The European Patients’ Forum Annual Report 2006
The European Patients Forum (EPF) was founded in 2003 to become the collective patients’ voice at EU level, manifesting the solidarity, power and unity on emerging EU patients’ movement. EPF facilitates exchange of good practice and challenging of bad practice on patients’ rights, equitable access to treatment and care, and health-related quality of life between patient organizations at European level and at Member States level. EPF’s vision for the future is a patient-centered, equitable healthcare throughout the European Union. EPF currently represents 23 European member organizations.
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Introduction

Welcome to the EPF Annual report 2006

This report is intended to give you a brief overview of our work during 2006. For more detailed information you are invited to visit the EPF website at www.eu-patient.eu or contact the EPF secretariat at info@eu-patient.eu

We have taken the opportunity in this report also to present a review of key activities undertaken by EPF since its establishment in 2003, and a little history and rationale behind the setting up of our organisation.

EPF’s vision is patient-centred, equitable health care in Europe. 2006 was an important and challenging year for the organisation in moving towards that vision. In 2006, we set up the secretariat in Brussels, with a small and highly committed staff to support EPF and our members in achieving our goals. The strategic planning process during 2006 involved the entire membership, and resulted in a clear blueprint and priorities for the coming years.

Our finances are stable through extensive fundraising efforts, and we are striving continuously to diversify our funding base.

The demands on EPF, to present a patients’ voice on key health care debates at EU level have never been greater, with major work taking place in 2006 around “information to patients”, health mainstreaming, the health service consultation, transparency and the new EU health strategy.

I feel we have the capacity to respond to these demands in an authoritative and professional way that genuinely reflects the views and aspirations of our diverse members. On-going consultation with the membership on position papers and statements have resulted in powerful input that I believe will really make a difference.

To facilitate our communication we set up the EPF internal mailing and launched a new website in 2006, both of which have been warmly received.

Partnership has been at the heart of much of our work in 2006 and we have developed and enhanced cooperation with a whole range of actors on the EU Healthcare stage.

I would like to take this opportunity to thank EPF members and our allies in the European Union for your significant investment in all this work and to congratulate you on our collective achievements. I look forward very much to our continued teamwork to ensure that patients are at the centre of all EU healthcare developments.

Anders Olauzon, President
Summary - EPF Key Achievements and Milestones for 2006

- Strategic input from a patients’ perspective to the High Level Pharmaceutical Forum, and other high level Commission-led initiatives of health (patient safety, stakeholder involvement, e-health).

- Focus on transparency and independence, with the development of relevant documentation and data on the EPF website, and contribution from a patients’ perspective to the EU Transparency Initiative.

- Policy influence in relation to major EU health developments including “information to patients”, health and telematics, medical devices, health services consultation, health policy strategy, structural funds, and the Seventh Framework Programme on Research and Development.

- Development of our relationship with selected MEPs with a commitment to patients’ rights, and relevant Council officials particularly in the contexts of the EU Presidencies.

- Keynote addresses at major EU healthcare events (e.g. Bad Gastein, European Health Policy Forum, Friends of Europe).

- Alliance-building with EU health-related NGOs, thinktanks, agencies and industry bodies, and recognition as a member of the EMEA working group on patients.

- Growth of the EPF membership with 5 new organisations set to join EPF, and a membership review to clarify status of existing members.

- Launch of the new website as EPF’s communication flagship

- Regular monthly mailings to EPF members and patient allies, to update, brief and consult this target group on EU health care developments from a patients’ perspective.

- Establishment of the EPF secretariat, with 4 staff in offices in the heart of the EU.

- Undertaking of a Strategic Planning Exercise with the members to be finalised at the beginning of 2007 to result in a five year strategic plan for EPF to tie in with the next EU financial framework.

- Achievement of a more solid financial base with a broader range of industry supporters, and setting the scene for Commission funding in the near future.
SECTION 1 – Pre-2006

A brief history of the development of European Patients’ Organisations

In Western Europe a number of patient organisations came into being during the 1970s covering a variety of chronic conditions. Most of those organisations were local or regional, under-funded and run by motivated patients or family members. Their aims and objectives were often unclear and there was little contact with health professionals or other stakeholders. During the 1980s a number of these organisations operating within the same disease merged to become a national body with a stronger voice and greater recognition politically. Paid staff were engaged and business plans prepared. Organisations became more professional and realised the advantages of collaborating with health professionals.

The next stage of the patient organisation evolution took place in the 1990s when national groups started to come together on a pan-European basis. This was, to some extent, in response to the growth in influence of the European agenda as more countries joined the European Union.

Patient groups advocated that a particular medical condition is the same throughout Europe. The symptoms are no different simply because the patient lives in Sweden as opposed to Spain, or Italy instead of Ireland. Additionally, treatments are, or should be, the same. Members of European patients groups come together to discuss and learn more about illnesses and disease on a European, not a national, basis. The same is true for health professionals and the congresses they hold. Experience tells us that no one country or organisation has all the answers and, we can all learn from one another.

Much of the work of the European Commission on Health rightly focused on the sharing of good practice throughout the European Union which, in turn, avoids wastage of scarce resources through constant wheel reinvention. In the 1990s patients began to recognise these facts more and more and there was a growing appreciation of the hindrance of geographical barriers to the value of sharing ideas and experiences.
As we entered the 21st century, pan-European patient groups realised that there was another stage to negotiate in the evolutionary progress towards maturity. That involved the bringing together of such groups from a variety of disease areas to create the European Patients’ Forum. The incentive for this was the High Level G10 process that was created to examine the development of innovatory medicines combined with the EU obtaining value for money from pharmaceutical companies. In effect, there was no meaningful consultation with patients on this subject. However, at the same time, patient groups appreciated how difficult it was for any section of the European Commission to nominate a "patient representative" as this would invariably give rise to criticism from other groups who were not consulted. With the creation of the European Patients’ Forum, both the Commission and the Parliament would have an automatic first point of reference on any issue relating to health that affects patients.

As a response to this, the European Patients’ Forum was founded by 16 pan-European patient organisations covering a variety of disease areas. Other groups joined the Forum during its first year of operation. The Forum wished also to work closely with the major European bodies representing doctors and nurses as well as with representatives from the pharmaceutical industry.

We all appreciate that the level of resources that may be devoted to health is finite. What we must strive for is to do more with those same resources. This can best be achieved through patient education, information and empowerment that will, in turn, reduce current levels of waste as a consequence of improved diagnostic and compliance rates. Patients should be at the centre of health care delivery. The rationale behind the creation of the European Patients’ Forum was ensure that the voice of the patient is not only heard, but respected and acted upon at a European level.
EPF’s key achievements pre-2006

Please note this is not exhaustive but pinpoints the major events.

In the earlier years, the effectiveness and potential of the Forum became apparent. Firstly, we provided a representative to serve on the Working Group looking at future mental health challenges in Europe. Subsequently, our nomination was accepted by the Commission to serve on the High Level Reflection Process on "Patient Mobility". This examined, amongst other things the possibility of cross border co-operation, the issue of an EU medical card for citizens within the EU and the creation of centres of excellence in Europe.

EPF Conferences pre-2006

EPF’s 1st Conference Driving Better Health in Europe

On 2 September 2004, EPF – in conjunction with Timbro Health Policy Unit - held a conference on the theme of Driving Better Health in Europe.

The conference addressed the areas of compliance and adherence. The aim was to explore how efficiently, or otherwise, health services were used in Europe and to investigate ways to improve the efficiency. The conference also examined the causes behind the current levels of wastage that occur through mis- and non-diagnosis. It was accepted that patients have a responsibility in using the healthcare services efficiently and effectively.

Over 60 people attended the conference, including patient groups from across the EU Member States.

The breakout sessions covered the themes of Doctors and Patients working in Partnership, Barriers to Compliance, From Health Education to Health Literacy, Health Information, education and the future EU health policy.

EPF 2nd Conference – The Value of Health Education and Compliance

On 22-23 June 2005, EPF held its second annual conference, on the theme of Health Education and Compliance. The objective was to show that through
health education and information, patients are empowered to understand their conditions, make informed choices and use the healthcare services in a responsible way. Over 80 people attended the conference, including patient groups from across the EU Member States. A broad spectrum of stakeholders spoke at the conference or moderated the break out sessions (European Commission, European Parliament, of Permanent Representations, patient representatives, health professionals, health NGOs).

The conference ended with specific recommendations that will be built upon to shape the EU health agenda (EU work on health literacy, access to health information, patients at the centre of decision making in health related matters, support of patient groups to facilitate their work). The recommendations are featured in the conference report that has been used since as an advocacy tool.

EPF/EFPIA Training Seminars: Strengthening Patient Groups in the EU

In line with EPF’s objective to provide support to the patient groups through education, empowerment and training, EPF in cooperation with EFPIA held training seminars in Brussels in November 2004, and October 2005. The latter targeted in particular the new Member States.

The aim of the seminars was to exchange best practice between patient groups and to introduce EU patient group representatives to EU health policy making and patient advocacy. Media skills and examples of cross border projects were on the agenda to provide the participants with concrete examples. Meetings between the patient representatives and one of their national Members of the European Parliament (MEPS) were also organised to initiate a relationship.

The second seminar gathered over 60 patient representatives from all ten new Member States. Romania, Bulgaria and Croatia were also represented.

The speakers from the European Commission and the European Parliament gave examples of EU initiatives, the patient representatives shared concrete experiences with past or on-going legislation, while a legal speaker provided some thoughts on patient mobility.

EPF Biosimilar Workshop

On 10 February 2005, EPF held an educational workshop on the topic of biosimilar medicines. The objective was to ensure that patient organisations understood the concept of biomedical products, biosimilar medicinal products, the issues and safety
concerns of these medicines, including their marketing authorisation.

The workshop was held in view of the consultation by the EMEA on its draft guidelines on similar biological medicinal products.

Over 30 people attended the workshop, including patient representatives from the new Member States.

The speakers represented the European Commission, health professionals, the biologic industry and patients.

A report of this workshop was produced and widely distributed and helped EPF shape its contribution to the European Medicines Evaluation Agency, EMEA, consultation with Patients' Organisation.

**Patient Safety Conference 2005**

EPF contributed to the Conference held under the Luxembourg Presidency on Patients Safety and the Declaration emerging from that meeting that outlined recommendations for action to the EU Institutions, National Authorities, and Health Care Providers. EPF also co-drafted and signed a Stakeholders Position on Patient Safety to take forward these recommendations in partnership.
EPF Governance in 2006

At the EPF Annual General Meeting in June 2006, Anders Olauson (EURORDIS) was re-elected as President, Jean Georges (Alzheimer Europe) was elected the new Vice President. Mike O'Donovan (European Multiple Sclerosis Platform) was elected as EPF’s new Treasurer, Astrid Scharpantgen (Europa Donna) and Susanna Palkonen (European Federation of Allergy and Airways Diseases Patients' Associations) were welcomed as board members without portfolio.

Rodney Elgie (GAMIAN), Mara Maccarone (European Forum for Psoriasis Associations), Christoph Thalheim (European Multiple Sclerosis Platform) and Colin Webb (European Coalition of Positive People) were thanked warmly by all members for their enormous contribution as board members to EPF since its inception in 2003. The European Coalition for Positive People was also applauded for its major in-kind contribution to EPF to help to set up the secretariat.

A membership review took place just prior to the AGM in June to clarify the membership status of existing EPF members, in the light of the revised Constitution adopted in January 2006 at an Extra-Ordinary General Meeting; where three categories of members were defined:

- Full;
- Associate;
- Provisional.

The revised Constitution also provided for the inclusion as full members of National Umbrella Patients Organisations, comprising at least 10 national patient organisations.
Policy orientation - EPF working with the EU Institutions

The High Level Pharmaceutical Forum- EPF’s contribution

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

EPF is involved in all three working groups of the Forum (Relative Effectiveness, Pricing and Reimbursement, and Information to Patients), represented by EPF President and Board Members and supported by the Secretariat. At the High Level Ministerial Meeting in September 2006, EPF President highlighted.

‘EPF’s vision is patient centred, equitable healthcare in Europe - as part of the European Social Model based on inclusion and non-discrimination. I think we would all agree that information to patients is core to this.’

Information to Patients

‘Patients have the right to information that enables them to make informed and educated choices about their lifestyle and treatment options.

We have the right to timely, validated information that can be trusted by patients, carers and healthcare professionals alike.

We have the right to information from a range of approved sources in a range of formats that can be understood. And from people and sources we can trust.’

Relative Effectiveness

‘In our view, the overall aim of health technology assessments must be to achieve better health outcomes. Our position is simple – health technology assessments must go beyond technology per se, to cover broader quality of life issues. Clinical effectiveness, cost effectiveness and impact indicators must stand alongside quality and longevity of life indicators, and critical impact assessments must be transparent to all stakeholders’

Pricing and Reimbursement

‘From a patients perspective, once a medicine has been approved it should reach all patients who need it, in a timely and efficient manner. And pricing and reimbursement strategies must never be an obstacle to patients’ accessing the treatment.’
During the working group meetings of 2006, EPF stressed the need for:
- A spectrum of high quality, relevant and validated information from a range of sources including patient organisations and the pharmaceutical industry on medicines and treatments.
- Access to medicines that have beneficial outcomes both in qualitative and quantitative terms according to Health Technology Assessment that operate to a European Standard throughout Member states.
- Increased and timely access to innovative medicines.

Documents produced by EPF in relation to the Pharmaceutical Forum
- 2 Briefings for the Membership on the Pharmaceutical Forum
- Explanatory note and Reference document on information to patients
- Response to a pricing and reimbursement questionnaire
- Response to the consultation on pharmacovigilence

During the latter part of 2006, EPF met the European Commission regarding the drafting of the Commission report on information to patients to be submitted to the European Parliament and European Council by April 2007. This was a useful opportunity to put forward the broad patients’ perspective on information to patients, in accordance with EPF’s position paper.

Commission High Level Working Groups
EPF was represented in 2006 on various Commission Working Groups including “patient safety”, “health stakeholder involvement” and e-health. The patient safety working group has developed a proposal on a European Patient Safety Network that will be submitted under the 2007 Call for Proposals under the Public Health Programme.

Seventh Framework Programme on Research and Development (FP7)
The EPF President is a member of a high level group for health research within the seventh framework programme on research and development, set up in 2006 by Commissioner for Research. During the course of 2006, the EPF secretariat has also researched opportunities for EPF’s involvement in selected projects responding to the Call for Proposals 2007.
The Transparency Initiative
The European Transparency Initiative aims to strengthen ethics rules for EU policy-makers and the estimated 15,000 lobbyists, NGOs and other pressure groups who seek to influence them in Brussels. EPF responded to the Transparency Initiative Consultation by the Commission in August 2006, following a debate at the Annual General Meeting in June, and consensus with the membership. EPF also revisited its own Code of Ethics in 2006, to ensure that it conforms with best practice at EU level.

Medical Devices Directive
In late 2006, EPF worked closely with the European Parliament regarding input from a patients’ perspective to the Medical Devices Directive.

The Finnish Presidency
The increasing emphasis on including health in all aspects of EU policy, driven by the Finnish Presidency, and the significant health component of the new structural funds framework and the 7th framework programme on research and development were welcome developments in 2006.

During the latter part of 2006, EPF’s working group on policy undertook some preparatory work on an EPF-led EU project focused on the meaningful involvement of patients’ organisations in all health-related projects. This will be submitted under the EU health programme in 2007.

In parallel EPF has developed further strategic relationships with relevant representations of the EU Institutions (Commission, Parliament and Council) and other stakeholders to achieve the above policy goals and
promote patient involvement in EU policy and programmatic work.

We also initiated in 2006 analysis and campaign work in relation to the new Public Health Programme and its budgets, prepared an initial response to the consultation on a future EU health strategy and White Paper, that was sent out to the membership for consultation at the end of 2006; and our response to the EU Consultation on Health Services and Patient Mobility.

An EPF working group was set up in 2006 to prepare the EPF Spring Conference 2007 focusing on empowerment, information and sustainability. Cooperation also took place with the European Voice Annual Health Conference to ensure synergies between the two meetings.

**European Medicines Agency, EMEA**

EMEA activities in which patients’ and consumers’ organisations are involved include:

- EMEA/CHMP Working Group with Patients' Organisations
- Quality review of documents (Product Information)
- Proactive involvement in guideline preparation
- Specific requests from EMEA Scientific Committees, Working Parties, Scientific Advisory Groups, etc.

In order to enable EMEA to establish contacts with the appropriate patients’ and consumers’ organisations on a transparent basis, the Agency together with the EMEA/CHMP Working Group with Patients' Organisations prepared a set of criteria to be fulfilled by patients’ and consumers’ organisations prior to involvement in the EMEA activities. EPF meets this criteria and in 2006, was given official status on the EMEA working group for patients, and played an active role in 2006.
EPF’s Strategic Planning Process in 2006

During the EPF Annual General Meeting in June 2006, it was agreed that a strategic plan should be developed to enable EPF to grow and work effectively during the next 5 years. A working group composed of four EPF members, including two board members, and the EPF director was set up to spearhead this work. This group met three times during the course of autumn 2006.

This draft strategic plan documents the key ideas and thinking emerging from these meetings, and develops priorities and actions fields identified during discussions. A framework was sent out for comment by the members in autumn 2006 and was also discussed by the board during a team-building session in September 2006. This plan was presented to the EPF board in January 2007 for comment and approval and then disseminated for written approval by the broader EPF membership by the end of May 2007.

The purpose of the strategic plan was two-fold: It provides a clear blueprint for the EPF membership and newcomers on the strategic direction of the organization over the next five years in terms of policy impact and organizational development. It will also become an important flagship for EPF for external health stakeholders to know who we are, what we are about and where opportunities exist for cooperation and collaboration.
Building Capacity and Setting up the EPF Secretariat in Brussels

In early 2006, EPF appointed its first Director, Nicola Bedlington who took up post in June 2006, and the EPF opened offices in the heart of Brussels. A webmaster (IT Consultant) Žilvinas Gavėnas, was also recruited in June, and trainee, Nicolas Pradalie joined the team as assistant policy officer in October 2006. Towards the end of the 2006 a recruitment process took place to appoint a full –time policy officer, Roxana Radulescu, who took up post in January 2007.

EPF contracted an accountancy firm in 2006 to manage the book-keeping and financial accounts in accordance with Belgian and Luxembourg law. An external auditor will audit the accounts for 2006 and these will be presented to the Annual General Meeting in June 2007.

Annette Dumas who managed the secretariat until March 2006, was thanked heartily at the EPF AGM for her contribution to the organisation. Don Marquis, who had worked as an external consultant for EPF for 18 months died suddenly in October 2006. A commemoration took place in early November to honour Don Marquis and his contribution to the establishment of EPF.

Strengthening Patients Groups in the EU –A Third Training Seminar

On the 20th and 21st November, EPF organized its 3rd seminar (“Strengthening Patient Groups in the EU; Exchange of good practice between patient groups”) with the support of EFPIA. The purpose of this seminar was to provide participants with comprehensive information on the EU Institutions, and how to campaign effectively in Brussels, together with good practice examples on EU advocacy in the field of public health. The event convened over 60 participants from 19 different countries.

One of the crucial aspects of the seminar was the opportunity given to the participants to meet an MEP from their country with a specific interest in health. 19 MEP meetings took place with 14 different countries. All delegates highlighted how valuable this opportunity was, to raise patient issues of concern at national and European level.
The MEPs that were unable to receive a delegation expressed an interest in the work of EPF and willingness to support EPF in future initiatives.

The seminar continued with a plenary session during which some members of the three main European institutions (Commission, European Parliament and European Council) explained their role in the definition of European health policy. The afternoon was dedicated to workshops in small groups on media training (how to be a good communicator) and advocacy skills (how to campaign effectively).

Feedback indicated that this seminar was very useful for participants, and EPF is planning to organise similar events in future years.
EPF – Growing the membership

EPF changed its Constitution at the beginning of 2006 to create three categories of members, full, associate and provisional members, and to enable national umbrella patient organisations which meet EPF’s criteria for membership and include at least 10 national patients associations, to join as full members.

During the course of 2006, EPF has approached key European patient organisations and national umbrella organisations to discuss their potential future membership of EPF.

By the end of 2006, the secretariat had received expressions of interest from 5 organisations, and one formal application.

The strategic planning process was an important opportunity to reflect with the existing Membership the added value of EPF for them, and it emerged that alongside the policy and campaign impact at EU level from a patient’s perspective, EPF’s role should be to act as a platform and conduit for exchange of good practice between patient organisations at European and national level. EPF has ensured that the strategic plan, and indeed the EPF work programmes and meetings reflect this very specific role.
EPF Building Alliances and Partnerships and External Representation and Alliances and Partnerships

During 2006, EPF devoted significant time to develop alliances and good working relations with a number of European organisations with which we have a common agenda.

Specifically, with regard to patient groups, EPF worked as closely as possible with the European Cancer Coalition, European Aids Treatment Group, International Diabetes Federation, European Heart Network, and the International Alliance of Patient Organisations. In future, EPF will endeavour to include their views and perspectives in EU policy work in which we are selected as the only patient representative.

EPF developed relationships with the wide range of the health NGOs organised at EU level, including the European Public Health Alliance, The European Standing Committee of Doctors, European Federation of Nurses, The European Pharmacists Organisation, PGEU, the European Hospitals Association, HOPE etc.

We also initiated contact in 2006 with the European Disability Forum, the European Platform on Ageing, the European Consumer Organisation, BEUC, and the European Platform of Social NGOs.

Participation in think-tanks and reflection groups
EPF is a member of the European Health Policy Forum, the EFPIA Think Tank, the GSK Patient Advisory Committee and attends CHES (Centre for Health, Ethics and Society) meetings and attended and presented at meetings convened during the course of 2006.

EPF going public – representation at external events
EPF was represented by the President, Board, or Director at several external events and conferences during 2006 to raise EPF’s profile and to advance our message on patient-centred, equitable healthcare in Europe.

These included:
- The Annual Meeting of The European Health Forum Gastein
- Friends of Europe Cross Fire Lunch on Information to Patients
- The European Association of Pharmaceutical Wholesalers Annual General Meeting
- The Finnish Presidency Conference on Nanotechnology
- The European Association of the Self Medication, AESGP Conference on ‘Self Care, Realising the Vision
- EFPIA Annual Meeting (Panels on Health and Wealth and Information to Patients)

- The European Standing Committee of Doctors’ Seminar on Continuous Professional Training

For a copy of presentations and meeting outcomes, please contact the EPF secretariat.
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EPF Knowledge management and communications

During the course of 2006, EPF developed a communications strategy comprising

- A new website for EPF – www.eu-patient.eu is the key external communication tool. The new Website was launched in 2006 to coincide with the High Level Pharmaceutical Forum.

- The development of comprehensive internal, external and media mailing lists

- The EPF internal mailing - produced on a monthly basis, that goes to EPF members and a whole range of EPF allies. The mailing is intended to provide an overview and briefings on key EU healthcare developments and EPF campaign, policy and representation activities. At the end of 2006 EPF undertook a survey amongst its members to evaluate the Internal Mailing and to make it as relevant and as useful for them.

- Several ad hoc mailings and press releases that went to the external and media mailing list highlighting news on the website and the launch of position papers and statements.
Funding Sources and Diversification – initiatives to the end of 2006

A major objective for EPF is to diversify financial sources to ensure a broad based, politically and financially sustainable funding base.

During the course of 2006, EPF adopted a concerted strategy and actions to complement successful fundraising work with pharma companies, specifically targeting non-pharma companies, foundations and statutory sources.

Much effort went into ensure financial stability for EPF, and securing an operational budget for 2007 and beyond and basic reserves. EPF’s income is made up primarily of unrestricted funding from the pharmaceutical industry. By the end of 2006, EPF was in partnership with 9 different pharmaceutical or health-care companies or Federations, in accordance with our frameworks on transparency and ethics.

Considerable preparatory work took place towards the end of 2006 to submit a project application to the EU Public Health Programme in 2007 focusing on patient involvement, and to become an associate partner in a project on patient safety.

EPF submitted an application to a Foundation in 2006, which was rejected. This experience however provided useful learning for future applications.

EPF also began an exploration of possible funding opportunities non-pharma companies and will pursue this further in 2007.

The Annual General Meeting in June 2006 agreed to restructure the membership fees that would reflect the annual turn-over of its membership. This will be implemented from 2007 onwards.
ANNEX I
EPF Audited Accounts 2006

ANNEX II
List of EPF Members, Board members, and specific working group members

ANNEX III
Getting involved