

European Marfan Support Network

(AND RELATED DISORDERS)

EMSN 2012 – Online Report

The European Marfan Support Network (EMSN) has 12 members from 11 different countries. The EMSN organises biannual meetings (annual up to 2011). The EMSN Co-ordinating Committee and the members collaborate on different issues between the meeting and exchange information and experiences. Every year the EMSN Co-ordinating Committee publishes a report about the work going on in the organisation and the member organisations. This short report collects the highlights from the EMSN 2012 Report. The full report is available for all members of the organisations part of the EMSN upon request to the national organisation or to the EMSN Co-ordinating Committee.

This report includes highlights for August 2011 till August 2012 for

- EMSN
- AUSTRIA: Marfan Initiative Österreich
- BELGIUM (FLANDERS): Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen vzw
- BELGIUM (WALLONIA): Association Belge du Syndrome de Marfan
- DENMARK: Landsforeningen for Marfan Syndrom
- FINLAND: Suomen Marfan-yhdistys ry
- FRANCE: Association française des Syndromes de Marfan et apparentes
- GERMANY: Marfan Hilfe (Deutschland) e.V.
- THE NETHERLANDS: Contactgroep Marfan Nederland
- SLOVAKIA: Asociacia marfanovho syndromu
- SWEDEN: Svenska Marfanföreningen
- SWITZERLAND: Marfan Foundation Switzerland

EMSN highlights

- Marfan Initiative Österreich, Austria, has become a member
- The EMSN Young Adults Meeting 2012 was arranged in August in Leuven, Belgium. There were eight participants from five countries at this first separate Young Adults meeting, as you can read more about in the short report from this meeting published online.
- The European survey on “Vision and life quality” has been set up and the first questionnaires have been sent out
- The EMSN also participated in an application for an EU-project who unfortunately did not get funding.
- The new website was launched in June 2012.
- The EMSN Mission Statement was updated to reflect the change to biannual meetings.
- Ongoing collaboration and contact between members and with other national and international organisations

AUSTRIA: Marfan Initiative Österreich

<http://www.marfan-initiative.at>

- We set up a new website www.marfan-initiative.at, as well as a new basic information folder.
- We took active part in building and shaping pro rare – the Austrian association for rare diseases. We hope that with this association we will have a stronger voice towards our political decision makers.
- We held our annual meeting, where main topic was the EMSN and the information we received at the meeting in Eutin.
- We took part in several medical congresses where we informed the medical staff and where we were able to get in contact with doctors for further cooperation.
- We sent one of our team to the EMSN Youth meeting 2012 in Leuven.
- We published an article in a newspaper for self help organizations.

BELGIUM (FLANDERS): Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen vzw

<http://www.bindweefsel.be>

Not received.

BELGIUM (WALLONIA): Association Belge du Syndrome de Marfan

<http://www.marfan.be>

This year, thanks to our fundraising actions and special donations, we could increase our support to research to 10000 Euros.

The website was completely remodelled and is now up to date with future activities. A Facebook page has also been created to help keeping our members posted on the upcoming events.

We tried to motivate some external members to be volunteers and help us with the organisation of some events, but this did not work out. However, thanks to the Young Adults Only meeting organised in Belgium, some Young Adults came up and seemed to be motivated to take part in the association.

The usual members' days and medical conferences have a constant attending the last few years. We hope to increase this by changing the family day to be in the spring/summer and the medical presentation in autumn.

DENMARK: Landsforeningen for Marfan Syndrom

<http://marfan.dk>

The organisation has approximate 330 members, of which approximate 170 have Marfan Syndrome.

Chairman is Bitten Kjærgaard, mother of a boy with Marfan Syndrome.

- In April 2012 we held a conference about recent research and social issues regarding Marfan Syndrome.
- In April 2012 we had our national meeting with presentations about challenges both in terms of diagnostics and in terms of every day life. A psychologist and a therapist facilitated group discussions on every day life, and our new patron was introduced.
- In April 2012, a private safari tour exclusively for children with Marfan Syndrom was arranged.

This year we are implementing a new organisational structure, where we due to financial constraints need to rely more on volunteers. Until May 2012 we had a full-time social worker/administrator. Now, we only employ a social worker for 4 hours a week.

FINLAND: Suomen Marfan-yhdistys ry

<http://www.marfan.fi>

The period August 2011 – 2012 has been quite normal for Suomen Marfan-yhdistys ry, except the fact that 2012 is our twentieth anniversary since the association was founded in spring 1992.

We had six board meetings, an annual general meeting, one peer meeting and two members of our association participated in the Scandinavian Marfan meeting in Stockholm, Sweden.

The annual general meeting made a unanimous decision to change the association's rules so that we now accept everybody with Marfan syndrome and with syndromes similar to Marfan and their families to join our association.

We published two member magazines and an A4 sized leaflet which purpose is to help the cooperation between school and home.

FRANCE: Association francaise des Syndromes de Marfan et apparentes

<http://vivremarfan.org>

Here are the main actions which have been carried out between August 2011 and August 2012:

- The publication of the book "Jeune et Marfan, oui, et alors...!?" ("Young and with Marfan, and so...!?" led the independent medical newspaper "Prescrire" to award us with the "Prix prescrire 2012".
- The fund-raising to finance our research project is going on and at the end of August we had about half of the total amount of the 3-year project which started on 1st October 2012.
- Our new website is really successful and the monthly visits (in average 3400) is beyond our expectations.
- The increase in the number of regional meetings between 2011 and 2012 should go on in 2013 thanks to the arrival of new regional delegates.
- Greg Romano, a humorist, now sponsors the AFSMa.

GERMANY: Marfan Hilfe (Deutschland) e.V.

<http://marfan.de/>

Marfan Hilfe (Deutschland) e.V. is an association with about 1200 members, organized in regional groups. We have a board of four chairs and also a scientific board. Our main projects in 2012 were:

- German Marfan Day (seminars, workshops, discussions)
- Seminar for relaxation
- Seminar for children and their parents
- Seminar for young adults
- Seminar for active members
- Booklet with stories from women
- Distribution of information for pediatricians
- Questionnaire about life quality

THE NETHERLANDS: Contactgroep Marfan Nederland

<http://www.contactgroepmarfan.nl/>

We have continued our PR campaign and extended our cooperation with universities to include Amsterdam and Ede. We have also prepared posters and a short documentary film.

A big challenge after the government announced that subsidies will be reduced, has been to prepare a realistic budget and still continue with our policies.

In October 2012

- we celebrated CMN's 30th anniversary
- the draft of the new **academic medical multidisciplinary guideline** which the CMN has contributed to was presented in October 2012

We have prepared

- an illustrated booklet with 10 personal stories from our members on the subject "How to live with Marfan"
- a new brochure called "**Marfan and pregnancy**", supervised by several doctors, "
- our journal "**Marfinfo**" and a digital newsletter when important news are available

We are active on social media like Twitter, Facebook and Hyves. Our website also proves to be an imported communication tool.

NORWAY: Foreningen for Marfan syndrom og andre marfanlignende tilstander

<http://marfan.no/>

Members: Per 31.12.2011 we have 298 paying members, 262 adults (over 16) and 36 children. 142 households ("main members") receive our members' bulletin Marfant'n.

The total membership fee was 49 300 NOK in 2011. We also receive government funding.

Our activities:

- A course for rehabilitation training for 16 members arranged at Valle Marina, Gran Canaria (Spain), 19 - 26 October 2011.
- Weekend meeting with the general assembly for all members at Gardermoen, Norway, in April 2012.
- Participated at the Nordic Marfan meeting arranged by the Swedish Marfan Association in March 2012. Norway will arrange the next Nordic meeting in August 2014.
- Course for our peers at Gardermoen, Norway, in November 2011.
- Participated at the Seminar "Tools for measuring life aspects in Marfan Syndrome", arranged by TRS, Sunnaas Rehabilitation Hospital, Norway.
- New website www.marfan.no released in January 2012
- Publishing the members' bulletin Marfant'n

SLOVAKIA: Asociacia marfanovho syndromu

<http://marfan.szm.sk/>

Our main activities:

- **Annual meeting 2011 with recondition and medical program**
- **Helping the Czech Marfan Association and establishment of a Marfan organization in Serbia**
- Activities and cooperation with organizations specially oriented for rare diseases.
- Helping individual patients to get into contact with special medical doctors and to **arrange appointments for their medical examinations**.
- Helping many patients **receiving invalidity status** resulting in regular benefit payments.
- **Providing a recommendation** from our association to patients who need it to obtain disablement cards, early retirement benefit, social and financial supports

The "**Marfan Care Centre**" continues their work under the supervision of associate professor **Michal Ondrejčák**. He is a geneticist who also **provides important genetic consultations** and recommendations for our patients, as well as for those who are not yet diagnosed.

New Board: president B. Lukovicova, viceprezident R. Dusinsky and 4 members, honorary president M. Dusinská

SWEDEN: Svenska Marfanföreningen

www.marfanforeningen.se/

2012 and 2013 we have a wellness project which contains; our wellness courses, a newsletter and a web page. There will be a follow-up meeting in 2013. The participants provide a reference group for a book with advices on how to live a healthier life. The book is to be spread to everyone with Marfan and, if interested, translated into other languages. At the courses we work with yoga, exercise, nutritional counselling and massage. The book will be about these topics especially adapted for Marfan.

We have not done much other than these wellness activities. We had an annual meeting and we have given out our magazine.

Sweden has created a national function for rare diseases. Their task is to develop a national strategy.

In March we hosted the Nordic Marfan meeting. We had Dr. Svend Rand-Henrikson from TRS in Norway, and doctors from Karolinska University Hospital.

SWITZERLAND: Marfan Foundation Switzerland

<http://marfan.ch/>

Following the financial consolidation from last year, 2012 has also been a consolidation year, with the focus on the organisation.

- New Web made available in the 3 languages, German, French and Italian. In addition we integrated a "forum facility", which allows the participants to chat online in a secure manner.
- Following the agreement stipulated in Eutin to exploit the synergy among the European organisations we imported and updated the brochure "Vivre avec Marfan" from the French organisation
- E-office project with the aim to increase the effectiveness of the daily operation implemented.
- Meeting for all the Swiss regions has been held and also various regional meetings organized by the Association.
- Participated at various medical meetings within our country.
- Invited by the Italian organisation to the yearly congress to outline our organisational principles.
- Improved cooperation with the American organisation NMF.