

CONSTITUTION

1. **NAME**

The name of the Society is the Laurence-Moon-Bardet-Biedl Society (hereinafter called "the Society").

2. **OBJECTS AND POWERS**

(a) The Society is established to:

- (1) preserve and protect the health and promote the welfare of persons suffering from Laurence-Moon-Bardet-Biedl Syndrome and their families;
- (2) advance the education of the medical and educational professions and the general public on the subject of Laurence-Moon-Bardet-Biedl Syndrome and its implications for the family.

(b) In furtherance of the said objects but not otherwise the Society may:

- (1) Create a positive supportive network of parents, families and professionals in order to share ideas experiences and give emotional support.
- (2) Recognise the emotional needs of Laurence-Moon-Bardet-Biedl Syndrome children and to encourage the recognition of the depth of feelings experienced by their families and provide support.
- (3) Increase the understanding of the relationship between the physical condition of Laurence-Moon-Bardet-Biedl Syndrome and learning development; and to aid the development of beneficial therapies and learning programmes.
- (4) Help parents obtain the best education and facilities for their children.
- (5) Help persons suffering from Laurence-Moon-Bardet-Biedl Syndrome to obtain appropriate housing, benefits, training and opportunities within the work place.
- (6) Support the parents and persons suffering from Laurence-Moon-Bardet-Biedl Syndrome in their right to be kept informed about the likely progression of Laurence-Moon-Bardet-Biedl Syndrome and more importantly of the outcomes of treatments offered at various stages.
- (7) Promote exercise and physical endeavours as a beneficial therapy.
- (8) Aid the development and understanding of the benefits of dietary control in Laurence-Moon-Bardet-Biedl Syndrome and of alternative forms of medicine.
- (9) Help and support parents and persons suffering from Laurence-Moon-Bardet-Biedl Syndrome in all their negotiations for financial aid and other

services.

- (10) Promote and support all activities leading to an improved quality of life.
- (11) Employ and pay any person or persons other than any member of the Executive Committee to supervise, organise and carry on the work of the Society 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.
- (12) Establish where necessary local branches (whether autonomous or not).
- (13) Bring together in conference representatives of voluntary organisations, Government departments, the medical profession, statutory authorities and individuals.
- (14) Promote and carry out or assist in or support organisations promoting and carrying out research into, surveys and investigations on and the management of Laurence-Moon-Bardet-Biedl Syndrome and publish the useful results thereof.
- (15) Arrange and provide for or join in arranging and providing for the holding of exhibitions, meetings, lectures, classes, seminars and training courses.
- (16) 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.
- (17) Undertake, execute, manage or assist any charitable trusts which may lawfully be undertaken, executed, managed or assisted by the Society.
- (18) 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 visual or both) as shall further the said objects.
- (19) 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 alter any buildings or erections necessary for the work of the Society.
- (20) Make regulations for any property which may be so acquired.
- (21) 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 Society.
- (22) 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.
- (23) Raise funds and invite and receive contributions from any person or persons whatsoever by way of subscriptions and otherwise PROVIDED THAT the

Society shall not undertake permanent trading activities in raising funds for the said objects.

- (24) Invest the moneys of the Society 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.
- (25) Pay a premium or premiums in respect of any indemnity or insurance policy to cover the liability of the Executive Committee established under Clause 5 (or any member of that Committee) which by virtue of any rule of law would otherwise attach to them in respect of any negligence, default, breach of duty or breach of trust of which they may be guilty in relation to the Society PROVIDED THAT any such insurance shall not extend to any claim arising from any act or omission which the Executive Committee (or any of them) knew or ought reasonably to have known was a breach of duty or breach of trust or which was committed by members of the Executive Committee (or any of them) in reckless disregard of whether it was a breach of duty or breach of trust or not.
- (26) Do all such other lawful things as are necessary for the attainment of the said objects.

3. **MEMBERSHIP**

- (a) Full membership of the Society shall be open to: any adult suffering from Laurence-Moon-Bardet-Biedl Syndrome and his/her family; and any family with one or more Laurence-Moon-Bardet-Biedl Syndrome children including legal guardians, foster parents, parents by adoption and subject to the agreement of the Executive Committee, the carers and grandparents. Each family shall have two votes. Any single member without family shall have one vote provided his or her name appears on the national electoral register.
- (b) Associate membership shall be open to those who are interested in furthering the work of the Society.

- (c) The Executive Committee established under Clause 5 below shall have the right:
 - (1) to approve or, if it is considered to be in the best interest of the Society and for good and sufficient reasons, reject applications for membership, and
 - (2) for good and sufficient reason to terminate the membership of any individual or organisation PROVIDED THAT the individual member concerned or the individual representing such organisation (as the case may be) shall have the right to be heard by the said Executive Committee before a final decision is made.

4. **HONORARY OFFICERS**

- (a) At the Annual General Meeting hereinafter mentioned the Society shall elect a Chairman, a Vice-Chairman, a Treasurer, a Secretary and such other Honorary Officers as the Society shall from time to time decide.
- (b) The Chairman and the Honorary Officers of the Society shall hold office until the conclusion of the Annual General Meeting of the Society next after their election but shall be eligible for re-election at that Annual General Meeting.
- (c) The Chairman and the Honorary Officers shall be ex officio members of the Society, the said Executive Committee and of any other committee.
- (d) The Society shall appoint one or more qualified auditors and may determine their remuneration (if any).

5. **EXECUTIVE COMMITTEE**

- (a) Subject as hereinafter mentioned the policy and general management of the affairs of the Society shall be directed by an Executive Committee (hereinafter called "the Committee") which shall meet not less than 2 times a year and when complete shall consist of not less than 7 or more than 11 members (including Officers).
- (b) The members of the Committee shall be elected at the Annual General Meeting of the Society in accordance with Clause 7 hereof.
- (c) Election to the Committee shall be for two years. One half of the membership shall retire annually but shall be eligible for re-election, the members so to retire being those who have been longest in office since the last election but not reckoning ex officio members. As between members who have been in office the same length of time, those due to retire shall be chosen by lot.

- (d) In addition to the members so elected and to those serving by virtue of Clause 4(c) hereof the Committee may co-opt up to 3 further members being full members or associate members of the Society whether individual or representative or a combination of both who shall serve until the conclusion of the next Annual General Meeting after individual co-option PROVIDED THAT the number of co-opted members shall not exceed one-third of the total membership of the Committee at the time of co-option. Co-opted members shall be entitled to vote at meetings of the Committee.
- (e) Any casual vacancy in the Committee may be filled up by the Committee and any person appointed to fill such a casual vacancy shall hold office until the conclusion of the next Annual General Meeting of the Society and shall be eligible for election at that Meeting.
- (f) The proceedings of the Committee shall not be invalidated by any failure to elect or any defect in the election, appointment, co-option or qualification of any member.
- (g) The Committee shall appoint and fix the remuneration of a General Secretary and of all such other staff (not being members of the Committee) as may in their opinion be necessary.
- (h) The Committee may appoint such special or standing committees as may be deemed necessary by the Committee and shall determine their terms of reference, powers, duration and composition. All acts and proceedings of such special or standing committees shall be reported back to the Committee as soon as possible.

6. **LOCAL BRANCHES**

The Committee shall have power to establish local branches for the furtherance of the said objects. Each branch so established shall comply with and be subject to the following regulations:

- (a) The branch shall act in pursuance of the said objects and of the policy of the Society and shall be subject to such conditions as may from time to time be laid down by the Committee.
- (b) The title of the branch shall be subject to the prior approval of the Committee. No branch shall be entitled to use the expression Laurence-Moon-Bardet-Biedl Society in its title unless at least one member of the branch's governing body is a full member of the Society.
- (c) The branch will be deemed to have adopted the model rules for branches as prescribed from time to time by the Committee unless it has, with the prior approval of the Committee, adopted other rules.

- (d) The branch may publish literature solely in the name of the branch for local purposes but such literature shall not contain any statement contrary to the said objects or to the policy of the Society.
- (e) Representations of whatever kind to other bodies and/or individuals may only be made by the branch through or with the prior approval of the Committee.
- (f) All legacies bequeathed to the Society shall be received by the Treasurer or other appropriate officer of the Society but, subject to any special trusts by which such legacies may be affected, the Committee shall have power to direct that any legacy or the income there from shall be paid to a particular branch.
- (g) The branch may be empowered by the Committee to receive donations and any money received or raised by it may be expended by the branch in its area solely for the furtherance of the said objects. The branch shall make returns to the Society in such form as may from time to time be determined by the Committee.
- (h) Subject to these regulations, the branch may generally manage its own affairs and shall be solely responsible for its own debts and liabilities and shall not pledge the credit of the Society or that of the Committee or of any individual member of the Committee.
- (i) The Committee may at any time, for good and sufficient reason, dissolve any local branch if it considers such action to be in the best interest of the Society.

7. **MEETINGS OF THE SOCIETY**

- (a) The First General Meeting of the Society shall be held not later than October 1994 and once in each year thereafter an Annual General Meeting of the Society shall be held at such time (not being more than 18 months after the holding of the preceding Annual General Meeting) and place as the Committee shall determine. At least 21 clear days' notice shall be given in writing by the General Secretary to each member. At such Annual General Meeting the business shall include the election of Honorary Officers; the election of full members to serve on the Committee; the appointment of an auditor or auditors; the consideration of an annual report of the work done by or under the auspices of the Committee and of the audited accounts; and the transaction of such other matters as may from time to time be necessary. Other items for the agenda must be delivered in writing to the General Secretary from the proposer and seconder not less than 10 days before the Annual General Meeting and shall be read by the Chairman before any debate thereon shall take place. Every matter shall be decided in the first place on a show of hands but the Chairman may order a poll and must do so if it is requested by more than 5 members.

- (b) The Chairman of the Committee may at any time at his/her discretion and the General Secretary shall within 42 days of receiving a written request so to do, signed by not less than 10 full members, whether individual or representative, and giving reasons for the request, call a Special General Meeting of the Society. 21 days' notice in writing of the time and place of the meeting shall be given to members.

8. **NOMINATIONS OF HONORARY OFFICERS AND COMMITTEE MEMBERS**

Both full and associate members of the Society shall be eligible to serve as Honorary Officers or members of the Committee provided that the proportion of associate members shall never exceed one third of the total members of the Committee. Nominations for Honorary Officers or members of the Committee must be made by full members of the Society in writing and must be in the hands of the General Secretary at least 10 days before the Annual General Meeting. Should nominations exceed vacancies, election shall be by a system of postal voting (the arrangements for which shall be made by the Committee) PROVIDED THAT the first members of the Committee shall be elected by personal vote at the first General Meeting of the Society.

9. **RULES OF PROCEDURE AT ALL MEETINGS**

- (a) **Quorum** The quorum at a meeting of the Society shall be representatives of ten families or one tenth of the families who are members of the Society for the time being (whichever is the greater) and the quorum at a meeting of the Committee or any committee appointed under Clause 5 (h) hereof shall be three or one-third of the total actual membership of the Society, the Committee or committee as the case may be (which ever is the greater) or such other number as the Society may in a previous General Meeting from time to time determine.
- (b) **Voting** Save as otherwise herein provided, all questions arising at any meeting shall be decided by a simple majority of those present and entitled to vote thereat. Arrangements for proxy voting may from time to time be made by the Committee PROVIDED ALWAYS THAT no such arrangements shall be made with regard to Clauses 13 and 14 hereof. In case of an equality of votes the chairman of the meeting shall have a second or casting vote.
- (c) **Minutes** Minute books shall be kept by the Committee and all other committees, and the appropriate secretary shall enter therein a record of all proceedings and resolutions.
- (d) **Standing Orders and Rules** The Committee shall have power to adopt and issue Standing Orders and/or Rules for the Society. Such Standing Orders and/or Rules shall come into operation immediately PROVIDED ALWAYS that they shall be subject to review by the Society in General Meeting and shall not be inconsistent with the provisions of this constitution.

10. **FINANCE**

- (a) All moneys raised by or on behalf of the Society shall be applied to further the objects of the Society and for no other purpose PROVIDED THAT nothing herein contained shall prevent the payment in good faith of reasonable and proper remuneration to any employee of the Society or the repayment to members of the Committee or of any committee appointed under Clause 5 (h) hereof of reasonable out-of-pocket expenses.
- (b) The Honorary Treasurer shall keep proper accounts of the finances of the Society.
- (c) The accounts shall be audited at least once a year by the auditor or auditors appointed at the Annual General Meeting.
- (d) An audited statement of the accounts for the last financial year shall be submitted by the Committee to the Annual General Meeting as aforesaid.
- (e) A bank account shall be opened in the name of the Society with Girobank, or with such other bank as the Committee shall from time to time decide. The Committee shall authorise in writing the Treasurer, the General Secretary of the Society and two members of the Committee to sign cheques on behalf of the Society. All cheques must be signed by not less than two of the four authorised signatories.

11. **TRUST PROPERTY**

The title to all real or personal property which may be acquired by or on behalf of the Society shall be vested in a corporation lawfully entitled to act as Custodian Trustee or in not less than 3 or more than 5 individual persons (not being members of the Committee).

12. **EXECUTIVE COMMITTEE'S LIABILITY AND INDEMNITY**

In the execution of the trusts hereof no member of the Executive Committee shall be liable for any loss to the property of the Society arising by reason of any inappropriate investment made in good faith (so long as he shall have sought professional advice before making such investment), or for the negligence or fraud of any agent employed by him or by any other Executive Committee member in good faith (provided reasonable supervisory steps had been exercised), by reason of any mistake or omission made in good faith by any Executive Committee member himself, or by reason of any other matter or thing other than willful and individual fraud, wrong-doing or wrongful omission on the part of the Executive Committee member who is sought to be made liable.

13. **ALTERATIONS TO THE CONSTITUTION**

Any alteration of this Constitution shall receive the assent of not less than two-thirds of the full membership of the Society for the time being whether individual or representative present and voting at a meeting specially called for the purpose PROVIDED THAT notice of any such alteration shall have been received by the General Secretary in writing not less than 35 clear days before the meeting at which the alteration is to be proposed. At least 21 clear days' notice in writing of such a meeting, setting forth the terms of the alteration, shall be sent by the General Secretary to each member of the Society PROVIDED THAT no alteration shall be made which would have the effect of causing the Society to cease to be a Charity at law and no amendment shall be made to Clause 2 above or Clause 14 below or to this Clause 13 without the prior written consent of the Charity Commissioners.

14. **DISSOLUTION**

(a) If the Committee by a simple majority decide at any time that on the ground of expense or otherwise it is necessary or advisable to dissolve the Society, it shall call a meeting of all members of the Society who have the power to vote, of which meeting not less than 21 days' notice (stating the terms of the Resolution to be proposed thereat) shall be given. If such decision shall be confirmed by a simple (two-thirds) majority of those present and voting at such meeting the Committee shall have power to dispose of any assets held by or on behalf of the Society. 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 Society as the Committee may determine but if and so far as effect cannot be given to this provision then to some other charitable institution or institutions.

(b) Nothing in this Constitution shall authorize an application of the property of the charity for purposes which are not charitable in accordance with section 7 Charities and Trustee Investment (Scotland) Act 2005.

15. **NOTICES**

Any notice may be served by the General Secretary on any member either personally or on its appointed representative as the case may be, or by sending it through the post in a prepaid letter addressed to such member at his, her or its last known address in the United Kingdom, and any letter so sent shall be deemed to have been received within ten days of its issue.

16. **INTERPRETATION**

For the Interpretation of this Constitution, the Interpretation Act, 1978, shall apply as it applies to the interpretation of an Act of Parliament.