

**A STRONG PATIENTS' VOICE
TO DRIVE BETTER HEALTH
IN EUROPE**



**EPF / Value + Advocacy Seminar
Vilnius, 27 November 2008**

Presentation

- Short Background on EPF
- EPF strategic plan – our key goals
- Achievements and challenges 2007/ 2008,
And linked to this,
- Priorities for EPF in 2009 and beyond



Why We Exist

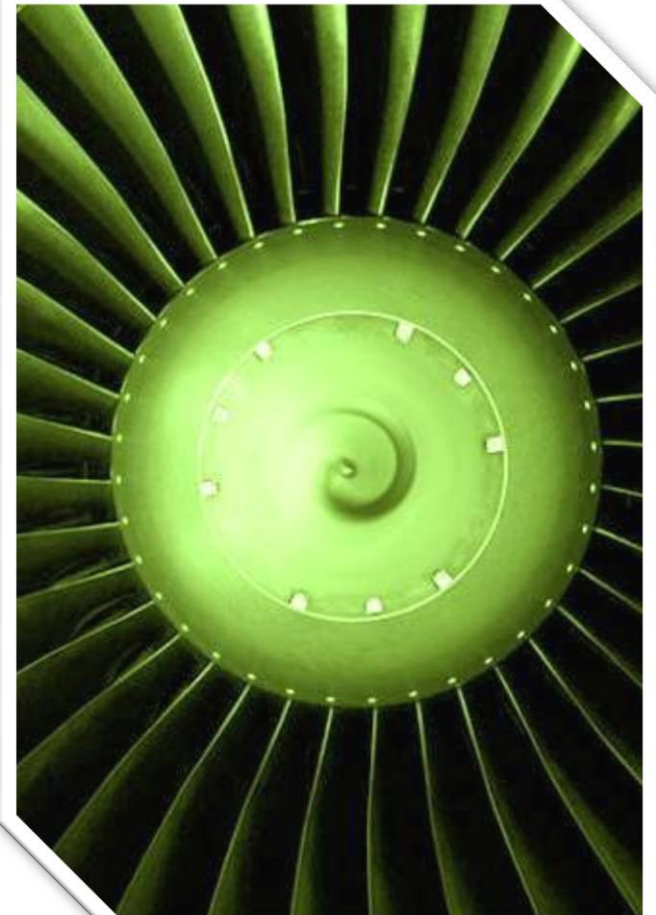
- High quality, patient centred, equitable health care in Europe
- A strong patients' voice in European healthcare debates
- 150 Million Patients
- Umbrella organisation of currently 36 representative European patients' organisations and growing.



What do we want to achieve

FIVE GOALS

- Equal Access for Patients
- Patient Involvement
- Patients' Perspective
- Sustainable Patient Organisations
- Patient Unity



Specific Objectives 2007-2009

- Build capacity
- ***Strengthen our policy impact- patients at the centre***
- Build the Patients' evidence base
- Extend our membership
- Build powerful communications and partnerships
- Diversify the funding base



Building Capacity

- Secretariat Team of 5, Independent office
- Three major EPF meetings in 2007/ 2008
 - AUTUMN ADVOCACY SEMINAR IN BRUSSELS 07
 - SPRING CONFERENCE – HEALTH LITERACY 08
 - ANNUAL GENERAL MEETING 08
- Working Groups and in depth Consultations
- END 2008 – Patients' Evidence Base Workshops, Autumn Advocacy Seminar - Lithuania



Patients at the centre

OUR POLICY PRIORITIES

- European Health Strategy “Together for health”
- Pharmaceutical Forum
- Information to Patients - Health Literacy
- Patient Safety
- E-Health
- Cross Border Healthcare



Patients at the centre

- Priority - PHARMACEUTICAL FORUM
 - Achievements
 - Patients' perspective in all three working groups, tangible outcomes and shift in mindset
 - Statement- High Level -Ministerial meeting
 - Next Steps
 - Dissemination strategy: Conference with Commission March 2009
 - Follow-up involving all stakeholders



Patients at the centre

- Priority - INFORMATION TO PATIENTS AND HEALTH LITERACY
- Achievements
 - Advocacy work on the legislative proposal
 - Continued push for a comprehensive ITP strategy
 - Health Literacy Conference and outcomes
- Next Steps
 - Health Literacy Declaration in the European Parliament
 - Concrete projects with health professionals



Patients at the centre

- Priority - PATIENT SAFETY
 - Achievements
 - Strong input in consultations on patients safety, pharmacovigilance, counterfeiting, medical devices
 - Respected member of High level Group- Patient Safety
 - Active in EUNETPAS
 - Role of patients in research
 - Next steps
 - Consultation and input – Patient Safety Initiative
- Autumn



Patients at the centre

- Priority - E-HEALTH
- Achievement
 - Keynote at Commission Conference “e-health without frontiers”, Slovenia Presidency
 - Liaison with OECD business and industry partners
 - Pre-consultation with the Commission on Communication on Telemedicines
 - Respected member of ehealth user stakeholder group
- Next Steps
 - Direct role for patients – guidelines on telemedicines
 - Calliope project
 - Collaboration with IT stakeholders – Presentation in EP 3rd December



Patients at the centre

- Priority - Patients' Rights in Cross Border Healthcare
- Achievements
 - Active dialogue with the Commission and EP on EPF's perspective on cross border healthcare
- Next Steps
 - Close work with Rapporteur in the EP
 - Campaign work through the Manifesto



Building the Patients' Evidence Base

- Project “Status of Patients in the European Union” to start in 2009
- Value+ “Involvement of Patients”
- EU Patients’ safety project EUNETPAS
- FP7 project on patient involvement and empowerment in clinical trials
- Young patients’ project and report
- Patients’ evidence base workshops
- New projects under review – criteria for engagement



VALUE +

- EU funded project: started February – 8 partners
- Basic premise: patients' meaningful involvement enhances project results- more effective policy making
 - Evidence based overview; current practices and trends
 - Showcase examples
 - Targeted resources for policy-makers, project promoters, and patients
 - Flagship conference under EU presidency Sweden 2009

Extending our membership

- From June 2006 – 23 to 36 member organisations (8 others in pipeline)
- Outreach work with national umbrella platforms
- Membership guide
- Common policy responses with key patient group allies
- EPF presence at members' key meetings
- Role of the Manifesto



Building powerful communications

- 50 external meetings – presentation or leadership role
- Communications Strategy - outreach and products
 - Mailing x 8 per annum
 - External Communiques, Extensive databases
 - Re-launched accessible website
 - Annual report and Meeting Reports
- Translation of key documents



Partnerships and Allies

- Close cooperation with patient group allies and future members
European Cancer Coalition, European Aids Treatment Group, European Heart Network
- Memorandum of Understanding with IAPO
- Reinforced impact - the European Union Health Policy Forum (EUHPF), EMEA Working Party, EFPIA Patient Think Tank



Partnerships and Allies

- Strong relationships with health professionals
- European Doctors (CPME) – joint principles – concrete work on ethics and ehealth, crossborder health care
- European Pharmacists (PGEU) – cooperation on patient safety, concordance – joint board meeting in September
- European Nurses (EFN) Cooperation on the structural funds – joint projects on health literacy



Diversification of the funding base

- Building sustainable relationships with current and new industry partners
- EU funding (Value + , Operational Grant from Public Health Programme, FP 7 opportunities)
- Revised Framework on Cooperation with Funding Partners
- Commitment to transparency and independence
- Responsible Financial Management



New opportunities 2009 & beyond

- New era – new challenges – new demands
- Focus on key policy priorities and projects
- Membership – cohesion and consensus
- Patients' evidence base – top level policy impact
- Enhanced outreach to patient networks at national level
- Manifesto work – pro-active, and agenda-setting



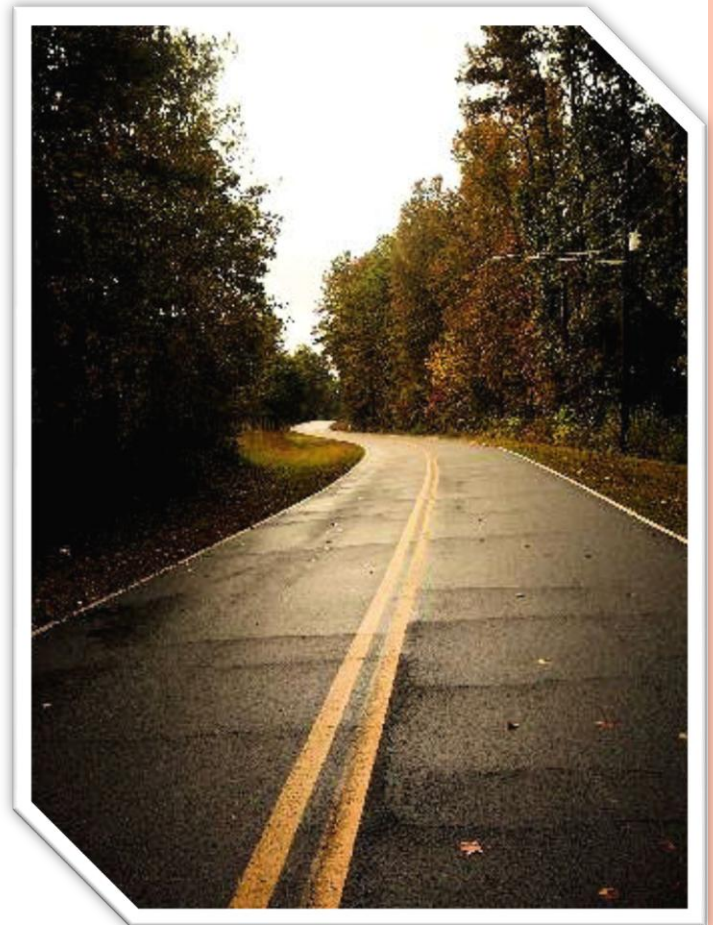
The EPF Manifesto

- 150 Million Reasons to Act
 - Equal and timely access to diagnosis, treatment and support - Better info and resources - A patients voice
- One year campaign , Launch in European Parliament, Sign up on Website- Outreach with Members
- Lead-up to EP election – new Commission Time for new political priorities, and commit to take action



Key meeting points in 2009

- AGM and members' policy review, Pharma Forum Conference **March**
- Patients ' Rights Day **18 April**
- Advocacy Seminar in Bulgaria, **September**
- Value + Conference under the Swedish EU Presidency, **December**
- Ongoing work with members and allies



EPF – a key player

- Our strengths
 - our members' expertise, experience and solidarity
 - our uniquely patients' perspective
 - our commitment to partnership
- We value your commitment and vision
- Moving Forward Together



More Information?

www.eu-patient.eu



The screenshot shows the homepage of the European Patients' Forum website. At the top, there is a navigation menu with links for Home, Membership, Projects, Policy, Publications, Core Documents, and About us. A large blue banner in the center reads "150 Million reasons to act" and "EPF Patients' Manifesto for the European Parliament and Commission 2009". To the right, a white box announces the "Launch of Patients' Manifesto in the European Parliament 16 September". Below the banner, there are three main content sections: "EPF's DRAFT response to the EC consultation on medical devices", "EPF Health Literacy Conference Report 2008 is now available!", and "EPF's Response to the Commission's Consultation on Patient Safety Consultation 20 May 2008". On the far right, there is an "EPF Mailing" section with links for "2008 June", "2008 April", "2008 March", and "2008 January", and a link for "All EPF Mailing issues".

Health-EU Portal

European Patients' Rights Day

A Strong Patients' Voice To Drive Better Health in Europe

europeanpatients'forum

Home Membership Projects Policy Publications Core Documents About us

150 Million reasons to act

EPF Patients' Manifesto for the European Parliament and Commission 2009

Launch of Patients' Manifesto in the European Parliament 16 September

Check this section from the 16 September to sign up and join in!

EPF's DRAFT response to the EC consultation on medical devices

EPF has responded to this consultation on 2 July 2008. This response is purely indicative of the direct feed-back EPF has had from members until that date. However, because of the tight deadline to respond, EPF has requested the Commission to reserve the right to provide a final response in September 2008, after a more extensive consultation with our members. [more...](#)

EPF Health Literacy Conference Report 2008 is now available!

European Patients' Forum is pleased to announce that the report of our EPF Spring Conference on health literacy (8-9 April 2008) is available [to download](#). If you would like to receive a hard copy, please contact the [secretariat](#).

EPF's Response to the Commission's Consultation on Patient Safety Consultation 20 May 2008

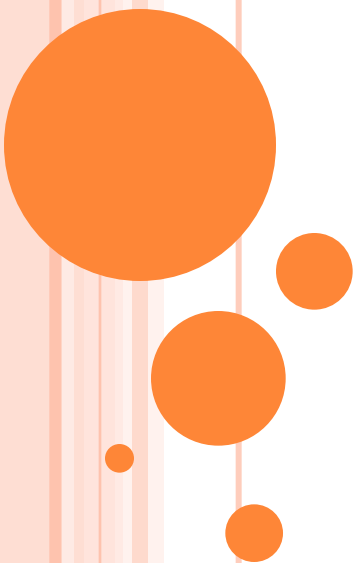
EPF has responded to the open consultation on patient safety in the European Union. We have urged for a strong partnership between all institutions involved in patient safety, in a "no shame no blame" culture, based on trust and values and for a meaningful involvement of patients organizations. [more...](#)

EPF Mailing

Read EPF's regular update on EU health developments from a patients perspective - if you would like to subscribe please [contact us](#)

[2008 June](#)
[2008 April](#)
[2008 March](#)
[2008 January](#)

[All EPF Mailing issues](#)



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