

Issue 105 | Spring 2022

BACKBONE

The bracing process

Rehabilitation programme following scoliosis surgery

Style & scoliosis

Preparing your child for surgery

Personal stories

Isobel Gray Award & Roll of Honour

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Christine Jaureguiberry

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 2022 *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 31st August 2022.



- The competition is open to people of all ages living in the UK and Ireland. (Employees and representatives of SAUK are excluded)
 - Only one entry per person is allowed
 - Please submit your entry by 31st August, 2022. 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 September, 2022**

Editors: Stephanie Clark
 Designed by: Natalie Cooper
 Cover cover: Enrico Garofalo
 Back cover photos: Sam Pearce
 W: www.sauk.org.uk
 E: info@sauk.org.uk
 T: 020 8964 1166

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LATEST NEWS

Cover Girl Kathy Messider

Our front cover for this issue is of Kathy Messider and was taken by Enrico Garofalo from Buckinghamshire New University.

Kathy says, "The picture is of a garment I created and modelled during my second year at Buckinghamshire New University, the piece was inspired by scoliosis and is a visual representation of how fragile scoliosis can make someone feel."

Big Give Christmas Challenge

SAUK took part in the Big Give Christmas Challenge for the first-time last year and thanks to all our supporters it was incredibly successful, in the end we raised over £11,000!

The Big Give Christmas Challenge is a match donation campaign. In the lead up to the event we secured pledged donations from key supporters totaling £2,500. This campaign couldn't have taken place without our pledgers, so we are very grateful for their support. The pledgers set the tone for the rest of the campaign and meant that we were eligible for Champion funding. Our Champion funders were The Hospital Saturday Fund who also pledged an additional £2,500.

We now had £5,000 in pledged donations which meant that during the weeklong campaign, 30 November – 7th December, every donation made up to £5,000 would be matched by funds from our pledge pot. We were overwhelmed by the generosity that was shown throughout this campaign and we quickly met our target and exceeded it.

Thank you very much to everyone who made a donation through this campaign. Like many small charities, we are still struggling with the after-effects of the pandemic and so many of our regular fundraising opportunities being shut down. The amount we raised is monumental for a charity of our size and makes up a large portion of SAUK's income this year.

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 ISAD, an event launched by SAUK in 2013.

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



ABOUT THE BSRF

BSRF



BRITISH
SCOLIOSIS
RESEARCH FOUNDATION

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

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

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

SAUK Helpline

Did you know that SAUK has a Helpline that supports thousands of people a year? Our Helpline is one of the most important ways we support the scoliosis community. We take calls and emails that cover a large range of issues and questions. Call us on 020 8964 1166 or email info@sauk.org.uk. We are a small team having to work with covid restrictions so if we can't answer your call right away, just leave a message and we will get back to you soon.

If you're newly diagnosed or want to see a scoliosis specialist, contact us and we can send you a list of both NHS and private scoliosis specialists in your area. Taking this list to your GP can help speed the process along by ensuring you're being referred to the correct team. We can also prepare you for what to expect and send you information about a lot of different aspects of scoliosis, depending on the issues you're facing.

Some of the people who call us are also just looking for someone who understands what they're going through. We can give general advice and talk things through with you. We can also help you get in contact with more of the scoliosis community so you can build up your support system and listen to the experience of people who have been in your shoes.

Christmas Cards and Raffle

Christmas 2021 was our best year for Christmas Card sales yet, raising over £2000! We sold out earlier in the year than we normally do so we do apologise if you missed out this time.

We have run our popular yearly raffle for some time now and the proceeds from it make up a significant portion of our yearly fundraising. This raffle has become increasingly challenging to run as, especially with covid, businesses are less inclined to donate prizes. We need your help to keep this raffle going. If you have any connections to a business that could donate products, services or funds to our charity raffle, please get in touch. Email us at info@sauk.org.uk

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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THE BRACING PROCESS

Rachel Adam and Kirsty Sutters, advanced spinal orthotists, Scottish National Spine Service

If you have been diagnosed with scoliosis, one of the treatment options is spinal bracing. Your spinal consultant will determine if this is an appropriate treatment for you and if so they will send a referral to orthotics. Availability and treatment may differ depending on the spinal unit you attend. An orthosis is an externally applied device used to modify the structural or functional characteristics of the neuro-muscular and skeletal systems. A spinal brace is a type of orthosis which is used to treat scoliosis. In Edinburgh, there are two types of brace that we use depending on your type of scoliosis. These are the corrective spinal brace and the postural spinal brace. The corrective brace we use is a custom made Boston Brace (Figure

1). This brace is used commonly for idiopathic scoliosis. It is worn for 20 hours per day. Commonly, the expectation is that the brace can correct the curve; however the aim is to stop or slow down scoliosis progression during a period of rapid spinal growth. In bigger curves bracing is used to delay surgery, which allows for as much natural growth and chest development as possible before scoliosis correction. This brace can be applied in children as young as 6-months-old until growth is complete. The postural brace used is a custom made two piece brace which allows for easy application (Figure 2). It is generally used for neuromuscular scoliosis and is worn during day time only. It does not correct the curve but uses the flexibility of the

curve to improve the child's sitting position. This process has many health benefits, including better respiration and digestion. Because the brace holds the child in a more upright position it also benefits eye contact, arm function, and general communication. This type of brace is worn through the day only. It can accommodate feeding tubes and can be removed for physical therapy when required. It works well alongside a supportive wheelchair. It can also be used from the point at which a good seating system is established and into adulthood.

Casting

Each spinal brace is custom made, and a plaster impression is taken of the child's spine using a casting frame called the Risser Frame. The plaster cast is the same for each type of brace. Taking a cast ensures the brace will be unique to the child's shape and as comfortable as possible. The frame also ensures the best possible position of the spine because gravity is eliminated. We apply longitudinal traction using a strap under the child's chin, which works together with a strap around the waist to keep the child secure on the frame and in a good position. There are at least two orthotists present for this procedure and it takes approximately 30 minutes. Whilst most casts are done with patient awake as an outpatient, on occasions we need to cast a child under a general anaesthetic if their level of cooperation is poor.



Figure 1. Boston Brace



Figure 2. Postural Brace



The Risser Frame

Blueprinting

Once the cast has been taken it is sealed and filled with liquid plaster. This gives us a 3D model of the child's spine to work on. The cast is adjusted to add areas of relief over bony areas, which makes the brace as comfortable as possible. The trim lines for the postural brace are generic. However, the trim lines for the Boston Brace are determined by a blueprint of the child's most recent X-ray, which ensures that the brace targets the individual child's curve(s) in the most effective way. A named orthotist will make the blueprint and the adjustments to the cast. The brace will be fitted approximately 4 weeks after the cast has been taken.

Manufacture

The spinal brace will be manufactured in our in house workshop by our team of technicians. It consists of a lining material for comfort and a plastic outer shell for strength. These materials are heat moulded under vacuum to ensure an intimate fit to the cast. At this point the child's choice of pattern for their brace is added, if the child has chosen one. The brace is then removed from the cast and trimmed to match the specified trim lines. The straps and corrective pads are added before the fitting appointment.

Fitting

The fitting appointment will last up to 2 hours and this is really important to ensure the brace fits the child comfortably. Any adjustments required will be done on the day and the family will leave this appointment with the finalised brace. The child will be given a tight fitting vest to wear underneath the brace and the rest of the clothes are worn on top of the brace. The braces are a very close fit and are not particularly visible under clothing. The orthotist will show the family how to put the brace on and take it off correctly. They will discuss how to build up optimum wear time. For the corrective brace we aim for 20 hours of daily wear, and day time wear only for the postural brace. The orthotist will discuss this with the child and their parents. The family will be given a leaflet at fitting that explains everything discussed at the appointment and there is also information available on the service's website.

Follow-up

We have a well established routine to check the fit of our patients' braces. The child will be seen by the orthotist and the spinal consultant about 6-8 weeks after the brace has been fitted. It is important within this time that the child establishes a good routine with the brace and reports any issues to the orthotist to allow these to be resolved. At the follow-up appointment the child will have the brace checked by the orthotist and any adjustments required will be done at this time. The child will then have an X-ray wearing the brace. It is important that the brace fits well and is fastened securely for the X-ray to provide maximum support to the spine. The spinal consultant will measure the curve(s) on the X-ray and discuss pad placement with the orthotist. There is a wire inside the corrective pads within the brace which shows up on the X-ray. If these need to be moved to optimise the support from the brace to the spine the orthotist will do this on the day. The brace must be as accurate as possible to achieve the best correction result. Corrective pads are only added to corrective braces. The child will then be reviewed 6 monthly by the consultant and orthotist and as required in between these appointments for brace-specific needs.

Below is an example of how effective corrective bracing can be. This is an X-ray of a 12-year-old patient with an adolescent idiopathic scoliosis. The patient was Risser grade 0 at the start of brace treatment which indicated a substantial amount of remaining growth (the growth plate across the upper end of the pelvis had not yet appeared). The left thoracolumbar curve measured 36 degrees before brace treatment and reduced to 6 degrees in the Boston brace. A wire can be seen in the X-ray in the brace and this is the outline of the corrective pad. This allows us to assess if the pad is in the correct position and alter it where necessary. This patient is very committed to brace wear and continues to wear it 20 hours per day without any complaints. Brace treatment for this patient will continue until the end of spinal growth and the aim is that when the brace is removed the curve will remain at least at a similar size to what it was before brace treatment, which will allow the patient to avoid scoliosis surgery.

Bracing data

In Edinburgh we are part of the Scottish National Spine Service. Any child living in Scotland with a diagnosed spinal condition can be referred for treatment. We are a team of five spinal orthotists working closely with three spinal consultants and two spinal liaison nurses. The bracing results we see are reflective of a well established team approach. This financial year it is projected that we will have supplied 340 braces to patients throughout Scotland. These are a mixture of corrective braces and postural braces. We recently looked at our data over an 11-year period that included 480 patients treated with a Boston Brace (corrective brace). Of the patients who have an idiopathic scoliosis our figures show that 54% of these patients did not require surgery at the end of brace treatment. For the 46% of patients who did require surgery brace treatment delayed spinal surgery for several years, preserving the growth of their spine and chest development. All patients who had completed

treatment filled out a questionnaire about brace treatment. They reported normal function, good self-image, and reduced pain, as well as high satisfaction in the group who required bracing only and those who required bracing followed by scoliosis surgery.

is a very active 3 year old who loves to swim, dance, and go to gymnastics. The brace can be removed for a maximum of 4 hours each day, which allows her to fully participate in all the activities she enjoys. We are extremely grateful that she has this time out of the brace since not only is it important for her to physically exercise, but also for her overall wellbeing. The standard of service we have received from our daughter's consultant and The orthotics team in Edinburgh has been outstanding. Nothing is ever too much bother and they always take time to explain any questions we have. With their support and expertise, we feel confident that our daughter is in safe hands".

IDIOPATHIC. Completed Treatment (2010-2021)



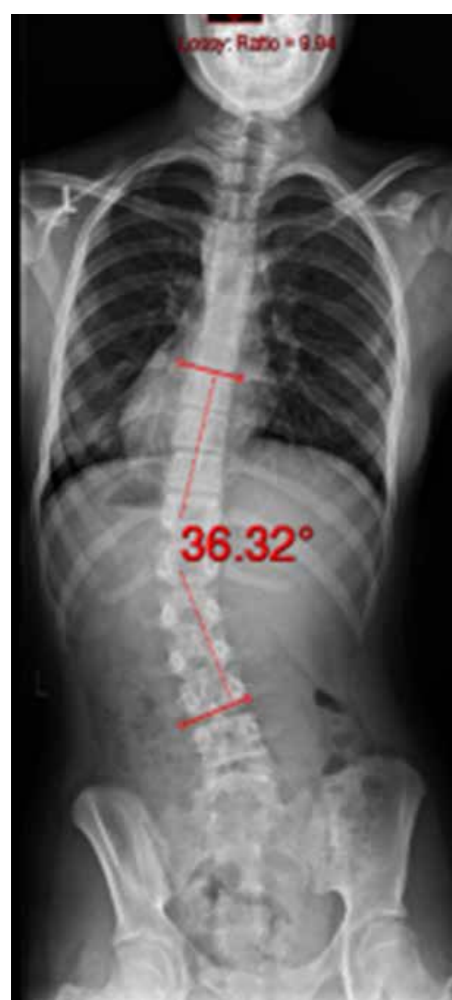
Patient comments:

"The orthotic service for my child's brace has been exceptional. Despite having some doubts about my son wearing a brace for his scoliosis, he has managed his daily activities well beyond my expectations. The constant communication and feedback from the orthotics and spinal team has been amazing and has established my trust. The team on board with my son is phenomenal. I would like to thank our orthotist and consultant surgeon for their work in helping my son cope with his brace"

We would like to thank our patients for their feedback and for allowing us to use their photographs and X-rays for this article – Rachel Adam and Kirsty Sutters.

"My child has been in her brace since she was 2. It was a big adjustment but gradually it just became part of everyday living. The orthotic team spend time making sure she is comfortable in the brace at every visit, especially when getting a new brace. She has coped well with the brace and we gave it a nick name 'Bear' because she was so young and thought it would help. Now she is 13 and it is still called Bear sometimes. The spinal service has been great. We are able to contact them if adjustments are needed and they are very accommodating with appointments around my work commitments. My child is still in her brace 20 hours per day and this has helped keep her spine as straight as it can be. The spinal team is great".

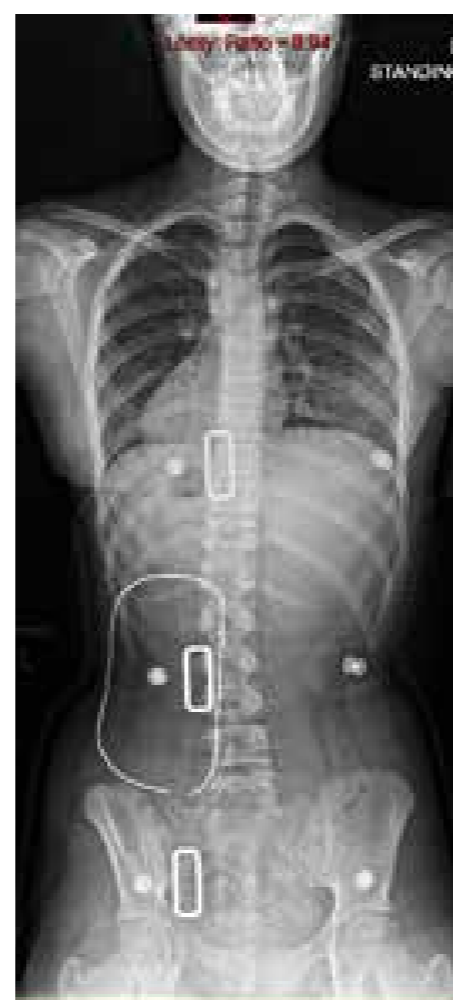
"Our daughter has been braced for about a year now and has adapted well to wearing her brace full time. Although it is going to be a long journey, our experience of bracing so far has been positive. She



Pre brace X-ray



Blue print of X-ray for brace



1st X-ray in brace



PREPARING YOUR CHILD FOR SURGERY

Cheryl Honeyman

Specialist nurse paediatric spine, James Cook University Hospital

Being well prepared will help your child or teenager to feel less anxious about surgery, which can in turn speed up recovery and reduce the emotional impact of the operation. Understandably, many parents are unsure about the best way to prepare their child, so we have put together some guidelines that may help.

At SAUK we receive a lot of calls from worried parents whose child or teenager has been put on the waiting list for surgery. We know that this is a difficult and often upsetting time; not only is there the anxiety of your child undergoing a complex operation but also the concerns about how the child is coping and how best to prepare them.

First of all, it may sometimes feel like you can do no right. Everyone deals with situations differently, but occasionally children and teenagers will refuse to talk about what is happening or may show extreme emotions. The care and support of those close to your child is absolutely vital at this time, so even if it doesn't always feel like it, you are doing more good than you know.



It is a good idea to try to have some positive family time before surgery so you can focus on something else, such as a holiday or trip out if possible. It is also important to remember that siblings need your attention at this time too. They may be worried about their brother/sister and also may be jealous of all the attention they are getting from you. If they want to, involve them when possible in the preparations, and give them the same information you give to your child having surgery so they are fully informed.

Explaining the process

It may be tempting not to talk to your child very much about their visit to the hospital in case you worry them. However, children of all ages generally cope much better if they understand what is going to happen and why it's necessary. It is important that they have a chance to ask questions and work through their concerns in advance.

The key is to provide information at your child's level of understanding. Helping your child to understand why surgery is needed, and to become familiar with the hospital and what will happen there, will greatly reduce fear and distress when the time comes. So that you're able to explain the process to your child, it helps to make sure that you understand it yourself and have had your own questions answered.

During appointments there is a lot of information to process, so it can be difficult to remember the questions you wanted to ask and to recall everything afterwards. When speaking with the surgeon, it's a good idea to write down your questions before you go, and to take notes. It is natural that you will be anxious but children very easily pick up on and reflect their parents' feelings. Familiarising yourself with the process will help you to explain it calmly to your child.

Anaesthetic is often one of the major causes of anxiety. For young children a simple, carefully-worded explanation can work well. One option might be to tell them that they will get special medicine during the operation so they stay asleep, but that the medicine will be turned off

when the operation has finished, and that they will wake up about 5 minutes later. It may be wise to avoid phrases such as 'being put to sleep' or 'knocked out' as these carry other meanings that may frighten a child. However, the most important thing is to know how your child likes to communicate, and what phrases may be reassuring for them. Young people can be worried that they will wake up during surgery, so they need to be reassured that this will not happen.

As a general rule, simple, honest, and reassuring explanations about the things that will happen at the hospital and the people they will meet will be of benefit to your child. It helps to encourage your child to talk about the operation and ask questions. For younger children, telling stories and using activities and games may help to prepare them. Encouraging your child to join in with some of the preparations, such as letting them help to pack their hospital bag, can help to reassure and involve them.

Teenagers may require a more detailed explanation of what will happen. It is important for them to feel in control of their health and body, so they should be included in discussions about the surgery and given the opportunity to ask questions of their surgeon. It may be helpful to give them a choice about how and when they receive information. Your child might want to choose whether they would prefer information to come from you or the surgeon, how much information they require, and how long before the surgery they would like to talk.

This can be a lonely and confusing time for teenagers; sometimes the worry about their operation is accompanied by concerns about their appearance, or by feelings that they are different from their peers, or that no-one understands what they are going through. Reading the stories of, or communicating directly with, other teenagers who share similar experiences can provide additional support.

Teenagers may also be worried about missing school when exams are imminent, so it is important to liaise with their school to make sure they can provide some work to do at home and that they will help your child to catch up when they return to school. The hospital teaching staff will also help with this.

Your teenager will usually be fully aware of your feelings, no matter how much you try to hide them, and they may be more worried about you than themselves. It is best to be open with them, whilst emphasising the positive outcomes of surgery.



Timing

The best timing for a discussion varies, depending on the age and maturity of the child. Teenagers will often be involved in discussions and decisions for weeks in advance, but the timescale might differ for younger children. As a guideline, a week before the operation is an appropriate amount of time for most children, and for children under age 4 about 2-4 days before hospital, and again on the day.

If your child or teenager is unable to talk about the operation or their behaviour is difficult to manage, a lot of patience may be needed. Using gentle encouragement with your child can help them to open up about their questions and fears. This approach can prevent your child from feeling pushed and will show that you are willing to listen when they are ready to talk.

For teenagers; printing out information and letting them know where they can find it will allow them to learn more in their own time, even if they aren't ready to ask. It might also help to avoid them surfing the internet and being frightened by some of the vast amount of inaccurate or exaggerated information out there. Always use information from accredited sources, such as the hospital at which your child will be treated, or the SAUK website, which is Information Standard approved. On the day, encouraging your teenager to take items to hospital that will provide a distraction, such as books, headphones, phones, and tablets, will help to reduce the stress of surgery and avoid a sense of isolation.



Post-surgery

After surgery, some children and young people will want to talk about and share their experiences and if so this should be encouraged. Some teenagers create blogs, videos, and photo diaries. For younger children you can ask them what bits they liked and didn't like, and whether being in hospital was how they thought it would be. They could draw pictures and you could write stories together about what happened.

However, there are some young people who prefer to move on and regard the experience as a closed chapter and if so, this should be respected. Occasionally, some struggle to cope both before and after surgery. There is help available but facilities do vary. If you are concerned, you should speak to the hospital about getting extra support for your child and help with behaviour management strategies.

Having a child who is undergoing surgery can be one of the most stressful and worrying times a parent can go through. One mum said that consenting to surgery is like sending your child out in a car you know is going to crash. That brings home the enormity of what parents go through at this time. However, we find that children and young people are generally very resilient and both you and your child being prepared can help to greatly reduce anxiety and distress.

Children with special needs

Children with special needs can find this process a particular challenge (as can their parents!), which can be because of disruptions to their routine, unfamiliar environments with unfamiliar people, and the hunger caused by fasting before the operation.

Additionally, sometimes children with special needs are not able to understand what is happening and why.

The medical staff looking after your child will wish to cause as little upset and distress as possible. Phoning the hospital in advance and speaking with the ward is a good idea. The staff will usually have a check list to go through with you so that they can be fully prepared to look after your child and they will welcome a pre-admission visit if arranged in advance. If your child has an information booklet about them at school or for carers, it is a good idea to take it into hospital to provide more information for staff.

Creating a time-line on paper that breaks down the visit to hospital into a series of steps can help children to manage one procedure at a time. This can be written or in the form of pictures and symbols, or both.



ISOBEL GRAY AWARD

Helen Gardner



We are delighted to announce Helen Gardner as the Isobel Gray Award recipient for 2022. Helen has made a significant contribution to SAUK as a Regional Representative for over 15 years. As Regional Representative, she has been there for countless people who have come to her in need of support and advice. Helen uses her experience of having fusion surgery 25 years ago to support others going through this now. Helen is a big proponent of the power of speaking up about scoliosis and has even shared her experiences in *Backbone* numerous times, recently reflecting on life post fusion and on pregnancy and birth with fusion. She shares these experiences so that she can be the light at the end of someone's tunnel, showing them that she has come out the other end and so can they. Helen didn't find SAUK until years after her own experiences, so she wants to be the person to help guide others along this journey that she could have used at the time. Helen has faced many challenges in her life, which comes with frustrations and sadness, but she believes her experience with scoliosis set her up to face those challenges headfirst, with determination and strength. SAUK is very fortunate to count Helen as a supporter.

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 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.

ROLL OF HONOUR

Lily-Rose Taylor, nominated by her mother Camilla Taylor

Lily-Rose was diagnosed with idiopathic scoliosis during the initial lockdown in May 2020. Whilst the world was staying home, we had to attend hospital for urgent X-rays and MRIs, plus they initially braced her to try and slow down her curve. She wore her back brace for 23 hours a day with no complaints for 3 months until it got too small. Her curve had progressed from 55° to over 70° in that time. She had surgery in May 2021 and is now fused T3-L4. She has had to cope with all the Covid restrictions, meaning she had no visitors post-surgery and was stuck with me for the 5 days we were in hospital. Since her diagnosis and spinal fusion, she has shown great strength and has taken it all in her stride. She has recovered amazingly well, and I have to keep reminding her she had major surgery only 5 months ago. She really is amazing and we as a family are so proud of her. Receiving this Award I know would mean so much to her.



Lauren Setford, nominated by her mother Kelly Backhouse

My daughter Lauren Setford is 13 we are at the start of the journey, being recently diagnosed with a 60-degree curve and currently braced awaiting surgery. Despite not wanting to talk about it, she finds the stories motivating and although she struggles with the diagnosis, I am extremely proud of how she is adjusting to the different ways of how her body is changing and how she is always full of smiles.

I just want her to be recognised and to show her and others that it's okay to not be okay at times, but I am proud of her and the journey so far.



Minnie Menzies, nominated by her mother Diane Menzies

Minnie really is a superstar and I'm super proud of how brave she's been. She has a double curvature of the spine, which is also rotating. She was in a cast from the age of 2 until 4. At age 5, Minny had her first spinal operation to put in growing rods. We've had three rods snap and we are hoping for operation number 11 very soon. She really is an inspiration.



Lucy MacLeod, nominated by her mother Rachel MacLeod

Lucy had a hemivertebra picked up on antenatal scans at 20 weeks as well as brain abnormalities which were subsequently diagnosed as trisomy 8 mosaicism. She had surgery in June 2019 aged 11 and is now fused T5-L5 and so far it has been life changing! She is now 13 and enjoying life pain free. Whilst we are cautious about the future she has always faced a challenge head on and is just so brave and resilient.



Amelia Mills, nominated by her mother Angela Bainbridge

Amelia was diagnosed with scoliosis at the beginning of lockdown in 2020, which came as a big shock to us all. Thankfully on the 10th of August 2021 Amelia had a spinal fusion along with costoplasty. She has recovered amazingly since. Her surgery was done at the Royal Victoria Infirmary (RVI) in Newcastle under the incredible spinal surgeons and their team. Amelia was approached by the hospital and producers of Channel 4 because they were making a documentary about various surgeries at the RVI to follow some of her story. Amelia showed amazing courage by agreeing to have her operation filmed; she told us, "I'd like to do it because if there are other children at home who are nervous about having the procedure, it may help them." We're immensely proud of her. Amelia's surgery and time at the RVI was featured on the fifth episode of Geordie Hospital on Channel 4. It aired in February and can be watched on catch-up. We are really hoping it will help to raise awareness around scoliosis.



Evie Saxelby, nominated by her mother Sarah Kerfoot

Evie has been waiting for her operation for the past 2 years. It keeps getting pushed back because of Covid. She is due to go for a Traction film but things keep coming in the way of that. However, we hope it will happen in March.

Evie also suffers with a condition called Charcot Marie Tooth. This means her nerves don't work as they should, and her muscles are weak. Evie is in a powered wheelchair full time. Because of her nerve pain, back pain, and hip pain, she is on constant pain relief medication every day. Even though she is in constant pain, she always has a smile on her face and works through everything life throws at her. She is so resilient, it's unbelievable. She deserves this recognition to encourage her to never give up!



Rebecca Tyler, nominated by her mother Jean Tyler

Rebecca, my youngest daughter, is 15 and had two spinal fusions for an 85-degree curve on 5th and 15th of July, 2021. The first fusion failed, because the screws came out, hence having two operations to rectify the curve. She was fused T2 - L4. She has had to wear a brace for over 3 months and is still wearing it for school since she

is on a phased return because of her anxiety. She suffers from PTSD (post traumatic stress disorder) from the operations, and she didn't have a very good time in hospital, unfortunately. Rebecca has been so brave and strong, especially since she was so sick after all the medications. She wasn't able to eat and lost 3 stones in weight. We were in hospital for 20 days and because I could not sleep all that time, I sometimes got a bit stressed. Rebecca asked the nurses to check up on me, even though she was so poorly herself.

When we came home, she was still so poorly and struggled to eat and keep food down for at least 8 weeks. We never found out what caused it. She was scared to leave the safety of her bed for a long time because she was petrified of the screws coming out again.

She is now doing great. Physically you would never know she had the operations, but mentally it will take a long time. We are so proud of her, as is the school, who have been very supportive.



Charlotte Heath, nominated by her mother Karen Heath

Charlotte (Charlie) was diagnosed with adolescent idiopathic scoliosis when she was 10 years old. She was braced for 2 years but the curve progressed quickly and she had a spinal fusion from T2 to L3 in July of 2019 at the Queens Medical Centre in Nottingham, a month after her 12th birthday. She had complications of paralytic ileus and anaemia. 2 and a half years on, she is still quite unwell and is currently having investigations into a possible superior mesenteric artery syndrome. She vomits, is constantly nauseous, and has lost a lot of weight. She still manages to give us a wee smile on her better days and her courage and determination to not let it beat her, and the gentle compassion she shows her family and friends, even when she feels so unwell, is truly humbling. Further to this, she has moved schools three times within this period because we are a Forces family and therefore, she has had to make new friends and explain her journey all over again. Something that I believe demonstrates courage.



Zara Brown nominated by her mother Rebecca Brown

Zara has been on a very long journey since 2016 when she first began wearing a back brace, and after delays due to Covid restrictions, she finally had an emergency spinal fusion in April 2021. Zara was only 2 months post-op in this photo. She was still in recovery but was determined to attend her end of secondary school prom. She was so proud of the journey she had been on and took pride in wearing a dress that showed her scar. She feels it is important for others who have been through, or are going through, a scoliosis journey, to wear their scars with pride and feel confident in who they are.



Eilidh Jays nominated by her mother Ruth Jays

Since being diagnosed with adolescent idiopathic scoliosis in 2021, Eilidh has coped amazingly well with the challenges she has faced. Eilidh has worn her brace every single day, often for longer than the 20 hours she needs to, and even needs to be reminded to take it off sometimes! She does have moments

when she gets frustrated but always manages to have a word with herself, and gets the brace back on, focusing on her goal of being brace-free and hopefully avoiding surgery. She's done this in the middle of the pandemic, when she missed out on so many of the adolescent milestones such as a primary school leavers' dance, school camp, and visits to high school. All of this is hard enough for a young person without the added hardship of wearing a brace. She goes to school every day wearing the brace and a face mask - still mandatory in the classroom in Scotland - and never complains. She's able to put on the brace herself so can take part in PE, sports clubs, and her favourite hobby, dancing. The way she just gets on with it is really inspiring and we are so proud of her. She's also using her experiences to help others and is supporting another girl through her scoliosis journey. We don't know yet whether Eilidh's bracing will be successful, but whatever happens next, I know Eilidh will cope with it.



Sophie Sykes (and the spinal team at ROH), nominated by her mother Catherine Sykes

Since Sophie was born, she has faced more challenges than children her age should need to cope with. At 6 weeks old, she was diagnosed with hip dysplasia and wore a corrective harness until she was 3 years old. Although it was a difficult time it worked, and her hips are now well.

When Sophie was 8, she had leg pain and a referral back to the hospital led to the sinking news that she had spondylolisthesis. The slip in the bones of her spine was squeezing her spinal cord and if left untreated could have resulted in paralysis from the waist down by the age of 21. At 9 years old, she had her first spinal fusion, and when she was 12 she had corrective spinal surgery to replace some of the screws and take some more bone from her hip to use to help the fusion. It was after the first operation that she developed scoliosis and wore a brace to try and prevent the curve from progressing. When Sophie was 13, the curve had worsened, and surgery became an option, because of Covid it was delayed; however in November 2021 she had her third operation. Nearly 3 months on she is doing well and has begun light exercise.

Even though she has been through so much, she is a strong, determined, caring, and inspirational person. She has managed to achieve her goals one step at a time, by completing triathlons, climbing Snowdon, getting her Bronze Duke of Edinburgh Award, gaining a grade 9 GCSE and grade 4 piano.

Sophie is open about her condition and willing to speak to others about it. Although we know there is still a long way to go, She remains positive. During her recuperation she has

composed her own melody since music has helped her to relax and focus.

Sophie has had tremendous support from the spinal team at the Royal Orthopaedic Hospital in Birmingham, particularly the surgeons and Helen, a specialist nurse, who has since left, so I would like to nominate Sophie, Helen, and the ROH team for the Roll of Honour.



Dionne Vickers, nominated by her mother Lynette Vickers

Dionne's scoliosis was diagnosed when she 6, almost 7, years old. She had to go for X-rays and an MRI scan at The Robert Jones and Agnes Hunt Orthopaedic Hospital (RJAH), under the care of a spinal surgeon. We were told that Dionne's curve was 46 degrees, and she was fitted with a Boston brace that she had to wear for at least 20 hours a day. Dionne has had regular check-ups and was on her third brace when she was sent for an X-ray during the first lockdown. That X-ray showed that the curve was growing rapidly, so the consultant was now recommending surgery, but warned we would probably be waiting a year for the surgery.

Dionne had really mixed feelings about it all, not helped by the fact that

she has global developmental delay. She had to be transferred to the Alder Hey Children's Hospital because RJAH don't operate until a child is 13 years old. We were given a date for surgery, 8th of December, 2021, but Covid pushed that back to the 6th of January, 2022. Dionne had an 8 hour full spinal fusion and was in hospital for 5 days. She is now doing amazingly well and is going from strength to strength. She used to love playing on her trampoline but now she's had to give it up as it's not recommended after spinal fusion surgery, so we need to find a new hobby. She will be 12 in April and is doing really well. Dionne is my scoliosis Warrior Princess



Scarlet Goodwin, nominated by her mother Tracey Goodwin

Scarlet has been through such a lot and has been so brave. She was diagnosed with idiopathic scoliosis aged 13 and was braced during the same year. She had pain in her lower back and in her chest and legs to the point that on some days she was in tears struggling to get through a school day. The pandemic isolation along with self-hatred of her curvy back brought anxiety symptoms, and my beautiful confident gymnast became a sad lonely and unhappy young lady confined to her bedroom.

However, with lots of love and support from family, Scarlet started going on more walks and swimming twice a week for exercise, which was not always easy for her. Her operation was pushed back but did go ahead in November, fusing T3–L4. Now nearly 4 months on, we are beginning to get our daughter back. She has less pain, more movement, and is finally getting her confidence and life back! The Royal Orthopaedic Hospital in Birmingham have been nothing less than amazing and we would also like to thank SAUK for the help and advice that we couldn't have been without.



Rachel Haacker, nominated by her mother Gillian Haacker

Rachel was diagnosed with scoliosis in July 2021. She was referred to a consultant spinal neurosurgeon at our local hospital in Dundee in October, then was asked to attend an appointment at the Scottish National Spine Deformity unit in Edinburgh the following week. Rachel was advised to have surgery, which she bravely accepted. We were told that surgery would be in about 12 weeks but on the afternoon of 4th January we received a phone call asking for

Rachel to go in for her pre assessment day the following day with surgery on 6th. Obviously, this was a huge shock, but Rachel agreed.

The way in which Rachel has selflessly and courageously dealt with her surgery and recovery has amazed me. In hospital her main concern was that she had caused me worry, saying if she hadn't had scoliosis I wouldn't be in this position. She managed to keep smiling in hospital, always thanking the nurses even when she was in pain. Rachel regularly says she is glad that it happened to her and not to her brother or sister.

Rachel is 17 and is used to going out every weekend. She is missing out on a lot of social events with her friends but never complains and has managed to keep her humour throughout. I think she is a very worthy recipient of this recognition.



Katie Wood nominated by her mother Laura Bennett

Katie saw a specialist in January 2019 and was advised that surgery was her best option, we went on the waiting list, and she carried on with life as normal. As we reached the top of the list for surgery, we went into lockdown - March 2020. In July

2020 she was X-rayed again, not much had changed and with the pandemic I was relieved that it wasn't going ahead at that time. 6 months passed and Katie was X-rayed again in December. Her X-ray confirmed her curves had progressed. We were told her operation would be around May 2021, however on Tuesday 23rd Feb I got a call from Alder Hey and they asked if we could go in sooner. We went into Alder Hey for an operation a week after on Friday 5th March. We checked in to the ward and she went down for surgery the Saturday morning. Katie was in surgery for 8 hours, was home after 5 days, and had a determination to get on with life. Katie has been a perfect patient, she went back to school after 5 weeks and got the all clear at 11 months and 3 weeks, and she has even been roller skating and ice skating! For her 1-year Spineaversary, we got her a balloon, cake, and a book voucher - because books have spines too!



A SHORT STORY BY NICOLA

Nicola's scoliosis was first noticed at a school medical when she was 7 years old. She had two plaster casts fitted from shoulders to waist, with their trademark tummy sized hole missing, and several removable braces over a period of 11 years.

"My hospital stays were at The Royal National Orthopaedic in the mid-late eighties and the staff there made it far less scary for me than it could have been. My consultant was a Mr Morley, who I remember to this day for his support and humour, and my curve was thankfully corrected without surgery. I was discharged from treatment at the age of 18 and I'm forever thankful for it allowing me to lead a near normal life ever since," said Nicola.

Nicola has written this short story about having scoliosis as a child, finding it therapeutic to put her feelings about having this condition onto paper.



Someone once said, 'to stand straight and tall, you must first be bent and small'. I decided when I was both bent and small that scoliosis was never going to define me.

I close my eyes and I am 7 again, thrilled to have been asked by my cousin to be a bridesmaid. My Mum lifts the dusky pink dress out of the box, and I gently touch the embroidery that runs in perfect straight lines on the top half, from neck to waist. Intricate stitches stand out in pink and green, and I notice tiny silk roses dotted here and there. It is quite simply the most beautiful dress I think I have ever seen, so soft and delicate. My mind races about how it will look, what shoes I might wear, and whether I will have my hair

up or down. My Mum smiles as she gestures to me to try it on, and I am brimming with excitement.

I try to read her expression, as I look down at myself in the fairy tale dress. My smile is wide, as my hands run up and down the smooth material, once again my fingers catching on the exquisite stitching. My Mum seems confused though, as her eyes settle on my chest and the lines that are now standing quite proud. But they are not straight. They do not run from top to bottom, up to down, point to point. All I see is that each one has a distinct curve and my young mind quizzes itself as to how that could be. In the box, the lines were straight, but now, with the dress resting on my little body, they are not. I look up, and my eyes reach my Mum's. She smiles, but it isn't the wide smile I had but a few seconds ago. Her face is concerned and confused; it is worried.

The clock in the hospital waiting room ticks so loudly it is as if it is the only sound in the world. The lady sitting in the chair opposite us is wearing a daffodil yellow coat and it hangs tiredly around her shoulders. I think about how old she might be as her hair is peppered with grey and I wonder if she is a grandmother. If she is, does she have a bedside drawer filled with sweets like my

Nan? Or maybe she cooks egg and chips on a Saturday afternoon for her granddaughter like my Nan does for me. I smile at the thought. Maybe she also tells her granddaughter not to worry about the stitched lines on the dusky pink dress, that do not look quite as they did when they were in the box. My name is called, and I stop thinking about the grandmother in her tired daffodil coat. We walk into the consultation room where there is an aroma of disinfectant, and I wrinkle my nose at the smell.

I think that scoliosis is a funny word. A long word that is hard to pronounce. Maybe it is a grown-up word I just haven't heard of before, although my Mum doesn't seem to



know what it really means either. I decide that it will be fine as we will just learn about it together. My X-ray is hanging on the light box and I almost giggle when I see my bones, like a funny little skeleton having had its photo taken. I know what part my head is, and I can see lots of straight bones going from side to side across my chest. My eyes stop as I take in the image of the big, long bone that goes from top to bottom, almost taking up the whole X-ray. I tilt my head to one side to look at it from another angle and I think it reminds me of a big letter S. I'm almost hypnotised by this big bony letter. It is actually inside my body, and I think that is amazing. I can hear the doctor talking to my Mum, but I just can't stop looking at the X-ray. Aren't we humans just the cleverest of things. I learn quite quickly that the big bone isn't supposed to look like a big letter S. It's supposed to be straight, more like a big letter I, and all my friends and family have that. I don't though, and nobody seems to know why that is. I conclude this to be the reason the lines on the dress do not sit just right. I have to bend and touch my toes for the doctor, and I feel his warm fingers

trace my spine as I stand in front of him. He runs his hands across each shoulder blade, as if he is quietly assessing my frame, measuring me, looking for differences. Sometimes it tickles and I laugh. He makes lots of notes with his dark blue pen, which is just like the one my Dad uses when he writes special letters. I can't see what the doctor is writing, but I don't think it's a special letter. As he makes me laugh again when his fingers tickle my skin, I look over at my Mum, but she isn't laughing. She is looking at the floor, and she's wringing her hands.

It is quite the adventure to stay in hospital I decide, but I am also very nervous. I notice that the ceilings are so high, and there are not many windows. Rows of beds are placed in one big square room, all with the same light blue blankets placed on them. I hold my Mum's hand tightly as we are led to my bed. It seems very high and I am already worried I will fall out of it during the night. There are other children walking around, some in wheelchairs too. I'm not really sure why I'm staying here, as I do not feel ill in the slightest.

The night seems like an endless dark void of hours and hours. I brought my teddy, Toby, with me and the tall nurse with fire red hair has given him a wrist band with his name on, just like I have. I am on Coxen Ward and my date of birth is 21.5.79. I read this on my wrist band time and time again, as it stops me worrying that my Mum is not at the hospital anymore. I don't sleep much as the little girl in the bed opposite me, Jodie, cries a lot. I notice that she is tiny and doesn't stand straight, in fact one of her shoulders is almost curved around toward her chest. Her frame looks crushed, and when the nurses help her turn over in bed, it seems to give her lots of pain. I screw my eyes shut tight each time she cries out, and hug Toby close to me.

It is explained to me the next day that I am going to have a plaster cast fitted soon, and it will act just like a brace put round the trunk of a young tree to help it grow tall and strong. I like this image and imagine I will grow as tall as an Oak, standing straight and proud. I just want this part to be over quickly, I don't like being in hospital and I miss home. School at hospital isn't the same as normal school, and the lunches which arrive on scratched plastic plates are really not nice. I am glad when the doctor comes and tells me that it is time for me to go to the theatre.

The theatre lights are bright, and I squint my eyes against them as I lie against the coolness of the bed. It's not a warm soft bed, and I think the metal feels hard as there is no mattress. There are several doctors and nurses walking around and they all seem to have an important job to do. A kind nurse gently pats my hand and explains that my body will be put into a position and will then be

plastered into place. Her words are a bit muffled in my ears as I am not really listening. I am mesmerised by her sparkling green eyes and how they perfectly match the colour of her face mask. She explains that it might feel a bit strange but that it shouldn't hurt. I nod, but I don't really understand. I think that I'm about to cry.

I notice that there are straps at my feet and a plastic chin cup resting on my chest, also with a strap attached to the top of the bed. The kind nurse with green eyes starts to fasten the cool leather around each of my ankles, and also the cup strap under my chin. My skin feels warm, and I start to breathe a bit quicker as a strange sensation takes over. The straps are tightened, and I feel my legs straighten involuntarily and the chin cup pushes my head upwards. I close my eyes and I feel tears leave them and roll down my cheeks and trickle into my ears. It tickles, just like when the doctor touched my skin, but this time I don't laugh.

As my fragile little body is stretched straight, the doctors and nurses begin their important jobs. Hot wet plaster is wrapped round and around my chest and back, and its smell is overpowering. Tiny splatters are thrown into the air and land in my hair and on my face. I can't wipe them away, and they start to feel heavy on me as they begin to dry. I try to take myself away in my mind to somewhere where I can no longer smell the acrid plaster or feel it starting to suffocate my skin.

I am back on the hospital ward a few hours later, and I try to sit up in my bed but I soon realise that I need help to do this. The cast is like a heavy plaster vest, shoulders to waist, and it is too heavy for me to

lift myself away from. I decide not to speak to anyone around me, as I do not want to risk crying again. I do feel a sense of relief however, that I can leave this place soon, as it is so full of children who carry such sadness and confusion within them.

Returning to school I know that I am different. My friends ask what is wrong with my spine most days, and why I always wear my hair long to cover my shoulders. I am excused from PE and I have to stay in the shade on hot summer days when my classmates play on the school field. I have stones thrown at my back in the playground. The other children cannot see my cast, but some know my chest and back appear hard to the touch. A strength test ensues – touching leads to prodding, prodding leads to punching, and punching leads to stones. My cast can take it, and it doesn't hurt me, but my mind is not always so resilient.

As I sit quietly, watching my friends on the field, I think about the dusky pink dress. The feeling it gave me when I touched its fine material, and

the wonder I had of how it would look with its tiny silk roses against my skin. I look down at the bulk of plaster that sits where the dress should be, and a wave of deep and painful sadness hits me like a physical strike.

But then, all at once, I feel something else that is far more powerful. I think of the Oak. The tall, strong, proud Oak tree, helped once by a brace, shaping it into what it's become. In that split second, I promise myself that I will always be proud to have been different as a child, and it would not be something I was to ever feel ashamed of or weakened by. Scoliosis would not determine who I was or what I could do in life, and I would always strive to be stronger than the curvature of my spine.

I smile as I continue to watch my classmates play and run in the warm sunshine and conclude that this is where I am meant to be. 'Bent but never broken', maybe sometimes sitting in the shade, but still with the strength of the sun, never faltering, always at my back.



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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.

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Anjini Baker
Anna Klein - Scoliosis Yoga
Bethany Roden-Wood
Bryony German
Charlotte Baker
Charlotte Gathercole
Charlotte Meredith

Chloe Ann Quinnell
Chloe Harris
Christine Thomson
Claire Barnes
Daniel Smith
David Sullivan
Dj Loopy
Eddie Lowe
Elaine Easton
Evie Jay
Freya Rose
Jacqui Strachan
Jareeda Wlb
Jenny Bush

Karen Boulton
Kerry Goodworth
Lizzy Rowland
Luke Simpson
Lynn Liston
Lynn Martin
Malcolm Skinner
Margaret Crosfield
Margaret Green
Matt Batten
Matthew Critchley
Melody Sevilena
Miranda
Michael Fox

Mylene Silvestre Lane
Olivia Miller
Priscilla Jane Derricott
Rebecca Bumpass
Sarah Northern
Scoliosis Pal
Shannon Newman
Siobhan Sasha Ramsay
Stacey Anne Slade
Stacey Reader
Tammy Williams
Thomas Taylor
Tiegan Manley
Vicki Davidson

REHABILITATION PROGRAMME AFTER SCOLIOSIS SURGERY

Sarah Charlton

Specialist spinal and scoliosis physiotherapist

Physiotherapy provision after scoliosis surgery varies across the country - at Addenbrooke's Hospital in Cambridge we have run a rehabilitation programme for over 10 years. As a physiotherapist I have worked with this group of patients for over 20 years. The programme was developed based on experience of helping referred patients who were struggling post operatively and turning the process around to offer all patients postoperative management to promote a good recovery for everyone.

The role of the physiotherapist in the Addenbrookes scoliosis service begins before surgery. We treat and help manage patients while they are waiting for surgery and guide them in the recovery phase. We meet patients on every part of their journey, from diagnosis to discharge. My colleague Claire and I work alongside our two spinal surgeons. The first part of the surgical

pathway is scoliosis counselling about surgery which takes place as part of a combined assessment day, including MRI, lung function testing, and medical risk assessment with a paediatrician. We call this the *Scoliosis One Stop Shop* or "SOSS" because we endeavour to complete all the appointments in 1 day, although Covid has made this more difficult. At the counselling stage we introduce advice about posture correction, fitness, and stretching, to improve flexibility of the curve in preparation for surgery.

After discussion at our scoliosis multi-disciplinary team meeting, patients will be added to the waiting list for surgery. Whilst on the waiting list patients can access the physiotherapy service to help manage their symptoms. As a result, we know our patients coming through the system.

The post-operative period starts with our physiotherapist on the ward

who works on early mobilisation and gentle exercises in the first few days post-surgery and sets the patient up with advice and gentle exercises to do at home during the first 6 weeks. Our scoliosis nurse practitioner will contact the patient to check on their progress and one or two patients will be referred to physiotherapy in the early period so we can do a video or telephone call if necessary.

Patients return to clinic at 6 weeks post-surgery for their post-operative consultation including an X-ray. On the same day we start our physiotherapy and hydrotherapy rehabilitation programme. We begin by looking at the X-ray and comparing the correction to the pre-op X-rays, which helps us to identify areas of postural correction to work on. Patients tend to lean or side shift towards their 'old' position because this is where they feel stronger and have better balance. We use a mirror to show them how to do small corrective movements and then assess which soft tissue structures are tight and therefore reinforcing the old movement patterns.

The main areas to work on are:-

- Shoulder posture – shoulders are adjusting to the change in position of the ribs.
- Lean or shift - due to muscle imbalance.
- Derotation or unwinding – due to the correction, if tighter muscles cannot curve the spine, they can sometimes cause trunk rotation instead.

The X-ray images help us to look at the framework of the bony skeleton

and then explain how the soft tissues (muscles and skin) all need to stretch and grow to fit the new, more balanced, and improved symmetry of the skeleton. At this stage the surgeons have completed their task of 'correcting' the skeleton and stabilising the curve, and physiotherapy can help improve any residual muscle imbalance as the soft tissues adjust.

The programme starts with a simple set of exercises promoting range of movement through the whole trunk and tight structures through the hips and shoulders. Everyone is offered sessions of guided exercise in the hydrotherapy pool; the warm water is a great environment to gain confidence in movement.

Between 2 and 6 months post-surgery most patients will complete up to four physiotherapy rehabilitation sessions. It is a group format, with two patients in the pool and two doing 1:1 exercise with the physiotherapist. The group sessions provide a great forum to discuss progress and advise about returning to school, activity levels, and participation in school PE and other sport. It is also a good opportunity for parents to chat, compare experiences, and reassure each other. Exercises are gradually progressed to include rotation and increase range of movement. The next stage is to work on balance and stability in their corrected posture and towards the end we are looking to improve fitness and stamina. Throughout the process we are checking posture and adding hints and tips for correction exercises – highlighting particularly tight areas such as the hip flexors being tighter on one side than on the other, which tends to cause trunk rotation and exacerbate rib prominence.

There are many facets to the recovery journey. We focus on three main areas to promote physical fitness:-

- Spine range of movement and

- stretching – moving the areas of spine that are not fused.
- Balance and stability in the new corrected posture.
- Regaining strength and cardiovascular fitness.

It is also a huge experience to process mentally and emotionally, and our group setting provides a forum to meet other patients who have had surgery and answer questions whilst also offering 1:1 advice and reassurance.

Patients return to clinic for formal review and X-ray at 6 months. As physiotherapists we lead these appointments on behalf of the consultants and are therefore able to check on individual progress. We focus on progress with return to school or work and activities. We can offer guidance on different activities and work through returning to sport with sports-specific advice. Many of our patients are still growing, and this can also affect their posture during the post-op years – this can usually be remedied with resumption of exercises and stretches to improve flexibility and accommodate skeletal growth. We are a regular port of call for parents and patients offering advice during their recovery and answering their questions – after the 6-month appointment patients are reviewed at 1, 2 and 3 years or until they have finished growing.

In the first year following surgery some patients wonder why they still find their normal day tiring, especially as they look well from the outside and feel like they should be doing better or more. It is always worth remembering how much work the bodies' systems are doing on the inside to strengthen the spinal fusion around the implants, heal the wounds, and recover from the anaesthetic and blood loss as well as the enforced rest period and lack of normal activity, reducing fitness levels. The best plan for a good

recovery is to pace it carefully. The trunk muscles fatigue quickly when working to hold the longer straighter spine. Take rest periods, lie down for short periods, if able, to rest those stretched spinal muscles so that they can recover regularly, ache less, and recharge for the next bout of activity that will ultimately help regain fitness. It is better to build strength and stability in the new posture for shorter periods with regular rests than it is to struggle on with an activity for too long and resort to a deteriorating posture to achieve it.

We always advise the patients to change position regularly, move often, and avoid prolonged postures – especially sitting for too long. This is great advice but hard to implement in the school / work setting so it helps to be able to discuss with a physiotherapist and work out the best way of achieving a steady recovery.

In the later stages, we encourage resumption of school PE, dance, and other sporting activities following the recommended guidelines for return to activity. For patients who were not sporty or active before their surgery we encourage simple exercise routines to maintain their comfort and flexibility.

Working with this group of patients is hugely rewarding, following patient's scoliosis journey, seeing them grow in confidence with relieved happy faces following the anxious pre surgery months gives great job satisfaction. I never lose enthusiasm for working on the little details that will make a difference and promote a healthy and active lifestyle into old age with a good knowledge of how to look after their back's and keep them moving comfortably.



STYLE & SCOLIOSIS

Our relationships with clothing and fashion can be complicated by scoliosis. We want to dress in a way that expresses our style and personality, but you're not alone if you've been frustrated by an item of clothing not sitting like it does on other people. This article features three women who have a real passion for fashion and are embracing their scoliosis and scars and are wearing whatever makes them feel happy and empowered.



Summer Gibson
[@summeregibson](#)

I have always loved fashion, from my crazy outfit pairings of leopard print leggings and bright red Doc Martin boots as a toddler (I still kind of love my younger self's bold fashion choices) to starting my styling blog on Instagram, inspired by the community on the social media app, especially the women of my hometown Brighton who share their unique style around the vibrant city.

When I was 15, I was diagnosed with an S-shaped scoliosis curve. For many people diagnosed with scoliosis, it is not only the physical impact of the condition that is difficult, but also the effect it has on body image. I try not to let scoliosis dictate my style - yes, some items might fit differently, but it's about making the clothes work for you -

both in terms of comfort and style. As time has gone on the support from my Instagram community means I've let go of the insecurities of not wearing something 'because of my back' - my favourite outfit from last year was my backless jumpsuit!

The world of social media can have both negative and positive effects on body image, so it's important to think about how to use these platforms as a positive tool wherever possible. I always recommend strongly thinking about the people who you follow on apps such as Instagram carefully. Curate your feed by following those creators and brands that inspire you, uplift you and help to put you in a positive mindset.



For me, creating different outfit styles and sharing with my Instagram community has become a brilliant creative outlet and a huge part of my work life too. I love thinking about new ways to style staple pieces in my wardrobe, and it's also given me the opportunity to connect with like-minded people and share my own experiences. There is space for everyone to share their own style story online - and you never know who that might help, many people will have shared similar experiences.

Here's to breaking down the barrier between what we think we should wear and what we want to wear, and on our own terms.



Beth Machin
[@bethpageants](#)

My name is Beth and I'm an 18-year-old pageant girl from Nottingham. In 2018 I was diagnosed with Scheuermann's disease. Once my kyphosis progressed to 94 degrees and my lumbar scoliosis was 25 degrees, my breathing became limited, and the pain was unbearable. I had surgery in 2020 to fuse my spine T3 to L4. My kyphosis embarrassed me when I was 15; I tried to hide it as much as possible by wearing hoodies, thicker clothes and coats, but as it worsened, it became impossible.

I never wore flimsy materials or anything that exposed my back. People would tell me to "stand up straight" and "stop slouching" but I couldn't - my body wouldn't let me. When competing in pageantry I accessorised with flowy capes and dresses with a full back, and I always wore my hair down to disguise my back. I wanted to disguise the fact that I had these conditions, but the effort was in vain though because after 6 hours on stage my body was so tired and sore that I could hardly walk.

I now embrace my scar when I compete. I choose outfits with open

backs that show my scar. There are usually four outfit changes during competitions, and I choose each very carefully because my fusion limits my ability to wriggle in and out of outfits as quickly as my competitors. I avoid clothes with buttons and lace up or corset backs as I can't fasten them on my own. I love wearing my hair up now as I want the judges and the audience to see my scar. I also choose a neutral-coloured shoe that I can wear in all the competition rounds because fastening shoe straps is very tricky and can be time consuming when you aren't able to bend.





Katherine Messider
@spinalfusionfashion

My relationship with fashion and clothing is and has always been a very positive one. My scoliosis was first noticed by my nan on a shopping trip when I tried on a spaghetti strapped top and she noticed my uneven shoulders. After my spinal fusion at Royal National Orthopaedic Hospital in Stanmore in 2012 I grew in confidence thanks to my new favourite accessory, my scar. I love to show it off and even began to wear more backless tops and dresses to really accentuate it. I truly love my scar as I think it's beautiful and shows how far I've come in the last decade.

I have such a love for fashion that I even have a BA honours degree in fashion design (which I completed in 2020 during the pandemic). Even during my degree I found ways to incorporate scoliosis and created two dresses which showed the fragility and control which scoliosis can have over someone. Since having my graduation ceremony in

2021 (where my low backed dress allowed my scar to peek out of the top of my graduation gown) I then started what has to be the dream job for me, working as a junior cutter and studio assistant for bridal company Suzanne Neville.

At Suzanne Neville everything is made to order so garments can be made to measure, meaning that there are no shapes or sizes that they can't create. When it comes to brides with scoliosis Suzanne and the team of pattern cutters know exactly what to do and so they create a bodice that is asymmetric but when worn by the person with scoliosis it looks symmetrical, I like to think of it as their own unique from of symmetry as every scoliosis or kyphosis dress is different as no two curvatures are the same.

My tips and tricks to navigating outfits with scoliosis; first off, try not to limit yourself, I know it's not always easy for everyone, but clothing and fashion is an amazing way to express your style and explore your own identity. Sometimes though, there are things that just don't fit right, so there are a few things I look



for on certain garments such as adjustable shoulder straps, so you can then have them at different lengths. Frills are also great at distracting the focus point or even in the case of peplum tops, they can even out the overall appearance of the spine. I also highly recommend finding independent fashion/clothing brands who hand make clothes made to order because some can make them to your specific measurements, on request. Always remember that fashion and clothing can be fun, so be brave!

BACK ON THE COURT

Samuel Pullen-Merriman is back to playing tennis after 2-stage spinal surgery over 2 years ago to correct his scoliosis. It has been a long road back, but he hit a major milestone when he competed in the local tennis club's final for the men's doubles last year.

I have played tennis since I was about 3 years old and played at a high level my whole life. I would get a lot of injuries in my lower back though, I'd go to physios, and they'd diagnose me with different back issues, but it got to be a real problem. Eventually, Mum saw that my back was a bit uneven, and we thought it was time to take this to a doctor.

The X-ray on that showed that I had quite severe scoliosis. I was about 17 at the time and I remember seeing the X-ray and almost passing out. I had two curves, one at the top and one at the bottom. I was so shocked at what I was seeing. The two curves had evened me out, but the X-rays showed how serious it was. My top curve was about 45 degrees, and the bottom was about 50. They knew straightaway that surgery would be necessary. We thought at first it would just be on the bottom one but the top one continued growing, so I had both corrected. It's not the diagnosis anyone wants to hear but there's something satisfying about getting an answer as to why I was in pain.

The consultant warned that fusion might affect how I played tennis because my flexibility would be limited. I was a bit worried about the risks around surgery so I wasn't sure if I should go ahead or put it off. It was a hard thing to accept at first. It was a tough year; a lot had happened, and I'd had loads of visits and X-rays, it was overwhelming. In the end I decided that earlier was better and that I wanted to get it over

and done with while I was young and would bounce back quickly. As it got closer to the date of my surgery it all sunk in a bit more, but I remember for a while just thinking 'surely this couldn't be happening to me, I'm an athlete, I'm healthy, I'd read that it was more common in girls, so why was this happening to me?'

The first 3 months after the surgery I wasn't allowed to pick up hardly anything at all. After 8 or 9 months I was getting back to some sports. I had lost strength in my whole body, having spent most of my time lying down. When I got back to the tennis court, I was really terrified that something was going to go wrong, and I didn't attempt to make big movements. I think that was more of a confidence thing. This spilled over to everyday life too, I was nervous about getting jostled around in a crowd, I'm very protective in those situations even now. I am experiencing hip pain after the surgery, but my back is feeling good as new, I can run without even thinking about it. It feels like a long time coming but it feels amazing to see how far I've come.

I stopped playing tennis as much when the injuries started to slow me down, and there was also a bit of a loss of interest and motivation. I rediscovered my love for the sport after the surgery. When you're away from it and physically can't do anything but sit there, you start to crave it more.

If anyone else is in my position, especially if your scoliosis is giving

you pain and back issues like me, you really may as well have the surgery if it's offered to you. Since I've recovered from the operation, I've not had any issues. There's also the baggage of it, if you leave it for a long time, it just hangs over you. It used to be always on my mind and now it's not something that I have to think of very often.



REBECCA WEIL

Rebecca Weil is a member of the British Scoliosis Research Foundation (BSRF) Grants Committee. The BSRF is SAUK's sister charity and exists to stimulate and finance high quality research into scoliosis.

Rebecca brings to the Grants Committee over 20 years of international experience in strategy and operations in the healthcare industry, and her lived experience of scoliosis.

She grew up in Boston, where, when she was 13, she was sent for routine scoliosis screening before gym class. She was told in the screening that her hips were uneven and that that was a sign of scoliosis, so to go see a scoliosis specialist. She was soon diagnosed with an S-shaped curve, as well as kyphosis and lordosis. On how she felt at the time of diagnosis, Rebecca says:

It made me very anxious. I kept thinking "what does this mean? Do I need surgery? Do I need a brace? Will the other girls at school know if I have a brace?" This was in the 80s, so I had a lot of questions, but I didn't know of an organisation like SAUK to go to for answers.

It was a lonely journey. I didn't know anyone else who had scoliosis during this time. I was fortunate that the curves were classified as moderate. I was monitored throughout my adolescence and did physiotherapy. When I reached 17 and the curves were still moderate, the specialist felt I was stabilised, so I didn't need any further intervention. It was a huge relief that I didn't have to have a major surgery.

For the next several years, the scoliosis didn't affect me much, so it slipped to the back of my mind. That was the case until I moved to London in my 30s. I had a busy lifestyle, working in healthcare, commuting, travelling, and with that I started to get more back pain. I suspected it was related to the scoliosis and kyphosis but wasn't sure. I started physiotherapy again and from there was fortunate to discover yoga.

A friend of mine was a physician and a yoga teacher, and she did a one-on-one class with me, just basic stretches and breathing. She helped me so much and learning yoga helped not only with pain

management but also with body awareness. When was I stressing my body too much? When did I need to rest? When did I need activity and movement to help me feel better? I still got some pain, but I learnt to manage it for many years. I also discovered Pilates, my Pilates teacher actually has scoliosis herself and she was one of the first people I met who shared that experience and with whom I could talk to about it. She's taught me a huge amount and also opened my curiosity and made me more interested to learn about this condition I'd been living with for many years.

The pandemic was a turning point for me too. I finally had the time and inclination to do yoga teacher training. As part of that, we had an anatomy course and the teacher did a module on scoliosis where she

explained the condition, showed examples of X-rays and talked about how it would affect students in yoga classes and why a teacher should be aware of it. I thought it was so great they were doing this as part of the yoga teacher training, since yoga instructors I'd seen in the past often didn't have that sensitivity and understanding of scoliosis. I was interested to learn more, so my teacher gave me a couple of books to read and some videos to watch.

When I finished the training, I found a yoga teacher in London doing an online yoga for scoliosis programme. Once again, that teacher herself had scoliosis and there were maybe five or six of us in the programme, mostly around my age, 40s or 50s, and all experiencing some pain relating to our scoliosis. Some of the other women had had



surgery or intervention and others, like me, had not. It was wonderful to have this community all of a sudden and people to talk to, not only about the physical side of it, but also this fear or denial that we'd lived with for many years but didn't really think about or articulate. It was really a gift to have that group. Shortly thereafter I got a herniated disc and nerve compression in my cervical spine, an acute episode. I had an MRI, saw a specialist and when he started talking about potential surgery for my neck, I had a panic attack in the office, which I'd never had before. I calmed down and went home and thought about what I could do. When I need to solve a problem in my job, I talk to experts and I educate myself, so I took that philosophy into this part of my life. I read everything I could find from reputable resources online, and that's how I found SAUK. I was looking for other adults who had idiopathic scoliosis since they were teenagers to see how that was affecting their spines now. I had a physiotherapist to help me with the acute pain in my neck and I asked her lots of questions too. One of my best friends is a doctor and she encouraged me to go see a scoliosis specialist even though

the herniation may or may not have been related to that. So, I did and was very nervous about it. I went for my X-rays, which I realised I hadn't done since I was 17, but fortunately it turns out my curves hadn't progressed. I remember the larger part of the S-curve being just below 30 degrees and it was still there. It felt really good to have that answer and to talk to a specialist as an adult, although it also made me question why I hadn't taken that step before.

As all of this was happening, I was looking for more opportunities to do volunteer work for charities in the healthcare area, because that's what I feel really passionate about and that's where my professional experience is. I came across the BSRF and spoke to a few people who were part of that group and learnt about the Grants Committee, which assesses the research funding applications the BSRF receive. They asked if I was interested in joining that committee and I was really grateful to have this opportunity. I was so impressed by the people, their commitment and the very specialised knowledge they bring, be it medical or scientific. I was also impressed that they wanted to have the voice of the patient represented

in the grants committee. I also learnt about the Scoliosis Priority Setting Partnership that the BSRF initiated a few years ago, in which people with scoliosis helped to identify the issues and questions they would like answered by research. When I thought about which research questions were interesting to me, I thought "why did this happen to me? Why did I get this condition when my mum didn't have it?" When I was a teenager, I was concerned with what the treatment options were besides surgery but now I question how, throughout your life, can you manage this condition in the best way? I feel like I muddled my way through, mostly thanks to good luck and meeting some very helpful and supportive people. I think the people who do live with moderate scoliosis are in a difficult position too because whilst interventional treatment may not be necessary, we do often live with pain and other consequences, and we may feel like we need to figure out for ourselves how to cope with this.

I found it so inspiring that BSRF is tackling these important questions by funding academic research around them. It's only been a few months since I joined and started to review grants. I feel really privileged to be able to bring a lived experience voice into these discussions. I'm also learning a lot from these discussions with the experts on this committee and truly believe that the more you can learn about the condition you're living with, the more empowering it is.

SAUK Fundraiser of the Year

Holly Rock

Holly Rock is fundraising for SAUK by taking on the 100 Mile Hike, South Downs Way challenge. Holly has done a fantastic job of fundraising and as of the 3rd of May has raised over £1,300. As part of Holly's JustGiving online fundraising page she has shared details about her scoliosis journey.

'I think it's important that people know what I went through and not to sugar coat the pain and the general day to day struggles. I have had so many people reach out to me saying that they can't believe the journey I went on and am still going through. The support I've had has been so overwhelming, it's amazing how generous people have been.'

SAUK is very grateful for Holly's fundraising efforts but we commend her in particular for the way that she is speaking up about scoliosis within her community. The following is Holly's account of her scoliosis journey, 4 years post-fusion.



My story from the beginning (age 13)

Two people very close to my mum approached her within the same week saying that my hips were wonky. They said you could see this in how I walked and that my mum should get me seen by the doctors. My mum then phoned the doctors straight away to get me an emergency appointment.

That following Monday I had an appointment at my local doctor's surgery and was told to do some stretches and poses to assess what may be wrong. At first the doctors weren't sure what exactly was

wrong; however, they could clearly see my spine wasn't straight. They got my mum to run her hand down my spine and she then knew there was a problem, something she had never noticed before. Within no time I was then referred to St. Heliers Hospital in Epsom. I was then looked after by an orthopaedic surgeon who advised me what would happen next. At this time, my curvature was at 37 degrees.

The back brace (age 14)

They started with the non-surgical route, which I was glad of because the thought of surgery absolutely petrified me, and I would have done anything to avoid it. I was measured for the brace and the measurements were then sent off to America for the brace to be made, which took roughly 4 weeks. When it arrived back in the UK, I had to go back to the hospital for it to then be cut into my physical body shape. The back brace was an off-white colour and had a hard plastic coating with three fabric straps at the back, like a corset, to pull you in super tight. This is definitely one of the saddest memories of my journey to this day. I had to wear the brace for 23 hours a day and was only allowed to take it off to wash

and do sports at school. Wearing the brace at school was hard since I was the only student with scoliosis and as you can imagine people weren't all that nice. It was so uncomfortable at first, especially at night, I used to cry my eyes out in pain, struggling to breathe and not being able to sleep and just not feeling comfortable, which is all completely normal but just not the normal for me. This was also very hard for my mum, she had to pull my straps tight and help me into the brace as I wasn't able to do this by myself. Mum brought me seamless vests for under my brace as it used to rub all the time and make my skin very sensitive. I knew in the long run that as long as I kept wearing it, it would make things better. I had regular check-ups and was just told to keep wearing the brace until they thought it was safe to be able to stop wearing it.

I was reviewed a few years later to see if my spine had stayed the same and not curved anymore, I believe I had just turned 17 at this point. I was told that I no longer needed to wear the brace as my spine had fused together and I won't grow anymore. I had an X-ray which showed the brace had brought my spine from 37 degrees to 23 degrees.

I couldn't believe it, all that time and heartache with the brace had paid off. The brace had become a part of me at that point. Mum was over the moon that all that time wearing the brace had really made a difference. So, if you're reading this and you're currently wearing a brace, please wear it as much as you can.

Discharged too early (age 20)

Unfortunately for me, a few years on I started having really bad knots in my shoulders. At first I thought maybe it was just stress from work and general life things; however mum pushed me to get checked by the doctors considering the journey I had already been on with my spine. They instantly referred me straight to a physio, which I did for a few weeks in my local town before they then referred me back to the hospital. I felt like it was happening all over again, and I was re-living my 13 year old self.

I was then referred to the William Harvey Hospital in Ashford and I was assigned as a patient to a surgeon. I attended the appointment alone as my mum was away and we just really hoped for the best and didn't think anything major was going to

happen. At the appointment the surgeon clarified that my spine had moved but he wanted to give it a year to monitor how it was progressing. This was hard to hear, especially now that needed to see what the next year would hold.

Over that year I didn't have any other problems other than the knots so I was praying that all would be okay, and an operation wouldn't be needed. I had never had an operation before but the thought of having such major surgery frightened me.

One year on (age 22)

I had many X-rays, MRI's, and examinations over that year and was eventually told that my spine had gone over the 45 degree mark, which meant I would be having the operation. This all came as a horrible shock to me and mum because I had worked so hard to wear the brace consistently and had been told just years earlier that I was in the clear and my spine had fused. You of course have the choice to have surgery or not but with how much my spine had moved, I knew there was a high probability that by the time I was 40 I would be really

struggling with this condition and my mobility might be affected. Even though I had a choice, I felt like I didn't. I was just so scared of all the possibilities and the problems I could now face. I almost started to feel angry at myself that I didn't just have it done at age 14. Part of me didn't want the operation because I should have never of been let go by the previous hospital and I was scared something would go wrong but after much discussion, I booked in for the operation.

There was a waiting list, I believe around 6 months, so in my mind this was my last 6 months of freedom before everything would come crashing down. I was petrified and thinking the worst. I have really bad anxiety, and for those who understand what anxiety is like, it sent mine through the roof. In the back of my mind, I knew this operation was for the best but I just didn't want to believe it was actually happening.

Date confirmed - Tuesday 8th May 2018, Guys Hospital London

After sleepless nights and pre-op assessments, the day had arrived. Me and mum stayed the night before in the hospital, not that we slept. I was the first patient for the morning. My surgeon came up to the ward to get me and wheeled me down to what I call the fridge. Correct term would be pre-op area. Since I had never been put to sleep before, I didn't really know what to expect but I just remember it being so light, with bright white walls and lots of doctors and nurses in this small room. I was lucky enough to have my mum in there with me, I think because I wouldn't stop crying, mums are the best to have by your side. The doctors and nurses showed me there was





nothing to worry about and were so friendly, just chatting away to me, I didn't even feel the needle going into my arm. My body was clearly having none of it though, the dosage they had given me only made me super drowsy as I was trying to subconsciously fight off the drugs, so in the end they had to put a gas mask on me to get me to sleep. I was then in surgery for roughly 4 hours.

Post-surgery

When I woke up all I remember feeling was just tired and nothing else. I was on so many drugs I didn't feel any pain. After being wheeled back to the ward, mum was waiting for me, but I can't really remember the rest of that day, it was such a blur. The next morning my surgeon came round and got me out of bed, I managed to take two steps and that was enough. The pain was excruciating, I think some of the hard drugs had worn off, I had massive padded sticky pads covering my spine as I could only lie on my back. I had a morphine button which I clicked every 5 minutes, so that relieved the pain a little. I couldn't do anything by

myself, I had to be bed bathed, and if I needed the toilet a nurse had to help me get out of bed, which could take me 10 minutes just to sit up. I couldn't lift anything other than my water bottle. I knew things were going to be tough, but I guess you forget that you use your back for everything and any slight movement cause different pains. I was lucky to have my own room in the hospital and was looked after day and night by the lovely staff at Guys Hospital. Nobody was allowed to stay over with me so once visiting hours were over, I felt like I was on my own. I didn't really sleep and when I couldn't I would call my grandad and he would just try and calm me down and put me at ease. I was in hospital for a total of 5 days. I was so determined to get out, like most people I'm not really a fan of hospitals. My surgeon checked on me every day (at 7am to be precise) and got me out of bed each time because he wanted to monitor my progress. I will always remember a nurse coming round in the morning to inject something in my tummy, which felt horrible. I guess the horrible parts always stay with you. I had physiotherapists who would also come and visit me once or twice a day which I loved -



they were amazing and just made the days go more quickly. They would monitor me walking (very slowly) to the toilet and back, which to do that walk now would take me about 5 seconds but at the time felt like a lifetime. They also helped me practice walking up and down steps again. Before they were happy with me leaving, I had to be able to walk to the toilet and back by myself and to the end of the ward and back. Nothing was stopping me from achieving this.

Once the 5 days were up and my surgeon was happy, I was discharged from hospital and was allowed to go home. I was prescribed some medications which mum kept a diary of as there were so many. I believe I took around 22 tablets per day. Mum took 3 months off work and she cared for me 24 hours a day. Big thank you to my mum who was my lifesaver. Then it was onto the long road of recovery, even now I feel like I'm still recovering, but I am forever grateful for my surgeon and the whole team at Guys Hospital who couldn't have looked after me any better. I am so glad I had the operation and hopefully I am able to inspire others to not be afraid. It really has made me who I am today.

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 their families for years to come. We are a small organisation who relies solely on the generosity of our supporters. Thanks to that generosity, we have been able to provide support, information and advice, and bring awareness to scoliosis for over 40 years. With your support, we will continue to do so for many more years to come. 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 on 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.





ISAD

International Scoliosis Awareness Day
Saturday, 25th June, 2022



#BACKINGSCOLIOSIS

