Euro-Dystrophy Myotonic Association statutes

In the following, the term Myotonic Dystrophy (abbreviated DM) refers to Myotonic Dystrophy type 1 also called Steinert disease (DM1) and Myotonic Dystrophy type 2 also called Proximal Myopathy (PROMM or DM2).

The AFM-Téléthon (France), FMM (Italy), MDA-Hellas (Greece), DGM (Germany), VSN (Netherlands), ASRIMM (Switzerland), hereinafter referred as founding members:

- Association Française contre les Myopathies, acting under the name "AFM-Téléthon", (association régie par la Loi du 1er juillet 1901, reconnue d'utilité publique) organized under the laws of French Republic, with its registered offices at Institut de Myologie, 47-83 boulevard de l'Hôpital, 75651 Paris Cedex 13, France, in this matter duly represented by Laurence TIENNOT-HERMENT, Président (hereinafter referred to as "AFM-Téléthon").

- Muscular Dystrophy Association Hellas, acting under the name "MDA Hellas", (Association founded in 2000) organized under the Laws of Greece, with its registered Offices at The House of MDA Hellas, 6 Elpidos Street, 10434, Athens, Attica, Greece, in this matter duly represented by Vana (Loukia) Lavidas, President (hereinafter referred to as "MDA Hellas").

- Dutch Association for Neuromuscular Diseases, acting under the name "Spierziekten Nederland", founded in september 1967, organized under Dutch law, with its registered office at Lt. Gen. Van Heutszlaan 6, 3743 JN Baarn The Netherlands, in this matter duly represented by Marcel Timmen, director (hereinafter referred to as "Spierziekten Nederland").

- German Association for Muscular Diseases, acting under the name "Deutsche Gesellschaft für Muskelkranke e.V.", founded in September 1965, organized under German law, with its registered office at Im Moos 4, 79112 Freiburg im Breisgau, in this matter duly represented by Joachim Spross, federal business manager (hereinafter referred to as "DGM").

- Fondazione Malattie Miotoniche, acting under the name "FMM", founded in March 2011, organized under Italian Law, with its registered R.E.A. Office MI-1960814, with Fiscal Code 97584670158, Lawyer's Office and Administration in Milan, Piazza Libia, 2, in this matter duly represented by Giovanni Meola, Founder and President.

- Swiss-French Association for Neuro-Muscular Diseases, acting under the name « ASRIMM » (Association Suisse Romande Intervenant contre les Maladies neuro-Musculaires), founded in December 1977, organized under the Swiss Law (CCS) under the articles 60, with its office in 1400 Yverdon-les-Bains, Rue Galilée 15,in this matter duly represented by Monika Kaempf, Director.

Recognize a number of opportunities for collaboration in the area of Myotonic Dystrophies,

Acknowledge shared commitment to advance translational research for DM,

Agree that this current context demands a new level of interaction and collaboration among several of the European leading organizations targeted to the understanding, treatment and cure of DM.

Therefore, decide to create together Euro-DyMA whose main goal is to organize and drive common actions in this domain at a European level.

In the following, the term “member” designates one of the associations constitutive of Euro-DyMA.

1. General considerations

The Association's name is “European Dystrophy Myotonic Association” abbreviated Euro-DyMA, its members are national DM patient groups and associations, registered in Europe and sharing a commitment to pan-European cooperation on DM issues.

The Association's residency is in France, deposited at Institute of Myology, 47-83 boulevard de l’Hôpital, 75651 Paris Cedex 13, France. Financial year is the calendar year starting on the 1st of January.

The working language of the Association is English. All produced documents, mails, meetings should use this language. Statutory documents required by the French authorities (annual activity report, annual financial report…) will be elaborated and shared in English before translation in French.

2. Purpose, Tasks and Objectives

The purpose of the Association is to provide a framework to stimulate collaboration, accelerate translational research pathways and disposal of validated drugs in DM, and promote patient care.

Cooperation between European organizations is meant to enhance and support the existing efforts of each association by identifying areas for collaboration that are mutually advantageous to the mission of each one.

Specific purposes, tasks and objectives of the Association are to increase European cooperation to achieve the following objectives:

- Improve the quality of life of DM patients,
- promote the interests of DM patients in European health policy,
- raise awareness of DM with the general public, healthcare practitioners, scientists and industry,
- identify, develop, promote and implement the best practice for DM,
- promote and sustain scientific and medical research in all fields of DM,
- increase collaboration between member countries.

The Association will plead for the enlargement of therapeutic methods in addition to the implementation and assurance of a pan European standardized and appropriate therapy of Myotonic Dystrophy. To this purpose, the Association will arrange events to provide further training and information, whilst arranging programs with the goal of an exchange of experience for DM patients and their specialists. The Association will also stimulate and forward research projects concerning the therapy of DM. To reach its objectives, the Association works in close cooperation with other national, European and worldwide organizations, groups and institutions of similar aims and objectives.

3. Public Interest

The Association pursues its objectives exclusively and directly in the public interest and in accordance with the regulations on "tax-deductible objectives" of the French fiscal laws.

The Association operates without self-interest. Its primary aims are not those of personal economical gains.

The Association's funds may only be used for statutory objectives. All members are volunteers. No member is allowed to receive any appointment from the Association’s funds. An exception to this rule is possible in case an office is installed requiring to appoint paid staff.

No person may benefit from expenditures not in line with the Association's objectives authorized by the Board (defined at section 8).

4. Members, Rights and Duties

The membership addresses 4 categories of members: founding members, executive members, deputy members, and associated members.

- The statute of founding member is granted to the 6 patient associations listed in preamble.

- The statutes of Executive and deputy members cover the additional associations joining Euro-DyMA, fully compliant with the Association rules in all objectives, goals and juridical structure. All these associations have the same rights and duties. The number of executive members is limited to 5. The number of deputy members is not limited. Differences between the two statutes are addressed at section 8.

- Associated members are organizations which are not fully eligible to access Euro-DyMA for any reason, but share objectives and aims as described at section 2 and provide exceptional pertinence in their field of activity in the DM pathologies.

All members are obliged to support the Association's objectives as best they can. Members will not take any action that may harm the Association.

Application for membership must be made in writing to the Executive Board, who will consider the application and select the applied category of membership.

The Executive Board, (defined at section 8), may pronounce a conditional approval. In that case, the condition must be formally documented to the applicant who is free to accept it or decline. If he declines, the application is abandoned. If he accepts, he commits to comply in full with the condition at all times.

Accepted applications must be presented to the General Assembly (defined at section 7) who holds the final decision at its next regular meeting.

If the Board (defined at section 8) has declined an application, the applicant may make once an appeal to the General Assembly. Any singular majority suffices and the decision is final.

Membership is terminated by dissolution of the member, resignation or expulsion.

- Resignation must be made in the form of a written declaration addressed to the Executive Board and come into effect immediately.

- A member may be expelled for violating the statutes, get into conflict with the interests of the Association or repeated misconduct. Appropriate justification in writing must be given. The

decision is made by the Board and requires a majority. Before the decision is made by the Board, the member must be given opportunity to send a written statement within a period of 14 business days. The decision must include the reasons for expulsion and must be sent to the member via registered mail. The member may appeal against the decision within a period of one month prior to the next regular General Assembly, where a final decision will be made. The General assembly must ratify the expulsion in the next meeting of the assembly by a singular majority.

- The termination of membership terminates all claims arising out of membership.

- In case of termination of membership concerning a founding member for any reason, the position is proposed to the following executive member based on chronological arrival inside Euro-DyMA. This association grants the statute of founding member.

5. The Scientific Advisory Board (SAB)

The SAB is composed of a team of experts in DM and advises the Board of the Association on medical and scientific matters.

The president of the SAB must have demonstrated in his career an exceptional and indisputable expertise in the domain of DM pathologies. He is appointed by the Board.

Candidates to the SAB can be proposed either by the board or by the SAB itself. Candidates must demonstrate a sufficient expertise background in the field of DM pathologies, validated by the President of the SAB.

Participants in the SAB are nominated by the board upon proposal of the SAB president. Although the main criteria to integrate the SAB is based on knowledge and experience, diversity of participating countries is encouraged.

6. Executive Bodies of the Association

Executive bodies of the Association are the General Assembly and the Board.

7. The General Assembly

Tasks of the General Assembly are:

- Passing of resolutions concerning the Association's platform of work
- Election of Board members and auditors
- Acceptance and approval of the Boards financial and activity report, annual budget for the coming year and policy papers
- Passing of resolutions on tabled motions and statutory changes, on concerns brought to its attention by the Board and on tasks arising from the statutes
- Passing of resolutions on the Association's dissolution
- Final vote on the membership application or expulsion of a member.

The General Assembly constitutes a quorum, if a minimum of 50% of members are represented.

Each member designates up to three representatives, adult persons affected by DM (patients, family, caregivers…).

- Founding, executive and deputy members participate in the General Assembly and share the benefits of their membership including the right of vote. Whatever may be the number of its representatives, each association member has 1 vote.

- Associate members participate in the General Assembly and share the benefits of their membership with the exception of the right to vote.

Any Euro-DyMA member can transfer its right to vote to another Euro-DyMA member. This transfer must be made by written authorization and must be presented prior to the General Assembly.

A General Assembly must be convened at a minimum of once per annum and in addition, any time necessitated by the Association's interests. Invitations are made in writing, through the President, or Vice-president if absent, or the "contact point" by proxy of the President or Vice-President and must include a provisional agenda and a minimum of four weeks' notice.

Additions to the agenda may be proposed by the Association's members, and must include an explanation and be presented to the President in writing, no later than four weeks prior to the meeting. The Board will approve the agenda by majority, no later than 2 weeks before the General Assembly. Applications arriving at a later date may be considered urgent applications and their inclusion on the agenda must be voted for by a 3/4 majority of the General Assembly. Excluded from this rule are changes in the statutes and other decisions of far reaching consequences for the Association. At the General Assembly the Board issues a statement on behalf of each application that has been made by a member.

The General Assembly is chaired by the President and in his/her absence, by the Vice-President. However, the General Assembly may select somebody else for the task of chairing the meeting.

Unless the statutes define otherwise, the General Assembly arrives at its resolutions by simple majority of all valid votes cast. Abstentions and invalid votes are not counted. The passing of resolutions is principally arrived at by acclamation or open ballot if deemed necessary by the President, unless legal stipulations or statutory regulations define otherwise.

At the General Assembly, two auditors are elected to carry out audits. These auditors must be independent to the Executive Board. Auditors are elected for an officiating period of 3 years. They remain in office until the following elections. One period of re-election is possible.

Auditors have to check the Board, Executive Board and the Scientific Advisory Board on their actions with respect to the statutes and House Rules. They will report yearly during the General Assembly meeting.

8. The Board

The Board consists of one representative of each eligible organizations, limited to 11 positions.

- The 6 founding members are permanent members in the Board.
- The 5 Board members are renewable by a fraction of 2/5.
- The deputy members do not participate in the board due to the size limitation.

Out of founding, executive and deputy members will be elected: The President, the Vice-President, the Secretary and the Treasurer called Executive Board.

Board participants exclusively belong to the member associations.

The Board manages the Association's business. It is obliged to administrate the Association's assets and resolutions. For the attention of running business it is entitled to install an office and to appoint paid staff if necessary.

The Association is represented externally at court and out-of-court by the President and the Vice-President, both of whom are individually authorized by the Board. For internal business between Board and Association, the Vice-President is only authorized to represent on behalf of the Board, if the President is unavailable.

The Board usually arrives at its resolutions during the course of the Board meetings, which are being called by the President and in his/her absence by the Vice-President. An advance notice of four weeks must be given and an agenda must be included.

In case some conclusions cannot be achieved during the meetings, a reasonable reply period, no longer than 3 weeks, is given to the members for returning their vote by writing. Decisions and resolutions made outside face to face meetings must be entered into the minutes of the next Board meeting and must include the result of the ballot.

A Board meeting can be called with a shorter advance notice (at least 2 weeks) if a minimum of two Board members request so in writing (including by e-mail), which must include a detailing of reasons for the calling of such a meeting.

The Board constitutes a quorum if 50% of the Board members are present face to face or by teleconference.

Resolutions are made by majority of valid votes cast. Abstentions and invalid votes are not counted. A parity of valid votes means that an application is turned down.

The Board will meet at least once a year face to face, and by teleconference more frequently if necessary. In exceptional urgent cases Board resolutions can be proposed through a member of the Board in writing and circulation to be voted by the Board.

The Board is entitled to appoint advisory committees and work groups to accomplish the Association’s objectives. These bodies work within the framework of the tasks that have been delegated to them and advise the Board on the factual issues in question. They may not decide on agendas of their own.

The following applies for the election of participants in the Board:

To become eligible, a candidate must be an adult nominated by a founding or executive member of the Association. As for the General Assembly, candidates should be persons affected by DM (patients, family, caregivers…).

The Board is elected for a period of two years. Every 2 years, at the time of the General Assembly, and based on their chronological arrival in the Board, 2 of the 5 executive members leave

the Board, their position is opened to deputy members and submitted to vote. Board members are eligible to stand for re-election when their term of office is completed.

Election is conducted by open ballot per any individual Board member. A paper ballot, i.e. a ballot by voting card, must be held if applied for by any participant of the meeting, who is eligible to vote. Elected are the candidates who manage to collect a majority of valid votes cast. Abstentions and invalid votes are discounted. If there is a parity of votes, a second ballot will be held. If the second ballot results in another parity, the vote will be decided by the drawing of lots.

For the duration of the elections the meeting will be presided over by the election committee. Members to the election committee are elected by open ballot. The election committee shall have three participants. These participants appoint a committee chairperson from amongst them. Members of the election committee may not concurrently be candidates for Board positions.

If a member of the Board withdraws from office before the end of term, the Board is entitled to self-completion through the appointment of (a) new member(s) of the Board (co-optation). The number of Board members appointed thus may not exceed two. The term of office of co-opted Board members lasts until the next General Assembly is called. At this meeting its participants elect a new Board member who then remains in office until the end of the term that the resigned Board member would have served.

9. Registration of Resolutions and Minutes

Meetings of the Association's executive bodies must be recorded in minutes, which must be signed by the meeting's chairperson and minute-taker.

The minutes must be brought to the immediate attention of members, either in writing, by fax or by electronic communication.

10. House rules

As a complement to the statutes, Euro-DyMA Board sets-up house rules formally summarized in a specific document. These rules are voted in the Board meetings as described at section 8. In case of overlapping conflicts between the statutes and the house rules, the statutes are predominant.

11. Thematic subgroups

Euro-DyMA may create sub-groups dedicated to specific tasks (expert committees, patient advisory groups, legal advisory groups…). Participants may be searched inside or outside the Association. The mission, lifetime, composition and operating rules of these groups are defined by the Board in respect of the statutes and house rules of the Association and published in the house rules. A representative of the Euro-DyMA Board is mandatory in each of them.

12. Finance

Each member organization pays for the participation of its representatives. Each member organization pays an annual membership fee, fixed by the Board, to ensure the running of Euro-DyMA.

Funds for the realization of the Association's tasks are exclusively received through:

- Members fees.

- Earnings from the Association's assets.
- Donations of money or in kind.
- Subsidies.
- Sponsorship by national or international organizations, after proper validation of the Board.
- Fundraising and advertising. No public fundraising is allowed interfering with national collects.
- Contracts with pharmaceutical/biotech industry according to specifications and requirements documents approved by the Board. No other funding contribution of any kind is accepted from pharmaceutical/ biotech industry.

Physical meetings are organized by the hosting organization, which is selected by the Board yearly on a rotating basis and taking profit of external events if any.

All costs relating to travels of representatives and to the organization of meetings are preferentially paid by their organization (hotel and transportation). Upon decision of the Board, Euro-DyMA may participate in these costs. A fraction of the annual budget is allocated to these expenses, defined yearly at the General Assembly.

In order to facilitate the funding engagements of the members, a preliminary budget of the Association is prepared by the Treasurer in summer of each year for the next year. It must be validated by the board, and communicated to the members in sufficient advance for inclusion inside the associations budgets and make secure the availability of funds.

13. Confidentiality

The representatives of each organization must sign a confidentiality agreement. Board discussions are confidential and must not be disclosed outside the Association without validation by the President, vice-President and Treasurer. Information release inside the Association is allowed and encouraged, under the previously mentioned confidentiality agreement.

Specific confidentiality rules may apply to the sub-groups addressed at section 11. These rules must be compatible with the statutes of the Association and approved by the Board before starting the activities of the group.

In addition, nominative confidentiality agreements can be requested from each person attending a meeting with representatives of the pharmaceutical/ biotech industry or for specific matters that are important to the governance of the association, such as the preparation of publications. In that case, information release inside the Association is exclusively driven by the terms of the confidentiality agreement signed by the people involved, and no information can be released outside the Association.

14. Statutory Changes, Changes to the Association's Objectives

Amendments of the statutes or the Association's objectives are carried by resolution of the General Assembly and with a majority of three quarters (3/4) of valid votes cast.

The Board is authorized to independently implement such statutory changes that are merely editorial or that have been made by a supervisory, judicial or fiscal authority. The members must be notified of these changes immediately and at the latest before the changes become active.

15. Dissolution of the Association

The dissolution of the Association is put into effect by resolution at an extraordinary General Assembly which must be called for this particular purpose only. To carry this resolution, a majority of three quarters (3/4) of valid votes cast is required. For the winding up of its business affairs, the General Assembly appoints three external liquidators.

If either the Association is dissolved or tax privileged objectives ceased, its assets return at equal proportion to the existing associations at the time of dissolution.