



Statutes of SMA Europe e.V.

§ 1 Name, Registered Office and Fiscal Year

- (1) The name of the association is SMA Europe e.V.
- (2) The registered office of the Association is Freiburg im Breisgau, Germany.
- (3) The fiscal year is the calendar year.
- (4) The association shall be entered in the register of associations.

§2 Objectives, Purpose, and Tasks

(1) SMA Europe is a non-profit umbrella organisation of spinal muscular atrophy (SMA) patient organisations who work together to bring earlier diagnosis, effective treatments and optimal care to everyone living with SMA (people living with SMA, family members and carers).

(2) The purpose of the Association is to promote the health, health care and wellbeing of people living with SMA, and to promote science and research in all areas of life affected by SMA, from diagnosis to treatment, care, and daily life activities.

(3) To this purpose, SMA Europe undertakes tasks in the following areas:

- a. Representing the interests of people with SMA among all stakeholders in European health policy.
- b. Developing a strong evidence base for the needs and wants of people living with SMA and their role in research.
- c. Supporting, stimulating, and promoting patient-relevant research, drug development and clinical trials.
- d. Ensuring people living with SMA across Europe receive timely and continuous access to diagnosis, treatment, and care.
- e. Communicating and disseminating comprehensive quality information regarding SMA, to among all relevant stakeholders, including the public.
- f. Providing quality information, educational and outreach programmes to empower member organisations and their representatives, including transfer of knowledge, information, and best practices with and among members.
- g. Collaborating on projects to the benefit of the SMA community, also on a global level.
- h. Building and maintaining a responsible, sustainable, and impactful organisation.

This list is not to be understood as exhaustive. The Association may take on other tasks if these serve the fulfilment and maintenance of its purpose.

§ 3 Common Good

- (1) The Associations exclusively and directly works for the common good as a non-profit organisation within the meaning of the section entitled “Tax -privileged purposes” of the German Abgabenordnung (AO).
- (2) The Association’s activities are charitable. It does not primarily pursue its own economic interest.
- (3) The Association’s funds may only be used for purposes in accordance with the Statutes.
- (4) Members shall not receive any gratuitous benefits from association funds.
- (5) No person may receive pay or reimbursement for expenses that are disproportionate or not related to the purposes indicated herein.

§ 4 Remuneration and Expense Allowances for Association Activities

- (1) Members of the board, delegates to the General Assembly and third parties who work for the Association are entitled to compensation for their necessary and reasonable expenses, verified with audit-proof receipts.
- (2) Members of the Board and Delegates may be paid remuneration if the scope of the business operations requires a commitment that can no longer be provided on a voluntary basis. The General Assembly shall decide on this requirement and the amount of the remuneration. A member of the Board may not transact business with himself and therefore, cannot conclude and terminate his own service or employment contract. The General Assembly may authorise individual members of the Board to conclude and terminate service or employment contracts with other members of the Board.
- (3) If the budgetary situation so permits, the board may appoint full or part-time employees to manage the association’s office.
- (4) The board is authorised to outsource tasks required of the association (e.g. external accounting, auditing, preparation of documents for the registration and tax authorities, organisation of congresses, undertaking of surveys...) for a reasonable fee or expense allowance, if the budgetary situation of the association allows it.
- (5) Further details on reimbursable expenses and remunerations may be stipulated by the General Assembly in supplementary rules of procedure which would then be subordinate in rank to these articles.

§ 5 Association Funds, Audits

- (1) The Association obtains for its operations, among other things, through the following:
 - Grants from national and international organisations, public or private.
 - Membership fees.
 - Remuneration for services rendered.
 - Proceeds from collections and promotions.
 - Donations, cash and in-kind.
 - Income from the Association's assets.
 - Other resources authorised by the German law.
- (2) The accounts of the Association shall be audited annually by at least one auditor. The auditor(s) shall be proposed by the Board and elected by the General Assembly for a period of 2 years. The

auditor(s) may not be a member of the Board or of a committee appointed by the Board or an employee of the association. A tax consultancy or auditing firm can also be chosen as auditor, which then assigns the audit to an employee of the firm. The auditor shall prepare a report and submit it to the board. A report on the annual audit is to be given to the general meeting, but this does not necessarily have to be made in person.

§6 Membership, Members' Rights and Duties

- (1) SMA Europe is composed of full and associate members.
- (2) Members of the Association are spinal muscular atrophy (SMA) and neuromuscular disease organisations, in the WHO Europe zone. In exceptional cases, non-European SMA organisations may also become members.
- (3) Members align with SMA Europe's mission and are willing and have the opportunity to represent the SMA community in their country. Moreover, they are committed to delivering common goals and to being financially and structurally transparent.
- (4) Only full members have voting rights.
- (5) Each member organisation will designate, according to its own rules, no more than 2 persons (delegates) to represent it in SMA Europe business. Delegates should hold important experience and/or expertise in SMA.
- (6) The annual membership fees are set by the General Assembly.

§7 Membership Acquisition and Termination

- (1) Application for membership shall be made in writing to the Board. The Board decides on the application, informing the General Assembly.
- (2) Members of SMA Europe must comply with the membership criteria as decided by the Board.
- (3) The membership criteria, membership application process and membership approval process are detailed in the by-laws.
- (4) Membership ends through
 - a. Dissolution of the member organisation
 - b. Resignation through a written notice of resignation, with a notice period of at least 2 months prior to the end of the financial year.
 - c. exclusion by the board for good cause.
- (5) With the termination of membership, all rights and responsibilities as a member are forfeited.
- (6) In addition to the provisions of these articles, the general meeting may pass rules covering membership and contributions which are subordinate to these articles.

§8 Bodies of the Association

The bodies of the association are:

- the General Assembly
- the Board

§9 General Assembly

- (1) Each member organisation will designate according to its own rules no more than 2 persons (delegates) to represent it in SMA Europe business. Delegates should hold important experience and/or expertise in SMA and should be appointed for at least 2 years.
- (2) At the general assembly, full members with voting rights participate with a maximum of 2 delegates each and associate members participate with 1 delegate.
- (3) Regardless of how many delegates attending the meeting, each member organisation entitled to one vote only.
- (4) A full member may assign its voting right to another full member of SMA Europe (proxy). Each member present may hold no more than two proxies. The process to vote by proxy is detailed in the by-laws.
- (5) The general assembly must be convened at least once a year as well as when the interest of the association so requires. The general assembly can be fully virtual, hybrid or fully in-person. The invitation shall be made in writing at least 3 weeks in advance of the general assembly.
- (6) Members may submit additions to the agenda to the President in writing, stating sufficient grounds for the same, at the latest two weeks before the scheduled meeting date. Requests received later may be treated as urgent requests and may be included on the agenda by a majority of $\frac{3}{4}$ of the voting members present at the general meeting. Exceptions to this rule are any amendments to these statutes and other decisions of importance to the association. For all agenda items submitted by members, the board will give an opinion at the general meeting.
- (7) The general meeting is chaired by the president; if unable to attend, then by the vice president.
- (8) The proceedings of the general meeting are valid no matter how many members are present (in person or virtually), except for the provision in §15 Dissolution of the association.
- (9) Unless otherwise stipulated herein or as required by law, the general meeting decides by a simple majority of the valid votes cast. Abstentions and invalid votes are not counted. In the case of a tie, the vote of the president or in his absence, the vote of the vice-president decides.
- (10) Decisions are generally made by open or secret ballots, including virtual ballots, if the chair of the meeting deems this to be necessary, unless these articles or the law stipulate otherwise.

§10 Duties of the General Assembly

The general meeting has the following statutory duties:

- Elect and recall members of the board.
- Receive the annual report and the annual accounts from the board and discharge the board.
- Approve the budget.
- Decide on amendments to these statutes or on dissolution of the association.
- Decide on motions submitted by the board, members, working groups, or the scientific advisory board and the duties assigned to it herein.
- Set the amount and due date of membership fees.
- Decide on ad-hoc amendments and additions to the agenda of the General Assembly meeting.

§11 Board

(1) The board consists of at least three and no more than 9 representatives of the member organisations. A maximum of 1 person from any member organisation may be nominated for election to the board.

(2) From the persons nominated by the member organisations, the following offices are elected:

- president
- vice president
- treasurer
- and a maximum 6 other members (extended board).

(3) The persons elected should come from different countries if possible. They are elected for a period of 3 years and may stand for re-election.

(4) The office of a newly elected board member starts directly after the election and acceptance of the office by the elected candidate. A member of the Board shall remain in office beyond his/her regular term of office until the next General Assembly and the election of a successor there.

(5) If a member of the board leaves before the end of his/her term, the board may choose from the ranks of the delegates of the member organisations another member to serve until the next general assembly.

(6) The board manages the affairs of the association. The board is responsible for all matters of the association, unless assigned herein or by law to the general assembly. The board is responsible for the administration of the association's assets and the execution of its decisions. It may set up a business office and hire staff to handle day-to-day business, if deemed necessary and if the financial situation of the association so permits.

(7) The association is represented by the president, the vice president and the treasurer, each on his or her own, both in and out of court per §26 of the German Civil Code (BGB).

Internally, the vice president and treasurer are only authorised to represent the association if the president is prevented from exercising the office or has authorised the vice president or treasurer to act on his/her behalf.

The Board is authorised to appoint a Chief Executive Officer (special representative according to § 30 BGB) for the general management, operation and administration of the organisation. The Chief Executive Officer shall be entitled to attend the meetings of the Board in an advisory capacity. The strategic steering of the association remains with the board.

(8) The board generally takes its decisions in meetings chaired by the president or by the vice president if the former is unable to attend. The processes and delays related to the convening and running of Board meetings, including quorum and voting procedures, are detailed in the by-laws.

(9) A board meeting must be convened within one month if at least two members of the board request it, stating the reasons in writing (including email).

(10) The board may appoint advisory boards and working groups to fulfil association tasks. Further details are regulated by §§12 of these statutes.

(11) The board may set its own rules of procedure for its work.

(12) The board is liable for damage to members and to the association caused by its actions, but only if done with intention. This also applies if the board receives remuneration for its activity.

(13) If the board is obliged to compensate another person for damage caused by the board in the performance of its duties, it may ask the association to indemnify it from said liability. Clause 1 does not apply if the damage was caused intentionally.

§12 Other Operational Entities

(1) Scientific Advisory Boards, Committees, Working Groups, Task forces, Steering Committees and other entities may be created as needed for the purpose of assisting and providing advice in the context of specific activities or projects of the association.

(2) The size and lifespan of these entities will vary according to the tasks entrusted to them and their creation is validated by the Board. The participants of these entities will be involved in the name of SMA Europe and must report to SMA Europe.

(3) The composition, governance, organisation and mandate of each entity will be established in separate by-laws.

§ 13 Authentication of Resolutions and Minutes

Minutes shall be taken of the meetings of the association's bodies.

The recording secretary shall be appointed at the beginning of the meeting by the president and, in his absence, by the vice-president or the treasurer.

The minutes of the General Assembly shall be signed by the president or the vice-president and by the recording secretary.

§14 Amendments to These Statutes, Change to the Association's Purpose

An amendment to these statutes or the purpose of the association is made by a resolution of the general assembly with a majority of $\frac{3}{4}$ of the valid votes cast.

Abstentions and invalid votes are not counted.

The board is authorised to make such changes to these statutes which are merely editorial in nature or which are required by a supervisory, judicial, or fiscal authority without prior approval by the general assembly. The members are to be informed immediately of these changes.

§15 Dissolution of the Association

(1) The dissolution of the association takes place by resolution of an extraordinary general meeting convened exclusively for this purpose. The resolution requires a majority of three-quarters ($\frac{3}{4}$) of the valid votes cast. Abstentions and invalid votes are not counted.

(2) The general meeting would then appoint three liquidators to wind down the association's affairs.

(3) In case of dissolution of the association or if its tax-privileged purpose ceases to exist, the assets of the association shall fall to a legal entity under public law in Germany or the in the European Single Market or another tax-privileged body in Germany or the in European Single Market, which also supports public health care in the area SMA or neuromuscular diseases and/or the promotion of science and research in the field of SMA or neuromuscular diseases according to §2 of these articles. This organization is selected by the general meeting with a simple majority of votes at the same meeting that decides on the dissolution of the association and the appointment of the liquidators.