

Issue 108 | Winter 2023

# BACKBONE



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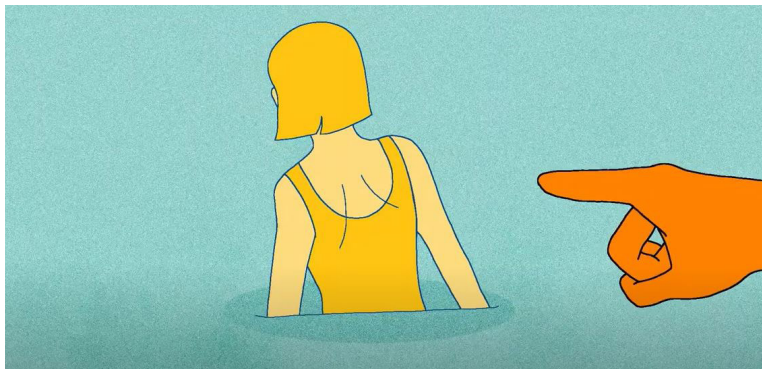
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A Scoliosis Journey by SAUK | YouTube

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# LATEST NEWS

## Ailie Harrison Art Competition

Thank you to everyone who submitted their artwork to the 2023 Ailie Harrison Art Competition. It was beautiful to see the ways you express yourselves through art. Congratulations to Beth Nettleship who took first prize with the very creative take on the task, photographing herself wearing the crochet scarf she made herself that features her spine in the pattern. Beth's photo can be found on the front cover.

"After noticing my right shoulder blade stuck out further than my left, I was diagnosed with a triple thoracic and lumbar scoliosis at the age of 12. With support from my wonderful consultant and orthotic nurse, I wore a Boston brace for 3 years, a daunting prospect at the time of just starting high school and trying to make new friends.

My mum found SAUK first and benefitted from online forums, talking to other parents and local information meetings run by SAUK. For me, having known nothing about scoliosis, learning that others were going through similar experiences and reading about their journeys really helped me embrace my scoliosis and wearing a brace, even encouraging me to go all out in getting my final brace in bright blue camo print. I felt more confident, and I wasn't nervous of people knowing about my condition. The brace helped to hold my curves just below the threshold required for surgery.

Now 21, and studying art, I do live with daily back pain but do not let this stop me doing what I enjoy. This summer I taught myself to crochet so I could 'wear and share' my condition in a fun way, because you never know if there is a scoliosis warrior standing beside you. Spreading awareness is so important, as just one photo or story can help someone view their condition in a new light. "

Congratulations to Lucie Williams who took second prize. Her artwork can be found on the back cover. Lucie was actually inspired by the stories her mum Corrina tells her about being diagnosed with scoliosis as a teen.

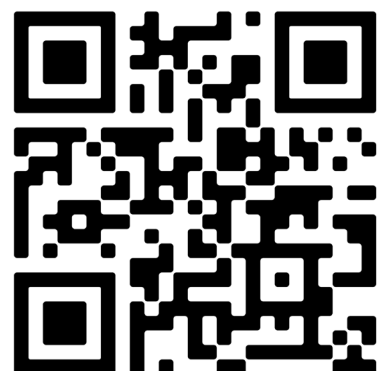
"I am very honoured to have come 2nd place in the Ailie Harrison Art Competition 2023. I decided to enter because my mum has scoliosis (having been diagnosed as a teenager) and I wanted more people to be aware of this condition. I was proud to be able to raise awareness of scoliosis through my artwork, which I love doing."

We also wanted to acknowledge and thank our other finalists; their artworks can be found on page 26-27.

## Set up an online fundraising page with JustGiving

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

Creating a fundraising page via our charity page on JustGiving is easy. Scan the QR code and click 'fundraise for us' to get started.



## Online support groups

There is much more to scoliosis than just what an X-ray says about the shape of your spine. Scoliosis and all the related issues it can bring can be overwhelming and isolating for a lot of people. We want to facilitate more discussions about the relations between our physical and mental health.

Over the past few months, we have started hosting small online support group sessions mediated by experienced counselling therapist, Toni Goodall, from Coastal Counselling. In each session there are up to 7 people who meet for an hour and a half over Zoom. Each group is for different age ranges so that you can feel comfortable speaking up and so you will be with people who are facing similar issues.

The goal of the group is to initiate a sense of belonging or relatability by hearing the experiences of your peers. The session being mediated by an experienced counselling therapist will help to expedite the conversation. Our hope is that people find it a cathartic, rewarding experience.

At the time of writing this we have run sessions for every age group from 13 – 65+, as well as a group for parents, and are starting the cycle again. We have given our members first access and these sessions have been so popular that the spots have been taken quickly for each session. We let our members know about upcoming sessions via email so if you're interested in taking part, please keep an eye out for emails about sessions for your age group and reply as soon as possible to put your name down. We will continue to run these groups regularly so please be patient because we will get to your age group. If the group has already been filled when you email us, you will be placed on a waitlist and will be the first to be told when an opportunity to join a group arises.

We hope you will consider joining a session when given the opportunity.

"I can't put into words how thankful I am for you hosting such an amazing support session. It was so eye opening and really warming to know that I am not the only one dealing with, and have dealt with, feelings of isolation and everything else that comes with it. I feel like I needed that session more than I actually knew." - anonymous online support group attendee.

## Vicky's scoliosis journey animation

On International Scoliosis Awareness Day, we posted a special video to our website and social media pages featuring the animated version of Vicky's scoliosis journey. You can watch the video on our the [sauk.org.uk](http://sauk.org.uk) home page or by scanning the QR code on this page. The video was created by freelance animator Olivia Wu.

Vicky Wong's story may be a familiar one to a lot of people with scoliosis, one of a chance diagnosis that led to a life altering series of events. After her fusion surgery, Vicky learnt that even though she had had this corrective surgery, scoliosis was always going to be a part of her. She would carry this experience with her forever, but the weight of this burden eased when she began forming connections with other people with scoliosis. Knowing how much she could have benefitted from knowing someone with scoliosis earlier, Vicky wants to be that person for others now. She has shared her story with us and talks about her journey within her communities, so that it might reach someone who finds themselves in her shoes.

The power to create positive public awareness of scoliosis is inside every scoliosis warrior. Scoliosis is not rare, 3 to 4 children per 1000 need specialist supervision, but it's not a condition that's front of mind until it impacts your life. You can be the one to spread awareness and education in your communities by speaking up about scoliosis. Doing so many even lead to someone receiving a diagnosis sooner or realising that they're not alone in this. Never underestimate the difference you can make.



## Scoliosis Awareness Month

Scoliosis Awareness Month took place throughout June once again. It's our favourite time of the year because we get to see how much love and support this community has to offer. This year we got to see this in person with the patient event we held in London on the last Saturday of the month. It was a really lovely day for people affected by scoliosis to learn something new about managing scoliosis and feel empowered by being in a room full of other scoliosis warriors. Thank you to all our speakers, Fady Sedra, Rachel Hunt, John Rutherford, Andrew Mills, Katie Peduto, Caroline Freedman, Christine Jaureguiberry, Emily Hale, and also Charlotte Champian, who performed her music for us. We do intend to host more events like this in other areas in the country so please watch for further announcements.

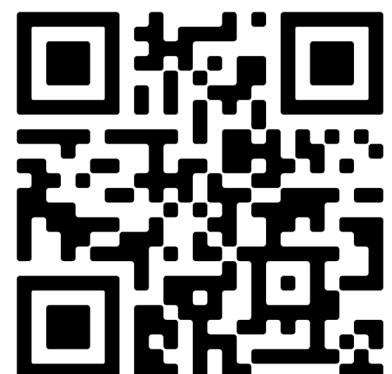


## Hill, Pedder, & Minns Fund

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

Who can apply?

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



# Leaving a gift in your will

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

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

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

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

A gift left in your will can help us maintain, expand, and develop our range of support services. Nobody should have to face the pressures of scoliosis without support. Leaving a gift in your will ensures that nobody has to.

## Should I use a solicitor?

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

## Will I pay tax on my gift?

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

## What type of gift can I leave?

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

## What is an Executor?

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

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

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



# Bracing Adolescent Idiopathic Scoliosis -The BASIS Study

A £2.5m research study is now open in the UK, looking at the effectiveness of a night-time brace in the treatment of adolescent idiopathic scoliosis. Led by Sheffield Children's Hospital, the Bracing Adolescent Idiopathic Scoliosis (BASIS) study is currently accepting patients from 22 NHS Trusts across the UK.

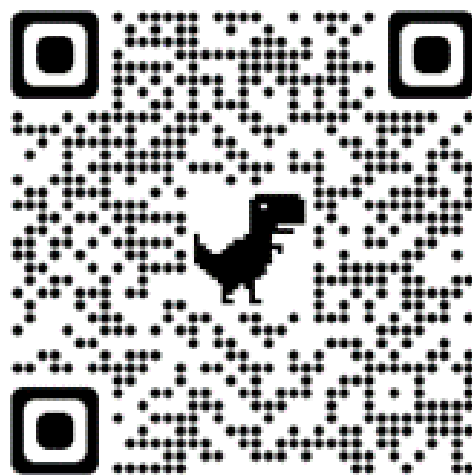
The "full-time" brace is the current back brace offered within the NHS, and this is usually prescribed to be worn for 20 hours a day. Although in many patients, it stops the curve reaching a size where surgery would be considered, the brace needs to be worn until growth has finished which is usually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

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

At the moment, there are 190 patients\* (correct as of 30th August 2023) taking part in BASIS, and roughly half are receiving full time brace treatment, with the other half receiving the night time brace. The study is aiming to involve 780 patients over the next 3 years, and all patients taking part will be followed up in the study until 2 years after they stop brace treatment.

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

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



## Follow us!

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

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



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



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# HYPER-CORRECTIVE SCOLIOSIS BRACES

Andrew J Mills Dip OTC, MBAPO, MISPO

Over the years braces have used several different principles with the aim of stabilising or correcting scoliotic curves, some with greater success than others. Whilst experts around the world have yet to agree on the best combination of principles there is consensus agreement on some. In 2019 the International Society on Scoliosis Orthopaedic and Rehabilitation Treatment (SOSORT) published the first consensus paper, The Classification of Scoliosis Braces. This paper was developed by SOSORT and endorsed by the Scoliosis Research Society (SRS), the International Society of Prosthetists & Orthotists (ISPO), and Paediatric Orthopaedic Society of North America (POSNA).

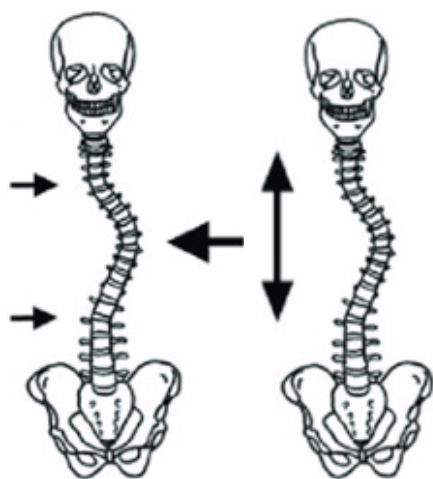
The earliest braces used simple and intuitive principles, stretching to elongate the body/spine and three-point pressure application, pressing on the apex of the curve whilst stabilising each end to straighten the body/spine.

The simple logic being that if the

body posture, distorted by the spinal curvature, were to be straightened, then the spine within should also be straightened. To an extent this strategy has some positive effect, particularly on small, flexible, single, curves with limited rotation (twisting of the spine). These early bracing principles were flawed in their simplicity, tending to treat mainly just one dimension.

With greater understanding of the true three-dimensional nature of scoliosis, more elaborate multiple three-point pressure systems were built into braces to address twisting of the body/spine associated with scoliosis and to some degree abnormal changes in lumbar lordosis and thoracic kyphosis. The overarching principle, however, remained to correct the body posture to a neutral balanced position within the brace. Milwaukee braces and the original Boston Brace used these principles, and are still used today in a high proportion of braces.

Experts within SOSORT continue to work on further defining bracing terminology. However, currently there is no agreed definition of the term hyper-corrective. Nevertheless, it is commonly used to describe braces that provide postural over-correction, a distinctly different principle to the postural symmetry sort by earlier braces. Hyper-correction is also frequently used to describe higher levels of in-brace correction achieved using postural over-correction braces. It is fair to say that most braces described as hyper-corrective are also mainly based on the principle of postural over-correction but not exclusively so. Braces aiming for postural symmetry generally average no more than 30 - 40% in-brace correction, whereas postural over-correction braces tend to average 50 - 60%, with the very latest Corrective Movement Principle braces averaging up to 70%. Higher levels of in-brace correction may offer potentially better outcomes; however, this very much depends on a child's remaining growth potential and their compliance with wearing the brace. In-brace correction is both a measure of brace effect and curve flexibility at the same time. For this reason, the same brace could potentially produce different levels of correction in curves of the same size. Whilst a high percentage of correction is a very positive sign, it is not an absolute guarantee of treatment success. On the flip side of this studies have shown in-brace correction of less than 30% to



3-point pressure Spine elongation



Boston brace



Milwaukee brace

correlate with poor outcomes. Out of brace correction after 6 months of brace treatment is now regarded as the most significant predictor of a successful outcome, since this considers the effect of the brace over a period of growth and compliance.

Recent studies have shown a strong correlation between out of brace correction and positive treatment outcomes.

### Corrective Movement Principle

The principle of treating scoliosis through postural rehabilitation is nothing new, and began in Germany during the early 1920's.

Katharina Schroth, born 1894, who had scoliosis, developed a form of treatment with specific postural correction, correction of breathing patterns, and correction of postural perception.

Her rehabilitation method tried to "mirror" the curvature, by overcorrecting with the use of curve pattern specific corrective movements.

A similar concept of postural over-correction was used as early as 1907 by Dr E G Abbott of Portland, Maine, USA. Dr Abbott used plaster jackets to flex and de-rotate the spine in scoliosis patients with some success.

The Chêneau brace, developed by Dr Jacques Chêneau, initially derived his concept from the Abbott technique but later from studying the more detailed three-dimensional German technique of Schroth.

In 1979 Dr Chêneau developed the first Chêneau orthosis, using bracing concepts wholly compatible with Schroth corrective exercises.

Notable features of Chêneau concept braces were voids/windows positioned at the spinal

concavities and corrective pressure points focused on curve apices



Chêneau brace

according to Schroth's curve-pattern classifications.

All scoliosis braces bearing the name "Chêneau" as part or all their designation, share a common history, originating with the Chêneau Toulouse Munster brace, developed by Dr Jacques Chêneau and Professor Matthias of Munster. Since then, several variations of this brace have evolved to enhance correction of scoliosis in three dimensions.

Design features based on the Rigo classification of scoliosis and further modifications by the co-author led to the Rigo Chêneau type brace. More specific curve classification was another significant step forward in refining conservative brace treatment. This was a highly significant step since curve classification informs brace design. Better definition and understanding of curves, their progression potential, and pattern can greatly improve outcomes.

In 1990 Professor Charles Hilaire Rivard MD; head of orthopaedic surgery at Ste Justine Hospital, Montreal, Canada, first conceived the idea of developing dynamic, rather than static, treatments for children with scoliosis.

Prof Rivard's initial team of experts

included Dr Hubert Labelle, Mr Jean Dansereau, Mr Jacques Deguise, Mr Paul Allard, Dr François Fassier, Dr Constantin Stanciu, Dr Guy Grimard, Ms Nancy Mayo, and most notably Dr Christine Coillard. Early in 1993 researchers produced the first 3-D Full Spine X-ray Images. These 3-D X-ray images combined with images taken from 3-D video motion analysis enabled researchers for the first time to build a clear picture of each patient's internal (spinal) and external (postural) scoliosis.

This was a massive leap forwards in the understanding of idiopathic scoliosis leading to the development of a brace specific curve classification based on both postural as well as radiological features. This intern led Dr Coillard to define the Corrective Movement Principle used today. Using postural over-correction, although more nuanced and scientifically based, led to corrective movement strategies remarkably similar to those defined by Schroth. The SpineCor brace developed using this principle was to become the first dynamic, fully flexible brace, for treatment of mild to moderate idiopathic scoliosis. Following several years of clinical trials, the SpineCor brace was released to the world and rapidly adopted as the treatment of patient choice in over 30 countries.

Despite inappropriate use by some, causing some negative publications, SpineCor remains a highly popular and effective brace in the hands of appropriately trained professionals. My positive experience using SpineCor treatment at the Sheffield Children's Hospital also positively influenced future rigid brace designs.

Dr Coillard's brace specific curve

classification in addition to Corrective Movement Principles



Corrective movement

SpineCor brace

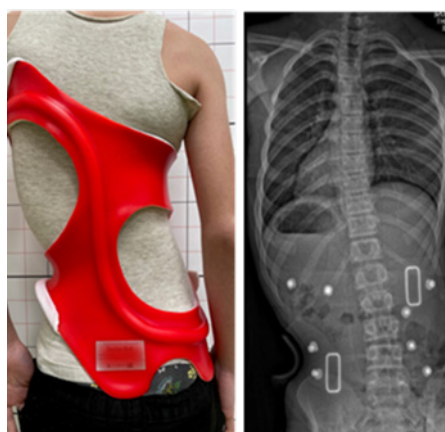
proved invaluable in improving the efficacy of rigid brace designs well beyond that achieved with early Chêneau braces.

Furthermore, understanding the significant advantages of dynamic treatment led to further evolution of rigid brace designs. Minimal contact areas and large windows in place of void areas built into current designs allow a greater degree of active movement both within and beyond the brace. Not only does this allow a greater degree of corrective movement increasing in-brace correction, the addition of active as well as passive correction also increases efficiency of vertebral growth modulation.

Braces may modulate remaining spinal growth by changing loading on individual vertebrae to prevent further progression or achieve a degree of curve regression.

Clinical results for patients treated using these latest brace designs have demonstrated not only increased in-brace correction but also some degree of out of brace correction in a high proportion of patients. Long-term data is needed to determine the percentage of patients achieving permanent correction and by how much, but early results are very promising for the numbers to be significant.

The US landmark randomised controlled trial (RCT) BrAIST published in 2013 concluded that bracing significantly decreased the progression of high-risk curves to the threshold ( $\geq 50^\circ$ ) for surgery in patients with adolescent idiopathic scoliosis (AIS). This was the first RCT providing high quality, level 1 evidence, that bracing reduces surgical rates. The study was stopped early when 72% of the non-braced control arm progressed to the surgical threshold whereas only 48% progressed in the control arm. This publication changed the view of many surgeons around the world previously skeptical about the value of brace treatment. Although good, the bracing outcomes in this study were far from optimum. The BrAIST study included many sites using less efficient, older, Boston style braces. A recent audit at the Sheffield Children's Hospital treating a matched cohort of AIS patients using postural-over correction, hypercorrective corrective movement principle bracing, demonstrated a 91% treatment success rate with just 9% progressing to the surgical threshold.



CMP brace

X-ray in brace



X-ray pre-brace X-ray post-brace

### Corrective Movement Principle Brace Treatment

The exceptional levels of curve correction found in the Sheffield audit are rare, but, possible in right circumstances. As always, early detection and treatment are key to treatment success; however, quality of brace treatment is also a major factor. Whilst complete curve correction is likely to remain a rarity, partial correction has been demonstrated in 58% of cases treated to date.

Ultimately the ability of the latest brace designs to provide a degree of true curve correction may change future indications for bracing. There is now growing evidence to support the use of brace treatment for curves greater than  $40^\circ$  in selected patients. The precise criteria for bracing larger curves remain to be established. However, early results show great promise.

I would like to acknowledge Prof Charles Hilaire Rivard, a colleague and friend who sadly passed away earlier this year. Over the 25 years I knew and worked with Charles, he taught me so much and inspired me to dedicate my career exclusively to the advancement of conservative scoliosis treatment.

# SPINAL BRACING ADVICE FOR SCHOOLS

As part of the NIHR funded BASIS study evaluating night-time and full-time bracing in AIS, researchers from the University of Liverpool interviewed patients to explore their experiences of bracing and the BASIS study. It was clear that patients wearing a full-time brace were struggling at school. The BASIS Study Team and the British Scoliosis Society have put together a leaflet to give advice to schools and hopefully improve the brace wearers quality of life.

If you're the parent of a child in a spinal brace or they are due to start wearing one soon, take the following information to their school and have a discussion about what can be done to make wearing the brace at school easier.

We are asking you to support your student who needs to wear a spinal brace to prevent their spinal curve (scoliosis) getting worse and avoid the need for surgery. A meeting with your student and their parent(s) would be helpful. They need to wear the brace for 20 hours each day until they finish growing and there will need to be regular hospital visits to adjust the brace and monitor the curve with X-rays. This is a big commitment for them and their family.

Please try to reduce any anxiety the student may have wearing a spinal brace and potentially feeling different from the other students. Have an open discussion about whether the student wants others in their class to know about their brace. Some younger children may need help taking the brace off and putting it back on. This is an easy process and the parent can demonstrate it to staff members.

## Taking the brace on and off

- It takes time.
- Your student will know how to take the brace off and put it back on but may need some help.
- They will need somewhere to lie down to put the brace back

on.

- They may need help fastening the Velcro straps if these are at the back of the brace. The straps will be marked with a line to indicate how tight they need to be.

## PE

- A 10 minute 'early pass' before and after PE if needed to take the brace off and put it back on again.
- The brace CAN be taken off for PE (store it somewhere safe), but some may want to keep it on depending on the activity.
- Some young people with scoliosis experience pain which may limit activity.

## Toilet

- The brace may need to be removed before going to the toilet depending on the design – please check with your student.

## Lessons

- Backless stools can be very uncomfortable to sit on when wearing a spinal brace.
- A short time to get up and stretch during a lesson may help but this should be balanced against drawing attention to

the brace.

- Carrying heavy bags whilst wearing a brace can be uncomfortable. If possible, storage may be helpful.
- Braces can move during normal wear and may need to be adjusted. Students may need to readjust the brace during school time. Please discuss this with your student to agree a way of managing this e.g., a student 'pass'.

## Clothing

- Braces are usually worn under clothing so new, 'bigger' sizes are required. This can be expensive so flexibility may be needed.

Please discuss these things with your student as this is always a balance between drawing attention to their brace and making their lives easier. All relevant staff should be aware the student needs to wear a spinal brace.



British Scoliosis Society

# SCOLIOSIS AND CORRECTIVE MOVEMENT PRINCIPLE BRACING: A PARENT'S PERSPECTIVE

Rebecca Stevens

I will never forget the moment I saw the X-ray of my 14-year-old daughter's spine. I was in shock. I had taken her to the GP who had made the referral as a precaution. I had expected to be told that everything was OK - it was just a muscular issue and could be relieved with some physiotherapy. Instead, I was told that she may have to have a very serious operation to correct quite severe scoliosis.

I am writing this to share my experience and hope that it might help other parents faced with the same shock who are at the start of their scoliosis journey.

My daughter had a double curve. Her 'Cobb angle' (degree of curvature) was 48 degrees in the lumbar spine and more than 20 degrees in the thoracic spine. We were told that this was within the range they would ordinarily consider operating. Although I am now aware that there are many successful operations to correct scoliosis, I am also a firm believer that surgery should always be the last resort - especially, I felt, where the spine is concerned given the associated risks, however small they may be.

My daughter is completely devoted to swimming. She dreams of becoming an Olympic Swimmer and spends more than 16 hours a week in the pool and several more hours doing supplemental strength, power, and stretching exercises. She competes at a very

high standard and my instant thought was that all that would be lost to her because of scoliosis and if she had to have an operation that would almost certainly end any chance of her achieving her swimming goal. It felt like double heartbreak.

However, thankfully, the consultant spoke of trying bracing as an alternative to surgery. My daughter still had probably around 12-18 months of growing left and a brace could prevent her having to have surgery. This felt like a life-line and we decided that we wanted to grab it with both hands.

Within a matter of weeks, my daughter was measured and fitted with her brace. The process itself was very easy and we were helped by a fantastic orthotist who explained everything to us. I can't say that seeing your child in a brace is an easy experience, but we had spoken at length about it before and had decided that the brace would be like her best friend - it meant that she would probably not have to have surgery - no big scar or metal rods in her back, it meant that she could still swim and be active, and critically, it was only temporary, but hopefully the effects would be life-long.

The first few days-weeks of brace wearing were not easy for my daughter. It took some time to get used to putting it on and it felt uncomfortable. Thankfully she persevered with it though, because within a matter of weeks she

became used to it, the discomfort subsided, and it became part of her everyday routine.

My daughter has now been wearing her brace for over 12 months and has a few months left in it. She has attended regular appointments and had the brace altered as she has grown or if a part has become uncomfortable. She wears the brace for 18-20 hours a day and when she is out of the brace she is normally swimming - I think staying active out of the brace has really helped maintain her core strength which will be really important when she is out of brace permanently.

The journey we have had with bracing has had its ups and downs - there have been the odd occasion (happily only a few) when my daughter has been upset, feeling fed up and frustrated with having to wear the brace, but for the most-part it has been something that has just become part of her day and she has just got on with it.

We recently had an 'out of brace' scan, after leaving the brace off the night before to see how her spine reacted when the brace was removed. My daughter's Cobb angle had reduced from 48 degrees to 33 degrees. We are absolutely delighted about this because it means that she is well outside of the operation zone! She still has a few months left of wearing the brace since she is still growing, but I am so very grateful that the scoliosis was detected before she had stopped growing and that she

was given the opportunity to wear the Corrective Movement Principle brace as an alternative to surgery.

If I could offer any advice to other parents in similar situations it would be this\*:

1. Don't be afraid to ask questions of your consultant and orthotist; it helps to write a list before you go to your consultation and ask your child to do the same, so that you don't forget what you wanted to ask.

2. Talk to your child throughout the whole process - about how they are feeling/dealing with wearing the brace and how they are coping physically and mentally. Be positive and encouraging. I remind my daughter that this is such a small period of time compared with the advantage that wearing the brace will bring for the rest of her life - she only has this one window of opportunity, because when she has stopped growing, it will be too late, and this method of correction will not be available to her. It is such a gift!

3. Sometimes getting the exact fit is a process. If your child is feeling particularly uncomfortable in the brace, don't be scared to go back; the orthotist will alter the brace and do their best to ensure the brace fits well without causing discomfort - the last thing anyone wants is for your child to be in pain - everyone wants the brace to fit well and do its job.

4. Encourage the 20 hours of wear a day. The number of hours in brace really makes a difference.

5. Night-time hours are 'easy hours' - always get them in!

6. Be as active out of brace as possible - this will help maintain the core muscles, and of course exercise is great for mental wellbeing.

7. Encourage your child to be open about their brace with their peers - the initial disclosure is difficult, but once it is out in the open it's done with. Most children are initially inquisitive and then accepting and it helps to have friends to whom they can talk about the emotional ups and downs of wearing the brace.

8. If there is a special social occasion every now and again, let your child go brace-free and wear what they want even if this means they don't get their brace-wearing hours in that day. They can always make up a bit of extra time brace-wearing over the next week. It makes their life more bearable and means that they are more likely to stick with the brace.

9. Holidays - again, subject to the advice of your specialist, be a little more flexible with the brace wearing - my daughter wore her brace around the pool with a cover-up/shorts and t-shirt, but would quickly remove it (she had

become very good at putting it on and off by then) and popped it under her lounge when she wanted to go in the pool/play sport etc. She would wear her brace most evenings, but some evenings she would go brace-free and wear the figure-hugging clothes that she wanted to.

10. Go shopping! We went and bought clothes that were fashionable but would hide my daughter's brace. It's difficult for a teenager who wants to be wearing figure hugging clothes and crop tops to be in a brace, but we compensated with cleverly chosen pieces, such as jackets, one shoulder tops, and nice skirts/shorts. And there is the promise of a shopping trip as soon as she is out of her brace to get a new wardrobe! It's important to keep reminding your child that brace wearing is not forever, but the effects will be!

I hope that this has given a little insight into brace wearing from a parent's perspective. I would recommend it to anyone with a child with scoliosis.

*\*Please note, all tips are, of course subject to the medical advice of your child's consultant and orthotist.*



Rebecca's daughter in the orange and grey swimsuit competing in the World School Games

# YOUR BRACING PHOTOS



Evie O'Connor in the midst of having her brace made and fitted.



17 year old Niamh Cripps has been wearing her Boston brace since she was 14. She's very happy that the brace has successfully controlled her curve.



11 year old Matilda who has been wearing her brace since she was diagnosed at age 7.



Simon Reynolds aged 10 in the mid-60s wearing a Milwaukee brace



Ruby Barrett, with puppy Frank



Abigail Howard



Maeve



Logan Morris



River Bucknall wearing her brace she calls Betty



Nazreen Ford wearing her TSLO brace post fusion

# FLAUNT YOUR CURVES

Michèle Mendelssohn

“Hey, good-lookin’!” When was the last time you caught a glimpse of your scoliosis in the mirror and said those words to yourself? How often do you think of your wavy spine and uneven hips as delightful? If your answer is that you rarely see your backbone as beautiful, you’re not alone. As a teenager newly diagnosed with scoliosis, my answer to both these questions would have been “Never. Ever.” Body-conscious teenagers worry about developing, sprouting, changing too fast or too slow. As a brace-wearing teenager, I felt especially self-conscious. I looked around for scoliosis role models, but I didn’t see any people whose spines looked like mine. Guardian columnist Lucy Webster remembers her body negativity well: “I was especially invested in whether a particular outfit I fancied

from Topshop accentuated or hid my scoliosis-curved spine, as if that was more noticeable than the wheelchair I was sitting in.”

Things have started to change. When Princess Eugenie got married in 2018, she chose a backless dress to flaunt her scoliosis surgery scar. Now as an adult with uncorrected scoliosis, I care less about how my curve looks. But I still wonder: where are our role models, the men and women who make uncorrected scoliosis look good?

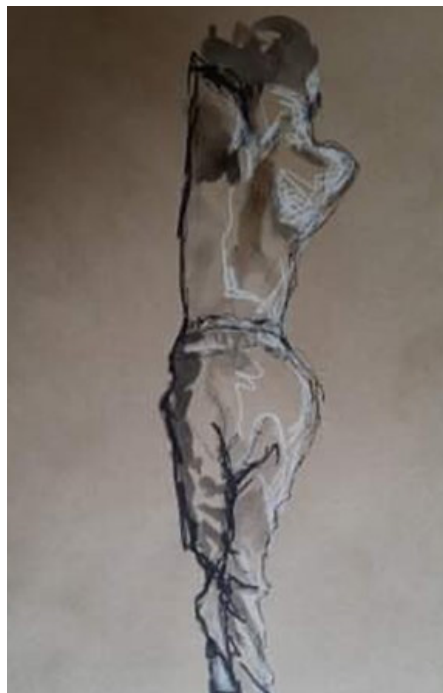
To answer that question, I spoke to two people who’ve been there and done exactly that. Martin Symons, 56, describes himself as having had “a whole collection of medical conditions” from birth. His scoliosis was very minor when he was

young. It got progressively worse after a respiratory failure in 2001. “My oxygen wasn’t going around properly because of my posture,” he explains. He uses a ventilator at night and a few hours in the afternoon, and works out at Able2B, an adapted gym near where he lives in Norwich. And he doesn’t let much stop him from seeking out thrilling new experiences.

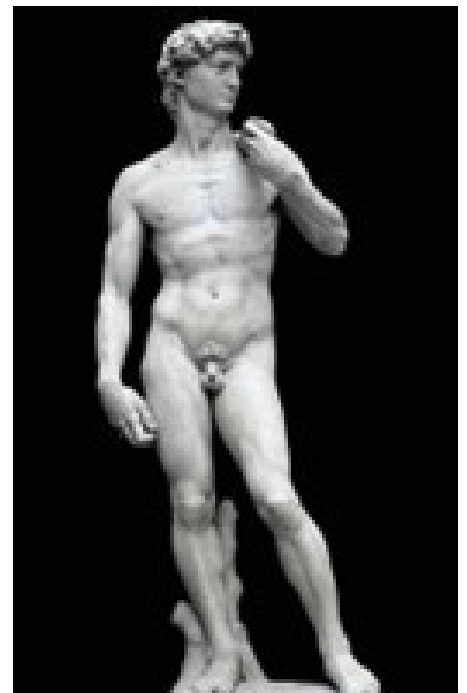
When Symons talks about his adventures, he lights up. He started horseback riding as a young adult to increase his mobility. “I’m only about 4’ 9” and horses are 18 hands high. I like a challenge,” he says matter-of-factly. He’s a veteran of weeklong cycle rides and canoe trips. He’s an experienced climber with an ascent in Nepal to his credit and, closer to home, Snowdon



Martin Symons



Martin Symons



Plaster cast of Michelangelo's David by Clemente Papi, 1856, via Victoria and Albert Museum, London

and Ben Nevis, too. Skydiving and ziplining excite him. He hopes to do both, one day.

Despite his intrepid nature, Symons admits he was apprehensive about modelling when he was asked to do a few sessions for an art class. “I never had trouble with how I look,” he says, but stripping down his top half and showing off his scoliosis to artists wasn’t a challenge that immediately appealed to him.

The first sitting as a model was a revelation: what the artists were able to sketch and come up with in 5 to 15-minute poses astonished Symons. Since then, he’s modelled online and face-to-face. When he shows me some of the portraits from his online sitting at the Norfolk Makers Festival, I’m struck by the different artists’ skilled use of line and shade, the nobility their attention brings to the poses. These sketches find beauty and interest in the subtle angles, curves, planes and swerves of scoliotic musculature. They don’t hide Symons’s scoliosis at all. On the contrary: they make a virtue of it. In one sketch, Symons’s chest is

puffed out, Braveheart style, with one arm crossed defensively across his chest and a kind smile playing on his face. In another, he stares straight out at the viewer with a look of quiet strength. His left hip tilts up in a classic contrapposto, a traditional art pose in which the model puts their weight on one leg.

In contrapposto, the unevenly distributed weight gives the body an interesting, effortlessly elegant, dynamic line. You’ve seen this pose before, on ancient Greek kouros sculptures, Michelangelo’s David, Botticelli’s *The Birth of Venus*, and countless sway-hipped Vogue and Instagram poses. A recent study by Dr Farid Pazhoohi, a lecturer in psychology at the University of Plymouth, used an online gaze-tracking experiment and found that the curvy posture is generally more visually attention-grabbing and attractive than others. For those of us whose scoliosis makes our spines naturally curvy, this may come as a surprise. Contrapposto is pretty much our normal stance. Perhaps it’s time to start thinking about uncorrected scoliosis as an asset.

Leah, 35, is unabashedly proud of her body. She’s also fiercely optimistic, a quality that may come from her mother, a great supporter of hers. Leah has had scoliosis all her life. She went through numerous operations and plastercasts from a young age to stabilise a rapidly progressing curve. “Rods were new then,” she says. “If I had had further surgery to reduce my back, the risks would have been very high and the cosmetic benefit very low.” She has an 89% lung capacity now, which is more than was expected.

Backless dresses have never been part of Leah’s wardrobe. She gets frustrated by horror films featuring hunchbacks and jokes about having “the hump.” She considered posing for a life drawing class and backed out at the last minute. But when she was pregnant with her daughter, something shifted. She posed for a photographer: in the portrait, she cradles her pregnant belly, a rose tattoo sleeve on her arm and an air of serenity in her gaze. Artfully draped and posed in profile, Leah appears to be striding forward, undaunted. It’s a tremendously powerful piece of art.



HRH Princess Eugenie



The Birth of Venus by Sandro Botticelli, 1480, via the Uffizi

# Leah's birth story

## Leah Unwin

My name is Leah, I have recently given birth to a beautiful baby girl and wanted to share my story of pregnancy and scoliosis, I appeared on the cover of Backbone magazine when I was 20 weeks pregnant. I have infantile thoracic scoliosis and two curves, one of which measures 108 degrees. Unfortunately, surgery was not successful for me as a child. However, I have always led an independent life, going away to university, travelling, and working full time.

I remember being 15 and asking my consultant if I could have children, he told me "Until you try, you never know if you are fertile but there is no reason why you couldn't. You are likely to be uncomfortable very early on (due to reduced body height) and they may be reluctant to give you an epidural."

So, there I was at 34, rigidly staring at the clock on my mobile phone refusing to look at the pregnancy test held in my other hand under the phone. 1, 2, 3, 4, 5 minutes passed. I moved my phone to look at the test. Two lines stared back at me... two, that was definitely two right!? I couldn't believe it; I thought it would take months to get pregnant but this happened straight away. Two lines, I'm pregnant! I repeated it over and over in my head, I'm pregnant, I'm pregnant!

I told my partner Ash that morning, naturally he was very pleased and excited and joked he was not going to give up his season ticket! We then told immediate family and a few close friends our news.

Soon after my mind started to wonder and anxiety set in about giving the baby the best start in life and carrying the baby to term, or the potential impact if I needed to have the baby early because of my scoliosis.

I contacted my doctor's surgery to inform them of my pregnancy and asked if there was anything that needed to be done because of my scoliosis. I was informed that there wasn't. When I met with the midwife at my first appointment, she referred me to maternal medicine to oversee my pregnancy alongside the midwife. I had my first appointment with maternal medicine as I entered the 2nd trimester, the consultant explained I would be seen by her and have regular growth scans to check on

When I reach Leah, I find her at home and still on maternity leave. Her daughter is napping, and she has a rare half-hour to talk to me. I tell her that her arresting photograph, which featured on the cover of the Autumn 2022 issue of Backbone, reminds me of actress Demi Moore's legendary Vanity Fair cover – the one in which Moore appeared seven months pregnant. Shot by Annie Leibovitz, the photo caused a furore back in 1991, when pregnancy photos were uncommon and, some thought, indecent. Leah smiles at the suggestion. "I just thought, 'Here's an opportunity,'" she says of her pregnant body. "Here's an opportunity to show that you can be pregnant with scoliosis. And also: look at me!" Image can be a struggle, but not one she lets control her life. Regular gym visits and reflexology make a big difference to her well-being. She's tried Build and Breathe online Pilates, a low-impact exercise, developed by an instructor with a T5-L4 spinal fusion.

When I ask about becoming a mother, she is pragmatic. "You have to ground yourself. Look at how lucky you are," she says, "I can still walk, talk, hear, see, dance. I just get up and lead my life. You can have children; you'll just be uncomfortable." While we're talking, she tells me she is used to pain; in fact, she has pins and needles going down her shoulder right now. "When people talk about pain, I say 'you need to MOVE!' It's true what they say: move it or lose it." Leah's ears prick up at the sound of her baby waking. Our time is up: her daughter, who is going to be 9 months next week, is stirring in her cot. She'll be crawling soon. It's time to move.



Leah on the Autumn 2022 front cover of *Backbone*

me and the baby. She also requested for me to have lung function tests during each trimester to assess the impact of the pregnancy on my lung capacity. I'd had a lung function test once before as a teenager and was fortunate that my lung capacity was much higher than expected. The consultant also referred me to the anaesthetic team who assessed me for anaesthetic and pain relief for the birth.

Over the coming weeks and months of appointments I was informed I would have the baby early and this could possibly be around 33 weeks. Following an assessment with the anaesthetic team we agreed that an epidural or spinal block would not be in my best interest; my vertebrae were very stacked and there were no gaps between them and so the anaesthetist felt that they may not be able to get access to administer the medication into my spine. They also advised of the unpredictability of how the anaesthetic could take and how long it would last with curvatures of the spine. Such as only numbing one side, not travelling high enough or travelling too high along the spinal cord or not working at all. An induction was also ruled out because I was likely to have the baby early.

As a spinal block was not an option for me, I had to have a general anaesthetic. From my previous operations I was extremely nervous about this. It also meant I could not be awake for the birth of our daughter and that Ash could not be with me or present for her birth. Having said this the hospital team were fantastic and they asked if there was any specialised equipment or support I would need during my hospital admission. The team were so supportive during my pregnancy, the C-section and for mine and our baby's aftercare.

I was extremely lucky that my pregnancy was uncomplicated, every growth scan showed a thriving baby who was measuring the top of the charts each time. My lung capacity was hardly affected by the pregnancy, only reducing by a couple of percent. Although I did become quite uncomfortable - but doesn't every pregnant woman!?

I tried to go for a walk every day and did some pregnancy-safe Pilates and stretching, which did become more difficult near the end of my pregnancy. I was able to go over the consultant's predictions of 33 weeks and a c-section was booked for 35 weeks. I was very pleased with this because a baby is classed as full term from 37 weeks and I knew that 35 weeks is a big

milestone for a baby's development. I also had steroid injections to support the baby's lung development.

The day arrived and I gave birth to a very healthy girl weighing 5lb 12.5oz. She was monitored by the neonatal team for 24 hours but was breathing independently and feeding well and so she came to me on the ward. Any baby born under 36 weeks has to stay in hospital for 5 days. After this we went home to start life as a family of three, where Ella has continued to flourish.

The consultant has followed up with me since having Ella and has stated should we want more children we would follow the same procedure again. Although they would like me to have lung function tests before being pregnant and during the first trimester if we were to become pregnant again. Therefore, my advice for anyone with scoliosis wanting children is to speak to your consultant and to also ask for an obstetrician's advice because my GP and midwife were not aware of the need for the lung functions tests earlier on.

Many people without health conditions or scoliosis may have premature babies or have full term baby's that require some medical support after they are born. I hope me sharing my story helps to reassure others with severe scoliosis.



# THE ROLE OF THE PAEDIATRIC SPINE CLINICAL NURSE SPECIALIST

Rachel Hunt, clinical nurse specialist, paediatric spine service, Evelina London Children's Hospital

Clinical nurse specialists (CNSs) are registered nurses who have gone on to develop expertise and skills in a specialist role in a specific service or area. The role of the CNS specialising in spines involves providing specialised care, education, advocacy and support to patients with a spine related condition and their families - in paediatric spine services this is most commonly scoliosis. We work in the inpatient and outpatient settings as part of the multidisciplinary team to help ensure the best possible outcomes for our patients.

The spine CNS usually starts to be involved in a patient's care once a diagnosis of scoliosis has been made or they have been put on the waiting list for surgery. We are often contacted via SAUK by a parent/carer in the early stages of diagnosis and find it so beneficial to work closely with SAUK in keeping these links and networks in place. The CNS can be a resource ensuring the patient and their family have access to information and advice about their diagnosis and treatment and be on hand to help make sense of the large amounts of often unfamiliar sounding information.

When I started this role there wasn't much written information readily available to support those affected by scoliosis, and a lot of

it on the internet came across as quite daunting. So we developed a booklet that is given to patients with scoliosis when they are put on the waiting list for surgery (we have separate idiopathic and neuromuscular/syndromic scoliosis information booklets). We explain what scoliosis is, the treatment, hospital and discharge care and the subsequent follow-up. We also include patients' stories, and resource recommendations and encourage people to link in with SAUK.

Many people may not have heard of scoliosis before they get their diagnosis, so they often report how helpful it is to meet or be in contact with other children and their families going through similar experiences. We have had several past patients who have kindly shared their experiences and supported patients going through surgery. This has been invaluable and had such a positive impact on a pre-operative patient's experience, helping to reduce anxiety. I have certainly learnt a lot from hearing patients' stories and experiences and it has been influential in my understanding and development as a CNS.

A key part of the CNS role is preparing the child and their family for scoliosis surgery because we oversee the pre-assessment

process. This includes ensuring the patient is medically fit for surgery (such as blood test results and clinical assessments) and is mentally and practically prepared as much as possible for the journey ahead.

There are many health professionals involved in a patient's scoliosis surgery journey, including the spine consultants, anaesthetists, physiotherapists, occupational therapists, play specialists and the pain team. For scoliosis patients with more complex medical health needs, the work up to surgery often involves many other health professionals such as orthopaedic surgeons, respiratory consultants, cardiologists, dieticians and neurologists, and the CNS is often the link between all these teams. We work closely with our physiotherapy and occupational therapy colleagues in ensuring that any extra equipment or adaptations needed at home are in place before the patient is admitted for surgery. We link in with community teams such as community nursing and social services to ensure care packages are in place for discharge as required. Planning before surgery helps promote a smooth patient journey and a timely discharge.

We know that scoliosis surgery is a big undertaking for the patient and

their family and a key moment in their life. There may often be other associated stresses and anxieties such as pain and the physical and psychological effects of scoliosis, as well as juggling surgery around school life and exams and hobbies and interests such as sports. Most of our scoliosis patients have one operation (usually posterior scoliosis correction and fusion) but some of our younger patients may be put onto the growing rod programme. Some patients with large, very stiff curves may require more than one operation and sometimes some traction intervention in between stages to gently stretch out the spine.

All patients are different with different experiences both before, during and after surgery, so care needs to be individualised and the appropriate preparation, for their age and level of understanding, put into place. We understand that the thought of surgery can be quite frightening and for some people there are extra concerns, such as fear of blood tests, so we link very closely with our play specialist and psychology teams to help make the process as smooth and positive as we can. As paediatric nurses we aim to support parents/carers at this often emotional time and promote family centred care.

During the hospital admission CNSs oversee the care of the scoliosis patient on the ward, change dressings, and arrange discharge plans. We discuss how to wean the patient off pain medication and ensure they have appointments for wound reviews, and also provide our contact details for any concerns or questions once home. We have a letter for schools with information on when we

would hope the patient can return and advice on how to reintegrate them safely. We give information on how quickly people can get back to certain activities which, particularly for our sporty patients, is a key aspect in their recovery.

We provide teaching sessions and education for our colleagues, especially nurses and student nurses, who care for scoliosis patients, and we are involved in service quality improvement projects through clinical audits and research. Part of our role too is helping to facilitate patients going onto the British Spine Registry (BSR) - a web-based database for collecting information about spinal surgery.

We work closely with our consultants, service managers and administration team in scheduling surgery. I need to mention that at this challenging time for the NHS, particularly the effect on surgery waiting lists, and we as CNSs are seeing an increase in being contacted by patients and families facing anxiety and concern as they wait for treatment. Because our older teenage patients move from paediatric to adult spine services, I am working with our adult spine nurse specialist colleague at Guy's Hospital to help make this a smooth process since we appreciate the transition can be quite daunting.

As CNSs we have the opportunity to attend relevant study days and conferences such as the British Scoliosis Society. Through these forums we have set up a Scoliosis CNS Link Group with colleagues from most of the UK's spinal hospital settings. This has been a great way to network, give support, share experiences and learn from each other as we care for our patients within our different settings.

I have been a Spine CNS for 16 years and it is a role I am still very passionate about and enjoy, and I am always learning new things. It feels so special to have the opportunity to meet patients and their families at the start of their scoliosis journey and follow their experience through surgery and follow-up appointments until they are finally discharged. I have had the pleasure of keeping in touch with many past patients and it is always so good to hear from them about how they are getting on.

The world of scoliosis continues to evolve and I have certainly seen many changes such as new treatments and techniques. It has been a privilege to work with some wonderful colleagues and to meet some truly amazing and remarkable children and their families and be part of their scoliosis story.



# SAUK - FUNDRAISERS

We are so grateful to all our amazing fundraisers for your fantastic efforts to support us. Thank you for all your hard work; we really couldn't continue our work without you. We greatly appreciate all the donations we receive, and you are vital in ensuring we can continue our important work of, providing support and information for people with scoliosis, and now for research too.

## Winton Wanderers u9 Wolverines and u9 Silverbacks

The team successfully got caked in mud at the wonderful Lidl Mudder event in support of SAUK!

"The excitement and anticipation were palpable as our young football players prepared to take on the junior Tough Mudder event known as Lidl Mudder. For months, they had been training and preparing for this moment, eager to take on the obstacles and challenges that awaited them on the muddy course.

But this event was about more than just having fun and getting dirty. Our team had chosen to participate in Lidl Mudder as a way to support a very important charity called Scoliosis Association UK.

As a grassroots football club, we understand the importance of giving back to our community and supporting those who are in need. And so, we saw Lidl Mudder as the perfect opportunity to not only have a blast with our teammates but also make a positive impact in the world.



On the day of the event, our team arrived bright and early, ready to take on the challenges that awaited them. They donned their team shirts, laced up their shoes, and checked their nerves as they approached the start line.

The course was no joke. There were mud pits to crawl through, walls to climb over, and obstacles to navigate. But our team tackled each challenge with determination and grit, refusing to give up even when things got tough.

And of course, there was plenty of silliness and fun to be had along the way. The kids laughed and joked as they sloshed through the mud, cheering each other on and high-fiving at every opportunity. They

even stopped to take a few silly selfies along the way, capturing the joy and excitement of the moment. But through it all, the kids never lost sight of their mission. They knew that every step they took and every obstacle they overcame was helping to raise money and awareness for Scoliosis Association UK. And that knowledge gave them an extra boost of motivation to keep going, even when their muscles were burning and their clothes were caked in mud.

As the finish line came into view, our teams dug deep and summoned every last bit of energy they had. They crossed the line together, arms raised in triumph, and were greeted with cheers and congratulations from their fellow participants.

But the real victory was the knowledge that they had made a difference. Through their participation in Lidl Mudder, our team had raised a significant amount of money for Scoliosis Association UK, helping to support those who are struggling with this challenging condition.



In the end, our team came away from the event exhausted, muddy, and thrilled with the experience. But more than that, they came away with a deep sense of pride and satisfaction, knowing that they had done something truly meaningful and important.

As a grassroots football club, we are proud to have been a part of Lidl Mudder and to have supported Scoliosis Association UK. We hope that our participation will inspire others to get involved and make a positive impact in their own communities. And most importantly, we hope that our efforts will help to make a difference in the lives of those who are affected by scoliosis."



### Georgia Gale

12-year-old Georgia, from Bath, did a 10-hour drumathon over International Scoliosis Awareness Month to raise scoliosis awareness and funds for SAUK. She started with a fundraising goal of £5000 and far surpassed that by raising £6653 plus gift aid!

"I found out I had scoliosis when I was 9. I never knew what it was until the doctors told me about it. It is where the spine has a curve in it and for me I have two curves so my spine looks like an 'S'. The doctor talked about back braces and recommended I wear one. The idea was that the back brace could prevent my curve from worsening

so that I wouldn't need surgery.

I've had four different back braces over the past 3 years. They are uncomfortable to wear and I have to wear one for 18 hours a day. I still do lots of sport and my favourite thing to do is drumming!

After about 2 years of wearing the back brace, my curve progressed significantly in a short space of time because I had a huge growth spurt - it went from 50 to 70 degrees in only 4 months. This meant that surgery was the right option and I'm now having my surgery in late July.

My surgeon told me all about the surgery and the risks, including paralysis, and I was scared. Surgery was never something I thought of or something people talked about often, making it even more frightening.

During the operation they fuse my vertebrae and insert metal rods, lengthening and straightening my spine. I will need to build up having the energy and strength to stand

up by myself, walk up stairs and sit for a long space of time. My surgeon told me it will feel very strange at first. I hope that I'll be back to doing sport after a year but I'll need to learn to move differently since my spine won't bend like before.

I have been drumming for 4 and a half years and, it's my favourite thing to do! I'm currently doing my grade 6 and am going to do my exam in the summer before my operation because I won't be able to drum for quite a while afterwards.

I have also been playing in a band for about 2 years now, which has been an amazing experience! I did this through music workshop in Bath. I love it there because all the people are great and it's such a lovely community.

I decided to do a drumathon for Scoliosis Association UK because there is so much we don't know about scoliosis treatment like new operative procedures and back braces, how to prevent it and where it comes from."



# MORE FUNDRAISERS...

## Fundraisers

[Lisa Kellighan](#) raised £348 running a yoga and pilates retreat.

[Amelie Townsend](#) raised £620 participating in the London Halloween Walk 2023.

[Louise Laurie](#) raised £3,667 participating in a 10 day trek to Machu Picchu.

[Grace Turner](#) raised £470 participating in the Royal Parks Half Marathon 2023.

[Emily Belton](#) raised £1,750 participating in the Great North Run 2023.

[Victoria Houghton](#) raised £669 participating in the Thames Path Challenge 2023.

[Elizabeth Amps](#) raised £575 participating in the Great North Run 2023

[Daniel Woodhouse](#) raised £415 participating in the Tough Mudder North West 2023

[Kaitlin Pitts](#) raised £611 participating in a skydive in August 2023.

[Georgia Gale](#) raised £6,653 participating in a drumathon in June 2023.

[Jack Baldwin](#) raised £365 participating in the Castle Run Series 2023.

[Ian Nelson](#) raised £1,000 participating in the Chase the Sun UK South 2023 bike ride.

[Rika Brixie](#) raised £ 535 running an online pilates class for scoliosis.

[Matthew Flenley](#) raised £1,896 participating in the Wicklow 200.



Louise Laurie celebrating her completed 10 day trek to Machu Picchu.

# SAUK DONATIONS

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

Jean Stevenson, Tina Brown, Margaret Crane, Ross Taylor, David Meredith, Margaret T Embery, Carol Worthington, Suzanne Wembridge, Michael Jackson, David Cove, Julie Christian, Kathryn Knowles, Catherine Duckworth, Deborah Middleton, Janet Bennett, Jemila Jaffa, Edmund Lilly, Daphne Snelson, Julian Harrop, Alan Crebbin, Patricia Strong, Brenda Wigley, Elaine Howarth, Nina Talbot, Graham Somers, Margaret Tomlinson, Karon Slade, Ray Adams, Jean Stark, Heather Evans, Tanya Hindle, Lisa Tomlinson, June Douch, Samantha Wellburn, Ian Churchward, Jayne Boniface, Lucie Rowlands, Rory Turnbull, Denise Jane Bailey, Caroline Coutts, Diana Lucas, Sonia Broddell, Victoria Margeson, Sonia France, Chris Hutchings, Michael Green, Hannah Padfield, Derek Randall, Clare Rice, Dyan Taylor, Nova Keown, Nazreen Shah, Victoria Beckett, Victoria Marks, Tom Harrington, Helen Clark, Moira Buckley, R M Couchman, Jane Manning, Samantha Miller, Cheryl Barnes, Jane Wareham, Karen Kemp, Joanna Langford, Philip Boxhall, Debbie Hughes, Alan Chapman, James Dale, Doreen Lindegaard, Anne Stubbs, Manish Trivedi, Martin Bourne, Julie Terry, Hannah Padfield, Michael Green, Trudi Parton, Margaret Ross-Bell, Saira Awan, Sharon Inglis, David Thornley, Robert Kayte, S Whitlock, Terence Bell, Laura Tisdall, Lorna Bennett, Emily Barden, Rachel Anderson, Margaret Milson, Carl Stick, Hannah Padfield, Rosa Alonso, Michael Forbes, Rafay Butt, Paul Hanselman, John Pickthall, Amanda Clarke, Nicola Beer, Martin Miller, Liz Brant, G Huisman, T Evans, Louise Stuart, Jayne June Ashford, L Meadows, Alex Davis, Judith Grimwood, Annette Kenny, Becci Howlett, Marie Wells, Julie Thomas, David J W Hardie, Emily Odoire, Walter De Maria, Elisa Fu, H Doherty, Tracy Vasabhuti, Jeremy Freedman, Andrew Gascoyne-Cecil, Sue Law, James Thomson, Helen Coulthard, R A Croshaw, Charlotte Croft, Sue Casson, Claire Russell-Bates, Nick Everett.

# Your Back Stories

## Amber Forsdike

Hi, my name is Amber, and I am 16 years old. Back in 2021, I was on holiday when my mum noticed my uneven shoulders. When we got back, we went straight to the doctors and a couple of months later I was diagnosed with a severe double curve at 50 degrees at the top and 35 degrees at the bottom. My surgeon wasn't very worried about having surgery too soon, but he knew that my curve was too severe to have a brace fitted. In the end he decided to leave it until around the summer of 2023, after my exams. 4 months later, I had a check up to see how the curve was progressing and it had increased very quickly within those 4 months and, was now around 70 degrees at the top and 55 degrees at the bottom. After finding out that I had a fast progressing curve, my surgeon decided that I needed to have my operation pretty quickly.

My operation was scheduled for 3 weeks later, on May 25th, 2022. In between these 3 weeks, I had

an MRI and X-rays to give more details for the surgery. On May 25th, I came to the hospital for my operation and went in to theatre at around 10:00am and came out around 6:30pm. My surgeon said that everything went very well, and I was in hospital recovering for a week. I had around 4 weeks off school recovering and came back around the end of June, 2022. During the first couple weeks of my recovery, I noticed a bump on my right shoulder but figured it was nothing since I had just had surgery. However, during the first 6 months of recovery, it kept increasing in size and was becoming uncomfortable and sore to touch or lean on. At 6 months post-op, we ended up going back to my surgeon to figure out what was causing it and if anything could be done. After more X-rays and a CT, we found that the metal work from the fusion had started to come loose at the top, around 1cm out. Unfortunately, my surgeon said that I would have to have another operation to fix the metal work because it was causing a lot of

discomfort. I had a date for January 4th, 2023. During this operation, my surgeon took some samples to try and figure out the cause and found that I had a bacterial infection, causing the metal work to protrude, so I was put on antibiotics for 6 months. During my recovery I also had an infected wound caused by the stitch knots irritating my skin, which meant I had to keep having a cover on my wound and having to go into hospital to have it continually checked and cleaned for a couple of weeks. After my course of antibiotics is over, I should be finished with my recovery and journey. I have since gone back to horse riding and sports at school and am now healing well. My curve now is estimated to be between 10-20 degrees.

## Anna Harlow-Griffiths

My name is Anna, and for Scoliosis Awareness Month 2023, I want to share my story.

I was first diagnosed with scoliosis when I was 9 years old. Throughout the next year, I had regular X-Rays, MRI scans, and appointments with a spinal consultant. However, the curvature in my spine developed rapidly, to 80 degrees. When I was 10 years old, I had fusion surgery to insert two titanium rods and 18 screws into my back. Before surgery I had been dancing with my local dance school and loved it, but I was worried about the effect that having spinal surgery could have on my dancing.

My surgeon was amazing, and about 3 months after the operation, I started to return to dance. I slowly increased the amount of dancing I



was doing per week. Since then, I have performed in many shows and competitions, both in a group and as a solo performer. I am so happy that I am still able to dance.

To anyone awaiting surgery or recovering from surgery I'd say to take it slowly and gently. The first exercise I did after my operation was gentle swimming, because this is a non-weight-bearing form of exercise therefore reducing the amount of pressure on the back, whilst increasing mobility and strength!

Fast forward to now and, I am 17 and am studying performing arts full-time in sixth form. I train in a variety of dance styles including ballet, contemporary, and jazz. The rods in my back do not bend, but I make my own adaptations to the movements when I need to, so it doesn't at all stop me from participating. In March this year, I performed at the world's biggest dance convention at ExCel, London. Towards the end of this year, I will be auditioning for vocational dance

colleges, where I am hoping to train after sixth form.

Although it was scary having a major operation aged 10, I am so glad I did. I don't know where I'd be now if I hadn't had it.

### Isabella McCabe

Scoliosis is a very hard subject for me to talk about. I was diagnosed at around age 2 or 3 and growing up with scoliosis was difficult, I'm not going to pretend that it wasn't. Being different and not being able to participate in certain activities can be confusing. It felt like I was trapped in my own struggles, living day to day isolated in my own thoughts. I'm also not going to pretend that it didn't drain me. But that negative side is very small compared to the positive side. Personally, going through with my spinal fusion was the best decision I have ever made. Yes, it was very hard for me to cope, but surrounding yourself with things you enjoy is more important than you think, that is what helped me get through my fight with scoliosis.

you, never think that you are at a disadvantage with this diagnosis because you are at an advantage because whatever you achieve, you are doing it whilst being strong and beating the fight with scoliosis. I have already achieved more than a lot of people have in life, and I'm sure you have too.

So, keep going, and once you complete this battle you will keep achieving and hopefully, like myself, you will feel happy and not alone or isolated. I hope this made you feel more at ease and more confident with going through with this back surgery, trust me, it will change your life.



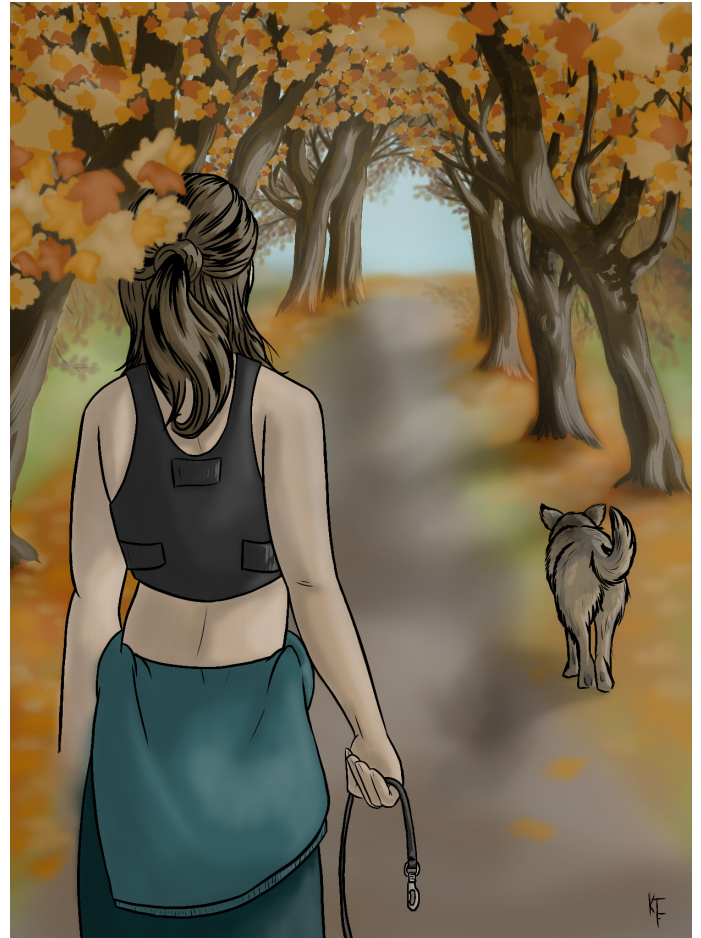
Knowing your self-worth is also massively important, it's about believing in yourself and knowing you can beat this tough struggle in life. I thought that my whole life I would be limited by my scoliosis but actually, once I had the spinal fusion, I felt free, proud, and like I can live my life to its full potential without these restrictions keeping me from showing the world my potential. Please know that you are not alone and people in this world understand



# Ailie Harrison Art Competition 2023



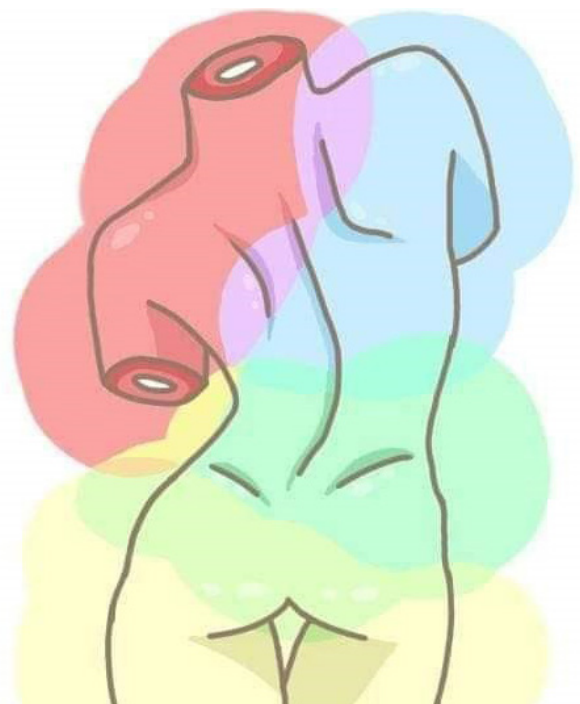
Victoria Twitchin



Kayleigh Forrest



Aimee Templeman



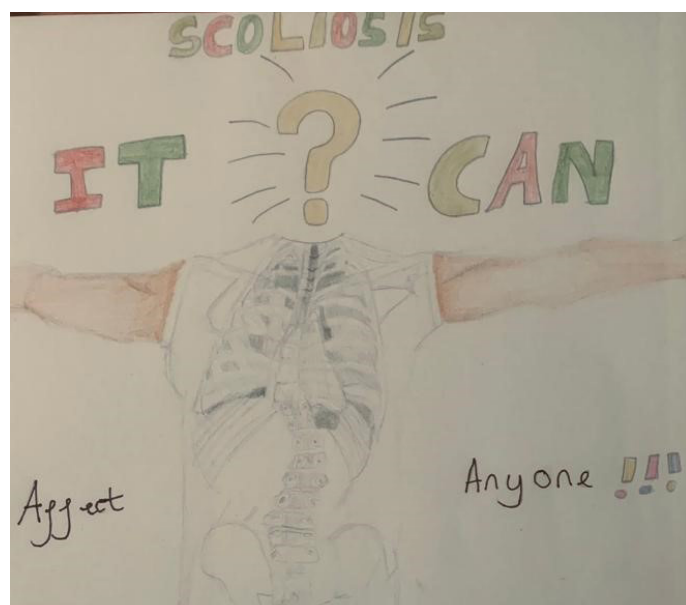
Madison Procter-Kirkley



Sofia Aguiar Young



Beth Fearon



James McGuinness



Jinghan Wang



Jasmine Brown

