

**DYSTONIA EUROPE IVZW**

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**Article I – Name and registered office**

1. The association is a legal entity with the legal form of an international non-profit association (internationale vereniging zonder winst oogmerk, abbreviated to “IVZW”), hereinafter referred to as “the association”. The association is governed by the provisions of the Companies and Associations Code.

2. The name of the association is “Dystonia Europe”, abbreviated to “DE”.

3. The Registered office of the association is situated in the Brussels Region.

4. The Management Board is authorized to relocate the registered office of the association within Belgium as long as the relocation does not require any change in the language of these articles of association in accordance with applicable law on the use of languages. This decision shall not require an amendment of the articles of association.

5. If the language of the articles of association has to be changed further to the relocation of the registered office, this decision may only be taken by the General Meeting, taking account of the requirements for the amendment of the articles of association.

**Article II – Disinterested purpose, object and duration**

1. The purposes of the association are to establish an international platform at European level that will:

- provide opportunities for the members to add value to their own activities and services that improve the lives of people with dystonia
- encourage research into more effective treatments and, in the longer term, find a treatment for dystonia.

2. The association will seek cooperation with individuals, a foundation or other institutions that share the objectives of DE, but it will retain its independence at all times. DE does not support and will not in the future support any particular party, political trend or religious movement.

3. The practical activities through which the objectives of DE are achieved include the following:

- Increasing awareness and being a guiding voice in Europe about the impact of dystonia;
- Sharing knowledge, providing the most recent information and resources for our members and being a source of information for other interested parties;
- Bringing people with dystonia, member organisations, caregivers, European policymakers, and the treatment industry into contact with one another to close the gaps in current dystonia treatment promoting training and education and training multidisciplinary teams and interested parties in the dystonia journey so as to optimize care and improve the quality of life promoting research.

4. In order to achieve its objectives, the association may obtain and manage all moveable and immovable goods, apply for subsidies, receive donations and bequests and have at its disposal contributions, grants, loans and other income or funds, which may or may not be paid periodically.

5. The association may carry out all actions that are directly or obliquely related to its disinterested purpose and object.

In addition, the association may develop all activities that contribute directly or indirectly to the achievement of the aforementioned disinterested purpose, including ancillary trading activities, the proceeds from which shall be intended for the achievement of the disinterested purpose.

6. The association is established for an indefinite period of time. It may be terminated at any time with a two-thirds majority of the voting members at a meeting properly convened for this purpose.

7. DE may achieve its objectives in the manner that it considers most suitable. Among other things, it may organise all sorts of actions and activities that contribute towards progress in dystonia and related fields.

### **Article III – Members**

1. There are three categories of DE members: Ordinary members ("OMs") who have the power to vote at the General Meetings, associate members ("AMs") - without voting rights, and honorary members ("HMs") – without voting rights.

2. The number of OMs is unlimited but may not under any circumstances be fewer than two.

3. The OMs are founding members of DE, European patient support organisations, foundations and medical/scientific/healthcare and other bodies with an interest in dystonia, legally established in accordance with the laws and customs of their country of origin. Each OM has one vote. Any organisation wishing to join as an OM shall hand over its memorandum of association and all other documents required to the Management Board in order to enable proper assessment of the application. The Management Board shall propose the acceptance or rejection of the application at the next General Meeting. At this General Meeting, the OM representatives shall vote on whether to accept, reject or postpone a decision on new applications. A majority of two-thirds of the OM delegates present at the meeting or represented by proxy shall be necessary for acceptance.

4. The AMs are individuals, non-European patients or other non-profit or commercial organisations or groups/associations that are not yet fully established in legal terms but are recognised in accordance with the laws and customs of their country of origin. All applicants in this category should submit their application to the Management Board in writing and must be in a position to demonstrate a credible interest in dystonia. A majority of two-thirds of the votes at the General Meeting is required for acceptance, at the proposal of the Management Board.

5. The HMs are individuals or organisations that have provided outstanding support for the objectives of DE and whose permanent presence as honorary members has been accepted by two-thirds of the votes at the General Meeting, at the proposal of the Management Board.

6. Every member shall present a suitable, well qualified member from among their own members as its DE delegate. This delegate shall represent the interests of his/her organisation in DE at the General Meeting.

7. Each member is free to submit his/her resignation from the association to the Management Board in writing. The resignation shall take effect immediately as soon as any outstanding membership fees have been paid. Until that time, the outgoing member remains fully liable for the obligations of membership.

8. The exclusion of a member can be proposed by the Management Board, after any comments from the member concerned have been heard, or after an opportunity has been provided to hear any such comments. The final decision to oblige a member to leave the association shall be taken by the General Meeting, with a majority of two-thirds of the OM delegates present or represented by proxy. Such decisions may be proposed, among other things, if a member fails to pay its annual membership fee, if the member brings DE into disrepute or if the member no longer fulfils the membership requirements.

9. A member that is in liquidation, no longer registered, has ceased to exist as a legal entity or no longer belongs to the association shall no longer be entitled to part of the funds of DE.

10. Members shall not be personally liable for the financial obligations of the association.

### **Article IV – General Meeting**

1. The General Meeting has all powers to bring about the achievement of the objectives of the association. The General Meeting comprises exclusively OMs. AMs and HMs may take part in the General Meeting in an advisory capacity but do not have voting rights.

2. The following powers are reserved for the General Meeting:
- possible amendments to the articles of association;
  - approval of the annual financial statements and the budget;
  - the voluntary dissolution of DE;
  - the exclusion of members and the election of new members;
  - the appointment and dismissal of members of the Management Board and, where appropriate, the determination of their remuneration;
  - granting discharge to the board members;
  - appointing and dismissing the auditor and establishing his/her remuneration (if applicable);
  - approving proposals to raise or modify the membership fees of the associations;
  - all other cases where this is required under Belgian law or by the articles of association.

All other powers are the responsibility of the Management Board.

3. The General Meeting shall assemble at least once per year. All members shall be kept informed of the place, date and time of the meeting ("convening notice"). The Management Board shall convene the meeting by ordinary letter, e-mail or fax, addressed to each member at least thirty days before the meeting, signed by the Chairperson or another member of the Management Board. The convening notice shall contain the agenda and the proposed resolutions.

4. The association can hold an Extraordinary General Meeting if this is decided upon by the Management Board or at the request of at least one-fifth of the members.

5. The General Meeting shall be chaired by the Chairperson of DE or, in his/her absence, by the Vice-Chairperson or, in his/her absence, by another member of the Management Board. The Secretary shall ensure that the minutes of the meeting are taken and recorded.

6. The General Meeting can only validly meet when at least 50% of the voting members are present or represented by proxy. The decisions of the General Meeting shall be taken by an ordinary majority of votes, unless expressly otherwise stipulated in these articles of association or by law. Abstentions and invalid votes shall not be taken into account when calculating the ordinary and special majorities referred to above, either in the numerator or in the denominator.

7. Each OM shall be entitled to be represented by a proxy holder chosen from among the OM delegates present at the General Meeting. A proxy vote is only valid if it is given in writing by ordinary post, fax or e-mail and presented at the meeting.

8. Members may take any decisions that fall within the remit of the general meeting unanimously and in writing, with the exception of amendments to the articles of association. In this case, the convening formalities do not have to be fulfilled. The members of the Management Board and, where appropriate, the auditor may take note of these decisions upon request.

9. In accordance with the provisions of the Companies and Associations Code, the Management Board may offer the members the possibility of taking part in the General Meeting from a distance by an electronic means of communication made available by the IVZW. The electronic means of communication must at least enable the members to take note directly, simultaneously and uninterruptedly of the discussions during the meeting and to exercise their right to vote with regard to all points on which the meeting has to express an opinion. It must also enable the members to exercise their right to vote and/or to ask questions. A member who takes part in the General Meeting from a distance in this way shall be equated to a member who is actually physically present at the General Meeting.

10. The Chairperson shall have the casting vote in the event of a tied vote for every resolution.

11. Decisions taken by the General Meeting shall be recorded in formal minutes, which shall be presented to the next General Meeting for approval and which shall be signed by the person who chairs the meeting that gives its approval and by another member of the Management Board. The minutes shall be sent to all members by ordinary post, fax or e-mail before the meeting at which they are presented for approval. All members may consult the minutes and decisions of the General Meeting at the registered office of the IVZW.

12. Notwithstanding that which is stipulated in Article 2:5 §4 of the Companies and Associations Code, each proposal calling for an amendment of the memorandum of association or for the dissolution of DE must be put forward by the Management Board or by an OM of DE. The Management Board shall submit the proposal to the Secretary at least ninety days before the General Meeting at which a vote has to be taken on the proposal. The Secretary shall forward the proposal in writing to all members of DE together with the letter convening the meeting. Two-third of the voting members must be present or represented by proxy at the General Meeting in order to enable decisions to be taken on these proposals. However, if fewer than two-thirds of the voting members are present or represented by proxy, another General Meeting shall be convened in the same way as described above. This meeting shall decide definitively and validly on the proposals by a two-thirds majority of the votes, irrespective of the number of voting members who are present or represented by proxy.

13. Amendments to the articles of association shall take effect after approval by the competent authority in accordance with Article 2:5 §4 of the Companies and Associations Code and after publication in the Annexes to the Belgisch Staatsblad/Moniteur belge (Belgian official journal) in accordance with Article 2:6 of the Companies and Associations Code.

14. In the event of dissolution, at any time or for any reason whatsoever, the remaining funds of DE, after payment of all debts and costs, after a decision by the voting members taken by an ordinary majority of votes, shall be transferred to an organisation with a good reputation that has similar objectives to DE or, in the absence of such an organisation, to a private non-profit corporate body with disinterested objectives.

#### **Article V – Management**

1. The association shall be administered by a Management Board consisting of no fewer than five and no more than eight voting members. A maximum of five members of the Management Board may be chosen from among the candidates put forward by OMs and a maximum of three other voting members of the Management Board may be appointed by the Management Board from among selected candidates from within or outside the membership of DE. Each candidate for election shall be a member of the OM organisation that nominates him/her. No single organisation shall have more than one selected member in the Management Board and there may not be more than two DE board members (elected or appointed) from each country.

2. DE board members shall devote themselves to the objectives and interests of the association as a whole and shall not represent the exclusive interests of of a single OM. Representation of the interests of a single OM is the role of the delegate at the General Meetings designated by the member. If a representative is elected or appointed as a member of the Management Board, he/she shall lose his/her capacity as representative and the OM concerned shall have to appoint another person as its representative at the General Meeting.

3. Ninety days before the General Meeting, the Secretary of DE shall invite the OMs by letter, fax or e-mail to submit the nominations for the election of the members of the Management Board to the Secretary. Nominations must be received by the Secretary at the latest sixty days before the General Meeting. A brief biography of the candidate shall be sent with each nomination. Thirty days before the General Meeting, the Secretary shall send a copy of all valid nominations to all members. The Board shall decide on the validity of the nominations, abiding strictly by the articles of association and any Internal Regulations.

4. The members of the Management Board shall be elected for a period of three years and shall be eligible for re-election twice. After a maximum of nine successive years' service on the Management Board, a board member may not be presented for re-election or appointment as a voting member of the Management Board until at least on calendar year has elapsed.

5. All deeds drawn up in accordance with the law and concerning the election, the revocation and the termination of the functions of the board members or of the persons who have the right to represent DE shall be sent to the Federal Public Service for Justice to be included in the dossier and shall be published, at the expense of the association, in the Annexes to the Belgisch Staatsblad/Moniteur belge (Belgian official journal).

6. Should a board member not complete his/her mandate, the Management Board may appoint a temporary replacement to complete the mandate. This appointment must be ratified by a two-thirds majority of the OMs present or represented by proxy at the next General Meeting. This new board member shall finish the mandate of the board member he/she replaces. In such a case, this replacement can be nominated again, at the appropriate time, in accordance with these articles of association, for re-election/reappointment for a maximum of two further terms, each of three years, irrespective of whether or not his/her predecessor has served more than one term.

7. If no replacement is put forward by the Management Board within 90 days for a member of the Management Board who has announced that he/she is planning to step down, then if appropriate this position shall be vacant and open for nominations for election/appointment at the next General Meeting.

8. A board member who resigns shall be obliged, after submitting his/her resignation, to fulfil his/her assignment until a replacement can reasonably be provided.

9. Every board member may be dismissed by the General Meeting at any time and with immediate effect by a majority of two-thirds of the votes of the OMs present or represented by proxy at the General Meeting.

10. The Management Board shall elect from among its members a Chairperson, Vice-Chairperson, Secretary and Treasurer. If the Chairperson is absent from a meeting, his/her tasks shall be taken over by the Vice-Chairperson or, in his/her absence, by another member of the Management Board present.

11. The Management Board may co-opt up to three people to ensure that it has skills that are otherwise unavailable and can determine the mandate and any other conditions. They shall not have voting rights, but shall act in a purely advisory capacity. Their appointment may be declared null and void by the General Meeting in accordance with the same procedure as that described in Article V.9.

12. The Management Board shall meet when necessary, but at least twice per year, at the request of at least two members of the Management Board or of the Chairperson. The meetings shall be convened by ordinary letter, fax or e-mail.

13. If the convening notice so specifies, the board member can take part in Management Board meetings from a distance. In that case, and electronic means of communication must be used that enables members to take note directly, simultaneously and uninterruptedly of the discussions during the Management Board meeting. It must also enable the board members to exercise their right to vote. A board member who takes part in the Management Board meeting from a distance in this way shall be equated to a board member who is actually physically present at the Management Board meeting.

14. Decisions of the Management Board may be taken by unanimous written consent of all the board members.

15. If a board member has an interest under property law, whether directly or indirect, that is contrary to the interest of the IVZW, he/she must inform the other board members of this before the Management Board takes a decision. A board member with a conflict of interest may not take part in the deliberations of the Board on these decisions or transactions or in the related vote. When a majority of the board members present or represented have a conflict of interests, the decision or the transaction shall be put before the General Meeting; if the General Meeting approves the decision or the transaction, the Management Board may decide to implement it. This provision shall not apply when the decisions of the Management Board concern customary transactions that are carried out under the terms and conditions and with the sureties that usually apply on the market for this type of transaction.

16. The Management Board may only validly deliberate and vote if at least half of its voting members are present or represented. Each board member with the right to vote can give a proxy in writing (post, fax or e-mail) to a fellow member of the Management Board with the right to vote, to vote on his/her behalf. No member of the Board of Directors may have more than one proxy.

17. Decisions of the Management Board shall be taken by an ordinary majority of the members present or represented by proxy. In the event of a tied vote, the Chairperson of the meeting shall have the casting vote.

18. 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 recorded in a register. All members may consult the minutes and decisions of the General Meeting at the registered office of the IVZW, as stipulated in Article 3:103 of the Companies and Associations Code.

19. The Management Board shall have all authority and power to decide and to implement the decisions of the Management Board in the light of the objectives of these articles of association. The Board shall be competent to deal with any problems whatsoever on behalf of DE, in the broadest sense of the term. Everything not expressly reserved for the General Meeting by law or by these articles of association falls under the competence of the Management Board. The Management Board shall carry out all activities of DE or have them carried out and shall ensure that they are carried out and shall ensure that the decisions of the General Meeting are implemented.

20. Board members shall in general act as volunteers and shall be remunerated for the reasonable costs incurred when carrying out their tasks, subject to proof of these costs. OM members of the Management Board shall otherwise not be remunerated by DE. However, in specific cases the Management Board may agree that one of its members can act as a paid advisor on a DE project, provided that the remuneration is agreed with a person, organisation or other sponsor funding the project. Funds intended specifically for the project in question must be used to pay such remuneration.

21. All documents that commit the association legally or financially shall be signed by the Chairperson and another board member, without the need for him/her to justify his/her authority in this respect.

22. The Management Board also has the authority to draw up internal regulations. The Management Board has the authority to modify this date in the articles of association.

23. Any legal action as plaintiff or defendant shall be taken by the Management Board represented by its Chairperson or by a board member designated for this purpose by the Chairperson.

24. Members of the Management Board shall be subject to strict confidentiality in respect of their DE activities. When the deliberations of the Management Board or the documents to be examined are declared to be confidential, an infringement of this duty of confidentiality shall grant the rest of the Management Board the right to suspend the defaulting board member from management activities by an ordinary majority of votes until the next General Meeting, at which the OMs may vote on the issue.

#### **Article VI – Budget and accounts**

1. The financial year commences on 1 January and ends on 31 December.

2. Every year, and at the latest within six months of the end of the financial year, the Management Board shall submit the financial statements for the previous financial year, together with the budget for the financial year following the financial year to which these financial statements relate, to the General Meeting for approval.

#### **Article VII – General provision**

1. The association shall fall under the provisions of the Companies and Associations Code for everything that is not expressly determined in these articles for association.

2. The provisions of the Companies and Associations Code that may not lawfully be deviated from shall be deemed to have been incorporated into this deed and any clauses that are inconsistent with the imperative of the Companies and Associations Code shall be deemed to be unwritten.

3. All documents shall be written in English. However, the official language of the association is Dutch. In the event of a conflict between the English and the Dutch version of a document, the Dutch version shall take precedence.

4. For the application of these articles of association, every member, board member, auditor or liquidator resident abroad shall elect domicile at the registered office of the association,

where all communications, reminders and notices of default, summonses and notifications may be validly served on them if they have not elected another address in Belgium for all relations with the association.

5. Should any disputes arise concerning the affairs of the association and the implementation of these articles of association between the association, its members, board members, auditors and liquidators, the courts or the legal district in which the registered office is established shall have exclusive jurisdiction unless the association expressly waives this.”

Statutes as revised 2 June 2023.

**Contact**

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