Issue #1 | Summer 2024

Scoliosis
Support & Research

BACKBONE

CONTENTS

LOOKING TO THE FUTURE

BY LESLEY MCGINTY, CHIEF EXECUTIVE

I would like to take this opportunity to share what has been going on behind the scenes over the last couple of years and how the change is helping us shape our future as we enter an exciting new chapter of the charity's history.

As you are all aware by now, Scoliosis Association UK (SAUK) and British Scoliosis Research Foundation (BSRF) formally merged in January 2023, and we changed our name to Scoliosis Support and Research (SSR) in January 2024 to reflect both areas of focus of the charity.

We have rebranded with minimal cost to reflect our new name and will be launching a new improved website and merchandise to help raise funds and awareness very soon.

Both charities had a long shared history – sharing staff and offices, so the two Boards decided the time was right to legally merge and become one unified voice for anyone affected by scoliosis. At the heart of both charities was the well-being of every one of you. A united charity provides a single point of contact for all things scoliosis and a stronger voice.

Patients will benefit as there will be greater opportunity for involvement in research – to help inform future treatments and clinical work, with a clear pathway to support and information.

Costs are reduced and simplified and wider objectives mean that fundraising can be much more effective, with a wider range of possible funders. Post-pandemic, raising significant funds is more important than ever for all charities and a blended, cost-effective approach will have more impact than separate approaches.

Looking to the future, our online Zoom Groups continue to be extremely successful, with waiting lists for many. Now that the pandemic is very much in the past we will be establishing regional meetings again and planning how best to resurrect our network of regional representatives to help support this. We would very much like your input on this and will be in touch soon, but if you would like to be a Regional Representative, please let me know.

We continue to attract high quality applications for research and have some fascinating topics being funded which will be published on the new website and highlighted in the next issue of Backbone. Our focus remains, quite simply, to try to identify the cause of scoliosis.

If you have any suggestions of how we can better support anyone affected by scoliosis, please email me direct on lesley.mcginty@ssr.org.uk. I am particularly interested to hear your ideas for the future direction of the charity.

I would like to finish by thanking each and every person who helps us in any way, be it through membership, fundraising, helping with our social media, leaving a legacy, working on research projects, or the myriad of other ways people are involved. Your support and input are invaluable.

Everything we do is for you, so please always keep in touch with us!

WHATEVER YOU DO, DO IT FOR US.

FUNDRAISING

For more information on fundraising, email ellie.wilson@ssr.org.uk.

> *"I am so grateful that I am physically able to attempt this challenge and to raise awareness for those who may not have heard of it."*
>
> *- SOPHIE MILLS*

LONDON MARATHON RUNNERS

We had seven wonderful runners take part in the London marathon for us this year. Challenging yourself to running 26.2 miles is a massive undertaking. We're immensely proud of all our runners. This year was exceptional in that out of our seven runners, four have scoliosis themselves and the other 3 were their family members.

One runner, *Sophie Mills*, said: "It was so the out a doubt one of the hardest things I have ever done but by far the most rewarding. I am absolutely honoured and beyond proud that I have been able to raise a total of £3,500 (I have £30 to add) for a community that is so close to my heart."

"I am so grateful that I am physically able to attempt this challenge and to raise awareness for those who may not have heard of it."

Between them, they raised over £13,000!

CHRIS' BOXING
By Chris Gray

Undergoing a scoliosis correction surgery in 2020 was one of the best decisions of my life. I had a great support circle with me who helped me through recovery and I couldn't be more thankful for them. Especially with how lonely it felt at times, as I've never met another man to this day who had also undergone scoliosis surgery and yet I came out stronger regardless. But I accepted that the metal in my back would hinder me from doing things a normal man could do. Back then I saw it as a disadvantage. But in 2023 when my friend came to me with a flyer for a charity boxing event, I had a lot to think about. I knew the dangers of becoming a boxer with scoliosis. I knew how much work had to be put in for me to keep up. And with that knowledge, I signed up. And since then, I have been putting double the effort in than a normal man would, becoming a fierce fighter in and outside the ring, mentally and physically.

In moments when I felt my back in pain during training, struggling to keep up with those around me, I would remember how much pain I was in before I had that surgery and how many lovely and supportive people I've met because of that experience, those emotions and feelings kept me going no matter what punch was thrown my way. And with that ferocity and tenacity that came from my training, I have been able to go '2-0', winning both fights, one through points, the other my opponent forfeited, and am hoping to achieve '3-0' come this November.

These events didn't just help me raise money for the charity that changed my life, it helped me realise the true advantages having that surgery gave me, as it made me the man I am today, and that's all that matters."

TIM & FUNDRAISING

New Partnership with the Sapphire Running Zone

If you're thinking about running an event for us, you'll now get plenty of training support.

We've partnered with the Sapphire Running Zone to offer all our runners a 12-month subscription package that normally costs £36 a year, totally free.

Email:
fundraising@ssr.org.uk
for a discount code.

This is for runners doing a physical or a virtual event for us. The Sapphire Running Zone is a place that brings runners together from all over the world. The subscription gives access to the extensive blogs, covering seven different running subjects, as well as detailed expert training plans. Market leading podcasts and videos, including profiling running achievements, and support from elite runners are all available. If you'd like to be involved in a podcast or video get in touch!

It's all managed by Tim Rogers, who broke the world record for running a marathon on all seven continents of the world, as well as being one of the first to run all six World Marathon Majors in a year.

VIRTUAL EVENTS

Sapphire Running Zone

Have you always wanted to run a marathon or half marathon, but haven't got time to train? Do you want to be part of an event, but don't want to travel? Virtual events are the ideal alternative. Head to and click on 'Our Events':

https://www.sapphirerunningzone.com/ssr

There you'll be able to find out much more. Sign up to any of our virtual events there and you'll have a full month to do your distance, so around a mile a day for the marathon if you pick that option. You'll get free training support from the Sapphire Running Zone and plenty of fundraising support from us.

Amy Matthews running the London Martahon for SSR.

LEAVING A GIFT IN YOUR WILL

THINKING OF LEAVING A GIFT IN YOUR WILL TO SSR?

Scoliosis Association UK (SAUK) and British Scoliosis Research Foundation (BSRF) merged in 2023 and are now known as Scoliosis Support and Research. We promote and fund high-quality research into scoliosis and other spinal conditions, whilst raising awareness and providing support and information to people affected by scoliosis in the UK.

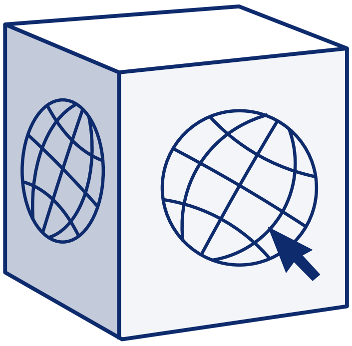
A Will is a way of looking after the people, causes and charities that you care about after you've died. It's the only way to ensure your wishes are carried out. If you die without a Will, you die intestate. This can cause added stress and financial cost to your loved ones. We strongly advise that you work with a solicitor when drawing up or amending your will. Gifts to charities are exempt from Inheritance Tax. They can even reduce the amount of tax your estate has to pay. Please visit the HM Revenue and Customs website for details.

Leaving a gift in your Will helps ensure that Scoliosis Support and Research can continue providing support and information to people affected by scoliosis and their families as well as funding vital and innovative research into scoliosis and other spinal conditions.

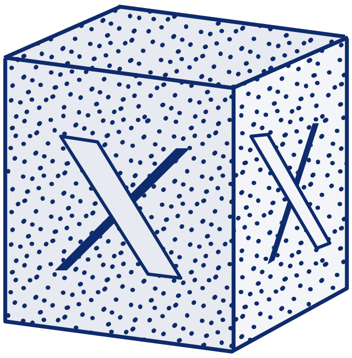
A gift in your Will can mean that people are diagnosed sooner thanks to greater awareness and better research, which can lead to improved outcomes. It can mean that those with scoliosis and their loved ones have a trusted source of information to prepare them for what lies ahead. It can mean that anyone in search of support or advice will have someone to talk to who is there to help and listen to them.

If you have any questions, please contact us on:

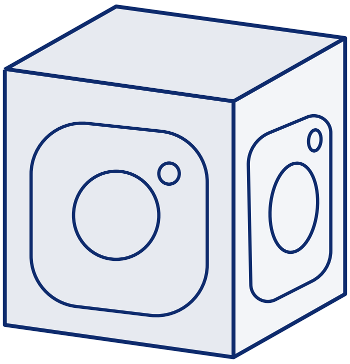
info@ssr.org.uk or
020 8964 5343



www.ssr.org.uk



@Scoliosis_SR



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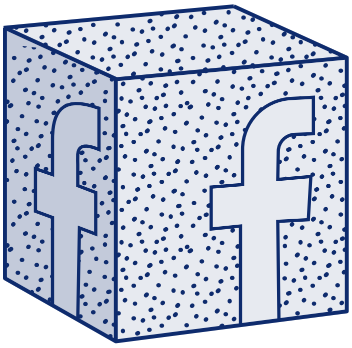


@ScoliosisSR

WHAT WORDING SHOULD I USE TO LEAVE A LEGACY TO SSR?

If you decide to leave a gift to SSR in your Will, there are three main options:

- A percentage of your ‘estate’ (basically, the combined value of everything you’re leaving behind).This is known as a residuary legacy.
- A specific sum. This is known as a pecuniary legacy.
- A specific item.

Depending on which gift you’d like to leave, you can ask your solicitor to use one of the following texts:

For a share of your estate (residuary legacy): I give all/a share of (please state fraction/percentage) of the residue of my estate absolutely to Scoliosis Support and Research, Ground Floor, 329 Latimer Road, London W10 6RA, Registered Charity number 1181463 to be applied by Scoliosis Support and Research for its general charitable purposes, and I further direct that the receipt of any proper officer of Scoliosis Support and Research shall be sufficient discharge to my executors.

For a specific sum (pecuniary legacy): I give to Scoliosis Support and Research, Ground Floor, 329 Latimer Road, London W10 6RA, Registered Charity number 1181463 absolutely, the sum of (amount in figures, amount in words) to be applied by Scoliosis Support and Research for its general charitable purposes, and I further direct that the receipt of any proper officer of Scoliosis Support and Research shall be sufficient discharge to my executors.
For a specific item: I give to Scoliosis Support and Research, Ground Floor, 329 Latimer Road, London W10 6RA, Registered Charity number 1181463 absolutely,(write in here whatever you wish to give) to be applied by Scoliosis Support and Research for its general charitable purposes, and I further direct that the receipt any proper officer of Scoliosis Support and Research shall be sufficient discharge to my executors.

INSPIRING FUTURE RESEARCHERS

AND MY EXPERIENCE WITH SSR

BY MATT BELLAMY

The prospect of starting a research project as a medical student was a daunting thought to me. Who would fund the work, who would have time to help me, where would I even start with ethics and approval. When joining medical school, I viewed research as something only qualified professionals started - not me as a medical student. I knew musculoskeletal health fascinated me and I wanted to be part of the clinical team that took on these complex questions and tried to answer them. As I sit on a train across Kenya for my medical elective, writing and reflecting on this, I am extremely grateful to look back and be proud that I took the leap and started my research journey at an early stage. I hope this short article can inspire further students to get involved with research in their medical school or university time. I am also extremely grateful to Scoliosis Support and Research for funding younger researchers like myself to push this research and my ambitions forward.

Since starting my research journey in my third year of medical school, I have been exposed to the latest advancements, developed my critical thinking and problem-solving skills and created a network of international collaboration. It has taught me hands-on experience in statistical analysis, literature reviewing, and scientific writing, growing my academic and critical thinking skills outside the traditional medical school curriculum. Additionally, involvement in research projects has allowed me to explore various specialties, build mentorship relationships, and has importantly inspired new research questions and novel projects, preparing me for my future career.

My research interest stemmed from an intercalated surgical research degree at the university of Sheffield, alongside the paediatric spinal team at Sheffield Children's Hospital. Two years on, the trials are ongoing and we continue to develop the work. The projects have been awarded multiple prizes at international conferences and we hope to publish this work soon. My main research interest has been building 3D spinal reconstructions using low dose bi-planar X-ray provided by EOS imaging. We use these reconstructions to help visualise the rotation and deformity in the spine in three planes at multiple time points. Traditionally vertebral rotation has been difficult to assess on X-ray, and MRI imaging is often taken lying down, changing the axial rotation. The bi-planar X-ray method of 3D reconstruction has potential advantages in the weight bearing acquisition, lower radiation exposure and measurements from a neutral pelvic stance. So far we have used these to assess the repeatability of 3D models, understand the post-surgical scoliosis spinal corrections and also thinking about the design of rigid spinal braces created for the treatment of idiopathic scoliosis.

If looking to start a research project in medical school, there are a few things I wish I had known before I started. I have listed below some top tips for any interested budding student researchers to know before starting a project:

- Build a great team. Finding a great mentor and team can be difficult but it makes a world of difference. Being proactive on elective or student selected placements during your university years is a great way to develop a team. Make sure to also research the clinical team before starting to make sure they are active in research publications and presentations.
- Consider starting with an intercalation. Taking a year out to learn and focus directly on research without added clinical work or exams is a great opportunity. Furthermore, intercalation supervisors are often experienced in supporting younger years researchers and maximising outputs.
- Complete what you start. In the early stages it may often be easy to say yes to lots of different research projects but don’t underestimate the amount of time that data collection, manuscript drafting and journal edits take once the project has been finalised.
- Apply for ethics early. Ethical approval can often take a number of months from submission to green light. Therefore it is best to start thinking about ethics early (often before your degree officially starts) so you can hit the ground running.
- Look out for local or national early research grants. Lots of universities or societies have dedicated money set aside for early career research. Grants such as the Charles Manning award are regularly open to applications and can really push your research forward.

Following on from this, a key factor in any successful research project or degree is support from the above mentioned grants and prizes. From my own personal experience, I have received funding from Scoliosis Support and Research during my early research projects through the Charles Manning fund. This has helped develop and secure further grant applications for larger funding. Receiving a small grant in the early stages of my research journey has been transformative. This fund has been vital in supporting the dissemination of this work, travel to conferences and collaboration between different research teams. This fund is open to any researcher at a pre-consultant level or an allied healthcare professional, looking for research support and financial contributions to develop, promote and help share their work. Successfully securing grants in these early periods boosts credibility, fosters networking opportunities, and provides essential experience in navigating the grant application process. If you have undertaken any study in spinal or similarly related research during your early career, I would highly encourage you to apply for this award to help fund your future work.

Starting your research journey in the early years of your career is an amazing opportunity. With the backing from Scoliosis Support and Research, I look forward to taking our projects forward and tackling new questions. For any aspiring future researchers, it is an exciting time to embark on the start of your academic career!

AN INTRODUCTION
A SHORT PIECE BY TONI GOODALL

Hi there. Thank you for taking the time to read this short introduction to me! My name is Toni and I'm the person behind the online support groups that are facilitated by Scoliosis Support and Research.

It is such a privilege to facilitate these groups, and to meet the wonderful people who make up this community! In April, it will be a year since I first started working with Scoliosis Support and Research (formerly SAUK). I can't believe how quickly that time has gone, and how much I have learned from those of you I have met.

I know it can be incredibly anxiety inducing to join a group – especially one in which you probably won't know anyone, and where there's no formal structure. I thought I'd introduce myself here so that you can at least get a sense of one familiar face!

As I said, my name is Toni, and I work predominantly as a counselling therapist.

I also facilitate several groups and provide training to fellow professionals and those working in helping roles. Before being a counsellor, I worked in the Disability Social Services Team, and in a hospice for children. This means I've spent a lot of both my personal life and working life straddling the worlds of medical diagnosis, hospitals, and clinical settings, as well as having my other foot in the world of mental health and wellbeing. My hope is that this experience allows me to truly understand the complexities of scoliosis – an experience which is both physical and medicalised but is also hugely impactful on what it feels like to live in our bodies in the world.

The groups are a chance for you to meet others who may be walking similar paths to you, or who may be able to resonate with what it's like to live in a body with scoliosis. Every group is different, and the themes that arise are personal to each group. However, I do have some formats that I follow. I always invite an introduction at the beginning – you can choose to tell people about who you are and what brings you to the group. You can also share your scoliosis story with others should you want to. From this, I gather the themes and questions that are coming up in the group and try to make sure we discuss the questions that have been asked. Sometimes I might share some information – for example about how our brains work in relation to mental health and managing pain. Often, we hear directly from each other the strategies and tools people use to live with scoliosis and to have fulfilling and meaningful lives.

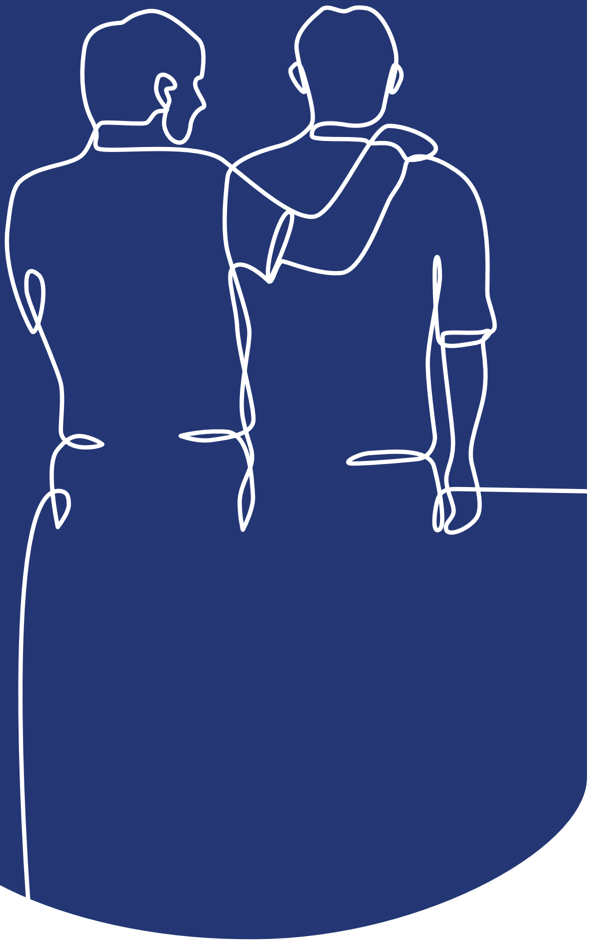
While I am facilitating the group, I hold a collegiate approach – we are all equal, and everyone's voice is valid. You get to contribute as much or as little as you want to the group – there's never any pressure to speak if you would prefer to listen. You can also get comfortable, fidget as much as you need, and have a nice cuppa with you if you want! I'm also always open to feedback about ways the groups can be shaped and shifted to meet your needs.

It really is such a gift to host these support groups as I absolutely know how much we need spaces like this. Humans are hard wired for connection, and we are especially in need of finding our tribe. It can be incredibly meaningful to find ourselves in a virtual room with others who 'get' it.

I hope to meet you in a group one day, or to see you again if you've already been!

Take good care,

Toni x



A TWISTED SOUL

A SCOLIOSIS STORY BY ROSIE LYNCH

When I was 14 years old, I started to experience back pain that became so constant, I went to the GP about it. Instead of being told it was "just growing pains", as I'd expected, I was diagnosed with adolescent idiopathic scoliosis.

MMy curve was only around 27 degrees at the time, and after numerous MRI scans, x-rays, and appointments with specialists, the decision was made that I could manage my curve and pain through daily physiotherapy and painkillers. I started to attend a physiotherapist at Scoliosis SOS in London every month, where they set me exercises to do twice a day. At this point, I had no idea what to expect by being diagnosed; scoliosis was still a very foreign word in my vocabulary. I tried to carry on as a normal teenage girl; dancing five or six times a week, which was such a huge part of my life, and still means so much to me. I remember how frustrated my ballet teacher had been when I told her about my scoliosis, and how upset she'd been to not have noticed it herself. Dance had always been my 'thing', and I used it to forget about my problems as dancing made me so happy.

The pain from my back started to worsen, causing nerve pain in my arms and legs, and making it hard for me to even sit through an hour of a lesson at school. I was given an 'exit card', meaning I could go and lie down and rest if my back pain became too uncomfortable. At this point I could tell that my back had gotten a lot worse. By the time I was 16 and during lockdown, just like everyone else in the world, my back pain was unbearable. The muscles on the left side of my back were so much more overdeveloped than the right, causing an obvious unevenness, even when I was wearing clothes. I hated what my body looked like; I could hardly recognise myself. And on top of that, I was in a constant state of pain, with the dull ache of my back muscles becoming impossible to ignore. On the outside, I was trying my best to put on a brave face, but it got to the point that I could no longer manage the pain day to day.

As soon as we could, my parents and I went to see a consultant and had more X-rays taken. Over the 2 years, my curve had worsened to 46 degrees. Seeing the X-ray shocked me into disbelief. There was no way the snake-like curve on the screen was my spine! The doctor told us I needed a spinal fusion as soon as possible, because the deterioration of the curve did not seem likely to be slowing down any time soon. I cried all the way home from the hospital; the daunting feeling of the unknown rose inside me.
So then as a 17-year-old, I had to face the next challenge in my scoliosis journey: a major spinal surgery to fuse together my vertebrae and keep my spine upright with two titanium rods. I never thought that this would happen and had been told it wouldn't. I was going to have no flexibility between my neck and my hips; never again doing ballet dance like I had done for most of my life, let alone even bend down to tie my shoelaces. As much as this hurt me, I knew that what was happening would, in the long run, all be worth it...

I went into hospital in September 2021

with my mum by my side, ready to face whatever was going to happen to me.
I went under the anaesthetic and woke up 6 hours later with my spine fused from vertebrae T-4 to L-4, with a zero-degree angle of scoliosis and having grown an inch and a half! I had to learn how to sit up and walk again, but after that I was allowed to go home. Over the next year, I was recovering, slowly going back to school, doing my A Levels and then enjoying my summer before starting university. I even managed to go to a music festival, and although I had to be very careful, I felt normal and confident in myself for the first time in 4 years.
Starting university was hard. Especially going to a very sporty university, where everyone seems to have their sport, or their 'thing', I found it challenging to navigate who I was anymore, without the ability to throw myself into dance, because of my spinal fusion. I started to embrace my love for writing more, engaging in my degree and writing in a journal every single day. Uni life slowly started to feel more normal.

Now I am a second-year student at the University of Exeter, studying English and Communications. I am finally feeling confident about my back; I am no longer in constant pain and I've really learned to embrace my scar and my imperfections, as they tell such an important story of my life, and act as a reminder of how strong I've been. I've even started dancing again! The Dance Society has been so welcoming and helpful in giving me alternative moves to do when my back gets in the way. I am so grateful to the girls there who have helped me to fully embrace my scoliosis, my strengths and my limitations. I knew that at some point, I would have to return to dance, as I have not found something that compares to how it makes me feel, physically and mentally. It is hard; I cannot do half of what I used to be able to do, but the sense of community and inclusion is what keeps me going. There is so much support and happiness out there. This community spirit and positivity is also equally felt through SSR. Being able to read through other people's stories, and access so much information about scoliosis has been helpful from the day of my diagnosis back in 2018, to now. I know my mum found it especially useful before any of my family really understood what it meant to have idiopathic adolescent scoliosis.

I want to be able to help others through sharing my own experience with scoliosis, as a lot of what we go through is invisible and can be easily overlooked by others. I think that especially being diagnosed as an insecure teenager, the mental effects of having scoliosis were particularly challenging. I remember feeling lost, and alien in my own body. Being able to read through other people's diagnosis stories and experiences on the website helped me to come to terms with my diagnosis and start to slowly accept my body.
I've recently started a scoliosis blog, which I want to use as a platform to further share my scoliosis story, from my diagnosis to the present day. If my story can reach even one other individual who may have gone through something similar or is currently struggling, I will be happy that I could help even the tiniest bit through sharing my experiences.
"Although my spine may be straight now, just like any ordinary one, a part of me will always be twisted, my experiences will stay with me forever."

THE BASIS STUDY

SUMMARY BY LIZZIE SWABY

The BASIS study has now been running for over 2 years, and there are currently over 280 young people taking part, in 22 hospitals across the UK. The study is being led by Sheffield Children's Hospital and the University of Sheffield and aims to compare the effectiveness of a night-time brace, compared with the currently available full-time brace, in the treatment of adolescent idiopathic scoliosis.

The "full-time" brace is the current back brace offered within the NHS, and is usually prescribed to be worn for 20 hours a day. Although in many patients, it stops the curve reaching a size at which surgery would be considered, the brace needs to be worn until growth has finished which is usually several years. It is recognised that this is a very difficult treatment for many young people.

The alternative, as part of the BASIS study, is a "night-time" brace, which is worn for around 9 hours whilst in bed at night. Because this brace works whilst the patient is lying down, it can provide a stronger force to push the curve straighter.

The night-time brace may sound like a more attractive option for patients, but there is currently not enough evidence to support its effectiveness. The BASIS study should be able to provide evidence that will inform treatment options in AIS in the future.

Of the 280 patients taking part, around half are receiving the full-time brace, and the other half are receiving the night-time brace. Patients remain in brace until they have stopped growing, and the study follows them up to 2 years after they stop brace treatment. BASIS aims to involve 780 patients by the time the study is finished, and we are accepting new patients onto the study until October 2026.

There is also a new study starting very soon for patients who reach the end of bracing as part of BASIS with a spine curve less than 50 degrees, called BASIS2. This new study aims to find out whether wearing a brace for a further 6 months after the end of growth, can reduce the chances of the curve getting bigger after bracing is stopped. We know that this can happen in some patients.

If BASIS2 is suitable for our current patients in BASIS, your local research team will discuss this with you at the appropriate time.
If you'd like to know more about the study, you can visit the BASIS website for further information, and contact details for the coordinating team.

https://basisstudy.org/

BEFRIENDING PAIN

BY MICHELE MENDELSSOHN

Magi, a medical secretary and a mum of three, was driving her son Adrian back to university when he noticed her peculiar driving technique. From the car's passenger seat, he noticed his mum had a quirky way of shifting gears. He watched as she took one hand from the steering wheel and used it to lift her leg and foot on and off the clutch.

"Can't you just move your foot, Mum? How come you need to use your hand to lift your leg?" he asked. Magi didn't know what to say. She had always changed gears that way. It was just how she had to do it: by using her hand to lift her leg and foot. Besides, she had a lot on her plate. Between working in a busy GP's surgery, the recent death of her father and her children studying at two different universities and school, she didn't have the time to look after herself much. So she kept her chin up and ploughed on.

Years later, Magi was catering her grandson's christening. Back and leg pain had become the norm. She carried on regardless. She had already had a battery of tests and scans, physiotherapy and two decompression operations. Nothing seemed to help much. Nobody had mentioned scoliosis. When she was referred to the Churchill Hospital's Pain Clinic in Oxford, the triage nurse recommended she see the pain consultant. There was another period of waiting. But today was the christening and Magi had food to prepare, trays to carry and a party to organise. She wasn't going to let pain hold her back. She never had, so why start now?

Adrian watched his Mum bustling about at the party and could see something wasn't right. He was now a spinal deformity surgeon in Birmingham. He suggested she saw two of his colleagues at the hospital and they led on Magi's treatment. The pain she was suffering, it eventually emerged, was partly due to scoliosis. She had an operation for it in 2015.

When I meet Adrian on Zoom, he is in his consulting room. He's a friendly grey-haired 48-year-old with a research interest in adolescent idiopathic scoliosis. In his practice, he sees patients "from birth to as old as you want." He is Research and Development Director for the Royal Orthopaedic Hospital. "Scoliosis at different ages needs different things," he says. "Young children may have problems with lung development and adolescents describe anxieties about the way their spine looks. As you get older the external is less of an issue. Older people tend to be more concerned with their inability to stand straight or walk as far as they want."

His advice to older patients who want to live better with scoliosis is to try and lose weight and increase their exercise to improve their overall function. "Exercising in water is very good because you're in a protected, supportive environment. The warmth of hydrotherapy helps with both pain and maintaining range of movement." Ultimately, patients' well-being pre-surgery and post-surgery depends on them being as fit as they can be, he says. Operating is always the last recourse. "Often patients don't understand the risks," he says. "Whilst spinal surgery in adults aims to make symptoms better and improve quality of life, it is a big operation that can take a year out of your life for recovery and leave you with spinal stiffness. There are risks associated with surgery that can include both paralysis and blindness alongside other complications."

Adrian is thoughtful about the treatments he advises and the impacts they can have."Is there something I can do to help you now? Is there something I can do to help you eventually? Is the price you pay for undergoing surgery going to be worth it in terms of the benefit? In my mother's case the price was 4 months of sleeping in a bed downstairs and another 6 months to get over her surgery; however she would say that the pain and disability that she had before the operation are much improved and that her quality of life is much better," he says.

Magi's scoliosis operation lasted 10 hours. Since then, parts of her spine have continued to "misbehave" as she has developed a kyphotic neck. Magi was 5'11". She now stands 5' 4".

Her resilience and willpower haven't shrunk a bit. Now in her 70s, she's effervescent and pragmatic. When medical practitioners ask her how she's doing she says "fantastic" and "amazing". She loves gardening (a bit too much, by her own admission), painting and going for walks with the family dog. She still gets pain in her neck, back and hip for which she takes painkillers. "Sometimes, I get so wound up with pain, I feel as though I will burst, like the Incredible Hulk!"

Her post-operative treatment included physiotherapy, psychological therapies and hydrotherapy, which she continues on her own. There's unalloyed delight in her voice when she tells me about her 30 minutes a week of star jumps and running steps in the hydrotherapy pool at Bath University. "I feel great afterwards." She also does an NHS scoliosis Pilates video workout, which she started in lockdown and has kept up since.

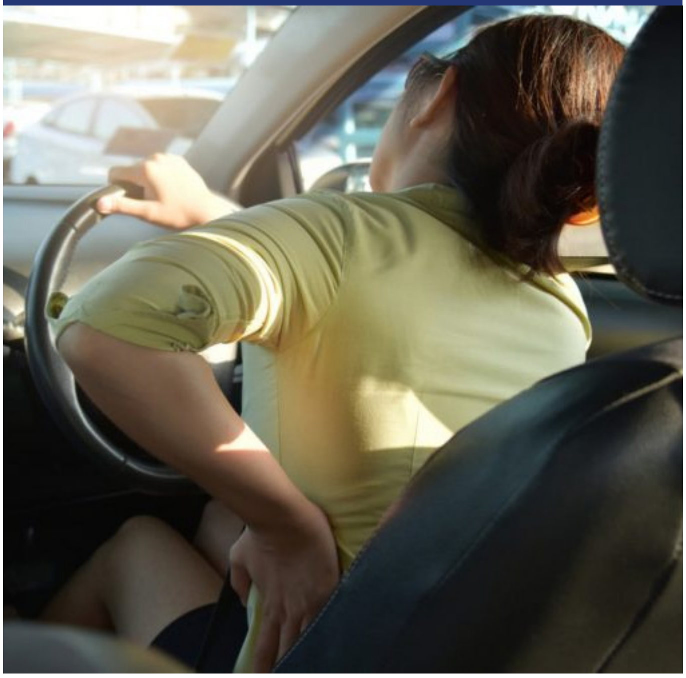
I get the sense that she regrets ignoring her pain for so long, and putting her wellbeing in the backseat. There were other priorities directing her life then. She admits she wishes she had done Pilates when she was younger, but she is making up for that now. She is currently awaiting a hip replacement and her consultant tells her she has the heart and lungs of a 21-year-old, which she is very pleased about. "All that was put into me, it's up to me to continue," she says cheerfully. Her health is her priority. When it comes to living well with the pain of scoliosis, Magi is in the driver's seat.

Links to resources referred to in this articleHydrotherapy at Worcestershire Royal Hospital:
https://www.worcsacute.nhs.uk/pain-management-services/pain-specialised-physiotherapy/

Bath Sports Training Village Hydro Pool:
https://www.teambath.com/sport/swimming/hydro-pool/

NHS Scoliosis Pilates video workout:
https://www.nhs.uk/conditions/nhs-fitness-studio/pilates-and-yoga/scoliosis-pilates-exercise-video/

This video demonstrates Pilates exercises that are suitable for those with scoliosis. This 32-minute class focuses on relieving tension and improving alignment and posture. Regular Pilates practice can help improve posture, muscle tone, balance and joint mobility, as well as relieve stress and tension.



MEET THE TEAM

I'm Lesley McGinty and I have been Chief Executive since April 2021. I've worked in the charity sector for nearly thirty years, working mostly in medical charities but with a lot of variety in between. I come from a fundraising and events background and it is my role to manage the staff team and work with the Board of Trustees to ensure that the charity continues to grow and thrive. We have seen a lot of change since our two charities merged and I am looking forward to a bright future.

LESLEY MCGINTY
CHIEF EXECUTIVE

I'm Ellie and I'm the Community Engagement Manager here at Scoliosis Support and Research. Before this, I worked in the finance industry so I've had a very dramatic career change, but one I am so happy I made! This charity has always meant a lot to me as I've had two surgeries for scoliosis myself. I feel extremely privileged to be able to help and support our community for my job. You'll find me answering our Helpline, engaging with you all via our social media pages and running our community fundraising. I've also loved putting this magazine together for you – I hope it's been interesting, informative and supportive.

ELLIE WILSON
COMMUNITY ENGAGEMENT MANAGER

I'm James and I am the Community Engagement Officer at Scoliosis Support and Research. This is a cause I am passionate about as I had a spinal fusion for Scheuermann's Kyphosis. In my role, I support Ellie and I also work on our Helpline a few days a week answering any questions or queries about scoliosis or kyphosis.

In my spare time I like watching films, going for walks, travelling, and spending time with friends.

JAMES ALCULUMBRE
COMMUNITY ENGAGEMENT OFFICER

JESS' DIARY ENTRIES

19th September 2021

This journal will track a journey that I am putting myself on. On Friday, the 17th September 2021, I finally received official confirmation that I have scoliosis… which I've actually known about for years! It was a HUGE step in the right direction for me after years of physiotherapy, osteopath appointments, pain and endless frustration of not being "cured". I want to write all this down because I am now being referred to a spinal surgeon in Preston which fills me with hope but, my God, it scares me. This is it now. I've waited so long just to get an X-ray and now we're talking about surgery!

24th November 2021

It's taken me almost a week to take in what actually happened.

The surgeon pulled up an X-Ray, That sucker curves in a way I least expected. In my appointment summary, he states that the curve is 60° which surprised me. It would be 10 years this summer when I started to experience pain in the top left shoulder into my neck. I asked if scoliosis affects your hip because mine stiffens up after standing up for too long. He put this down to a rib potentially rubbing against my hip bones.

I like my surgeon. I understand that boxes have to be ticked, checks have to be made and all things have to be considered but I just don't want to be fobbed off like I have been for the last 10 years.

5th May 2022

I regrouped with my surgeon on the 21st April. I thought it was best to bring my mother along too. Whilst we were waiting, my Mum asked me "If you can have surgery, would you have it?" I looked at her and nodded. "I wouldn't be here if I didn't" I said.

My surgeon is lovely, he's so welcoming to both me and my Mum. I'm anticipating the words "There's nothing we can do" whilst he is re-measuring the curve of the new X-ray and MRI scan. He then explained how bad the curve has to be for surgery "We don't look into surgery unless you're hitting about 50° to 60°" My eyes lit up. "Looking at the measurements here… I put you at the 50° mark"

Someone actually believes me! After all

this time!

The recovery time seems more daunting than anything else:

1. 1 week in hospital
2. 3 months recovering whilst the bones are fusing together
3. 6 months until I can do physical activity

I confessed to the room "I'm glad we are having this conversation. I've seen other people have surgery at such young ages but when it came to my case, it's like I never mattered" I looked at my Mum and we both started bawling. My Mum is the only other person who understands what I've gone through. She's driven me across Lancashire to multiple hospitals to fight doctors. It felt right that she was with me on that day.

And so, I am now on a very long, 12-18 month waiting list for spinal fusion surgery.

31st July 2023

I have been waiting for an operation date for 16 months. I've just come off a support call set up by Scoliosis Association UK (now SSR) and it was lovely. We had a good discussion about accepting bodies which has taken a long time for me. I didn't realise how my curve affected my physical appearance. I would try to get rid of this little fat pocket on my belly, but it would never go away. I suddenly accepted my body, it had a reason that it was the way it was. One girl mentioned how she would always have long hair to hide her "hump" that was caused by her spine. It was extremely accepting to hear other people's experiences. I am disappointed that I'm still waiting. I ring the hospital every week to see what's happening and any general updates, last week they told me they're waiting for confirmation if they can use Leeds hospital.

5th January 2024

My surgery is in 2 weeks. Yesterday morning I received a phone call from my surgeon secretary. She asked me to come in the next day to Preston hospital to see him, get some new X-rays and new bloods taken. Today I went with my Mum, I know she had her own questions and concerns. My mum is amazing. She's been through this whole journey with me from the day I started feeling pains in my legs as a young girl. I have faith because our journey together has finally led us here to where we have wanted to be.

21st January 2024

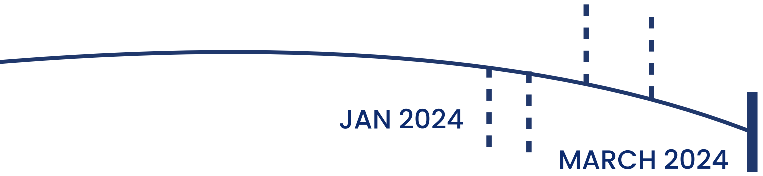
Surgery is complete!
I'm currently in the critical care unit. Morphine can send you into a crazy deep sleep straight away so if I fall asleep for 10 minutes it can feel like an hour! Becky the physiotherapist is brilliant. She got me to roll onto my side with my knees up and sit up in my bed... then I stood up! One thing I've learned is morphine makes you so itchy... like when you have a hair on your arm BUT IT'S ALL OVER YOUR BODY.

My hormones are everywhere. When my toast came this morning, I started crying! My parents visited this afternoon and it was so nice to see them. I think this is where I'm going to struggle most - getting through the week mostly on my own. I know I'm surrounded by a great team of nurses who are treating me so well, but the real work starts now."

30th January 2024

I am 10 days post op. It's a Cliche but it really has been a roller coaster of emotions. The day I came home wasn't easy. The car journey home was the worst pain I've ever experienced. Sitting has been an uncomfortable posture for me as my right hip feels like it's on fire. I felt like my recovery was really starting and now I have to be more independent about looking after myself. I will miss buzzing the nurses for a surprising cocktail of painkillers at 4 in the morning.

10 days on I am really proud of myself. It's a rocky road but I do feel myself on the mend.



12th February 2024

I have pictures of me aged 8, 17 and 21 with friends in my room. I'm now 25 and the three versions of me couldn't be any more different from each other. The 8 year old is just a girl with her future at the palm of her hands. To the left of this picture is the 21 year old at uni. She's still working through it but she's coping and smiling through the pain. On the right is the 17 year old. The first thing I feel is that I let her down. This was the peak of the sadness, pain, confusion, and anger. She contemplated jumping in front of a bus outside college so the doctor's would have no choice but to notice what's going on with her.

Now, 3 weeks post op, I feel like I'm a new Jess. I feel stronger even though I'm still weak in my recovery. I know I can't live in regret. What's done is done and the past can't change, but I bring the power back to me now. I want the next photo on my shelf to be this new exciting era of my life. One that shows my new found strength and the bright future I have ahead.

Tuesday 5th March 2024

I have just passed 6 weeks post surgery. I may be stiff and still a little bit achey, but I am okay. My scar is looking great and I am back to driving! I am still taking cocodamol to handle some pain that I experience in my lower back and hips but I'm not relying on it as much as I was a month ago.
I would say the hardest part has been the anxiety. I don't like being around crowded areas in case I get bumped into.
My X-rays are amazing. Seeing the before and after pictures just blows my mind!
It's been extremely important to listen to my body and my mind to ensure that I can get the most out of the recovery period.
I never thought I would ever be in this position after so long. I am so grateful for my family and friends who have helped me over the years.
I did it.

"The waves crash in, the tide rolls out. I stand before my weakness now" - The Ocean, Tonight Alive.

ANNETTE HOGAN

A SCOLIOSIS STORY

My story began in 1977, at secondary school. One of my fellow pupils commented that my back was a weird shape. I went home and told my Mum. The next thing I knew, I was at the family GP who then referred me to the hospital. It was confirmed after numerous tests that I had Scoliosis.

The day came where I was told to wear a Milwaukee Brace for 24 hours a day. I thought my world had ended. School was the worst time as I had become the school freak. The cruelty of other kids was immense. Fortunately, after a few months, my consultant was happy with how my curve was progressing and so I was allowed to leave it at home and not wear it at school.

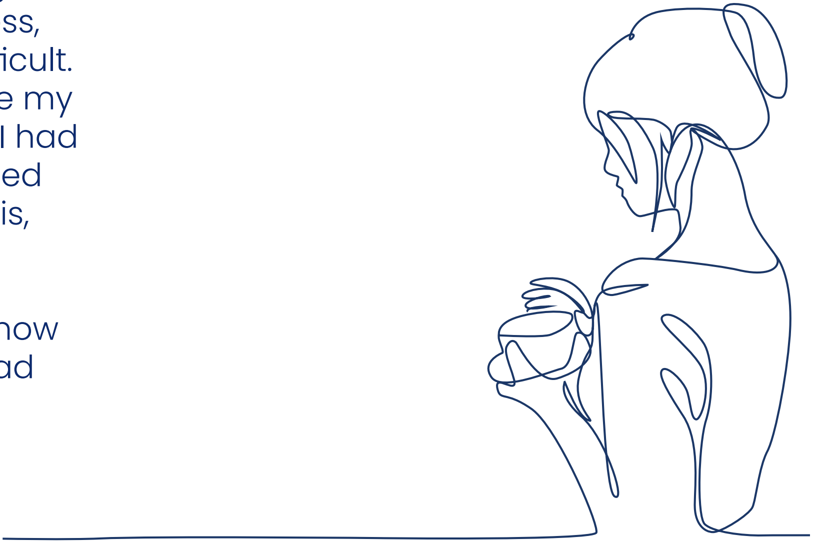
Fast forward to when I was 18 and I had been wearing my brace for four years. Finally the day came. The doctors confirmed that my curve had not worsened and so felt it was time to stop the treatment. I was elated. I could now enjoy my teenage years.

Throughout these years I never experienced pain or felt restricted in my movement. I also felt that my shape was okay. I was blessed to get married and have three boys. However, when I got to my early 50's, things started to change.... I would have lower back pain, tightness, and certain movements became difficult. I eventually thought it was time to see my GP, who referred me to a consultant. I had a full set of X-rays and it was confirmed that I had a spinal imbalance, Lordosis, Thoracic Kyphosis, disc degeneration & an asymmetrical disc collapse. He advised surgery. I was shocked but I now understood why I felt lopsided and had lost height.

I'm now 60 and I know things have worsened. I was (and still am) too scared to have surgery so I cope with my scoliosis as best I can on a daily basis. I have a referral to see a consultant again. I've been waiting a while but these are the times we are living in.

I try not to be down-hearted. I've got five amazing grandchildren who I try to keep active with. I have to keep moving but I know my limits. I felt fine for so many years, so I wonder if it's simply getting older that's made my scoliosis deteriorate. The good thing is, there's so much more information and help now.

I'm still being active - I go on my daily walks, drink lots of water water and stay positive. I like to think this all helps. It's great that so much help is available now. Thank you for listening.



OTHER

AILIE HARRISON ART COMPETITON

Thank you to everyone who submitted their artwork to the previous Ailie Harrison Art Competition. It was beautiful to see the ways you express yourselves through art and we are so happy to be launching this again!

We are looking for aspiring artists, designers, and people who have great creative ideas to design our next Backbone front cover! You can use any artistic medium to do so, be it a drawing, painting, digital artwork, or a photo. The winning artwork will be used as the Autumn/Winter 2024 Backbone magazine cover. Finalist artworks will also be displayed on SSR's social media sites.

There are also cash prizes up for grabs!

First prize:	**£100**
Second prize :	**£50**
Third prize:	**Your choice of item from the new SSR shop**

About the Ailie Harrison Art Competition Ailie Harrison co-founded SSR (previously SAUK) with Stephanie Clark in 1981. They met while working for the late Dr Phillip Zorab, a chest physician at Brompton Hospital, who was researching the effects of scoliosis on the heart and lungs at the Cardiovascular Institute in London. Ailie sadly passed away in July 2014, and she is dearly missed. Alongside SAUK, Ailie's real passions in life were painting and drawing. She was a very talented artist. In memory of Ailie and her tireless commitment to us over many years, we are delighted to offer thiscompetition.

Send your design with your name and age by email to communications@ssr.org.uk by 1st October 2024.

by Aimee Templeman

HILL, PEDDER AND MINNS FUND

Andrew Minns was a founding SSR (formerly SAUK) member and Trustee who left money to set up a fund to support those affected by scoliosis. In 2018, Mrs Patricia Hill and Mrs Daphne Pedder, long time members and supporters of the charity, passed away and left us funds. Part of their legacies have been added to the Andrew Minns Fund to create the Hill, Pedder, and Minns Fund to ensure we can support as many people as possible.

Who can apply?

Members of SSR affected by scoliosis are eligible. Small grants are available to those who require equipment or travel expenses to appointments. The maximum amount granted is £500 and applicants can apply only once a year. Visit our website for further information:

https://ssr.org.uk/supporting-you/hill-pedder-and-minns-fund/

Scoliosis
Support & Research

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