europeanpatients'forum

EPF Annual Report
2008

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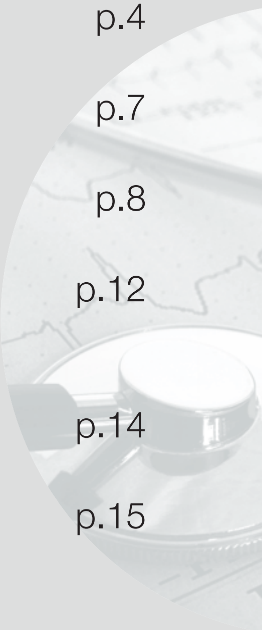

Introduction

Anders Olauson

Welcome to the EPF Annual Report for 2008. This report gives you a brief overview of our work during 2008. For more detailed information you are invited to visit the EPF Website at www.eu-patient.eu or contact the secretariat at info@eu-patient.eu.

EPF identified six objectives in its work plan for 2008:

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

2008 has seen increasing evidence of our impact on behalf of our members, with ongoing high quality input, from a uniquely patients' perspective, in all relevant EU health developments and some exciting new projects on the horizon:

- We launched our EPF Manifesto '150 million reasons to act' calling for action at both EU and national level on patient-centred healthcare.
- We have been an active partner with the European Commission in the EU Campaign 'A Europe for Patients'.
- Several new member organisations joined us in 2008 and several more potential members are ready to join us in the near future.
- We have invested in powerful communications and key events to get our policy messages across both internally and externally; our partnerships with fellow health stakeholders have strengthened greatly in 2008.
- We have extended our funding base with more sustainable corporate partners from the broader healthcare arena, and embarked on 4 EU-funded projects.
- Our updated Code of Ethics and Framework for working with funding partners reflect our unequivocal commitment to transparency and independence.

I would like once again 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 that 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.

Anders Olauson
EPF President

Five Core Strategic Goals for EPF

EPF developed a five year strategic plan in close consultation with our 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. No patients' organisation is too small to contribute to our work.

Executive Summary: Key EPF Achievements and Milestones in 2008

EQUAL ACCESS FOR PATIENTS

- The theme of EPF's Annual Spring Conference in April 2008 was 'Health Literacy'. The Conference convened a wide range of players to address health literacy and how to ensure it becomes a political and programmatic priority throughout the European Union. We were honoured to welcome Commissioner Vassilou who gave a keynote speech exploring health literacy in the context of the EU Health Strategy 'Together for Health'.

- Cross Border Healthcare - a major policy arena in 2008 has been the draft Directive on patients' rights in cross border healthcare, which we welcomed and are supporting, because of its focus on patient safety and quality of care. We have also campaigned actively for some changes in the Directive to make it as inclusive and equitable as possible.

- Information to patients continued to be a top policy theme for EPF in 2008. EPF responded to the Commission's consultation on a legislative proposal on information to patients in April and discussed this extensively at both internal and external meetings. A package comprising a proposal on information to patients, fake medicines and pharmacovigilance was adopted in December 2008 and will be a major focus of EPF's work in 2009.

- We have continued to engage very actively and given concrete input from a patient's perspective in all aspects of the High Level Pharmaceutical Forum. This is reflected in the final conclusions and recommendations adopted by the High Level Ministerial Meeting in October 2008. Significant time towards the end of the year was devoted to the co-organisation, in cooperation with the European Commission, of a major Conference on the outcomes of the Forum for patients and other stakeholders to be held in March 2009.

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 and was launched successfully in February 2008. Our regional advocacy seminar in November 2008 was a great opportunity to review the initial findings of VALUE + and explore their relevance with patient leaders in the region.

- EPF's representation in major EU level Health Forums, Consultative Committees and Working Groups has continued to grow. 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 and will become a working group on quality of care), the Pharmaceutical Forum and the European Union Health Policy Forum, the Open Health Forum, the Health Systems Working Group, we are involved in the Editorial Board of the Health Portal, and the eHealth Users' Stakeholders Group, the EMEA Management Board and the EMEA Patient and Consumer Working Party.

- EPF has been actively involved in the European Commission's campaign 'A Europe for Patients' and our President gave a speech at its launch in September and chaired a specific session on 'A Europe for Patients' at the Open Health Forum in December where stakeholders reviewed the added value of the campaign and how it could be taken forward at member state level. This will continue to be a key area of work for EPF in 2009.

- EPF has also cooperated with Active Citizenship Network regarding the promotion of a European Patients' Rights Day on 18 April, and their efforts to obtain recognition of the Day with all the Institutions.

PATIENTS' PERSPECTIVE

- EPF's Manifesto '150 Million reasons to act' was launched in the European Parliament and applauded widely by key 'health-focused' MEPs. By the end of 2008 our campaign to promote the EPF Manifesto, in preparation of the European Parliament Elections in June 2009, was well underway both in Brussels and throughout the European Union, thanks to our member organisations' engagement and support.

- EPF drafted, consulted and agreed the following position papers / statements with our membership in 2008:

    - EPF's response to a Commission consultation on a legislative proposal on information to patients
    - EPF's response to a Commission consultation on patient safety
    - EPF's response to a Commission consultation on pharmacovigilance
    - EPF's response to a Commission consultation on medical devices
    - EPF's response to DG Sanco's 'Future Challenges' Paper 2009 -2014
    - EPF's statement on the Commission's draft Directive on Patients Rights in Cross Border Healthcare
    - A joint NGO statement on cross border healthcare
    - EPF's response to the Telemedicines Communication

- We also cooperated with IAPO regarding a response to the Commission's consultation on counterfeiting of medicines.

- A Press Release / Mailing was circulated on the following issues:

    - The Spring Conference outcomes on Health Literacy
    - The EPF Patients' Manifesto
    - EPF cooperation with PGEU (European Pharmacists)

- EPF has participated as speaker, chair or moderator in over 50 EU health meetings in 2008, presenting EPF and its membership'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 and many have been active in supporting the EPF Patients' Manifesto and the European Parliament Health Literacy Declaration, that we are promoting as part of the Manifesto.

SUSTAINABLE PATIENT ORGANISATIONS

- EPF has been successful in diversifying its funding sources with some income from the Commission for 4 projects initiated in 2008. EPF's application for core funding was not accepted in 2008, and further applications will be made in the framework of the new Public Health Programme 2009. EPF has also been able to extend its range of industry sponsors to the broader healthcare environment.

- For the first time, EPF held our Autumn Advocacy Seminar at regional level. 50 patient leaders from the Baltic countries, Czech Republic and Poland participated in a seminar in Lithuania in November. The seminar was very well received by all involved and EPF is in the process of following up recommendations linked to the EPF Manifesto and ongoing action at member state level regarding our policy work.

PATIENT UNITY

- Linked to the goal to nurture and promote solidarity and unity across the EU patients, the EPF membership was enlarged to 36 members by the end of 2008. We were pleased to be able to welcome umbrella patient organizations from the UK and Latvia.

- The EPF Annual General Meeting in April 2008 was well attended with lively discussion. In terms of governance, EPF's audited accounts and annual report for 2007 were accepted, and a new board was re/elected for a further 2 year term.

This Annual Report pinpoints some of the highlights for EPF during 2008. It has again 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, particularly through our regional seminar and our Manifesto work at national level.

It was also a year of some disappointment – notably the rejection of our proposal for an operational grant which would have helped to ensure an even more diversified funding portfolio and provided opportunities for further development work.

Enlarging our funding base will certainly be one of our central aims for 2009 - alongside ensuring the array of proposals emerging from the Commission with a direct impact on patients, really put patients at the centre.

EPF Governance in 2008

The EPF Annual General Meeting in April 2008 welcomed four organizations as new full members: the Long-term Conditions Alliance in the UK, the Polish Patients Forum, the Thalassaemia International Forum, and the European Federation of Associations of Patients with Haemochromatosis. Mental Health Europe, and Movimento Consumatori were approved as associate members.

A further four member organizations were accepted by the board during the second half of 2008, to be ratified at the AGM 2009.

The AGM re-elected unanimously EPF President Anders Olauson, EPF Vice President Susanna Palkonen, and EPF Treasurer Mike O'Donovan. A further two new board members were elected: Panos Englezos from Thalassaemia International Federation and Paul Arteel from Gamian Europe, who stood down in August, due to a national appointment as Ombudsman in Belgium (Flemish Community).
The board then co-opted Rainald Von Gyswki from Retina Pigmentosa Europe.

Albert Jovell, President of the Spanish Patients' Forum and Christian Saout, President of the National Platform of Patients' Organisations in France continued their second year of office.

Jean Georges (Alzheimer Europe) stood down as Member of the Board and was warmly thanked for his significant contribution to EPF since its foundation in 2003. Mr. Georges expressed his ongoing and active commitment to EPF as a non-board member in the future.

The Annual General Meeting approved unanimously the Annual Report and accounts for 2007 and the EPF Work Plan and budget for 2008.

The new EPF board met for a one day 'retreat' in Ghent, Belgium, in June 2008, where the board re-examined our strategic plan, work priorities, branding and relationships with fellow health stakeholders.

EPF made application to the Commission's On-Line Registry of Interest NGOs set up in October 2008 as part of the European Transparency Initiative.

EPF Policy Orientation in 2008

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

EPF has worked extremely hard to enhance its political impact in 2008 and its capacity to be pro-active and agenda-setting. This section gives an overview of the major initiatives undertaken throughout the year.

THE EPF SPRING CONFERENCE 2008 ON HEALTH LITERACY

The EPF Spring Conference 2008, a unique opportunity to address the theme of health literacy at EU level, brought together 130 patient leaders, health policy makers and health stakeholders from throughout the European Union to explore health literacy, its importance and why and how this should be taken forward as a policy priority.

Opening the conference, the new Health Commissioner Androulla Vassiliou said: "The patient-centred vision of healthcare today calls for greater empowerment for patients. This is an essential step if we are to achieve improved quality of care and health outcomes leading to a better quality of life. Patients' empowerment and health information should be seen as an objective that can only be successfully achieved through a series of partnerships, involving all the relevant stakeholders. There is a need for co-ordinated actions involving other policy areas, such as education, social and economic policies".

The main conclusions and recommendations emerging from the two days' discussions have been included in a comprehensive report on the Conference available on the EPF website.

These recommendations focus upon:

- The need for further research, particularly regarding the costs of health illiteracy
- The importance of setting up an EU level Health Literacy Network
- Wider distribution of health information and information to patients that meets core quality criteria
- Patient and health professional education and productive dialogue between patients and healthcare providers
- The meaningful involvement of patients

Collectively, these recommendations will be used to strengthen the 'health literacy' component of the EU Health Strategy 'Together for Health'. The European Patients' Forum is committed to contributing actively in taking forward these recommendations in partnership with the European Commission and other stakeholders.

With the support of a number of key 'health' MEPs, we are working towards the adoption of a Health Literacy Declaration within the European Parliament.

We will also engage in cooperation with a project due to commence in early 2009 that will set up a health literacy research network in a number of Member States.

THE PHARMACEUTICAL FORUM

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.

The final meeting of the High Level Pharmaceutical Forum took place on 2 October in Brussels. EPF was represented by our President Anders Olauson. The primary focus of the meeting after three years' work, was the adoption of the final conclusions and recommendations for the future. Participants were also invited to comment on the process and reflect on how to take the results forward. All of the documents pertaining to the Pharmaceutical Forum are on the following website http://ec.europa.eu/pharmaforum/.

EPF and our representatives and staff have been very committed to the entire Pharmaceutical Forum process and have contributed constructively and actively to all of the work areas: information to patients (Susanna Palkonen), pricing and reimbursement (Christoph Thalheim) and relative effectiveness[1] (Albert Jovell), from a patient's perspective. This contribution is largely reflected in the Conclusions and the Recommendations of the Forum, and the final report, which we were able to support wholeheartedly.

The Conclusions and Recommendations were adopted formally during this last meeting and all Member States were positive about both the process and the outcomes, in spite of some of the clear challenges. They committed to taking forward the results at national level and engaging in follow up activities.

In his statement to the Forum on behalf of EPF, the EPF President said: "EPF would like to express once again our congratulations to the Commissioners, their officials, the Member States and all of the stakeholders for their tremendous efforts and cooperation — and the achievements. Noone can say this was an easy process – so many different players with very different perspectives – but a crucially important one because of that. We have gained a greater insight and understanding and I believe the recognition of the importance and value of working in partnership – Member States and stakeholders together. We can all be proud of this legacy.

With regard to the specific outcomes, we believe that the wide range of tools and reference documents produced in each of the working groups will be of lasting value on a number of levels. A pertinent example is the inclusion of 'quality principles on information to patients' in the forthcoming Commission proposal on information to patients, providing clarity and authority on what constitutes high quality information.

We know from talking to patient group allies at national level that these tools could be widely used in patient communities across Europe.

We are very pleased that the Pharmaceutical Forum recognises the need to enhance health literacy as a policy at both European and national levels. From a patient's perspective, health literacy is critical to enable patients to genuinely manage their health and condition. We cannot circumvent this.

We also welcome the clear sign posting towards a comprehensive and coherent information to patients strategy at EU level and how it could be taken forward in practice – this is one of the key 'by-products' of the Pharmaceutical Forum in our view and one that will help to ensure that all patients throughout the EU access the information they need, when they need it."

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[1] *Scientific and health economic assessment of relative effectiveness of medicinal products*

For a complete version of Anders Olauson's intervention, please go to the EPF website www.eu-patient.eu/.

EPF will be co-organising a conference on the outcomes of the Pharmaceutical Forum and their dissemination among patient groups and the Health Community at large. The Conference will take place on 25 March 2009 and will be followed by the EPF Annual General Meeting on 26 March 2009.

The conference should provide patients' leaders and health stakeholders throughout the European Union an opportunity to share the knowledge gathered by the members of the Forum on information to patients, pricing & reimbursement and relative effectiveness, to explore the solutions proposed and to put forward proposals for actions for implementation and follow up with their respective organisations.

EPF – PUTTING PATIENTS AT THE CENTRE OF EU HEALTH POLICY

- EPF drafted, consulted and agreed the following position papers / statements with the Membership in 2008:
    - EPF's response to a Commission consultation on a legislative proposal on information to patients
    - EPF's response to a Commission consultation on patient safety
    - EPF's response to a Commission consultation on pharmacovigilance
    - EPF's response to a Commission consultation on medical devices
    - EPF's response to DG Sanco's 'Future Challenges' Paper 2009 -2014
    - EPF's statement on the Commission's draft Directive on Patients Rights in Cross Border Healthcare
    - A joint NGO statement on cross border healthcare
    - EPF's response to the Telemedicines Communication
    - EPF's contribution to the eHealth Patient Charter

For further details and timelines on these policy inputs please visit the EPF website.

EPF INVOLVEMENT – EXAMPLES OF INVOLVEMENT IN COMMISSION HIGH LEVEL GROUPS

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 organisations 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.



EHEALTH USERS’ STAKEHOLDERS GROUP

EPF is a member of the Commission eHealth Users’ Stakeholders Group, which is an advisory group of the 2010 Subgroup on eHealth, 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 eHealth Interoperability and the Commission Working Document on processing personal data related to electronic health records.

A major focus of the work in 2008 was the Commission Communication on Telemedicines

THE EUROPEAN UNION HEALTH POLICY FORUM

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

In December, the EU Open Health Forum took place and convened over 500 health stakeholders at member state level to explore advances in the EU health policy. The EPF President chaired a parallel session on a ‘Europe for Patients’ and EPF speakers gave presentations in the other sessions on e-health and health and young people. This helped to raise awareness about EPF and our input in these priority areas.

COOPERATION WITH THE EUROPEAN MEDICINES AGENCY EMEA

EMEA activities in which EPF is involved include:
- 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 was represented in the EMEA Patient and Consumer Working Party by Mike O’Donovan, who at the end of 2008 was appointed as one of two patient representatives to the EMEA Management Board.

SEVENTH FRAMEWORK PROGRAMME ON RESEARCH AND DEVELOPMENT (FP7)

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

EPF is involved as an associate partner in a project funded under FP7 entitled ‘RESPECT’ that will explore the meaningful involvement of young patients in clinical trials.

EPF Harnessing the Patients' Evidence and Experience

THE EPF AUTUMN REGIONAL ADVOCACY SEMINAR

For the first time, EPF held our Autumn Advocacy Seminar at regional level in Vilnius, Lithuania on 27, 28 November: over 50 leaders of patient organizations from the Baltic countries, the Czech Republic and Poland met for two very intense days of work.

This year the seminar was linked to the project VALUE + and was therefore prepared in cooperation with the partners of the project, in particular the Health Policy Center of Lithuania.

The purpose of the seminar was to build knowledge and know-how on working at EU level through and with EPF and explore initial findings from the VALUE + project. The delegates represented patients' organizations mainly from Lithuania, Estonia, Poland, the Czech Republic and Latvia.

The first part was dedicated to an introduction to EU policy-making and decision-making processes. The perspectives were quite diverse since the speakers came from the European Parliament, different bodies of the European Community, the patient community and the Czech Republic Government. The audience appreciated greatly the practical and concrete insights the speakers brought from their experience and expertise.

The other main focus was VALUE +, which was introduced to the delegates. VALUE + is conducting an assessment of patient involvement in health-related projects supported by the European Commission. The findings to date were shared.

Delegates had the opportunity to address more in depth some of the issues touched upon during the plenary sessions in a series of workshops.

The full report of the seminar can be found on the EPF website.

The seminar was supported by an unrestricted educational grant from EFPIA.

VALUE +

In February 2008, EPF began its first major EU project, VALUE +, that focuses on meaningful patient involvement in EU health projects. Coordinated by EPF, VALUE + involves 7 other partners and will last for two years.

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 both EU and 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; 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.

After almost one year of intensive work, VALUE + has made great progress in assessing the real involvement of patients in health projects already completed. We worked through surveys and a focus group and further activities will be undertaken in 2009. The preliminary findings of this assessment were presented at the EPF Autumn Seminar in Vilnius in November 2008. The presentation can be found on www.eu-patient.eu.

The seminar itself was a real success in sharing experiences on challenges and benefits of involvement both at European and national level.

We also agreed cooperation with a number of projects still running or recently started. We plan to help them look into the involvement of patients in their projects and work towards improving it. The core of this work will happen next year.

The knowledge we are acquiring from the field is being completed by a thorough literature review that we carried out to help us identify barriers to involvement and factors affecting it.

Much dissemination work was also done through EPF's various communication channels as well as those of VALUE + partners'. A specific web page was created where you can access more detailed information: www.eu-patient.eu/projects/valueplus/index.php.

RESPECT

The purpose of RESPECT is to empower children and adolescents participating in clinical trials with the ultimate aim of increasing paediatric trials and provide treatments and drugs more appropriate and effective for children than those actually provided.

The project kicked off in June 2008 and to date we are engaged in a literature review and also interviewing young patients participating in clinical trials in different countries. Further activities will be focus groups, surveys and workshops. More information is available at: www.eu-patient.eu.

EPF Capacity Building and Development of the Secretariat in 2008

THE EPF SECRETARIAT

The EPF Secretariat welcomed three new team members in 2008. Liuska Sanna joined EPF in January 2008 as Programme Officer and Valentina Strammiello joined in October 2008 as Office Manager.

Elisabeth Kalsingam who joined us as an intern and assistant policy officer in October 2007 left at the end of 2008. A new intern, Sophie Letorey joined the secretariat in December 2008.

Zilvinas Gavenas continued to work with EPF as IT consultant / webmaster.

Amanda Casey continued to support EPF with the coordination of our Spring Conference on Health Literacy.

Roxana Radulescu who joined the team as full time Policy Officer in January 2007 was promoted to Senior Policy Advisor at the end of 2008.

Nicola Bedlington continued as EPF Executive Director.

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 2007 accounts and these were presented to the Annual General Meeting in April 2008. They were then posted on the EPF website.

In March 2008, EPF moved to new accessible offices on Rue Belliard, very close to the EU Institutions. The office includes meeting space and an office facility for member organizations visiting Brussels.

EPF Growing the Membership – Initiatives in 2008

EPF's membership grew from 30 to 36 members in 2008. The most significant area of growth is in relation to national platforms of patients' organizations. Such 'umbrella' platforms composed of national patients' associations from UK and Latvia became full members.

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

We were also very pleased to welcome Mental Health Europe as an associate member, 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 2009.

EPF Alliance Building and Representation at External Meetings during 2008

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 2008. 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 of all of these meetings;

A few highlights include presentations at:

- The European Patient Education and Health Literacy Conference, January 2008, Barcelona, in which EPF also played a co-ordinating role;
- The IAPO Conference, Session on Information to Patients, February 2008, Budapest;
- The Patients' Rights Day Conference, 18 April 2008, Gorizia;
- The EU Slovenian Presidency Conference 'E-Health without frontiers', May 2008;
- The EU French Presidency Conference on Health Challenges in Europe, September 2008, Paris;
- The EU French Presidency Conference on an EU for patients, October 2008, Paris;
- The EU Health Forum Gastein – Plenary session on ethics, and presentations on prevention and the Pharmaceutical Forum, October 2008, Gastein;
- The European Health Technology Assessment Conference, November 2008, Paris;
- The European Parliament / CONTINUA Seminar on Telemedicines, December 2008, Brussels;
- The European Policy Summit 'Long Live Europe – Shaping our Healthcare Revolution', December 2008, Brussels;
- The EU Open Health Forum, December 2008, Brussels

EPF ALLIANCE BUILDING

In 2008, EPF continued to place much importance on continuing to foster alliances and good working relations with European organisations with which we have a common agenda. These include the European Public Health Alliance (EPHA), the European Standing Committee of Doctors (CPME), the European Federation of Nurses (EFN), the European Pharmacists Organisation (PGEU), the European Hospitals Association (HOPE), the European Health Management Association (EHMA), the European Consumer Association (BEUC) etc.

We also continue our close relationship with our sister organisation at international level, the International Alliance of Patients' Organizations, in line with our Memorandum of Understanding.

The following are some specific examples of our partnership work:

- IAPO and EPF have worked together on core policy themes, for instance, IAPO supported EPF's work on information to patients, and EPF supported their work on counterfeiting.

- In September, the EPF board and director held a joint board meeting with the board and key staff of PGEU to discuss our respective work and future cooperation.

- EPF and CPME adopted a set of 'Joint Principles' that look at the new Doctor / Patient relationship, at our respective Annual General Assemblies in 2008. This has been followed up with specific cooperation on the theme of health literacy and cross border healthcare.

- EPF worked also with the European Public Health Alliance and the European Health Management Association in relation to developments on cross border healthcare. This resulted in a joint statement to the Council in December 2008, encouraging stronger leadership and commitment to principles around patient safety and quality of care.

- EPF Treasurer and Director met with leading representatives of the Royal College of Physicians to discuss their work on meaningful involvement of patients and how to promote health literacy.

- EPF cooperated closely with EFN with regard to promoting the potential of the EU structural funds to advance EU policy commitments to health at member state level. An illustration of this is the high level meeting set up with representatives of DG SANCO and DG Employment to address the way forward.

PARTICIPATION IN THINK TANKS AND REFLECTION GROUPS OUTSIDE THE COMMISSION

EPF is a member of:

- The EFPIA Think-Tank with patients groups that met 4 times in 2008 and is a member of its steering group
- The GSK Health Advisory Board
- The EUROPA BIO Patient Advisory Board
- The steering group of the Centre for Health, Ethics and Society (CHES)
- The steering group preparing the French EU Presidency Conference ‘An EU for Patients’

In 2008, we have been active in building relationships with consortia such as CONTINUA in relation to e-Health, and COCIR in relation to medical devices.

EPF Knowledge Management and Communications – Developments in 2008

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, and with a clear archiving system to facilitate research.

EPF continues to produce our EPF 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. It is now also available on the EPF Website.

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 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. For example, we featured in the European Parliament Magazine's special issue on health where we launched the EPF Patients' Manifesto.

During the course of 2008, 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 their impact. This has been implemented throughout 2008. A medium-term objective for EPF is to recruit a communications officer.

A key communications / campaign tool developed during the course of 2008 is the EPF Patients' Manifesto '150 Million reasons to act', launched in the European Parliament in September 2008.

The European Parliament Elections and new Commission 2009 offer a unique new opportunity for the European Patients' Movement, through the EPF membership and patient group allies to mobilise politicians and policy makers to commit to act, and to work towards equitable, patient-centred, high quality healthcare for all patients throughout the European Union.

This will only be achieved if there is a consistent and persistent campaign at both EU and national level that demonstrates unequivocally the strength of the united patients' voice and our 'political' power – through 150 million patients and their families and allies, who are citizens and voters. EPF has developed, alongside the Manifesto, a campaign guide and further tools to support our membership in their campaign work on the Manifesto at national level.

Funding Sources and Diversification – Initiatives to the end of 2008

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

EPF has 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 Ethics and Framework, revised in 2008, ensures that EPF's relationship with sustainable funding partners meets the highest standards of transparency and independence.

A funders meeting was held in September 2008 to discuss with all our funders progress and successes in relation to EPF's work plan 2008 and our plans for 2009 and beyond.

The EPF Board and Secretariat were proud to launch our first EU-funded project in 2008: VALUE +. We 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. We are also active in a project called 'CALLIOPE', looking at the interoperability of health systems across the EU. All four projects commenced in early 2008.

EPF allocated considerable resources to apply for an operational grant in 2008 under the Public Health Programme. Unfortunately, this was rejected. EPF is in close dialogue with the Commission on this issue and will re-apply for Commission funding in 2009.

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

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

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

EPF Members Organisation 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
Albert Jovell - Spanish Patients' Forum - Board Member
Raynald Von Gizycki – (Retina Europe) - Board Member
Christian Saout - CISS (Patients' Forum, France) - Board Member
Panos Englezos - (Thalassaemia International Federation) - Board Member
Paul Arteel - (Flemish Association for Mental Health) - Board Member

EPF Secretariat Team

Nicola Bedlington - Director
Roxana Radulescu - Senior Policy Officer
Liuska Sanna - Programme Officer
Zilvinas Gavenas - IT/Web Consultant
Valentina Strammiello - Office manager
Sophie Letorey - Assistant Policy Officer

Full Members

Organization	Representitive	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
Age Related Macular Degeneration (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

Collectif inter associatif Sur la Santé (CISS)	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)	Vida Augustiniene	Gedimino av. 28/2 – 404 LT 01104 Vilnius Lithuania	Tel: + 37 05 26 20 783 Fax: + 37 05 26 10 639 info@dia.lt info@pacientutaryba.lt www.pacientutaryba.lt
EUROPA DONNA - The European Breast Cancer Coalition	Susan Knox	Piazza Amendola, 3 20149 Milan Italy	Tel: +39 02 36 59 22 80 Fax: +39 02 36 59 22 84 susan.knox@europadonna.org
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[at]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[at]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[at]pp.inet.fi rod.mitchell[at]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[at]brutele.be www.efhpa.com

European Federation of Associations of Patients with Haemochromatosis	Jean Rialland	1 Bld Jeanne d'Arc 35000 Rennes France	Tel: + 33 299870515 jean.rialland@club-internet.fr www.european-haemochromatosis.eu
European Genetic Alliances Network - EGAN	Cor Oosterwijk	C/o VSOP - Dutch Genetic Alliance Vredehofstraat 31 3761 HA Soestdijk The Netherlands	Tel: + 31 35 603 4040 Fax: + 31 35 602 7440 egan[at]egan.eu c.oosterwijk@vsop.nl www.egan.eu
European Heart and Lung Transplant Federation	David Walker	513 Victoria Road South Ruislip Middlesex HA4 OHA United Kingdom	Tel: (+44) 20 8845 4113 Fax: (+44) 7737 462731 walker_david8@sky.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	Timo Nerkko	Käskynhaltijantie 14 A 4 FI-00640 Helsinki Finland	Tel: + 358 50 559 3367 timo.nerkko@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
European Multiple Sclerosis Platform	Christoph Thalheim	Rue Auguste Lambiotte 144/8 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 (ENUSP)	Peter Lehmann	Zabel-Krüger-Damm 183 13469 Berlin German	Tel: + 49 30 85963706 (Mo, We & Fr, 10 a.m. - 4 p.m. Central European time) Fax: + 49 30 40398752 info@enusp.org info@peter-lehmann.de www.enusp.org
EURORDIS European Organisation for Rare Diseases	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

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 www.federacjapp.pl
Foro Español de Pacientes	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 Global Alliance of Mental Illness Advocacy Networks	Guadalupe Morales	C.E.O - Richmond Foundation- 9 Valletta Road Mqabba ZRQ 08 Malta	Tel: 619 07 31 12 Tel: 91 356 78 73 Fax: 91 361 52 73 guadalupemorales@mundobipolar.org www.gamian-europe.org
International Diabetes Federation - Region Europe	Lex Herrebrugh	Regional office Avenue Emile De Mot 19 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 United Kingdom	Tel/Fax: + 44 1503 250 668 Mobile: + 44 7736 366 137 david@ipopi.org www.ipopi.org
Long-term Conditions Alliance	David Pink	202 Hatton Square 16 Baldwins Gardens London EC1N 7RJ United Kingdom	Tel: + 44 207 813 3637 Fax: + 44 207 813 3640 info@ltca.org.uk
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
SUSTENTO The Latvian Umbrella Body For Disability Organization	Marta Kozireva	Nicgales str.26 Riga Latvia	Tel: + 371 67594137 Fax: + 371 67802546 sustento@sustento.lv
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

Associate Members

Organization	Representitive	Address	Contacts
APAI Associazone 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
Debra Europe Organisation of people with epidermolysis bullosa	John Dart	Debra House 13, Wellington Business Park Dukes Ride Crowthorne Berkshire RG45 6LS United Kingdom	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 United Kingdom	Tel: + 44 207 704 31 41 Fax: + 44 207 359 14 47 post@gig.org.uk www.gig.org.uk
European Coalition of Positive People - ECPP	Colin Webb	2 Whitehorse Mews Westminster Bridge Road London SE1 7QD United Kingdom	Tel: + 44 20 7401 9942 Fax: + 44 20 7401 9690 cwebb@ecpp.co.uk www.ecpp.co.uk
Hungarian Osteoporosis Patient Association HOPA	Klara Zalatnai	Karolina 27 1113 Budapest Hungary	Tel: + 36 (1) 209 0361 obme@obme.hu
Mental Health Europe	Mary Van Dievel	Boulevard Clovis, 7 1000 Bruxelles Belgium	Tel: + 32 2 280 04 68 Fax: + 32 2 280 16 04 info@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

Provisional Members

Organization	Representitive	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

Provisional Members to be approved at 2009 AGM

Organization	Representitive	Address	Contacts
Pro-Chiropractic Europe	Ann-Liis Taarup	Frederikkevej 2 A Hellerup Copenhagen DK- 2900	Tel: + 45 39400540 Fax:+ 45 39400540 etogalt@mac.com
LUPUS Europe	Rudolph Hocks	Yvonne Norton MBE 8/Legge Lane Coseley, West Midlands UK- WV14 8RQ	Rhlupus@aol.com
Pancyprian Federation Of Patients Associations and Friends	Pavlos Dinglis	P.O.BOX:23966 Nicosia 1687 Cyprus	Tel: + 357-22378539 Fax: + 357-22378381 cardio@cytanet.com.cy

Accounts and Audit Report

European Patient Forum Balance sheet as of December 31, 2008

	2008	2007
ASSETS		
I Fixed Assets		
Computer's equipment	0.00 EUR	2,504.90 EUR
Guarantee to Nci and Axa	10,706.72 EUR	4,250.00 EUR
II Current assets		
Accounts receivable	1,619.74 EUR	0.00 EUR
Cash in bank and on deposit	463,023.89 EUR	421,448.30 EUR
Accruals	7,126.00 EUR	0.00 EUR
TOTAL ASSETS	482,476.35 EUR	428,203.20 EUR
LIABILITIES		
I Capital and reserves		
Funds brought forward	221,130.62 EUR	156,108.24 EUR
Surplus for the year	59,651.62 EUR	65,022.38 EUR
II Debts		
Payment received in advance	125,396.65 EUR	0.00 EUR
Accounts payable	76,297.96 EUR	34,072.58 EUR
Income to be received	0.00 EUR	173,000.00 EUR
TOTAL LIABILITIES	482,476.85 EUR	428,203.20 EUR

European Patient Forum Profit and Loss account - 31 December 2008

	2008	2007
INCOME		
Membership fees	7,252.00 EUR	5,353.00 EUR
Corporate Sponsorship	322,500.00 EUR	275,000.00 EUR
Spring Conference	109,203.35 EUR	107,000.00 EUR
Autumn Seminar	35,000.00 EUR	75,000.00 EUR
Value +	52,617.51 EUR	
Other Projects	50,646.40 EUR	
Interest - Other Income	12,310.52 EUR	8,962.24 EUR
TOTAL INCOME	589,529.78 EUR	471,315.24 EUR
EXPENDITURE		
Staff and fees	-261,551.24 EUR	-201,629.04 EUR
Office costs	-66,681.64 EUR	-45,995.58 EUR
Travel	-27,173.47 EUR	-25,909.62 EUR
Events (Spring Conference)*	-109,227.27 EUR	-107,807.24 EUR
Events (Autumn Seminar)*	-29,780.30 EUR	-69,187.90 EUR
Value +*	-88,524.77 EUR	
Other Projects*	-50,900.00 EUR	
Communications	-20,955.57 EUR	-4,222.81 EUR
Bank fees and holyday pay provision	-11,555.83 EUR	-5,444.89 EUR
TOTAL EXPENDITURES	-666,350.09 EUR	-460,197.08 EUR
SECRETARIAT INCOME	136,471.93 EUR	53,904.22 EUR
SURPLUS FOR THE YEAR	59,651.62 EUR	65,022.38 EUR

* *See note included*

European Patients’ Forum Non-for-profit Organization

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

Report for the year ended 31 december 2008

We have audited the financial statements of European Patients’ Forum (“the Organization”) for the year ended 31 December 2008, which show a balance sheet total of **€482,476** and a profit for the year of **€59,652**.

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 2008 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.

A branch has been opened in Belgium in 2008.

Project accounting might require a full analytical accounting system, as in my opinion the current accounting system does not meet this requirement.

Brussels, February the 20th, 2009
FIDINTER BVBA, represented by F.Léonard, director

Acknowledgement of Financial Support

EPF wishes to thank the following sponsors for their support in the form of unrestricted grants for EPF's operational programme 2008:

GIRP	2,500 EUR
EFPIA	15,000 EUR
GE-Healthcare	15,000 EUR
GSK	40,000 EUR
Astrazeneca	50,000 EUR
MSD	50,000 EUR
Novartis	50,000 EUR
Pfizer	50,000 EUR
PhRMA	50,000 EUR

EPF wishes to thank the following sponsors for their support in the form of an unrestricted grant for EPF events in 2008:

EFPIA	35,000 EUR for the EPF Regional Advocacy Seminar 2008
GSK	50,000 EUR
And Pfizer	50,000 EUR for the EPF Spring Conference on Health Literacy 2008

EPF wishes to thank the European Commission for their support in 2008 in relation to EPF's role in the following projects:

Value + (EPF- coordinator)	Total subsidy over 2 years: 300,000 EUR Income in 2008 - 52,617.51EUR
RESPECT (EPF- Associate Partner)	Subsidy for 2008: 19,600 EUR + 20,000 EUR carried forward to 2009
EUnetPAS (EPF- Associate Partner)	Subsidy for 2008 7,646.40 EUR

www.eu-patient.eu