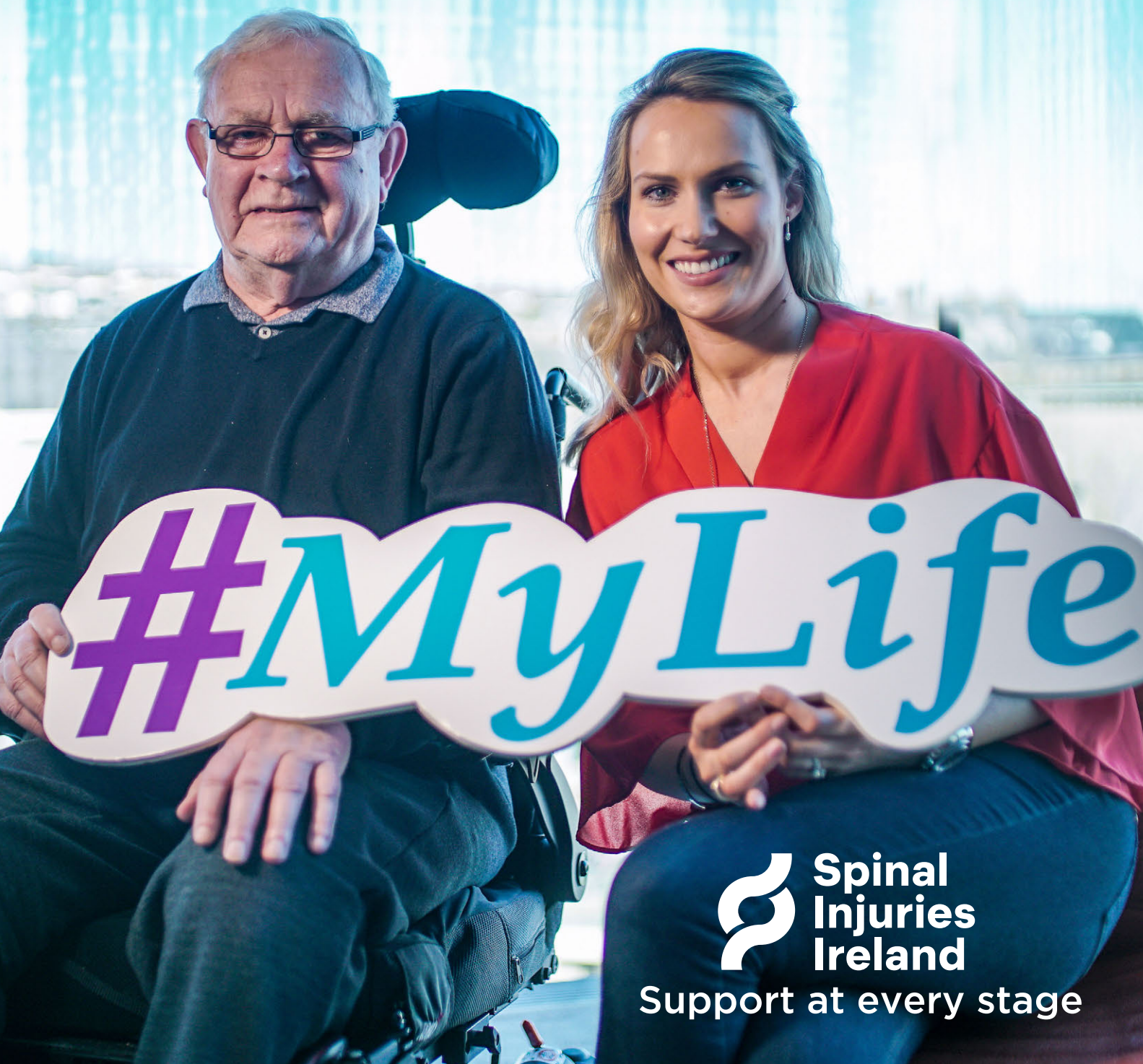


SUMMER 2018


SPINAL NEWS

**SII My Life Wellbeing Conference
massive success**



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WELCOME

2018 has been a record breaking year for Spinal Injuries Ireland and we are still only half way through the year.

In September 2017, we moved from the NRH Campus after 23 years to facilitate the building of the new hospital and after four months in temporary office accommodation we moved to our new state of the art Resource Centre on Pottery Road in January, just at the back gate of the NRH.

We are very grateful to Minister Finian McGrath T.D. and the HSE for their support of the services we provide by funding this new centre and also for the support of our volunteer architect Tiernan McCarthy who reached out to suppliers to provide pro bono furniture, graphics and carpets.

It was a huge honour to name the Resource Centre the Aileen McCarthy Resource Centre after Sr Marie or Sr Aileen as many of you would know her. Supports and services for people with a spinal cord injury would not have developed without the dedicated commitment of Sr Aileen over the decades. You can read Sr Aileen's story on pages 20-21.

The second major event in 2018 saw Spinal Injuries Ireland host the first patient centred national conference called the My Life Wellbeing Conference in the RDS, Dublin. Over 250 people attended the conference which saw international speakers, all of whom had sustained a SCI, talk about their lives and offer advice. We would like to say a huge thank you to Coloplast who yet again have supported our services by sponsoring this ground breaking event. Shortly, we will be releasing all the talks on You Tube so make sure you look out for them and watch them if you did not make the conference. You can read about the conference on page 6-7.

Finally, funding to cover the cost of SII's essential services still remains a challenge. According to last year's top raffle ticket seller Joe Murphy, if everyone with a spinal cord injury in Ireland sold two books of tickets (enclosed) for our Summer Raffle, it would generate €100,000 and enable us to continue with the work we do. So, I would ask everyone to help us achieve this goal over the next few months.

We are here to serve you so please contact us if you require any services and if you are in the NRH for a check up, pop in to the Aileen McCarthy Resource Centre for a cuppa.

Looking forward to seeing you all over the coming months.

Yours sincerely,

Fiona Bolger CEO



CONTENTS

- 4 News – Opening of new SII premises, Racing 92 match
- 5 News – SII Needs Not Means campaign
- 6 News – My Life Wellbeing Conference 2018
- 8 Services – Karen Rogan obtains grant through SII
- 10 Feature – Returning to work with a SCI
- 12 Health feature – Cauda Equina Syndrome, what you need to know
- 14 Fundraising
- 16 Health feature – Sexual health with a SCI
- 18 Feature – Purchasing a wheelchair
- 20 Feature – Sr Aileen's story
- 22 Gallery

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



SII OPEN THE NEW AILEEN MCCARTHY RESOURCE CENTRE

We look forward to welcoming all our service users to the new resource centre

Spinal Injuries Ireland officially opened our new SII Aileen McCarthy Resource Centre on Monday 26 March in Dun Laoghaire.

The Minister for Disabilities, Finian McGrath T.D., officially opened the new resource centre and in attendance on the night was Sr Aileen, Paralympian John Twomey, SII Board Members, local businesses, politicians, NRH staff, and most importantly SII service users and their families.

SII is now no longer based on the National Rehabilitation Hospital (NRH) campus but we are situated across the road at Pottery Business Centre in Dun Laoghaire. We moved to facilitate the development of the new NRH hospital.

The new resource centre is officially named after Sr Aileen McCarthy (89), as not only was she one of the founding members of Spinal Injuries Ireland in 1992, but she also dedicated her life to the rehabilitation of people who sustained a spinal cord injury since the 1960s.

CEO at SII, Fiona Bolger, spoke at the opening of the new resource centre and said: "This is a very exciting time for us here at Spinal Injuries Ireland as we now have a state of the art resource centre where we can welcome patients from the NRH, their family members and our service users all year round. We are very grateful to Minister McGrath and the HSE for working with us over the last year to secure this premises as it will allow our dedicated staff to continue to deliver our vital and important services to people living with spinal cord injuries around Ireland.

She added: "We are delighted to name our new resource centre after Sr Aileen as we are indebted to her for the tireless work she has carried out for patients undergoing rehabilitation at the NRH and for people living with spinal cord injuries around Ireland. Her constant campaigning, care and kindness to people living with spinal cord injuries over the last six decades is the cornerstone on which our organisation is founded."

Minister for Disabilities Finian McGrath T.D. said: "I am delighted to officially open the Aileen McCarthy Resource Centre on behalf of Spinal Injuries Ireland. It is imperative that the work of this dedicated organisation continues, as it is of enormous importance to its service users."

To read Sr Aileen McCarthy's story, turn to page 20 & 21.



RACING 92 FLY MATTHEW & FAMILY TO BILBAO

Matthew McGrath & his family got to see the European Rugby Champions Cup Final event live

At the beginning on May, Matthew McGrath and his family travelled to Bilbao to watch the European Rugby Champions Cup Final take place between Leinster and Racing 92.

Matthew, who has a high level spinal cord injury, is a massive supporter of Leinster Rugby but had not managed to obtain tickets for the match.

The owner of Racing 92, heard that Matthew really wanted to see the match and so he went about organising a dream trip for Matthew and his family.

Alan McCarthy, Matthew's father explained: "We've known the owner of Racing 92 for a number of years and he's always been great at keeping in touch with us. He organised for a private jet to pick us up in Dublin and fly us over to Bilbao to see the match.

"It was a great experience and a brilliant game to see live. I went over with Matthew and his sister Nicola and it was a fantastic day. We were delighted when we found out we were going and it was amazing for us all to go together. Matthew was delighted!"

#NEEDSNOTMEANS



Help SII make the Medical Card automatic for people living with SCIs

SII officially launched our Needs Not Means campaign at in April this year to secure the medical card for all people with serious spinal cord injury (SCI).

With Budget 2019 due for announcement in October this year, Spinal Injuries Ireland is calling on all our service users to help us lobby the government to make medical cards automatic for people with serious SCIs.

As all our SII service users will know, the medical card is currently granted on a means tested basis.

SII believes this is wrong and does not promote equality for people living with SCIs around Ireland.

SII officially launched our Needs Not Means campaign at our My Life Wellbeing Conference in the RDS this year but we need your help to spread awareness of the difficulties of obtaining and keeping the medical card.

If we work together, we believe we can help lift the ban on a guaranteed medical card for all people with a serious SCI.

SII is asking our service users to get involved with this campaign in 4 ways:

- Call or write to your TDs - ask them to support the campaign and cut the red tape
- Spread the word - Tell your family and friends about the campaign. Ask them to call or write to their TDs too
- Share - share the campaign on social media. Remember to include the hashtag #NeedsNotMeans
- Tell us - Contact SII for help and support at any time.

Tell us how you got on with your TD visit or contact/Take a picture of you with your TD and send it to us

**NEEDS
NOT
MEANS**

If you are unsure about who your local TD is, then simply log onto www.whoismytd.com for a list of TDs in your constituency. TDs often hold their clinics on Mondays or Fridays but if you check your TDs website you will find details of the best days to visit them.

For more information on how to get involved with the Needs Not Means campaign, call SII on (01) 6532180



MY LIFE WELLBEING CONFERENCE

Our inaugural SII My Life Wellbeing Conference was a great success

The first ever patient centred conference for people living with spinal cord injuries in Ireland took place on Saturday 21st April at the RDS, Dublin.

The event was called the **My Life Wellbeing Conference** and it was organised by Spinal Injuries Ireland with support from Coloplast.

The conference was a huge success with over 250 people in attendance on the day and we were delighted to see so many of our service users come along and enjoy what the conference had on offer.

On the day, we had a schedule of lectures that took place including talks from a line up of international speakers (who each have spinal cord injuries themselves), information stands from accessible companies, a panel discussion, and music from the Rathfarnham Ukulele Band.

The international speakers that spoke covered a broad array of topics and each of our attendees went home with a range of information along with plenty of new ways to improve their health while living with a SCI.

The first speaker to take to the stage at the My Life Wellbeing Conference was





Niek Van Den Adel from Holland who was paralysed from the chest down in 2010 following a motorcycle crash when he was just 28 years old. Niek spoke about living with chronic pain, how he overcomes it and his plans for the future.

Our second speaker was **Rob O'Byrne** from Dublin who took to the stage with physiotherapist Lorenza Caffola. Rob sustained a C5 spinal cord injury in July 2005 after a diving accident on holiday with his family. After completing a degree in business management, he later went back to college to become a qualified gym instructor and personal trainer. Rob gave a demonstration of exercises people with SCIs can do on stage at the conference.

The next speaker to take to the stage was **Suzanne Edwards** from the UK. Suzanne was paralysed from the waist down in 2011 when a balcony she was standing while on holiday collapsed. Suzanne now works at Accomable, the accessible travel section at Airbnb. She also competes in international tournaments playing wheelchair tennis

and is on the Great Britain Development Squad. Suzanne gave a great talk all about going back to work after she sustained her SCI and how she has achieved success as an international athlete.

The fourth speaker on the day was **Kevan Baker** from the UK. Kevan was paralysed at the age of 19 when he was involved in a serious road crash. Kevan is a successful Paralympian and was honoured with an OBE by HRH Queen Elizabeth II in 2012 for his voluntary service to disability sport. Kevan spoke about bowel & bladder care and gave great tips and advice on how to tackle ongoing health problems.

The last speaker of the day was **Annemarie de Vries-Postma** from Holland. Annemarie is a well-known model/author/chef from Holland and she was paralysed from the waist down when she was just 11 years old following an untreated tick bite. She was the world's first professional model with a visible disability and she is now a best-selling author with a focus on staying healthy using the power of food.



Annemarie spoke passionately about how she stays healthy while living a sedentary lifestyle.

At the conference, we also featured a range of information stands from companies including: Care to Comfort, Lyncare, DM Mobility, Gary-B Wheelchair Accessories, ISB Mobility, What's Your Excuse Fitness, Accuscience/Exo Bionic Suit, Coloplast and MMS Medical.

"We would like to thank all our service users for coming along to our first ever My Life Wellbeing Conference," said Fiona Bolger, CEO at SII.

"We hope that everyone enjoyed the day and took something away from it. We are already planning our next conference for 2019 and we can't wait to see everyone there again."





APPLYING FOR GRANTS VIA SII

SII Community Outreach Officer Sorcha Silke helped Karen Rogan obtain a grant of €4K to buy a SCI medical device

In 2014, Karen Rogan from Co. Galway sustained a T9 spinal cord injury when she suffered a spinal stroke soon after the birth of her twin girls Tess and Roisin.

As a result of the spinal stroke, Karen was paralysed from the waist down.

Through extensive rehabilitation and physiotherapy, Karen regained most of the mobility in her left leg but her right leg was left with permanent damage.

“I had a good bit of recovery which was great and I’m very thankful for that, but my right leg slows me down. I can’t do a straight leg raise with the right leg and that’s really where the issue is for me. The nerves over my

muscles on my right quadriceps are dead so I can’t get my right leg to do what I want it to do.”

Karen’s physiotherapist Martyn recommended that she try out a medical device called a Bioness L300 to improve her leg and gait while walking.

Karen explained: “The Bioness thigh device provides functional stimulation of the leg via a leg cuff that goes around the thigh. Electrodes are then transmitted through the leg cuff to deliver stimulation to the part of the leg that needs it the most which is fantastic for me when I’m walking.”

When Karen decided to purchase the Bioness L300, however, she found out

that it cost €4,000 which was out of her budget range.

Karen had linked in with Spinal Injuries Ireland’s (SII) Community Outreach Officer Sorcha Silke when she was discharged from hospital in 2014. Sorcha provided ongoing support to Karen while she was transitioning home from the National Rehabilitation Hospital and organised physiotherapy and hydrotherapy sessions for her as she continued with her recovery.

“Sorcha is just fantastic. She has really acute antennae and just picks up on things without me having to say anything,” Karen explained.

“When she visits me at home and

someone else just happens to drop into the house, they would honestly think that Sorchia was just having a chat and a cup of coffee. She is such a great support to me and you definitely feel like she's in your corner. You really do feel like she's there for you."

Karen spoke to Sorchia about the Bioness L300 and Sorchia came up with a plan to obtain a grant from the Elizabeth Finn Fund in the UK to help Karen purchase the device.

The Elizabeth Finn Fund provides direct grants and support to people who may be in financial difficulty, who have a professional background, and who meet the grant-giving criteria.

"Sorchia was amazingly tenacious and she just kept pushing for the grant on my behalf. She filled out all the paperwork and got everything done for me. She's got a great way of being persistent but not falling out with people which is actually quite a hard thing to do! She got me the grant and she did it all really well."

Karen was delighted when she got the news that she had been awarded a grant of €4,000 from the Elizabeth Finn Fund which covered the full cost of the Bioness L300.

"I didn't have to pay a thing and it was amazing to know that I could have my own Bioness L300 to use at home. "



“ Sorchia is just fantastic. She has really acute antennae and just picks up on things without me having to say anything. ”

Karen now uses the device for three hours a day and has seen improvements in her leg as a result.

"What the device does for me is it stops the muscles in my legs from shrinking any more than they have already. Unfortunately, the muscles in the quads haven't contracted as much as I thought they would, but the device stops the muscles from getting worse which is what I want.

"It also really helps my gait when I'm walking as I have foot drop in my right leg. The device forces my right foot to walk from heel to toe which means I'm less likely to fall which is great too. I use the device a lot when I'm walking on the treadmill as it helps to lift my foot up to walk properly when I'm walking. So that's why I use it and that's why it's very important to me."

Karen said she is delighted that she had the opportunity to purchase her own Bioness L300 and explained that it was all down to Sorchia's help.

"She's brilliant, she really is. She's really organised and really good at her job. She does a lot for me and her other clients too and is always there to help when I need her."



If you would like to find out more about securing financial assistance for equipment, contact SII on 01 6532180 or email Info@spinalinjuries.ie



Photo Creation by Donal Hackett
Tel 0877747124

RETURNING TO THE WORKFORCE - ARE BUSINESSES DOING ENOUGH?

Geraldine Lavelle talks about her experiences of employment since she sustained her SCI.

Recently I've been thinking about my experience with employment since my injury and I've come to realise how much of a sense of fulfillment work gives me. It's now recognised that working has health benefits adding to self-worth, self-esteem and a feeling of self-reliance.

After my accident I prioritized retuning to work, and almost one year after incurring my disability I re-entered the workforce. My employer at the time of my accident, a multi-national healthcare company called Abbott, was excellent in aiding me to get back to employment and making me feel like a valuable member of the workforce once again. They did this in a number of ways. They transferred me to a different branch (closer to where I now reside), they reallocated me with a new post more in line with my subsequent abilities, they made

some essential changes to my place of work, and they allowed me to be accompanied by a personal assistant until I became familiar with my new surroundings.

I was one of the lucky ones. A significant employment gap between disabled and nondisabled people exists in Ireland at the moment, along with the poverty that generally accompanies disability. A big player in independence is your 'financial resources' with poverty and independence being closely related. This is an invisible community, who for the most part are suffering in silence as they try to cope with the day-to-day struggles.

Even though for the most part I have been lucky with regards to securing employment, I have also had a few negative experiences. One such was being told by a person specially

trained to help disabled people find suitable jobs that "it would not be worth an employer's time to employ you". Despite his 'invaluable advice' I have obtained several paid roles in the past three years where I was just as capable as my non-disabled counterparts. His attitude towards disability was most definitely not leading the way but lagging behind. This staggering negative perception and attitude around disability is what prevents employers from hiring disabled people and this needs to be addressed. Unfortunately, people with disabilities are still seen as incapable, with stigma surrounding mental aptitudes and ability still existing. In 2018, disability discrimination should have no place in our society, including our work environments. It's crucial that we point out examples of good workplace practice and it's important to highlight where businesses in general are going wrong with accessible employment.

In my opinion, there is too little guidance, support and training to help those with long-term conditions return to employment, and once again the myriad initiatives designed to lift people out of isolation and segregation fall short. The system prevents so many disabled people from joining or re-entering the workforce and becoming independent. This can create a mentality that there's little disabled people can add to the state: instead, they remain a stigmatic liability due to their disability. Work opportunities need to be given and barriers need to be overcome. Facilitation for all with regards career options should be central with a focus on skills instead of the disability. Employers need to take a positive approach to disability and offer interviews to all disabled applicants who meet the minimum job criteria with a view to a diverse workforce.

BIO

Geraldine Lavelle is a writer and blogger at Spinal Cord Injury Blog where she writes about living with her acquired disability. You can view her blog by logging onto <http://spinalcordinjury.ie> Geraldine sustained a C6 spinal cord injury in 2013 following a cycling accident. She lives in Sligo and is a strong advocate for people with disabilities in Ireland.

I leave you with this last thought; Do you think enough is being done to promote diversity in the workplace, when thinking about disability in particular?



COMMUNITY FUNDRAISING AROUND IRELAND

Thank you to everyone who took part in community fundraising events this year!

A number of amazing community fundraising events were organised in April and May this year in aid of SII and we would like to say thank you to everyone who got involved!

In April, Michael Brislane organised a fantastic table quiz in Limerick in aid of SII. Michael, who is a service user, had a great turnout on the night and raised over €1,200 for SII. Thanks so much to Michael for planning and organising the whole night.

In May, the inaugural Got Your Back Ireland event took place in Dublin. It was the first ever inclusive fitness & wellbeing event organised by pilates instructor Denise Coughlan from Resolute Pilates & Wellness. On the day there was a host of fitness classes including chair yoga and a para-fit class. SII would like to say a huge thank you Denise for organising such a fantastic day and for raising over €1,000 for SII.



SII's CEO TAKES ON CYCLING CHALLENGE

Our CEO Fiona Bolger has taken on a major challenge this year to raise funds for Spinal Injuries Ireland.

Fiona will cycle from Paris2Nice which will see her cycling 700km in six days. She admits that she hasn't cycled a bike since she was a child until she bought her bike in March 2018!

Fiona has also persuaded three other people to join her in her challenge, Jacquie Carroll (pictured with Fiona), Risteard Cooper from Après Match and Yvonne Kelly, a training instructor.

In addition, David Lloyd Riverview, Dublin has taken on the SII Paris2Nice challenge as their charity of the year and will host a number of events over the coming months to help the cyclists achieve their €40,000 challenge.

If you would like to follow or support Fiona's campaign you can donate here - <https://paris-2-nice-2018.everydayhero.com/ie/fiona-bolger>

SOLICITORS SKYDIVE FOR SPINAL INJURIES IRELAND

In March this year, two brave ladies – Avril Flannery and Kathrina Bray from Callan Tansey Solicitors – took on the challenge of a lifetime by completing a skydive to raise vital funds for Spinal Injuries Ireland.

Avril and Kathrina work as solicitors in the Medical Negligence Department of Callan Tansey Solicitors in Sligo.

Avril explained: "Through our work, in acting for people who have suffered a spinal cord injury as a result of medical negligence or personal injury, we have seen the catastrophic devastation and life changing effects that a spinal cord injury can cause to people and

their families. Without the expert support and assistance of Spinal Injuries Ireland, individuals would not know where to turn or what their new participation in life can be."

Avril & Kathrina are now challenging other law firms to take on the same challenge in aid of SII.

Kathrina said: "We had a brilliant time doing the skydive, it was a genuinely an amazing experience."

Massive thanks to the two ladies for completing their skydive and donating the proceeds to SII.



One of the most distressing symptoms of cauda equina syndrome is urinary dysfunction, which is manifest as inability to pass urine or inability to control urinary leakage. It is essential that a urologist is involved in the early management of all CES cases and subsequently involved in monitoring and treating complications and difficulties.

The importance of prevention cannot be over-emphasised. At presentation the presence of saddle anaesthesia, which is a change in sensation in the area around the bottom and genitals, in association with acute onset back pain and abnormalities of sensation and motor function in the legs, is an absolute indication for an urgent MRI scan (hours not days) to establish spinal compression with the prospect of immediate surgical decompression.

If decompression occurs before the onset of incontinence or inability to pass urine, the outlook for voiding is extremely good. Even if urinary symptoms are present, the outlook in the first 12 to 24 hours remains good. Failure of the medical staff to recognise this symptom complex, and provide urgent treatment and investigations is litigable negligence.

After the decompressive spinal surgery the ability to pass urine spontaneously with good bladder emptying must be closely monitored.

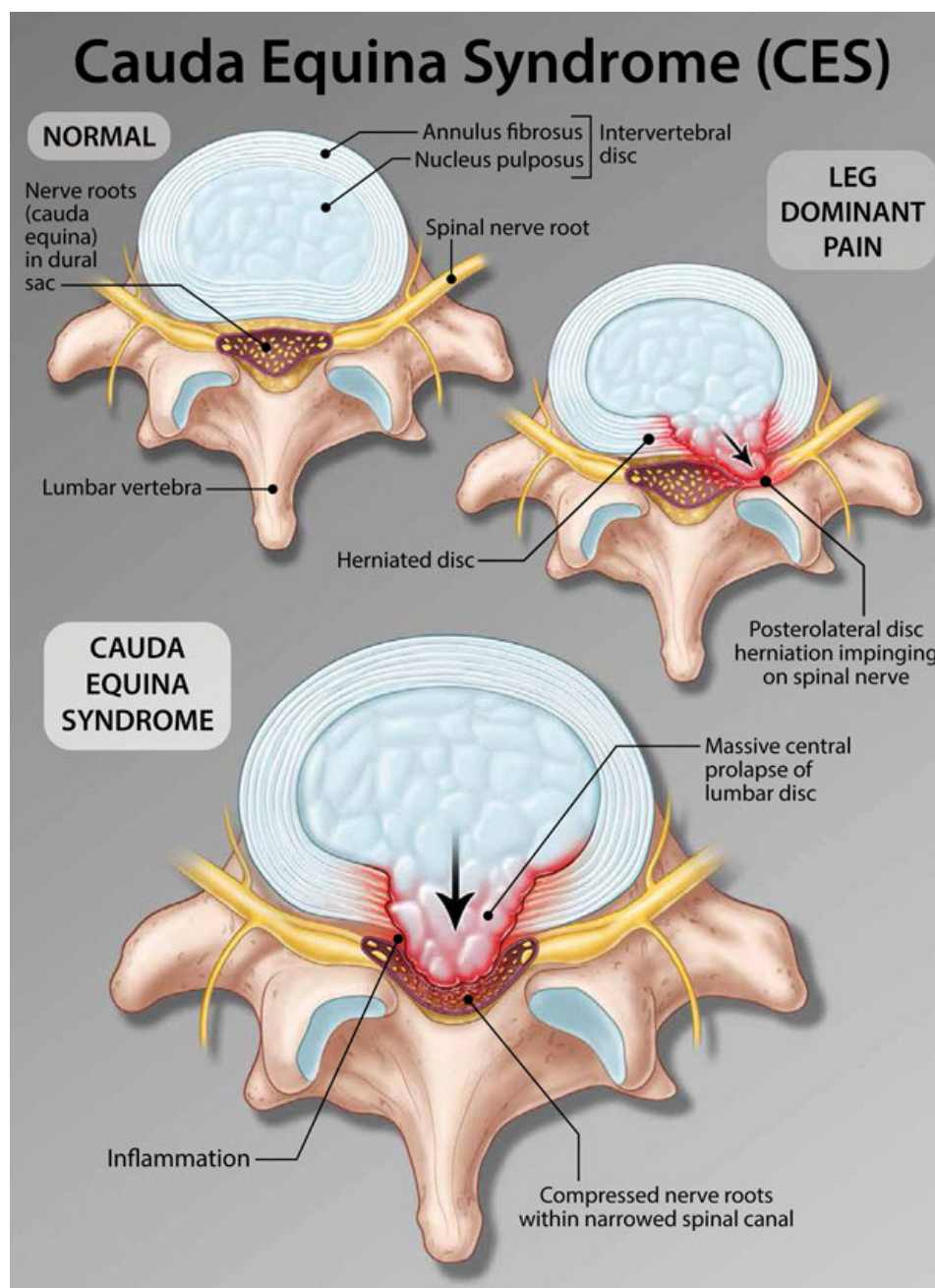
Inability to void with lack of sensation of bladder filling requires timely catheterisation. Overdistention of the bladder at this stage may lead to permanent bladder damage. After a short period of an indwelling catheter, a trial without catheter should determine whether or not there are any problems. If there is no progress the teaching of clean intermittent catheterisation is vital by a member of the urology team before discharge with an appropriate appointment for a urologist specialising in urological complications of CES.

In the first six months such an inability to void is likely to continue being managed by intermittent self-catheterization. Importantly there is considerable prospect for

improvement over an 18-month period following the spinal nerve decompression. This improvement may allow spontaneous voiding, but can also cause an important change from an atonic non-functional bladder to a hypertonic over-active bladder with incontinence. Both atonic and

hypertonic bladders may suffer from stress incontinence (being wet when moving, laughing, coughing, or during sexual relationships).

A post cauda equina decompression symptomatic bladder is known as a neuropathic bladder. In order to



divide these bladders into two groups, non-functional low pressure and over-active high-pressure bladder, video urodynamic tests are essential. These will determine the type of bladder and the most appropriate treatment.

Low-pressure Atonic Bladder (patient unable to void):

These bladders are managed by intermittent self-catheterisation usually four to six times in a 24-hour period. Most patients remain continent between episodes. Some may require a sling operation to correct stress incontinence caused by pelvic floor weakness. Infections are managed with culture-directed antibiotics if symptomatic. Multiple infections may require long-term low-dose treatments with antibiotics. These patients require yearly ultrasound tests and blood tests to establish normal kidney function. There is an increased risk of urinary tract stone disease. In the terminal years of life permanent urethral/suprapubic catheter are often deployed.

High-pressure Over-Active Bladders with Incontinence:

This group of patients is far more difficult to manage. In some, intermittent self-catheterisation can prevent the point at which the bladder becomes unstable which means that the bladder suffers from high-pressure contractions resulting in the irresistible need to void immediately, resulting in incontinence. Another important cause of incontinence is lack of the ability of the bladder to relax when filling (compliance) resulting in urgency and incontinence.

Many will benefit from anticholinergic drugs such as Solifenacin which dampens down bladder contractions, or the newer drug Mirabegron which can be used in combination with Solifenacin.

Failure to respond to these measures will lead to the use of Botox

injections, which are applied by day case cystoscopic injection on a 9 to 12-monthly basis. At best these will restore reasonable voiding, at worst intermittent self-catheterisation will be required because the bladder is fully paralysed, but the patient is usually continent in the interval between catheterisations.

In cases which fail these treatments, posterior tibial nerve stimulation, sacral nerve stimulation and ileocystoplasty operations can provide an improved quality of life. Both these treatments are available at specialist centres for the relatively small group of patients who will require such treatment.

All patients who suffer from a hypertensive over-active bladder will require annual assessments and further urodynamic tests when symptoms change.

The implantation of an artificial urinary sphincter can replace the loss of function of the external urinary sphincter which controls continence in patients who suffer from sphincter weakness incontinence. The operation involves the placement of an inflatable cuff which occludes the urethra which can be opened by activating a control device. Once again, this operation is available at specialist urology centres.

Unlike spinal injury patients, because CES patients are able to walk and appear normal it is unlikely they will receive the specialist help in a rehabilitation centre which can make such difference to coping with urinary and faecal incontinence, sexual problems and psychiatric issues. I would urge all CES patients to seek such help. All such centres (National Rehabilitation Centre Republic of Ireland) have excellent urological expertise available.

Conclusion:

The objective of all urological treatment is to provide continence in a low-pressure bladder thus

preserving kidney function while at the same time managing infections and the risk of urinary stone formation. All such patients should remain under the supervision of the Urology Department and their knowledgeable and helpful urology nurse practitioners. In cases which have been negligently managed, a urologist is able to provide vital evidence to support proof of substandard treatment as well as defining the outcome, likely future problems and needs for those wishing to pursue a legal course of action.

**Article written by Ronald A Miller
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BIBLIOGRAPHY

Ronald Miller is a Consultant Urological Surgeon with more than 30 years' experience at consultant level. He now works in private practice having previously been Head of Department at The Whittington Hospital, Honorary Consultant Urologist at University College Hospital and the Royal Free Hospitals in London, and Honorary Senior Lecturer at the Institute of Urology. For more information log onto www.ronaldmiller.com

MAKE A MONTHLY GIFT

When you choose to make a regular gift to Spinal Injuries Ireland, you are supporting those affected most from a spinal cord injury. We are there from the time a devastating spinal cord injury occurs, to support those affected and their families and for as long as needed.

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SPINAL INJURIES IRELAND SUMMER RAFFLE

We're delighted to announce SII's annual summer raffle is back – will you be this year's winner?

Your tickets, and everything that you need to get started are ready and waiting for you with this magazine. So all that is left to do is to get selling!



How does it work?

Each ticket in your book is €5 **but** when you sell 5 tickets from the booklet we will give you the last one free! When you have sold your tickets then just pop your ticket stubs with your donation slip into the freepost envelope provided and stick them into the post. We will then enter you into the draw – it's as simple as that! donation slip in the freepost envelope provided and we will enter your tickets into the draw – it is as simple as that!



What's up for grabs?

This year, you can win some fabulous cash prizes, thanks to our sponsors Windsor Motors.

1st Prize
€5,000

2nd Prize
€2,000

3rd Prize
€1,000

Top Sellers
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Drive happy



Top Sellers – we haven't forgotten our hard-working sellers, so we have a special prize for the person who sells the most amount of tickets by the closing date!

Closing date – all entries must be sent back to us by the 24th September and the draw will take place on 27th September.

Extra Tickets – we have lots of extra tickets so if you need any, please contact Ciara on 01 653 2180 or ciara@spinalinjuries.ie. We would love to hear from you.

CHECK OUT LAST YEAR'S WINNERS





SEXUAL HEALTH - THE ELEPHANT IN THE ROOM

Communication is key when it comes to sexual health with a SCI

Sex and sexuality are often considered a taboo subject to talk about and therefore becomes 'the elephant in the room'. The Sexual Wellbeing service at the NRH endeavours to overcome this barrier and open the way for discussion.

What is Sexuality: Sexuality is an integral part of us all, it encompasses all the feelings, attitudes and behaviours that contribute to a person's own sense of being a man or woman. Sexuality is inherently tied to a sense of self in all its dimensions and is highly influenced by what society in general defines as appropriate male or female roles, patterns of functioning and specific behaviours.

Understanding the impact of spinal cord injury on a person's sexuality is not simply a matter of understanding the sexual physiology or even the medical side of the disability, but we also need to understand the psychosexual impact of the disability on the person.

Spinal cord injury can often alter the way a person experiences and expresses their sexuality; this can range from physical difficulties such as perception, change in sensation, balance, and sexual dysfunction

to emotional problems such as depression, altered body image and self-esteem. The nature of the changes often depends on the level and completeness of the injury.

It is inevitable that as a result of such an injury, people begin to doubt their completeness as a man or woman, but sexuality has as much to do with one's mental attitude as one's physical state.

SCI can impact both positively and negatively on a relationship, on the positive side often bringing couples closer together with previous irritations and conflicts not seeming to matter as much, and the attitude of 'we got through this we can get through anything'. On the negative side there is the physical separation and intimacy during rehab which sometimes extends to home, the increased worry about financial wellbeing, the uncertain future and the unclear roles or change of roles.

SCI may require an adaption to the dynamics of the relationship. There may be issues around dependence versus independence. The couple may want to 'protect' the other person to the point of creating a barrier for support and communication.

When the communication is limited or unclear it's likely you will *create your own reality*, where you can conjure up all sorts of issues that are non-existent. Avoiding talking about the 'hot topics' to minimise stress can create stress. There can be a fear of hurting the partner leading to limited touch and affection.

Talking about ***the elephant***, sex, remember partners are often affected by the experience and they may have their own issues. Encourage discussion and be prepared to listen, then talk, then discuss, including the fears you may have about sexual rejection or breaking up. Try to avoid arguments. Arguments can often be brought up as a way of avoiding having to talk. Spend time getting used to body changes and touch. Ask for what you need, try and focus on the positive. Remember that time apart is as important as your time together.

Individuals who are not involved in a relationship at this time may feel that they will never meet anyone now. They may need to consider how they met people before their injury. Most likely you met them in various aspects of your life, at work, at college, in

the pub or nightclub or through your friends. The only place you didn't meet them was sitting at home. The same can be said for now. The first thing you need to do is get back out there. Try to get comfortable talking about yourself and your injury. People are naturally curious and will often open conversations. If you don't make the effort don't expect others to.

Men and women with SCI have different physical problems with sexual activity and fertility. The Sexual Wellbeing service of the NRH is run by a Clinical Nurse Specialist in Relationships and Sexuality, who is open to discussing all and any of these issues. As a Registered Nurse prescriber she can prescribe treatments for sexual dysfunction and establish fertility programs if necessary. But her biggest qualification to the service is being married 27 years to a person with a spinal cord injury and with two children of her own living a bit of the 'been there, done that'.

For more information contact Pauline Sheils at the Sexual Wellbeing service of the NRH. Phone 01-2355288 or email pauline.sheils@nrh.ie





PURCHASING A WHEELCHAIR

MMS Medical talk us through the best way to find the correct wheelchair for your needs

Selecting and buying the best wheelchair for your needs is essential. It is one of the most important pieces of equipment you will ever own and it is important that you are happy with your purchase.

There are many ways to ensure that buying a wheelchair is an easy process but one of the most important things you can do is consult a product specialist. By doing this, you will be guided on how to buy a wheelchair that is the perfect fit for optimal comfort, optimum posture & pressure relief, manoeuvrability indoors and outdoors and support for your daily living requirements and independence.

Selecting a wheelchair depends on many elements – diagnosis and injury level, age, body type, activity level, functional ability, transportation and daily usage. Life is busy and your chair must reflect your personality, lifestyle and ambitions.

Wheelchair Options

1. Manual Wheelchairs - Self Propel or Transit

Large rear wheels allow the user to self propel the wheelchair. A self propel chair type is suitable for occasional, rehabilitation or long term use when the user has the upper body strength to steer and drive the chair themselves.

Made to measure

It is important to ensure that you get the right size wheelchair to suit you. A made to measure chair is the optimum solution. It is important that you are assessed and measured for your wheelchair to ensure the ideal width, depth and height of the seat as well as the height and angle of the leg rests and footplates. Some models offer adjustment to the seat width, seat depth, armrest height, backrest height and tension. A made to measure chair will ensure the user and wheelchair work in unison.

Also, it is important to note that the lighter the wheelchair, the less energy you need to push – it's as simple as that.

Folding or rigid frame?

Rigid, or non-folding, frames are stronger, more durable and have a very stable feel to them. A folding chair is easier to transport but it is important to note that most tilt-in-space wheelchairs are non-folding. If you love to travel, it might be best to consider a portable folding chair.

Functional options

Like everything, there is a wide range of options available on your wheelchair to suit your needs and preferences. Functional options include cushions, wheels, tyres, castor wheels, handles, armrests, footrests and many more and will be evaluated at the time of your assessment with an occupational therapist and product specialist. Upholstery and frame colours will be considered at this stage. Professional advice from a product specialist is vital in making the right choice.

2. Power Wheelchairs

A power wheelchair is the ideal solution for users requiring additional assistance. They are suitable for users with reduced upper body strength. They operate via motors to power the main drive wheels and are, most commonly, driven by the user via a joystick control. With a range of drive options – front, centre or rear wheel drive – a power chair combines excellent indoor manoeuvrability with outstanding outdoor performance. Adult, Paediatric and Bariatric models are available.



How to Choose a Power Wheelchair

When deciding to buy a power wheelchair there are many things to consider. Powerchairs are essentially made up of two major components. The first is the power base which covers a number of components including the: motors, wheels, controller and batteries. The other is the seating system. There are a wide range of models available for each component and a large range of compatible options and accessories. With so many options now available, it is important that you choose the right powerchair for you.

3. Assistive Technology - Add-ons and Accessories

If you're looking to go further for longer, there is a range of add-ons that you can buy for your wheelchair which provide power assist to your arms. As these add-ons are a form of assistance, you can continue to work yourself as little or as much as you like. It's up to you to choose from moment to moment. These power solutions provide the users with easy to attach and power control for their manual wheelchair.

SmartDrive

The SmartDrive MX 2 reduces the number of repetitive pushes you do each day by taking over once you get going. It's like a cruise control which you set by the speed of your push. It has an anti-rollback feature that allows you to stop on a slope and then easily get going again. It will go for miles on a single charge.

Power assist wheels

With power assist wheels, all the engineering is compactly and discreetly integrated in the wheel hub. The electric motors provide you with extra power at each propelling movement. Often there is a sensor fitted to the push rim of the chair which determines exactly the right amount of support. These types of power assist wheels allow you to remain on the move to reach your destination more quickly, efficiently and with less effort.

Power packs

A small compact power pack will add force to your arms and there are different types of power packs that you can purchase for your wheelchair.

The Benoit Light Drive's compact design, for example, will fit into a small car and is handy to take on holidays as it can travel on the plane in the luggage compartment. Once on holiday you have much greater freedom of movement. It also works on many types of terrain and has a reverse gear to get over larger obstacles like pavements and small steps. The Light Drive is controlled with a joystick and yet remains as manoeuvrable and as easy to use as a manual chair.

Accessories

For those who want to explore the outdoors or simply get to the office faster, you should consider choosing a handbike or FreeWheel.

Handbikes

There are a number of handbikes available at the moment including the Batec Manual which is an add-on handbike for manually powered wheelchairs. You can attach it to your chair and it is ideal for both getting about on a daily basis and for keeping fit, as it gives your torso a thorough exercise session. Hybrid and Electric models are also available.

FreeWheel

The FreeWheel is designed to be used on a manual rigid frame or folding wheelchair. The FreeWheel allows you to easily and safely traverse any rough terrain. With the FreeWheel your wheelchair casters are lifted off the ground, turning your chair into a 3-wheeler, so you simply roll over any obstacle: curbs, dirt trails, grass, gravel, snow, and sand.



MMS Medical Assessment and Demonstration

MMS Medical is one of Ireland's leading medical equipment suppliers. In areas such as mobility, rehabilitation, disabled access and community care products, MMS is Ireland's largest supplier. MMS Medical have product specialists that offer first hand wheelchair experience and combined with their extensive clinical and technical knowledge, they will work with you and your family to find the best solution to meet your individual needs.

You can arrange to have one of MMS Medical's highly experienced mobility advisors visit you at your home anywhere in the country to perform a product demonstration and/or chair assessment. Or you can arrange to visit their showroom in Cork where you can try out their latest products and speak to their advisors. For more information call MMS Medical in Dublin on (01) 4500582 or in Cork on (021) 4618000, or log onto www.mmsmedical.ie



SR AILEEN'S LEGACY

The new Spinal Injuries Ireland (SII) Resource Centre is officially called the Aileen McCarthy Resource Centre because she is the linchpin on which the organisation was founded in 1992.

Sr Aileen also played a pivotal role in the founding of the National Rehabilitation Hospital in 1961.

Without Sr Aileen's passion and dedication over the last six decades, the lives of people with spinal cord injuries might have played out very differently in Ireland.

Sr Aileen's Story

Sr Aileen was born in in Cork in 1928 to a family of four siblings - three brothers and one sister.

Aileen was a keen sportswoman from an early age and when she was in her teenage years she was a competitive swimmer where she won medals at swimming galas. She also enjoyed playing hockey, tennis, badminton and was a keen poker player for many years.

Sr Aileen's real love of sport came into play, however, when she began playing golf. She excelled at golf and was picked to play at a very high level.

"I was a scratch golfer and I represented Ireland on the Irish international women's team before I entered the Sisters of Mercy convent," explained Sr Aileen.

Her passion for golfing continued well into her later years even though nuns were not technically supposed to play golf!

Her proud nephew Paul McCarthy explained: "It was unheard of for a nun to compete in golf events so Aileen got around this by playing under the pseudonym Aileen Driver!"

In 1952, Sr Aileen entered the Sisters of Mercy convent where she studied for four years to become a nun.

"I had very religious parents. My mother and father were both Catholics, so I got my faith from them. I was given the name Sr Marie of the Cross while I was at the convent so many people still know me as Sr Marie."

After Sr Aileen took her vows to become a nun, she began training to become a nurse and as part of her training she worked in the Mater Hospital in Dublin 7 and St Michael's Hospital in Dun Laoghaire.

In 1960, Sr Aileen travelled over to England with one other nun, Sr Bernadette (who subsequently became the Matron at the NRH) and two nurses Brid Murphy and Anne Kilcoyne. The group worked together at Stoke Mandeville Rehabilitation Hospital, and a number of other training centres in England. They worked in the UK for over a year and took part in rehabilitation nurse training.

"We did a six-month training course over in Stoke Mandeville. Stoke Mandeville Hospital was the pioneer rehabilitation unit for spinal injuries in England - if not in all of Europe. The spinal injuries unit was run by Dr Ludwig Guttman who had just escaped from the Nazis in Germany.

"A lot of the patients that had escaped World War 2 with spinal injuries came to England and that's where we learned about the rehabilitation of spinal injuries. We learned a lot over there."

When Sr Aileen returned to Ireland, she began working with Dr Thomas Gregg from the Mater Hospital who had the idea of opening a rehabilitation hospital for patients with spinal cord injury.

At that time, the NRH was called the Our Lady of Lourdes Hospital and it was primarily used to treat patients who had Tuberculosis (TB).



Sr Aileen explained: "The hospital cared for TB patients then, but the disease was almost eradicated and they began winding down the hospital. It was unclear what would happen with the empty hospital building but Dr Gregg had a great idea to turn it into a rehabilitation hospital. So, after we came back from training in England, we started getting the hospital ready for Dr. Gregg."

Dr Gregg was appointed as the first Medical Director of the NRH and he became a pioneer in the treatment of patients with spinal cord injury in Ireland.

Patients began to be transferred from the Mater Hospital to the new rehabilitation facility, and it eventually went on to be renamed the National Rehabilitation Hospital in 1994.

"That started the hospital on its path until it grew to the size it is now. I was there from the very beginning along with Dr Gregg, Sr Bernadette, Brid Murphy, Anne Kilcoyne, Dr Paddy Carey and a few others."

Sr Aileen played a key role in running the wards of the NRH from the very beginning. In 1961, she commenced her first ward manager position in the NRH Spinal Unit which was then called St Joseph's Ward. This was the first ever rehabilitation unit in Ireland.

"The role of the rehabilitation nurses evolved over the years. The nurses play an integral part of the multidisciplinary team now, but it was a little bit different in my day!"

Some years later following an agreement, a Board of Management was established

at the NRH, and Sr Aileen was appointed to the Board where she remained in her role until she retired in 2012.

Over the years, Sr Aileen became increasingly interested in what happened to patients once they were discharged from hospital. This led to her establishing the Spinal Injury Liaison Service which was in essence, an early form of Spinal Injuries Ireland.

The Spinal Injury Liaison Service allowed Sr Aileen to leave the hospital and visit patients throughout Ireland to review their progress post-discharge from the NRH.

In those days, Sr Aileen regularly risked life and limb traveling around the country on her Honda 50 motorbike to visit these patients.

Eva Wallace, a retired urology nurse at the NRH, explained: "Over the years, Sr Aileen always put patients first which included supporting accessible holidays and taking patients home and staying with them for a couple of days until the family were trained in the necessary skills. This helped to promote independence and prevent complications ensuring an enhanced quality of life for both patient and family members.

"When necessary, Sr Aileen would fundraise to achieve her aim. She fundraised to purchase a wheelchair accessible van to take patients out on trips and visit their homes. Most notably she also fulfilled one patient's dream of arranging a trip to Cork by helicopter to allow him visit his friends. There he was treated like a king for the day. The patient had a high level spinal injury with



complex care needs and he was a C4 quadriplegic. He lived on that day for the rest of his life."

Sr Aileen explained: "I enjoyed doing things like that, especially that day in Cork. That particular patient had been with us in the hospital for 13 years, as there was no place for him to be discharged. That was in the earlier years of the NRH, we weren't as efficient as they are now."

In 1992, Sr Aileen played a pivotal role in establishing Spinal Injuries Ireland with a number of former NRH patients who had spinal cord injuries.

"Spinal Injuries Ireland started with Colm Whooley, Joan Carty, Christine Bradshaw, Eugene Cahill and a few others and myself. They had all previously stayed in the NRH together and the organisation was based on the grounds of the NRH campus. They were founded 25 years ago this year, and a lot has changed since then.

"Over the last few years Fiona took over as CEO and she has done an amazing job along with my nephew James McCarthy who is on the Board of Spinal Injuries Ireland. My other nephew Tiernan McCarthy, who is an architect, recently designed the entire fit out of the new resource centre too which was brilliant.

"Together the organisation has continued on the work I started by carrying out nationwide visits to patients in their homes through their Community Outreach Team. The organisation has come a long way and I'm very proud of the work they carry out. It is very important that the organisation continues to grow and I'm looking forward to seeing it develop further over the coming years.



OPENING OF SR AILEEN SII RESOURCE CENTRE



SII held the official opening of the new SII Aileen McCarthy Resource Centre on Monday 26th March. Minister for Disabilities Finian McGrath T.D. opened our new resource centre and we had huge support on the night from our service users, Sr Aileen's family & friends, local politicians & businesses, and previous SII colleagues. It was a brilliant night and we welcome anyone to drop into see us anytime!..



EUROPEAN RUGBY CHAMPIONS CUP EVENT

The European Rugby Champions Cup Lunch hosted by Apres Match's Risteard Cooper took place on Saturday May 12th in aid of SII. In attendance on the day were three rugby legends - Brent Pope, Paul Wallace and Denis Hickey - who held a panel discussion on the match with Risteard before, during and after the match. We had a great turnout on the day and we would like to thank Risteard and all the attendees for their brilliant support.



SPRING LUNCH

The annual Spring Lunch took place on Saturday April 14th at the Intercontinental Hotel in Ballsbridge, Dublin. We had an amazing turnout this year and we would like to say a massive thank you to the committee members and all who attended on the day for their great support.



SII REGIONAL MEETINGS

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

SUMMER

Cork:	Wednesday 6th June	Nemo Rangers, Douglas	2-4pm
Kerry:	Tuesday 12th June	Rose Hotel, Tralee	2-4pm
Galway:	Tuesday 12 th June	Westwood Hotel, Galway	7-9pm
Cavan:	Wednesday 13th June	IWA Centre, Corlurgan Business Park, Cavan	7pm
Limerick:	Thursday 14th June	IWA Roxboro, Limerick	2-4pm
Mayo:	Tuesday 19 th June	Castlebar	5.30-7.30pm
Leitrim:	Wednesday 20 th June	IWA Centre, Carrick on Shannon, Leitrim	7pm
Dublin:	Thursday 21 st June	SII Resource Centre, Dun Laoghaire	6-8pm
Louth:	Thursday 21 st June	Crowne Plaza, Dundalk, Louth	6.30pm
Cavan:	Wednesday 11 th July	IWA Centre, Corlurgan Business Park, Cavan	7pm
Waterford:	Wednesday 11 th July	Viking Hotel, Waterford	2-4pm
Wexford:	Thursday 12 th July	Maldron Hotel, Wexford	2-4pm
Laois:	Friday July 27 th	Portlaoise National Learning Network	1.30-3.30pm

AUTUMN

Cavan:	Wednesday 8 th August	IWA Centre, Corlurgan Business Park, Cavan	7pm
Donegal:	Monday 20 th August	IWA Letterkenny	2-4pm
Galway:	Tuesday 28 th August	The Westwood Hotel, Galway	7-9pm
Mayo:	Tuesday 4 th September	Castlebar	5.30-7.30pm
Cavan:	Wednesday 12 th September	IWA Centre, Corlurgan Business Park, Cavan	7pm
Cork:	Wednesday 19 th September	Nemo Rangers, Douglas	2-4pm
Leitrim:	Wednesday 19 th September	IWA Centre, Carrick on Shannon, Leitrim	7pm
Waterford:	Wednesday 19 th September	Viking Hotel, Waterford	2-4pm
Dublin:	Thursday 20 th September	SII Resource Centre, Dun Laoghaire	6-8pm
Louth:	Thursday 20 th September	Crowne Plaza, Dundalk, Louth	6.30pm
Wexford:	Thursday 20 th September	Maldron Hotel, Wexford	2-4pm
Kerry:	Tuesday 25 th September	Gleneagle Hotel Killarney	2-4pm
Limerick:	Thursday 27 th September	IWA Roxboro Limerick	2-4pm
Laois:	Friday October 5 th	Portlaoise National Learning Network	1.30-3.30pm

WINTER

Cavan:	Wednesday 14 th November	IWA Centre, Corlurgan Business Park, Cavan	7pm
Donegal:	Monday 26 th November	IWA, Letterkenny	2-4pm
Kerry:	Tuesday 27 th November	Rose Hotel, Tralee	7-9pm
Galway:	Tuesday 4 th December	The Westwood Hotel, Galway	7-9pm
Cork:	Wednesday 5 th December	Nemo Rangers, Douglas	2-4pm
Leitrim:	Wednesday 5 th December	IWA Centre, Carrick on Shannon, Leitrim	7pm
Dublin:	Thursday 6 th December	SII Resource Centre, Dun Laoghaire	6-8pm
Louth:	Thursday 6 th December	Crowne Plaza, Dundalk, Louth	6.30pm
Limerick:	Thursday 6 th December	Maldron Hotel, Roxboro	7-9pm
Laois:	Friday December 7 th	Portlaoise National Learning Network	1.30-3.30pm
Mayo:	Tuesday 11 th December	Castlebar	5.30-7.30pm
Cavan:	Wednesday 12 th December	IWA Centre, Corlurgan Business Park, Cavan	7pm
Waterford:	Wednesday 12 th December	Viking Hotel, Waterford	2-4pm
Wexford:	Thursday 13 th December	Maldron Hotel, Wexford	2-4pm

NEW MEMBERS OF STAFF!

Zowie Curran - Finance Manager



Zowie joined SII as the Finance Manager in October 2017. She is a qualified ACCA Accountant since 2005 and has over 20 years experience in all areas of finance. Zowie has always had a special interest in SII as both her father and grandfather worked in the NRH over the last 30 years.

Ciara Mealy - Fundraising Manager



Ciara joined Spinal Injuries after working for 10 years in the not for profit world and she looks forward to bringing this experience to the role. She is looking forward to meeting & working with our service users in the future and says: "I am always at the end of the phone for a quick chat about anything fundraising!"