

Research Strategy

1 - INTRODUCTION

This paper defines the Scoliosis Support and Research (SSR) research strategy from 2015 onwards. SSR is the only UK wide organisation providing support for people affected by scoliosis and funding research into scoliosis and other spinal conditions in the UK.

SSR 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, specializing 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.

SSR 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.

SSR 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-three years.

4 - VISION AND MISSION

The SSR'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.

5 – 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

6 – 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 - SSR GRANT CATEGORIES

SSR Research Grants are 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 applications.

8 - SSR SELECTION PROCESS

- SSR 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.
- SSR 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.

9 - APPLICATION PROCESS

The Grants Committee assesses applications throughout the year.

10 - REVIEW PROCESS

All applications are initially reviewed internally by SSR'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 SSR trustees, making recommendations on approval or rejection for all the grant applications received. In some situations, where a clear decision is not reached by the trustees, 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.

Funds are provided to successful applicants subject to adherence to the standard research agreement.

11 - GUIDELINES ON AMRC GOOD RESEARCH POLICY

SSR 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.

12 - ROTATION OF GRANTS COMMITTEE

- a.** Individuals will be invited to be members of the Grants Committee for a term of three years. This can be extended for up to three years by agreement between SSR, the Chair of the Grants Committee and the individual concerned, to ensure a rolling turnover of Grants Committee members.
- b.** Grants Committee Chairs will also be invited for a term of three years, which can be extended for up to three years by agreement with SSR.
- c.** Following resignation from the panel after two consecutive terms, committee members are eligible to apply for committee membership after a period of absence of three years.

13 - SSR PARTNERS

SSR 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 SSR with funds for research and holds regular meetings where SSR-funded research results can be presented and discussed.

14 - STRATEGY DEVELOPMENT

This strategy has been developed in conjunction with Scoliosis Support and Research, the British Scoliosis Society, and the SSR trustees. It reflects a number of regular discussions at trustee meetings on how best to achieve the organisation's Mission. The Strategy was approved at the trustee meeting in September 2013, and was reviewed again in 2017.