

# European Marfan Support Network

(AND RELATED DISORDERS)

## EMSN 2011 – Online Report

The European Marfan Support Network (EMSN) has 11 members from 10 different countries. The EMSN organises annual meetings (biannual from 2011 onwards). Every year the EMSN Co-ordinating Committee publishes a report after the meeting which also reports on the work going on in the member organisations. This short report collects the highlights from the EMSN 2011 Meeting Report. Note that Austria attended the meeting as guests and is therefore also included. 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 from:

- The EMSN Meeting 2011
- AUSTRIA: Marfan Initiative Österreich (guests)
- BELGIUM (FLANDERS): Vlaamse Vereniging voor Erfelijke Bindweefselaandoeningen vzw
- BELGIUM (WALLONIA): Association Belge du Syndrome de Marfan
- DENMARK: Landsforeningen for Marfan Syndrom
- 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
- SWEDEN: Svenska Marfanföreningen
- SWITZERLAND: Marfan Foundation Switzerland

## The EMSN Meeting 2011

The EMSN Meeting 2011 was held in Eutin, Germany, 11-14 August 2011, with delegates and guest from Austria, Belgium, Denmark, France, Germany, the Netherlands, Norway, Sweden and Switzerland. The EMSN Meeting 2011 included a Young Adults Meeting (age 18-28) with participants from four countries.

We are happy to report that Sweden is now a member of the EMSN, and that Austria considers joining after attending their first EMSN Meeting as guests. The Annual Assembly furthermore decided to have the EMSN Meetings every second year from now on. The next meeting will be in Switzerland in 2013.

The EMSN Meetings are all about exchanging and sharing of information and experience, through presentations and inputs from the members and through the numerous conversations amongst the participants. In addition, the programme included medical presentations from German specialists on the topics vision and life quality, Marfan and sleep apnoea, and the Ghent nosology. A rare disorder centre in Norway presented their on-going study on "Living with Marfan syndrome", and a collaboration with the German specialists was established.

We also celebrated the 20<sup>th</sup> anniversary of the EMSN with a dinner with invited guests of honour. We were very happy that Diana and Robin from the UK, who founded and run the EMSN for the first years, and the former Chairs Helga from Norway and Béatrice from Switzerland could join us in this celebration.

## AUSTRIA: Marfan Initiative Österreich (guests)

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

We held a few meetings; our main meeting included a successful charity event selling paintings and a medical lecture. Within a summer project a team (coordinator, designer, artist and journalist) worked out the first steps to a marketing strategy, our associations' philosophy, our corporate design, and organized a charity event.

The goals of our association are:

- INFORMATION latest news on medical as well as lifestyle issues for people with the marfans syndrome in various communication channels
- NETWORKING on a national and international level, with other marfan associations, other associations of rare diseases as well as doctors
- PUBLIC RELATIONS raising the awareness within the media, the society, the medicine and the government
- EXCHANGE OF EXPERIENCES share the experiences with other marfan patients

## 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>

The Belgian «Association Belge du Syndrome de Marfan (ABSM)», was founded in 1999 by Yvonne Jousten who has been chair since then.

The main goals of the association are to keep the members up to date on medial issues by having medical conferences, and a newsletter that is published approximately 4 times a year. Beside this, we also provide support for Marfan patients by phone contact and meetings, we are involved in several actions to promote Marfan syndrome and last but not least, we organize fundraising actions to promote research on MFS through the Ghent Marfan Center.

### DENMARK: Landsforeningen for Marfan Syndrom

<http://marfan.dk>

The organisation has approx. 300 members, of which approx. 170 have Marfan Syndrome.

- In September 2010, we hosted the European Marfan meeting.
- In autumn 2010, we arranged both a single day and a weekend - mainly for new families.
- In January 2011, we had a course about rehabilitation for adults.
- In April 2011, we had our national meeting celebrating our 20 years' anniversary and with presentations on Marfan backs, Teeth/Jaw, and Eye problems.

In 2011, Bitten Kjærgaard, mother of a boy with Marfan, has become new chairman.

We are planning a new organisation structure, because Bodil retires May 2012 and a full time counselor is no longer possible due to decreased public funding.

### FINLAND: Suomen Marfan-yhdistys ry

<http://www.marfan.fi>

- Founded in 1992
- 153 members of which 94 with Marfan
- Chair Jenny-Jessica Lindgren
- The board has 4-5 meetings yearly
- Activities financed with membership fees
- Member of FPD–Finnish association of people with Physical Disabilities

#### Activities

- Newsletter twice a year
- Summer meeting (weekend)
- Annual meeting with a medical lecture
- We have a medical expert team
- Co-operation with other associations for rare diseases
- Co-operation with University of Helsinki–“Marfan-model” for medical students
- Nordic Co-operation
- Brochure for schools, teachers and nurse personnel

FRANCE: Association française des Syndromes de Marfan et apparentes

<http://vivremarfan.org>

Short summary not received.

GERMANY: Marfan Hilfe (Deutschland) e.V.

<http://marfan.de/>

During our "Marfanday 2011," the Marfan Hilfe celebrates its 20<sup>th</sup> anniversary, in addition to workshops and lectures. Smaller seminars focussed on families, fitness, volunteer work and for the first time a women-weekend.

We got funding for the booklet "Education and Professional Life", the publication of the new Ghent nosology and for a public information campaign with posters at train stations. Much work flow into planning the EMSN meeting for finding sponsors and making affordable prices.

We received donations, especially for research on Marfan syndrome. Therefore we put out a call for applications for a research award of € 5.000.

The work in our local groups is varying. Not only medical issues, but also support and recreational activities are important.

THE NETHERLANDS: Contactgroep Marfan Nederland

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

The number of family members increased from 260 in 2000 to 310 in 2010, which now represent about 35-40%.of the Marfan patients in the Netherlands.

The medical Advisory Committee established 3 years ago now has 13 members (mostly members of the Marfan expert and research teams of our four Marfan clinics). Our members put forward questions of various medical natures, which are treated confidentially and quickly. A Paramedical Advisory Committee with 5 members was established in 2010. A Social Advisory Committee will follow in 2011.

In 2010 medical specialists started developing the official Dutch guideline "Marfan syndrome" to be published in the fall 2012. This multidisciplinary medical guideline covers all the major medical symptoms of Marfan syndrome. The basic themes are "diagnosis, monitoring, and treatment", and everything is "evidence based".

NORWAY: Foreningen for Marfan syndrom og andre marfanlignende tilstander

<http://marfan.no/>

Paying members pr. 31.12.2010: 294. This is divided by 258 adults over 18 years, and 36 children under the age of 18.

Of these are 131 "main members" which have been diagnosed with Marfan. Total membership fee received in 2010 48750 NOK, we also receive government funding.

Our logo for the organization has been changed.

Activities:

- A camp for rehabilitation training for 18 members.
- Weekend meeting for all members in Bergen, Norway.
- A summer camp for youth had 7 participants in the age between 13 and 18 years.
- In addition, a membership paper, which all the paying members get.

Our specialist centre (TRS) is making a study about "Living with marfan".

SLOVAKIA: Asociacia marfanovho syndromu

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

- Annual meeting 2010 with recondition and medical program
- Establishment of the Czech Marfan Association
- The first common Czech and Slovak Marfan Meeting
- Logo creation
- Emergency card for patients
- Help individual patients: contacting special medical doctors, arranging the appointments for their medical examinations.
- Help patients receiving invalidity status resulting in regular benefit payments
- Provide recommendations 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

## SWEDEN: Svenska Marfanföreningen

[www.marfanforeningen.se/](http://www.marfanforeningen.se/)

Planning for a national centre for rare diagnostic groups in Sweden in management of The National Association of Rare Disorders has started.

We have investigated the possibility to initiate training for contact persons. The ambition is to launch an interactive education for them.

We are member of EURORDIS, a non-governmental patient-driven alliance of patient organisations representing more than 479 rare diseases patient organisations in 45 European countries.

Our association has been a member in EMSN previously but abandoned it for the last ten years because of our small economy. After we had a representative at their meeting in Denmark 2010, the board decided to join EMSN. The meetings are valuable, containing several medical lectures.

## SWITZERLAND: Marfan Foundation Switzerland

<http://marfan.ch/>

2010/11 was a year of consolidation especially in the financial area. We could close 2010 with a positive balance.

We have

- built the medical body called „medizinischer Beirat“.
- launched the project „young adults with Marfan syndrome“ to facilitate the cooperation among the young adults.
- launched a project looking abroad for existing documentation.
- reviewed the cooperation between the two bodies Foundation and Patient Association to ensure better cooperation and maximize synergies.
- redesigned and reorganized our web site.
- launched the on-going project „the e-office“ aiming to simplify and increase the efficiency of our daily operation.
- held meetings for all the Swiss regions.
- published two editions of our newspaper.
- participated on various medical meetings within our country.