



Batten Disease Family Association Registered Charity No: 1084908

CONSTITUTION

Adopted on the 13th day of April 2000

Revised on the 5th day of October 2008

Amended on the 10th day of October 2009

Amended on the 15th day of June 2010

Amended on the 19th day of November 2016

1. Name

The name of the Association is **Batten Disease Family Association** (“the Charity”)

2. Administration

Subject to the matters set out below the Charity and its property shall be administered and managed in accordance with this constitution by the members of the Executive Committee constituted by clause 7 of this constitution (“the Executive Committee”)

3. Objects

The Association is established to:

- a) Preserve and protect the health and promote the welfare of persons affected by all types of Neuronal Ceroid Lipofuscinosis (NL) commonly known as Batten disease.
- b) To advance the education of the medical profession and the general public on the subject of Batten disease and its implications for the family.

- c) To promote research into the management of Batten disease and to publish the useful results thereof and to support organisations promoting research into Batten disease.

4. Powers

In furtherance of the said objects but not otherwise the Association may:

- a) Create a positive supportive network of parents, families and professionals in order to share ideas, experiences and give emotional support.
- b) Recognise the emotional needs of children affected by Batten disease and to encourage the recognition of the depth of feelings experienced by their families and provide support.
- c) Increase the understanding of the relationship between the physical effects of Batten disease and learning development; and to aid the development of beneficial therapies and learning programmes.
- d) Help parents obtain the best education and facilities for their children.
- e) Support the parents in their right to be kept informed about the likely progression of their child's condition and more importantly of the outcomes of treatments offered at various stages.
- f) Promote exercise and physical endeavours as a beneficial therapy.
- g) Aid the development and understanding of the possible benefits of dietary control in children with Batten disease including issues surrounding alternative feeding techniques and of alternative forms of medicine.
- h) Help and support parents in all their negotiations for financial aid and other services.
- i) Promote and support all activities leading to an improved quality of life.
- j) Employ and pay any person or persons (who shall not be members of the Executive Committee, Members of the Executive Committee may only be employed in accordance with Clause 9) to supervise, organise and carry on the work of the Association and make all reasonable and necessary provision for the payment of pensions and superannuation to or on behalf of employees and their widows and other dependents.

- k) Bring together in conference representatives of voluntary organisation, Government Departments, the medical profession, statutory authorities and individuals.
- l) Promote and carry out or assist in promoting and carrying out research, surveys and investigations and publish the useful results thereof.
- m) Arrange and provide for or join in arranging and providing for the holding of exhibitions, meetings, lectures, classes, seminars and training courses.
- n) Collect and disseminate information on all matters affecting the said objects and exchange such information with other bodies having similar objects whether in this country or overseas.
- o) Undertake, execute, manage or assist any charitable trusts which may lawfully be undertaken, executed, managed or assisted by the Association.
- p) Cause to be written and printed or otherwise reproduced and circulated, gratuitously or otherwise, such papers, books, periodicals, pamphlets or other documents or films or recorded tapes (whether audio or video or both) as shall further the said objects.
- q) Purchase, take on lease or in exchange, hire or otherwise acquire any property and any rights and privileges necessary for the promotion of the said objects and construct, maintain and later any buildings or erections necessary for the work of the Association.
- r) Make regulations for any property which may be so acquired.
- s) Subject to such consents as may be required by law, sell, let, mortgage, dispose of our turn to account all or any of the property or assets of the Association.
- t) Subject to such consents as may be required by law, borrow or raise money for the said objects and accept gifts on such terms and on such security as shall be deemed to be necessary.
- u) Raise funds and invite and receive contributions from any person or persons whatsoever by way of subscriptions otherwise. PROVIDED THAT the Association shall not undertake permanent trading activities in raising funds for the said objects.
- v) Invest the money of the Association not immediately required for the said objects in or upon such investments, securities or property as may

be though fit, subject nevertheless to such conditions (if any) as may for the time being be imposed or required by law.

- w) Do all such other lawful things as are necessary for the attainment of the said objects.
- x) Establish where necessary local branches (whether autonomous or not).

5. Membership

- a) Voting Membership of the Charity shall be open to Parents, Guardians, Carers of children and any person over the age of 18 interested in furthering the objects and who has paid the annual subscription laid down from time to time by the Executive Committee.
- b) Every member shall have one vote.
- c) The Executive Committee may by unanimous vote and for good reason terminate the membership of any individual: Provided that the individual concerned shall have the right to be heard by the Executive Committee, accompanied by a friend, before a final decision is made.

6. Honorary Officers

At the Annual General Meeting of the Charity the members shall elect from amongst themselves a chairman, a secretary and a treasurer, who shall hold office from the conclusion of that meeting.

7. Executive Committee

- a) The Executive Committee shall consist of not less than **7** members nor more than **15** members being:
 - i. The honorary officers specified in the preceding clause; plus
 - ii. Not less than **4** and not more than **12** members elected at the Annual General Meeting who shall hold office from the conclusion of that meeting;
- b) The Executive Committee may in addition appoint not more than **5** co-opted members but so that no-one may be appointed as a co-opted member if, as a result, more than one third of the members of the Executive Committee would be co-opted members. Each appointment of a co-opted member shall be made at a special meeting of the

Executive Committee called under clause **10** and shall take effect from the end of that meeting unless the appointment is to fill a place which has not then been vacated in which case the appointment shall run from the date when the post becomes vacant.

- c) Members of the Executive Committee shall retire from office at the end of the Annual General Meeting after they have served between a one to three year period as agreed on the date on which they came into office but they may be re-elected or re-appointed for a further one to three years term of office
- d) The proceedings of the Executive Committee shall not be invalidated by any vacancy among their number or by any failure to appoint or any defect in the appointment or qualification of a member.
- e) Nobody shall be appointed as a member of the Executive Committee who is aged under 18 or who would if appointed be disqualified under the provisions of the following clause.
- f) No person shall be entitled to act as a member of the Executive Committee whether on a first or on any subsequent entry into office until after signing in the minute book of the Executive Committee a declaration of acceptance and of willingness to act in the trusts of the Charity.

8. Determination of Membership of Executive Committee

A member of the Executive Committee shall cease to hold office if he or she:

- a) Is disqualified from acting as a member of the Executive Committee by virtue of section 45 of the Charities Act 1992 (or any statutory re-enactment or modification of that provision);
- b) Becomes incapable by reason of mental disorder, illness or injury of managing and administering his or her own affairs;
- c) Is absent without the permission of the Executive Committee from all their meetings held within a period of six months and the Executive Committee resolve that his or her office be vacated; or
- d) Notifies to the Executive Committee a wish to resign (but only if at least three members of the Executive Committee will remain in office when the notice of resignation is to take effect).

9. Executive Committee Members not to be personally interested

No member of the Executive Committee shall acquire any interest in property belonging to the Charity (otherwise than as a trustee for the Charity) or receive remuneration or be interested (otherwise than as a member of the Executive Committee) in any contract entered into by Executive Committee except with the written prior consent of the Commission.

10. Meeting all proceedings of the Executive Committee

- a) The Executive Committee shall hold at least two ordinary meetings each year. A special meeting may be called at any time by the chairman or by any two members of the Executive Committee upon not less than 4 days' notice being given to the other members of the Executive Committee of the matters to be discussed but if the matters include an appointment of a co-opted member then not less than 21 days' notice must be given.
- b) The chairman shall act as chairman at meetings of the Executive Committee. If the chairman is absent from any meeting, the members of the Executive Committee present shall choose one of their number to be chairman of the meeting before any other business is transacted.
- c) There shall be a quorum when at least one third of the number of members of the Executive Committee for the time being or three members of the Executive Committee, whichever is the greater, are present at a meeting.
- d) Every matter shall be determined by a majority of votes of the members of the Executive Committee present and voting on the question but in the case of equality of votes the chairman of the meeting shall have a second or casting vote.
- e) The Executive Committee shall keep minutes, in books kept for the purpose, of the proceeding at meetings of the Executive Committee and any sub-committee.
- f) The Executive Committee may from time to time make and alter rules for the conduct of their business, the summoning and conduct of their meetings and the custody of documents. No rule may be made which is inconsistent with this constitution.
- g) The Executive Committee may appoint one or more sub-committees consisting of three or more members of the Executive Committee for the purpose of making any inquiry or supervising or performing any function or duty which in the opinion of the Executive Committee would

be more conveniently undertaken or carried out by a sub-committee: provided that all acts and proceedings of any such sub-committees shall be fully and promptly reported to the Executive Committee.

11. Receipts and Expenditure

a) The funds of the Charity, including all donations, contributions and bequests, shall be paid into an account operated by the Executive Committee in the name of the Charity at such bank as the Executive Committee shall from time to time decide. All cheques drawn on the account must be signed by at least two members of the Executive Committee.

~~b) None of the association's assets may be distributed or otherwise applied (on being wound up or at any other time) except to further its charitable purposes.~~

12. Property

a) Subject to the provisions of sub-clause (2) of this clause, the Executive Committee shall cause the title to:

- i. All land held by or in trust for the charity which is not vested in the Official Custodian for Charities; and
- ii. All investments held by or on behalf of the charity;

to be vested either in a corporation entitled to act as custodian trustee or in not less than three individuals appointed by them as holding trustees. Holding trustees may be removed by the Executive Committee at their pleasure and shall act in accordance with the lawful directions of the Executive Committee, the holding trustees shall not be liable for the acts and defaults of its members.

b) If a corporation entitled to act as custodian trustee has not been appointed to hold the property of the charity, the Executive Committee may permit any investments held or in trust for the charity to be held in the name of a clearing bank, trust corporation or any stockbroking company which is a member of the International Stock Exchange (or any subsidiary of any such stockbroking company) as nominee for the Executive Committee, and may pay such a nominee reasonable and proper remuneration for acting as such.

~~c) Nothing in this constitution shall authorise an application of the property of the charity for purposes which are not charitable in accordance with section 7 of the Charities and Trustee investment (Scotland) Act 2005.~~

13. Accounts

The Executive Committee shall comply with their obligations under the Charities Act 1992 (or any statutory re-enactment or modification of that Act) with regard to:

- a) The keeping of accounting records for the Charity
- b) The preparation of annual statements of account for the Charity;
- c) The auditing or independent examination of the statements of account of the Charity; and
- d) The transmission of the statements of account of the Charity to the Commissioners.

14. Annual Report

The Executive Committee shall comply with their obligations under the Charities Act 1992 (or any statutory re-enactment or modification of that Act) with regard to the preparation of an annual report and its transmission to the Commissioners.

15. Annual Return

The Executive Committee shall comply with their obligations under the Charities Act 1992 (or any statutory re-enactment or modification of that Act) with regard to the preparation of an annual return and its transmission to the Commissioners.

16. Annual General Meeting

- a) There shall be an annual general meeting of the Charity which shall be held in the month of October in each year or as soon as practicable thereafter.
- b) Every annual general meeting shall be called by the Executive Committee. The secretary shall give at least 21 days' notice of the annual general meeting to all the members of the Charity. All the members of the Charity shall be entitled to attend and vote at the meeting.
- c) Before any other business is transacted at the first annual general meeting the persons present shall appoint a chairman of the meeting. The chairman shall be the chairman of subsequent annual general meetings, but if he or she is not present, before any other business is

transacted, the persons present shall appoint a chairman of the meeting.

- d) The Executive Committee shall present to each annual general meeting the report and accounts of the Charity for the preceding year.
- e) Nominations for election to the Executive Committee must be made by members of the Charity in writing and must be in the hands of the secretary of the Executive Committee at least 14 days before the annual general meeting. Should nominations exceed vacancies, election shall be by ballot.

17. Special General Meetings

The Executive Committee may call a special general meeting of the Charity at any time. If at least ten members request such a meeting in writing stating the business to be considered the secretary shall call such a meeting. At least 21 days' notice must be given. The notice must state the business to be discussed.

18. Procedure at General Meetings

- a) The secretary or other person specially appointed by the Executive Committee shall keep a full record of proceedings at every general meeting of the Charity.
- b) There shall be a quorum when at least one tenth of the number of members of the Charity for the time being or ten members of the Charity, whichever is the greater, are present at any general meeting.

19. Notices

Any notice required to be served on any member of the Charity shall be in writing and shall be served by the secretary or the Executive Committee on any member either personally or by sending it through the post in a prepaid letter addressed to such member at his or her last known address in the United Kingdom, and any letter so sent shall be deemed to have been received within 10 days of posting.

20. Alterations to the Constitution

- a) Subject to the following provisions of this clause the Constitution may be altered by a resolution passed by not less than two thirds of the members present and voting at a general meeting. The notice of the general meeting must include notice of the resolution, setting out the terms of the alteration proposed.

- b) No amendment may be made to clause **1** (the name of charity clause), clause **3** (the objects clause), clause **9** (Executive Committee members not to be personally interested clause), clause **21** (the dissolution clause) or this clause without the prior consent in writing of the Commissioners.
- c) No amendment may be made which would have the effect of making the Charity cease to be a charity at law.
- d) The Executive Committee should promptly send to the Commissioners a copy of any amendment made under this clause.

21. Dissolution

If the Executive Committee decides that it is necessary or advisable to dissolve the Charity it shall call a meeting of all members of the Charity, of which not less than 21 days' notice (stating the terms of the resolution to be proposed) shall be given. If the proposal is confirmed by a two-thirds majority of those present and voting the Executive Committee shall have power to realise any assets held by or on behalf of the Charity. Any assets remaining after the satisfaction of any proper debts and liabilities shall be given or transferred to such other charitable institution or institutions having objects similar to the objects of the Charity as the members of the Charity may determine or failing that shall be applied for some other charitable purpose. A copy of the statement of accounts, or account and statement, for the final accounting period of the Charity must be sent to the Commissioners.

This constitution was mended on the date mentioned above by the persons whose signatures appear at the bottom of this document.

Signed