ill People - EUFAMI	Kevin Jones	100, Diestsevest 3000 Leuven Belgium	Tel: +32 16 74 50 42 Fax: +32 16 74 50 49 secr.general.office@eufami.org www.eufami.org
European Federation of Allergy and Airways Diseases Patients' Associations - EFA	Susanna Palkonen	35, Rue de Congrès 1050 Brussels Belgium	Tel: +32 2 227 27 12 Fax: +32 2 218 31 41 susanna.palkonen@efanet.org www.efanet.org
European Federation of Crohn's and Ulcerative Colitis Associations - EFCCA	Micke Lindholm	Gropmorsvagen 28 10520 Tenala Finland	Tel: +358 19 24 506 00 Fax: +358 19 24 508 60 micke.lindholm@pp.inet.fi rod.mitchell@infodor.fsnet.co.uk www.efcca.org
European Federation of Homeopathic Patients' Associations	Jacques Hirsch	Clos du Cheval d'Argent, 9 1050 Brussels Belgium	Tel: +32 2 672 33 51 Fax: +32 2 672 13 63 jacques.hirsch@brutele.be www.efhpa.com
European Genetic Alliances Network - EGAN	Cor Oosterwijk	C/o VSOP - Dutch Genetic Alliance Vredenhofstraat 31 3761 HA Soestdijk The Netherlands	Tel: +31 35 603 4040 Fax: +31 35 602 7440 c.oosterwijk@vsop.nl www.egaweb.org
European Heart and Lung Transplant Federation	Terry Mangan	69 Landsdowne Park Dublin 16 Ireland	Tel: + 353 1 495 0940 Fax: + 353 1 49 1959 info@ihlta.com www.ehtf.info
European Infertility Alliance	Helen Browne	c/- NISIG Box No. 131 Togher Cork Ireland	Tel: +353 8779 75 058 eia@icsi.ws www.icsi.ws/regionalalliances
European Kidney Patients' Federation - CEAPIR	Knud Erben	Eingerstrasse 10e 80993 Munchen Germany	Tel: +49 89 1495768 Fax: +49 89 1416270 epf@ceapir.org www.ceapir.org
European Men's Health Forum	Erick Savoye	Rue de l'Industrie 11 1000 Brussels Belgium	Tel: +32 2 234 30 58 Fax: +32 2 230 33 00 office@emhf.org www.emhf.org

# EPF member organisations list

European Multiple Sclerosis Platform	Christoph Thalheim	Rue Auguste Lambiotte 144/8 B-1030 Brussels Belgium	Tel: +32 2 305 80 12 Fax: +32 2 305 80 11 ms-in-europe@pandora.be www.ms-in-europe.org
European Network of (ex)users and survivors of psychiatry	Peter Lehmann	Pimpernel, 3 1902 JJ Castricum The Netherlands	Tel: +31 251 655 800 info@enusp.org www.enusp.org
EURORDIS	Anders Olauson	c/o Plateforme Maladies Rares 102, rue Didot 75014 PARIS France	Tel: (33) 1 56 53 52 10 Fax: (33) 1 56 53 52 15 anders.olauson@agrenska.se ariane.weinman@eurordis.org www.eurordis.org
Foro Español de Pacientes Joined in 2007	Albert Jovell	Casa Convalescència - UAB C/ Sant Antoni Maria Claret, 171 08041 Barcelona	Tel: + 34 93 433 50 76 Fax: + 34 93 433 5036 albert.jovell@uab.es fep.webpacientes@uab.es www.webpacientes.org/fep
GAMIAN Europe	Dolores Gauci	C.E.O - Richmond Foundation- 9 Valletta Road, Mqabba ZRQ 08, Malta	Mobile: + 356994473 489 ceo@richmond.org.mt www.gamian-europe.org
International Diabetes Federation - Region Europe Joined in 2007	Lex Herrebrugh	Regional office Avenue Emile De Mot 19 B-1000 Brussels Belgium	Tel: +32 2 537 1889 Fax: + 32 2 537 1981 info@idf-europe.org www.idf-europe.org
International Patient Organisation for Primary Immunodeficiencies IPOPI	David Watters	Firside Main Road Downderry PL11 3LE UK	Tel/Fax: +44 1503 250 668 mobile: +44 7736 366 137 david@ipopi.org www.ipopi.org
Retina Europe	Christina Fasser	Retina International Ausstellungsstrasse 36 8005 Zürich Switzerland	Tel: +41 1 444 10 77 Fax +41 1 444 10 70 cfasser@e-link.ch www.retina-international.org

## Associate members

Organization	Representative	Address	Contacts
APAI Associazione Patologie Autoimmuni Internazionale	Christine Gammon	via Degli Uliveti 8 64029 Silvi (TE) Italy	Tel: +39 085 9353560 Mobile: +39 333 7027420 apai@assoc-apai.org www.assoc-apai.org
European Coalition of Positive People - ECPP	Colin Webb	2 Whitehorse Mews Westminster Bridge Road London SE1 7QD UK	Tel: +44 20 7401 9942 Fax: +44 20 7401 9690 cwebb@ecpp.co.uk www.ecpp.co.uk/
Debra Europe	John Dart	Debra House 13, Wellington Business Park Dukes Ride Crowthorne Berkshire RG45 6LS UK	Tel: +44 1344 771961 Fax: +44 1344 762661 john.dart@btinternet.com www.debra-international.org/
European Alliance of Genetic Support Groups	Alastair Kent	C/o Genetic Interest Group Unit 4d, Leroy House 436 Essex Road London N1 3QP UK	Tel: +44 207 704 31 41 Fax: +44 207 359 14 47 post@gig.org.uk www.gig.org.uk/

## Provisional Members

Organization	Representative	Address	Contacts
European Forum for Psoriasis Patients's Associations in Europe	Mara Maccarone	Via Tacito, 90 00193 Roma Italy	Tel: +39 06 3211545 Fax: +39 06 3211545 maramacca@virgilio.it
AMD Alliance International	Rainald von Gizycki	Lutherstraße 4-6 D-61231 Bad Nauheim	Tel: +49 6032 30 66 90 Fax: +49 6032 30 66 91 rainald.vongizycki@charite.de www.amdalliance.org
Thalassaemia International Federation	Androulla Eleftheriou	P.O. Box 28807, 2083 Strovolos 31 Ifigeneias Street, 2007 Strovolos, Cyprus	Tel: +357 22 319 129 Fax: +357 22 314 552 thalassaemia@cytanet.com.cy www.thalassaemia.org.cy

## Provisional Members to be approved at 2008 AGM:

Organization	Representative	Address	Contacts
Federation of Polish Patients	Tomasz Szelagowski	Gagarina Street 7, PL 00-735 Warsaw, Poland	Tel: +48 22 84 11 067 Fax: +48 22 72 00 709 Mobile: +48 665 18 24 34 t.szelagowski@federacjapp.pl
European Federation of Associations of Patients with Haemochromatosis	Jean Rialland	1 Bld Jeanne d'Arc, 35000 Rennes, France	Tel: +33299870515 jean.rialland@club-internet.fr www.european-haemochromatosis.eu
Mental Health Europe	Mary Van Dievel	Boulevard Clovis, 7 B-1000 Bruxelles	Tel: +32 2 280 04 68 Fax: +32 2 280 16 04 mvandievel@mhe-sme.org www.mhe-sme.org
Movimento Consumatori	Valentina Cicinelli	Via Piemonte 39/A 00187 Rome, Italy	Tel: +39064880053 Fax: + 39064820227 Valentina.cicinelli@movimentoconsumatori.it www.movimentoconsumatori.it
Thalassaemia International Federation	Androulla Eleftheriou	P.O. Box 28807, 2083 Strovolos 31 Ifigeneias Street, 2007 Strovolos, Cyprus	Tel: +357 22 319 129 Fax: +357 22 314 552 thalassaemia@cytanet.com.cy www.thalassaemia.org.cy



# Accounts and Audit Report



## European Patient Forum Balance sheet as of December 31, 2007

	2007	2006
<b>ASSETS</b>		
<b>I Fixed Assets</b>		
Computer's equipment	2504,90	598,83
Guarantee to Nci and Securex	4250,00	4200,00
<b>II Current assets</b>		
Accounts receivable	0,00	61400,00
Cash in bank and on deposit	421448,30	199625,82
Accruals	0,00	13783,50
<b>TOTAL ASSETS</b>	<b>428203,20</b>	<b>279608,15</b>
<b>LIABILITIES</b>		
<b>I Capital and reserves</b>		
Funds brought forward	156108,24	2995,79
Surplus for the year	65022,38	153112,45
<b>II Debts</b>		
Payment received in advance	0,00	108750,00
Accounts payable	34072,58	14049,91
Income to be received	173000,00	700,00
<b>TOTAL LIABILITIES</b>	<b>428203,20</b>	<b>279608,15</b>

*in Euros*

## European Patient Forum Profit and Loss account - 31 December 2007

	2007	2006	
<b>INCOME</b>			
Membership fees	5353,00	2900,00	
Corporate Sponsorship	275000,00	342500,00	
Spring Conference	107000,00	0,00	
Autumn Seminar	75000,00	0,00	
Interest - Other Income	8962,24	135,02	
<b>TOTAL INCOME</b>	<b>471315,24</b>	<b>345535,02</b>	
<b>EXPENDITURE</b>			
Staff and fees	-147724,82	-123737,98	
Office costs	-45995,58	-27634,75	
Travel	-25909,62	-24784,48	
Events ( Spring Conference )*	-107807,24	0,00	
Events ( Autumn Seminar )*	-69187,90	0,00	
Communications	-4222,81	-12481,44	
Bank fees	-5444,89	-3783,92	
<b>TOTAL EXPENDITURES</b>	<b>-406292,86</b>	<b>-192422,57</b>	<i>in Euros</i>

\*Note about the Spring Conference and Autumn Seminar

1 - Spring conference:

The breakdown is as follows:

Direct expenses:	80855,13
Overhead ( staff )	14000,00
Meeting, info dissemination..	12952,11
<b>TOTAL</b>	<b>107807,24</b>

2 - Autumn Seminar:

The breakdown is as follows:

Direct expenses:	42235,79
Overhead ( staff )	14000,00
Meeting, info dissemination..	12952,11
<b>TOTAL</b>	<b>69187,90</b>



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

Incorporated in the Grand Duchy of Luxembourg

François Leonard

### Report for the year ended 31 December 2007

We have audited the financial statements of European Patients' Forum ("the Organization") for the year ended 31 December 2007, which show a balance sheet total of €428.203,20 and a profit for the year of €65.022,38.

### 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 a reasonable basis for our opinion.

In our opinion, the financial statements for the year ended 31 December 2007 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.

# Acknowledgement of financial support

EPF wishes to thank the following sponsors for their support in the form of unrestricted grants for EPF's operational programme 2007

Astrazeneca:	€20,000
Baxter's Healthcare:	€15,000
GSK:	€40,000
MSD:	€50,000
NOVARTIS:	€50,000
PFIZER:	€50,000
PhRMA:	€50,000

EPF also wishes to thank the following sponsors for their support in the form of an unrestricted grant for EPF events in 2007

GSK:	€72,500
and PFIZER	€72,500 for the EPF Spring Conference 2007
EFPIA:	€75,000 for EPF Autumn Advocacy Seminar 2007





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