

Memorandum of Association

**concluded per the founder's meeting held on the 03.11.2007 in
Trieste / Italy**

§ 1 Name and registered domicile

- (1) The Association is hereby registered as the "European Chromosome 11 Network".
- (2) Subsequent to entry in the register of associations, the affix "Eingetragener Verein" i.e. "Registered Association" ("e.V." in the short form) will be attached to the association name.
- (3) The Association domicile is hereby specified as being in Wiernsheim (Germany) and is thus subject to registration in the Maulbronn (Germany) District Court register of associations.
- (4) The Association's fiscal year is hereby set as being in accordance with the calendar year.

§ 2 Association objectives and duties

- (1) The Association is constituted by a group of individuals with disabilities subsequent to an anomaly on the long arm of chromosome 11, their parents, some relatives, experts and professionals, sponsors and friends.
- (2) The Association pursues exclusively and directly non-profit-making goals compliant to and within the meanings and provisions per the "tax-deductible and tax-privileged objectives" section in the German Fiscal Code. The association engages in altruistic, non-profit activities. It does therefore not primarily aim at its own economic interests, concerns and/or objectives. Association assets and/or funds may only be implemented in pursuance of the objectives as set forth per the articles of association herein. The Association Members are not granted any profits or bonuses and neither can they, in their capacity as members, be granted any benefits whatsoever arising per the Association's assets and/or funds. In no way can any person be favoured or benefit by way of disbursements that are not compliant to the Association's objectives as set forth per the articles of association herein, and/or by way of disproportionately high payments and/or salaries.
- (3) The objectives and purpose of the Association is to support individuals with disabilities subsequent to an anomaly on the long arm of chromosome 11, their parents and/or relatives.
- (4) The Association performs and achieves its objectives particularly by way of:
 - a) non-bureaucratic and direct assistance, through
 - talks and discussions
 - the facilitation of contacts amongst and/or with other parents and/or relatives also involved
 - procurement of contacts to other information centres and helpdesks, organisations and groups
 - b) the organisation of international conferences for the exchange of experiences and for information updates provided by doctors, researchers and other professionals, with the issue of a conference report

- c) Information newsletters sent to all members
 - d) www.chromosome11.eu – the network's homepage providing contact data for all parties involved
 - e) advancement, promotion and sponsorship of research on the Chromosome 11 Syndromes and related consequences
 - f) public relations activities
- (5) The Association is hereby granted the right to participate in any national or international Associations and/or Organisations and/or Societies sharing the same objectives and purposes, as well as the same non-profit-making goals.

§ 3 Association assets and funds

- (1) The assets and funds required for the fulfilment and performance of Association duties are raised by way of:
- a) membership fees
 - b) donations in money and in kind
 - c) benefits
 - d) additional or special benefits
 - e) income from association assets
- (2) Determinations on assets and fund disbursements:
- a) up to an amount of € 500,00: to be undertaken by the treasurer plus one board member.
Information thereof to be relayed to the Chairman.
 - b) for amounts higher than € 500,00: to be undertaken by the treasurer plus board majority (put to vote)

§ 4 Membership

- (1) Association members may be any natural or any corporate and/or legal entity and/or body.
- (2) Membership is acquired via the deposit of the relative declaration of accession.
- (3) Members are required to pay in an annual subscription fee, as determined by the assembly of delegates.
- (4) Memberships may be ended due to withdrawal, debarment, or, in the event of corporate and/or legal entities and/or bodies, subsequent to termination or wind-up.
- (5) Voluntary withdrawal is acknowledged by way of a written declaration issued accordingly by a board member. Withdrawal is subject to compliance with a 3-month's notice period, to be prior to the closing term of the currently valid membership year.
- (6) The board may resolve to debar a member from the association, with immediate effect, in the event that:
- a) the member may be or act contrarily and/or adversely to either any one of the Association's objectives and interests, or to any board resolutions;
 - b) the member may, afore the general public, cause damage to the Association's standing or reputation

- c) in spite of reminders, the member is overdue with the payment of membership fees for longer than 3 months.
- (7) The member is hereby granted the right to apply for appeal against debarment, via a general meeting of members. Said application for appeal must be notified to the board in writing within a validity term of at least one month subsequent to issue of the resolution on debarment. Provided that the application of appeal has been notified in a timely manner, the board is required to submit it to the next general meeting of members for decision thereon. Opposition to debarment will wield a suspensive effect on the resolution. In the event of disencumbrance or release by the general meeting of members, the member is hereby granted no right to the arrangement of any legal judgment whatsoever, as to the effectiveness of the resolution on debarment.
- (8) In all possible cases resulting in the termination of membership, the obligation to membership contribution will not expire until the end of the calendar year that is currently underway. Withdrawing members cannot claim or have any right to any Association asset whatsoever, even in the event of possible conflicts and/or disputes.

§ 5 Managing Board

- (1) The managing board is composed of the chairperson, a proxy person plus at least three other members, for collective conduction of association operations.
- (2) In compliance with article 26 of the German Civil Code and to all extrajudicial extents, the Association is duly represented by the Chairman of the board and for internal issues, in case of inability to attend, by the proxy member plus one further board member. The reasons for said inability need not be accounted for.
- (3) The election of the members of the board is performed by a general members' meeting, for a maximum five-year term. Re-election is hereby approved. The current managing board is required to remain in office, until appropriate re-election of a new management board, even if the set term of office has in the meantime expired. The members of the board are required to be Association members and direct family members to Chromosome 11 patients.
An association member can be elected as a member of the board even if unable to attend the general members' meeting, by way of timely, written notification expressing willingness to be elected as a board member.
- (4) The managing board elects the chairman of the board and relative proxy from amongst its members.
- (5) Regardless of the number of participants, the managing board is regularly constituted and competent to resolve at all times. Board resolutions are passed by simple majority, within board meetings or by written consents in lieu of meetings.
All resolutions passed by the board are to be documented in writing and undersigned for approval by at least two of the board members.
- (6) Board meetings will be called and held as needed, although they are to be held at least once a year. Meetings are called by written invitation sent either

by mail or by e-mail, either directly by the Chairman or by any other board member, at least 8 weeks prior to the set date.

- (7) In the event of withdrawal by a board member prior to expiry of his/her term of office , the managing board is hereby granted the right to appoint a new board member to cover the remaining time of the withdrawing member's term of office.
- (8) The managing board is hereby granted the right, whenever operative support and/or professional advice is required, to appoint either advisory boards and/or committees.

§ 6 General members' meetings

- (1) General members' meetings will be held every 2-3 years, on occasion of the international conferences held by the Association. Attendance is subject to invitation by a board member, sent either by e-mail or in writing, together with or stated in the conference invitation. Members will also receive the general members' meeting agenda, attached to the invitation.
- (2) The general members' meeting will be conducted by a member of the board. If none of the members of the board are present, a conductor will be elected amongst one of the available members.
- (3) Each general members' meeting called per the articles of association herein is deemed as being regularly constituted and competent to passing resolutions. Resolutions will be passed by simple voting majority.
- (4) The duties of the general members' meeting are:
 - a) to elect the members of the managing board;
 - b) to discharge the managing board;
 - c) to determine the amount of the membership fees;
 - d) to make any changes to the articles of the memorandum of association
This requires 2/3 of overall member votes.
Any changes to the articles of the memorandum of association, required per the formal provisions of supervisory, judicial or financial administration authorities, can be passed directly by the managing board members as required. Information thereon can then be provided on occasion of the subsequent general members' meeting.
- (5) Each member or each family membership is granted one vote. For the performance of individual voting rights, it is possible to authorise another family member in writing to vote-on-behalf. Other assignments of voting rights are not permissible.

§ 7 Written minutes/recording of resolutions

- (1) All resolutions passed by the general members' meetings are recorded into minutes and undersigned by the current meeting conductor and/or by the individual/the secretary put in charge of writing and/or recording the minutes.
- (2) If the Secretary is absent, at the beginning of the meeting is necessary to appoint another member in charge of writing and/or recording the minutes.
- (3) A copy of said minutes will be sent to each member and will also be published on the Association's website.

§ 8 Dissolution/Termination of Association

(1) Dissolution/termination of Association requires a majority vote of $\frac{3}{4}$ of the overall available votes by the general member's meeting.

In the event of dissolution/termination of the Association any Association assets or funds remaining subsequent to deduction of each and every accounts payable, are to be transferred to:

[Lebenshilfe Pforzheim e.V.](#)

Gablonzer Str. 17

De - 75181 Pforzheim

www.lebenshilfe-pforzheim.de

The first form of the Memorandum of Association herein is duly constituted and executed per the founder's meeting, held on the 03.11.2007.

Trieste, the 03.11.2007

European Chromosome 11 Network

The Memorandum of Association herein is duly registered today,
in the Maulbronn District Court Register of Associations, under registration number VR 650.

75433 Maulbronn (Germany), the 08.08.2008
Registration office

(illegible signature added)

Nisi, judicial employee

(illegible stamp added)