

# BACKBONE



Celebrating 40 years

Neuromuscular  
scoliosis and its  
treatments

Managing pain in  
scoliosis

Back to school

Determining the  
effectiveness of  
treatment

Backing scoliosis

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## LATEST NEWS

### ISAD

At SAUK, the month of June is all about uniting people across the world to create positive public awareness of scoliosis, promote education, and bring together those affected by the condition. The celebrations peak each year on the last Saturday of June with International Scoliosis Awareness Day (ISAD), an event launched by SAUK in 2013.

SAUK advocates for scoliosis in everything we do. For over 40 years we have been providing support, advice, and information to people affected by scoliosis and raising awareness amongst health professionals and the general public. SAUK's sister charity, the British Scoliosis Research Foundation, backs scoliosis through their commitment to funding high-quality research into the causes and treatment of scoliosis in the UK. The two charities work together to improve the lives of all those affected by scoliosis.

This year's awareness month theme was #BackingScoliosis. It was an invitation for others affected by scoliosis to join us in advocating for the condition in all parts of society. It was a joy to see you all embrace the message and use the hashtag across social media to share your own scoliosis journeys. A scoliosis champion is brave and honest about how scoliosis has affected them. By speaking up about scoliosis, they show others in the community that they're not alone and promote greater understanding and respect for those touched by scoliosis.

### Set up an online fundraising page with JustGiving

Setting up an online fundraising page is an easy way to fundraise for SAUK. Your supporters donate via your page and at the end of your fundraiser, the funds are securely sent directly to SAUK.

The fundraising website Virgin Money Giving will cease operating on the 30th November, 2021. The good news is that we have partnered with JustGiving, creating a fundraising page via our charity page on JustGiving is super easy. Follow the link and click 'fundraise for us' to get started. <https://justgiving.com/scoliosisassociationuk>

### Isobel Gray Award and Roll of Honour

Isobel Gray was a founding Trustee of SAUK, who tragically died some years ago. As part of our recognition of her huge contribution to SAUK we set up an award in her memory for people who have contributed much to the organisation. Each year in November the Trustees decide who should receive it that year and make the Award in the new year. SAUK also awards places on our Roll of Honour every year to children and adults who have shown outstanding courage while undergoing treatment for scoliosis.

To nominate someone, contact us by the 28th February, 2022. Include who you are nominating and why and a picture of them. Please also include your email address, your name, and the address of the person you have nominated (so we can send them a certificate). Return your nominations to [communications@sauk.org.uk](mailto:communications@sauk.org.uk) or 4 Ivebury Court, 325 Latimer Road, London, W10 6RA. Winners will be announced in the Spring 2021 Backbone.

### Follow us!

You can find SAUK on Facebook, Instagram, and Twitter. Follow us to stay up-to-date on news, events, new articles, resources, and more.

You can also join our private Facebook support group; Scoliosis Association UK (SAUK) Group- to be a part of a great community that offers advice and encouragement to each other.



[www.sauk.org.uk](http://www.sauk.org.uk)



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# CELEBRATING 40 YEARS

Stephanie Clark, SAUK Chairperson and Co-founder



Stephanie Clark

In the summer of 1981 Ailie Harrison asked me if I would join her to form a group for patients with scoliosis. I did not have to think long about her proposal – I said yes immediately. The rewards have been great.

Ailie and I worked for Dr Phillip Zorab, a chest physician with a strong interest in scoliosis, at the Royal Brompton Hospital in South Kensington in London. We did research into scoliosis – I looked at causation and Ailie respiratory problems. We became firm friends when Ailie came to Institute Calot in Berck-Plage in northern France to set up a laboratory there for a collaborative project with Dr Yves Cotrel who was the scoliosis surgeon at that hospital. Ailie spoke French and I did not, so her services were invaluable to me!

The idea of a support group came from a patient of Phillip Zorab, Isobel Gray. She had said to Ailie in a clinic at the Royal Brompton Hospital that what was needed was a special group for people with scoliosis, a means whereby



Ailie Harrison

people could help each other and share their experiences and pass on information that was difficult to come by in busy clinics. Isobel was a redoubtable Scottish lady who had a severe scoliosis but led a full and active life, and we are grateful to her for her idea that sparked off a chain of events culminating in the formation of a support group. She was looked after by Dr Phillip Zorab for her breathing problems, which are not uncommon in adults with serious, often untreated, scoliosis. We remember Isobel each

year with the Isobel Gray Award and Roll of Honour, in which we recognise people who have made an extraordinary contribution to the work SAUK does and celebrate those who show outstanding courage while going through treatment or living with scoliosis.

Ailie approached Phillip Zorab, who agreed to write to 500 of his patients inviting them to join a patient support group. About 200 responded that they would indeed be interested, and the Scoliosis Self-Help group (SSHG) was born.

We registered the group as a charity, and our aims were simple: to put people in touch with each other, should they so wish, to provide information about scoliosis, and to raise awareness of scoliosis among the general population and doctors. In the first few years we ran the group from Ailie's dining room! We asked our new members to provide us with details of their scoliosis, their diagnosis, whether they were children, parents, or adults, and



Dr Phillip Zorab



Stephanie Clark and Isobel Gray

where they were treated and lived. We grouped them according to the National Health Service regions. We passed on the names and addresses of people to others who lived nearby and had experiences in common. In that way they could get in touch with each other and provide support if needed. Ailie produced a newsletter four times a year. This publication was packed with useful information, such as help available for people with transport difficulties, advice with asymmetric backs, and the location of centres of excellence. We also had a large correspondence section. 104 issues later and that newsletter is still going strong and, we hope, packed with useful information.

We held our first patient meeting in London at Brompton Hospital. The format has not varied much since and we have continued to run 2-3 of these a year, up until 2020 when Covid forced us to pause these in-person meetings. They are great days, and we look forward to being able to run them again. We invite speakers who are surgeons,

physicians, physiotherapists, and others who provide services for people with scoliosis.

After a few years we acquired six trustees – Isobel Gray, Andrew Minns, Min Mehta FRCS, Woodthorpe Harrison, Ailie, and myself. Isobel and Andrew were members, Woodthorpe (Thorpe) was Ailie's husband, and Min was a surgeon who treated babies with scoliosis and worked at the Royal National Orthopaedic Hospital at Stanmore. We used to have our Trustee meetings in Ailie's house in Chiswick, and they were constructive and friendly occasions, ending up with a glass of wine to toast the success of the organisation. Sadly, Isobel, Andrew, Thorpe, Ailie, and Min are no longer with us, but were wonderful Trustees and are fondly remembered.

We decided that the SSHG needed more gravitas and changed its name to the Scoliosis Association UK (SAUK) in 1986. We outgrew Ailie's dining room and moved into a small office on the top floor of the Disabled Living Foundation in west

London, where Pauling Grey and Brenda Sullivan joined the team. Ailie had retired by that time and needed help with the expanding organisation – our membership was now in the thousands, rather than the hundreds when we started out. We expanded so much in the late '80s and early '90s that we had to seek larger premises. Ailie found our present office in Latimer Road.

We had a lot of publicity in the media on occasions, and every time there was a newspaper report or a TV or radio programme about scoliosis we were inundated with calls from desperate or interested people wanting more information about scoliosis. We realised that we needed to set up a Helpline, so we applied to the Department of Health for a grant to run that and were successful. The DoH supported us for 10 years and we are very grateful to it for that help. We still run the Helpline today, over the phone and by email. We answer about 2000 calls and, now, emails a year from people at various stages of their scoliosis journeys, seeking advice, information, help navigating the health care system, or just someone to talk to who understands.

In 2000, we were fortunate enough to be awarded a lottery grant to run an awareness campaign, Getting It Straight. The campaign was in three parts. The first entailed producing a teaching pack featuring scoliosis for schools, the second was to be an exhibition of photographs of the back by our Patron, Patrick Lichfield, Earl of Lichfield and renowned photographer, and the third a poster and leaflet for General Practitioners emphasising the importance of early referral to a specialist centre.



We moved into the virtual age when our website was first set up in January, 2000. It's been through a few upgrades over the years, with the most recent one just this year. The website is an important part of what we do and the way that many of you find us and learn more about scoliosis. Social media is a relatively new addition when you look back on the last 40 years but it has proved a very effective way of connecting with and building the community. In November, 2006, SAUK became officially affiliated with the British Scoliosis Research Foundation (BSRF). They are the only charity that exists solely to promote research into the treatment of scoliosis in the UK. Each year the BSRF funds a great deal of research into scoliosis and periodically holds an international symposium to spread the knowledge gained from research. The two charities

have a common goal on improving the quality of life for people with scoliosis, through providing support and information and funding research into treatment. In 2019, the two charities worked on the Scoliosis Priority Setting Partnership with the James Lind Alliance to identify the most common unanswered questions about the diagnosis and management of scoliosis put forward by patients, family members, and medical carers. These findings will inform future research to align with what matters most to those directly affected. SAUK had not run a dedicated campaign focusing on raising awareness of scoliosis among healthcare professionals for around 20 years, so when we received a legacy of over £60,000 from Patricia Hill in 2018, the Trustees and I decided it was high time we

did so. We wanted to run a project that would build the skills and confidence of GPs and healthcare professionals in primary care working with people with scoliosis. SAUK partnered with the Royal College of General Practitioners (RCGP) and agreed to fund a new dedicated e-learning module focused on scoliosis in childhood. Working in partnership with the RCGP gave SAUK the opportunity to offer our education module to their large national audience. Covid has made it a hard time to be a charity, but SAUK continues to grow and there is no sign that the need for the help and services we provide has diminished over the years. Thanks to all our members for your support, no matter when in the last 40 years you joined us. SAUK is committed to continuing our work supporting those affected by scoliosis. Here's to the next 40 plus years!



London Meeting 1987



Hampton Court Garden 2003

# HILL, PEDDER, & MINNS FUND

Andrew Minns was a founding SAUK member and Trustee who left money to SAUK 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 SAUK, passed away and left SAUK 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 SAUK 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://www.sauk.org.uk/hill-pedder-and-minns-fund/hill-pedder-and-minn-fund>

## Alice Fitzgerald

When I was 13 years old I was diagnosed with adolescent idiopathic scoliosis (AIS). I wore a back brace for just a little over 2 years until I finally stopped growing. I'm currently 27 years old so technically I have had scoliosis now for longer than I haven't, which feels like a big milestone. For as long as I can remember I have had pain flare-ups, mostly caused by muscle tightness on one side, and I'm always looking for ways to help manage this - you name it, I've tried it! A chiropractor I started seeing began using a Theragun on my back at the beginning of treatments, which always helped really loosen up my tight muscles. I'd looked at buying a Theragun myself but they were so expensive so I pretty much gave up on the idea. I was scrolling through the Scoliosis Association UK website one day looking for any advice and I came across the Hill, Pedder and Minns fund - which offers up to £500 a year to those affected by scoliosis for equipment or travel expenses to appointments. I sent off an application asking about a Theragun and they quickly approved it and sent me the funding. I've had the Theragun for a few months now. I use it a few times a week and it has made such a difference to keeping on top of my pain management - I am so grateful to the fund and SAUK for this - thank you so much!



## Leaving a gift in your will

Legacies left to SAUK in the past have made such a difference and have allowed us to fund grants like the Hill, Pedder & Minns fund and fund projects like our GP e-learning module. A gift left in your Will can help us maintain, expand, and develop our range of support services. Nobody should have to face the pressures of scoliosis without support. Leaving a gift in your Will can help to ensure that nobody has to.

We have a guide on our website to help you make or amend your will to include leaving a gift to SAUK <https://sauk.org.uk/wp-content/uploads/2021/08/A-guide-to-leaving-a-gift-in-your-Will.pdf>. Or please contact us and we can help steer you in the right direction.



# NEUROMUSCULAR SCOLIOSIS AND ITS TREATMENTS

Mr Hilali Noordeen, Royal National Orthopaedic Hospital, Stanmore  
Naadir Nazar and Chadi Ali, University of Bristol



Neuromuscular scoliosis (NMS) is the second most frequently encountered cause of scoliosis and presents a significant and complex clinical challenge with higher complication rates than for patients with idiopathic scoliosis. It can be subclassified into neuropathic or myopathic causes and include conditions such as cerebral palsy, Duchenne muscular

dystrophy, myelomeningocele, spinal muscular atrophy (SMA), and Friedreich's ataxia. It is also widely accepted that there may be overlap with congenital (eg, spina bifida) and syndromic causes. A scoliosis can present in any individual with a pre-existing neuromuscular diagnosis and can be further exacerbated if the patient cannot walk or dependent on a wheelchair. Muscular imbalance, discoordination, and reduced head and trunk balance are shared features of most neuromuscular conditions. However, it is important to understand that it is difficult to generalise NMS into a single condition owing to the large number of underlying diagnoses and pathologies associated. While the orthopaedic manifestations of many patients may be similar, the nuances and complexity of the various underlying medical conditions makes each case unique and challenging. The two main types of scoliosis, idiopathic and neuromuscular, are

diagnosed when the curve present is greater than 10 degrees. However, patients with NMS tend to develop long, sweeping S-shaped and or C-shaped curves that can involve the entire spine and sacrum, which is in stark contrast to idiopathic scoliosis in which curves are generally restricted to smaller spinal segments. NMS curves are more likely to progress, and therefore the spinal curvature presents a daily functional challenge to patients and families and affects personal hygiene, sitting balance, and skin integrity. Individuals also experience difficulties in daily care, positioning, and walking. Pelvic imbalance can increase, which results in a loss in sitting balance/positioning and the ability to sit independently. These issues serve as indications to begin and guide treatment.

## Techniques

Non-operative management is indicated for some patients with early onset neuromuscular scoliosis (EOS). This can be sub-divided into congenital, infantile, and juvenile groups and is defined as scoliosis seen anywhere before the age of 9. Conservative interventions include observation and wheelchair and seating modification, which involve contouring the seating to the shape of the back. The next step involves wearing a firm moulded plastic brace around the upper body for a minimum of 19 hours a day and can limit the worsening of the curvature

during periods of growth. Some limitation of curve progression was shown by Olafsson et al whilst improvements in the curve angle was exhibited by Nakamura et al in their studies of bracing in NMS patients. However, most studies generally find bracing to be ineffective with little effect on progression. Brace wearing is primarily seen to support and improve sitting function as well as postpone the need for surgical intervention.

As the scoliosis progresses, pulmonary function can deteriorate owing to weak breathing muscles, the inability to clear secretions, and the spinal curvature itself. Other vital organs may also be affected and include the cardiovascular, genitourinary, and gastroenterology systems. Surgical intervention is indicated when the curve continues to progress, resist conservative interventions, and worsen sitting function. Through surgery the aim is to improve and maintain the patient's (upright) posture, improve or restore sitting position/balance, and prevent the decline of lung function and other vital organs. The hope is to provide the patient with the best achievable functionality and quality of life.

Before any decision is made, a full pre-operative assessment is required to see if surgery can be safely undertaken. It involves a wide array of specialists taking a multi-disciplinary approach to obtain the best possible outcome. The benefits of surgical intervention are weighed against its difficulty and potential risk of complications in a risk-benefit analysis to help the team make an informed decision. Using detailed information of the patient and their

current condition, individuals are classified into three main groups: not for surgery, almost ready for surgery, and ready for surgery.

Surgery in neuromuscular scoliosis is more complex than for other types of scoliosis and requires long and extensive instrumentation. There are three main types, which include MAGEC rods, traditional growth rods, and definitive spinal fusion. For early onset cases a MAGEC or traditional growth rod (TGR) can be considered once conservative options have been exhausted or if the curve has progressed severely. The aim of these growing rods is to maintain spinal growth during the rapid growth of a child and prevents the need for an early spinal fusion which can result in a short trunk and long limbs.

The TGR is a growth sparing technique that is currently the most common and desirable form of treatment for EOS. However, downsides exist and implantation of these TGR's requires frequent open surgical distraction every 6 months to allow for growth. For instance, a 5-year-old girl will require around sixteen distractions if skeletal maturity is reached at 13 years of age. These procedures are a particular issue for neuromuscular patients because of the high incidence of complications, which include wound infection and restrictive lung disease. Some individuals may even be deemed too unfit for repeated anaesthesia. The complication rate seen can be as high as 19% whilst the overall wound complication rate increases by 24% with each procedure. Furthermore, a study by Noordeen et al found that distraction forces significantly rise after repeated lengthening and the length obtained

for each procedure exhibits a decreasing trend. There is also a need to consider the psychological and physiological effects of repeated surgery.

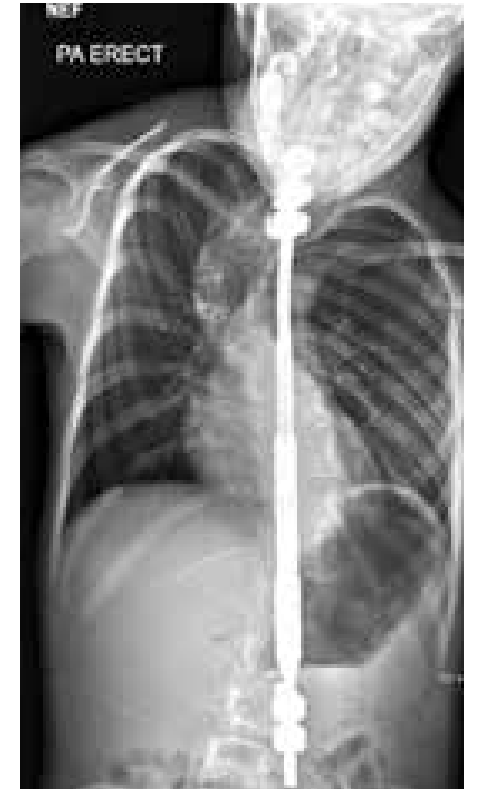


Figure 1 -Traditional growth rod

For these reasons our practice recommends the use of the magnetic growth rods (MGR). We use thoracic vertebra T4 as the upper vertebral limit for instrumentation and in most cases the lower limit is at the lumbar vertebra L5. The pelvis may be included if there is severe pelvic rotation. This decision is based on the individual case and the preference of the surgeon. The MGR system represents a fairly new technology that requires only an external, painless non-surgical distraction in the clinic or office setting with the patient awake throughout. It needs an electrically powered remote controller that uses an electromagnetic field to distract and lengthen the spine. Several studies have explored the MGR and conclude that it shows effectiveness for curve correction that is very similar to that of the TGR. We did a

multicentre study of EOS patients that showed the mean monthly T1–T12 and T1–S1 growths in MGR individuals were comparable with both normal growth and the growth achieved with the standard traditional growth rod. This technique also achieved and maintained a similar initial scoliosis angle correction to that of the TGR. Similarly, a significant improvement in both pulmonary function (FVC, FEC1) and curvature correction was seen in a study of MGR treated patients with EOS secondary to neuromuscular disease.

(see article—Yoon W, Sedra F, Shah S, Wallis C, Muntoni F, Noordeen H. Improvement of Pulmonary Function in Children with Early-Onset Scoliosis Using Magnetic Growth Rods. *Spine* 2014; 39: 1196-202.).

Complications associated with MAGEC rods include their potential to break in early onset cases. If this occurs, we leave the rods in situ since the breakage itself does not cause any significant issues. If there is evidence of any complications or subsequent curve progression, we will then intervene. Furthermore, the electromagnetic field used for repeated distractions is not associated with any persistent or major side-effects. Concerns have also arisen about the MGR's potential to generate excessive metallic debris when the rods slide in the guiding fixtures. However, an analysis of our EOS patients showed that levels of aluminium and titanium in the blood were not clinically significant (see arBorde M D, Sapare S, Schutgens E, Ali C, Noordeen H. Analysis of serum

levels of titanium and aluminium ions in patients with early onset scoliosis operated upon using the magnetic growing rod—a single centre study of 14 patients. *Spine Deformity*, 2021; 9: 1473–78.). Overall, the magnetic controlled growth rod presents a safe and effective modality to treat NMS while allowing for spinal growth. In comparison with other methods, it is seen to have better long-term health gains and fewer complications while also providing a safe gradual correction of severe curvatures in young individuals.



**Figure 2 – MAGEC rods**

If the patient is close to complete skeletal maturity, then definitive spinal fusion surgery is offered. As with other types of scoliosis, the goals of this surgery in NMS patients are to achieve a solid bony arthrodesis of the spine to correct the curvature, prevent further progression, and restore overall standing or seating balance. Fusion balances the trunk in the

frontal and sagittal planes and centres the head over the pelvis. A large proportion of NMS patients cannot walk and therefore the fundamental aim is to create and maintain an upright posture. The surgical approach alongside the proximal and distal extent of the instrumentation and fusion are important technical considerations in this patient group. Most often a posterior spinal fusion approach is used because of long and extensive instrumentation and fusion needed for neuromuscular patients. Usually, surgeons stop above at T4

to prevent conjugal kyphosis and fix down to no lower than L5. Once again, the pelvis may be included, which is dependent on the degree of its displacement. The next question is whether to use a single or double rod. Dual rod segmental spinal instrumentation has been the standard surgical procedure for the management of NMS. This method has proven effectiveness in achieving a solid arthrodesis and stabilising the spine but has been associated with very long operative times, increased blood loss, and infection. We did a study of 28 consecutive neuromuscular scoliosis patients fused with a single corrective rod to assess its safety and effectiveness. The results from this study indicate that unilateral instrumentation and fusion achieves satisfactory curve correction that is maintained at final follow-up. Furthermore, significantly shorter volumes of intraoperative blood loss

(675 ml) and operative times (196.6 minutes) as well as no cases of deep wound infection were recorded - all of which reduces patient morbidity. Careful preoperative patient



**Figure 3 – Bilateral spinal instrumentation and fusion**

preparation is also vital in reducing the rate of postoperative complications in this patient population. These findings are highly promising and justify a comparative analysis of the single rod versus the current standard dual rod technique.

#### Complications & Conclusion

Scoliosis surgery has associated risks involved, some of which have been listed above. These risks are small, but it is important that patients and their families are aware in order to have a clear understanding of the treatment being offered. Neuromuscular patients are at a higher risk of peri-operative and post-operative complications because of underlying comorbidities, with the complication rate ranging from 18

to 75%. Deformities of the thoracic cage, aspiration issues, decreased mobility, inadequate nutrition status, and cognitive impairment are some examples of comorbidities associated with an increased complication rate. Infection and metalwork breakage/failure are seen and neurological, gastrointestinal, respiratory, and spinal complications can also occur. Late post-operative complications include chronic infections, non-union, coccygeal pain, turning of the ribs (crankshaft phenomenon), and implant-related issues.

An infection rate of 5.5% for NMS compared with 1.4% in adolescent idiopathic scoliosis (patients was reported by the Scoliosis Research Society Morbidity and Mortality Committee. Similarly, the new neurological deficit rate was 1.03% for neuromuscular patient's vs 0.73% for AIS.

(see Smith JS, Shaffrey CI, Sansur CA et al. Rates of infection after spine surgery based on 108,419 procedures: a report from the Scoliosis Research Society Morbidity and Mortality Committee. *Spine* 2011; 36: 556–63).

Despite these issues, there are procedures we can implement to circumvent and treat most complications. A standardised preoperative assessment should be done so that all risk factors are considered and dealt with appropriately. Respiratory rehabilitation and nutritional care are also important before intervention. For instance, pre-operative non-invasive ventilation (NIV) strengthens respiratory muscles and reduces the rate of complications in children with cerebral palsy. Perioperative management strategies, such as spinal cord monitoring, can decrease

the number of complications post surgery, while infections can be treated with antibiotics or wound debridement. Most complications associated with NMS can be treated successfully and should not be the only deterrent for surgical intervention.

Failure to treat NMS can lead to long-term physical and emotional complications. The spine can become increasingly deformed, leading to heart problems and worsening lung function. Seating may become increasingly problematic to the point that the problem can no longer be addressed surgically, and the deformity itself can become so bad so that it is no longer treatable for medical reasons as opposed to surgical reasons. Adequate emotional support for the child during all stages of treatment is essential.

Neuromuscular patients are challenging but good outcomes can be achieved through careful assessment and planning, and by taking a multi-disciplinary approach. As a result of the advancements of operative and peri-operative techniques, more complex cases with a significant number of co-morbidities are now seen as candidates for intervention. Depending on the stage of the deformity and the individual case there are various treatment options available which have been described in this article. These are all very well tolerated by the patient and can greatly improve their functionality and quality of life.



# BACK TO SCHOOL

Coming back to school after scoliosis treatment can be a challenge. Be it bracing, growing rods, or fusion, you're healing and getting to know the new and different way your body moves while dealing with being thrust back into your everyday activities alongside your peers. There are some things you can do though to make this transition back to school easier. We've collected some firsthand accounts from people who've been in this position, and their parents, so that you can benefit from their advice. What they all have in common is that it's so important to reach out to the school for help. Whatever you can do to make yourself more comfortable and confident is worth it.

## Maddie Venner

I had my fusion surgery 2 months before starting my first year at college. My advice would be if you are moving between different classrooms all day, try to leave any textbooks, workbooks or anything like that in the classroom where the lesson is taught. Unnecessarily carrying around heavy books all day can be very painful! Make sure that your teachers know that you have scoliosis and make sure that you are allowed to get up and regularly take a short walk. If your wound is still healing, request that you leave 5 minutes before your class finishes so that you can avoid crowds on your way to your next lesson. Trust me, there is nothing worse than being bumped into when you're still feeling a bit sore. And definitely use

a backpack, as opposed to a shoulder bag. Having the weight of the bag on both shoulders reduces the strain on your back, making it a lot more comfortable than a shoulder bag.

## Rebecca Jamison

My daughter was diagnosed in November, 2020, and has been able to go to school only for a few hours a day and sometimes she has had to stay at home because of pain. The school has been great and we keep them up to date with what is going on and we send in doctor's letters. Ellie takes in a cushion for her chair, and they have said she can leave her bag in the classroom since it is so heavy with all the books. She can also have a lift pass and leave class early to go to next lesson.

## Angela Winton

My daughter's school was amazing when she went back after surgery. We built it up slowly with a couple of periods, then a half day, etc. She was allowed to arrive 5 mins late and leave 5 mins early to avoid crowds. She had a 'bag buddy' to carry her school bag from class to class. They gave her access to the lift so she didn't have to use the stairs to other floors and changed her locker so she didn't have to bend to access hers. We had talked it all through before she returned, so the school had all these things in place ready for her.

I found the first day she went back so stressful because she had been with me every minute of the day since her surgery, so to not be there to protect her was really tough, but kids are resilient and getting back to a normality is good for them.

## Joss Graham

I'm in my last year of secondary school and have had a brace for a few years now. Tell your teacher exactly what you need and explain why. Teachers often don't know or can't tell a pupil has scoliosis and wouldn't know how to help anyway, so tell them how to help you. For me with my brace, some combinations of chairs and desks didn't work because they made my back hurt. I use rest breaks in exams to walk around so no aches set in.

## Christine Lampert

What I found most helpful on my return to school was being allowed to leave classes 5-10 minutes earlier than the others. It allowed me extra time to move between rooms so I could go at my own pace and have space so that I didn't have to walk in large groups of other people where I could get accidentally knocked into. Although it often meant I didn't get to walk with my friends between classes, and I sometimes felt a little embarrassed packing up before everyone else, I definitely think it helped me. I was quite worried about getting bumped into and falling over for a long time after my operations, so this allowed me to ease back into things.

I let my teachers know that I would probably need to stand and stretch or walk around for a few moments. Personally, I found sitting in my classes, which were often more than an hour, quite taxing, especially sitting in the same spot at a desk. It was a little embarrassing to me at the beginning, because I didn't want to cause a disruption to the class, but I think everyone got used to it pretty quickly and knew I needed that time. I recommend asking for anything you think you might need, such as a cushion for school chairs, help with carrying heavy bags, a break room to rest in, etc, because, in my experience, teachers and schools are more than willing to accommodate, they just need to know what it is you need. I had some help carrying my bags at the beginning and was allowed to leave stuff in my classrooms instead of taking it home, which meant that I didn't have to carry anything heavy. For those taking exams, I went back into Year 11 and was offered extra time to complete my exams in case I needed to take a walking break,

which was incredibly helpful for me, even though I didn't use it all the time. I think just having the option of it being available was reassuring to me more than anything.

Going back to school was emotionally quite challenging at times because I had to be careful and couldn't necessarily do the same things as my friends and had to sit out classes like PE, so I felt a little left out. I also felt a little left behind after my time away, but my friends and teachers were hugely supportive, which really helped me feel welcomed back. It wasn't easy, but it was definitely more manageable with this help.

## Charlotte Black

I was home tutored while braced and then after bracing finished, I went to the education room at the local hospital before going back into school. When I returned to school, it was agreed that I could leave 5 minutes early with a friend before each lesson to avoid the busy corridors in secondary school with all the jostling and pushing. I remember the tall science stools being really uncomfortable and so if a different type of chair or stool is available, with a back, then that'd be best. I was exempt from PE for a while, especially contact and team sports. This helped my confidence and made me feel more comfortable.

I found that I needed to switch positions a lot when I first started wearing the brace. Too long standing, sitting, or lying down would result in an awful backache so I would switch positions regularly to build my tolerance up.

Before my surgery, the physiotherapist explained to me about using my stomach muscles to pull and adjust my trunk so that I'd build muscle

memory and it wouldn't feel so strange when the brace was then put on. This was a huge help and helped me prepare for how my body and posture would feel. I still do this now when I notice that I am standing to one side.

## Catherine Peck

When I was 15, I had a severe S-shaped double curve and needed two operations to correct it, around 6 months apart. Between operations I had a brace fitted that I wore 10 hours a day.

After the initial surgery and the brace fitting, I found that I got tired very easily, and ended up having a wheelchair for a few months. You can get these for free or very cheap at a Red Cross or through your hospital or GP, and if you're really struggling with walking then it's worth doing.

During this initial stretch I was home-schooled since I couldn't attend in person and would still have friends visit so that I could stay up to date on what was happening and feel like I was still somewhat 'in the loop'. This helped to make it feel less daunting when I was able to start going back to school part time, and of course it was a great distraction to see people.

Before returning to school, we did two things that really helped - the first was taking a few short day trips where we'd go for a short walk, stop at a cafe, another short walk, etc to get the hang of moving around and confirm to myself that I could do it. The second was a rather excellent shopping spree! It may sound callous, but I really cannot recommend it enough ahead of going back to school. Your body has changed shape, you're not totally comfortable in your own skin, plus with a brace I struggled to find trousers that I could wear. Buying a



few new sets of clothes meant that I could find clothes that would work with my brace – long, baggy t-shirts hid it very well, and we ended up getting large trousers and just duct-taping them over the brace rather than having them sit under and letting them rub. It also meant that I felt far less self-conscious about how I looked, as well as giving me a fun way to process my worries about having to go back after such a long break.

Once I returned to school, we made a few small adjustments that were really helpful:

The school was aware of my situation and had a dedicated ‘comfy area’. I think it was literally just two chairs next to each other in the school office, but if my back was sore, I could just go there and lie down for a bit which was a big help.

Not carrying a heavy backpack! Really do avoid this at all costs. I just had a friend who had agreed to carry mine for me but having a wheelable pack or leaving a small pack in each classroom also works. Remove anything non-essential.

Take some sort of seat cover/ pillow/ cushion with you. I felt a bit self-conscious doing this, but the chairs in the classrooms were just so uncomfortable that I couldn’t lean back on them and would get tired out very quickly.

Finally, find a pain management treatment to relax your back after school that works for you. I found a sports masseuse who was amazing, as well as having regular physiotherapy. On a day-to-day basis heat was a big help in relieving back pain, so have hot baths or use heated blankets or anything like that. You can get small single use self-adhesive heat pads to use during the day at school as well which are really useful.

### Naomi Mutale

Being open about scoliosis and treatment with close friends helped relieve some stress because then I didn’t have to put so much energy into trying to hide it from everyone. Emotionally, it was quite hard trying to figure out who to tell or whether to hide it and the right way to tell people. I was nervous about people’s response to it so I didn’t really want to go through that a lot. For the most part, people took it well but there were some kids that were quite cruel about it and that was hard to deal with.

In terms of bracing and returning to school, I would wear a vest over my brace and then my uniform which I found helped hide the bulges of the brace a bit. I was given a buddy (who I chose) to come with me to the toilets to get changed for PE. I found sitting on a chair during assembly really helped after returning to primary school after treatment.

I have a blog where I talk about dressing with a brace, amongst other things, and I also have a book which I wrote some time back with lots



Naomi Mutale

of advice for people with scoliosis, parents (which my parents helped write), and friends supporting someone with scoliosis (which my friends helped write.)

<https://amzn.to/3Gb6Jkb>

<https://spinetospine.wordpress.com/>

### Stacey Benjamin-Mcfarlane

It was a very nerve-racking time going back to school. I felt different from my peers and aware of being knocked or bumped into. Some things that helped were:

- I was allowed to use a laptop in class because writing by hand took me longer.

- I was given a locker so that I didn’t have to carry all my books, but I also used a backpack instead of a satchel, so the weight was evenly distributed instead of on one side of my body

- If lessons were upstairs, I would go up and stay in class during breaks to prevent me going up and down, or I had my work brought downstairs and I worked in the library.

- I was also allowed to stay indoors on cold or wet days.



Stacey Benjamin-Mcfarlane

# MANAGING PAIN IN SCOLIOSIS

Dr Rebecca Berman, Consultant in Pain Medicine , RNOH

Back pain is very common in the general population and is even more so in those with scoliosis. For some people pain may be very severe and affect every aspect of daily life, but many others do not have pain or it is not a major issue. There are many reasons why pain may occur such as problems with joints under strain that have become worn or inflamed. Pain may be due to bad posture, causing tension and fatigue of muscles and ligaments. It may also be caused by pressure on nerves that have been irritated, squashed, or stretched as a result of the curvature of the spine. This is not a complete list. Indeed, often we may not be able to tell for certain what is causing pain for a person.

There is also a big overlap in the causes of pain between the different types of scoliosis. For example, much of the pain of adult-onset scoliosis is due to uneven wear of the discs, which sit between the vertebrae and act as a kind of cushion. The worn discs themselves may cause pain but the strain on the facet joints (the paired joints at the back of the spine) may lead to further pain, as may the strain on muscles if posture becomes unbalanced. The curvature may also squash and stretch nerves. All or some of these problems can also be seen in some adult patients who had scoliosis as children, especially if their scoliosis has not been treated.

To make things more difficult, although an enormous amount has been discovered in the past 50 years about the science behind what causes all of us to have pain at different times, what we experience is personal to ourselves. Although we can try to describe how we are feeling to other people, no-one (and that includes doctors) ever truly knows what another person is feeling. This can be very upsetting because it can be difficult to explain our suffering to family, friends, and doctors, which can cause people to feel lonely and misunderstood. It is not uncommon for people to say things like ‘the doctor didn’t believe me’ or the ‘the doctor thinks the pain is all inside my head’, or even for a doctor to say ‘I believe you have pain’. None of this is helpful.

What we each experience does not depend on whether or not someone else believes us, not even if that person

is a professional. Also, all our experiences are ultimately inside our heads whatever is going on in the rest of our bodies or the outside world. This may all sound somewhat philosophical, but these are important points because pain is what we feel and not what causes it.

For example, if you have a slipped disc, what you experience depends on all sorts of factors. These include not only the irritation and pressure on the nerve but how well our nervous system can block these signals from

“Although we can try to describe how we are feeling to other people, no-one (and that includes doctors) ever truly knows what another person is feeling.”

reaching the brain. There are nerves that come down from our brain to our spinal cord that can reduce the signals going back from the spine to the brain and so can reduce what we ultimately feel as pain. How well these nerves work in reducing pain signals can depend on our genes, environment, medication, and even our beliefs. This all happens automatically so we cannot always say for certain what is causing our pain. All that we can do is describe it to others as best we can.

So, what can we do to manage our pain? Often this is simply a matter of looking after ourselves by controlling our physical activities or taking over-the-counter pain killers when the pain gets very bad. More severe or long-lasting pain may be managed by your doctor (GP) who can help with diagnosis, arranging outpatient physiotherapy, and providing stronger pain killers. GPs may be able to refer patients to psychological services such as counselling.



Psychological services can help when pain is long term, and when physical and chemical treatments do not work well. A type of counselling called cognitive behavioural therapy (CBT) can be used to help patients manage pain. During CBT a psychologist will discuss with a patient the patient's views on the causes of their pain and how this affects the way they manage it. A good example would be a patient with a back spasm who believes that staying in bed is better for them because the pain is much worse when they get up. They are afraid that this means they are doing more damage to their back by moving when the opposite is true.

This behaviour may make their back weaker so they take much longer to recover, which can have a bad effect on their work and family life. The psychologist works with the patient to challenge these understandable but incorrect beliefs to help them take back control of their life. This type of therapy can be helpful for some patients with scoliosis. However, because scoliosis is a life-long condition and people often have their own ways of coping with pain CBT does not always work as well.

If the GP is not able to help, then they may refer patients to a pain clinic. Pain clinics have teams of staff who specialise in different areas. They all differ slightly from hospital to hospital depending on the needs of their patient groups. The point of these large teams is that spinal problems are complex and often the specialist knowledge of a wide range of people is needed. For example, a patient

may benefit from physiotherapist advice on posture. The psychologist may help them to deal with the difficulty of coping with ongoing disability and pain or treat conditions such as depression. The surgeons may be needed at times when surgery could stop things becoming worse or could help with pain. There is an overlap in the skills of these groups of staff. The areas that pain medicine specialists like myself, work in, include spinal injections and medication.

In treatment with spinal injections steroids are injected into the nerves and joints to help ease pain. Doctors can't agree on how well they work and whether they should be used. Injections do seem to be helpful for some patients. However, for people with long term conditions such as scoliosis the effect of injections nearly always wear off. Also, if a patient keeps having injections, they often seem to have less effect over time. It is rare for things to go wrong, but nerve damage from injections is possible. Therefore, injections are used sparingly and only when we have good reason to think they will help. They are often useful in the short to medium term but generally not in the long term.

In special injection treatments needles containing wires are used to burn off the tiny nerves to the facet joints at the back of the spine. This is known as radiofrequency denervation and can give much longer pain relief than ordinary injections, sometimes for several years. However, it usually lasts for about 6 to 9 months and is difficult to use on a curved spine. Therefore, it is a treatment that may only be useful for a small group of patients. Another

treatment that we are now using for people with pain from damaged spinal nerves, is spinal cord stimulation. This is where electrical wires are placed along the back of the spinal cord and attached to a small stimulator box that can be buried under the skin and controlled with a handheld remote control.

Nearly all patients who are sent to the pain clinic are on some form of medication to relieve pain. These include opioids (morphine, oxycodone, codeine, fentanyl patches, buprenorphine patches), non-steroidal anti-inflammatories (ibuprofen, naproxen, diclofenac, celecoxib, etc), nerve pain agents (gabapentin and pregabalin are the most common of these), or hybrid medications such as tramadol and tapentadol. Tricyclic antidepressants such as amitriptyline can also be used as pain relief because they have a direct effect on pain as well as mood. Paracetamol can help. Diazepam is sometimes used alongside other medications for very severe pain, but it is very addictive so usually much more trouble than it is worth and would not be prescribed at all in most pain clinics.

Even with such a wide range of pain medication, it is no simple matter to control chronic pain. Chronic pain behaves very differently from acute pain because it alters our nervous systems so that the pain will not easily be switched off by pain killers alone. The body also adjusts to the presence of pain killers. This means that pain killers (especially opioids) can become less effective over time, sometimes very quickly. Patients can become physically dependent on a drug, which means their body becomes used to the drug and so if they stop taking it, they have symptoms as the body readjusts, which can last from days to weeks. Much rarer but by no means uncommon is addiction. It is not something that we can control directly although we can fight it with the right help. Opioids also often produce severe constipation, part of a condition known as opioid bowel syndrome. They can also impair our ability to think straight. Because of all these issues, pain clinics will keep doses of opioid medications low and monitor their effectiveness. If there are side-effects or lack of benefit they will be stopped.

The non-steroidal anti-inflammatories have also been through rises and falls in popularity. There were concerns over effects on the stomach and bowel and later concerns over the effect on the circulation. Again, like opioids, they

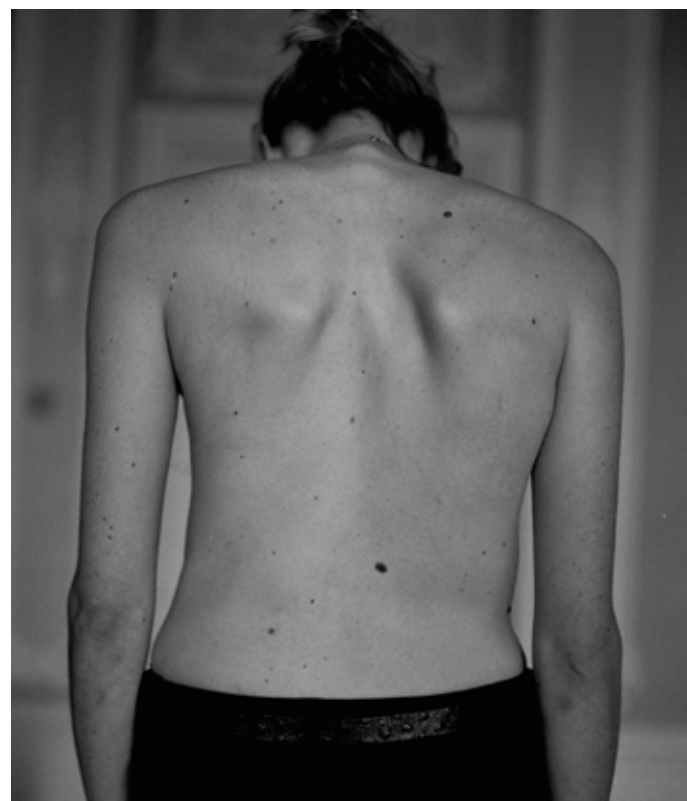
have a place for use in some patients at carefully monitored doses. Even paracetamol must be used with caution and daily doses are now often limited to 6 tablets a day where possible.

All this may sound somewhat gloomy, and I do apologise if it appears that way. We do continue to prescribe all these medications, but we are careful how we do so. Unfortunately, we cannot completely entirely get rid of pain for many people but by working and cooperating as a team with our patients we can give them the means to help manage their pain and make it less of a limiting factor in their daily lives.



Whether you want general guidance or advice or just to talk things through; the SAUK team are here to lend a listening ear. We receive calls from people who have just been diagnosed, worried parents, people who have lived with scoliosis for many years and many others.

You can call us on 0208 964 1166 or if you prefer email [info@sauk.org.uk](mailto:info@sauk.org.uk)



# SAUK DONATIONS

A huge thank you to all our amazing supporters for your generous donations. We greatly appreciate all the donations we receive, and you are vital in ensuring we can continue our important work, providing support and information for people with scoliosis.

Agnes Fletcher, Alan Chapman, Alan Francis, Alice McKay Hill, Amanda Clarke, Amanda Newman-Webb, Amoré du Plessis, Andrew Cleland, Ann Culley, Ann Margaret Hunter, Anne Kim Cameron, Anthony Curnow, Barbara Curnow, Barbara Sinclair, Bryony Crossland, C Hoare, Camilla Drax, Charlotte Croft, Christina Collins, Christine Mills, Christine Nixon, Daniel Harrison, Daphne Bailey, David J W Hardie, David Lynch, David McKay, David O'Connor, Denise Jane Bailey, Denise Minter, Diana Lucas, Dionne Ross, Eileen Harding, Elizabeth Baker, Elizabeth Findlay, Emma Lewis, Emma Nendick, Enda Hendron, Ewan Campbell, Francesca Pulford, G Huisman, George Georgiou, Georgina Chisholm, Georgina Neal, Gillian Carr, Gillian Warwick, Greig Hardie, H Doherty, H Orr, Hazel Keyte, Helen Clark, Ian Churchward, Jack Lewars, Jane Clemens, Jane Manning, Jane Wareham, Janet Cleaver, Jayne Boniface, Jayne June Ashford, Jean Greaves, Jemila Jaffa, Jennifer Moseley, Jill Trant, Jill Warsop, J Le Gresley, Joan Henderson, Joan Richardson, Joanna Langford, Joanne Larner, John Dorgan FRCS, John Dove FRCS, John Fawcett, John Southam, Jonathan Charles, Jonathan Fish, Josephine Edwards, Judith Grimwood, Julia Pallant, Julia Welford, Karen Kemp, Karen Stretch, Kate Stein, Kath Skillern, Kathleen Jenkins, Kathryn Minett, Keith Gibson, Kirsten Barrow, L Fell, L Meadows, Laura Tisdall, Liam Chipchase, Lisette Keats Khalastchi, Lorna Bennett, Lorna Flannery, Louise Wilson, M J Dunne, Malcolm Derrick, Mandy Jarvis, Margaret Tomlinson, Marion and Ray Watson, Marion Hunter, Martin Bourne, Martin Miller, Mary Hall, Michael Edgar Mchir FRCS, Michael Forbes, Michael Green, Michele Pacteau, Mrs B Aitken, Muriel Mariucci, Myk Baxter, Nick Everett, Nicola De Cruz, Nicola Murphy, Olivia Lawton, Pamela MacDonald, Patricia Billington, Patricia Shubbrook, Paul Hanselman, Pauline Price, Peter Grosch, PSH Law Limited, R A Croshaw, R Hallan, R K Evans, R Lacey, R M Couchman, R O' Malley, Rachel Jevons, Rachel Simpson, Ray Adams, Rebecca Hilsely, Rebecca Minett, Rebecca Smith, Richard Litherland, Richard Marshall, Ronald Lowrie, Rosa Alonso, Rosie Banham, S Parkin, Saira Awan, Sally Oxley, Samantha Miller, Sarah Kessler, Sharon Inglis, Sharon Ludbrook, Shirley Cole, Sonia France, Stacey Colton, Steph Walker, Stephen James Fawcus, Sue Osborne, Susan Joan Kelly, Susan Parashar, Susan Rose, Sylvia Horlock, Thea Dickin, Tim Morley FRCS, Tracy Charley, Victoria Margeson, Victoria Marks

## In memory of...

Our thoughts are with those who have lost loved ones and we are so grateful they chose to donate to SAUK in their memory.

£129.25 was received via Much Loved in memory of [Irene Bell](#)

£239.40 was received via Much Loved in memory of [Andrew O'Brien](#)

£30 was received in memory of [Patricia LeBlanc](#)

£29.92 was received via Much Loved in memory of [Elsa Green](#)

£105 was received in memory of [Joyce Dorothy Thorne](#)

£100 was received in memory of [Shane Keyte on his birthday](#)

£376.17 was received via Much Loved in memory of [Daniel Bell](#)

£25.00 was received in memory of [Christine Predeth](#)

£385 was received in memory of [Judy Johnston](#)

£994 was received in memory of [Arthur Tamin](#)

£250 was received in memory of [Joan Henderson](#)

£30 was received in memory of [Malcolm Derrick](#)

## Legacy

£1000 was left to SAUK by [Rachel Elizabeth Collins](#)

# SAUK - FUNDRAISERS

A huge thank you to all our amazing fundraisers for your fantastic efforts to support us. We are so grateful for all your hard work; we really couldn't continue our work without you. We realise that times are difficult at the moment, but anything you can do to fundraise for SAUK is vital to our being able to continue to support you.

## Fundraisers

Jo Farley  
Keya Shah  
Joanne Smart  
Simon Wainwright  
Ellen Ross  
Abbie Blake  
Alice Mitchell

Toni Craig  
Abbie Blake  
Claire Rose  
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Amae Van Zyl  
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Emma Grace



Orry and his siblings completing the mini Parish Walk to fundriase for SAUK

## Facebook Fundraisers

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# LONDON MARATHON

Look at them go! On Sunday 3rd October, after training for 2 years, 80 000 runners took to the streets of London to run the London Marathon. Among them were those running in support of SAUK and SCF.

## Anton Perkins

After nearly 2 years of very early rises and lots of aches and pains I'm pleased to say that I ran the iconic London Marathon on the 3rd October, 2021. Through all the ups and downs of the training it really doesn't prepare you for how emotional it is on the day. This year was different because people just wanted to get back out there after COVID, and everyone wanted to be part of something special again. The atmosphere is hard to describe, from listening to the bands on route to the cheers from the crowds encouraging you on.

For the last few miles you really have to dig deep and the spectators really do help bring out the last bit of energy to get you over the finish line. I really believe it does help you be mentally strong, focusing on your goals and achievements. It is such a satisfying experience that I would recommend it to anyone thinking about taking on a marathon. I know the training can be tough, but the rewards can really be beneficial mentally.

The most important part that helped push me on was to raise money for the Scoliosis Campaign Fund and since I have a 47-degree curve it really was emotional to raise funds for a charity so close to my heart.

I would like to take the opportunity to thank everyone who has sponsored me with their messages of support (you know who you are!) – I couldn't have done it without you and you certainly got me over the finish line.



Anton Perkins



## Rod and Kellie

Rod and I had a fantastic day, we loved every minute (even the painful ones)! The support from the crowds was amazing and carried us through the later miles. It made it extra special that our family (including eldest daughter with scoliosis) were there to encourage us and see us finish what has been a long 2 years of training and fundraising. We were delighted to exceed not only our original target of £2k but our reset goal of £3k too. We wore our bright orange vests with pride (the best charity vests by far in our unbiased opinion!) which spurred us on to achieve our target finishing times (4 hours for Rod and 3hrs 54 for me). Sadly, we weren't allowed to run together as I qualified under the good for age scheme but we still made the best of the whole experience.



Rod and Kellie Townes



Paul Lewis



Katie James



# BACKING SCOLIOSIS

## Matt De Redman

Matt's kyphosis journey started after his heart surgery in 2007, when a slight curve in his spine was noticed, but there was no further investigation. By the time he was 14 his back was bothering him more and his rugby coach pointed out that he should check on the reason behind his poor posture.

So that's what Matt and his parents did. He was seen by a scoliosis specialist who diagnosed a 42-degree curve. Following the consultation, he had various physio treatments and was fitted with a brace. He wore the brace at school but in PE, he was teased about it looking like a bra. Thankfully, his PE teacher was incredibly supportive and put a stop to any bullying.

Matt's curve became noticeable at an age when body confidence can be shaken by rude comments and boys pointing out his differences in the change room. He wouldn't let it get to him and would tell them "Well at least I have plenty of backbone!".

Matt went through three pre-ops over the next few years



but never actually had the surgery. The first time, he was busy applying for university so his doctors decided they could give him a year to get settled. The second time, he had acne on his back. Because of the risks of infection, they couldn't go through with surgery, and it was delayed.

By the time he got ready for surgery the third time, in 2015, it was decided that the best thing to do was not go ahead. He was busy training for sports and led a very active lifestyle and the surgeon said that he may not have been able to compete at the same level after surgery. As the scoliosis wasn't progressing rapidly Matt and his surgeon decided that he could manage living with this curve.

Matt works for a professional Rugby club and is still very physically active, taking part in sports and going to the gym. He has access to the team physio, who has been incredible with advising stretches and exercises.

Pain is a part of Matt's life, but his active lifestyle means that this has been manageable. He has become good at listening to his body and knowing when to slow down too. At 25, Matt wants to manage his scoliosis through making good lifestyle choices and complementary therapies for as long as possible.

Matt writes:

"Stiffness is probably my biggest problem and I struggle to sit for longer than half an hour without getting stiff. This is managed by taking stretch and exercise breaks and knowing my own body and when to stop. I pride myself on working hard and thankfully my Managing Director is very supporting and helped me adapt.

For a while I struggled to date and find someone who saw past the disability. For some reason despite been very physically fit and active, ladies would think it was an issue. However, I have now met Amelia who is the most supportive person I have ever met. She fully embraced me for who I am and all my craziness.

I remember talking about it for the first time and it happened as our relationship started to develop and become serious. We were lying next to each other and going through our challenges. I explained how I have this 45-degree curve and her response brought a tear to my eye. Amelia loves me for who I am, no matter how I may appear.

The reason why I am speaking so openly and want to share this is because there will be people out there who are in similar positions and feel alone, vulnerable, scared, or

uncomfortable with their bodies. I have faced challenges and overcome every one by using my support networks and I hope to help others find the right support networks and develop confidence and resilience.

If I'm able to raise awareness and encourage more young men to talk about it then that's going to make a difference. It's the same with any kid at school struggling with any physical difference – if talking about it makes them feel more comfortable in their bodies, then I'm more than happy to do it."

About Kyphosis

Scheuermann's kyphosis is a condition in which the front sections of the vertebrae (bones that make up the spine) grow more slowly than the back sections during childhood. This difference in growth means the vertebrae grow into the shape of a wedge, when they should grow into the shape of a rectangle. These wedge-shaped bones don't stack up in a straight line. As a result, the spine develops a forward angle as it grows. The forward bend of the spine is called kyphosis.



## Naomi Mutale

Naomi was diagnosed when she was 3 years old. Her mum noticed a rib hump when she was giving her a bath, when it didn't go away, they took her to the hospital and Naomi was diagnosed with scoliosis. Naomi was braced initially from the age of 4 to 9. At that point, the specialists could see that the curve was continuing to grow, so it was time to start operations to insert and manage growing rod.

Growing rods are used to treat young children with severe scoliosis. They help control the curve and allow the spine and the trunk (middle part of the body) to grow. Traditional growing rods need to be lengthened every few months by making a small incision in the back. Naomi has had eight operations in total, with her final one, spinal fusion, coming aged 16. When she started shaving these procedures, she had an 81 degree curve and still has a 43 degree curve after fusion. She continued to be braced between her operations and only stopped that at 14.

Naomi says: "Initially, I really hated my brace. I really struggled with it. It was uncomfortable and it would poke through my clothes. I'd do anything and everything to hide it. The kids in primary school when they did notice it would poke at it and ask questions about it that I didn't even know the answer to. It felt never ending, I had to wear it for 23 hours a day and if after 6 hours I was fed up, I knew that was nothing compared with how much longer I had to be in it".





Naomi grew up being in and out of hospital and having to go through these challenges that her siblings didn't have to face.

She said: "Initially, I didn't notice any difference between me and my siblings. My family was so normal about it. When it was time for surgery, it wasn't a big deal, it was just 'okay Naomi, time to pack your bags', it wasn't a big send off or anything. Eventually it dawned on me that not everyone goes through all this and after the operations I started to feel it and had questions such as, why me? It started to bother me that I didn't have as good a correction as others who had maybe just had one operation. So, it was why me out of everyone in my family and then why don't I even have an amazing straight spine at the end of it all, and, what was the point? I'd look at my siblings backs and think, if only!"

Over 10 years on from her last surgery, Naomi has long been discharged but it took her a while to feel that the treatment and surgery part of her life was over. She never really believed that that last operation would be the last. She says: "I had been waiting for the last operation for a long time and had been told that my spine would be bolt straight and I wouldn't experience pain, and everything was going to be great. That wasn't the case so there was never relief. I was always waiting for that moment to have that straight spine. When I realised that that moment wasn't coming, the need for that relief had gone as well." Naomi didn't know about SAUK at the time of her treatment and found it quite lonely to go through

everything without someone to talk to who would truly understand.

She noted that: "The other side of my family not making a big deal about me having scoliosis meant that there wasn't space for me to talk about it openly. Afterwards, when I sought out people with scoliosis, I was just seeing stories of people who had had only one operation. That's when I got involved with SAUK as a volunteer so that I could be that person for others and share my experience of multiple operations and growing rods."

### Caroline Freedman

Caroline Freedman is a personal trainer and author of 'The Scoliosis Handbook of Safe and Effective Exercises Pre and Post Surgery'. This was a career move taken after realising that she herself as someone who knew how to help those with scoliosis could address the gap in the knowledge of scoliosis in other personal trainers.

It was at an exercise class when Caroline was 15 years old that her scoliosis was first noticed. She had bent over a bar to do a stretch and her friend noticed the curve. The friend's mum told her parents who took her to a GP, and she was referred to a scoliosis specialist. At that point, Caroline didn't need surgery. At 19 though, after coming back from a gap year, things had progressed, and she had no choice but to have surgery to fix an 80-something degree curve.

'Caroline said "What seems to be different about me is that my rib cage was severely out of place and rotated. To correct this, I had five ribs removed for bone grafting and

to correct the rotation. I had a long Harrington rod put in, and that was that."

She was told that being strong before surgery was important for a good outcome. She was always into exercise so this was something she enjoyed. It was during one of these exercise classes a few years later that things went wrong.

She told us: "When I was around 23, I snapped my rod in half when I was doing a back bend. It was a stupid thing to do – I was showing off. It turns out that one of the fusions hadn't taken and it was weak. So, I went back into surgery and had the long rod taken out and two short ones put in. I had another rib or so taken off and had to wear the brace again."

About 5 years ago, Caroline had yet another operation. She said: "My spine had rotated around, and I had two ribs sticking out. I couldn't lie flat, and it was really irritating me. I was so fed up that I went to see a surgeon to have one of the rods taken out, have the other one shaved off, and another couple of ribs taken out. That was the best thing I've done; I woke up from surgery and was amazed to feel the left side of my back and be able to lie flat."

With her operations spread out over the years, Caroline has witnessed the changes in how surgery and pain relief are approached. Being asked to consider the effect scoliosis and three operations has had on her mental wellbeing is new to Caroline. It's only been through her exposure to the scoliosis community online that she's realised that this is something that others are speaking about.

She says "I never thought about the emotional side. I've realised that people would ask me 'how are you doing?' and I'd always take it as them asking me how I was physically. It never even crossed my mind that they might be asking me how I was feeling emotionally. I'd answer, 'yeah I'm fine, not in so much pain today'. When I wrote my book, I really wanted it to be very uplifting. I wanted mothers to pick it up and see I was doing all this stuff and isn't it great, rather than all doom and gloom. I didn't want my book to be a horror story. So, I didn't write about my emotional journey much at all. It wasn't until a few weeks ago that I thought about this, and it made me cry. I see other young girls talk about the emotional side of things and realised that I've blocked that out," said Caroline.

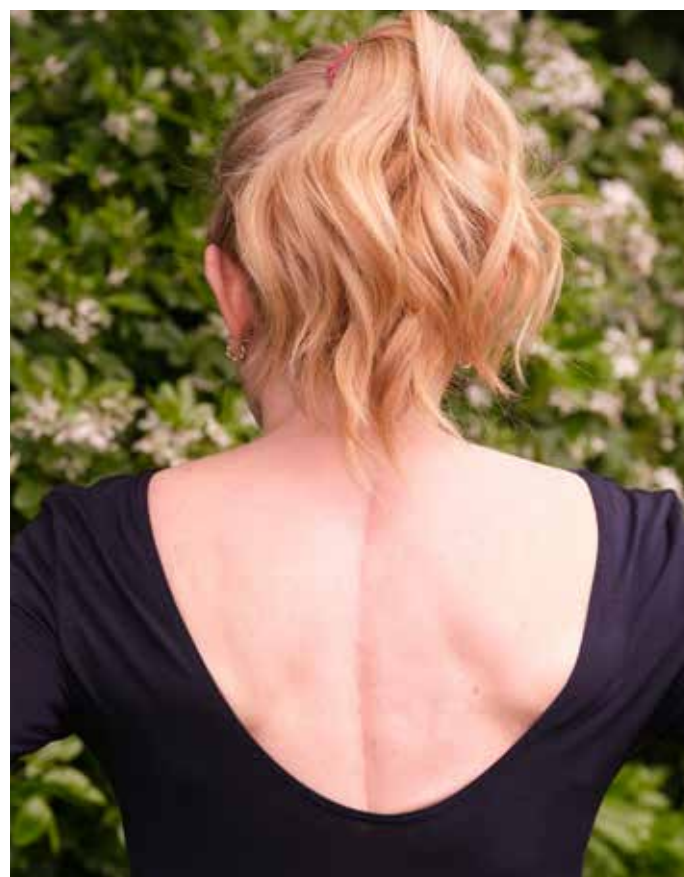
Caroline needed a trainer to help her because again, she was told it was really important to be strong in order to be pregnant. She found a great, well recommended trainer, Nikki Waterman, but Nikki said she didn't have experience training people with scoliosis so wouldn't feel comfortable training Caroline. Caroline kept insisting until Nikki finally agreed. It turns out Nikki agreed because she had a celebrity client with scoliosis and

needed to pick Caroline's brain. Caroline was such a star pupil that her trainer convinced her to become a trainer herself. Nikki is no longer with us but played a big part in Caroline's life and her career as a trainer.

Caroline said: "The way I really built up my strength after surgery was doing a high plank to a downward dog, loads of those. They work out your whole body using just your body weight. I was thrown out of a Pilates class once because I couldn't get the right movement and the teacher came up to me and said, 'your back isn't sitting right', and I said, 'well no, it can't, but I know how to adapt the movement', she wasn't comfortable with that, and I was asked to leave in the middle of a busy class. I was so humiliated I didn't even complain, I just sat in my car and cried."

Caroline was asked to write her book by Liz Bord from ASPIRE Leisure Centre at Royal National Orthopaedic Hospital because there just wasn't any literature out there to help scoliosis patients with exercises.

"I'm hoping that I can be of help to physios, trainers, and those affected by scoliosis. Sometimes I see people who are too scared to go to the gym because they just don't know what to do or think that their body can't move in the right way. There are ways to adapt exercises to make it work. There's no need to be scared but you do have to be careful," said Caroline.





## Vicky Wong

Vicky was diagnosed at 14 by chance. She was having a pool day and her cousin noticed her back looking a bit unbalanced. Her back had been hurting but she thought it was normal growing pains. Eventually she saw a chiropractor for that pain who suspected scoliosis, which led to an official diagnosis. Vicky's scoliosis was causing more and more pain and the curve was growing so fusion surgery was recommended to her.

She writes: "Coming from a small town, I had to be referred to a hospital quite far away from my home. Because of some unfortunate administrative errors, I had only a day's notice before my surgery. I turned up at the hospital for what I thought was a normal check-up, which turned into an overnight stay to prepare me for surgery the next day. I was told if I cancelled, I'd have to wait 6 months for the next chance to have surgery. I was obviously quite shocked, but in the end I took the opportunity and haven't looked back since. Even after surgery I wasn't guaranteed a straight back and I was going to have a big scar – all that seemed scary. I was in hospital for a week afterwards and had to learn how to stand again. I wasn't expecting the recovery to be that hard and to have lost that much mobility. It was a year before I could run properly and do anything physically straining. I had to get back to school during my recovery. I felt I had to push myself to get back to normal but I struggled. It knocked my confidence. I was carrying a cushion around and sitting in a special chair so I felt a bit different. I'm the eldest in my family and prefer being independent. But then I suddenly had to be dependent on others, where everything was about how I was doing. I obviously really appreciate the love and support but I hated feeling like a constant burden. I had to learn that it's okay to ask for help and reach out to people."

Vicky wished she had had someone around to relate to in the moment. Scoliosis is more common than people

think but in her small town, she struggled to connect with anyone who had it. That changed later in life, when she was speaking to one of her best friends about her scoliosis and discovered she also had scoliosis. It meant so much to her to have this connection so that when she discovered SAUK she volunteered to help others by being a relatable person for those with scoliosis to talk to.

She says: "A condition like scoliosis can be very emotionally and mentally challenging. Struggling by yourself isn't the healthy way to deal with it. By reaching out to people it's been really empowering for me. Now, I'm in a better place and feel more content with myself. I want to help others reach this point too! I strongly identify as someone with scoliosis now. Scoliosis put me through a lot of hardships but at the end of the day, it's a special and defining part of my life."



## Emily Hale

Emily Hale was diagnosed with scoliosis at age 14 with a 54 degree curve and went on to have fusion surgery a year later. She was a dancer and figure skater before her operation so was keen to get back into the activities she loved. She found it harder than expected though and it shook her confidence to realise what she could do had changed. Emily tried to find other ways of being physical and to build strength in recovery and that's how she found Pilates. Emily now works full time as a Pilates instructor and has this to say: "Figure skating has been hard. I haven't been able to do that in the same way. You need to have some level of back extension to lift your legs on the ice. The first time I got my skates back on and got on the ice it was heartbreaking because I couldn't do it anymore. I think that had a really big influence on my recovery and made me more hesitant to throw myself into things because I thought that I wasn't the same as I was before and I couldn't do the things I did before."

Emily's surgeon had recommended Pilates as a way to build core strength and she found it had the flavour of dance and really took to it. She came out of her bad experience with figure skating and thought about what she could do, rather than what she couldn't. Her attitude was: "I've done some really cool things, even after fusion. I did get back to dance training and did dance

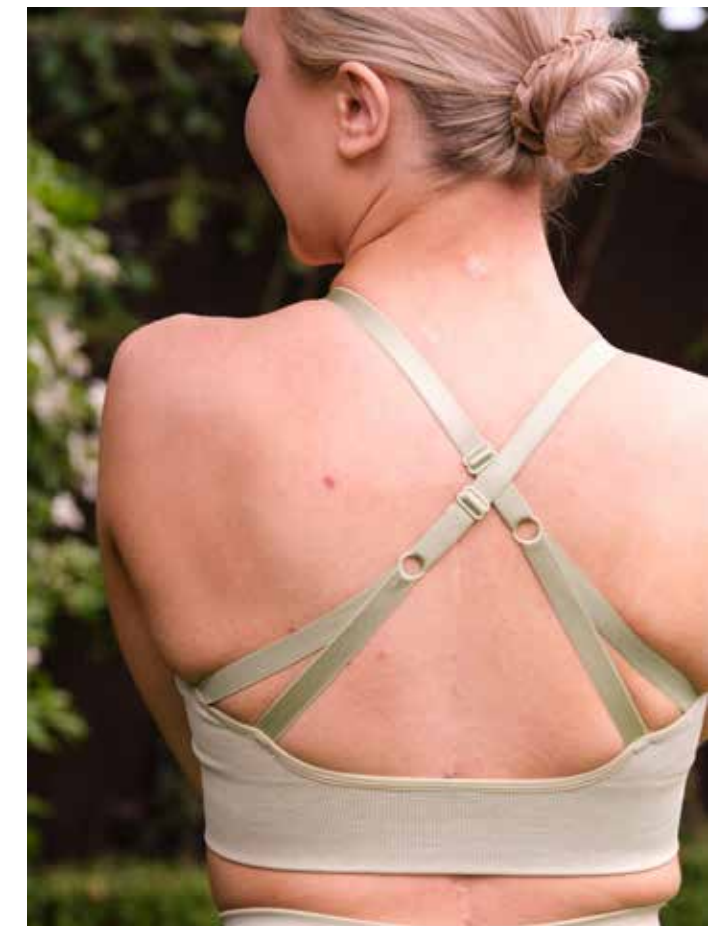


competitions. I trained as a surf instructor in Australia, went on a trip to Ethiopia, and climbed mountains. I proved there were things I could do. I was hesitant and heartbroken but I turned it around. Pilates was the constant throughout."

It was while Emily was working at a desk job that everything went sour, as she goes on to say:

"I was sitting for 8 hours a day, plus the commute, and it was just awful. I used Pilates to help with that, which led to me qualifying to be a Pilates instructor and work on that full time. I just wanted to learn more about my body by doing the Pilates training course at first. A lot of Pilates classes get you scrunched up in positions that I couldn't do, and it was so frustrating. I needed to work out how my body worked and find movements that worked for me."

Emily is a big part of the scoliosis community on Instagram, sharing her experience with scoliosis and her tips and tricks for managing it, as follows. "It was at the start of lockdown that I found all these support groups and pages on Instagram about people's scoliosis journeys and fusion. I was really taken a back, I thought 'oh wow, we're allowed to speak about it?!' My closest friends now are people I connected with through Instagram about this shared experience. That connects you in such a deep way, you can try to explain your fusion to someone else but they can never quite get it unless they've been through it. It's been amazing speaking with people in the same boat."





Being part of the community has highlighted things within myself that I didn't think was connected to scoliosis, but I've now seen that reflected in dozens of others, one of those being stress and back pain. My back would be a nightmare whenever I was stressed at work. A lot of people have that pattern though and I now see that when I reduce my stress, I reduce my back pain. That's been a game changer for me, working to balance my life better to mitigate my back pain as much as possible. That's a real benefit of the community, knowing you're not alone with the symptoms you're having."

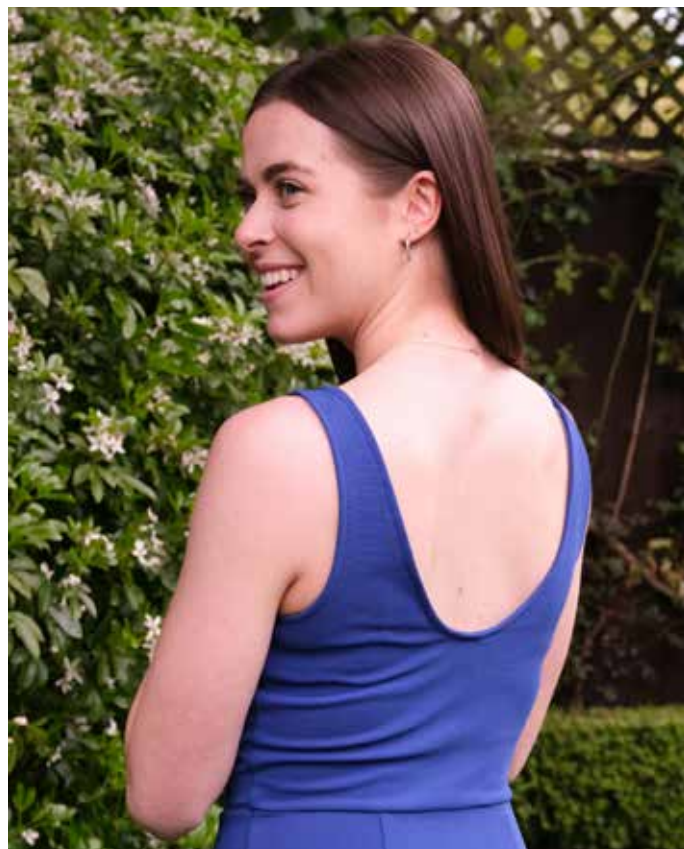
Emily wants others with scoliosis to see the strength in what your body has gone through, especially post-fusion. She goes on to say: "What I see a lot of is hesitancy post-op but you can do much more than you think after your recovery—you don't need to be wrapped in bubble wrap. To build that confidence, people have to start small and work their way up. For me, body confidence means more than just how I look. It's knowing that your body is still strong, and you still have a huge amount of things you can do, with scoliosis or post-fusion."

## Katie Towner

Katie has been dancing since she was 2 years old. She knew very early on she wanted to be a dancer, until she discovered musical theatre that is. Katie is now 20 years old and is studying musical theatre at the Emil Dales School of Performing Arts. By reading her scoliosis journey, you will come to understand why that is such an amazing achievement. We hear from a number of dancers who are just beginning their scoliosis journey and are scared about what a scoliosis diagnosis means for them. Katie wants to share her story so that other young dancers being diagnosed with scoliosis know that it doesn't necessarily spell the end of their dancing careers.

Katie was living in America where they screen for scoliosis in school. Interestingly, in June, no scoliosis was picked up. Katie and her family then moved to London in August so that Katie could attend the Sylvia Young Performing Arts School. Before she started she was sent for health screening where they told her, "You know you have mild scoliosis right?". They were told it was so mild it wasn't anything to worry about. By Christmas though, Katie had bent over, and her mother noticed how uneven her hips were getting. They booked in to see the GP and Katie was referred to a scoliosis specialist. At that point, she was 12 years old and had a 40-degree curve.

By February, she was having a lot of pain and eventually she had to stop dance altogether because of the pain. By March, the curve had grown to 45 degrees and so the conversation turned to surgery. Katie was taking pain killers, going to physio, and doing a lot of water therapy



to cope with the pain. Despite this, she had to stop attending classes as the journey from Kent to school in London was proving to be impossible with the level of pain she was in. Katie has this to say:

"Swimming was the one time when I felt the pain completely go away. I'd swim several times a week because that was the only thing I could do. Before swimming and after swimming, I was in pain, but while I was in the water, it all went away. By early May, I got a wheelchair because I was becoming housebound. We went to the Red Cross where, for a small donation, we could use their wheelchair for several months. This made such a big difference and got some normality back into my life. I'll always remember visiting Brighton for my 13th birthday and being pushed down the broadwalk in my wheelchair."

On Katie's next visit to the specialist in May her curve had grown to 50 degrees and she was told they would go ahead with surgery now as they had been waiting for her growth plates to reach maturity. Katie had fusion surgery in the first week of June, 2014, 10 months after first being told she had mild scoliosis. She says:

"At first, surgery was something I was not looking forward to at all. I remember crying during the appointment thinking I'd have to stop dancing and the surgery would take that away from me. There was no promise that I'd go back to dancing at the level I was after the fusion. The situation completely flipped by April. I wasn't doing anything at all, so anything I could do after the surgery would be an improvement.

I can do more now than I expected to post-fusion. I can

do pretty much everything I could before. I remember when I was in hospital the first few days post-surgery, everyone was saying, 'just wait till you get to 6 weeks post-surgery, you'll feel much better' I couldn't believe that I could go from how bad I was feeling to better in just 6 weeks but there really was a drastic change after that and the pain got so much less. I went back to school in September. I start dancing again 6 months after my operation with light moves, but I felt so ready to get back to it. By February, I was performing again in dance solos. That's not to say that there weren't moments of pain and difficulty. I had to learn when to take a break."

Coping with this big life change and experiencing chronic pain had a significant effect on Katie's mental health. She describes the challenges:

"I had issues coming off the Tramadol pain killers and experienced withdrawal symptoms for about 6 weeks. This was between weeks 6 and 12 after surgery, so I was dealing with withdrawal on top of recovery. One night I was in such a bad state, I was hallucinating and shaking and couldn't recognise my parents. The memories of that, being in hospital and the pain stuck with me and I struggled with that. It took a while to process everything I'd been through but a year after surgery I started counselling where I was told I had PTSD from everything I'd been through and was put on antidepressants.

I remember not wanting to talk about that side of things at all outside of counselling, but I think things have



been changing over these past few years. Mental health awareness is growing and it's no secret anymore that a physical condition like scoliosis can lead to mental health issues because of how traumatic it is to go through. By sharing my story, I want to play a part in getting more people to recognise their mental health needs and realise that they will need to recover mentally and emotionally, as well as physically."

## Christine Jaureguiberry

Christine is from Germany where they screen for scoliosis in children. Her curvature was picked up when she was 5 or 6 years old. She had a lot of physiotherapy to manage it but there was never talk of surgery. As a teenager she was feeling more pain and wore a heel lift in her shoe to try to correct her uneven hips. Christine sought out a lot of complementary therapies to manage the pain, seeing chiropractors, acupuncturists, and physiotherapists to find a solution.

She describes her early experience: "I always felt very misunderstood. Nobody could figure out how to help me or how to make this better. I moved to London in 2004 and started to go to yoga classes and that was a turning point. Immediately, I felt better. I found something I could do myself; I didn't need anyone else or to have something done to me to fix me. It morphed into an investigation exploring what I could do to feel better, more balanced, and stronger. After a few general yoga classes my





awareness of my body increased, and I started to realise I needed exercise that was more tailored to my needs. Eventually that led me to become a yoga teacher because of this passion. Yoga is not about correcting, changing, or getting rid of your scoliosis but about finding the best way of being in the body you've been given. I've been in yoga classes where I've been corrected without the instructor knowing that I won't look like everyone else doing that move. It can feel like you're doing something wrong or there's something wrong with you."

Christine has dedicated her work to supporting the scoliosis community. People's instincts when they're in pain can be to not move at all, or they're afraid of exercise because they don't look or move the same as others. This can be harmful because movement and exercise are such a big part of managing pain. Stories like Christine's shows us that we can't give up on discovering the best version of ourselves.



# INSPIRING FUNDRAISERS

## Louise Laurie

Louise was diagnosed at 14 with a 70 degree curve. The specialists recommended surgery but her parents weren't comfortable with that so instead she went back to the specialist every year for the next decade to check if her curve was progressing. She remarked: "I felt really alone and really scared throughout this time. I felt I was the only person out there with this condition. This is before the internet and all of that, so it felt quite isolating." Her curve was progressing, but it was when she was 24 that she started to consider how having the surgery might change her life. She was in a lot more pain and discomfort and having this hanging over her was affecting her mental health. The idea of surgery was very scary to Louise so it wasn't a decision she took lightly, as she describes:

"I researched the surgery myself and joined a few forums and that's when I joined SAUK. I made quite a few friends through this – people who'd had the surgery and people who weren't sure if they should. It felt really good to not be alone anymore and to talk to people who knew what I was going through. After reading about people's positive experiences with the surgery it helped me decide that it was something I wanted, to stop the curve progressing, which it had been doing."

Thankfully, the surgery did go well. Recovery was very difficult and painful, the hardest thing she's ever been through, as she says:

"Recovery was hard, having to re-learn how to sit up in bed, get out of bed, and walk down the corridor all over again. It took me about a year to feel properly recovered. Being in my 20s it was probably a bit harder than it is on teenagers. It took me a long time, probably 9 months to



even think about going back to the gym. I built up what I was doing but I was quite scared because I thought I would damage something. I didn't start running again until a few years after surgery but the more I did, the more confident I got and the more I realised I could do things I couldn't do even before my operation.

Having the surgery had given me a new lease on life and made me want to do as much as possible and push myself as much as I can to prove that I can do it. I joined a run club a few years ago and have started to do all sorts of things, including park runs and seven half marathons. I'd been training for a marathon before the pandemic and I'm still waiting for that to go ahead. I signed up for a Machu Picchu trek before the pandemic as a way to celebrate 10 years since my spinal fusion. I wanted to do something big to mark that occasion, but it's been pushed to September, 2022, because of Covid, so fingers crossed that goes ahead. A few years ago, I trekked the Great Wall of China to raise money for SAUK. It was such a great experience and I love raising awareness for scoliosis and raising money for SAUK, plus it's a great challenge and I meet all sorts of people.

For me, having the surgery was the start of my life. I would say to people struggling with the decision that it could really improve your quality of life. I still get back pain, some numbness and muscle spasms but I can live with that, and it doesn't stop me from doing things. Resting or sitting down will ease the pain now but before my operation that pain never really went away, despite me trying everything I could. My spine still isn't straight because trying to correct a curve as large and stiff as I had is very difficult. My mental health and the way that I feel about myself has improved too. I was really self-conscious before because my ribs were rotated, and I





had a large 'hump', but those outwardly noticeable signs of scoliosis are gone now. I was very anxious about how much worse the curve could have gotten so to not have that anxiety anymore is great. Not being in pain now is great, but the biggest effect the surgery had was on my mental health. I can put my scoliosis to the back of my mind now and just live my life, which was never possible before."

Donate to Louise's Machu Picchu Trek Fundraising page <https://justgiving.com/fundraising/lifewithscoliosisblog>

## Alicia-Louise Clark

17-year-old Alicia is swimming the length of the English channel (21 miles, which equals 1350 lengths of a 25m pool), within only 6 weeks to raise funds for SAUK.

In 2016, at 12 years old, Alicia was diagnosed with a 64 degree curve. After months of back pain, her spinal curvature begun to progress at a rate of 2 degrees a week. She was left with a 90 degree curve and a twist in her spine, resulting in her ending up in a wheelchair and unable to swim and often to walk.

She says: "Swimming has always been at the forefront of my life and being an elite swimmer it was extremely difficult to have my world changed within the space of a couple of months. Everything felt very out of control and the rapid progression of my curve and diagnosis of a Chiari malformation definitely exaggerated that feeling." In September 2017, at the age of only 13, she underwent spinal fusion. Alicia now has a 20 degree curve and feels the surgery both saved and changed her life, as she describes..



Alicia post-surgery



Orry is his brace



Orry and his siblings on a walk

"My mindset all the way through treatment was that the surgery would give me the ability to get my life back and it did just that. It gave me control of my body again and a sense of normality back. After an hour operation I walked the next day and was out of the hospital in a week. Having my surgery filled me with the drive I needed to return back to 'normal', better than before."

Alicia has already completed the first leg of her challenge, joined by two others who are completing the challenge in her support. She continues: "This is a challenge that I would have been unable to complete 4 years ago. I am determined to share my story and give back."

## Orry Mitchell

6-year-old Orry was diagnosed with scoliosis 3 years ago. A few months later he got his first brace. He doesn't always like to wear his brace because he can get hot and uncomfortable. However, he always tries to remember how important it is to wear his superhero armour.

Orry said he wanted to walk the 85-mile Parish Walk. This is a bit too much for young Orry so instead, he and his family have set the challenge to walk, run, and cycle 85 miles before the end of last August, plus do the mini Parish Walk for kids. The family had a great time completing this challenge and spending valuable time together in the great outdoors.

SAUK has supported this family through Orry's scoliosis journey so far. We are touched that the family chose to support SAUK by taking on this challenge to raise funds for us. They raised £200, plus had a donation of £150 from the photographer they worked with, Amoré du Plessis.

# Scoliosis Book Club

Scoliosis is an often misunderstood condition, not helped by inaccurate portrayals of characters with scoliosis in the media. Sarah, a SAUK member who has had scoliosis since she was 11, wanted to use this space to instead celebrate the books and TV shows that she thinks got it right. These books are targeted to young adults who can perhaps see themselves in these characters and feel a little less alone in what they're going through.

## Braced by Alyson Gerber

This book is about a girl named Rachel Brooks who, like all school kids, is excited about the new school year. She has finally earned a place as a forward on her soccer team. Her best friends make everything fun. And she really likes Tate, and she's pretty sure he likes her back. After one last appointment with her scoliosis doctor, this will be her best year yet. Then the doctor breaks some upsetting news: the sideways curve in Rachel's spine has worsened and she needs to wear a back brace 23 hours a day. The brace wraps her in hard plastic from shoulder blades to hips. It changes how her clothes fit, how she kicks a ball, and how everyone sees her – even her friends and Tate. But as Rachel confronts all the challenges the brace presents, the biggest change may lie in how she sees herself.

## About the Author

Alyson Gerber wore a back brace for scoliosis from the age of 11 to 13, an experience that led directly to Braced.

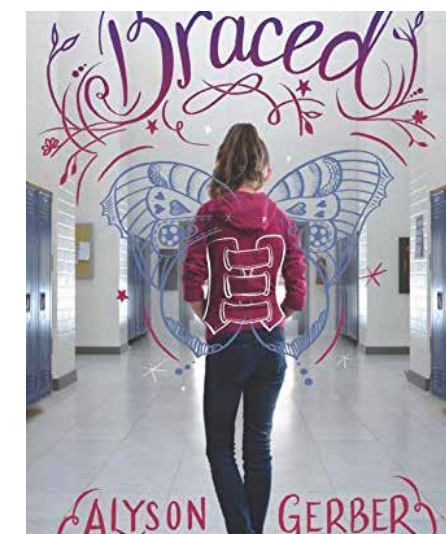
## Deenie by Judy Blume

The story centres around a 13-year-old girl named Wilmadeene Fenner or Deenie. She is always being taken to modelling agencies by her mother Thelma who wants her to be a model and also wants Deenie's 16-year-old sister Helen to be a doctor. She states that "Deenie is the beauty, Helen is the brains!" At a modelling agency

Deenie is told that she needs to work more on her posture. Her gym teacher also tells her the same thing. She is then taken to a doctor who diagnoses her with scoliosis and prescribes a back brace that should be worn for 4 years.

When Deenie sees the brace, she wants to scream, FORGET IT! A positive thing that comes from the back brace is that she is no longer being dragged to modelling agencies and can now focus on her best friends, Janet and Midge, and especially on her crush, Buddy Brader. She even befriends a girl with eczema called Barbara. Deenie used to not want to touch her, because she was afraid that she would catch her rash.

Meanwhile, Helen has fallen in love with a boy named Joey, who works for the family's business, a petrol station. Thelma gets Joey fired from the petrol station because she notices that Helen is preoccupied with him and is now distracted from her school work. She insists that Joey was let go because of the family's doctor's bills

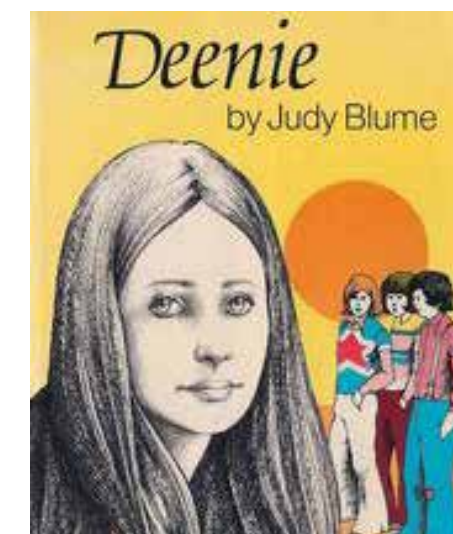


for treatment of Deenie's scoliosis. This causes Deenie to worry that Helen will hate her because of that. Fortunately, Helen doesn't blame Deenie and they become closer.

Deenie asks her parents if she can take the brace off for a party she is going to. Her mum says yes, but her dad says no. This makes Deenie angry, and she takes separate clothes to the party, with a plan to change into them as soon as she arrives at the party. At the party Deenie and Buddy end up kissing and she changes her mind and decides to keep the brace on.

## About the Author

Judy Blume's books deal with sensitive issues for teenagers such as childhood angst, body image, sexuality, and divorce. She often used a first-person narrative with controversial language and characters with whom the younger tweens and teens could identify in order to explore these issues.





# DETERMINING THE EFFECTIVENESS OF TREATMENT

A research team at Queen's University Belfast, led by Dr Lisa Graham-Wisener and Dr Paul Toner, aims to develop a core set of outcomes to determine the effectiveness of treatment for adolescents and young adults with adolescent idiopathic scoliosis (AIS; scoliosis without a known cause). The study (called 'SPINE-COS-AYA') is funded by the British Scoliosis Research Foundation.

The effect that a treatment has on an individual is measured on the basis of predefined outcomes. Some examples of outcomes for scoliosis treatment may include 'pain' (ie, the amount of pain a patient has before and after treatment) or 'spinal curvature' (ie, the Cobb angle before and after treatment). When researchers and healthcare professionals use different outcomes to measure if a treatment is successful, it makes it difficult to compare findings across different research studies. This means that some research evidence is not as high quality as it could be and as a result patients and healthcare professionals may be unsure which treatment is most effective.

The SPINE-COS-AYA project aims to develop a minimum list of outcomes for researchers and healthcare professionals to use when assessing if a treatment has worked for a young person with AIS (a 'core outcome set', or COS). If researchers and healthcare professionals across the world are using the same outcomes to measure if a treatment has worked, they can more easily compare and combine their findings. For example, this could mean it is easier to compare findings from a clinical trial of a new surgical approach to findings from a clinical trial of an already established surgical approach. Over time, with all researchers and healthcare professionals using the core outcome set this will improve the quality of the research evidence base and in turn, treatment outcomes for young people with AIS.

As well as ensuring that researchers and healthcare professionals are using the same outcomes to measure treatment success, it is also essential that they are measuring what are judged to be the most important outcomes. In the SPINE-COS-AYA research project, the researchers are interviewing the individuals best placed to know what outcomes are most important - young people with AIS, their parents, and a range of healthcare professionals. Through these interviews, the researchers are interested in finding out what is important to each

of these groups, and why it is important. Many core outcome sets for assessing treatment for other clinical populations have been developed without the input of young people, with researchers speaking only to healthcare professionals and sometimes to parents. The current research project places young people centrally in the core outcome set development process, recognising that they are best placed to speak about what is important to them. To help ensure this, the team have also set up a Young Person Advisory Panel. The panel is made up of young people with AIS living in Northern Ireland, who are helping to inform the research to ensure it meets the needs of young people with AIS.

At the end of the SPINE-COS-AYA study, the researchers will have a longlist of important outcome areas that have been identified by young people with AIS, their parents, and healthcare professionals. The researchers will then apply for more funding to conduct an international survey, to provide agreement on which outcomes from this long list should be measured by researchers and healthcare professionals appraising surgical or conservative treatment such as bracing for AIS.

## How you can help

The research team are currently interviewing young people with AIS (within 5 years of surgery or bracing), their parents, and healthcare professionals. There has been great interest so far, but we need more young people and parents to take part. If you are a young person or the parent of a young person who has received care (surgery or bracing) from the Northern Ireland Regional Scoliosis Service in the previous 5 years, please consider helping with the research by taking part in an online or telephone interview. Young people will be given a £10 Amazon voucher as a thank you for taking part.

There is more information about the study available on the study website at <https://cutt.ly/Qubscoliosis>, or by contacting the research fellow Dr Julie McMullan

who is undertaking the interviews. Julie can be contacted via email ([Julie.mcmullan@qub.ac.uk](mailto:Julie.mcmullan@qub.ac.uk)) or by phone (07919511950).

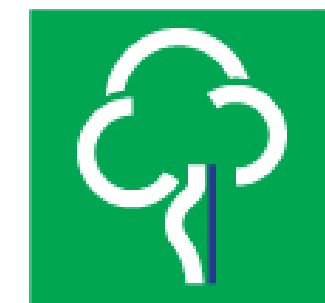
If you do not live in Northern Ireland but would like to be kept up to date with future stages of the research, please consider following the team on one of their social media pages - Facebook (@qubscoliosis), Twitter (@qubscoliosis), or Instagram (@qubscoliosis). We hope to involve young people across the UK and internationally in future research, so please do follow us.

The goal of this research programme is for treatment decisions in the future to be based on better quality evidence, which will lead to better treatment outcomes.



## ABOUT THE BSRF

# BSRF



BRITISH  
SCOLIOSIS  
RESEARCH FOUNDATION

SAUK has a sister organisation, the British Scoliosis Research Foundation (BSRF). The BSRF exists to promote research into the treatment of scoliosis in the UK. Each year the BSRF funds research into scoliosis, and it holds an international symposium every 2 years to spread knowledge gained from research. The next one will take place in London in June, 2022.

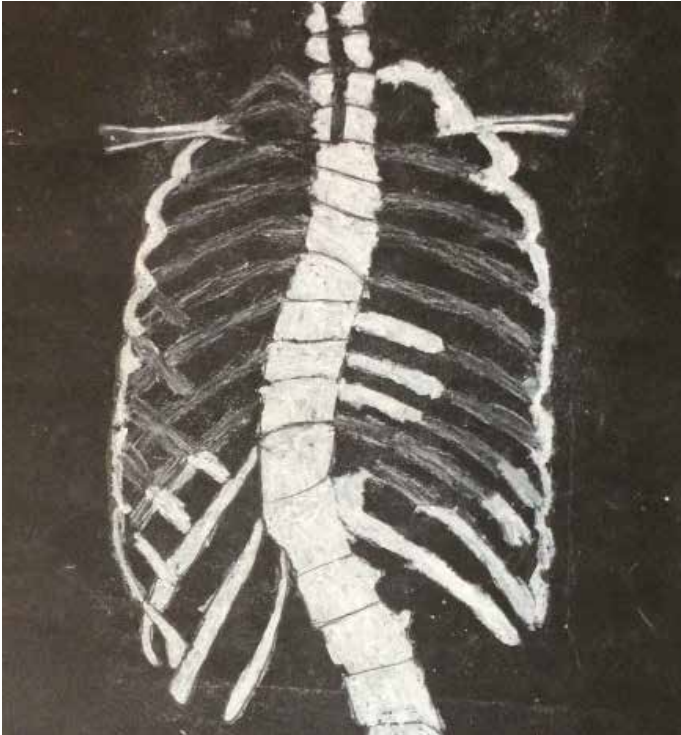
Although treatment exists, there is currently no cure for scoliosis and in most cases the cause remains unknown. Each year, the BSRF provides funding, subject to a formal application and review process, for those doing high quality research into all aspects of scoliosis.

BSRF funded research has provided better understanding of both the causes and treatments of scoliosis, resulting in earlier intervention and better treatment for patients. Currently the BSRF is funding several grants to people engaged in research into scoliosis.



# AILIE HARRISON ART COMPETITION

Ailie Harrison co-founded SAUK with Stephanie Clark in 1981. 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 SAUK over many years, we are delighted to offer this competition. Thank you to all who submitted art works. Our stunning front cover artwork is by Mike England and the artwork on this page is by our other finalists, Emily, Darcy, Diana, and Enya.



Amily Sinka



Darcy



Diana Seidl



Enya van Uffelen