BACKBONE

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Coming together, growing together

By Lesley McGinty, Chief Executive

As we approach the end of another busy year at Scoliosis Support & Research, I find myself reflecting on just how much our community has achieved together. At the heart of everything we do is our community: the people living with scoliosis, their families and friends, our volunteers, fundraisers, supporters, healthcare professionals, researchers, and everyone who helps us reach more people and make sure no one has to face scoliosis alone. It has been wonderful to see this community grow throughout the year.

We are exceptionally proud of the development and growth of our **volunteer programme**. Our volunteers have become an increasingly important part of our work, helping us reach people in their local communities and raise awareness of scoliosis. From visiting schools and sharing information, to supporting local awareness activities and bringing people together through Walk Together, they have already made a real difference. We are incredibly grateful to every volunteer who has given their time, energy, and personal experience to support others. This is just the beginning, and we are excited to continue growing our volunteer network and creating even more opportunities for people across the UK to get involved.

Our focus on community was particularly clear during **Scoliosis Awareness Month in June**. This year's campaign brought people together across the country to share experiences and raise awareness. A real highlight was Walk Together, which became our biggest event yet, with more than **600 people across the UK** taking part in local walks. Seeing so many people come together, whether walking with friends and family, meeting others affected by scoliosis, or simply showing their support, was incredibly inspiring. None of this would have been possible without our volunteers and everyone who helped organise, promote, and take part. We look forward to building on this in the years ahead.

Alongside our awareness work, we have continued to strengthen the support we offer to people affected by scoliosis. Demand for our **support groups, Talking Therapy, and patient events**, continues to rise, giving more people opportunities to connect, ask questions, share their experiences, and access the support they need. These services are an essential part of our work. Scoliosis can affect so much more than the spine. Having somewhere to turn, whether that is a conversation with someone who understands, professional support, or the opportunity to meet others with



similar experiences, can make a significant difference. As our community grows, so does the need for these services, and we are committed to reaching and supporting more people year after year.

Research remains a vital part of our mission, and we are continuing to explore new ways of investing in the future of scoliosis. We want to ensure the research we support addresses the needs of people affected by scoliosis, while encouraging new ideas, approaches, and the next generation of researchers. This year has seen an upturn in funding applications received, demonstrating further positive engagement from within the research community.

As we move towards the end of the year, our Christmas campaign will be an important opportunity to help us continue this work. Every donation helps us reach more people and provide the information, support, and community they need.

When I look back at the year, I am incredibly proud of what we have achieved, but most of all, I am proud of the people who have made it possible. Our community is at the heart of everything we do, and it is a privilege to see it continuing to grow. Together, we are building a stronger, more connected community for everyone affected by scoliosis.

Thank you for being part of it.

Celebrating our incredible fundraisers

Every year, we are inspired by the creativity, determination, and generosity of the SSR community, and 2026 has been no exception. From marathon runners and mountain trekkers, to cake sales, dance challenges, sponsored runs, and everything in between, you have found brilliant ways to raise funds and awareness for people affected by scoliosis.

One of the biggest highlights was **Walk Together**, which brought more than 600 people across the UK together and raised an incredible **£30,000+**. To everyone who took part, organised a walk, raised money, or showed their support, thank you. You showed just how powerful our community can be when we come together.

We have also seen supporters take on incredible personal challenges, from marathons in London, Brighton, Manchester, and Edinburgh, to the Scafell Pike Trek, alongside countless local fundraisers, happening across the country.

We wish we could name every single one of you, but there simply isn't enough room! Here is just a snapshot of some of the amazing people who have fundraised for SSR this year. Your support helps us support more people, raise awareness, and invest in the future of scoliosis.



Cambridge Walk Together



Imogen Byrne – 60 miles in 30 days

Cardiff Walk Together



London Walk Together





Scafell Pike Trek - June 2026



Caitlin - Aberdeen Kiltwalk



Dorothy Fellows - Ten Tors 35-mile Challenge



Leah Savage - "Everesting" Saint Patrick's Mountain

Glasgow Walk Together



Ailie Harrison art competition

Thank you so much to everybody who submitted an entry to the Ailie Harrison Art Competition. We have had some incredibly unique, creative, and personal entries and picking a winner was extremely difficult.

Please see our 3 winners below:

1st Place - Sonya Samoylenko



2nd Place - Quinn Pedelty - Age 11



3rd Place - Amelie Abraham - Age 10

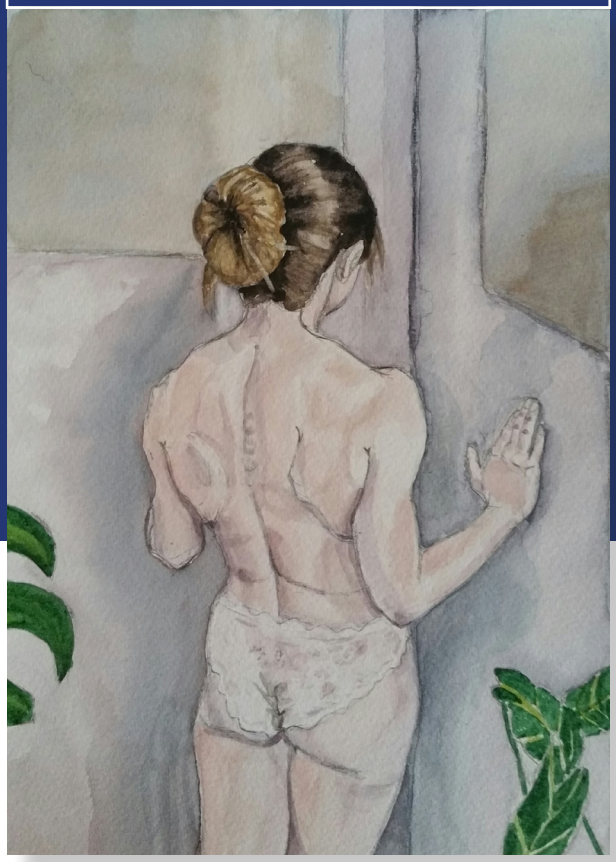


And our runners up / honourable mentions:

Runner Up - Julie Hickman - Age 64



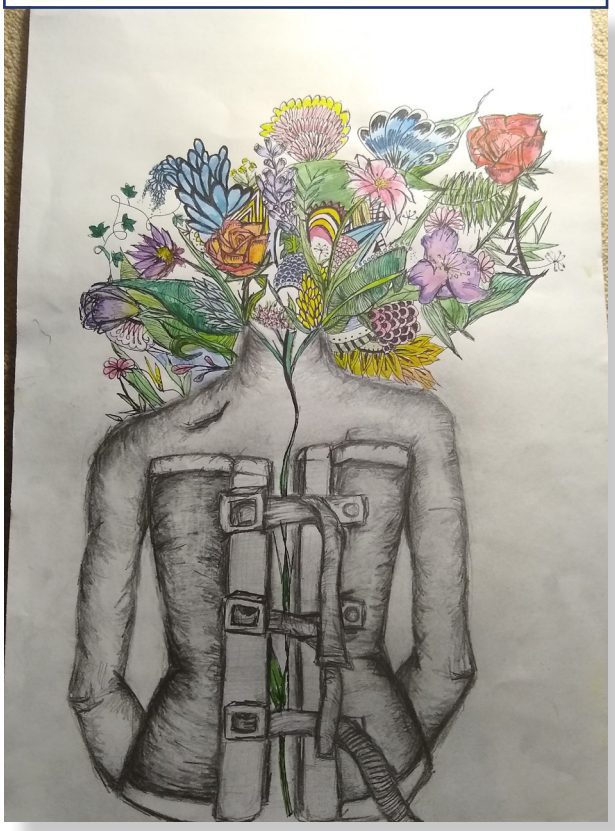
Runner Up - Barbara Hulme



Runner Up - Rachel Boden - Age 43



Runner Up - Charlotte Boggon - Age 23





Meet Grace Winterburn, host of Beyond the Curve

Have you listened to Beyond the Curve yet?

We recently introduced you to Grace Winterburn, the host of our brand-new podcast, Beyond the Curve. Since then, Grace has been sitting down with inspiring guests to talk about scoliosis, spinal fusion, life after surgery, and much else.

Across the first four episodes, Grace has been joined by Gabby Allen, Rita Simons, Tony Betts, and Ellie Franklin, each sharing their own experiences, perspectives, and stories.

But who is Grace, and what brought her to scoliosis advocacy and podcasting in the first place?

Hi, I'm Grace, host of Scoliosis Support & Research's Beyond the Curve podcast.

I was diagnosed with scoliosis at age 8, and by 11 I was told I needed major spinal fusion surgery to correct my 90° and 60° curves, as my scoliosis was too severe for a back brace. In 2015, little me was wheeled down to theatre at the Royal Orthopaedic Hospital in Birmingham.

When I woke up, I was surrounded by doctors and my parents, who told me: "You didn't have the surgery, you vomited under anaesthetic."

As devastated as I was, I had to accept that surgery would be attempted again two weeks later. On 26 February 2015, we tried again. This time, everything went to plan. 12 hours later, a very drowsy me woke up. The first thing I tried to do was sing (I'm a singer!), because I was so worried the fusion would affect my voice.

The next morning, with the help of nurses and a physiotherapist, I stood up and realised I had grown 3 inches overnight. I walked as far as I could, determined to prove to myself that I still could.

During surgery, I lost 2 pints of blood and later needed a transfusion. I also had an anterior release procedure, meaning surgeons accessed my spine from the side and removed two ribs. My right lung had to be deflated, and I had a chest drain inserted, which I can confidently say was the most painful part of the entire experience.

After 5 days in hospital, I went home. I had to do breathing exercises while my lung recovered, and 3 months later, I was back at school.

Fast forward 11 years.

At 23, I am now living life to the fullest with 2 titanium rods and 23 screws in my spine, and a residual 19° curve. I document my fitness and life-after-fusion journey on Instagram and TikTok to help inspire others with scoliosis and spinal fusion, because our curves and scars tell powerful stories.

The little girl who had to learn to walk again could never have imagined becoming a woman deadlifting 80kg, learning pull-ups, and running for miles.

In May 2025, I completed my first half marathon, the AJ Bell Great Birmingham Run, raising money for the Royal Orthopaedic Hospital to give back a fraction of what they gave me: a new spine and a new life. Crossing that finish line in the city that saved me was so emotional. 11-year-old me would have been so proud.

In October 2025, I completed my first HYROX race, again in Birmingham, proving once more that scoliosis and spinal fusion do not make us weak.

Life after spinal fusion has been incredible. I continued to dance, sing, and perform throughout my teenage years, and later began my dream career in television, most recently working on BBC's Morning Live as a social media assistant, producer, and photographer for nearly 2 years.

I now work freelance as a content creator, photographer, podcaster, and singer, and have recently been travelling around Thailand and Australia with a heavy backpack, may I add, something I never thought I'd be strong enough to do!

I also host my own podcast, The Screw Loose Podcast, where I have had the privilege of meeting so many inspiring people in the scoliosis and spinal fusion community.

That experience is part of what made Beyond the Curve such an exciting opportunity for me. I know how powerful it can be to hear someone else talk openly about their experiences, whether they are going through surgery, navigating life after fusion, dealing with the challenges scoliosis can bring, or simply trying to figure out what comes next.

That is what I hope Beyond the Curve can do. Across our first four episodes, I have had the chance to sit down with Gabby Allen, Rita Simons, Tony Betts, and Ellie Franklin and hear their very different experiences and perspectives. There are stories about scoliosis, surgery, recovery, fitness, careers, mental health, and life beyond the curve.

If you haven't listened yet, now is the perfect time to catch up.

Search for Beyond the Curve wherever you listen to podcasts, and join us for conversations that go beyond the diagnosis, the X-rays, and the surgery. Without spinal fusion, I can't imagine where I would be. What I do know is this: we are stronger than we think we are.

I can't wait for you to hear these stories.



Lucy's story

Learning to live fully in the body I have

In this deeply personal story, Lucy shares her journey with scoliosis, from her diagnosis at 14 and spinal fusion surgery at 16, through years of chronic pain, further surgery, and learning to advocate for herself. Lucy's story is one of resilience, but also of the uncertainty, frustration, and difficult decisions that can come with living with scoliosis. From questioning whether her pain was "worthy" of action, to completing a marathon and continuing to challenge herself physically, Lucy reflects on what recovery has really meant to her.

At 14 years old, I was diagnosed with scoliosis. I remember crying in the hospital car park, trying to hide it from my parents before going back to school that day because I wanted to pretend everything was normal and fine.

2 years later, I was told I needed spinal fusion surgery.

Once I came to terms with it, my attitude was essentially: "OK. Let's get this over with." I have always had a black-and-white relationship with my scoliosis: either everything is fine, or we fix it. Of course, life is never that binary, but that was how teenage me coped.

I don't need to tell the readers of this magazine how painful and frightening spinal fusion surgery is. Being 16, I was placed on the children's ward. I was in the hospital for 6 days, 2 of them in the ICU. My parents stayed with me for most of that week; I think it was scarier for them than for me. They gave up their summer to look after me.

Going back to school 2 months later was hard. 16-year-olds are not renowned for their empathy. I became very depressed around this time, though it was only years later I realised it stemmed from the major, traumatic experience my body had endured.

But the story gets better.

Over the next year, I recovered, returned to something resembling normal life, and went through the usual chaos of being a teenager. During this time, I divided my pain into two categories: scoliosis pain (having a bent and twisted spine) and surgery pain (having been cut open and rearranged).

The surgery pain was diminishing as expected. But a third kind of pain was emerging: rod pain. It felt as though I was being stabbed in the back—literally.

Over the next few years, I complained about this pain at appointment after appointment, only to be told: "Sorry, that's scoliosis."

I felt like I was staring down the barrel of a lifetime of chronic pain before I'd even found what made life meaningful. I gave up sports I enjoyed, lost sleep, and felt entirely alone.

As a child, someone tells you: here is the solution. It sounds simple. Yes, it will be painful, but the pain is



temporary. As an adult, everything becomes more complicated.

At 20, after 3 years of back-and-forth with consultants, we decided to remove the right-hand rod from my spine because it was rubbing against my back muscles. The surgery was much easier than the first. I spent 3 days in the hospital and felt an immediate difference. I was incredibly grateful that my surgeon offered me that option. It genuinely changed my life.

I had just started university. Life was beginning, and I felt as though I was emerging from a cocoon. I graduated, moved to London, got a job in animation, and started building a life of my own. I took up running, climbing, and Pilates. Scoliosis was gradually taking up less space in my head.

I no longer believe surgery is a cut-and-dried solution. It can help enormously, but it always comes with side-effects. My operations were worth it, but I now see them less as individual events and more as part of a longer journey.

Surgery is only one part of how I manage scoliosis. There are activities, yoga, mental health support, family and friends, and proper rest. It's about learning what my body needs and, most importantly, learning to listen to it.

For years, I avoided the phrase "chronic pain." I just thought I was in pain sometimes.

Chronic pain is defined as pain persisting for more than 3 months. After 18 years, I had to admit I have it. It's just a label, but for a long time, it made me feel old and broken—as though admitting to chronic pain meant giving up on getting better. Eventually, I realised the opposite was true.

Naming it gave me permission to feel it. It allowed me to forgive myself when pain made life harder. I asked for allowances at work and invested in pain management like massages. Admitting this was part of my life, rather than something I had failed to overcome, was liberating.

Recovery is not linear. Most days I was fine; some days I was far from it.

As I grew older, I thought the pain was worsening again, but perhaps I had simply forgotten how bad



it was before. Pain is so subjective. Some days I went to work but cried in the bathroom from ache and exhaustion; other days I went climbing and screamed in pain, but the joy made it worth it. I don't know how to place these moments on a 0–10 scale, or where you must sit on that scale before someone deems your pain worthy of action.

At 27, I went back to my GP about my back pain. This time, it led to an X-ray, a CT scan, and an MRI. I was shocked to be taken seriously after so many dead-end visits.

The consultation to review my scans was different from any previous appointment. I was alone—an adult living in London, without my mum beside me. I had travelled an hour to a tiny hospital to meet a consultant I'd never met before.

He was kind. He listened. He took me seriously.

He said: "You're still relatively young. You have a lot of life left to live, and I imagine you don't want to be in pain."

I felt seen and heard. I wasn't wasting the NHS's time.



Then he showed me the scans. Two screws were in my spinal canal. He told me, very calmly, that it was a miracle I was walking. Was this the source of 10 years of pain, or just another piece of bad luck?

I requested a transfer to a specialist spinal hospital. While waiting 2 years for a second opinion, I carried on with life. I built myself up from running occasional 5K runs and swimming to completing a half-Ironman triathlon. I am not fast, but I am immensely proud.

In 2024, I secured a ballot place for the 2025 London Marathon.

I had watched my dad run it in 2012 for the Scoliosis Association alongside runners who had undergone spinal fusion surgery, rods and springs in their spines just like me. Standing there with a pint, watching them cross the finish line, I was in absolute awe. I couldn't fathom how anyone with a back like mine could run 42km when I couldn't reach the end of the road.

14 years later, I ran that same race. Dad says I inspired him to run his marathon, but he certainly inspired me to run mine. My parents stood on the sidelines in their Scoliosis Support and Research T-shirts.

It was a very hot day, and despite months of training, getting to the finish line was incredibly hard. I cried my eyes out at the end. It was a once-in-a-lifetime experience I will never forget and never repeat.

By spring 2025, I faced a much bigger decision. Advocating for myself to secure a third surgery took perseverance, bravery, and patience. I second-guessed myself constantly: Did I deserve it? Would it be worth it?

The long wait helped; it gave me time to think. This surgery was completely elective. My first surgery had essentially been decided for me; this time, the choice was mine.

The doctors were hesitant to put me at risk, making it clear the choice was entirely mine. I worried about how stupid I'd feel if something went wrong, and I downplayed it to my family to avoid scaring them. I spoke to a therapist to process it all. She helped me consider the positive outcome: What if life is better? What if I don't have



to be in pain every day?

So I took the risk.

The operation went well, and recovery was straightforward. I spent 24 hours at St George's Hospital. Every hospital stay reminds me how lucky I am. Sharing wards with remarkable women facing far harder circumstances inspires me to live fully.

The first 2 weeks post-surgery were tough. I hate sitting still and felt quite down, but my parents looked after me and friends brought flowers and books.

2 weeks later, I competed in a hill climb with my cycling club. I saw that familiar look in people's eyes that said: "You're mental."

I see it a lot—when I plan to ride 400km in a day or run a half-marathon before a festival. But perhaps living through something like this makes you a little mental. I wouldn't have it any other way.
For a long time, I thought the goal was to fix my spine and get back to normal. I thought recovery meant a final destination where scoliosis stopped being part of my life.

I don't think that anymore. I am 32 and 10 months post-surgery. Physically, I feel better than I have in years.

My spine isn't fixed, and my body isn't perfect. I still have pain, numbness, nerve pinches, and a hump on my right side. I still have moments when I wish my body looked and felt different.

But I ran a marathon. I travel, go to festivals, and do ridiculous things with my friends.
I spent years trying to decide whether my body was broken or fine. Now I think it can simply be mine.

Recovery hasn't meant fixing everything—it has meant learning to live fully in the body I have.

Seeing the curve

A radiologist's guide to scoliosis imaging

About the SPINE Study
The Scoliosis Patient Imaging Need Evaluation (SPINE) Study is funded by the National Institute for Health and Care Research through its Research for Patient Benefit programme (NIHR RfPB). The study is sponsored by South Tees Hospitals NHS Foundation Trust and has been supported through collaboration between the Academic Centre for Surgery (ACeS) at South Tees Hospitals NHS Foundation Trust and the University of York.

Contributed by Professor Maya Jafari, Chief Investigator of the SPINE study and Consultant Musculoskeletal Radiologist, South Tees Hospitals NHS Trust on behalf of the SPINE team

As a consultant musculoskeletal radiologist and Chief Investigator of The SPINE Study, I have the privilege of working with young people with adolescent idiopathic scoliosis (AIS) and their families, as well as healthcare professionals delivering AIS care in the NHS.

Together, we are exploring ways to improve imaging and care for those with AIS. In this article, I hope to explain different types of imaging used for scoliosis, how to manage radiation safely, and why research in scoliosis imaging and care is important.

What is scoliosis?

Scoliosis is when the spine twists and curves and can develop during adolescence. When no cause is found, the condition is called adolescent idiopathic scoliosis (AIS).

The role of imaging

Imaging means taking pictures of the inside of the body. Most people have heard of X-rays or some of the other common ways to take images, including magnetic resonance imaging (MRI) scans, computed tomography (CT) scans, or ultrasound. For AIS, there are some special types of imaging, such as EOS and surface topography, that are available in some hospitals.

In scoliosis, imaging is used to:

1. Measure and assess the curvature of the spine.
2. Diagnose scoliosis.
3. Monitor how the spine changes as someone grows.
4. Decide whether surgery is needed and to plan surgery, if necessary.
5. Check the spine after treatment such as bracing or surgery.

Imaging is a vital part of scoliosis care, but it is only part of the patient's journey. An X-ray can tell us the shape and size of the spinal curvature, but it cannot tell us everything about the person living with scoliosis. It cannot tell us how someone feels, whether they are in pain, how scoliosis is affecting their confidence or perceptions of their body image, or what matters to them the most. Good scoliosis care looks at the person as a whole, using imaging alongside their symptoms, concerns, and goals.

Meet the radiology family

It takes a whole team of healthcare professionals to make sure that patients get the right image, at the right time, and in a safe way.



Radiology assistants

Radiology assistants help get patients ready for their imaging, accompany them into imaging rooms, and provide practical support to patients and their parents.

Radiographers

Most people are familiar with radiographers. They are trained professionals who operate the imaging equipment and know how to capture good-quality images. Radiographers working with X-rays also have particular expertise in radiation safety and help keep radiation exposure as low as possible.

Medical physicists

Medical physicists are experts in the science and safety behind medical imaging. They make sure that scanners are working correctly and that the appropriate amount of radiation is used. They also check safety measures to protect staff and patients.

Radiologists

Radiologists are specialist doctors who interpret medical images and provide reports for the care team. Radiologists check every imaging request to make sure that the imaging requested is needed and is likely to help with the patient's care.

What does imaging tell us in scoliosis?

Different types of imaging give different information, and importantly, not all imaging uses radiation.

X-rays

- **What do they show?** Bones and curvature of the spine.
- **What does this mean?** X-rays show the shape of the spine and allow the curve to be measured.
- **Uses radiation?** Yes, a small amount.

Low-dose X-rays (where available)

- **What do they show?** Bones and curvature of the spine.
- **What does this mean?** They also show the shape of the spine and allow the curve to be measured, but use less radiation than standard X-rays. EOS is a form of this type of imaging.
- **Uses radiation?** Yes, but less than a standard X-ray.

Surface topography (where available)

- **What does it show?** The surface shape of the back.
- **What does this mean?** It maps the outside of the body to help estimate the shape and curvature of the spine.
- **Uses radiation?** No.



MRI

- **What does it show?** The spinal cord, nerves, and soft tissues.
- **What does this mean?** MRI shows structures that cannot be seen clearly on X-rays. Nerves are like cables that carry messages between the brain and the body, helping us to move and feel. The spinal cord is like the body's main communication motorway, carrying messages between the body and the brain.
- **Uses radiation?** No.

CT

- **What does it show?** Very detailed images of the bones.
- **What does this mean?** CT produces detailed images of the bones and spine from different angles.
- **Uses radiation?** Yes, generally more than an X-ray.

There is no single best type of imaging for AIS and other forms of scoliosis. The right type of imaging



depends on what the care team needs to know at the time.

For example, an X-ray is useful for assessing and measuring the curvature of the spine while you are standing, so we can see how your spine looks when it is supporting your body. Most MRI scans are done while you are lying down. MRI provides detailed images of the spinal cord, nerves, and soft tissues such as the muscles and discs in your back. An MRI can answer questions about the spinal cord and the development of your spine.

Should I worry about radiation?

When a scoliosis diagnosis is given, there can be a lot of information to take in, and questions to ask about what will happen next and the impact of the condition.

One question that young people and families might ask is, "Should I worry about radiation?"

Some imaging, like X-rays and CT, uses radiation. Very high levels of radiation can damage our genetic make-up – our DNA (think Mutant Ninja Turtles, Hulk, Fantastic Four!).

X-rays use small amounts of radiation. But even small amounts of radiation can cause tiny amounts of damage to our DNA. Thankfully, our bodies are very good at repairing this damage. If DNA damage is not repaired correctly, it can sometimes cause a cell to grow or behave abnormally. Over many years, this can contribute to the development of cancer. This is why repeated exposure to high levels of radiation can very slightly increase the risk of developing cancer over a lifetime.

The amount of radiation used in medical imaging is carefully controlled and is much lower than levels that can cause immediate harm.

The aim is simple: to make sure you have the imaging needed, but no more than what is needed.

What about having lots of X-rays?

Some young people with scoliosis may need several X-rays as they grow. They are used to monitor the spine over time or see how it responds to treatment, like bracing.

The amount of radiation received during scoliosis care can vary. It depends on how often imaging is needed and the type of equipment used for imaging.

Research has shown that the radiation exposure from scoliosis imaging is low. Young people with AIS who need surgery will have a slightly higher exposure compared with those who do not (Cool et al., 2023).

One study looked specifically at the total amount of radiation received by young people with scoliosis who have surgery. These patients may have repeated X-rays during assessment and monitoring, surgical planning, and during surgery. The researchers used these radiation doses, together with the expected lifetime risk of cancer in the general population, to estimate lifetime risk of cancer.

They estimated this to be 50.3% for boys with AIS and 50.5% for girls with AIS. This is very similar to the general population, where the chance of being diagnosed with cancer during a person's lifetime is around 50% (Cancer Research UK, 2023; Loughenbury et al., 2021).

Importantly, these figures suggest that the possible additional lifetime risk from radiation used during scoliosis imaging is small, even in young people with scoliosis who need more imaging. The overall estimated risk was only slightly higher than that of the general population. It is important to remember that these are estimates of possible risk based on radiation exposure, rather than cancer rates actually observed in people with AIS.

These studies help us understand the potential impact of repeated X-rays. That is why radiology teams aim to use the smallest amount of radiation needed to get a clear image and provide safe and effective care. It is also why research into even lower-dose imaging matters.

Does having an X-ray mean I will get cancer? No.

This is really important.

For someone having a necessary X-ray today, the risk from an individual X-ray is very small.

If an X-ray is needed to look after you, the benefit of getting important information from that X-ray is much greater than the potential risk of the radiation.

Radiology teams follow two simple principles: **Only do an X-ray when it is needed, and use as little radiation as possible.**



This is called justification and optimisation.

Research can help us put these two principles into practice. It can help us understand when imaging is needed and develop ways of using less radiation while still getting the images we need. This is one of the reasons why research into lower-radiation imaging technology is so important.

And this brings us to the SPINE Study.

The SPINE Study

The SPINE Study is an NIHR-funded research project aiming to explore how imaging is currently used in the care of young people with AIS in England. We also wanted to understand how imaging and the wider care pathway for AIS in the NHS could be improved by gathering experiences and priorities from young people, their families, and healthcare professionals delivering AIS care.

To do this, we:

1. Reviewed existing medical publications on different AIS imaging technologies.
2. Spoke to patients, their parents, and healthcare professionals involved in AIS care in England to understand their experiences and perspectives.
3. Held a national event with patients, parents, and healthcare professionals to identify priorities for improving AIS care and future research.

We have now completed the study. Using the results, we hope to improve AIS pathways in the NHS and support better, consistent, patient-centred scoliosis care.

Five things I would like every family and young person with scoliosis to know

1. Imaging is central in scoliosis care.
Imaging helps healthcare professionals understand the spine, monitor changes in the spinal curvature over time, and make important decisions about treatment.

2. Every image has a purpose.
Different types of imaging give us different information. You may not need every type of imaging.

3. Radiation is taken seriously.
Radiology teams work hard to keep radiation as low as possible for each patient. When an X-ray is needed, the lowest amount of radiation needed is used to get a useful image.

4. Do not be afraid to ask questions.
Always ask questions of any member of the care

team, including the radiology team. Questions like 'Do I need this X-ray?', 'How much radiation will I be exposed to?' or 'Are there other options?' are all reasonable.

5. Your voice matters.
There is still a lot we can learn about how to improve scoliosis care. Through The SPINE Study, we have been privileged to hear directly from those with AIS and their families. It is important that this level of involvement continues.
Look out for opportunities to get involved in research through organisations such as Scoliosis Support and Research.

Finally…

Scoliosis imaging is not just about taking pictures of your spine. It gives healthcare professionals the information to make the right decisions, at the right time. The challenge is making sure each patient gets the imaging needed for their care – no more, no less.

Through the SPINE Study, we are bringing together scoliosis centres across England and listening to the experiences and priorities of young people with AIS and their families. Our aim is to identify how scoliosis care can be made safer, more consistent, and better tailored to what matters to young people with AIS and their families. That is our vision for the future of scoliosis care.

Further reading

1. Cancer Research UK, Lifetime risk of cancer, 2023.
2. Cool et al., 2023, Estimated cumulative radiation exposure in patients treated for adolescent idiopathic scoliosis. https://dx.doi.org/10.1007/s00586-023-07651-2
3. Loughenbury et al., 2021, Estimated cumulative X-ray exposure and additional cancer risk during the evaluation and treatment of scoliosis in children and young people requiring surgery. https://dx.doi.org/10.1007/s43390-021-00314-6
4. Luan et al., 2020, Cancer and mortality risks of patients with scoliosis from radiation exposure: a systematic review and meta-analysis. https://dx.doi.org/10.1007/s00586-020-06573-7
5. Pace et al., 2013, A comparison approach to explain risks related to X-ray imaging for scoliosis, 2012 SOSORT award winner. https://dx.doi.org/10.1186/1748-7161-8-11
6. Simony et al., 2016, Incidence of cancer in adolescent idiopathic scoliosis patients treated 25 years previously. https://link.springer.com/article/10.1007/s00586-016-4747-2



David's story

Living with scoliosis, nearly 60 years on

David was diagnosed with scoliosis as a child in the 1960s and underwent spinal fusion surgery at 16, receiving a Harrington Rod at a time when scoliosis surgery was still very new. Nearly 60 years later, David reflects on the experience of his surgery, growing up with its lasting effects, and the changes he has noticed as he has got older. He also shares how recent investigations have helped him better understand the impact scoliosis and his surgery have had on his breathing and quality of life.

I am 74 years old, and my scoliosis story began in the 1960s when curvature of my spine was suspected during a routine primary school medical examination. After several years of monitoring and weekly physiotherapy, my parents were advised that surgery was the best course of action to arrest the curve.

In 1967, at age sixteen, I had a Harrington Rod inserted by Mr Harry Piggott, Consultant Orthopaedic Surgeon at the Royal Orthopaedic Hospital, Woodlands, in Birmingham. Following the operation, I was fitted with a full torso and neck plaster cast. This was replaced after 6 months with a smaller version and removed 3 months later. Several months after that, I had a follow-up operation—which I now know is called a costoplasty—to improve my shoulder alignment. In my mind, I was never convinced this second operation was successful, as my right shoulder has protruded ever since.

I am one of four siblings and the only one diagnosed with curvature of the spine. It was only recently, while investigating my medical history, that I learned my condition was likely adolescent idiopathic scoliosis (AIS). Back then, I received no follow-up, aftercare, or invitation for assessment after my final operation.

I am aware that scoliosis surgery techniques have greatly improved over the decades. However, the operations I had left me with a distorted torso and restricted chest capacity. I become breathless easily because my lung function was reduced, but I accepted this as the price of resolving a problem that could have affected the rest of my life.
I do not recall the full implications of the surgery being explained to me or my parents. Perhaps they weren't fully known in the 1960s, but as a 16-year-old, the prospect was daunting.

When admitted to hospital, I was placed near a boy of similar age having the identical operation a day before me. He didn't know what to expect either. Seeing him lie horizontally in a post-operative plaster cast after recovery was quite a shock, and I had a sleepless night watching him, knowing I would be in the same state the next day.

A few days later, he was taken from the ward and returned incarcerated in a full torso and neck cast. The following day, I was in the same condition.

When I was helped out of bed later that week, moving was hard work. I can relate to an experience described by Rosie in Backbone (Issue 1, Summer 2024), where she mentions how difficult it is to have no flexibility between your neck and hips. I soon realised I had lost that flexibility permanently. Because of my extended stay in the children's ward, schooling was provided every morning with GCE O-Levels only months away. Studying while lying in bed was conducive to sleeping, and the teacher often had to wake me up! For my second operation, I was admitted to an adult ward and spared the schooling.

Despite the cast, I passed my O-Levels and A-Levels and earned a place at Leeds University.



I escaped my final plaster cast just weeks before starting university and went on to lead a normal student life, even regularly playing squash after a while.

Since then, I have been fortunate to live a functional family life in a village near Bristol, working as a consulting engineer throughout my career without too much discomfort.

Recently, however, things have changed. I began experiencing increased breathlessness when doing chores or walking up inclines, along with more frequent discomfort on my concave left side. I wondered whether this was simply ageing or a long-term consequence of my condition.

Several years ago, I was hospitalised with flu. Before discharge, a chest X-ray was taken to check my lungs. Out of interest, I asked to view it to see my scoliosis. The X-ray revealed that the top hook of the Harrington Rod had disengaged from the rod itself. Neither the hospital nor my GP commented on this, simply calling the X-ray "adequate," leaving me to wonder when it happened and whether it mattered.

Seeking answers, I saw a private consultant spinal surgeon. He reassured me that the disengagement probably occurred in the first few months or years after my initial surgery. He explained that this was very common, and even when disengaged, the rod and screws are usually firmly fixed in bone graft.

He suspected my lower back discomfort was due to age-related degenerative changes rather than a major concern. He noted that my spine looked remarkably good, with strong truncal balance and my head aligned over my bottom—an outcome I didn't realise was considered a major success of scoliosis surgery. He explained that a Harrington Rod extending to L3 or L4 provided a one-dimensional correction, resulting in a flat back.

Addressing my breathlessness, he noted that my right lung field was under-developed and that the costoplasty had affected my respiratory function. He recommended seeing a sespiratory consultant. Unsurprisingly, he confirmed nothing could be done about my chest shape now—it sits with a Cobb angle of 63° and thoracic kyphosis, but is solidly fused.

My GP arranged a CT scan and referred me to a respiratory specialist at Bath Royal United Hospital. Tests confirmed a restrictive lung deficit: my right lung field is under-developed and my left lung is pulled into an irregular shape. The scan also showed left lower lobe bronchiectasis. Overall, my lung capacity is roughly 50% of average for my age, height, and gender. While it's unclear if costoplasty or fusion directly caused the bronchiectasis, it sits within the distorted left lung field and is a key driver of my breathlessness.

In Backbone (Spring 2025), Natalie describes scoliosis as a hidden disability that causes discomfort during long queues or standing. I relate to this completely. All my life, I have been self-conscious about my back and wear loose clothing. I also relate to feeling embarrassed about my body shape; while I look normal dressed, I have never had the courage to take my shirt off in public.

Though my story has both positive and negative aspects, I remain forever grateful that something was done to allow me to lead a full life. I have never felt sorry for myself or asked "why me?" Instead, I have managed my condition as best I can—and will continue to do so.



Scoliosis and breathing

Contributed by J.J.M. (Jeroen) Renkens, MD, orthopaedic surgeon, Spine Surgery, Erasmus MC, Rotterdam

Shortness of breath is not the first thing that comes to mind when talking about adolescent idiopathic scoliosis (AIS). Although shortness of breath is a complicated complaint and can have many different causes, and scoliosis can be one of them.

Large studies have shown that patients with scoliosis can have diminished pulmonary function. These studies also show a relationship between the magnitude of the curve and pulmonary function. And, of course, it makes sense that with a large curve, it can be more difficult to breathe. However, difficult breathing is not the only factor that is important.

Scoliosis is a three-dimensional condition of the spine, but it does not only affect the spine. It also causes a distortion of the chest. You would expect that the larger the curve, the more it influences the chest and lung function. However, the relationship is more complicated than this. As described by Prof. Anita Simonds, pulmonary function cannot be predicted accurately from the Cobb angle alone. Other factors, such as the level and extent of the curve and the degree of loss of normal thoracic kyphosis, also play a role.

This raises an interesting question: is it not only the size of the curve, but also the way the spine rotates into the chest that influences lung function?

Spinal penetration and lung function

In a recent study of patients with AIS who were planned for surgery, we found an even stronger relationship between the degree to which the spine rotates into the chest and pulmonary function.

We call this spinal penetration. We measured spinal penetration on CT scans by calculating the surface area occupied by the spine as a percentage of the total surface area of the chest at a cross-section through the apex of the curve.

What we found is that spinal penetration correlates with pulmonary function, as measured by pulmonary function tests (PFTs). In other words, the more the spine penetrates into the chest, the more the pulmonary function is affected.

This means that it can be more difficult for air to move in and out of the lungs and that the total volume of the lungs can also be reduced.

This is in line with what we already know about scoliosis. Scoliosis can cause a restrictive ventilatory defect, meaning that the size of the lungs and the amount of air that can be moved in and out are reduced.

We also confirmed the reduction in lung volume by measuring lung volumes on the CT scans. Measuring lung volumes manually on a CT scan is very time-consuming. Therefore, an AI-based algorithm was used to automatically measure the lung volumes.

Looking at the structure of the lungs

Pulmonary function tests and lung volumes tell us how much air can be moved through the lungs. However, they do not tell the whole story about the structure of the lungs.

To learn more about lung structure, we can measure the diameter of the larger airways and the artery running alongside these airways. This can be done using special inspiratory and expiratory CT scans of the chest. The relationship between the airways and the arteries gives us additional information about the structure and function of the lungs.

This type of measurement provides a lot of information, but doing these measurements manually is very time-consuming. It can take up to 2 to 5 days for a person to analyse a single CT scan.

A newly developed AI-based tool, originally designed for patients with lung diseases such as cystic fibrosis, can do these measurements automatically. This made it possible for us to analyse 60 CT scans before and after surgery in patients with AIS who required surgery.

The results gave us a lot of new insights.

First of all, the structure of the lungs in patients with AIS appears to be normal. So, even though the lungs have less space to expand, the structure of the lung itself is unchanged. This is an important finding and is also in line with the observation that primary lung disease is unusual in patients with idiopathic scoliosis.

On the other hand, we found larger areas in the lungs where air was trapped. This means that air could not move properly in and out of the smaller airways.

This was especially seen in the lower parts of both the left and right lungs. The degree of trapped air was also related to the degree to which the spine rotated or penetrated into the chest.

This is particularly interesting because airway compression or twisting can occur in scoliosis. CT scanning can help to identify these changes.

Does every patient with scoliosis have shortness of breath?

Although we can see an influence of the spine on pulmonary function in idiopathic scoliosis, this does not mean that every patient with scoliosis experiences shortness of breath.

Shortness of breath is influenced by many factors. In addition, patients can adapt to a reduced pulmonary function over time. This may explain why a reduction in pulmonary function does not necessarily result in noticeable symptoms.

The good news is that the majority of people with thoracic scoliosis do not develop significant cardiorespiratory problems.

What is the effect of surgery on pulmonary function?

After surgery, we see an improvement in the Cobb angle and in spinal rotation. Patient-reported outcomes also improve in almost every domain.

But what we did not observe was an improvement in spinal penetration a year after surgery. As a consequence, we also did not see a large improvement in pulmonary function.

There was a small improvement in pulmonary function, but it is debatable whether this increase is clinically relevant.

On the other hand, we did see an improvement in lung volume a year after surgery. This could be a result of surgery, but it could also partly be the result of natural growth.



The good news is that lung volume can still increase after an operation.

Although there was not really an improvement in the amount of trapped air, we did see an improvement in the relationship between the airways and the arteries.

We can also conclude that pulmonary function did not decrease after surgery. Instead, it remained stable.

Why did pulmonary function not improve more after surgery?

The main reason may be that there was no specific focus on improving or decreasing spinal penetration.

Restoring spinal penetration by improving hypokyphosis was not at the centre of attention during our study.

However, there were some cases in which we did see an improvement in pulmonary function and a decrease in trapped air.

These cases are particularly interesting because they raise an important question for the future.

What can we learn for the future?

In the future, when we look at pulmonary function in patients with AIS, we should focus not only on the Cobb angle but also on the three-dimensional shape of the spine and, in particular, on spinal penetration into the chest.

The next step is to investigate whether improving spinal penetration can lead to an improvement in pulmonary function.

This may give us a better understanding of why some patients with scoliosis develop pulmonary limitations and others do not. It may also help us to develop better surgical strategies in the future, with the aim not only of correcting the spinal curve, but also of improving the shape and function of the chest.



Turning experience into support

Our volunteers bring something incredibly valuable to the SSR community: lived experience.

For many people affected by scoliosis, finding someone who understands what they are going through can make an enormous difference. Our volunteers use their own experiences to raise awareness, create connections, and help others feel less alone.

In this feature, two of our volunteers, Sita and Katie, share their very different scoliosis journeys and what inspired them to give back to the community. From building scoliosis support in Hong Kong to hosting local walks in the UK, both are using their experiences to make sure others can see themselves, find support, and know that they are not alone.



From struggle to strength: Sita's journey with scoliosis and her mission to help others

My scoliosis journey started when I was 12. Back then, the diagnosis felt like a scary word. I did not really understand what it would mean for my future.

As a teenager, I felt constantly worried. I was terrified of facing the truth, so I avoided treatment completely. When my curve became more noticeable, people made fun of me. This made me feel very insecure about how I looked. I started to doubt myself and hid my body under baggy clothes to cover up what I thought was a defect. Even as an adult, I was always afraid of people finding out. I avoided certain types of clothes and even missed out on job opportunities just to keep my condition a secret.

"I started to doubt myself and hid my body under baggy clothes… Even as an adult, I was always afraid of people finding out."

The turning point: surgery and recovery

10 years ago, things took a turn for the worse when my lung function started to drop. A check-up showed that my curve had gone from 35 degrees to over 75 degrees.

I had a major 8-hour operation to place 18 screws and 2 titanium rods along my spine. Waking up in intensive care and learning how to walk all over again was incredibly hard, but I was determined to do it.

Finding purpose: connecting communities

While recovering, I realised there was a massive lack of support for scoliosis. I felt completely lost until I met a group of fellow patients. Together, we set up the Hong Kong Scoliosis Support Society. We wanted to make sure that patients and their families would never have to deal with this lonely condition on their own.

Now, I am so proud to be part of the SSR family here in the UK. My new goal is to bring that same support from Hong Kong to my new home in Manchester. I want to bridge the gap between medical treatments and the mental health support that patients and parents truly deserve.

Taking action in Manchester

Just last month, I had the wonderful privilege of leading the SSR Walk Together event in Manchester. Meeting so many amazing people on the same journey was incredibly moving. As we walked, we shared our stories, opened up about our struggles, and cheered each other on.

The deep connection we felt that day reminded me why I love this work. I want everyone reading this to know: you are not alone. Whether you are in Hong Kong, here in Manchester, or anywhere else in the world, there is a community ready to walk right beside you.

Spinal fusion surgery completely changed how I look at life. I have chosen to turn it into a mission. I want to use my own experiences and scars to help other patients feel confident on their own path to recovery.



Katie's story: Being the person I needed

Hi, I'm Katie, and I have kyphoscoliosis, which is both scoliosis and kyphosis. My journey with scoliosis started when I was 4, when my paediatrician found a slight curve in my spine. By the time I was 5, it was over 100 degrees, and I had my first operation to fit growth rods and a back brace – this was the start of a long journey.

I spent years having operations and wearing back braces, up until my first spinal fusion when I was 10. Unfortunately, this one failed, and I had to have another a year or so later.

After my second spinal fusion, we thought that was it for me, that I was finally done with surgery and could be a 'normal' kid. But unfortunately, that wasn't the case. At 12 years old, the pressure of my curve crushed my spinal cord, resulting in a spinal cord injury. I was told I would never walk again, but by some miracle, I'm able to! It started with just a movement in my toe, and now I'm able to walk short distances.

Why did I become an SSR Volunteer?

I became an SSR Volunteer as I know what it's like to grow up with scoliosis and how isolating it can feel. I never saw anyone who looked like me or heard of anyone going through something similar, and I really want to be a part of that change – to be the person I needed!

What activities have I been involved in?

Earlier this year, I hosted my local 'Walk for Scoliosis' event, and it was such a good turnout! People travelled far to attend, and everyone seemed to get on well. I loved having a yap with other people and hearing their journey with scoliosis, how it started, and how it affects them now. I would love to do something like this again.

Why do I think volunteering and community support are important for people with scoliosis?

Everyone deserves to see themselves represented, to have someone to relate to, and to have someone who gets it.

Raising the bar: how modern bracing is transforming scoliosis care

By Steve Hewitt, scoliosis specialist orthotist, Sheffield Children's Hospital

Conservative scoliosis care is undergoing its most transformative era in decades. For clinicians, patients, and families, the landscape looks very different from the days of traditional, low-correction bracing. With new technologies, expanding evidence, and a cultural shift towards accountability in treatment outcomes, the future of non-surgical scoliosis care has never looked brighter.

In the 20 years that I have been working with scoliosis bracing, I have seen the transition from more traditional, symmetrical Boston Brace-type bracing to postural over-corrective bracing. For my first 8 or 9 years, I saw constant resistance from many professionals across the country to accepting that bracing works. This was incredibly frustrating for those clinicians working with bracing and seeing the benefits first-hand. It wasn't until the BrAIST study came out in 2013 that the argument over whether bracing worked or not should have been put to bed.

The BrAIST study greatly helped build bracing services across the world. However, since then, the standard and style of bracing has continued to develop, and we are now seeing the results of what more modern bracing can achieve. We are now at a time when we should be resetting the bar for what bracing outcomes are considered a success.

Recently, when lecturing to orthotic students at Strathclyde University, I realised that this is the generation of clinicians that will probably get to see the full benefit of more modern bracing. They will work at a time when postural over-corrective bracing is considered normal practice, as well as having the means to understand scoliosis, growth, and the effects of bracing better.

In this article, I wanted to highlight some of the main areas in which conservative care is changing for the better.

From holding curves to correcting them

Scoliosis bracing has evolved from a largely preventative technique into a proactive corrective treatment. Where traditional braces often aimed simply to slow progression, today's postural over-corrective designs target significantly higher in-brace corrections. When curve size and flexibility are appropriate to achieve high levels of in-brace correction, along with patient compliance, we can expect long-term curve improvement.

A growing body of research is reinforcing what clinicians are seeing first-hand.

Postural over-corrective bracing is more effective not only at avoiding surgery, but also at reducing final curve magnitude and preventing progression altogether. This shift has opened the door to redefining what success in bracing truly looks like.



Historically, bracing success has purely been defined by whether it avoided progression to what is considered the 'surgical threshold' at 50°, and even now, this is the marker set by many scoliosis clinics, even though we should be aiming much higher.

When consulting with parents and patients receiving brace treatment from other clinics, they will often ask whether their child's brace is a 'good one' and how they can know if it could be better. I will always tell them **that brace effectiveness and quality should be measured by the in-brace correction achieved and the ability to meet the required level of compliance.**

A Sheffield Children's Hospital (SCH) audit, presented at the British Scoliosis Society meeting in 2023, demonstrated that meaningful out-of-brace improvement is most commonly seen once a threshold of around **40% in-brace correction (IBC)** is achieved. SCH's in-brace audit results over the past 5 years show average in-brace corrections ranging between 63% and 74%, with a 66% overall average for this period.

Traditional brace designs rarely achieve this 40% threshold consistently, another indicator of how far modern bracing has progressed.

A systematic review published in 2024 (Lee et al., A Comparison Between Boston Brace and European Type Braces in AIS Patients) showed a noticeable superiority of European-type, postural over-corrective bracing when looking at the secondary outcomes of curve correction, stabilisation, and progression. European Cheneau-type braces achieved correction in 55% of patients, compared with 3% in Boston braces, while Boston bracing saw progression in 55% of patients, compared with 12% in European Cheneau-type braces.

Being satisfied with achieving success if curves haven't progressed to a surgical size is outdated, and is not the standard we should now be aiming for. If today's bracing can deliver more, should our definition of success evolve too?

In my clinics, I like to take the approach that, when looking at the end outcome of bracing, if a curve has been prevented from reaching the surgical threshold, this could be considered a **Bronze** level achievement. If the curve is held where it started throughout treatment, then this could be considered **Silver** level, and for those who achieve correction at the end of treatment, this is a **Gold** level achievement.

This framework could help clinicians and families conceptualise what is possible, and what should be expected, from truly modern bracing.



The BASIS Study: A catalyst for change

Perhaps the most influential driver of this new era in the UK has been the landmark BASIS study, the largest scoliosis research project ever conducted worldwide, completing recruitment later in 2026. Its effect on NHS bracing pathways is already unmistakable.

Through the study, centres have adopted routine in-brace X-rays to measure effectiveness, gained wider access to modern brace designs such as CMP and Providence, commonly used in the night-time arm, increased accountability for achieving meaningful in-brace correction, and brought the wider multidisciplinary team closer together so they can understand the role of bracing in each patient's journey more specifically.

As a result, many NHS centres have re-evaluated their standard-care braces, shifting towards designs capable of delivering higher, more consistent corrective forces. The study promises to deliver unprecedented levels of evidence that could reshape conservative scoliosis treatment for years to come.

Expanding evidence across patient groups

The surge in research is not limited to bracing for idiopathic scoliosis. Several key areas are seeing continued growth. This includes **physiotherapy-specific scoliosis exercises (PSSEs)**, with more NHS sites now training staff in Schroth and other PSSE methods, integrating them into routine conservative care clinics, and offering families a more holistic, evidence-supported pathway.

Bracing for **neuromuscular scoliosis** has also seen some of the first meaningful evidence published (Dansuk et al., 2025, The Effect of TLSO Orthosis on Scoliosis Progression and Chest Deformity in Children with Type 1 Spinal Muscular Atrophy: A Randomised Controlled Trial).

Although professional experience has long supported bracing in conditions such as spinal muscular atrophy (SMA), research was limited, largely because success cannot be measured using idiopathic benchmarks like 'avoiding progression to 50 degrees'.

Newer studies are addressing this gap, helping define realistic, patient-centred outcomes for neuromuscular cohorts.

Technology that's rewriting the rulebook

The development of new technology is what often drives improved healthcare, and this is no different in scoliosis care. We are understanding more and more about the smaller details that are so critical for effective scoliosis treatment. Advanced imaging and maturity assessment techniques have become key differentiators in modern care.

We are now benefiting from more reliable and repeatable indicators of skeletal maturity. The Risser sign, once the gold standard for assessing skeletal maturity, is now known to be too unreliable to guide such critical decisions as whether to start or end bracing.

Although it is the most documented maturity scale historically, it can risk inaccurate decision-making around growth. This could mean delaying brace treatment when it could be most effective, removing brace treatment when the patient is actually still growing and risking curve progression, or keeping patients in a brace for longer than required, resulting in over-treatment.

Hand-wrist X-rays paired with AI-generated skeletal maturity software provide clearer timelines of remaining growth and pinpoint peak growth periods, when brace effectiveness and compliance are most crucial. Families benefit from realistic expectations, while clinicians benefit from precision.

EOS (low-dose radiation X-ray) systems are becoming more available, with several private clinics using them and a growing number of NHS sites having access to them. They allow clinicians to view the spine with minimum radiation and can offer a true 3D understanding of rotation and Cobb angulation in and out of the brace when reconstructed in 3D format, which can't be achieved from traditional X-rays.

This, in turn, supports better brace design and more accurate tracking of progress.

Earlier detection: A critical missing link

Several published audits across major hospitals in the UK reveal a similar, concerning pattern. They show that only 10% of new referrals are appropriate for bracing, while 50% are already at or near surgical thresholds.

Smaller curves, being more flexible, respond far better to bracing and show significantly higher in-brace and long-term improvements. This raises a crucial question: **Is it time to revisit school scoliosis screening?**

This was a process previously abandoned at a time when there was little faith in bracing, and so no real benefit was seen from detecting curves earlier.
If early-stage referrals increased from this 10% to even 20% or 30%, the potential benefits would be profound: more children qualifying for bracing, more flexible curves treated, and more opportunities to correct rather than simply stabilise.

As research expands, technology advances, and practitioners raise standards of care, conservative scoliosis treatment is poised for a new era, one defined by correction, confidence, and consistently better outcomes for young people around the world.



If I were a superhero: meet Scolioman

Creative writing by Thomas, Year 8

Climbing buildings, breathing underwater, stopping a speeding train: all abilities held by superheroes. So, I suppose, it begs the question: if you had the chance to be a superhero for a day, what would you be?

I'm sure the range of heroes and powers would be immense, stretching to the far edge of the solar system, quite literally, if some of them hail from the icy asteroids in this belt or that. But I think that, for me, there could only be one option: Scolioman.

Scolioman would dress in grey, with patches of blue across his suit. His logo? A curved spine, representing what he has grown through.

He can be located not swinging between skyscrapers in New York, not in his underwater palace or hidden cave deep in the mountains, but in the countryside. The Garden of England. Kent.

His mission? Spreading his message via his story.

You see, when Scolioman was little, just a boy, he was diagnosed with a condition, one which left him in and out of hospital all the way through school. He vowed to make sure that no one would have to go through the pain he went through, the feelings of worry, not knowing what would happen next.

And so, he did.

Scolioman is not like other superheroes. He can't shoot webs, nor crush things with his bare hands. Through compassion and kindness, he helps to inform others of his condition.

He goes into schools, educates people, and helps them to understand. He tells them that, while his condition came early, most don't, affecting people as they get older, go through secondary school, and grow up.

He speaks to them about the effects, what they do, and what they should do if they are spotted. All so that no one will have to go through the same experience as him.

So that's who I, if I were a superhero, would want to be.

Not for money. Not for fame or glory.

But to help others, and make them feel, overall, a little bit less scared.

This Christmas, give the gift of support.

Because no one should face scoliosis alone

Over the past year, one thing has become clearer than ever: support matters.

A diagnosis of scoliosis can bring a huge amount of uncertainty. There are questions about treatment, surgery, pain, school, work, relationships, mental health, and what the future might look like. Sometimes, people simply need someone to talk to who understands what they are going through.

That is why expanding and strengthening our support services has been such an important part of SSR's work this year.

Our support groups have had their biggest year yet, bringing people affected by scoliosis together to share experiences, ask questions, and connect with others who understand. Our Talking Therapy Service continues to give people a safe space to talk when living with scoliosis feels overwhelming, while our helpline and information resources are there to provide trusted answers and reassurance when people need them most.

We have also continued to bring people together through our patient events, creating opportunities to hear directly from healthcare professionals, ask questions, and meet others living with scoliosis. And, through our growing volunteer network, we are building an even stronger community of people who can help raise awareness, share their experiences, and make sure no one feels alone.

James, our Community Services Manager, says:

"Talking therapy can be beneficial for people suffering from chronic pain, body image worries, anxiety, depression, trauma, and difficult emotions.

Our support groups are also a very helpful way for people with scoliosis to connect with others who can relate. They allow people to talk about issues that are important to them in a helpful and supportive setting, which is facilitated by a qualified counsellor.

Research indicates that 1 in 5 people will experience mental health difficulties. As a charity it is a priority of ours to ensure the mental wellbeing of our community is supported through counselling, support groups and our confidential helpline."



This Christmas, we are asking our community to help us take that work even further.

Our **Give the Gift of Support** Christmas campaign is all about giving something that can genuinely make a difference. Instead of another present that might be forgotten, your donation could help someone find the information, support, or community they need at a difficult moment.

And there is something special you can give to someone you love, too. Every Christmas donation comes with a beautiful SSR eCard, so you can let someone know that a gift has been made in their name to help people affected by scoliosis.

From trusted information and our Helpline, to support groups, talking therapy, our volunteer network, and patient events, your support helps us make sure that people affected by scoliosis have somewhere to turn.

Because no one should have to face scoliosis alone.

This Christmas, give the gift of support by visiting ssr.org.uk/christmas



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