



Sjögren's UK

Research policy and terms and conditions for research grants and assistance (April 2025)

1. Objectives

Under the terms of the Memorandum and Articles of Association of the British Sjögren's Syndrome Association (BSSA), the Trustees may promote research into the causes and treatment of Sjögren's disease 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.

Sjögren's UK is the working name of BSSA. All applications for research proposals must be put forward initially by completing the application form available on the charity's website and submitting that form electronically to office@sjogrensuk.org. Following the submission, the applicant(s) agree to provide any further details as requested by the Trustees.

2. Research where no financial support is requested

It is anticipated that on occasion, Sjögren's UK may be asked to publicise the existence of a research project, and/or to provide contact information in the charity's Newsletter, or through other means to inform members who may wish to contact the researcher(s). A decision to either support or reject the request may be made by the Chairperson of Sjögren's UK (or in their absence another Trustee acting as their deputy). If it is felt to be more complex, the Chairperson may refer it to the Board of Trustees for consideration and/or to members of the charity's Medical Board for guidance.

Requests for circulation of research questionnaires to Sjögren's UK members will be considered on a case-by-case basis. The preferred method is to circulate the research opportunity to members and invite those interested to make direct contact with the researchers. Where applicable, demonstration of appropriate research ethics approval must be provided. Legal responsibility for the project lies with the researcher.

3. General policy in relation to the award of grants

Before awarding a grant, the Trustees require that the lead applicant(s) 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 Grant holder(s)").
- b) Provide adequate information regarding the identity and financial status of the organisation at which the applicants will undertake the research and of the status of the lead applicant within the organisation. Sjögren's UK will not act as a Sponsor of the research.
- c) Provide adequate evidence that the appropriate infrastructure and resources will be made available to the Grant holder(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-funded research project:
 - i. has obtained appropriate Research Ethics Committee approval (in which case full details of the terms of such approval must be supplied) or confirmation that such approval is not required;

- 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-funded research 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-funded research project and has adequate public and employer's liability insurance.
 - iv. is fully compliant with all relevant UK 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 institution 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 or to be developed further.
- b) The Trustees will not normally approve the use of research funds for:
 - organisations or individuals based outside the United Kingdom
 - institutional overheads
 - travel/conference fees
 - computer equipment
- c) The maximum duration of a grant-funded project is 24 months.

5. Priorities for support

The Trustees may, from time to time, set out priorities for funding. Applicants will be notified of any such priorities when the funding round opens. Any priorities will be reviewed before each funding round is announced and may be changed in accordance with the Trustees' view of the most effective allocation of available funds.

6. Grant Applications

- a) All applications for grants should be submitted via email to: office@sjogrenuk.org It is the responsibility of the lead applicant to ensure that any application has been safely received by Sjögren's UK.
- b) Applicants should provide a fully completed application form including a Plain English lay summary of the work that they wish to undertake, together with details of the support requested, the timescale for the project and CV for each applicant and research staff to include selected research publications. Additional material may also be requested at the Trustees' discretion.

The research must be of relevance to Sjögren's disease and should be related in some way to the understanding of the causes or management of Sjögren's disease. Sjögren's UK reserves the right to triage applications and select only those that satisfy these criteria for full review.

7. Research Review Committee

- a) A research review committee will be convened to review all grant applications (see Terms of Reference document for the Research Review Committee). Such a committee will comprise at least five members, including one lay member and will be reviewed annually. The research review committee will normally include a Trustee representative, a non-Trustee member of the Medical Board and at least three external members drawn from a range of relevant medical specialities or those with relevant translational science expertise.
- b) Members must not be in receipt of an active grant from Sjögren's UK or be applying for a Sjögren's UK grant in the year that they serve. Any member with a conflict of interest (as defined below) must step down from the research review committee for that year. The research review committee may also request additional reviews of applications from external professional advisors, including additional written reviews for grant applications of high complexity or cost. The lead applicant may be requested to provide further information in response to comments received by such professional advisers and committee 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.
- c) Members of the research review committee or other professional advisers will be asked to complete a declaration of interest (DOI) document outlining whether they have any potential conflicts of interest as outlined below with any of the applications and the nature of any potential conflict of interest. This confirmation must be received from all committee 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 a committee 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 committee 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.

8. Conflicts of interest policy

When committee members are connected with an application or policy discussion in any way that they believe presents a potential conflict of interest (including but not limited to the examples given below), they should declare this, prior to any meeting request or discussion).

The charity considers the following relationships to be a conflict of interest:

- a) The committee member is the lead applicant, co-applicant, head of department or a named collaborator on an application in the given round.
- b) The committee member is at the same institution as the lead applicant, co-applicant, or a named collaborator on an application in the given round.
- c) The committee member holds or has held a grant which has ended in the last 3 years, with the lead applicant or co-applicant on an application in the given round.
- d) The committee member has published original research in the last 5 years with the lead applicant or co-applicants on an application in the given round.
- e) The committee member has a vested interest in the success or failure of this application (e.g. has a personal relationship with one of the applicants or the applicant's work is in direct competition with the committee member).

f) Where the Chair of the committee is a lead applicant or co-applicant on a grant application, they should not be involved in meetings associated with the given round.

The following is not a conflict of interest:

The committee member has been a member of a consortium / working group / committee within the last three years, with the lead applicant, co-applicant, head of department or a named collaborator with an applicant in the given round.

The charity reserves the right, in exceptional circumstances and with the discretion of the Research Review Committee Chairperson, to consider individual cases in which a committee member has given just cause that one of the criteria given above does not apply. However, any potential 'conflict' should still be declared openly to both the Chairperson and the rest of the committee prior to any discussion of the application.

9. Advertising & timing of award

The Trustees will determine the mode of advertisement, closing dates and timing of award of grants at their absolute discretion.

10. 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 an interim progress report at the mid-point of their project together with:

- i. a signed statement of actual expenditure to-date against budget headings;
- ii. details (where appropriate) of any other funds applied to the same project.

b) Reports must demonstrate appropriate progress to ensure continuation of grant funding. Failure to submit an interim report on time will jeopardise the continuation of the charity's support and the Trustees reserve the right to withdraw the grant on consideration of these reports.

c) Monitoring visits by the Chairperson, and/or one or more of the Trustees or members of the Medical Board may be expected. The Trustees also expect to receive copies of any accepted articles/outputs, which may result from the project, which must acknowledge the support from the Sjögren's UK 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 six months of the end of the grant, detailing fully the results, outputs and dissemination arising from the project. The grant holder should inform Sjögren's UK of any extenuating circumstances whereby the submission of the final report is delayed.

e) Unless otherwise agreed by the Trustees the grant holder will be expected to deliver a lecture at the Sjögren's UK annual patient conference within 12 months following the end of the project and produce a Plain English lay summary of the research for publication in the charity's newsletter.

Any academic journal articles resulting from the project must be published in an Open Access publication.

Terms & Conditions for Research Grants

Any offer of a grant from the Sjögren's UK is subject to the following Terms and Conditions. By accepting the award of any grant offered by the charity, 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 Sjögren's UK 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, 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 Sjögren's UK.
 - iii. "The Charity" refers to Sjögren's UK
 - iv. "the Trustees" refers to the Trustees of Sjögren's UK
 - v. "The Medical Board" refers to a sub-committee of Sjögren's UK 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 Sjögren's UK Research Policy and confirms that they are accurate.
- c) The grant holder confirms that the grant awarded by Sjögren's UK 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 Sjögren's UK as soon as reasonably practicable and
 - ii. at the Trustees' discretion, the grant may either be withdrawn and repaid 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 research ethics 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 research ethics committee necessary, (if not already granted) or further approval necessary, the grant holder undertakes to seek such approval or further approval having first informed Sjögren's UK 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 Sjögren's UK 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 Sjögren's UK as to the nature, effect or risks of the grant project. Similarly, no opinion or suggestion expressed by Sjögren's UK 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 Sjögren's UK 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 Sjögren's UK 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 or other legislation or codes of practice.
 - iv. accepts that Sjögren's UK does not act as a research Sponsor and, where appropriate, has confirmed a research Sponsor for the project and will inform Sjögren's UK 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 Sjögren's UK on the degree to which material published in relation to the grant project names and associates Sjögren's UK with the project;
 - ii. the grant holder(s) should notify Sjögren's UK when any papers, abstracts or other outputs arising from the grant project are accepted for publication and provide the charity with a copy.
 - iii. permit Sjögren's UK to receive appropriate acknowledgement and, if required, recognition in respect of the grant project, any results and/or publications arising from it. All research outputs must acknowledge funding and include a disclaimer as follows: *"This project was funded by / received funding from the charity Sjögren's UK. The views expressed are those of the author(s) and not necessarily those of Sjögren's UK."*
 - iv. at all times permit Sjögren's UK to publish material which associates it with the project and identifies the general nature of the project;
- h) At all times during the course of the grant project, the grant holder will maintain adequate insurance in respect of:
- i. (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 and payment schedules
- i. Where the Trustees award a grant for a project payment will usually be made in three instalments; the first at project commencement, the second at the mid-point of the grant and the final instalment after the project ends. The second and third payments will not be made unless and until the grant holder has submitted either an interim progress report or a final report, together with a signed statement of actual expenditure and (where appropriate) of any other funds obtained from third party sources and applied to the same project.
 - ii. Subject to consideration of the interim progress report, the Trustees may, before making any second or subsequent payment, consider the results of a monitoring visit.
 - iii. The Trustees in their absolute discretion reserve the right, following consideration of the interim 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 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 Sjögren’s UK, 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 Sjögren’s UK 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 Sjögren’s UK 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 Sjögren’s UK. 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 Sjögren’s UK.
- vi. If either the grant holder or Sjögren’s UK 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 2018) 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 Sjögren’s UK when assessing applications and monitoring grants and to Sjögren’s UK accountants for independent review.

Revised: April 2025

To be reviewed: April 2028

NOTE TO APPLICANTS: The research policy and grant terms & conditions may be subject to further revision in light of any changes to requirements in the UK Policy Framework for Health and Social Care Research or Association of Medical Research Charities guidance.