



**Programme – Marfan Europe Networks meeting
1–4 October 2015 in Kalmar, Sweden**

Thursday 1 October

- 16.00 Welcoming members, check-in and instructions
- 18.00 Dinner
- 19.00 Opening of the Marfan Europe Networks meeting 2015 – Annual assembly, part 1
Chairman: Martin J Skov, Denmark.
- Introduction round of participants
 - Election of auditors (To look into the papers and the balances. They have to do their work the following day and then give their report.)
 - Questions on your WORK and VISION in your Marfan Association:
 1. What achievements are you especially proud of and how did you do it?
 2. What are your biggest challenges you are facing right now?
 3. What aspect of your work do you see as your strength and what can other organizations learn from you?
 4. In what areas of your work would you benefit from advice of other organizations?
 5. Every organization is in a different state of organizational development – where are you right now – what are the next steps – what is the goal?

Friday 2 October

- 08.30 Breakfast
- 09.30 Marfan organisation and Counselling:
 - Continuation presentation of the countries work
- 10.30 Short break with fruit
- 10.50 Reports of the Coordinating committee – Annual assembly, part 2
 - Minutes EMSN meeting 2013
 - Report of the chair and “brainstorming session” about our network and how we would like to organize it and the meetings in the future
 - Report of the treasurer
 - Suggestion about changing the financial year to January 1 until December 31
 - Report of the auditors
 - Membership fee 2016–2017
 - Budget 2016–2017
 - Changes in mission statement/rules and regularisations
- 12.30 Lunch
- 14.30 Dr Bertil Romanus, Consultant and Associate Professor at Sahlgrenska University Hospital in Gothenburg. He specializes in foot and hip problems, and will talk on this in relation to Marfan syndrome.

- 15.30 Break
- 16.00 Discussion about a new idea for Marfan Europe: Compiling of reports concerning special themes in English, to be published on our website. This could make sure that the basic knowledge about Marfan is available in every country. Marina Vogler will tell us more.
- 17.00 Medical yoga workshop with Karin Olsson as an instructor
- 17.30 Free time
- 18.30 Dinner
- 19.30 Informal conversation

Saturday 3 October

- 08.30 Breakfast
- 09.30 Topics from the participating countries
- 10.30 Break
- 11.00 Dr Acke Ohlin, Consultant and Associate Professor at University Hospital MAS in Malmö, Orthopedics. He will lecture on spinal deformities in Marfan syndrome
- 12.00 Lunch
- 14.00 Dr Cecilia Gunnarsson, Clinical Geneticist, Laboratory Medicine Linköping University Hospital. She will lecture on genetic related to Marfan syndrome. She is also project manager for building up a regional competence center for rare diseases and will tell us about that.
- 15.00 Medical presentation about pain and what can be done to relieve pain
- 16.00 Coffee break
- 16.30 Sightseeing at Kalmar castle
- 19.00 Dinner and social gathering

Sunday 4 October

- 08.30 Breakfast
- 09.30 Annual assembly, part 3
 - Elections of Coordination Committee for the next four years
 - Postponed decisions
- 10.30 Presentation of the Young Adults report 2015
- 11.30 Next meetings and young adults meeting, where and when?
Evaluation of this year's meeting
End of the meeting 2015
- 12.00 Lunch