



SPINAL NEWS

WINTER 2019

CES Public Awareness Campaign

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Ships Challenge 2020

Raffle Winners
announced

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Injuries
Ireland

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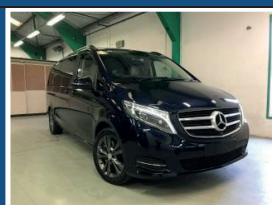
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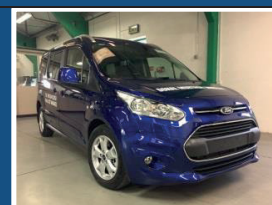
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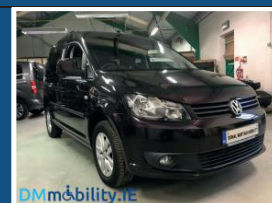
Citroen Berlingo
2014, 1.6D, Multispace Model, 3-4 Seater & Wheelchair Chair Occupant, ** Choice of 15, 2011 - 17 **



Peugeot Partner
2013, 1.6D, 3-4 Seats Plus Wheelchair Occupant, ** Choice of 16 from 2010 - 2017 **



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WELCOME

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As we approach the festive season, we would first and foremost like to wish all our service users and their families and friends a very happy Christmas and health and happiness for the New Year.

This year we unfortunately lost one of the founders of rehabilitation services in Ireland, Sr Aileen McCarthy, who passed away in May. Aileen was a pioneer who devoted herself firstly as a nurse and then as a Board Director of both the NRH and Spinal Injuries Ireland. Just last year Sr Aileen attended the opening of SII's new Resource Centre which is named in her honour and she continued to advise the organisation until the end. We are determined that SII will continue the work she started and strive to be pioneers for improved services for people with a spinal cord injury.

It has been a year of many firsts for SII in our 26 year history. In May, we were delighted to set sail on our first Tall Ship Challenge. 24 service users and supporters sailed the Tall Ship the Lord Nelson from Cork to Poole. It was a life changing experience for everyone and you can read all about it on Page 13.

This year we also launched our first health awareness programme; the Red Flag Alerts for Cauda Equina Syndrome. In addition to a national roadshow, leaflets were distributed to GPs nationwide and the programme also received a lot of media attention. The CES Red Flag Alert programme was developed with support from Coloplast.

The issue of waiting lists for appropriate care is a major growing concern for people with a SCI. We highlighted this issue to the media over the last few months and are planning to advocate further in the 2020 as the lists grow longer for inpatient and community services.

Finally we were delighted to be acknowledged by the National Lottery Good Causes Awards. This gave great profile to the organisation and we were delighted to be one of the finalists.

We could not continue to do the work we do without the support of all our service users, staff, volunteers, board, stakeholders, donors and supporters. We thank you for being part of the SCI community and hope to grow over the coming year to a stronger support and voice for people who have sustained a SCI.

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

COMMUNITY NEWS

RAFFLE WINNERS

A huge thank you goes to all of our service users who took the time to sell raffle tickets on behalf of SII this summer. The Annual Raffle is a mainstay of our fundraising calendar and all income raised goes directly towards supporting our front line services. This years' winners were Thomas Murphy from Wexford who won 1st prize of €5,000, Conor Houston from Dalkey who won 2nd prize of €2,000 and Megan Gallagher from Bundoran who won our 3rd prize of €1,000. And a special thanks goes to Joey O'Neill from Brittas Bay who won the sellers prize of €500. We are very grateful to our sponsor Windsor Motors who provided all the prizes.

COMMUNITY FUNDRAISING HEROES

Mark Nugent:

After sustaining a T2 complete spinal cord injury following a cycling accident in 2016, Mark Nugent was determined not to let his injury get in the way of him living his life to the fullest. This summer, only a few short years after his accident, Mark completed a hand cycle from Malin Head to Mizen Head in aid of SII. Not only is Mark a fantastic Ambassador for SII (he recently spoke at our Summer BBQ in the Royal St. George Yacht Club, where his impressive speech roused a standing ovation), but he has also been a fantastic fundraiser for us, raising an incredible €25,000 on his cycle. From every one of our staff, volunteers, service users and their families, we'd like to say Thank You, Mark. You've been a great friend to Spinal Injuries Ireland and the spinal injury community.



Michael Lynam:

Another special thanks goes to Michael Lynam, who ran the Belfast Marathon this year in aid of SII. On top of running the 26.2 miles around Belfast in under 4 hours, Michael raised over €12,000 for SII, an incredible achievement on both fronts!

Mark White:

We were the chosen charity for The Tangoray Reunion gig in the Horse Show House on in September and are over the moon with the support and response. It was a great night of tunes and banter with the lads in the band giving it their all on stage. Together they raised an incredible €10,500 for Spinal Injuries Ireland in the process. Huge thanks and a massive congrats to Mark White and everyone who helped organise, took part and came along to make the night so special.



Stephen Dardis:

We would also like to acknowledge the fantastic contribution made by Stephen Dardis who cycled a stage of the Tour de France for us and raised €4,325. Stephen was also a spokesperson for our CES campaign for which we are very grateful.

LIMERICK CREW FUNDRAISERS

We have some amazing supporters in Limerick, but none more so than Mike Brislane, Paul Fitzhenry and their crew! Not only did our friends in Limerick spend a few days playing ukuleles and running a bucket collection on our behalf in the Crescent Shopping Centre for Colour Me Friday, but they also held a hugely successful table quiz night. And on top of this, Paul created a calendar from his own personal sketches of Limerick landmarks with all proceeds going to SII.

We're so grateful to have such wonderful supporters up and down the country. We couldn't do what we do if it wasn't for the grassroots support that so many of our friends provide.

SII FAMILY RESEARCH

At the very core of our ethos, SII want to make sure to collaborate with our service users to ensure all our services are evidence-based, appropriate and as effective as possible for those who need us. That is why we work in partnership with UCD Public Patients Involvement (PPI) Ignite. SII are a stakeholder of UCD PPI who are working with people who are seldom heard when developing research, education and support. Earlier this year we were successful in securing funding for our project: **An exploration and identification of research priorities utilising a co-design approach between family caregivers of Spinal Cord Injury (SCI) patients.**

We worked together with Dr Sarah Donnelly, School of Social Policy, Social Work and Social Justice, UCD to conduct a research focus group. The research group was for family caregivers to inform our strategic process and ensure SII are innovators by authentically understanding what the research priorities are from their perspective.

We invited family members to participate in a focus group to identify future research projects which are viewed as priority by SCI family caregivers and create a forum whereby the hard to reach voice of SCI family caregivers can be heard. We also hoped this will be an empowering exercise for SCI family caregivers which we hope will lead to a co-designed SCI family caregiver education and support programme.

The focus group took place in March where a group of family members came together to a session which was facilitated by SII Head of Services and Dr Sarah Donnelly, UCD. The morning session explored the research needs. The mindfulness session in the afternoon supported the attendees to explore the importance of self-care while being a caregiver. To add to the valuable information gathered from the group, we also needed to gain a broader, representative insight so we also administered a national online SurveyMonkey questionnaire addressing the subjects identified in the research prioritisation focus group.

Of the 56 respondents, the majority were aged from 35-64 years old, with only 1 respondent who was under 18. 44 respondents were female, 11 were male and one did not disclose their gender. The top five areas of research priority identified were:

- Access to transport and transportation options in Ireland
- Medical Card, Long Term Illness and Drug Payment Scheme Eligibility
- Home supports and home care packages
- Inappropriate placement of people with SCI in nursing homes
- Home adaptations and equipment

Since the findings of the focus group, we conducted a further survey with SII service users to learn more about the need for medical cards among those with a SCI for a pre-budget submission. A total of 272 Spinal Injuries Ireland clients took part in the online survey in June and July 2019. The results demonstrated that participants who had a medical card were more likely to report having financial concerns. We are also advocating on home supports and home care packages and inappropriate placement of people with SCI in nursing homes.

These study findings will help inform service development and research priorities for SII. Funding opportunities will be explored in order to carry out further research stemming from our research prioritisation exercise going forward.

COMMUNITY OUTREACH TEAM

ASSISTIVE TECHNOLOGY COURSE 2019



SMART HOME

At the start of 2019 SII launched our Strategic Report and plans for the coming four years which was informed by an in-depth research piece conducted for us by NUIG. One result strongly highlighted by this SII Service-User research project was the strong interest within the SII community around emerging assistive technologies and thus SII set about prioritising Assistive Technology knowledge and expertise within our SII Services strategy going forward.

In March of this year, four of our Community Outreach Officers embarked on a course covering foundations in assistive technology with Enable Ireland. The course was accredited by Dublin Institute of Technology, through their Faculty of Engineering and was delivered using a combination of 3 days of face to face training on site in Microsoft, with the remainder of the course delivered on-line. In total, the time commitment required per officer was approximately 100 hours training following by completion of a course project around the application of a specific form of assistive technology and how it could be utilised by a person living with a spinal cord injury to meet a specific goal.

The aim of this course was to support the SII Services team in expanding our knowledge of Assistive Technology (AT) and how it might better enhance our ability to advise on tangible and practical solutions for challenges in our service-user's daily lives. The course was an opportunity to explore new and emerging technologies, engage in the discourse surrounding AT, and gather more hands-on experience with a range of Assistive Technologies guided by expert AT users.

Each of our Community Outreach Officers carried out a case study which focused on a specific application or piece of moderately accessible, assistive technology and explored how their chosen form of AT might best work (or not) to meet a service-users needs.

CASE STUDY 1

By Greta Fogarty

AT to offer autonomy for Young Male Student with high level SCI

This was a retrospective case-study looking back over AT options that were trialled to help this service user to communicate verbally and virtually, while giving him autonomy and privacy when communicating with friends and family on social media and downloading movies to watch. He would also need to explore his options for switch access to drive his wheelchair independently.

My case study subject was a young man with a complete C1 spinal cord injury, leaving him paralysed and dependent on a ventilator for breathing. For him, this resulted in total loss of independence and autonomy, so finding a device that suited his needs was imperative for his quality of life. I also explored possible considerations for the future to give him optimal independence with adjusting his environment to his liking autonomously.

As a first step we discussed the use of word and letter cards initially and noted the frustration and exhaustion experienced both by the service user and his family as communicating a simple sentence or instruction was very time consuming. We also tried voice recognition devices such as the Samsung Galaxy phone and tablet however, this was also frustratingly unsuccessful due to the background noise in the ward in which he was in situ, along with the noise of the ventilator upon which he is dependent on. With these learnings as a base line we explored wider options that could be used with voice, eye movement and/or head control and landed upon eye-gaze technology as a potentially viable option.

We availed of a trial of an Eye Gaze computer. An Eye gaze computer facilitates the user to use a computer comfortably by using his eyes as a computer mouse. Although this would prove to be very costly, coming in at approximately €6,000, this would prove to be the device of choice for the service user. Our case study subject had regained the ability to speak however the future risk of losing his voice for short periods due to illness was probable, so the Eye Gaze would give him an extremely effective communication tool that would not be diminished causing added distress in times of illness. This eye-gaze device also gave the service user the autonomy to browse the internet and communicate effectively with friends and family with privacy as spoken word was not necessary.



VOICE ASSISTANT

GET STARTED

Simultaneously, we also opted to trial a mid-wheel steering wheelchair with bilateral head switch which would command the steer and stop functions. The head rest had to be custom made to the user's preferred specification and along with the wheelchair itself, the cost came in at just over €15,000. Funding was received from the HSE (with a degree of difficulty and delay) along with an annual service agreement.

While training to use the Eye Gaze and wheelchair took some time, almost immediately the service user reported he felt like 'his life had been returned to him'. He now uses his Eye Gaze to research and do assignments for his degree in university. With recent improvements in software, he is also now able to use voice recognition to use his phone. He finds the Samsung Galaxy X the most appropriate for his needs.

Given the success of these initial adoptions of AT this service user is planning to explore further technologies in the home such as Alexa/Google Chrome. As his study progresses, we also plan to explore Dragon voice recognition for larger assignments may benefit him as he progresses with his university course.

The timeframe from applying for funding and trialling the equipment to receiving it took approximately 7 months. However, at the AT study days, there were reports of people waiting for over a year for funding and some also being refused funding for necessary equipment, which is disappointing when considering the huge improvement AT brings to people's independence and autonomy in such adverse circumstances. Though the upfront cost of this eye gaze technology and specialised wheelchair were high, the life-changing impact and autonomy that the user regained has improved his quality of life and vocational opportunities exponentially.

CASE STUDY 2

By Hilary Keppel

Maximising Environmental Control Systems with Smart Home Technology

This case study focused on a person with a high-level SCI who has limited movement of her upper limbs. Her wish was to have more control over everything in her home and to use whatever environmental control systems would work best for her. Her speech was unaffected by her injury and so we decided to concentrate on voice activated technology initially as a control mechanism. This will be used over WIFI as she lives in an urban area with excellent coverage.

For this individual, having a high-level SCI means that everyday life is lived surrounded by pieces of equipment aimed at supporting, care and health. Getting up usually requires the use of a hoist from a profiling or turning bed. The day is spent in a manual or powered wheelchair with supportive or moulded seating, tilt-in-space functionality, as well as wheelchair trays and/or arm gutters to position paralysed upper limbs. Travel usually involves being seated in the wheelchair as opposed to being transferred into a seat in accessible public transport or an adapted vehicle with a lift and lowered floor.

Environmental control systems (ECS), also known as electronic aids to daily living (EADL), enable people with high-level SCI to control and access everyday electronic devices in their environment. Smart home technology is an extension of home automation and offers many of the features of ECS together with monitoring and automation functions.

This individual already had an Amazon Echo prior to her accident so we decided to use this as a starting point to make the rest of her home “smarter” and therefore more usable for her. She purchased a second Amazon Echo for her bedroom (Approx. €110). Although the Amazon Alexa can control lots of smart home devices, many of the integrations require a smart home hub to act as a middleman. This is because current Alexa devices lack the radios needed to communicate directly with these devices. She decided to go with the Samsung SmartThings Starter Kit. (Approx. €90)

When looking at lightbulbs she compared some of the “smart bulbs” on the market at present. She had the advantage of already having a smart hub so could use the Phillips bulbs if she wanted to as they require a hub to function. She compared prices but for ease of buying decided to go with the Philips Hue lights (from €29) as there was a variety of light colours available which she felt would be good in

her bedroom in regard to changing colours and dimming lights. They are very easy to set up and they pair easily with Alexa.

When looking at items that needed to be plugged in that she wanted to control, we looked at WIFI enabled plugs for lamps, chargers and kitchen appliances. She had one with the Smart Things Hub and decided to buy some more so that they'd be in situ where and when she needed them.

All in all, with the initial outlay on equipment of approximately €400-500 the benefits of this added technology far outweighed the cost involved and proved excellent value for investment. Each connected item has removed a small hurdle in the user's environment to the point that she is planning to add in more connected technology over time. She has further planned to look at possibly getting a BJOY ring to connect to her powerchair joystick and as she already has the WIFI technology in her home. The BJOY Ring is a USB device that converts your wheelchair's joystick into a mouse to control your computer and compatible tablets and smartphones. For ease and swift usability, the service user in this instance hired an AT installation company to help with her exploration and integration of these technologies but we did note that it is possible to install these devices without being highly technically minded. Each of the products are now available online and in high-street stores and can be expanded upon over time depending on the individuals needs, preferences and environment.



CASE STUDY 3

By David Fitzgerald

Vocational Assistive Technology

This case study was based upon a youthful 64-year-old lady who has enjoyed a successful career in horticultural education. In 2017 she suffered a traumatic L4 incomplete spinal cord injury as a result of a medical condition. She was discharged from hospital in mid-March 2019 to embark on a life of independent living. The service user now finds herself to be a full-time power wheelchair user with limited use of her upper limbs. She also has very limited hand and digital functionality.

Despite her new-found situation this service user has a problem-solving mindset. She never allowed her disability to defeat her and treats every situation as a challenge. After much reflection she had decided to take early retirement from her full-time salaried role however she had no desire to terminate her career at this point. After much reflection and research, she had decided to continue her work on a self-employed consultancy basis. There are many advantages to this not least being the ability to work from home at times that suit herself.

The aim of the project was to research and trial alternative methods of computer access technology to enable and empower the service user to pursue her goals and ambitions going forward. While she can currently use a standard keyboard and mouse, her limited hand functionality and compromised digital dexterity means that this is done with great difficulty. With this in mind, we examined whether an alternative

mouse and the use of voice recognition software would enable her to use her PC more efficiently going forward.

Speech recognition is a now widely available technology that allows spoken input into systems. You talk to your computer, phone, or device and it uses what you said as input to trigger some action. The technology is being used to replace other methods of input like typing, clicking, or selecting in other ways.

At the time of the assignment the service user was only back in her home 10 weeks and still adjusting to the very many challenges of a life of independent living. While it is still very early days for her the impact of the trial to date has been dramatic and one of her more successful achievements.

At the start of this journey, while eager to trial and test AT solutions, the service user was somewhat cynical about technology's ability to deliver the solutions she required. Her success to date has renewed her confidence in her abilities and potential.

The use of speech recognition and wireless peripherals, trackball mouse and headset, that meet her needs has given her the inspiration to persevere with her exploration of AT solutions. She acknowledges there is much more practice required but at only six weeks into her AT journey she had the belief that AT solutions can empower her to achieve her full potential despite her new-found physical challenges and limitations.



CASE STUDY 4

By Philippa O'Leary

A focus on Smartphone Apps and their role in transitioning from a hospital setting to independent living at home

This project aimed to explore how Assistive Technology accessible through Smart Phone Applications could support a 71-year-old gentleman with a C5 spinal cord injury in his transition to independent living after almost three years in hospital settings.

This was the first phase in an ongoing supportive plan into how Assistive Technology can support this man's independence moving home. For this project we focused on his smartphone and android applications (Apps). A range of apps were trailed over a four-week period to see how accessible and useful they are for this gentleman with each app then reviewed by the user himself. The hope is that by supporting the use of apps initially in phase one, it would help with transitioning to the second phase using apps and home controls.

Health, Medical and Safety Apps:

ICE: In Case of Emergency was the first app installed. It is free and creates a permanent notification on the lock screen of a phone. Setting it up was very straightforward and the details appear on your notifications screen.

FlareDown App: – This is a free app designed to assist with remembering health concerns, symptoms, queries for doctor visits. The app works by the individual inputting their symptoms, medications, mood, activity, mental health, etc. These will then be succinctly recorded, and you can then show your doctor/public health nurse all the information needed.

Lofric APP: This free app is a Micturition chart which allows people to record the fluid intake and the urine you pass over two or three days (48/72hrs). When the time frame is completed, you can either show your doctor at appointment or email it to your nurse/doctor. All the reports are then automatically emailed in HTML format which you can copy to other formats like excel.

Updoc: This is a free app where an individual can log information daily on various aspects relating to health. It enables a person to keep track of their health symptoms, measurements, medications and examinations. Files are saved and you can track weekly, monthly or yearly if desired. You can share information with your doctor/nurse if desired or bring app to appointment.

Convenience/Planner Apps

What's App: WhatsApp Messenger is a free, cross-platform messaging and Voice over IP service owned by Facebook. It allows the sending of text messages and voice calls, as well as video calls, images and other media, documents, and user location.

Galaxy note 5: Voice Control App – (in built) As with many phones, they have some great inbuilt features on the phone, it's just a matter of going into the settings to get started. To set up voice control, press Apps > S voice> Use Voice Control> and then say in your own words what you want the phone to do e.g. 'Camera', 'Call (Contact)' or 'Internet Search'



Google calendar:

This is a time-management and scheduling calendar service developed by Google. Google Calendar app allows users to create and edit events. Reminders can be enabled for events, with options available for event type and time. Event locations can also be added, and other users can be invited to events. If the user has an email account with Gmail, it can be a good option to trial. As a lot of information is directly taken from Gmail, a calendar is automatically populated with some events.

My Supervalu APP:

The free Online Shopping app from SuperValu Ireland allows you to shop online from your local SuperValu store. This App can be used to place a new order, change existing orders and check special offers. There is a shop from “My Usual’s” which shows favourites from past orders. You have option to select local shop or another one in the similar vicinity.

Although this was only the initial phase of an ongoing input of AT and its ability to support the service user, we felt it was an important and successful stage. We were able to support this service user to build on his strengths in using a smartphone with stylus-for almost 6/7months. By simply assisting this service user to trial these apps and see what supports are available, he was far more confident and competent in his smartphone use and ultimately excited to move back to independent living.

In this instance our service user has become a strong advocate for how AT can positively impact on one’s life and he is looking forward to progressing onwards in the coming months now that he has just moved home. Some of these apps offered a great autonomy and a sense of control back, such as doing his food shop and having it delivered via Supervalu app. To some it may seem like a small thing, but the service user often felt people were telling him to buy this instead of that when it came to shopping since he acquired a spinal cord injury and he was delighted to choose groceries he wanted himself.

The next phase for this service user will be progression onwards to look at environmental home controls. We aim to apply for an HSF grant through Spinal Injuries Ireland seeking some assistance towards funding these AT devices which we hope to reduce the financial and mental strain for this service user going forward. He is hoping to look at options such as Alexa and google home.



Conclusion

From an outreach worker perspective it is wonderful when someone has a positive experience when trying something new, especially in terms of technology which can often be daunting for those who did not use it regularly. This can encapsulate the entire spectrum of assistive technologies from the smart phone in your pocket through to specialised wheelchairs, vehicle adaptations and custom eye-gaze functionalities. Although Apps may seem like a relatively basic part of the greater world of AT it is phenomenal to see how many options are available for a variety of needs. A real positive from each of these case studies is that having some of these items can make such a huge difference to an individual in terms of their independence and confidence.

There is a bigger suite of assistive technology options than ever before, offering greater choice and better accessibility in terms of availability and financial investment which certainly offers more hope for a better quality of life for people with a spinal cord injury going forward. Though success was reached in each case study this began by collaboratively exploring each individual's needs and frustrations and examining the most effective and appropriate solution with their resources, environment and usability in mind. In each instance the service user also trialled some technologies that did not work to his/her liking or specification and these were important opportunities to highlight that one size does not fit all when it comes to technology. This emphasises important learning for the professionals supporting people entering the world of assistive technology, so that we do not become complacent and more importantly that we keep researching and investigating the developments being made in all areas of AT. With that in mind there are a lot of positives to be gained from embracing the advancing world of assistive technology and it is the aim of SII to keep our finger on the pulse and continue to advocate for greater funding and accessibility for those who will benefit most from AT going forward .

JOIN OUR 2020 TALL SHIPS CHALLENGE



“Put it this way, if you want to forget about your injury then go on this trip because I haven’t thought about it since we started”~ Tim Rice, 2019 Crew member.

At the start of 2019, SII put out the call and 24 individuals signed up for a Spinal Injuries Ireland Challenge like never before; our very first Tall Ships Challenge. Some of these brave folks had sailed before, some had never even been on the water before, and none knew precisely what to expect except for a challenge and adventure and the chance to do something extraordinary.....and they were ready to take the plunge. What followed was a life-changing voyage of camaraderie, pushing boundaries and proving that what might seem impossible can be achieved when we set a goal, come together, and truly support each other.

In May 2019 the Lord Nelson Tall Ship set sail from Cork Harbour to Poole on a 6 day trip via the stunning Scilly Isles. This epic, custom built ship was crewed by the Ship’s Captain, watch leaders and the SII Team which was led by SII Chairman and Paralympian John Twomey. There were no passengers on-board. Everyone was a hands-on member of the crew working in shifts and carrying out tasks from raising the sails to manning the kitchens, polishing the brass to keeping watch on the horizon. As this group formed and introduced themselves it emerged that each person had their own reasons for wanting to be part of this challenge, but as they disembarked it was clear that each achieved something great, learned something about themselves and made memories and friendships for life. The voyage was a success in many ways as it showcased what is achievable when we focus on ability not disability. Through their participation this amazing SII crew raised an amazing €60,000 too! The proceeds of which directly support our Community Outreach Services across the country.

Following the highs of our Cork to Poole voyage we decided it couldn’t be long before Spinal Injuries Ireland took to the ocean again and this time we wanted to make it an even bigger adventure! Thus 2020 will see Spinal Injuries Ireland commission the SV Tenacious Tall Ship and lead a crew of 36 people of all abilities on another voyage of a lifetime.

Our second Tall Ships Challengers will become the crew of the SV Tenacious for 8 days boarding in Cadiz, Spain and disembarking in Lisbon! This will include a showcase of the vessel to the public as it is docked in Cadiz, training on everything Tall Ship sailing and then becoming a full-blown competitor in the Tall Ships Sailing Race from Cadiz to Lisbon. Our crew shall be made up of 36 people from all backgrounds and abilities including wheelchair users, walkers with aid and able-bodied adventurers. As with our 2019 voyage, no sailing experience is required. Every person has a role, every person is an equal member of the crew, and every person contributes to the success of this voyage.

This next SII Tall Ships Challenge will take place from July 11th-18th, 2020 and we are currently recruiting crew members. Places are booking out fast so if you think this might just be the fresh adventure for you do get in touch.

To find out more about our 2020 Challenge or to watch our video from the 2019 Challenge you can visit www.spinalinjuries.ie/getinvolved.

Alternatively, you can contact Phil on 01 653 2180 or phil@spinalinjuries.ie

A SERVICE FIRST AND FOREMOST THE DCU EXOSKELETON PROGRAMME

Advancements in the area of assistive technology have taken leaps and bounds in recent times in terms of progress, the diversity of options, and the growing accessibility to new forms of adaptive and assistive tech. One such area in which this has become more and more visible is the field of robotics. The idea of technology overcoming paralysis often represented solely in science-fiction has quickly become more tangible as a scientific and even commercial endeavour for many researchers and investors around the globe.

“For many years there was nothing exciting or ground-breaking in terms of rehabilitative therapies but in the last 5 years alone there have been proper leaps forward” notes Ronan Langan as he talks us through the new DCU Exoskeleton Programme which officially launched in September 2019. Having spent over 12 years working as Senior Physiotherapist specialising in Spinal Cord Injury in the National Rehabilitation Hospital, Ronan is well known to many Spinal Injuries Ireland service-users who might have worked with him in the NRH as part of their post-SCI rehabilitation. His decision to move on from the NRH and take on the running of the DCU Exoskeleton Programme needed no explanation as from the moment we started speaking Ronan’s enthusiasm and passion around the ethos and aims of the project became powerfully apparent. **“The DCU Exoskeleton Programme is a service first and foremost. With the resources we have, we offer free, universal and unbiased access to this cutting edge technology making it available to those people affected by paralysis who can really benefit from its use. The project is research building which is critical in this field, but our goal is primarily to simply help.”**

Launched by Dublin City University, in collaboration with renowned explorer Mark Pollock, who himself sustained a spinal cord injury in 2010, the project utilises technology designed by Esko Bionics to bring next-generation robotic technology to people who are looking to improve upon their prognosis following spinal cord injury. Currently Ronan is Clinical Lead seeing 20-25 people per week managing approximately 20 weekly sessions working with people with all manners of spinal cord injury. Every person who attends to participate in the programme is assessed in terms of mobility and individual goals and once they meet the medical and safety criteria necessary to take part, they are prescribed a number of sessions (usually 10-15) to work towards their potential goals. Each session lasts 60 mins with an average of 20-25 mins spent supported in the exoskeleton suit followed by a debrief on the session.

For each participant the process, progress and outcomes will be different depending on their level of injury and individual circumstances. For some they may be utilising the exoskeleton for cardio-vascular, orthopaedic or pain management benefits. For others they may be working towards improving mobility in terms of building up muscular strength, balance and stamina. There is no one-size-fits-all treatment plan with this type of technology.





Technology are as personal as the injury itself. However, Ronan believes there are some health benefits to be had for every service user who participates in the programme. “In one example, we worked with an advanced exoskeleton user with an incomplete sci who transitioned from being a full-time wheelchair user who used a walking frame purely therapeutically for short sections of their day, to a person who can now walk with aid for the majority of the day”.

Currently there is a waiting list of approximately 40-50 people with a spinal cord injury to join the programme however Ronan and the DCU team work on a revolving door basis so that new people can keep joining the programme, whilst others can maintain that connection and return to advance their goals further. **“Once you have completed your prescribed sessions you can go back on to the waiting list and take your turn again when the next available slot comes around”.** This means that progress is being made in terms of building up research around the technology in a live environment, but users of the service can also continue to consider use of the exoskeleton when mapping out plans for achieving and maintaining long-term health goals.

So, now that the programme is up and running, what is the medium and long-term plan for the Exoskeleton Programme in DCU?

Ronan answers this question leading with the fact that he is ‘an eternal optimist’ but we think also a realist! Having seen the advancements made on a technological level, alongside bearing witness to the progress and often elation of many of the participants who have taken part so far, Ronan has a lot of hope for the future and sees a lot of avenues to explore. The next step for him would be to gain the funding to introduce a second suit that would be available to advanced users. This would mean that those who have completed a set amount of sessions could utilise the suit in situ with a trained up personal assistant, friend or family member so that they can continue to see the benefits over longer periods of time whilst also making a great difference to waiting lists. Ronan would also love to see the availability of a paediatric exoskeleton suit in Ireland in the near future as currently the suit isn’t suitable for anyone under 5ft tall. Ultimately though the aim is to help more people, and to make that help more accessible and more impactful. With more scientific progression, and vitally more investment going into these areas Ronan would also like to look into incorporating a wider spectrum of technologies for application in rehabilitation in the future. The dream would be a ‘Centre for Advanced Rehabilitation Technologies’ right here in Ireland.

Today though, Ronan poignantly nods to a position that a lot of people who have sustained a spinal cord injury find themselves in following discharge from the National Rehabilitation Hospital; where leaving the environs of the NRH and returning back to the community can feel like ‘falling off a cliff’. This is something we hear from SII service-users time and time again and was one of the main motivating factors for the foundation of Spinal Injuries Ireland some 25 years ago. For the team in DCU they know that right now making the use of the exoskeleton available to people won’t mean a cure for their paralysis, but they feel that bringing more advanced, beneficial technology to people can ‘help to make that landing a little bit softer’ and offer benefits that weren’t previously accessible to those who might benefit from this advanced technology the most.

SII FAMILY OUTREACH PILOT PROGRAMME

Mater Hospital



Last year we appointed our new Family Outreach Officer to provide a comprehensive support service with special emphasis on providing practical and ongoing support to family members. This new and exciting role enhances the range of services we offer to our service user by providing one to one support to the family or the designated support person of those with the SCI.

We know that family life is disrupted the moment the injury occurs, and new and unfamiliar responsibilities combined with emotional distress is the new reality. From our research with NUIG, and from our focus groups with family members conducted with UCD PPI Ignite Programme, we understand family members have their own specific concerns and information needs distinct from the service user with SCI. They need professional support and assistance with navigating the health system as well as practical and emotional support through this daunting time.

The Family Outreach Officer role was championed by Mr Keith Synnott, Clinical Lead in the Mater Hospital and National Clinical Lead for Trauma Services in Ireland. The National Trauma Strategy outlines the need for such a role as follows:

'The HSE should ensure that a Family/Patient Liaison Officer is included in the trauma team activation and be able to remain with the patient/family at each stage of their hospital journey and particularly on discharge from hospital.'

With this in mind, SII collaborated with the spinal team in the Mater Hospital to engage with key health care professionals to gain their support to introduce the service to new SCI patients and their families from the start of their journey. We were welcomed by the whole Mater team and commenced our outreach clinic twice a week, engaging with family members. Our Outreach Officer now engages with family members in the family room on the spinal unit where a safe and confidential space is guaranteed.

Even though the National Trauma Strategy suggests the best time for support for the patients is on discharge from the hospital, we learned from our research this is not the case for family members. From the moment of injury, the medical emergency takes priority, which is essential. The family needs are not a top priority at this time. The whole family is thrown into a medical world which is totally alien to anyone who has not been exposed to a hospital environment before. With the uncertainty about the future and the impact of living with a SCI the family need individual attention and support which can be delivered by SII Outreach. With the introduction from staff in the spinal unit, our Outreach Officer engages with the family to start the process of support. They can outline what to expect, and what practical steps can be taken in planning for the rehabilitation phase before being discharged from the Mater spinal unit.



Our aim for the pilot programme is in line with our 2019-2023 Strategic Objectives:

To provide quality and relevant support to people with SCI and their families

To achieve our Goal we started out the pilot Family Outreach programme by:

- Creating awareness of SII and our services among health care professionals in the spinal unit and St. Agnes ward in Mater Hospital
- Engaging with family members of newly diagnosed people with a SCI
- Engaging with family members prior to admission to NRH and commencing support at earlier stages
- Enhancing and complementing the support given from the staff in the Spinal Unit and St Agnes Ward
- Developing specific information for our new service including a referral guideline, consent form, service leaflet and awareness stand
- Conducting focus groups with UCD PPI to generate research-based evidence and identify gaps in the support for the family members at crucial points after SCI.
- Evaluating the pilot programme using questionnaires for family and staff

“We found [the SII Outreach Officer] most helpful because we knew so little to start with”

“An early referral from hospital to SII would be really helpful as we weren’t aware of the service until researching on the internet”

The Family Outreach Pilot Programme was supported by the Iris O'Brien Foundation.

Findings from the evaluation of the pilot

- The Family Outreach Programme was very well received by the family members and HCP in the Mater who engaged with the pilot
- Appropriate, relevant, information and support was provided
- Professional and confidential service maintained
- Due to the waiting list for a bed in the Mater Spinal Unit, families felt they would have liked to be referred to a Family Outreach officer sooner; particularly while in Regional Hospitals
- Patients have a short stay in the Mater Spinal Unit (some only 24 -48 hours) therefore some family members missed the opportunity to engage with SII staff given that the family outreach officer was in the unit on Monday and Thursday
- Patients repatriated back to referring regional hospital after the Mater to wait for NRH bed felt isolated and lost for direction on next steps
- Non traumatic SCI patients who do not attend the Mater or NRH were not aware of Family Outreach Service and were not engaged with SII

The pilot programme has been a great opportunity for SII to expand our services to all those affected by a SCI and to develop further appropriate supports. Our next steps, in line with our strategy, will be to roll out the programme nationally. We aim to do this by engaging with all allied stakeholders and regional hospitals to create awareness of SII services and how those affected by SCI can access support from SII. We will also collaborate with healthcare professionals by advocating on behalf of the SII service users and family members when participating and contributing in the Major Trauma Audit Governance Committee meetings. We will train family peer volunteers to support other family members and develop specific support and education sessions based on the specific needs of that group.

CAUDA EQUINA SYNDROME

CES Awareness

Over recent years SII has recognised that there is a severe lack of information and understanding about Cauda Equina Syndrome in Ireland, and thus, launched a nationwide campaign to increase awareness of this condition, its symptoms and the multiple hidden challenges this CES presents to sufferers.

Launched in the Royal College of Physicians in November, our campaign saw us produce informational leaflets for healthcare professionals and the general public which were distributed to over 140 GPs, Clinics and Hospitals nationwide. These were developed in conjunction with leading SCI specialists in Ireland and supported by Coloplast. We also hosted a series of CES Awareness talks around the country in Galway, Limerick, Cork and Dublin. We were glad to be picked up in the media nationwide including interviews on Newstalk FM, Cork 96fm and in medical news outlets. SII plan to build on this campaign going forward in line with our strategy.

What is Cauda Equina Syndrome?

Cauda Equina Syndrome (CES) is a condition that occurs when the bundle of nerves below the end of the spinal cord known as the Cauda Equina is damaged. The term Cauda Equina means 'horses tail' in Latin and describes the spray of nerves that come off the bottom of the spinal cord and activate the bladder, bowel, sexual organs and legs. When these nerves are compressed or damaged the impact on the sufferer can be devastating. Signs and symptoms of CES include lower back pain, pain that radiates down the leg, and loss of bowel or bladder control.

What causes CES?

- Back/Spine problems such as a slipped disc
- Tumours near the spine
- Trauma/Injury to the area

How is CES diagnosed/treated?

An MRI is necessary to diagnose CES. It can then be treated with surgery to your spine. It is important to treat CES early to help avoid nerve-damage problems like problems with bladder, bowel and sexual function, lasting pain and potential paralysis.

In working with people who have sustained a spinal cord injury as a result of Cauda Equina Syndrome we are aware that the pathway of care can be incredibly uncertain from case to case and the lack of information around CES has caused added distress for many who have sought help after a late diagnosis. We are working to help improve this for people affected going forward.





What are the warning signs people need to know?

KNOW THE 5 FIVE RED FLAGS OF CES

S- Saddle Anaesthesia

Weakness, tingling or numbness in your 'saddle region' - the parts of your body that would touch the saddle if you were sitting on a horse. Upper inner thighs, groin, buttocks and genitals

P- Pain

Pain, weakness, tingling or numbness in your lower back, backs of thighs, lower legs and feet.

I- Incontinence

Loss of control, urgency or finding it hard to pee or poo. Any strange sensation or numbness when you pee or poo.

N- Numbness

Numbness in your lower back, backs of thighs, lower legs and feet. Loss of feeling around your groin during sex.

E- Emergency

Any of these can be a warning sign of CES. Go to your GP or Emergency Department without delay. SII are campaigning to make health care professionals and the general public aware that delay can equal disability. CES is rare and these symptoms can be the result of other causes, but it is important to get any symptoms checked out. For more information on Cauda Equina Syndrome you can contact the team through info@spinalinjuries.ie and we can add you to our CES mailing list.

This campaign has been developed by Spinal Injuries Ireland and is supported by Coloplast

"Coloplast are proud to work with Spinal Injuries Ireland and support the Cauda Equina Syndrome Campaign. By working in partnership, we are committed to making lives easier for people dealing with intimate healthcare needs"

Annemarie Van Neck – General Manager Coloplast UK and Ireland

IMPROVING THE PATHWAY OF CARE FOR PEOPLE WITH A SPINAL CORD INJURY

As we go to print there are 49 people who have sustained a spinal cord injury on the waiting list for the NRH. This is a critical situation that Spinal Injuries Ireland brought to the media's attention in November 2019, with the story of Helen Grace who has spent one year in an acute hospital awaiting specialized rehabilitation care. 85% of the people currently waiting on rehabilitation are inpatients in acute hospitals with the other 15% either in nursing homes or in their own homes depending on the level of injury.

The delays in admission to rehabilitation frequently result in complex medical complications as well as undue anxiety to patients and their families at a time when they are extremely worried about their futures. The reality for these patients is that in the majority of cases they have not been assessed for their rehabilitation needs, or for mobility aids such as wheelchairs, and this means that they are confined to the acute hospital for the length of their wait. According to the NRH Annual reports, in 2014 the average waiting time was 37 days and in 2018, the average wait was 77 days. It is estimated that this wait will get longer year on year unless immediate action is taken.

In August 2019, the Irish Medical Journal published 'A prospective audit of inappropriately occupied hospital beds in patients with newly acquired traumatic spinal cord injury'. (E. Smith, K. Synnott). The conclusion was that valuable health care resources are being wasted because TSCI patients cannot move seamlessly from one phase of care to the next. This impacts negatively on the quality of care being delivered to this patient cohort. It is perceived in Ireland that there are worsening barriers to the effective and timely transfer of TSCI patients from the acute setting to rehabilitation and back to their communities. As a consequence, patients are occupying beds in settings that are inappropriate to their care needs resulting in a waste of valuable healthcare resources and poorer outcomes. (1)

An ICU bed in an acute hospital costs €1800 per day. A bed in the NRH costs €1000 per day. A 24 hour homecare package costs €600 per day. Why are we wasting healthcare budget by holding patients in inappropriate settings?

Investment has not been made in rehabilitation and community services despite the publication in 2017 of the Model of Care for the Provision of Specialist Rehabilitation Services in Ireland which stated that centralised funding should be available for managing complex cases.

Prolonged waits for specialised care leads to increased risk of avoidable complications such as pressure ulcers, contractures and urinary tract infections not to mention the undue psychological impact that it has on the individual and the family. These avoidable complications can, in turn, further increase the length of stay for these patients while they are treated, thereby delaying the admission of subsequent patients. Families are being left in a vacuum not knowing what the next steps will be or when.

There is a considerable waste of resources and money in a system which denies SCI people timely access to services, but Spinal Injuries Ireland will continue to campaign for better services.

URGENT RECOMMENDATIONS

- Implement centralised funding for complex cases as recommended in the Model of Care for the Provision of Specialist Rehabilitation Services in Ireland, to eliminate delays with the approval of funding for home care packages.
- Develop a clear and consistent process for funding community rehabilitation services through the HSE and house adaptation grants from the county councils.
- Issue emergency medical cards to all SCI patients for the first 2 years of their injury
- Implement adequate staffing of inpatient rehabilitation services particularly when the new development at the NRH opens

References

(1) É Smith, K Synnott A prospective audit of inappropriately occupied hospital beds in patients with newly acquired traumatic spinal cord injury. *Ir Med J* 2019; 112: 971-5



SII GREAT DAY OUT CHRISTMAS APPEAL

In 2019, Spinal Injuries Ireland has helped over 2,100 people with a spinal cord injury, as well as over 20,000 of their family members. One such person is Ian O'Connell. Ian had only just turned 16 when a cycling accident left him paralysed from the shoulders down. In the blink of an eye his whole life was turned upside down. Football, hurling, rugby, swimming, all the sports Ian had loved playing so much growing up, gone in a flash.

Despite this devastating blow at such a young age Ian has spent the years since his accident making the absolute most out of life; with his rehabilitation, in his friendships and with the loyal social media following he has built up through his authentic and inspiring messages about hard work, determination and self-belief.

Ian's motto is 'If you can't stand up stand out', and he embodies this not only in his day to day life, but on behalf of others who may not be in the position to speak up or have the confidence in themselves yet. As well as giving motivational school talks to young people who may be struggling with where they are in life, Ian has also kindly agreed to help SII out in our 2019 Christmas Appeal to raise funds for our Great Day Out Programme.



"It is so important for people living with a spinal cord injury to do something special every now and then to get their minds away from their problems. Accessibility challenges can be exhausting to deal with. Planning a day out can be hard at first and for some, the thoughts of even leaving the house can feel like a mountain to climb. It'd be very easy to lose hope. You could end up sitting looking out the window thinking about what might have been."

But that's not how I live my life, and in my opinion, nobody in a wheelchair should be made to feel that way. Just because you have a spinal cord injury doesn't mean you can't do great things like you done before your injury. Like I always say to people, a wheelchair isn't who I am. It's just how I get around."
~Ian O'Connell

SII believe everyone should be able to treat themselves every now and again, so the Great Day Out Programme is there to help people with spinal cord injuries do just that.

If you'd like to help contribute to the Great Day Out Christmas appeal you can donate by calling 01 653 2180 or visiting the SII website on www.spinalinjuries.ie

To find out more about the Great Day Out Programme get in touch with the team on info@spinalinjuries.ie



Q BALL

The annual Q Ball took place at the Ballsbridge Hotel on Saturday 28th September. The event raised over €60,000 which will go towards helping SII deliver increased services to our service users and their families, including an expanding Family Outreach Service, Peer Mentoring, and Activities Programme. Guest Speaker Jenna Fitzgerald travelled from Enniscrone to share her personal experience since she sustained a devastating spinal cord injury after diving into a swimming pool aged just 27. Included amongst the 400 attendees were Mark Pollock and Simeone George, Sarah Lipsett, and Paralympian John Twomey. Huge thanks to event organiser Philip Quinlan and everybody who contributed to the night's success.



BAG IT

On 18th October many gathered for our pre-loved designer handbag auction. Kindly hosted by Marah Curtin and Davy Stockbrokers, guests enjoyed champagne and canapes on arrival and the auction raised almost €9,000 of much needed funds for SII services. We would like to extend our gratitude to Marah Curtin, Fiona Darcy, Brian Dempsey, Venetia Quick and everyone who donated the divine bags!



CORK JAZZ BALL 2019

Our 3rd Cork Jazz Ball in the Clayton Silver Springs Hotel was held on the 26th October and was a huge success. A massive thanks to the organising committee and everyone who contributed to the event as it continues to grow. This year both numbers in attendance and funds raised significantly increased from last year with 300 guests arriving in their finery, raising a fantastic €40,000. Entertainment was provided by the inimitable Jabronis.



SPRING LUNCH 2019

The Intercontinental Hotel was the venue for the annual charity lunch in aid of SII held on April 6th. 440 guests, including Risteard Cooper, Rosanna and Diane Davison, Bairbre Power, Melanie Morris, Gerald Kean with Sonya Valadi, along with Rosalind, Sarah and Avila Lipsett, enjoyed a fantastic afternoon and raised almost €60,000 for Spinal Injuries Ireland's peer-to-peer and family support services. SII would like to sincerely thank Philip Quinlan and his amazing committee for their superb organisation of the event and guest speaker Jack Kavanagh for his incredibly motivating address.



PARIS2NICE

September saw a fantastic team of 7 take on the 700km cycle over 6 days on behalf of SII. We are incredibly proud of their achievement and extremely grateful for the €39,000 they raised in sponsorship. Congratulations to Patrick Broderick, Alan Eustace, Avril Flannery, Caitriona Gallagher, Caoimhe Costigan, Clare Sheehan and Cathy Brooks. Please contact us if you are interested in taking up this exciting challenge in 2020.



SUMMER BBQ 2019

The magnificent summer finally came to an end, with the annual SII Barbecue at The Royal St George Yacht Club, Dun Laoghaire on 14th September. Over 300 guests attended the event which included a delicious BBQ, great entertainment by Sean Boland and Downtown Motown and a charity auction which saw guests furiously bidding on some great lots. Thank you so much to Ger Dargan and her committee who worked hard to ensure that the evening was a huge success raising €40,000 of much needed funds.



Keep your *bladder* healthy



Catheter users have
2.7 UTIs
on average per year¹

UTIs are a common problem among some catheter users.

Reviewing and assessment of your current ISC routine could help.

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To arrange your free review please contact Emer Molloy on:

 **086-2566597** or  **gbemy@coloplast.com**