

WINTER 2018

# SPINAL NEWS

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## WELCOME

As the year draws to a close, we would first and foremost like to wish all our service users and their families and friends a very happy Christmas and a great New Year.

It's been a very busy yet strong year for SII. Our new independent resource centre is now in full swing, with a large training room which has been put to great use over the past 11 months as well as a private counselling room to allow for confidential service user support. We have had new staff members joining the team, whom we are delighted to introduce to you in this news edition.

Through our community outreach work, our awareness and advocacy work, and our fundraising events we have had the honour of working with so many members of the spinal cord injury community over the past year. Hearing stories, seeing goals set and achieved, and seeing true resilience in the face of adversity. The growing engagement we have experienced with our service users has been incredible this year and this will serve to help us raise awareness of the specific needs of people who have sustained a spinal cord injury and their families in the year to come.

As we move into 2019, we reach an important point in the organisation's development. We are currently conducting research to inform our strategic plans for the coming 4 years. A large part of that research has been hearing from you, our service users, through the surveys you received so we wish to thank you for your invaluable feedback and insight. With our new strategic plan, we look forward to bringing Spinal Injuries Ireland forward with strength, knowledge and purpose.

Lastly, and most importantly, we wish to thank each and every one of the individuals who have worked hard during this busy year to ensure that Spinal Injuries Ireland's services could reach their utmost potential; staff, volunteers, fundraisers, the NRH team and supporters alike. It is each of you who make our work possible.

We are always at the end of the phone so if you are in need, know that you can always get in touch. We hope you have a lovely Christmas and we look forward to an exciting year ahead.

Yours sincerely

Fiona Bolger CEO

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With very special thanks to everybody who shared their stories with us for this edition. Further thanks to our sponsors, donors, volunteers and contributors who continue to support SII, through 2018 and beyond.

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



## CONTINUED PROFESSIONAL DEVELOPMENT EVENTS (CPD)

A big thanks to O' Herlihy Consultants and Callan Tansey Solicitors who hosted CPD events recently with all attendee fees being donated to Spinal Injuries Ireland.

The focus of these events were on accessibility and medical negligence respectively. Entitled 'Accessibility and Universal Design in Practice' and 'Proactive approaches to preventing and minimising the impact of medical negligence situations for patients and the medical profession'; some very important topics which are important to be front and centre in the minds of these professionals.

## SORCHA SILKE'S RESEARCH

Community Outreach Officer for the North-West, Sorcha Silke completed her Masters in Family Support Studies recently and presented her findings in the NRH in October.

The title of her research project was 'An explorative study of the social supports that promote resilience in persons after a spinal cord injury'. In attendance were members of the multi-disciplinary team at the NRH and team members from SII.

Her findings yielded insight into the power of resilience and the ways in which service providers, families and friends can better facilitate resilience in people post-injury. A huge well-done to Sorcha for the tremendous amount of work and the research that went into this valuable study.

## STRATEGIC PLANNING

This year we set about a huge research project to look at SII and our services from all perspectives. This included our service-user's research survey sent out over the past few months, for which we are incredibly grateful for the feedback. This research project will be the basis upon which we build our strategic plans for 2019-2022. We look forward to sharing with you our key findings and our plans for the coming year in due course.

## FUNDRAISING



We wish to thank everybody involved in so many successful fundraising events and campaigns throughout the year. To those who hosted, contributed to and attended our fundraising efforts, we wish to share our appreciation. Here are examples of just some of the results.

Old Belvedere Barbecue: **€32,000**

Brian Smyth Quiz: **€4,500**

Our Summer Raffle: **€37,000**

Bag It: **€9,500**

The Q Ball: **€45,000**

The Cork Jazz Ball: **€25,000**

Colour Me Friday: **€18,000**







## RIB EXPERIENCE

**As many of our readers and service-users know, SII maintains and runs a specially adapted RIB powerboat crewed by volunteers throughout the spring and summer months.**

Moored in Dun Laoghaire Harbour, our incredible team of trained volunteers allow for weekly trips out to sea, across Dublin Bay and up the River Liffey, sometimes as far as the Four Courts.

This year over 30 of our service-users braved the water for this exhilarating experience. Those who've gone out in the boat have included new patients to the NRH and service-users from around the country along with their families and friends. One of those partakers said that the experience of getting back out on the water and feeling the salt air on their skin made them cry with that true sense of feeling alive with a sense of adventure.

SII have been nominated by the Dun-Laoghaire-Rathdown Community Awards for the RIB experience under Social Inclusion which is a heartening nod to impact at the end of the 2018 season. We are also delighted that we have secured funding to refurbish the seating in the boat so that riding in the RIB will be even more comfortable, secure and fun in the new year. Though docked for the winter months, we look forward to taking to the water with many more service users in early 2019.



injury are 'not looking for an easy route, they are hard-workers and are just looking to make living their lives and working on their farms possible'.

There was a call out for more specific support, and the issue of a lack of grant aid or VAT relief for adapting farming machinery and tractors was of huge importance to the group. This is something that Embrace Farm are working on in terms of advocating for change. Another major topic raised was the area of physical care and minding your shoulders. Given the intensity and longevity of farm labour, the importance of taking care of shoulder joints and ensuring that shoulder rest is built into the working week was highlighted strongly. The real success of the day came from the level of engagement and interaction amongst the farmers themselves; talking about practical issues in getting back to work, adapting machinery and farming equipment, feelings of isolation or a lack of support in their area.

Embrace FARM were established since 2013 as a network to support farm families who have lost a loved one or suffered serious injury in a farming accident. They provide a peer network where farmer's who have been affected by an accident can speak with other's in a similar situation to support them and offer advice and understanding.

SII, Embrace FARM and the NRH look forward to hosting a similar event and working together closely in the future to support members of the farming community with their specific issues. Keep an eye out for next year's event.

For further information about embrace you can visit [www.embracefarm.com](http://www.embracefarm.com).

If you would like to find out more about Farmer's events such as this one you can contact our services team on [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) or 01 6532180.



## NRH AND SII FARMER'S DAY

**Our second annual Farmer's Day took place on Friday, November 2nd, hosted by SII and the NRH.**

Attended by over 25 farmers with spinal cord injuries and their families the aim of the day was to share the common experiences and issues that affect farmer's specifically post-injury. Farm workers account for 6% of Ireland's working population but 40% of workplace accidents in Ireland are farm accidents. This fact, for us, is why we believe such specific meet-ups to be of such value to those affected.

On the day, Dr Eimear Smith welcomed the attendees and shared her own experience of her farming background. Speaker, Peter Gohery, from Embrace FARM hosted a discussion on several key points. Stories, issues and practical tips were shared in a free-flowing group talk which attendees found to be invaluable on a number of levels. Peter noted that farmers with a spinal cord



# Support at every stage

## MEET OUR NEW HEAD OF SERVICES, NAOMI FITZGIBBON.

### Naomi joined Spinal Injuries Ireland as our new Head of Services in June of 2018...

#### Tell us a little about your previous experience

I have a background in nursing originally. I trained as a nurse in Beaumont Hospital where I saw quite a few spinal injuries during my training. Early in my career, I left Dublin to work in London where my last role was Ward Sister during which time I even looked after some members of the Royal Family. My most recent role, prior to Spinal Injuries Ireland was as Cancer Information Service Manager in the Irish Cancer Society where I was responsible for Ireland's only national cancer information service. I lead a dynamic team of specialist cancer nurses who responded to over 5,000 enquires each year. Engaging with patients and families to develop vital services on any aspect of cancer was core to my work. To further my skills in the area I studied my MSc in UCD and became a Fellow of the RSCI School Of Nursing. As an experienced nurse I enjoyed being a patient advocate and representing the patient's voice at a national and international level.

#### What led you to come work for Spinal Injuries Ireland?

The service user focus of Spinal Injuries Ireland is what appealed to me instantly. The commitment to provide a service that is both supportive, goal orientated and individual to the service user is what I identified with first and it is at the core of what SII do on a daily basis.

#### What does your role entail?

I have a busy role supporting those who provide our key services, the community outreach officers, peer support volunteers, vocational activities coordinators, counsellors and advocacy workers on behalf of our 2000 service users and their families. I am learning so much about the organisation which has been in existence for 25 years. Being a nurse and having undertaken my MSc in Clinical Leadership, I am enjoying the challenges and seeing opportunities that lie ahead. I am currently orientating new staff and working with our CEO to review our current strategic plan and implement the goals of our next strategic plans for 2019 - 2022. Exciting times ahead!

#### What does a typical day/week look like?

My day can vary considerably. The service users come first, so ensuring our team are equipped to respond to their queries and support them in achieving their goals comes first. Following that, requests from Fiona Bolger our CEO comes next. As I am still relatively new to the organisation I am meeting key stakeholders in other organisations so we can collaborate to support our service users. I'm constantly researching about the effects of a spinal cord injury and the impact on the individual and family to ensure I have a deeper understanding of their experience. Nothing beats chatting to the service users themselves and listening to their story firsthand.



In SII, we are close team who work very hard, so lunch times are important to catch up. We have a wonderful resource centre with a great kitchen where we congregate, compare lunches and talk about the latest offers in Lidl!

#### **What insight has your nursing career given you in terms of SII services?**

I've been in so many different situations in my professional career to date, from looking after members of the royal family, to supporting people just diagnosed with a life-altering disease and what always amazes me is a person's ability to bounce back and fight to overcome the hard days. Human beings are amazing and that never ceases to amaze me. I have been involved in so many different scenarios both happy and sad. I feel very privileged to have met so many wonderful patients and family members during my career and work with them from the many different perspectives of care and support.

#### **Are there any services that you would hope to introduce or develop further?**

As part of the current review of SII's strategy we have conducted a survey of all our service users and other key stakeholders. I'm a firm believer in finding the evidence for developing any new services. So, once we have those results, we can look at the gaps in services and go from there. I've made sure I've met many service users since I started whom have inspired a few ideas, so hopefully the research stacks up!

#### **What are the challenges, you feel, that SII face currently?**

We are acutely aware of the gaps in services for those with a spinal cord injury, so addressing those gaps, while creating sustainable services are key. Advocacy is also a factor in addressing these gaps. We need to be realistic in our goals as ensuring we are delivering a consistent service, to the highest standard is first and foremost.

#### **What motivates you and your team most?**

Seeing service users achieving their goals and setting new ones. We always celebrate the gains someone has made, no matter how big or small. A spinal cord injury is such a specific injury for each individual and thus every bit of progress holds significance. As a team, knowing that you have played some part in helping a service user to achieve one of their personal goals is extremely rewarding. It is also highly motivating towards making sure our services are the best they can be for each and every person who needs help, no matter what stage they are at in their journey.

#### **Do you have a favourite saying or personal motto?**

Necessity is the mother of invention. I guess it goes back to my nursing training, when difficult situations arose, you just had to find a way around, while staying safe and not harming anyone. Hence, I rarely say no to a new opportunity, I always try and find a way to get something done, and if I can't do it, to find the person who can!

**You can contact Naomi on [naomi@spinalinjuries.ie](mailto:naomi@spinalinjuries.ie) or 01 6532180**

## MEET THE NEW SII TEAM MEMBERS

**We have had a few changes in our team as of late with some staff moving on and a new crew joining the team. We'd like to take the opportunity to thank our departing staff for the wonderful hard work and dedicated service they have given to SII over their time with us.**

**As we move into 2019, we are delighted to introduce you to some of our newest team members who will be working on your behalf in SII.....**



#### **Brian Lawlor Our New Peer Support Coordinator**

My name is Brian. I'm originally from Templeogue, Dublin. I was unlucky enough to receive a spinal cord injury in September 2012. Even at the age of 16, I knew that this was a life changing injury. At probably the scariest point in my life I was able to breathe a little easier when I was put in touch with a wonderful team from Spinal Injuries Ireland. They answered every question my family and I had, and they introduced me to alternate avenues of education and sport I hadn't thought possible.

After volunteering with them for a year they asked me would I join their team. I work as the organisation's Peer Support Coordinator in the National Rehabilitation Hospital in Dun Laoghaire. Now at 23 years of age I can honestly say Spinal Injuries Ireland have helped shape the person I am and are still helping me. I'm only thrilled to be a part of the organisation and hope to be for many years into the future.



## Our new Community Outreach Officer for Dublin, Hilary Keppel

I'm originally from Carlow but I've been living in Dublin for quite a few years. I've been working in social care for over 15 years in the areas of disability and mental health most recently with women who would have spent time in Magdelene Laundries. I would have worked primarily on the basis of supporting people to lead as independent lives as possible in their own communities.

I like the ethos of Spinal Injuries Ireland and their approach of advocacy and empowerment of their service users. It's very much where I'm coming from in terms of practical and real support.

I will be working as a Community Outreach Officer providing support to those with spinal injuries and their families. I'm very much looking forward to getting to know how the organisation works to provide meaningful assistance to service users and be part of that support.

In my spare time I like to upcycle/restyle furniture, so our spare bedroom always has a piece of furniture and lots of paint in it! I love creating something new from an unwanted and unloved piece.

## Our Early Days Community Outreach Officer, Gretta Fogarty

My name is Gretta and I am a very proud mother to three amazing grown up children who are the centre of my world, along with my wonderful husband Kevin. I love meeting people and really enjoy socialising and spending time with family and friends. I try to live each day to the fullest and enjoy every second like it's my last.

Prior to SII, I studied midwifery as a mature student and worked as a midwife in WRH (among other places), looking after mums and their new babies.

Back in 2013 my son suffered a high-level spinal cord injury. I was introduced to Spinal Injuries Ireland after that and was amazed by how much they helped us and got us back on track with our lives. I honestly do not know where we would be without them.

I am so excited about my new role with SII as a Community Outreach Officer, incorporating early day's programmes. My role includes developing an introductory pack to present to newly injured individuals and their families at a very difficult stage of their injury, outlining how Spinal Injuries Ireland can help them through every stage they encounter. I will be rolling it out to all the hospitals in the country and when newly injured people are ready, I, along with the support of my colleagues, will be there to support them and their families every step of the way.

I love a challenge and hope that this role will bring many of them. I am excited about meeting and getting to know everybody. I also love Christmas and would like to wish everybody a very happy and healthy one and a happy new year.



## Emer Hanley, Fundraising and Communications Officer.

My name is Emer. I'm originally from Church St in Dublin. My interests in life are music, politics, cooking and animals. I love to hang out with family and friends and have a good debate... We rarely do small talk! I play concertina so a good trad session is my happy place.

Having studied social policy, the facts I've learned and the personal stories people who sustained a spinal cord injury have shared with me, moved me to want to be a part of something positive that really offers help. I love that the team here is small, so everybody is hands-on and fully-invested in the organisation and our service users.

My role in SII will be quite varied. I'll be working with Ciara Mealy, our Fundraising Manager, on campaigns, events and collections throughout the year. I'll also be working on building awareness of SII and the work that we do amongst the media and the public. It's an exciting role with a lot of facets and lots of potential. It's a chance to support the services team across the board with funding and awareness which I hope ultimately will help grow the supports we can offer. I look forward to working with, and getting to know, our amazing volunteers, service-users and their families as time goes on.

I love that service-users needs are at the absolute heart of everything SII does and in the midst of laying down plans for the coming year, I'm really looking forward to the year ahead and seeing what we can achieve as a team and a community.





## DISCOVERING THE POWER IN ME

**Would you like to explore and challenge your thought processes and become more focused on what you can achieve in your day to day life?**

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**The Spinal Injuries Ireland services team are offering the Discover the Power in Me webinar programme again this year. Our most recent course started on November 6th running for 4 weeks and due to the ongoing success of the programme we will be running another course in the New Year.**

Trained by the Pacific Institute to deliver 'Discovering the Power in Me' in Ireland, our team have seen great results in many of the participants who have gone through their DPM courses to date. For over 35 years, The Pacific Institute has been a world leader in empowering individuals to recognise their ability for growth and personal excellence through their Discovering the Power in Me programme.

'Discover the Power in Me' is a self-empowering 4-week course exploring how each and every one of us can make positive changes to help shape the future we want.

Each week we will have themes including:

- Building a Stronger Me
- The Power of Self Talk
- Goalsetting
- Challenging our Boundaries

To take part in the course all you need to do is login online and listen.

**'I found the Discover the Power in Me programme hugely helpful. I could contemplate my life and work on breaking down the negativity I was carrying'**

Our university partner NUI Galway, will contribute by providing an objective evaluation of the project. In order to fulfil this role the NUI will not be directly involved in project management or delivery. This strand of the project is led by Dr Pádraig MacNeela and his colleagues at the Community Engaged Research in Action (CERA) research cluster.

This is a Spinal Injuries Ireland initiative following research carried out on understanding the needs and establishing the barriers of people with a Spinal Cord Injury and to help them overcome any such barriers (Dr Collins; 2014). This programme is available to all service-user and their families nationwide.

To register your interest for further DPM course contact Philippa O'Leary on [philippa@spinalinjuries.ie](mailto:philippa@spinalinjuries.ie)





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## CHOOSING A SOLICITOR FOR A PERSONAL INJURY CLAIM

**Please note that this article was initially produced by the Spinal Injuries Association in the UK and has been amended for Irish legislation around no win, no fee**

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Following an injury there may be a time where you feel that another person was at least partly at fault for your spinal cord injury. In this case, you may consider seeking legal advice from a specialist solicitor. To assist you with making your decision, you should consider the following points:

### **Do you feel at ease with your solicitor?**

You need to be able to communicate with your solicitor and feel that you can work with them. You should therefore ask whether the person you meet will be the person running your file. You also need to be able to trust your solicitor and to feel confident that they know what they are doing and that they understand your difficulties.

### **Is your solicitor easily contactable?**

Solicitors are individuals, and each has their own unique approach to cases and clients. You should consider how easy it will be to get hold of your solicitor and if they will be able to speak with you out of hours if the need arises.

### **Does your solicitor have experience of acting for clients with a spinal cord injury?**

You must ensure that the solicitor you choose has the appropriate level of expertise. Ask the solicitor about their caseload.

### **Ask the solicitor about their knowledge of spinal cord injury professionals.**

It is important that your solicitor has the key contacts necessary to obtain reports to help put your case together. One way for your solicitor to keep up to date with medical and legal

developments that relate specifically to spinal cord injury cases is to attend specialist training courses. You should ask your solicitor if they have done so.

### **How can your case be funded?**

Following an initial meeting with your solicitor, you should then begin to discuss funding opportunities. In some cases, a no win, no fee agreement can be put in place with your solicitor. However, it is against the Law Society of Ireland's regulations to advertise this and one should be wary of any firm who is actively promoting this. Finally, one should be aware that in some cases, a no win, no fee arrangement may stipulate that even if your case is unsuccessful you may still have an outlay to pay. Further to this, you may also be liable to pay the other sides legal fees if you are unsuccessful.

### **Disclaimer**

This factsheet has been prepared by SIA and contains general advice only which we hope will be of use to you. Nothing in this factsheet should be construed as the giving of specific advice and it should not be relied on as a basis for any decision or action. SIA does not accept any liability arising from its use. We aim to ensure the information is as up-to-date and accurate as possible, but please be warned that certain areas are subject to change from time to time. Please note that the inclusion of named agencies, companies, products, services or publications in this factsheet does not constitute a recommendation or endorsement by SIA.

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Spinal Injuries Ireland has a relationship with three law firms who specialise in personal injury settlements. This is by no means an exhaustive list but below are the contact details of these firms.

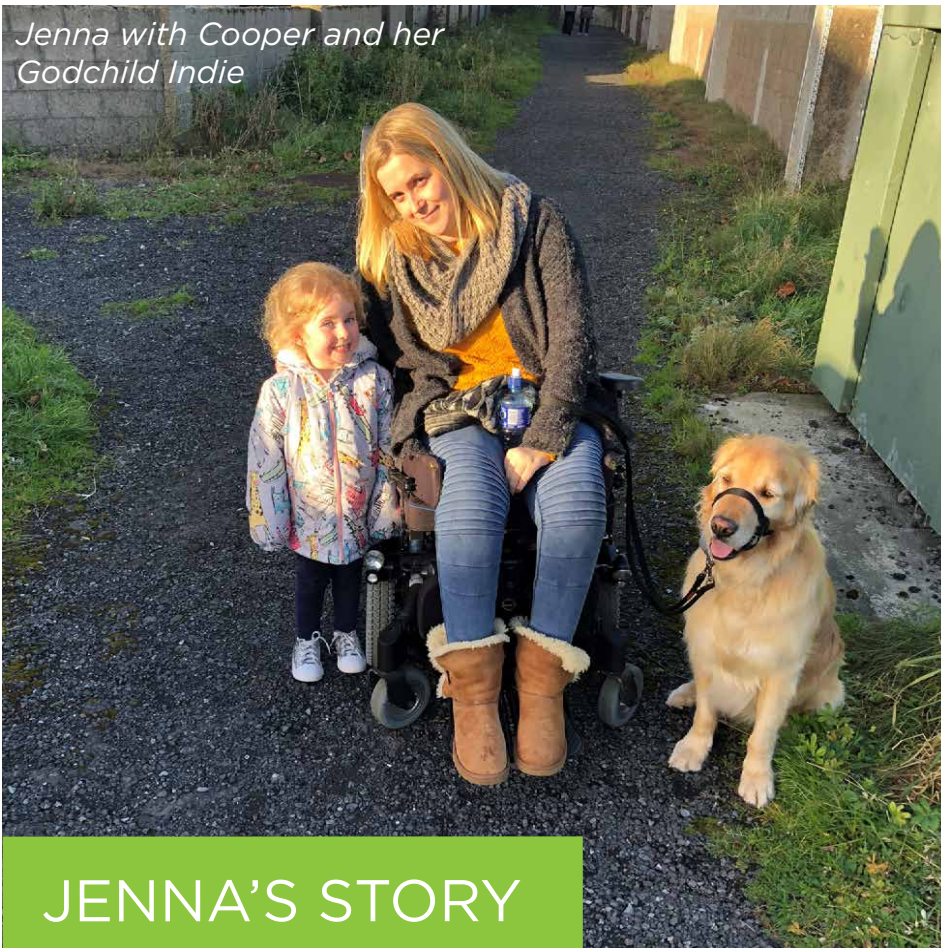
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Brian Gill, Callan Tansey Solicitors, [bgill@callantansey.ie](mailto:bgill@callantansey.ie),  
[www.callantansey.ie](http://www.callantansey.ie)



Jenna with Cooper and her Godchild Indie



## JENNA'S STORY

### My Path to Independent Living

On September 3<sup>rd</sup>, 2014, Jenna Fitzgerald's life with a spinal cord injury began. As bridesmaid to a close friend, Jenna was celebrating at a post-wedding party in Spain when she dived into the shallow end of their villa's pool. In that instant Jenna suffered a devastating injury. She sustained a high cervical spinal cord injury at C5/6 leaving her paralysed from the chest down with extremely limited hand function. Life as Jenna had known was shattered in that moment. She had been training to be a psychiatric nurse, was living in her own apartment in Enniscrone, and loved the outdoors. Now she found herself in a hospital bed, no longer having the future she had planned for.

Jenna's story over the past four years is one of resilience having come through many dark times and seemingly insurmountable challenges. After 6 and a half weeks in a coma in a Spanish Hospital, Jenna was faced with the steep mountain ahead. With the support of friends and family, she pushed to be transferred home to

Ireland and was moved to the Mater Hospital for specialist treatment in Dublin. It was at this stage that Jenna was told that she would be in a wheelchair for the rest of her life and then the milestones and learnings began. To begin, Jenna needed to come off ventilation and her feeding tube. Her first sip of water came 2 months after the wedding party.

**'Living Independently was the biggest thing for me. Lying in that hospital bed, all I could think about was getting home to my apartment and my golden retriever puppy Cooper'.**

Whilst in the NRH, Jenna didn't know that the idea to have Cooper trained as an assistant had been floated amongst family and friends and a committee was formed to see how to raise the funds to make it happen. Cooper would need intensive training which carried huge cost, so the decision was made to host the first 'Super Cooper 5k run' on Good Friday. It was an overwhelming success and

bowled Jenna over to see the amount of support she had within the local community. Over 1000 people turned up to take part with cake-sales, competitions, raffles and dressed-up dogs adding to the fun and the fundraising too. The success of the event meant Cooper's new role as an assistant-dog became a reality and he was to become not only Jenna's best friend, but her mobility aid, bodyguard and canine-carer. Cooper now had few new basic commands to understand his tasks so having him to assist meant that when Jenna would be alone, she would have help.

As the time to be discharged from the NRH approached, Jenna was determined to get home to her own apartment' **'Independent social housing seems to be non-existent for people with disabilities. There simply aren't accessible accommodations and the option of moving in with my parents just wasn't right for me. I was always incredibly independent having moved out at 17. It's part of who I am'.** She applied for a Home Adaptation Grant and had her home refitted to suit her needs. The success of the Super Cooper 5k also yielded enough for Jenna to fit out her home with the appliances and furniture she needed. Once home, Jenna's care team would come to take her in and out of bed, but they would be scheduled to do this at 2:30 every second afternoon and then to return her back to bed for 9pm. Jenna had no autonomy and could make few decisions in her days which became one of her biggest frustrations. **'There was a lot of bureaucracy, red-tape and barriers to getting the care I really needed to progress.'** These barriers to being more autonomous in almost every aspect of her days severely affected Jenna's mental health and morale. This was the lowest moment for Jenna and she decided to try to end her own life. Thankfully, she pulled through and reached a turning point. **'I looked into my parent's eyes and thought. This is it, sink or swim again. And I decided I needed to get my fight back'**

With her Spinal Injuries Ireland Community Outreach Officer and her NRH team, Jenna started looking at more options to overcome her frustrations. She attended counselling to help with her mental health and also opted to have a tendon transfer



performed on her right arm. This meant a large operation and then more time in the NRH but was worth it for the hope of increased function in Jenna's right arm. The operation was successful and meant that Jenna could now relearn to do things for herself like dry her own hair, do her make-up and turn the key to her front door; all things that she was told she would never be able to do. Being back in the NRH a few years after her injury and seeing people just beginning their journey helped Jenna reflect on how far she has come too. She was able to speak with people with new injuries and offer them a vision of what someone's life can be like afterwards. Once Jenna gets to where she wants to be, she sees her mission in life being to help others. **'I've always been a caring person and can't wait to give back and "pay forward" support like the support I have received from so many people.'**

The frustrations around her home-care package were her next battle to take on and with her SII Community Outreach Officer, Jenna started working with a not-for-profit company called Aiseanna Tachíochta (AT). AT enable direct payments to people with disabilities so that they can purchase their care based on their own specific needs. This was a game changer for Jenna. Fully supported by AT, she could interview, hire and schedule her own staff around her own life. She became the sole decision maker in her household again. She says, 'I am actually saving the HSE money now and my staff are happier'. AT helped Jenna with policies, procedures, training and better budgeting. It involves a lot of paperwork and determination, but it has been worth it for the independence and flexibility she has gained.

With greater ability and greater possibilities in her days, Jenna set her sights on hand-cycling equipment to further her ability to get out and about and exercise. A second Super Cooper 5K was organised and funds were raised for a Batec Hand-bike which is attached to her wheelchair and can be used to hand-cycle long-distances. Jenna can now take Cooper for walks along the beach and is planning to cycle her own 5K at next



years Super Cooper 5k Fun Run in April.

What's next on Jenna's to-do list? Now back at work in the Diamond Coast in Enniscrone, Jenna has her sights set on driving. With her COO, she is looking into getting a van that can be adapted to her needs and can be accessed by her power chair. Having driven for 10 years before her accident Jenna knows well the independence that comes with driving and looks forward to getting back on the road. Jenna believes independence was a resource, that itself added to her progress.



**“ Living Independently was the biggest thing for me. Lying in that hospital bed, all I could think about was getting home to my apartment and my golden retriever puppy Cooper. ”**

**'Living at home alone, if I need something, I have to get it. I have to figure out a way'.** There's been support at every stage of Jenna's progress and she says **'If it wasn't for Spinal Injuries Ireland, I wouldn't be here today'** but Jenna is in the driving seat of her recovery, progress and independence. Once she has a vision of what could enhance her life, she goes for it. In her early post-injury days, something a nurse said to Jenna in the Mater, when she didn't ask for what she needed, sticks in Jenna's mind and has become her own personal motto **'It's the squeaky doors that get oiled'**.

If you have been affected by any of the contents of this article you can contact Pieta House or the Samaritans. Freephone 116 123. If you would like to look for further support, you can contact your Community Outreach Officer or our services team on 01 6532108.

For further information on details mentioned in this feature see:

Aiseanna Tachíochta  
[www.theatnetwork.com](http://www.theatnetwork.com)

Batec Hand Cycles  
[www.batec-mobility.com](http://www.batec-mobility.com)

The Super Cooper 5k  
[www.facebook.com/supercooper5k/](https://www.facebook.com/supercooper5k/)



## SHAUN'S STORY

### Shaun Fogarty is the first ventilated wheelchair user in Ireland to go to college as a full-time student.

Travelling home from work on a summer's evening, Shaun Fogarty was just 19 when he was in a car accident that resulted in the most devastating injury. When found, Shaun didn't have a scratch on him, but he had sustained a C1 complete spinal cord injury. For the following few days in the hospital, Shaun was covered with tubes and wires. No one knew what to tell his family as no one knew if Shaun would survive. Only 2% of spinal cord injuries are C1/C2 as most at that level are fatal.

Before Shaun's injury he was an outgoing, ambitious teenager who lived life to the full. He was in his first year studying Applied Physics in UL, played Rugby for Feakle Rugby Club, trained in Martial Arts three times a week and worked as much as he could both on building sites and as a bartender. Following the accident, Shaun was paralysed from the neck down and fully ventilated, needing specialised 24hr care. Transferred from Clonmel hospital to the Mater to be operated on, and after long spells in both hospitals, Shaun needed to move on to rehabilitation. However, there

was nowhere that could cope with Shaun's needs in Ireland, so Shaun was transferred to a specialised unit in the UK.

**'It was an eye-opener. To see people with injuries as serious as mine not just surviving but getting on with life, having jobs and being as independent as possible'**

When the time came to return to Ireland, there was difficulty returning as nobody knew who held responsibility for Shaun's care. Shaun's family and SII fought hard to get him home and he returned to the Mater for 6mths. It was a struggle for him and his family being in Dublin, far from his native Cahir, Tipperary, so eventually he was transferred to Clonmel again. There was talk of placing Shaun into a nursing home, but Shaun and his family knew that wasn't right for him, being so young and determined, Shaun fought to get home.

**'It was a struggle for the HSE as they were afraid to think outside the box and explore the unknown'.**

Shaun was the unknown in Ireland. He and his family have always focused on the solution more than the problem, so Shaun worked closely with the staff in Clonmel Hospital who were very onboard with his plan to get home. A care team, organised though Home Instead, was put together and Clonmel Hospital worked with them to do training in the ICU to meet Shaun's specific needs before he could be discharged home. With the equipment and staff in place, Shaun returned to his home on December 2<sup>nd</sup>, 2016 and his family had their first real Christmas together since the accident.

**'Dad cooked a huge dinner and the house was packed with people for the celebrations.'**

Since those first days, settling in and finding his rhythm at home, Shaun has come a long way. He is now back in college full-time studying in UL. He is into his 2<sup>nd</sup> year of his Mobile Communications and Security Degree. When he tells people about the subject most say, 'I wouldn't be able for that, that would be way over my head', but Shaun is finding it really interesting and is preparing for his Christmas exams at the moment.

**'Being in college 5 days a week is full on but my only 9am lecture is on Tuesdays so I'm up and out by 7am'**

Returning to college, for Shaun, was always a must.

**'It was never in doubt for me- It was a case of how, not if'.**

When he first started applying the college had some doubts as to whether Shaun would have the stamina for a full-time course, but Shaun, as he consistently tends to do, showed them he was able for it. Shaun has a 24hr care team and the support of his family which is a huge part of him being as independent as possible, but it is Shaun who never lost his ambition and is always thinking outside the box to find a way.

Shaun is the first ever ventilated patient to go back to college as a full-time student in Ireland. He and his family hope that the path that they have carved out to get to this point will be a help and inspiration to others and are grateful for the support, and care they managed to put in place along the way.

**“ Hopefully, I've paved the way for others like me ”**





# Home Instead

Home Instead is an international care company, founded in Omaha, Nebraska, USA, and has been operating in Ireland since 2005. In the first 6 months of this year, Home Instead provided 1.3 million hours of home care from 24 offices employing over 4,500 people throughout Ireland.

Home Instead initially provided services to older people, and our current radio advertisements reflect this core expertise. However, as more and more people look for support at home, the expanse of services and age profile of Home Instead's service users has changed.

In August 2018, RTE reported that 1,313 people living with disabilities, under the age of 65, were living in nursing homes for older people in Ireland. And that this was an increase of over 5% from the previous year. Home Instead recognises the fundamental right of people to live where they wish and has expanded the scope of our service to allow people to do so.

In 2016, Home Instead were delighted to be chosen by the HSE to provide intensive medical home care in Co. Tipperary. This involved the recruitment and training of a specialist team of nurses, physiotherapists and carers, led by a clinical nurse lead to provide clinical services, such as tracheostomy and ventilation services, in the home.

Since 2016, Home Instead have worked with Shaun Fogarty and his family in his move from ICU directly to his family home. Shaun's team are trained specifically to meet his needs and empower him to live the fulfilling life he is living.

Home Instead Tipperary has invested significantly in training resources and upskilled its team to meet the clinical requirements of HSE service users and private clients. This will allow more and more people to choose home care as an option, as opposed to living in a residential care setting.

**Home Instead Tipperary is very happy to meet families to discuss services on offer.**

**Please call Majella in confidence on 083 829 7416.**

**Alternatively email Michael Wright at [Michael.wright@homeinstead.ie](mailto:Michael.wright@homeinstead.ie)**



## PARIS TO NICE

### Jacqui Carroll's journey from Paris 2 Nice

Jacqui Carroll's journey from Paris 2 Nice began when she attended a meeting arranged in David Lloyd Riverview about putting a team together to take on the Paris 2 Nice Challenge. Cycling from Paris to Nice has been on her bucket list for years so when she heard Fiona Bolger, CEO of Spinal Injuries Ireland speak she knew the time was now.

### Cycling

While Jacqui has been cycling for years, taking on Paris 2 Nice would mean some serious commitment and training. She and her brother often cycle together, and they are both part of a cycling club, The Orwell Wheelers. But Jacqui knew that she wanted to do Paris 2 Nice by herself, for herself.

**"I had a hard year last year and I knew that I wanted to challenge myself".** It wasn't something that Jacqui had ever done but she knew from her previous cycling trips and races that it was a great way to meet people. She also takes her safety on the bike very seriously **"I dress up like a Christmas tree to make sure that I'm seen"**, she laughs.

### The Trip...

Training for the trip had been arduous as excitement began to build in the days leading up to the trip, Jacqui went about preparing all of the things that she would need for her 700km cycle – including lots of dioralyte and lots and lots of sudocreme!

The team were blessed with near perfect weather, in fact Jacqui jokes that it was almost **"too warm"** but fortunately they had been able to prepare for it with the fantastic weather that we enjoyed this summer at home in Ireland.

**"They took such good care of us from the very start to the very end of the trip. They meet you in the airport and are with you every step of the way."**

Remarkably Jacqui even suffered through a kidney infection for her final two days, but she knew that this was the only time that she would attempt to do this trip so she finished it **"I wanted to have no regrets!"**

### The Finish Line...

All the hours that she spent on her bike training with the Paris 2 Nice team paid off and except for some tricky hills, Jacqui was able to fully enjoy her

experience. She never got off her bike and she really showed herself what she was capable of.

The crystallising highlight was crossing the finish line, **"it was like the Olympics"** After months of training and 6 days, the team bond was palpable. They had been through laughs, tears, blisters, beautiful scenery and even an 11km climb.

Paris 2 Nice challenged Jacqui in many ways but she has come out better for it. The fundraising was no exception. The fundraising target for Paris 2 Nice was €3,000 and Jacqui smashed it by raising €6,900! She held a fundraising night in the Goat Grill where she had her brothers Motown group with a raffle including flights to London.

Jacqui grabbed Paris 2 Nice by the handle bars, she pushed her own boundaries and really took herself out of her comfort zone and is all the better for it.

Overall the Paris 2 Nice team raised over €30,380 which was an absolutely fantastic achievement and we are so grateful for all of their efforts.

***She will be putting together a Paris2Nice team again for 2019 so if you, or someone you know would like to take part, contact us on [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie) for further info.***



## LAURA HARDY – 2018 SUMMER RAFFLE WINNER

**We're delighted to introduce this year's €5000 summer raffle winner who is a SII service user. Laura has been living with Cauda Equina since 2011 following an accident.**

### Laura's story

Laura was training to be a nurse in the UK when she met her husband Steven, they were both playing hockey in University. They lived in the UK for 7 years but decided to move home to Ireland because where else can you watch Leinster play on a Saturday, go scuba diving on a Sunday in Dublin Bay and visit some of the spectacular sights that Ireland has to offer in just a few hours? As you can tell, Laura believes that life is for living and living with a spinal cord injury doesn't need to be any different.



While living with Cauda Equina has been challenging – Laura had to stop walking for the most part because of her pain, she doesn't let it get in the way of her living a full and happy life. She still goes all around the world including the US, Barbados and most recently Venice for herself and Steven's 20-year anniversary.

### The Lucky Raffle Ticket

One big dream that Laura had when they moved into their beautiful house was to be able to bring the whole family for a walk in the nearby Malahide castle. This dream was made possible when one day she decided to enter that SII Summer Raffle that runs from May to September each summer.

She had been using an old mobility scooter that was very unreliable and often she couldn't make the 10-minute walking journey to her daughter's creche without it cutting out. So, when she received the call from Spinal Injuries Ireland telling her that she had won the top prize, she knew that she wanted to do something important with the money – *not to just pay bills*.

After careful consideration Laura decided that she would buy a new mobility scooter – or as her family call it, The Batmobile! She says that it has given her



Laura on a recent trip to Venice

back 100% of her independence. Her son loves being collected from school on the scooter – she had always hated driving the car to the school and having to lug her wheelchair in and out of it. Now she can make the 2km journey on her scooter and even stop off in the castle on her way home. Getting out in the fresh air every day is great for her mental health and loves when she and her kids come back with rosy cheeks after an afternoon outside.

### Runners Up

Winner of our second place €2000 prize went to, Ellen Fitzpatrick who runs Ellen's Hair Salon in Kilcullen. Ellen found out about SII through her mother who sold her the ticket and she says she's going to become a ticket seller next year.

Third Place went to Pat O'Donnell from Letterkenny, who was unavailable to take a photo but was delighted to get the call telling him the good news.

In addition, the Top Seller of our Summer Raffle for the third year in a row was Joe Murphy from Dublin. Joe took home a cheque for €500 as our Top Seller.

Huge Thanks to Windsor Motors in Liffey Valley, who sponsored our Summer Raffle, we had some amazing prizes on offer to four lucky people. We are grateful to everyone who got involved with our Summer Raffle this year. We were delighted with all the support we received, and the success of the funds raised.





# 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. Spinal Injuries Ireland are there from the to support those people when they need us, where they need us and how they need us at every stage after their injury. We could not do this work without the help of our donors. As little as €7 a month can make a real difference. Please sign up today.

## Please Sign Up today!

### SEPA Direct Debit Mandate



Unit G3 Pottery Business Centre, Dun Laoghaire, Co Dublin, A96 Y932

Unique Mandate Reference

(To be completed by the biller)

Creditor Identifier

(To be completed by the biller)

GB23ZZZSDDSELN00000003671715SPIN

By signing this mandate form, you authorize (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

Please complete all the fields below marked \*

\*Your Name:

\*Your Address:

\*City/Post Code:

\*Country:

\*IBAN Account Number:\*

Type of payment: Monthly ☐

Please tick

One off ☐

€7 ☐

€10 ☐

€15 ☐

€21 ☐

Other ☐

€.....

\*Date of Signing

\_\_\_\_ / \_\_\_\_ / 20\_\_\_\_

\*Signature

Please return this mandate to **Freepost, Spinal Injuries Ireland, Unit 3 Pottery Business Centre, Dun Laoghaire, Co Dublin A96 Y932**

We may pass the information you supply to us to third parties engaged by us to process your payments. Your personal data and transaction history may be used by these partner companies to assess the appropriateness of payment methods and for crime prevention and detection purposes. Our partner companies may also share such assessment with us and other third parties for these purposes. By supplying us with your account details you agree to your personal information being used in this way. Your information will not be used for any other purpose without your explicit consent.



## HYDROTHERAPY COURSES

**Following on from the success of our hydrotherapy courses in Galway and Limerick, we have successfully obtained funding from the National Lottery Grant Scheme to hold further courses in Holy Angel's Hydrotherapy pool in Carlow which will allow 10 participants to benefit from 10 weeks of hydrotherapy in 2019.**

In Limerick, the courses ran in March and May in collaboration with their local Sports Inclusion Disability Officer and our Community Outreach Officer (COO), Philippa O'Leary, supported by the Limerick Sports Partnership. Galway saw, our COO Sorcha Silke run courses in junction with MS Ireland and supported but the Galway Sports Partnership. The courses, also subsidised by the Spinal Injuries Ireland Short Course Fund, can help to enhance rehabilitation and assist in chronic pain management for people.

Led by a trained-instructor, participants are taken through movements specially designed to their abilities and needs. One-to-one trained staff are also on hand to guide the class-members through their movements. Our Limerick courses also have an engaged team of 4th year Health and Leisure students from UL on hand for one-to-one assistance in the water and participants are monitored for their weekly progress to assist with their individual goals.

The hydrotherapy facilities are fully and comfortably accessible. At 36-37C the pools warmth allows for muscle relaxation;

helping with pain and inflammation. Participants don't need to be able to swim to take part as a specialised hoist can lift an adapted shower chair into the water.

The benefits of hydrotherapy are wide-reaching and include enhanced aerobic capacity, improved circulation and muscle strength along with decreased muscle fatigue and joint pain. The buoyancy of the water helps with promoting greater endurance and freedom of movement in a supported, low impact setting.

As well as exercise, attending hydrotherapy is a chance to meet new people and boost your confidence. It is a very sociable environment where the class members often grab a coffee or lunch together afterwards and have a bit of craic too.

If you have an interest in participating in future courses, contact your Community Outreach Officer or call our services team on 01 6532180. Note courses will be subject to demand.





## THERESA'S STORY

### Support for me is about being able to give back too.

Theresa Collins hails from Newmarket, in Co. Cork and has been a Spinal Injuries Ireland service user since 2016. Over the Christmas period in Dec 15th 2015, Theresa had a fall and initially up with a severely sprained ankle and a lot of pain. In the following days and weeks Theresa's health worsened and she found she didn't have full control over her movement or functions. Return trips to the GP and the hospital for screening revealed problems with Theresa's spinal cord and she was quickly diagnosed with Cauda Equina; a condition caused by the compression of the lower nerves in the spine. Following that moment of diagnosis, Theresa along with her family suffered through a 50 hour wait in the hospital for emergency surgery. After the surgery Theresa was transferred to the NRH for 6 weeks of recovery and learning how to cope on a day-to-day basis with her new injury. Theresa has paralysis in her left leg and foot and many

hidden injuries that make daily planning and personal care a huge challenge, as it is for so many after a spinal cord injury.

Upon discharge from the NRH Theresa returned home to live with her mother whom she says is simply a

fantastic person and is her key support. A Home-Help package for assistance in the mornings was set up, which, though so invaluable in terms of enabling her to have independence throughout the day, was strange for Theresa to adjust to this change. 'You don't ever contemplate the impact of



needing something like that before you need it'. It took a while to adjust to accepting help however, through peer mentor support, Theresa realised that she could embrace the help for her needs and yet still focus on her strengths, abilities and goals.

Theresa linked in with Spinal Injuries Ireland upon leaving the NRH when her Community Outreach Officer, Philippa O'Leary, called out to her home. Since then Philippa has been a resource across the board, working with Theresa to have her specific needs met. Philippa secured a mobile scooter grant for Theresa to further her independence and has worked with Theresa to secure courses and qualifications that she never thought possible. Following a course in Mallow College, Theresa is now a qualified reflexologist and helps others, including her mother, with any pain or relaxation issues. 'It is a lovely skill to have, to be able to help soothe and improve another person's difficulties. Doing the course and meeting all the other girls in my class was fantastic too. It wasn't just learning the new skills and earning the qualification; It was working hard and making friends and the sense of achievement in the end.' Theresa is now looking forward to starting a Technology course in Charleville in the new year.

Support is a word that can mean so many things to so many people. For Theresa it's the little things and the consistent things the people in her life do. It's being there with sincerity whether it is for big moments of stress or simply a cup of tea and a chat about the little things in life. Getting in contact with people who have similar injuries and sharing stories, challenges, tips and even just a few laughs are where meaning is found. Attending a regional Woman's Support Group organised through SII has been another lease of life for Theresa. 'We get the WhatsApp about where the next meet-up is going to be and we just get together, talk about where we are at, what we're struggling with, what we're up to and aiming to do, and have a laugh. It's so valuable for me to have that level of understanding with each other'

Theresa also attends Peer Mentoring led by Brendan Glynn once a month where peers can talk about the wider issues that effect each individual with a spinal cord injury.

Going to the gym is another aspect of Theresa's life that has become a big passion. She has been coached and guided by her trainer Paul on nutrition and exercises for the past 2 years and she notices a confidence in her that she could not have imagined. Again, it's not just about the goals in the gym, it's the process, the camaraderie and the learning. People compliment me now in the street, noticing the difference in me since I've lost over 21lbs, but it's also my confidence and the way I hold myself' Before the accident, she would never have thought about going to the gym and now it has become a real dedication. 'People have so much going on in their lives and their heads. When you get into the gym your mind clears and all that falls away as you pass the door. You're there to work' It's a case of getting stuck in and being focused. It's important in terms of mobility; maintaining and improving function where possible too. Although Cauda Equina impacts every day for Theresa, it is not what defines her and not what people see when they share tips and laughs in the gym.

“ You have bad days and good days, I'm working on making sure the balance is right and the good days by far outweigh the bad. That's my way of coping. ”

Completing the Discover the Power in Me (DPM) programme was life changing for Theresa as it really helped her see the level of negative thoughts that she was having and living with every day. The course is accessed online and has a structured approach to break down thought cycles, reflect on issues and resilience and use coping tactics to set achievable goals. DPM massively boosted Theresa's awareness and determination in how she was



thinking, choosing to approach the next steps in life and setting goals. 'You have bad days and good days, I'm working on making sure the balance is right and the good days by far outweigh the bad. That's my way of coping.'

Theresa's determination most often comes from her deep desire to be there for family and friends when they need her, as they are for her. She has also learned that she needs to put herself first when she can, and work on her ambitions in order to be able to be a support for others. 'I'm a really outgoing person. I love meeting people'. That's what means the most to me in life now; family and friends. I have nieces and nephews who I love and want to be there for, so I feel that by pushing myself, working hard and putting myself out there I hope to make them proud and be a positive part of their lives. It's been a testing 2 years for Theresa since her accident but going from having a support network to being an active member of a support network has enriched her days and given her a new sense of fulfilment and determination for the future.

**For information on Discover the Power in Me see page 7. You can also contact us on [info@spinalinjuries.ie](mailto:info@spinalinjuries.ie)**





## ASSISTIVE TECHNOLOGY

### Technology is transforming the way we all live our lives.

Most of us have become dependent on our phones and mobile devices to manage our daily lives. Many more of us have adopted smart home devices such as the Amazon Echo and Google home to assist us in so many mundane, and not so mundane ways: finding a recipe, getting the news and weather forecast and booking a taxi. It's probably safe to say that for all of us, technology not only makes things possible: it makes things easier, often, much easier. For many people however, standard mainstream technologies are only part of the picture. Assistive Technologies have a real and vital part to play in enhancing independence for people with challenges across the life spectrum, from pre-school to older age.

Enable Ireland has been committed to exploiting the benefits of Assistive Technology since it established its National Assistive Technology Training Service in 2001.

#### What is Assistive Technology?

Assistive Technology refers to practical tools that enhance independence for people with disabilities and older people. It can be defined as

*"any item, piece of equipment or product system whether acquired commercially, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities"* (World Health Organisation & World Bank 2011).

Some of the most exciting and practical advances in Assistive Technology in recent years have the potential to make a real and positive impact on the lives of people with spinal cord injury.

#### Just for starters:

**Speech Recognition Software:** enables individuals control their environment using voice. This solution has revolutionised the lives of many who need to find alternatives to manual access and control. Surfing the net, dictating e mails and social media posts, creating assignments in education or at work, and scheduling meetings are just some of the tasks that can be readily completed using speech recognition.

**Eye Gaze Technologies:** speech may not be a practical solution for everyone. All of the above tasks can also be undertaken, simply using eye movements to control a computer, mobile device or smart phone. Individuals with high level spinal cord injury may be particularly interested in trialling eye gaze technologies as a means of increasing their personal autonomy at home, at work and in the community. We've even seen test examples of people driving their power wheelchairs using eye gaze, although this option isn't yet widely available in Ireland. Special Effect is a UK charity which has been undertaking some groundbreaking work around the provision of eye gaze solutions to people with spinal cord injury.



## Access to gaming/leisure:

Technology is at its best when it comes to leisure. The recent launch of Microsoft's accessible X Box controller, along with the development of switch accessible games is steadily bringing gaming within reach of many individuals who previously were excluded.

## Access to AT in Ireland

Unfortunately access to AT in Ireland is limited by virtue of the extent of state funding currently provided. However, many technologies are now far more affordable than they were previously, thanks to the avalanche of mobile devices (tablets and smart phones) which provide the ideal platforms for some of the AT solutions mentioned already. Enable Ireland and the Disability Federation of Ireland have been working hard to develop a national strategic approach to the delivery of AT services and supports. In 2016 we published an AT Discussion Paper, which identifies a series of key recommendations, including the establishment of an AT Passport system, to assist people transitioning across various stages of their lives from home to education, education to employment and so on.

We've also created a number of videos which illustrate the impact which AT can have on peoples' lives. Our experience has taught us that real life experiences count for so much more in helping us all to understand the impact that AT can have.

## Community Hub for Assistive Technology

Enable Ireland and the Disability Federation of Ireland have also partnered in the establishment of a national Community of Practice, focused on bringing together diverse stakeholders who have an interest in AT. With three meetings per year, the Community Hub For AT (CHAT) sees AT users, family members, service providers, makers, suppliers, policy makers and funders come together to resolve the daily living challenges which people encounter, through the use of Assistive Technology. Why not check out details of our next CHAT meeting on December 3rd on our Linked In page.

## Online Resources

Information in power and we are keen to ensure that any information we have, we share. Why not check out our online resources here:

**Blog:** [www.atandme.com](http://www.atandme.com)

**YouTube Channel:** [www.youtube.com/enableirelandat](http://www.youtube.com/enableirelandat)

**Website:** [www.enableireland.ie/at](http://www.enableireland.ie/at)

**Twitter:** @atandme @freedomtech\_irl

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## COLOUR ME FRIDAY

SII would like to thank everyone that took part in our annual Colour Me Friday Campaign on Friday October 5th, 2018. This year we saw some lovely green get-togethers all contributing greatly to funds raised throughout October. #gogreen



## CORK JAZZ BALL 2018

Our 2nd Cork Jazz Ball took place on Saturday October 27th in the Silver Springs Hotel and was graced by over 200 attendees in their finest attire. The night was a huge success raising over €25,000 for SII services in the region. A huge thanks to the organising committee and everyone who worked and contributed to this great event. We already can't wait for next year...



## Q BALL

The annual Q Ball, held in the Ballsbridge Hotel Dublin, took place on Saturday September 29th. Over €45,000 was raised on the night which will go to supporting our service-users and their families. SII would like to say a massive thanks to event organiser, Philip Quinlan, and everybody who contributed to the night's success. The legendary after-party was the icing on the cake and is sure to return in 2019...





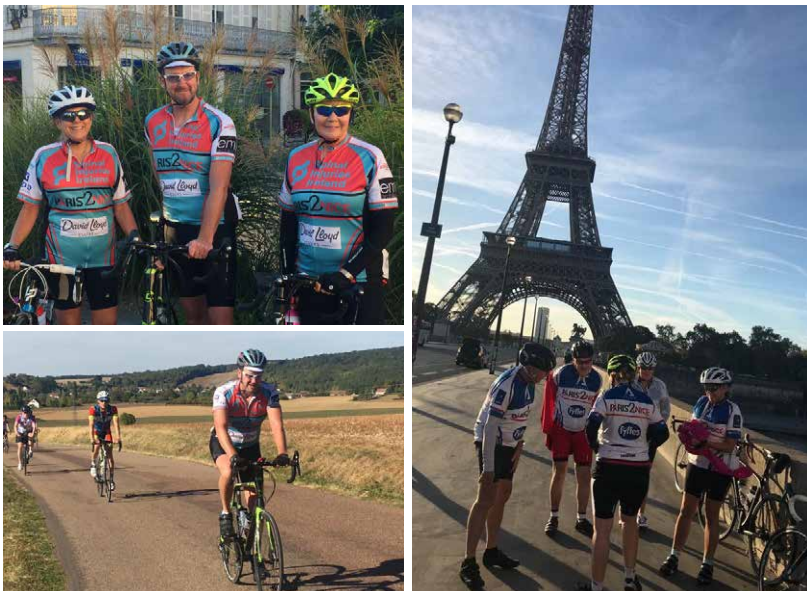
## BAG IT

Our pre-loved designer handbag auction returned this year to great success. Kindly hosted by Marah Curtin and Davy Stockbrokers, attendees enjoyed champagne, canapes and auction-excitement. In all, the event raised €9550 in total, a huge success by all accounts. Huge thanks to Fiona Daly, Brian Dempsey, Davy and the Designer Exchange and everyone who made this event possible.



## PARIS2NICE

September 2018 saw our CEO Fiona Bolger lead our SII team of Paris2Nice cyclists which included Apres Match's Risteard Cooper and Jacqui Carroll of Harry's Bikes. The cycle took place over 6 days and saw the team cycle over 700km to reach the finish line. The team raised over €33,000 for SII services and we are in awe at the determination and achievement. Recruitment for participants for next year is already open, so contact us if you are up for a challenge in 2019



## SUMMER BBQ

On September 1st 2018, Our Old Belvedere committee, led by Ger Dargan, hosted another fabulous event which was attended by over 150 supporters. An auction was held on the night along with a raffle and guests were entertained by the wonderful crooner, Sean Boland, and DJ Doug. A big thanks to all involved in making the barbecue such an enjoyable event.





## Pain. Bladder. Bowel. Skin. Mobility. Fatigue. Mental health.

Has anyone ever asked you which aspect of the consequences of your spinal cord injury you would most like medical research to concentrate on to improve your day to day life? No? I haven't been asked either.

I remember years ago my Grandparents only wearing their "good clothes" if they had to visit the doctor. If someone was sick enough requiring a house visit the place would be spic and span as a sense of reverence was bestowed upon the doctor coming to the house. In GP surgeries and hospitals doctors were treated as medical deities. You took the medicine you were prescribed, stopped if it didn't agree with you got on with life if it did.

Like other former pillars of Irish society, times have changed. It is a slow journey but a necessary one, the role of the patient in the world of medicine has also undergone a metamorphosis.

It is no longer acceptable to do things "to" the patient who basically acted as a mute recipient. Ignoring the patients-rights as central to all decision making has, in the past, often resulted in horrific consequences for hundreds of Irish people and their families. Times may be changing but it is slow.

In recent years we have witnessed a swell in the power and role of patients in medicine and health system development. Patient organisations and individual patients have a central role to play in this. Public Patient Involvement (PPI) is an integral part of our health products and systems development. 'Public' means anyone who has an interest in health and social care as a public service including potential users of the service. Patient refers to service users, clients or carers. In Ireland the HRB (Health Research Fund) has put together an implementation plan to support public and patient involvement through HRB supported projects and programmes. Many of our universities take part in PPI Ignite project which aims to address the central role the public and patient play in making research relevant. Rather than an academic deciding what it is they "think" would be a worthwhile question answered, patients give first hand experiences of what is like to live with a condition and what research would be most relevant to them in improving their quality of life. Patients are also asked to

review grant applications and dissemination of results to put scientific results into plain language that patients find easier to understand.

Pharmaceutical companies now recognise the valuable insight patients have in developing new medicines. Patients are now being included in every step of development from concept, ethics committees, clinical trial design, presentation of scientific data and results and patient leaflet information. It takes approximately twelve years to develop a new medicine. It is a hugely complex process involving interdepartmental and multidisciplinary teams developing new drugs from molecules to medicines. Involving patients in research can hugely benefit the medicines development process by bringing in their priorities and perspectives. Patients can contribute to developing better treatments for them and others. Greater patient involvement in research and development will boost the efficacy and safety of new treatments and increase public support for medical research.

The HSE and HIQA have also made progress in recent times, inviting patients to report their direct experiences of services and asking for patient representatives to sit as equal partners at stakeholder meetings for proposed additions to our health system. The HSE has also added positions for two patient representatives to their Board.

This new public patient involvement has meant a sea change in approach to the world of our health. Many patients have an ingrained fear of speaking out. The European Union Patient's Academy on Therapeutic Innovation (EUPATI) has recognised that, in order for patients to be seen as equal stakeholders, there is a need to equip people with knowledge on how medicines are developed and how health systems work. EUPATI aims to increase the capacity of "patient experts" and well informed patients in patient organisations to be effective advocates and advisors in medicine research development. It also endeavours to empower patients to provide patient relevant advice and insight into industry, academia, authorities and ethics committees at a national and at EU level. EUPATI offers an eighteen month training course. It is

a combination of e-learning and face to face training. Twelve Irish patient advocates have completed this training.

EUPATI has platforms in fourteen European Countries with eight more being developed. In Ireland we have the Irish Patients Platform Organisation Science and Innovation (IPOSSI). The importance of a strong patient voice is being called for in Ireland, however there is currently a shortage of contributors with the right skill set. IPOSSI recently piloted a course that ran for six months. It delivered a programme for Irish Patients on health research and innovation including modules on clinical trials, medicines regulatory affairs and health technology assessment. IPOSSI has recently invited applications for its new Patient Education programme – closing date Sunday 18<sup>th</sup> November.

We, the patients who live with spinal cord injury, are the experts by experience. Researcher's, policy maker's and service provider's idea of what might be important research is just that – their idea. Without asking, how do they know what research is most important to us. Finally, the recent Scally report into the appalling treatment of patients' states "it was difficult to see who was representing the patient and public interests". If we as patients don't speak up for ourselves and each other who will?

For further information on Expert Patient Advocacy Training see [www.eupati.eu](http://www.eupati.eu) or [www.ipossi.ie](http://www.ipossi.ie).



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**CHALLENGE YOURSELF LIKE NEVER BEFORE**



## **Join Our Fully-Inclusive Tall Ships Challenge**

We are hosting an extraordinary 6 day sailing adventure this May 2019.

You'll have the opportunity to join a uniquely diverse crew and learn how to sail the Lord Nelson - one of the only fully-accessible tall ships ever built allowing every member to play a fully hands-on role.

This is a challenge like no other. No sailing experience is needed and all crew members will be given the support, guidance and tools to be an equal crew-member sailing the ship from Cork to Southampton.

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This is the challenge for you.