

CONSTITUTION

Adopted on the 22nd July 2000

1) Name

The name of the Association is Diamond Blackfan Anaemia Support Group, UK (“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 :

- a) For the relief of sickness of those suffering either directly or indirectly from Diamond Blackfan Anaemia (DBA), and associated conditions.
- b) To educate the general public through promotion of research and the dissemination of knowledge about Diamond Blackfan Anaemia (DBA).

4) Powers

In furtherance of the said objects but not otherwise, the Diamond Blackfan Anaemia Support Group, UK may :

- a) Create a positive supportive network of parents, families and professionals in order to share ideas, experiences and give emotional support.
- b) Increase the understanding of the effects of DBA and to aid the development of beneficial therapies and learning programmes.
- c) Support the patient in their right to be kept informed about the likely progression of their condition and more importantly of the outcomes of treatments offered at various stages.
- d) Suggest sources of information for available services or financial aid.
- e) Promote and support all activities leading to an improved quality of life.
- f) Employ and pay any person or persons (who shall not be members of the Executive Committee) to supervise, organise and carry on the work of the Diamond Blackfan Anaemia Support Group, UK 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 dependants.
- g) Bring together in conference representatives of voluntary organisation, Government Departments, the medical profession, statutory authorities and individuals.
- h) Promote relevant research and disseminate information and publish the results thereof by making presentations at relevant meetings, exhibitions, seminars and written information to the membership.

- i) Arrange and provide for or join in arranging and providing for the holding of exhibitions, meetings, lectures, classes, seminars and training courses.
- j) 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.
- k) Undertake, execute, manage or assist any charitable trusts which may lawfully be undertaken, executed, managed or assisted by the Association.
- l) 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.
- m) 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 any buildings or erections necessary for the work of the Association.
- n) Make regulations for any property which may be so required.
- o) Subject to such consents as may be required by law, sell, let, mortgage, dispose of or turn to account all or any of the property or assets of the Association.
- p) 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.
- q) 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 substantial permanent trading activities in raising funds for the said objects and shall conform to any relevant requirements of the law.
- r) Invest the money of the Association not immediately required for the said objects in or upon such investments, securities or property as may be thought fit, subject nevertheless to such conditions (if any) as may for the time being be imposed or required by law.
- s) Do all such other lawful things as are necessary for the attainment of the said objects.
- t) Establish where necessary local branches.

5) Membership

- a) Membership of the charity shall be open to the following categories of people :
 - I. The parents and guardians of any individual, child or adult, affected by DBA.
 - II. Affected individuals over the age of 18 years.
 - III. Other immediate family members, over the age of 18 years (brothers, sisters, children) of any affected individual, child or adult.
 - IV. Any individual over 18 years or corporate body with a demonstrable genuine interest in DBA.
- b) Every member shall have one vote.
- c) Non-voting associate membership shall be open to all other individuals.
- d) 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 until the next AGM.

7) Executive Committee

- 1) The Executive Committee shall consist of not less than 3 members nor more than 12 members being:
 - a) the honorary officers specified in the preceding clause, plus
 - b) not more than 9 members elected at the annual general meeting who shall hold office from the conclusion of that meeting
- 2) The Executive Committee may in addition appoint not more than 3 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.
- 3) The members of the Executive Committee shall hold office for a period of three years but no more than one third should stand for re-election at one time.
- 4) 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.
- 5) 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.
- 6) 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 1993 (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

- a) 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.

10) Meetings all proceedings of the Executive Committee

- b) 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.
- c) 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.
- d) 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.
- e) 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.
- f) The Executive Committee shall keep minutes, in books kept for the purpose, of the proceedings at meetings of the Executive Committee and any sub-committee.
- g) 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.

- h) 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 and 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) The funds belonging to the Charity shall be applied only in furthering the objects.

12) Property

- 1) Subject to the provisions of sub-clause (2) of this clause, the Executive committee shall cause the title to :
 - a) all land held by or in trust for the charity which is not vested in the Official Custodian for Charities; and
 - b) 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. Provided they act only 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.

- 2) 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.

13) Accounts

The Executive Committee shall comply with their obligations under the Charities Act 1993 (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 March 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) Notice

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 this 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.

22) Arrangements until first Annual General Meeting

Until the first annual general meeting takes place this constitution shall take effect as if references in it to the Executive Committee were references to the persons whose signatures appear at the bottom of this document.

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

Signed	Name

