

MEN Online report 2019 meeting

This year a record of 11 young adults (age 18-28) from Austria, Belgium, Finland, Germany, Norway, Switzerland and The Netherlands attended the YA program organized by Karina Zeyer (DE) and Lauren Simons (NL).

Thursday

On Thursday afternoon, the Young Adults took part in the official opening of the MEN meeting. This also included a short introduction round of all participants. The YA group gathered after the official part to have informal conversations over dinner.

Friday

On Friday morning, all Young Adults met in their meeting room to start with the YA program. After a very short introduction round, different games were played to get know each other better. In one game, the young adults had to think of three statements about themselves, out of which one was false. The other participants had to guess the false one. It was a great way to learn about each other. To focus more on Marfan specific topics, we extended this game to a new version called „My Marfan life“. Different statements about Marfan syndrome had to be made out of which one was false. This was a great opportunity to discuss many Marfan topics in a relaxed way. Moreover, it also became obvious that it is very different from person to person which statements apply. Statement that were used in this game are:

- *I tell all my friend/class mates/... that I have Marfan syndrome.*
- *I am the tallest one among my friends.*
- *I like/don't like dancing at a club.*
- *Marfan does (not) play a major role in my life.*
- *I love shopping. At least we don't have the problem of choosing between too many shoes/clothes.*
- *Sometimes I wish to be „normal“*
- *I had to give up sports because of Marfan.*
- *Sometimes I am worried about my future.*
- *I like being tall.*
- *Only my family knows that I have Marfan syndrome*

- *Marfan influences/does not influence my choice of studies/profession.*
- *I hate going shopping. I can never find clothes/shoes in my size.*
- *When I go out in the evening, I have the feeling that people stare at me.*
- *Marfan has a great impact on major decisions in life.*

Afterwards, the Young Adults could choose to either attend the medical talk together with the adults or spend time with the other young adults. Since all participants were very much involved in discussions, everyone decided to stay with the Young Adults group.

At the end of the morning, the Young Adults had a walk through the city of Drammen. It was a good experience for everyone to walk around in a group of tall people. It created a feeling of cohesion.

In the afternoon session, the Young Adults watched the movie MO. This is a movie about a boy with Marfan syndrome that also shows some experiences that many of the Young Adults are familiar with. The movie raised quite some topics for discussion, like friendship, dating, school, family,...

In a medical workshop, the Young Adults had the possibility to ask all their medical questions in a relaxed and informal environment. In the morning session, different questions were collected which were then presented to a medical doctor from Norway, Svend Rand-Hendriksen. Dr. Rand-Hendriksen started the workshop by asking everyone whether they knew which specific mutation they have and why this is so important. He gave an overview of genetics in an easy and understandable way so that everyone could follow his explanation. Afterwards, different topics were discussed including the following ones:

- *Aortic surgery: what is the best time to have surgery? Is it better to have prophylactic surgery at a younger age when the overall health is still better than when you grow older and have more medical issues? Is the PEARS procedure a good alternative?*
- *How can Marfan syndrome lead to cardiac arrest?*
- *Is there a link between Marfan syndrome and mental illness?*
- *Can Marfan syndrome cause a lot of headaches? Does medication play a role?*
- *What are the options for family planning (prenatal testing and preimplantation genetic diagnosis)*
- *Is there a link between smoking and having a pneumothorax?*
- *Sports: Is there an upper limit for the heart rate?*
- *Are there additional risks for drug use or alcohol when you have Marfan syndrome and you have to take medication?*

Saturday

On Saturday the Young adults had a creative workshop where they dealt with the topic of Marfan syndrome in many different ways as part of a visual project. In groups of 2 they had to either create a short movie or take photographs or do some drawings. The topic was: My (Marfan-) self – between outside perception and self-perception. The young adults could represent themselves in the end product in any way they liked.

In the afternoon session, the results of the visual projects were presented. A lot of different topics were covered in the projects: how we see ourselves, how others see us, having lots of plans but at the same time struggling with fatigue, characteristic situations (going shopping, being clumsy, being able to eat anything without gaining weight),...

In the late afternoon, all participants of the MEN meeting went for sightseeing to Spiralen in Drammen.

Sunday

On Sunday morning, the Young Adults prepared their presentation for the adult participants of the MEN meeting. The movies, photographs and drawings were presented to the adults.

The Young Adults discussed possibilities to stay in touch until the next meeting. They created a WhatsApp group that is open for other Young Adults. Also the Facebook group will be used more actively. Once a month, there will be a discussion topic in Facebook, so that people have a chance to exchange ideas and stay in touch. The Young Adults group decided to have a YA meeting in 2020. Karina will look into funding and explore whether it can be held in Germany.