

Bylaws of 22q11 Europe (the “Association”)

European Network of 22q11 Deletion Syndrom Support Groups

Sec. 1: Name, Registered Office, and Scope of Activities

- (1) The name of the Association shall be **22q11 Europe**.
- (2) The Association shall have its registered office in Brussels, Belgium.
- (3) The Association shall carry out its activities internationally.

Sec. 2: Purpose

The Association is not for profit and pursues exclusively and directly the purpose of promoting the wellbeing of people living with 22q11 Deletion Syndrome (“**22q11 DS**”).

Sec. 3: Means to Achieve the Purpose of the Association

- (1) The purpose of the Association shall be achieved through the immaterial and material means listed under paras. 2 and 3.
- (2) The immaterial means shall be
 - a) promoting and stimulating collaboration and exchange between people with 22q11 DS and organizations which support people with 22q11 DS;
 - b) research, education, applied works, and advocacy regarding the causes, consequences, and outcomes of 22q11 DS;
 - c) stimulating and promoting clinical, scientific, pharmacological, educational, and social research and applications in the field of 22q11 DS;
 - d) encouraging people with 22q11 DS to contribute to these research and applied activities;
 - e) coordinating scientific expertise, clinical know-how, and educational and social impacts internationally;
 - g) collaborating with national governments and national and international organizations which defend the interests and needs of people with 22q11 DS;
 - h) raising awareness for the wishes of people with 22q11 DS, promoting a positive attitude of the broad public towards people with 22q11 DS and strengthening the self-confidence of all those directly or indirectly affected by 22q11 DS;
 - i) lectures and meetings;
 - j) conferences and symposia (e.g., scientific conferences, meetings of patient groups, presentations, receptions, etc.);

k) meetings of people with 22q11 DS with family members, friends, donors, sponsors, and supporters;

l) discussion and training events;

m) publications (academic journals, books, newsletters, informational brochures and folders, first person narratives, etc.), information in electronic media (e.g., Internet, e-mail-newsletter, CD-ROMs, DVDs, podcasts, etc.);

(3) The required material means shall be raised through:

a) registration and / or membership fees;

b) subsidies;

c) donations;

d) fundraising campaigns and collections;

e) bequests;

f) sponsoring;

g) co-operation with companies and organizations;

h) national and international funding and funded projects;

i) licenses and patents;

j) proceeds from events or the Association's activities and other benefits received.

Sec. 4: Types of Membership

(1) The Association is the European network of national or regional 22q11 DS support groups. The members of the Association are either Full Members, Associate Members, or Honorary Members (**together "Members"**).

(2) Full Members shall be European regional or national 22q11 DS support groups which are legally constituted as a not-for-profit organization under the legislation of their own countries and which fully participate in the activities of the Association.

(3) Full membership is not open to individuals. However, the Board may grant Associate or Honorary membership to persons or organizations, on a case by case basis.

(4) Associate Members can be any association or persons, from any country, having a link with the 22q11 DS or wishing to support the purpose of the Association or for their contribution to the promotion or understanding of 22q11 DS.

(5) Honorary Members shall be persons or organizations that are awarded honorary membership for their special achievements for the Association or for their contribution to the promotion or understanding of 22q11 DS.

Sec. 5: Becoming a Member

(1) All requests to become a Full Member or Associate Member of the Association will be addressed in a written form to the Board.

(2) It shall be at the discretion of the Board to decide upon granting Full membership or Associate membership status to persons or organizations that want to support the Association.

(3) Membership may be denied without reason. The General Assembly shall be entitled to appeal in favour, or against, the granting of Full or Associate membership.

(4) Honorary membership shall be awarded by the General Assembly. The Board or any Full Member may propose a person or organization for Honorary membership.

Sec. 6: Termination of Membership

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

(2) Members may only resign with at least three months' written notice to the Board.

(3) The Board may expel a Member if, in spite of having received two written reminders and having been set a reasonable grace period, it has defaulted in paying the membership fees for more than six months. This shall not affect the Member's obligation to pay the due membership fees.

(4) The Board may also order the expulsion of a Member from the Association for gross violation of other membership duties or for disreputable behaviour.

(5) Upon an application by the Board, the General Assembly may resolve to withdraw Honorary membership status for the reasons mentioned under para. 4.

Sec. 7: Rights and Obligations of Members

(1) All Members are entitled to attend all events of the Association and to use all facilities of the Association. The voting right at the General Assembly and the right to elect ~~and stand for election~~ shall be reserved for Full Members.

(2) Each Member is entitled to demand a copy of these Bylaws from the Board.

(3) At least two -tenth of Full Members may request the Board to convene an extraordinary General Assembly.

(4) In the course of each General Assembly the Full Members shall be informed by the Board about the Association's activities and the management of the Association's finances. If at least two-tenth of the Full Members requests additional information and gives reasons for their request, the Board shall provide such information to the Full Members within four weeks.

(5) The Members are obliged to make their best efforts in order to promote the interests of the Association and to refrain from any actions which might affect the reputation and purpose of the Association. They shall observe the Bylaws of the Association and the resolutions adopted by the Association's bodies. The Full and Associate members are obliged to pay, in a timely manner, the registration fee, and the membership fees in the amounts agreed upon by the General Assembly.

Sec. 8: Bodies of the Association

The bodies of the Association shall be the General Assembly (secs. 9 and 10), the Board (secs. 11 to 13), the Auditors (sec. 14) and the Arbitration Board (sec. 15).

Sec. 9: General Assembly

- (1) The General Assembly is the meeting of Members. An ordinary meeting of the General Assembly shall be held, once a year – either in person or virtually.
- (2) Extraordinary meetings of the General Assembly shall be held within four weeks upon:
 - a) a resolution by the Board or by the ordinary General Assembly;
 - b) the written application by at least two tenths of the Full Members;
 - c) the request of the Auditors / an Auditor;
 - d) the resolution of a court-appointed trustee (sec. 11 para. 3 last sentence of these Bylaws).
- (3) All Members shall be invited to participate in both the ordinary and the extraordinary meetings of the General Assembly, notified at least two weeks in advance in writing, or by e-mail (to the e-mail address notified to the Association by the Member). The invitation to the General Assembly shall state the agenda. The meetings shall be convened by the Board (para. 1 and para. 2 lit. a – b), by the Auditors/an Auditor (para. 2 lit. c), or by an appointed trustee (para. 2 lit. d).
- (4) Items will be considered for addition to the agenda if notified to the Board in writing, or by e-mail, at least three working days prior to the date of the General Assembly.
- (5) Valid resolutions – except resolutions on motions to convene an extraordinary meeting of the General Assembly – may only be adopted on items on the agenda.
- (6) Each Full Member shall have one vote. A Full Member unable to attend and vote in person may appoint a proxy to vote on its behalf.
- (7) The General Assembly has a quorum regardless of the number of Full Members present.
- (8) Normally, elections held and resolutions passed by the General Assembly shall require a single majority of the valid votes cast. Resolutions to amend the Bylaws of the Association or dissolve the Association shall require a qualified majority of two-thirds of the valid votes cast.
- (9) The General Assembly shall be chaired by the President, or in his/her absence, by the Vice President. If the Vice President is also prevented from attending, the most senior member of the Board who is present shall chair the meeting.
- (10) Associate and Honorary Members shall be invited to attend a General Assembly but shall not be entitled to vote.

Sec. 10: Tasks of the General Assembly

The following tasks shall be the reserve of the General Assembly:

- a) resolutions on the budget;
- b) accepting and adopting the statement of accounts;
- c) electing and expelling members of the Board;
- d) official approval of the actions of the members of the Board;
- f) determining the amount of the registration fee and the membership fees for Full- and Associate Members;

- g) awarding and withdrawing Honorary memberships;
- h) adopting resolutions on amendments of the Bylaws and the voluntary dissolution of the Association;
- i) deliberating upon resolutions on other issues pertaining to the agenda.

Sec. 11: Board

(1) The Board shall be composed of the President and Vice President, the Secretary, the Treasurer, and other persons nominated by the Full Members or proposed by the President and elected by the General Assembly.

(2) Whilst it is hoped that the Board will be representative of all of the regions where **22q11 Europe** is represented, there shall be no requirement for this to be the case.

(3) The Board shall be elected by the General Assembly. Upon resignation of a Board member, the Board shall be entitled to co-opt a replacement Board member, who shall be approved at the following meeting of the General Assembly. If the Board would cease to exist for good, or for an unforeseeable period of time without adding new members by means of co-opting, each Auditor shall be obliged to immediately convene an extraordinary meeting of the General Assembly for the purpose of electing a new Board. Should the Auditors also be incapable of action, each Full Member who becomes aware of the emergency situation shall without delay file an application with the competent authority to have a trustee appointed, who shall convene an extraordinary meeting of the General Assembly without delay.

(4) The term of office of the Board shall be four years; members may be re-elected. Each function on the Board shall be exercised by the respective members in person.

(5) The Board is convened, in writing or by e-mail, by the President, in his/her absence by the Vice President. If the Vice President is also prevented from attending for an unforeseeable period of time, any other member of the Board shall be entitled to convene a meeting of the Board.

(6) The Board has a quorum if all members have been invited and at least half of them are present.

(7) The Board shall pass its resolutions by simple majority of the votes cast; in case of a tie the President shall have the casting vote.

(8) The meetings of the Board shall be chaired by the President, in his/her absence by the Vice President. If the Vice President is also prevented from attending, the most senior member of the Board or a member appointed by the majority of all other members of the Board shall chair the meeting of the Board.

(9) Apart from death and expiry of the term of office (para. 4), the office of a member of the Board shall also be terminated by means of removal from office (para. 10) and resignation (para. 11).

(10) The General Assembly may at any time remove the entire Board or individual members of the Board. The removal shall become effective upon appointment of a new Board or a new member of the Board.

(11) The members of the Board may at any time declare their resignation in writing. The resignation shall be addressed to the Board or, in case the entire Board is resigning, to the General Assembly.

After a resignation, the resigned members shall be replaced as soon as possible, either by means of co-opting a successor or in the course of the following election.

Sec. 12: Tasks of the Board

The Board shall be responsible for managing the Association. It shall be responsible for all tasks which are not allocated to another body of the Association by virtue of these Bylaws. The Board shall meet at least once a year. Its responsibilities shall include, without limitation, the following matters:

- (1) establishing an accounting system which meets the requirement of the Association, the minimum requirements being the current recording of receipts and expenditures and keeping an inventory of assets;
- (2) preparing the budget, the statement of accounts, and the financial statements;
- (3) preparing and convening the General Assembly in the cases described under sec. 9 para. 1 and para. 2 lit. a – b of these Bylaws;
- (4) informing the Members of the Association about the activities of the Association, the administration of its assets, and the audited financial statements;
- (5) managing the Association's assets;
- (6) accepting and expelling Full, Associate, and Honorary Members of the Association;
- (7) hiring and dismissing employees of the Association.

The Board shall maintain a bank account in the name of “**22q11 Europe**” for managing all financial transactions. The account is only to be used for the Association's business. In the case of payments exceeding EUR 10,000.00, two signatories shall be required, of whom one shall be the Treasurer or the President.

The Board can appoint a scientific committee or other working groups, or persons, to help the Association achieve its objectives.

Sec. 13: Special Duties of Individual Members of the Board

- (1) The President shall manage the current transactions of the Association. The Secretary shall assist the President in managing the affairs of the Association.
- (2) The President shall represent the Association to the outside world. Written documents of the Association shall be signed by the President and by the Secretary in order to be effective, if financial matters are concerned (dispositions regarding assets) the signature of the President and of the Treasurer shall be required. Legal transactions between members of the Board and the Association shall be subject to the approval of another member of the Board.
- (3) Power-of-attorney to represent the Association to the outside world and/or to sign on behalf of the Association may be granted exclusively by the members of the Board listed under para. 2.
- (4) In the case of imminent danger, the President is entitled to independently give instructions, even in matters falling within the scope of responsibility of the General Assembly or of the Board, in his/her own responsibility; internally these instructions shall, however, require the subsequent approval of the competent body of the Association.

- (5) The President shall chair the meetings of the General Assembly and of the Board.
- (6) The Secretary shall be responsible for the minutes of the meetings of the General Assembly and the Board.
- (7) The Treasurer shall be responsible for the proper management of the finances of the Association.
- (8) If they are prevented from exercising their duties, the President, the Secretary, or the Treasurer shall be represented by their deputies.

Sec. 14: Auditors

- (1) The General Assembly shall elect two Auditors for a period of three years. The auditors may be re-elected. The Auditors must not be members of any body – except for the General Assembly – whose activities are the subject matter of the audit.
- (2) The Auditors shall be responsible for auditing the current transactions and the management of finances of the Association with a view to proper accounting. The Board shall submit the required documents to the Auditors and provide them with the required information. The Auditors shall report to the Board on the results of the audit.
- (3) Legal transactions between the Auditors and the Association shall be subject to the approval of the General Assembly. The provisions of sec. 11 paras. 9 to 11 shall apply analogously to the Auditors.

Sec. 15: Arbitration Board

- (1) The Association's internal Arbitration Board shall be responsible for settling all disputes arising in connection with the Association.
- (2) The Arbitration Board shall be composed of three Full Members of the Association. To set up the Arbitration Board, one party in dispute shall nominate in writing one Member to the Arbitration Board as an arbitrator. At the request of the Board, which shall be made within seven days, the other party shall then nominate another Member of the Arbitration Board within 14 days. After having informed the Board accordingly within seven days, the nominated arbitrators shall within 14 days elect a third Full Member as the Chairperson of the Arbitration Board. In case of a tie, the Chairperson shall be chosen from among the nominated Members by lot. The members of the Arbitration Board must not be members of any body – except for the General Assembly – whose activities form the subject matter of the dispute.
- (3) The Arbitration Board shall come to its decision after having heard both parties in the presence of all its members by simple majority of the votes. It shall decide to the best of its knowledge and belief. Internally, its decisions shall be final for the Association.

Sec. 16: Voluntary Dissolution of the Association

- (1) The voluntary dissolution of the Association may only be resolved upon in a meeting of the General Assembly convened for such purpose and shall require a two-thirds majority of the valid votes cast.
- (2) The same meeting of the General Assembly shall also decide on the liquidation of the Association's assets, provided that such assets exist. In particular, it shall appoint a liquidator and

pass a resolution on to whom the liquidator shall transfer the assets remaining after deduction of all liabilities.

(3) The same meeting of the General Assembly may decide that the capital contributions paid in and the fair market values of the contributions in kind, which shall be determined as of the date of making the contribution, shall be paid back to the members.

(4) In the case of voluntary dissolution, dissolution of the Association by order of the competent public authority, or loss of the Association's tax-privileged purpose any remaining assets of the Association must inure to the benefit of not-for-profit entities.

(5) The last Board of the Association shall notify the competent authorities about the dissolution of the Association in writing within four weeks after adoption of the resolution.