

MARFAN EUROPE NETWORK

And related disorders

Established 1990

MISSION STATEMENT - 1998 – AMENDED 2004, 2012, and 2015

FOR THE CO-OPERATION BETWEEN MARFAN SUPPORT ORGANISATIONS WITHIN EUROPE.

It is proposed that:

Marfan organisations within Europe form a Network to support and encourage each another by exchanging and sharing information and working for the benefit of people with Marfan syndrome or related disorders and their families. This Network was originally called the “European Marfan Support Network (EMSN), and has been renamed to "Marfan Europe Network (MEN)".

To qualify as a member, an organisation applying to join must be recognised officially in its own country. Normally one organisation is admitted from each country, but in exceptional cases (e.g. different ethnic groups/organisations in one nation) a maximum of two organisations per country can join.

If possible, one meeting should be arranged every second year which can be attended officially by two representatives from each member organisation, specifically delegated by their national organisation. The meeting should be held in a different country and hosted by the local organisation.

At this meeting a co-ordinating committee of up to 5 members shall be elected by the members present, to handle the affairs of the Network. Each member shall be elected for a 4 year term with the possibility of re-election for a further 4 years. The committee shall be composed of a Chairman, Vice-Chairman, Secretary, Treasurer and one other member.

The Chairman has to be elected directly by all the MEN members present at the meeting. In the same way, the other members of the co-ordinating committee must be elected by the MEN members present at the meeting, but they can decide between themselves what office they hold on the committee and allocate roles on the committee between themselves each year. The MEN members need to be informed about the roles of the committee members as soon as possible.

The duties of the committee are to ensure:

1. Liaison with European Institutions (e.g. European Community, European Disabled Forum (EDF) etc.)
2. Liaison with participating organisations, particularly to provide support to the host organising the meeting.
3. Production of an annual newsletter

Voting can be done by mail for issues that cannot be postponed to the next meeting. The issue must be notified to the member organisations in written form one month prior to the voting date.

Procedures for elections and voting meetings:

- a. Every country has two votes. Should a country be represented by two organisations, each of these organisations has one vote. However, if one of the two organisations is not present at a meeting, then the organisation at the meeting has two votes.
- b. The meeting can make decisions when a simple majority of the members are present.
- c. A resolution becomes effective when it obtains the majority of the votes at the meeting.
- d. Should the above (b and/or c) not be met, the issue must be brought to the attention of all members – in written form. Voting/election can then be done by mail or the decision can be postponed to the next meeting.

Procedures for voting between meetings:

- a. Every country has two votes. Should a country be represented by two member organisations, each of these organisations has one vote.
- b. A voting is effective when a simple majority of the members have voted within the notified voting date.
- c. A resolution becomes effective when it obtains the majority of the votes in the voting.
- d. Should the above (b and/or c) not be met, the issue must be notified all members in written form. A new voting date can be set or the decision can be postponed to the next meeting.

Any proposed amendment to these duties and procedures must be notified to the member organisations for consideration two months prior to the voting.

“TOGETHER WE CAN”

But success depends on our close liaison and collaboration