

Statutes of the European Multiple Endocrine Neoplasia Alliance (EMENA)

§ 1: Name, Registered Office, Financial Year, Working Language

(1) The Association, having full legal capacity, is named „European **M**ultiple **E**ndocrine **N**eoplasia **A**lliance“, abbreviated to „EMENA“, and shall be referred to in the statutes and by-laws as „EMENA“.

(2) The Association shall be included in the official registry of associations and is seated in München.

(3) The financial year runs from January 1st to December 31th.

(4) The working language is English.

§ 2: Objectives

(1) The Association shall pursue directly and exclusively non-profit and charitable purposes in the meaning of the section “tax-favourable purposes” of the German Tax Code.

(2) The purpose of EMENA is the advancement of public health. In particular, this purpose will be achieved through

- The publication of medical, social and legal information or recent scientific developments with regard to Multiple Endocrine Neoplasia (MEN);
- The organisation and implementation of scientific events related to MEN;
- The promotion of MEN patient groups worldwide, the improvement of the network of existing MEN patient groups by providing an umbrella organization in terms of a multilingual platform for patient groups, clinical staff and scientists for the exchange of information on medical, social and legal issues or recent scientific developments related to MEN.

(3) The association is a charitable organisation; it does not primarily pursue its own financial purposes.

(4) In addition, the association may grant moral and financial support to other tax-privileged corporations, public corporations as well as foreign corporations in order to morally and financially support the public health sector.

§ 3: Mission statement of EMENA

The mission statement of EMENA is the improvement of the diagnosis, treatment and quality of life of people affected by MEN. The activities of the associations shall promote the awareness and sympathy for people affected by MEN by expanding international cooperation in order to enable methodologically sound and clinically relevant research concerning MEN.

§ 4: Funding

(1) Material means required may be attained from admission and membership fees, proceeds from donations and collections, sponsors, sponsorship agreements, funds raised from EMENA events and activities, subsidies and public founding, bequests and other contributions.

(2) Members may be required to pay an annual membership fee, to be established by the General Assembly.

§ 5: Use of Funds

EMENA funds may only be used for the purposes stipulated in the statutes.

Upon their resignation from EMENA Members do not receive any invested capital just as well as their annual membership fee.

§ 6: Types of Membership

EMENA has the following sorts of members:

- 1.) Full members, being the individual founding members and national MEN organizations recognized in their country as non profit associations within Europe, independent of authorities, political parties, the pharmaceutical industry and commercial organizations. National MEN organizations are represented by their patient group representative and their medical advisor, who together have one (1) vote to exercise on behalf of their national member organisation/country.
- 2.) Affiliated members are individuals from European countries where no National Association for MEN is in existence. An affiliated member may attend all EMENA meetings as observer without the right to vote. The President may permit an affiliated member to address the meeting.
- 3.) Sponsoring members: members can be individuals who support the goals of EMENA. They may attend all EMENA meetings as observer without the right to vote.

§ 7: Membership Eligibility

Application for membership must be submitted in writing to the Board. The General Assembly decides upon the application.

1. Full Members

Non-profit MEN organisations registered in countries within the European Union. These organisations can apply for membership by writing to the Board and the General Assembly must agree per majority on accepting their application for membership. If there are equal votes, the President has two votes (of which one is the deciding vote). Once accepted, they are represented in EMENA and have the right to vote in EMENA elections.

The organisations and/or individuals who founded EMEMA (Founding Members) automatically gain full membership status and need not apply for membership.

2. Affiliated Members and Sponsoring Members

Affiliated members and sponsoring members do not have voting rights in EMENA elections. Membership applications can be submitted to the Board in writing and the General Assembly will decide to accept or refuse their admission by simple majority vote. If there are equal votes, the President has two votes.

§ 8: Termination of Membership

(1) Membership is terminated upon death, with regard to juristic persons and legal partnerships upon loss of their juridical personality, upon voluntary resignation or expulsion.

(2) Membership termination and reasons thereof must be submitted to the Board in writing no later than one month before the end of the financial year.

(3) The expulsion of a Member of EMENA can be ordered by the Board for gross breach of other Membership duties or dishonourable behaviour. The decision must be made with at least 75% majority. Appeal is possible to the General Assembly, who will have the final verdict. A decision by the General Assembly regarding expulsion must be made with 75% majority.

(4) Membership is personal and cannot be transferred or inherited.

§ 9: Rights and Duties of Members

(1) All Members have the right to participate in all EMENA events and to make use of EMENA facilities. The right to one vote each and the entitlement to elect and stand for election is only granted to Full Members.

(2) Every Member has the right to request a printed copy of the statutes.

(3) Members have no right to claim financial compensation for their duty-bound actions. Only costs incurred on behalf of EMENA may be reimbursed, and the relevant receipts must be presented. This includes necessary travel expenses and accommodation costs. The details are set forth in the EMENA Rules.

(4) At least one tenth of the Full Members may request the Board to call a General Assembly. This request shall be send by post, fax or e-mail.

(5) In the course of each General Assembly the Board shall inform the Members about the activities and the financial bearing of the Association. Upon reasoned request of at least one tenth of the Members, the Board has to provide those Members with the respective information within four weeks time.

(6) Members are obliged to further the interests of EMENA to the best of their abilities and to refrain from any action that could harm the reputation and purpose of EMENA. Members shall have to observe the statutes and the resolutions of its executive bodies. Members are obliged to pay any admission and memberships fees on time and to the sum resolved in the General Assembly.

(7) Each member organisation maintains full autonomy within their own country for their organisation's work in line with their own mission and objectives; at the same time each member organisation is committed to promote EMENA activities within its own country.

§ 10: Membership fees

(1) The Membership fees are due annually. The amount and due date shall be decided by the general assembly.

(2) The Association can receive donations in kind or money as well as other grants.

§ 11: Bodies of the Alliance

The bodies of EMENA shall be

the General Assembly,
the Board and
the Medical and Scientific Advisory Committee.

§ 12: The General Assembly

(1) The General Assembly is the highest authority of EMENA and must ensure that the Alliance is operated in a manner that does not contravene the appropriate laws of its country of registration.

(2) The General Assembly is the Meeting of Members according to the terms of the Association and is held annually. The General Assembly is chaired by the President or a person designated by him/her in the seat or office specified on the written invitation.

(3) This written invitation is sent via email with the agenda by the Board at least 30 days prior to the date set for the General Assembly.

(4) An item may be added to the agenda if a minimum of one tenth of the members requests this. This request may be send by post, fax or email in advance to the General Assembly or verbally at the start of the General Assembly.

(5) The president must convoke a special General Assembly if this is requested by the Board or one tenth of the full members represented at the General Assembly.

(6) Each national MEN Organization being full member is represented in the General Assembly by one patient group representative and one medical advisor per country, who together have one vote.

(7) The representatives of each member country will be chosen by their patient group.

(8) Absent Members can be represented by another Member equipped with a written power of attorney. However, one Member – himself included – may represent no more than two Members.

(9) The votes cast by Full EMENA Members are submitted either in EMENA's annual General Assembly or prior to the annual General Assembly on ballot papers, which Members receive well in advance either by post, fax or email or a combination of the three, giving all Members the right to vote. If the votes are tied, there must be a second vote held for the office in question.

(10) If a second or further assemblies need to be called, a majority of a third of EMENA Members is required.

(11) Meetings may also be held virtually (e.g. via video-conferencing).

(12) The General Assembly approves the accounts of the past year and, on the Board's proposal, the budget for the coming year by a simple majority of votes.

(13) The General Assembly decides, on the Board's proposal, by a simple majority of votes:

- on resolutions regarding the strategic policy of MEN Europa
- on annual membership fees
- on the Board's annual reports and agenda
- on the admission or refusal of Members
- on amendments to statutes as voted for by two thirds of all Association Members.

(14) With the exception of special cases mentioned in these statutes, resolutions are passed in the General Assembly by a simple majority of the votes of Members eligible to vote (or their named representatives) and communicated to all Members.

(15) The General Assembly shall form a quorum, regardless of the number of attendees.

(16) The resolutions passed in the General Assembly are recorded in the minutes, which are signed by the President and then retained by the Secretary who forwards them on to the Members.

(17) The General assembly may decide in written form (i.e. by email) without a meeting if all members of the General Assembly do agree. .

§ 13: The Board

1) An individual President, Vice-President, Secretary and the Treasurer form the Executive Committee of the board in terms of § 26 BGB.

(2) Other board members may be elected as necessary.

(3) The Board is elected by the General Assembly. In the absence of an elected Member, the Board has the right to co-opt another eligible Member in their place, which must subsequently be approved in the next General Assembly.

(4) A Board member's functional term is three years and it stays in office until a new board member is elected. Re-election is possible. Every function on the Board must be carried out in person.

(5) The President, or in his/her absence, Vice President, convenes the Board in writing (post, fax or electronically) or verbally. If the President is unavailable, any other Member of the Board may convene the Board.

(6) The Board shall form a quorum if all Members of the Board were invited to the meeting and at least half are present.

(7) The Board finalizes its resolutions by a simple majority of the votes; should the votes tie the President casts the deciding vote.

(8) The Board is chaired by the President, or in his/her absence, Vice President. If he/she is also unavailable, the Board shall be chaired by the Board Member with the highest number of years in service from all those present at the meeting, or the Member who receives the majority vote from the other Board Members.

(9) With the exception of death or expiration of the term of office a Board Members' role is revoked through dismissal or resignation.

(10) The General Assembly may dismiss the entire Board or individual Members thereof at any time. Dismissal does not become effective until the appointment of a new Board or Board Member.

(11) Board Members may submit their resignation at any time in writing. Letters of resignation must be addressed to the Board; in the case of the entire Board resigning letters should be addressed to the General Assembly. The resignation only becomes effective once a successor is elected or co-opted.

(12) Responsibilities of the Board include:

- overseeing the activities and development of the Alliance
- addressing continuous funding of the infrastructure
- supervising the preparation and particularly translation of information
- propose new rules, policies or procedures not covered by these statutes for voting at the General Assembly
- organizing plenary meetings if necessary
- reporting to all members at the General Assembly about the committee's duties.

§ 14: Special Duties of Individual members of the Board

(1) The President shall be responsible for the ongoing business of the Association and shall be assisted by the Secretary.

(2) The President shall represent the Association publicly. Internally, written documents of the

Association shall become valid upon signature by the President and the Secretary. In financial matters (fund deposits), the signatures of the President and the Treasurer are required. Legal transactions between Members of the Board and the Association shall be subject to the approval of another Member of the Board.

(3) Externally, legal powers to represent the Association publicly or to sign on its behalf can be granted only by the two Board Members named in section 2. The General assembly may determine to give single power of attorney to a Board Member and to release a Board Member from the restrictions set forth in § 181 BGB.

(4) In case of extraordinary circumstances, the President shall be entitled to take measures independently, even in matters falling within the competence of the General Assembly or the Board; such measures shall, however, require the subsequent approval of the relevant body of the Association.

(5) The President directs the Board in the General Assembly and in the Board office.

(6) The Secretary is responsible for the minutes taken in the General Assembly and in Board meetings.

(7) The Treasurer shall be responsible for the financial bearing of the Association.

§ 15: Audits

(1) Two auditors shall be elected by the General Assembly for the period of one year.

(2) The Auditors are to audit the current business and the financial bearing of the Association for the proper character of accounting and to examine whether the funds are used as provided for in the statutes. The Board has to provide the Auditors with the necessary documents and to give the required information. The Auditors shall have to report to the Board about the results of their audit.

(3) New auditors shall be elected every third year of operation of EMENA.

§ 16: Medical and Scientific Advisory Committee

(1) The General Assembly may set up a European Medical and Scientific Advisory Committee, composed of doctors and scientists specialized in MEN. These specialists shall be nominated by the appropriate national organisation.

(2) The Scientific and Medical Committee shall at least but not only

- reflect the multidisciplinary nature of the care and treatment of patients with MEN
- establish a minimal set of standard guidelines regarding patient care
- advise the Board and General Assembly in medical and scientific issues
- address funding particularly via EU- or international grants

(3) The Medical and Scientific Advisory Committee shall meet every second year. Meetings may also be held virtually (e.g. via video-conferencing).

§ 17: Liquidation of EMENA

(1) The voluntary liquidation of the Association may only be decided in a specially convened General Assembly and requires a majority of two third of the valid votes cast by all Members present or represented. Invitations to this Assembly shall be issued at least three months in advance.

(2) This General Assembly shall also pass a resolution concerning the assets of the Association, if such assets exist. The General Assembly shall appoint a liquidator and – subject to clause 3 below – pass a resolution to whom it is to transfer the assets of the Association remaining after the payment of its debts.

(3) In the case of liquidation or dissolution of EMENA or the discontinuation of its previously beneficial purpose, the remaining assets shall be transferred to a corporate body under public law or tax-exempt entity that shall directly and solely use it for purposes of the advancement of public health according to Section 2 of these Statutes.