

Pursuant to Article 8(3) of the Societies Act – ZDru-1 (Official Gazette of the Republic of Slovenia No. 64/2011-UPB2), the Assembly comprising the members of the European Alliance of Neuromuscular Disorders Associations at its founding general meeting held on 22 April 2016 adopted, and subsequently at its correspondence meeting held on 31 August 2016 amended in line with the legislation of the Republic of Slovenia, the following

STATUTE OF EUROPEAN ALLIANCE OF NEUROMUSCULAR DISORDERS ASSOCIATIONS

Article 1 (Name)

The name of the Alliance is “European Alliance of Neuromuscular Disorders Associations” (hereinafter referred to as “EAMDA”).

Article 2 (Seat)

The registered office of EAMDA is in Ljubljana (Republic of Slovenia).

Article 3 (Bodies and their Terms of Office)

- (1) The bodies of EAMDA are:
 1. The General Assembly;
 2. The Executive Committee.
- (2) The members of the Executive Committee shall be elected officials; they shall be elected for a 4-year term of office with the possibility of re-election.
- (3) The elected officials' and Executive Committee members' terms of office may cease before the end of the term of office if member authorization has expired, if a member organisation has withdrawn from membership in EAMDA, if the General Assembly has dismissed them from office due to violation of this Statute, EAMDA's general acts or decisions of its bodies or if they act contrary to the interests of EAMDA.

Article 4 (General Assembly)

- (1) The General Assembly is the highest governing body of EAMDA and shall have all the powers required to achieve EAMDA's objectives. These powers include approval of the annual action programme, the financial plan and financial operations and activities reports for the previous year. The General Assembly shall also control the disposal of EAMDA's assets and its financial and material operations. Such control shall be performed before the adoption of the annual report.
- (2) The Annual General Assembly shall be held every year before the end of December.
- (3) The Executive Committee may convene an extraordinary meeting of the General Assembly at any time and shall convene it within 90 days of receipt of the written request signed by at least one quarter of EAMDA members stating the reason for the meeting. If no meeting is convened by the Executive Committee within the above stated deadline, it may be convened any time after that deadline expires by at least one quarter of EAMDA members; such notice shall be made in writing and shall state the reasons for the meeting. At extraordinary meeting the General Assembly may only decide on the issues for which it was convened.

- (4) The notice convening the meeting of the General Assembly shall be sent in writing to the members and associate members of EAMDA at least 28 days in advance.
- (5) The General Assembly shall be chaired by the President. In the absence of the President such meetings shall be chaired by a Vice President and, in the absence of all, a chairman to be elected by the General Assembly.
- (6) The official language of EAMDA in all matters shall be English, whilst Slovenian shall be used as the official language of the state of EAMDA's registration.
- (7) Each EAMDA member shall be represented at the General Assembly by one representative who shall have one vote. Unless stated otherwise in this Statute all decisions shall be taken by a simple majority of members present and represented. All proposals shall be decided by vote by a show of hands. The Chairperson of the meeting can impose a vote by ballot and must do so if requested by more than seven members.
- (8) The General Assembly may also hold meetings by correspondence, if decided so by the convener. Decisions shall be deemed adopted at the meeting by correspondence, if the majority of General Assembly members vote in favour of the decision within the prescribed period of time. The provisions of this Statute shall apply mutatis mutandis to convening and carrying out meetings by correspondence.
- (9) The General Assembly shall have the sole power to amend the Statute of EAMDA. Any such resolution shall be adopted by a majority of two-thirds of the votes of members present or represented.
- (10) Minutes shall be taken of the work of the General Assembly and its adopted decisions, which shall be signed by the Secretary General and two verifiers of the minutes.

Article 5
(Executive Committee)

- (1) The Executive Committee is in charge of the management and running of EAMDA in accordance with the decisions adopted by the General Assembly and is responsible for its work to the General Assembly. The Executive Committee shall:
 1. act on behalf of the General Assembly between its meetings and implement its decisions, recommendations and policies;
 2. adopt the basic programme of activities and the budget for the forthcoming financial year as well as reports on their realization; both those documents shall be approved by the General Assembly;
 3. represent EAMDA throughout the world and take care of public information;
 4. advise and assist its members in implementing the goals and principles of EAMDA;
 5. admit new members and associate members of EAMDA;
 6. identify violations of responsibilities by EAMDA members and report them to the General Assembly;
 7. prepare the agenda and rules of procedure for the General Assembly;
 8. draw up reports and submit them to the General Assembly for approval;
 9. propose amendments to the Statute;
 10. decide on the change of EAMDA's registered office address.
- (2) The Executive Committee shall be composed of the President, two Vice Presidents, the Secretary General and three members; they shall be appointed, elected or dismissed at the General Assembly.
- (3) The Executive Committee may delegate the day-to-day management of EAMDA to the Secretary General or to one of the members or to any other person or body.
- (4) The Acts adopted by EAMDA shall be signed by the President or by two members of the Executive Committee. The President shall represent EAMDA in any legal matter and shall be the legal representative of EAMDA. The Vice Presidents shall carry out the tasks of the President acting under powers delegated by the President.
- (5) The Executive Committee may appoint one or more sub-committees consisting of at least one member of the Executive Committee and two or more persons from member associations for the purpose of making any inquiry or supervision or performing any function or duty which in the opinion of the Executive Committee would be more conveniently undertaken or carried out by the sub-committee provided that all acts and proceedings of any such sub-committee shall be fully and promptly reported to

the Executive Committee.

- (6) The Executive Committee may appoint a person as may be necessary from time to time for carrying out certain tasks and may lay down their duties and their remuneration. The Secretary General may by special arrangement delegate the day-to-day management to the person authorised by the Executive Committee.
- (7) The decisions of the Executive Committee shall be adopted by a majority vote of all its members. At least four members shall constitute a quorum for the Executive Committee meeting.
- (8) The Executive Committee meeting may be organized also using the teleconference or any other modern ICT application. Conference voice recordings shall be kept for at least one year.
- (9) Any person who is employed or remunerated by EAMDA or who receives from EAMDA any fees or payment other than reimbursement of validated expenses incurred in relation with the operations of EAMDA shall not be eligible for membership in the Executive Committee.
- (10) The Executive Committee shall identify violations of responsibilities committed by EAMDA members and associate members and report them to the General Assembly. Such violations may refer to undermining EAMDA's reputation or violating the provisions of this Statute.
- (11) The Executive Committee shall initiate the proceedings referred to in previous paragraph on its own initiative or on the initiative of individual members or the General Assembly.
- (12) The Executive Committee may impose the following sanctions: reprimand or exclusion. The member may file an appeal against the imposed sanction within 15 days. The decision on the appeal shall be made by the General Assembly.

Article 6 (Purposes, Goals and Tasks of EAMDA)

- (1) Purposes:
 1. improving the quality of life of people with neuromuscular disorders (NMD) in terms of equal treatment, technical aids, personal assistance, accessibility, independent living and full participation in the society;
 2. providing support, assistance, advice and facilitating exchange of information in the areas of healthcare, social services, social inclusion, social skills, education and training, employment, sports and recreation, culture, independent living and full participation.
- (2) Goals:
 1. to represent, protect and enforce the rights and interests of persons with neuromuscular disorders;
 2. to facilitate everyday life of persons with neuromuscular disorders;
 3. to raise awareness of the public through the network of NMD associations across Europe;
 4. to prevent and alleviate the consequences of disability caused by neuromuscular disorders;
 5. to train persons with neuromuscular disorders for self-help and to teach family members and volunteers on how to live and work with disability.
- (3) Tasks:

With the aim to achieve the above purposes and goals EAMDA shall carry out the following tasks:

 1. to arrange meetings and promote workshops with the aim to disseminate information on developments, treatment and practices in the field of neuromuscular disorders and to publish the results;
 2. to develop and improve research in the disciplines connected with neuromuscular disorders and related early diagnosis, treatment and rehabilitation services, and to provide assistance with fundraising of such research;
 3. to promote higher education, self-employment and the creation of special living environment (smart homes);
 4. to co-ordinate and develop opportunities for the collection, distribution and exchange of specialised knowledge in this field;
 5. to collect and disseminate general information on neuromuscular disorders;
 6. to promote and encourage the formation and development of associations working in the field of neuromuscular disorders;

7. to support and assist the development of EAMDA Youth Organization (EYO);
8. to subscribe to and maintain membership of any organization which promotes the goals conducive to the purposes and goals of EAMDA;
9. to support the adoption of legislation which may bring direct or indirect benefits to EAMDA or persons affected by neuromuscular disorders;
10. to carry out publicity campaigns to the benefit of persons with NMD, to represent them and to publish professional publications on neuromuscular disorders and on accommodated living for persons with NMD;
11. to perform advocacy on behalf of persons with NMD and their parents;
12. to promote vocational training of persons with NMD as well as their employment and living under special conditions.

Article 7 (Membership)

- (1) Any national neuromuscular disorders association operating in the territory of the state in which it is registered may become a member of EAMDA.
- (2) Any European interest association working in the field of neuromuscular disorders can become an associate member of EAMDA.
- (3) Membership in EAMDA shall be open to all European interest associations that unite and represent persons with NMD and operate at the state level.
- (4) In order to gain membership or associate membership an association shall submit an application for membership to EAMDA in which it shall state its desire to become a member, express its consent with the purposes, goals and tasks of EAMDA stated in the Statute, provide information on its name, head office, identification number and the legal representative and enclose a copy of the registration decision. The Executive Committee shall decide on granting membership or failure to fulfil the conditions for membership laid down in this Statute.
- (5) Each member and associate member of EAMDA shall have the right to send its representative to all General Assemblies of EAMDA.
- (6) Any member may resign from EAMDA by submitting a three months notice in writing to the President. Any member who resigns from EAMDA will no longer be entitled to the privileges and services of EAMDA.
- (7) The Executive Committee shall decide on the eventual exclusion of a member. If a member files an appeal against the decision of the Executive Committee, the final decision on exclusion shall be made by the General Assembly.
- (8) The rights of EAMDA members shall be: to vote and be voted to the bodies of EAMDA, to adopt decisions, to give proposals and initiatives, to be informed on the work of EAMDA and to enjoy other rights that EAMDA ensures to its members.
- (9) The duties of EAMDA members shall be: to carry out the tasks entrusted to them, to attend the meetings of EAMDA bodies and participate in other forms of EAMDA activities, to pay membership fee, to act in line with the purposes and goals laid down in the Statute and to carry out other tasks in line with the Statute and other acts of EAMDA.
- (10) EAMDA associate members shall have the following rights:
 1. to attend the General Assembly;
 2. to be represented at the General Assembly;
 3. to have a representative at the General Assembly who shall have the right of voice, but not the right to vote;
 4. to receive all the publications of the Executive Committee, including circulars;
 5. to receive services from the Executive Committee, as practicable, in the form of visits, the possibility to participate in courses and seminars, as well as other types of assistance.
- (11) Until the 30th March each year the members shall pay annual membership fee the amount of which shall be determined by the General Assembly.

- (12) EAMDA associate members shall have the same duties as EAMDA members. The provisions of paragraphs 5, 6, 7 and 11 above shall apply to EAMDA associate members in the same way as they apply to EAMDA members.
- (13) Any member failing to pay the annual membership fee pursuant to Article 11 above shall forfeit its voting right at the General Assembly held in that calendar year. The above provision shall not apply if the General Assembly meets during the period from 1 January to 30 March.
- (14) Associate members shall pay the annual membership fee in the amount determined by the General Assembly.

Article 8
(Financial Issues)

- (1) EAMDA's financial and material operations shall be carried out in line with the valid provisions and in accordance with the adopted annual financial plan of revenue and expenditure and on the basis of decisions adopted by the General Assembly. EAMDA shall keep its books of account using the double entry method. The books of accounts revealing data on material operations shall be kept in line with the Societies Act and accounting standards applicable to societies.
- (2) The Executive Committee shall be responsible to EAMDA for keeping EAMDA's bank accounts. The bank accounts and the administration of finances of EAMDA shall be operated in accordance with such guidelines as shall be determined by the Executive Committee.
- (3) At its General Assembly EAMDA may appoint a Treasurer upon such terms as it may consider desirable if EAMDA members estimate the work of EAMDA would be carried out in a more satisfactory way by virtue of such an appointment.
- (4) The Executive Committee shall be responsible for keeping EAMDA's bank account into which all sums belonging to EAMDA shall be paid.
- (5) The financial year shall end on 31st December and EAMDA's financial accounts shall be presented to EAMDA by the Secretary General at the next Annual General Assembly. The financial accounts shall be certified by an auditor appointed for this purpose by the Executive Committee.
- (6) All the costs and expenditure incurred in the running of EAMDA shall be covered by EAMDA's revenue.
- (7) If a surplus of revenue over expenditure is generated by EAMDA it shall be used in order to realise EAMDA's purposes and goals or to carry out the non-profit activities laid down in this Statute.

Article 9
(Financing of Operations)

- (1) EAMDA may obtain the funds for its operations from:
 1. membership fee,
 2. material rights and its own activities,
 3. voluntary work,
 4. donations and sponsorships,
 5. public funds,
 6. assigned share of personal income tax, and
 7. other sources.

Article 10
(EAMDA's assets)

- (1) EAMDA's assets shall comprise the movable and immovable property owned or used by EAMDA and entered as such in the fixed asset register as well as financial and other resources in hand and on current account.

- (2) EAMDA may acquire assets by purchase or otherwise and may exchange, sell and lease assets in its ownership or use them for the purposes of EAMDA. EAMDA's assets shall be managed by the Executive Committee in accordance with the decisions adopted by EAMDA at the General Assembly.
- (3) EAMDA may not divide its assets among its members. Any division of EAMDA's assets among its members shall be null and void.

Article 11
(Public Information)

- (1) EAMDA shall operate publicly. Its members and the public shall be informed of EAMDA's activities through posts on EAMDA's website and in printed media, while the members shall have the right to access the minutes and other documents of EAMDA.
- (2) The public may be excluded in cases when this is required due to business and other secrets.

Article 12
(Dissolution)

- (1) EAMDA shall be dissolved in case its membership fee is paid by less than three members, upon its merger with other societies or merger by acquisition with another society, in case of bankruptcy, on the basis of court decision prohibiting it to operate, pursuant to the law or by a three-quarter majority vote of members present and represented at the General Assembly called to discuss this issue. Upon dissolution and after all expenses and debts are paid, the assets and funds of EAMDA may be transferred to an association having similar purposes and goals as EAMDA in line with the legislation of the Member State where EAMDA's Statute is registered.

Article 13
(Amendments to the Statute)

- (1) This Statute may be amended or replaced by the General Assembly. Any proposal to amend the Statute in force must be submitted in writing to the Executive Committee at least 28 days before the General Assembly which will consider the proposal.

Article 14
(Transitional and Final Provisions)

- (1) If EAMDA's membership is not sufficient to have the number of members in EAMDA's bodies as laid down by this Statute and if there are not sufficient candidates to fill in the positions, EAMDA's bodies may have a smaller number of members. In such case EAMDA shall have at least the President, the Vice President and the Secretary General. During that period EAMDA's bodies shall carry out their tasks acting in their full competence.
- (2) The General Assembly shall be competent for the interpretation of this Statute in line with the valid legislation of the state in which EAMDA has its registered office.
- (3) This Statute shall enter into force on the day it is validated by the competent administrative body.

In Ljubljana, on 31 August 2016

Secretary general



Tomislav Goll



President



Boris Šuštaršič

Note:

Amendments to the Statute in line with the Slovenian legislation were prepared by the lawyer Mojca Sušec.