



# **ANNUAL REPORT 2016**



Gretta Fogarty, mother of Shaun Fogarty who sustained a high level spinal cord injury, from Tipperary

On an ordinary July day, the centre fell out of Gretta Fogarty's world. Her 19year-old son, Shaun, had broken his neck and his spinal cord had been badly damaged in a horrific traffic accident.

Shaun was in his prime – in employment and studying Applied Physics. She knew that he would now be profoundly disabled and would need the help of a ventilator to breathe. Gretta was about to find out how frightening, exhausting and frustrating it is to fight for the rights of a family member who has a spinal injury – and the huge gaps that exist in the system.

"One of my first battles was discovering that Shaun – for various administrative reasons – was not entitled to a Medical Card to allow him to obtain a wheelchair or his all-important eye gaze computer. This was the first time I really felt discriminated against as a tax payer. After two months of fighting, Shaun was eventually granted a disability allowance and a Medical Card." Then Gretta received the devastating news that Shaun was not eligible to become a patient at the National Rehabilitation Hospital because he was ventilator dependent. Eventually, following a six month battle with the HSE, Shaun was transferred to the Stoke Mandeville Hospital in the UK.

"We learned so much there about how to live as normal a life as possible with a spinal cord injury but our happiness turned to anxiety when we realised that bringing Shaun back home to Ireland would not be an easy process."

Due to HSE delays in approving funding for an operation in the UK, his discharge date was pushed back. "To our complete astonishment and horror, no one was willing to accept Shaun home. This meant we were now stuck in the UK with a bill of £1,100 per day accumulating – and a growing concern that this colossal bill would land on our doorstep. Not to mention the huge cost of me staying in the UK for the duration of his rehab." Following a lengthy battle and lobbying, Shaun was finally repatriated back to the Mater Hospital. It was now over nine months since he had arrived in the UK. It then took another exhausting six months of struggle before he was transferred closer to home, albeit to the intensive care unit of South Tipperary General Hospital.

"The worst part of it all was that Shaun was losing faith that he would return home alive, which broke my heart. His consultant even stated that every day he spent in ICU, fighting all the infections he was unnecessarily exposed to, was a day more that his life was at risk."

It was at this point that Gretta linked in with Spinal Injuries Ireland and with the help of CEO, Fiona Bolger, the two women lobbied politicians for help.

"Spinal Injuries Ireland were fantastic. Fiona came down to us early one morning and we went to all the politicians in Tipperary. She presented Shaun's case so well. It was very shortly after that, we were awarded Shaun's home care package to allow him to transition back home to us."

"Spinal Injuries Ireland made it possible for Shaun to go to my sister's wedding last year. They set up a driver and a bus and brought him. It made her day for sure and it made mine too. It was amazing."

"The Early Days programme would be of massive benefit to families. Spinal Injuries Ireland is a wonderful service, we're so happy with it. There's so much crucial help we have got from Spinal Injuries Ireland – things that we could not have done on our own."





## **CHAIRMAN'S STATEMENT**

2016 was a momentous year for Spinal Injuries Ireland as we held our first nationwide roadshow supported by Coloplast to raise public awareness about the lack of support and services for people with a spinal cord injury. Almost 500 people attended the public meetings and signed a pledge to ask Government to improve services and supports.

This roadshow was one element of management working to re-structure the organisation and to provide additional services. Funding continues to be a challenge and we would like to thank all those who have supported SII during 2016 and hope that you can continue to do so as the organisation cannot continue to provide the current level of services without your support.

The organisation reported an operating deficit for 2016 and this is of concern for the Board however the deficit is reducing year on year and management is focussing on developing the fundraising function within the organisation.

The imminent relocation of the Resource Centre from the NRH Campus remains a concern. Although Spinal injuries Ireland welcomes the development of the new hospital, a new premises will put further strain on the organisation and I can report that both the Board and management continue to seek funding from the HSE for a new premises and are hopeful of securing some support in 2017.

I would like to take this opportunity to thank all the staff for their commitment to improving the lives of people with a spinal cord injury and to all our volunteers who support us in this mission and to all our donors without whom we cannot exist.

James McCarthy Chairman



# **CHIEF EXECUTIVE'S REVIEW**

During 2016 the profile and reach of Spinal Injuries Ireland increased through further engagement with our service users and stakeholders. Almost 500 people attended the first roadshow in 10 different venues nationwide and the exposure that this generated led to our first parliamentary briefing hosted by Margaret Murphy O'Mahony T.D., Fianna Fail Spokesperson on Disabilities.

In the autumn we met with the Minister for Disabilities Finian McGrath, TD who then spoke at our AGM at which he pledged to work with SII to improve services but also to assist SII in our move off the NRH Campus to facilitate the building of the new hospital which is expected to start in 2017.

During 2016 SII also received Dormant Account Funding from Pobal to introduce 'Discovering the power in me' life skills programme developed by the Pacific Institute in Canada. This is the first step in Spinal Injuries providing back to work programmes.

Our 6 strong community outreach team continued to provide active support to 1853 service users whilst organising regular meet ups and peer support.

The fundraising team was strengthened and this accounted for an almost one third growth in fundraising income year on year. A trend we hope will develop in the coming years.

Thank you to all our stakeholders during 2016 especially the support from the HSE towards our outreach service. We could not operate without this funding.

Fiona Bolger CEO

### ABOUT SPINAL INJURIES IRELAND



# Vision

By 2018, all people with a Spinal Cord Injury (SCI) in Ireland will have access to the necessary supports and services to live a fulfilled life and an equal opportunity to participate in the social, economic and cultural life of the community.

# Mission

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

# **Our Values**

Our values govern what we do and how we interact with all stakeholders

# **Innovative & Dynamic**

We will be flexible and positive about change to achieve our Vision and Mission.

### Fair & Respectful

We treat all our staff, members and stakeholders in a fair manner and free of bias. We will promote a positive working environment, with clear boundaries and decision-making processes.

# **Clarity in messaging**

We ensure that all our internal and external audiences are clear about what they need to do and when.

### Accountability & Transparency

We are accountable for the decisions we make and the work we undertake and support one another in our decisions. We will make the best use of the resources available to achieve our goals by providing a unique service to our members. We are compliant with the Governance code for charitable organisations and promote good practice.

# KEY OUTCOMES FOR 2016

1853	PEOPLE availed of services
197 PEOPLE used the Information service	51 PEOPLE Participated in sports and social outings
819 GOALS Set with individuals	679 Home visits by the Community Connect Team
<b>560</b> Att	PEOPLE ended regional Meet Ups
<b>96</b> PEOPLE Availed of Peer Support	90 hours of counselling

**184** FAMILY MEMBERS

 Attended regional Meet Ups



During May 2016, Spinal Injuries Ireland supported by Coloplast visited 10 towns and cities across Ireland to engage with people with a spinal cord injury (SCI) and their families and friends.

The aim was to build a community that can influence change and improve supports and services for people living with the impact of this life changing injury. In addition to people with a spinal cord injury, their families and carers, local representatives, healthcare and service providers and the media attended these meetings. The information gathered would also form the basis of an advocacy programme, providing a voice for people living with a spinal cord injury in Ireland.

#### **Objectives:**

Discussion at the events focused on:

- Lack of public knowledge about SCI
- Delays accessing services for SCI patients
- Inadequate services for SCI patients
- Lack of care packages to support independent living and lack of training for PAs and Carers
- Unemployment level of 76% amongst the SCI population and 40% living on or below the poverty line
- What external services are provided

At all meetings it was stated by attendees that a louder voice is needed for those living with a SCI and the campaign aimed to reach out to people with an SCI, their families, friends and health services professionals to build a community which will influence change and improve supports and services. The pledge to support better lives for people living with a spinal cord injury was created to raise further awareness with an objective of building this one voice support system.

Through the support of Coloplast SII was able to produce four short video's which demonstrate the difficulties of living with a spinal cord injury and educate the public about the devastating impact that a spinal cord injury can have on an individual's life. These can be viewed here:

#### www.spinalinjuries.ie

### **Dates & Venues of Roadshows**

- 11th May 2016 Galway (32 Attendees)
- 12th May 2016 Sligo (28 Attendees)
- 16th May 2016 Waterford (55 Attendees)
- 17th May 2016 Cork (62 Attendees)
- 18th May 2016 Tralee (29 Attendees)
- 19th May 2016 Limerick (68 Attendees)
- 23rd May 2016 Letterkenny (30 Attendees)
- 24th May 2016 Portlaoise (45 Attendees)
- 25th May 2016 Dundalk (51 Attendees)
- 26th May 2016 Dublin (84 Attendees)





MY LIFE

Each event included a screening of the videos along with a short presentation based around the objectives listed above, followed by a Q&A session with SII services staff and different healthcare professionals depending on the location.

**Take Action!** 

Each event asked attendees to sign a pledge card to support better lives for people living with a spinal cord injury and were encouraged to get members of their community to sign also. Over 650 signatures and email addresses were gathered.

### Outcomes of This Is My Life Roadshow

Events: 10

Attendees: 483

Pledges: 650

Media: 44

(interviews, radio print & TV)

New Referrals: 10

### **Irish Healthcare Award**

SII was awarded a special commendation award for 'Patient Organisation Project of the Year' at the Irish Healthcare Awards 2016.

SII received the award for the dedication and hard work that went into organising the This Is My Life campaign 2016.

This was the first time SII was ever nominated and won an award at the Irish Healthcare Awards



### DÁIL BRIEFING

On the back of the This Is My Life campaign, SII was able to secure a Dáil briefing on the 22nd June 2016 in Leinster House. Each individual that had signed the pledge card was emailed a sample letter to send to their local public representative to encourage them to attend the briefing.

The Dail briefing was organised by Margaret Murphy O'Mahony TD, Fianna Fail Spokesperson on Disability and was attended by over 40 TDs and Senators including the Minister for Disability Finian McGrath TD.

SII outlined how the government can improve quality of life and active participation in society for people living with a spinal cord injury. Service users Gretta Fogarty, Susan Campbell and Stephen Cluskey also presented their individual stories. A full briefing document was provided and presented to each attendee asking them to take action in three ways:

- 1. List SCI as a long term illness
- 2. By 2020 deliver on essential services
- **3.** SII to provide relevant supports and education so people with a spinal cord injury can participate fully in society

Throughout SIIs nationwide meetings, as part of the This Is My Life roadshow, it was found that these three areas were most prevalent to people living with SCIs. SII then moved to request a meeting with the Minister for Disability Finian McGrath TD which was secured and took place on 12th September 2016.





### **MEETING WITH MINISTER FOR DISABILITY, FINIAN MCGRATH TD**

SII met with the Minister for Disability, Finian McGrath TD on 12th September 2016 to discuss the need for additional funding to ensure the provision of services for people with SCIs in Ireland.



The meeting with the Minister took place in Leinster House and was the culmination of SII's 'This is my Life' campaign.

SII also outlined four key recommendations that we felt could be implemented as a matter of priority.

#### They included:

- 1. An increased and ring fenced budget for home-care packages for complex cases to clear the pathway of care and free up beds at acute and rehabilitation stages
- 2. Immediate investment to address staff shortages and training for healthcare professionals in both inpatient and community settings
- 3. The granting of medical cards based on medical need rather than income
- 4. The initiation of a central strategic approach to case management.

SII informed the Minister that with the increased number of people living with SCIs in Ireland, the lack of government investment is putting limited and underfunded services under further pressure.

As a result of the This Is My Life campaign, SII heard hundreds of individual stories from across the country of the difficulties that people with a SCI face every day and these were presented to the Minister.

### MINISTER FOR DISABILITY, FINIAN MCGRATH TD, VISITS SII OFFICES

# SII invited Minister Finian McGrath TD to deliver the opening address at our annual AGM on 19th October 2016 at the SII Resource Centre.

This marked the first time the Minister addressed our AGM and it ensured that there was a great attendance on the day, with over 30 service users attending the meeting. Many topics were covered on the day and following the Minister's speech, attendees took part in a question and answer session with Minister McGrath where he discussed issues including PA hours, medical cards, suitable housing for people with SCI, home care hours, and accessibility.

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

Mr Maguire informed SII that, in addition to working on the availability of the medical card for people with SCIs, he will also support SIIs request for funding to continue to provide a national service.





### **COMMUNITY CONNECT**

SII employs 6 Community Outreach Officers nationwide.

Goal setting with clients using the principle of active support. The following was achieved:

Number of individual clients visited 2016:	356
Number of outreach visits in 2016:	679
Number of goals set in 2016:	819
Total number of goals achieved in 2016:	349

### **EXAMPLES OF PERSON CENTERED GOALS ACHIEVED**

#### **Short Term:**

Organised a multi-disciplinary meeting in hospital where client resides

Secured a work experience opportunity

Attended bingo one night a month

Tried and joined wheelchair rugby

Engaged with employability service

Secured household benefits package and fuel allowance

Organised an appointment with the pain clinic

#### Medium Term:

Explored ways to increase social circle

Met with MABS to get financial debt under control

Returned to education

Returned to driving

Sourced a course in adult literacy

Went to Debs with her friends

Secured extra PA hours to enable him to atted a course

Returned to work

#### Long Term:

Moved out of residential unit to live independently

Accessed housing outside of the family home

Returned to education

Found team sport that he enjoyed

Returned to work

Applied for the social housing list

Explored ways to improve bladder issues



# **SOMEONE LIKE ME**

. . .

The peer support programme grew in 2016 with almost a 100% increase in the number of people availing of this service at the NRH and also in Cork. In addition a number of groups have formed to provide support for one another regarding specific issues such as Cauda Equina as a result of 'This is my Life' roadshow.

'The best thing that happened to me just before I left the NRH was that I attended a SII peer support session and met a man around the same age as myself with a similar injury.

We had coffee a few times but his support was the most useful when I returned home and I could phone him for a chat – he was the only person who really knew what I was going through.

Talking to him helped me to realise that life will get better'..

Number of patients attending support at the NRH	74
Number of patients receiving 1:1 peer support in the community	22
Number of new peer volunteers trained	16
Total number of peer volunteers nationwide	40

All our volunteers are trained by Peer Mentoring Resources and facilitation skills training was provided by IBEC





### **ACTIVE ME AT THE NRH**



Number of patients availing of 'Active Me'

51



#### Active Me provides sport and social outings to patients at the NRH. Activities include cinema, concert and sports events including weekly airsoft.

From May to October SII operates a weekly powerboat trip from Dun Laoghaire for patients followed by fish n Chips. This activity is obviously weather dependant and unfortunately was cancelled many times in 2016.

'After 10 weeks rehab and feeling I would never enjoy a family day out again, Spinal Injuries Ireland took me and the kids out on the boat. We had never been on a motorboat before and we were able to go up as far as O'Connell Bridge – the kids had a great time waving at everyone. Two years later and they still talk about it. A great memory'



### GRANTS

SII provides a number of grant opportunities for service users. These grants can be applied for through the Community Connect Team.

#### SII SHORT COURSE FUNDS 3 APPLICATIONS APPROVED

The purpose of this fund is to provide an opportunity to take a first tangible step towards a long term goal and help to reduce social isolation, increase workforce readiness and employment opportunities, along with developing personal and social skills, building selfconfidence and improve physical and mental health.

#### Grants approved for

- Therapeutic horse riding lessons
- Contribution to third level education fees
- Contribution to Dyslexia Teaching Course

HOSPITAL SATURDAY FUND (HSF) 25 APPLICATIONS APPROVED

HSF is a registered charity who provide grant assistance to people with a disability towards specialised equipment or practical forms of treatment. Applications can only be processed directly through SII Community Connect Team.

#### Selection of grants approved include:

- Hydrotherapy treatments
- Physiotherapy treatments
- Assistive technology to help with communications
- Hand-controls for new car
- Dry needling for pain relief
- Recliner Chair
- Orthopedic mattress
- Mobility Scooter

#### SAIL TRAINING IRELAND 2 SAILING TRIPS APPROVED

SII awarded two bursaries through Sail Training Ireland in conjunction with Irish Cruising Club and Jubilee Sailing Trust. The bursary provides opportunity for one person and a buddy to sail on a fully accessible ship.

#### Selection of voyages available include:

- Lord Nelson voyage from Cornerbrook in Canada around the Canadian coast
- Lord Nelson voyages around the coast of UK & Ireland

### **RESOURCES AND INFORMATION SERVICES**



#### Number of queries researched and reported 197

#### SIGNPOSTING TO OTHER AGENCIES **INCLUDED:**

### DISCOVERING THE POWER IN ME

### **44 SERVICES USERS AVAILED OF THIS** PROGRAMME

.....

Spinal Injuries Ireland were delighted to partner with The Pacific Institute on the 'Discovering the Power in Me' programme (DPM), which was funded through The **Dormant Accounts Fund, and evaluated by the School** of Psychology, NUI, Galway.





DPM is a programme developed by the Pacific Institute, Canada, in collaboration with people who have sustained a traumatic injury as well as professionals in the field.

Initial funding received from The Dormant Accounts Fund covered a pilot project to deliver the programme to a total of 80 young people (aged 15 to 25 years) who have sustained a traumatic injury.

In July 2016 ten SII staff members were trained in facilitating the DPM Programme.

Between July and December 2016. 44 people, including services users, carers and family completed this empowering programme which comprises 12 units that refer to different life skills such as positive thinking, goal setting, cognitive functioning and personal motivation.

The units are integrated in a 'whole person' approach to personal effectiveness and teaches helpful tools to develop inner strength and resilience required to reassert control over life. The twelve learning units are delivered over a 2 day period.

At any stage in the journey of recovery, hope, belief in self and resiliency are essential. The programme provides the foundation upon which these attributes can be built. Translated into practical tools and techniques, participants easily understand and apply these concepts, thereby laying a strong foundation for growth, change, hope, self-worth and inner peace.

DPM has proven successful outcomes whereby participants have achieved a higher quality of life, more expansive goals and the ability to successfully problem solve.

DPM is designed to encourage participants into gainful employment and to develop an expanded capacity for independent living.

A consistent theme in feedback received was the realisation that individuals need to shut out and limit exposure to negative thoughts and feelings having an impact on their life and preventing them for achieving their life goals.

### **Income and Expenditure Account Year ended 31st December 2016**

	2016 €	2015 €
Income Interest receivable and similar income Other Income	753,163 4,317 1,000	605,367 18,664
Gross income for the reporting period	758,480	624,031
Expenditure Depreciation and charges for impairment of fixed assets	919,008 31,049	807,637 39,406
Total expenditure in the reporting period	950,057	847,043
Net income/(expenditure) before tax for the reporting period	(191,577)	(223,012)
Tax payable	-	-
Net income/(expenditure) for the reporting period	(191,577)	(223,012)

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 2016**

	2016 €	2015 €
<b>Fixed Assets:</b> Tangible Assets	57,850	84,071
<b>Current Assets:</b> Debtors and prepayments Cash at bank and in hand	17,624 1,268,690 1,286,314	11,074 1,439,272 1,450,346
<b>Liabilities</b> Creditors: Amounts falling due within one year	(33,257)	(31,933)
Net current assets:	1,253,057	1,418,413
Total assets	1,310,907	1,502,484
The funds of the charity: Restricted income funds Unrestricted funds Total charity funds	13,127 1,297,780 1,310,907	40,138 1,462,346 1,502,484

# LEGAL AND ADMINISTRATIVE DETAILS

Spinal Injuries Ireland is a company limited by guarantee, incorporated in Ireland on 24th November 1994 under number 225205 in accordance with the Companies Act 2014. The charity does not have a capital share and consequently the liability of members is limitied, subject to and undertaking by each member to contribute to the net assets or liabilities of the charity on winding up such amounts as may be required not exceeding  $\leq 1.27$ .

It is registered as a charity under the Taxes Consolidation Act, 1997, under reference CHY 11535.

The registered office and principal place of business are NRH Campus, Rochestown Avenue, Dun Laoghaire, Co Dublin.

The charities Chief Executive Officer is Fiona Bolger.

Other relevant organisations or persons providing banking services or professional advice to the charity and the board of trustees are as follows:

#### **Auditors**

Connelly Auditing Services Limited Chartered Certified Accountants & Statutory Auditors Greenville School Road Rathcoffey Co Kildare

#### **Solicitors**

McMahon Goldrick Solicitors 45 Dawson Street Dublin 2

#### **Bankers**

Bank of Ireland plcKBGPhibsboroughSarDublin 7Dublic

KBC Bank plc Sandwith Street Dublin 2

# MARK NUGENT -TAKING TO THE SEA

After sustaining a T2 complete spinal cord injury last summer following a cycling accident, Mark Nugent took his first trip out to sea on a rib with Spinal Injuries Ireland while still a patient in the NRH.

He had heard about the rib trips with SII and although he had a fear of boats, he decided to face his fear head first and in doing so he found a new love for the sea.

"I don't like boats at all. I was petrified the first day we went out, I didn't know what to expect. The only boat I'd ever been on was a ferry and I would always get sea sick so it was my partner Jackie who pushed me to go for it."

Mark, from Maynooth, explained that one of his worries about going out on the boat trip was being hoisted onto the boat as he was unsure of how it would work.

"I was petrified of being hoisted onto a boat and being uncomfortable, but the guys were so well organised. They just used the hoist as you would normally, and got me onto the boat. They even had blankets for us when it got cold. The first night I went out I was freezing cold because I can't control my body temperature. It was a beautiful evening that night and I went out in short sleeves and a t-shirt and when we came back in I had a jacket on me, a silver blanket and a blanket over my legs to keep me warm. Everything that we needed was on the boat.

Heineken

 $\mathbf{\Omega}$ 

"The whole thing was very well organised because a bus picked me up at the door of the hospital, dropped me off at the door on the way home, and we got fish and chips on the way home. The next time we went out we got sausage and chips on the way home, and ice-cream another time. It's just a brilliant trip."

For the first trip he went on, the rib took Mark, Jackie and two other patients around Dalkey Island and up the River Liffey.

"It just happened to be the nicest day of the year last year when I went out for the first time. It was a beautiful sunny day. It was great to get out on a Tuesday evening from the hospital. At the time, because I was still a patient, I wasn't used to leaving the hospital. I wasn't even going home at weekends at that stage. So to be able to get out of the hospital environment and to have a bit of a break from the hospital setting was just brilliant."

Mark explained that on both of the trips he did with Spinal Injuries Ireland, he travelled up the River Liffey. "On one of the trips we went as far up as the Four Courts, and on the other one we went up as far as O'Connell Bridge. We also stopped off for coffee and tea. Then on the boat trip on the way back we stopped off at the Poolbeg yacht club and it was the nicest cup of tea and a snack bar that you will get!

"To go up the Liffey and see Dublin in a completely different way, in a way that you've never seen it before in your life, is just amazing. I don't like boats, I don't like them at all, but this trip was different. Even to go from Dun Laoghaire, across Dublin Bay and up the Liffey, it's just a rush.

"We were coming back one night and we were bouncing over the waves, and I was holding on for dear life but the two guys that were with me, they were just loving it!"

Mark explained that he would highly recommend heading out on the rib with SII and said it is something everyone should try to experience.

"It was one of those things that I will always remember as being brilliant, and the photographs I got were amazing too. I got loads of photographs going out on the boat and going up the Liffey. The rib trips were one of the highlights of last year. It's definitely up there with one of the best two things I did while I was in Dun Laoghaire and I'd highly recommend to anyone thinking of doing it, to go for it."





ciste na gcuntas díomhaoin the dormant accounts fund









Comhshaol, Pobal agus Rialtas Áitiúil Environment, Community and Local Government

