

## Background

The British Sjögren's Syndrome Association (BSSA) is a charity of approximately 2500 members founded in 1986 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 and informal local support groups. There is an annual meeting of the membership in the Autumn. Its office is currently based in Birmingham and there are two members of staff. Because of its small size the Trustees effectively operate as its management committee. There is one subcommittee - The Medical Council - who meet at the AGM.

Since 2004 the BSSA has been able to establish a more formal organizational structure, to incorporate the charity (completed 2004) and to offer a number of awards of variable value towards research into the causes and treatment of Sjögren's syndrome as allowed for under the terms of the Memorandum and Articles of Association.

This document aims to set out the principles regarding the priorities for current and future funding.

## Timeframe & Stakeholders

It is intended that this (revised) document will cover the period up to the 2019 AGM.

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 available on the BSSA website. Any modifications to the Research Strategy arising from member feedback will be incorporated into the next version of the Strategy.

## Objectives

The objectives 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**

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 to funding research into the field of Sjögren's Syndrome offering awards in the UK. Research charities such as Arthritis Research UK (ARUK), The Wellcome Trust or MRC, may 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 ARUK 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. It has been successful in attracting suitable applicants and grants have been awarded following a competitive review process.

## **Publicizing the scheme/timetable of awards**

The award is advertised in appropriate journals/newsletters in the fields of ophthalmology, oral medicine/surgery and rheumatology and through fliers at appropriate national meetings.

The timetable for the awards is currently as follows: February/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 the Trustees formally decide on the award which is announced at the Charity AGM in early October.

## **Public support (fundraising)**

In order to expand the research role of the BSSA ongoing fundraising is required. The BSSA aim to award a research grant annually and reviews the amount awarded dependant on the Charities financial resources within year.