

Statutes for
DYSNET
European Dysmelia Reference Information Centre

These Statutes replace the original statutes (referred to as Regulations) for DYSNET which were adopted at the founding of the organization on 13 October 2008. These Statutes were adopted by two Extraordinary Meetings on 20 October 2011, in accordance with § 21 of the Statutes.

In these statutes, “Days” means calendar days.

§ 1 Name, registration and official language

The name of the organisation is DYSNET.

DYSNET is a not-for-profit Non Governmental Organisation (NGO) registered in Stockholm, Sweden.

The official language of DYSNET is English.

§ 2 Objective

The objective of DYSNET is to safeguard the interests of persons with Congenital Limb reduction Deficiencies (Dysmelia). The issues of interest are political, legal, social, medical and financial issues relating to public bodies or others affecting persons with Dysmelia.

DYSNET will monitor the existence and occurrence of Dysmelia in the European Union (EU) and elsewhere in order to:

1. Provide an information service to all patient groups affected by Dysmelia and related diseases.
2. Build and maintain a network permitting the sharing of information between Dysmelia patient groups in the EU and elsewhere.
3. Advocate, support and maintain research aimed at establishing the most appropriate support for people affected by Dysmelia.
4. Develop and maintain a network of specialist practitioners and centres demonstrating best practice for the support, care and management of individuals affected by Dysmelia.
5. Promote, support and maintain the use of Assistive Technologies (AT) intended to facilitate and provide independent living by individuals affected by Dysmelia.
6. Research and develop systems for management of clinical information relating to the health care needs of individuals affected by Dysmelia.

7. Advise and assist National Authorities in ways of measuring comparative degrees of disability and managing and supporting individuals affected by Dysmelia.
8. Research and promote social and economic inclusion for people with Dysmelia.

§ 3 Membership

DYSNET is an open organisation for patient groups and organisations that represent people affected by Dysmelia. All legal entities that fulfil this criterion have the right to apply for membership.

Applications for membership are handled by the Board of Directors (the Board).

All legal entities led by people affected by dysmelia that accept the objectives and statutes of DYSNET shall be accepted as members of DYSNET. Other legal entities may be accepted at the Board's discretion.

Membership entails the obligation that the member in general follows DYSNET's defined objectives, conforms to these Statutes and other policies and decisions.

§ 4 Members' rights

All members and their representatives have the right to receive information on and to take part in the activities and actions planned by DYSNET. This applies to all activities that are arranged. The Board is obliged to keep all members of DYSNET informed of the organisation's work.

§ 5 Members' duties

It is the duty of the members of DYSNET to:

- Pay the membership fee to DYSNET in accordance with the resolution passed at the Annual General Meeting.
- Work for the development of DYSNET.
- Abide by these Statutes and decisions made in accordance with these Statutes.
- Promote DYSNET within their own networks;
- Remain loyal to the objectives of DYSNET and any decisions lawfully made by Annual General or Extraordinary Meetings or the Board in the implementation of such objectives. § 6

Expulsion

Subsection 1:

Expulsion may be decided when a member:

- Has gained membership by wilfully stating inaccurate information the knowledge of which would have caused the Board to deny membership at the time of acceptance.
- Acts in a manner which brings DYSNET into disrepute.
- Commits serious breaches of the Statutes or otherwise commits a material breach of § 5.

--- Does not pay the membership fee.

Subsection 2:

Expulsion is carried out by the Board. The decision shall be communicated to the expelled member in writing immediately following the Board's decision.

Subsection 3:

The expelled member can appeal against the decision and the matter will be considered at an Annual General Meeting or Extraordinary Meeting of the members. Request for such a matter shall be delivered to the Board no later than thirty (30) days after the expelled member has been notified of the expulsion.

§ 7 Withdrawal

Members can make a request for withdrawal from the organisation in writing. Such a request shall be granted.

DYSNET is not obliged to refund any part of the membership fee paid on withdrawal.

§ 8 Decision-Making Bodies

The organisation's decision-making bodies are:

- Annual General Meetings in accordance with § 9 and 10.
- Extraordinary meetings in accordance with § 11.
- The Board in accordance with § 12.

§ 9 Annual General Meetings

Annual General Meetings shall be held before 30 April, every year.

Notice to attend the Annual General Meetings shall be sent to all members of DYSNET a minimum of thirty (30) days and a maximum of sixty (60) days before the meeting is to be held.

Attendance may be in person, by telephone, video-conference, online conferencing or by other appropriate means.

Members who wish to have a motion considered at an Annual General Meeting shall submit this motion in writing to the Board no later than twenty-one (21) days before the scheduled date of the Annual General Meeting.

The documents that shall be considered at the meeting shall be enclosed with the notice to attend the meeting.

All proposals from members for consideration at the Annual General Meeting shall be distributed electronically to all members by the Board no later fourteen (14) days before the scheduled date of the Annual General Meeting.

Extraordinary meetings are particularly regulated in § 11.

§ 10 At Annual General Meetings

At Annual General Meetings the following issues shall be considered:

- The previous year's operating statement.
- The previous year's accounts and auditor's report.
- The retiring Board's release from liability for the previous year.
- Motions from individual members.
- The number of individuals to be elected to the Board is determined.
- Election of chairperson and deputy chairperson of DYSNET.
- Election of other members of the Board.
- Election of auditors.
- Election of deputy auditors.
- Election of Nominating Committee.
- Establishment of (principles for) fees and other remuneration.
- Establishment of membership fees for the following year.

§ 11 Extraordinary Meetings

The Board shall assemble an Extraordinary Meeting when necessary or when at least one third (1/3) of the members make a written request for one. The issues to be considered shall be stated in the notice to attend.

At an Extraordinary meeting only issues giving rise to the Extraordinary meeting will be considered.

Unless the situation requires a shorter notice period the Extraordinary Meetings shall require the same notice periods as Annual General Meetings.

Attendance may be in person, by telephone, video-conference, online conferencing or by other appropriate means.

§ 12 Eligibility and voting rights for Annual General Meetings and Extraordinary Meetings

1 Subsection:

The members of DYSNET with voting rights are those that:

- 1) Have paid the fees which are due.
- 2) Otherwise meet the terms and conditions of §§ 4-7.

2 Subsection:

Voting takes place by acclamation except if a majority cannot be determined or if someone makes a request for the counting of votes, in which case a counting of votes shall take place.

Unless provided for otherwise, all decisions of the Annual General Meetings and Extraordinary Meetings shall be taken by a simple majority.

3 Subsection:

Every member represented at a meeting can represent up to five (5) other members when given written and signed authorization. The authorization is filed with the voting list.

Members, who are not in agreement with the majority, can upon request have this noted in the minutes. This shall be registered in writing during the meeting.

§ 13 The Board

1 Subsection:

The Board is responsible for the overall management of the organisation during the mandate period. The obligations of the Board are decided by the Annual General Meeting, the Extraordinary Meeting, these Statutes and lastly by its own policy decisions. The Board also has the task of managing the organisation's funds in accordance with the Annual General Meeting and the Extraordinary Meeting's decisions and recommendations.

The Board shall consist of a minimum of four (4) and a maximum of nine (9) elected individuals, of which the chairperson and deputy chairperson are elected by the Annual General Meeting.

The Board will appoint a team of Operating Officers to manage the organisation on a day-today basis. The Chief Operating Officer has the right and the duty to attend meetings of the Board, unless the Board decides otherwise.

The Board has the right to co-opt up to three (3) members of the Board until the next AGM, and subsequently for a period of one year at a time.

The majority of the Board shall consist of people with Dysmelia.

The Board is elected for periods of two years.

Retiring members of the Board may be re-elected for two further periods of two years. They may be re-elected for a new term after a period of at least 12 months from the end of their term of office.

2 Subsection:

Should a member of DYSNET be expelled from DYSNET, a member of the Board representing the expelled member of DYSNET shall be deemed to have resigned from the Board effective on the date of the expulsion of the member has entered into force. The same applies to other assignments within DYSNET.

A member of the Board may, for exceptional reasons, leave his/her position during an ongoing mandate period. Such a request should be granted.

3 Subsection:

Board meetings shall be convened by the Chairperson at least four (4) times per year.

Attendance may be in person, by telephone, video-conference, online conferencing or other appropriate means.

Notice shall be given to members of the Board, by telefax, email or mail at least seven (7) days in advance and shall include time, place and an agenda.

Each member of the Board shall also be entitled to request that the Chairperson convenes a Board meeting, which the Chairperson shall then convene within five (5) days, providing seven (7) days written notice.

In case of urgent matters, notice of Board meetings may be given with such advance notice as the situation requires.

Necessary documentation regarding the matters to be brought before the Board shall be distributed at least seven (7) days in advance by the person, who has requested that such matter is brought up.

In case a Board meeting has been urgently convened as described above, the necessary documentation shall be distributed as required by the situation at hand to permit the members of the Board to prepare for the meeting.

The Board shall form a quorum when more than half of the members of the Board elected by the Annual General Meeting are present at the meeting.

All decisions of the Board are made by a simple majority.

Any Member of the Board not in agreement with the decision of the majority shall, upon request, have his/her dissent noted in the minutes of the Board meeting.

§ 14 Remuneration:

The Annual General Meeting shall decide on remuneration for travelling, loss of income and other fees to be paid to the Board members and operating officers.

§ 15 Signing on behalf of the organisation.

Authorized to sign for DYSNET (to legally bind it), pursuant to decisions adopted by the relevant decision-making body, shall be each of the following:

- (i) the Board; or
- (ii) two Board members acting jointly; or
- (iii) upon appointment by the Board to a list of signatories any two persons acting jointly

§ 16 Accounts

The organisation's accounts shall be kept in accordance with accepted bookkeeping principles.

The accounts are closed each financial year. They shall then, together with minutes and other documents providing information on the organisation's administration, be handed over to the appointed auditor by 15 February each year.

§ 17 Audit

The accounts shall be audited by at least one auditor with at least one deputy.

§ 18 Confidentiality

The Board members and others that undertake assignments are obliged to handle personal data in a manner prescribed by law and any confidentiality regulations established by DYSNET.

§ 19 Amendment of the Statutes and dissolution of the organisation.

An amendment of these Statutes requires decisions at two Annual General Meetings, or two Extraordinary Meetings, or one of each.

For decisions on an amendment of the statutes, a qualified majority is required, i.e. two thirds (2/3) of the members represented voting must vote for an amendment.

The dissolution of DYSNET may take place when at least two thirds (2/3) of the organisation's members that are eligible to vote request the dissolution of DYSNET in writing. The decision shall then be confirmed by a qualified majority at the next Extraordinary Meeting.

When dissolving the DYSNET, liquid assets shall be distributed among the members.

§ 20 The Statutes' validity

These Statutes are applicable from the date of the latter of the two meetings referred to in § 19 above.

Signed for and on behalf of DYSNET in accordance with the decisions of the two Extraordinary Meetings of 20 October 2011, in compliance with the Statutes of DYSNET, § 20.

..... Date.....

Björn Håkansson,
Föreningen för de Neurosedynskadade (FfdN)

..... Date.....

Martin Johnson,
Thalidomide Trust

..... Date.....

Rolf Olofsson,
White & Case LLP, 62, Rue de la Loi, Brussels
Chairperson of Extraordinary Meetings of 20 October 2011