

Young Adults Meeting 2014

FINAL REPORT

14. – 17. August 2014, Klagenfurt – Austria

Thursday, 14.08.2014



This year we didn't emphasize on medical aspects but on psychological aspects of dealing with the Marfan Syndrome. As these are very personal and sensitive topics, it was very important for everybody to feel comfortable in the group. To be sure about this, we took the Thursday evening as well as the Friday morning to create a group.

For this part we were lucky to get support by Julia Starke, who is experienced in handling and creating a good group feeling through her work as a first semester student guide.

For two hours we played different games which made it easy to share some funny but also serious things and as we shared, we found connection points within the other group members.

For most of us the trip to get to Klagenfurt was long and tiring, so after the Dinner at 19:00 there were no activities.



Friday, 14.08.2014 – PSYCHOLOGICAL ASPECTS

Friday morning started with the greeting of the last participants who arrived later at Thursday. Starting again with games to feel comfortable around each other we moved on to talking about the meeting. We answered four questions concerning the meeting:

1. Why are you here?
2. What do you expect from the meeting?
3. What do you expect from the group?
4. What topics are you interested in?

The answers to these questions you see in the picture on the right.

After dinner we went for a walk altogether to see the lake and start to have a group discussion in the park near the lake Wörthersee.



Input: Marfan @ Work

The group discussion started with an input on how to deal with the Marfan Syndrome concerning profession. Heidemarie Egger works in an Austrian organization which specializes on the topic of employment with disability. Based on this experience she presented 5 tips:

1. Focus on your strengths – not on your disease
2. Take all the counselling and help you can get
3. Decide if, when and how you talk about Marfan Syndrome.
4. Be prepared for any question and insecurity – if you are confident that you can do your job, your company will be as well.
5. Know the legal and public funding situation in your country



Coping strategies for people with Marfan Syndrome

Back in the meeting room we had our final input from Christa Künzig. Because of her psychological background as well as her work in the field of disability she not only presented theoretical input. She also framed the input with different psychological techniques. We started by free writing, individually we wrote what we wanted to say to Marfan Syndrome. For 5 minutes we just wrote without thinking and we knew, that we wouldn't have to present it or share it, if we didn't want to.

Later Christa explained the outcome of the German dissertation "Aspekte des psychischen Befindens und der Krankheitsverarbeitung bei Menschen mit Marfan-Syndrom" (<http://d-nb.info/993162592/34>, Hamburg 2009) from Dagmar M. Ernst-Horstkorte.

"Coping strategies for people with Marfan Syndrome" was the title of the presentation. After we got the input we split up in 4 groups discussing and writing down the answers to questions concerning with what kind of

strategies we and our families are coping with Marfan Syndrome. One very important question was for what situations and aspects we don't have any strategies yet.

The Friday ended with the American movie "Moe" about a boy who has Marfan Syndrome. In movies and series Marfan Syndrome is most often portrayed as fatal. In discussing the movie afterwards we decoded how very dramatic the Marfan Syndrome was portrayed. Even though all of us were touched about the movie, it was very important to discuss it and put it into the place of a movie apart from our reality.



Saturday, 15.08.2014 - CREATIVITY

The Friday was for everyone a challenging day, not only because of the program and inputs. Especially also because of the topics we discussed, which were very personal and I think no one took it easy.

The meeting was set up in the way that the Saturday with the creative workshop gives everyone the time and space to think and reflect.

Barbara Annerl, one of the Austrian participants, was so kind to prepare and explain the creative part of the meeting.

The Idea:

*"Who am I really?
Just do something that represents yourself. You can represent your habits, your feelings, how you look or whatever. You can draw, make a collage, write a text, take pictures, make a movie, sing a song, dance or something else. You can use everything you can find. There is no true or false. It's just have to represent you. You can be as creative as you can."*



We prepared different materials, such as watercolours, paper, glitter etc. It was also possible to work with the professional photographer Susanne Bayer who helped 3 people to realize their picture ideas. We took time from 9 in the morning until 13 o'clock.

After the lunch we had our leisure time as planned. Unfortunately the weather was not as good as we wished and it was too cold to swim in the lake. But together we agreed to take boats and to explore the lake in this way. Everyone had a lot of fun



In the evening we had a very nice Austrian dinner in the city of Klagenfurt.

Sunday, 16.08.2014 - PRESENTATIONS

We started the day with the presentations of all the individual creative projects. Understandably we will not show the very personal outcomes here. Three people decided to take a picture, one presented herself as unicorn – showing how she feels being the only one having the Marfan Syndrome in her family. Another participant presented herself as a witch and played with her appearance. One participant wrote a story, showing how she started to get along with her appearance and even started to feel pretty. The rest drew what they felt showed their personality and also used this time to reflect.

The last feedback-round showed that all the participants enjoyed the meeting.

Support and Sponsoring

Without the support of Julia Starke, Susanne Bayer and Lisa Altenberger this meeting wouldn't have been possible. They helped without expecting anything in return.

