

European Marfan Support Network

(And Related Disorders)

EMSN 2013 – Online Report

The European Marfan Support Network (EMSN) has 12 members from 11 different countries. The EMSN organises biannual meetings. The EMSN Co-ordinating Committee and the members also collaborate on different issues between the meetings 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 2013 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 2012 till August 2013 regarding:

EMSN HIGHLIGHTS

EMSN highlights August 2012 to August 2013

EMSN Meeting 2013

SHORT NATIONAL REPORTS

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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

NORWAY: Foreningen for Marfan syndrom og andre marfanlignende tilstander

SLOVAKIA: Asociacia marfanovho syndromu

SWEDEN: Svenska Marfanföreningen

SWITZERLAND: Marfan Foundation Switzerland

EMSN HIGHLIGHTS

European Marfan Support Network

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EMSN highlights August 2012 to August 2013

- The first EMSN Young Adults Meeting was arranged in August 2012 in Leuven, Belgium with participants from five countries.
- Marfan Initiative Österreich, Austria, became an official member in December 2012.
- The EMSN Mission Statement was updated in December 2012 to reflect the change to biannual meetings.
- Follow up of the ongoing European survey on “Vision and life quality”.
- Ongoing collaboration and contact between members and with other national and international organisations.
- Planning of the EMSN Meeting 2013.

EMSN Meeting 2013

The meeting was held in connection with a very large medical congress with Marfan specialists from Europe and US. The conference included a total of more than 20 presentations by about 20 specialists divided into sessions on Genetics, Ophthalmology, Psychology, Lungs/thorax deformity, Cardiology/Cardiac surgery, Maternity, Orthopaedics/pain therapy, and Marfan Clinics.

The American organisation was represent at the meeting and spoke about their new branding strategy and how their organisation is moving forward.

The assembly elected a new Co-ordinating Committee with Martin J. Skov from Denmark as the new chair. He is joined by committee members from Germany, Sweden, Austria, and Denmark.

The meeting also included a Young Adults meeting with participants from four countries. They attended the medical programme and spent the rest of the time on discussing different topics particular relevant for their age group.



EMSN meeting delegates

SHORT NATIONAL REPORTS

AUSTRIA: Marfan Initiative Österreich

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

August 2011 – September 2013:

We held a few informal meetings as well as two big yearly meetings. Our main meeting 2011 was about the information we received at the EMSN Meeting, the main meeting 2013 was about the problems associated with sight (medical presentation).

In the last two years we followed our goals:

- **INFORMATION**
A new website, a Facebook page as well as a new e-mail newsletter informed our members about our work.
- **NETWORKING**
On a national and international level, with the EMSN as well as other Marfan associations (Germany), other associations of rare diseases (pro rare – Austrian umbrella association for rare diseases) as well as doctors.
- **PUBLIC RELATIONS**
Raising awareness by participating at medical fairs and conferences as well as at the walk for rare diseases in Vienna.
- **EXCHANGE OF EXPERIENCES**
We shared our experiences on Marfan syndrome in various informal meetings, as well as online via stories of experiences.

BELGIUM (FLANDERS): Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen vzw

<http://www.bindweefsel.be>

- In November: organised Patient Conference with a specialist guest speaker speaking on pain.
- In November: a change in the Board of Directors.
- In February: participated in Rare Disease Day, an awareness campaign via Facebook, Flemish Media with coverage on National TV, local TV senders and in printed media.
- In March: large conference with guest speaker talking about the psychological effects as well as impact on personal live and environment.
- Organised several regional meetings spread over Flanders.
- May and June 2013: special info sessions about ergonomic aids and tools (more in the fall).
- We have started to change and update our website.
- Working hard on growth of foundation, making contacts with other foundations. We mainly focused on getting the foundation back healthy and breath some new life into it.

BELGIUM (WALLONIA): Association Belge du Syndrome de Marfan

<http://www.marfan.be>

The goal of the Association Belge du Syndrome de Marfan (ABSM, Belgian Wallonian Association) is first of all to inform Marfan patients, but also to facilitate contact between Marfan patients and doctors.

Several telephonic conversations were held with patients worrying about Marfan matters, and the website (www.marfan.be); the forum and the Facebook page allowed our members to be up to date for our activities and to keep in touch with each other.

This year's medical presentation of Dr. Julie De Backer, cardiologist of Ghent was a big success. Our fund raising event (the sale of Marzipan and sweets and a theatre play) permitted us to fund some research in Dr Anne De Paepe's Marfan Research group in Ghent.

Among these specific ABSM matters we are also involved in Eurordis (European Rare disorder group), RadioOrg (Belgian Rare Disorders group), LUSS (patient organisation), the «Marfan quality of life»-international group, and attended the French AFSMa Day as well as the international meeting on Ehlers-Danlos in Ghent.

DENMARK: Landsforeningen for Marfan Syndrom

<http://marfan.dk>

The organisation has 358 members, of which about half has Marfan syndrome

In August 2012, we attended the Nordic meeting for Marfan syndrome

In September 2012, we arranged a course and get-together for our volunteers.

In April 2013, we had our national meeting with presentations on Marfan and pregnancy, and Marfan and feet/back problems.

In April 2013, Sven Back, who has Marfan, became our new chairman.

In June 2013, Hanne Lindhardt, started as our new part-time employed secretary.

In rest of 2013, we have planned a weekend course for volunteers, and a weekend with courses in genetics & ethics, and with themes in family planning.

FINLAND: Suomen Marfan-yhdistys ry

<http://www.marfan.fi>

The period of August 2012 – 2013 has been quite the same as other years to Suomen Marfan-yhdistys ry. We had six board meetings, an annual general meeting and three peer meetings. In April 2013 the National Board of Patents and Registration of Finland accepted the change in our association rules so that we now accept everybody with Marfan syndrome and with syndromes alike to Marfan and their families to join our association. We published two member magazines and we are planning to publish a booklet of Marfan diagnostics soon.

FRANCE: Association française des Syndromes de Marfan et apparentes

<http://vivremarfan.org>

The milestones of the French Marfan association AFSMa this year:

- **2012 Prescrire award** (medicine newspaper) for the book *Jeune et Marfan... oui, et alors?!* (Young and Marfan... so what ?!)
- New **website**, new **e-newsletter distribution**, increasing **social media** usage (Facebook, etc.)
- **Sponsorship** from a great promising young **humorist, Greg Romano**
- Patients' groupings and events: **Marfan's Day** in June, Members' **Weekend** in October and even more **regional** meetings
- **Patients' support actions**: hotline and e-mails
- **Fundraising** events and operations: concerts, bingo, race meetings, etc. Approximately € 66,000 was raised for a research project (cf. below)!
- **Scientific research financing**: M.D. Ph.D. L. Olivier-Faivre on revised Ghent nosology, M.D. Ph.D. H. Plauchu on ophthalmic forerunner to get an early screening of the Marfan syndrome, M.D. G. Collod-Berroud on a **database capturing worldwide Marfan patients' biological information** (work in progress).
- In preparation with the US Marfan Foundation: **9th International Research Symposium** on Marfan Syndrome and related disorders – Paris, September 2014

GERMANY: Marfan Hilfe (Deutschland) e.V.

<http://marfan.de/>

The German *Marfan Hilfe* continues its efforts to improve and ensure the quality of life for people suffering from the disease. We offer our members ways to obtain information and hints for improving their every-day life.

Events

- "Marfan-Day" in Homburg with lectures and discussions
- Weekend for women
- Health-weekend
- Parent-child seminar
- Seminar for young people
- The "meeting for active members" serves to motivate old-timers and new members alike.

Publications and PR

- Stories written by our female members
- Book written by adolescents
- Leaflets covering different aspects of the disease
- Newsletters, newspapers, journal
- preparation for a film
- presentation at self-help fairs

Research

- Research Award of 6000 € to Dr. Horbelt of Berlin for his work on abnormalities in the metabolism of TGF- β

- Joint pilot intending to be able to offer restorative health measures geared towards Marfan sufferers similar to Norway
- Questionnaire on Eyes
- Questionnaire on life quality

THE NETHERLANDS: Contactgroep Marfan Nederland

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

Activities in 2013:

- Active cooperation with other care unions:
We've contacted other unions, for cooperation and support. These are unions that are related to our own
- Cooperation with universities of higher education:
Several universities have done researches for the CMN, concerning the youngsters. Also they made a digital oracle for our members and other visitors
- Development of the medical guideline:
The CMN was engaged in developing a medical guideline, to make sure each Marfan patient is treated according to the best medical practices.
- Several moments of "member-contacts":
Our members, and their relatives, can meet during several moments, in the year, organized by the CMN
- Starting on research "Marfan and aging":
The Marfan patient, getting older, and having special questions
- Development of the website and social media
- Development of digital maps for public speeches:
The map is to be used by children in primary school to help them telling about Marfan

NORWAY: Foreningen for Marfan syndrom og andre marfanlignende tilstander

<http://marfan.no/>

During August 2012 - July 2013, the Norwegian Association for Marfan syndrome and related conditions has carried on its work through

- organisation of peer work, which is our backbone of knowledge
- professional knowledge
- organisation of social events

During recent years, we have focused increasingly on young members.

In October 2012 we arranged a course aimed at youths and their families. Key subjects were

- choice of education and profession
- thoughts about the Self: who I am
- leisure and sports activities

The annual Marfan Conference was held in April 2013, with the following themes in focus:

- Cardiac surgery
- Results from TRS cross-section study "Life with Marfan syndrome"

- Optical aids and techniques
- Orthopaedic aids and assistance
- Peer discussions

In June 2013, we participated in the Three-Country Diagnostics Symposium in Germany, with scientists and member organisations from Germany, Belgium, and Norway. Issues on the advancement of diagnostics and treatment were discussed.

SLOVAKIA: Asociacia marfanovho syndromu

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

Our main activities are:

- **To get MFS disease into public and professional awareness.**
- **Annual meeting 2012 with recondition and medical program, october 2012**
- Relax meeting : **"Marfans need help", April 2013**
- **Lot of print articles and TV documents about MFS**
- Help to Czech Marfan Association and establishment of Marfan organization in Serbia
- Activities of the Association were mainly focused on activities and cooperation with organizations specially oriented for rare diseases.
- Help individual patients to get into contact with special medical doctors and to **arrange the appointments for their medical examinations.**
- The association has helped many patients in **receiving invalidity status** resulting in regular benefit payments.
- For patients who needed help, we **provide a recommendation** from our association to different authorities for obtaining disablement cards, early retirement benefit, social and financial supports
- The **"Marfan Care Centre"** continues their work. The Centre is under the supervision of associate professor **Michal Ondrejčák**, geneticist, who also **provides important genetic consultations** and recommendations for our patients, as well as for those who are not yet diagnosed.

Board: president B. Lukovicova, vicepresident R. Dusinsky and 4 members, honorary president M. Dusinska

SWEDEN: Svenska Marfanföreningen

www.marfanforeningen.se/

Our Wellness Project has been successful. We have held 4 fitness sessions with 40 participants.

The meetings have had the same set up:

- physical training
- medical yoga
- healthy food
- tactile massage

One feature has been that we have talked to many members during the year to invite them to the meetings, but also talking to everyone and hearing how things are. It has also been a web page devoted to the wellness year.

Now we will put together a book of wellness counselling specifically for people with Marfan and there will be a follow-up meeting.

In March we hosted the Nordic meeting where representatives from Denmark, Norway and Finland met.

In October the Ågrenska Foundation had a family week.

In October 2011, the Social Board established a national function for rare diseases; the aim is to ensure that people with a rare diagnosis better can access resources for good health.

In late November, there was a big conference, organized by the National Association Rare Diagnoses, where the strategy was presented.

SWITZERLAND: Marfan Foundation Switzerland

<http://marfan.ch/>

During the reporting period we continued to pursue our primary goal to improve the support of our patients in the various areas, meanwhile we count around 700 members affected by Marfan, Loeys Dietz and Ehlers-Danlos

In the following the major activities:

- **We intensified the cooperation and coordination with the medical specialists** and family doctors in the country, especially with our Marfan Clinic in Bern, the Children Hospital in Zürich and the Center of Genetics in Schlieren.
- We started in cooperation with other bodies a project with the aim to **adapt the health insurance standards in favour of our patients**.
- **We improved the communication from patient to patient** with the introduction of a Web based forum, which allows an informal, protected and secure communication among the participants.