

European Marfan Support Network

(AND RELATED DISORDERS)

Invitation

EMSN Meeting 2013

and

EMSN Young Adults Meeting 2013

5 – 8 September 2013

Zürich, Switzerland

Invitation	2
Participants and guests at the EMSN Meeting.....	2
Participants at the Young Adults Meeting.....	2
Outline of the agenda for the EMSN Meeting 2013	2
Contributions from the members.....	2
Medical presentations	3
Annual Assembly	3
Outline of the Young Adults programme	3
Venue, registration and prices	4
Prices	4
Payment	4
Cancellations	4
Registration form	5

European Marfan Support Network
Head Office Address:
Hilde Sande
Støperigata 25, NO-4014 Stavanger, Norway
Tel.: +47 41 62 53 22
E-mail: cc@marfan.eu

Invitation

Dear EMSN friends,

We are pleased to invite you to participate in the EMSN Meeting 2013 and the EMSN Young Adults Meeting 2013 to be held in Zürich, Switzerland in September.

Our host is the Marfan Foundation (Switzerland) and they plan to collect world wide specialists to this year's meeting! We would like to welcome delegates, guests and young adults from the European Marfan organisations to meet, hear from and discuss with specialists from the US and Europe.

There will also be time for the traditional discussions on aspects of living with Marfan syndrome and sharing experiences with counselling and organisational challenges.

Participants and guests at the EMSN Meeting

Each member organisation can participate at the entire meeting with two delegates, who are eligible to vote, and two guests.

This year we also invite additional guests to attend the medical part of the meeting (Friday and Saturday). These can be additional guests from a member organisation, but also guests not connected to a member organisation.

Guests from other European Marfan organisations that are interested in joining the EMSN are also welcome to attend the entire meeting as guests.

Participants at the Young Adults Meeting

Each member organisation can participate with up to four young people aged between 18 and 28. The participants at the EMSN Young Adults Meeting will attend most of the medical presentations, but will get time to discuss these in the group as well. There will also be time to discuss other topics relevant for the young adults. Please pass the invitation on to your young people and encourage them to take part!

Outline of the agenda for the EMSN Meeting 2013

Thursday 5 September: welcome and presentations from around 17:00 followed by dinner and social get-together.

Friday 6 September: The EMSN Assembly will be held before lunch. After lunch we have the first medical part followed by dinner and social get-together.

Saturday 7 September: Medical part most of the day with a morning EMSN session if needed. In the evening there will be an event dinner.

Sunday 8 September: EMSN discussions and closing of meeting at lunchtime.

Contributions from the members

All members have already been asked to suggest specialists from their country for the medical part. Any additional suggestions to the medical part have to be done as soon as possible.

We ask all members, attending or not, to send your contributions to the Co-ordinating Committee, cc@marfan.eu, by 30 July on the following points:

- the annual report of your organisation with a short summary

EMSN 2013 Invitation

- topics from your country that you want to present or discuss
- topics for the young adults to discuss
- any proposal for agenda items for the Annual Assembly

We ask everyone to send the annual reports, written in English, to us before the meeting, so that the report from the members can be sent to all members prior to the meeting. At the meeting you will get the chance to present some highlights from the report, but the full reports will not be read. Further instructions will be given.

If you have important issues or items to report, please let us know, and we will make room for it in the agenda. The EMSN is all about sharing information and experiences, and even with the extended medical part this year, the success of the meeting does rely on your participation and input.

Medical presentations

The following specialists have already been confirmed:

- Reed Pyeritz, US
- Irene Maumenee, US
- Klaus Kallenbach, Germany
- Yskert von Kodolitsch, Germany
- Julie De Bakker, Belgium
- Niels Holmark Andersen, Denmark
- Thierry Carrel, Switzerland
- Christine Attenhofer, Switzerland
- Gabor Mathyas, Switzerland

We are awaiting replies from additional specialists from the US and Norway.

The medical part will start after lunch on Friday and continue most of Saturday. Additional guests are invited to join the medical part, see the registration form for further details.

Annual Assembly

This year the Co-ordinating Committee needs new members! All members are up for election and some of us have already done the allowed two terms in the row. So please think of potential candidates for the committee that can help us bring the European Marfan Support Network into the future!

The EMSN does not hold the rights anymore to use the EMSN logo we have been using. Therefore our network needs a new logo and we hope to have some suggestions ready for the assembly to discuss.

We also have to plan for future meetings, so please let us know if you are interested in organising one of the future meetings.

At the moment there are no other major issues for the assembly. If you have proposals for agenda items for the Annual Assembly 2013, please send them by 30 July to the Co-ordinating Committee at cc@marfan.eu.

Outline of the Young Adults programme

Thursday 5 September: Welcome and getting to know each other, followed by dinner and social get-together.

Friday 6 September: Group discussions before lunch. Medical presentations after lunch, followed by dinner and social get-together.

Saturday 7 September: Medical presentations of choice with discussions or time to rest in between. In the evening there will be a joint event dinner.

Sunday 8 September: Discussions about the medical presentations and/or other topics. Planning the proposed EMSN Young Adults only meeting in 2014. Closing of the meeting by lunchtime.

The Young Adults will be given the opportunity to attend the medical parts. At all times there will be a room to gather and discuss for those not attending a presentation (or time to rest if needed).

As the last years, Lauriane Janssen will lead the group, and we hope to see many young participants from different countries in Zürich. We invite all members and the young adults in particular, to submit ideas of topics and/or issues for the Young Adults meeting to the Co-ordinating Committee at cc@marfan.eu by 30 July.

Venue, registration and prices

The meeting and accommodation will take place at Zurich Development Centre, Keltenstr. 48, 8044 Zürich. Directions will be given together with the confirmation of your registration.

Please register for the meeting and book your room by sending the attached registration form to cc@marfan.eu before June 15.

Any questions about the venue or the meeting should be directed to the EMSN Co-ordinating committee (cc@marfan.eu / +47 41 62 53 22) or the Marfan Foundation (info@marfan.ch) .

Prices

The cost for EMSN delegates, young adults and up to two guests from each member organisation will be **280 Euros per person for the entire meeting**. This includes all meals, meeting costs and accommodation (all in single rooms).

For additional guests who want to attend the medical part the price will depend on when they are arriving and how long they are staying. Arriving before lunch on Friday and staying until Sunday morning will cost 205 Euros. Staying just for the medical part, leaving before dinner at Saturday will cost 112 Euros. Please indicate on the registration form when you will be arriving and leaving.

Payment

The meeting has to be paid in advance. After you have registered, you will get a confirmation with the total price. **Please pay by 15 July to:**

Bank: PostFinance (www.postfinance.ch)

Account Number: 49-2619-4

Account holder: Marfan Foundation (Switzerland)

IBAN CH92 0900 0000 4900 2619 4

Cancellations

Cancellation and changes done before 15 July is free of charge.

Cancellation after 15 July has to pay full price.

