"ANNUAL REPORT 2012"

Brief highlights





2012 Achievements



- **Building capacity** within the governance structures, the secretariat
- Reinforcement and extension of our membership
- Feeding Project and Patient Evidence into policy
- Consolidating of our policy impact
- Solidifying of our **funding base**
- Building strong partnerships and representation work
- Evaluation and effective communication

reinforcing and extending the membership, and diversifying / solidifying funding

(GOALS 1-5) OBJECTIVE 2 - Consolidating our policy impact (GOALS 1-3)

→ OBJECTIVE 3 - Feeding Project and Patient Evidence into policy (GOALS 1-3)

▼ OBJECTIVE 4 - Building powerful and effective communications and partnerships (GOALS 1-5)

2012 marked a new milestone for EPF as we started to develop a new Strategic Plan for 2014 to 2020. This will be a critically important perfod for patients in Europe and EPF will do its best to engage in and influence EU and national developments that impact on patients' lines.

CAPACITY BUILDING ACTIVITIES The EPF Capacity Building Programme for patient organisations was launched and piloted in 2012. This Included 20 patient organisations from Hungary and Romania and five pan-European disease-specific patient organisations. The objective of the programme is to so that they can achieve their goals more effectively. As a result, they will be able to feed their expertise into the work of EPF and translate this in a national context.

unreserved success. Patients' organisations from four Mediterranean countries representing 15 diseases came to learn how to enhance their fundralsing skills, diversify

Europe Colon, the European Network of Fibromyeigle Associations (ENFA) and the World Federation of Incontinent Patients (WFIP), as well as one associate

We continued to forge strong alliances with other European health organisations and voice patients' Interests through our representation work at more than 50 EU events on health policy issues.

EPF has continued to play a pro-active role in promoting a patient-centred philosophy and agenda throughout 2012

We have highlighted equitable access to healthcare for all patients across Europe in three priority areas; health Inequalities, access to medicines and the revision of the EU Transparency Directive.

empowerment through several activities focusing or information to patients and health literacy and the reflection process on chronic diseases, not to mention

We have adopted strong positions on data protection and clinical trials and supported the European Innovation Partnership on Active and Healthy Ageing.

Agency (EMA), to ensure that the perspective of patients is taken into consideration in medicine regulation, and

Safe, high quality healthcare across the EU was another main policy thrust in 2012. This revolved around three Quality of Care and Patient Safety, our contribution to

2012 Highlights



Strategic Planning

- ✓ 2014-2020
- ✓ Involvement of our membership at all stages
- ✓ Endorsement at the AGM



- ✓ Need for a fundamental shift
- ✓ Need for an empowerment strategy (health literacy, involvement in the innovation process)
- ✓ Call for an integrated, patient-centred approach
- → The patient is part of the solution towards sustainable healthcare





2012 What we achieved



- Strengthening the capacity of patients' organisations
 - **✓** EPF Capacity Building programme (2012-2014)
 - ✓ EPF support for EU legislation implementation at national level: toolkits on cross-border healthcare and pharmacovigilance
 - ✓ European Patients" Academy on Therapeutic Innovation (EUPATI) project (2012-2017): an Academy to educate patients on therapeutic innovation
 - ✓ 5th EPF Regional Advocacy Seminar: resourcing patients' organisations



- ✓ Policy topics: Information to Patients and Health Literacy, Access to Therapies, Health Inequalities, The Rights and Needs of Older Patients, Gender, Nutrition
- ✓ Youth Project: EMPATHY

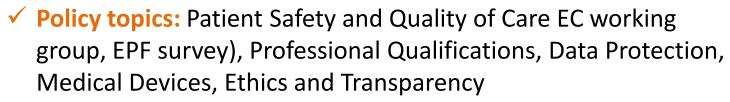




2012 What we achieved



High Quality and Safe Healthcare





- ✓ Joint Action European Union Network on Patient Safety and Quality of Care (PASQ)
- ✓ Partnerships Patient MedTech Dialogue

Our work towards the next EU programming period

- ✓ Health for Growth
- √ Horizon 2020
- ✓ EU Strategy on Chronic Diseases
- ✓ InterQuality project: Healthcare Financing Mechanism



2012 Major themes



- **Innovation and Technology**
 - ✓ Policy themes: Patient-centred Innovation, Personalised Medicines, Clinical Trials
 - ✓ Events: Patient Evidence Workshop
 - ✓ eHealth: Building evidence to substantiate our policy work
 - o Projects: Chain of Trust, Sustains, RENEWING HeALTH, eHealth Governance Initiative
 - o eHealth Task Force Report, eHealth Stakeholder Group
 - ✓ Health Technology Assessment (HTA): Building evidence to substantiate our policy work
 - AdHopHTA project



EUNetHTA project



✓ SmartCare Project







2012 Meeting Europe's patients



The European Union Agency for Fundamental Rights (FRA) Stakeholder Meeting, February 2012, Vienna, Austria

The European Organisation for Research and Treatment of Cancer (EORTC) 50th Anniversary Conference, March 2012, Brussels, Belgium

The IAPO Global Patient Congress, March 2012, London, UK

The Patient-MedTech Dialogues, April & November 2012, Brussels, Belgium The IPPOSI Information Day on Health Technology Assessment, April 2012, Dublin, Ireland

A High-level conference on future EU health systems, May 2012, Brussels, Belgium

Innovation in Healthcare, May 2012, Brussels, Belgium

A meeting of the eHealth Task Force, May 2012, Copenhagen, Denmark eHealth week, May 2012, Copenhagen, Denmark The IMI stakeholder Forum, May 2012, Brussels, Belgium

2012 Meeting Europe's patients



The 3rd EU Societal Impact of Pain symposium, May 2012, Copenhagen, Denmark

The Nordic Conference on cross cooperation on rare diseases, May 2012, Reykjavik, Iceland

The European Alliance for Personalised Medicine, June 2012, Brussels, Belgium

The Hospage Conference, June 2012, Berlin, Germany

The Economist Conference "New responses to non-communicable diseases", October 2012, Geneva Switzerland

The Patient Link Workshop "High Impact Patient Advocacy", November 2012, Brussels, Belgium

The Friends of Europe's annual Healthcare Summit, November 2012, Brussels, Belgium

The EFPIA Patient Think Tank, March & November 2012, Brussels, Belgium The DuQue Final Conference, November 2012, Berlin, Germany



2012 Evaluation



- Objective 1: Building capacity
 - ✓ Involvement of EPF membership and Youth Group in the Strategic Planning process
 - ✓ Strengthening the capacity of our members
- Objective 2: Consolidating our Policy Impact
 - ✓ Effective inclusion of EPF's position in EU health policy
 - ✓ Challenges in engaging the members in the consultation process
 - ✓ Several EPF comments integrated into EU institutions positions and initiatives
- Objective 3: Feeding evidence from projects and patients into policy
 - ✓ Patient Evidence Workshop
 - ✓ eHealth and HTA draft position papers
- Objective 4: partnership
 - ✓ Effective communication strategy's implementation
 - ✓ Nurtured cooperation with other stakeholders

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