

EUROPE, LISTEN UP TO YOUNG PATIENTS!

Brussels, 12 July 2013 – More than 25 young patients from several EU Countries gathered on 8-11 July for the [‘EMPATHY’ seminar](#) entitled “Europe meets young patients”. The young adults from 15 to 25 spoke up about their different needs as well as their expectations.

Young patients call for the **recognition of ‘chronic disease’ as a ground of discrimination**. Marek said: “I went to a job interview and the employer did not want to hire me as he presumed I would not be able to fulfil my tasks because of my condition. Finally he reconsidered it but I refused to take the job because I felt already rejected with his first reaction.” Young patients are discriminated against on the grounds of a chronic disease but also of problems linked to their age; this must fall within the scope of an explicit regulation that protects them and promotes their equal chances.



The participants identified the **lack of information as the main barrier** as it leads to misperception. One of the seminar role plays illustrated this with the example of an exam session: a student with diabetes could not bring her blood sugar meter with her and another student with Crohn syndrome lacked time to finish her exam because of going back and forth to the bathroom. “This happened just because the external examiner was unaware of their condition and could have been avoided”, concluded the young attendee.

Young patients call for **raising awareness** about their different needs. As a solution, they suggest launching information campaigns to educate people and help them understand that their condition does not stop them from working or studying or to live normally; there is just a need for adjustment.

On the other hand patients also need to be **informed about their own rights** to be able to take responsibilities in their treatment. They are experts in their condition, they are able to search information and advocate for their own needs. However they need support from healthcare professionals and their parents to be empowered to do so. Particular challenges they encounter include unaccompanied transition at 18 from paediatric care to adult system, and difficulties to access healthcare when travelling or going on an Erasmus programme.

Finally young patients need a **relation based on empathy** with their healthcare professionals. “When the doctor talks to my parents about my condition, I feel ignored and this is rude” said Aneela. “We, as young patients, are anxious and have plenty of questions to ask. We would expect the physician to have the necessary skillset to adapt and interact with us with feeling”, she continued.

In addition to a more human approach in healthcare and adapted support, **patients’ organisations also play a crucial role**. They can help young patients through acting as a bridge between them, their parents and healthcare professionals and by providing peer support.

More information

The **European Patients' Forum (EPF)** was founded in 2003 to ensure that the patients' community drives policies and programmes that affect patients' lives to bring changes empowering them to be equal citizens in the EU.

EPF currently **represents 61 member organisations** - which are chronic disease specific patient organisations working at European level, and national coalitions of patients organisations. EPF reflects the voice of an estimated 150 million patients affected by various diseases throughout Europe.

EPF's viewpoint is that needs and expectations of young patients do not necessarily match those of adult patients. Being a patient inevitably impacts on every aspect of one person's life. For a chronically ill youngster this means that the condition and the way he/she relates him/herself with the condition have important repercussions on his/her growth process and hence on his/her life as a grown up.

EPF's **first youth initiative** dates back to 2008 with the implementation of the Young Patient Perspective Project. EPF dedicated the 2010 Regional Advocacy Seminar to sharing good practice of young patients' participation in patient groups. The EPF Youth Strategy was developed and adopted by EPF 2011 Annual General Meeting. On that occasion the EPF Youth Group was established and the first Youth Assembly was held in Brussels, on 19-21 August 2012.

The **EPF Youth Group** is the backbone of the EPF Youth Strategy. The group is currently made up of 11 young patient representatives between 15 and 25 years of age with different chronic conditions who have been nominated by EPF member organisations. The Group was established to become the reference group through which needs and expectations of the young patient community are formulated and communicated to EPF and its members.

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