

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 are committed to generating all necessary funds.

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 usually 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, this Board also meet biannually to ratify the NSC’s recommendations. Trustees are 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. Having recently dispensed with joining fees and subscriptions, we prefer and enjoy regular voluntary donations at any time.

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 usually mend 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. INSPIRE is currently funding project ‘**Abdominal FES**’, in Glasgow 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, Pain management, Pressure sores and Sexual function.

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 what is sometimes referred to as, 'the cure'.

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 project TRUNK FUNCTION.

INSPIRE's journey. While our research started in 1987, our last 10 years are summarised here:

1. **Research.** In 2012, our commitment was to a medical survey and one project costing **£37,000**. Today's five year programme of nine projects is costing **£1.4 million**.

2. **Fundraising.** Our 'chicken & egg' evidence proves that good quality projects are the catalyst for successful fundraising. Our current audit is still underway but in the difficult COVID year, our income was approximately **£211,300**. Recent audited figures were:

	FY	Income	Av. Research Expenditure
Av. audited income	FY 2010-16	£120,679	£104,973
Av. audited income	FY 2017-20	£328,711	£269,873
Actual audited income	FY 2020-21	£214,904	£185,666

3. **Research Footprint.** We are now funding one project in Salisbury, our home base, but our footprint is national with NSC scientists from the north of Scotland to Southampton, four projects in Glasgow and others in London, Birmingham, Bournemouth and Stoke Mandeville.

4. **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. SCO48863) and our membership with the **Association of Medical Research Charities (AMRC)** was re-confirmed for a further five years on 2 September 2021.

5. **COVID-19.** The pandemic has presented significant challenges, both in our ability to conduct research and of course to raise funds. For eighteen months, our programme was caught up in a national embargo on medical research in hospitals and many universities with the SCI community placed in the vulnerable category and unable to assist in our projects. As the UK slowly emerges from COVID-19, we look forward to our programme re-gathering momentum although we do not underestimate the time it may take to find our exciting pre pandemic tempo.



Rory Steevenson
Director

www.inspire-foundation.org.uk

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