Issue 106 | Autumn 2022

BACKBONE

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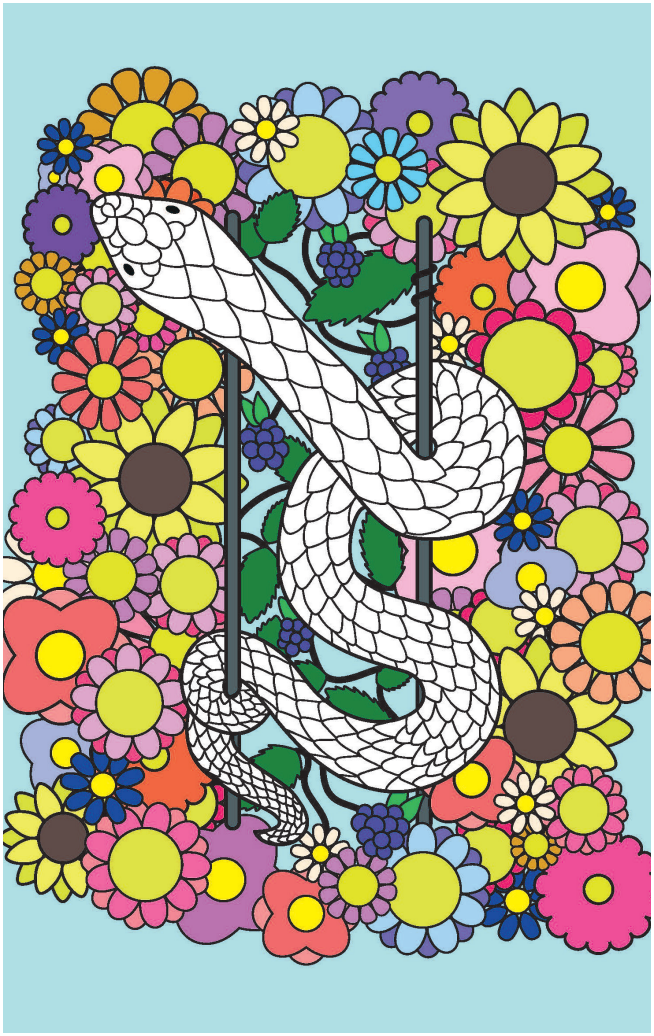

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LATEST NEWS

Cover Girls

Leah Unwin, who is on the front cover of this issue took first place in the Ailie Harrison Art Competition for the photo of herself 20 weeks pregnant with her first baby. Leah has infantile thoracic scoliosis and two curves, one measuring 108 degrees. She wanted to reassure people with scoliosis that they will be okay during pregnancy and that having scoliosis doesn't rule out having children.

Molly Macfarlane's artwork is on the back cover of this issue. Molly took second place for her painting. Molly painted this after meeting others with scoliosis and feeling proud and brought together by this shared experience.

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 have only two full-time staff and one part-time person at the moment 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.

Roll of Honour 2023

SAUK awards places on our Roll of Honour every year to children and adults who have shown outstanding courage while undergoing treatment for scoliosis.

To nominate someone, contact us by the 28th February, 2023. Include the name of the person you are nominating, why you are doing so, and a picture of them. Please also include your email address, your name, and the address of the person you have nominated (so we can send them a certificate).

Return your nominations to communications@sauk.org.uk. The awards will be announced in the Spring 2023 Backbone.

How to set up a JustGiving fundraising page

Setting up an online page for your fundraising is a secure and brilliant way to raise funds.

1. Sign up or Log in to JustGiving at www.justgiving.com
2. Click 'Start fundraising'.
3. Click 'A Charity', to the question "What are you raising money for?"
4. Search for and select Scoliosis Association UK.
5. Select the type of activity or event you're doing.
6. Choose your Fundraising page URL– this is the link you'll be sharing when asking the people to donate.
7. Click 'Create your page'.
8. You can now go into your fundraising page and personalise it by selecting 'edit page'. Make it your own by sharing photos and adding text about your activity or event, how scoliosis has affected you, and why you're supporting SAUK.
9. Your Fundraising Page is now set up and ready to accept donations. JustGiving will send the money that you raise to SAUK every week, so there is nothing else you need to do.

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 13 NHS Trusts across the UK, with another 6 Trusts in set up, hoping to join in the very near future.

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

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

At the moment, there are 44 patients taking part in BASIS, and roughly half are receiving full-time brace treatment, with the other half receiving the night-time brace. The study is aiming to involve 780 patients over the next 3 years, and all patients taking part will be followed up until 2 years after they stop brace treatment.

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

To find out more, visit the BASIS study website using the URL or QR code below - https://basisstudy.org/

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

THE BASIS STUDY

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.

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Life after fusion

Colin Nnadi, orthopaedic spinal surgeon, Oxford University Hospitals

Most of the advice given to you about how to manage post-fusion centres on those important first 6 weeks of recovery. What about months down the line or even years after fusion surgery? We answer your frequently asked questions on life after fusion with the help of Consultant Spinal Surgeon, Colin Nnadi.

Are there activities I shouldn't do, even if I'm many years post-op? eg., Skydiving, trampolining, or going on rollercoasters?

What you want to avoid is an intense sudden jolt. People who've had spinal fusion are at greater risk of dislocation above the fusion and there is a risk of the metalwork snapping in an accident. A smooth landing in skydiving or a roller coaster where you're well secured doesn't necessarily pose a threat, but if you end up in a situation with an intense sudden jolt, you're more at risk than a person who hasn't had fusion. There has to be a bit of common sense to choose the safest way to do something, jumping up and down on a trampoline isn't the risk, but trying to do a flip that ends with you landing badly is a riskier move.

Pain / discomfort years after surgery. How normal is it and when should I see someone about it? Are there reasons to have a follow-up appointment with a scoliosis specialist years after being discharged?

A certain level of aches and pains even after you recover from surgery is normal. Exercise that strengthens your muscles will help you to cope with this. Particularly popular in the scoliosis community are low impact exercises like swimming, yoga, and Pilates. Pain becomes a concern when it's persistent and is interfering with daily living. or If you're relying on pain killers to get you through the day, it's interfering with your sleep, work, or everyday activities, then you should be checked by a scoliosis specialist. They will ascertain the source of pain from history and examination and pursue non-operative measures to control symptoms.

Will my ability to do high-intensity or high-effort sports and activities be diminished post-fusion?

You will retain the ability to do most activities but the change in your range of motion might limit the techniques you're able to do, impacting your ability to compete at the same level as your peers. There are exceptions to this and it's not always the case but it's a discussion we have with patients who are involved in certain sports at a competitive level.

Will fusion change the way I bend/twist/lift?

The change in the way you bend and lift will depend on the length of your fusion. A fusion of your thoracic spine might not make that much of a difference as it's already an intrinsically stiff part of our back. A long lumbar fusion will change the way you bend, meaning you will be limited to bending at the waist, hips and knees. If you're picking something up off the floor, make sure you're bending at the knees, which is the proper technique recommended to anyone picking something heavy up anyway. You'll have to get used to pivoting instead of twisting, rotating your feet and pointing your whole body in the direction you want to go, instead of twisting at the spine.

Is feeling or seeing the metal in my back normal?

This isn't unusual and is more likely if you have a slight build or have had some weight loss. What is a concern is if the sensation of feeling the metal work is sudden and comes with pain. You should immediately speak to your doctor if this happens so that you can be seen by a scoliosis specialist.

Is there a risk of the non-fused parts of my spine curving?

This risk does exist, more so if a child who is still growing has been fused. Signs of this will usually show within a year of the surgery. Most scoliosis centres will not discharge you until a year after surgery, sometimes 2 years. You'll have several check-ups in that time to see how you're doing and that the fusion is taking successfully. At each follow-up appointment you'll be cleared for more of your activities to return to normal.

Aspects of psycology relevant to AIS

Professor Adrian Gardner, orthopaedic spinal surgeon, Royal Orthopaedic Hospital, Birmingham and Dr Emily Russell

Introduction (Adrian Gardner)

Adolescent idiopathic scoliosis (AIS) is a condition seen in teenagers and presents with asymmetry of the spine and chest, both to the back and the front of the body. When someone with AIS comes to see someone like me (a clinician to look after their AIS), I will talk to and examine that person and then look at their X-rays. The majority of the decisions around treatment are based on measurements taken from those X-rays and the Cobb angle is the main number that we all recognise.

However, we know that there is actually more to having scoliosis than what a doctor and the X-rays say about the shape of the spine. This represents how the individual feels about their back and their body shape, within their own life. In lots of ways, this matters more than what the X-rays show, but by its very nature, it is far more difficult to be able to quantify, analyse, and manage.

It is just worth at this stage noting that there is a difference between the definitions of psychology and the definitions of mental health. Psychology is defined as the scientific study of the human mind and its functions especially those affecting behaviour in a given context. Mental health is defined as a state of wellbeing in which an individual realises his or her own abilities and can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community. Whilst these definitions are the true scientific definitions, the terms psychology and mental health do overlap significantly and for our needs can probably be used interchangeably.

So, it is important to recognise why psychology and mental health is important in AIS, and that is around the fact that AIS is not the spine. AIS is about a person whose spine is 'wonky' and has asymmetry of their back and that person comes with lots of other features that overlie and affect their own view of their spinal shape. This can be a long list and can include such things as relationships with their family and friends, fears and issues around school, clothing, pregnancy, sport, exams, future jobs, limitations in activity. There are then concerns about what treatment may involve, which may or may not be completely based in fact but could include concerns around paralysis, blindness, infection, stiffness, and pain. If a young person with AIS is going to get the best care, an understanding of them as a person, combined with all the above features and how they interact with that person's view of their spine, is key.

Unfortunately, celebrity culture does not help in this sphere. As I am now 'getting on a bit', this is something I see from the outside. But I recognise the effects of social media and television shows that project a view of how people should be, look, behave. Programmes such as 'Keeping up with the Kardashians', 'Love Island' and 'Made in Chelsea', can give a false impression about what "normal life" actually entails. There are also a large number of social media channels which young people interact with regularly on a daily basis. All have the potential to affect a young person's view the world. Certainly, there are reports on the negative effect of social media on the social identity of adolescents.

The other key thing around the understanding of a young person and their scoliosis, is that a young person comes with a family, and that family will bring its own fears and concerns along with their own understanding of scoliosis. That family unit may also need to deal with other children and what scoliosis might mean for them.

The academic literature highlights the potential negative effects on the psychology and mental health caused by their scoliosis on people. The science suggests clinically significant psychological and emotional distress in up to 32% of adolescents with idiopathic scoliosis.

My own work identified that, of a group awaiting surgery for scoliosis, 18% met the criteria for being depressed and 59% met the criteria for social anxiety. Other papers note 40% of young people with scoliosis experience psychological alterations in their quality of life. The major things that come through from all this work is that self-image and body shape, both a person's own view of themselves and the view of others seeing them, are a major source of concern. Of interest, it is noted that poor mental health is not necessarily solved by surgery, suggesting that the size and shape of the scoliosis may well not correlate with the young person's mental health, pre or post-surgery. Certainly, being a teenager is hard!

However, in saying all of that, I recognise that I am a consultant who treats scoliosis, but I have never had scoliosis. An understanding of the psychology of mental health with scoliosis in young people is best related by someone who has real life experience of what it is like to have scoliosis and have treatment. Consequently, what follows is written by Emily Russell, who has scoliosis and has had surgery and will give her perspective on the psychology and mental health challenges of AIS.

Personal History (Emily Russell)

I was 13 when I was first diagnosed with scoliosis.

Up until this point, I hadn't been aware that there was anything "wrong" with me, and the news came as a bit of a shock to me and my parents. Having addressed my initial concerns (Is it dangerous? And do I have to stop dancing?), we went through the rather clinical process of X-rays, angle measurements, examinations, assessments of the degree of scoliosis and my "rib hump" before my very kind surgeon sat down and explained to me his recommendations. At this point, since I had two curves which were both under 40° and compensated for each other, the recommendation was not to have surgery but rather to watch and wait. If the curves progressed beyond 40° then a new discussion could happen.

So now I was 13 years old, very aware and rather well informed about how my body was different from "normal". I also hadn't had any intervention to fix this problem, and at the moment there wasn't any intervention that was recommended. I also happened to go to an all-girls school, which I imagine didn't help with my insecurity. A school friend referred to my back as "freaky" when we played leap-frog and my rib hump was visible. I started wearing baggy tops and jumpers to cover myself up.

Pre-op rib hump

Adolescence is a tricky time for most people, not made easier by an awareness of how you don't fit in. Whilst I had a supportive group of friends with whom I could laugh and joke about my "wonky back", outside this comfort zone, I lacked self-esteem. I remember one nurse (who was a complete stranger to me) making a comment to me about how I mustn't slouch – I hadn't been slouching at the time, and small comments like this stuck with me for much longer than they otherwise might have. I now recognise this sort of behaviour as a problem with the person rather than with me, but as a young woman it could make me feel quite upset. Regardless of this, I still made it through adolescence fairly successfully, and I'd like to think reasonably well-adjusted. It is perhaps interesting then, given that I had come to terms with my back in the absence of intervention, what happened to me after I had the surgery.

Once I was at university the back pain got worse. Initially I didn't realise it

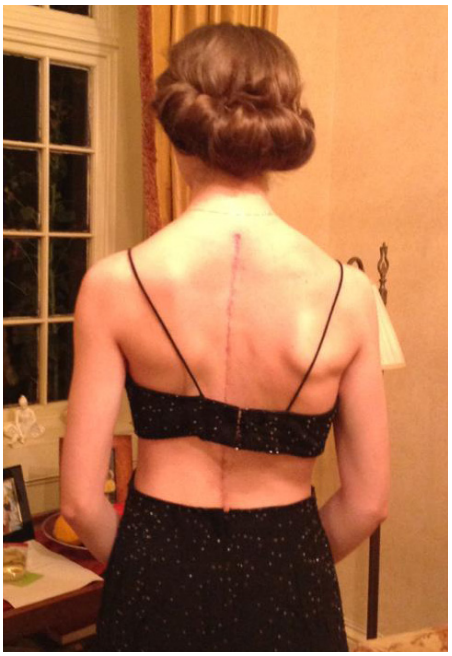
Post-op current

was anything other than the back pains that everybody else gets, and I kept my head down and tried to work through it. It was only when I went to the GP for stronger painkillers that they recognised that my spinal curvature may have progressed and referred me on to a spinal surgeon. These curves were now over that magic number of 40°, and so surgery was recommended. I was advised that this was a cosmetic procedure, and it was not guaranteed to reduce my pain. The surgery was performed successfully, I was out of hospital in 8 days, and everything seems to be going perfectly. At this point I was in my third year of university.

However, 6 months down the line, some rather worrying symptoms started to appear. I was getting shooting pains into my feet that would wake me up in the middle of the night. I would regularly get pins and needles in my little and ring fingers of both hands. If I sat down for any length of time my feet and lower legs would go numb. Sometimes my arm would feel like it didn't belong to me. Over a matter of months, the symptoms became worse, and much more frequent. I became increasingly anxious about these symptoms and mentioned them to my spinal surgeon at my next clinic follow-up.

Up to that point they had been preparing to discharge me from follow-up. However, with my new symptoms, and increasing concerns about spinal impingement (although they told me straight away this was incredibly unlikely this far down the line having had a very successful initial surgery) I ended up having CT and MRI scans which couldn't find the problem. Increasingly anxious, I was referred to a neurologist. My neurologist was absolutely brilliant, and when I compare my experience of this condition to that of others, I am incredibly grateful for his confidence in his diagnosis, and the sensitivity with which he explained things to me.

The symptoms, in the presence of normal scans, examinations, and nerve studies, implied that there was nothing physically wrong with my brain, spine, or nerves. He then explained to me that I was experiencing somatisation.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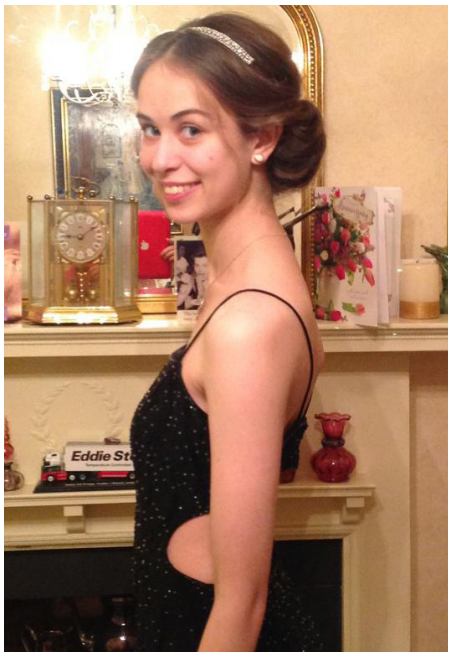

Post-op

It will not be a surprise to anyone when I say that emotions can change how the body functions physically.

When we are upset, our eyes spontaneously water. When we are anxious, our heart pounds and our hands become sweaty. These are well accepted by the general population as normal responses to emotion. However, sometimes emotions can't express themselves that way. This has become associated with an undeserved stigma, and the idea that it must be "all in your head" and that people must be making their symptoms up.

Essentially, after the surgery had happened, with my recovery going so well, I was very anxious to tune into my body to know early on if anything went wrong. Just as you had forgotten you had socks on until I reminded you of it here, my body hadn't been telling me about occasional pins and needles until I started paying very close attention to when they happened. Every time I had a symptom that I could relate to my spine, I would pay attention to it, and focus on it, and so my brain would now automatically draw my attention to it where previously it had not done.

My neurologist was brave enough to suggest that if I acknowledged my symptoms when I experienced them, but then gave their presence no weight, they would go away. He also validated my experience of the symptoms, explaining that he understood that for me the

symptoms were very real, even though there was no underlying nerve damage to explain them. He never made me feel like they were just in my head. Four months later I was completely better.

I have had other colleagues praise me on being so open about the fact I have experienced somatisation, which surprises me every time, because very many of us will have done, and this should not be stigmatised, I should not have to be brave to admit it. Many people experience headaches when they are stressed, or tummy pain that no one can explain when they are anxious. The problem with somatisation, is that it takes a very confident doctor to tell you that there is no organic underlying disease. As a result, many people have lots of investigations for their symptoms, many of which are invasive, without any cause being found.

Whilst the lack of a life-threatening cause should be good news, the hunt for an underlying diagnosis becomes forefront in the mind, and a source of anxiety for patients. When it then sounds like doctors are implying they are making their symptoms up, this is clearly then very frustrating and alienating.

The result of my personal experience with scoliosis, and how I feel it affected my mood and body image, means I am entirely in support of the suggestion that in order to holistically care for a teenager with scoliosis, there needs to be an appreciation of the potential for underlying impacts on mental health, and provision for support of this within orthopaedic clinics. Whilst all the surgeons I met were clearly brilliant men, I did not feel as a young woman able to ask them all the questions I had without feeling vulnerable: in particular, questions around body image, future pregnancy, and childbirth. This situation is becoming easier, and I know that support exists through my doctors, friends and family, colleagues, and support groups such as SAUK.

Conclusion (Adrian Gardner)

So, in conclusion young people who have scoliosis are more than just their X-ray. For them to have the best outcome, there is a need for good communication between the treating clinician and the individual with scoliosis, around all the things that aren't seen on the X-ray but that matter to that person. It may well be that the help that is required is not via a spinal surgeon, and that others need to be involved. A holistic view has to be in the young person's best interest.

Certainly, there is research that can be taken forward in the future and as researchers in the field of scoliosis, this is being considered. There is also work to be done normalising the differences in how people look. The work done by the charity 'Changing Faces' in normalising differences in people's appearance has been ground-breaking. There is no reason why the same can't be done for scoliosis.


Pre-op Emily in mothers wedding dress


Emily in her actual wedding dress


Emily currently

Explaining kyphosis

Thanos Tsirikos, orthopaedic spinal surgeon, Scottish National Spine Service

What is kyphosis?

A normal spine, when viewed from behind, appears straight. However, a spine affected by kyphosis shows evidence of a forward curvature of the back bones (vertebrae) in the upper back area, giving an abnormally rounded appearance.

Kyphosis is defined as a curvature of the spine measuring 50 degrees or greater on an X-ray. The normal spine can bend from 20 to 45 degrees of curvature in the upper back area. While the condition usually develops in the upper back (thoracic spine), it is also possible to develop kyphosis in the cervical spine (neck) or lumbar spine (lower back). Scoliosis and kyphosis can occur together, which is often called kyphoscoliosis.

Types of kyphosis?

Kyphosis can affect the young and the old. These are the three primary types of kyphosis:

- Scheuermann's kyphosis refers to a type of kyphosis where the vertebrae have developed a wedge shape. This type of kyphosis can worsen with growth and causes a rigid, non flexible, curve — changing position won't change the curve
- Postural kyphosis is thoracic kyphosis greater than 50 degrees with normal-shaped vertebrae. This type of kyphosis is flexible and often improves with exercises. Changing positions can change the curve
- Congenital kyphosis assumes a difference in the shape of one or more vertebrae. This difference is present at birth. This curve may become more noticeable with growth

Causes of kyphosis

- The cause of Scheuermann's disease is unknown. Research shows that there are probably a lot of factors responsible but that it may run in some families.
- Poor posture
- Osteoporosis, a common cause of kyphosis in adults due to vertebral fracture
- Degenerative, kyphosis develops due to wear and tear on the spine over time. The underlying cause of the kyphosis is typically spinal arthritis with degeneration of the discs
- Metabolic problems
- Neuromuscular conditions such as cerebral palsy, osteogenesis imperfecta, muscular dystrophy, or spina bifida
- Spinal infections
- Spinal tumors
- Spinal injury

Diagnosis

Kyphosis can usually be diagnosed by examining your spine and taking an X-ray. An examination is done to tell if the curve is postural or structural. If your spine straightens when you lie down, it's likely that your kyphosis is caused by poor posture (postural kyphosis). However, if your spine still curves while you're lying down, it's likely that kyphosis is caused by a problem with the structure of your spine. An X-ray can usually confirm the diagnosis and determine the cause of the kyphosis. Sometimes additional tests will be done to determine if there is an underlying cause.

Scheuermann's kyphosis usually appears in adolescents when they are around 10-16 years old. Patients with Scheuermann's kyphosis often have back pain, especially during the early teenage years. Other signs are tightness of the pectoral muscles (chest muscles), hamstrings (strong bands of tissue at the back of the thighs), and hip flexors (inner hip muscles). About a third of people with Scheuermann's kyphosis also have mild or moderate scoliosis. It can often take a while for Scheuermann's kyphosis to be diagnosed because the symptoms (signs of the condition) can be blamed on poor posture.

There is little information about the natural history of Scheuermann's kyphosis. Natural history means what happens to the spine if no treatment is given. Many patients have no serious problems or disability and the symptoms settle once the spine is fully grown. However, people with severe kyphosis (a curve that is bigger than 80 degrees) when the patient is fully grown can continue to get bigger, which can cause a large curve and severe back pain.

Treatment

Most cases of kyphosis don't require treatment. Postural kyphosis can

usually be corrected by improving your posture through exercises.

Whether treatment is needed will depend on the size and progression (worsening) of the curve, the patient's age, and how much growing they have left to do, whether the patient is in pain, the effect of the curve on the patient's appearance, and (in rare cases) the risk of cardiopulmonary (heart and lung) or neurological (nervous system) problems.

Because a curve of up to around 45 degrees is regarded as normal, it is only considered a large curve at around 60-80 degrees. If a Scheuermann's kyphosis patient who is not yet finished growing has reached this level, then a brace, along with an exercise programme, is a common course of treatment.

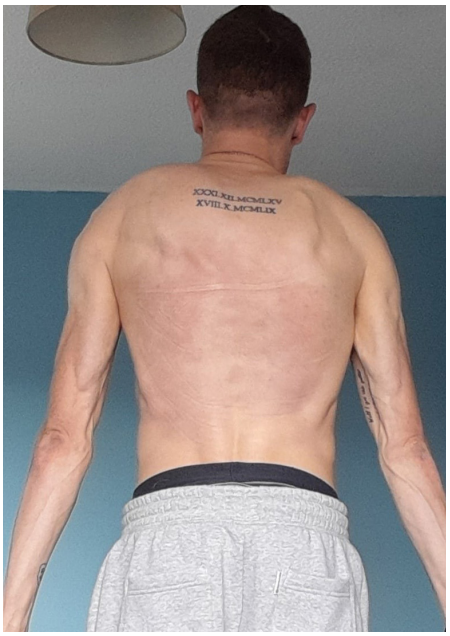
The exercise programme includes exercise and strengthening of the back and stomach muscles and stretching of the hamstrings and pectoral muscles. On their own the exercises will probably help with back pain but will not affect the chance of the curve getting bigger. Exercises are often used along with brace treatment. Bracing is not recommended for adults who have stopped growing because it won't correct the position of the spine.

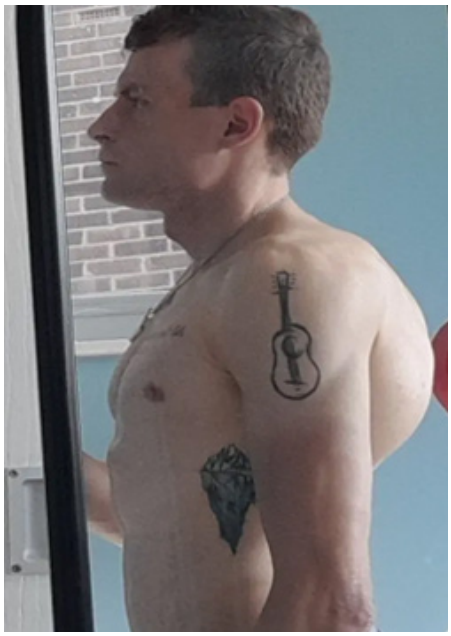
Not all specialists agree that bracing works as a treatment. Some say that there is a high risk a patient's curve will continue to get bigger after they stop wearing the brace. Also, that wearing a brace as a teenager can cause distress and low self- esteem.

Surgery may be an option if the curve continues to progress (get bigger) to more than 70 degrees and causes pain or the patient is concerned with how noticeable their curve is. An operation might be offered if there is a risk of neurological issues (problems with the nervous system). Surgery is only recommended for more severe cases of kyphosis, where it's felt the potential benefits of surgery outweigh the risks.

Phil Buckley

Phil was diagnosed at 15 with adolescentidiopathickyphoscoliosis, three curvatures in all. His diagnosis came after a holiday during which he took his shirt off, and when he went to bend down to pick something up his mother noticed his back didn't look right. Phil wanted to share his story as someone with kyphoscoliosis who chose not to have surgery and is thriving.





"I remember being a bit scared because I'd never heard of scoliosis before so I had no idea what it meant or what could happen. I remember being told it was more common in girls.

I had regular check-ups by a specialist for about 3 years just to check if the curves were progressing and if surgery would be needed. I was given the all-clear and told that I could have surgery for cosmetic reasons if I wanted to but I didn't need it. I'm very lucky because I have never experienced any back pain from scoliosis and the appearance has never bothered me much.

In terms of appearance, I think the kyphosis is much more obvious than the scoliosis. As a teen, I'd get comments from classmates and when I was a teacher I had to contend with the usual hurtful remarks like 'hunchback' and 'Quasimodo' from my students.

I've never been bothered about how it looks, mainly because I can't see it and as long as I'm healthy and can still keep fit and active (which I do), that's what's most important to me. If people want to make unkind, shallow comments the problem is with them, not me.

When I was first diagnosed, I was into horse riding and windsurfing and the specialist allowed me to continue those activities. These days, one of my biggest passions is calisthenics, building strength and fitness using your own bodyweight as resistance.

I wouldn't pretend to be an expert, but I do wonder how much of a part exercise has played in maintaining strength in my back muscles and encouraging better posture."

London Marathon

Thank you to the incredible people who ran the London Marathon in support of Scoliosis Association UK and our sister charity British Scoliosis Research Foundation. Every year, many of our runners themselves have scoliosis and have been through fusion surgery. Running 26.2 miles is an impressive enough feat for anyone, let alone someone with titanium rods in their spine! Thank you to our 2022 runners, Sarah Tait, Robert Watson, Sophie Mills, Antony Wilson, Mark Elmore, Victoria Steele, Luke Stevenson, Hayley Cook, and Stephen Worral who together raised over £15,287! If you're interested in running for us in future years, please get in touch with us at fundraising@sauk.org.uk

Luke Stevenson


Luke Stevenson

Victoria Steele


Victoria Steele

Stephen Worrall

Antony Wilson

Sarah Tait

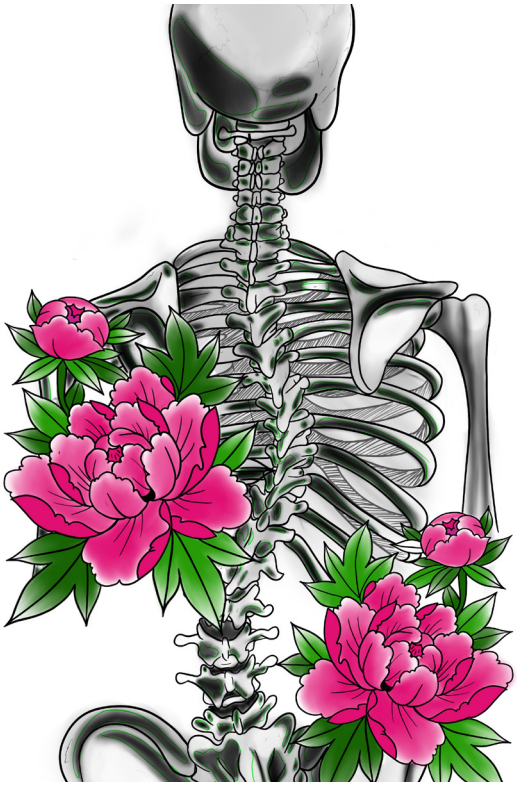
Sophie Mills

Rob Watson

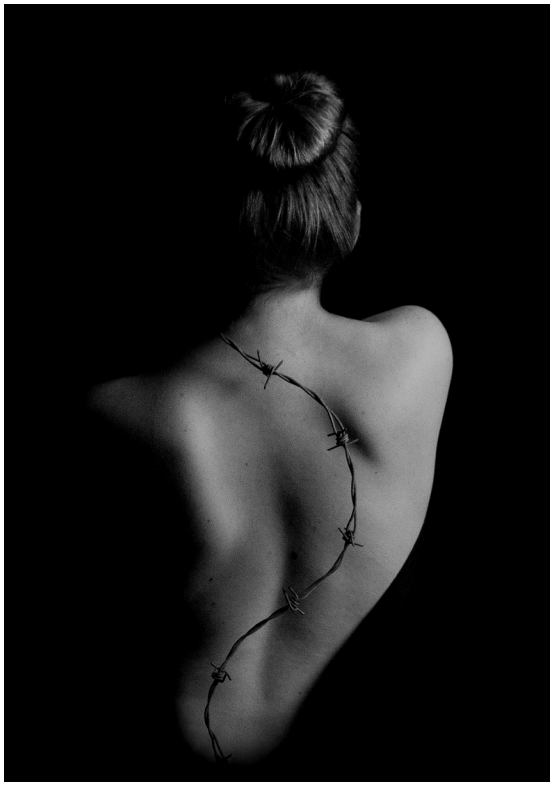
Mark Elmore

Ailie Harrison art competition

Thank you to everyone who submitted their artwork to the 2022 Ailie Harrison Art Competition. It was beautiful to see the ways you express yourselves through art. Congratulations to Leah Unwin, our cover girl and Molly Macfarlane, who came in second place and whose artwork is gracing our back cover. We also wanted to acknowledge and thank our other eight finalists.



Amber Ray Jamieson

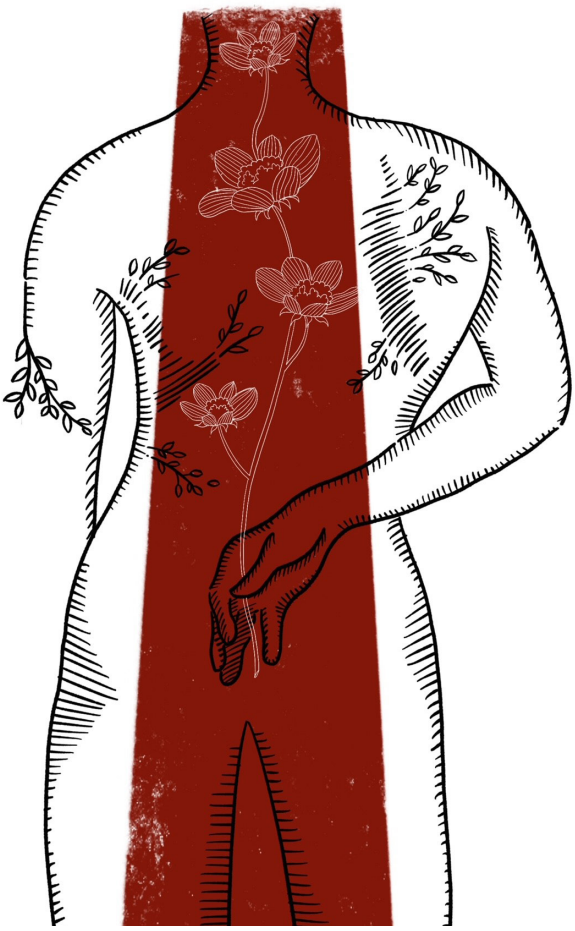


Boe Wilcox

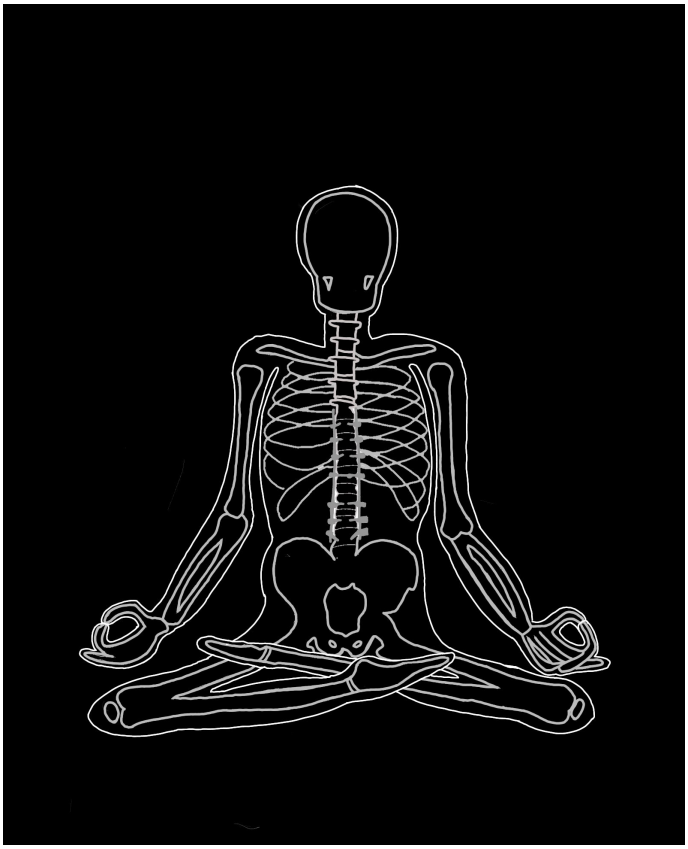
Chanel Waring

Hannah Christie

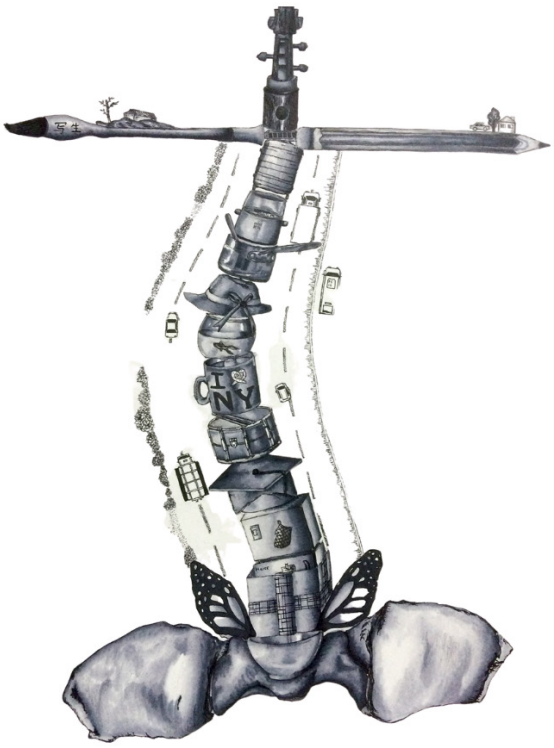
Isla Bell



Judy Bainbridge



Annabel Goodworth



Yanning Wu

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.

Alan Chapman, Alessio Marin, Alice Mckay Hill, Angus Bearn, Ann Margaret Hunter, Anne Stubbs, Antony Brown, Ava-Beth Hudson, Barry Lewis, Brian Blackmore, C Reid, Catherine Burns, Catherine Webb, Charlotte Croft, Cheryl Barnes, Chloe Cann, Claire Russell-Bates, Clare Rice, Colin Smedley, Daniel Harrison, Daphne Bailey, David Bonnett, David J W Hardie, David Lynch, David Patterson, Deborah Gillard, Denise Jane Bailey, Diana Lucas, Dionne Ross, Elaine Pepperman, Emmanuella Olaore, Enghim Chua, Ethan Spearink, Evelyn Brennan, Fiona McRobert, G Huisman, Geoffrey Rees, H Doherty, H Orr, Hazel Keyte, Helen Clark, Helen Coulthard, Ian Churchward, J Bouchard, Jane Manning, Jane Wareham, Janice Mason, Jayne Boniface, Jayne June Ashford, Jean Pritchett, Jennifer Moseley, Jeremy Cooper, Jill Barton, Jill Best, Joanna Langford, Joanne Larner, Joe Baldock, Josephine Edwards, Joyce Lubell, Judith Grimwood, Julia Pallant, Julie Farrow, Julie Thomas, K White, Karen Kemp, Karen Lamond-Lowson, Kate Barber, Kate Meiklejohn, Kate Stein, Kathleen Jenkins, L Meadows, Laura Tisdall, Limbic Ai, Lisette Keats Khalastchi, Liz Brant, Lizzie Heselwood, Loraine Martin, Lorna Bennett, Louise Stuart, Lucille Thomas, Lynne Ridgway, M Tomlinson, Marjorie Roberts, Martin Bourne, Martin Miller, Martin Radford, Michael Forbes, Michael Green, Michele Beadle, Miriam Wilcher, Nazreen Shah, Neil Warren, Nick Everett, Nicola Abraham, Nicola Beer, Nicola Murphy, Paul Hanselman, Philip Diamond, Phillippa Rackham, R A Croshaw, R K Evans, R M Couchman, R O' Malley, Rebecca Ng, Richard Marshall, Rosa Alonso, S Whitlock, Saira Awan, Sally Oxley, Samantha Miller, Sarah Kessler, Sharon Cashin, Sharon Inglis, Sian Cathryn Turnham, Sonia Broddell, Sonia France, Sowmya Iyer, Stephen Ingram, Stephen James Fawcus, Sue Roach, Tony Armstrong, Tony Dickin, Victoria Beckett, Victoria Margeson, Victoria Marks

In memory of...

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

£19.10 was received in memory of Daniel Bell

£250 was received in memory of Eileen Huxham

£127.75 was received in memory of Carol Anne Lewis

£150 was received in memory of Shane Keyte

£37.64 was received in memory of Christine Jackie Smith

£23.70 was received in memory of Steven Foster

£75 was received in memory of Stella Kay

£59.76 was received in memory of Howard Roberts

£1205 was received in memory of Susan Pridmore

£28.65 was received in memory of Kerry Burgess

£190.60 was received in memory of Sandra Robinson

Legacies

We have been extremely forutnate to receive several signifcant legacies this year that will allow us to develop specific services for our members in a way we have not been able to do before. 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 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. 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.

SAUK - Fundraisers

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

Sounds Familiar Choir

Paul Morris and his family showing off their backs

Sounds Familiar Choir

Paul Morris doing the Cotswold Way Challange

Fundraisers

Yvonne Halliwell
Victoria Steele
Sara Noakes
Antony Wilson
Robert Watson
Mark Elmore
Sarah Iankshear
Vicky Quantrill
Hayley Cook
Michael Cason
Eleanor Angell
Emilia Holder
Andrew Milburn
Sarah Tait
Robyn Johnson
Amy Collins
Paul Morris
Katie Hilder
Philip Buckley
Alison Hopkinson
Victoria Houghton
Anne Gordon
Ellie Mae
Ruth Bennett
Paul Todd
Jai Shukla
Josh Wiggett
Phoebe Barber
Ross Taylor
Heather & Eric Jackson
Wirral Grammar School for Girls
Sounds Familiar Choir

Facebook Fundraisers

Kirsty Louise
Jo Lowe
Tracy Archer
Louise Caunce
Phil Lowe
Abi Lessels
Emme Williams
Mimi King
Beth Mitchell
Louise Robinson
Lesley Gilks
Lucy Parkyn
Sara Moraity
Kayleigh James
Chloe Hurst
Courtney Edwards
Billy Wilkinson
Lynsey Hardy
Gillian Leary
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Tracey Mehaffey
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Jess Broadberry
Charlotte Stephens
Nicki Moore
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Sophie Crichton
Emily Marie
Amy Wiseman
Chelsea Tapp
Gillian Wills
Emma Owen
Lily Sheppard
Rachael Homewood
Ruth Bennett
Jennie Syson
Kayah Taylor

Using wearable devices to monitor balance in AIS

Fraje Watson, research assistant, division of surgery & interventional science, University College London

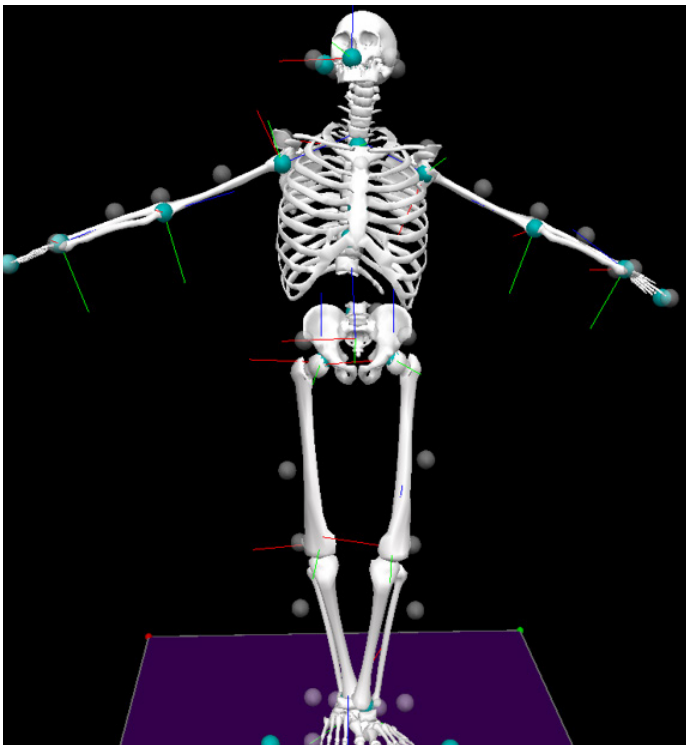
Researchers from University College London (UCL) and the Royal National Orthopaedic Hospital (RNOH), Ms Fraje Watson, Professor Rui Loureiro, and Mr Julian Leong, have been investigating balance in children with adolescent idiopathic scoliosis (AIS).

Many researchers are interested in how children with AIS move, either in comparison with typically developing children, between different curve types, or in response to treatment such as spinal fusion surgery. Movement research is important to help us understand how scoliosis starts, how it develops, and how it responds to treatment, and to help clinicians monitor patients over time.

A review of existing research on movement in children with AIS suggests that measurement of balance provided strong and consistent information about them However, most of this research was on standing balance only, and not walking balance. Fraje uses the Motor Learning Laboratory at the RNOH, where the movement of each part of the body can be analysed, to measure balance during walking. Using these data, she calculates the Margin of Stability (MoS) to measure walking balance. The MoS is commonly used to monitor balance in lots of other musculoskeletal populations. Walking balance is important because it is used continuously throughout daily life.

Fraje's research asks three overall questions: (1) is the MoS different between children with AIS and children developing normally, (2) could it be measured using a wearable device, and (3) does it change with increasing curve magnitude? This research will help us find out whether the MoS could be a useful means to help clinicians detect and monitor children with AIS in the future. Additional monitoring information like this could help to reduce the number or frequency of X-rays needed to monitor a patient. If the MoS can be measured with a wearable device, then patients could record data at home in their usual environment, and benefit from telemedicine monitoring, reducing necessary trips to their hospital.

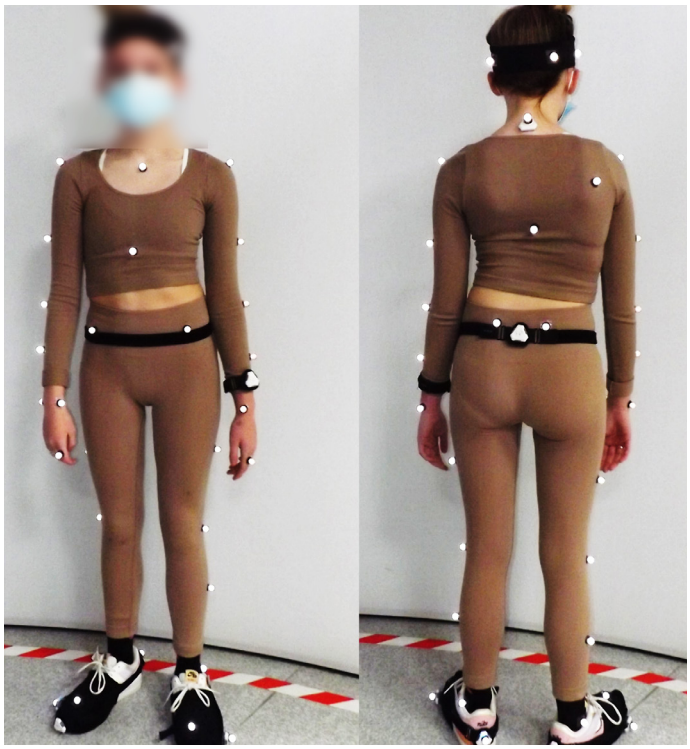
Data for this research are collected at the RNOH Motor Learning Laboratory. This laboratory contains a Gait Real-time Analysis Interactive Laboratory (GRAIL) with a dual-belt instrumented treadmill, surrounded by ten motion capture cameras. During motion capture gait analysis, participants wear lots of small reflective markers on their skin. The movement of these markers is recorded by the motion capture cameras. The position of these markers can be used to generate a computer model of each participant used to calculate the MoS. Motion capture gait analysis is used at the RNOH for lots of reasons such as assessment, research, and rehabilitation. Worldwide, motion capture technology is used in musculoskeletal medicine, for professional sports analysis, and in film industries to



capture actor movement and facial expressions before they are converted to Computer Generated Imagery (more commonly known as CGI).

Fraje's research also measures movement data using a wearable device system and app called Notch. Each Notch is an Inertial Measurement Unit (IMU) that includes a tiny accelerometer, gyroscope, and magnetometer. Smart phones contain similar sensors, which is how they know if they're upside down, or allow them to be used to steer a car on Mario Kart! The Notch is connected to an app that calculates the movement. For this research, participants wear seven Notchs in total: three on each foot, and one at the base of the spine. To see if we can use the Notchs to measure the MoS of children with AIS, we compare results from them to the motion capture data (which is the gold-standard).

So far, this research has shown that the MoS is different in children with AIS and children developing normally in the forward-backward and side-to-side direction. This means the MoS could be used as a marker of AIS. Additionally, the MoS changes as the spinal curve gets bigger which means it might be good at monitoring curve progression or response to treatment. The Notch wearable devices are able to measure the side-to-side MoS reliably and we hope with further research and development, they will be able to reliably measure the forward-backward MoS too.



Recently, three online focus groups were advertised on the SAUK social media accounts. These sessions were intended to build upon the work started by the James Lind Alliance Priority Setting Partnership by focusing on children with AIS. The sessions were organised so that young people with AIS could discuss their ideas and priorities for research into children like themselves. These types of session (formally known as Patient and Public Involvement) provide opportunities for patients (and their families or carers, etc.) to be involved in generating ideas, providing feedback, planning, managing, and designing research. Each session had a theme (technology, screening, and conservative management), and the outcomes will be used to guide further applications for research funding and direction.

This kind of research and Patient and Public Involvement doesn't happen without patients volunteering their time to take part. We would like to extend special thanks to all the children (and their parents) who took part in our study and focus groups because we sincerely couldn't have done it without you. We'd also like to thank Matt, Olivia, and Roisin from the RNOH Motor Learning Laboratory and the British Scoliosis Research Foundation for the funding that enabled this research.

About the BSRF

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 or 3 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.

Early Onset Scoliosis

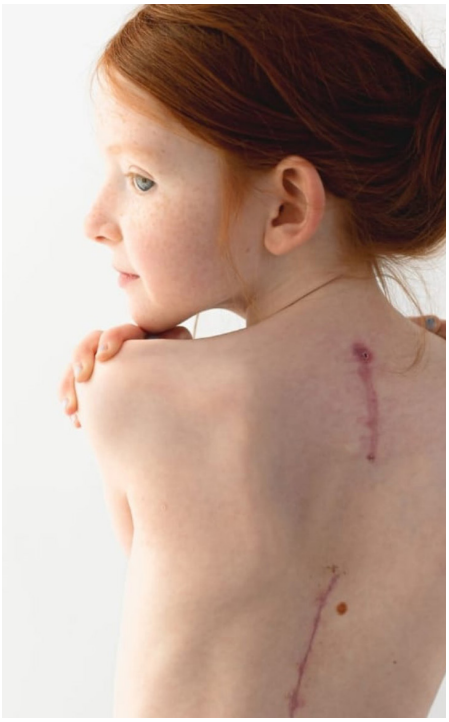
Quinn Pedelty's story, by mum Rebecca Pedelty

Quinn, my daughter, was diagnosed with scoliosis in September, 2020, just before her 6th birthday. We hadn't noticed a curve developing and she hadn't before complained of any pain or discomfort. The morning Quinn did complain, I had a quick look before school and made an appointment with the GP thinking she had simply pulled a muscle. When Quinn came home from school later that day, I asked to have a proper look at her back and could immediately see a double curve taking the shape of an 'S'. Our GP confirmed that it was scoliosis but suggested that waiting times for the initial appointment with the spinal team was around 9 months. We had heard of scoliosis but didn't know what that meant for Quinn, so we decided to go private for the initial consultation as we weren't prepared to wait and worry for such a long time, we did some research and found out who the GP had referred us to and made an appointment within 2 weeks.

Quinn was diagnosed with a double curve of 60 degrees thoracic and 40 degrees lumbar and a treatment plan was explained. Within 3 months of diagnosis Quinn was in her first plaster jacket. She was able to take everything in her stride as children often do, but as parents we were heartbroken for our daughter, not knowing the journey she had ahead of her.

The plaster jackets were tough, especially in the summer. We managed to make sure she didn't feel excluded. At school if there were any water fights or activities that involved water Quinn took part, albeit it a rain jacket, but she was there, with her friends, having as much fun as she should. Other than contact sports and being able to go on a trampoline, every other activity was fair game, and Quinn made sure she didn't miss a thing. For a year, Quinn was casted every 12 weeks, with short breaks in-between where we made the most of the time off and booked swimming, rock climbing, and roller skating before the next cast. The aim of casting was to hold the progression of the curve, and if this had been successful, then a brace could have been an option. This is something we clung onto as parents as we really did not want surgery for Quinn because at her age it wouldn't just mean one definitive surgery but several operations until she was at an age where spinal fusion would be an option.

However, a year into casting we were told that the curve had progressed to the point where it could potentially start to affect her lung development, so surgery was now the only option. At each stage



and with each cast we managed to explain things to Quinn in a way in which she didn't worry too much. Before each cast and even before her surgery she would know the plan but not the date it would happen. We followed advice from the hospital and only told her with a few days' notice, so she didn't have too much time to worry or get upset.

In January, 2022, following a pre-op and an MRI that determined that the scoliosis was idiopathic, Quinn had growing rods implanted and the next stage of the journey began. We had discussed other options from the concept of an early fusion, tethering, and magnetic growing rods. Each option came with its own limitations and traditional growing rods were the best option for Quinn. The surgery carried risks, as with everything, but Quinn sailed through with no problems. Recovery was rough for a few days, mainly down to the side-effects of the anaesthetic, but thankfully she did sleep a lot of the time and her pain was managed with regular medication. Following the operation, Quinn was reluctant to get out of bed, more out of fear than anything else, but the physiotherapist persisted and managed to get her up on day 2 for a few steps. From there on out she came on in leaps and bounds, the catheter and cannula were removed, and we were able to take short walks around the ward before being discharged home on day 4.
Quinn was casted after the surgery, (her very last cast) which gave her great support and almost the feeling of being protected. 12 weeks after surgery the cast came off and everyone was pleased with the results. In June, the first (of many) rod lengthening procedures was done, the surgery and recovery are much quicker and usually done as a day case. Quinn was back to school within the week. Rod lengthening will be need be done every 6 months as she grows until she is of the right age for a spinal fusion.

You would never know that Quinn has scoliosis, or the operations that she's been through so far, her courage and determination shine through every day.

Grace Mcdonagh's story, by mum Sara Mcdonagh

My daughter Grace is 5 years old and was born with infantile idiopathic scoliosis. Grace is the second youngest of my 7 children and I could tell there was something different about her soon after she was born. My concerns were waved off at first but when Grace was 5 months old and trying to sit up, it became even more noticeable. I took Grace to her doctor who suggested it could be scoliosis and referred her to the scoliosis centre near us.

After seeing Grace, her surgeon immediately suggested casting, with the aim to hold the curve to prevent it from worsening. Grace's cast was replaced every 3 months.

Grace is a bright little girl, not someone you can get anything past. She is starting to ask more questions, noticing a difference

between her and her siblings. Grace asked me recently why she was born this way and I explained that everyone is different and unique, and that Grace is like a tree, a tree is not always going to grow perfectly straight but is still beautiful.

Casting didn't successfully control the curve as much as hoped unfortunately, and her curve did continue to grow over the years, with it now sitting at 100 degrees. The casting has stopped now and Grace will very soon go in for surgery to start a new phase of treatment, growing rods.

I have learnt not to take anything for granted. Our goal is to get Grace to a point where she can take ballet classes. Grace loves anything to do with ballet but isn't very steady on her feet at the moment. The thought of that will be something to look forward to and remind her of the reason she's going through these treatments. Grace has had photos taken each year of her life with her in her brace, a tradition they will continue with. I want my daughter to look back on this and see what she's gone through, for her to see how strong she is and to take pride in her scars and experiences because it will show how hard she worked. I would say to other parents going through this to stay positive and stick to their goals.

Allie Sumner's story, by mum Ivana Sumner

My 3-year-old daughter Allie has infantile early onset thoracolumbar scoliosis. Allie was a happy, healthy baby when she was born but had a very prominent birth mark on the base of her spine. When she was about 4 months old my sister felt a lump on the baby's side, like her back was sticking out further on one side. I could feel it too, but Allie was hitting her milestones early and it didn't seem to bother her. When Allie started crawling I noticed that one side would always give way, always the same side, the side opposite her lump. I wondered if this was related to the lump but never having heard of scoliosis, it didn't seem like an issue that needed to be brought up because other than that, Allie was doing great.

Allie was about 14 months old when she started walking and I noticed her gait was off, she was standing curved, and her balance was off. Allie was at one point seen by an orthopaedic specialist who said that the birth mark itself was a sign of a spine deformity. Allie was taken in for an X-ray and afterwards I thought she was looking at an example of a spine with scoliosis, but was shocked to find out it was my daughter's spine and that it was larger than I ever would have guessed by looking at her.

This specialist referred Allie to their nearest scoliosis centre in Edinburgh which was still 120 miles away for us. Allie was then diagnosed with a 65-degree curve at 18 months old. An MRI and CT scan was ordered to see if there was an underlying cause, but it was confirmed that Allie's scoliosis

was idiopathic. This was hard for me to accept – that my daughter's spine could be this curved without knowing why. Allie was also booked into a moulding for a cast so that could be fitted as soon as possible to try to contain the curve. Her spine is rotating, as well as curving and the specialist had to explain to me that this could put Allie's lungs and heart in danger of being squashed so they had to act fast. Every step up until the point of seeing the scoliosis specialist had seemed so slow so this was a shock and quite upsetting.

In November of 2021 we went back to the specialist, and the curve had reduced to 50 degrees from 65 degrees. Ivana was ecstatic but the specialist wasn't. Allie had grown so much in the 6 months that he was worried that she was growing too fast, and they had to get her in a brace as soon as possible. In subsequent visits, Allie's curve has continued to grow after that initial 15-degree correction. At first it went up to 52 degrees but the last time they checked it was up to 56 degrees. The treatment plans can change every time they see the surgeon because they're reacting to how Allie is responding to the latest brace. In the last appointment the surgeon explained that the brace is delaying surgery, but that Allie would have to have growing rods to further control the curve while she grows, and that this would need to happen sooner than they had aimed for. I worry going into each appointment but reminds myself that it can be treated, and it will be treated, but it's a long process finding the right way to treat idiopathic scoliosis.

Allie calls her brace 'knock-knock' for the sound it makes when you knock on it, but she has no idea why she has to wear it, she doesn't understand that there's something wrong with her back. Each brace is traumatic for Allie, it fits differently from the previous one, it hurts her, and she has to get used to it again. The specialist is compassionate, and Allie loves him, but he has had to be very honest and to the point with us. I don't want to be kept in the dark and want the facts so that it pushes me to keep up with bracing and make sure Allie is wearing it for 20 hours a day, as prescribed. We have built a good routine with the brace and this has been so important. Allie knows she can have her knock-knock off just before dinnertime and for bath-time, so when she smells her dinner, she will come up to me and say 'knock-knock off!'.

Allie is full of energy, just as rambunctious as any kid out there, jumping on trampolines and doing somersaults. There are going to be points in time where she won't be able to do that but, in the meantime, I want her to enjoy it.

Putting on a brace can be difficult at first. You're shown by the orthotist but as soon as you are home by yourself, you question everything. You get used to it and figure it out, listening to your child and taking notice of the way they move can help. There are a few struggles, and each new brace starts a new period of settling in and pulling on the top strap is never fun.

As a parent of a young child with scoliosis, even though it's the child actually going through this, it's the parents who understand what's happening and have to agonise over every decision. This isn't really any different from how any parent feels though, and you never know if you're doing it right, you just do what you have to do to get it done.

Explaining casting vs bracing

Many young children with scoliosis will need their spine to be guided into its normal position as they grow, which can be done by putting them in a cast. The cast starts from the underarms and covers the top half of the body. The cast is made of light materials. It cannot be removed but is changed regularly as the child grows and the shape of the back starts to change. Casts need to be made and fitted in a special way. They have a hole in the chest area, which allows the lungs to expand so that the child can breathe properly. In children under 2 years old, the cast will be changed every 2-3 months with the aim of making the spine straight. Many parents find it easier for their child to wear a cast instead of having the problem of getting them to wear a brace each day.

If the curve is getting bigger, and the child is still growing, the specialist may want to put the child in a brace. A brace when applied properly helps to reduce the size of the curve. The aim of bracing is to stop the curve getting bigger. Wearing a brace can mean that the child can keep growing for longer before a more permanent treatment, such as surgery. As the child grows, new braces will need to be made.

Your Back Stories

Zoe Gibber

I was never embarrassed or scared to have braces, in fact I was happy to get them. Everybody else had metal squares on their teeth, they all looked okay so why shouldn't I? Finding out I needed braces for my teeth was just another excuse to get an afternoon off school when I finally got an orthodontist appointment. They were chunky, ugly, and completely visible yet I didn't seem to care. I continued to smile.

Then came my second brace, one that was practically invisible, only known if I told people and rare amongst the vast majority I knew. Somehow that was the embarrassing one. I was always aware of scoliosis. My mother, having at the time had two operations, never stopped going on about it, always stopping me when I was topless to check my spine, in truth it drove me insane. She was cautious like any parent that her problems would become mine.

The day I got told I needed a brace a million thoughts ran through my head. The main one being, will it make me look fat? As a teenager, already being faced with bloating and body worries, the last thing I needed was extra inches tied around my waist. I only knew a brace as metal things that went in your mouth or that awful thing Charlie wore on his head in Charlie and the chocolate factory. I had no idea what to expect.

Fast forward a week, the brace arrives. Thick, white, plastic. It was gross, looked like something out of the Victorian days. I think I cried for the first month every time I had to wear it, but then, like everything, it got easier. I know how this sounds, very negative, I'm just setting the scene. I don't think it would be normal if I told you all I got a back brace and I loved wearing it, who would?

'The girl with the brace', 'screwed up back girl', 'hunchback'—these are the names I thought my friends would come up with for me, the scenarios I created for myself. That never happened. At school I had a big group of friends, guys and girls and I couldn't have had more support. It was amazing. This thing, this brace that I was so embarrassed about, so nervous to show anyone or tell anyone actually became a reason I got closer to people. No one laughed at me or made me feel weird, they just accepted I had a problem that needed fixing. They had more acceptance for it than I did.

I think sometimes we doubt people more than we should, the brace not only fixed my curve which of course is the main positive of this entire story, but it showed me that people are way better than you think they are.

One thing that I found really hard was telling my boyfriend about my brace and I haven't even worn it for 10 years. How ridiculous is that. We were on holiday and talking about braces, the dental ones of course. Nervous little me used it as a way to mention the thick, white clump of plastic, and he had no reaction. The lack of reaction clarified for me all those years ago that having a disability like scoliosis is nothing to be ashamed of. There is also hope in talking about something that others may feel comfortable to come forward too. Isn't there that saying, 'a problem shared is a problem halved'. I don't see my brace as a negative anymore, it's part of my story, my back story.

Niki Predko

I'm 57 now but only found out I had scoliosis when I was 42. There are signs that point to me having this for a lot longer than that, but for the first 42 years, ignorance was bliss. The diagnosis came about because I was having a pain in my neck, so I went to the doctors for help. The doctor suggested an X-ray, but in the meantime being in so much pain, I went to a chiropractor to see if they could give me some practical relief.

After taking notes of my medical history, the chiropractor examined me and informed me I had scoliosis, was I aware? No, I wasn't, I hardly knew anything of the condition at the time. By coincidence, my doctor telephoned me later that same day to let me know he received the X-ray results, nothing untoward with the cause of my neck pain, but he too noted I had scoliosis, how bizarre.

Fast forward to November, 2018, I pulled my back trying to get something heavy from behind my front car seat. I carried on for some months with the pain, some days better than others. I was working as an Executive Assistant for a global firm with the benefit of private health insurance and in Spring, 2019, at a routine appointment with my doctor, she noted I was having trouble sitting comfortably and short of breath and asked what the problem was. When I replied I had done something silly to my back nearly 6 months previously, she requested an MRI scan, together with treatment with a physio. The results were interesting!

The people who SAUK mentions in their posts make me feel so minor compared with them, but I admire each one of them, they're inspiring. I have not had corrective surgery as a teenager because I didn't know I had the condition. I do remember odd things like the fact I have one leg longer than the other and with flares/bootleg jeans in fashion at the time, it seemed so obvious to me and therefore to everyone else in the universe, that my jeans/trousers were odd lengths! I used to drop the hem on my right leg to make the lengths match. I also remember jeans never used to fit on my hips properly, I would drag my poor dad shopping to get a pair of jeans that were made "properly" and would sit level on my hips, for the zip not to be twisted, I remember saying to my Dad, 'why are jeans not made straight and why do they sit crooked on me', but I now know, it wasn't ever the jeans, it was me!

I am an active person, I walk, run, cycle, swim, do gym classes for dancing, yoga, body pump, and unless you know what you are looking for, I don't think you would ever know otherwise. I am super grateful for what I have and what I am able to do.

Nicholas

Before January, 2022, the word 'scoliosis' was not one that I was familiar with. However, over the next few months this would change and this particular word would go on to dominate many conversations.

Diagnosis (January and February, 2022)

One afternoon as I was putting some water bottles in the fridge, my mum noticed that when my back was bent, my shoulder blades and waist looked uneven. It looked as if one side of my back was higher than the other. My mum was familiar with scoliosis as her spine is not completely straight, something that was only picked up when she was an adult. It hasn't caused her any problems and she never had any treatment for it. Initially, neither my family nor I were too worried, although my back was noticeably more curved than my mum's. My dad googled scoliosis and even tried measuring my curve with a ruler to find out the degree! My mum concluded that since only a small percentage of scoliosis patients have surgery, the odds were that I would be absolutely fine. I had an appointment with my local GP a week or so later who suggested I had a scoliosis curve of around 10 degrees and referred me to a spinal specialist in London. During that appointment I had a series of X-rays taken. The radiologist showed me an image of my spine and the curve was very obvious. It was at this moment that we thought that this could be more serious than we anticipated. The specialist measured the Cobb angle and it turned out that my curve was around 52 degrees. Both my parents and I did not expect this outcome and the recommendation to have surgery. Because the curve had progressed past the 40-45 degree mark, if I didn't have surgery, it was likely that it would worsen with time and cause further problems and pain as I got older.

Build-up to the surgery (Spring)

I wasn't really bothered by the prospect of having surgery to be honest and was probably more worried about my upcoming GCSE exams than the operation, which was going to take place in July. In the months leading up to my operation, I had another meeting with my surgeon and we discussed everything that would happen pre, during, and post-surgery. I had to travel to London for a series of pre-surgery meetings. I met with a physiotherapist who walked me through what I would do on each day after the operation as well as what I could expect to do in the months afterwards. I had my blood taken to check for my blood type, they tested my lung capacity, and I had an ECG to ensure that there were no heart problems. A nurse with overall responsibility for the operation explained every single detail from pre-surgery to going home. The thing that intrigued me the most was how anaesthesia works and the meeting with an anaesthetist was really fascinating. All the nurses and doctors I met were extremely experienced and left us with the sense that they knew exactly what they were doing and that everything was going to be absolutely fine. After these meetings, I felt reassured that there was nothing to worry about. I didn't feel it was a big deal and was happy to talk to my friends about it. The thing I looked forward to the most was gaining an inch or a bit more which meant that I would be as tall or a little taller than my older brother.

Pre-Surgery

The day before the operation I had my blood tested again and was told to eat a huge dinner and have a big snack later in the evening as there would be no food for some time after the operation. I was still very calm, despite my mother telling me repeatedly over the last few months that the recovery would be harder than I imagined. I even looked up images of scoliosis surgery online and wasn't fazed by this however, but in hindsight, I recommend that you skip this part.

Day of the surgery

We arrived at the hospital 2 hours before the scheduled time for the operation. I went to my room, unpacked my bags and then had

another load of tests done, checking my blood pressure, temperature, etc. My surgeon stopped by to make sure everything was fine and for us to sign the authorisation forms. The anaesthetist also stopped by to see if I had any last-minute questions and to explain everything that would happen between now and when I came out of surgery. The nurse put a cannula in my left hand and this is where all the medicines and anaesthesia would be fed into my body from now until 2 or 3 days after the operation. Soon after, I was wheeled down to the theatre and said good-bye to my parents. The anaesthesia felt cold as it entered my hand and then everything went dark.

Post-Surgery

I woke up in the ICU a few hours later and drifted in and out of sleep for some time after. There were lots of different machines around me and my left hand had numerous tubes connected to the cannula. I spent 24 hours in the ICU and most of it is a blur. I had a bit of food, a pot of yoghurt, in the evening but did not feel like food. The next morning, just over 24 hours after surgery, two physiotherapists stopped by to see me and asked me to sit on the side of my bed and stand up. I found this quite easy and they asked if I would like to take a few steps. Not only did I take a few steps but I ended up walking around the whole ward! They were with me every step of the way as I was still light-headed. A side effect of morphine is that your head is not always in the right state – at one point I had confessed to murdering SpongeBob and blabbered on about watching the formula 1 driver Max Verstappen play tennis at Wimbledon. My nurse described this as dancing with the fairies.

Hospital Time

Initially I wanted to leave hospital as quickly as possible; however, I soon realised that it might take a bit longer than I originally anticipated to get back on my feet. I was in hospital for 4 days and there were many ups and downs but there was a big change between the start of the week and the end. Initially I didn't eat much but I had to drink a lot of water. I was very comfortable with walking – on day 2 I walked around the ward multiple times and on day 3 I climbed the stairs, up and down, and walked more than the day before. I was also able to have a shower for the first time after the operation. The really hard bit for me was sitting in the chair. I didn't realise, but sitting puts more pressure on your back than standing or walking. That took a while to get used to and by the time I left hospital I could sit for very short periods of time only.

I initially received pain medication through the cannula and had a button that I could push for an extra dose of morphine in the first 2 days. After that, the cannula was removed. Initially I had morphine orally and then on day 4r I switched to another less strong pain killer that I could also take at home. Time passed very quickly in the ward with most of the time spent watching the news or Wimbledon. However, I would be lying to you if I told you my time in the ward was fun. It was very hard to adjust after my operation, which came as a surprise to me as I thought it would be very easy. Morphine drips made me very nauseous, but if I didn't take painkillers my back would start to hurt so it felt like a no-win situation. The worst was when I took four morphine shots in one hour (I should point out that the mechanism does not allow you to overdose) making me very sick and the motion of gagging hurt my back a lot. Although this was a tricky situation you must keep in mind that the pain is temporary while the results are permanent, and I have absolutely no regrets of having surgery.

Out of Hospital

Once I left the hospital, I still took pain medication for another few days and went out for walks every day, a couple of times a day. Every day it got a little bit easier, but it did take a while for me to be able to sit for longer periods of time. It's been 3 months since my operation and I feel pretty much normal except that I can't play sport yet and have to be careful not to bend or twist. I do get tired easily and going back to school was a bit of an adjustment. I can only carry a fairly light ruck sack and have a second set of text books at home as they are pretty heavy. I hope to be able to start swimming soon.

The Future

Throughout the next year I will go and see my doctor again several times for regular check-ups and X-rays and I hope to be able to play cricket next summer.

Although my journey wasn't easy, I have no regrets and I am very pleased with the outcome of my surgery and hope to get fully back to normality next year.

Kamilia Anuar

I was diagnosed with scoliosis at age 16. Around that time, a schoolmate had remarked that my hips were "imbalanced" but I thought nothing of it. Persistent shoulder pains triggered me to ask my parents to see a doctor. I was brought to a chiropractor who ordered X-rays and diagnosed me. I was told I had a lumbar curve measuring 56 degrees, and that it was "a lot". I remember my father and I sitting in the consultation room in stunned silence. The next thing I know I was brought to an orthotist to have a Boston brace fitted, I was given a heel lift for my left shoe, and there was talk of how I might need surgery.

I hated the brace at first. It was bulky and very uncomfortable to wear initially, especially as I lived in Malaysia at the time where temperatures are consistently around 30 degrees during the day. But I soldiered on and wore the brace faithfully. My parents brought me to have chiropractic adjustments and massage therapy, but whilst it managed any pain and discomfort, it of course did nothing for my actual scoliosis.

At age 18 I switched to a different treatment centre and was given the SpineCor brace. I went to physiotherapy each week for some months and was also taught a "corrective movement" which I later found out was based on the Schroth method. As my curve still retained some flexibility, this managed to bring my curve down to 48 degrees. My curve was stable, and I was almost fully skeletally mature, so I was not pushed to have surgery.

I've lived with my curve now for at least 12 years, throughout school, university, and my early professional years. I won a scholarship to study law in the UK and my braces were still by my side for the times I needed a bit of extra back support - some chairs in the libraries could be very unsupportive and I struggled at times with long study shifts. Happily, I graduated with a first-class law degree and eventually stopped wearing the brace altogether.

I go for check-ups every few years to assess my curve and it has barely changed. Recently, one health professional measured my curve at 45 degrees another measured it at 50. I saw a scoliosis surgeon to discuss if surgery was recommended and we concluded that I didn't need it for the time being - the risks weren't worth it in my case, particularly as I would need fusion to L4 and consequently lose significant mobility. Instead, I have been working with a Schroth physiotherapist to try to improve my hip alignment and happy to say I've been seeing results just after a few weeks.

I'm only 28 so perhaps my youth has spared me much trouble so far, but I've been able to live a full, active life with scoliosis with minimal pain. I have held down full time office jobs and will soon be training to be a lawyer. I also maintain an active lifestyle - I swim, go for spin classes, Zumba, yoga, and weight train. Sometimes my hip alignment still bothers me, but I love fashion and have learnt to dress in a way that flatters my body type! Scoliosis is so individual and affects each person differently. I have anxieties about possibly needing the surgery one day. But for now, I'm going to live well, keep active, and hope to continue to avoid it.

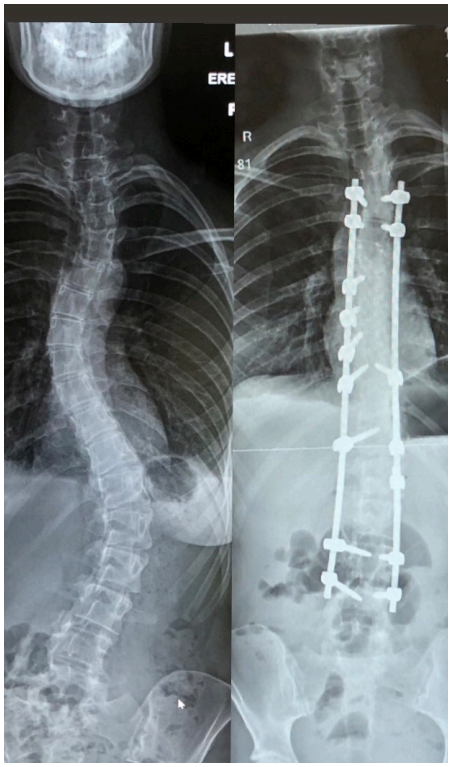
Rebekah Beattie

My name is Rebekah, and I am a 23-year-old medical student with adolescent idiopathic scoliosis.

I first noticed something unusual about my body when I was a teenager and struggled to find clothes that fit my uneven waist. I had always been active, healthy, and pain-free, so I didn't think much of it and attributed my "wonkiness" to a growth spurt, hoping I would grow out of it. I am the first person in my family to go to medical school, so at this point, I had never heard of scoliosis. It was only when I gained awareness of the condition that I suspected I might have it myself.

I made an appointment with my GP when I was 19, who referred me to see a spinal surgeon and have scans. One of the most difficult moments was when I saw my first X-ray. Aside from my waist asymmetry, my scoliosis was never noticeable to the naked eye. I was hopeful that my curvature would be mild and could be managed with physiotherapy. Unfortunately, this was not the case. I remember looking up at the screen to see a large, S-shaped curve spanning the length of my spine, and my ribcage rotated sharply to one side. Because I had stopped growing, I was told there was a 50/50 chance my scoliosis would remain stable or continue progressing. I felt devastated and very anxious about the future.

I agreed to manage the condition conservatively over the next few years, regularly attending physiotherapy whilst having scans to monitor for progression.



Unfortunately, my lumbar curve continued to progress by several degrees per year, and I started to experience much more pain. Multiple overuse injuries due to imbalances coming from my spine meant I had to give up running, something I still miss greatly. Physically demanding placement at medical school became more and more challenging, and I had to rely on strong painkillers.

After much consideration, I began to think about surgical management and decided to go for it. I was put on a waiting list for spinal fusion, and around 6 months later, I received a phone call with a surgery date. I finished my exams in June and flew home soon after for pre-op assessments.

The operation itself took about 5 hours, fusing my spine from T4-L4. I then spent some time in recovery before returning to the ward, where I could see my family. The next few days were a hazy blur - I think I spent most of it asleep. The physiotherapy team helped me to stand on day 3 and take my first cautious steps on day 4. I left the hospital 7 days after surgery.

When things have been tough, I try to focus on what I have gained from the experience. I may never run competitively again, but I have a newfound respect for my body's adaptability and resilience. In my search for alternative pain management methods, I discovered a new passion for Pilates. I would recommend Pilates to anyone with scoliosis – it was one of the most significant factors in keeping my pain at bay. I love that it allows me to incorporate elements of meditation and mindfulness into a bodyweight workout that improves my alignment. I'm now learning to adapt my practice to strengthen my spine post-operatively. Exercise is a huge privilege that many with scoliosis, due to pain or impaired mobility, are not afforded. I'm grateful for each day that I can enjoy joyful movement, as it is the most important item in my pain management toolkit. Pre-

operatively, my flare-ups would usually follow periods of being sedentary (usually during exam times!).

It has been difficult managing chronic pain whilst being at medical school. It is more difficult to manage this pain when one inhabits a body that appears completely healthy externally. I have struggled to articulate the experience of chronic daily pain adequately to medical professionals, and I have met many patients who face the same struggle. Admittedly I've always felt that it is something we, as medical professionals, do not always manage well. I can only hope that this dual experience as both medical student and patient will make me a better doctor, enabling me to better understand and help my future patients.

I wanted to write this article in the hope that I could somewhat demystify the process for anyone about to undergo spinal fusion. It can be scary - I naively thought my experience in the operating theatre as a medical student would make things easier. This could not have been further from the truth – I still felt completely paralysed with fear as I was wheeled into the anaesthetic room. Surgery is not for everyone and is not without risk, but I can honestly say it has been one of the best decisions I have made for my health. I also hope to reassure anyone who is considering surgery in their twenties. One of my greatest fears was that I would be told I was too old to have spinal fusion, but I'm happy to say that this was not the case, and I have encountered no complications thus far.

I have since been recovering at home and am looking forward to starting my final year of medical school. I am incredibly grateful to my surgeon and my family – I could not have done this without their continuing love and support.

Walking the wall with Lexi

Lexi is my daughter. She is 13 years old and we live in Carlisle, Cumbria. Her big sister, Kayla, started studying medicine in 2021 and received a stethoscope for Christmas. In January, 2022, she asked Lexi if she could practice a check-up with her new stethoscope. She did a full respiratory check and came to me afterwards and said, "Lexi's back is weird". And this is where the story began. We booked to see our GP, not easy during covid, explaining that Lexi had a prominent bulge in her lower back. The GP was concerned, thinking it might be something sinister and referred Lexi for an urgent spinal MRI. The waiting was awful - by the end of January we had been reassured there was no soft tissue mass but that there was "significant scoliosis" and Lexi should be referred urgently to a scoliosis centre. We were seen in April by a wonderful doctor in Newcastle. He confirmed with further X-rays that Lexi did indeed have scoliosis. He was brilliant and asked Lexi what she knew about this condition. Lexi had done her research and told him all she knew about S-shaped and C-shaped curves and about different treatments!

He explained her curvature was in the lumbar region and was already 58 degrees. She would need an operation but waiting times were 1-2y. He then took some extra measurements and was concerned about Lexi's hypermobility, arm span and her long limbs. He suggested we should be seen by the genetics doctors as he was querying Marfans syndrome. This all came as a bit of a surprise, but Lexi took it all in her stride.

Why this challenge? I had been hoping to challenge myself with a big walk in my "significant birthday" year. Part of Hadrian's Wall is on our doorstep so this seemed like a good idea. I discussed it with Lexi and we wondered whether we could "Walk the Wall" together and raise awareness, and maybe some funds, for scoliosis in the hope we could make other people understand it more. So, the day after her diagnosis, we started at the western most point on 9th April 2022. We've fitted the walks in around life - each time having to plan the start and end points for transport. And also, not wanting to cover too far a distance since Lexi's back gets sore the longer the walk. Our planning also had to await fair weather!

Myself, Lexi, and Monty the dog walked the whole distance over 14 legs ranging from 4 to 11 miles. We were joined by 22 other friends and family on different legs as well as three other canine friends as we walked from Bowness-on-Solway to Wallsend. Different books say different lengths but our guidebook said 85.8miles! Lexi completed this on 3rd September, 2022, and has raised over £1300 for SAUK.

Her most memorable part was definitely Sycamore Gap - stunning scenery and yet also one of the hardest slogs because it is so undulating. Lexi wouldn't claim to be an enthusiastic walker but she enjoys good company, beautiful scenery, the history, and the odd bag of sweets to spur her on!

She is back to see the consultant soon as well as awaiting genetics results.

Lexi is positive and upbeat - she has her friends, family and faith to keep her strong. She really is a superstar and a scoliosis warrior!