



Spinal
Injuries
Ireland
Support at every stage



ANNUAL REPORT 2019

RUTH'S STORY

Almost 7 years ago Ruth Shaw should have been planning the celebrations for her 40th Birthday Party. Instead she had a very different challenge to face; - she had to learn to walk again. "June 26th, 2013 is a date forever etched in my mind," says Ruth from Passage West. "I was back from a shopping trip to the Kildare Village Outlet. I went to bed at around 11 or 12 and my legs started to shake and I had severe back pain which was unusual. I had no power through my right leg and that feeling spread to my left leg," explains Ruth.

"I thought it was bizarre, but I didn't think it was anything serious". It turned out to be very serious and life changing!

Ruth contacted her brother John at 6am the following morning and he brought her to CUH, Cork. Numerous blood tests and an MRI were carried out to identify what was causing the unusual symptoms.

"I imagined I had tumours or maybe MS, either way I knew I was in trouble",

Ruth had contracted the rare neurological disorder, Transverse Myelitis, an inflammation of both sides of one section of the spinal cord. This neurological disorder often damages the insulating material covering nerve cell fibers (myelin). Transverse myelitis interrupts the messages that the spinal cord nerves send throughout the body. This can cause pain, muscle weakness, paralysis, sensory problems, or bladder and bowel dysfunction. It is extremely rare. She was in big trouble. "From T10, the vertebrae at the base of the spine, I was paralysed" she says. "My bowel and bladder shut down and it was a 50/50 chance if I'd make it or not. The more sudden the onset of the virus, the worse the recovery process".

Ruth had a massive battle on her hands. Her neurologist told her that her recovery was 95% mental and 5% physical so she got battle ready!

It was an uphill battle, requiring steely determination and a can-do attitude. Ruth had both in spades. Ruth continued her rehabilitation in the NRH. The journey back to health and mobility seemed never ending. "There were some very dark days," admits Ruth.

"The rehabilitation I had to go through was very tough and it was very daunting. It tested me to the limits. The panic was often unbearable, it was horrendous."



Ruth's first encounter with SII was when she was a patient in the NRH. Upon discharge Ruth was put in contact with a Community Outreach Officer, Philippa O'Leary, who Ruth says has been a great help. Philippa helped Ruth identify and apply for benefits and grants that she was entitled to. "In particular, she got me a HSF grant for physiotherapy."

"Knowing my Community Outreach Officer is there for me when days are tough is so important to me"

Ruth still puts a brave face on things. Her boss persuaded her to return to work and she built up her hours over weeks. "I was a bit anxious and nervous meeting people, now that I have a bad limp. Sometimes I'm a bit wobbly and I imagine people may think I am drunk!" She loved being back at work but sadly a fire destroyed the boutique, so Ruth is out of work which also means she had to give up her automatic car.

Seven years on, Ruth believes this is as good as she will get. She used to love power walking but now swims in the Rochestown Park Hotel. She uses a stationary bike most days and does stretching exercises every morning as she finds they are very important for balance.

"The constant pain is something I have to learn to live with," says Ruth. "Pain management is a big thing".

Ruth is a fighter. She fought all the way and has now learned to live her life a different way. She has an incredible outlook, "I am very lucky to get to where I am now in comparison to others who suffered a spinal cord injury. I was unlucky, but lucky. The paralysis could have spread to my lungs. I take the negatives out of the positives and my confidence is coming back all the time".

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CHAIRPERSON'S ADDRESS

GOOD GOVERNANCE IS AT THE CORE OF SPINAL INJURIES IRELAND. WE AIM TO OPERATE IN AN EFFECTIVE, ACCOUNTABLE & TRANSPARENT WAY.

The directors and staff of Spinal Injuries Ireland are committed to maintaining the highest standard of corporate governance and we believe that this is a key element in ensuring the proper operation of our activities. As part of this commitment the directors continually undertake reviews of policies and procedures. In addition, we launched our strategic plan in January 2019 which directs the business of Spinal Injuries Ireland for the next four years.

Spinal Injuries Ireland became accredited to the voluntary Code of Practice for Good Governance of Community, Voluntary and Charitable Organisations in Ireland in 2018 and we have continued to adhere to this Code. The Charities Regulator has issued a new Charities Governance Code for implementation in 2020 & we have formally committed to adopting this code in 2020.

In 2019, we finished the year with a small surplus. This is the second year in a row that we have managed to have a surplus and I would like to thank the staff for the careful management of expenditure and increase in fundraised income for the year. A big thank you to the board members who have contributed so generously of their time and expertise.

Finally, on a personal note, Sr Aileen McCarthy passed away in May. Aileen was one of the founders of the NRH and Spinal Injuries Ireland and she dedicated her life to improving services for people with a spinal cord injury. Originally from Cork, she was dedicated to her mission and I remember as a young boy of 14 how she dealt with me during my rehabilitation.

I am sure Aileen is watching over us now and ensuring that SII continues with her work.

John Twomey
Chairman



CHIEF EXECUTIVE'S REVIEW

OUR SERVICE USERS ARE AT THE CORE OF ALL OUR DECISION MAKING & THEY INFORMED THE DIRECTION OF OUR NEW STRATEGIC PLAN

We started 2019 with the launch of our strategic plan 2019-2022. This plan was developed following service user research, which was carried out by Padraig MacNeela, School of Psychology, NUIG in late 2018. We also carried out some focus groups with family members and that indicated the strong need for increasing our levels of services to family members especially when the patient incurs their spinal cord injury. Subject to funding it is planned to increase these services over the next four years.

The Spinal Cord community nationwide again supported our work during the year by attending events and fundraising for us and we are very grateful for this. I would also like to acknowledge the public funding that we receive from the HSE and Pobal and our corporate partnerships especially Coloplast and Windsor. Of course, we could not operate without the support and hard work of the SII team and our volunteers. I am very grateful to all the hard work that you contribute.

We have a very strong relationship with the NRH and I would like to thank all our colleagues there for a number of different collaborations during the year and we at Spinal Injuries Ireland are looking forward to the opening of the new Spinal Unit in 2020.

Later in the year we launched the Cauda Equina Syndrome education campaign to both the public and healthcare professionals. The campaign was supported by Coloplast and promoted by HSE Health Promotion. This was the first of a number of planned public education programmes that we are planning during the life of this strategic plan.

Our very first all-inclusive tall ships challenge was a huge success in July and we are looking forward to running a second one in 2020 along with other very exciting inclusive challenges.

Kind Regards

Fiona Bolger
CEO

SII SERVICES REVIEW 2019

THE YEAR IN NUMBERS....

PEER SUPPORT

42

SESSIONS

ACTIVITIES

98

TRIPS WITH SERVICE
USERS AND FAMILY

405

SERVICE USERS
GOALS ACHIEVED

2,158

SERVICE
USERS

WATER SPORTS
INCLUSIONS GAMES
CORK

102

PEOPLE OVER 2 DAYS

35

GRANTS APPLIED FOR

ALL SERVICE
USER
INTERACTIONS

20,871

NEW HIRES 2019

Spinal Injuries Ireland recruited four new team members in 2019.

We are continuing to grow as an organisation and are very happy that we are successfully adding to the strength of the in-house team.



Eric O'Connor

joined SII in June 2019 as
Finance Manager



Sharon Dagg

also joined in June 2019.
Sharon looks after
Corporate and Philanthropy
Fundraising.



Phil O'Kelly

joined in July 2019 as
Head of Fundraising.



Lucy Grant

joined us in November
2019 as maternity
cover for the
Communications and
Fundraising Officer role

SERVICES REVIEW

2019 started with the launch of our new Strategic Plan focused on delivering our vision and mission.

SII's mission is to engage with people with a spinal cord injury and their family members, to address barriers to full participation in society and to empower members to work towards achieving personal, social and vocational goals.

Our ambitious targets for Services are based on the following goals

1. To provide quality and relevant support, information and advice meeting the needs of people with a SCI, their families and carers, professionals, and the wider community;
2. To communicate effectively with stakeholders, to raise awareness and to improve public awareness of SCI and to advocate for the rights of those with a SCI, their families, and carers;
3. To present relevant training and education services to people with a SCI, their families, carers, and healthcare professionals.

In order to commence implementation of the Strategic Plan each member of the services team was assigned key objectives to achieve our targets. We commenced the year with the launch of our Strategic Plan in the Mansion House Dublin for our stakeholders. This was followed with presentations to key collaborators such as staff in the NRH and allied healthcare professionals at regional and local level.

Collaboration is a key element of our strategy to ensure we are working with likeminded individuals and organisations to deliver on the mission and vision of the organisation to ensure no one with a SCI or their family and carers are on their own.

Our highlights for 2019 included supporting more service users that ever before, expanding our family outreach programme nationally, training and supporting our peer volunteers and activity volunteers along with delivering Ireland's first public awareness campaign for Cauda Equina Syndrome (supported by Coloplast.)

Other highlights included our Head of Services, Naomi Fitzgibbon, being invited to represent SII on UCD Public and Patient Interest (PPI) Representative and to engage with the National Office for Clinical Audit -Major Trauma Group. The Head of Services also presented our research findings (NUIG, 2018) at MASCIIP Conference, Loughborough.

2019 was a busy year on the Activities side. One of our community outreach team accompanied the service users on the Tall Ships Challenge crew providing vital support and encouragement to all. There were plenty of trips out on our ever popular and exhilarating inflatable power boat, the 'Niamh'. Our incredible volunteer crew also went and took the boat to the Water Sports Inclusion Games in Kinsale, Cork.

We received Lottery Grant funding for our activities programme which included art classes, activity weekend for families and hydrotherapy classes, and enabling our service users access vocational supports free of charge. Other collaborations included University of Limerick Physiotherapy students working with Service users to support and promote the importance of physical activity.

We continued to strengthen our partnership with the NRH with monthly meetings with the Spinal Cord Injury Team, hosting education sessions and supporting study day. These included patient focused education sessions and health care professional study days. We delivered our volunteer peer programme weekly to newly injured patients with the support of NRH staff. We hosted monthly psychological support sessions facilitated by a psychotherapist addressing issues of mindfulness, resilience, and chair yoga, delivered face to face and via webinar.

All our goals are aligned to our robust strategy and grounded in clear guidelines and policies to ensure a consistent service is delivered nationwide. Our staff attended mandatory training, in line with the Governance Code. 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 the 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 followed 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. They also completed Volunteer Leadership training in Volunteering Ireland.

Family Outreach Programme

2019 Pilot programme kindly sponsored by the Iris O'Brien Foundation

In line with our first strategic goal we commenced the pilot programme for our Family Outreach Service. From our research with NUIG, 2018, and anecdotal evidence it was clear that family members and carers of those with SCI have their own specific concerns and information needs that differ from the concerns and information needs of the person with the SCI. We started our pilot programme with the spinal team in the Mater Hospital where we met with new SCI patients and their families right at the start of their journey. We complemented the spinal team by providing non-medical support. We provided access to peer support and emotional support as well as practical help for each step in the recovery phase. We held family support sessions in the Mater Spinal Unit twice a week. We engaged with family members guiding them through uncharted waters prior to admission of the SCI patient to the NRH. We also connected with patients who were in regional hospitals around the country waiting for rehabilitation in the NRH, which was months for some.

The feedback was excellent. “We were very grateful for the support we received during his stay in the hospital (Mater)”

“SII provided practical information we found hard to come by elsewhere”

“An extremely positive experience – the support has been fantastic”

We concluded the pilot programme in the Mater Spinal Unit by conducting an evaluation with those who engaged with the programme. The evaluation reviewed the goals of the pilot, the overall learning, and established the next steps of the programme for 2020. We are most grateful to Mr Synnott, Lead Consultant for the Spinal Unit and Ms Geraldine Jordan CNM 3 and her nursing team for their support with this programme.



To further develop our evidence for developing the family outreach service we collaborated with UCD Public Patients Involvement (PPI) Ignite. PPI in health and social care relates to research in education and training, professional practice and administration. As a key stakeholder with PPI we received core funding to conduct a joint project with Dr Sarah Donnelly, School of Social Policy, Social Work and Social Justice, UCD. The Project: An exploration and identification of research priorities utilising a co-design approach between family caregivers of Spinal Cord Injury (SCI) patients.

Two focus groups were conducted to explore and gauge interest in the future development of an education programme designed by family caregivers for family caregivers. They informed the future direction of future research projects which are viewed as a priority by SCI family caregivers. In addition, it created a forum whereby the hard to reach voice of SCI family caregivers can be heard through focus groups and contributes to the development of a programme designed by family caregivers in line with our strategic objective peer support for family caregivers. We are grateful to UCD for funding support for this work.

In line with Goals 2 and 3 we launched the Cauda Equina Syndrome Awareness Campaign. See Page 12.

ACTIVITIES AND VOLUNTEERS

National Lottery Funded Activities

With National Lottery funding SII ran art classes facilitated by artist, teacher and SII service user Susan Farrelly in Abbey Art Studios, Ardee, Co Louth. The classes started in October and ran for 6 weeks. This was run in a creative accessible studio environment. The style of tutoring aimed to celebrate the good points of everyone's work, and develop paths for each individual to improve in whatever medium they felt most comfortable with. The artists plan to exhibit at the rescheduled My Life Wellbeing Conference which was originally scheduled for April 2020 but has been postponed until 2021 due to the Covid 19 pandemic.

In September 2019 a group of service users and their families spent a weekend at the fantastic Share Discovery Village on the banks of Lough Erne in Fermanagh thanks to funding from the National Lottery. This included 3 generations of the one family. The Irish weather did not deter this group from getting wet and speeding through the water in Lough Erne, sharpening their aim with some archery and enjoying the warmth of a welcome jacuzzi. SHARE's fully accessible residential activity centre offered the opportunity to have great experiences and create memories with the variety of activities on offer that are disability friendly.

Our Hydrotherapy course in the Holy Angels Hydrotherapy Unit in Carlow was incredibly popular. 10 participants took part in the 4 week course.

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.

9 participants took part in the Being Well Gym Group at UL sports Arena from 12th Feb to 26th March



Watersports Inclusion Games Kinsale Yacht Club August 2019

What an amazing weekend at the third annual Water Inclusion Games in Kinsale in August 2019. We were delighted to be part of the offerings again this year alongside so many other great organisations, volunteers and individuals who came together to make the event such a success. Big thanks to Ciaran Murphy from Irish Sailing who transported 'Niamh', our SII RIB, down from Dun Laoghaire to Kinsale and to the amazing team who crewed her for the weekend. It was a joy to welcome so many wonderful people on-board to experience some time out on the waters. Many thanks to our wonderful volunteers Frank Lawlor, Eugene Power, Glen Heron, Sue McGrath and Community Outreach Officer Hilary Keppel.

SII ran monthly workshops/webinars at the SII Resource Centre from September to December with approximately 40 participants.

Sept: Ways to build resilience

Oct: Chair yoga and relaxation

Nov: Continuing on the road to resilience

Dec: Chair Yoga practice, guided meditation and use of sound and chant

Vocational Courses Funded by JP Mc Manus Benevolent Fund

Nail Technician Course

9 participants - 2 full day course - Feb 3rd and Feb 10th

Life Coaching Workshop

3 hour workshop on 13th March - 2 full days of one to one follow up sessions with every participant on March 20th and 21st

Assistive Technology Course

9th May - 15 participants - 1 full day intro to AT

IKKAIDO

Activator Inclusive coaching training - 15th and 16th October - 12 participants - 2 full days

Hospitality and Front of House Office Skills

6 Participants - 6 weeks (2 days a week for 2 ½ hours each day) - 1st May to 12th June

Tour Director Course

1 participant - 8 weeks (3 days a week)

"The course content was wide and varied and included several familiarisation trips to several well known tourist attractions around Ireland, including a trip to Belfast. The course covered geology and history, going back to when Ireland was first discovered and presentation techniques. We also learned about dealing with hotels, site management of your guests, microphone techniques, complaints and time management.

The course fee which was very kindly sponsored by Spinal Injuries Ireland was only part of the equation. There was three nights' accommodation and travel costs and meals each week. This added considerably to the overall cost of the course which I estimated to be approx. €4,000. My plan was that I would earn a portion of this outlay back over the tourism season of 2020 but unfortunately the Corona Virus came along and the season came to a sizeable full stop before we got started. But we go forward, in reasonable health, to brighter and better things for 2021.

A huge thank you to my Community Outreach Officer for her ongoing encouragement and continuous support to help me stay focussed and to become a better equipped person to deal with the hand that I have been dealt. I would also like to thank everybody connected with Spinal Injuries Ireland for their continued support since 2017 when my own personal virus came to visit me. I sincerely hope that the Covid 19 virus jogs on a hell of a lot quicker than my GBS/CIDP has done." Paul Fitzhenry

Tall Ships

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. It would be a challenge, an adventure and the chance to do something extraordinary.....and they were ready to take the plunge. What followed was more than just a lesson in sailing and a 6 day journey at sea...It 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 voyage via the 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 you back people of all abilities and provide the supports that are needed to make sport accessible; when you focus on ability not disability. It was a huge success too in that, together, this amazing team raised an amazing €60,000 through their participation and through spreading the word about the work that Spinal Injuries Ireland do.

Thank you to Dr Noelle Cassidy, from the Mater Hospital National Spinal Unit who was our volunteer Doctor onboard.

'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.



2019 FUNDRAISING REVIEW

2019 was a good year for fundraising with all our major fundraising events organised by Philip Quinlan and his committees seeing a strong increase in both numbers and revenue.

The annual Spring Lunch saw 440 guests gather for a wonderful afternoon in the Intercontinental Hotel in Ballsbridge on 6th April where an incredible €90,000 was raised. Thank you to our Spring Lunch committee, (Catriona Ryan, Lizzie Burke, Kerry Johnston, Nuala Kelly, Fiona McGoran and Una Kearns), who helped organise the event, SuperValu Deansgrange for sponsoring the wine and everyone who attended. We really appreciate your support.

Another record-breaking fundraising event for Spinal Injuries Ireland was our Summer BBQ which raised over €45,000 for the first time ever. The success of this annual event is down to the incredible BBQ Committee, Ger Dargan, Anne Dargan, Clodagh McCarthy and Marie Fitzpatrick. A big thank you to our sponsor Ardagh Group, we couldn't run the BBQ without your support, and to the Royal St George Yacht Club for a wonderful night.

In September, the same month as the Summer BBQ, the Q Ball took place at the Ballsbridge Hotel on Saturday, 28th. It was a fantastic night, as always. One of the mainstays on the SII fundraising calendar, a huge thanks to everyone involved, from our dedicated committee, (Anna Killeen, Lily Killeen, Wendy Harris, Orla Dunlea), who helped pull it all together, to those who attended, bought raffle tickets and bid in our auction. A huge thanks also to Dunnes Stores for sponsoring the wine. The €85,000 raised makes a huge difference to our service users, thank you from everyone here.

The 2019 Cork Jazz Ball (our 3rd Jazz Ball), was our most successful ever. This year both numbers in attendance and funds significantly increased from last year with 300 guests arriving in their finery, raising a fantastic €40,000. Entertainment was provided by the inimitable Jabronis. A huge thanks from everyone here at Spinal Injuries Ireland to our wonderful Committee, (James Whelan, John Twomey, Brendan Manning, Sean Cusack, Anne-Marie Lenihan and Deirdre Griffin), who work tirelessly to not only fill the tables but also to put on such a great night's entertainment.

Thank you to everyone who donated to Bag It! 2019, we were delighted with the night, raising almost €8,000 towards our front-line services. We had bags from Alexander McQueen to Prada and Louis Vuitton, and the night was a huge success. A special thanks to our supporters Davy Stockbrokers, who hosted the night on our behalf.

September also saw a fantastic team of 7 take on the 700km Paris2Nice 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. In particular we'd like to thank Alan Eustace from David Lloyd Riverview, who supported the team in advance of the challenge with spin classes. Well done to all involved!



Mizen to Malin Challenge

A special mention and thanks must go to **Mark Nugent**, who hand-cycled from Malin to Mizen, raising an incredible €25,000 as he rode with further donations coming in for months after he completed the challenge. This 603km challenge had been on Mark's bucket list for a while and despite sustaining a T2 complete spinal cord injury in a cycling accident in 2016, he was determined not to let this get in the way of him living life to the fullest.

"It had always been on my bucket list when I was cycling so I decided to do it on the hand bike and raise funds for charity." Not only this, but Mark kindly agreed to be our guest speaker at our Summer BBQ, where he had his audience in awe at the feats he has achieved.

Women's Mini Marathon

Thanks to our dedicated team who took part in the women's mini-marathon. We had nine ladies walk and run the 10Km for SII, raising over €3k for our service users. Thank you one and all.



In May 2019 SII took on its first Tall Ships Challenge. Seven service users, including SII's Chairman, John Twomey set sail from Cork along with two members of the SII staff and 15 supporters. The trip was a fantastic success and there was an incredible team spirit on board and the reaction from each crew member was incredibly positive. Service user Tim Rice said "This challenge to me means freedom; freedom in my chair. I think if I can sail a Tall Ship in my wheelchair, I can do anything. I never thought I would have the opportunity to do anything like this again...and for me, life now is about focusing on what I can do, not what I can't". Tim has already signed up for the next challenge. Together, the crew raised €60,000 for Spinal Injuries Ireland.

We'd also like to thank **Stephen D'Ardis**, who cycled a Stage of the Tour de France for SII, raising over €4,300 by his inspirational efforts.

Thanks also to **Mark White and Tangoray** who held a gig for us in the Horse Show House. An amazing night by all accounts, which raised over €14,000 for our front-line services. Well done, Mark, an incredible achievement!

We'd also like to thank **Michael Lynam**, who ran the Belfast Marathon for Spinal Injuries Ireland - 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!

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.

Our annual SII raffle is a key fundraiser each year and its success is a true reflection of the dedication of each of our supporters who sell tickets across the country to raise vital funds. The enthusiastic work of each person who took part this year saw us raise over €45,000, a significant increase on the €27,000 raised in 2018. Thank you to all involved and a very special thank you to Windsor Motors for their continued support of the raffle again in 2019.

2019 saw the first SII Christmas Appeal which brought in approx. €15,000. This was lower than we had forecasted and its value will be reviewed for 2020. Thank you to everyone who donated.

Our Committed Givers who support us on a monthly basis make a great contribution and give us the confidence to plan ahead and tailor our services to the needs of our service users.

We would also like to thank our **Corporate Sponsors Coloplast, Windsor Motors, David Lloyd Riverview, Davy and Baxter.** Your generous support makes such a positive impact on the lives of our service users. It enables us to reach more people and to provide them with a wider range of care and support from the moment they are injured and in hospital for as long as they need us. You help us support their families at what is undoubtedly one of the toughest challenges they will have to face and experience as a family unit. We are truly grateful.

In summary, 2019 was a good year for fundraising with a total of €559,105 raised. A massive thank you to all who contributed in any way.



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.

This Cauda Equina Syndrome (CES) awareness campaign was dual-focused. We targeted the general public to create an awareness of the symptoms and the need for urgent medical attention and the Irish Health Care Community to amplify and support their knowledge around CES. The dual aspect of this campaign aimed to succinctly impart knowledge around the early onset of symptoms- The Red Flags of CES. We targeted our audience through 4 nationwide meetings for health care professionals and the public.

Our primary objective was to highlight the syndrome itself, it's initial symptoms and urgency in seeking medical assistance should these symptoms arise. We also aimed to encourage further professional education, research and advocacy given the epidemiological rise in the instances of non-traumatic spinal cord injury in Ireland. We also wanted to provide vital support to those living with CES and their families.

Cauda Equina Syndrome (CES)

YOUR 5 RED FLAGS TO SAVE YOUR SPINE

S	SADDLE ANAESTHESIA
P	PAIN
I	INCONTINENCE
N	NUMBNESS
E	EMERGENCY

SII Spinal Injuries Ireland
Support at every stage

www.spinalinjuries.ie



Promotional Elements

Flyers: DL leaflets visually outlining the Red Flag symptoms for the public and allied health care professionals and guiding towards further info.

We developed 2 leaflets for the campaign using the principles of Plain English in line with NALA standards. We collaborated with service user focus group, Mr Keith Synnott National Clinical Lead for Trauma Services and Dr Eimear Ryan Rehabilitation Consultant NRH. The leaflets were delivered to GP clinics and health centres nationwide.

Website: Dedicated webpage on

<https://spinalinjuries.ie/caudaequina syndrome/>

Social Media: Focused Social Media Plan targeting cross-sections across gender, age and location.

Expert Content- Expert speaker at each event

Dublin: Royal College of Physicians: Professor Mark Delargy, Clinical Director NRH

Patient Advocate: Stephan Dardis, Joanne Jacobs (RGN)

Galway: Mellow park Hotel

Mr Fergus Byrne, Trauma and Orthopaedic Consultant UHG

Patient Advocate: Carol Ahern

Waterford: Viking Hotel

Seamus Morris – (Unavailable) Naomi Fitzgibbon

Patient Advocate: Cathy Blackbyrne

Cork: Radisson Blue Hotel Little Island

Dr John McFarland, Rehabilitation Consultant CUH

Patient Advocate: Denise Culhan (Paramedic)

Attendees: 252 in total

Enquirers: 60 new enquirers seeking information and support

New Service users: 20 new CES service users and family engaged with SII

Digital Roll-Out of content from key spokespeople including Medical Consultants, Coloplast Bowel and Bladder Experts and SII **Services Providers**, HSE Health Promotion Department, 122 CES and ME- Series of short interviews with NCP and peers who live with CES discussing onset and impact and offering advice to any potential future patients:

Cathy Blackbyrne: CES Patient Advocate

<https://youtu.be/IkaBmCkakuE>

Stephen Dardis: CES Patient Advocate <https://youtu.be/h-yUKJHA4kI>

Dr Maeve Nolan Psychiatrist NRH

<https://youtu.be/sA8HBrBibeo>

Naomi Fitzgibbon, Head of Services, SII https://youtu.be/don-LwMXa_Y

Events

National launch at the Mansion House Dublin and PR campaign focussing on Health correspondents

Feedback – Health Care Professionals and Service users

“I am a Clinical Specialist Physiotherapist working in Spinal Triage in Tallaght University Hospital. Our service of advanced practice physiotherapists work under the clinical governance of 2 spinal surgeons to screen, diagnose and directly manage patients with spinal pain. I recently saw your CES alert leaflets and I think they are really valuable and patient-friendly”

“The CES document is very clear and concise. It is well written in lay man terms so should be easily understood by the general public. The SPINE anagram is striking, and those red flags should hopefully stick in people's minds. Thank you for giving me the opportunity to provide my input. I sincerely hope this document will encourage people to access emergency services as soon as possible” CES patient

Additional Outcomes and Next Steps

- Engage with Clinical Specialist Physiotherapist in MSK / Ortho Triage Letterkenny: Quality Initiative programme in CES referral pathway as per UK NICE Guidelines – Public event in Sligo and Donegal tbc
- Individual professional counselling sessions with CES sufferers who were extremely distressed
- All new services user contacted and engaging with SII Community Outreach Team
- Peer volunteers living with CES trained to provide one to one support to those with CES – completed Jan 2020
- CES leaflets distributed at National Office Clinical for Audit (NOCA) conference December 2019, NOCA Trauma Group
- Engage with NOCA Trauma group to build data on number of CES diagnosis in Ireland per year
- Develop ‘credit card size’ card as requested by HCP
- Look at opportunities to seek funding for PPI research for those living with CES in Ireland
- Arrange visits to other regional hospital for public events

COMMUNICATIONS AND ADVOCACY REVIEW

Our communications programme continued to raise awareness of Spinal Injuries Ireland's mission and work on local and national levels throughout 2019. The two biggest media campaigns surrounded the launch of our Strategic Plan and our Cauda Equina Awareness campaign.

On Thursday 11th April, Spinal Injuries Ireland (SII) released two pieces of research that were undertaken by Dr Eimear Smith Consultant in Rehabilitation Medicine at the Mater Hospital and the NRH and by Dr Padraig MacNeela, School of Psychology NUIG.

The two pieces of research which formed the basis of the new strategic plan for Spinal Injuries Ireland were launched by The Minister of State with Special Responsibility for Disabilities, Finian McGrath TD who welcomed the research, adding "I am very aware and grateful for the invaluable supports that Spinal Injuries Ireland has been providing to its service users for over past 25 years. Throughout their lives, people with disabilities should be supported in maximising their potential, by removing barriers which impact on access to services, education, work or healthcare. I want to wish all the team at Spinal Injuries Ireland every success with their new Strategic Plan. It is imperative that the work of this dedicated organisation continues as it is of enormous importance to its service users."



We achieved plenty of media coverage around the launch with one of the highlights being Brian and Frank Lawlor featuring on Virgin Media News.

As was laid out in our Strategic Plan "we will increase public awareness and advocacy issues with well informed campaigns. We will deliver relevant education and information by collaborating with our key stakeholder and experts' in the area of SCI". This goal was very much addressed in the Cauda Equina Awareness Campaign this year with excellent media coverage being attained. See the CES review on page 12.

SII also worked on raising awareness and of the high numbers of people who had sustained spinal cord injuries who remained in acute hospitals waiting for rehabilitation in the NRH in Dun Laoghaire. We worked with Leanne and Helen Grace and secured some important media coverage including an article in the Independent and Fiona Bolger and Leanne also featured on RTE's Today with Sean O'Rourke radio show.

Another media highlight was a feature on RTE's Seascapes of our Tall Ships Challenge and VIP Magazine once again featured our Spring Lunch and Q Ball.

On May 25th 2019 sadly we lost one of our founders, Sr. Aileen McCarthy and a wonderful obituary in the Irish Times described her as "a visionary who pushed the limits of rehabilitation medicine". She will always be fondly remembered by everyone at SII and we will continue to work hard to grow and strengthen the organisation in her memory.

We also worked hard on the organisation's social media presence by highlighting service users' stories, fundraising campaigns (both organisational and community based), activities, peer mentoring, and vocational and advisory programmes available to our members. This is an area in which we have seen fantastic increases in engagement with our Facebook followers increasing from 3,916 to 4,946 and our page likes increasing from 3,988 to 4,684. Also our LinkedIn following saw an increase of 103, rising from 120 to 223.

We are so grateful to our SCI community who share their stories which highlight the challenges facing people living with an SCI in Ireland. Ian O'Connell was the ambassador for our Christmas Direct Mail appeal with both Jack Kavanagh and Jennifer Hestor recording radio advertisements with Q102. People are interested in people and not statistics so the stories that you guys are willing to share are such a powerful tool to us. When it comes to providing services, advocating for change at policy level, educating stakeholders, fundraising and general communications it is your individual stories that we need to help people understand what it means to live with a spinal cord injury. It is through sharing your stories that we can give people living with a SCI a voice. We do what we do for you but we couldn't do it as efficiently without your input so thank you to everyone who has shared their story.





FINANCIAL STATEMENTS

Income and Expenditure Account Year ended 31st December 2019

	2019	2018
Income	1,097,731	1,001,690
Interest receivable and similar income	1,419	1,340
Gross Income for reporting period	1,099,150	1,003,030
Expenditure	1,084,443	988,933
Depreciation and charges for impairment of fixed assets	9,452	10,363
Total expenditure in the reporting period	1,093,895	999,296
Net Income/ (Expenditure) before tax for the reporting period	5,255	3,734

All income and expenditure arise from continuing operations.

There were no other recognised gains or losses during the period under review.

Balance Sheet as at 31st December 2019

	2019	2018
Fixed Assets		
Tangible Assets	25,437	32,458
Current Assets		
Debtors and prepayments	37,244	29,344
Cash at bank and in hand	1,185,128	1,146,082
Total	1,222,372	1,175,426
Liabilities		
Creditors: Amounts falling due within one year	(73,024)	(38,354)
Net current assets	1,149,348	1,137,072
Total assets	1,174,785	1,169,530
The funds of the charity:		
Restricted Income Funds	7,532	8,774
Unrestricted Income Funds	1,167,253	1,160,756
Total Charity Funds	1,174,785	1,169,530

Directors/Trustees and Other Information

Directors/Trustees

John Twomey
James McCarthy
Keith Mangan
Donal O'Flynn
Herman Wilmink
Eimear Smith
Brian Dempsey
Emma Cahill

Company Secretary

Louise Moore

Chief Executive Officer

Fiona Bolger

Registered Office

G3, The Pottery, Bakers Point,
Pottery Road,
Dun Laoghaire
Co Dublin
A96 Y932

Company Registration Number

225205

Charity Regulatory Authority Number

20031855

Charity Number

CHY 11535

Principal Bankers

Bank of Ireland Plc
371 – 373 North Circular Road
Phibsborough
Dublin 7
D07 XF65

KBC Bank Ireland Plc
Sandwith Street Upper
Dublin 2
D02 X489

Solicitors

Augustus Cullen Law
7 Wentworth Place
Wicklow
A67 FX59

Auditors

Power & Associates
Chartered Certified Accountants
Statutory Auditors
1 Sussex Street
Dun Laoghaire
Co Dublin
A96 C8N3

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Windsor
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Baxter  International Foundation

David Lloyd
— CLUBS —



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

CHY: 11535

Registered Charity Number: 20031855

www.spinalinjuries.ie

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Support at every stage