



Purpose

Marfan Europe Network is all about making it possible for European national organisations for Marfan Syndrome to share, collaborate and exchange information. It's main purpose is to organise biannual meetings. This short report collects the highlights from the meeting in 2015.

Meeting highlights

All members shared ideas and experiences from their national organisations. A lot of things in terms of practical physical tools like pamphlets, books, hand-outs etc. were shown. Online tools were also presented and these included mobile apps, Marfan School videos, membership databases etc. Furthermore, every organisation shared what the year is like in their own organisation in terms of courses and meetings as well as communication with members.

The medical programme included presentations on genetics, foot and hip problems, and pain. All presentations were specifically addressing people with Marfan Syndrome. In addition, a review of recent articles about Marfan Syndrome was presented to members.

A group discussion was held about ideas for what the purpose of the organisation should be besides coordinating meetings. A list of ideas including idea newsletters for communication, online library for resources, video conferences, suggestions to funding, were all brought to the table by members. The co-ordinating committee will now consider when and how to implement ideas from this group discussion.

The meeting included a Young Adults meeting with participants from 4 countries. They attended the medical programme and spent the rest of the time on discussing different topics particular relevant for their age group. As their masterpiece for the meeting, they recorded and edited a video with a combination of fun dancing and serious talks.

Organisation highlights since latest meeting in September 2013

- Planning of the meeting in Kalmar has been the main activity
- Arranging a Young Adults meeting in Klagenfurt in Austria in 2014
- Presenting preliminary results on European survey on "Vision and life quality"
- Setting up a Facebook page to increase communication with members
- Implementing a new logo and new name