

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 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. Four Trustees live with the effects of SCI.

Patronage and Membership. We enjoy the support of 13 **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. Five of our Patrons live with SCI. 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 debilitating pressure sores sometimes many years after their injury.

Areas of Research Interest. Our areas of interest are: Bladder and Bowel function, Hand function for Tetraplegics, Mobility for Paraplegics, Pain management, Pressure sores and Sexual function. We welcome new SCI research enquiries in any of these areas at any time.

Caveats. The INSPIRE Foundation's commitment is to SCI and nothing else. Our specific focus 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'.

Projects in outline. Projects tend to be of 18 months – 42 months in duration. We are also committed to and very proud of, the '**INSPIRE Foundation PhD Scholarship**' which enables PhD students to research a thesis in an SCI related subject, while working for 3 or 4 years within a world class research team. Recent scholars include **Dr Sean Doherty** (who qualified in 2019) now working on **NEUROMOD II** at University College London and **Alison Symon**, currently working with **Dr John Riddell** on the **SPINAL PAIN** team, at the Queen Elizabeth University Teaching Hospital in Glasgow.

INSPIRE's evolving journey. Raised in 1987, the last ten years are summarised below:

1. **Research.** In the difficult financial climate of 2012, INSPIRE was able to fund two projects costing **£37,000**. Today's five year programme of nine projects is costing **£1.4 million**.

2. **Fundraising.** The 'chicken & egg' evidence summarised below, is that good quality projects are the catalyst for successful fundraising, in turn the key enabler for more research.

	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 2019-20	£257,787	334,576

3. **Footprint.** We are funding one project in Salisbury, the charity's home base, but our national footprint includes scientists from all over the UK with four current projects in Scotland and others in Birmingham, Bournemouth, Stoke Mandeville and two in London.

4. **Profile.** As a relatively small charity our profile is not insignificant. The NSC has established its base at the renowned **Royal Society of Medicine (RSM)**, convenient for 'up country' members and more viable than other regional options. We are members of the **Association of Medical Research Charities (AMRC)** and are registered both with the **Charity Commission** (No. 296284) and the **Scottish Charity Regulator** (No SCO48863).

5. **COVID-19.** The pandemic has presented significant challenges in research and financial terms. After a very promising start to this FY, it became evident in early 2020 that there was unusual pressure on normally supportive grant making trusts to consider other new causes. This is reflected in a lower than average income, currently **£105,000**. In addition, many universities and hospitals had to scale back their research, causing delays to some of our projects. We predict an easing of this impasse and look forward to increased funding and research in the New Year.



Rory Steevenson
Director

27th November 2020

www.inspire-foundation.org.uk

'...researching independence, quality of life and dignity after spinal cord injury...'