

# Articles of Association

Given the continuing lack of an effective therapy for the hereditary disease Charcot Marie Tooth (CMT), scientists, clinicians and therapists, with the support of the "European CMT Federation" (ECMTF), are committed to establish a close collaboration to pave the way for joint interdisciplinary research efforts for the benefit of patients and for containing the high socio-economic costs of this rare, yet relatively common disease (prevalence 1 : 2500). For this purpose, they adopted the following statutes on June 12, 2024:

## **§ 1 Name, registered office, financial year**

- (1) The Association shall bear the name European CMT Research Association (ECRA) e.V. The Association shall be registered in the German register of associations; after registration, it shall bear the addition "e.V." in its name. The Association shall also be referred to as "ECRA" for short in the following text of the Articles of Association.
- (2) The association has its registered office in Cologne.
- (3) The Association's financial year is the calendar year.

## **§ 2 Purpose, non-profit status**

- (1) The association pursues exclusively and directly charitable purposes within the meaning of the section "Tax-privileged purposes" of the German Tax Code, namely the promotion of science and research. The association is selflessly active; it does not primarily pursue its own economic purposes.

- (2) The purpose of the Articles of Association is realized in particular as follows:

ECRA unites European CMT specialists from various disciplines who want to join forces to achieve the following goals:

1. Promotion of innovative CMT research in Europe in close cooperation with patient organizations and industry partners, in particular to,
  - a. encourage and support the development and implementation of innovative joint research projects, including the introduction of new technologies in CMT research;
  - b. provide seed capital and expert advice on applying for grants for national, EU and international programs;
  - c. secure further long-term funding for CMT research and enable the development of new therapies by industry, private organizations and public institutions.
2. Initiate and provide technical support for the establishment of a European patient-led CMT patient registry/health database based on existing registries and ensure free access to relevant data for researchers, including
  - a. the development of an adequate infrastructure to both collect information and provide access to patients with various forms of CMT who are willing to participate in research projects and clinical trials for newly developed drugs and therapies;
  - b. providing registered patients with up-to-date information on research progress, the

- development of new drugs and therapies and the organization of clinical trials;
  - c. ensuring that all necessary steps are taken to ensure data protection in accordance with the General Data Protection Regulation and developing and implementing appropriate ethical guidelines for the management and use of health data.
3. Promote the next generation of CMT scientists, clinicians and other healthcare professionals, the dissemination of CMT-specific scientific knowledge and the education of the medical profession and in particular:
- a. propose and organize workshops on CMT-related research topics such as clinical research, pathophysiology, molecular targeting and therapy development, including artificial intelligence (AI) and other innovative technologies;
  - b. promote, supervise and support the mobility/training of young and advanced scientists, clinicians and therapists;
  - c. establish an ECRA website that reports on ECRA's work, current research results and publications in its public section and offers a digital communication system for ECRA members in a private section.
4. Ensure international involvement, interaction and collaboration on a global level, in particular by promoting close collaboration with related scientific and patient organizations such as INC, CMTR, PNS, WMS, ICNMD, ENMC, Treat NMD, ERN Euro-NMD, NORD, EAMDA, etc.
- (3) The Association's funds may only be used for the purposes set out in the Articles of Association. Notwithstanding the promotion of projects within the meaning of § 2 Para. 2 No. 1, members shall not receive any benefits from the Association's funds. No person may benefit from expenses that are alien to the purpose of the association or from disproportionately high remuneration. The payment of lump-sum remuneration for work or time spent (remuneration for activities) to the Executive Board is permitted; however, it may not be unreasonably high.

### **§ 3 Acquisition of membership**

(1) Membership is open to

- (a) all European researchers engaged in scientific research on CMT, including but not limited to basic science, clinical research, development of outcome measures and clinical trials, and research in allied health fields.
- (b) the European CMT Federation (ECMTF) and its member organizations, represented by their elected delegates, to participate on an equal footing in the work of ECRA and its operational committees.

(2) Industry partners are invited to nominate research representatives as their delegates who can participate in the work of ECRA in an advisory capacity if required. They have no voting rights.

(3) New members or delegates of the industry partners shall be admitted by the Board of Directors upon application in text form in which they state their particular skills and interests.

### **§ 4 Termination of membership**

(1) Members and industry partners may resign from ECRA by notifying the President in text form.

(2) A member or industry partner can only be expelled for good cause. Important reasons include, in particular, conduct that is detrimental to the objectives of the Association, breach of statutory obligations or arrears in contributions of at least one year. The Executive Board shall decide on expulsion. The member or industry partner has the right to appeal against expulsion to the General Assembly, which must be submitted in writing to the Executive Board within one month. The General Assembly shall make the final decision within the Association. The member reserves the right to review the measure by appealing to the ordinary courts.

## **§ 5 Membership fee, accounting**

Members are required to pay contributions. The amount of the contributions and their due date are determined by the General Assembly.

## **§ 7 Bodies of the Association**

The bodies of the association are the Executive Board and the General Assembly.

## **§ 8 Executive Board**

(1) The Board of Directors is elected by the General Assembly for a three-year term of office and consists of the President, the Vice President, the Secretary and the Treasurer, as well as up to five other members of the Board of Directors. Of these other Board members, the three with the highest number of votes are initially elected for a term of office of six years, while the term of office of the others is three years. Subsequently, all Board members, with the exception of the President, Vice President, Secretary and Treasurer, are elected for a term of six years. All Board members can be re-elected once. If a member of the Board of Directors resigns prematurely, the remaining Board of Directors may elect a successor for the remaining term of office of the resigning member.

(2) The Executive Board of the Association within the meaning of Section 26 BGB consists of the President, the Vice President, the Secretary and the Treasurer. They are each authorized to represent the Association individually.

(3) The Executive Board ensures the implementation of ECRA's tasks in accordance with § 2. It develops the strategies and coordinates the work of ECRA, including the committees in accordance with § 11.

The Board of Directors submits proposals for the annual plan and the budget to the members. It may also draw up a strategic plan or a multi-year plan for long-term developments. At the end of the financial year, it informs the General Assembly of the results in terms of money and activities.

(4) The President of ECRA

a) represents the association,

b) chairs the meetings of the General Assembly and the Board of Directors,

c) submits recommendations from the committees to the Executive Board for resolution and monitors their implementation as required,

d) reports to the General Assembly.

(4) The Vice President shall represent the President in the performance of his duties if the

President is unable to do so or - in the case of special matters - at his request.

(5) The Secretary supports the President and the Vice President, keeps minutes of the meetings of the General Assembly and the Board of Directors and is responsible for communication.

(6) The Treasurer shall ensure the accounting and other financial affairs of ECRA. The Treasurer is responsible, in particular, for

- a) setting up and managing the ECRA bank account,
- b) the collection of contributions and donations,
- c) accounting and preparation of the ECRA budget,
- d) regular reporting to the FBC pursuant to § 11 para. 1 lit. d).

The Treasurer's accounts are audited by the auditor, who reports to the General Assembly.

## **§ 9 Meetings and resolutions of the Executive Board**

(1) The Board of Directors shall meet once every two months for an online or face-to-face meeting. If urgent decisions are required, the President may convene extraordinary ad hoc meetings; the subject matter and urgency of such ad hoc meetings must be explained in the invitation.

(2) At the proposal of the President or on its own initiative, the Board of Directors shall adopt, by a majority of the votes of its members, all resolutions necessary to implement these Articles of Association and the general rules adopted by the General Assembly.

(3) The President or the Vice President or the Treasurer or the Secretary shall make all administrative decisions on business questions and problems arising from the work of ECRA. Such decisions may be reviewed, withdrawn or replaced by a majority of the Board of Directors at the request of one of the other Board members.

(4) The minutes of all meetings shall be kept and signed by the Secretary and submitted to the President no later than one month after the end of the meeting. The President shall countersign the minutes and make them available to all members and partners on the internal part of the ECRA website. All minutes are stored in ECRA's electronic archive.

## **§ 10 General Assembly**

(1) The members and the delegates of the industry partners of ECRA form the ECRA General Assembly, which meets at least once a year.

(2) Each member has one vote at the General Assembly. Another member entitled to vote may be authorized in text form to exercise the right to vote. However, a member may not represent more than three third-party votes. Authorization must be granted separately for each meeting of the General Assembly.

(3) At the proposal of the Executive Board, the General Assembly shall adopt the general rules necessary for the realization of the objectives set out in § 2 with a majority of two thirds of the votes cast.

(4) The General Assembly shall decide with the majority of the votes cast in particular on:

- a) the election of the President, the Vice President, the Secretary, the Treasurer and the other members of the Board of Directors,

- b) upon the auditor's report, the discharge of the treasurer,
- c) the discharge of the Board of Directors following its report on the status of the implementation of ECRA's tasks.

(5) Meetings of the General Assembly can be combined with a scientific event at which the latest research results on CMT in general and the implementation of ongoing research projects in particular are reported and discussed.

The date and location of the next General Assembly meeting shall be determined and communicated by the Executive Board within a reasonable period.

(6) The invitation to each General Assembly and the agenda shall be sent to all members and partners in text form at least two months before the date of the meeting. The President shall convene an ad hoc meeting if one tenth of the members request this in text form, stating the purpose and reasons.

General Assemblies can also be convened as hybrid meetings or purely virtual meetings. If a hybrid or virtual meeting is convened, the invitation must also state how member can exercise their rights by means of electronic communication.

Meetings of the General Assembly are held in English.

(7) The minutes of the General Assembly shall be kept and signed by the Secretary and submitted to the President no later than one month after the end of the meeting. The President shall countersign the minutes and make them available to all members and partners on the internal part of the ECRA website. All minutes are stored in ECRA's electronic archive.

## **§ 11 Committees**

(1) At the proposal of the President, the General Assembly may appoint committees, in particular for the following tasks:

- a) establishment and financing of joint research projects (Research and Financing Committee, RFC);
- b) planning and setting up a patient register and data management (Patient Register and Data Management Committee, PDC);
- c) promotion of young scientists and education (Committee for Science and Education, SEC);
- d) financial matters, contributions, donations, budget (Finance and Budget Committee, FBC);
- e) international cooperation and global networking (International and Global Networking Committee, IGC);
- f) ad hoc committees as required.

A committee may be dissolved by resolution of the General Assembly on the proposal of the President.

(2) The committees shall elect their Chair by majority vote and adopt rules of procedure at their first meeting.

(3) Each committee shall independently determine its work program as well as the date and place of its meetings, insofar as this is necessary for the fulfillment of its specific mandate. It shall report to the Board of Directors.

## **§ 12 Confidentiality**

- (1) All members and partners of ECRA are obliged to treat all information about other members and partners of the association and their scientific work and achievements as confidential.
- (2) Any disclosure of such information to third parties shall require the prior consent of the data subject; this consent shall be given in text form with a copy to the President.
- (3) The President shall be informed and decide on all matters relating to confidentiality between members and partners.

## **§ 13 Amendments to the Articles of Association**

- (1) The Articles of Association may be amended by the General Assembly at the proposal of the Executive Board. A majority of three quarters of the votes cast is required to amend the Articles of Association.
- (2) The proposed amendments shall be communicated by the President to all members and partners together with the invitation and agenda for the General Assembly.
- (3) The Board of Directors is authorized to adopt and register amendments to the Articles of Association that are deemed necessary by the registration court or the tax office for legal reasons.

## **§ 14 Dissolution of the Association**

- (1) The Association may be dissolved by the General Assembly with a majority of two thirds of the members present, based on a proposal by the Executive Board. If the association is dissolved or cancelled or if its tax-privileged purpose ceases to exist, the assets of the association shall be transferred to a legal entity under public law or another tax-privileged corporation for the purpose of promoting science and research in the field of CMT.
- (2) Unless the General Assembly decides otherwise by a simple majority, the President and the Vice President are jointly authorized liquidators.

(Berlin, 12 June 2024)

Signatures