

**STATUTES
OF
DYSTONIA EUROPE
formerly
EUROPEAN DYSTONIA FEDERATION
Incorporating change of name to “DYSTONIA EUROPE”
And other changes agreed by the delegates
On Sunday 23 October 2011 – at the Annual General Assembly
held in Barcelona, Spain and again at a Special General Assembly in Brussels, in the presence
of a notary on 11 May 2012**

Article I - Name and registered office

1. An association international sans but lucratif (international non-profit-making association) (“the association”) was created on 18th September 2004, with the name European Dystonia Federation, and is entitled to use the designated form “EDF”. This association is governed by the dispositions of Title III of the Belgian Law of June 27, 1921 on the non-profit-making associations, the international non-profit-making associations and the foundations (hereafter called ‘the law of June 27, 1921’).
2. From 23 October, 2011, the name of the association shall be “Dystonia Europe”, with the designated abbreviation “DE”.
3. The office of the association is established at Square de Meeus 37 – 4th Floor, B-1000 Brussels, Belgium. It may be transferred, by simple decision of the Board, to any other place in Belgium. This decision will be published in the annexes of the Belgian Official Journal and communicated to the “Federal Public Service of Justice” (Service Public Fédéral Justice)

Article II - Objectives and duration

1. The aims of the association are to establish an international platform at the European level which will:
 - provide the possibilities for members to add value to their own activities and services which improve the lives of people living with dystonia
 - stimulate research for more effective treatments and, in the longer term, to find a cure for dystonia
2. The association will seek to work in partnership with any individuals, foundation or other bodies who/which share the aims of DE, but will preserve its independence at all times. DE does not, and will not, support any particular party, political tendency or religious movement.
3. In order to realise its objectives, the association may acquire, receive and manage all personal or real estates, apply for subsidies, receive donations and legacies and dispose of all contributions, grants, loans and other income or funds, whether periodically paid or not.
4. The duration of the association shall be unlimited. It can be terminated at any time by a two thirds majority decision of the voting members at a meeting, properly convened for the purpose..

5. DE may realise its objectives by whichever way it deems most appropriate. It can, inter alia, organise all actions and activities which contribute to the advancement of dystonia and related areas

Article III – Members

1. There shall be 3 categories of DE members: Ordinary members (“OM”) who/which have the power to vote at General Assemblies, Associate members (“AM”) – non-voting, and Honorary members (“HM”) – non-voting.

2. The number of OM shall be unlimited, but shall not be less than three.

3. The OM are the founding members of DE, European patient support organisations, foundations and medical/scientific/healthcare and other bodies with an interest in dystonia that are legally constituted following the laws and customs of their country of origin. Any organisation applying for OM shall send to the Board its constitution and any other required documents to enable proper consideration of the application. The Board shall propose acceptance or rejection of the application to the next following General Assembly. At that General Assembly, the delegates shall vote on the acceptance or rejection or delaying a decision on new applications. A majority of two thirds of the OM delegates present or represented by a proxy at the meeting shall be required for acceptance.

4. The AM are individuals, non-European patient or other not-for-profit or commercial organisations, or groups / associations which are not yet fully legally constituted but are recognised following the laws and customs of their country of origin. All applicants in this category should apply in writing to the Board, and must be able to show a credible interest in dystonia. AM shall be accorded at the entire discretion of the General Assembly.

5. The HM are: individuals or organisations who have provided outstanding support for the aims and objectives of DE and whose standing as honorary members shall have been agreed by two thirds majority vote of the General Assembly, on the proposal of the Board,

6. Each member organisation shall nominate an appropriate, well qualified member of its own as its DE delegate. This delegate shall represent the interests of his/her organisation in DE at the General Assembly.

7. Any member is free to resign from the association by submitting his/her/its resignation to the Board in writing. Such resignation shall take effect immediately once any outstanding membership fees have been paid. Until that time the leaving member remains fully liable for any obligations of membership.

8. The removal of a member may be proposed by the Board, after having heard, or given the opportunity to be heard, any observations of the member concerned. The final decision to require a member to leave the association shall be taken by the General Assembly, by a two thirds majority of

the OM attending or being represented by proxy. Such decisions may, inter alia, be proposed and decided if a member fails to pay its annual dues, if it brings DE into disrepute, or if it no longer fulfils the stated requirements for membership.

9. Any member which is liquidated, de-registered, ceases to exist as a legal entity or who no longer belongs to the association has no rights to any part the funds of DE.

10. Members shall have no personal liability for the financial obligations of the association.

Article IV- General Assembly

1. The General Assembly possesses all powers to permit the realisation of the objectives of the association. It shall be composed of the OM only. AM and HM may attend the Assembly in a consultative capacity but may not vote.

2. The following are reserved to the competence of the General Assembly:

- any amendments to the statutes;
- the approval of the annual accounts;
- the voluntary dissolution of DE;
- the expulsion of members and the election of new members;
- the election and expulsion of members of the Board.
- the approval of any proposals to levy or vary membership fees of the association

All other matters shall be the responsibility of the Board.

3. The General Assembly shall meet at least once a year. All members shall be informed of the place, date and hour of the meeting (“convocation”). The Board shall convoke the meeting by ordinary letter, email or fax, addressed to each member, at least sixty days before the meeting, signed by the President or by one other Board member. The convocation shall include the agenda and any proposed resolutions.

4. The association may meet in Extraordinary General Assembly if decided by the Board or at the request of not less than one quarter of the OM of DE.

5. The General Assembly shall be chaired by the President of DE or, in default, by the Vice-President or, in default, by any other member of the Board. The Secretary shall ensure that minutes of the meeting are taken and recorded.

6. The General Assembly shall be quorate if at least 50% of the voting members are present or represented by proxy. The decisions of the General Assembly shall be made by a simple majority vote unless these Statutes or the law specifically stipulate otherwise.

7. Each OM has the right to be represented by a proxy chosen from among the delegates of the OM present at the meeting. Each delegate who is appointed as proxy may not cast a proxy vote for more than one other member. A proxy vote shall be valid only if it is given in writing by ordinary mail, fax or email, and presented to the meeting.

8. The Chairperson shall have a casting vote, in the event of an equal vote on any resolution.

9. Decisions of the General Assembly shall be recorded in formal minutes, which shall be presented for approval at the next following General Assembly and shall be signed by the person presiding at the meeting which gives approval, and by another Board member. The minutes shall be circulated to all members by ordinary mail, fax or email before the meeting at which they are to be presented for approval. The original of the signed minutes shall be retained in a file at the registered office.

10. The accounts for the financial year shall be closed each year on the 31st December. They shall be presented to the next following General Assembly for approval, after having been the subject of proper scrutiny by an independent and qualified financial accountant.

In case of voluntary dissolution, the General Assembly shall, if required by law, designate one or two liquidators and determine their powers.

11. Without prejudice to articles 50 §3, 55 and 56 of the law of June 27, 1921, any proposal calling for an amendment to the constitution or for the dissolution of DE must be made by the Board or by an OM of DE. The Board shall submit the proposal to the Secretary at least ninety days prior to the General Assembly at which the proposal shall be voted upon. The Secretary shall send the proposal in writing to all members of DE with the letter calling the meeting. Two thirds of the voting members must be present or represented by proxy at the General Assembly, to allow decisions to be made on such proposals. However, if less than two thirds of the voting members are present or represented by proxy, a new General Assembly shall be called on the same basis as previously described. This meeting shall decide definitively and validly upon the proposals by a two thirds majority vote regardless of the number of voting members present or represented by proxy.

12. The amendments to the statutes shall have effect only after approval by the competent authority in conformity with article 50, §3 of the law of June 27, 1921 and after publication in the annexes to the Belgian Official Journal according to article 51, §3 of this law.

13. In case of dissolution, at whatever time or for whatever reason, the residual funds of DE, after payment of any debts and charges, shall be transferred, following a decision of the voting members by simple majority vote to an organisation of good standing having similar objectives to DE or, by default, to a private non-profit-making corporate body with disinterested objectives.

Article V - Administration

1. The association is managed by a Board comprising not less than five and not more than eight voting members. Up to five Board members shall be elected from candidates proposed by OMs, and up to 3 further voting Board members may be appointed by the Board from candidates selected from inside or outside the membership of DE. Each candidate for election shall be a member of the OM organisation which nominates him/her. No single organisation shall have more than one elected member on the Board of directors and there can be no more than two DE Board members (elected or appointed) from any single country.
2. DE Board members shall work for the aims and interests of the whole association and shall not represent the sole interests of any OM in that role. Representation of a single OM's interests is the role of the member's appointed delegate at General Assemblies. When a delegate is elected or appointed to the DE Board he/she will lose his/her capacity as delegate and the OM involved must then appoint a different person as its delegate to the General Assembly.
3. Ninety days prior to the General Assembly the Secretary of DE shall invite OMs by letter, fax or email to submit to the Secretary any nominations for election of Board members. Nominations must be received by the Secretary at the latest sixty days prior to the General Assembly. A short biography of the candidate shall be sent with each nomination. Forty five days prior to the General Assembly the Secretary shall circulate to all members a copy of all valid nominations. The Board shall decide the validity of nominations in strict accordance with the Statutes and any Bylaws.
4. Elected Board members shall be elected for a term of two years and are eligible for re-election twice. Similarly, Board members who are appointed shall serve for two years and be eligible for re-election twice. After a maximum of six continuous years of service on the Board, a Board member may not again be nominated for re-election or appointment as a voting Board member until at least one calendar year has elapsed.
5. All acts established in conformity with the law and concerning the election, the revocation and the cessation of the functions of the board members or of the persons entitled to represent DE, are communicated to the Federal Public Service of Justice in order to be deposited in the file and are published, at the association's costs, in the annexes to the Belgian Official Journal.
6. In the event of a Board member (elected or appointed) not completing his/her mandate, the Board may appoint another person to fulfil that mandate if they feel it to be necessary, but such appointment must be approved by a two-thirds majority of OMs present or represented by proxy at the next following General Assembly, for the balance of the term of the Board member that the appointee has replaced. In any such case, an appointee may be nominated again at the appropriate time, according to these statutes, for re-election/re-appointment for up

to two further terms, each of two years, whether or not his/her predecessor had already served more than one term.

7. If no such replacement is proposed by the Board within 90 days of a Board member giving notice that he/she intends to resign office, then that position shall be vacant and available for nominations for election/appointment, as appropriate, at the next following General Assembly.
8. A Board member who resigns office shall be deemed to remain in office until the end of his/her mandate, even though he/she shall take no further part in Board meetings or decisions.
9. Any Board member may be removed by the General Assembly by a two-thirds majority vote of the OM who are present or are represented by proxy at the meeting.
10. The Board shall choose from among its members a President, Vice-president, Secretary and a Treasurer. If the President is absent from any meeting, his/her functions shall be assumed by the Vice-President or, in default, by any other Board member present.
11. The Board may co-opt up to 3 persons to provide otherwise unavailable skills, and may establish terms of office and any other conditions. They shall have no vote but will act only in an advisory capacity. Their appointment may be annulled by the General Assembly, following the same procedure described in Article V.9.
12. The Board shall meet as required, but at least twice a year, at the request of at least two members of the Board or of the President. The convocations shall be by ordinary letter, fax or e-mail.
13. The Board may deliberate and vote validly only if at least half of its voting members are present or represented. Each voting Board member may give a proxy in writing (mail, fax or email) to a fellow voting Board member, to vote on his/her behalf. No Board member may hold more than one proxy.
14. Decisions of the Board shall be taken by simple majority of those present or represented by proxy. In the case of an equal vote, the chairperson of the meeting shall have a casting vote.
15. At the next Board meeting the minutes of the previous meeting shall be approved and signed by the chairperson of the meeting and one of the Board members and shall be kept in a register. This register shall be kept at the registered seat of DE. The Board shall regularly circulate the main decisions and events described in the minutes, to the DE members.
16. The Board shall have all powers and all authority to decide and implement all of the Board's acts in pursuance of the objectives of these Statutes. The Board is competent to

deal with any issues on behalf of DE, in the broadest sense. All matters not expressly reserved by the law or these Statutes to the General Assembly shall fall under the competency of the Board. The Board shall carry out or cause to be carried out, all activities of DE and shall ensure that the decisions of the General Assembly are fulfilled.

17. Board members shall generally act in a voluntary capacity and shall be re-imbursed their reasonable expenses incurred in the execution of their duties, against expense vouchers, OM Board members shall not otherwise be remunerated by DE. However, in specific cases, the Board may agree that any of its members may act as a remunerated consultant on any DE project provided the remuneration is also agreed by any person, organisation or other sponsor which finances the project. Payment of such fees must come from funds specifically designated for the project in question.
18. Any documents which formally commit the association legally or financially shall be signed by the President and one other board member, neither of whom requires to justify his/her power to do so.
19. The Board shall establish any Bylaws it considers necessary for the proper functioning of the association.
20. Any legal action as plaintiff or as defendant shall be pursued by the Board represented by its President or by one Board member appointed by the President for that purpose.
21. Board members shall be subject to strict confidentiality in relation to their DE activities. Where the deliberations of the Board, or documents it reviews, are stated to be, or identified as confidential, any breach of that confidentiality will entitle the rest of the Board, by simple majority vote to suspend the defaulting Board member from Board activities until the next following General Assembly, where the OMs may vote on the matter.

Article VI – Budget and accounts

1. The financial year shall commence on 1st January and end on 31st December.
2. According to article 53 of the Law of June 27, 1921, the annual accounts for the Financial Year just completed and the budget of the next financial year shall be prepared each year by the Board and shall be submitted for approval to the General Assembly.
3. The books and records of the Treasurer shall be subject to proper scrutiny annually by an independent and qualified financial accountant. The accounts shall be communicated to the Federal Public Service of Justice in conformity with article 51 of the law.

Article VII – General dispositions

1. The dispositions of Title III of the law of June 27, 1921 will provide for any matters not covered by the present constitution, especially the publications in the annexes to the Belgian Official Journal.
2. In exceptional cases and where the circumstances justify it, as an alternative to physical meetings, any meeting may take place by telephone, e-mail or by telephone or video conference. Convocation and other provisions concerning physical meetings shall apply.
3. All documents shall be written in English. However, the official language of the association is French. In case of a conflict between the English and French version of a document, the French version shall prevail.