



european**patients'** forum

The EPF Youth Strategy

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A strong Patient voice to drive better Health
in Europe

Why a Youth Strategy

Premises

- EPF viewpoint is that **needs** and **expectations** of **young patients** do not necessarily match those of adult patients
- Young patients faces a number of **additional challenges** associated to **growing up with a condition**
- **Patient organisations** need to be able to **listen to young patients** and provide them with appropriate **tools** and avenues through which such **needs and expectations** can be **put forward**

Why a Youth Strategy

Overall goal

To enable **EPF** to **recognise, understand, meet** and effectively **represent** the **needs** and **expectations** of young patients through their **meaningful involvement** and **empowerment**

Background

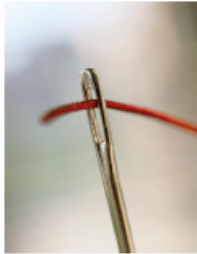
- Young Patient Perspective project 2008
 - To explore barriers between the young patient and the society
- Budapest Advocacy Seminar « Involving Young Patients » October 2010
 - To explore how to involve young patients in patient organisations



Both helped us shape the EPF Strategy

Project report:

**Young
Patient
Perspective**





In Europe

Objectives

EPF Strategy

To enable EPF to **recognise, understand, meet** and effectively **represent** the **needs** and **expectations** of young patients through their **meaningful involvement** and **empowerment**



- | | |
|-------------|---|
| Objective 1 | Strengthening the involvement and representation of young patients in EPF as well as in our member organisations |
| Objective 2 | Promoting young patients' rights and recognition of their needs and expectations within and beyond health policy area |
| Objective 3 | Promoting a better cooperation between young patient and adult patient advocates |
| Objective 4 | Strengthening young patients' advocacy skills |

Implementation of the Strategy

Stepwise approach

Subsequent 2-year operational Work Plans

1st Operational Work Plan 2011-2012

2 key objectives:

- **establishing and consolidating the EPF Youth Group**
- **strengthening the capacity and the empowerment** of the members of this group in order for them to be able to become gradually involved in EPF activities and, in the long run, in EPF governance structure.

The Youth Group

In order to be able to achieve the 4 strategic goals, EPF will establish a Youth Group

- **Criteria**

- be a patient
 - be between 15 and 25 years of age
 - be member of a patient organisation which is member of EPF or a member of an EPF member
 - be not employed as a staff member within the patient organisation
 - have a working knowledge of English
 - be available to attend 1-2 physical meetings every year and quarterly teleconferences
 - show strong motivation and willingness to take a proactive role in engaging with the local young patient community
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- **Kick-off meeting possibly in August 2011 in Brussels**
 - **Envisaged size: 12-15 members**
 - **Still 5-6 places available: 16 May deadline to send nominations**

Governance and other Implications

Short term

- **Representativeness**

Members of the Youth Group will participate as second delegates to those EPF meetings where the participation of youth delegates is envisaged, particularly the AGM

Medium-long term

- **Election of a Youth Board Member**

- **Nomination of a Youth Member for the Policy Advisory Group**

- upon successful implementation of capacity-building activities
- the Youth Strategy and its *modus operandi* have attained a sufficiently adequate level of maturity
- Phasing-in period (1 year observer capacity)
- Representing the Youth Group
- To be elected/nominated by the Youth Group itself



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Thank You

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