



Marfan Europe Network

Meeting Report - 2017

Purpose

Marfan Europe Network is all about making it possible for European national organizations for Marfan Syndrome to share, collaborate and exchange information. Its main purpose is to organize biannual meetings. This short report collects the highlights from the meeting in 2017.

Members sharing ideas and challenges

These meetings always start with members being able to present the work in their national organizations. This includes what achievements that they are especially proud of, what they see as their strength, what other organizations can learn from them, and what challenges they are facing.

Presentations are based on the national reports, which are available for all members in Dropbox.

Several items were discussed in detail, a matter of particular interest are each organization's specific funding efforts and possibilities. Some room was given to explanations and information about the aims and the work of the ERNs (European Reference Networks) and ePAGs (European Patient Advocacy Groups). Charissa Frank from Belgium (Flanders) has already been elected as patient representative in VASCERN European Reference Network on Rare Multisystemic Vascular Diseases and in ReCONNET Rare Connective Tissue and Musculoskeletal Diseases Network and will distribute some further information/links to all participants after the meeting. For most patient representatives, it is important to know that the ERNs do not pay the travel expenses of ePAG members attending a meeting.

The subject of data security and accessibility was raised and discussed. Obviously, it is important to have backup systems for cases of emergency. It is also evident that - especially for small organizations - it should be carefully decided and arranged that access to data must not be restricted to one person but, e.g. in case of sickness of the person responsible for the administration of data, there is always someone else reliable and qualified to have access to the data. This has caused problems in more than one organization, and hence, it was important to highlight it again.

A lot of things in terms of practical physical tools like pamphlets, books, hand-outs etc. were shown.

Medical lecturers in Corpus surroundings

"Guidelines for Marfan Syndrome" and "Multidisciplinary care in The Netherlands", "Losartan studies", and "Aortic surgery" were among the presentations on Friday. These lectures were presented at the Corpus in Leiden, also known as the place for the exposition "A spectacular journey through the human body". That location gave an extra twist to the lectures.

All lectures will be made available to our members on video shortly on Youtube platform in agreement with the lecturers, and the links were shared via separate emails.

On Saturday, the medical program included presentations on "Parents' perspectives on the impact of Marfan syndrome on daily life functioning, family life and the care needs of children with Marfan syndrome" and "(Dis)ability in children with Marfan syndrome: lessons learned and future aspects", which both included new insights into the respective fields.

Young adults

As always, a separate meeting was held for Young Adults with participants from Netherlands and Germany. Although they are free to join the assembly and the lectures, it is completely up to themselves how they choose to spend their time. At the end of the meeting, the Dutch Young adults presented the results of the discussions that they had. Principally, they would like to meet annually to establish a closer network of personal contacts. At this point it will not be possible to arrange the next meeting in 2018 already, but for the future it should be considered by the Co-ordinating Committee.

Young adults furthermore would prefer to focus on subjects of everyday life, youth related problems and open discussions without a given theme to begin with. They find it difficult to listen to several lectures in a row confronting them with medical issues and would rather have more opportunities for active communication.

Organization highlights since latest meeting in October 2015 (details in the minutes of the assembly 2017)

- Support of the planning of the meeting in Leiden has been the main activity
- Interacting with non-member European organisations
- Setting up a regular newsletter to improve communication
- Increasing activity on Facebook to make communication better

Evaluation of this year's meeting

In the final round of comments everybody expressed her/his thanks to Jeroen and his wife Mariëlle for doing an excellent job organizing such a large event, the most illustrative walk through the Corpus, the very interesting lectures and the nice dinner at the beach. Some items to be considered for improvement in future meeting were also brought up:

- For some participants, the meeting lasted too long and the agenda was too tight. The CC should talk about allowing some flexibility regarding the duration of the meeting and the time allowed to relax in-between sessions.

- Although everybody enjoyed the excursion to the Corpus some found it exhausting and difficult not to be able to lie down for a short period during a break in a long program. This would, of course, restrict the place of the meeting to the hotel.
- Most participants would like to learn more about fundraising. A workshop about this important item would seem a good idea for the next meeting.
- It appears that some of the presentations led to questions and subsequent dialogues regarding specific details that were not always of common interest and affected to attention of the audience as a whole. Everybody should try to stick to the theme and feel free to interrupt if discussions become too lengthy.
- In order to keep the attention of the participants and enable them to concentrate better during the "sitting" sessions, they should be interrupted by some team building or exercise-like (eg. Yoga) measures.

These comments will be taken into account for the organization of future meetings.

To the participants, thanks for joining the meeting, and to other readers, thanks for your interest.