



# BSRF Research Strategy



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## **1 - INTRODUCTION**

This paper defines the BSRF's research strategy from 2015 onwards. The British Scoliosis Research Foundation (BSRF) was registered as a charity in July, 1990, and is also a Company limited by guarantee. It is the only charity in the United Kingdom that exists solely to promote research into scoliosis. The BSRF was formed by Dr Phillip Zorab and was formerly known as the Phillip Zorab Scoliosis Research Fund.

BSRF is a member of the Association of Medical Research Charities (AMRC) and abides by the Association's best practice guidelines and membership criteria.

## **2 - WHY RESEARCH INTO SCOLIOSIS IS REQUIRED**

Scoliosis is a lateral curvature of the spine that can affect all ages, but is most common in 10-18 year olds, where it affects 3-4% of the population. The cause of the disorder is not known. Approximately a tenth of those affected require specialist hospital treatment, with about 2000 surgical interventions undertaken in the UK every year. Despite continuing improvements in treatment and indications that there may be a genetic component to some forms of scoliosis, many questions remain to be answered that could contribute to our understanding of the causes, the prevention of, and the best treatments of this poorly understood condition. For example, we know very little about the mechanisms that control normal spinal growth and development after birth. What are the genetic or biochemical factors that drive abnormal spinal development? If we could identify children at risk from progressive curve development, we might be able to intervene earlier or we might find a non-surgical basis for prevention and treatment. In addition to these long-term projects, we also need to be able to improve successful outcomes and reduce the morbidity and complications associated with current treatments. Good quality research is needed to address the need to improve the quality of life for the many affected by this emotionally distressing condition.

### **3- BACKGROUND AND ACHIEVEMENTS**

● Dr Zorab was a chest physician at the Brompton Hospital, London, specialising in respiratory problems caused by scoliosis. He worked closely with Charles Manning, FRCS, at Royal National Orthopaedic Hospital, Stanmore. He was the first person to organise international symposia on scoliosis in the 60's and 70's. These meetings brought together physicians, surgeons, and scientists with an interest in children and adults with scoliosis. As a result of his first symposium, he set up a research collaboration with Dr Yves Cotrel at Institute Calot, Berck Plage, France, looking into the possibility that a disturbance of bone collagen was a cause of the disorder. He subsequently directed research into the muscle structure and function in scoliosis. The symposia also stimulated research into scoliosis worldwide and the formation of the British Scoliosis Society and the Scoliosis Research Society in the USA.

● The BSRF has funded projects all over the UK and have worked with leading basic scientists and clinicians in scoliosis and allied fields. More than 50 projects have been funded so far, with a total committed expenditure of more than £700 000. Our portfolio includes research looking at all forms of scoliosis, with special interest in the causes and management of idiopathic scoliosis.

● The BSRF also continues to hold internationally acclaimed symposia, known as the 'Zorab Symposia', to spread the knowledge gained from research. These symposia now take place every two years, with the next one due in 2019. The 14th Zorab Symposium was held in London in June, 2017.

### **5 - VISION AND MISSION**

The BSRF's vision is to have contributed within 10 years to discovering the cause of idiopathic scoliosis so as to improve quality of life for people with all types of scoliosis. The organisation's mission is therefore to stimulate and finance high-quality research into:

- The causation of, prevention of, and potential cures for idiopathic scoliosis.
  - The assessment of new forms of treatment – surgical and otherwise.
  - The encouragement of basic scientific research that might add to knowledge of the changes in scoliosis.
- It also aims to support research by young surgeons to stimulate an interest in scoliosis in newly qualified doctors.

### **6 – PRIORITY AREAS FOR RESEARCH FUNDING**

- a. The aetiology and pathogenesis of scoliosis (to include genetics, endocrinology, neurology, biomechanics, and other related topics).
- b. The prevention, management, and treatment of scoliosis (assessment of new treatments, clinical trials and long-term outcomes).
- c. Scoliosis in related conditions such as spina bifida, cerebral palsy, and muscular dystrophy.
- d. Respiratory and cardiovascular aspects of scoliosis.
- e. Neurophysiological aspects of spinal deformities.
- f. Creation and maintenance of a scoliosis patient database with genotype and phenotype information available to scoliosis researchers around the world.

### **7– UNDERLYING PRINCIPLES IN RESEARCH DELIVERY**

- a. To promote the case for new research into the aetiology of scoliosis to the scientific community in Centres of Excellence.
- b. To promote the assessment of operative techniques and other treatments and their short-term and long-term outcomes.
- c. To support, in cooperation with sister organisations such as the Scoliosis Research Society and the Cotrel Foundation, the undertaking, publication, and discussion of new research into the aetiology of scoliosis.
- d. To provide a regular forum for bringing together leading international scoliosis researchers for improving understanding and stimulating new research.

## **8 - THE BSRF GRANT CATEGORIES**

The BSRF General Research Grant is open to appropriately qualified professionals such as scientists, clinicians, and allied health professionals (eg, nurses, psychologists, and physiotherapists). All applications will be considered. However, applicants are advised to submit their proposal under one of the following three headings:

- **Small exploratory grant**

This grant is designed specifically for new investigators who have a preliminary idea they would like to develop into a research project. The maximum grant award for this category is £15,000. The maximum duration of research is one year. This grant does not require pilot data. It should, however, be able to generate pilot data that could be used when applying for a larger grant.

- **New investigation grant**

This grant is specifically targeted to new investigators. The maximum award is limited to £40,000; however, the duration of research may extend up to two years. Some preliminary data would be desirable although not absolutely required.

- **Major research grant**

This grant is awarded a maximum of £100,000 per year up to two years' duration. These grant applications may be in any area of spinal deformity research. These grant applications require evidence that the investigator has the experience and resources to complete the proposed research. As such, preliminary data are generally required. Such grants will be awarded only for outstanding

## **9 - THE BSRF SELECTION PROCESS**

- The BSRF will consider applications from appropriately qualified professionals such as scientists, clinicians, and allied health professionals. The lead applicant should be employed by a university, hospital, or other recognised research centre institution.
- The BSRF is currently only considering applications for research projects based within the British Isles or, if from outside the British Isles, applicants must be partnered with a British research centre.

## **10 - APPLICATION PROCESS**

The BSRF's ability to fund research is highly dependent on the level of funds raised for the purpose of research, and this funding level is reviewed annually in November to set the level of grant funding available for the following year.

The Grants Committee assesses applications twice a year. The first deadline is the 31st January with the grant being awarded in June. The second deadline is the 30th June with the grant being awarded at the end of November.

## **11 - REVIEW PROCESS**

All applications are initially reviewed internally by BSRF's Grants Committee. Among the factors taken into account during this initial review will be the quality of information provided, the clarity of the research hypothesis, the utility of the expected research outcomes, the realism of the cost estimates, and the affordability of the project. Those projects that are prioritised to be taken further are then sent to external international experts for written peer review. Once these reviews have been received, the Chair of the Grants Committee prepares a report for the BSRF Council, making recommendations on approval or rejection for all the grant applications received. In some situations, where a clear decision is not reached by the Council, the comments of the Grants Committee and the peer reviewers are fed back to the applicant, who is then invited to resubmit the application, taking into account the feedback received. All applicants are informed in writing of the out-come of their application and, in the event of a rejection, there is an appeal procedure available, where applicants can review in detail and challenge the reasons for the rejection.

For successful applicants, funds are usually provided in two tranches, 50% once all the starting criteria such as obtaining Ethics Committee approval have been met and 50% once the Final Report on the research has been received.

## **12 - GUIDELINES ON AMRC GOOD RESEARCH POLICY**

The BSRF, as a member of the Association of Medical Research Charities, follows the AMRC 'Guidelines on Good Research Practice' which cover ethical practices for animal and human research, intellectual property, researcher integrity, publication practice, supervision and training of researchers, amongst other matters.

## **13 - ROTATION OF GRANTS COMMITTEE**

**a.** Individuals will be invited to be members of the Grant Review Panel for a term of three years. This can be extended for up to three years by agreement between the BSRF, the Chair of the Grant Review Panel and the individual concerned, to ensure a rolling turnover of Grant Review Panel members.

**b.** Grant Review Panel Chairs will also be invited for a term of three years, which can be extended for up to three years by agreement with the BSRF.

**c.** Following resignation from the panel after two consecutive terms, panel members are eligible to apply for panel membership after a period of absence of three years.

## **14 - BSRF PARTNERS**

**SAUK** - The BSRF is affiliated with the Scoliosis Association UK (SAUK) – the national patients' support organisation. SAUK was founded in 1981 and is the only independent support group for scoliosis in the UK. SAUK aims to provide information about scoliosis to adults, adolescents, and their families, and offers contacts for shared experiences. This affiliation has enabled a clearer understanding of patients' concerns in selecting research projects for funding and a stronger core of fundraising activity to generate new funds for research.

**BSS** - The BSRF also work closely with The British Scoliosis Society (BSS). The BSS is the organisation for doctors specialising in the treatment of scoliosis. The BSS was established in 1975 to advance the study of, research into, and treatment of scoliosis and other spinal deformities for the public benefit. The object of the British Scoliosis Society is to provide an open forum for scoliosis surgeons, scientists, and health care professionals to engage in debate about scoliosis aetiology, pathogenesis, and treatment, and the presentation and encouragement of scoliosis research. The BSS provides BSRF with funds for research and holds regular meetings where BSRF-funded research results can be presented and discussed.

## **15 - STRATEGY DEVELOPMENT**

This strategy has been developed in conjunction with the Scoliosis Association (UK), the British Scoliosis Society, and the Council members of BSRF. It reflects a number of regular discussions at Council meetings on how best to achieve the organisation's Mission. The Strategy was approved by the Council meeting in September, 2013, and was reviewed again in 2017.