

European Marfan Support Network (And Related Disorders)

2013 YOUNG ADULTS MEETING REPORT

5 – 9 September
Zürich, Switzerland



Report from a young adult

Hello, my name is Mira and I am a new member of the Marfan Group.

As I got the message that the Marfan Group of Germany was searching for a young adult to go to the Marfan meeting in Zurich, I decided to accept. They said that I need not to pay for the accommodation and the train ride. On the 5th of September I started my journey to Zurich. I was very nervous because I did not know what to expect and if my knowledge of English was acceptable.

The accommodation was pompous! Everyone got their own room with a double bed and a minibar. The food contained of a morning buffet, a three course lunch and a four course dinner. The accommodation had his own bowling alley, a fitness centre and a wellness area. Drinks and food were always available.

As I arrived, I was led outside on a beautiful terrace where the other young adults sat. The others were six adults aged 18-29, four Swiss, a Frenchman and a Norwegian.

In my previous opinion, I had always thought that people who have Marfan syndrome tend to be more careful and don't participate in many activities. I was shocked to hear that this was not the case and listened to one person's story about his world trip. The stories were very adventurous and I still think that he could have written a whole book about it. Another person told me about his fascination for paragliding. It was clear that we couldn't do some things, but we still had to look at the things and activities which were important for us.

We also talked about the subject of how we had been diagnosed with Marfan syndrome. Everyone, except myself, had received the diagnosis as a baby and had grown up knowing they had this disease. In our family, there had been problems knowing exactly which diagnosis we had and only after a genetic test two years ago did we know that we have atypical Marfan syndrome, also known as Loeys-Dietz syndrome.

In the evening after a feast, we drove down into the city and went into a beer garden which was near the river. We talked about stereotypes about people from a certain country. For example, I am German, but I don't like beer and the Swiss girl from our group didn't like cheese. Does that make us any less German/Swiss in comparison to others?

After breakfast the next day, we met with an ergotherapist and a doctor, both of them from Norway, to talk about life with Marfan syndrome. Difficult topics such as ethics and quality of life were part of the conversation. We all agreed that the quality of life can't be measured. We thought that genetic tests were redundant. If someone knows that they have a certain probability of getting e.g, breast cancer, then that could be very damaging for the psyche.

In the afternoon, we listened to some medical lectures about the eyes, psychology, and the lungs. The lecturers came from America, Switzerland and Norway. The lectures were in English, but it was possible to obtain a German, French, or Italian translation. Questions were possible after the lecture but also in a private conversation. One of the main conclusions of many lectures were that further research was needed to make more concrete statements about the Marfan Syndrome. For me, some of the most interesting lectures were about deformities, because it is something I have as well. In the breaks between the lectures we talked about the topics of the lectures, but also about operations and other personal experiences we had had.

In the evening, we went bowling. We divided into groups to bowl in two alleys. The funniest part of it was when one of the bowling alleys didn't work. One of the boys tried fixing it but with little success. He was very motivated but it still didn't work.

During the next day, we were very tired but still tried to concentrate on the topics of the lectures. We didn't have to, but we were still very interested about the topics of the aorta and pregnancy. One of my personal conclusions from this part of the lecture was that it was very important to participate in regular check-ups at the doctor's and that a pregnancy with Marfan syndrome is possible with many precautions.

During the afternoon, we talked about the topics of orthopedics, sports and pain management. After that, some clinics with a special emphasis on Marfan syndrome treatment were introduced. I talked to a doctor from Bern about the diagnosis of Loeys-Dietz and if it was a good idea to be in the Marfan group with this disease. He said he thought it was a good idea because the symptoms of the two conditions are very similar. This was quite a relief for me.

After that, there was a photoshooting for the young people. This was a joy for all of us. We tried out different poses in different locations. We especially liked the picture which was made in the smoker's lounge. We sat on sofas but one

of us didn't fit because there was no room for all of us. This person was seen in the mirror like a portrait. After that we went bowling again and most of us improved. Practice makes perfect!

We then went to the city center to enjoy some drinks. The weather was hazy, so we found refuge in a telephone booth which actually played music. We took a walk in the rain and the city strongly reminded me of Venice. Zürich was still very beautiful even though it was raining. After that, we sat in a restaurant. One of the camera men who had filmed the contributions for the Marfan website invited us. I had the feeling that the Swiss are more generous than the German people, because I got invited all the time. The restaurant also had a dancing area, where we went to dance for a while with some people.

It was difficult to get up the next morning. We had to think of a presentation about our conclusions. The motto of our presentation was "**Please, help yourself.**" We had read this slogan the whole weekend on various self-service signs. In our opinion, the motto meant that one should get what one needs, for example information. But we also thought that it could mean that everyone is responsible for their own life and should help one's self.

For us, it was very clear that we wanted to meet again because we had all gotten along so well. Having a rare genetic disease makes people closer to each other. We also wanted to found a group on Facebook for the exchange. At the end of the presentation, we held up signs with the slogan: "Victory is..." with every person continuing the slogan in their own personal way. My continuation was "to know that there are others". Knowing that other people also have this disease makes it easier for me to come to terms with my symptoms. One of the young Swiss people presented his A-Level essay on the topic of Marfan syndrome and showed that everyone can do their own research. Because I still had some time left, we went to a Vietnamese restaurant. After that I bought a tasty "Luxemburgerli" (a type of sweet cookie) and sent a postcard. We said goodbye to each other with "Please, help yourself!"