

CONNECTIONS

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Restoring Function

Research on different techniques aimed at improving and restoring limb function for our community. (Page 6)

A Complex Challenge

A look at the biology behind tetraplegia and how it affects so many of our supporters. (Page 3)



Understanding Tetraplegia, Restoring Function,
Fantastic Fundraisers, Meet the Team, Leaving a Lasting Legacy.

Dear readers,

Welcome to your new look 'Connections' regular newsletter! My name is Andy Russell and I'm part of the Marketing and Communications team here at Spinal Research. I suffered a C4/5 spinal cord injury as a student which means I am a full-time wheelchair user with limited upper body movement and function. Even though I had my accident over 25 years ago, adjusting to my "new" body still feels like a very surreal challenge. Like most with similar injuries, one of the hardest adjustments has been my lack of hand dexterity and arm function. Everyday tasks such as holding a cup of coffee, picking up a pen, or even brushing my teeth take time and concentration. But, without sensation in my hands, it's the little things like the feel of different temperatures, the sensation of running water, and even holding hands with loved ones that I miss the most.

At Spinal Research, our work focuses on restoring lost function for those with paralysis. Today, with more than a hundred institutions focused on research into spinal cord injury, and multiple trials taking place around the world, it feels like the first-generation of life-changing treatments are within our grasp. Now more than ever, your support is crucial to ensure these promising treatments progress and go on to transform the lives of those living in our community.



Thank you,

Andy Russell

Marketing and Communications Manager.



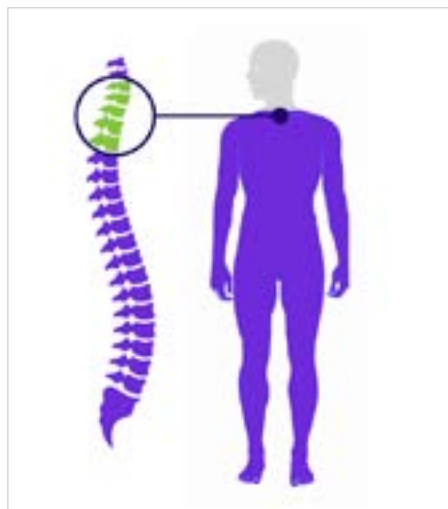
A complex challenge

Understanding tetraplegia

It's estimated that someone has a spinal cord injury every four hours in the UK and Ireland, with over half of injuries resulting in reduced sensation or function in all four limbs. We take a look at the biology behind tetraplegia and highlight some of the implications for so many of our supporters.

Disruption to the body's superhighway

The spinal cord enables communication between the brain and the rest of the body. It contains nerve cells, called neurons, and bundles of nerve fibres, or axons, that carry signals to and from the brain. Unfortunately, any damage to the spinal cord can disrupt these communications, impairing critical 'functions' we take for granted. How and where this damage takes place to the spinal cord will determine which functions will be affected, and how an individual's life will change.



Area of spinal cord injury that causes tetraplegia - loss of limb function and complete paralysis below the neck.

A cocktail of complications

The lack of movement and control associated with tetraplegia, limits the ability to perform simple, everyday tasks, drastically impairing the ability to live independently. Without sensation, there is an increased risk in secondary health complications, including pressure sores. In some cases, the injury can disrupt one's ability to breathe independently, which leaves many dependent upon ventilatory support. Extremely personal routines, such as bladder and bowel management, may not be able to be performed independently. Beyond the immediate physical health challenges, tetraplegia imposes significant social, economic, and lifestyle limitations. Carer dependency for daily tasks affects an individual's independence and privacy, potentially leading to emotional and psychological distress.

Focus for research

There are a number of exciting treatments in development designed to restore function for those living with tetraplegia. New technology, such as brain-spine implants, can circumnavigate the damage to the spinal cord, wirelessly taking signals from the brain to the spinal cord. At Spinal Research we have a number of studies looking specifically at restoring upper limb function, some of which are profiled in this issue of Connections.

Meet the researcher

Dr Shin-Yi Chiou



Dr Shin-Yi (Chloe) is a researcher at the University of Birmingham. Combining her passion for research, rehabilitation, and working with patients, Chloe is working to restore trunk function for those with SCI.

Did you always want to be a scientist?

Growing up I wanted to be a teacher. But I read a book by a scientist called Richard Feynman and I thought how cool it would be to be a scientist. My role as a clinical scientist means I can work with people alongside my passion for research.

How did you progress into your current role?

I trained as a physiotherapist in Taiwan and spent six months in the neuro rehab facility. This really changed my horizons and led me to do a PhD in neuro rehabilitation. I then transferred to Imperial College London for my post doctorate, where I started working with those with spinal cord injuries. I then took the position at the University of Birmingham which brings together my interest in research and rehabilitation.

Can you tell us about your current research study?

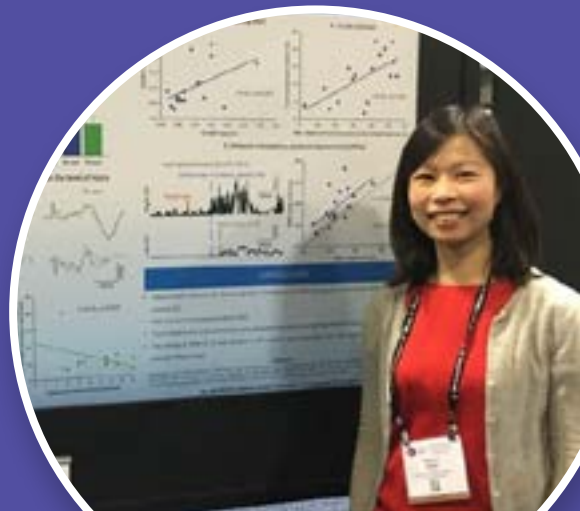
Trunk control is such an important function affected by spinal cord injury. My research is looking to create an accessible, patient led rehabilitation programme which uses the upper body to increase trunk motor control. One technique we are exploring is

using an arm crank hand cycle device which we combine with a “peleton” style experience i.e. using a virtual track, guided video, and music to make the exercise more interactive and interesting.

How will your research help the SCI community?

The main driver is to improve trunk and motor control within the home environment. Since we can deliver the project virtually, it means we can bring research based clinical science to the community. From a neurological perspective, we’ll use a number of different scientific measurements to assess the impact of the programme. This includes measuring electrical activity within the nerves and muscles, as well as the speed and size of nerve responses to stimulation.

“ There are so many trials taking place now, we need participants to get involved! ”



Developing new research

Ellinor Michel



With more and more research trials looking for participants, we spoke to Ellinor Michel, a member of the SCI community and recent volunteer.

Tell us a little about yourself

I am a biodiversity researcher, originally from the US but now fully settled in London, working at the Natural History Museum. I am an evolutionary biologist and I specialise in freshwater animals in the Great Rift Lakes of Africa.

Can you describe the nature of your injury?

In 2000, I developed an infection on my spinal cord which damaged my vertebrae and later led to a spinal syrinx. This “bubble” in my spinal cord presses on and destroys the nerves in my neck, or cervical region. Although my injury is currently classed as incomplete, the condition is degenerative.

How does this affect your day-to-day living?

I have all the usual “downstream” problems from a high-level (neck) injury. Although I can stand and walk for limited distances, my upper body is weak and my hands have very limited function. The issues I face range from lack of proprioception (feeling where my limbs are), to bowel and bladder trickiness, to lack of temperature regulation and autonomic dysreflexia. It's a fascinating set of problems, but makes daily living very difficult without support.

Can you tell us about your experience in a research trial?

My involvement took place over three months at the University of Leeds, testing the effectiveness of transcutaneous (over the skin) electrical stimulation on restoring upper body function.

What did this involve?

My trial involved passing a modulated electrical current across the site of my injury using electrode pads on my neck. I would then repeat a number of simple manual tasks, e.g., moving small pegs with my hands, drawing, and lifting light resistance. The results were compared between the ‘treatment’ and ‘control’ sessions, that’s with and without the stimulation ‘zapping’, and any changes were tracked over time.

What were the results?

Trial participants showed different responsiveness to the treatment of ‘zapping’ plus training. Some had a dramatic improvement in manual function. Others showed no measurable change. I had a measurable, small positive response, but did not gain a significant or long-term increase in function over this timeframe.

Could you help develop new research?

Find out how to get involved in a trial, just visit: spinal-research.org/home/our-research/take-part-in-research

Restoring function

Arm and grasp

Sensation and function is often lost below the level of spinal injury. We are running a number of research projects, using different techniques which aim to improve and restore these important functions for our community.

PROJECT 1

University of Glasgow

Determining the effects of electrical spinal stimulation in chronic (long-term) complete tetraplegia.

- Stimulation of the spinal cord through modulated electrical pulses has shown the potential to restore function post injury.
- Stimulation can be delivered safely through the skin. This is known as transcutaneous stimulation.

In a nutshell

Building on promising results from previous studies, this study aims to investigate the use of transcutaneous spinal cord stimulation (tsES) in the recovery of function and sensation. The stimulator used in this study could become a low-risk treatment and can easily be adopted in rehabilitation or community settings. There is a potential for individuals with SCI to benefit from the recovery of lost sensory and motor function with lasting improvements leading to increased independence and quality of life.



PROJECT 2

University of Birmingham

Using arm crank exercises (ACE) training to enhance recovery early after spinal cord injury.

- Arm crank exercise training (ACET) can be delivered using an ergometer. This is an inexpensive exercise machine that can test the exertion produced by muscles.
- Researchers are now hoping to investigate the effects of ACET on motor function, focusing on individuals who have been injured for less than three months.
- Participants will undergo a series of exercise sessions and later be assessed using an array of functional recovery assessment tools.

In a nutshell

Studies have shown that early rehabilitation post injury can improve upper limb function compared to later interventions. This study will use arm crank exercises with patients who have been injured for less than three months to monitor and measure functional, as well as neurological changes, in the spinal cord.



Meet the team

Shajia Shahid



Introducing Shajia Shahid, our new Clinical Research Network Manager. Shajia has joined the team to increase collaboration between researchers and clinical institutions, accelerating the development of new treatments for those with SCI.

Can you tell us a little bit about your background?

After completing my undergraduate degree in neuroscience, I was selected to undertake a training programme, specialising in neurophysiology (the study of nerves). As part of my training, I completed a Masters in Clinical Neurophysiology. With my last role, I worked as part of the surgical team monitoring the health of the spinal cord, whilst undergoing spinal operations.

Can you tell us about your new role?

My new role at Spinal Research is Clinical Research Network Manager. My role involves fostering collaboration among researchers, medical professionals, and institutions, at both a national and international level. This allows them to bring together resources and share knowledge to accelerate progress in the development of treatments and care standards for people with spinal cord injuries.

What are you looking forward to in your new role?

I am excited to visit spinal cord injury centres across the UK. It is a fantastic opportunity to meet with clinicians in the hospitals, and researchers to understand the similarities and differences across different units. I am also looking forward to planning the network's upcoming meeting in June, where we will have the opportunity to get together in person for the first time.

How will this help our mission to cure paralysis?

It is essential that we bridge the gap between clinicians and researchers across the UK, and support them to work together. By establishing a robust network of clinicians, healthcare providers, and researchers, I believe that we will be able to help share ideas, data, and resources. This will allow us to collectivise expertise, which can be used to drive meaningful research initiatives and help the community.

Why not reach out and say hi?

If you like to find out more about Shajia and her new role please email: shajia@spinal-research.org

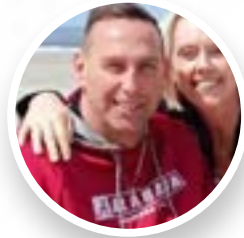
Fantastic fundraisers

With the better weather coming, it's a busy time for our fundraising team and amazing supporters. Every pound raised means we can support more life-changing research projects, bringing us ever closer to a cure for paralysis.

Meet the Fantastic Four - the incredible fundraisers who are pushing themselves to the limit through ambitious personal challenges to raise vital funds to advance research.

Shaun

In October, Shaun will be embarking on a 300km canoe trip down the Zambezi River. He will be joined by two other paraplegics, Michelle and Liam, for an epic 5-day adventure.



Jon

Jon will be climbing the summit of South Wales's highest mountain with a 28-strong team of friends and family. Jon will be using a specially adapted wheelchair made for him by his engineer brother, Jamie.



Lloyd

As well as joining Jon on his epic mountain climb, Lloyd Collier will travel to the Sahara just six days later to take on the gruelling Marathon Des Sables: a 250km trek over 5 days through the Sahara desert of Morocco, enduring average temperatures exceeding 40°C.



Connor

Family and friends of Connor, who was paralysed after a university rugby match, are aiming to cycle nearly 1,100 miles from Land's End to John O'Groats. With a custom-made hand cycle, Connor is also hoping to join the Scottish leg of the challenge with family members and friends.



Big thanks

These are just a few of the people who have helped make a difference. A big thank you goes out to each and every one of our supporters who, together, form #TeamSpinal!

Meet two remarkable #TeamSpinal members who ran the London Marathon 2024!

Andy

Devon policeman, Andy Elliott, tackled the 26.2 miles in a standard wheelchair in tribute to his close friend, Andrew Russell, who suffered a spinal cord injury over 25 years ago.



Pete & Vince

Pete Linnett, Britain's strongest disabled man, and his training partner, Vince Sutton, tackled the London Marathon on April 21. For every 5 minutes Vince ran, Pete bench pressed 60kg ten times – all to support Spinal Research.



Could you be a hero and help us to find a cure?

Fancy taking on a personal challenge to raise vital funds for research? Scan the QR code below for inspiration and ideas for how to get involved.

Some upcoming events and ideas:

- Great North Run
- Three Peaks Challenge
- Royal Parks Half Marathon
- Parallel Windsor
- Alpine Experience



What your legacy could achieve



People like Bel have had to live incredibly difficult lives due to spinal paralysis. More funding could help us find a cure.

Hoping for a brighter future

Bel was just eight years old when she fell from a climbing frame and sustained a spinal cord injury that left her paralysed from the top of her shoulders down. It was the sort of tumble a child has every day. But for Bel, it had devastating consequences. "I was playing in a neighbour's garden; I lost hold of the climbing frame and fell. I was rushed to hospital where the doctors found I had broken my neck." Bel spent months in intensive care and she remains paralysed with a C2 injury. Whilst she has learnt to breathe via her tracheostomy tube, she remains dependent on a ventilator at night. Today, Bel is a Fundraising Assistant here at Spinal Research.

“ I'll never give up hope. I know that science will find a way to cure my paralysis. All it will take is more research. ”

Your gift could make a big difference

Our most recent projects include clinical studies for restoration of hand and arm function, bladder and bowel function, and the reduction of debilitating nerve pain. We know that improvements in these functions will have an enormous impact on the independence and overall quality of life for people living with paralysis. This life-changing work is only made possible through the generosity of supporters like you.

By making the incredible decision to include us in your Will, you can become part of our mission to transform lives and create a world where paralysis is no longer a life sentence. To find out more and learn about our free Will writing service, scan below.



Puzzle time

Just for fun, test your grey matter and see if you can solve these puzzles!



WORDSEARCH

Word searches are easy, right? How quickly can you find all the words listed below within this grid?

| | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| G | G | A | T | E | R | P | B | O | A |
| T | H | E | R | A | P | Y | I | H | I |
| S | E | E | D | S | E | L | R | C | G |
| S | S | C | I | F | A | N | D | R | E |
| L | I | G | H | N | Y | I | S | H | L |
| B | R | E | I | U | C | A | Q | E | P |
| G | R | P | D | N | L | R | K | N | A |
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| H | C | R | A | E | S | E | R | X | P |

PARAPLEGIA GENE PHD
 SPINAL THERAPY HAND
 RESEARCH SCI BRAIN

SUDOKU

Use the numbers 1-9 to complete the Sudoku. Only use each number once in each row, column and grid.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 3 | | 4 | | | | 8 | 5 |
| 8 | | 4 | | 3 | 2 | | | 1 |
| | 1 | | | | 5 | 7 | | |
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| | 6 | 9 | | | 7 | 5 | 2 | 4 |
| 5 | | | 6 | | | | | |
| | | 1 | | 7 | | | 5 | 9 |
| 3 | 2 | | | 4 | 8 | 1 | | |
| | 9 | | | | 6 | | | 2 |

SPOT THE DIFFERENCE

See if you can find all five differences between the images below.



Dates for your diary



Wednesday 16 October 2024

Wetherby Race Day

Wednesday 28 May 2025

Alpine Experience – secure your place on the team!



**spinal
research**

Ambassador applications are open!

Spinal Research Ambassadors are a group of passionate supporters with one common goal – to help cure paralysis. We are always looking to welcome new members into our ambassador family. If you're interested in this role, please visit: spinal-research.org/ambassadors

Feel free to get in touch

If you have any questions about anything in this newsletter, please don't hesitate to drop us a line. You can write a letter, email, or pick up the phone. Our office and phone lines are open Monday to Friday 9am – 5pm.



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Curing paralysis together
spinal-research.org

