



# Young Adults Meeting Report - 2017

## **MEN Young Adults Meeting 2017 in Leiden, the Netherlands**

One thing became abundantly clear for the Young Adults-group when the biennial Marfan Europe Network meeting in Leiden was opened this year. Participation needed to be bigger, the youngsters concluded as they did a head count. The group existed of just three people, and this was not enough. So the trio took it upon themselves to set up a plan to enhance the participation for the Young Adults-group. During their time in Leiden, they sat down together to write down the aims and goals and presented these to the European representatives present.

While enjoying the pleasure of a nice hot beverage in a café in Leiden on a rainy Saturday morning, the three agreed on the following things.

First of all, even though Marfan may influence an individual's life greatly, the focus of the meetings shouldn't be on Marfan, but on *you*, the person. Having these meetings is about socializing with other young people who share one important aspect of their life, yet at the same time they are all very difference people. By encouraging this individuality - thus by focusing on the person and not on the disorder - we might learn from each other, we can help each other and think about solutions to problems that people might encounter.

Secondly, it is important to acknowledge that there are differences between the interest and needs of adults and young adults, and therefore the program of the biennial meetings should be adjusted. The Young Adults-group should have its own program with activities and guest speakers that meet their expectations.

Last, but not least, the social network shouldn't be limited to the biennial meetings that are held all over Europe. It should also live on, as an online platform perhaps, as a chain of connections which people can turn to. It should grow to become a self-sustaining network that gets passed on from generation to generation. These things can be achieved if the European Marfan's associations help us spread the word to their adolescents and young adults. In this way, potential new members can be made aware of our existence and can even be personally invited.

With these new goals in mind, action should be taken. But help is needed! The representatives present in Leiden were all very enthusiastic about our ideas, and we hope the flame is kept alive. The associations should start spreading our word to its members, so young adults who meet the criteria are located and invited to join us. Refer to our Facebook-page (Marfan Youth of Europe group), collect contact information of your members to we can get in touch with them, or give our contact information to them. All three of us are reachable via email, phone or social media. For the next meeting in 2019, a program is going to be creating specially designed for the Young Adults-group, and we are hoping that a big enthusiastic group of youngsters will be present to enjoy it with us!

Also on behalf of Lauren Simons  
Karina Zeyer  
(YA Representative)  
And Lina de Nijs