

# EMSN set of rules and regulations

In addition to the mission statement.

## The EMSN is a network for European Marfan patient organisations (Minutes 2006)

The EMSN continues to be a patient organisation which is represented by people affected by Marfan syndrome.

All official delegates sent to the EMSN-meeting by a member organisation have to be affected by Marfan syndrome or a related disorder.

Affected means they are either a patient themselves or have a family member or a person they share their daily lives with, with Marfan syndrome or a related disorder.

The profession of the delegates is of no relevance whatsoever.

Observers however are not bound by any restrictions, but they cannot vote nor can they be elected. (Annual Assembly 2006)

## Language

The official language of communication in the EMSN is English (confirmed by the Annual Assembly 2006).

## Elections and voting

Members of the Co-ordinating Committee are elected by ballot, and any other voting is by a show of hands. (Annual Assembly 2006)

## New members

Interested countries can attend as observers for one year before officially joining. Subsequently the membership fee is halved for the first year and from the second year onwards the full fee is due. Organisations re-entering the EMSN will have to pay full price.

New organisations need to be vetted, voted in by the Annual Assembly and have to abide by the EMSN rules.

Re-entries will have to pay full price.

## Members in difficulties

Member organisations having financial problems can have their membership fee reduced by unanimous decision of the Co-ordinating Committee.

## Exclusion of members

Members who did not pay their fee for two years running will be proposed for exclusion from the EMSN at the Annual Assembly.

## Co-ordinating Committee

Election of the members of the Co-ordinating Committee and its duties - see mission statement.

The EMSN pays the expenses for a pre-meeting to organise the annual meeting.

To ensure that elected members of the Co-ordinating Committee can attend the annual EMSN meeting, they can claim travelling expenses from the EMSN. These should not exceed 2/3 of the membership fee of that year and only economy class fares will be accepted.

### Members contributions

These are an essential part of the EMSN work and the annual meetings.

### Young Adults

Young adults are those aged between 18 and 28 inclusive. This includes affected people, who can be accompanied by their partner or a sibling. A maximum of four young adults per country can attend the meeting.

A co-ordinating person for the Young Adults is to be designated who will be the contact person for the Co-ordinating Committee and attends the pre-meeting to organise the next EMSN meeting at the expense of the EMSN.

EMSN Annual Assembly 2007