

# “ANNUAL REPORT 2012”

## Brief highlights

“ A STRONG PATIENTS’ VOICE  
TO DRIVE BETTER HEALTH IN EUROPE ”



# 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**

## EXECUTIVE SUMMARY

### 2. Executive Summary 2012

EPF identified four objectives in our 2012 Work Plan that relate to our strategic goals:

- ✔ **OBJECTIVE 1** - Building capacity within the governance structures, the secretariat, and through 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 period for patients in Europe and EPF will do its best to engage in and influence EU and national developments that impact on patients' lives.

#### 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 strengthen the advocacy capacity of these organisations 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.

Our Regional Advocacy Seminar held in October was an unreserved success. Patients' organisations from four Mediterranean countries representing 25 diseases came to learn how to enhance their fundraising skills, diversify their funding base and bolster their advocacy capacities.

We welcomed three new provisional members - Europa Galica, the European Network of Fibromyalgia Associations (ENFA) and the World Federation of Incontinent Patients (WIFIP), as well as one associate member, the Bulgarian Association for Patients' Defence (BAPD).

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.

#### OUR POLICY IMPACT

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.

We have added significant value to patient empowerment through several activities focusing on information to patients and health literacy and the reflection process on chronic diseases, not to mention our own projects.

Health innovation and research are also key priorities. We have adopted strong positions on data protection and clinical trials and supported the European Innovation Partnership on Active and Healthy Ageing.

We have worked closely with the European Medicines Agency (EMA), to ensure that the perspective of patients is taken into consideration in medicine regulation, and also the European Commission's Platform on Access to Medicines and Platform on Ethics and Transparency.

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

- **Strategic Planning**

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

- **Health and Patients in times of austerity**

- ✓ 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
  - ✓ 5<sup>th</sup> EPF **Regional Advocacy Seminar**: resourcing patients' organisations
- **Accessible & Inclusive Healthcare**
  - ✓ **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**

- ✓ **Policy topics:** Patient Safety and Quality of Care EC working group, EPF survey), Professional Qualifications, Data Protection, Medical Devices, Ethics and Transparency
- ✓ 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

- Projects: Chain of Trust, Sustains, RENEWING HeALTH, eHealth Governance Initiative

- 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



- **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

# THANK YOU FOR YOUR ATTENTION!

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**More information:**

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