

British Sjögren's Syndrome Association

RESEARCH POLICY and TERMS & CONDITIONS for Research Grants and Assistance

1. Objectives

Under the terms of the Memorandum and Articles of Association of the BSSA the Trustees of the BSSA may promote research into the causes and treatment of Sjögren's Syndrome in such a manner as the Trustees shall from time to time in their absolute discretion think fit provided that the useful results of such research are published.

All applications for research proposals must be put forward in written form to the Chairman of the BSSA, with any further details as requested by the Trustees.

2. Requests where no financial support is requested

It is anticipated that from time to time the BSSA may be asked to publicise the existence of a project and/or to provide contact information in the BSSA Newsletter or other materials for BSSA members to contact the researcher(s). A decision to either support or reject the request (or, if it is felt to be more complex to refer it to the Trustees) may be made by the Chairman (or in their absence another Trustee acting as their deputy) and the President of the Medical Council (or, in their absence, the Vice-President or other member of the Medical Council acting as their deputy).

While each request will be considered on its merits the circulation directly to BSSA members of research questionnaires is likely to be problematic.

3. General policy in relation to the award of grants

Before awarding a grant, the Trustees require that the applicant should:

- a) Inform the Trustees of the names of those who are to be involved with the actual research ("the Researchers"), and the identity of the person(s) who will be responsible for the administration of the grant ("the Grantholder").
- b) Provide adequate information regarding the identity and financial status of the organisation at which the applicant will undertake the research and of the status of the applicant within the organisation.
- c) Provide adequate evidence that the appropriate infrastructure and resources will be made available to the Grantholder(s) and/or Researcher(s).
- d) Provide assurances to the Trustees which are confirmed in writing by an authorised member of the organisation that the grant project:
 - i. has obtained appropriate Ethical Committee approval (in which case full details of the terms of such approval must be supplied) or does not require such approval;

- ii. is fully authorised by the organisation which accepts full responsibility for its proper management, including the management of any staff employed through the grant, the responsibility to investigate and deal with any suspected research fraud or misconduct in relation to the grant project;
 - iii. has and will be adequately insured both in relation to any equipment and facilities purchased by the grant but also in relation to any risk of injury arising by reason of the grant project including injury to those participating in or operating the grant project and has adequate public and employers liability insurance.
 - iv. is fully compliant with all relevant UK, EU or other legislation or codes of practice.
- e) Undertake to comply with the Terms and Conditions below and agree to be bound by them. Where appropriate, the Trustees will require the applicant and/or organisation to whom the grant is offered to enter into a formal Grant Deed containing these provisions.

4. Principles

The following principles will be observed by the Trustees in awarding grants:

- a) Research grants will primarily be given to enable new research to get underway or existing research to continue and grants will not normally commit expenditure over a longer period than two years.
- b) The Trustees will not normally approve the use of research funds for:
 - i. organisations or individuals based outside the United Kingdom
 - ii. institutional overheads;
 - iii. travel/conference fees.
 - iv. computer equipment
- c) In the interests of equity, the Trustees will take into consideration the geographical spread of grants made.

5. Priorities for support

The Trustees may, from time to time, set out priorities for funding. Applicants will be notified of any such priorities at the time of their application. These priorities will be reviewed from time to time, and may be changed in accordance to the Trustees' view of the most effective application of available funds.

6. Grant Applications

- a) All applications for grants should be made in the first instance to the Chairman of the BSSA care of:

British Sjögren's Syndrome Association (BSSA)
 PO Box 15040, Birmingham B31 3DP
 e-mail: office@bssa.uk.net

- b) Applicants should provide at least a brief description of the work that they wish to be supported, together with details of the support requested and timescale for the project. At the Trustees' discretion a formal application form may be sent for completion, together with a request for a full protocol (in the case of a research proposal) and, if appropriate, a copy of the applicant's, or other staff's CV and list of publications. Additional material may also be requested as the Trustees see fit.
- c) Appropriate expert advice will be sought from a panel of members of the BSSA's Medical Council or other professional advisers with regard to the application. Such a panel will comprise at least eight members normally including the Chairman of the BSSA, the President and Vice-President of the Medical Council each normally serving for a period of 7 years and at least five other members each normally serving for a period of three years. Members will be drawn from a range of specialties and at least one member, who, as an alternative to the Chairman of the BSSA or their deputy, may be asked to act as Chairman of the panel, will be independent of the BSSA and Sjögren's research. The panel may also request additional reviews of applications from professional advisors outside of the panel itself. The applicant may be requested to provide further information as a result of comments received by such professional advisers and panel members. The Trustees' final decision on the application will have due regard to the expert advice received although the Trustees retain the right not to award any grant at their absolute discretion
- d) Members of the Medical Council or other professional advisers will be asked to declare in writing to the President of the Medical Council whether or not they have any potential conflicts of interest with any of the applications and the nature of any conflict of interest. This confirmation must be received from all panel members before applications are considered and will be kept as a matter of formal record. In the event of an application being considered from a member of the same institution as the panel member they will be required to absent themselves from all consideration of the application. If the application is from a member of the same department, or where the panel member themselves is an applicant or collaborator on an application, or where any other close/direct conflict of interest exists, they should absent themselves from the process entirely and not review or influence the decision on any of the applications.
- e) The Trustees will determine the mode of advertisement, closing dates and timing of award of grants at their absolute discretion. Notwithstanding this it is likely that grant applications will be considered at a meeting of the Medical Council of the BSSA acting as a professional panel at their annual meeting, which is generally held in September/October of each year.

7. Progress reports and final reports

- a) It is the policy of the Trustees to monitor all grants made. To this end, grant holders will be asked to submit annual reports of the progress of their projects, together with:
 - i. a signed statement of how monies awarded have been spent for the year;
 - ii. details (where appropriate) of any other funds applied to the same project.

- b) Reports must demonstrate appropriate progress to ensure continuation of a grant made for longer than a period of one year. Failure to submit interim reports on time will jeopardise the continuation of the BSSA's support and the Trustees reserve the right to withdraw the grant on consideration of these reports.
- c) Monitoring visits by the Chairman, and/or one or more of the Trustees or members of the Medical Council may be expected. The Trustees also expect to receive copies of any published articles, which may result from the project, which must acknowledge the support from the BSSA as directed by the Terms and Conditions set out below.
- d) Following the conclusion of the project, the grant holder will be expected to submit a final report, normally within 3 months of the end of the grant, detailing fully the results and outputs from the project. The grant holder should inform the BSSA of any extenuating circumstances whereby the submission of final report is delayed.
- e) Unless otherwise agreed by the Trustees the grant holder will be expected to deliver the Joan Patel Memorial Lecture at the AGM of the BSSA in the year following the award of the grant.

British Sjögren's Syndrome Association

TERMS & CONDITIONS for Research Grants and Assistance

Any offer of a grant from the BSSA is subject to the following Terms and Conditions. By accepting the award of any grant offered by the BSSA, the applicant and the organisation upon whose behalf the application is made agree to be bound by these terms and conditions, and also agree that in the event of a breach of the terms, the Trustees will be entitled to withdraw the grant and to repayment of any sums awarded under the grant.

- a) For the purposes of the BSSA's Research Policy and its Terms and Conditions for Research Grants,
 - i. "the grant project" means the purpose and/or activities for which the grant is used including research, research fellowships, care treatment and the purchase and operation of facilities and equipment.
 - ii. "the grant holder" includes the applicant and/or the organisation or body who apply for and receive a grant from the BSSA
 - iii. "The Association" refers to the British Sjögren's Syndrome Association (BSSA)
 - iv. "the Trustees" refers to the Trustees of the BSSA
 - v. "The Medical Council" refers to a subcommittee of the BSSA set up to advise the Trustees on academic, clinical, education and research matters.

- b) The grant holder confirms that he/she has provided the information and assurances required by the BSSA's Research Policy and confirms that they are accurate.

- c) The grant holder confirms that the grant awarded by the BSSA will be used only for the purposes of the grant project as defined in the application, and that in the event of any significant alteration in the grant project (i) the grant holder will inform the BSSA as soon as reasonably practicable and (ii) at the Trustees' discretion, the grant may either be withdrawn and repaid or it may be renewed and (iii) in appropriate circumstances the grant holder may be required to resubmit a new application to justify the continuation of the grant.

- d) In relation to any grant project which requires ethical committee approval, the grant holder undertakes to comply with the terms of that approval and in the event of any circumstances arising, which in the course of the grant project which makes approval by the appropriate ethical committee necessary, (if not already granted) or further approval necessary, the grant holder undertakes to seek such approval or further approval having first informed the BSSA of such circumstances and the details of the approval application.

- e) The grant holder accepts that the Trustees will, in deciding whether or not to offer a grant, apply only the BSSA's own criteria under the Memorandum and Articles of Association and other policies, and the offer and award of a grant does not imply any other judgement or representation by the BSSA as to the nature, effect or risks of the grant project. Similarly, no opinion or suggestion expressed by the BSSA or Trustees in relation to the grant project will be treated as advice or relied on as such by the grant holder. Nor does the offer or award of

a grant for purposes which consist of or include the payment of any salary in connection with, or in support of, the grant project imply that the BSSA takes upon itself any of the responsibilities of an employer or is to be regarded as such.

- f) Accordingly the grant holder:
- i. undertakes full responsibility for the grant project, for the employment of any person in connection with the project, and for ensuring that it is operated in a competent and safe manner and that any person or patient who participates in, is treated under, or is the subject of a grant project, is properly advised and forewarned of any risk to health;
 - ii. agrees and accepts that the BSSA has no responsibility or liability for the operation of the grant project and that the grant holder will bear any liability or claim caused by the grant project.
 - iii. confirms that they are fully compliant with all relevant UK, EU or other legislation or codes of practice.
 - iv. accepts that the BSSA does not act as a research sponsor and, where appropriate, has confirmed a research sponsor for the project and will inform the BSSA of their details.
- g) During the period of the grant, the grant holder will permit the Trustees or their representatives to visit the grant project and will
- i. consult with the BSSA on the degree to which material published in relation to the grant project names and associates the BSSA with the project;
 - ii. at all times permit the BSSA to publish material which associates it with the project and identifies the general nature of the project;
 - iii. permit the BSSA to receive appropriate acknowledgement and, if required, recognition in respect of the grant project and successful results and/or publications arising out of it.
- h) At all times during the course of the grant project, the grant holder will maintain adequate insurance in respect of (a) any equipment and facilities purchased and/or operated with the benefit of the grant; (b) any risk or injury to health which occurs by reason of the grant project whether to the grant holder itself or its servants, agents or employees or any other person or party including in particular any subject or patient of the grant project (c) employers and public liability insurance.
- i) Monitoring of grants
- i. Where the Trustees award a grant for a project anticipated to continue for more than one year payable by instalments, the second or subsequent instalment of the grant will not be made unless and until the grant holder has submitted an annual progress report assessing the progress which has been made in the project against the terms of the original application, together with a signed statement as to how the grant

monies have been spent during the preceding year and details (where appropriate) of any other funds obtained from third party sources and applied to the same project.

- ii. Subject to consideration of the annual report, the Trustees may before making any second or subsequent payment require to consider the results of a monitoring visit.
- iii. The Trustees in their absolute discretion reserve the right, following consideration of the annual progress report and of any monitoring visit, to terminate the grant or to withhold payment of the second or subsequent instalments of the grant upon such terms or conditions as they shall think fit in the circumstances.

j) Intellectual Property

i. *Definitions*

The "Intellectual Property Rights" include results, discoveries and inventions, concepts and ideas whether or not patentable or otherwise registrable as an intellectual property right and all other rights in equity and law and for the avoidance of doubt include copyright, design right, confidential information, know how and trade secrets.

An invention "issues from" the grant project if it is conceived, first reduced to practice, or developed, in whole or in substantial and identifiable part in the course of the grant project.

- ii. The ownership of and exclusive rights of use of the Intellectual Property Rights issuing from the grant project are to be owned in equal shares (as tenants in common) by the grant holder and the BSSA, unless otherwise agreed.
- iii. The grant holder warrants that it has and will take all such steps as are necessary to secure the right and power to assign and grant the rights to the Intellectual Property Rights issuing from the grant project without any reservation or incumbrance other than involuntarily imposed by law.
- iv. The grant holder shall notify the Trustees promptly after identifying an Invention issuing from the grant project, and supply the Trustees with all the documentation, information and results in support of the identification.
- v. The grant holder and the BSSA may jointly take such steps as are appropriate to secure registration and protection of the Intellectual Property Rights issuing from the grant project. All costs of taking such steps will be shared equally between the grant holder and the BSSA. The ownership of any rights which may arise there from shall be owned in equal shares (as tenants in common) by the grant holder and the BSSA.
- vi. If either the grant holder or the BSSA elects not to exercise its option to apply or make a joint application for protection or decides to discontinue the financial support for its share of the prosecution or maintenance of the protection, the other party may on its own behalf proceed with any such application and all matters relating thereto at its own cost thereafter.

k) Data Protection

- i. Personal data (as defined in the Data Protection Act 1998) will be kept in accordance with the principles and provisions set out in that Act.
- ii. Information (including personal data) supplied in respect of a grant application and any grant subsequently awarded may be recorded and used to manage and analyse applications and grants, and may be kept during the life of the grant and for so long thereafter as may be required for reference purposes.
- iii. Copies of some or all of this information (including personal data) may be given to individuals and/or organisations consulted by the BSSA when assessing applications and monitoring grants and to the BSSA's accountants for audit purposes.

Revised: December 2003

NOTE TO APPLICANTS: The research policy and grant terms & conditions may be subject to further revision in the light of the requirements of the NHS Research Governance Framework).