

# European Marfan Support Network

(AND RELATED DISORDERS)

## EMSN Young Adults Meeting - 2012

YouthHostel *De Blauwput* Leuven, Belgium

### Meeting Report



In the afternoon of Thursday 23 August seven young adults were welcomed to Leuven, Belgium, by the Young Adult representative of the EMSN, Lauriane Janssen, and the secretary of the ABSM (Belgian Marfan Association), Léon Brandt. The participants came from Austria, Belgium, Germany, Slovakia and the Netherlands. The first evening was spent getting to know each other and discussing how Marfan affect the participants.

Friday morning started with a game to get everyone "up and going". Then it was time to discuss important topics related to being a young adult with Marfan syndrome. These were the main topics (with some keywords):

- Acceptance – by yourself and by others
- Taking responsibility – while trying to be "normal" and discovering your boundaries
- Work experience – what to tell when and meeting prejudice when not able to work full time
- Family life – finding a partner, having children, risk of pregnancy

An important discussion came up; *what if we could change ourselves and not be Marfan anymore, would you do it or not?* Surprisingly, everybody said that they would **NOT!** Because Marfan has influenced who they are today, including the qualities they are proud of. Everyone would however preferred to be guaranteed no more complications from now on

The Young Adults Meeting also included medical presentations and discussions. Dr Fransiscka Malfait gave a presentation about "pain in Marfan syndrome". She was taught as a rheumatologist and works in the *centrum voor medische genetica* in Ghent as a researcher and a MD. To kickstart the medical discussions, Karina and Lauriane had prepared a small presentation of different aspects of Marfan syndrome and the cause of it, starting from the "marfan-bunny" affected with several Marfan conditions (see the pictures below). Relations to doctors, pain management and life improving tricks were some of the topics discussed.

Another important topic of the meeting was the involvement of young adults in Marfan associations. What do the different countries do today, what is important to attract young adults, and how should future EMSN Young Adults Meeting be like. Next year there will be a Young Adults Meeting together with the EMSN delegates meeting in Switzerland, and the Netherlands has taken the challenge

to organise one in 2014.

The discussions and sharing continued during the leisure activities as well, which included an afternoon at the swimming pool and a visit to the local brewery.

Here are some of what was said about this meeting and, of course, the “Marfan-bunny”:

**If you were not there, you missed something!**

**Don't miss next year's meeting!**

**United in disability ;)**



**Meeting, laughing and talking with other young Marfis makes you feel understood. There are no stupid questions and there are no stupid answers.**

**Meeting other young people and get to know how they live with the challenge of Marfan syndrome was inspiring for my own life.**

**Being young and having Marfan syndrome is like dancing around your limits, sometimes you need to go too far to feel alive. Sharing these experiences is the best you can do.**

**“Enjoyable meeting with nice people, in pleasant surroundings and an interesting programme.....it was an amazing trip for us of what we have an unforgettable experience and memories! Thanks to all of you, guys (especially Laurianne)!”**

