

Funding Research into Spinal Injury

Background. INSPIRE is a medium sized, national charity which raises funds for a scientific programme to ‘research independence, quality of life and dignity after spinal cord injury’ (SCI). Such injuries are life changing, often permanent and affect approximately **50,000** people in the UK, with three new cases every day. Unlike other larger research charities, we receive no NHS or Government funding support, so we absolutely depend on support of grant making trusts.

Management. Our office is located in Salisbury adjoining one of the UK’s 11 spinal injuries units. With a small part time staff, **Director Rory Steevenson** undertakes all fundraising, the management of the research programme, publicity and the programme of events. He acts as Secretary to the charity’s two executive **Governing Bodies:**

1. The National Scientific Committee (NSC). The NSC consists of eleven subject matter experts from universities and hospitals throughout the UK, from Aberdeen to Southampton and Newcastle to Glasgow. They meet twice a year in London at the **Royal Society of Medicine** to monitor and assess current projects and consider new research applications. Their focus is on ‘rigorous scientific relevance and merit’. Those new applications it recommends are then submitted for Trustees’ funding approval.

2. The Board of Trustees. With backgrounds in business, medical science and law, Trustees also meet biannually to ratify the NSC’s recommendations. They are also responsible for managing the charity’s Five Year Research Programme and overseeing other funding and management issues. Three Trustees live with the effects of SCI.

Patronage and Membership. We enjoy the support of 16 **Patrons** from a disparate array of backgrounds. Their non-executive role as ‘roving ambassadors’, ensures our cause is known within their professional and social circles. Six of our Patrons including Baroness Masham of Ilton live with SCI, three of them as a result of horse riding accidents. We also have a wide network of friends and voting members across the UK. We have dispensed with joining fees and annual subscriptions but enjoy regular voluntary donations throughout the year.

What is spinal cord injury? SCI is a neurological rather than orthopaedic condition, often caused by the catastrophic dislocation of vertebrae. ‘Broken backs’ and ‘broken necks’ normally relate to damaged nerves in the spinal column rather than broken bones, which can repair with time. The spinal column shields a complex array of delicate nerves relaying ‘motor’ messages from the brain to the body and communicating ‘sensory’ messages back to the brain. When spinal nerves are damaged, functionality and sensation below the level of the ‘lesion’ is impaired and can be lost altogether. Currently, severed spinal nerves cannot be repaired.

Tetraplegia/Paraplegia. A high spinal lesion in the neck (Tetraplegia) can result in impaired hand and arm function, upper trunk problems and breathing issues. In extreme cases, the use of a mechanical ventilator may be necessary to ensure a constant supply of oxygen to the lungs. One of our current projects in Glasgow ‘Abdominal FES’, is addressing this very issue. Lesions in broken backs (Paraplegia) can result in lower body issues, especially paralysis. All those who experience SCI are likely to encounter bladder, bowel and pain issues as well as frequent and recurring pressure sores, sometimes many years after their injury.

Areas of Research Interest. Our areas of interest focus on quality of life and independence and include bladder and bowel function, hand function for Tetraplegics, mobility for Paraplegics and pain management. We are also keen to develop research into pressure sores.

Caveats. The INSPIRE Foundation's commitment is to SCI and nothing else. Our specific purpose is in researching practical issues that could benefit people living with the effects of SCI anywhere in the UK. We do not sanction R & D for commercial manufacturers nor do we address 'the cure'. Instead our focus is on improving the lives of those living with SCI.

INSPIRE Foundation PhD Scholarship. Our PhD Scholarship enables Master's students to embed with INSPIRE funded project teams while completing their thesis. Recent scholars include Dr Sean Doherty (who qualified in 2019) now a lead scientist at UCL on NEUROMOD II, Alison Symon, on the SPINAL PAIN team at QENSIU Glasgow and from the Netherlands, Joeri F.L. van Helden at University of Birmingham working on TRUNK FUNCTION.

INSPIRE's journey. Our research started in 1987, but in the last 10 years we have seen considerable growth.

1. **Research.** Ten years ago, our commitment was to a medical survey and one project costing **£37,000**. Today's five year programme of nine projects is costing **£1.5 million**. Our projects (some multi-sited) are in Salisbury, our home base, four in Glasgow and others in London, Stoke Mandeville, Birmingham and Bournemouth. Our 3 year average annual research expenditure until 2020 was **£269,873**, reduced by the pandemic to **£156,775** in 2021/22.

2. **The need for further Fundraising.** Our 'chicken & egg' evidence proves that good quality projects are still the catalyst for successful fundraising. To date we have secured **£600,000** towards the programme, so while we have made considerable headway, we still have a financial mountain to climb. The difficult pandemic period made this especially challenging but we are persevering and making gradual headway. The irony is that we have a considerable list of scientists with new exciting projects currently on hold and if only we had the funds, we could develop and expand our programme further.

Profile. As a relatively small charity, our profile is not inconsiderable. The NSC has its London base at the **Royal Society of Medicine in London**. We are registered with both the **Charity Commission** (No. 296284) and **Scottish Charity Regulator** (No. SC048863) and our membership with the **Association of Medical Research Charities (AMRC)** was re-confirmed with the successful 5 Year Audit on 2 September 2021.

COVID-19. The pandemic clearly presented significant challenges, in running existing and new projects and our ability to raise funds. For nearly 2 years, our programme was caught up in a national embargo on medical research hampered by the SCI community being shielded while placed in the extremely vulnerable category. As normality re-emerges, we look forward to our programme gradually gathering momentum. However, we do not underestimate the time it may take to re-discover our exciting pre pandemic tempo. For further information please visit our website, email office@inspire-foundation.org.uk or call 01722 425098 at any time.



Rory Steevenson
Director

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www.inspire-foundation.org.uk