

STATUTES of the European CMT FEDERATION

ECMTF

Article I - name and Head Office

A not-for-profit association is created under the name of "European CMT Federation" (referred to below as the acronym ECMTF).

This Federation is governed by the provisions of title III of the Belgian law of June 1921 on non-profit associations, international non-profit associations and foundations (hereinafter referred to as "the law of 27 June 1921").

The association is headquartered at the University Foundation, 11 Rue d'Egmont, B-1000 Brussels.

It may be transferred, by a simple decision of the Board of Directors, in any place in Belgium.

This decision will be published in the annexes to the Belgian Official Journal and transmitted to the Federal Service of Justice.

Article II - objectives and duration

The Federation will mainly work at the international level as the main interlocutor of the European Institutions and national Associations.

The objectives of the Federation, not-for-profit organization, are:

- to promote rapid and accurate diagnoses, treatment and care for people with Charcot-Marie-Tooth disease (hereinafter designated by the acronym CMT) or similar;
- to promote better access to accurate and understandable information for people with the CMT, particularly in European countries where there is no association dedicated;
- to promote awareness and understanding of CMT by the public, health authorities and the medical profession;
- to fund and facilitate research on CMT and foster collaboration among researchers;
- to help the creation of CMT patients' associations in European countries where there is not yet one.

The Federation will work closely with all appropriate agencies or charitable organisations, while remaining independent.

It will not support any party, or political or religious movement.

The Federation will be able to achieve its objectives by all means at its convenience. Notably, it can undertake all actions and activities that contribute to progress in the areas of CMT and through:

- the European Commission, the European Parliament and any institution, association or entity European or international;
- collaboration with health professionals;
- collaboration with the organizations;
- the organisation of conferences;
- the preparation of guidelines for the optimal management of the CMT;
- collaboration in international organization and the promulgation of research projects;
- collaboration in the creation of registries and databases of treatment centres, teaching and research in neurological diseases;
- the publication of newsletters and other information materials using electronic media development;
- conducting campaigns at the European level;
- assistance to the development of European patients associations;

and all activities that the Board of Directors may judge appropriate.

Article III - members

The ECMTF members must be European CMT patients associations or wider organizations or associations including a subsection devoted to CMT, whose mission is equivalent to those of ECMTF objectives and who will be legally constituted under the laws and customs of their country of origin.

The number of members will not be limited, but should not be less than three.

Members of the ECMTF will be the founding members * and other associations who will join later. Any organisation nominating its candidacy to become a member will have to submit its statutes and any other documents to the Board of Directors of the ECMTF allowing it to consider its candidacy with full information.

The Board will have authority to admit a new organization as a member at any time.

Each member organization shall appoint a well-qualified representative of the organization, as its delegate to the ECMTF, to represent it in the ECMTF, and in particular, in its Board of Directors.

Any Member may resign from the ECMTF by presenting his resignation in writing to the Board of Directors. This resignation will take effect immediately once the current contributions will have been addressed. Until this moment the resigning Member will remain entirely responsible for all the obligations of membership.

The removal of a member may be proposed by the Board of Directors, after he has heard or had the opportunity to hear the comments of the Member concerned. The final decision to request a member to leave the Federation shall be taken by the Board of Directors, by a majority of two thirds of the members present or represented by proxies. This decision could be proposed and taken if one member failed to pay its annual dues or if it no longer meets the conditions required to be a member.

Any association member in liquidation, de-registered or no longer existing as a legal entity is no longer a member of the Federation, has no rights with a view to the work of the ECMTF.

Membership dues will be set each year at the proposal of the Board of Directors.

Delegates have no personal responsibility with regard to the financial obligations of the Federation.

Article IV - General Assembly

The following decisions are reserved for members at the general meeting:

- any amendment to the articles of Association;
- approval of the annual accounts;
- the election and dismissal of the members of the Board of Directors;
- the voluntary dissolution of the Federation;

All other issues will be the sole responsibility of the Board of Directors.

The General Assembly shall meet once a year. All members will be informed of the place, date and time of the meeting, by letter or e-mail - at the convenience of the Board of Directors and addressed to each Member at least sixty days before the meeting, and signed by the Secretary-General or, if it is absent, by an administrator.

Mail should include all the legal documents, including the agenda, the proposed resolutions and essential work documents.

The General Assembly shall be chaired by the Chairman of the Board of Directors or failing that, by the Vice-president or failing that, by any other Director or by any delegate of a member association.

The Secretary General shall prepare the minutes of the meeting.

The General Assembly will achieve its quorum if at least 50% of the members are present or represented by proxy (the members present will not be able to present more than one proxy each).

The decisions of the General Assembly must be approved by a vote of at least 51% of founder members and 51% of the other members present.

The decisions of the General Assembly must be registered on the official minutes signed by the Chair of the meeting and by an Director.

The originals of these minutes shall be kept in a place where each Member must be able to consult them, without being able to subtract any document.

The minutes of each General Assembly must be approved at the next General Assembly and a copy shall be delivered to the members, by letter, fax or e-mail.

In the case of voluntary dissolution of the Federation General Assembly shall, if required by law, appoint one or two liquidators and determine their powers.

Without violating articles 50, 53, 55 and 56 of the Act of 27 June 1921, any proposal asking for an amendment of the statutes or the dissolution of the ECMTF must be made by the Board of directors or by a voting member of the ECMTF.

The Board of Directors will have to submit the proposal to the Secretary at least 60 days before the General Assembly during which the proposal shall be voted on.

The Secretary shall address the proposal in writing to voting members with the invitation to the General Assembly during which the proposal shall be voted on.

The General Assembly may validly decide on any amendment of the statutes or dissolution of the Federation only if two-thirds of the voting members are present or represented by proxy (a single power of attorney by Member present).

In case less than two thirds of the voting members are neither present nor represented a new General Assembly will be convened under the same conditions as above.

This meeting will be able to take a final and valid decision on the proposals by a majority of two thirds of the members present voting, regardless of the number of members present or represented.

The amendments to the Constitution will take effect only after approval by the competent authorities, in accordance with articles 50 and 53 of the Act of 27 June 1921, and after publication in the annexes of the Belgian Official Journal, in accordance with articles 51 and 53 of this Act.

In the case of dissolution, at any time and for any reason, the remaining funds of the Foundation, after payment of the debts and charges, will be transferred, in equal parts, to each member association.

Article V - Administration

The Federation is administered by a Board of Directors, of no less than 3 or more than 9 volunteer Board members chosen from among the delegates candidates proposed by the member associations.

This choice must be confirmed by a vote by simple majority of the members - present or represented - to the next following general meeting.

No association may have more than one representative to the Board of Directors.

The directors shall be elected for a term of three years and will be eligible for re-election indefinitely.

60 days before a General Assembly for the General Secretary of the ECMTF must ask members to submit their possible applications to the Board of Directors no later than 40 days before this Assembly.

A brief biography of the candidate should be attached to his application.

Thirty days prior to the general meeting the General Secretary shall provide all members a copy of applications approved by the Board of Directors in strict compliance with the statutes.

A Director resigning before the end of his term may suggest another representative to the Board of Directors at the next General Assembly for the remainder of his term.

If no replacement can be found to a Director who expressed his intention to resign is proposed within 90 days of his resignation, the directors may propose a new Director of the Board of Directors, of their choice, to a vote of the next General Assembly, for a full term of 3 years.

Any Director may be removed by a vote by a majority of two thirds of the members present or represented at the general meeting.

The Board of Directors must choose among its directors, a President, a Vice-president, a Secretary General and a Treasurer, who will be his Office.

In the absence of the Chairman of a meeting its functions will have to be provided by the Vice-president or, failing that, by any Director present.

In the case of a vacancy occurring during the year an acting Director may be appointed by the Board of Directors.

The Board of Directors may co-opt up to 4 people to supplement the available skills, there is no limit to their term of office, but they cannot vote. Their appointment shall be approved at the next General Assembly.

The Board may meet as necessary, but at least once a year, either physically or by any suitable digital means for all administrators to hear each other. Notices can be done by mail, fax or e-mail.

The Board of Directors cannot deliberate and vote valid unless at least half of its members are present or represented.

Each Director will be able to give a proxy vote in writing (letter, fax or e-mail) to another Director to vote in his place but no Director may vote more than one proxy.

The decisions of the Board may be taken by simple majority of those present or represented.

If the vote to equal the Chairman shall have a casting vote.

The minutes of meetings of the Board of Directors will be approved and signed by the Chairman and a Director at the meeting following, and be kept in a register.

This register must be kept at the headquarters of the ECMTF. The minutes should be regularly communicated to the voting members and will be considered as the form of notification of the decisions of the Board of Directors.

The Board will have all powers and authority to decide and apply all actions to achieve the objectives of the present statutes. It is competent to deal with any issue on behalf of the ECMTF, in the broadest sense. All matters not expressly reserved by law or the articles to the general meeting will be its field of competence.

It will run or will execute all the actions of the ECMTF and will ensure that all decisions of the General Assembly are met.

The Board of Directors may appoint a Director/s with the authority to represent the Federation at the banks.

Any document that formally commit the Federation legally or financially, after approval by the Board of Directors, must be signed by the Chairman and another Director.

Any legal action, as plaintiff or defendant, shall be brought by the Board of Directors represented by its Chairman or a Director appointed by the President for this reason.

The official language of the Federation will be English.

Directors will be held to the strictest confidentiality about their activity to the Federation.

Where the deliberations of the Board of Directors, and the documents that it reviews are considered as confidential: any breach of this confidentiality will give the right to the Board of Directors to request the replacement of the offending Director, by a vote by simple majority to which he will not be able to participate.

All established acts in accordance with the Act and concerning the election, dismissal and the cessation of function of the directors and of the persons authorized to represent the ECMTF, will be shared with the Federal Public Justice Service to be archived and published, at the expense of the Federation, in the annexes to the Belgian Official Journal.

Article VI - Budget and accounting

Accounting year begins January 1st and ends on 31 December of each year.

According to article 53 of the Act of 27 June 1921 accounts for the accounting year ended and the budget of the following year must be prepared each year by the Board of Directors and submitted for approval to the first following General Assembly.

Article VII - General provisions

When circumstances warrant, the meetings may be held by telephone, e-mail or video conferencing as an alternative to physical meetings, with the same provisions.

The provisions of title III of article 53 of the law of 27 June 1921 will apply to any matter not covered by these statutes, especially for the publications in the annexes to the Belgian Official Journal.

All other provisions not specified in these statutes will be governed by a separate document (rules of procedure).

* The founding members of the Federation ECMTF are the following national Associations:

- ACMT-RETE for Italy
- CMT-FRANCE for France
- CMT - UK for United Kingdom
-
- SPIERZIEKTEN NEDERLANDS for the Netherlands
- SPIERZIEKTEN VLAANDEREN for Belgium (Flanders)