

SUMMER 2021

SPINAL NEWS

**CYCLE THE
ALGARVE
CHALLENGE**

**Pre-Budget
Submission
re Medical Cards**

**Bowel and Bladder
Survey Results**



jii Spinal
Injuries
Ireland
Support at every stage

Delia



Cycle the Algarve

9th - 16th October 2021

sii Spinal
Injuries
Ireland
Support at every stage

Supporting Seriously
Injured Players
IRFU
CHARITABLE
TRUST
IRFU

Tel: 01 653 2180
spinalinjuries.ie/cycle

ALL LEVELS OF EXPERIENCE AND ABILITY CATERED FOR

All EU Covid guidelines will be strictly adhered to.

Spinal Injuries Ireland and the IRFU Charitable Trust are co-hosting an accessible cycling challenge in the Algarve from 9th to 16th October 2021.

- 5 days cycling, a different route each day
- a choice of 3 routes of varying distances available each day to cater for all levels of experience and ability (over 100 Kms per day for advanced cyclists).
- support van with spare parts, nutrition and collection option available each day.
- both able bodied and disabled cyclists welcome.

Fundraising: €3,700 (€300 non-refundable deposit plus €3,400 additional fundraising)

A reduced cost of €2,000 will be made available to partners of participants. Partners will not take part in the cycling and are free to explore Quinta and/or enjoy the hotel on a daily basis.

COVID-19: all health and safety measures will be in line with EU guidelines with a designated Covid Officer to ensure compliance.

WHAT'S INCLUDED:

- Return flights Dublin to Faro
- Transfers to and from airport and group activities.
- 7 nights shared accommodation * and full board at the 5 star Wyndham Grand Algarve
- 5 days cycling including ** bike hire, guided routes, support van, rest day group activities (see provisional itinerary)
- Farewell meal on the last night in Bovino Steakhouse

**single rooms are available with a single supplement*

*** specially adapted bikes and hand bikes will need to be supplied by the participant*

Visit spinalinjuries.ie/cycle to register your interest or phone Phil on 01 6532180



WELCOME

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This magazine contains real life features and SII does not endorse any products or services listed within.

It is hard to be believe we are almost three quarters way through 2021 and 18 months in to Covid 19. Let's hope that the vaccination programme will work against the virulent Delta variant and let us get back to some form of normality.

We are working away online with our Community Team keeping in contact with our service users by phone and zoom and as I write we are currently planning our autumn and winter online schedule of peer support coffee mornings and education sessions. We are receiving incredible feedback about the online coffee mornings. Many service users like the fact that they do not have to leave their own homes to have a chat with their peers who have similar injuries to themselves. We have heard some great feedback of people connecting from all parts of the country or people who had been in the NRH together and had not been in contact in years. If you have not joined a coffee morning, look out for them in the autumn and try one out.

Of course, the highlight of the winter schedule will be the Annual Conference on 20-22 October which will feature national and international speakers and the latest news from the spinal cord community.

Thank you to everyone who responded to our two surveys over the last few months and we are happy to publish the results of both in this magazine. Our new website is going from strength to strength and one new feature which I would like to bring to your attention is the online community forum or SII Connect as we call it. Have you a question that needs answering or have you some useful information that you would like to share with your peers? Log on and you can start whatever conversation you want to.

This year is proving to be another difficult year for our fundraising. All our events have been cancelled but we are hopeful that our two challenges will go ahead in the autumn. If you fancy some sun and are anxious to get back on your bike again, why not join SII & the IRFU Charitable Trust for our inclusive cycle in the Algarve from 09 – 16 October. We are also looking to recruit people for 'A Day in My Wheels' on 30th September to raise awareness of what it is like to spend 24 hours in a wheelchair and raise much needed funds.

We are always here for you so please do not hesitate to pick up the phone and call us or email us if we can help you or if you need information or resources.

Kind Regards

Fiona Bolger CEO

SERVICES UPDATE

Finally, the summer has arrived, bringing beautiful weather and restrictions are easing for everyone. The Services team have been busy delivering all our services virtually and contacting you by phone, email, and text. Over 550 of you attended our education sessions, weekly peer support meetings and updates from many key speakers. We hosted education sessions on the medical aspect of living with a spinal cord injury as well as the practical and caring for your mental health. We know it is not the same as meeting you face to face, but many of you appreciated being able to attend from home and meet with people from all over the country online. There was a total of 3,800 interactions supporting service users and family members.

“I like the way the majority of people participate in the chats and give their tuppence worth. Makes you feel that you are not alone, and others are dealing with same problems or hurdles”. Virtual Coffee Morning Attendee

Our peer support programme has gone from strength to strength with weekly coffee mornings for people with different levels of injury and at different stages of recovery. We also included coffee mornings for family and carers of people with spinal cord injuries. This provided an opportunity for families and carers to connect online with each other, to discuss issues that they were having and share information or tips on certain aspects of caring for people with spinal cord injuries. They are also supported by family peer support volunteers for SII.

It has been a challenging and isolating year and it was easy to feel alone at times. These coffee mornings were not about agendas, themes or speakers. They were purely an opportunity for people to share what they wanted to or just to drop in, meet others, say hello or just listen. People joined for as long or as short a time as they wished.

“I enjoyed knowing others are in the same boat and hearing about one of the family members who is a peer support volunteer, who is now living at peace 8 and half years on”.

We also linked in with the NRH to connect with newly injured people and they were overwhelmed to speak to people who could relate to their fears and concerns and provide the hope they need at the start of their injury. Our wonderful peer volunteers are taking a break over the summer and we are planning

an autumn series of coffee mornings. In the meantime, the peer volunteers are available to speak to you on a one-to-one basis. Feel free to get in touch by phone or email to arrange support.

“It was my first time using the internet and talking with people who had a similar injury to me”.

Education

We know that looking after your mental health is just as important as your physical health. Brid Keenan spoke at our conference last year about the traumatic impact a SCI can have on some people. This year Brid followed up with a 4 week course to offer support to people who are living with spinal injuries to support an understanding of how trauma affects not just our bodies but how we live in the world. The course covered what happens when trauma occurs and how we survive in the aftermath of terrible events, issues of chronic pain, impact of surgical intervention and what happens to our sense of self in the aftermath of life changing events. The course aimed to reflect the needs of the individuals and provide the opportunity to explore their own experiences for consideration when looking at the impact of trauma.

“My experience has been very much isolation when discharged after surgery and believing I should be just getting on with life as though I had had a thorn removed. Thankfully I found you and thanks to you I feel I'm not going crazy and there are genuine changes in my body that I have to learn to adapt to.”

Surveys

Bowel and Bladder Survey: Bowel and bladder issues are a major concern for people aging with a spinal cord injury and how this will impact on your life.

Thank you for taking the time to reply to the Bowel and Bladder survey in partnership with Coloplast. We know this is a topic of great importance for you and we are working with Coloplast in addressing the needs you raised in the survey. See pages 10 and 11 for the full results.

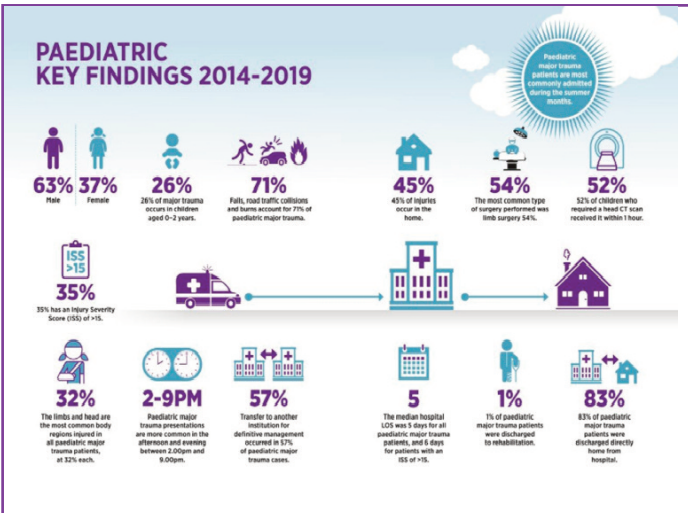
Covid Survey

Thank you for responding to our Living during Covid 19 survey. We have received 128 responses so far. See page 7 for the preliminary results.

NOCA PPI Committee

Naomi Fitzgibbon, our Head of Services, represents the voice of those living with a SCI on the National Office Clinical Audit PPI (Public/patient involvement) committee. As a result, SII supported the launch of the first Paediatric Major Trauma Report. This report highlights the key findings on how major trauma occurs in children and what can be done to prevent it. See the key messages below.

Naomi also participated in the announcement of the Trauma Centres and Units in Ireland by the Minister for Health. The introduction of the Major Trauma Centres and Units is to ensure anyone who sustains a life-threatening injury receives the right care, at the right time, in the right place. SII will be working closely with these centres and units to support patients and family from the moment of injury.



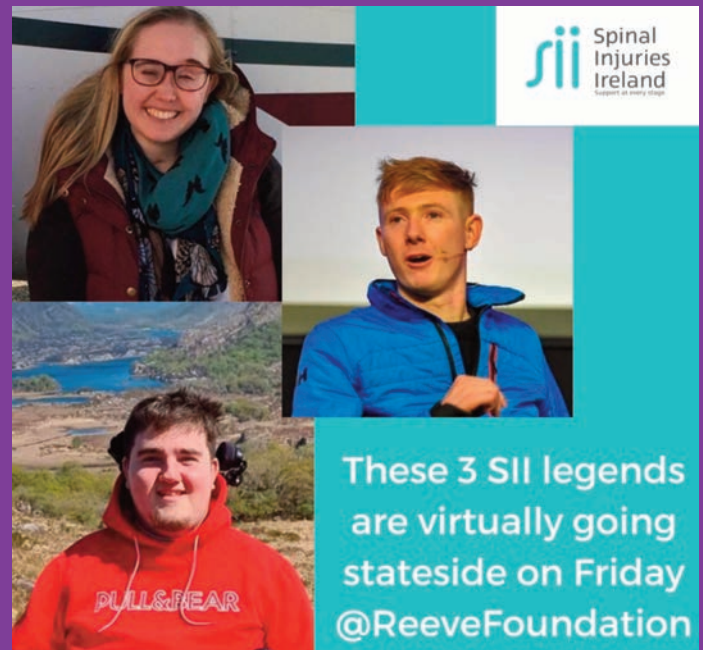
NOCA National Office of Clinical Audit

KEY RECOMMENDATIONS

- The MTA continues to highlight the need for implementation of the Trauma System for Ireland strategy and to address the needs of paediatric patients in this system by developing paediatric major trauma pathways of care.
- The MTA will engage with national organisations to use the information from this report to inform injury prevention strategies for children.
- Each hospital should have a local MTA hospital governance committee who actively use the data for quality improvement.
- NOCA will develop a research group and further develop public and patient involvement in the audit.

Christopher and Dana Reeve Foundation Partnership

We started our collaboration with the Christopher & Dana Reeve Foundation by hosting an Instagram takeover with three of our Service Users sharing their lives with a spinal cord injury with an amazing 4,307 views of their posts on the Reeve Foundation Instagram Page. Huge thanks to Gemma Willis, Ian O’Connell and Jack Kavanagh for taking the time to share their stories, for their enthusiasm and positive attitudes and for their technical know-how.



Conference – Save the Date

We are very excited to be planning our next virtual conference on 20 – 22nd October. We are putting the programme together based on your feedback from last year. We will cover a variety of topics including the physical, medical, practical and emotional aspects of living with a spinal cord injury for you and your family. Keep an eye on the Events page on the website for the full programme and speakers in the next few weeks and put the date in your diary.



COLD SHOWER CHALLENGE

Tom Hannon was born and raised in Dublin. He suffered an incomplete spinal cord injury in his final year of secondary school which confined him to a wheelchair. He went on to study law in Trinity College and the Kings Inns. He practiced as a barrister for nine years, and up until August '20 worked in the insurance industry. He took the last year out to study in UCD and in the next month will be looking to rejoin the workforce.

This is Tom's challenge for you.



How Low Can You Go?

So? The morning shower, the warm, scented start to the day. But what if this ritual included a nerve shredding icy torrent of two minutes of the coldest water you could tolerate? And what if this mini test of endurance was possibly the most important part of your day? Would the question be, 'How Low can you Go?'

Probably you've heard the talk about the power of freezing cold showers, and in this time of Covid it is tempting to dismiss it as another fad which will die off once 'normal life' returns. Well, this is something I've been attempting over the last several weeks, the coldest water I can tolerate for the longest time. And I can honestly say it does have an extraordinary effect.

At the end of my shower I'm more alert, more 'centred', more, to sound a little grandiose, alive. Have I got to two minutes? No! Not even close! Thirty seconds feels like a brain crushing lifetime but, at the end of it, there is no arguing that I feel more refreshed and energised.

If it works for me, it'll work for you. If I can (try) to do it, so can you. So, How Low Can You Go?

Cash prizes to be won every month



**Next draw Friday 3rd September
If you're not in, you can't win!**

The monthly prize draw is a fantastic way to support those in Ireland living with a spinal cord injury. Even one ticket at just €7 per month makes a huge difference. This type of regular donation helps us to budget and plan in a way that one off donations can't. This consistent means of support helps make us sustainable as an organization and allows us to plan with confidence into the future.

So, please help spread the word to friends and family

Laura Jackson was helping her friend move house when she got a call from us.

"I have a friend with a spinal cord injury who told me about Spinal Injuries Ireland's Monthly Prize Draw. I bought a few tickets and thought nothing more of it. I then got a wonderful call a few weeks later telling me that I had won €1,000 in their monthly prize draw. I was absolutely over the moon and couldn't believe that I had won. Many thanks Spinal Injuries Ireland." Laura Jackson

In the first 6 months of 2021 we have given away €10,500 euro to 15 winners. Yes, you read that correctly. Two people have been lucky enough to be prizewinners more than once!

We can't promise to make anyone rich but by donating as little as €7 per month you do have the chance that we will start your weekend off well by calling you on a Friday afternoon and giving you a grand.

Coleman Hudson, the first prize winner in our inaugural draw said the call gave him and his family a great lift during the pandemic.

"A very big thank you to all at Spinal Injuries Ireland. It was so unexpected to receive the news that I had won first prize. This has given my family a huge boost in the current wearying environment." Coleman Hudson

spinalinjuries.ie/raffle/



SURVEY ON THE IMPACT OF COVID-19 ON THOSE LIVING WITH A SPINAL CORD INJURY

SII COVID-19 SURVEY INTERIM RESULTS

There were 128 responses, so far

- Do you have any secondary complications that were affected by covid-19?

17 yes 91 no 19 don't know.

Conditions such as: diabetes, high or low blood pressure, cardiovascular conditions, arthritis and bowel and bladder issues.

- Did their conditions worsen during covid?

36 yes 75 no 13 don't know.

- How are their symptoms now, compared to pre-covid?

9 better 32 worse 84 about the same.

- Did you receive any treatment for your symptoms during covid?

36 yes 75 no 17 waiting for an appointment.

- Have you had Covid 19?

5 yes 123 no

- Have people been satisfied with the amount of information that you received on covid?

55 happy 23 unhappy and 48 neither happy nor unhappy.

- Did reading or hearing about covid, make people anxious?

54 yes 46 no 26 maybe

- Have people felt isolated during the pandemic?

64 yes 48 no 66 maybe

- Where people normally obtain support.

103 family and friends 5 GP 6 NRH 7 SII
5 District Nurse 3 Community 5 Counsellor
10 Internet/social media/forums 12 Other.

- Which of the following SII services did you find most helpful.

22 online coffee mornings

13 online education programme

1 Counselling service

28 Contact from the community

23 other, which included: partners, family and friends, the magazine, knowing spinal injuries were at the other end of the phone, workshops and the quiz.

- Have you received your Covid Vaccine?

113 people have received the covid vaccine, 6 have not, 8 still waiting.

- Some of the things people have found difficult during the lockdowns:

Not being able to go out, social isolation, hospital appointments being cancelled, caring for family and friends, separation from family, anxiety, fear of catching the covid.

- What has kept people going during the pandemic?

Family and friends, Netflix, meeting friends/family on zoom, exercise, scrabble, gardening, studying, walking the dogs and work.

MARCO'S STORY

My Life Journey



Hi. I am Marco. This story is about me and my life before and after a spinal cord injury.

I came from a mixed background of a Sicilian father and an Irish Traveller mother. I was born in London in July 1958 and was placed into the care of Dr. Barnardo's from where my biological father and his Scottish wife took me home to care for me.

I first became interested in martial arts at the young age of 8 when I started Karate and it has been an important part of my life since then. I enlisted in the army when I was 20 years old and I served as a military bodyguard, then as a bodyguard instructor for 6 years and a further 3 years as a regimented Physical Training Instructor. I did not serve in Northern Ireland as my mother was Irish and I was Catholic.

I left the army and became a freelance photo journalist and went to Bosnia (Former Yugoslavia) early in '92 during the conflict. Whilst I was there, I offered my services as a voluntary medic and therapist in an orphanage in Bosnia. It was during this time that I sustained my spinal cord injury.

One day our vehicle hit a landmine and the young man who was driving was killed outright. I tried to stand up and the next thing I knew I woke up in hospital. I assumed it was the following day but apparently it was 10 days later. The pain was immense and I was told I had an incomplete injury at the base of my spine and that I needed to go to a specialist unit back in the UK as soon as I could.

A few days after sustaining my injury I was arrested by the Croatian Special Police, imprisoned and tortured, on top of my recent injuries. The torture, coupled with the lack of medical care, caused a lot more damage. It took approximately a month for the British Consulate in Croatia to discover where I was and what had happened to me. It was only once they became involved that the Special Police ceased dealing with me and I was given legal representation for the first time. I was then released in a matter of days, my passport was returned to me and stamped with a 10 month ban on not coming back to Croatia, (as if I wanted to). During my incarceration, I lost approximately 8 stone in weight, not a diet I would recommend.

My original accident occurred just before Christmas 1994, and I was eventually repatriated to the UK. I spent approximately 8 months in a spinal unit in London. Unfortunately, I then became street homeless as I was unable to access my first floor flat and the local government where I formerly lived would not help me because of being wheelchair bound as all their emergency accommodation was upstairs in B&B's. This was in Westminster, the nicest and most affluent borough in London.

I remained sleeping on the street for just under two years, before I was rehomed to an area I did not want to be, in East London.

It was while I was living there, I met with John who became a Tibetan Buddhist Monk and he invited me up for a holiday to stay at the Monastery, where I later became a Buddhist Monk and travelled to many places helping people in need.

Psychologically I found coming to terms with my disabilities extremely difficult, as I have always been a very active person, living on the edge, i.e., body guarding, mountaineering, parachuting and doing many sports. For a couple of years I found being confined to a wheelchair extremely daunting.

It was only because of Buddhist philosophy and my Catholic faith that I came to the realisation that it wasn't my disability which was restricting me, but rather society putting limitations on my life.

I moved to Ireland and due to Idiopathic Pancreatitis, I had to have my pancreas, gall bladder and spleen removed, which led to a 16 month stay in hospital where I had to be resuscitated 6 times and went from 19 stone to approximately 10 stone. Again, not a weight loss programme I would recommend. Owing to losing the pancreas I immediately became an insulin dependent diabetic with Type 1 Diabetes. I was given an antibiotic to treat repeated urinary tract infections, which resulted in the tendons in my legs shrinking which eventually led to me having to have a bilateral amputation to my legs, above the knees two years ago. The surgeons were concerned about healing because of my diabetes and phantom pain, but I am delighted that I have no problem with either. I am, however, still waiting on rehab following the surgery as there was nowhere available immediately and then Covid 19 struck.

I am a former member of Spinal Injuries UK, and when I came to Ireland many years ago, I discovered SII and the Irish Wheelchair Association.

I became a member and subsequently got involved with their outreach team and became friends with Philippa O'Leary who has been a great support. She has helped

me researching information, applying for and receiving a grant for a piece of assistive technology called Dragon Professional software. This is a speech recognition software where you speak and words type up on the computer screen. This is useful due to limited hand mobility and fatigue and I am using this to write my book. Unfortunately my laptop has since died so I am desperately trying to replace that and Philippa has helped me to apply for a grant for this.

In general, life is much better as I've been able to get back to driving, martial arts and going to the gym, and also being both a member and actively involved with the Irish Wheelchair Association and Spinal Injuries Ireland has opened up many more opportunities for me.

The present situation with COVID19 and having to cocoon has put a stop to many of these activities for the time being, which is very difficult as I am normally very active. Even through tough times, I'm proud to say that I have never given up and I am constantly looking for new challenges and opportunities.

My main goal for the future is to open my own martial arts school which will be open to all ages and abilities. Currently I am linking in with Grand Masters based in Israel to put together a format of adapted Krag Mava. This will be taught to people with various abilities and/or limited mobility and is adapted to each individual person. I hope to establish teaching in Clonakilty first and then expand the program nationally. Everyone has capacity in some format to engage in martial arts and it benefits not only physical health but mental health as well. "Limitations are your own".



BOWEL AND BLADDER SURVEY RESULTS

Thanks to everyone who took the time to complete the bowel and bladder survey. We understand from previous surveys that information and support about bowel and bladder care is one of your top priorities. We received almost 440 responses. Following the survey, SII Community Outreach team contacted 189 people to offer a phone consultation with a Coloplast nurse. The Coloplast Nursing Team have been working through the pandemic, supporting people in the community.

We are working together with Coloplast who are committed to making life easier for people with intimate healthcare needs by providing specialist nursing support, covering ISC (Intermittent Self Catheterisation), bowel management and stoma care. Following the survey results we are working to address your information needs as reported in the results below.

BOWEL AND BLADDER SURVEY RESULTS APRIL 2021

437 SURVEYS WERE RETURNED

189 PEOPLE REQUESTED CONTACT FOR FOLLOW UP

115

PEOPLE STATED THEY WERE RELUCTANT TO GO OUT OR LEAVE HOME DUE TO THEIR ROUTINE

121

PEOPLE HAVE DIFFICULTY IN MAINTAINING THEIR BOWEL AND BLADDER ROUTINE

104

PEOPLE SAID THEIR ISSUES WERE NOT RESOLVED WITH INTERVENTION

• Where people live

220 Urban areas
208 Rural areas

• Marital status

163 Single
219 Married/civil partnership
38 Long term relationship
12 Widowed

• The length of time people sustained their SCI's

173 people have had their SCI between 1 and 10 years
122 people have had their SCI between 11 and 20 years
138 people have had their SCI for 20 + years

• The cause of peoples SCI's

113 RTA
26 Sport
106 Fall
81 Medical
24 Other

● Mobility status

231	Full-time wheelchair user
39	Part-time wheelchair
80	Walker with aid
76	Walking independently

● Quality of life using their current bladder routine

111	Happy
168	Not happy
156	Not happy or unhappy

● People who would like to look at alternative ways of managing their bladder routine

156	Yes
204	No

● Quality of life using their current bowel routine

99	Happy
182	Not happy
154	Not happy or unhappy

● People who would like to look at alternative ways of managing their bowel routine

170	Yes
207	No

● People who have bowel and bladder accidents

214	Bladder
107	Bowel

● Does their bowel and bladder routine impact their relationships

100	Yes
241	No
78	Maybe

● When was the last bowel and bladder management review

74	Less than 6 months ago
72	Between 6 and 12 months ago
129	Between 1 and 3 years ago
125	Over 3 years ago

● Where do people seek advice regarding their bowel and bladder issues

190	GP
135	Spinal unit
8	Pharmacist
51	Internet/social media/forums
17	Patient associations (Spinal Injuries Ireland)
38	District nurse
27	General hospital
67	Don't look for help
32	Other

● When help is sought are issues resolved

158	Always
83	Temporarily
104	Not really

in association with



Coloplast

COMMUNITY AND FUNDRAISING NEWS

We were obviously extremely disappointed to have to postpone many of our annual fundraising events such as the Spring Lunch, Q Ball, Summer BBQ, and the Cork Jazz Ball due to Covid. We can't wait for everything to progress to a level where all restrictions are lifted and we can host these popular events once again.

We do, however, have two fundraising challenges later this year. Our inaugural Algarve Cycle, which was due to take place in October 2020, will now take place from the 9th to 16th October 2021. This is a fully accessible cycle, hosted in conjunction with the IRFU Charitable Trust and we would love to see some of you taking part. Mark Rohan, Paralympian gold medallist is looking after all the logistics for us and planning some lovely routes. Mark will be hand cycling, as will our very own Philip Quinlan so we are really hoping a few more of you will consider joining us. It is open to cyclists and hand cyclists alike. You don't need to be Olympic standard Mark assures us as he has three different routes for each day, from beginners to advanced. (see page 2).

The second challenge is really aimed at the business community and is both a fundraising and an awareness campaign. A Day In My Wheels takes place on the 30th of September and we are asking members of the Irish business, entertainment, sport, and political communities to put their shoulders to the wheel in support of people whose lives have been affected by a spinal cord injury (SCI) by spending 24 hours in a wheelchair. By taking on this challenge, they will be getting a snapshot of what life in a wheelchair is like, while also raising much needed funds. They will be challenged by accessibility issues in workplaces, shops, public spaces and facilities. They will learn a different way of dealing with everyday situations such as opening doors, crossing roads, and even moving about their own homes. They will gain a whole new perspective on how people in wheelchairs are viewed and treated.

Our Tall Ships Challenge also had to be postponed and we are currently working with the Jubilee Sailing Trust to confirm new dates and a new voyage and hopefully will be in a position to share this information with you soon so don't give up hope any of you who were signed up or indeed anyone who is looking for a new challenge for 2022!

One of our stalwart supporters, Fiona D'Arcy, launched a brilliant campaign earlier this year – Bank the Plank. She challenged people to do a 60 second plank, donate €6, post their video on social media and then challenge 6 friends to do the same. It was a great success with over 170 people donating over €7,500. A special thanks to all the team at Linesight too for their brilliant support.



For the first time this year we signed up with the Charities Institute Ireland and iDonate in a joint fundraising venture to virtually travel Around the World on the weekend of the 19th June. A huge thank you to everyone who participated, particularly Grainne Sugars, Geraldine O'Donnell, Eileen Goldup and Tom Cardas who together raised over €6k. We are happy to say that together all the charities did manage to make it around the world!

Mark Walsh is showing support for his friend who recently sustained a spinal cord injury by doing a sky dive on the 27th August. He has already smashed his fundraising target of €500 ahead of the jump with a running total of €1,600 so far.

Service User Mary Pielage was delighted with her new wheelchair accessible vehicle which was kindly donated by Richard Considine of Evra Motors. The second-hand vehicle is in great condition and we wish Mary very happy motoring. Mary and her family made a very generous donation to SII as a thank you which was totally unnecessary, but very much appreciated.

Thanks to Malachy Coyle for his very generous donation and to his employer's Bernstein who matched his donation. We were also delighted to be selected by Vistra as one of their charities of the year. Huge thanks to their MD John Dunleavy.

Our thanks also to Derrinstown Stud for their generous annual donation and to O'Brien Lynam Solicitors for their great support.



CHARIOT is an Irish-owned brand of Lifestyle Apparel, creating garments which are inclusive and eco-conscious by nature. Work hard, play hard, adventure hard - whether you sit or stand!

Chariot is the brainchild of Nathan Kirwan, ably abetted by his sister Aisling. Nathan sustained a complete C5 spinal cord injury in 2013 when he fell from a tree on the way home from a night out with friends. After a considerable stay in hospital and extensive rehabilitation Nathan started the charity Helpful Steps which provides state-of-the-art rehabilitation devices and training for wheelchair users. This includes the exoskeleton and an anti-gravity treadmill.

Sadly, Nathan's choice of career in Marine Engineering was no longer viable from a wheelchair so he had to change direction and returned to university to do a business degree. It was during this course that the idea for Chariot Clothing was born. Nathan found that there were difficulties with a lot of trousers he had. Not so much with the dressing but with the practicalities of their function such as the pockets and plenty of slippage when transferring in and out of the car. Having researched the market, Nathan decided to design a pair of his own and had them manufactured in India.

Subtle features designed around a sitting position make these trousers comfortable, practical, and stylish. Features include a higher waist at the back which

provides more coverage; deeper pockets positioned below the hips allow for easier access when carrying the essentials; phone, wallet, keys.... mask (for now); a longer zipper provides a larger opening for easier access; no back pockets add to the comfort and relieves pressure and quad loops allow people with poor dexterity to do up the button effortlessly. Loops can be easily removed if not required. The range also includes shorts. While the wheelchair clothing is currently only available for men, Nathan assures us that he is currently collaborating and working on a range for women.

Nathan and Aisling set up the business and website and began selling the clothing. Many of their friends were keen to support the business and liked the branding so they wanted some products available to them. "With concern for the environment we noticed our consumers also wanted to avoid fast-fashion. We decided to create a stylish range of sustainable clothing which suits people who love living their best lives, with or without wheelchairs!"

They now offer a full range of hoodies, t-shirts, jumpers and hats and even some accessories both for men and women.

When I pushed Nathan on where the name Chariot originated, he said he just liked what it represented: Power, strength, ferocity, freedom, speed, resilience!!!

[Check out chariotclothing.com](http://www.chariotclothing.com)

CHARIOT

Designed from real experience, our range of adaptive clothing are for those who live life from their wheelchairs. Subtle unique features designed around a sitting position make these trousers comfortable, practical, and stylish.



Check out the full range at www.chariotclothing.com
Women's range coming soon.



Features include:

Higher waist at the back provides more coverage.

Deeper pockets positioned below the hips allows for easier access.

Longer zipper provides a larger opening for easier access.

No back pockets add to the comfort and reduces pressure.

Quad loops allow people with limited dexterity to do up the button effortlessly. Loops can be easily removed if not required.



@thisischariot



In July 2002, Cheri Hopper reached out to the newly launched Paralysis Resource Center (PRC) at the Christopher & Dana Reeve Foundation for help. In the year since she'd sustained a T4 injury, Hopper had spent hours on the phone with government agencies and service organizations, seeking guidance about complicated insurance coverage, catheters that weren't delivered on time and doctors who didn't know how to treat patients with spinal cord injuries. Nobody knew how to answer her questions; even worse, no one seemed to want to.

Hopper assumed the PRC would be another dead-end—but just days after she skeptically filled out a form requesting a call, her phone rang.

“I was absolutely stunned,” she says. “There was this person who called me back and actually cared. I felt like someone turned the light on. I felt like I had a chance.”

Dana Reeve founded the PRC because she understood the disorienting shock of a life upended in an instant—and the desperate need to find answers to questions that can't wait. After Christopher was paralyzed in a 1995 equestrian accident, he and Dana searched in vain for information as they struggled to quickly understand and adapt to their new lives.

“It didn't seem like there was one place where we could call and ask five different questions that seemingly had nothing to do with one another,” she said.

For too long, too many people believed that spinal cord injuries signaled the end of a life—or at least any hope for a happy one. Scientists largely ignored the field of spinal cord injury research, while doctors grimly warned patients to expect little of their future. Families grappling with the realities of new injuries were on their own.

Christopher and Dana Reeve famously chose to live with hope—to fight for changes that would improve the lives of millions of families like their own. After establishing the Foundation to spotlight and support spinal cord injury research, Dana realized there was much more to be done; families needed a centralized place to seek practical and emotional support for their day-to-day lives. The Foundation, already connecting a network of people living with paralysis across the country, was perfectly positioned to provide the resources that had long been missing.

“Who else if not us?” she said.

From the moment the PRC opened, the urgent need for its services was clear.

“In the early days, the phone rang all day, every day,” Senior Information Specialist Donna Lowich recalls. “There was a pent-up need for the PRC. As soon as it opened, everybody wanted to get information. People were calling from everywhere. Indiana, Florida, California. It was amazing.”

Lowich, one of seven original PRC staffers, helped field the steady stream of inquiries arriving not only by telephone, but fax and even old-fashioned snail mail. Scouring nursing manuals, academic journals and healthcare newsletters, the team logged every question and answer, slowly building a database of knowledge designed to be the comprehensive resource for people living with paralysis that hadn't existed until then. Among the PRC's earliest publications were guidelines on how to choose a rehabilitation center and what to expect when first coming home from the hospital—finally offering individuals and families a much-needed roadmap for the overwhelming early days after injury.

It was only the beginning, but thank you notes quickly found their way to the PRC's tiny New Jersey offices. For Hopper, and countless others, the careful attention offered by Information Specialists was as transformative as the practical help they provided.

“When somebody listens to you, you realize you have an ally and you're not just fighting by yourself,” Hopper says. “After that, I knew I had people behind me.”

Dana died just four short years after the PRC opened, but the astonishing scope and impact of its work serves as her living legacy. Since 2002, more than 108,000 people have received assistance from Information Specialists and accessed the vast resource library, which has been translated into more than a dozen languages including Arabic, Japanese and Hebrew. Today it is known as the National Paralysis Resource Center, funded by an \$8.7 million dollar federal grant from the Administration for Community Living, part of the U.S. Department of Health and Human Services.

Guided by Dana's vision, the PRC's services remain free and dedicated to improving the quality of life for those living with paralysis. Over the years, we have grown with, and in response to, the needs of our community. Our Information Specialists serve as the heartbeat of the organization, responding to more than 7,000 queries in 2020 alone on topics ranging from the coronavirus to finding employment to accessing funding for wheelchairs. There is not a one-size fits all approach; all disabilities are different, as are individual needs. Information Specialists help families develop personalized plans that, on any given day, may tackle



Credit: Timothy Greenfield Sanders

how to travel with a wheelchair, secure housing near rehabilitation hospitals or find a physiatrist. Most importantly, with a wide-ranging and constantly updated database and state-by-state resource lists, the PRC helps callers find and build support networks in their own communities.

Dana was clear-eyed about the challenges facing both individuals living with paralysis and their loved ones, but she believed that knowledge was power. In 2003, the PRC published the Paralysis Resource Guide (PRG,) a comprehensive guidebook, meant to anticipate all the questions families might have on every aspect of life with paralysis, including secondary conditions, travel, employment, financial planning, mental health, disability benefits, and sports and recreation. Now in its fifth edition, the PRG has been sent to thousands of families around the world— including Ireland— along with a growing library of factsheets and booklets that are updated annually and cover an array of subjects, such as the dangers of autonomic dysreflexia, pain management, and parenting with paralysis.

But sometimes information alone isn't enough. In 2011, the PRC launched its Peer & Family Support Program to directly connect individuals living with paralysis and their caregivers with others experiencing similar circumstances. The program has certified 1,024 peer mentors over the years, including 14 dedicated individuals who volunteered in its first year and have remained active ever since.

Like the PRC itself, the response to the program testifies to its importance: since its inception, 18,275 people from all 50 states and the District of Columbia have been matched with peer mentors. Similarly, the Foundation's Military & Veterans Program (MVP)

focuses on supporting the specific needs of veterans living with paralysis and their caregivers. The MVP's trained volunteers and staff, who have ties to various branches of the armed services, have helped veterans or military service people access equipment, specialty care and government services.

By simultaneously providing resources and bolstering community connections to ease isolation, the PRC aims to foster both the physical and mental health needed for a successful life. But no matter the strength and spirit a person living with paralysis may possess, reintegration and engagement with society also requires inclusion and access. One of Dana's most cherished initiatives at the PRC was the Quality of Life Grants Program, through which the PRC has awarded roughly \$30 million to more than 3000 service organizations serving and empowering people living with paralysis. Recent grants have aided veterans participating in suicide prevention programs; children who found joy and a sense of belonging at camps serving kids living with disabilities; and patients treated by doctors trained to better care for people with spinal cord injuries. Stories like this ripple through communities served by the grants.

When she envisioned the PRC, Dana understood that its work would be deeply personal. And it remains so to this day, for the thousands of families around the world living with paralysis—and also for me.

At the age of 16, I broke my C2 vertebrae. Waking up in the hospital is a moment that still takes my breath away. I was lucky, and fully recovered, but couldn't help wondering what might have happened if I hadn't—if I had been paralyzed in the accident. What resources would I have wanted and needed?

For more than two decades at the Reeve Foundation, I've worked to ensure that people living with paralysis are supported to live empowered—and am thrilled to find an organization across the ocean with a shared sense of purpose and determination.

The Reeve Foundation's partnership with Spinal Injuries Ireland (SII) will serve as a powerful bridge to further connect and strengthen our community. As the only support and service agency for those who sustain spinal cord injuries in Ireland, SII's expansive efforts—including counseling, peer mentoring and activity programs— have already proven life-changing for countless families. Our partnership will expand outreach, share resources, and support fundraising efforts that will accelerate research and the development of widely available, effective treatments. Together, we will continue the work begun by families like the Reeves who rejected the notion that there was nothing to be done for spinal cord injuries. Like Christopher and Dana, we will choose hope, and fight for the future everyone deserves.

We are currently preparing a pre Budget submission to Government which we will publish at the end of August. In the interim please see below extracts from the submission and if you have anything to add we would appreciate if you could contact us at info@spinalinjuries.ie.

In consultation with our service users and other key stakeholders, SII has identified three core priorities, which, if implemented, would make a material improvement to their quality of life.

These are:

- Provision of Medical Cards, based on need and on a permanent basis
- Improvement in funding and the provision of community services
- Implementation of the National Strategy for Neuro-rehabilitative services, including “A National Trauma System for Ireland”

In 2019, Dr. Pdraig McNeela, School of Psychology, NUI Galway, published an analysis of a qualitative survey of 272 SII service users. The survey was conducted in June and July 2019. The responses are grouped by survey respondents who do have a Medical Card, and those who do not have a Medical Card. Across both groups, there were common perspectives and shared experiences on the challenges of living with a SCI in Ireland. These included:

- Their sense that a SCI is a life-long condition, with complex and varied associated burdens. It should therefore be classified as a life-long condition, similar to diabetes or epilepsy
- Medical challenges as a result of a spinal injury remain life-long, regardless of whether someone is walking or in a wheelchair – nerve damage is irreversible, and there are a range of additional conditions and requirements, including the need for bowel and bladder management, pain control and management, physiotherapy, specialised footwear, electric wheelchairs or mobility aids, bed hoists, pressure sores and skin management, care and medication
- In some cases those with a Spinal Cord Injury are unable to return to their former employment. In addition, it is common for a spouse or family member/partner to give up their employment to care for their family member at home, once they have been discharged from an acute care or rehabilitation setting.

It is estimated that 25% of those with a SCI live below the poverty line.

- Work and employment emerge as a key issue – the role that work could have in improving quality of life and fulfillment, yet there are concerns about limiting salary or the amount of hours worked because of the concern about losing the Medical Card.

NEEDS NOT MEANS – SII calls for Medical Cards for all people with a serious Spinal Cord Injury

“The vision of Sláintecare is to achieve a universal single-tier health and social care system, where everyone has equitable access to services based on need, and not ability to pay.”

(Sláintecare Implementation Strategy & Action Plan 2021 – 2023, Government of Ireland, 2020)

“Ever since Ireland ratified the UN Convention on the Rights of Persons with Disabilities, we have signaled to those with a disability that we are now serious about making a difference – a difference that will make things better. The ratification raised awareness of the lived experience of people with disabilities, but we have much more to do.

In doing more, we now need to improve the services available through better implementation and by working together across Government in a better way. We want to empower and give those with a disability the ability to choose the supports that most meet their needs. “

(Programme for Government, June 2020)

There is a very deep chasm between the aspirations referenced in both of the recent Government documents above, and the everyday experiences of those living with a Spinal Cord Injury in Ireland in 2021.

Dr McNeela’s analysis reveals real difficulties for both those with a Medical Card, and those who have been deemed to be ineligible for a Medical Card.

Medical Card Holders

Many of the Medical Card holders outlined the efforts and difficulties inherent in securing and retaining a card, and many write in stark terms about their worries and concerns about losing a card:

- **Spinal Injury should be a recognised illness for Medical Cards** – “A spinal cord injury is a lifelong injury”

- **The cost of Medical Cards would balance out economically, and confer dignity -**

“We do not want to be part of a ‘hand out’ culture, but deserve a hand up that will allow us contribute actively to the economic and social system”

- **The scale of the loss associated with Spinal Injuries** – “Without a medical card I would not be able to use the toilet as my catheters cost €900 per month”

- **Medical Cards are a necessary support to cope with the challenges involved in having a Spinal Cord Injury** – “Life with a spinal cord injury is very unpredictable. Employment is difficult to secure and our health can change or fluctuate. None of us know what our future holds, especially as we age.”

- **Compensation and Claims – negative impact on Medical Card** – “We lost our Medical Card straight away on receipt of compensation – we were not informed – just could not use it. Others in same situation didn’t lose theirs. Our appeal was unsuccessful as compensation is classed as means”

- **Difficulty getting a Medical Card – stressful process, repeated applications, not receiving full Medical Card** “I was refused a Medical Card when I first applied. I suffered lots of medical issues re bowel and bladder. I reapplied and contacted (public representative). Also got my daughter to outline my situation. I am now in receipt of a Medical Card”

- **Overwhelming fear and concern about the possibility of losing the Medical Card**

“My first medical card was rejected twice before I finally got approved ... I was penniless at the time and the medical card dept knew this. I got a three year card but when it came for renewal this year I received one for 12 months this time. It feels like a hangman’s noose around my neck ... the negative effect this has on my mental health is tremendous”

- **Employment and Medical Cards – Fear of losing the card and not being able to develop full potential**

“This is such a pivotal topic. I have spent years studying, developing myself to get back to a baseline where I can have a successful life. Going back to work and the future possibility of starting my own company put my medical card in jeopardy. I am currently appealing after a failed medical card review.

The testimonies above illustrate the constant state of fear and uncertainty which exists for those with a Spinal

Cord Injury, even when they are granted a Medical Card. This is due to the arbitrary and opaque process through which an application is considered, as well as the fact that the intervention of a public representative may be necessary in order to reverse a rejection of an application. In addition, it underlines how the current criteria for being awarded and granted a Medical Card can hamper those with a SCI from seeking to return to work, or to seek to fulfill their true potential in a work environment.

Non-Medical Card holders

While those with a Medical Card expressed their concerns about its temporary nature, non-Medical Card holders experience an even deeper level of fear and financial stress.

- **The expenses of medical care, GP visits, prescriptions, mobility aids, professional services and home adjustments** “A medical card would help me replace medical equipment such as electric wheelchair, bed, hoist, etc. As a quadriplegic I cannot even get a quote for private health insurance. This means I have to wait on the public waiting lists to see consultants and procedures. I am not in receipt of any social welfare assistance. We are a one-income family. State says I’m entitled to nothing. I attend doctor and chemist regularly with no support or medical card to help. My GP has started only charging me 20 euros to help me”

- **Barriers to getting a Medical Card** – employment status, family income, pensions, claims, age, uncertainty about entitlement. Self-employment, spousal income, insurance claims, age, or receiving a pension are also cited by the HSE as reasons for not granting a Medical Card.

“I am [over 70] and a Medical Card would greatly ease my situation. I am told I am ineligible because I have a Pension”

Each person with a Spinal Cord Injury has individual requirements, and it is therefore not possible to identify an ‘average’ or ‘optimum’ monthly or annual cost for medical care, equipment, bowel and bladder care, pressure relieving equipment, etc.

Quite simply, the current situation where Irish citizens, with a life-long condition, do not have the basic resources, to provide for items essential for their personal hygiene, mobility, pain management and dignity is absolutely unacceptable.

A Spinal Cord Injury is a permanent condition. SII call on the Government to acknowledge this fact, and to extend the Medical Card to those with a Spinal Cord Injury, based on need, in Budget 2022.

SPINAL INJURIES IRELAND WEBSITE

By David Fitzgerald

The New Year saw the launch of our new website, www.spinalinjuries.ie. It looks different, it feels different, it is different. It's much more than a make-over, we have completely redesigned the whole website from top to toe with you in mind and made it a far more user-friendly site to use.

Whatever way you're choosing to access the website, from your laptop, tablet or mobile phone, there's a radically improved new look, feel and user experience to be found.

Whether you're living with a spinal cord injury, a supporting family member or indeed a healthcare professional looking for information there's a whole host of new and exciting features and resources for you to explore.

So what's new?

The website has been designed with three main pillars to support the spinal cord injury community. There's so much new content it's hard to know where to begin, to give you a taste of what awaits I'll highlight one or two of the new sections.

1. Get Support

Whether newly injured or living with an injury for some time, explore here to get information on topics such as SII Peer Support for those with a spinal cord injury or their family members. Our Peer Volunteers, Community Outreach Team and the SII virtual community are all here for you.

- **SII Connect:** One of the biggest innovations on the website and one we are all very excited about here, is our brand-new community forum, SII Connect.

Very often, it's someone just like you who is the real expert, someone with first-hand experience who really understands the challenges of living with a spinal cord injury.

Have you a question that needs an answer? Perhaps you have some knowledge or wisdom you'd like to share? Log on and give it a try, go explore SII Connect today.

- **Get in Touch/Get Support:** Another innovative feature of the new website is the number of options for you to get in touch with us here at SII.

With almost every click you will be presented with a "Get in Touch" or a "Request Peer Support" or a "Get Support" button inviting you to send an instant message to us here.

There's also the live chat feature allowing you to chat with one of our team directly through the site in real time.

For those who prefer the tried and trusted methods of an email or phone call our contact details are prominently displayed throughout the website.



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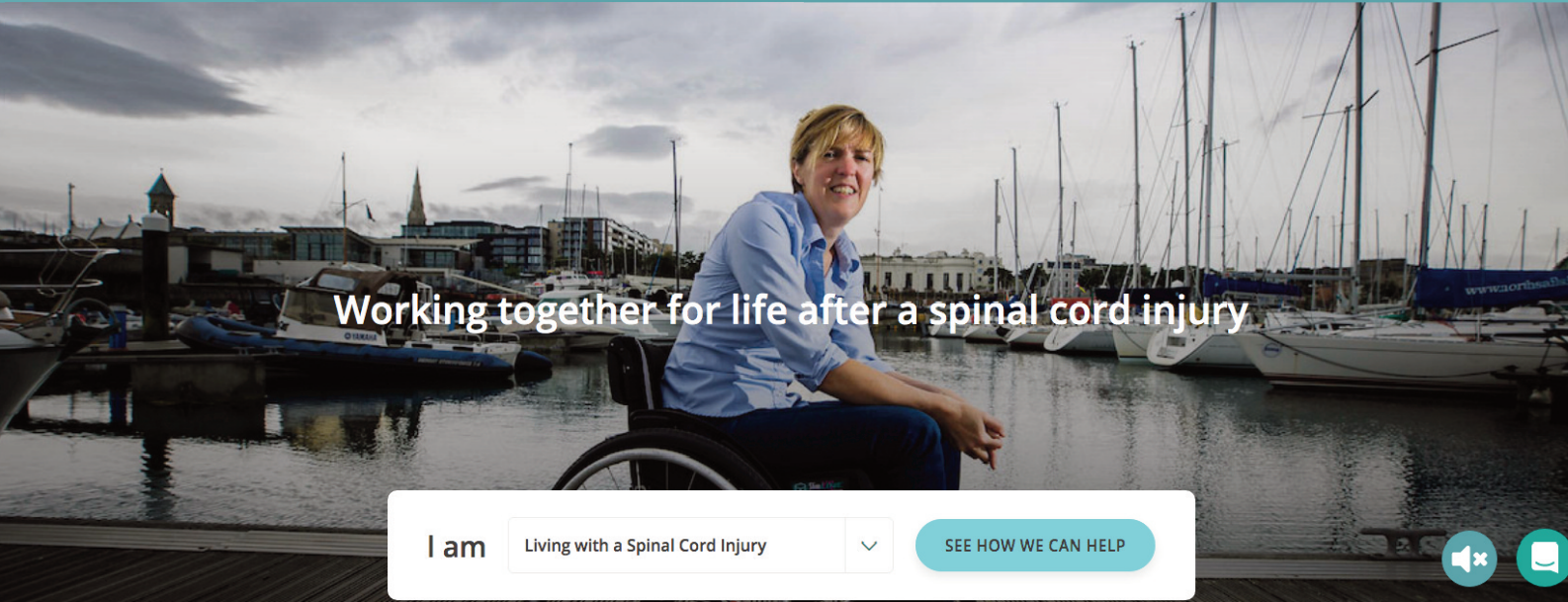
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SII Connect

Often, it's someone just like you who's the real expert. Have you a question that needs an answer? Have you knowledge you'd like to share?

Welcome to [SII Connect](#) - Your Space to Share

VISIT SII CONNECT



Working together for life after a spinal cord injury

I am

Living with a Spinal Cord Injury



SEE HOW WE CAN HELP



2. Your Resources

What do you need to know? Find everything here from information on managing a spinal cord injury to your healthcare entitlements. Visit our brand-new media library and view our fantastic back catalogue of magazines and videos and much more!

Our services

Living with a Spinal Cord Injury
Our Community Outreach Officers (COO's) are instrumental in empowering the Service User to set and achieve realistic goals using the principles of active support.

[READ MORE](#)

Supporting Those With A Spinal Cord Injury
The Community Outreach Officer (COO) also supports the family, giving them practical advice and information to help ease the burden of this life changing event.

[READ MORE](#)

As time goes by - your SII support
Community Outreach officers (COO's) engage with service users to provide ongoing support at a local level to ensure the person with a SCI have access to essential local services.

[READ MORE](#)

● **SII Media Library:** The media library is the new home of our back catalogue of Spinal News magazines and our growing video resources.

During the past year COVID-19 and the restrictions it imposed have enlightened us all to the value of the online or virtual world.

In response to the COVID-19 lockdowns, SII commissioned a series of online courses and workshops specifically designed and tailored to meet the needs of people of all abilities.

In the media library you will find videos on a wide variety of topics from health to assistive technology and the list is growing.

Feel free to browse, there's something for almost everyone.

3. What We Do

This is the place to find the services on offer from SII. From our Community Outreach service to the SII professional counselling service, designed to help with coping skills needed to live with the often-devastating impact of a spinal cord injury.

Health Care Professionals (HCP's): Contact with SII, both during hospitalisation and after discharge is a crucial factor in helping people to envisage a life with SCI and to come to terms with the reality of injury and disability.

One of the services we are focussing on at the moment is providing support for healthcare professionals who are working with people with a SCI, in both the acute hospital setting and in the community.

With this in mind we have given the HCP's their own dedicated resource on the website to facilitate that valuable contact and support to get started as early as possible once an injury has occurred.

4. Some other new features

News and Events: Another notable new feature is the events diary which will enable you to keep up to date with what's coming up in the SII/SCI community. Be it an online peer support coffee morning or an educational webinar follow our events guide and you won't miss a thing.

Our news section will keep you updated on all things SII and SCI locally, nationally and internationally.

So go take a look, have a browse and let us know what you think.

PAULINE'S STORY



Steven is my fifth child of six, my first son after four girls. As a result we all spoilt him. Steven was afraid of the dark so his sister would go to bed with him until he fell asleep and then retreat to her own bed. As a baby he suffered with asthma and hay fever and was in hospital a lot with his asthma. He also broke his arm in two places falling off his bike when he was six or seven.

As a child, Steven had the kindest heart and the funniest humour. In school he helped other children and the teachers and was always bringing friends home. He loved sport and played hurling and soccer, but his passion was, and still is, rugby. Unfortunately, he had to give up playing with a shoulder injury.

Steven was always a hard worker who enjoyed the craic and was always smiling. He worked in security for festivals and concerts with a security firm every summer which he loved as he got to listen to all the bands, meet the VIPs and he made so many friends throughout Ireland and England.

It was coming home from working at a festival in Waterford on the 2nd August 2019 that Steven was involved in an accident when the car he was a passenger in came off the road in the early hours of the morning. Steven was 24. He was transferred to Waterford University Hospital. When we arrived we were told that Steven was very low and that his condition was critical. He needed an MRI urgently but at six foot three and

twenty three stone he did not fit into their scanner. As a former rugby player and security guard there was nothing standard about Steven's size. The doctors knew he had a spinal cord injury and he was transferred to the Mater Hospital in Dublin where the scanner was also too small and he had to go with a lovely nurse across the city to a bigger machine. We were not allowed to go with him but I knew he was in safe hands with Anne Marie.

Seeing my son hooked up to tubes and hearing that he couldn't feel his legs was devastating but we had hope. The following morning Steven had a 12-hour operation. He had dislocated his C5 and C6 and had completely severed his spine. His consultant said it was one of the worst surgeries he had ever had to perform. We didn't get to see Steven that day as it was 9pm before we got word from the doctors, but our hope vanished when they told us he was paralysed from his chest down, had partial paralysis in his arms and hands and that he would never walk again.

Our hearts were broken and we just wanted someone to wake us up and say it was all just a bad dream.

Steven spent the next two months in the Mater; first in ICU, then HDU and then the Spinal Ward. The care Steven received was the very best. He was treated like their son and he made so many friends. We were so thankful for all their help and can never repay them for their care. Steven was then transferred back to

Waterford. Here he received the best care possible but they were not equipped to cater for Steven and his particular injuries. He could not receive the physio and rehab that he needed and he kind of went backwards with his recovery. So, we had to make a decision to place him somewhere where he could get the care he needed until a place became available in the NRH so Clarenbridge Nursing Home was his next stop.

This was the most heart-breaking decision we had to make. He had just turned 25 and had to go to Galway for care as our home was too small and we needed to get it adapted before we could bring him home.

Steven spent six weeks in Clarenbridge before his place was available in the NRH and just after Christmas 2020 he was on his way to Dun Laoghaire to really start his rehab. It was terrifying for him but his attitude from the start was so positive. He spent 3 months in the NRH and the work they did with Steven was excellent. He learned how to be independent again and to do a lot for himself. He called them his family.

While all this was happening, we were trying to get our home adapted to get an extension for Steven and we needed help. There was so much going on. We were trying to come to terms with what had happened. All our lives had changed in the blink of an eye and we didn't seem to have time to think. I cried every day for nearly a year and the guilt I felt was overwhelming. So many times I wished for it to be me and I questioned if there was a God and if there was why would he let this happen.

There was nowhere to turn. We felt as if we were alone and the only ones this had happened to.

We were introduced to Spinal Injuries Ireland. We met Gretta first and then Emily to bash things out with. But at home in Tipperary we had nowhere to turn. There was no helpline, no social media site to ask questions and get answers from someone else who was going through or went through this nightmare and our lives had to continue as normal with work and everyday living when at times I wanted to throw in the towel.

Covid19 then arrived while Steven was in the NRH and we didn't see Steven for a year. Because of this he returned to Clarenbridge and everything stopped. We lived in Tipperary and Steven was in Galway, one hour and forty minutes away. We weren't allowed visit and Steven didn't want us travelling for 5 mins of a chat so the only contact was by phone and text. His grandparents missed him and were trying their best to get him home. Everything is so slow when applying for permission to build. Spelling a word wrong or leaving a word out means having to reapply again. This needs to be changed as this was an urgent application but it took over a year to get



started. There was a mountain of paperwork and form signing. Everything had to be followed up on and reports obtained because they can't take your word for anything.

We eventually got the money through fundraising and finally got permission to build and adapt our house, but it was going to be another few months yet before Steven could come home. I had only seen him once since March 2020 and the pressure to get him home was the worst. We needed training and carers put in place but Covid was holding it all up. I just wanted him home.



Finally, in April of this year Steven got to come home. We were excited but also terrified of what was about to become our new everyday life. At first his carers completely took over looking after him, showering him and looking after his personal care and bowel care. We had to do his meds and look after emptying his urine bag. Then he had a frightening episode. Steven suffers with Autonomic Dysreflexia. It's his body's way of telling him something is wrong and he has to have urgent medical care. His blood pressure is unreadable, he gets sweats and a violent headache and if not treated quickly, it can lead to a stroke. It was panic stations. We called carers and nurses and eventually an



All our lives changed forever that day. His parents, his four sisters, his younger brother, his nieces and nephews, not just Steven's. Sometimes it's hard to accept that this is what happened to him and my heart will never mend, but Steven is alive and we get to see him and speak to him and have family gatherings that he is still here for. That alone is a blessing. I don't have to visit my sons grave to lay flowers. I get to have him home.

I wish there was more information available and it would help to have someone to talk to that is going through or has been through the same thing. We are not great at asking for the help and only for Gretta and Spinal Injuries Ireland, in the beginning, we would have been lost.

We can never thank the people of this country enough for their help in getting Steven home and to Emily, our Community Outreach Officer with SII, the Mater, Waterford University Hospital, Clarenbridge and the NRH we are so grateful for your care of us and Steven.



ambulance. That night the cause was a blockage in his catheter which his Dad and sister eventually cleared and the ambulance stayed until everything returned to normal to avoid another trip to hospital.

Steven's care involves checking his skin for pressure sores, helping him set up for a shave which he manages with the razor in a strap tied to his hand as his fingers don't work, cooking his meals and cutting up his meat but he can do so much for himself. He helps and explains everything that you need to do. He knows exactly what has to be done, when and how, and this is so reassuring for us.

Every day is a learning day, but Steven's positivity and outlook is amazing.

He has never admitted defeat and accepts that this is his new life. Three months later it's like Steven was never away and we are so much more settled with him. Things still worry us and we have to make sure his needs are met before we can do anything else, including work.

I worry every day for fear of something happening and he is not the best at taking advice. He thinks I treat him like he's six. I probably do sometimes but it's a mother's instinct. But he is so independent, it's hard to fuss.

Steven does say a day without a smile is a day wasted and what a smile he has. It's not all doom and gloom and it's up to you to make the best of every situation and look after you because without you there is no us.

Pauline Simmons

CRANN CENTRE

You may not have heard of the term “neuro-physical disability” before. We at Crann coined it to distinguish our clients who have acquired or congenital spinal injury, including Spinal Cord Injury, Spina Bifida, Hydrocephalus, Muscular Dystrophy, Cerebral Palsy and Childhood Stroke.

For those unfamiliar with us, Crann has been around for a few years. At our purpose-built facility in Cork we provide Mobility, Counselling, Psychological Wellbeing, Health & Continence, Social Capital, Education, and Independent Living services to individuals, their parents, siblings, and other family members.

Our services moved online last year due to the Covid-19 pandemic, but we are looking forward to gradually reopening over the summer. All going well, we will be back in full swing for Autumn/Winter services, so keep an eye on our website – www.cranncentre.ie.

We recently launched our new mobility programme, led by experienced Occupational Therapist and Seating Therapist, Eoin O’Mahony. Eoin has spent years working with people with an acquired spinal cord injury. Feedback so far has been very encouraging, and we look forward to opening to more clients as restrictions ease.

Some of you may have met our Health and Continence Manager, Eimear Daly, at SII’s My Life Wellbeing conference in October, where she presented an overview of pressure care.

Eimear hosts “It Only Takes a Minute©”, a programme which gives clients the tools they need to recognise and prevent pressure ulcers.

She also leads a weekly bowel and bladder clinic, which has proven very successful in helping our clients improve their bowel and bladder management. This runs inhouse and online for those who are unable to come to Crann’s facility.

We spent the past year in consultation with the children, teens, adults, and families who use our services about their experiences using play and leisure spaces.

We worked with the School of Occupational Therapy at UCC and the Department of Physical Therapy at Indiana University to explore how we could deliver a space with maximum potential for outdoor physical activity, play, socialisation, and mobility programmes based on our clients’ input.

The result is that on June 9th we turned the sod on a ¼ acre area at Crann’s facility where Crann’s client families can have fun, learn, and improve their skills in a fully inclusive and accessible play and leisure space. The design is led by the lived experiences of people with neuro-physical disabilities in using public leisure spaces, which are not always as accessible or inclusive as they appear to be.

It will be a space where families can enjoy time together, without compromise. We hope it will be a catalyst for more inclusive play and leisure areas in the future.

If you feel like you or your family could benefit from our services, please reach out to us on 021 021 428 9267 or info@cranncentre.ie. We would love to hear from you.

Thanks to SII for inviting us to contribute to their SII magazine. We have worked with SII since Crann’s inception and value the partnership we’ve developed with the SII team.



A DAY IN MY WHEELS

Roll with us on September 30th 2021



A DAY IN MY WHEELS



We are looking for business leaders to put their shoulders to the wheel in support of people whose lives have been changed forever by a spinal cord injury. Show your leadership by taking on the challenge yourself or sponsor someone in your business to spend 24 hours in a wheelchair.

By taking on this challenge, you will get a first-hand glimpse of what life in a wheelchair is like, while also helping provide a one-to-one support service for people with a spinal cord injury and their families from the moment they are admitted to hospital and for as long as it is needed.

Call 01 653 2180

spinalinjuries.ie/wheels