

BSSA RESEARCH STRATEGY

Background

The British Sjögren's Syndrome Association (BSSA) is a charity of approximately 2500 members founded in 1985 to support patients with Sjögren's Syndrome. It produces a quarterly newsletter and other information materials for patients and the public, operates a patient helpline and has a number of formal/informal local support groups. There is an annual meeting of the membership in the Autumn. Its office is currently based in Birmingham and there is one full-time member of staff. Because of its small size the Trustees effectively operate as its management committee. There are two subcommittees - The Medical Council who meet at the AGM and a Regional Liaison Officers group who have met twice yearly over the past two years.

As a result of a legacy to the BSSA of circa £150,000 in the past 5 years the BSSA has been able to establish a more formal organizational structure, to incorporate the charity (completed 2004) and to offer an annual award of £10,000 towards research into the causes and treatment of Sjögren's syndrome as allowed for under the terms of the Memorandum and Articles of Association.

At the 2004 AGM the Trustees approved the Research Policy Document (June 2004), which sets out:

- ◆ The Trustee's discretion re the priorities of any award
- ◆ That consideration should be made of the equity of geographical distribution of awards
- ◆ The Peer review process regarding making awards
- ◆ The contractual and regulatory framework
- ◆ The requirements regarding ethical approval and sponsorship
- ◆ The timing of awards
- ◆ The reporting structure from grantholders to the BSSA

I.e. it sets out the 'how', 'who', 'where' and 'when' of the current research awards. The scope and breadth of this is limited by current financial constraints.

This document aims to set out the principles and limitations regarding the priorities for current funding and the strategy for developing increased funding in the future.

Timeframe & Stakeholders

It is intended that this document will be available for consultation by the Medical Council, the Regional Liaison Officers and members attending the 2005 AGM with the aim of having a final version for approval by the Trustees in January 2006. The strategy will cover the period up to the 2008 AGM. The intention is that an updated document will be presented at that AGM (if not before – see below). The Research Policy will also be reviewed at that time.

The stakeholders include the clinical/scientific community interested in the field of Sjögren's syndrome and members of the BSSA i.e. patients, family members and others. Following approval by the Trustees the Research Strategy and Policy will be put onto the BSSA website and members will be made aware of it through an article in the Newsletter with an invitation to feed back comments. The results of this members survey will be presented to the Trustees and to the 2006 Medical Council meeting. Any modifications to the Research Strategy arising from this survey will be incorporated into the next version of the Strategy.

Objectives

As a small charity with limited financial means and staffing resources the BSSA has to be realistic in terms of its research objectives: £10,000 per annum will not fund a major scientific or clinical project.

The objectives as discussed at the meeting of the Medical Council in 2004 therefore are to fund research that:

- ◆ Is of high quality
- ◆ Adds value by pump priming a pilot project leading to a full application for a larger award elsewhere or contributes critical funds towards a larger project
- ◆ Makes a difference to patient care
- ◆ Encourages an established or new researcher to develop an interest in the area of Sjögren's syndrome
- ◆ Will lead to a publication(s) or otherwise increase awareness of Sjögren's syndrome or the BSSA as a result of the research
- ◆ Will reflect a balance between basic science and clinical research
- ◆ Will reflect a balance between different disciplines
- ◆ Will support research by clinicians, scientists and allied health professionals if they meet the criteria set out in the Research Policy

To meet these objectives the evaluation form used by the Peer Review Panel has three components: an evaluation of the individual/group proposing to carry out the research, an evaluation of the scientific merit of the application and an evaluation of the likelihood of the research leading to a publication(s).

Priorities

Because of the size of the award the Trustees have made a specific decision not to prioritise any specific area of research. The above criteria will be applied.

Partnerships and Relationships

There are no other research charities specifically directed exclusively or largely to funding research into the field of Sjogren's Syndrome offering awards in the UK. Research charities such as the Arthritis Research Campaign (ARC) will make competitive awards to researchers in the area of Sjögren's syndrome if the applications meet their criteria.

The BSSA would regard it as desirable to develop partnerships with larger charities such as the ARC, e.g. to make a joint award and the Trustees of the BSSA have discussed this internally. Realistically a larger sum of money would need to be made available from the BSSA than its resources currently allow and therefore this is not an area that is being progressed at present. Other opportunities will be pursued on an *ad hoc* basis as and when they present themselves.

Evaluation of the current research portfolio (impact & quality of applicants)

The current scheme under the terms of the Research Policy was started in 2004. The first award was made to Professor Costantino Pitzalis of UMDS, London for the project 'Role of Lymphoid Chemokines in the organisation of the inflammatory infiltrate in Sjogren's Syndrome: relationship with disease outcome and progression to lymphoma'. This was approved for funding by the Trustees at the 2004 AGM. This was one of four applications and the Trustees were satisfied with their quality. It is too soon to evaluate the impact of this award on the objectives set out above.

Publicizing the scheme/timetable of awards

The size of the award is such that paying for advertising space in journals such as the British Medical/Dental Journals was felt to be an inappropriate use of the BSSA's resources. The award was therefore advertised in 'free' journals/newsletters in the fields of ophthalmology, oral medicine/surgery and rheumatology. In view of the quality of applications received in 2004 it is intended to continue this approach for 2005-8 although this will be reviewed annually at the Medical Council meeting.

The timetable for the awards is currently as follows: March/April – advertise the scheme, June/July – closing date, July-Sep review panel scores the applications and makes a recommendation to the Trustees, Sep/Oct Trustees & Medical Council review the recommendation and formally decide on the award.

Public support (fundraising)

In order to expand the research role of the BSSA a substantial increase in income is required. This will require a substantial increase in fundraising. In order to assist with this a fundraising strategy is being developed and this will be presented in a separate document.