

Articles of Association of the NCL Group Deutschland e. V.

Self-help organization for persons suffering from neuronal-ceroid-lipofuscinosis

(Resolved at the Extraordinary General Meeting on 22.11.1989 in 4770 Soest / Westphalia)

Last update: Annual General Meeting September 2010

I. Name, seat and purpose

§ 1 Name and registered office

- (1) The association is **named NCL-Gruppe Deutschland e.V.** (abbreviation: NCL-Gruppe).
- (2) The NCL Group is based in Hamburg. She is registered under the number VR 12492 in the association register at the District Court of Hamburg.
- (3) Place of performance and jurisdiction shall be Hamburg.
- (4) The fiscal year is the calendar year.

§ 2 Purpose

(1) The Association has the following objectives:

- (1) Regular personal exchange in groups to better deal with the disease and its consequences.
- (2) Information, counseling, practical assistance to persons affected by NCL and their relatives as well as orphaned relatives.
- (3) Financial support for needy individuals involved in attending NCL relevant events.
- (4) Call for facilities such as counseling centers and / or facilities for the accommodation and care of persons with NCL.
- (5) To inform the public about NCL and its effects.
- (6) impact on state and private institutions, social groups and individuals with the aim of effectively and comprehensively supporting the interests of NCL sufferers and NCL research.
- (7) to support NCL research in order to make this disease accessible to therapy.

(2) The stated aims of the association are to be achieved in particular by

- (1) regular exchange of experience between the relatives of NCL patients.
- (2) Participation in the development of technical tools.

(3) Publication of information and documentation material about NCL.

(4) advising the members on matters relating to education, training and vocational and social rehabilitation.

(5) maintaining contacts and cooperation with national and international organizations, institutions and persons from the fields of medicine and science, disabled care, public life and businesses.

(6) stimulate and support NCL research as well as participation in research projects.

(7) Regular regional and interregional meetings and events.

(3) The association is political, ideological and religiously neutral.

§ 3 Non-profit-making purposes

(1) The association pursues exclusively and directly non-profit purposes within the meaning of the section "tax-privileged purposes" of the tax regulations in its valid version.

(2) The association is selflessly active; It does not pursue primarily economic purposes. Means of the association may only be used for the purposes of its intended use.

(3) The association is financed through contributions, grants and subsidies. They are used exclusively to fulfill the charitable purposes mentioned in paragraph 2.

(4) Members may not receive any profit shares or, in their capacity as members, any other contributions from the association's resources. The members of the association are active on an honorary basis, unless otherwise stipulated or permitted by the Articles of Incorporation. However, the Management Board may, if necessary, decide on remuneration in accordance with a compensation expense within the meaning of § 3 No. 26a EStG. The association may employ full-time and non-executive staff to carry out the tasks.

(5) Members shall not receive any grants from the association's resources. Even in the case of dissolution of the association or upon termination of the membership the members are not entitled to the association assets.

(6) No person may be favored by expenses which are foreign to the purpose of the association or by disproportionately high remuneration.

II. Membership

§ 4 Members

(1) The Association has full, sponsoring, correspondent and honorary members.

(2) Full members may be members of the family, including those who have already died, as well as legal

guardians of persons who are ill with NCL, if they or the sick persons are domiciled or habitually resident in the Federal Republic of Germany. Persons within the meaning of the Articles of Association are the persons named in § 383 Section 1 No. 3 of the Code of Civil Procedure, as well as nursing parents and nursed children.

(3) In individual cases, persons may also be admitted as members who have their domicile or habitual residence in another country if they can not be connected to a national organization or if they are Germans within the meaning of the German Basic Law.

(4) Natural and legal persons as well as associations of persons who are ready to promote the NCL Group in a non-material or financial way can be accepted as a sponsoring member.

(5) Corresponding members may include disabled organisations and caregivers who have looked after NCL patients at events of the NCL Group.

(6) Honorary members may be appointed to persons who have acquired special merits for the NCL Group.

§ 5 Start and End of the Membership

(1) Admission as a regular, sponsoring or corresponding member can only take place on the basis of a written application. In the case of persons with a limited working capacity, in particular with minors, the application must be signed by the legal representative, who is thus obliged to pay the membership fees for the restricted person. The Executive Board decides on the admission application. In the event of a refusal, the applicant may appeal within one month to the ordinary General Meeting; the appeal shall be addressed in writing to the Management Board.

(2) Membership of ordinary and sponsoring members shall be terminated by death in the case of a legal person or by the removal of its legal capacity or by dissolution in the case of an association of persons; by withdrawal, by deletion from the membership list or by exclusion.

(3) The withdrawal of membership may take place only at the end of a financial year; It must be declared in writing to the Management Board three months before the end of the financial year. In the case of persons with a limited legal capacity, in particular minors, the declaration of dismissal must be signed by the legal representative.

(4) A member may be removed from the list of members by resolution of the Board of Directors if, despite a twofold written reminder, he is in arrears with the payment of membership fees. The deletion may be decided only after two months have elapsed after sending the second admonition and the deletion has been threatened in this reminder. The decision on deletion shall be communicated to the member.

(5) Members may be excluded by the Executive Board if they have breached the interests of the NCL Group or have seriously violated the duties which they have committed towards the NCL Group. Members shall be given the opportunity to give oral or written statements before the expulsion. The Member concerned may appeal against the exclusion within one month; the appeal shall be addressed in

writing to the Management Board.

(6) The membership of corresponding members may be annulled at any time and without giving reasons by resolution of the Board of Management.

(7) Honorary members shall be appointed by the General Meeting at the suggestion of the Executive Board. In the same way the honorary membership may be removed.

§ 6 Rights and obligations of the members; Re-electability

(1) All ordinary, sponsoring and honorary members, if they have reached the age of 18, have the right to vote and vote in the General Meeting. Each member has one vote. Electable to the Executive Board are only ordinary and sponsoring members, electable to an honorary position are only members over the age of 18.

(2) All members who are entitled to vote have the right to submit proposals to the General Meeting and participate in the events of the Association.

(3) Those entrusted with an honorary office or appointed by an association body shall be entitled to compensation for the actual and proven necessary expenses.

(4) The members are obligated to promote the aims of the association to their best efforts and to pay the contribution; The contribution is to be paid as of 1 July of the financial year (calendar year); it must be paid in full by the end of the year at the latest.

A. If the membership ends in the course of the financial year, the full annual amount shall be payable. The Executive Board may, in appropriate cases, waive the fee in full or in part.

B. Corresponding members do not pay.

III. Organization

§ 7 Bodies

(1) The bodies of the NCL Group are:

- The General Meeting
- The Executive Committee
- The Coordinating Committee
- The Regional Groups

§ 8 Annual General Meeting

(1) The General Meeting shall be convened and directed by the first chairperson, in the event of his / her

being prevented by the second chairperson, in the event of the prevention of both by a board member appointed by the first chairman or by his / her second chairman. If no member of the Executive Board is present at the Annual General Meeting, the meeting shall determine the meeting chairman. The Annual General Meeting takes place once a year.

1. An Extraordinary General Meeting shall be convened if at least one fifth of all members with voting rights apply for this in writing stating the purpose and reasons or if the interest of the Association requires such a meeting.

2. At least three weeks prior to the meeting, the General Meeting shall be notified in writing with the announcement of the agenda. The invitation can also be made in the internal newsletter. The deadline begins with the day following the sending of the invitation. The invitation shall be deemed to have been received by the Member if it is addressed to the last address notified by the Member to the Association in writing.

3. When the Annual General Meeting is held, efforts should be made, as far as possible, to ensure that members' groups with special disabilities, in particular multiple disabilities, can follow the course of the meeting and exercise their rights.

(2) The following tasks shall be the responsibility of the General Assembly:

1. Election and dismissal of the Executive Board and the cash auditors

2. Determination of the annual contribution

3. Acceptance of loans above 10,000 €

4. Acceptance of the activity report and the cash report of the Managing Board and the audit report of the cash auditors

5. Discharge of the Executive Board

6. Resolution on the Articles of Association

7. Resolution on the dissolution of the NCL Group

8. Approval of all business orders for the Association

9. Establishment of the directives for the work of the regional groups

10. Completion of orders, complaints and appeals

11. Appointment of honorary members and abolition of honorary membership

12. Purchase and sale of land ownership

13. Treatment of other matters submitted by the board on account of its particular importance.

(3) A member may delegate in writing his / her authority to exercise the voting right. The authorization

must be given separately for each General Meeting. A member may not represent more than 3 foreign votes.

(4) In the case of votes, the simple majority of the valid votes cast shall be decided, unless otherwise specified; abstentions are not included in determining the majority. The voting shall take place in open form by means of hand signals, insofar as the Articles of Incorporation do not specify otherwise, or the General Meeting decides to vote in writing.

(5) Amendments to the Articles of Association and the dissolution of the Association shall only be validly passed at the Annual General Meeting if such items have been expressly submitted to members, together with the invitation or within the invitation period, as the agenda item. Amendments to the Articles of Association that are required by supervisory, judicial or financial authorities for formal reasons can be made by the Management Board on its own initiative. These changes must be communicated to all members of the Association in writing as soon as possible. In addition, the General Meeting may only decide on motions which are not mentioned in the invitation as agenda items, as long as they are urgent motions. Independently of this, the Annual General Meeting may at any time decide that the Management Board should examine the proposals submitted and submit them for discussion at the following meeting of the Annual General Meeting.

(6) The election of the Management Board and the cash auditors shall take place in an open vote unless the General Meeting decides to make a written or secret vote. Candidates are elected in separate polls in the following order:

A. Board of Directors

1. 1. Chairperson
2. 2. Chairperson
3. Board member at the same time 1. Cashier
4. Board member at the same time 2. Cashier
5. Board member at the same time 1. Secretary
6. Member of the Executive Board at the same time 2. Secretary
7. Member of the Executive Board at the same time 1. Counsellor
8. Member of the Executive Board at the same time 2. Counsellor

B. Cash auditors

1. 1. Cash auditor, not a member of the Management Board
2. 2. Cash auditor, not a member of the Management Board

The chairman of the election of the first chairman shall be elected by the electoral board (one electoral

director and several assessors); All other elections are chaired by the first chairman. Elected is who receives the most valid votes. In the event of a tie, a second ballot is required. In the event of a double tie, a lot to decide is to be drawn by the meeting chairman.

(7) A memorandum shall be drawn up for each General Assembly, to be signed by the meeting chairman and the secretary; It must reflect the resolutions of the General Assembly and the results of elections. The members of the NCL Group are to be informed of the results of the Annual General Meeting.

§ 9 Management Board

(1) The Management Board shall consist of the 1st and 2nd Chairmen, the 1st and 2nd Treasurer and the 1st and 2nd Secretary. The Management Board is appointed and recalled by the General Meeting; The dismissal is permissible only for an important reason, at the same time new elections are to be made.

(2) The 1st and 2nd chairpersons are members of the executive committee as defined by the Civil Code. The NCL Group is represented in court and out of court by the first chairperson or by the second chairperson. The 1st cashier has power of representation for all transactions which usually involve the cash management and management of the NCL Group's resources, including revenue and expenditure.

(3) The first and second chairpersons must be regular members of the association. Of the remaining members of the board, 50% must be ordinary members, the other 50% may be sponsoring members.

(4) The term of office of the Management Board is 3 years. However, the Management Board remains in office until a new Board of Directors has been elected. The Executive Board and individual members of the Management Board may be re-elected. Upon termination of the membership, the office of a member of the Management Board also ends. If a member of the Management Board leaves during the term of office, the Management Board may determine a successor for the remaining term of office of the departed.

(5) The Executive Board is responsible for all matters of the Association, insofar as they are not transferred to another body by the statutes. The Management Board is in particular responsible for management decisions; insofar as a decision is not reserved for the Annual General Meeting.

(6) The Management Board shall establish its own rules of procedure in which the distribution of tasks shall also be regulated.

(7) The Executive Board may appoint special representatives from the members of the Board of Directors for specific business areas and form committees for the respective term of office. Special representatives shall be appointed, in particular, for research, press, social affairs, organizational questions, donation activities, technical assistance (aids) and the branch office. Details are provided in the rules of procedure of the Management Board. The special representatives and the committees are to be announced to the members in the usual form.

(8) The members of the Executive Board and the special representatives may delegate other members of the Association with the performance of individual tasks from their business area.

(9) The first chairman shall invite to the board meetings, in the event of his / her unavailability the

second chairman. The agenda does not need to be announced. A convocation period of 2 weeks is to be observed. The Executive Board is quorate if at least the 1st or the 2nd chairperson and a further member of the Management Board are present. In all votes, the simple majority of the valid votes cast shall be decided; abstentions are not included in determining the majority. In the event of a tie, the first chairperson's vote, in the absence of which the second chairperson's decides the vote.

A. Resolutions of the Executive Board may in case of urgency also be made in writing or by telephone if the majority of the members of the Management Board declare their consent to the proceedings in writing or by telephone.

B. Written or verbal resolutions of the Board of Directors shall be recorded in writing and signed by the Secretary.

C. All resolutions of the Board of Directors must be recorded and signed by the secretary (s).

§ 10 Coordination Committee

(1) The Coordinating Committee consists of the Executive Board and the heads or speakers of the regional groups or their representatives. He has to advise the other association bodies on matters of fundamental importance to the regional groups. It makes recommendations which should be taken into account in the decisions to be taken by other association bodies.

(2) The Coordination Committee should meet at least once a year or as necessary. §9 (9) shall apply *mutatis mutandis*.

§ 11 Regional Groups

(1) The Regional Groups are working associations of the members of the NCL Group at a regional level. They are not legal bodies. They are responsible for the tasks of the NCL Group (§ 2) at the regional level. A regional group belongs to all Members of the NCL Group who have their domicile or habitual residence in the region concerned.

(2) A contact person (spokesman or regional group leader) should be present in each regional group.

(3) Further details on regional groups, in particular on their organization, tasks and administration, shall be determined by the directives to be adopted by the General Assembly.

(4) Depending on the number of ordinary members, the regional allocation may change.

§ 12 Liability

(1) The association is not liable towards its members for damages or losses caused by slight or simple negligence, which arise within the framework of the association enterprise and at club events, insofar as these risks are not covered by insurance contracts.

(2) The association is not liable towards its members for damages resulting from a behavior of the representatives of the association, if they are based on easy or simple negligence.

IV. Other provisions

§ 13 Cash check

At least two cash checkers have to be chosen, which are representing each other. The term of office of the cash auditors corresponds to the term of office of the Management Board. The cash auditors have the right at all times to check with the Board of Managing Directors the cash register as well as the bookkeeping system and all the supporting documents. An examination must be carried out at least once a year. A report shall be made on the examination. Unannounced inspections may also be carried out.

§ 14 Newsletters

The Management Board shall publish a newsletter to provide comprehensive information and advice to its members. It can transfer the editorial business to an editorial committee.

§ 15 Scientific Advisory Board

(1) The Association shall encourage the formation of a Scientific Advisory Board, which shall serve the exchange of information and experience between the Association and the sponsors of NCL research and science. Members of the Scientific Advisory Board may also be members of the Association.

(2) The associations' organs are required to support the Scientific Advisory Board and to advise on scientific and research issues. They should provide comprehensive information to the Scientific Advisory Board.

§ 16 Dissolution

(1) The change of the purpose of the association, as well as the dissolution of the association, may only be decided in a meeting convened for this purpose by a majority of at least three quarters of the valid votes cast.

(2) In the event of dissolution of the association or in case of the abolition of tax-privileged purposes, the association assets fall to the national association Hansestadt Hamburg eV of the German Paritätischer Wohlfahrtsverbandes, Wandsbeker Chaussee 8, 22089 Hamburg, which directly and exclusively has to use it for charitable or charitable purposes. The General Meeting appoints three liquidators.

§ 17 Entry into Force of the Articles of Incorporation

(1) These Articles of Association enter into force after the passing of the General Meeting by the date of entry into the Association Register. Upon entry into force, all previous statutes, if any, shall be repealed.

(2) The association bodies may already take resolutions on the basis of the adopted statutes, which become effective when they are registered in the association register.