

Issue 107 | Spring 2023

BACKBONE



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Artwork by Consultant Spinal Surgeon Thanos Tsirikos as part of the BackBone project p24-26

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LATEST NEWS

Scoliosis Association UK and British Scoliosis Research Foundation merger

We are excited to announce that as of 1st January, 2023, the Scoliosis Association UK (SAUK) and the British Scoliosis Research Foundation (BSRF) have merged. BSRF has, for the past 50 years, promoted and funded high-quality research into scoliosis in the UK, whilst SAUK has worked to raise awareness of scoliosis and provide support, advice, and information to people affected by scoliosis in the UK. The two charities have been affiliated since 2006, but in an effort to become one unified charity that supports both those affected by scoliosis, and the future of scoliosis research, we have made the decision to merge. The charity will operate under the name of Scoliosis Association UK for the first year of the merger, after which a new trading name will be chosen.

The people who SAUK supports have always been interested and invested in seeing the understanding and treatment of scoliosis to be improved. It's in the best interest of everyone affected by scoliosis that we nurture the development of research. Our combined energy and passion will allow us to make a stronger contribution to the scoliosis community.

International Scoliosis Awareness Month (ISAD)

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. This month of celebrations peaks on the last Saturday of June with International Scoliosis Awareness Day (ISAD), an event launched by SAUK in 2013. This year's ISAD falls on the 24th of June. We hope that you'll join us in celebrating, celebrating the scoliosis community, celebrating how far the understanding and treatment of scoliosis has progressed in past decades, and of course celebrating you and how far you've come in your scoliosis journeys. Take this month to celebrate your resilience, your strength, your support networks, your curves, and your scars. Happy Scoliosis Awareness Month!

Why do we ask you to share your scoliosis stories?

For the people who also have scoliosis and didn't realise they knew someone they could speak to about it.

For the people who have never heard of scoliosis and walk away better informed about how it affects people.

For people to learn how to spot the signs of scoliosis.

For people who are struggling to see that having curves and scars doesn't make them any less beautiful.

For people who need to see it's possible to live a full, active, healthy, and happy life with scoliosis.

For people who need to learn pain management techniques.

For the people who have had their mental health affected by this journey and need to see that they are not alone in their struggles, but that people come out the other side of this.

For you and your own journey. Speaking up about your scoliosis experience is a way of processing it and all you've been through.

Speak up about your scoliosis journey this Scoliosis Awareness Month.



THE AILIE HARRISON ART COMPETITION

Calling all aspiring artists

SAUK is looking for aspiring artists, designers, and people who have great creative ideas. We would love for you to design our next Backbone front cover!

We are looking for striking artworks that we can print on our front cover. Use any artistic medium to do so, be it a drawing, painting, digital artwork, or a photo. The winning artwork will be used as the Autumn 2023 Backbone magazine cover. Finalist artworks will also be displayed on SAUK's social media sites. To be considered for the Backbone front cover, your artwork will need to be sent to us digitally, via email. What's more, there are cash prizes up for grabs too:

First prize - £100

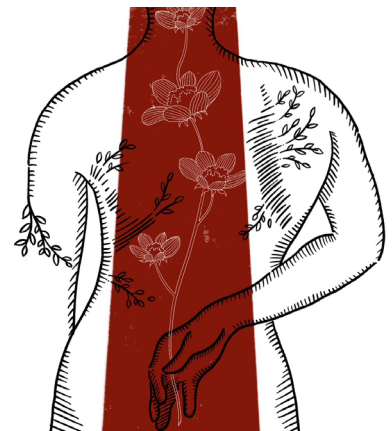
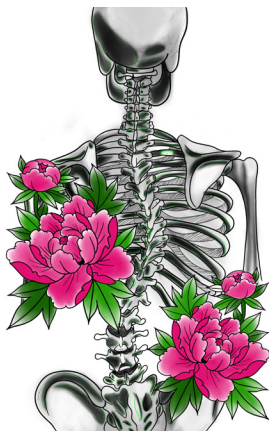
Second prize - £50

About the Ailie Harrison Art Competition

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



Send your design with your name and age by email to communications@sauk.org.uk by 1st September, 2023.



- The competition is open to people of all ages living in the UK. (Employees and representatives of SAUK are excluded)
- Only one entry per person is allowed
- Please submit your entry by 1st September, 2023. No late entries will be accepted
- Submissions must be original works
- The judges will be a selection of SAUK employees and Trustees
- SAUK reserves the right to reproduce all pieces of artwork in any form it deems appropriate for promotion and publicity purposes
- SAUK reserves the right to make minor changes and additions to the design
- Participants agree to the use of their names and entries by SAUK
- Winners will be announced in October, 2023

Leaving a gift in your will

Leaving a gift in your will helps ensure that SAUK can go on to provide support and information to people affected by scoliosis and continue to advance the treatment and understanding of scoliosis through research and collaboration for years to come. We are a small organisation which relies solely on the generosity of our supporters. Thanks to that generosity, we have been able to support the scoliosis community for over 40 years. With your support, we will continue to do so for many more years to come.

Scoliosis is a difficult condition to come to terms with at all ages. For young children it can mean multiple cast fittings and repeat surgery; adolescents may have to wear a brace or have spinal fusion at a time of life when such a diagnosis can be a major blow to self-confidence; and in mature years pain and immobility can have a significant impact on a person's quality of life. However, research has led to huge advancements in scoliosis treatments over the years allowing patients to better manage their condition and enjoy a much improved quality of life. SAUK strives to stimulate and fund high-quality research into the causes and treatments of scoliosis. If scoliosis has affected you or anyone you know then you will know that it is a life changing diagnosis. By supporting SAUK, you're supporting this research. You're making a difference so that in the future there will be better understanding, support, and treatment options available.

A gift in your will ensures that no one has to face scoliosis alone. It will mean that people are diagnosed sooner thanks to greater awareness. It will mean that there is always a trusted source of information about scoliosis. It will mean that anyone in search of support or advice will have someone to talk to who is there to help and listen to them. It will mean that people with scoliosis and their loved ones can connect with a

community of people with similar experiences, helping each other through the tough times and celebrating their achievements.

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 ensures that nobody has to.

Should I use a solicitor?

We would strongly advise you to do so. A solicitor's expertise will give you the peace of mind of knowing that your wishes will be respected, are legally correct, and that your estate will go to the people and causes you hold dear.

Will I pay tax on my gift?

No. Gifts to charities are exempt from Inheritance Tax. They can even reduce the amount of tax your estate has to pay. Please visit the HM Revenue and Customs website for details.

What type of gift can I leave?

There are two types of gifts you can leave to a charity. Many supporters prefer to leave a residuary gift, or percentage of their estate. This type of gift gives people the reassurance of knowing their gift will be protected against inflation. You could also choose to leave a pecuniary gift, which is a fixed sum of money.

What is an Executor?

An Executor is the person you choose to make sure your wishes, as laid out in your Will, are adhered to. This can be a family member, friend, or trusted professional.

I already have a will, how do I add a codicil to leave a gift to the Scoliosis Association UK?

We recommend you talk to your solicitor before adding a codicil. If you do, it's a good idea to keep it in a safe place with your existing Will.



Bracing Adolescent Idiopathic Scoliosis -The BASIS Study

The BASIS study is still underway, looking at the effectiveness of a night-time only brace, compared with the current available full-time brace, in the treatment of adolescent idiopathic scoliosis. Led by Sheffield Children's Hospital and the University of Sheffield, the Bracing Adolescent Idiopathic Scoliosis (BASIS) study is currently accepting patients from 20 NHS Trusts across the UK, with another 2 centres in set up, hoping to join in the very near future.

The "full-time" brace is the current back brace offered within the NHS, and this is usually prescribed to be worn for 20 hours a day. Although in many patients it stops the curve reaching a size at which surgery would be considered, the brace needs to be worn until growth has finished, which is usually several years. It is recognised that this is a very difficult treatment for many young people. The alternative offered as part of the BASIS study, is a new "night-time" brace, which is worn for around 9 hours whilst in bed at night. Because this brace works whilst the patient is lying down, it can provide a stronger force to push the curve straighter.

The night-time brace may sound like a more attractive option for patients, but there is currently less evidence to support its effectiveness. And this is why the BASIS study is taking place!

At the moment, there are 128 patients taking part in BASIS, and roughly half are receiving full time brace treatment, with the other half receiving the night-time brace. The study is aiming to include 780 patients over the next 3 years, and all patients taking part will be followed up in the study until 2 years after they stop brace treatment.

If you'd like to know more about the study, you can visit the BASIS website for further information and contact details for the coordinating team.

This study is funded by the NIHR Health Technology Assessment (HTA) programme (NIHR131081). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.



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



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COVER GIRL-AMELIA BLACK

Mattel, the makers of Barbie, has introduced its first-ever doll with scoliosis. The toy company launched its new Chelsea doll, who is Barbie's little sister, with a curved spine and a removable back brace. Mattel worked closely with a specialist in children's complex spinal disorders to develop the doll. We can't currently find the doll in stock in the UK but you may find it on eBay or Amazon.



Amelia was diagnosed with infantile idiopathic scoliosis just before her 2nd birthday. We had noticed the top of her rib cage seemed to stick out more on the left side than the right. After seeing the GP and a private consultant we were referred to The Scottish National Spine Service at The Royal Hospital for Children and Young People in Edinburgh. Her consultant explained that at Amelia's age some patients have a resolving type of curve which improves with age, whilst others have a curve which can progress, requiring treatment. Amelia was required to go for an

MRI scan which came back clear and was asked to attend a further X-ray in four months' time, which would determine whether she would require treatment or not. The X-ray showed that Amelia's scoliosis had deteriorated and that she would require treatment in the form of bracing for 20 hours per day until she stops growing.

Amelia was cast for her brace under general anaesthetic then within about 3 weeks she received her first brace. We were required to gradually build the brace time up over the course of a few weeks. We introduced the brace as Amelia's special or magic vest that was going to help her grow big and strong.

We were worried about how Amelia would cope wearing the brace and it was hard being the one strapping her into it, wishing she didn't need to wear it but knowing she had to. Looking back, I do think it was harder on us as parents than it was on her because, unbelievably, she didn't complain once. The hospital put us in touch with another family whose child was a similar age to Amelia but had been wearing his brace about a year at this point. Chatting with them reassured us and helped us to see how Amelia's future might look.

Two years down the line and in brace X-rays show that Amelia's

curve has more than halved in size. We are extremely compliant with the brace and most days she has it on for more than 20 hours. Amelia will never remember a time where she didn't wear her brace and she has adapted really well to wearing it. It does not stop her from doing anything. Amelia is very active and her brace can be removed to allow her to take part in her gymnastics, swimming, and dancing classes which she loves attending. For the time being our experience of bracing has been very positive but we are aware of how things can change with growth spurts and how Amelia's views of her brace may change as she gets older. Currently she is very proud of her brace and shows it off to all of her friends and teachers at nursery.

After seeing the Barbie Chelsea doll on the news, we purchased one for Amelia and she loves having a doll that wears a brace just like her. We also got her a soft toy with a hard brace the exact same as hers from Higgy Bears online. She was ecstatic to see the brace has the same pattern as hers and she couldn't wait to show it to her friends. I think it is important to have dolls/toys that are inclusive and represent everyone and I am pleased that this is something that we are beginning to see a lot more of.

We are so proud of Amelia and how she copes with her brace. Her positive attitude really is inspirational. Her wonderful consultant and amazing orthotist have been fantastic with Amelia, and we can't thank them both enough.

STRUCTURAL VS NON-STRUCTURAL SCOLIOSIS

Zacharia Silk FRCS, Oxford University Hospitals NHS Foundation Trust
Almas Khan FRCS, Leeds Teaching Hospitals NHS Trust

Scoliosis is a medical term describing a curvature of the spine that is different from normal. It can affect people of all ages but is most commonly diagnosed in children and adolescents during the growth spurt occurring just before puberty. Although there are several ways to categorise the type of scoliosis a person may have (e.g. idiopathic, neuromuscular, syndromic, congenital, etc), one of the main features doctors look for is whether the curve is structural or non-structural. Both types of scoliosis can negatively impact an individual's quality of life, but they are treated differently.

Structural scoliosis

Structural scoliosis occurs when the spine is distorted in such a way that the curve cannot be fully corrected through normal movements or exercises. The

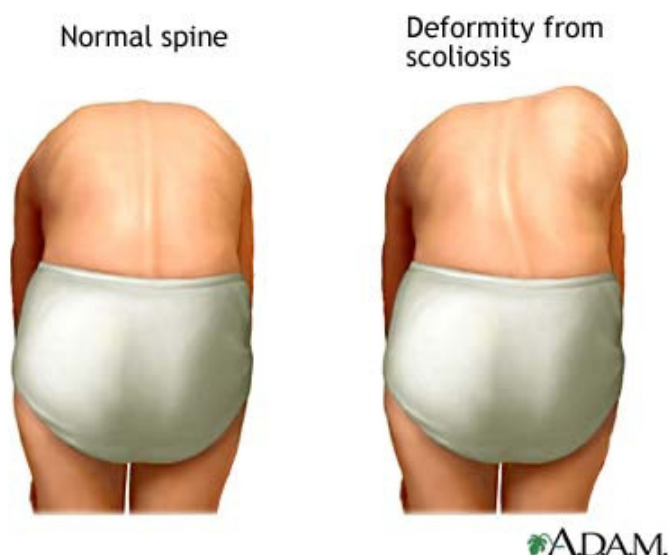
exact cause is unknown, but is thought to be related to genetics, congenital abnormalities, or other underlying medical conditions (e.g. cerebral palsy). Structural scoliosis is considered a permanent condition and can cause serious problems if left untreated. Some of the common symptoms include uneven shoulders, a prominence of one side of the rib cage, waist asymmetry, and a tilt in the hips. In some cases, it can affect lung function, or cause pain.

To diagnose structural scoliosis, a doctor will perform a physical examination and order imaging studies such as X-rays, and, in some cases, an MRI scan. Once the diagnosis is confirmed, the doctor can determine the severity of the curvature and whether treatment is necessary. In mild cases, the doctor may simply monitor the patient over time and check for progression

of the condition. In more severe cases, however, treatment may be necessary to prevent the curve from getting worse and causing further problems.

One treatment for structural scoliosis is bracing. A brace is a device that is worn around the torso and helps to keep the spine in a straight position, thereby encouraging it to grow straighter. Bracing is therefore typically recommended for children and adolescents who are still growing, since the spine is still flexible and can be moulded into a more normal shape. It is generally not recommended for adults, because the spine has stopped growing and the curvature is permanent.

In severe cases of structural scoliosis, surgery may be necessary. The goal of surgery is to improve the curve as much, and as safely, as possible, and prevent it from getting worse. The type of surgery that is done will depend on the severity of the curve and the age of the patient. In most cases, a spinal fusion is done with the insertion of rods and screws to hold the spine in place while the bones of the spine (vertebrae) join or "fuse" together to form a single column of bone. Spinal fusion stops the operated part of the spine from moving back into its old (and curved) position. The procedure is sometimes delayed in particularly young patients to allow the spine and chest to continue growing and



Adams forward bend test - a screening method to determine if there are indicators for scoliosis

if surgery is required, different rods can be used to allow continued growth of the spine over this time. Aside from these two methods of surgical scoliosis correction, emerging techniques such as vertebral body tethering (VBT) and posterior dynamic distraction (PDD) are undergoing clinical trials, but until these have been proven to be as safe and effective as existing treatments, their role in the treatment of structural scoliosis will be limited.

Non-structural scoliosis

Non-structural scoliosis occurs when the spine appears curved, but the curve can be corrected through normal movements or exercises. This type of scoliosis may be caused by painful conditions of the spine such as muscle spasms, nerve problems, spinal infections, or even a person's posture. It can also be caused by a difference in the length of one leg to the other. In this situation, the unequal leg lengths cause the pelvis to tilt one way or the other. Since the spine sits on top of the pelvis, it will tilt in the opposite direction to help balance the individual's centre of gravity.

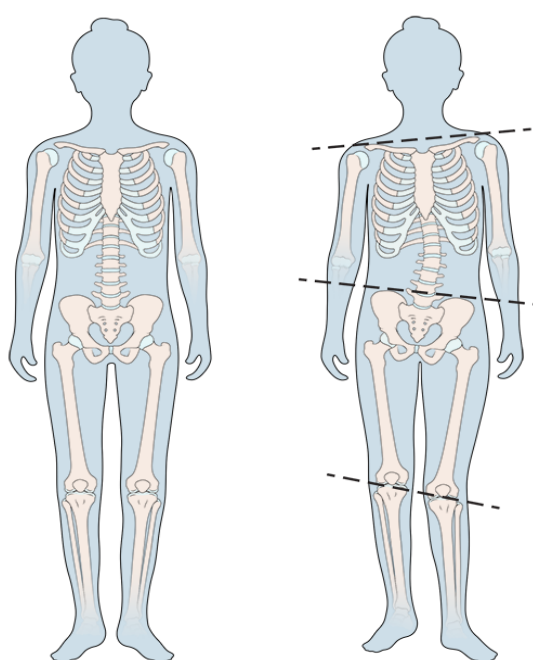
Non-structural scoliosis is regarded as a temporary condition and can be treated effectively if the underlying medical condition is addressed. Exercise-based treatment has been shown to be effective in patients who have postural curves and do not have underlying medical causes of their scoliosis. Many structural curves also have a non-structural (i.e. flexible) component to them. Exercise based treatments can help in this situation but are not effective at improving the structural component of these curves.

To diagnose non-structural scoliosis, a doctor will do a physical examination and order imaging studies such as X-rays, and in some cases, an MRI scan or other specialist investigations. The doctor will also look for other underlying medical conditions that may be causing the scoliosis. Once the diagnosis is confirmed, the doctor will determine the cause of the scoliosis and develop a treatment plan.

The treatment for non-structural scoliosis depends on the underlying cause of the condition. In some cases, physiotherapy or exercises may also be recommended to help alleviate pain symptoms. In other cases, medications may be prescribed to enable exercise-based treatment. In some cases, surgery may be necessary to treat the underlying medical condition causing the scoliosis. For those with unequal leg lengths, shoe raises are available to even out the differences between the two sides.

Conclusion

Scoliosis is a side-to-side curvature of the spine that can significantly affect an individual's quality of life. There are two main types of scoliosis, structural and non-structural. Structural scoliosis is a permanent condition that may require treatment, such as bracing or surgery, to prevent it from getting worse. Some patients with a structural scoliosis may also have a non-structural component to their curve. Structural curves benefit from exercises to maintain flexibility, which may improve the outcome of surgery, and improve the recovery process after an operation. Non-structural scoliosis is a temporary condition that can be treated effectively by addressing the underlying medical condition causing it. Exercise-based treatments are always beneficial to help look after spine health, improve strength, reduce pain, and improve mobility, especially for non-structural curves. Both types of scoliosis require thorough assessment by a doctor so that they can form an effective treatment plan to improve the individual's quality of life and prevent future complications.



Leg length discrepancy may cause problems with posture such as tilted shoulders or hips and angled knees.

One wonderful thing

Michèle Mendelssohn, author and Professor of English and American Literature at Oxford University

Can you imagine feeling wonderful about your scoliosis? For many – myself included – that’s a stretch. But can you imagine feeling a bit better about your scoliosis? Perhaps that feels more manageable. This new column is going to feature the things you have done, big and small, ordinary and extraordinary, that have helped you feel more comfortable in your body, and more at ease with yourself.

The idea for this column came to me while listening to Just One Thing with Dr Michael Mosley, a programme that showcases one thing that people should be doing to improve their health and well-being. What about one thing people with scoliosis can do? I wondered. And that, my friends, is how “One Thing Wonderful” was born. In each issue of *Backbone*, this column will feature someone from the scoliosis community who has done one thing wonderful towards living better with scoliosis. This may be something physical or material, but it might also be something psychological, or emotional. Maybe you’re doing morning stretches or salsa-dancing, you’re inspired by a YouTuber or a TikTok you follow, you’ve found a physiotherapist who gets you, you got a back tattoo, you swear by arnica bath salts and microwaveable heat packs for your aches and pains. Whatever it is, no matter how tiny, it helps you deal with your scoliosis.

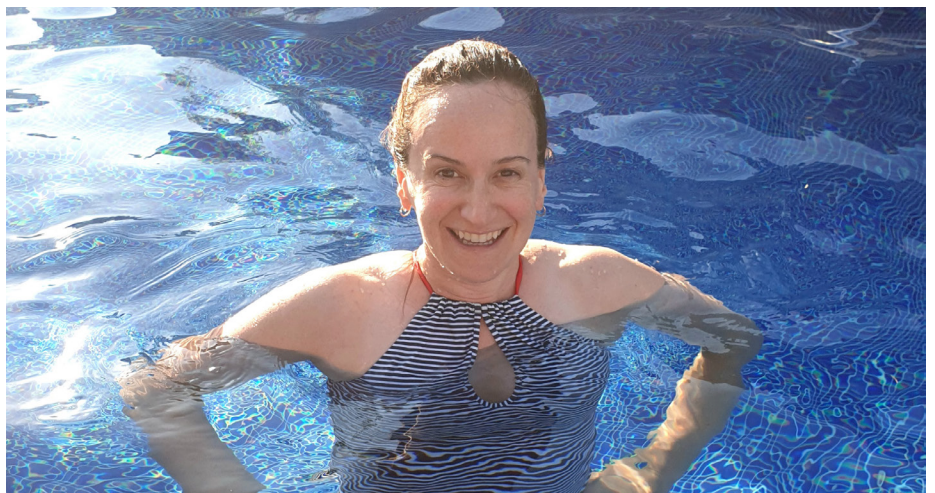
For me, there are two parts to living with a snake-shaped spine: the fact that, from the age of 13,

I have lived with a 40+ degree curvature, and the feelings I have had about that fact in the 30+ years since my diagnosis. The fact of having scoliosis has been pretty straightforward, the feelings, in contrast, have been about as pleasant as discovering a slithering cobra scrunched up inside me. The fact could be addressed with a hard plastic brace that poked out of my school uniform, weekly chiropractor visits and physiotherapy during my growth spurt, massage, and lumbar support on my chair. The feelings of sadness, anger, shame and, at times, total body-hatred have taken longer to tame, but I feel better about my back now than ever before. You might say I’ve managed to charm the snake.

One thing that has helped me do that is swimming. Flashback: a year ago, I could doggy paddle half a pool length and the thought of wearing a bathing suit and baring my body was mildly alarming. I credit TV presenter Sue Perkins with changing all that. One night, my back was hurting, as it often was at the end of a day at my desk. I curled up on the sofa to watch her

documentary about Japan. Then a bunch of irrepressibly joyous elderly Japanese women swam onto my TV screen: known as ‘ama’ these remarkable 60 to 80-year-old free-diving fisherwomen catch seafood in the Pacific. Watching these supercool geriatric mermaids, I started thinking about whether I would be as alive and kicking when I was that age. Then I felt worse about my back, worried age would crumple me, and that maybe my scoliosis boa constrictor would win.

A few days later, I signed up for an adult swim class at my local pool. And the rest, as they say, is history. A year on, I can swim 12 laps continuously. I will never be a contender for the Olympics but my back feels better than ever, my pain feels more manageable, and I don’t worry about the snake half as much as I used to. Instead, I look at the people at my local pool – elegant mermaids and mermen of all ages, shapes, and levels of ability – and I imagine my older self as a mermaid slithering and slicing through the water alongside them.



Swimming “strengthens the entire body. It is good both before and after scoliosis surgery,” explains personal trainer Caroline Freedman in *The Scoliosis Handbook*. “YES – Wonderful!” she says. Freedman had three scoliosis and rib correction operations herself. Her surgeon had her swimming every day when her brace came off. “It is very safe – you really can’t do much damage,” she writes.

I narrowly avoided surgery. Managing my scoliosis is part of my every day. It’s a fact of life for me, as it may be for you or someone you care about.

I’m not endorsing any particular approach and I’m not a medical doctor. The advice this column will offer will not replace treatment. But it may give you inspiration and ideas about living well with a differently shaped body, and all that entails.

Do you have an experience to share? Have you done something that helps you live well with your scoliosis? If so, I’d love to hear about it. In the first instance, please get in touch by emailing communications@sauk.org.uk some information about yourself, your scoliosis journey, and your “one thing wonderful”. I look forward to your stories. Over to you!

Michèle Mendelssohn is Professor of English and American Literature at Oxford University. She has written for newspapers and has published seven books. Her latest book, *Making Oscar Wilde*, was a semi-finalist for the PEN America Biography Prize and a finalist for both the Biographers’ Club Slightly Foxed First Biography Prize and the LGBTQ Polari Prize.

How has swimming helped you manage your scoliosis?

Laura Mathieu

Swimming is my happy place; my normally tired aching body is free! I can just float around or do some physio work, even minimal swimming can give you a really good workout. I’m pre op and cannot run or jump or ride a bike, so swimming is really making a huge difference to my physical and mental health right now.

Melanie Ince

I’m not a good swimmer but I benefit from aqua aerobics classes. I feel more mobile because the water supports me. I also feel that being in the water is relaxing and that is good for me and my back too.

Carrie-Ann Sarah Sudlow

I’ve moved to the sea just so I can swim more. I feel free in water and it’s great for lung function.

John Rooney

Swimming got me moving again after surgery. The feeling of weightlessness was amazing. My surgeon credits the fact I have such good rotation in my arms with all the swimming.

Cheryl Petitt

As a youngster swimming was ‘my sport’ with almost daily training sessions. This kept me fit, flexible, and improved the strength of muscles supporting my spine. At 22 I had my spinal fusion. After a full recovery I got back into training. During my two pregnancies I swam regularly, and afterwards too. Now as a 60 year old I’m still swimming. To date I’ve had many operations for complex issues, and am still benefiting from swimming

Fay Ronald Cooper Holmes

I had my surgery in 1986. I’ve recently started swimming again after a very long break. It’s been a joy to find something I can do. It helps hugely. I can feel better in the water about all the things on land I can’t articulate, such as nerve damage and weaknesses in my legs. My neck and head are held high because I can’t drop them and I can only do the breast-stroke but on a good day, I do 32 lengths which is 1/2 a mile in our local pool, which is a huge difference to me on land. Just as long as nobody’s actually watching my technique, all is good!

Michaela Anne Demetriou

Swimming and karate were great for our son. Definitely kept him fit, healthy, and supple.

Jane Goodwin

I’m not very good at swimming but after spinal infusion in 2018 I started going weekly and loved it. Sometimes just moving around in the water is helpful. I started having pain at the top of one of my rods and had to stop going. I would recommend going at any age. I’m 60 this year and am waiting to go in and have surgery again. I will definitely be returning to swimming after that.

Jill Wise

I have thoracolumbar scoliosis, kyphosis, degenerative spine disease, and bad widespread inflammatory arthritis. I swim three times a week, for two hours each time, just gentle breast-stroke. It is honestly the only place my body feels “normal” and happy and I love it. When I get out, gravity lets me know how much I have wrong. As somebody has already said, it’s my happy place.

Caroline Freedman Gibber Brower

6 months post op I was sent to an aquatic physio for a few sessions and then told to swim a few times a week. Swimming is excellent for gently building muscle / stretching / range of movement and getting everything working again. I struggle with front and back crawl as my range of movement is limited and so I end up swimming diagonally across the pool - very annoying for other people. I do breast-stroke but am careful to make sure my head is in line with my body and have my face up to my nose in the water.

Elizar Ai

Swimming helps me with my pain management. Backpain is manageable when I do regular swimming, like twice week.

Kimberley Bailey

Swimming is the best thing I ever learnt. I am thankful that I was pushed to become a good swimmer. I believe it prevented my spine deteriorating through my teens. It saved my life through the fitness I had built up when I had sepsis after a traumatic birth of my sons. It gave me confidence when growing up and now although I struggle to get to the pool even once a week it is by far the best thing for my body. I go in barely able to move sometimes and afterwards I feel like I've been oiled. It has always been the one thing I can do that allows me to move my whole body and the most effective aerobic exercise for my fitness.

ISOBEL GRAY AWARD

About the Isobel Gray Award

Isobel Gray was a founding Trustee of SAUK, who 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.



Co-founder and Co-Chairperson Stephanie Clark with Isobel Gray

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.

Isobel was a patient of Dr Phillip Zorab's who was a chest physician with a strong interest in scoliosis, at the Royal Brompton Hospital in South Kensington in London. It was Isobel who came up with the idea of a support group and spoke about it to co-founder Ailie Harrison. Isobel said that what was needed was a special group for people with scoliosis, a means whereby people could help each other and share their experiences and pass on information that was difficult to come by in busy clinics. She had 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, SAUK.

Carol Richards



"Carol joined as a SAUK Trustee in 1997, as a parent of a child with scoliosis. In those days, Ailie Harrison was Chair of the Trustees. Ailie and Carol worked together on various projects, the most notable of which was a scoliosis garden at the Hampton Court Flower show. Linford Christie, the Olympian runner, opened the garden. Carol was fantastic at finding celebrities for SAUK. Her daughter Hannah posed for Patrick Lichfield, who was photographing people's backs for an exhibition as part of our awareness campaign funded by Lottery money. Lord Lichfield asked her how she would like to be photographed and she said, "as a fairy princess", so that is what he did. Personally, I am so grateful to Carol because she provided me and SAUK with the most tremendous support and practical help. She really was a star of a Trustee. Thank you, Carol. You deserve this award in no small measure," - Stephanie Clark, SAUK Co-Chairperson.

Stuart Spencer



"I first met Stuart in 1972 when we were both researchers, together with Ailie Harrison, working for Dr Phillip Zorab at the Brompton Hospital. When Ailie retired as Chair of SAUK the Trustees invited Stuart to join us as her replacement. He too has made an invaluable contribution to SAUK, both as a scientific adviser and as an editor. He has given me much support personally and been a great believer in the good that SAUK does, often sitting in on SAUK's Regional Meetings and helping with office duties such as recruitment. I especially appreciated his advice and wisdom over many issues and ideas. I can't thank Stuart enough for all he has done for SAUK and am delighted he is the recipient of this award. Both Stuart and Carol have also served as Council members on the British Scoliosis Research Foundation, the charity that SAUK officially merged with in January, 2023 – Stuart as a scientific representative and Carol as a patient representative. As such they have both contributed so much to the wellbeing of people with scoliosis." - Stephanie Clarke, SAUK Co-Chairperson.

ROLL OF HONOUR

Evie Ash, nominated by her mother Rachel

Evie was diagnosed with scoliosis 2 years ago (thoracic and lumbar curves). She had surgery to correct the curvature on 29th January, 2022, at the RNOH and was recovering well at home. Unfortunately, 2 weeks after her operation, Evie suffered from a very rare complication called superior mesenteric artery syndrome (SMAS). It took several days for this to be diagnosed, during which time Evie lost a vast amount of weight and suffered horrific vomiting and nausea.

Due to the SMAS, Evie was rushed to St George's Hospital via ambulance where she stayed for 9 nights. Evie had to have a nasojejun tube fitted to enable her to be fed, which she had to come home with for a further 2 weeks which meant no birthday cake for her on her birthday in March. Fortunately, her SMAS was corrected quickly and the nasojejun tube was removed just a few days after her birthday.

During all this time, Evie maintained an unbelievable level of strength despite what was a very scary time for us all. Her amazing attitude made it much easier for us as her family to cope during this incredibly stressful time. She was a perfect patient throughout much pain, sickness, and uncertainty.

I'm delighted to say that Evie has gone from strength to strength since the tube was removed, returning to school just 6 weeks after surgery despite SMAS. Evie took part in her Bronze Duke of Edinburgh expedition in May, 2022, just 4 months after her

operation, and she is determined to carry her rucksack for her Silver Expedition. She has finished a full season back at competitive football, which she started again in September, 2022. Evie continues to amaze us all with her strength and determination.



Ria Page, nominated by her mother Laura

Ria Page has shown outstanding courage during her scoliosis treatment. She's had spinal fusion not once, but twice, after the original surgery failed, leaving her with a fracture in her spine.

Ria had her first operation in December 2021, fusing T4-T12. Shortly after the 8-week check we noticed her back was in a very odd shape. We quickly discovered the fusion had failed, leaving a fracture. At the end of March, 2022, her second fusion took place, fusing T4-L4.

Despite being the scariest time of her (and our) lives, Ria has shown such bravery throughout, and managed both operations with such courage. She is now heavily involved in a Facebook page, called 'scoliosis teen

support UK' which supports children going through surgery, answering questions honestly and providing advice and support when needed.

Ria is incredibly proud of her story; she shares it often and we are incredibly proud of our 14-year-old young lady that has taken this in her stride. I'm not sure we could have been as brave!



Megan Dunwell, nominated by her mother Emma

Megan is 13 with a rare chromosome disorder. Her scoliosis has been monitored since she was 2 years old. 5 years ago, we were told she needed to go on the surgery list. There was a lot of hiccups along the way. Delays, covid, pre op after pre op. She went to surgery twice, but the spinal monitoring didn't work so the surgeon wouldn't go ahead.

After lots of discussions the surgeon agreed to do the operation. She had waited so long they had stopped the X-rays at 110 degrees. She was in pain, her spine was sitting on her pelvis, she had skin breakdowns, bowel issues, and issues eating.

Megan has had so many operations throughout her life, since she was just 9-months old. This operation was the worst though. We were told they probably couldn't get a good correction due to spine stiffening in the time we had been waiting. Finally in May last year she had the operation. She's back in school now after having nearly 3 years out and her quality of life has improved. She has more movement in her legs and hands, her bowels are much better, she's eating three meals a day and snacks. We couldn't be prouder of her; she's done so well.



Lauren Wilkinson, nominated by her mother Tammy

Lauren is 13 and was diagnosed with scoliosis in 2019. With heavy pressure on the NHS due to COVID19, Lauren had to wait a long time to get the help she needed. After having numerous appointments cancelled, she was finally told that surgery was the necessary option.

In 2019, Lauren was diagnosed with a curve of over 90 degrees, alongside a hip hump. She was also told that her spine was rotating which caused pain and numerous complications. After a long journey, Lauren is due to have

surgery early this year. She has been so brave throughout this period; and we couldn't be more proud of her.



Isobel Brushneen, nominated by her mother Gemma

Isobel (now 12) was diagnosed with early onset scoliosis at 8 years old in early 2019 and was told she would need surgery due to the severity of her curve. Just before the first lockdown in 2020 she had her first growth rods (shilla surgery) fitted. Because of COVID pressure on the NHS she was unable to book in follow up appointments, which led to discovering in early 2022 that one of her screws had come loose. After a long wait, she was finally able to have her spinal fusion in August, 2022. The surgeons had success in straightening her spine but were unable to fix the severe rotation. A follow-up procedure to remove ribs will probably be needed when she is a bit older.

Throughout it all she has been so brave, never complaining and rarely taking pain medication. After her operation last August, she was back at school by the start of the September term - despite being fused from T2 to L2. We are so proud of her and despite everything she's gone through she's done it with a smile, good humour, good manners, and determination.



Rhiannon Kenney, nominated by her father Trevor

Rhiannon was diagnosed with scoliosis at 13 years old in 2021. At 14, in January, 2022, she had spinal fusion. Rhiannon has always had a 'never give up and be told no' attitude. Right from the very start of Rhiannon's journey, she tackled it head on. She was very intent to know everything about her scoliosis, as well as having a huge list of questions for the consultants and surgeons every time we went. She would also do loads of self-research, joined groups, and contacted people that had already been on the journey so she could understand every aspect. She made friends with one particular girl, Charlie, who was 6 months into her post op journey. She was a huge help and was always there to answer any questions Rhiannon had.

The operation was a great success! Rhiannon always managed to muster a smile as if to reassure us that it was going to be ok, regardless of the amount of pain she was in.

Rhiannon is a dancer and keen horse rider. We were told by the surgeon that these are two things she may find difficult in the future. If you tell her she cannot do something, then she will be determined to prove you wrong.

Within 3 months she was touching her toes again, and after 6 months the progress was so good the surgeon said she could go back to horse riding. Her dancing is back to normal, and the surgeon was astounded by a video we provided him of her dancing. Unfortunately, at 10 months, Rhiannon had a fall from a horse and fractured her collar bone. Luckily the main impact was on her collar bone and she was instantly asking when she could get back on the horse again. She never lets anything stop her, she embraces every second of life with scoliosis and she shows every day how having scoliosis doesn't have to mean the end of a normal life.



Ruby Barrett, nominated by her mother Jude

Ruby is 9 and was diagnosed with a moderate/severe curve of 40.5 degrees in November last year. Ruby has shown such courage during her X-rays and MRIs. She was diagnosed with a tic disorder and scoliosis within a day of each other and is currently waiting for the results of dyslexia screening. She is aware that she faces major spinal surgery and still faces each day with a smile and determination. She works hard to achieve good grades and she's the

most polite, kind, and thoughtful kid, often putting the needs of others before her own.

Ruby has recently been measured for her brace and we couldn't be prouder of her. Her school is doing a special assembly to talk about bracing and how it affects young people in preparation for her returning to school. She has been an absolute superstar and coped amazingly well!



Inayah Rafiq, nominated by her mother Riba

Inayah (age 9) has shown great bravery and courage over the past few years. During peak COVID, we noticed a significant change in her spine. Navigating through countless appointments led Inayah to a diagnosis of neurofibromatosis. A major part of this was being diagnosed with significant scoliosis. Over the last year Inayah has been through a rollercoaster of a journey, in which the use of a back brace made little difference to her spine. She also suffered from numerous breathing issues resulting in many A&E trips over this period. After a long journey Inayah was able to have spinal fusion in December, 2022.

Throughout this painful journey,

Inayah has smiled and stayed positive, and we are proud of everything she has endured.



Crystal Hume, nominated by her mother Amanda

After being diagnosed with scoliosis at just 12 months old, Crystal was referred to the royal orthopaedic hospital in Birmingham where she had several plaster jackets. Then at the age of 3 she started having spinal braces, which restricted her breathing and led to her having numerous asthma attacks.

At the age of 8 years in 2016 she underwent spinal surgery to have rods fitted. Unfortunately, after three successful lengthening's the rods failed. After speaking with the consultant, we came away with all the information and 3 months to decide what operation would be best. Crystal decided herself after researching and weighing up the options that she wanted to go for spinal fusion.

She underwent successful spinal fusion in January, 2019. She's had many check-ups since and in October, 2021, she was permanently discharged from hospital. Crystal has never once complained or moaned

and has always stayed a happy and positive child. She has been through so much in her life, having been in and out of hospital for most of her life. She is such an inspirational young lady who always aims to please and help others. Because of her life experiences her dream is to be a spinal nurse, in the hope of helping other children with similar problems like hers.



Imogen Smith, nominated by her mother Zoe

Imogen is 14 and was diagnosed with scoliosis when she was 7 years old. She went through the bracing process but unfortunately without much success. About 4 and a half years ago she had spinal rod surgery but is now at the stage where she needs more surgery. Unfortunately, this is more complex as Imogen has an undiagnosed genetic condition and is growth hormone deficient and therefore still small in stature. Despite all of that, Imogen takes everything in her stride and gets on with whatever is thrown at her with a smile on her face and true determination.

She has recently worked hard on a presentation at her school about scoliosis to help raise awareness and she will be doing the presentation as part of a programme called;

'Champions for Change', in front of children from other special needs schools across South Devon. We could not be any prouder of how she deals with everything.



Robyn Johnson, nominated by her mother Debbie

Robyn is 16 and had spinal fusion in September, 2021, for a severe double curve. During her recovery she got an infection and in November, 2021, needed washout surgery. The infection caused a few issues and Robyn was on antibiotics for nearly 6 months - during this time she missed a lot of school.

When Robyn returned to school, she was asked to share her story and X-rays with a PE teacher. Because of her story and the X-rays she shared, the teacher noticed another student who seemed to be displaying symptoms and after a trip to the doctor the student was also diagnosed with mild scoliosis.

In June, 2022, on Scoliosis Awareness Day Robyn completed a 50km sponsored hike raising £705 for Scoliosis Association UK. Since completing this walk Robyn has become a Charity Ambassador for her school and partakes in many charity

events, also being a spokesperson at school for scoliosis.

In November, 2022, Robyn completed a week's work experience with the spinal team at Nuffield Hospital, during which time she sat in a few consultations and was able to share her experience with some patients waiting for their own surgery and helped to put them at ease and reassure them. Most recently Robyn has had to have more scans and X-rays because she has a hairline fracture, a slipped disc, and spinal decompression, yet through it all she smiles and keeps going, determined not to let scoliosis stop her.

Robyn would like to become a spinal surgeon after school so that she can give people the same new lease of life that she had after her operation.



Marley Wright, nominated by her mother Louise

Marley is 14 and went through his first operation to correct his 83 degree spinal curve in May, 2022. Sadly, surgery was unsuccessful, which meant he had to spend a good amount of time in hospital. A week later, Marley went through his second operation in which the surgeons were able to correct 50% of his spinal curve.

He has shown such courage and bravery and has gone through so much at such a young age. The complications with his surgery were really scary for Marley, but he has always come through it and we couldn't be prouder of him!



Phoebe Flowers, nominated by her mother Claire

Phoebe was diagnosed with scoliosis in July, 2020, aged 8 during lockdown. From the day she was diagnosed with a double curve measuring 48 degrees on top and 45 on the bottom she has taken every appointment in her stride. Phoebe has shown so much courage and determination. We are now in the 3rd year of wearing a back brace full time and she is taking every day as it comes.

Over the last few months Phoebe has really grown in confidence. She started secondary school in September, 2022, and has really thrived. She amazes me every day.

Phoebe has been dancing since the age of 5. She is now 11 and regularly dances with a dance school but also with a group at her school. She performs every year in a show and has never let scoliosis stop her. She has an amazing positive outlook on life and has started to talk more about

scoliosis with her close friends.

Phoebe is an amazing young lady who is so determined and is growing in confidence every single day. She is a true inspiration and we are all so proud of her.



Erin Massey, nominated by her mother Sadie

Aged 15, Erin was diagnosed with scoliosis. She handled it amazingly and carried on with her usual life despite being in pain and discomfort. She had a successful spinal fusion in October, 2022.

Although Erin had a few complications, including her kidneys shutting down and fluids on her lungs, she still managed to get 9 GCSES and start college. She's absolutely amazing and the bravest person I know!



Asher Cooper, nominated by his father Blayne

In May, 2022, Asher (aged 7) had his first of many operations - inserting two metal rods in his back to correct a 65 degree curvature. Asher has also only just recently undergone his second operation and first lengthening of his rods.

Asher is the most resilient little man I have ever met. He has never complained about his back or the operations he has had. We have an amazing surgical team here and we know he is in great hands. Asher's school friends are all rooting for him and always keep an eye on him at school. The operations and rods have not stopped him leading an active life - he is a keen swimmer and continues to enjoy running around with his older brothers.



Olivia Daly, nominated by her mother Nikkie

Olivia is 11 and was diagnosed with a double curve last year. Olivia has coped incredibly well with her diagnosis and adjusting to life wearing a back brace even through the hottest summer on record!

She is always smiling and has shown incredible resilience. We are especially proud of the fact that not long after she was diagnosed, she felt

able to give a presentation to her class all about scoliosis and she continues to raise awareness for scoliosis, including writing an article for the school magazine.



Holly Davis-Lallah, nominated by her mother Clare

Holly has a neuromuscular condition which is the underlying reason for her scoliosis. She was diagnosed in March, 2021, and by November of that year her curve was at 94 degrees. She dealt with the diagnosis with bravery and resilience, despite being in increased pain daily.

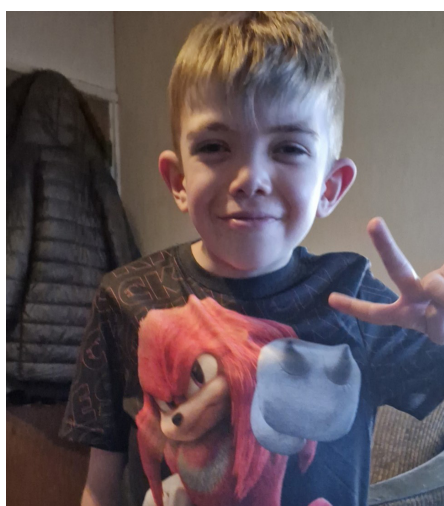
Holly underwent 8-hour surgery in May, 2022. Holly has always been so brave, maintaining her humour and positive outlook throughout the whole process. She was walking again on day two after the operation, despite the discomfort she may have been in. We are all so very proud of her!



Keith Innes, nominated by his family friend Ann

Keith is 9 and has had a lot of health problems including scoliosis. He is the most amazing young boy and an inspiration to me and many others. He has had operations every 6 months or so and always bounces back so quickly and never lets anything bring him down. He also suffers with neurofibromatosis type 1 and asthma, and has three kidneys. His mother Sarah is at every appointment and constantly takes time off work for his operations and appointments.

He has so much love to give, and he never complains, despite the pain he may be in. Keith deserves a medal for what he goes through. He is a true inspiration!



Maya Wetherall, nominated by her friend Scarlett

Maya has recently recovered from spinal fusion to correct her two curves, one at 62 degrees and the other at 55 degrees. Maya returned to school after only 6 weeks post op and throughout her recovery Maya has worked hard to maintain her good grades to which she has succeeded. She has been unable to play netball for 7 months, a sport which she is very passionate about and it is evident how tough it has been on her. Although she cannot play, she has continued

to support her club by still going to training every single week to help umpire. Maya has shown tremendous resilience and is an inspiration to all her friends and family.



Elise Price, nominated by her mother Kirsty

Elise is 8 and had major spinal surgery in January, 2023. Elise is one of her surgeon's more challenging patients. She has had four previous operations but this was the longest and most high risk. Elise was in Edinburgh for 3 weeks during her surgery, and after 5 days in ICU she continued her recovery on the ward and received fantastic care.

Elise continues to recover from her major surgery and we are so proud of her.



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, and now for research too.

Daniel Harrison, Karen Lamond-Lowson, D Coventry, Hebe Mast-Hughes, Avril Burrell, Julie Cranfield Technology Park Investments Ltd, Sandra Dalziel, Jean Greaves, Denise Minter, Samantha Eason, Sarah Brice, Eve Madderson, J K Webb FRCS, Anne Kim Cameron, Stacey Colton, Susan Joan Kelly, R Lacey, Shiena Bowen, Rachel Jevons, Neil Warren, Dionne Ross, Amanda York, Jeremy Cooper, Joanne Larner, Elizabeth Huckerby, Debbie Helkin, Malcolm Peters, Marcus Connolly, Repton School, Beverley Aitken, Jacqueline Bardsley, Ronald Lowrie, Anne Smith, Catherine Thompson, John Dove FRCS, Lynda Williams, Tony Dickin, Sandra Watson, Chris White, Thelma Brightwell, Enda Hendron, Paul Morris, Patricia Magennis, Francesca Brown, Albert Dawson, Carol Richards, Simon Caslaw, Kathryn Minett, Eileen Harding, Roger Proudfoot, Freddie Bagley, R Hallan, R Westby, Michael Edgar Mchir FRCS, Nicola Briggs, Jonathan Fish, Ewan Campbell, C Hoare, J E Barkham, M J Dunne, Rachel Haacker, Lois Hibbert, Christine Nixon, Keith Gibson, Victor Leo Poon, John Dorgan FRCS, Carol Wainwright, Camilla Drax, Colette Ray, Tim Morley FRCS, L Fell, Alan Francis, Hazel Keyte, Suzanne Wells, Paul Britton, C Maynard, Margo Wordie, Tracy Charley, Peter Grosch, Greta Stringer, Jonathan Charles, Nicola De Cruz, Kirsten Barrow, Guy Pender, Rosie Banham, Susan Bourne, Glen Kilpatrick, Ann Culley, Chris Young, Mathew Hunsley, Steven Bland, Harry Massey, Laura Owen, Chris Dunsheath, Martin Crofts, Jose Garcia, Donna Bland, Kay Heald, David Patterson, Mary Hall, Fran Steptoe X, Janet Robinson, Michael Gorely, Arthur Derrick Caley, Samantha Richardson, Dennis Richard Bury, Oliver Hill, Jenny Stevenson, Chris McGuire, George Georgiou, Rachel Lockwood, Ann Liebeck, Tracey Goodwin, Dianne Watt, Sarah Fox, Caroline Harding, Rosalind Hale, L J Bryant, Gillian Warwick, Preston and Valerie Thomas, Emma Nendick, Shirley Cole, N Andrew Purcell, Helen Sansom, Ruth Hammond, Jeremy Fairbank FRCS, Denise Randle, Georgina Chisholm, Agnes Fletcher, Barbara Blurton, Roy Atkinson, Mark Todd, Jay Wallace, Kay Drummond, Diana Seidl, V C Green, Lindsay Cant, Lorraine Farr, Karen Dickinson, Gillian Haacker, Tina Brown, K White, Jemila Jaffa, Judith Brindle, Jill Warsop, Jane Clemens, Alan Chinn, Ray Adams, Letitia Ann Jones, Jean Stark, Rebecca Ng, Richard Smith, Derek Randall, Geoff Waddoups, Denise Murdock, David J W Hardie, Jacob White, Kirsten Barrow, Alan Chapman, Sandra Dalziel, Julia Exton, Chewton Mendip Primary school, Julie Thomas, Mary Ellis, Eric & Heather Jackson, Martin Wright, James Caslaw, Roger Jack

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.

£165 was received in memory of [Rhoda Bignell](#)

£151 was received in memory of [Dennis Bedford, the late father of Jill Warsop](#)

£15 was received in memory of [Anna Llovet](#)

£5 was received in memory of [Michael Hearty](#)

£115 was received in memory of [Christine Predeth](#)

£660.00 was received in memory of [Nigel Riley](#)

£163.24 was received in memory of [Joy Firth](#)

£30 was received in memory of [Alan Sear](#)

£110 was received in memory of [Lucille Connolly](#)

£106.70 was received in memory of [Trevor Moseley](#)

£301 was received in memory of [Susan Elizabeth Caslaw](#)

SAUK - FUNDRAISERS

We are so grateful to all our amazing fundraisers for your fantastic efforts to support us. Thank you 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

[Phoebe Barber](#) raised £1,115 participating in the Olympic Park Half Marathon.

[Ross Taylor](#) raised £130 participating in the Bristol Half Marathon.

[Kate Burton](#) raised £620 walking up and down Mount Snowden.

[Ross Gay](#) raised £175 participating in the Great Bristol 10K.

[Chris Reeves](#) raised £1,257 participating in the Victoria Park Half Marathon.

[Ben Connell](#) raised £1,680 participating in the London Marathon 2023.

[Rhi Maylin](#) raised £535 participating in the London Marathon 2023.

[Martin Hicks](#) raised £3,671 participating in the London Marathon 2023.

[April Suarez](#) raised £785 participating in the London Marathon 2023.

[Jolaine Phillips](#) raised £445 participating in the Chelmsford Half Marathon.

[Paul Lewis](#) raised £809 participating in the London Marathon 2023.

[Bannerman House](#) raised £1,660.

[Jack Baldwin](#) has raised £70 so far for running the castle Run half marathon.

[Callesia Brown](#) has raised £182 so far doing a hike for scoliosis with her sister.

[Elizabeth Amps](#) raised £5 participating in the Great North Run.

[Dawn Bate](#) at Ginger Hair Studios raised £115 with a book sale

[Jenny Walker](#) raised £100 from sales of her home made greetings cards

Facebook fundraisers

[Aimee Johnson](#)

[Annie Bamber](#)

[Ben Mcallen](#)

[Catherine Saleh](#)

[Chloe Ann Quinnell](#)

[Ciara Driver](#)

[Claire Broadhead](#)

[Georgia Cook](#)

[Jennie Syson](#)

[Jerry Thompson](#)

[Jorja Sehmbi](#)

[Kayah Taylor](#)

[Keith Champion](#)

[Kelly Jones](#)

[Kerry Goodworth](#)

[Laceyella Chillery](#)

[Liana Strickland-was Nash](#)

[Madizon Walker](#)

[Martin Crofts](#)

[Melanie Brierley](#)

[Priscilla Jane Derricott](#)

[Sara Gutteridge](#)

[Shannon Newman](#)

[Stacey Anne Slade](#)

[Storm Shannon Wallis](#)

[Victoria Wickes](#)



Bannerman House students from The High School of Glasgow

Bannerman House students from The High School of Glasgow decided to fundraise for SAUK, a charity that is close to the hearts of a Bannerman second year pupil who underwent surgery for scoliosis last year. Throughout a week filled with fun activities and learning about scoliosis they raised a staggering £2469. Thank you to the Bannerman students for your enthusiasm and thank you to the school community for your generosity.

FUNDRAISER OF THE YEAR

RUTH BENNETT

The idea to hike to Everest Base Camp (EBC) started from my husband in late 2020 after watching a documentary about people climbing Everest - not that we wanted to climb to the top, but having really got into hiking through this year, trekking to base camp sounded like it would be an exciting challenge, and a once in a lifetime trip.

At that time, I didn't know anything about scoliosis or SAUK and had no idea my nephew would end up with this condition. He was just like any other teenage boy, liked to go out with his mates, play sports, the usual things. It was during a family holiday in August, 2021, that my sister noticed his spine had a curve and after a visit to the doctor in September, 2021, he was diagnosed with scoliosis. With the curve in his spine increasing to 87°, he was in constant pain and couldn't enjoy doing the things he used to, having to sit or lie down most

of the time because it was too painful to walk and move about too much, and would obviously need surgery sooner than later.

Since my husband and I were still preparing for our EBC trip, and my nephew was clearly facing extensive spine surgery, we decided we would try to raise some money and awareness for SAUK, who had given my sister and nephew so much advice and information about his scoliosis and was now a charity we felt we had a family connection with.

I set up a JustGiving page and was sharing it on social media, just asking if friends and colleagues wanted to donate anything, no matter how small, and thought if I could only get a couple of hundred pounds or so that would be brilliant and would still be something to give to SAUK.

By September, 2022, I had managed to raise about £90 and one morning

I texted the Chris Moyles Radio Show, not really expecting anything as they must get hundreds of texts every day, but then to my surprise my text was read out. They talked about it and mentioned my hike to EBC to raise funds for SAUK and asked for listeners to give something if they can, with Chris Moyles himself donating £100.

As I listened to the show and logged in to my JustGiving page, I was shocked to see complete strangers were donating money, and not just small amounts, people were giving £10, £20, £30 or more at a time - I couldn't believe it!

As I watched, it went to £300, £700, and then £1000 - this was more than I ever thought possible, and they just kept coming in, and by 8pm that night it had reached over £3000. I was so shocked; I couldn't believe how many people who had never met me were willing to give so much money. For me, this was absolutely mind blowing, and I can't thank Radio X, the Chris Moyles Show team, and of course all the listeners enough for what they did.

When I told my sister and nephew how much we had raised, my nephew first thought that funds raised were for him directly - I think there was a few seconds where he was wondering which Formula 1 race tickets he would buy! - but we explained that it's for SAUK so it can help him as well as others.



The day eventually came for my nephew's surgery in September, 2022, 12 months after his diagnosis, but unfortunately had to be cancelled. He took this in his stride but was obviously disappointed as he had built his hopes up for being pain free for the first time in over a year, but then in January, 2023, he finally had the surgery he so desperately needed, achieving an 80% correction. He is currently doing great, he was up and walking just a few days after his operation and is now doing well with his physiotherapy and is getting stronger every day. In time, when his spine has settled a bit more, he will need to do some light exercise and start to build some strength up in his back. There's still a way to go for him yet, and some work to do, but he is tough and has so much determination we are all sure he will make great progress.

So what was the trek like?

In October, 2022, we set off to Nepal and the adventure of a lifetime, starting with a flight in a tiny plane to Lukla airport, built on a steep mountain slope, regarded as the most dangerous airport in the world. I think this is one of the scariest things I've ever done!

Once the trek started, the scenery was absolutely stunning, everywhere you looked was just glorious mountain views that nothing else that could compare to.

We stayed in small 'teahouses' which though very basic, were comfortable, the worst thing being the cold because the only heating is in the communal dining room, but not the bedrooms.

This meant having to fill a bottle

with boiling water at night to keep you warm in your sleeping bag, and any water in my backpack would sometimes be frozen the next morning as it was as cold as -6C inside our bedroom!

We visited the world's highest Irish Pub at Namche Bazaar (3,400m), but only to drink tea, because alcohol hinders your ability to acclimatise to the altitude. The views just got better and better, walking over a few long and very high suspension bridges made of steel mesh that bounced and swayed as you walked along them.

The trek itself is not particularly steep most of the way, apart from a few sections which are very steep, but is pretty much constantly an uphill hike of 65km over 10 days. This doesn't sound like too much, but what really gets you is the altitude and lack of oxygen at that height, which just makes everything so much harder.

At about halfway in Dingboche at 4,300m, my husband was very short of breath from the lack of oxygen, getting out of breath just getting dressed, his oxygen saturation

measured 74%, so we stayed at that height for an extra day to acclimatise and it raised to 89% and so was safe to continue.

On the day we would finally reach base camp, it was a cold but clear and sunny day, trekking up the valley we followed along the side of a glacier, and as the sun came up over the mountains, it was a simply stunning view. Arriving at base camp, and seeing the infamous base camp rock was overwhelming, all the hard work from training, hiking, cold nights, and altitude effects was suddenly more than worth it to stand there. To have actually seen Mount Everest with my own eyes, to stand at the base of it and know I had done it was exhilarating; and to know that I had not let down all those people who had donated and sponsored me to get here, that I had done what I said I would, is a feeling I don't know I will ever have again.

My JustGiving page has raised just over my target of £5,364 which was set as that is the height of EBC with the last donation being made by a good friend who also has scoliosis.



BACKBONE: INTERDISCIPLINARY CREATIVE PRACTICE AND BODY POSITIVE RESILIENCE

Dr Catherine Baker, Birmingham City University

"The first piece [of artwork] was a way of healing, but the next was me now; it was me allowing everything to go into the past. I did this transition without even realising it, and I truly believe that this project allowed me to heal my thoughts and move on".

This quote is taken from a description by one of the participants in an interdisciplinary research project led by Dr Catherine Baker, an artist and researcher based at Birmingham City University (BCU) and Mr Thanos Tsirikos, Consultant Spinal Surgeon at Edinburgh's Royal Hospital for Children and Young People and SAUK Trustee.

The project, similarly named Backbone, sits at the exciting meeting point between art, health, society, and place. The opening quote describes the journey made

over the course of two artistic workshops that took place in Edinburgh in 2022 that culminated in a public exhibition at the prestigious Edinburgh Printmakers. The project was primarily anchored in arts practice methods, but its interdisciplinarity aspect acted as the main theoretical framework for the conception, delivery, and review of this unique project which is situated in the growing area of interest of medical humanities.

The interdisciplinary team working on Backbone consisted of Dr Baker and Mr Tsirikos, Senior Developmental Psychologist, Dr Olga Fotakopoulou (BCU), Dr Nina Morris, Senior Lecturer at the School of Geoscience at the University of Edinburgh, and Dr Flora Parrott, Associate Lecturer at the University of Creative Arts.

A key motivation of the project was

to use a range of methods, outside a medical setting, to open dialogue and create imagery exploring the gap between the patients' own assessment of aesthetic deformity and the results of the radiological review.

Working with ten female participants, all previously patients of Mr Tsirikos, the workshops took place in The Botanics Cottage, set against the beautiful background of the Royal Botanic Gardens in Edinburgh. The art activities took inspiration from the gardens, using imagery of unusual growth patterns of trees, mostly sourced from the gardens as a starting point. The photographs documented trees that for unknown reasons had grown differently than anticipated, in many ways they aligned with the medical description of idiopathic scoliosis. The ten patients were operated at an average age of 14.6



Holly Smith (22), workshop 1



Melissa McDermott (18) with Thanos Tsirikos in workshop 2



Dennon Boyle (18), collaging in workshop 1

years and all of them have over 2-year post-surgery follow-up with Mr Tsirikos at Edinburgh's Royal Hospital.

The participants were all keen to take part in the project, and highly motivated to give back to the NHS and to contribute to research activities that might impact on the future scoliosis experience for others. The group had some nervousness around taking part in art activities probably because current school-age art education tends to reward the ability to copy things accurately. However, post school art education is far broader, exploring the value of art as a communicative tool that has the ability to capture that which might not be possible through words. The research itinerary included a series of focus groups for all the different participants. A sense of comradery emerged immediately for parents and participants who felt that there were people present who understood them and their scoliosis experience, which proved particularly freeing conversationally. In these sessions the young people described similar responses to their surgery 'not even crying', not wanting to feel sorry for themselves, feeling that the other younger children who were more visibly ill than them in the hospital were much worse off. On returning home, they described the difficulty a long recovery and the 'dehumanising' feeling of needing to be helped with simple tasks such as showering and getting dressed. The group also had a similar perception of their body and of their new image and struggled with seeing themselves. The patients talked about the importance of the support of their families but also of the impact of the diagnosis,

surgery, and pain management on relationships within the family. It is understood that suppressed emotions and signs of poor mental health are often detected in the clinic environment.

As part of the process of gathering objective data during the workshops, the team used the participants SRS-22r quality of life assessment, these questionnaires are used as a standard part of the patients' treatment in clinics. In addition, the group was asked to fill in a TAPS (Trunk Appearance Perception Scale) before and after the workshops. The group demonstrated a high score in the Trunk Appearance Perception Scale form (TAPS) indicating smaller perception of having a curved spine and a positive affect and satisfaction with their body image.

Over the two weekends, there were garden walks and art workshops and short talks, through which participants with AIS and their families were able to express themselves and share their experiences. The mixed methods data collected was rich and extensive and at the end of the final art workshop, there was a large discussion group to think through the art works produced and the experience of exploration through artistic techniques.

Art practice proved an effective way of thinking through and with scoliosis, facilitating an exploration of the experience of scoliosis from diagnosis to present day. It became clear that making the artworks enabled the participants to reveal long-held anxieties and to articulate their thoughts in more depth through image making.

The aesthetics of imperfection was explored through material processes that focused on the body as both an object and how it is experienced using the metaphor of tree images. What emerged throughout, despite the small group size, was that dissatisfaction with body image was less present than current research indicates; however, what proved dominant was the need to express the experience of spinal surgery and the significant impact it had on the lives of the young people present and those they share their lives with.

The project enabled a 'shifted' body discussion to take place through the use of metaphor and how one might articulate the experience of scoliosis to others through art. Only a small number of the group took part in the workshop because of an interest in art and as a result there was some apprehension around the artistic processes at the start of the workshops. One of the participants described the initial reservations around art making:

"The art and workshop [were] the thing I was most worried about as I'm not a very confident artistic person, but I really enjoyed it and how free it was. It has 100% changed my perspective on art and the creation of it."

As a way of opening up new artistic processes, Catherine Baker demonstrated a range of cutting and collaging techniques that the group could use and interpret as a way-in to finding their own artistic language.

Confidence soon grew within the group and the art outcomes became more sophisticated in their

communicative potential and it was wonderful to see the participants discussing their artistic choices with each other throughout the workshops.

The team noted that through the questioning nature of contemporary art practice, artworks can become more complex and unfamiliar, but this is actually part of a sophisticated development in the art making process. The language of making overtakes one's ability to explain the material and metaphorical relationships taking place in the image, in words. Art proved an effective way to explore the gap between experience and language, enabling an emotional, psychological, or socially motivated outward expression through which participants could affirm their identity. Perhaps this speaks to a desire to reflect the complex, negative, and painful experience of scoliosis as much as to communicate moving on, repair, and positivity.

"This project allowed for a safe space of complete understanding, allowing me and those around me to open up and fully allow ourselves to have the closure we needed. I for one did not realise how much I needed this experience to put the past behind me and hold onto the positives"

The group expressed a sense that, eventually, they became proud of the 'battle scars', the marks on their bodies. Despite stories of being bullied at school, loss of friendship groups, even friendship betrayal emerging as a theme, there was a huge sense of pride in their bodies, what they've been through, their individuality, their uniquely marked skins, their scars making

them part of a minority collective. Throughout the activities, there was a strong sense of the shared learning and openness to new ways of thinking that can take place in a successful interdisciplinary project. This was particularly strongly felt in the end discussion in which a group of the AIS participants and one of the siblings shared their responses to one another's artworks and used the images as a way to discuss their experiences.

The artworks produced during the course of the workshop were displayed and celebrated in an exhibited at the prestigious gallery at the Edinburgh Printmakers alongside an exhibition of work by Dr Catherine Baker titled 'Held' in September, 2022.

"All I have wanted since this surgery is to help spread awareness and develop a better understanding and overview of what I and the others went through. So, you're definitely going to be stuck with me now!"



Anna MacIver (14) with her sister Katie MacIver (16) in workshop 2

We felt it was particularly important for the participants voices to be reflected in the analysis and review process that happens at the end of a research project so three of the workshop participants, Melissa McDermott, aged 18, Holly Smith (22), and Jamielee Stevenson (24), joined the team in London for a 2-day review session, to represent all the participants who took part in BackBone. Melissa, Holly, and Jamielee wish to act as mentors and contributors in the next phases of the research and are interested in developing a programme of creative scoliosis podcasts. The project has enabled them to be important spokespeople for AIS, indeed many of their fellow BackBone companions are also keen to be involved in future activities. Dr Baker is in the process of developing a larger co-funded application with Kew Gardens in London, who are eager to join the research team to co-design the next version of BackBone to expand the scope of the project in the future. It is intended that these future plans will lead to the recruitment of a much larger number of scoliosis participants from across the UK.

This project was supported by:



Your Back Stories

Helen Cowell

My journey began in 1983, when I was 12 and sitting in the bath. My mother came in to collect something and noticed that my spine had an unusual curve. She took me to the GP, and the GP confirmed it was indeed scoliosis, and he sent me to the physiotherapist in a local community hospital. I did the exercises she told me to do for about a year or so. However, probably about a year later, it was decided that the curve was still progressing, so I was referred to the Nuffield Orthopaedic Hospital in Oxford, where I was looked after by an orthopaedic consultant who specialised in adolescent idiopathic scoliosis and for the next 5 years I was under their care. At age 15, the curve had progressed further to 40°. It was a largely lumbar curve, and I was told at the time that they didn't operate on lumbar curves because it didn't have any effect on breathing like a thoracic curve, so I was placed in a Boston brace when I was 15 and remained braced until I finished growing at about the age

of 17. It was obviously not great fun for a teenage girl to be wearing a bulky and uncomfortable plastic brace for 2 years, 23 hours a day!

I was discharged from the scoliosis clinic at 17 and told that I was fine. I wasn't going to have any more problems with my back, which was largely true for the next 25 years. In that time, I had three daughters, and although my back niggled and could be uncomfortable, I wouldn't say that was ever painful.

I absolutely hated the fact that I was shortened in the waist, I had no waist on one side, and one shoulder was higher than the other. I hated that bra straps always fell off my shoulder and that I didn't have a waist, although I was pretty slim. So I got very clever about hiding it, knowing what to wear and what not to wear to hide my rib hump.

Then something suddenly changed in my early 40s; my back suddenly became excruciatingly painful with specific "triggers". I quickly realised

wearing high heels, pulling a suitcase, and carrying heavy bags would cause massive muscle spasms and nerve pain that would take my breath away. I'd have to find a position and wait for all to settle down. It was awful. I got a referral to my local district General Hospital which, I have to say, was superbly unhelpful. I was told that they would have to fix my spine from top to bottom, which wasn't going to be the right thing to do, so to go away. The only helpful thing they suggested was I try to find a chiropractor because that might help.

My chiropractor was brilliant and kept me moving for the next five years, but at the age of 48, I realised that my quality of life was going to be so impaired by my back that I needed to try and find a surgical option again.

I realised that my breathing was being affected and I'd also lost quite a lot of height. So, I needed to try another route. After a chance conversation with a friend's mother-in-law, who had been seen at the Royal National Orthopaedic Hospital in her 60s for a correction of her scoliosis, I set about finding myself a surgeon. Luckily, I had private health insurance with my company, and I will be forever grateful because I'm not sure I would've been offered this operation on the NHS. I was lucky to see a fantastic surgeon at the Royal National Orthopaedic Hospital. He was very sure he could help me. I was going to have to have fixation from T3 all the way down to L4. I was also going to need two cages inserted into my bottom



vertebrae to try and stabilise my spine, but it very much felt that this was going to be something that was going to transform my life. First, take away the pain; second, stop the progression; third, give me a waist back. So, in January, 2020, I was admitted to the Royal National Orthopaedic Hospital and had a two-step fixation done, so the first day, I had about a four-hour operation to insert the cages into my bottom two lumbar vertebrae, and then the next day, I had an eight-hour operation with something like 24 screws and two titanium rods inserted into my spine. The results are amazing, it's completely straightened my spine, and I grew about two inches.

It was very sore afterwards. I spent the first night on the high-dependency unit and the first 5 days in an awful lot of pain that didn't seem to respond to morphine, but after that, things started to improve very quickly, and I was home after a week. After 3 weeks, I'd come off all painkillers, I had my 20-year-old daughter at home to look after me, and after 6 weeks, she went back to university, and I could look after myself doing light housework etc. After 3 months, I returned to full-time work and have never looked back. The whole thing has been transformational. I'm 51 years old and 3 years post-operative, and I haven't had one issue with my back.

Victoria Steele

Running a marathon has been on my bucket list for a long time, despite my hatred of Cross Country at school, which I did for 8 years!

I was diagnosed with scoliosis in 2013 and had surgery in December of that year, fusing my spine from T2-L3, at the age of 17. At

the time, I loved to dance, and was attending dance classes four times a week. I was lucky enough to return to dance 3 months post-op, performing at Disneyland and Sadlers Wells, and gaining 94% in my dance exams 6 months after surgery. Being active post-op was important to me; I returned to the gym, started running again, went skiing, continued dancing, and took up cheerleading at university.

In my first year at university, I decided to apply to run the London Marathon for SAUK. However at the time I was not running regularly, I tried to increase my mileage too quickly and ended up with shin splints (nothing to do with my back) and sadly had to drop out. This experience was tough, and honestly embarrassing, to not be able to complete something I wanted to. Running took a back seat in my life, and I continued instead with dance and cheerleading, occasionally running a few miles on the treadmill. In 2018, I had a second operation to remove three screws from the top right side of my spine following pain. This surgery was a success and recovery was so much quicker.

During lockdown, like a lot of people, I took up running to get out the house, keep fit, and stay sane whilst working as a mental health practitioner. This time, I removed the pressure I put on myself, stopped thinking about my time and distance, and used it to look after myself and my mental health. I slowly increased my mileage, running an extra mile every week, and eventually found myself running a half-marathon! Once I'd done this, I knew I wanted to run an organised half-marathon. I moved to London and found

running an amazing way to see the sights of my new area, running along the Thames and into the city, I also joined a running club and found it an ideal way of meeting new people. I ran the Richmond half-marathon in 2021, and was incredibly proud of my time, but also for completing it. At the time, I was struggling with pain in my back. I have often suffered with screws rubbing in my back and sitting quite close to the surface of the skin, causing pain. This is nothing to do with running, and I often found that running helped to ease the pain and helped me with the frustration of being in pain; getting out the house and moving always helps me to feel better. Even if it's just a short walk. On days when I don't want to run, I know that if I can get through the first 5 minutes, it gets so much better and easier.

Following the half marathon, I knew I was in a much better position to be able to train for the marathon. I had increased my mileage gradually; my shins were no longer causing pain and I knew I was at an ideal time of my life to train. I contacted SAUK and was lucky enough to get a place on their team.

Training for a marathon is tough! I did a lot of running over the summer, though arguably nicer than dark winters, it was an incredibly hot summer. Early starts on the weekend to get 15 plus miles in was hard, especially after going out the night before, as well as dragging myself out after long days at work. Running for 3 plus hours can be lonely and mentally challenging but I found podcasts really helped me and kept me motivated to keep going. Living in London also meant I have some

amazing running routes. I loved running into the city centre, seeing the sights, running up the Mall and over Tower Bridge, round the Tower of London and through Hyde Park on many occasions. I hate to be one of those people, but I also enjoyed running on holiday, I ran in gyms whilst holidaying in America, and an early morning run in extreme humidity with my brother in New Orleans was also an experience!

I think the experience of surgery makes us so much more resilient to things, when runs were hard, I knew I could get through it because I'd got through surgery. I also found myself thinking about 16-year-old me, being diagnosed with scoliosis, being unsure what life would look like and scared, and hopefully I've made her proud!

October 2nd, 2022, was a day I will never forget. Though nerve-racking standing at the start line knowing I had 26.2 miles ahead of me, I loved it. Lots of people have asked whether I ran alone, and I did. It would have been fun to do it with a friend or family member, but I

think it made it more special that it was an experience and challenge that I did alone. I was able to see my family and friends' multiple times along the route, as well as taking in the shouts and cheers of so many amazing supporters. Everyone says you hit the wall around mile 20, knowing you have 6 miles left and probably at least an hour of running to go. It was mentally difficult but there was so many people watching, I couldn't stop. Miles 22 to 24 were probably the hardest of me, but I kept putting one foot in front of the other, had some good music and the thought of a glass of champagne and a burger at the end kept me moving. The last 2.2 miles were amazing, the crowds and atmosphere, with the sights of London and knowing I had nearly completed it. I even had what felt like a sprint in me, coming past Westminster, Birdcage walk and along the mall to the finish line of the London Marathon! With the iconic tinfoil blanket and medal around my neck I was able to call myself a marathoner.

I am incredibly lucky that my back does not suffer at all with the impact of running, I experienced no pain during my training, only getting pain in my neck and shoulders towards the end of a run – due to tightness, but this is a common experience for runners anyway. I would recommend getting correct trainers as I believe the correct trainers has made such a difference to my running journey. Go to a running shop and talk to their experts about your scoliosis or surgery/fusion, they will watch you run on a treadmill or down the road and help you get trainers that support your feet, your natural running style and support your back. Start slowly, and try to forget about your time or pace, run for time not mileage and remember a 9-minute mile and a 15-minute mile is still a mile! Walk at first and then try jogging, and always listen to your body. Running after surgery might not be right for everyone, but there is only one way to find out, so give it a go!



Milly Wiggin

After complaining for years about chronic nerve pain down my arms and back, when I was 13, I went to my local osteopath where she suspected that I had scoliosis. I was immediately taken to Oswestry hospital where an X-Ray of my spine showed that I had a 25-degree curve, and the consultant told me that I needed spinal fusion surgery. Mum, Dad, and I, decided that we would do everything in our power to prevent me from having the operation.

Following my consultation at Oswestry Hospital, my Mum spent every waking hour researching every single alternative treatment for scoliosis. At that time, we had never heard of the condition, and we were introduced to only one other person who we got put in touch with who had been diagnosed. This as you can imagine made research and our ability to come to a decision quite challenging. She eventually came across a clinic in London that specialised in Schroth exercises. The following Monday I found

myself spending the next month at their clinic doing Schroth spinal exercises and treatment for 8 hours a day in a room full of individuals who also had severe scoliosis. It was the most traumatic, emotional, and awful month of my life. I have only come to terms with the damage it did to my mental health and body image over the last 2 years. A vulnerable 13-year-old girl spending 8 hours a day for a month staring at your abnormally wonky body in a room full of bars and mirrors was always going to be damaging. Following the course, I then spent 45 minutes every morning doing specialist scoliosis exercises. Don't get me wrong, the exercises massively improved my posture and subsequently the way my back looked. However, the clinic then spoke with my local newspaper in Shropshire claiming to have 'got rid of the problem'. This language was misleading and detrimental to the narrative around scoliosis. There is, unfortunately, no cure for scoliosis, the only option is to have the spinal surgery. Once your spine reaches a certain Cobb-angle (degree), there is

no way that it can improve unless you are operated on. In the 2 years that followed my time at that clinic, my spine continued to excessively curve and rotate as I continued to grow. During my annual check-up at the Nuffield in Cambridge, the X-Ray showed that my spine had regressed to 52 degrees, and I now had two quite severe curves in my spine. Again, my consultant told me that I should be operated on. Next thing you know, Mum was back on her research train and came across the SpineCor back brace. Off to Sheffield it was where I met with an amazing orthotist. I then spent the next 2 years in a SpineCor back brace. This was a dynamic brace that I wore for 20 hours of the day. The idea was that it would enable me to live a more relatively normal lifestyle than with the traditional Boston brace. However, it was a serious challenge trying to find clothes that would fit over the top that weren't disgusting, albeit whilst being a 15-year-old girl. To really top off my look, the brace caused such bad sores and cuts on my body that I had to wear Spanx underneath. As you can imagine, this was not a pretty sight. The idea of the brace was that it would halt the regression of my spine whilst I was growing.

Following my brace, an X-Ray showed that my back had stabilised and remained at 52 degrees, which was amazing. In addition, once you are fully grown, your spine shouldn't get any worse. I am now (we hope) out of the woods with regards to my scoliosis regressing anymore. I have spent the past 14 years seeing every type of specialist, surgeon, and doing every type of treatment and exercise possible. Although I am in pain almost every single day and I struggle daily with the way



my body looks because my legs are different lengths, my shoulders are wonky, one rib cage protrudes out, my right scapula protrudes out so every time I sit in a chair that has a hard back it is agony. I am also rotated to the right, and those are to name but a few ailments. However, I have never felt so strong and happy in the position that I currently am in and proud of the methods I took to avoid having the surgery. There is no one size fits all with regards to dealing with scoliosis and it really is a case of finding what works for you. In my case, exercise, a brace, and regular treatment works but that does not mean it comes without difficulties. I will be forever grateful to my parents who gave up so much to enable me to see the specialists, and I don't want to begin to imagine how many miles they have driven me all around the country to go to the very best specialists and hospitals. There are so many people who have been a massive part of my journey, and I will never be able to thank them enough. I know now which types of treatment and exercise work for me, and I hope to continue to live a normal life without having the operation. I have a weekly appointment with a musculoskeletal pain specialist, I have regular massages, acupuncture, and physio, I swim, I do reformer Pilates, I play tennis, and I do high intensity interval training. My experience has made me so in tune with my body and how important it is to have the right people on your side whilst moving your body in the right way.

I want to remind people that there is light at the end of the tunnel. It is a hell of a scary time but there are enough people out there who have been through it and hopefully reassure you that you are not alone. My scoliosis is a huge part of who I am, and I am incredibly proud of the place that I have got to with the condition. I have met some of the most amazing people through my diagnosis and built some great relationships along the way. I have learnt a huge amount about myself, and it has given me great perspective in life and commitment to a condition that is not spoken about enough. I am wonky as hell but am so proud of the experiences that I have been through to enable me to get to a point where I can speak out and help others going through the same.

Speaking up makes a difference

You can have all the love and support from your family and friends but there's something special about talking to someone who doesn't have to imagine what it's like to be in your shoes. Hearing from others with scoliosis can be a validating experience, showing you that your struggles have been felt before and people have come out the other side of it. We asked you on Instagram how it felt the first time you spoke to someone with scoliosis, and these were your responses:

'I didn't feel alone, I felt like I wasn't the only one, I felt like I fit in somewhere.'

'Like I wasn't alone.'

'I felt so emotional knowing it can be even more severe for other people.'

'Not alone! It made me realise that there's life beyond hospital appointments and pain.'

'It felt amazing to speak to someone who finally understood how I was feeling.'

'Absolutely incredible. Having support is always so much easier than doing it alone!'

'Freeing and a sense of relief! I felt like I burdened people who didn't get it before.'

'Reliving! I felt understood.'

'It's good to share my experiences with someone who has a similar thing to me.'

'The most validating, beautiful, and connecting experience! I finally felt heard and much less isolated.'

'A weight off my shoulders.'

'Like I wasn't alone.'

'Heart-breaking, validating, and emotional.'

'Very reassuring! Knowing there are others out there helps so much.'

'I no longer felt alone. I went 2 years without meeting someone who had the same thing as me.'

'I thought it was weird for so long until I started finding people like me, I was so happy.'





ISAD



International Scoliosis Awareness Day
Saturday, 24th June, 2023

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