



Spinal Injuries Ireland

SUMMER 2016

Support at every stage

THIS IS
MY LIFE

by Spinal Injuries Ireland
supported by Coloplast

Meet BRAD

- Gregarious 52 year old, fun loving gentleman
- Media technology consultant
- Enjoys DJing with vinyl and can “scratch just like Grandmaster Flash”

“I can boogie with the best of them!”



Brad Francis
SpeediCath® Compact Set User

BRAD'S LIFE CHANGED AT 29...

“I was 29, happily married, great career – incredibly happy. And then my life changed. I went from being an independent, fun loving guy – to all of a sudden being **vulnerable and needing help.**”

AND THEN HE FOUND SPEEDICATH COMPACT AT AN EXHIBITION...

“Oh my god – it's fantastic!

The first thing I noticed is they came in this compact little box – usually my catheters come in great big boxes.”

For more information on our SpeediCath range and other continence solutions -

Go to www.coloplast.ie/spinalnews - where you can find the right one for you and request a free sample. Alternatively please call us on **1800 409 502** where you can speak to one of our advisors.

BRAD TOOK A WHILE TO COME TO TERMS WITH THE CONCEPT OF ISC...

“I found previous catheters messy and difficult to use – so I chose not to catheterise at all. I would frequently have episodes where I would wet myself. Social occasions, parties.”

It was really pretty embarrassing.

BRAD NOW FEELS THAT SPEEDICATH COMPACT HAS CHANGED HIS LIFE FOR THE BETTER...

“It really promotes confidence.

The freedom to catheterise while out at a bar, or a friend's house, or at home is amazing!”

Visit us on





WELCOME

I hope you all have had a chance to enjoy the sunshine in May.

It was great to see the countryside in full bloom as we travelled around Galway, Sligo, Waterford, Cork, Tralee, Limerick, Letterkenny, Portlaoise, Dundalk and Dublin as part of the 'This is My Life' campaign which sought to create a community of people living with spinal cord injury who will work together to influence change. Over 500 people attended the events and everyone signed a pledge asking the government to improve support services for people with a SCI. You can read all about it on pages 10 and 11.

There have been a lot of changes in Spinal Injuries Ireland this year. We were very sad to say goodbye to the Munster Community Outreach Officer, Deirdre Griffin who moved on to a new job. Deirdre has now been replaced with Philippa O'Leary who will be based in Cork. Rhona Coughlan has also joined the team as Peer Support Co-ordinator and will work in both Dublin and Cork on this programme. We also added to the Fundraising Team with Kevin Dempsey who will lead the department. As we rely on over 60% of our funding to come through fundraising, Kevin would be delighted to hear from anyone that has any ideas but in particular he would be delighted if you could assist with selling the enclosed raffle tickets.

In July we will be launching a very exciting new vocational programme 'Discovering the Power in Me' which was developed specifically for people with a SCI by the Pacific Institute in Canada. We are delighted to receive funding from Pobal to train young people 15-25years old in this programme which will be evaluated by the School of Psychology, NUIG.

We hope you enjoy reading this magazine and all the latest news and if you would like to send us your story or any news we would be delighted to hear from you.

Yours sincerely
Fiona Bolger CEO



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DISCOVERING THE POWER IN ME

‘DISCOVERING THE POWER IN ME’ IS A PROGRAMME DEVELOPED BY THE PACIFIC INSTITUTE, CANADA IN COLLABORATION WITH PEOPLE WITH A SCI.

‘Discovering the Power in Me’ programme comprises 12 learning units that refer to separate cognitive and behavioural life skills (e.g., positive thinking, goal setting, cognitive functioning, and personal motivation). The units are integrated in a ‘whole person’ approach to personal effectiveness.

At any stage in the journey of recovery, hope, belief in self and resiliency are essential. Building these attributes is vital. The Pacific Institute’s education provides the foundation upon which these attributes can be built.

Translated into practical tools and techniques, participants easily understand and apply the Institute’s concepts, thereby laying a strong foundation for growth, change, Hope, Self-Worth and Inner Peace.

What are the outcomes?

To achieve a higher quality of life for the participants, more expansive goals, innovative problem solving, gainful employment and an expanded capacity for independent living.

- To support successful transitions and progression to contribute futures for project participants with higher support needs
- To enhance participants creativity, problem solving and personal development skills
- To support and maximize participants expectations and experience of independence
- To support self-directed goals to further training and future employment successes through effective thought patterns

These outcomes will be monitored by NUIG

How to apply to get on a course

Please forward applications to participate on the course to Mary Dunne at mary.dunne@spinalinjuries.ie.

Please include Name, Address, Phone no. and spinal cord or brain injury type.

Or Please advise nature of your injury – Spinal Cord or Brain injury.

This project was approved by Government with support from the Dormant Accounts Fund.



Who is it for?

Spinal Injuries Ireland has received funding for a Discovering the Power in Me pilot project training 80 young people from 15-25 years who have sustained a spinal cord or brain injury. This pilot project will be evaluated by the School of Psychology, NUIG.

What will it do for someone?

This project through empowering young people with a disability will raise the expectations of the individual, assist in developing progression plans, provide occupational guidance and support them in the transition to mainstream settings.



**OÉ Gaillimh
NUI Galway**



**THE
PACIFIC
INSTITUTE®**



OUR SERVICES EXPLAINED

Following rebranding, we have new titles for all of our services as well as some new job titles. The Community Liaison Officer (CLO) who may have visited you in your home is now called a Community Outreach Officer. Here is an outline of our pathway of support at every stage of your Spinal Cord Injury (SCI):

IN THE ACUTE HOSPITAL

Early Days: This is a support service for patients in acute services and their family members. A Community Outreach Officer is available to meet and provide support to family members while the person with SCI is in the acute setting. They can also visit the person with SCI in the acute hospital if requested.

WHILE IN THE NATIONAL REHABILITATION HOSPITAL

Future Me: This programme is for patients who want to start thinking about their options for education, training and employment. Whilst at the NRH, patients can link in with the Vocational Team. This is a collaboration between SII and the NRH and involves an NRH Occupational Therapist, NRH Social Worker and an SII Community Outreach Officer. If a patient participates in this programme, goals set towards education, training and employment can continue to be supported by the local Community Outreach Officer after discharge home.

Active Me: This is an opportunity to have some fun while discovering new possibilities whilst being a

patient in the NRH. During the summer there is a weekly trip out on our RIB (speedboat) and in the winter, we offer trips to the cinema or shopping. If a patient in the hospital would like to try a different activity that they enjoyed prior to their Spinal Cord Injury or have a particular interest in, we endeavour to organise this with them.

Someone Like Me: This is a peer mentoring programme run on site in the hospital in collaboration with the NRH. It is run every other Monday for patients in the hospital and is about sharing experiences with other people in a similar situation in a relaxed environment.

AT HOME

Community Connect: This is our range of services delivered by your local Community Outreach Officer. It includes:

- One to one support visits in the home
- Referral to SCI counselling while other measures are being put in place if required
- Local meetings and talks
- Active Support and goal setting

What is active support and goal setting?

Active Support is:

'The encouragement of individuals to maintain independence and abilities and to maximise potential and independence'.

By using active support, your Community Outreach Officer can work with you to identify and set long term goals.

Together you can then break down the long term goals into achievable steps. These steps become your short and medium term goals.

Active Me Connect: This is our national adaptive sport and outdoor activity programme. It supports people with SCI across the country who want to join their local club, while also supporting the club to facilitate the new member. Where possible, we will link you in with someone with a Spinal Cord Injury who is already enjoying your chosen activity to support you through the process.

Someone Like Me: This is the expansion of our peer mentoring programme into the community. One to one peer mentoring can be arranged for any member who requires this type of support for a period of time. Peer mentors will also be arranging small tea / coffee mornings for SII clients in their locality. This is currently available in the Cork area and will be rolled out nationwide as funding becomes available.

The Active Me, Active Me Connect and Someone Like Me programmes would not be possible without the support of our volunteers to whom we are very grateful. If you are interested in putting yourself forward as a peer volunteer, please contact Rhona Coughlan at rhona@spinalinjuries.ie

What is a Community Outreach Officer?

Spinal Injuries Ireland has 6 Community Outreach Officers in 6 different areas of the country. Our Community Outreach Officers are available to all people with a Spinal Cord Injury in Ireland.

The job of a Community Outreach Officer is to meet you one to one in your home, or in a place of your choosing. Their purpose is to support you at any stage of your journey after Spinal Cord Injury.

They can:

- Provide or source information you require.
- Link you with other services that you want to access.
- Work with you to maximise your independence and quality of life.
- Help you to overcome barriers in your life.
- Connect you with others with similar circumstances.
- Support you through SII's active support / goal setting programme.
- Provide information / support to your family members.

AN UPDATE ON REGIONAL MEETINGS

Regional meetings have been running in 13 different locations around the country for the past few years.

The purpose of these meetings is for SII clients to come together and listen to a speaker on a topic of interest and have the opportunity to chat to each other afterwards in a relaxed and informal environment.

For 2016, we will be trying something new in some areas. Rather than having a

speaker, we will be having even more informal, social meet ups where the opportunity is just to meet and chat, with maybe a small activity thrown in for good measure.

The schedule for the regional meetings and social meet ups for the remainder of 2016 is as follows:

AUTUMN

| Location | Venue | Date | Time | Topic / Speaker |
|------------|---|----------------------|-----------------------------------|--|
| Kerry | The Rose Hotel, Tralee | Mon 29th Aug 2016 | 12pm to 2pm | Social gathering - introduction to your new Community Outreach Officer. |
| Cork | Nemo Rangers, Cork | Weds 17th Aug 2016 | 1pm to 3pm | Social gathering - introduction to your new Community Outreach Officer. |
| Clare | IWA Ennis | Weds 24th Aug 2016 | 11am to 1pm your new Community | Social gathering - introduction to Outreach Officer. |
| Limerick | IWA, Limerick | Thurs 25th Aug 2016 | 11am to 1pm | Social gathering - introduction to your new Community Outreach Officer. |
| Galway | Westwood Hotel, Galway | Tues 6th Sept 2016 | 7pm to 9pm | Assistive Technology. |
| Wexford | Maldron Hotel, Wexford | Weds 7th Sept 2016 | 2pm to 4pm | Positive mental health. Linda Thorpe - Mental Health Ireland. |
| Mayo | Ballina Family Resource Centre | Tues 13th Sept 2016 | 6.30pm to 8.30pm | Coffee and Tea meet up |
| Waterford | Viking Ramada Hotel, Waterford | Weds 14th Sept 2016 | 2pm to 4pm | Physical exercise and eating well. |
| Leitrim | Landmark Hotel, Carrick On Shannon | Thurs 15th Sept 2016 | 2pm to 4pm | Leitrim Adult Guidance Centre - short courses, back to education and contacts for all surrounding areas. |
| Donegal | The IWA, Glenview, Carnamoghagh Upper, Letterkenny | Tues 27th Sept 2016 | 2pm to 4pm | Nutrition |
| Portlaoise | NLN, Portlaoise | Fri Oct 14th 2016 | 1.30pm to 3.30pm | 'What the budget means to you'. Guest speaker from Citizens Information Centre. |
| Louth | Crowne Plaza Hotel, Dundalk | 29th September 2016 | 7pm to 9pm | Bladder management after spinal cord injury. Theresa Rohan (B Braun). |
| Dublin | SII Offices, Dun Laoghaire. | 19th September 2016 | 7pm to 9pm | Bladder management after spinal cord injury. Theresa Rohan (B Braun). |

WINTER

| Location | Venue | Date | Time | Topic / Speaker |
|------------|---|--------------------------|------------------|----------------------|
| Kerry | The Rose Hotel, Tralee | Mon 28th November 2016 | 12pm to 2pm. | Christmas gathering. |
| Donegal | The IWA, Glenview, Carnamoghagh Upper, Letterkenny | Tues 29th November 2016 | 2pm to 4pm | Christmas gathering. |
| Cork | Nemo Rangers, Cork | Weds 30th November 2016 | 1pm to 3pm | Christmas gathering. |
| Wexford | Maldron Hotel, Wexford | Weds 30th November 2016 | 2pm to 4pm | Christmas gathering. |
| Limerick | IWA, Limerick | Thurs 1st December 2016 | 11am to 1pm | Christmas gathering. |
| Leitrim | Landmark Hotel, Carrick On Shannon | Thurs 1st December 2016 | 2pm to 4pm | Christmas gathering. |
| Portlaoise | NLN, Portlaoise | Fri 2nd December 2016 | 1.30pm to 3.30pm | Christmas gathering. |
| Galway | Westwood Hotel, Galway | Tues 6th December 2016 | 7pm to 9pm | Christmas gathering. |
| Louth | Crowne Plaza Hotel, Dundalk | Weds 7th December 2016 | 6.30pm to 8.30pm | Christmas gathering. |
| Waterford | Viking Ramada Hotel, Waterford | Weds 7th December 2016 | 2pm to 4pm | Christmas gathering. |
| Clare | IWA Ennis | Thurs 8th December 2016. | 11am to 1pm | Christmas gathering. |
| Dublin | SII Offices, Dun Laoghaire | Mon 12th December 2016 | 6.30pm to 8.30pm | Christmas gathering. |
| Mayo | Ballina Family Resource Centre | Tues 13th December 2016 | 6.30pm to 8.30pm | Christmas gathering. |





SOMEONE LIKE ME

IN THE FINAL QUARTER OF 2015 WE RAN TWO VERY SUCCESSFUL TRAINING COURSES FOR SII CLIENTS INTERESTED IN BECOMING PEER VOLUNTEERS.

One session was run in Dublin to expand our programme on site at the NRH.

8 volunteers attended and have since successfully joined our team of 6. Thank you to all those who

participated and all those (past and present) who volunteer for this programme. Thank you also to the NRH for their continued support of the programme.

We also had a great day down in Cork attending training with 7 SII clients. The morning session consisted of peer mentoring training and the afternoon session focused on

facilitation skills. Thanks to everyone in Cork who got involved, we loved meeting you all. If you are living in Cork County, you will be contacted soon to see if you want to attend a local small gathering of SII clients facilitated by your local peer volunteer. Please support them by going along to find out for yourself what it's all about!



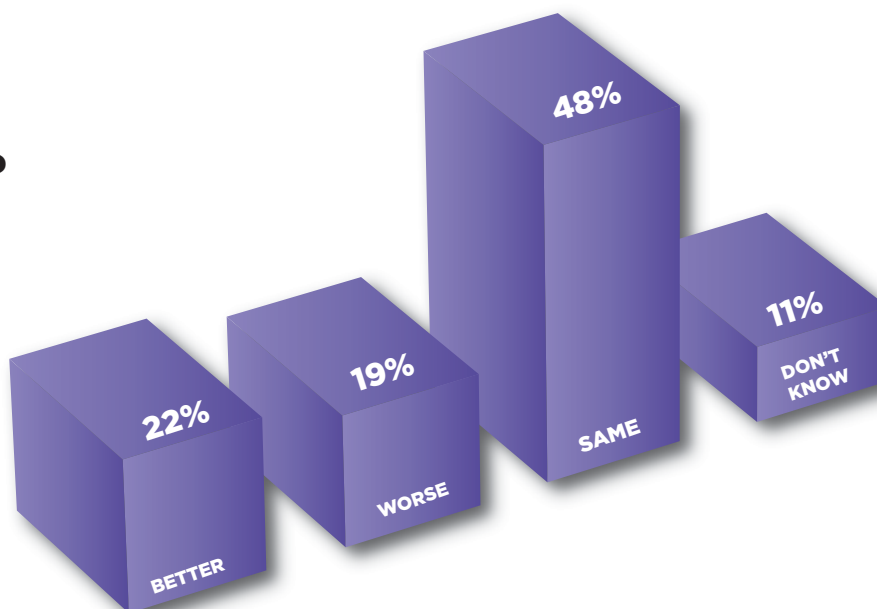
What is Peer Mentoring?

Peer mentoring is a form of mentorship that usually takes place between a person who has lived through a specific experience (peer mentor) and a person who is new to that experience (peer mentee). A peer mentor is someone who has successfully faced a similar experience and can provide good counsel and empathic understanding to help the peer mentee adjust to their new circumstances.

RESEARCH UPDATE – PAIN

You may remember that back in January 2015 you were contacted by us to participate in a survey related to pain. This research was being carried out by Dearbhla Burke from UCD School of Public health. Dearbhla and SII would like to sincerely thank all those who participated in the research. Here is a summary of the results:

HOW HAS YOUR PAIN DEVELOPED?



Summary:

- A total of 43% of surveys were returned
- Pain is a dominant issue. 70% of respondents reported pain in the last week and almost 40% reported experiencing neuropathic pain.
- More than half said that pain began within six months after SCI and few said it had improved since then.
- Pain is described as relentless for most, more than half those with pain said they feel their pain all of the time

Impact on Daily Life:

- Those with pain reported that it is having an enormous impact on their daily life including sleep and family activities.
- The quality of life reported by those with no pain was significantly better than those with pain of any kind.
- Rates of employment were 10% lower in those with neuropathic pain versus those with no pain.

Describing pain:

- Those with pain had three different problems – the back, lower legs or feet and neck and shoulders were the most common painful areas.
- Common words to describe pain were aching, hot or burning and tiring or exhausting.
- More than half of those with pain had not received a diagnosis for it.

Pain treatments:

- Anticonvulsants, paracetamol and non-steroidal anti-inflammatory drugs were the most commonly used medications for pain.
- The most popular treatments for pain were massage and heat.
- Exercise therapies of choice were stretching and standing.
- GP's and physiotherapists were the healthcare professionals seen the most by those with pain in the previous six months.

- Very few respondents had participated in a pain management programme.

The study concluded that the key areas of focus for the future are:

- Improved referral systems to pain clinics
- Increased availability of pain management programmes
- Further education on pain after SCI and best practice management
- Further research to analyse treatments which have the most effect of relieving pain and improving health related quality of life post SCI.

Following this research, Dearbhla Burke is working with the NRH to implement a pilot Pain Management Programme. SII is supporting this programme and will continue to collaborate with UCD on the issue of pain. Updates will be provided in the future.



“THE CRAFTY GARDENER”

SUMMER IS HERE AND THE GARDEN IS LOOKING GOOD.

It will be my 4th year at this vegetable garden so things should be getting easier, although you're always adding in something new.

.....

Last year I added a compost box which has made a great improvement. This year I will add in some new flower beds, one on top of the compost box and one behind it. Another project I am looking forward to this year is the hanging baskets for my strawberries. The strawberries are beginning to take up too much room on the ground so I'll have to make some hanging baskets out of timber frames to put them in. it will be a garden of strawberries in the sky. Dermot Gavin eat your heart out!! As much as I like gardening I try not to let it take up all of my time, even though I consider it great therapy when I'm not feeling the best. At the moment I've been doing some craft work, it is great for the winter months. I've made a craft tall ship and some Celtic wooden spoons. Its great because it keeps me linked to people

in my local town when I go in to buy materials and to show off my work. They also make great presents for my family and friends.

I've converted the garage into a bit of a workshop over the years. It's primitive enough as I only have some basic tools, but it works for me. You'd be surprised what you can do with some basic tools. If I ever need anything I go to my local Men's sheds and they are more than helpful lending me any machines or saws or knowledge I need.

It sounds as if I have a busy life, I would have nothing if it wasn't for my two daughters. They really do keep me going. I look forward to seeing them every week. Emily is in college now and Caitlin is doing her school exams. I am so proud of them not only for what they are doing but also because of the people they have become. They are such amazing girls with big hearts and I am thankful for them every day. I would also like to thank my family who have always been there for me and encouraged my gardening and crafts all the way. I would also like to thank my cousin Brendan who comes over from time to time to cook me dinner! I also must thank my brothers Sean and Tommy



“Dermot Gavin eat your heart out!!”

who always take time out of their lives to come and visit me and care for me when I need it most which really keeps me going. A final thank you goes to my Community Outreach Officer Deirdre, for coming to see me and help me out when I need the support. I would like to leave you with this final message, “Take care and remember that you are all as important as anybody else in this world”

-Seamus Galvin

Support
at every
stage

Take Action!

I pledge to support better lives for people with spinal cord injury and their families:

Signed: Liam McLaughlin T.D.

THIS IS
MY LIFE

by Spinal Injuries Ireland
supported by Coloplast



THIS IS MY LIFE ROADSHOW

During May 2016, Spinal Injuries Ireland, supported by Coloplast and Nissan Ireland, visited 10 towns and cities across Ireland to engage with people with a spinal cord injury (SCI) and their families and friends. A huge thank you to both Coloplast and Nissan, without whom our 10 events, entitled "This Is My Life", would not have been possible.

The aim of our events was to build a community to influence change and improve supports and services for people living with the impact of this life changing injury. As well as people with a spinal cord injury, their families and carers, local representatives, healthcare and service providers, and the media all attended. Our events proved that the support of Spinal Injuries Ireland is very valued and is essential to many families learning to cope with a changed future. It was re-assuring to confirm that the services we provide as part of the current strategy are badly needed and that we are investing our resources in the right area. The bigger problem is that we have identified a greater need for our services which we cannot introduce until our funding is addressed. This was reflected by the fact we received 10 new referrals

from regional hospitals or by people attending meetings because they heard the radio interviews. 'Some of the stories we heard were heart-breaking and it is embarrassing to be part of a society that does not look after its most vulnerable and so we must lobby for change. You will be pleased to hear that we just recently held a parliamentary briefing in Leinster House on Wednesday 22nd June and we will be updating you on the outcomes of this meeting in due course.



PLEASE NOTE THAT WE WILL EMAIL UPDATES ON THE 'THIS IS MY LIFE' CAMPAIGN – so to ensure you are included in all mailings please email your name and email address to info@spinalinjuries.ie



Some of the great stats from the roadshow are as follows:

Events: 10

Attendees: 483

Pledges: 650

Media: 44 (interviews, radio print & TV)

Facebook Engagement: 4,179 (Reach: 23,791)

Twitter Impressions: 34,291

Politicians: 9

Healthcare Professionals: 18

Mileage: 2075KM

People living with a Spinal Cord Injury (SCI) in Ireland are calling on the new government to deliver on improved services for people with a spinal cord injury and their families. 1,800 people in Ireland live with a SCI which is acknowledged by the World Health Organisation as one of the most devastating and life changing injuries that a person can sustain.

SII says that a louder voice is needed for those living with an SCI and is reaching out to people with an SCI, their families, friends and health services professionals to build a community which will influence change and improve supports and services.

In a survey carried out in April 2016, SII identified huge gaps in the pathway of care for people from delays in services to inadequate or lack of services and poor education for healthcare professions. "Rehabilitation is acknowledged as the poor relation of the health service," says Fiona Bolger, Chief Executive Officer, Spinal Injuries Ireland (SII) "and despite promises by previous administrations, there has been no progress. People with a SCI have identified ten key issues that impact on their lives from transport to health to employment* and we request that the new government moves services much further up the list of priorities. While



we very much welcome the building of a new National Rehabilitation Hospital, a new physical space does not mean new, improved services particularly when people return to home to their own community."

"A spinal cord injury is regarded as one of the most devastating injuries that a person can sustain. It is of real concern that more than half of people with such injuries feel the medical staff entrusted with their care in the community do not have the right experience to manage their condition. It is critical that access to essential services is universal and consistent across the country.



Spinal Injuries Ireland – Dáil Briefing

On Wednesday 22nd June we held a parliamentary briefing in Leinster House organised by Margaret Murphy O'Mahony TD (Fianna Fail Spokesperson on Disability), which was attended by over 40 TD's and Senators including the Minister for Disability Finian McGrath TD. We outlined how they can improve quality of life and active participation for people living with a spinal cord injury. Service users Gretta Fogarty, Susan Campbell and Stephen Cluskey also presented their individual stories. You can view our full Briefing Document on www.spinalinjuries.ie which was presented to each attendee asking them to take action in three ways:

List SCI as a long term illness

By 2020 deliver on essential services

SII to provide relevant supports and education so people with a spinal cord injury can participate fully in society

We have now requested a meeting with the Minister for Disability Finian McGrath TD and we will work with TD's to set up a cross party committee that can implement the changes that are needed.

SII SUMMER RAFFLE

TICKET NO.



Spinal Injuries Ireland Summer Raffle!

€5 Each or full book for €25

Name: _____

Address: _____

Phone: _____

Email: _____

Sellers Name: _____

Phone: _____

All monies, counterfoils and unsold tickets to be returned to Spinal Injuries Ireland, NPH Campus, Rochestown Ave., Dun Laoghaire, Co. Dublin.

TICKET NO.

Spinal Injuries Ireland Summer Raffle!



First Prize
€5,000

Second Prize
€2,000

Third Prize
€1,000

Top Sellers Prize
€500

Draw Date: Friday 30th Sept 2016

Thank you for buying this ticket and helping us to provide better lives for people with a spinal cord injury and their families across Ireland.

• Talk to us on 01 2355317 •

• Closing Date: Mon 26th Sept 2016

• €5 Each or full book for €25

License granted by District Court 23 to Spinal Injuries Ireland (CHY 11535) on 4th May 2016. See www.spinalinjuries.ie for full terms and conditions. Winners will be notified by telephone or post.

We are delighted to launch our very first Summer Raffle! It's so easy to take part and we have €8,000 worth of prizes to give away that you along with friends, family and colleagues could win. How to enter...

You will have received two books of 6 tickets with your Spinal News magazine and each ticket costs €5 but you can purchase a full book for just €25, meaning that one ticket is completely free! Just remember to post back the books using the freepost envelope provided and fill out the donation form.

Prizes

There are lots of great prizes to be won in this year's raffle, and thanks to our sponsors Windsor Motor Group, all proceeds will go towards supporting people living with a spinal cord injury and their families. The cash prizes include:

- **1st prize €5,000**
- **2nd prize €2,000**
- **3rd prize €1,000**

Top Seller's Prize

We also have a fantastic Top Seller's prize of €500 to give away to whoever has sold the most tickets by the end of the closing date. Everyone has started with 2 books so if you would like to request more just email events@spinalinjuries.ie or call us on 01 2355 317.

Draw details

The draw will take place on Friday 30th September 2016 so it is very important that you get your tickets back in to us by Monday 26th September. All winners will be notified by telephone, email or post and will be announced on the Spinal Injuries Ireland website. If you do not wish to participate in the raffle simply send your tickets back to us in the envelope provided.

See www.spinalinjuries.ie for full terms and conditions.

Good Luck!



ORGANISE AN EVENT FOR SII!

Organising a fundraising event is fun, rewarding, and can make a real difference to the work of Spinal Injuries Ireland.

Whether you want to hold a concert, a golf event, a fashion show or something else, we can give you tips on how to promote and run your event on the day as well as what to do with the money you raise.

It's quick and easy to register your event and receive your SII fundraising pack by contacting our team on events@spinalinjuries.ie or calling us on 01 235 5317.





COLOUR ME FRIDAY

Colour Me Friday is back on the 7th October 2016 and this year we plan on making it bigger and better than before. We will be asking workplaces, sports clubs, schools and event organisers across Ireland to 'go green' and celebrate our brand colour while supporting people with a spinal cord injury.

“This year we plan on making Colour Me Friday bigger and better”

SII launched our very first Colour Me Friday campaign in 2015 raising over €10,000 and there was a lot of creativity from our supporters who donned fancy dress, baked green cakes and organised green tea parties all in the name of SII.

This year we are asking that you get your friends, family and colleagues to organise a green event or you can just keep it simple and 'go green' for SII while texting CORD to 50300 to donate €4 to Spinal Injuries Ireland. Don't forget to post your photos on social media using #siigreen on the day.

You can contact our team for your Colour Me Friday pack on events@spinalinjuries.ie or call us on 01 2355317 for more information.



FUN NEVER GROW'S UP – SII & HULA HOOPS



Spinal Injuries Ireland will be partnering with Hula Hoops across the summer for their 'Fun Never Grow's Up' campaign to raise funds and awareness for SII.



Hula Hoops are aiming to get 10,000 people hooping and they will donate €1 to Spinal Injuries Ireland for every person who does! They will be popping up at different nationwide events across the summer including the Longitude and Independence festivals so make sure and spread the word and help to get Ireland Hooping!



TAKE ON A CHALLENGE FOR SII

WOMEN'S MINI MARATHON



Over 20 women took part in the 2016 Vhi Women's Mini Marathon for Spinal Injuries Ireland on June Bank Holiday Monday. Despite the rain just before the start everyone was in high spirits and we are so grateful to everyone who travelled from all over the country to take part and who made such efforts to fundraise before the event.

Take a look at some of the events you can take part in for Spinal Injuries Ireland and contact us for your fundraising pack:

- Tough Mudder 2016 – 9th July 2016
- Hell & Back Challenge – 10th September 2016
- Run a Muck – 24th September 2016
- Limerick Women's Mini Marathon – 30th October 2016
- Dublin Marathon – 30th October 2016
- Run in the Dark – 16th November 2016

If you along with any friends, family or colleagues would like to take on a challenge and join the Spinal Injuries Ireland team you can contact us on events@spinalinjuries.ie or call us on 01 235 5317.

WINGS FOR LIFE.

Wings For Life 2016 took place on 8th May in Dun Laoghaire and we were delighted to have a team of runners participating and making it to Bray and beyond in aid of Spinal Injuries Ireland.



This included the staff of Arvato who were running and raising funds for SII, along with our Wings For Life ambassador Felix Jones. Wings For Life 2017 will take place on Sunday 7th May 2017 and we are looking to recruit our biggest team yet!



BECOME A FRIEND OF SPINAL INJURIES IRELAND

As a 'Friend' of Spinal Injuries Ireland you will join a valued community of supporters who provide a vital source of funding for our programs. This is because by donating on a regular basis you enable us to plan for the future.

We stay in touch with you with regular updates so you can see the difference your ongoing support is making. Your contribution will make a huge difference to the individuals and families that we help.

If you are a tax payer in the Republic of Ireland and you donate €21 per month or €250 or more to SII in any year, your donation is eligible for tax relief and as a Revenue registered

charity Spinal Injuries Ireland can claim back the tax paid on your donation resulting in your donation being increased by 45%, at no extra cost to you!

To become a 'Friend' of Spinal Injuries Ireland you can simply complete the form opposite and return it to the address provided or call us on 01 235 5317 for any questions that you might have.





PRESSURE SORES

When you have a spinal cord injury, the nerves that normally signal discomfort and alert you to relieve pressure by changing position may no longer work. This can cause pressure sores, which are injuries to the skin and the tissue under the skin.

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They often develop on skin that covers bony areas such as the hips, heels, or tailbone. Pressure sores can also occur in places where the skin folds over on itself.

Pressure sores (bed sores) are an injury to the skin and underlying tissue. They can range from mild reddening of the skin to severe tissue damage-and sometimes infection-that extends into muscle and bone. Pressure sores are described in four stages:

Stage 1 sores are not open wounds. The skin may be painful, but it has no breaks or tears. The skin appears reddened and does not blanch (lose colour briefly when you press your finger on it and then remove your finger). In a dark-skinned person, the area may appear to be a different colour than the surrounding skin, but it may not look red. Skin temperature is often warmer. And the stage 1 sore

can feel either firmer or softer than the area around it.

At stage 2, the skin breaks open, wears away, or forms an ulcer, which is usually tender and painful. The sore expands into deeper layers of the skin. It can look like a scrape (abrasion), blister, or a shallow crater in the skin. Sometimes this stage looks like a blister filled with clear fluid. At this stage, some skin may be damaged beyond repair or may die.

During stage 3, the sore gets worse and extends into the tissue beneath the skin, forming a small crater. Fat may show in the sore, but not muscle, tendon, or bone.

At stage 4, the pressure sore is very deep, reaching into muscle and bone and causing extensive damage. Damage to deeper tissues, tendons, and joints may occur.

Preventing pressure sores

You or your caregiver can help prevent pressure sores. These steps can help keep skin healthy:

Prevent constant pressure on any part of the body.

Change positions and turn often to help reduce constant pressure on the skin. Learn the proper way to move yourself or to move a person you are caring for so that you avoid folding and twisting skin layers.

Spread body weight. Use pressure-relieving supports and devices, especially if you are confined to a bed or chair for any length of time, to help prevent pressure sores. Pad the metal parts of a wheelchair to help reduce pressure and friction.

Avoid sliding, slipping, or slumping, or being in positions that put pressure directly on an existing pressure sore.

Eat a balanced diet that includes plenty of protein.

Keep the skin clean and free of body fluids or faeces.

Use skin lotions to keep the skin from drying out and cracking, which makes the skin more likely to get pressure sores. Barrier lotions or creams have ingredients that can act as a shield to help protect the skin from moisture or irritation.



The 23rd September 2012 is a day I will not forget in a hurry. That was the date of my wedding anniversary, it was also the day I discovered I had a pressure sore, and so began the hell of the last 3 years.

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Just to give you a picture of my life up to this. I was involved in a Road Traffic Accident in 1972. I was a front seat passenger. I fractured my spine at T12 level and then spent a long period of time in the Rehab in Dun Laoghaire, first in bed and then for rehabilitation. After being released I did a secretarial course in the Vocational School in Kilkenny and at the end of that I got a job with the HSE in Kilkenny. Through this I made good friends and began to socialize. Socializing was difficult in a lot of ways at that time, accessibility was not good and accessible toilets were few and far between.

Over the years before this pressure sore we were both enjoying life. We were working fulltime, I was driving my own car, we were going on one or two foreign holidays a year, going out for meals whenever we wanted and generally enjoying life. But of course all that came to a halt when I got the pressure sore. I was treated at home as I was told no beds were available in Dun Laoghaire. That meant complete bed rest and dressings by the Public Health Nurses. Suddenly everything in the house had to centre around my bedroom. The television was moved in from the sitting room. Michael had to take over all the cooking and house hold duties that we had always shared as well as looking after me. The whole balance of the home and family was changed completely. Eimear asked me to write this article to help people who are in a similar situation of having to remain in bed for long periods, to tell people how I coped. To be honest it was a terrible



ordeal and I don't think there is any easy way to get through it. I had Home Help twice a day but even so I spent an awful lot of time alone. I love to read and this was a blessing as it kept my mind off thinking about the position I was in. I also like to knit and crochet. I found it difficult to knit in a lying position but I did a lot of crochet. I recently finished a blanket that I started while in bed and I also did one for my daughter. Lisa went on holiday to America and brought me back an iPad and I must say I found this a great help, I joined Facebook and so could keep up with people that way.

There were times when nothing would make me happy and there were times when I felt I couldn't cope and of course there were tears. For my 60th birthday I was still in bed and wasn't thinking of celebrating in a big way but Michael my husband arranged a surprise party with all the family coming to my house for lunch and spending the afternoon together. I took part as best I could from by bed and I did appreciate the thought. When I look back now I think I did spend a lot of time putting a brave face on things and trying to take one day at a time and telling myself there will be an end to this and I will get back to a normal life again.

Nowadays I am up and about most of the time and can go out for meals and short trips. I am not driving at present as all the transferring in and out of the car would be too much of a risk. I am in the process of retiring from my job as I would not be able for it any more. So as you can see this has changed our lives a lot. However I am improving all the time and even though my life is different I look to the future with optimism and hope.

-Ann Byrne

Warning signs

The first sign of a pressure sore may be a red area on the skin. If the redness does not fade after pressure is removed, stay off the area affected. If this is your buttocks area or tailbone, you may have to stay off area for a number of days until redness goes. Check that your pressure relief cushion is not damaged and is functioning correctly. If there is no change, consult your GP or Community Nurse.

THE NATIONAL HYPERBARIC CENTRE

The National Hyperbaric Centre Ireland offers hyperbaric oxygen therapy for a variety of conditions.



Hyperbaric oxygen therapy is a prescription drug under European Directive and is the only non-hormonal medical treatment approved by the FDA for biologically repairing and regenerating human tissue. The National Hyperbaric Centre offers treatments for off-label use that have shown promising results for diseases and health issues that research suggests it may benefit.

How Hyperbaric Oxygen Therapy works;

Oxygen is normally carried by the red blood cells only, but when HBO therapy is administered, the oxygen reaches all of the body's fluids and therefore the oxygen is delivered to places in the body that are in need of the extra oxygen. This assists the body in natural healing. Some of the benefits of HBO therapy are the aiding of white blood cells in fighting bacteria and reduction of tissue swelling, which allows new blood vessels to grow in affected areas more efficiently.

They include: closed head injury/concussion, stroke, cerebral palsy, autism, Lyme disease, swelling (oedema), joint-related issues, peripheral neuropathy syndromes/diabetes, poor circulation, reflex sympathetic dystrophy, complex regional pain syndrome, chronic fatigue syndrome, osteoradionecrosis, crush injuries, brain oedema and an average of 70% faster recovery following cosmetic/plastic/reconstruction surgery.



HSF HEALTH PLAN IS AN EMPLOYEE HEALTH BENEFITS PROVIDER.

It is a trading company of the charity, The Hospital Saturday Fund.

We provide employee cash plans to help cover the cost of everyday health care expenses like GP fees, prescription costs, dental fees and glasses. Benefits include hospital, physiotherapy and complementary treatments, specialist consultations, health screening, personal injury and eye laser surgery. We also provide an Employee Assistance programme, HSF Assist® which includes access to a GP Advice Line, Virtual Doctor and Counselling Service.

Unlike other types of health insurance HSF health plan schemes are not claims or age related. Our plans can be introduced as a compliment to exiting PMI Schemes or as an alternative.

Everyone who joins HSF health plan, just by belonging, are making a contribution to the important work of the charity, as the profits from the health cash plan go to the parent charity. Not something which usually happens when an insurance policy is taken out.

For more information on HSF health plan please contact us on 1890 451 451 or email enquires@hsf.ie





CO-ORCH CONCERT

On Thursday 14th April, Co-Orch, Dublin's newest and most exciting instrumental ensemble, hosted a concert in aid of Spinal Injuries Ireland.



Co-Orch is an orchestra with a difference; a young, vibrant collective bringing life to beautiful classical pieces in unconventional settings.

Our concert in Smock Alley Theatre; a beautiful, historic building in the heart of Dublin, was attended by 150 people. Co-Orch performed Schumann, Ravel and Tchaikovsky to resounding applause. It was a truly enjoyable event which left loyal fans and new listeners alike wanting more!

SII was delighted to partner with Co-Orch for this unique fundraising event.

BAG IT!

SII was delighted to hold a pre-loved designer handbag auction in Harvey Nichols, Dundrum Town Centre on 7th April 2016.



The event raised nearly €8,500. Thanks to everyone who kindly donated bags and attended the event. Of course it wasn't just handbags on offer on the night, other prizes included an afternoon of styling and advice with stylist Marietta Doran, a signed rugby ball from former Ireland rugby captain Paul O'Connell and a host of vouchers for the Westbury and Merriam Hotel.



SPRING LUNCH!

What a fantastic event the Spring Lunch was this year with more attendees than ever before who were all extremely generous in their support of Spinal Injuries Ireland.



BAG PACKING EVENTS

SII has organised 5 days of bag packing so far in 2016.

Our most recent bag pack in Dunnes Stores Cornelscourt raised €2,091.57.

We have already raised a total of €7,256.10 through bag packing so far this year!



We are very grateful to all 61 volunteers who have kindly donated their time to Spinal Injuries Ireland to help us raise much needed funds, without whom these events would not have been possible.

We look forward to holding further bag packs this year. Our next bag pack will be in July on July 14th and 15th at Super Valu Dun Laoghaire. Drop into us if you live in the area!



TALL SHIPS

I fell off a wall at the age of 16 and broke my neck at C4/C5 level. As a result I'm paralysed from the chest down with no use of my hands and limited use of my arms. My disability was one of a whole host of reasons why I was both excited but also nervous about joining a Jubilee Sailing Trust voyage.

I fell off a wall at the age of 16 and broke my neck at C4/C5 level. As a result I'm paralysed from the chest down with no use of my hands and limited use of my arms. My disability was one of a whole host of reasons why I was both excited but also nervous about joining a Jubilee Sailing Trust voyage. I had heard of the JST but had never had the motivation or finance to get up and apply for one, until, one day while at work I received an email stating that Spinal Injuries Ireland and Sail Training Ireland were offering a bursary for a voyage. I have an attitude of "never let an opportunity pass you by" so I applied and to my surprise and great delight I was successful!

I was excited because I wanted to work on an accessible tall ship, alongside

crewmates whether able bodied or not, where your best is expected from you, and an accessible tall ship where the focus was not on the word disability anymore but on the word ability. I wanted to be on those tall ships because I knew that on the voyage people wouldn't be worried about what I can't do but what I can do. I knew also that if I did use my abilities to carry out a task I wouldn't be patronisingly applauded for it I would be expected to do it again shortly and to do it better next time.

That certainly proved to be the case. While I was unable to assist in any great way with pulling ropes for bracing or hoisting sails (I wished I had my power chair at times to show exactly what I could do) I was still required to: learn about the ropes and sails and sometimes remind those pulling as to which rope was which, to carry out all watches (where I watched out for anything in our path other than water) to work in the galley (or kitchen) drying dishes for Chef Simon and his assistant Roxie, and the greatest task of all, to avoid getting seasick. I was excited to prove that there is more to me than just a disability and I think I did just that.

I was nervous about joining a JST voyage because at home I have always used the best of facilities and technology in order to make life easier. I use a profiling bed, a



“I've rolled around on this planet for longer than I've walked on it.”

large sturdy hoist, a spacious bedroom, a fast power wheelchair which can raise up into a standing position, and a laptop and phone the settings of which can often allow me to navigate them without even touching the screen. I was nervous because I knew the voyage would be stripped back to the bare essentials and I was not sure how I and my girlfriend Anna, who was acting as my primary buddy, would cope with a tiny cabin, a tiny bed, a tiny portable hoist, and my own manual wheelchair. However, we

quickly fell into the routine of the ship and learned to deal with any challenges that came our way.

What helped alleviate some of my nerves were my Forward Starboard watch team. All voyage crew were divided into different watch teams directed by watch leaders who were directed by the Captain and often by other members of the permanent crew like "Nursey" Mandy. We were a complex blend of abilities and personalities but we bonded pretty quickly thanks in no small part to our watch leader Jim Haig, a man who, let's put it like this, was "quite a bit wiser" than the rest of us. Despite his wisdom, however, Jim was livelier, fitter, and more determined than the rest of us put together. Jim was the perfect watch leader and had the distinct and hugely important skill of being able to balance leadership and companionship. He would give his morning briefings and dish out any necessary orders in his broad Scottish accent but all with a smile on his face and often followed by a charming joke to make us feel at ease.

The Jubilee Sailing Trust were aware of the extent of my disability and assigned a second buddy to me as a result, a Kildare man named John Ward. At first I was unsure about having a second buddy, I was wary that if we didn't get on in such an intense and confined setting it would make the voyage awkward and uncomfortable. I

needn't have worried. John had a similar sense of humour to mine and it was instantly comfortable, another Irishman amongst many Englishmen and women. John was also a great help. Without John assisting Anna to manoeuvre me around the ship during the rough seas I would have had to remain in the one spot all the time or even worse I'd have ended up overboard! I think it would be fair to say that John was out of his comfort zone



“It wasn't a holiday... it was an adventure”

assisting a person with a disability for the first time but like most things on the ship John took to it like a duck to water. He seemed to have an innate skill for anything he put his hand to whether it was clamping a wheelchair to the floor or climbing a mast or helming the ship into Port. I know we will remain friends.

I joined the JST voyage for another very personal reason, recently I have passed the point at which I am now using a wheelchair longer than I had been walking. I was 16 when I had my accident, now I am 32 and enough months to mean I've rolled around on this planet for longer than I had walked on it. There have been different points since my accident where I have realised like a puppy, it's not just for Christmas it's for life. This has been one of those points. I had hoped that a voyage on the JST would help to prove to myself that there's still life in the old dog yet! That was in my mind as I sat on the first platform midway through my assisted climb on Lord Nelson's main mast. I sat there chatting with Nick and DD, two members of the permanent crew, and

enjoying the beautiful views of La Gomera and Lanzarote in the distance and realised that I have probably achieved and done more in those sixteen "disabled" years than I ever would have had I not had my accident and that I have many many more adventures yet to come.

Having returned home everyone asks "how was the holiday?", my response is always the same "it wasn't a holiday... it was an adventure". On Lord Nelson we worked hard and we played hard. We had holiday experiences too. We stopped over on islands, ate great food, enjoyed the sun, did bus tours, Anna swam too, and I went up the mast. We slept like babies throughout. It was definitely one to tick off The Bucket List but it was still an experience that I would be interested in repeating.

I must express my deepest appreciation to Spinal Injuries Ireland and Sail Training Ireland. Without that email that kicked me into action and, more importantly, without their financial support of a bursary for me and Anna to join a voyage I never would have had an unforgettable experience!

-Padraig Hannafin



SAIL TRAINING IRELAND BURSARY INFORMATION

Would you like to sail on a tall ship like Padraig? SII has 2 bursaries to offer on one of the following ships The Bursaries may not include full costs. If you are interested please contact mary.dunne@spinalinjuries.ie and tell us why you would enjoy a tall ships voyage.

-ICC-Gulden Leeuw Voyage- Tall Ship Races

-ICC-Spirit of Oysterhaven Voyages

Date: TBC- there is no specific voyage outlined for this bursary but if applicants are interested in a 'local' 5 day voyage then this is the one for them.

-ICC-JST Lord Nelson and Tenacious

This vessel has FULL ACCESS and is super wheelchair friendly. All ships are subject to availability and bursaries are curtesy of Sail training Ireland and the Irish cruising club.



GRANTS



Who we are

A not for profit agency, our sole aim is to provide support to people with a spinal cord injury and their families at every stage of their experience.

Grant Opportunities

SII works with a number of partners to provide grant opportunities to people with Spinal Cord Injury.

SII has 6 Community Outreach Officers in 6 different nationwide available to all people with spinal cord injury. If you would like to avail of one of the grants, your Community Outreach Officer will visit you to discuss your eligibility and assist you in the application process.

SII Short Courses Fund

Your Community Outreach Officer can work with you to identify and work towards short, medium and long term goals. The goals set may be towards education, training, employment or participation in community and social life.

The SII Short Courses Fund is available to SII clients who wish to participate in a short course as a step towards an identified goal. The maximum amount available to one individual is €500.

To be eligible for this grant you must have a genuine need for the funds and make a small personal contribution towards the chosen course. There must be no other funding source available for your course.

HSF

The Hospital Saturday Fund is a registered charity who provide grant assistance to people with a disability towards specialised equipment or practical forms of treatment. The fund covers some equipment under the following headings:

- Specialised Mobility Equipment (wheelchairs, mobility scooters, car adaptations)
- Special Appliances and Aids

(Hearing aids, nebulisers, specialised vision aids)

- Specialised Computer Equipment
- Therapeutic Equipment / Treatment (Orthopaedic beds, mattresses or pillows, riser/recliners chairs, lift hoist/aids, physiotherapy, hydrotherapy, acupuncture, speech therapy, osteopathy, chiropractic treatment, reflexology, massage therapy and aromatherapy)
- Home adaptations (walk in showers, accessibility adaptations to bathrooms, access ramps, non slip flooring, stair lifts)

To apply for this fund your Community Outreach Officer will gather the required information with you and submit this to the HSF on your behalf. Members of the public cannot apply on an individual basis without going through a partner organisation. Please note that financial information is requested as part of this application in order to ascertain need and HSF will make the final decision.

Turn2Us - Elizabeth Finn Fund

Turn2Us is a charity that helps people living in financial hardship in the UK and Ireland. The organisation provides grants to individuals through their Elizabeth Finn fund. The grants are usually a one off award and can be available for help towards:

- Household items
- Disability equipment, aids and adaptations
- House repairs for homeowners
- A flexible grant to spend as needed (up to €1,300 for a single person and €2,000 for a couple, family or parent with a child)
- Costs of moving to a more affordable home
- Help with transport, work or care costs
- Costs of education or training where it will help you return to employment (excluding first or second full time degrees)

To be eligible for the grant you must have less than €5000 in savings, be on a low income or claiming benefits, have Irish or British nationality and be living in Ireland or the UK for at least half of the year and you or your partner must have worked in certain professional occupations. There is a list of 120 eligible occupations all of which require a degree or FETAC Level 6 and above. The fund may also assist people who have run their own business with employed staff or who have earned a living from the arts.

Turn2Us requires financial information as part of the application. Your Community Outreach Officer will assist you with the application process and submit it on your behalf. Turn2Us make the final decision.

To find out more information on any of the grants listed or to find out how to apply for them please contact your local Community Outreach Officer or email info@spinalinjuries.ie.

The Grants Programme is supported by:

Hospital Saturday Fund



Turn 2 Us



Irish Cruising Club



Jubilee Sailing Trust



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or email us at info@bluebirdcare.ie

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Legal Advice Clinics

IF YOU OR SOMEONE YOU KNOW HAS SUSTAINED
A **SPINAL CORD INJURY** IT IS IMPORTANT TO GET
SOUND LEGAL ADVICE



As part of the service provided by Spinal Injuries Ireland we can arrange for our members to receive sound legal advice in their own home (if member can not travel) or at the offices of SII.



Legal advice clinics take place every Wednesday at SII Office 2:30pm - 4pm.



Our legal advice centers are staffed by fully qualified legal experts who are specialist in the area of personal injury and have extensive experience in dealing with people who have sustained a spinal cord injury. You can be assured that you are getting the best advice for your situation.

Make an Appointment

To make an appointment to attend the legal advice clinic:

Telephone: 01- 2355317

Email: info@spinalinjuries.ie

