

at the second

BARENT OF THE SUPPORT AT EVERY STAGE

SpeediCath® - Setting the standard with a range of catheter solutions for you

Meet BRAD

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

⁶⁶ 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...

Visit us on

It really promotes confidence.

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



You



WELCOME

Happy Christmas to all our service users and family members and best wishes for 2017.

As the year draws to a close it offers the team here at Spinal Injuries Ireland time to reflect on the development of Spinal Injuries Ireland over the last year. The organisation launched its first public affairs campaign 'This is my life' in May 2016 which involved 10 townhall meetings nationwide. This offered people with a spinal cord injury and their families a platform to voice their worries and concerns for the lack of support and services for them. This campaign led to a parliamentary meeting in Leinster House in June and a visit by the Minister for Disabilities Finian McGrath to the SII AGM in October. The Minister has agreed in particular to examine the fact the people with a SCI are not listed as a long term illness and vowed to look at introducing medical cards irrespective of means. To assist the Minister in this campaign SII surveyed its members in November and a full submission will be made to the Minister in the coming weeks.

2017 will bring many challenges to SII, not least our move from the NRH where we have resided for 23 years to facilitate the build of the new hospital. We are seeking assistance to find a new premises either financially or through subsidised or low rent accommodation. However we would like to assure everyone we will continue in our role as the patient voice in improving supports and services for people with a SCI in Ireland.

Happy Christmas

Yours sincerely Fiona Bolger CEO



CONTENTS

SII meet with Minister for Disability
Minister for Disability attends SII AGM
Medical card survey
Bursary to sail the seas
An Update on Regional Meetings
Irish Healthcare Awards 2016
Discovering the Power in me
Peer Support and You
Colour Me Friday
SII Summer Raffle
Martin's Story
Vicky's Story
Kerrie's Story
Maria's Story
Gallery of events

Editor - Fiona Bolger Deputy Editor - Sive O'Connor Design - Tracey Barlow Print - Sooner Than Later General Enquires- Spinal Injuires Ireland HQ Tel 012355317 Email info@spinalinjuries.ie



SII MEET WITH MINISTER FOR DISABILITY

Spinal Injuries Ireland (SII) met with the Minister for Disability, Finian McGrath TD on September 12 to discuss the need for additional funding to ensure the provision of services for people with spinal cord injuries (SCI) in Ireland.



The meeting with the Minister took place in Leinster House and was the culmination of SII's 'This is my Life' campaign. On the agenda at the meeting were four key areas that urgently need funding from the government. They included: 1) An increased and ring fenced budget for home-care packages for complex cases to clear the pathway of care and free up beds at acute and rehabilitation stages; 2) Immediate investment to address staff shortages and training for healthcare professionals in both inpatient and community settings; 3) The granting of medical cards based on medical need rather than income; 4) The initiation of a central strategic approach to case management. In discussion with the Minister, Fiona Bolger, CEO at SII, explained In discussion with the Minister, Fiona Bolger, CEO at SII, explained that the average incidences of spinal cord injuries have increased from one person per week in 2015, to almost two people per week in 2016

that the average incidences of spinal cord injuries have increased from one person per week to almost two people per week in 2016.

She said that this is putting limited and underfunded services under further pressure.

"Throughout the summer we heard hundreds of individual stories from across the country of the difficulties that people with a SCI face every day and these were presented to the Minister. We also outlined the four key recommendations that we feel could be implemented as a matter of priority."

In addition, she added that due to current delays in the pathway of care, Spinal Injuries Ireland is providing support to people and families who are awaiting treatment and/or home care packages. "This has caused unprecedented pressure on the Community Team of six (three full-time and three part-time employees) and additional funding is required to continue to provide these services," she explained.

"We hope that by bringing these issues to the Minister, he will begin to highlight and implement these changes at government level."



MINISTER FOR DISABILITY ATTENDS SII AGM

The Minister for Disabilities, Finian McGrath TD, gave the opening address at Spinal Injuries Ireland (SII) AGM on October 19.



The AGM took place in the SII Resource Centre on the National Rehabilitation Centre (NRH) campus in Dun Laoghaire. This marked the first time that any politician addressed the Spinal Injuries Ireland AGM and it ensured that there was a great attendance on the day, with over 30 service users attending the meeting. Many topics were covered on the day and James McCarthy, Chairman at SII, spoke of the need for people with spinal injuries to automatically be entitled to medical cards. He said: "The Minister has introduced domicilary medical cards for children with certain illnesses and this is discretionary. So we feel that the same should be the case for people with SCIs." Mr McCarthy also highlighted the challenges that SII face as the only support agency for families and people with SCI.

In response, the Minister said that Mr McCarthy made a "good point" and added: "You all know what happened over the last eight years and now we are trying to rebuild our system."

"I strongly believe that people with SCIs should be entitled to a medical card. I have said that to Minister for Health Simon Harris and I will say it to him again. We moved to help 10,000 children so why not 1,800 people with SCI."

Following the Minister's speech, attendees took part in a question and answer session with Minister McGrath where he discussed issues including PA hours, medical cards, suitable housing for people with SCI, home care hours, and accessibility.

The Minister answered all the questions directed at him and assured attendees that





he would be taking on board the issues raised at the AGM.

He said he would give particular attention to the fact that SCI is not listed as a long term illness and the fact that people with SCIs are not automatically entitled to a medical card.

In the week following the AGM, SII CEO Fiona Bolger was invited to meet with the Minister's advisor on disabilities, Gerry Maguire.

Mr Maguire informed SII that, in addition to working on the availability of the medical card for people with SCIs, he will also support SIIs request for funding to continue to provide a national service. Following on from the visit of the Minster for Disabilities, Finian McGrath, SII conducted a survey among its services users to provide him with up to date statistics on the impact of a lack of automatic entitlement to the medical card for people with SCI. You can view this survey overleaf.

The results of this survey will be forwarded to the Minister.



MEDICAL CARD SURVEY

FOLLOWING ON FROM THE VISIT OF THE MINSTER FOR DISABILITIES, FINIAN MCGRATH, SPINAL INJURIES IRELAND CONDUCTED A SURVEY TO PROVIDE HIM WITH UP TO DATE STATISTICS ON THE IMPACT OF A LACK OF AUTOMATIC ENTITLEMENT TO A MEDICAL CARD FOR PEOPLE WITH SPINAL CORD INJURY.

The results of this survey have been forwarded to the Minister and his staff following two meetings with SII and the Minister's office, as well as the Ministers' attendance at the SII AGM in October 2016. The survey was emailed to 716 Service Users and phone calls were made to a further 220 service users. A total of 389 surveys were completed (41% of those contacted).

Q.1 How old are you?

15 (4%) respondents were aged between 15 to 25 years old 42(11%) respondents were aged between 26 to 35 years old 94 (24%) respondents were aged between 36 to 45 years old 96 (25%) respondents were aged between 46 to 55 years old 81 (21%) respondents were aged between 56 to 65 years old 61 (15%) respondents were aged 66 years and older

Q.2 What year did you sustain your spinal cord injury?

374 respondents answered:

107 (29%) sustained their injury in the past 5 years 85 (23%) sustained their injury between 2005 and 2010 61 (16%) sustained their injury between 1999 and 2010 124 (32%) sustained their injury previous to 1999.

Q.3. Which of the following best describes your current occupation?

388 respondents answered:

71 (18%) in full or part time employment
159 (41%) unemployed
18 (5%) in full or part time education
6 (1%) undertaking voluntary work
21 (5%) at home full time with children
27 (7%) self employed
86 (22%) other

Q4. Do you have a medical card?

389 respondents answered: 272 (70%) - Yes

117 (30%) - No

Q.5. If the answer to Q4 is 'yes', is your Medical Card:

314 respondents answered:
161 (49%) - Means tested (issued based on your assessed household income)
104 (31%) - Discretionary (issued based on medical need though your household income may be over the threshold)
66 (20%) - I do not have a Medical Card

Q.6. If the answer to Q.4. is 'no', have you been previously issued and then subsequently lost your Medical Card?

314 respondents answered:

69 (22%) – Yes 121 (38%) – No 124 (39%) – Not applicable, I have a Medical Card

Q.7. Has taking up full or part time employment resulted in you losing your Medical Card?

364 respondents answered:

38 (10%) - Yes 132 (36%) - No 194 (53%) - Not currently employed

Q.8. Does fear of losing your Medical Card prevent you from seeking paid employment now or in the future?

356 respondents answered

155 (43%) - Yes 102 (29%) - No 99 (28%) - Not applicable, I am currently employed

Support at every stage 7



The JST is a registered charity whose mission is to promote the integration of all physical abilities through the challenge and adventure of tall ships aboard the Nelson and Tenacious.



"It wasn't a holiday... it was an adventure"
Padraig, JST Voyager.

The JST is a registered charity whose mission is to promote the integration of all physical abilities through the challenge and adventure of tall ships aboard the Nelson and Tenacious. They offer both able bodied and disabled people holidays on board the tall ships. Every aspect of ship board life is accessible and available to all from setting sails, going aloft and helming the ship. You are required to use a manual wheelchair whilst on board and you and your buddy are there to support each other and be part of the on board team.

The Irish Cruising Club in partnership with Sail Training Ireland have developed a bursary scheme specifically to support young people that would not otherwise have the opportunity to undertake cruising and Sail Training voyages on yachts and tall ships due to financial, social, physical, learning or other limitations.

Sail Training Ireland and Spinal Injuries Ireland have worked together on individual ICC bursaries, these provide funding for participants and a buddy from SII on board the JST's 'Lord Nelson' which is a fully accessible Tall ship that caters for wheelchair users and people with visual or hearing impairments and learning disabilities.

Would you like to sail on a tall ship and have the adventure of a lifetime? If so you can contact mary.dunne@spinalinjuries.ie or call us on 01 2355317 and tell us why you would enjoy a tall ships voyage.





SII works with a number of partners to provide grant opportunities to people with a spinal cord injury.

HOSPITAL SATURDAY FUND



The Hospital Saturday Fund (HSF) is a registered charity who provide grant assistance to people with a disability towards specialised equipment or practical forms of treatment. In 2016 Spinal Injuries Ireland were able to secure successful HSF grant applications towards the following:

Ireland were able to secure successful HSF grant applications towards the following:

- Hydrotherapy
- Car hand controls
- Physiotherapy
- Assistive Technology
- Toilet adaptations
- Dry needling for pain management
- Recliner chair
- Vibration plate for pain management
- Orthopaedic mattress
- Bioness FES device
- Mobility scooter
- Medical scans

"I can't thank my outreach officer enough for helping me to secure a HSF grant" – Geraldine, HSF grant recipient.

Members of the public cannot apply on an individual basis without going through a partner organisation. To apply for this fund your Community Outreach Officer will gather the required information with you and submit the application to HSF on your behalf.

Please note that financial information is requested as part of this application in order to ascertain need and HSF will make the final decision.

OTHER GRANT OPPORTUNITIES

SII Short Courses Fund

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.

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 adaptions
- 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.

The Community Outreach Team are located in 6 different areas of the country and are available to visit you and discuss your eligibility for any of the above grants. 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



AN UPDATE ON REGIONAL MEETINGS

Regional meetings will be running nationwide in various locations around the country for 2017.

.....

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 2017, SII will continue to run meetings across the country with a wide variety of topics covered.

The schedule for the regional meetings and social meet ups for 2017 is as follows:

SPRING

Location	Venue	Date	Time	Topic / Speaker
Location	Venue	Date	Time	Topic / Speaker
Louth	Crown Plaza	Feb 1st	7-9pm	Positive Mental Health
Cork	Nemo Rangers	March 1st	1-3pm	Employability Services
Limerick	IWA Roxboro Limerick	March 2nd	2-4pm	Mental Health Ireland
Kerry	The Rose Hotel	March 6th	2-4pm	Bladder Care
Leitrim	The Landmark Hotel, Carrick-or	n-Shannon	March 10th	11.30-13.30 Assistive Technology
Portlaoise	Portlaoise NLN	March 10th	1.30-3.30pm	Bladder Care
Donegal	The IWA, Letterkenny	March 14th	2-4pm	Chronic Pain
Galway	The Westwood Hotel	March 21st	7-9pm	Nutrition
Waterford	The Viking Hotel	March 21st	2-4pm	Employability Ireland
Мауо	Ballina Family Resource Centre	March 28th	6.30 - 8.30	Coffee Meet up
Wexford	Maldron Hotel	твс	твс	Mental Health Ireland
Dublin	SII Office	твс	7-9pm	Positive Mental Health

SUMMER

Location	Venue	Date	Time	Topic / Speaker
Portlaoise	Portlaoise NLN	June 2nd	1.30-3.30 pm	Assistive Technology
Donegal	The IWA, Letterkenny	June 6th	2-4pm	Rights & Entitlements
Leitrim	The Landmark Hotel, Carrick-or	n-Shannon	June 10th	12-2pm Senior Physiotherapist
Kerry	Rose Hotel	June 12th	2-4pm	Disability Federation Ireland
Galway	The Westwood Hotel	June 13th	7-9pm	Rights & Entitlements
Cork	Nemo Rangers	June 14th	1-3pm	Citizens Information Q&A
Мауо	Ballina Family Resource Centre	June 20th	6.30 - 8.30pm	Rights & Entitlements
Limerick	IWA Roxboro Limerick	June 22nd	11am-1pm	Volunteer Ireland
Wexford	Maldron Hotel	твс	твс	Accessible Wexford
Waterford	Viking Hotel	ТВС	твс	Chronic Pain
Louth	Crown Plaza	ТВС	твс	Assistive Technology
Dublin	SII Office	твс	твс	Nutrition

10

SII WINS AT IRISH HEALTHCARE AWARDS 2016

Spinal Injuries Ireland (SII) was delighted to receive a special commendation award for 'Patient Organisation Project of the Year' at the Irish Healthcare Awards 2016.

The awards took place in November and SII was nominated for its work in the 'This Is My Life' campaign which was sponsored by Coloplast.

Speaking after the awards ceremony, Fiona Bolger, CEO at SII said she was delighted that Spinal Injuries Ireland were acknowledged for the 'This Is My Life' campaign.

"This is the first time SII have been nominated at the Irish Healthcare Awards and we were thrilled that our campaign won this commendation. A lot of work went into the campaign and we were proud at its success. This award really meant a lot to myself and the team and we look forward to running the campaign again next year as we continue on our mission to raise more awareness about the challenges people with spinal cord injuries face on a daily basis."

The aim of the 'This Is My Life' campaign is to build a community that can influence change and improve supports and services for people living with the impact of a spinal cord injury (SCI).

As part of the campaign, SII visited 10 towns and cities across Ireland, held meetings, and engaged with people living with SCIs while also providing support to their family and friends.

At the meetings many topics were covered including a lack of public knowledge about SCI, delays accessing services for SCI patients, inadequate services for SCI



patients, lack of care packages to support independent living, lack of training for PAs and carers, and unemployment levels of 76% amongst the SCI population with 40% living on or below the poverty line.

The information gathered helped to form the basis of an advocacy programme, to



help provide a voice for people living with a spinal cord injury in Ireland.

"One of the main points that came up at most of the meetings was that a louder voice is needed for those living with SCI," explained Fiona Bolger.

"The 'This Is My Life' campaign aimed to reach out to people with an SCI, their families, friends and health service professionals to build a community which will influence change and improve supports and services. Our main objective is to build this one voice support system."

As part of the campaign, SII collected over 650 signatures from people who pledged support to help people with a spinal cord injury live better lives.

These signatures helped SII secure a Dail briefing in Leinster House in June and culminated in a meeting with the Minister for Disabilities Finian McGrath in October (see page 4&5).



IN AUGUST THIS YEAR, A GROUP OF SIX PEOPLE WITH SPINAL CORD INJURIES (SCIS) TOOK PART IN A TWO DAY COURSE IN SPINAL INJURIES IRELAND CALLED DISCOVERING THE POWER IN ME.

Its aim was to empower participants via a programme comprising of 12 units. These 12 units related to various life skills including positive thinking, goal setting, cognitive functioning, and personal motivation.

Jack Shannon-Cole (18) from Shankill in Dublin took part in the Discover the Power in Me programme and explained how he felt the programme benefited him.

"We were taught how to go about achieving the very most that we can achieve personally. It was very much trying to open the eyes of the participants on the course to what is available to them if they had the urge to go and get it. "It has helped me. An awful lot of it was based on being positive and proactive and not letting the negative stigma of having a spinal cord injury or being in a wheelchair bring you down to lower depths."

Jack, who sustained a spinal cord injury four years ago this month when he fell off a wall and broke his back, said that the course was very inspirational. The group learned how to take control of their own destiny.

"As part of the course, we did an exercise where we looked at a photo. For 20 minutes we all sat and looked at this photograph and none of us could make out what was in the photograph. It was one of those illusion photographs. Then after 20 minutes each and every single one of us had given up and he turned the



photo upside down and we could clearly see that there was an elephant in the photo. We couldn't see it before we were told. The message was that sometimes in life things aren't very clear until you take a step back and realise the bigger picture."

Jack explained that as part of the programme, the group opened up to each other about living with an SCI.

"The course taught us to open our eyes and realise that you don't have to keep all your complications of your



spinal injury to yourself. For example, you can't talk with an able-bodied person about your bowel programme but you can talk to a person in this group because everybody is in the same boat."

The course also focused on how to avoid negative feelings.

"The course makes you realise that you need to try to shut out and limit the amount of exposure you have to the negative things that are having an impact on you. The programme also teaches you how to acknowledge the bad things in your life and how to prevent yourself from doing them even though they may be the easier thing to do than the good thing. It was quite enlightening."

Discovering the Power in Me was developed by the Pacific Institute, Canada and is being rolled out nationwide by Spinal Injuries Ireland. This is the first time the course has been run in a European country. Blake Williams, Managing Director of the Pacific Institute, trained SII staff on the delivery of this course. We were taught how to go about achieving the very most that we can achieve personally



SII received Pobal funding for a Discovering the Power in Me pilot project to deliver the training programme to a total of 80 young people (between the ages of 15 and 25 years) who have sustained a spinal cord injury or brain injury. SII has partnered with National University of Galway to evaluate the outcomes of the course. It is anticipated that this will lead to further funding for the course for all SII clients who wish to participate.

If you are aged 15 to 24 and interested in applying for a place on 'Discovering the Power of Me' contact Mary Dunne at Mary.dunne@spinalinjuries.ie or call (01) 2355317. If you are outside of this age group and interested in attending the course, please contact us as limited spaces are currently available.

> ciste na gcuntas díomhaoin the dormant accounts fund





SII'S 'SOMEONE LIKE ME' PROGRAMME IS A PEER MENTORING PROGRAMME AVAILABLE TO PATIENTS WITH SPINAL CORD INJURY IN THE NRH.

"The 'Someone Like Me' programme provides support in whatever way works best for the individuals involved.

.....

Mentors have varying levels of SCI and the programme is about sharing experiences with other people in a similar situation while in a relaxed environment. Peer support is an effective buffer for stress and is shown to increase a person's sense of empowerment and self-efficacy. The peer support programme has expanded further in 2016 and this is a trend we want to continue in 2017. In the autumn of this year, SII organised 2 peer support training days in Dublin and Cork. In Dublin, nine new volunteers were trained on the 26th of September 2016 and in Cork. seven volunteers were trained on the 20th of October 2016.

Peer support weekly sessions take place in Dublin in the NRH every Monday evening from 7pm to 8pm. Sessions There is a short group discussion followed by the option to have a chat with other people in the group. This is a comfortable way to discuss and understand the process of adjusting to spinal cord injury and a great way to meet others living with SCI" – Kate Duggan, SII Services Manager.

take place in the lecture room and patients

can join to have an informal, relaxed chat with one of the SII peer volunteers. Refreshments are available for those attending. A patient and peer volunteer can meet outside of the Monday sessions also and SII encourages this if both sides would like to continue the peer support relationship.

In Cork, following on from the peer support training in October, small local coffee mornings have begun. These are currently taking place in Cork City, Mallow and Clonakilty. We very much welcome people based in Cork to attend these coffee mornings. If you would like to find out more information about these or would like to go along, please contact Philippa or Finbarr, based in our Cork office.

We are always looking for more peer volunteers in the Dublin area. If you are 3 or more years post injury and think this could be for you, please contact Kate Duggan kate@spinalinjuries.ie or call 01 2355317.



Support at every stage



SII was delighted to see our annual fundraising campaign Colour Me Friday grow bigger in its second year.



Over 150 companies and supporters took part in our campaign; organising in-house events, green parties and generously donating to SII. Sunway Travel, The Talbot Hotel Stillorgan, MMS Medical in Cork and the Irish League of Credit Unions were just a few of those who donned green and showed their support for people living with a spinal cord injury. We were delighted that a number of our members and supporters organised events around the country in aid of SII this year. From Roscommon to Dundalk to Dublin, there was such enthusiasm and creativity behind these colourful events. Artists came together

to paint green motifs; community raffles and auctions were held; barbers and tattoo artists united in aid of SII! Through these extra supports, we have already surpassed our 2015 campaign amount.





G We're looking forward to next year's Colour Me already!



A huge thank you to everybody who attended the community events organised by our Outreach Officers around the country and donated to SII on 7th October. We're looking forward to next year's Colour Me already!



SII launched its first ever Summer Raffle this year with great support from our members across Ireland. Windsor Motors sponsored our raffle prizes which meant that in total SII gave away a combined amount of €8,500 to our lucky winners.

SII was thrilled to raise over €25,000 so a big thank you to everyone who took part and supported the raffle. Our raffle draw was held at the end of September after a busy summer of ticket sales with the following results:

Our first prize of €5,000 went to Clive Keenan; the 2nd Prize of €2,000 went to Paul and John O'Riordan and the third prize of €1,000 went to Brendan Sullivan.

Our top seller was Joe Murphy who sold over 200 tickets and won €500! Our runner up in the top seller's prize was Joey O'Neill. Thank you to everyone who took part.

Congratulations to all our winners and special thanks to Windsor Motor Group. We will be holding another Summer Raffle in 2017 so don't miss your chance to win!

RUN IN THE DARK & THE DUBLIN MARATHON 2016

For the second year running, SII entered a team into Run in the Dark on Wednesday 16th November. Run in the Dark is organised every year by the Mark Pollock Trust with the aim of raising money to help fund research to find a cure for paralysis. This year there were runners from many different companies who ran in aid of SII and represented us on the night. This is an event we take part in every year so if you would like to run next year in aid of SII, keep it in mind!

The end of October saw runners take to the streets of Dublin for the Airtricity Marathon. One young lady in particular made an incredible effort on behalf of SII in the marathon. Emma Porter understands the value of SII having come through a difficult injury and operation. She decided to take on the marathon and fundraise for SII and has raised an incredible €1,230.

A huge thank you to Emma and all our Run in the Dark runners for their efforts.



On the 20th of September this year (2016) I will be celebrating my 40th year of living with a spinal injury.

.....

In 1976, I was in a car crash. I had a complete C5/C6 spinal cord injury. I was put on traction for weeks. I was lucky that I learned to accept my disability quickly and never blamed anyone for what had happened. It was much harder for my family and friends as they had to look at me in bed and then in a wheelchair.

It was hard coming to terms with being paralyzed at the start. I was and still am unable to do anything for myself independently. Someone has to feed me. To get out of bed, I have to be dressed and hoisted out. Today's electric chairs have improved things a lot. There was no accessible public transport and no accessible taxis which made getting around very hard. The first time I went home was the worst, I realized for the first time life would never be the same. We had to move house and my family had to slowly learn how to look after me. I can't take a break from my disabilities, I'm still paralysed but I've learned to cope.

Over the years, I have studied many things. I studied Computer Programming and worked at it for two years. I studied at The Open University and got a degree in Social Science. I took up watercolor painting and had success with a solo exhibition in The Guinness Hop Store in Dublin.

I have travelled all over the world from Australia to America, from camping in France to a safari in Kenya. I have been to many sporting events; including the American Cup in Rhode Island, Euro 88', Italia 90, baseball at Fenway Park and a Soccer International in Lansdowne Road (you could drive into the grounds and park between the stands in 1979).

For 10 years, I campaigned for rights for people with disabilities (mainly with the Forum of People with Disabilities). We got to sit with the then Taoiseach, Albert Reynolds, and got the Cabinet to agree that a percentage of civil servants would be people with disabilities, that public buildings must be accessible to all disabled persons, that building regulations would be changed, that Dublin Bus would only buy accessible buses and that curbs would be ramped. I had many letters and articles published and appeared on TV and radio. I hope I did my bit for the cause. But after all those campaigns, a lot more still needs to be done.

The greatest thing that happened to me was meeting my now wife. We have been together nearly 25 years. She has put up with me and cared for me through many ups and downs. She has encouraged me to keep going and we now have a son who has changed my life.

In recent years, I have spent a lot of time in General Hospitals with pressure sores. Unfortunately, they still do not know how to look after people with SCI in general hospitals. They get used to you but showering and bowel management are



In those days the NRH was only learning how to care for people with spinal injuries.

nightmares. Then you have the problems of the HSE and the government. They keep changing the rules about grants and what you are entitled to. A SCI is not recognised as a long term illness and unfortunately you are not entitled to a medical card. Moreover, it's almost impossible to get health insurance for a person with a SCI.

After 40 years, life is a struggle but well worth fighting for. I am one of the lucky ones. I have a family and friends, live independently, and thankfully I am not totally dependent on the State or charities.

Martin Sinnott BSc. July 2016.





In 2004, at the age of 17, Vicky Hayes sustained an L1-L2 incomplete spinal cord injury when she fell out of her bedroom window.

"The night it happened, my Mam actually thought I was having a nightmare because I was screaming and saying 'I fell off the mountain' and that I couldn't move my legs. My Mam came upstairs and she was calling out for me and I kept saying 'I'm here, I'm here, I fell off the mountain.' It was only when my brother came into the room and happened to glance out the window that they saw me lying on the ground."

In the days following her accident, Vicky was informed that she had an incomplete spinal cord injury and she would most likely never walk again.

"My life was hard in the beginning because my friends didn't really know what to do. In the hospital it was good because you could talk to people openly about your bowels and bladder but when I left hospital it was hard not having anybody understand that side of things. On the pain side, my Dad understood because he suffered a back injury and is in chronic pain as well."

In 2013, things started to change for the better when Vicky met with Siobhan

O'Driscoll, Community Connect for Dublin

and North East, from Spinal Injuries Ireland (SII).

"When I met SII, I started getting involved with the regional meetings and I met other people with spinal injuries which was great. I went on an activity weekend with SII and I got to go canoeing and learn archery. I'd canoed before in school but I hadn't done it since. I thought I'm not going to be able to do any of that. So that really opened my eyes that I could do these things."

Vicky also has an interest in making jewellery so SII linked her in with a 10 week jewellery making course. "The course was great, Siobhan got the funding through the SII short courses fund for me. I do that on and off still. It keeps me going and it is a good distraction for me. Last Christmas and the Christmas before I made bracelets for my friends." Vicky also took part in the Discovering the Power in Me programme run by SII which helped her set new goals.

"Siobhan and SII really helped me a lot,

especially with meeting people and taking part in the Discovering the Power in Me course. The course was really good and a few of us have added each other on Facebook and we talk to each other.

"We've set up a message group on Facebook and if one of us has a problem we just ask the question and they tell us what they go through and how they get through it which is really good. It's great to have them there as well as a support." Over the years, Vicky struggled with her mental health but in many ways she credits her injury with saving her life.

"I suffered with depression before the injury but I only got a proper diagnosis when I had the injury. So in some way the injury kind of saved my life but unfortunately the physical limitations and chronic pain didn't help the depression. But at least I was finally getting the help I needed.

"The Discovering the Power in Me programme has really helped with this too."

Vicky explained that the last few years have had their ups and downs but she is in a good place now and is looking forward to starting a new job in the next few weeks.

"Siobhan really encouraged me to link in with different organisations to look for a job. I recently applied for the position of a receptionist in Tallaght through a CE Scheme. Two weeks ago I went for the interview and I got the job. I was just waiting on an electric wheelchair and yesterday it came so I should hopefully be starting the job in the next week or two. I'm really looking forward to it."



I don't remember much, I woke up in hospital and I was told that I had slept-walked out of my bedroom window.



It is amazing what just over five years brings you. Where will you be in 5 years time is a question you get at every job interview and quite honestly I don't have a clue. If I have learned anything from rereading the last "Kerrie's Story" it is that the path you lay before you is not always the path you leave behind.



Five years ago, I thought I would be a Film Studies graduate. I was internally freaking out because my peers would be ahead of me given that I had repeated the Leaving Certificate. I never thought I would do a 180-degree turn within 12 months.

In 2010, I enrolled in DIT to do Film and Broadcasting with French. Having finished First Year, I quickly decided that I did not want a career in the field and dropped out of the course. During Christmas 2011, I applied for a role with the London Olympics and Paralympics, hoping for the best and expecting the worst. I suffered a deep depression. To try and counteract it, I became involved in archery, and I applied to go back to college the following year.

Soon after Christmas, I was called for two job interviews for the Olympic and Paralympic Games and I got a job! I was invited to my first para archery competition in Stoke Mandeville. Off I went to the UK for both. Summer 2012 was a whirlwind and the best experience I have ever had. How am I going to top getting to see Katie Taylor's gold medal match or finally completing The Iliad! To top off the summer that was, I was accepted to Maynooth University and started a degree in Equine Business that September.

I returned home to start in Maynooth and graduated last September. I joined the archery club and currently hold the student record in my discipline. That includes able-bodied archers as there isn't a separate para category. One of the more fulfilling parts of college was the #NoLabelsNoLimits campaign started in 2015 that took legs, (pardon the pun), in 2016, becoming a national event. We

Summer 2012 was a whirlwind and the best experience I have ever had

wanted to celebrate the students of Maynooth University and the differences that make the campus unique. Although we ran events such as wheelchair basketball and blind football for those with a physical disability, like myself, there are many hidden disabilities and these too should be acknowledged. Students with epilepsy, autism, Asperger's, to name a few, all have a place on our campus. The campaign won the USI Student Achievement Award in 2015 and was a national campaign in 2016. It is a legacy that I hope sustains in Ireland's universities and can become a national event across the entire education system.

I have spent the last year focusing solely on archery and qualifying for the Rio Paralympics. Last summer, I headed to the 2015 World Archery Para Championships in Germany and finished 9th. I then went to the 2016 European Para Archery Championships in France and came 3rd in the qualifying tournament, finally finishing 7th in the last qualifying tournament in the Czech Republic. All just outside securing my ticket to Rio. Let's not dwell on that though, the journey was captured on my Facebook page,

https://www.facebook.com/kerrieleonardri o2016, if you want more details of the ups and downs. It has not deterred me and I'll start it all again as Tokyo is only 4 years away.

In the last year, along with friends, I set up a new archery club in Trim, County Meath called Fusion Archers. We are an inclusive club that came from very small beginnings. I coach the club's beginner courses and you can find us at www.fusionarchers.com or https://www.facebook.com/FusionArchers.

Nttps://www.facebook.com/FusionArchers. We have a very relaxed atmosphere and love gaining new members. If you are interested in taking up the sport or want to find a club in your area, just get in touch.

Until 2021, Kerrie 🙂





I am now 28 years old and my accident happened when I was 20 years old.

I had grown up around horses and my grandparents always had ponies at home. It was a passion which I had from a very young age. I always wanted to work with horses and competed in showjumping at a novice level and attended pony club like many young girls. When I was 16, I went to a Breeze Up yard, a yard where where they would prepare young horses for their journey to become race-horses. I worked there on weekends between school and studies and when I finished school I continued to work with them and travelled to Italy, France and the UK with their young horses. I loved my job so much. I loved the breaking in process and the involvement I had with these young thoroughbreds. I had the best group of friends and the best boss you could ask for. It was a fantastic team. Unfortunately on one particular trip to Paris in April 2008, when I was riding one of the horses, I had a fall and the horse I was riding went through the running rail and managed to fall on top of me. I was taken to Beaujon hospital in Paris where I under went scans and x-rays to discover I had a compound fracture to my L1 and compression on the spinal cord. I still had a mixed feeling sensation in my legs but

obviously knew something wasn't 100%. Luckily the French doctors were fantastic and I underwent surgery straight away to pin the spine in place. I have still got six pins and two rods fixed between T11 and L2 and have an incomplete SCI. After the surgery I remained in Paris for another week and then was airlifted back to Ireland to CUH. It was soon after the surgery that I discovered the incontinence issues and this has not changed. I am now, almost 8 years later, still doubly incontinent. I do think however that I am very lucky to be walking and I always believe there are people in a much tougher position than me. I guess I had a very positive outlook and in the end it was mind over matter - I just had to get on with things and not let this hinder my quality of life. The following January, nine months later I went travelling to Asia and Australia for a couple of years. My parents would post me catheters and were extremely supportive. I was quite headstrong and did not want this to stop me. When I returned from Australia I continued to work in the thoroughbred industry as this was where my passion lay. I attended the bloodstock auctions worldwide and I knew that I wanted to have a career in the equine business. After a lot of time and effort and working for nothing at times, I finally found the position I wanted to begin my long term career in. I am now extremely lucky to be working for an organisation called

Shadwell which specialise in breeding and racing thoroughbred horses. It is owned by Sheikh Hamdan Al Maktoum and I work in the racing department for racing manager, Angus Gold. I love my job and feel very lucky that things have worked out for me. At the end of October I was devastated to know that a friend, Freddy Tylicki, a jockey in the UK had fallen from his horse in a race on Halloween. The mount clipped heels and came down, bringing down three other horses. He has sustained T7 paralysis. This has truly rocked the racing community and our thoughts and support are with him for the future challenges that lav ahead. "

- Maria Ryan



20



RIB TRIPS AND SEA ACTIVITIES

From April to October, SII ran a number of RIB trips from Dunlaoghaire harbour for patients in the National Rehabilitation Hospital (NRH).

As part of the trips, patients were brought out to sea on an adapted speed boat and they got to see some of the stunning views that surround the Irish coastline.

......

In addition, SII ran a kayaking day in Shannon River Adventure Centre, Rooskey, Co Roscommon on Saturday September 24.

SII would like to thank all our volunteers who run the RIB trips and all the people who took part in the kayaking event in September. We couldn't do it without your support





BBQ EVENT

Over €25,000 was raised in aid of Spinal Injuries Ireland at this year's BBQ event which took place on 1st October 2016. The event was held in Old Belvedere Rugby club in Dublin and it was organised by a committee of volunteers.

"The event was a great evening and we were overwhelmed with the response from people who supported us" said committee member Ger Dargan. SII would like to thank all the sponsors and supporters of the BBQ event this year.



YOGA CHALLENGE!

Another fantastic SII volunteer Emma O'Toole hosted the inaugural yoga challenge which saw supporters take on a challenge to complete 108 Sun Salutations in one sitting.



It took the group over six hours to complete the challenge and it was an impressive team effort from everyone involved while also raising vital funds for SII.

This event was organised by volunteers from around Ireland and all money raised went to SII.

SII will be running this event again in 2017 so make sure to keep an eye out for it in the coming months.



SII GOES ICE SKATING

Dun Laoghaire Christmas on Ice very kindly offered a Free Accessible Ice Skating session for local Spinal Injuries Ireland members and their families. The highlight of the event was a Mannequin Challenge, which is a viral Internet video trend where people remain frozen in action!



Q-BALL

The 2016 Q-Ball took place again this year in the in the Ballsbridge Hotel.

More than 500 people attended the prestigious black-tie event this year with guests including people living with spinal cord injuries, health care professionals, politicians, socialites, and celebrities.

Fiona Bolger, CEO at SII, said: "It was a truly amazing night and it is an event we look forward to every year.

"This is the 12th year SII have hosted the Q-Ball and we would like to thank all those who supported us on the night and throughout the year."







Creditor Identification No.: IE79ZZZ360517

Unique Mandate Reference:

To be completed by Spinal Injuries Ireland

By signing this mandate form, you authorise (A) Spinal Injuries Ireland to send instructions to your bank to debit your account and (B) your bank to debit your account in accordance with the instruction from Spinal Injuries Ireland.

As part of your rights, you are entitled to a refund from your bank under the terms and conditions of your agreement with your bank. A refund must be claimed within 8 weeks starting from the date on which your account was debited. Your rights are explained in a statement that you can obtain from your bank.

Supporter Details:																																	
Name																																	
Address																																	
Account No. (IBAN)				-					-					-					-					-					-				
Swift BIC																																	Ī
Creditor Name: Spinal Injuries Ireland, National Rehabilitation Hospital Campus, Rochestown Avenue, Dun Laoghaire, Co. Dublin. A96 A7PO)																				
Payment Type: Recurrent One-Off {Please tick √}																																	
Signature(s)																			Dat	te S	ign	ed:	Γ			Γ			2	0			٦
																							L						<u> </u>				
×																																	
Supporting Spinal Inju														_				_															
I wish to make a month	nly rec	urri	ing	doı	nati	ion	of	€10				€15	5		€	21	*		(Dth	er	£											
starting on the 1 st day o	of			Мо				_/_	 Y	 ear		-	u	ntil	fur	the	er n	oti	ce a	is p	er	the	Dir	ect	De	bit	Ma	and	late	abo	ove	•	
Or I wish to make a sin	gle on	e-o	ff g	ift d	of€					·		'																					
Make your gift to Spinal Injuries Ireland (SII) worth even more* 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!												n																					
Contact Details:																																	
Land Line																				M	lob	ile											
Email Address																																	
Signature																		[Dat	e Si	igne	ed:							2	0			٦
Spinal Injuries Ireland may send you information in future on other fundraising activities. If you would prefer not to receive information on fundraising activities, please tick here:																																	
I hank you for your support																																	
Spinal Injuries Treland, National Rehabilitation Hospital Carr pus, Rochestown Avenue, Dun Laoghaire, Co Dublin. A96 A7PO												0																					
Telephone (±353) 1 2355317 Email info@spinatinjuries.ie Web www.spinatinjuries.ie																																	



THANK YOU TO EVERYONE WHO HAS SUPPORTED US IN 2016! WE HAVE LOADS OF FUN WAYS THAT YOU CAN SUPPORT SII NEXT YEAR AND BELOW IS JUST SOME OF THE EVENTS THAT WILL TAKE PLACE IN 2017.



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.

To become a 'Friend' of Spinal Injuries Ireland you can simply complete the form on page 23 and return it to the address provided or call us on 01 235 5317 for any questions that you might have.



Morry Christmas

