

*Real people.
Real stories.
Real lives.*

Annual Report
2019/20



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Legal status

Spinal Injuries Association (SIA) was founded in 1974 as a registered charity (No.1054097). The company was incorporated as a Charitable Company (No. 3175203) limited by guarantee on 19 March 1996 and is registered in England and Wales. The governing instrument for the charitable company is the Memorandum and Articles of Association updated May 2017.

Company number: 3175203 Charity number: 1054097

01

SIA SUMMARY

We are creating a network of support for everyone affected by spinal cord injury (SCI).



A thriving community of SUPPORT

FOR EVERY INJURED PERSON



Nik Hartley OBE
Chief Executive Officer



"We take - and demand - immediate action to save lives."

Every four hours another person is paralysed, another family torn apart.

Welcome to our Annual Report for 2019/20. Thanks to the generosity of our supporters – individuals and organisations alike – we’ve been able to reach more people affected by spinal cord injury (SCI) than ever before.

But every four hours another person is paralysed – another family’s life torn apart. We have big plans to make sure we can reach every single one of these people and we outline how on pages 13 - 34.

This year we wanted to tell our story through the words of our service users. The heartfelt thoughts and feelings they’ve shared with us highlight how important SIA’s expertise has been to each of them. Whether it’s peer support from other SCI people who can give practical advice and positive insight; advocating on behalf of someone with an SCI to defend their rights or improving patient care through our SCI Nurse Specialist service. We share their stories here under three strands of inform, advocate and support.

It is sadly still the case that only one newly injured person in every three will get access to the best possible care in a specialist NHS SCI Centre. It makes no moral or economic sense that every year approximately 1,700 people have their potential stunted, their recovery delayed, and their lives put at risk by inadequate care in a non-specialist setting, often at many times the cost.

As part of our mission to address this, and thanks to the amazing support of The October Club, we’re delighted to have trebled the reach of our SCI Nurse Specialist services. Now with five SCI Nurse Specialist

colleagues, we’ll be able to train 1,000 healthcare professionals each year and reach at least 1,000 of the 2,500 people who will sustain an SCI in the coming year.

A major part of this work is ensuring that all NHS Trusts have up-to-date policies, procedures and trained staff in place to manage SCI patients’ bowel care properly. Following an SIA-instigated Patient Safety Alert issued by NHS England to all NHS Trusts warning that patients’ lives were being put at risk, we saw a 100% increase in uptake on our ‘Managing the Neurogenic Bowel’ Study Day and by autumn 2019 the number of Trusts with a bowel care policy in place increased to 54%. We’re still campaigning to ensure that SCI people admitted to any general hospital get the basic care, respect and dignity they need and deserve.

We also launched 'More than a number', our manifesto demanding immediate action to save lives. Through our unique Continuing Healthcare casework service, we hear so many stories of shocking decisions to cut and even remove people’s healthcare funding.

And as this financial year ended, coronavirus struck. We re-deployed the charity’s services to support, advise and represent not just our own members but all of the 50,000 SCI people across the UK – many of whom are classed as high risk

– to avoid the virus, get the right care and equipment when needed and manage their SCI if faced with entering the hospital system during the pandemic.

Please keep supporting us in whatever way you can. We are committed to expanding our reach and raising our voice to drive change and deliver support to those who need it most. Your ongoing commitment will get us closer to that vision of a fulfilled life for everyone affected by SCI.



Dr Rupert Earl
Chair of Trustees

Spinal cord INJURY AT A GLANCE



It is estimated that **50,000 people** live with a spinal cord injury in the UK, with **2,500 people** sustaining an injury every year.



Causes of spinal cord injury **resulting from an accident** include falls, road traffic accidents and sporting accidents.



Causes of spinal cord injury as a **result of illness or condition** include degenerative conditions, infection and tumours of the spine.



The effects of spinal cord injury include full or partial paralysis, as well as loss of mobility, bladder and bowel control, and sexual function. Many people also live in pain. The combination of these various consequences inevitably can also **impact on people's psychological wellbeing**.



There are 11 spinal cord injury centres in the UK.



Research projects are taking place to discover how to repair the spinal cord, but at present it is **not yet possible** to do so.



Last year

- **2,416** patients were referred to SCI Centres in England, of which **63%** were not admitted.
- **55%** of injuries were caused by accident and **45%** were caused by illness or a medical condition. No cause of injury was reported in **26%** of those referred.
- The most common cause of injury resulting from an accident were falls (**57%**).
- The most common cause of injury resulting from an illness or condition was epidural abscess (**16%**).
- **50%** of injuries resulted in paraplegia and **50%** tetraplegia.
- **77%** of injuries were incomplete and **23%** were complete.
- **67%** of people referred to an English SCI Centre were male, **33%** were female.
- The biggest age group of new injuries was **55-59** years old.

Two out of three recently injured people do not get the expert care and support they need.

Findings sourced from The Annual Statement of the National Spinal Cord Injury Database 2018-19. Statistics based on people admitted to SCI Centres in England, 2018-19. Most publicly available statistics at the time of going to print.

Our VALUES

Here for everyone who needs us

Our vision

A fulfilled life for everyone affected by spinal cord injury.

Our purpose

To be in partnership with the spinal cord injury community to create quality and equality of life by campaigning, educating and supporting.

Our values

- Work together in an environment built on respect and mutual support.
- Always be user-led in our decision-making and development.
- Empower spinal cord injured people as the experts in managing their lives.
- Be committed to the ever-changing needs of spinal cord injured people by campaigning for the best treatment and care.
- Challenge perceptions and behaviours towards spinal cord injury, ensuring a more inclusive society.
- Have integrity in our work, collaborating with others where a greater impact can be achieved.



Fulfilled Lives - a five year strategy

As a user-led charity, our members and their needs are at the heart of everything we do. In 2017, spinal cord injured (SCI) people told us what barriers they faced and what needed to change to achieve a fulfilled life. This feedback formed the basis of our five-year strategy, **Fulfilled Lives**.



Below is a summary of some of the key targets set for 2019/20:

1. Influence the quality of health and care services received by SCI people.
2. Support the wellbeing of SCI people and their families.
3. Enhance the inclusivity of SCI people in society.
4. Build engagement with the SCI community to make our voice stronger.
5. Deliver existing and new high-impact services to support SCI people.

Our performance-monitoring framework keeps us on track and supports SIA's Leadership Team. Key performance indicators from across the Charity are measured and reviewed on a quarterly basis and areas requiring any additional focus are identified so we can report to the Trustee Board and the wider SCI community on our progress in meeting our vision.

We also consult members annually in a 'pulse survey'. Responses to the 2019/20 survey included:

- 84% of respondents had confidence in SIA's ability to provide support and information to meet their needs.
- 93% of respondents had confidence in the charity's ability to campaign for positive change.
- 81% felt confident that SIA empowers them to understand the rights and opportunities available to them.

We have now completed the third year of our strategic plan, and while many of the numbers in this report indicate real success and impact, it has become clear that SCI people need and want more representation, a louder voice, more influence on policy and much better, joined-up services from charities, companies and government services.



A NETWORK OF SUPPORT FOR EVERY injured person

Following our conversations with SCI people, we've received the clear message that SIA should link users to all of the people, services and organisations that can build their voice and influence in society. With that imperative, we have committed to reaching out to all those who share our vision of a fulfilled life for every SCI person: other charities, the NHS and the wider health and social care system, as well as our friends in the legal sector and beyond to build an SCI support network across the country.

Responding to changing needs

To achieve this re-targeted ambition, moving into year four of the strategy, SIA has begun to build a structure focused on building support networks of trusted partners region by region to meet the diverse needs of SCI people. Complementing this will be a more joined up national digital platform, plus increased access to advocacy and representation for the growing clinical, social and economic challenges and barriers facing our community.

This new structure was ready for roll-out in the final quarter of the financial year when the coronavirus pandemic struck. SIA had a stark choice: to either batten down the hatches or respond to the urgent calls from SCI people in need of information, support and representation as coronavirus took hold. Every member of staff and volunteer unanimously agreed that the latter was our mission as our new structure and plans were about this very moment.



Our coronavirus response

We rapidly redeployed our frontline staff and volunteers to provide a joined-up response offering information, advocacy and support via a 111-style support line with extended opening hours. A triage team took calls, referred enquiries to nursing, peer support and advocacy colleagues as necessary and arranged a ring-back service for all callers. Alongside this we curated written and video content on our website with a dedicated landing page and co-hosted virtual cafes via Zoom with partners. All these programmes continue at the time of writing into 2020/21 and form the three-tier basis of our expanded work.

The three strands are:

Information & advice

This programme has offered information and advice services with:

- a 111-style freephone support line: 0800 980 0501, Monday to Friday, 9am till 5pm
- regularly updated details on dedicated pages at www.spinal.co.uk/coronavirus

- daily social media posts using #coronavirusSCI #TogetherinIsolation
- weekly blogs and podcasts on health and mental wellbeing, for example from SCI Ambassador Karen Darke, a qualified counsellor and coach
- videos from experts in clinical care, diet, nutrition and mental wellbeing on our website and YouTube channel.

Advocacy & representation

This programme has focused on the rapid increase in demand for representation for SCI people needing to fight for appropriate care while managing the impact of coronavirus.

That included:

- ongoing Continuing Healthcare casework to secure care

- negotiations with Clinical Commissioning Groups for crucial personal protective equipment for PAs and carers
- an SCI Nurse Specialist liaising with hospital staff to ensure care is safe and appropriate, should an SCI person need to be hospitalised.

Support network

This final programme has been the most exciting expansion which will last long into the future – building that trusted network of people and organisations demanded by SCI people – increasingly linking and referring SCI people to other regional or national services whether:

- telephone counselling

- expert advice on maintaining physical fitness during lockdown
- how to access financial support should income be affected by the pandemic
- virtual cafes connecting SCI people with each other during self-isolation and to experts and inspirational leaders and organisations.



An accelerated move to digital

All colleagues quickly got to grips with Microsoft Teams as the main means of communication and our digital channels have become the main focus of our expanded offer, learning fast as we responded to the demand for daily written and video content about all aspects of coronavirus and SCI. This is now the basis for building our coordinated digital offer for all SCI people next year under the leadership of a new Digital Engagement Manager. Plans include a new CRM database and partner website so that everyone affected by SCI can visit a 'one-stop shop' online to find the information and support they need, as well as online education for healthcare professionals through our expanding SIA Academy.

ACHIEVEMENTS *and performance*

NO ONE SHOULD FACE LIFE AFTER INJURY ALONE

With a workforce of 49 employees and 252 volunteers, this year we provided a range of services to support our membership of more than 12,000 people. Whatever their connection to SCI – whether it be personal or professional – we ensured that everyone who needed to access expert information, advice and support was able to do so when they needed it most.

Advice Line: 1,589 enquiries were addressed by the Advice Line. Around one caller in every six was referred to our Advocacy service for more in-depth support on topics including disabled facilities grants, travel issues and car parking.

Peer Support: 4,337 support sessions were provided to SCI people in hospitals, NHS specialist SCI Centres, out in the community and in people's homes.

1,308 support sessions were provided to families and friends of SCI people in hospitals, NHS specialist SCI Centres, out in the community and in people's homes.

SCI Nurse Specialist service: Our SCI Nurse Specialist service received 337 new referrals and supported SCI people a total of 1,404 times during the year.

SIA Academy: 567 healthcare professionals attended CPD-accredited education and training sessions delivered by the SIA Academy.

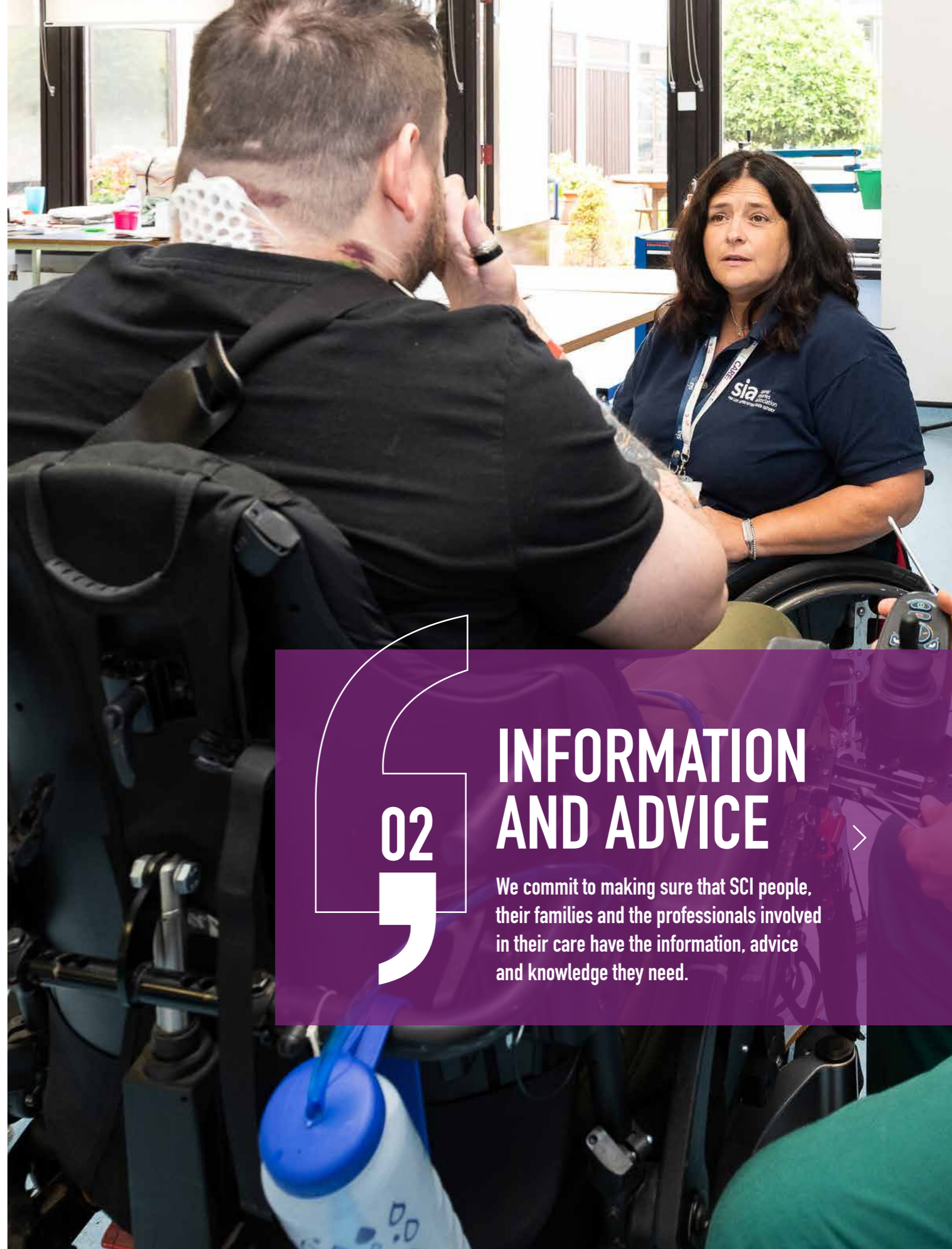
Volunteers: 252 volunteers supported the Charity, contributing 5,553 hours of support. 83 of our volunteers have an SCI.

Casework: 196 people received Continuing Healthcare Casework support that specifically met their needs to live independent lives within the limits of their disability.

85 people received Social Care Casework support that specifically met their needs to live independent lives within the limits of their disability.

Telephone Counselling: 141 telephone counselling support sessions were provided to SCI people and their families and friends.

★ The rest of this report conveys the three areas of our work and is brought to life through the stories of the people who use our services. Where impact shows progress towards the objectives of our five-year strategy we've highlighted this with a star icon.



02

INFORMATION AND ADVICE

We commit to making sure that SCI people, their families and the professionals involved in their care have the information, advice and knowledge they need.

INFORMATION *and advice*

A 111-STYLE ADVICE SERVICE FOR INJURED PEOPLE'S NEEDS



★ Marc's was one of 1,589 requests for support addressed by our Advice Line last year. Around one caller in every six, like Marc, went on to benefit from other SIA services such as peer support and clinical advice.

We commit to making sure that SCI people, their families and the professionals involved in their care have the information, advice and knowledge they need. We supply this daily via our Advice Line and various communication channels alongside regular training for professionals through our SIA Academy education programme.

Advice Line

Our Advice Line is often the first port of call for many people struggling with any aspect of life after SCI. SIA member Marc recalls how his first call to our Advice Line changed his life.

"I'd lost the use of my legs, couldn't lift my hands and had no control over my bladder or bowels. I was discharged from hospital with a wheelchair, colostomy, 'nappies' for urinary incontinence and a basic care package – just four brief visits a day – to help me wash, dress and eat. I hardly saw anyone because I was too embarrassed to spend time in company. I spent my days and nights alone, increasingly depressed and anxious, over four long years."

Once he'd discovered our Advice Line and was armed with the knowledge about what was available to him and what he could

expect, Marc felt empowered to live life on his terms again. From nursing advice on managing continence to peer support that helped him regain the confidence and independence to go out, get his own shopping and enjoy the company of his friends again.

"Life changing, when I needed it most."



1,589

requests for support addressed by our Advice Line last year.

SIA ACADEMY

Building confidence to care

"My work saves lives. By sharing my skills with other professionals, more injured people will stay safe and well."

Carol Adcock, SCI Nurse Specialist.



Nurse Specialist training

This year, SIA Academy's team of SCI Nurse Specialists delivered CPD-accredited education and training sessions to around 567 healthcare professionals.

In 2019/20, we ran a healthcare professional Study Day in Manchester – a second session of our popular 'Continence Matters: Introduction to Managing the Neurogenic Bowel in SCI', which 54 healthcare professionals from 30 different district general hospitals, rehabilitation centres and private companies attended.

The safe and appropriate provision of bowel care is one of our members' biggest concerns, which is why we delivered 15 'Managing the Neurogenic Bowel' training days. Unfortunately, some of our outstanding requests for in-house bowel training could not be scheduled for this year, or were postponed, due to the coronavirus pandemic. However, as the year came to an end, other methods of support were being introduced including online training using platforms such as Zoom.

We also held eight in-house 'Good Clinical Practice in SCI' Study Days, which enabled healthcare professionals to learn important key skills in their own working environments.

"Having attended SIA's training on managing the neurogenic bowel, I now feel empowered and confident to support patients with bowel management, educate colleagues and review our bowel management policy." Neurogenic bowel training attendee from a general district hospital.

In-service training

"Building relationships and sharing best practice means healthcare professionals know where to find additional support for everyone who needs it." Carl Martin, Peer Support Officer, South Coast.

Solicitors' training

Our SIA Academy teams up with other experts in the field of SCI to host training days to give legal professionals and expert witnesses greater insight into the complexities and lifelong impact of SCI. We aim to host two solicitors' training days annually but, due to the coronavirus, had to cancel our session in Manchester planned for 12 March. At our October training in London, organised with Outer Temple Chambers, we had 57 attendees including 38 delegates, six exhibitors and several expert speakers. We also hosted our Expert Witness seminar in February, with 23 attendees and six speakers. The aim of all these sessions is to generate income and to ensure that those who work alongside people affected by SCI can support them to lead a fulfilled life.

Solicitors' guide

This printed guide lists specialist personal injury lawyers and – as a new addition this year – wealth managers. It gives information about physical access to firms' premises, shows their areas of expertise and number of years' experience.

SIA's SCI Nurse Specialists delivered CPD-accredited education and training sessions to around

567

healthcare professionals.

★ Our Peer Support Officers hosted 88 in-service training sessions for 1,500 healthcare professionals during 2019/20. This activity was a fundamental step in achieving our long-term strategic objective of influencing the quality of health and care services received by SCI people.

COMMUNICATIONS

Keeping SCI people informed and connected

Getting connected and keeping informed

- 84% of respondents to our 2019/20 pulse survey had confidence in SIA's ability to provide information to meet their needs.
- 81% felt confident that SIA empowers them to understand the rights and opportunities available to them.

Our digital presence

This year, 90,970 people visited our website – www.spinal.co.uk – an increase of 12% on the previous year. It's used by a growing number of people affected by SCI as a go-to source of information.

Our monthly eclips newsletter, summarising SCI news, reached 11,153 people during the year, with 1,368 new subscribers signing up to receive our regular updates by email.

Our Twitter followers grew by 8.5% to nearly 17,095, while our followers on Facebook grew by 1.78% to 7,874. Personal insights into SCI people's lives and details of how to access our services achieve the best reach and engagement.

We secured a Google Grant and look forward to using that to grow our digital presence in 2020/21 under the leadership of a new Digital Engagement Manager.

Sharing stories and expertise

Our bi-monthly FORWARD magazine plays an essential role in informing the SCI community on issues that matter most to them. As well as giving SCI people a platform to share their stories, we publish articles from leading experts and partners, providing crucial access to specialist knowledge for an ever-increasing number of readers.

Spreading the word beyond the SCI community

As part of our goal to enable every SCI person to lead a fulfilled life, we need to raise the profile of SCI beyond those immediately affected by it. This year we've worked with broadcast and print media outlets to provide interviewees who can give insight into life with SCI and how our services can help. National coverage on Channel 4 and the Radio 4's You & Yours programme was complemented by regional coverage on BBC Three Counties Radio, MK Radio and BBC Radio Northants.

Coronavirus communications

To support our response to the pandemic, regular, frequent communications over digital channels became paramount. The Communications & Engagement team worked with all colleagues and partners to create and curate online written and video content relating to coronavirus and SCI.

84%

of respondents to our 2019/20 pulse survey had confidence in SIA's ability to provide information to meet their needs.



"SIA is doing excellent work keeping people up-to-date with information and help during this pandemic."

Respondent to our members' annual 'pulse' survey



03

ADVOCACY AND REPRESENTATION

We commit to making sure that SCI people, their families and the professionals involved in their care have the information, advice and knowledge they need.

ADVOCACY *and representation*

A SYSTEM THAT WORKS **FOR ALL**

We know that only one person in every three who sustains an SCI will receive specialist care and rehabilitation at one of the UK's 11 NHS SCI Centres. It's our mission to make sure no one misses out and that everyone with an SCI gets the best possible care from the moment they are injured for the rest of their life, at home or in hospital.



SCI Nurse Specialist service

Our SCI Nurse Specialist service uses its clinical expertise in SCI nursing to offer information, advice and guidance on all aspects of care.

Whenever an SCI person is receiving treatment in a non-specialist setting (for example, a district general hospital or rehabilitation unit), our SCI Nurse Specialists will work alongside the treating care team to raise awareness of and understanding about SCI-specific issues such as bowel and bladder management, skin care and autonomic dysreflexia (a medical emergency characterised by high blood pressure and falling heart rate).

Our SCI Nurse Specialists also work directly with SCI people, offering support and guidance on issues like bowel management in hospital and at home.

"SIA's specialist nursing service never fails to respond and provide information and advice...giving me reassurance and support when I need it. They arranged a hospital visit from an SCI Nurse Specialist when we most needed it for my Mum and have followed up ever since."

Daughter of SCI person

- ★ Thanks to The October Club's generosity we expanded our SCI Nurse Specialist team in 2019/20. This means we can now train 1,000 healthcare professionals each year and reach at least 1,000 of the 2,500 people who sustain an SCI every year.
- ★ In 2019/20, our SCI Nurse Specialist service supported hundreds of SCI people, with 337 new referrals – a 50% increase on the previous year – through 1,404 visits and follow-up support sessions.

CONTINUING HEALTHCARE (CHC) casework

People with high-level SCI can be dependent on carers for essential day-to-day care such as showering, eating and taking medication.

This is funded by NHS Continuing Healthcare (CHC) and allocated by local Clinical Commissioning Groups (CCGs). All too often funding is refused or taken away from SCI people who desperately need it. Michael was one such person. SIA's unique CHC casework service means we can support and advocate on behalf of SCI people like Michael to get the care they need to return home and rebuild their lives with their families.

"We never expected Michael to be declined funding. His hospital team felt he more than qualified. It was a complete body blow when we received the news. We didn't know which way to turn."

"Then we heard about SIA's Advocacy service and met Simon, Advocacy Manager for SIA. Simon's expertise and knowledge became apparent immediately. We placed all our trust in him, and it was such a relief for the whole family."

Michael's wife, Margaret

★ Michael is just one of the 196 people we supported this year through our CHC Casework service. Through our campaigning work we're fighting for a better system that's quick, accurate and fair.

★ We continued to provide our unique CHC online learning tool free of charge to SIA members to empower people with the knowledge they need during the application process.



"Simon's expertise and knowledge became apparent immediately."

Margaret, Advocacy service user

CAMPAIGNING PUSHING FOR A BETTER DEAL FOR ALL

Sadly, there's still a huge need to campaign for better care for SCI people. Lives are being put at risk by dangerous, misinformed decisions taken behind desks and beside hospital beds.

More than a number: our manifesto for change

This landmark report, with support from Aspire and Back Up, describes the impact on people's lives of NHS Continuing Healthcare, an NHS-funded package of care intended to support people with the highest healthcare needs to live independent, healthy and fulfilled lives once they leave hospital. The report demanded urgent action to save lives, driving desperately needed policy change to ensure some of the most vulnerable SCI people in our society are no longer excluded, neglected or put in danger, insisting that:

1. Care packages must meet people's needs and support them to live where they choose – not forcing them into care homes against their will.
2. Eligibility decisions must comply with the Care Act – simplifying eligibility criteria to make decision-making faster and more accurate.
3. Clinical Commissioning Groups must be held to account – penalties for unlawful approaches, inappropriate recommendations and a proper complaints and appeals process that's fast, efficient and independent.

Better bowel care

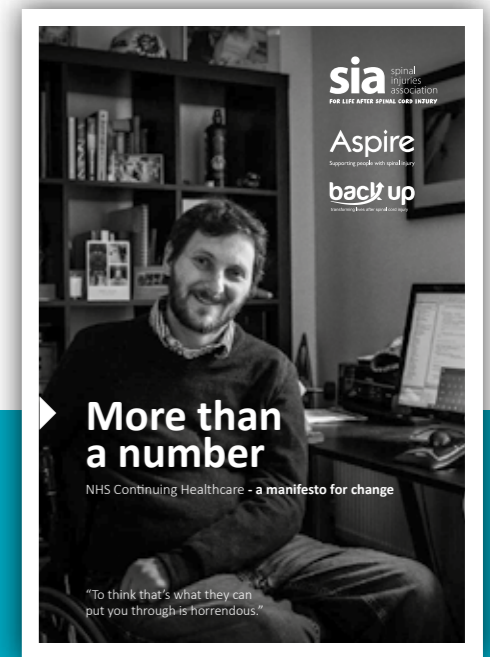
Some SCI people may learn to walk again – but bowel care is something that will affect everyone living with SCI for the rest of their lives. Most SCI people establish a routine that works for them but if this is interrupted – by illness or inappropriate care – the consequences can be life-threatening.

"We need to remember the sense of confidence, personal dignity and self-respect that good bowel care brings to daily life, which can be taken for granted."

Dr Rupert Earl, Chair of Trustees

93%

of respondents to our annual 'pulse' survey of SIA members had confidence in the charity's ability to campaign for positive change.



★ Following an SIA-instigated Patient Safety Alert, informed by SIA members' feedback and issued by NHS England to all NHS Trusts, we saw a 100% increase in uptake on our 'Managing the Neurogenic Bowel' Study Day and by autumn 2019 the number of Trusts with a bowel care policy in place increased to 54%.

"Catherine is my wife, she's not my carer – why should she give up work to care for me? The care package allows me to work, have a life. I can be a husband to my wife, not a burden."

Peter Hamilton, C5/6 tetraplegic, husband, dad, business owner and SIA Trustee

WORKING WITH NHS ENGLAND

and the Department of Health and Social Care

SIA has worked in partnership with both NHS England and the Department of Health and Social Care during the year, to ensure the needs of SCI people are considered as part of any policy or strategic developments.

In doing so, we have achieved the difficult balance of being viewed as both a trusted partner and a constructively critical friend. We will be expanding this vital role in 2020 and beyond.

Working with MPs

During 2019/20, we worked with a number of MPs to further our campaigning aims of better care for all SCI people at home or in any setting. SIA members arranged introductions to their local MPs; we met with the (former) Minister for Social Care, Caroline Dinenage MP, and arranged visits to specialist spinal centres to increase MPs' awareness of SCI.

All-Party Parliamentary Group on SCI

SIA continues to provide the secretariat for the All-Party Parliamentary Group (APPG) on SCI, which gives MPs an insight into the issues facing SCI people and how they can help address these. Ian Lucas MP has chaired the group since its inception in 2008 but didn't stand for re-election in December's General Election so the APPG will go forward with a new Chair. SIA thanks Ian for his tireless support and commitment and wishes him every success in the next phase of his career.

- ★ Our campaigning activities are vital to achieving our long-term objective of influencing the quality of health and care services received by SCI people. In the year ahead, we'll continue this work via online channels in consideration of social distancing due to coronavirus.

Rebuilding Lives Awards

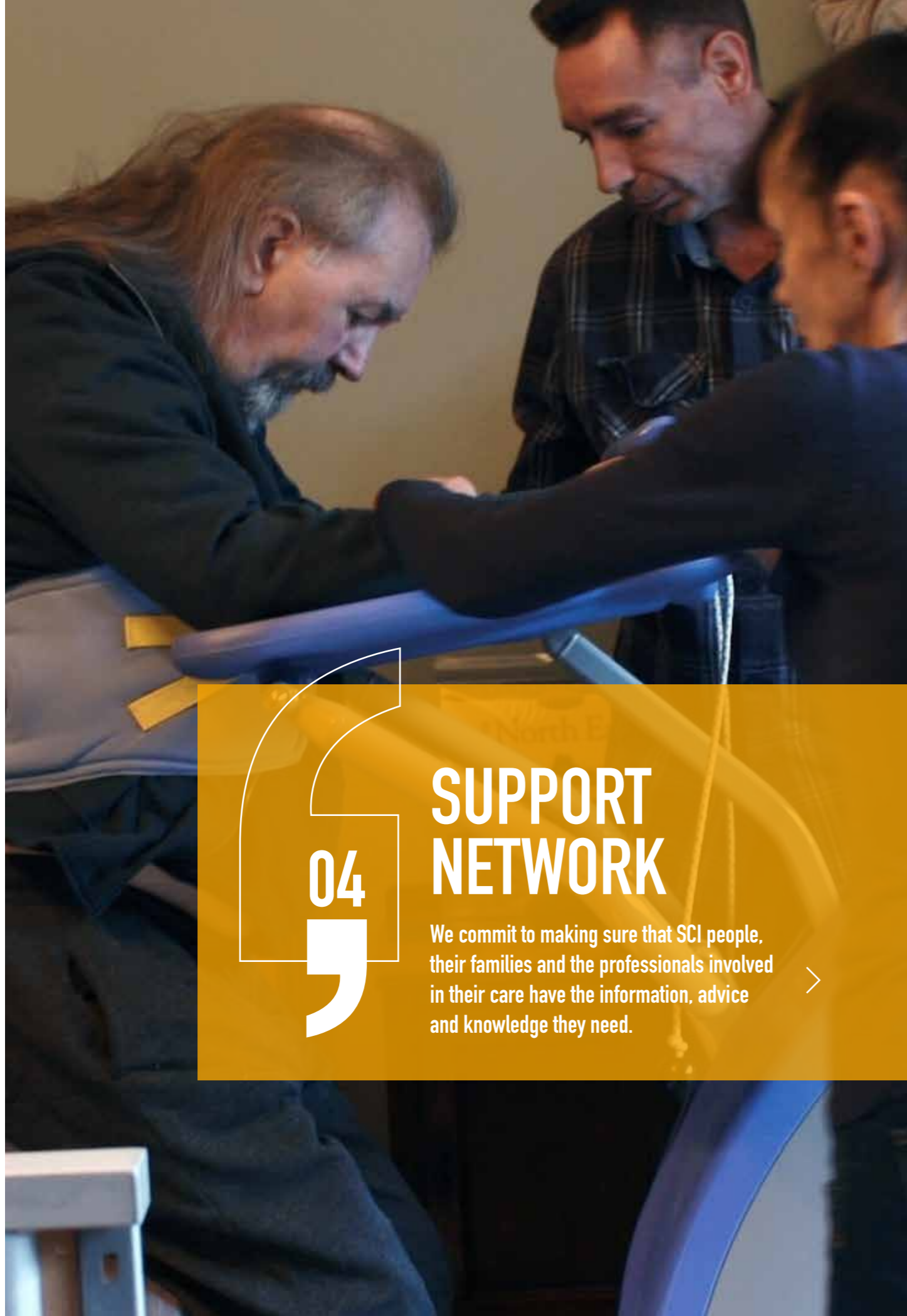
We were delighted to welcome our Patron, HRH The Princess Royal, to our seventh annual awards ceremony kindly hosted by Williams Racing in July 2019.

Our annual awards celebrate the achievements of inspiring people and teams who have gone above and beyond to help SCI people lead fulfilled lives. Award categories recognise the outstanding achievements of individuals and groups in the SCI community, who inspire others through their work, hobbies or during their rehabilitation. As well as acknowledging people's successes and the impact of these on others, the awards play an important role in raising awareness within and beyond the SCI community.

- ★ We received over 130 nominations to the 2019 awards, with nominees from right across the SCI community.



SIA believes there will be exciting opportunities to expand and consolidate these relationships in the future, to the benefit of all SCI people.



04

SUPPORT NETWORK

We commit to making sure that SCI people, their families and the professionals involved in their care have the information, advice and knowledge they need.

SUPPORT network

BY YOUR SIDE,
EVERY DAY.

2019/20 saw the beginning of our commitment to grow a network of support across the country for every injured person. Support from people who have lived experience of an SCI gives newly injured people and their families practical advice and emotional support as well as positive insight into life beyond injury. Ongoing support is crucial, especially during difficult transitions such as returning home from hospital or going back to work.

"It is such a comfort to have someone who I can be completely honest with who understands my frustrations and who gets where I'm coming from. Ian gave me the confidence to get back to work – and to the rock concerts that have provided the soundtrack to almost every decade of my life to date!"

Peter Smith, 63, C2/3 tetraplegic, Professor, Dad, Grandad and rock gig goer



You can watch Peter's story on our YouTube channel here: <https://youtu.be/EgGGBRvrdQ0>

★ Peter was just one of the 4,337 SCI people who were supported this year by our Peer Support service. Delivered by a 13-strong team who all have lived experience of SCI, a total of 1,308 support sessions were given to SCI people and their families and friends, providing vital practical and emotional support when it was needed most.

100%

of our Peer Support Officers are spinal cord injured



SUPPORT network

"Please continue being a conduit to other agencies and opportunities."

Respondent to our members' annual 'pulse' survey



Counselling

This service, offered free-of-charge to people affected by SCI, provides support to SCI people and members of their family with any issues affecting their mental health and wellbeing. Although our Peer Support Officers are well equipped to provide emotional and psychological support, having a qualified counsellor is an important addition to our support network. To meet increasing demand, we have brought this role in-house from April 2020 with the added benefit of a peer-led perspective.

Cafes

We launched our virtual cafes in conjunction with partners This is Spinal Crap and Back Up as part of our response to the coronavirus pandemic towards the end of the financial period. It has proved a positive and cost-effective way to connect SCI people with each other, our own in-house specialists and experts in fields as varied as nutrition, rehabilitation, mental health and psycho-sexual wellbeing. It fulfils our new objective of linking the SCI community with the people and organisations they need to lead a fulfilled life and so it is something we plan to develop next year.

★ **Our counsellor provided 141 counselling sessions to SCI people and their families and friends last year.**

OUR WORKFORCE staff and volunteers

HALF OUR STAFF AND ALMOST ALL OF OUR TRUSTEES ARE THEMSELVES INJURED

With so many of our staff and volunteers having lived experience of SCI, we have a strong insight into the daily challenges that face everyone affected by this condition. This valuable understanding helps maintain focus on our key strategic objectives and how we'll achieve them. We recognise that our staff team is our biggest asset and, with continued investment, will provide us with much of the expertise needed to achieve our goals.

- ★ **252 volunteers gave 5,553 hours of their time – a huge increase of 20% on the previous year. Our volunteers all offer a unique skillset that can be employed across various areas of our work, including fundraising, peer support, administrative support and content contribution to our bi-monthly FORWARD magazine.**

- ★ **Next year, we're launching a recruitment campaign to expand the breadth of our Peer Support Volunteers, as part of our vision for a regional model of support that will help us reach more people who need us.**

Two volunteers explain the mutual benefits of volunteering for SIA.

Volunteering: fundraising support

"When I entered a room, I felt defined by my medical injuries. I was the girl who had the car crash. I spent years trying to move past this to become just a friend, a sister, a colleague – just Steph.

"Volunteering with SIA and working with people who live with SCI has helped me see that you can be both things – you can embody an identity where your accident is part of who you are. When I volunteer for SIA, I feel confident and proud to be part of such a worthwhile organisation that helps so many people." **Steph Watson, SIA volunteer**

Volunteering: peer support

"Carl Martin, one of SIA's Peer Support Officers, really helped when he visited me while I was working out my place in the world during those first few weeks after my accident. Peer support made such an impact on me that I felt I would like to be able to help others in a similar position through their journey.

"As well as supporting SCI people in hospital, we build relationships with medical professionals and explain how the charity can help those who are newly injured. We can also visit people in the community to support them and their family later in their journey. It's an incredibly rewarding position, feeling that you are making a difference when someone needs it the most."

James Dwyer, Peer Support Volunteer for the South Coast

OUR PARTNERS *and supporters*

TURNING PASSION INTO PROGRESS

Our life-changing work is only possible thanks to the generosity of our supporters.

Fundraising income exceeded the target for the year, mainly due to SIA being chosen as the 2019 charity partner of The October Club which raised more than £880,000 to be used over the next three years. There were no material differences to fundraising expenditure for the year. The Investments and Partnerships team, responsible for fundraising, underwent a minor restructure to build capacity in the following key areas: developing compelling funding and partnership propositions; enhancing donor and partner relationships; delivering a suite of engaging fundraising events; and supporting de-centralised fundraising. This positions us well to grow and diversify sustainable income streams.

When people affected by SCI support us, not only are they securing the future of the charity, but they also find a focus and purpose. Fundraising often provides an opportunity to meet and engage with new people. By helping us to help others, many SCI people are taking steps to rebuild their own lives by forging new connections in their own communities.

In 2019/20, we received income from 1,586 donors, 235 fundraisers, 109 charitable trusts and more than 100 companies.



SIA was delighted to be chosen as the 2019 Charity Partner of The October Club. Through a raceday at Ascot in the summer and a dinner at The Savoy Hotel in the autumn, members of The October Club raised significant funds towards the expansion of our Specialist Nurse service and vital capacity-building activities.



We'd like to thank **everyone** who has supported our work throughout the year.

SIA was chosen as the 2019 charity partner of The October Club which raised more than

£880,000

to be used over the next three years to expand the SCI Nurse Specialist service

OUR PARTNERS and supporters

"SIA supporters helped to raise money for SIA by taking part in a range of events."



Challenge and community events

SIA supporters helped to raise money for SIA by taking part in a range of events including the Virgin Money London Marathon, the Prudential RideLondon, Superhero Triathlon, an overseas cycle ride, fish and chip suppers, plus many of their own creative challenge and community activities.

"SIA's overseas cycle events are a real physical and mental challenge – but the sense of achievement is one that will stay with me forever."

Gary Dawson, SIA Peer Support Co-ordinator

Yuki Brien raised almost £600 from a coffee and craft morning with her friends and family. She decided to do something for SIA after our Advocacy team supported her son, Kai, whilst he was studying at university in Birmingham. Representing Kai, we worked with the university and the local council to resolve some issues with his living and learning arrangements.

Regular giving and legacy income

This year we received more than £26,600 from 329 regular donors, including payments received via direct debit and payroll giving. We are always privileged to receive gifts in Wills from people who have supported us throughout their lives. This kind act safeguards the future of the charity and allows us to make and achieve long-term plans. This year, we gratefully received £77,798 through gifts in Wills. We offer all bereaved supporters the option to set up a tribute fund on our MuchLoved platform.

Charity of the Year partnerships

It's an honour to be selected by a company or community group as their Charity of the Year partner, and this year eight organisations chose SIA so they could further our fundraising efforts.

Corporate sponsors and partners

More than 100 companies contributed to our work this year through strategic partnerships, corporate membership, sponsorship of our services and events, entry in our Solicitors and Wealth Managers Guide and/or charitable donations.

Events

We had to make the difficult decision to cancel this year's Cornflower Ball, due to take place on 12 March 2020, because of the coronavirus pandemic. Instead, we held a virtual version of the event and were amazed at the generosity and engagement it attracted.

Williams Racing has again been very generous in their support. SIA is the Team's Life Charity Partner and they once again hosted our annual Rebuilding Lives Awards in July 2019 at the Williams Conference Centre, Oxfordshire, which was a wonderful opportunity to celebrate the efforts and achievements of the SCI community.

Trusts and Foundations

All of our charitable services – Peer Support, SCI Nurse Specialists, Counselling, Campaigning, Advocacy and our Advice Line – have benefited from the support of 109 charitable trusts and foundations this year.

Fundraising during and beyond the coronavirus pandemic

At the time of writing the new financial year faces a £1 million income shortfall. In response, we are focusing our resources on income streams that are proving to be more resilient during these challenging times, including corporate partnerships and trust fundraising. We have built capacity in these areas and redeployed other staff across SIA to support the charity's fundraising efforts. Other fundraising activities include a high-value appeal centred on our coronavirus response for SCI people; a second appeal for individual supporters reiterating that message with more personal and specific insights into the difference we're already making, virtual fundraising events and activities, as well as applications to newly-created funding programmes available to charities.



SIA does not pay external professional fundraisers to fundraise on behalf of the charity and we do not have any commercial participator agreements.

We adhere to the Code of Fundraising Practice for the UK as set by The Fundraising Regulator. We have not had any complaints registered with the Fundraising Regulator or any breaches we are aware of with the Code of Fundraising Practice.

To ensure the high quality of our fundraising practices and the protection of vulnerable people, our fundraising staff and volunteers also adhere to SIA's policies on data protection, equality and diversity, health and safety and vulnerable adults.

SOCIAL ENTERPRISE

extending our reach and impact

SIA Case Management

Launched in March 2018, in partnership with Bush and Co Rehabilitation, this service works to identify, plan and meet the long-term care needs of SCI people with a personal injury legal settlement to help them rebuild their lives.



SIA Healthcare

Established in partnership with Bullen Healthcare in 2014, SIA Healthcare is a home delivery service for our members to meet their urology, stoma, pharmaceutical and lifestyle needs. With over 3,000 registered users, this service has been especially valuable to members during the pandemic. The following feedback from the 2019 annual customer satisfaction survey highlights its value.



“Zoe... made my rehab work and found the people to suit me best. Thank you, Zoe for everything. I will keep working and hopefully improving thanks to you.”

SIA Case Management client

“I had terrible problems getting appliances from my local pharmacy. SIA Healthcare changed all that. It’s a five-star service, reliable 100% of the time, with warm and friendly advisors who are always ultra-helpful. They deliver on time, every time. I’d recommend this service to anyone.”

SIA Healthcare member

★ Our SIA Healthcare Call Handlers speak to over 2,000 injured people per month about their appliance and pharmaceutical needs



05

FINANCIAL ACTIVITIES

SIA is committed to the efficient, effective and economic use of all of its resources.

Consolidated statement of financial activities

Spinal Injuries Association

Consolidated statement of financial activities (incorporating an income and expenditure account)

For the year ending 31 March 2020

	Unrestricted £	Restricted £	2020 Total £	Unrestricted £	Restricted £	2019 Total £
Income from:						
Donations and legacies	933,414	247,924	1,181,338	638,248	-	638,248
Charitable activities						
Information and advice	290,079	1,760	291,839	341,425	1,800	343,225
Advocacy and representation	102,126	96,094	198,220	79,745	150,438	230,183
Support network	119,412	221,903	341,315	149,000	185,186	334,186
Other trading activities	466,952	511,555	978,507	578,864	-	578,864
Investments	7,052	-	7,052	4,601	-	4,601
Total income	1,919,035	1,079,236	2,998,271	1,791,883	337,424	2,129,307
Expenditure on:						
Raising funds	539,167	-	539,167	634,687	-	634,687
Charitable activities						
Information and advice	443,789	1,693	445,482	457,701	11,121	468,822
Advocacy and representation	300,721	228,833	529,554	362,097	103,963	466,060
Support network	489,857	200,848	690,705	485,196	134,935	620,131
Total expenditure	1,773,534	431,374	2,204,908	1,939,681	250,019	2,189,700
Net income/(expenditure) for the year	145,501	647,862	793,363	(147,798)	87,405	(60,393)
Transfers between funds	-	-	-	-	-	-
Net movement in funds	145,501	647,862	793,363	(147,798)	87,405	(60,393)
Reconciliation of funds:						
Total funds brought forward	2,442,526	128,505	2,571,031	2,590,324	41,100	2,631,424
Total funds carried forward	2,588,027	776,367	3,364,394	2,442,526	128,505	2,571,031

All of the above results are derived from continuing activities. There were no other recognised gains or losses other than those stated above.

Balance sheet

Spinal Injuries Association

Balance Sheet

As at 31 March 2020

	The group 2020 £	2019 £
Fixed assets		
Tangible assets	1,580,917	1,608,058
Intangible assets	4,755	9,511
	1,585,672	1,617,569
Current assets		
Stock	9,850	24,625
Debtors	599,270	324,935
Short term deposits	850,000	425,000
Cash at bank and in hand	581,649	346,969
	2,040,769	1,121,529
Liabilities		
Creditors: amounts falling due within one year	(262,047)	(168,067)
	1,778,722	953,462
Net current assets	3,364,394	2,571,031
Funds		
Restricted income funds	776,368	128,506
Unrestricted income funds:		
Designated funds		
Property and fixed assets funds	1,585,672	1,617,569
Other designated funds	128,533	8,241
General funds	873,821	816,715
Total unrestricted funds	2,588,026	2,442,525
Total funds	3,364,394	2,571,031

Approved by the trustees on 18.7.20 and signed on their behalf by

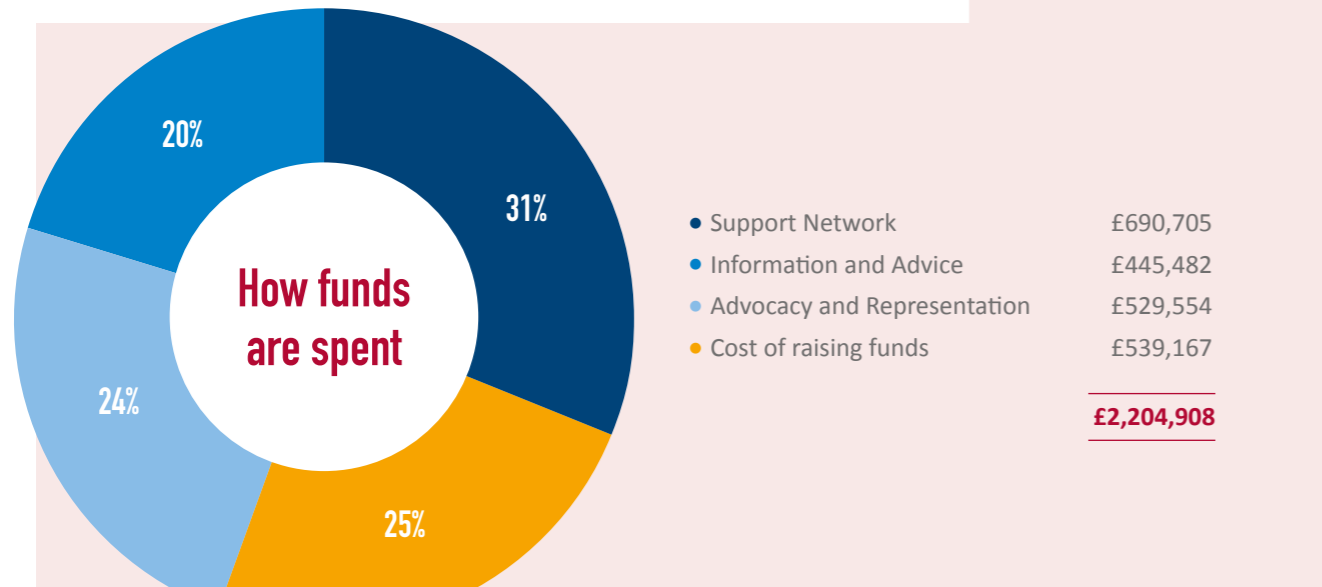


Dr Rupert Earl
Chair and Company Director

A full set of accounts audited by Sayer Vincent LLP are available from the charity commission or on request.

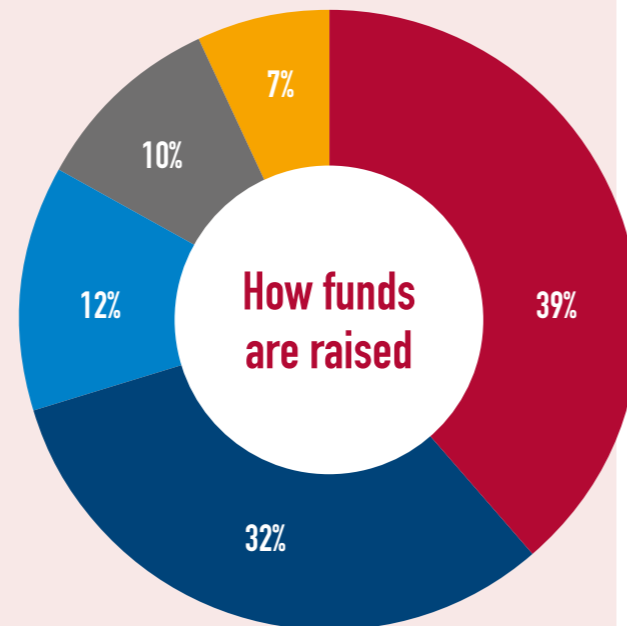
WHAT WE DO

with our money



75% of our expenditure was directly related to our programmatic work.

• Donations & Legacies	£1,181,338
• Grants	£375,756
• Sponsorships & Corporate Membership	£293,125
• Education, Training, Publications	£195,044
• Other income incl. fundraising events and our social enterprise	£953,008
Total	£2,998,271



Together we are transforming the lives of injured people

We would like to thank the following trusts and organisations for their donations of £5,000 or more to fund our services throughout the year. It would be impossible for us to help our members and their families and friends without such invaluable support.



Trusts and Foundations

ABF The Soldiers' Charity
 The ALBORADA Trust
 The Alice Ellen Cooper-Dean Charitable Foundation
 The Bernard Sunley Foundation
 The Brenley Trust
 City Bridge Trust
 Eranda Rothschild Foundation
 The Eveson Charitable Trust
 The February Foundation
 Goldcrest Charitable Trust
 GS Gives Foundation
 James Tudor Foundation
 The James Weir Foundation
 The Lloyd Square Foundation
 Muil Charitable Trust
 The National Lottery Community Fund: Awards for All England
 The Persula Foundation
 Queen Mary's Roehampton Trust
 RAF Benevolent Fund
 Rockcliffe Charitable Trust
 Sobell Foundation
 Sir James Knott Trust
 Sir William Coxen Trust
 Sobell Foundation
 Stewarts Foundation
 The TJH Foundation
 Wesleyan Foundation

Organisations

Active Care Group
 Bolt Burdon Kemp
 Brethertons LLP
 CFG Law
 Coloplast Ltd
 Freeths Milton Keynes Branch
 Harrowells Solicitors
 Hemlow Ltd
 Hollister Inc UK
 Irwin Mitchell LLP
 Leigh Day
 Mid Kent Golf Club
 NewLaw Solicitors
 No5 Chambers
 The October Club
 Outer Temple Chambers
 Pertemps
 Premium Care Solutions
 Royds Withy King
 Simpson Millar LLP
 Slater and Gordon UK LLP
 Sofina Foods
 Total Community Care Ltd
 Toscafund
 Trethowans LLP
 Vanquish Tech
 Wellspect
 Whitefields Golf Club
 Williams Racing

Thank you also to the many people who have made personal donations to SIA this year, ranging from £1 to £85,000. Every penny makes an enormous difference to what we can achieve for spinal cord injured people, their families and healthcare professionals.

Together we
can do so
much more.

Spinal Injuries Association
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www.spinal.co.uk

Patron: HRH The Princess Royal
Life President: Baroness Masham of Ilton
Vice Presidents: Claire Williams OBE, Lady Gillian Howard de Walden,
Paul Roy BEM, Gerard McDermott QC

Registered Charity No: 1054097
Registered Company No: 3175203

As a charity, we rely on donations
and legacies from individuals to
continue providing expert support to
everyone touched by spinal cord injury