

Issue 103 | Spring 2021

BACKBONE



Scoliosis in adulthood

Scoliosis research and
the bracing trial

Possible effects of titanium
debris

Children's spinal deformity
in adulthood

Making adult spinal
surgery safer

Isobel Gray Award

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THE AILIE HARRISON ART COMPETITION

Are you a budding artist?

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

We are looking for striking artworks that we can print on our front cover. Use any artistic medium to do so, be it a drawing, painting, digital artwork, or a photo.

The winning artwork will be used as the Autumn 2021 Backbone magazine cover. Finalist artworks will also be displayed on SAUK's website, and on the SAUK Facebook and Twitter sites. What's more, there are cash prizes up for grabs too:

First prize - £100

Second prize - £50

Under 12's prize - £25

12-18 prize - £25

About the Ailie Harrison Art Competition

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



Send your design with your name, email, telephone number, and age group by email or post.

communications@sauk.org.uk or 4 Ivelbury Court, 325 Latimer Road, London, W10 6RA

Rules, terms, and conditions

- The competition is open to people of all ages living in the UK and Ireland. (Employees and representatives of SAUK are excluded)
- There is no entry fee
- Only one entry per person is allowed
- Please submit your entry by 31st August, 2021. No late entries will be accepted (if sending by post, please allow sufficient time)

Submission process

- Each entry must be accompanied by the required contact information
- Please do not staple or glue that information to the artwork

Selection Process

- The judges will be a selection of the SAUK trustees.

Disclaimer

- SAUK reserve the right to reproduce all pieces of artwork in any form it deems

appropriate for promotion and publicity purposes

- SAUK reserve the right to make minor changes and additions to the design
- Participants agree to the use of their names, and entries by SAUK
- SAUK will not be able to return your original submissions

Winners will be announced in late September, 2021

LATEST NEWS

Q&A Sessions

We have started running a series of very popular Q&A sessions with scoliosis experts. They are hosted on Zoom and are a way to offer our members an accessible way to pick the brains of these experts. Each session covers a different area of concern. We have so far had Thanos Tsirikos, scoliosis surgeon in Edinburgh and SAUK Trustee, present on congenital and neuromuscular scoliosis, Mr Tsirikos was also part of our talk on recovery pathways, alongside his Spinal Liaison Nurses Hilary Sharp and Caroline Hanley. Other presenters we've been fortunate to have taken part are Lee Breakwell, scoliosis surgeon in Sheffield, on breathing and scoliosis, Ian Harding, scoliosis surgeon in Bristol, on paediatric scoliosis in adulthood, and Ashley Cole, scoliosis surgeon in Sheffield, and Andrew Mills, orthotist, covered bracing for scoliosis.

We hope to continue offering these sessions as a SAUK members only benefit. Eventually we will be able to start in-person patient meetings again but we're glad that the popularity of these online platforms has made it easier for more people to engage remotely.

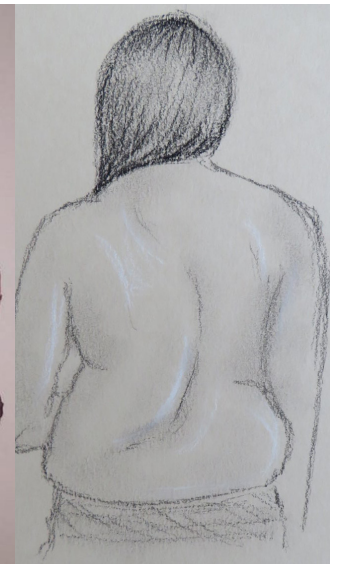
Each session is recorded, and recordings are made available to members after the session. The session begins with a presentation on the chosen topic and then moves on to a Q&A, with questions taken through the chat function. We are thrilled with the response we have had and want to extend our sincerest thanks to the presenters who have given us their time. Invitations to these events are sent out via email so if you email is registered with us, please keep an eye out for those (they may end up in your junk email, so check there too!).

Life Drawing

In February there was another of the ever-popular online life drawing events featuring models with scoliosis. This last session, which happened just after Valentine's Day, was themed around 'Love Your Body'. These events are a fantastic experience for both the artists and models to come together, share their experience, and celebrate curves, scars, and different body shapes. Thank you to Sarah O'Gormon for bringing art and scoliosis together in such an enjoyable way. Look out for announcements of future sessions on our social media channels.



Adam Busby



Liv Bonsall

International Scoliosis Awareness Month

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

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

This year's awareness month theme is #BackingScoliosis. We want those affected by scoliosis to join us in advocating for the condition in all parts of society. A scoliosis champion is brave and honest about how scoliosis has impacted them. By speaking up about scoliosis they show others in the community that they're not alone and they educate the world so that there is greater understanding and respect for those affected by scoliosis.

Roundups

Pledge pennies to SAUK as you spend by signing up to Roundups. Roundups rounds up your card payments and donates the pennies to SAUK. Round your payments up to 10p, 50p or £1: it's your choice, and you can also set a weekly cap for how much you want to donate. Go to www.roundups.org/sauk to support us with penny donations.

500 Club

The 2020 500 club prizes have been awarded:

First place prize of £100 -

Natalie Christie

Second place prize of £50.00 -

Nicholas Wheatley

Third place prize of £25.00 -

Bert & Cath Kaye

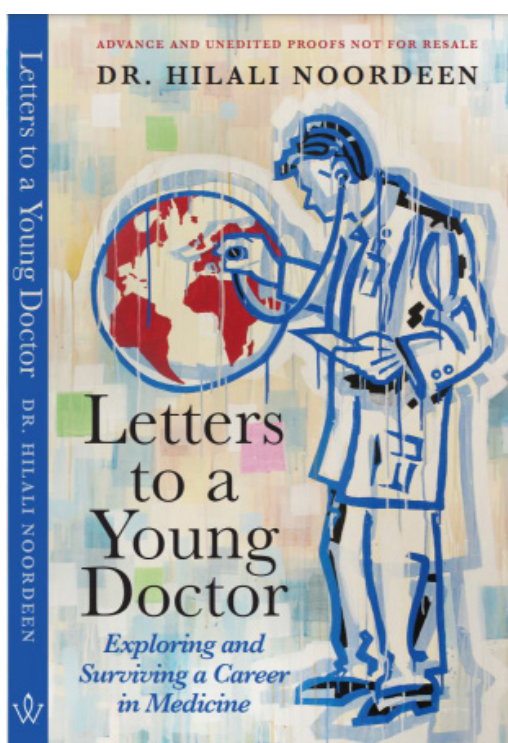
To buy a number and be entered into the annual cash draw costs just £12 and you can increase your chances by purchasing as many numbers as you like. Visit our online store to purchase shares.

Welcome to SAUK

We have said goodbye to Anne Rowlands our Office Manager. She did so much for SAUK during a very difficult year and we wish her well in her plan to develop her counselling skills. We are delighted to welcome Lesley McGinty as our Charity Director, a new role for SAUK. Lesley joined us in mid-April and will take on more responsibility for SAUK, reporting to the Board of Trustees. Lesley has more than 20 years' experience of charity work. She has worked as a fundraiser, communications manager, business development manager, head of income generation and communications, for charities such as Daniel's Den (mothers and toddlers group), The Mulberry Centre (support for people with cancer), Rethink Mental Illness Service, and the MPS (mucopolysaccharide) Society, to name but a few of her roles. Lesley has a big fundraising campaign to organise because SAUK, like many charities, has suffered a drop in income during the Covid crisis. She will also guide us through an office move and a much needed reorganisation of our policies and security measures. Most importantly she will lead our support efforts for our members and plan events to raise awareness of scoliosis, along with the rest of SAUK's team.

Christmas Cards

Thank you to everyone who bought Christmas cards from us last year. All profit made goes towards continuing the vital work we do to support people with scoliosis. Sales of cards raised a splendid £1964



Letters to a Young Doctor

Letters to a Young Doctor by Dr Hilali Noordeen (who serves as a BSRF Council Member) is an insider's guide to a life in the NHS – and how to survive it – by one of the UK's most eminent surgeons.

Letters to a Young Doctor is both a meditation on the practice of modern medicine and a manual that aims to identify the profession's problems, while prescribing possible solutions. The author Hilali Noordeen (scoliosis Surgeon at Great Ormond Street Hospital, London) gives an understanding of the practice of medicine as it currently is, so that expectations of students and young doctors can be more realistic. The book also prescribes a way to manage the consequent disappointment, or alienation, that prompts many to leave medicine. By focussing on healing within as well as without and using an introspective method akin to soul-searching or a profound spiritual awakening, aspiring doctors and practising medical professionals can achieve the change or equilibrium they need to find true fulfilment in the practice of medicine.

CHILDREN'S SPINAL DEFORMITY IN ADULTHOOD

Mr Ian J. Harding, Consultant Orthopaedic Surgeon, Bristol, UK



Spinal deformity presents in many ways at different ages. In adults, pain is a common presenting feature whereas in children there may be no symptoms other than the noted change in the shape of the spine. Spinal deformity in children is relatively common with the largest group being scoliosis in adolescents, occurring in up to 5% of the population. Many of these children will never even know they had a spinal deformity; others may present to doctors for advice and treatment. Many require no treatment, a minority require bracing, and even fewer go on to have surgery, because, in most patients, the natural history, what happens if you do nothing, is favourable. Less common types of scoliosis seen in childhood include congenital scoliosis and those curves that are caused by a known underlying condition such as neuromuscular scoliosis. In congenital scoliosis, a child is born with bony abnormalities in the spine that usually cause no problems but a minority, if untreated, can have severe deformity and problems later in life. Therefore, recognition is key in all cases of childhood scoliosis - usually to reassure but also to identify those cases that have a high chance of developing problems in the future. In adults, spinal deformity can develop de novo due to wear and tear in the spine and is

called degenerative scoliosis - this is much more common than childhood scoliosis and increasingly prevalent after age 60 and will not be discussed here.

The natural history of spinal deformity – whether it be scoliosis, kyphosis, or spondylolisthesis—depends on many factors, including the underlying cause, the magnitude and site of the problem, and particularly its magnitude at the end of growth. No natural history study can perfectly predict what is going to happen to an individual, but we can make estimates of what is predicted to happen and how this may affect the patient. For example, we know that scoliotic curves larger than 50 degrees tend to progress and that when those curves are bigger than 80 degrees some patients describe some difficulty breathing. We also know that most children with spinal deformity take their spinal shape into not only young adulthood but also later life and have a normal life expectancy. It is well known that wear and tear occur in all of us – whether or not we have a spinal deformity – and is very common in the spine, as is back pain. It follows therefore that there will be many patients who have a spinal deformity from childhood who have spinal problems in adulthood, whether or not they have had surgery. The challenge is then to ascertain if the spinal deformity is contributing or causing the symptoms that one has in the spine and whether anything should be done about it. If the abnormality is in the lumbar area where ribs do not support the spine there can be particular problems and even small curves can become quite symptomatic, associated with slipped discs, nerve compression, and pain.

Any childhood curve in the spine can progress in adulthood, the larger the curve at the end of growth the more likely it is to do so. This may make a previously asymptomatic curve symptomatic with pain or have a knock-on effect on adjacent levels of the spine, particularly in the low back or neck. In adulthood, the symptoms usually determine treatment whereas in children treatment is often dictated by X-ray findings even if no or relatively few symptoms are

shown, on the basis that they are likely to cause problems in the future. In childhood, a curve may be more flexible, correctible, and smaller, whereas in adulthood the curves are often bigger, stiffer, and less correctible. Furthermore, children recover more quickly from surgery than adults do and have significantly fewer complications with better corrections. Because they are in education recovery periods can be fitted around this easily. Having a major operation as an adult with a family, employment, and other dependents is a further consideration to add to the higher complication rate and longer recovery periods. With that in mind, one might ask why we do not operate on more children – the answer being that there is still risk and importantly natural history in most is favourable. The net result, however, is that we do see adults with progressive non-operated childhood scoliosis that is symptomatic.

In the previously non-operated patient with childhood spinal deformity presenting in adulthood, carefully assessment is mandatory to ascertain exactly what the problem is and where it is coming from since often it doesn't come from the curve itself but from adjacent levels. Pain is the most common symptom but has many sources: degenerative changes in the spine, muscle pain from the deformity, rib impingement in the pelvis. The history and examination are key – helping pinpoint the pain source and ensuring no other cause is evident. Treatment is usually non-operative with physiotherapy, chiropractic, osteopathy, and pain management. Sometimes supportive underwear or bracing in some form may help and providing one understands the limitations

“The operative decision-making process has to be patient-led based on their level of symptoms, how bad they are, how good they want to be, how good a surgical procedure can make them and the complication profile of the procedure.”

of these they can be tried. Non-operative treatments may help greatly and are very unlikely to cause problems or affect any potential further invasive treatment and if one is to have surgery it is generally always good to have tried everything else first!

Patients presenting in adulthood who have previously been operated upon as a child can present a different challenge, but the same rules still apply: ascertain a source of pain from history and examination and pursue non-operative measures to control symptoms. Operations



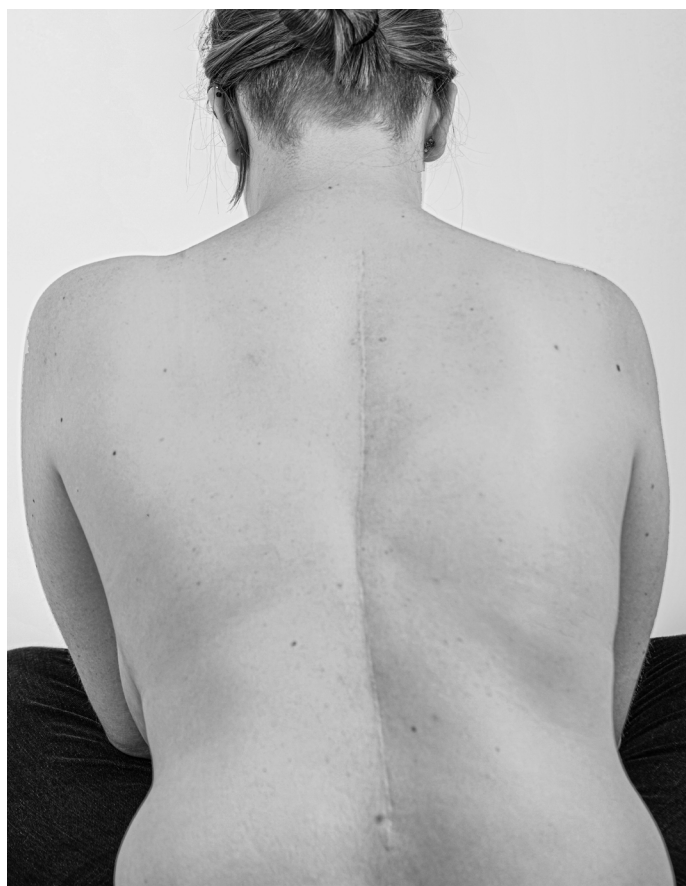
for spinal curvature started in the early 20th century with prolonged stays in hospital, no metalwork, and use of traction with casts to control spinal shape while bone fused the spine in that position. In the 1960s and 70s, metalwork started to be used to correct spinal curvature more commonly after some sporadic use before, the most famous one being named the Harrington rod. This was a single distracting rod acting very much like a beanpole to hold the spine up and provided a nice correction of the spine in one plane but often flattened the side-on or sagittal plane, which is meant to be curved. Throughout the 1980s a more three-dimensional correction was attained by segmental fixation and into the 21st century, we have not only a better understanding of the three-dimensional nature of the deformity but also improved techniques and instrumentation. Computer-based advanced planning, robotics, and navigation have transformed the landscape of spinal deformity surgery to make it safer and more predictable, and to aid patient selection. However, we still see problems in patients from all eras of such surgery although those having had Harrington rods are now in their 50s and beyond.

Long-term problems can either be within or from the construct itself or from adjacent levels that have suffered a knock-on effect, or both. From the operated levels metalwork may be loose or prominent and/or bone

may not have fused. Sometimes metalwork has been historically removed and the curvature recurs in the area even though the spine is 'solid' – this is because bone is alive and responds to forces placed upon it. Rarely infection may present late – many years after surgery with pain and swelling but does need to be considered. The biggest problem with previously operated curves that we see is suboptimum three-dimensional alignment. Harrington rods flattened the back out too much (particularly the lumbar area) and more recently overzealous correction with pedicle screw constructs overcorrected scoliosis resulting in the same problem of a flat back – although often in the thoracic region. If one were to consider surgery for any of these problems, they all represent a major surgical challenge – removing old metalwork, 'clearing' infection, getting bone to heal, and having to break and restore the spine to restore alignment. Complications are high and recovery is long – careful decision making is key.

If one has had surgery, whether perfectly aligned or not, then there will have been disruption to spinal musculature and stiff segments, which place different forces on adjacent levels and non-operated segments. These can develop disc or facet problems with back or nerve pain and have to be treated as one would usually with consideration given to the underlying driving force and contribution of the spinal deformity. Often these problems can be treated in isolation but sometimes one needs to address the presenting problem and the previously operated levels – a big undertaking with high complications.

In summary, most children with spinal curvature do not need any form of invasive treatment and most of those treated in the past do not need invasive treatment as adults, although many may have symptoms that are usually self-managed or controlled with pain management in all its forms. In those with major problems not responding to non-operative measures who have or have not had previous spinal surgery decision making can present a difficult challenge. The operative decision-making process must be patient-led, based on their level of symptoms, how bad they are, how good they want to be, how good a surgical procedure can make them, and the complication profile of the procedure. In carefully selected cases there are many options available to help and surgery can be transformational when irreversible complications are avoided.



HILL, PEDDER, & MINNS

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

Who can apply?

Members of SAUK affected by scoliosis are eligible. Small grants are available to those who require equipment or travel expenses to appointments. The maximum amount granted is £500 and applicants can apply only once a year. Visit our website for further information: <https://www.sauk.org.uk/hill-pedder-and-minns-fund/hill-pedder-and-minn-fund>

Fiona Sim

I was diagnosed with a major double curve scoliosis at the age of 20. It was a complete surprise as I always just thought I had one leg longer than the other. I had no significant symptoms, other than occasional backache, and only orthotics (bracing) was recommended.

I am now 56 years old and have been through two total hip replacements, probably attributal to years of walking lopsided! I have substantial discomfort from paraspinal muscle spasm because of deterioration of both my curves and am having to use crutches to get around. I have also had to retire early from my job as a specialist nurse.

I was referred for intensive spinal physiotherapy by my consultant at the Royal Victoria Infirmary in Newcastle and because of that am working hard on daily exercises to build up my core strength to help support my spine. The grant from the Hill, Pedder, and Minns Fund has enabled me to buy an exercise bike and Sissel cushion recommended by my brilliant physiotherapist to use as part of my programme and will help me to manage my symptoms better.



Follow us!

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

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



www.sauk.org.uk



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SCOLIOSIS IN ADULTHOOD

Helen Gee

I'm 44 now but I first noticed something wasn't quite right in my early 20s when I was experiencing lower back stiffness and noticed that my sides were uneven and that one trouser leg hung higher than the other. X-rays confirmed my scoliosis, but I was not referred to a specialist, instead the GP referred me for physio at a local rehab hospital.

Around 2010, after giving birth to my son, I started practising Pilates and visiting someone who practised body stress release, a type of targeted, deep tissue massage. This combination and using heat on my lumbar muscles seemed to keep me in check for a few years.

I went back to the GP a few times over the years wanting to further investigate the scoliosis but in 2019, I was determined to get a referral to a specialist so I could find out more about my curve and receive a proper diagnosis. I was questioned on this by the doctor. She asked if I wanted surgery, to which I said not really but I didn't know as I didn't feel well enough informed. She said that a referral wouldn't get approved by the triage team at the surgery but that she could refer me to the pain clinic. I left in tears,



felt really let down. All I wanted was to understand what was going on with my body and it felt like no one could help. In October 2020, I self-funded a consultation with an orthopaedic surgeon. I received a proper, standing spinal X-ray and in my follow-up consultation, I finally discovered the Cobb angle for the first time - 55 degrees. Seeing the X-ray like this was very emotional for me; it looked so much worse on the inside! The surgeon recommended fusion surgery to avoid the curve worsening. His view is that the curve worsened by 10 degrees in the 2 years between X-rays.

I do not want spinal fusion surgery. I will do this only as a last resort, and I am doing everything to try and avoid it. In 2019, I qualified as a Pilates instructor as I understand the value of a strong core and daily movement. I don't think I would have retrained in the wellness/fitness industry without my scoliosis. I manage my pain through exercise, stretching, and releases and heat packs. Until such time that I really feel I need surgery, that is the last option for me. My advice to others is to keep pushing to understand what you're dealing with, read as much as you can on the subject, and follow fellow scoliosis warriors on social media, it's a supportive community and there are often some great tips shared by others.

Simon Reynolds

Born in November 1955, I was diagnosed early on with polio. The scoliosis caused by polio led me to wear a Milwaukee brace from age 4 to 15, when I had my spinal fusion. The curvature led to reduced lung capacity, but I've had a pretty active life, nevertheless. I am about to retire at the end of February, 2021, aged 65 and having worked full



time since I was 18 years old.

Treatment other than the Milwaukee brace consisted of 6-monthly check-ups and every 2 years I spent 3 months in a full body plaster cast – I designed, I believe, to stop the scoliosis getting worse until I had nearly stopped growing and it was appropriate to undergo spinal fusion.

Between diagnosis and fusion, I was looked after by the late Mr Charles Manning at the Royal National Orthopaedic Hospital (London and Stanmore) and also the late Dr Philip Zorab from the Brompton Hospital. It was only fairly recently that I learnt of the importance of their combined research. We were so keen to stick with Mr Manning and Dr Zorab that we stayed with them when we moved from Orpington, Kent to Wilmslow, Cheshire, in the early 1960s. Visiting me in RNOH Stanmore nearly every weekend for 4 months over the time of my operation was pretty tough on my family. I quite enjoyed the 6-monthly daytrips to London with my Dad for my 6-monthly check-ups, though.

Katie Peduto

I was diagnosed with scoliosis at the age of 29. I had lower back pain for as long as I can remember and had seen

various specialists including physios and chiropractors but had never been given a cause. I went to my GP to confirm my scoliosis after my husband noticed the curve.

After X-rays and an MRI scan, my surgeon confirmed that I had a thoracic curve of 54 degrees and a compensatory lumbar curve of 51 degrees. As I was an adult and the curves were stiff, I was advised that the surgery would need to be done in two stages – anterior fusion of the lumbar curve and then 2 days later a posterior fusion from T4 to L3. I remember breaking down in clinic – I was so unprepared and so shocked, and the enormity of the surgery overwhelmed me. My surgeon advised that the curves would probably progress without treatment, particularly post menopause, and I would probably have pain and complications, so I decided to go ahead.

In November, 2011, I had the surgery. The first procedure involved the removal of a rib. I had a chest drain and so was required a stay in the high dependency unit, and then a couple of days later I had the second procedure. I did develop a chest infection which required additional respiratory support and antibiotics.

Following my surgery, I moved back to live with my Mum. This was very difficult as I was newly married, but my husband worked full time and I needed someone around. I felt very frustrated over this period because I was used to being independent. I was very bored but found it hard to concentrate on much, largely because I was exhausted, but also because of the pain medication. I was surprised how quickly I lost muscle mass and found the simplest things exhausting.

I worked as a Macmillan nurse and took a total of 3 months off work and went back with a phased return. I still work as a nurse now; I have found a role that involves a good mixture of movement

and desk work, although too much of either and I can get flare ups of pain.

I have also become a mother since my fusion. I did have to see a gynaecology consultant through my pregnancy, and I had to get a letter from my surgeon advising the anaesthetist about my fusion should I have needed an epidural. Other than that, my pregnancy was uncomplicated and I had a natural delivery. I did find feeding a newborn trickier since I cannot bend and playing on the floor can be a bit uncomfortable, but I have found ways around this!

I still have issues with pain, particularly



in my right shoulder over my rib hump and into my neck. Finding a great physio, regular massages, and keeping fit help with that. I have done Pilates since my fusion and this year came across 'Build and Breathe Pilates', run by someone who also has a fusion; it has been amazing to find someone who 'gets it'.

The psychological impact of the diagnosis, and the enormity of the operation itself is overlooked, and I am only just starting to delve into all that I went through, and what it has meant for me mentally. The surgery is not a quick fix and has its own lifelong challenges. Explore all options so that if you do decide that surgery is the right option for you, you feel confident in

that decision.

Leah Unwin

I have infantile thoracic scoliosis. I was diagnosed at 10 months old. I had a plaster cast brace and neck support. However, my curve was progressing too quickly and so I had two spinal operations at age 5. During the operation, bone was placed between the vertebrae of my spine to try and prevent my curve from progressing further, but unfortunately this did not work as hoped.

I have kyphosis and my spine is S-shaped with two curves, one measuring at around 108 degrees. I have been seen by several consultants and have had enough X-rays and MRIs to fill a library. Unfortunately the risk of paralysis if further surgery were tried is too high. An operation might reduce the lump on my back by only half an inch – I think you will agree the benefits do not outweigh the risks!

My scoliosis can be painful and has reduced my body height, lung capacity, and upper body strength. Having said this, I lead a "normal" life. I work full time, drive a manual car, and enjoy everyday things, and have even travelled the world alone. I try to manage my pain by keeping active, going to the gym, walking, and have recently started Pilates. I also have reflexology around every 5 weeks which has helped my pain considerably.

For me one of the biggest challenges can be the public and the way scoliosis is portrayed in the media, such as the



villain having scoliosis or a curved spine being the blunt end of a joke. I look physically different and receive comments and looks from others daily. I have joined a local scoliosis support group and am aiming try to promote awareness of scoliosis and reduce the stigma and discrimination of the condition. Since my scoliosis is very severe, I want to show people that this diagnosis shouldn't hold them back and that they can lead a great life. I want people to be proud and empowered by their scars from their surgery and realise that scars are a normal part of life and that having a scar or scoliosis should not stop them from being who they are and doing what they want to do. Be you, be proud, flaunt your quirks, scars, and imperfect perfections!

Doreen Lindegaard

I have lived with scoliosis for more than 70 years. When I was aged 13, the school doctor tutted and gave me a note to give to my parents. Nobody else in my class had a note. I knew instinctively it was bad news.

Mum and Dad were distraught. Any form of deformity was a stigma, something which must have been inherited from them. At the local hospital, the surgeon told me to bend over and touch my toes. He then took a biro and drew a line down my back to show my anxious mother where my spine "ought to be". After I was X-rayed two or three times the surgeon said an operation might be available but offered little chance of success stating baldly "she might spend the rest of her life in a wheelchair," and added "It's your decision." This was the only advice my mother received.

They decided to deal with 'the problem' in their own way. They told me to ignore it, never to talk about it, and "if anybody says anything, say you had an accident." So much preferable to the awful 'born like it' that the neighbours might

suspect. They were good and loving parents and thought they were doing the best for me. Neither I nor they received any other form of counselling, my 'case' was not followed up, and I have no idea whether the school was ever told. In the meantime, my brother received a scoliosis diagnosis. Our parents, who were now certain that the deformity was hereditary, received advice this time. Fortunately, he did not appear to suffer the anguish and body shame that haunted me, or at least if he did, he never let it get him down. He became very well known; he was the late Professor Colin Pillinger, FRS, the lead scientist behind the Beagle 2



Mission to Mars.

I am now in my 84th year. I was a late developer and eventually an academic. I have led an eventful and often adventurous life. I would not have survived this long without the love and support of my husband of 54 years. Our three children are grown up, though one was diagnosed with a mild form of scoliosis when she was in her 40s. The hereditary aspect interests me – but as she has no children, at least perhaps mercifully, it cannot be passed on. Our four teenage grandchildren do not display any hint.

I am telling my story to show how times have changed. I am grateful that afflicted children can these days have what is still a difficult and painful operation to straighten their spines

with an excellent chance of success. I hope and pray that all receive the sympathetic counselling I so sadly lacked. I am fortunate that though my scoliosis has advanced considerably as I have grown older, I have never suffered any pain.

On a purely personal and cosmetic note. I love fashion and I wish I could have worn stylish clothes, anything tight or 'fitted' causes me actual discomfort, and I still try to disguise the curvature as much as I know how. I am occasionally 'advised' by a well-meaning but 'straight' person, who tries to be helpful, but really has no idea.

Mandy Veale

My story begins back at school when the nurse spotted my curvature and sent me to my GP, who sent me to a specialist. In those days – early 1980s – there was no 'fix' so I had to wait until the curvature was as bad as it could be before I could have an operation.

The operation day eventually arrived in February, 1984. Sadly, my blood pressure was sky high, and I was discharged as it would have been too much of a risk to proceed with the operation. It was established that one of the tubes from my kidneys had grown too long and it was contributing to my high blood pressure. I had an operation in June, 1984 to correct the tube. I then had the operation on my spine in November, 1984. On admission I was 5'1" and during the operation they were able to partly straighten my spine and after the operation I was a 'lofty' 5'4". Unfortunately, as they were only able to partly straighten my spine, I was left with a rib hump.

To aid in my recovery I had to wear a plaster cast for 6 months from my armpits down to cover my hips. During this time, I returned to school and was subjected to names from the other school children like 'hunchback' and other cruel words.



I have always dressed so my rib hump does not show, and friends have been surprised when I tell them my condition because I had never told anyone because I was worried about 'hunchback' comments. I very bravely took part in the last photo shoot for the Scoliosis Association in 2019. While the photos were excellent, I found the greatest benefit was from speaking to others. One lady said, "if it wasn't for my scoliosis, I would have been a different person in a different place and it's now part of my story". I put the photos from the photo shoot on Facebook and all the comments were incredibly positive and one friend couldn't get over my bravery for posting the photos and sharing my story. He hoped it would help other people in their story and I hope the same. I am braver now and have had a tattoo on my back along my spine to say, "Bent Not Broken" and if anyone comments on my back or rib hump, I am now able to tell them my story!

Jayne Bostock

I was 18 when I was finally diagnosed with scoliosis. I say finally because I had already been experiencing back pain for about 4 years by then, but my local GP had dismissed it.

Luckily, my university GP was a lot more thorough and on presenting with back pain she asked me to do the forward

bend test and then immediately sent me to the hospital for X-rays and MRI scans, where I was diagnosed as having a moderate right thoracic idiopathic scoliosis.

At the hospital, I recall asking the spinal surgeon what could be done for my pain and being told that there wasn't a lot I could do and that I should accept that I would have pain for the rest of my life. That was 2003 and I had never heard of scoliosis before, never mind having met anyone else with the same condition. At the time, it wasn't so easy to connect with people as it is now thanks to social networks like Facebook.

By the time I graduated, I was taking a combination of three different pain medications as well as sleeping medications and yet was still in so much pain, especially when I was sitting down studying. I wish I had realised at that age that I couldn't look for the answers in a pill but only in a regular exercise. I also wish I had found a community for I felt so lonely.

2 1/2 years after my diagnosis, I began to see a pain psychologist as part of my chronic pain service treatment, and this ended up being quite a turning point in my life. She helped me to come to terms with my shame as well as encouraging me to find a way to better balance my studies and my pain. With the help of physiotherapists, I started to develop a stretching routine and although I still felt pain all the time, I began to feel a lot more in control. With the support of the psychologist I finally began to tell my friends about my pain, applied for disability support at university, and even applied for an internship that summer for disabled students, where I had the chance to finally meet other people my age with disabilities and developed lasting friendships. I can't reiterate how important it is to get to know other people with similar conditions so that you can share experiences and realise you aren't alone.

That summer I also realised that I could still live an exciting and fulfilling life. I applied for an internship to teach in Europe and finally achieved my dream of going to live abroad. Living on a Portuguese island was perfect for my back; I'd go to hot springs and swim in the ocean nearly every day.

Since then, I've visited over thirty countries and lived in seven. I've paraglided, learned to scuba dive, and driven a motorbike and solo travelled across South East Asia! It has not been easy travelling with chronic back pain, but it definitely is possible if you put your mind to it.



With 2020 forcing me to have to stay in one place, I've developed an exercise routine and found a sense of community through the Yogaberry Yoga for Scoliosis course I've been taking. I've also begun keeping a pain diary and using the app Curable, which is helping me to cope better with pain using meditations and visualisations as well as understanding more about pain. I firmly believe that it is of the utmost importance to take charge of our scoliosis and that developing a regular exercise and meditation routine is probably the best thing I personally can do to manage my pain. I also feel it is empowering knowing that there is something I can do myself to improve how I feel rather than having to rely on someone else.

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.

Stephen Alcock, Mrs Allison, Andrew & Andrew Solicitors, Hunter Ann, Kirsten Barrow, Veronica Bell, Lorna Bennett, Jane Blackstock, Eunice Bliss, Clare Bostock, Richard Braithwaite, Alex Brennen, Paul Britton, Rosemary Bromley, Edward Burkitt, Ewan Campbell, Lindsay Cant, Christina Chachdiades, Peter Chillingworth, Sally Chin, Dale Cunningham, Barbara Curry, Karen Curtis, Sandra Dalziel, Maureen Davison, Albert Dawson, Pat Del Vecchio, Maria Delves, Mary Dicker, Karen Dickinson, Lindgaard Doreen, Michael Edgar, Carol Eremiowicz, Amanda Farr, Rosalind Fell, Maud Fellows, Joan Foxwell, Steve Freak, Susan Fussey, Janice Gordon, Vivienne Green, Reginald Hancocks, Kay Heald, Pauline Hill, Elizabeth Hitchins, Marion Hopwood, Elizabeth Huckerby, Susan Hudson, Steve Jarvis, Mrs M Jarvis, Dickson Jean, Thomas Julie, Susan Kelly, Ernest Lond, Fiona Lowrey, Martyn Lucas, Wilma McCann, Melissa Milne, Margaret Milson, Christine Paice, Susan Parkhouse, Julia Pavey, Rackham Phillippa, Miss Pickering, Sheila Pritchard, Maureen Reeves, Patricia Reid, Jill Ridgeon, Martin Rogers, Lynda Ronan, Isobel Sampson, Miss A H Summers, Rev. Thompson, Daphne Tigue Tighe, Sue Watson, Suzanne Wells, J P Williams, Colette Woo, Chris Xinari, David Yarrow, Abbie Blake, Alliance, Allison Johnson, Andrew Cleland, Barbara Sinclair, Brooke Baker, Camilla Seckin, Caroline Lothian, Charlotte Dodd, Charlotte Wells, Chris Young, Christopher Mould, Claire Allan, Clare Paleit, Clare De Freitas, Corporate Collection, Daniel Harrison, David Lewis, Denstone College, Donald Dinsdale, Donna Riley, Eileen Hoare, Elaine Tisdall, Emma Vaughan, Emma Felstead, Emma Richardson, Eva Butterly, Gabriela Toyos, Santamaria, Hannah O'Gorman, Helen Atkinson, Jeannie Ninis, Jennifer Vanstone, Jennifer Butcher, Jennifer Vanstone, Jessie Perrett, John Fawcett, Jolene Green, Jonathan Ducker, Judith Brindle, Julie Costello, Julie Wilson, Karen Trainor, Kathryn Mackey, Kim Farmer, Kimberley Briggs, Kirsty Hanks, Lila McTear, Linda Clarke, Lucie Marples, Lucy Walker, Marcus Ingman, Marion Arundel, Matt Parker, Matthew Price, Matthew Watson, Michael Robinson, Michaela George, Niamh, Nigel Shaw, Oliver Hill, Oliver Mankerty, Oscar, Pat Warner, Rachel Meredith, Radhika Mistry, Rebecca Donovan, Robert Hall, Sam Brunell, Shabana Hussain, Simon Coupland, Simon Napper, Sophie Bryan, Steven Lewis, Susan Roe, Susan Cripps, Tara Morse, Team D, Ted the elf and Avery Hawkins family, Veryan Cooper, William Mabey, Zelia Ward

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.

A further £130 was received in addition to the £140 already received in memory of [Christine Predeth & her father Stanley Richardson](#)

£75 was received in memory of [Shane Keyte](#)

£150 was received in memory of [Brenda Searle](#)

£50 was received in memory of [Theresa Paxton](#)

£100 was received from Sandra Dalziel in memory of her sister [Isobel Gray](#), [Founding Trustee of SAUK](#)

Legacy

[Theresa Paxton](#) left the sale of her jewellery to SAUK - £2967.80

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

Contact us to find out more about leaving a gift to SAUK in your Will.

SAUK - FUNDRAISERS

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

Katherine Messider

Katherine has so far raised an amazing £220 for SAUK from selling face masks throughout the pandemic.

"During the pandemic I heard of so many other scoliosis warriors who were having their spinal fusions delayed due to Covid-19, so I decided to raise money for SAUK by making and selling masks. SAUK has helped me and given me so much advice and support during and after my own spinal fusion and so I thought this money could help them continue giving amazing support to other scoliosis warriors, especially in this complex time," said Katherine.

Find Katherine on @spinalfusionfashion on Instagram and her Etsy store here <https://www.etsy.com/uk/shop/KatherineMessider>



Ross Taylor, £321.25, Belfast Marathon

Ellen Ross, £6.25, Raffle

Jade Beale, £368.75, Running 10 Miles

Denise Mott, currently on £324.50, Running 1,200 Miles in a Year

Helen Rayner, £1560.50, 2020 Virtual London Marathon

Colin Wallace (BOTH SAUK AND SCF), currently on £521.25, Survival Challenge

Jonny Driver, currently on £1316.25, 2020 Virtual Marathon, 2021 London Marathon

Facebook Fundraisers

Joshua Bleakley & Andrew Hankinson, Georgia Winter, Amelia Hine, Melody Tata, Amy Croft, Claire Webb, Julia Gooding, Alisha Hamer, Si Rothery, Emma Dixon, Niamh Mae, Michael Fox, Jazmin Lewis, Debbie Merifield, Gill Cowley, Jamie Bethel, Johann Agius, Kat Faye, Blythe Button, Chloe Manley, Sarah Northern, Jo Schiff, Renai Thompson, Priscilla Jane Derricott, Seb Carney, Paige Phillips, Loretta O'Bee, Dawn Shelley, J Anne Villanueva Rillon, John Lazenby, Lorraine Roberts, Gyp Bellucci, Sam Harrison, Evie, Simon Napper, Katrina Cruickshank, Tracey Goodwin, Arrianne Johns, Tracy Lynne Rotheram, Olivia Wallis, Claudia Codling, James Watkins, Lucy Blight, Maxine Wingell, Helen Williams,

Claire Simone Simpson, Rachel Wizenfield, Joshua Bleakley, Carys Williams, Andrew Hankinson, Louise Knowles, Belinda Tricker, Neil Patterson, Simon Griffin, Jessie Mason, Abbie Louise Wilson, Alison O'Connor, Michelle Reynolds, Carol King, Julia Pullin, Thomas Taylor, Rosie Townsley, Anne Browne, Dan Wilson, Anne Rowlands, Rosaleen O'Brien, Karl Jemmott, Olivia Marron-Shepherd, Dora Reeves, Lily Kavanagh, Joe- Ria Twidale, Stephe Batten, Cathy Darby, Dubravka Watkins, Rachel Oxley, Elaine Taylor, Rebecca Portman, Emma Louise Roberts, Maria Houghton, Eddie Lowe, Estelle Marilyn, Cindy Setelvad, Bill Homer, Catherine Saleh, Esther Brown, Isabella Stokes, Annie Bamber, Naomi Burgin

SAUK Fundraiser of the Year

Helen Rayner

Helen set out to run the 2020 Virgin Money Giving London Marathon to raise funds for SAUK but when that was cancelled, she took up the opportunity to run the Virtual version instead. Helen ended up raising an incredible £1560.50 which goes a long way in supporting what we do.

Ben, who turns 13 in March, was diagnosed with scoliosis as a baby. We were given the 'watch and wait' advice by his surgeon, but by the time he was 18 months old it was very clear that it was progressing quite rapidly. At 2 years old he was fitted with his first body cast. He had only just learnt to walk, and we were concerned how it would affect his physical mobility. However, within 24 hours he was back on his feet! These casts were replaced every 3 months under a general anaesthetic. At 3 and a half he moved to having a removable brace. This was worn at all times apart from when he had a bath or went swimming. He was amazing throughout all of it and never complained, even when he had chicken pox!!

At 5 years old, Ben had his first set of growing rods fitted. This was obviously a very worrying experience, but again he dealt with it brilliantly. Initially these were

extended every 6 months with another operation. When he was 7, his surgeon decided to swap the rods to the MAGEC growing rods, which was fantastic as it meant the lengthening could take place in outpatients rather than with another operation. In November, 2020, he had his third set of MAGEC rods inserted. This will hopefully be the last operation before the final spinal fusion operation. In total he has had seven (or possibly eight – we seem to have lost count) back operations. Every time he has bounced back with remarkable speed. People who know him are astonished with what he does so soon after big surgery. Ben is very active and loves football, he plays for a Pan disability team, as well as running and bike riding. He will give anything a go. We have approached his scoliosis with the attitude that it shouldn't stop him from doing anything, although there are obviously a few things that he has to avoid such as gymnastics and rugby.

We were given a SAUK leaflet by Ben's surgeon when we were first told that he would need to be in a plaster body cast. He told us that the charity was invaluable for advice and support, which we found to be absolutely true. We were put in contact with another family who had a child the same age as Ben and at that point had been through the same treatment, so we were able to





share experiences and normalise things. SAUK were also able to reassure us that the surgeon Ben was seeing was excellent at what he does, which was important knowing that we were in this for the long haul.

I am a keen runner and doing the London Marathon is something I always had in the back of my mind as a challenge I wanted to do. I put in for the ballot in April, 2019, (not thinking for a minute that I would get a place, but at least I could say that I had tried!) and I was one of the fortunate ones to get a place for the 2020 marathon. As soon as I had a place, I knew that raising funds for a charity that we have benefitted from personally was something that I wanted to do. The training was going well so it was a real disappointment when it was

cancelled in March, 2020. I managed to keep my running ticking over but lost motivation with the long distances. I was not hugely keen to do the virtual marathon at first, but the thing that persuaded me was that I wanted the funds I had raised to go to the charity sooner rather than later as it was clear that charities would be struggling throughout the pandemic.

I had so much support from friends and family. The first 16 miles I ran with my training buddy Emma and another friend supported us on her bike as the weather was appalling. For the middle 6 miles there was a group of six of us running past many friends' houses in the small town where I live. Having friends come out in the pouring rain to cheer and wave banners was a real boost. The final section we ran around the local park and Ben joined me for this. It wasn't the London Marathon I had in mind, but it was a fantastic experience, particularly as I knew that I was raising money for such a lovely charity. The generosity from those who sponsored me was quite overwhelming at times, and it really did help me to get through the miles. Our friends and family know the journey that we have been on with Ben, and scoliosis has not always been easy, so it means so much that they have supported me in raising such a fantastic amount of money.

I still have the real London Marathon ahead of me this year and amazingly my husband has got a place in this year's ballot so we will both be able to run.



MAKING ADULT SPINAL SURGERY SAFER: STRATEGIES AND LIMITATIONS

Jwalant Jwalant S. Mehta,
Consultant Spinal Surgeon, Birmingham



Spinal deformities in adults are more common than reported. Most patients can compensate for the spinal column malalignment and carry on with little or no functional disability. However, a longer lifespan and a desire to stay active can prompt some to seek medical attention. While a substantial number of adults with spinal deformities can be treated by non-operative methods, a small, though notable proportion will require surgery. The magnitude of the surgical intervention is based on the patients' symptoms, functional demands, and expectations. The spectrum of the operations ranges from decompressions to long fusions into the pelvis with three column osteotomies with anterior surgery. This end of the spectrum of complex spinal column reconstructive surgery bears the maximum risk of complications and adverse events, some of which are potentially life changing.

Surgical re-alignment operations in adults pose unique challenges within healthcare. A successful outcome is borne out of a holistic assessment of the patients' problems rather than the focus on the technical success of the surgical reconstruction. Although the technical aspects form the primary basis of discussion between the patients and the surgeon, an appraisal of the general health and functional disability are far

more relevant in the surgeons' decision to offer an operation.

Patients' expectations and symptoms are central to the formulation of the individualised surgical plan. Pre-operative assessments are done by specialised spinal deformity anaesthetists who are well versed with high-risk patients. Although the surgical procedures may be within the abilities and the comfort zone of the surgeon, the risks of such procedures can be considerably high. Some reports mention that the risks can range from 20 to 80%. The complications are considered on the lines of the extent of morbidity as major or minor or based on the time of onset as during the operation, early (under 90 days) and late (over 90 days). A large proportion of the complications are systemic – ie, stroke, myocardial infection, wound problems, infections, thromboembolic disease, and, rarely, death. However, a proportion of the complications are linked to the actual operation and are mechanical in nature. These can occur because of sub-optimum bone health, technical issues with the screws and rods, or surgeon judgment error.

Bone health is frequently underestimated. A sedentary lifestyle with poor mobility, certain medications, and smoking contribute to osteoporosis. DEXA scanning (Dual Energy X-ray Absorptiometry) provides an objective measure of bone mineral density. Results of this scan guide the surgeon towards specific treatment to increase bone mass. This treatment may be initiated by the GP but may need specialist input. Delaying the operation to achieve this target is desirable because it prevents complications related to the implants and problems with fusion across the operated segments. This lack of fusion is called pseudarthrosis and commonly presents as broken rods, requiring further surgery. The rod fracture can present innocuously as pain, clicks in the back not previously noted, or a loss of posture.

Surgery for spinal problems in adults requires fusion of several levels, often with osteotomies to allow for the re-alignment and additional anterior surgery. If the implant placement is sub-optimum, it could result in a neurological injury requiring revision surgery. The use of imaging during the operation is critical. Most major spinal units in the UK use two-dimensional C-arm image intensifiers in the operating theatre. Newer three-dimensional imaging in the theatres allows for a safer surgery with earlier identification and rectification of mal-placed implants. However, this type of technology is expensive and not freely available. The other downside of this technology is the potential for exposing patients and healthcare personnel to higher levels of radiation. The use of navigation and robotics is being developed and is a work in progress in some centres.

Spinal cord injury is a potential life-changing complication of a major spinal re-alignment operation. This type of procedure necessitates the use of multi-modal spinal cord monitoring to reduce the risk of spinal cord injury during correction of the spinal

curvature. It is a mandatory requirement for most complex spinal procedures.

Erect X-rays allow the surgeon to plan the optimum alignment of the spine and set the surgical goals. Much research has been done on what constitutes optimum alignment. Several objective measures involving the spine and the pelvis have been described. Several software applications allow measurements and surgical simulation to be made. Achieving the optimum goals with surgery improves quality of life. Recent studies have shown that alignment goals should be age matched. Although these may appear to under-correct the spinal alignment, studies have shown that this strategy results in fewer mechanical complications. One of the common problems closely linked to over-zealous surgical correction is a loss of alignment in the normal spine above the operated spine. This junctional problem can be avoided with a well-tempered surgical judgment. When it does occur, it can be disabling and requires more surgery to rectify the problem.

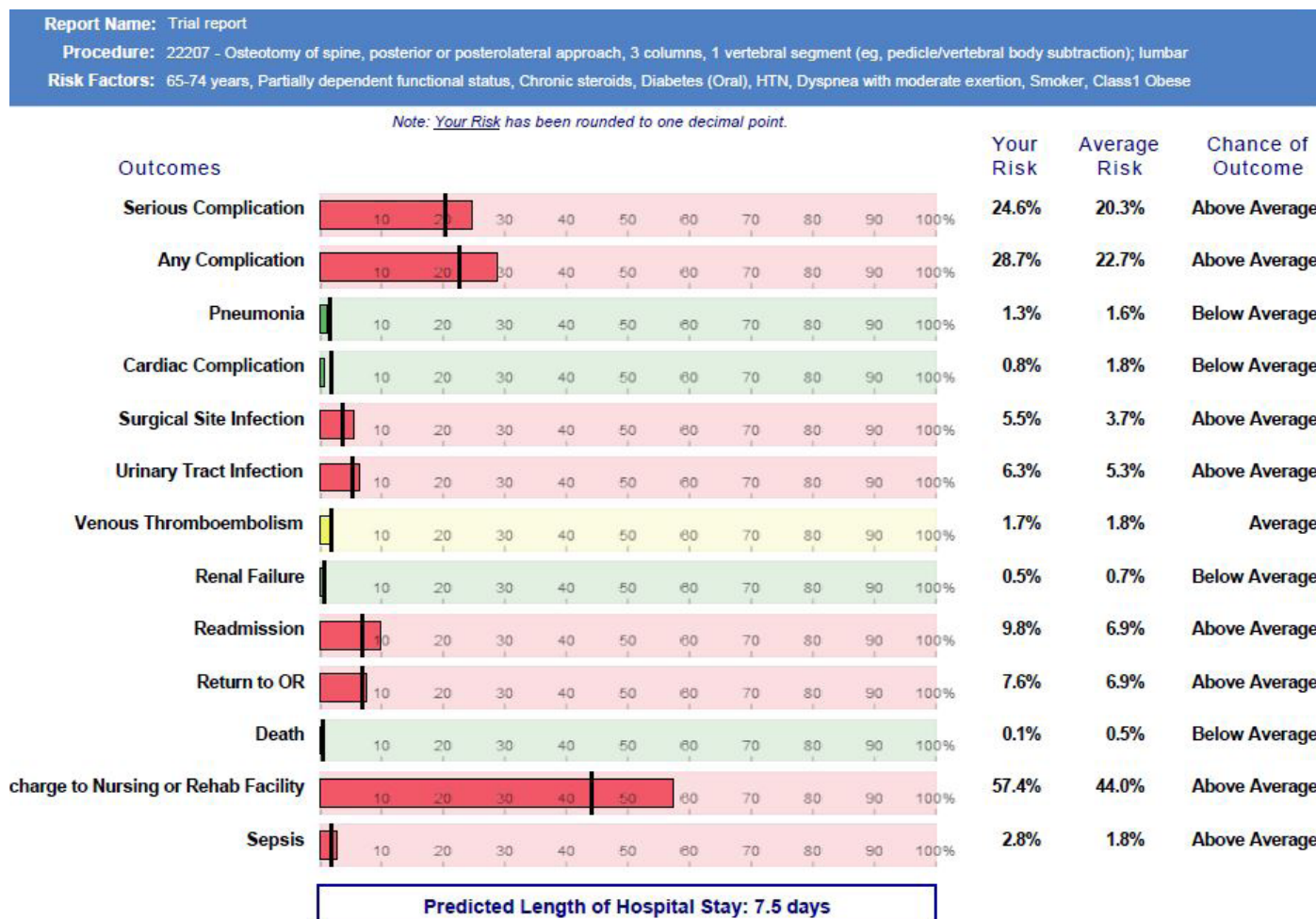


Figure 1- An example of the risk stratification for a patient with a list of medical conditions and for a defined operation. The output form details the individuals risk comparing to the average risk for different conditions. It also predicts the length of stay in the hospital, the possibility of requiring rehabilitation and the percent risk of morbidity and mortality.

A detailed assessment of medical co-morbidities and general health requires input from different medical sub-specialties. This effort is led by the specialised spinal deformity anaesthetist and the pre-operative assessment team. Investigations to assess the heart, lungs, liver, kidneys, and blood clotting profile help to create granularity, which in turn allows for a detailed risk assessment. The assessments should ideally be on the lines of physiological age rather than chronological age. Frailty is a medical condition

that is characterised by strength, endurance, and physiological function that increases the individuals' vulnerability for developing an increased dependency and/or death.

There are several indices reported to measure frailty, one of which is the ACS-NSQIP

(<https://riskcalculator.facs.org/RiskCalculator/PatientInfo.jsp>). (figure 1)

This type of objective assessment assists the anaesthetic and surgical teams to predict adverse events.

The assessments are done on the

basis of the planned operation. The risks for the patient will vary depending on the operation complexity.

Consequently, reducing the complexity can improve the risk profile for the patient. This can help the surgeon discuss the risk-benefit equation and allow for realistic expectations from the operation. The surgical plan can be modified if the risks are perceived to be unacceptable.

A strategy from the car manufacturing industry has reduced the complication profile and improve surgical outcomes. The Toyota philosophy is based on lean methodology. It was developed by Taiichi Ohno, a Toyota engineer. It is based on his observation that a particular workflow that is variable, unpredictable, and ambiguous is inefficient. It is difficult to identify value from the waste within the workflow. If the workflow is standardised, the variables can be controlled and refined to improve efficiency. This concept when applied to surgery in adults allows the 'workflow' to be stream-lined as pre-operative, intra-operative, and post-operative.

This system has been refined by a team of spinal deformity surgeons led by Dr Rajiv Sethi from Virginia Mason in Seattle as the Seattle Spine Team Protocol (figure 2) They describe a three-pronged systematic approach to risk management that addresses the complication profile and makes the surgery safer. This includes a multidisciplinary pre-operative complex spine conference, a collaborative team approach, and a rigorous intra-operative monitoring protocol.

One of the important features

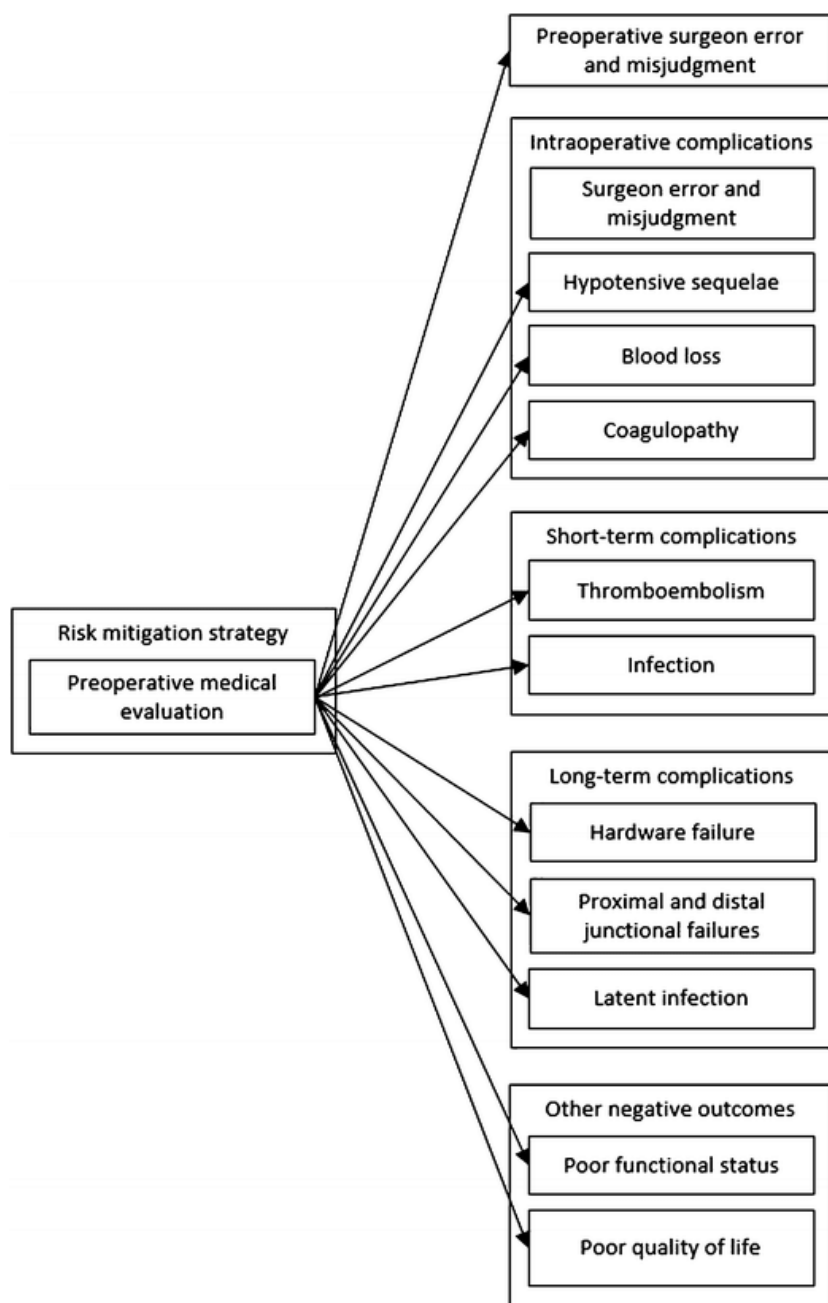


Figure 2: The schematic outline of the Seattle Spine Team Protocol

of this protocol is the multidisciplinary team meeting, which provides an opportunity for the treating team of professionals to discuss the various nuances of the individual patient. This is invaluable in complex problems, from both the medical and surgical perspective. This concept is based on the understanding that increased sub-specialisation allows for a more in-depth involvement of different teams to identify, mitigate, and hence avoid complications. A dispassionate discussion is likely to provide a more balanced range of opinions than a surgeon working in isolation. This mechanism can be used in deciding whether to operate or not; deciding on alternatives to the operation; creating clarity around the technicalities of the operation; or planning the details of the operation. This equal voice inclusivity has been reported as producing fewer complications and improves patient outcomes.

A collaborative intra-operative surgical team focussed on increasing the efficiency and working as a dual Consultant surgical team and a specialised complex spinal surgical anaesthetic team. Rigorous intra-

operative spinal cord and anaesthetic monitoring protocols that include blood conservation strategies and enhanced recovery protocols are in use in several units. The nature of the rehabilitation requirement can be planned well in advance. Hospital stay should be minimised, and early commencement of physiotherapy is encouraged. Recovery times vary according to the operations. However, a positive outlook by the patients and the healthcare teams should be encouraged.

These approaches have reduced but not eliminated risks and the high rate of complications, which is inherent to this surgical group. The risk of stroke, myocardial infarctions, wound infections, thromboembolic diseases, and rarely death can be stratified to allow for a better-informed patient when consenting to the operation. The presence of some conditions such as previous malignancies, chronic diseases, and blood disorders allows for more robust strategies to counter possible complications.



SCIENCE OF MOVEMENT

Scoliosis patient and UCL student Yaning Wu interviewed Dr Nachiappan Chockalingam, a researcher based at Staffordshire University. His most recent work, titled “How does curve type and magnitude affect locomotor function in adolescent females with scoliosis?” is being funded by the BSRF and holds exciting implications for the future of scoliosis monitoring and treatment. Here is a summary of their conversation.

What is this research about and how is it being done?

Dr Chockalingam is studying the biomechanical aspects of scoliosis, or in simple terms, how patients move. His hope is that the results that he and his colleagues report will lead to further understanding of movement patterns and result in new treatment options including surgical techniques and instrumentation.

There is a current gap in our knowledge of gait and its relation to spinal curvature; within the NHS and in health services across the world, gait analysis is commonly used only for children with cerebral palsy and other musculoskeletal disorders. The use of similar techniques with a more common condition will drive the clinical world, including surgeons, physiotherapists, and

medical device developers, forward. Dr Chockalingam's research focuses on 10 – 16-year-old female patients with all types of adolescent idiopathic scoliosis (AIS) and with a Risser sign of 0-4, meaning that their bones have not reached maturity. He chose to study AIS patients for this project because the condition is the most common type of scoliosis, affecting 80% of those with scoliosis, and it is easier to classify AIS patients into separate groups. His original plan was to obtain data in the USA; Utrecht, the Netherlands; and Cardiff, Wales, but because of the changes brought by COVID-19, he is now shifting to centres in Sweden, Serbia and the UK. The study is both qualitative and quantitative, with initial stages involving a questionnaire being sent out to participants asking them

about what activities of daily living (ADLs) are important to them.

ADLs are an important consideration in Dr Chockalingam's research because of his belief in individualised treatment plans. When determining functional disability, he avoids using standard frameworks to assess the young people he is studying, but will instead use their experiences of physical activity to determine what their greatest needs and difficulties are.

To visualise back movement in the upper and lower thoracic and lumbar regions of the spine Dr Chockalingam and his colleague Dr Tom Shannon used a cluster-based marker approach, a technique developed by their research group to analyse the movement of the back, and Microsoft Kinect, the device used for playing games.



The software that Dr Shannon has developed to use in conjunction with Kinect allows for innovative surface topography assessment that is simpler and less expensive than what is available on the market. They are now testing these kinematics technologies in Serbia and Bulgaria. Whereas previous research only hinted at total range of motion in degrees, Dr Chockalingam's research can investigate in more detail what happens when segments of the spine (eg, upper thoracic) interact with each other.

What experience does Dr Chockalingam have with conservative and traditional scoliosis management strategies?

Although his primary research interest is not the clinical management of scoliosis, Dr Chockalingam has worked on a Cochrane review of spinal bracing, exercise and surgical intervention and recently has also completed a systematic review on cervical collars. He has collaborated with both spinal fusion surgeons and those practising the innovative technique of VBT (Vertebral Body Tethering), studying the effects of surgery on patients' range of motion. When asked about the effectiveness of these procedures, he insisted that better patient data are needed for new approaches – only then could we make accurate and representative conclusions.

Why scoliosis?

Although Dr Chockalingam doesn't have personal experience of scoliosis, he has been studying scoliosis and its related conditions since his PhD years, when he

submitted a thesis on the topic. He enjoys this area of research because it is full of unknowns, especially on the biomechanics side, and sees the potential his work has to contribute substantially to improving patient outcomes. In recent years, computing and IT tools used to analyse body movement have rapidly developed, making Dr Chockalingam's work ever more exciting. He wants to raise the profile of scoliosis research in the biomedical engineering and biomechanics communities because the subject is still relatively unknown and underfunded.

How has COVID-19 changed this research?

Dr Chockalingam's in-person work has paused during lockdown, and his team are now working virtually. However, he hopes to continue obtaining patient data from early October (2021) sending written questionnaires to study participants in the meantime. There will be a substantial logistical challenge with spinal fusion recipients, who are

required to self-isolate for 2 weeks before and after their procedure. This means that Dr Chockalingam must modify his study design – by, for example, measuring patients' body motion a month before surgery instead of closer to the date as previously planned. Post-fusion measurements should not be affected by these restrictions.

What is in the future?

The eventual aim of this research is to develop patient-specific interventions that don't come off the shelf. The interventions include spinal instrumentation, bracing, and other technologies that affect range of motion. He is also considering taking the study to low-income and middle-income countries in the global South, whose clinicians can take advantage of affordable technologies to address the treatment gap in their communities.

Yaning would like to thank Dr Nachiappan Chockalingam for having this conversation with her about his intriguing research.



ISOBEL GRAY AWARD

Anita Simonds



We are delighted to give the Isobel Gray Award, 2021, for services to SAUK to Professor Anita Simonds. Anita has retired as a Trustee of SAUK, which she was for well over 20 years, and we are very grateful for all she did for the organisation and its members. Anita works as a consultant chest physician at the Royal Brompton and Harefield Hospitals, following in the footsteps of Dr Phillip Zorab who helped to set up SAUK with Ailie Harrison and Stephanie Clark. Anita is very eminent in her specialty and was President of the European Respiratory Society until this year, a very prestigious appointment and an honour. She is well known to people with scoliosis who have chest problems and she looked after Isobel Gray, who was a founding member and Trustee of SAUK. Anita wrote a book about pregnancy and scoliosis for SAUK many years ago and updated the information in an erudite and well informed article in our Autumn 2020 edition of Backbone. She was an invaluable Trustee and we will greatly miss her quiet wisdom and dedication. We are very sorry to say goodbye to her but wish her well in her next ventures.

ROLL OF HONOUR

Nomination for Ava Bell from her mum Sandra Bell

My daughter Ava Bell was diagnosed with scoliosis at age 6. She had a severe S shape curve with a thoracic curve of 41 and lumbar curve 28. She was braced in the Boston brace and was always a little star wearing it and rarely complained.

Ava's curves would go up and down, but did continue to grow and when one reached 60, we were told that Ava needed the MAGEC rods. These were implanted when she was just 9 years old in December, 2018. This was around the time the Panorama documentary aired detailing the failure of the rods. Ava's spine went on the British Spine Registry.

She took the surgery in her stride and recovered very well. Ava had a rod lengthening in September, 2020,



and it was at this appointment that we discovered Ava's screw had a halo so it had moved slightly and that the rods failed to move. Ava was only 10 years old when the consultant recommended fusion! We were

flabbergasted as we knew this would be her future but not for many years yet. Ava was in so much pain and discomfort that she was missing school. We decided that we didn't have many other options, Ava couldn't have the rods again due to the suspension of the MAGEC rods and she definitely couldn't stay the way she was.

Her surgery went ahead on the 3rd November. Because of the pandemic there was nowhere to really to stay in the hospital, so my husband and I sat in our car right outside the hospital. After

many hours we received a phone call to say come up to the theatre. We were greeted by the two slumped consultants who told us that the monitoring alarms had gone off

around T7 and they couldn't get a signal back, so they had to undo 80% of what they had just spent hours doing.

She lost a lot of blood and needed a blood transfusion. Ava had five vertebrae that had already fused by themselves that hadn't been picked up before surgery. When we finally got to see Ava, we told her there had been complications. Her initial response was "I have to do it again?" It was just heart breaking.

Ava went on to suffer an ileus for 10 days and needed a further two blood transfusions. She was so ill that she didn't eat or drink and had a drainage bag inserted. She had to have a Total Parental Nutrition (TPN) bag set up, which is a feeding bag tailored to what your blood suggests your body needs.

On the 16th November, Ava got her line out and began to eat again. By this time, Ava had spent 2 weeks flat on her back. Ava had 1 week to get herself as well as possible to undergo surgery again. Our little girl turned 11 years old on the 21st November and spent it separated from her twin sister and family while eating birthday cake on her back with another huge operation pending.

It took another 7 hours, but everything had gone to plan; they were able to get a correction for Ava and secure her spine and break the five fused vertebrae. Ava did suffer a short ileus again and needed another blood transfusion. We spent a further 2 weeks in hospital, and she was discharged on the 7th December.

As I write this, she is 10 weeks post op and still recovering. She still has pain and discomfort but is slowly able to take on some self-care and even amazed us with attempting some home schooling.

As we look back, we have definitely suffered trauma, we are a little numb, shocked, and emotional. However, Ava has been the shining star throughout. She has tackled everything that has thrown itself at her by taking it one thing at a time. We have had amazing community support with equipment, amazing fast response physio, and her community physio who has started a virtual Pilates class with our daughter. I hope you will agree that this young girl has demonstrated strength beyond her years.

Nomination for Victoria Williams from Charlotte Dodd



I would like to nominate Victoria Williams for the Roll of Honour. Victoria has struggled with her mental health, suffering from extreme anxiety and depression. Victoria had her spinal fusion in August, 2020. She went in with sheer determination to have the surgery and to recover from it. Victoria has come on in leaps and bounds but still struggles a lot with her mental health. This hasn't stopped Victoria from focusing on her recovery though, her school work

(she's on track for straight A's in her A Levels, doing all this from home!), and helping other individuals that are going through spinal fusion surgery. I think Victoria is a huge inspiration and deserves this recognition. Victoria is the kindest, most selfless individual I know and always helps others.

Nomination for William Henderson from his mum Rebecca Henderson

William is 15 years old and was diagnosed with scoliosis and a spinal cord syrinx in 2016, the same year that he was diagnosed with autism.

Despite wearing a Boston brace, his scoliosis progressed rapidly over

the next few years. We were advised that a spinal fusion was the only option to stop his internal organs from being compromised long-term.

William was not having any pain and was not concerned about his appearance so could not comprehend why he needed surgery and would not believe that the scoliosis was going to continue to worsen, as that was "only the surgeons' opinion" and "they might be wrong!".

William was worried that a fusion would stop him from growing as tall as his friends,

would prevent him from joining the police force, and might impact on his ability to continue with his passion for bell ringing.

We were fortunate to meet two other boys who had recently had surgery and talking to them helped to allay some of his fears. The real turning point was meeting another young person who had just been diagnosed and this inspired William to agree to the operation so that he could help

others facing the same situation.

He very bravely underwent a posterior spinal fusion surgery (T2 to L2) in August, 2020, at the RHOH, Stanmore. The operation was a success, for which we are all extremely grateful. William's autism has meant that the whole process, from diagnosis through to his ongoing recovery from the surgery, has been incredibly challenging for him and we are so proud of how he has coped with everything.

He is looking forward to returning to bell ringing when his surgeon (and Covid) allows and hopes to be able to meet up with other young people with scoliosis to share his experiences.



Nomination for Louise Williamson from Mark Williamson

After operations and many a body brace at a very young age, Louise has always worked hard to not let her disability stop her from leading a fulfilling life.

Louise is struggling physically now that she's in her mid-40s and because certain medical procedures available



now were not available in the 70s and 80s. There is little to no chance things can be corrected for her situation to improve. Knowing this, Louise continues to remain positive, and she continues to raise awareness through various charities and organisations.

Nomination for Louise Williamson from Tricia Colledge

Louise is a great and supportive friend of mine. I met her on a crime writing course, she was knitting socks at the time. When I first met her I, admittedly patronisingly, thought she was a poor wee soul.

It didn't take me long to realise that I was wrong. Lou is a talented knitter, a gifted writer, and has a sharp sense of humour and is acutely perceptive.

I have known Lou for several years, meeting up at book launches and crime writing festivals. During this pandemic, things have been hard for Lou who had to shield for the duration. Still, she was the one who was supporting me while I was struggling with these strange times.

Not only that, during Lockdown she also posed as a model for a life drawing class to highlight those living with scoliosis.

When I think of Louise, I don't think of a 4ft 10inch woman with scoliosis, because she is the biggest person I know. She is talented, clever, funny, strong, and fearless. I know if I ever struggle, she will help me if she can. I am proud that Louise considers me her friend.

Nomination for Louise Williamson from Alison Lambert

I am nominating Louise for her honesty and bravery for baring her body for a life drawing session raising funds for SAUK. She was very honest about how nervous she was, which takes bravery as far as I am concerned. To not only do the session but do it as a fundraiser (and therefore publicise it to others) really raised awareness of SAUK. Louise has been frank about what scoliosis has meant for her – its impact, the operations, etc, and that has led to greater understanding of it for many of us.

Nomination for Florence from her mum Corrine Taylor

Florence was born prematurely, weighing just 3lb 14oz. She is one of triplets, (one of whom is also her identical twin).

In April, 2016, at 7 years old, Florence was diagnosed with scoliosis - I noticed she didn't sit quite straight and luckily, I could 'compare' her with her identical twin and noticed a difference.

In May, 2017, it was decided that she would benefit from a brace. Florence



wore her brace for over 3 years. She never complained, even when her brace rubbed and caused sores - she just carried on and accepted her 'uniqueness'. Sometimes she would get upset at bedtime when we'd chat about things. She didn't understand why she had scoliosis and her sisters didn't, especially Evie, being her identical twin. Generally, she was happy, had a can-do attitude, and wanted to do whatever she could alongside her sisters - the brace was not going to stop her ...she even worked out that she could still do cartwheels, even when wearing her brace!

By November, 2019, Florence understood from her amazing consultant that although she'd done everything that we'd asked and worn the brace exactly as she should; she would need surgery. 'Growth-rod' surgery was suggested, which would mean several operations for her. I researched any other options (MAGEC rods were off the

table as at that point the licence had been revoked). We found a procedure called VBT (vertebral body tethering) - but this was available only privately. We would have to fundraise at least £50,000 for her surgery. Flo, as ever was upbeat, she agreed we would try and fundraise, so we opened a Just Giving page and started planning fundraising events.

Florence was (and is) very slight, if surgery was going to be an option, we had to find a way for her to put enough weight on. She was seen by a dietician and was provided with milkshakes, she had to drink two a day - and hated them ... but drank them because she knew she had to put the weight on.

By March, 2020, all our fundraising events were cancelled due to COVID - we honestly thought VBT was unachievable and that we'd be looking at several operations. We'd been told by another surgeon from RNOH that Flo wasn't really suited to multiple surgeries, she also has Ehlers Danlos Syndrome and hypermobility - meaning that her skin would not cope well or heal well with surgery.

In August, 2020, a friend quietly contacted the BBC Midlands Today team - Flo is quite a shy person, but she agreed to have the team come out and cover her story. At this point in 9

months, we'd only managed to raise £18k of the £50k needed. After the story went out on the BBC, in just 36 hours we had reached our fundraising target.

Finally - She could have VBT - one operation (hopefully) that would control her curve whilst allowing her to grow. On 30th November, 2020, during a global pandemic, we flew to Istanbul in Turkey for Florence to have her surgery. She was in a foreign country, with a different language, different sights, smells, foods, and still she was so brave.

On 4th December, 2020, at 11 years old, Flo spent 10 hours in surgery. She woke later that evening, her first words being "Is it done?". The relief that we could say 'yes' was overwhelming for us all. She spent a few days recovering in the hospital where she walked with 24 hours, did all her breathing exercises, ... and mostly took the meds!

On 12th December, 2020, we flew home to be together for Christmas. She is now pain and brace free, thanks to many members of the public who supported her Just Giving page and thanks to the amazing staff at Acibadem Maslak Hospital, Istanbul. Florence is happy, 4 cm taller and brace free and feels re-connected with her sisters. We are all so, so proud of her!



SCOLIOSIS RESEARCH AND THE BRACING TRIAL

Ashley Cole, FRCS

Consultant Orthopaedic Spinal Surgeon, Sheffield Children's Hospital

How are new treatments introduced in the NHS?

Once new treatments are developed, it is important that we know whether they work or not and if they should be used only in certain groups. 'High-quality' research gives us these answers. New treatments are not always better but marketing, social media, and low-quality research can make them seem much better than they really are and can affect the growth phase of the graph in Figure 1. In the past, when doctors considered new treatments, introduction of them was decided from experiences in their training, maybe recent experience of the new treatment, and what they considered important in the scientific journals. The use of new treatments is now more regulated with the research supporting them being reviewed by the NHS before introduction to ensure that only safe and effective treatments are given to NHS patients. A recent example in scoliosis is vertebral body tethering (VBT) for which the NHS reviewed the

evidence and decided not to routinely commission until there is further high-quality research:

We are hopeful that high-quality research will match the early reports for VBT. Whilst research is increasingly important for new treatments, there are also good examples for existing treatments, and this will be considered for scoliosis bracing below.

What is the difference between high-quality and low-quality research?

Low-quality research includes 'case-series' where a group of patients are all given the new treatment and the researcher follows them for a period to see how well they have done. This is often compared to the effectiveness of the 'old' treatment which is usually well known from previous studies. Unfortunately, the results of these studies cannot be relied on and are often shown to be incorrect.

High-quality research gives us the best scientific evidence into new treatment options and can be done in two ways:

1. 'Randomised controlled trials' (RCT). These studies use a computer to randomly split patients into two groups – one group treated with the 'new' treatment and the other with the current 'gold-standard' treatment. The group of eligible patients is carefully defined

so that we know who the results apply to. The outcome measure is chosen to reflect the most important feature that the treatment must achieve and is important to patients. These studies are difficult to perform and expensive.

2. Although not fully accepted scientifically, the results of data from large patient databases known as 'Registries' seems to agree with the results of randomised controlled trials. The British Spine Registry (BSR) was developed by myself and one of my colleagues, Mr Lee Breakwell, and launched in 2012. The NHS mandates that all spinal surgical procedures should be recorded in the BSR. Quality of life questionnaires are completed by patients electronically before and after surgery. It is important that patients and surgeons use this resource to increase our knowledge of the effects of scoliosis surgery as the results will only be meaningful if most of the patients complete the questionnaires.

There is a new trend to combine evidence from several studies on the same subject. This process is called a 'systematic review' and where the data in the original scientific publications allows the use of statistics it is called a 'meta-analysis'.

Where are we with scoliosis research in the UK?

The British Scoliosis Research Foundation (BSRF) was formed in 1973 and funds high quality research into scoliosis and works closely with SAUK

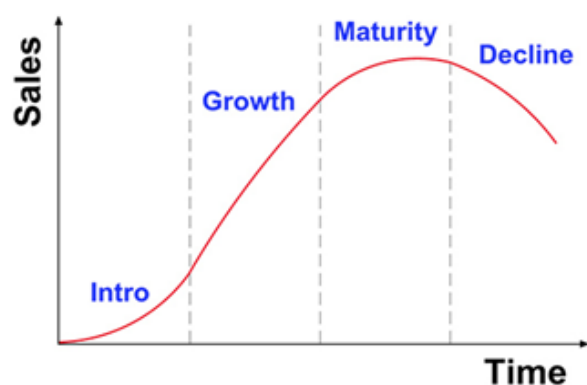


Figure 1: Typical life cycle for a new medical treatment.

and the British Scoliosis Society (BSS). In 2017, after a series of surveys and meetings involving patients, doctors, SAUK, BSRF, and BSS, the James Lind Alliance published the scoliosis research priorities in December, 2017, (<https://www.jla.nihr.ac.uk/priority-setting-partnerships/scoliosis/the-top-10-priorities.htm>). These priorities set out the research questions considered most important to patients and doctors for future research projects.

In late 2020, possibly as a result of the published research priorities, the National Institute for Health Research (the nation's largest funder of healthcare research) have funded a study, Bracing Adolescent Idiopathic Scoliosis (BASIS), which is a randomised controlled trial comparing full-time bracing with night-time only bracing (see below). The study will run over the next 10 years and gives the scoliosis community a unique opportunity to promote scoliosis research.

How has research affected full-time bracing for Adolescent Idiopathic Scoliosis (AIS)?

Doctors have been bracing young people with AIS for many years, but the evidence has always been

questioned. The full-time brace is prescribed to be worn at least 20 hours per day. A large multicentre study of 286 AIS patients showed success in 74% of braced patients and 34% who did not have a brace and were just observed, and was published in 1995. However, the scientific quality of the study was criticised, and bracing remained 'unproven'. As a result, bracing remained an uncommon treatment in the UK.

This all changed in 2013 after publication of the first 'randomised controlled trial' of bracing in AIS – the BrAIST study. This study 'randomised' AIS patients into full-time bracing or observation (no treatment). Curve progression to 50 degrees was the outcome measure chosen as the definition of 'treatment failure'. This outcome measure is based on the 60-year study of untreated patients from Iowa, USA, showing that in AIS, curves larger than 50 degrees continue to progress after growth has finished and curves smaller than 50 degrees rarely progress during adult life. In the BrAIST study 72% of the braced patients had treatment success compared with only 48% in the observed group. Bracing in AIS had finally become accepted as a

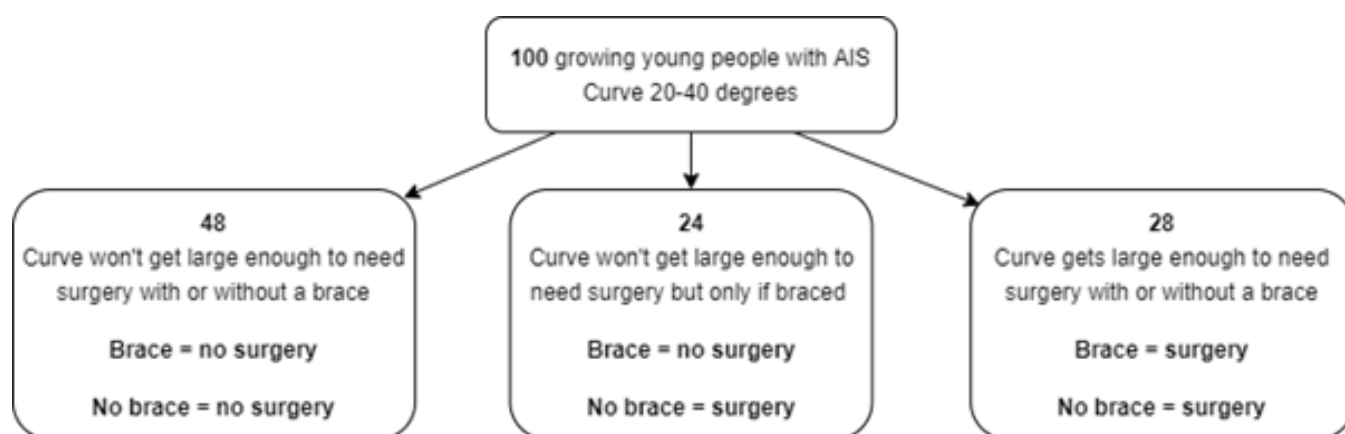
result of the high-quality evidence provided by the BrAIST study and is now normal practice in the UK.

Is bracing in AIS all about success?

We know that scoliosis curves in AIS get worse because of growth and that brace treatment aims to reduce the chance of the curve worsening. Young people with AIS are braced until they finish growing, and how long they spend in a brace varies because the teenage growth spurt occurs at different ages. Generally, this is somewhere between 1.5 and 3.5 years with an average of 2.5 years. Studies have shown that self-image, mental health, and vitality are all negatively affected by bracing. So, it becomes a balance between the proven benefit of bracing in terms of reducing the chance of surgery and the negative effects of the brace itself.

How to decide whether to have a brace in AIS?

Figure 2 summarises the findings of the BrAIST study. Bracing has a 72% success rate made up of 48% who would not require surgery with or without a brace and 24% who will only avoid surgery by wearing a brace.



	Surgery - curve progresses to 50 degrees or more	No surgery – curve less than 50 degrees at the end of growth
Brace	28	72
	Wore a brace and ended up having surgery anyway. Most are happy they did everything they could to avoid surgery	A good result although some curves would not get worse even without a brace
No Brace	52	48
	May have progressed even if they had been braced but we will never know.	This group have avoided a brace and surgery.

Table 1 Results of 100 young people with AIS.

Factor	Summary	Quality of evidence	Can we change it?
Compliance with bracing	If the brace is worn more hours per day, it is more successful	Moderate	Yes
In-brace correction	The less the curve size reduces in the brace the more likely bracing will fail	Moderate	Largely driven by curve flexibility
Remaining growth	Limited evidence that those with more growth remaining are less successful with bracing and those with less growth remaining are more successful	Low	No
Curve size, curve rotation	Inconclusive evidence regarding the effect of curve size and rotation on bracing success	Low	No

Table 2. Factors influencing the success of full-time bracing.

Can we predict or influence the success of bracing?

Ideally, we would predict those who won't progress even if they don't have a brace because there is no need to brace this group. Also, if we could predict those who would progress despite bracing we could save them even trying a brace. We could then just brace those who will benefit from it. Unfortunately, we are unable to do this at present. Recently there have been a few meta-analyses of the numerous studies which have looked at factors affecting the success of bracing. These are summarised in Table 2. The only factor we can modify is increasing the number of hours the brace is worn each day.

If bracing only changes the outcome in 24 in 100 patients, why do it?

This is the obvious question from Figure 1 which shows that bracing only changes the outcome in about one in four young people with AIS by avoiding surgery, with two in four avoiding surgery with or without bracing. However, scoliosis surgery has risks which are thankfully rare but can be life changing. The US Scoliosis Research Society recently published the results from their database of 84,320 AIS patients who had undergone surgical correction of their scoliosis. The overall complication rate was 1.5% (three of every 200 patients). The commonest complications include wound infection (one in 200 patients); nerve or spinal cord injury (one in 300 patients); and problems with the metalwork (one in 500 patients). 5-10% of patients need further surgery over the following 10 years. Long-term studies comparing young people with AIS patients treated with and without surgery suggest no difference in pain or quality of life, but more research is needed.

What is the Bracing Adolescent Idiopathic Scoliosis (BASIS) study?

The BASIS study, which will compare full-time bracing with night-time only bracing. Night-time braces are a different type of brace worn only in bed at night but the evidence for their effectiveness is less clear. They may be preferred by young people, but we don't know if they are as easy to sleep in as full-time braces. The principle is that on lying down a scoliosis curve reduces in size because gravity is eliminated. Also, a night-time brace can be designed to apply more force to the spine whilst lying down but would be too uncomfortable to wear during the day. Also, growth occurs mainly at night, when growth hormone levels are highest, so holding the spine in a corrected position at night may be more important.

For patients and doctors, there is a clear balance of uncertainty between these two brace options – we call this 'equipoise':

- Full time bracing where we have high-quality evidence that it reduces the risk of the curve getting worse, but it needs to be worn 20+ hours per day.
- Night-time bracing where we only have low-quality evidence that it reduces the risk of the curve getting worse, but it is only worn 8-12 hours per day. It is this lack of high-quality evidence that means we cannot offer this brace as NHS standard care.

We will ask children with adolescent idiopathic scoliosis (aged 10-15 years) who have not previously received bracing to take part in this study. For those who agree, children will be fairly allocated to one of the two different braces through a process called randomisation. The study needs 780 patients from 19-23 UK paediatric

spinal centres, enrolled over 4 years, starting in September, 2021.

The aim is not only to compare the effectiveness of the two braces but also to look at the effects of each brace on quality of life and the patient's experiences. The child will remain in brace until they have finished growing or need to have surgery. At each hospital appointment (every 6 months) their doctor or nurse will find out how they are doing and X-ray their back. Questionnaires will be completed every 6 months and can be done electronically on a computer, tablet, or phone using a link which will be emailed. At the end of growth, after the bracing is stopped, there will then be two further clinic visits at 1 and 2 years for further X-rays and questionnaires. The X-rays will be the same as those usually done during bracing.

There will be newsletters about the study and a regular prize draw for completing the questionnaires. SAUK will be kept informed about the study and how we are doing with recruitment. So far, two patient groups and an online survey of SAUK members have inputted into the study. Members of SAUK are co-investigators in the research and are part of the committees that will guide the study as it progresses. We will be seeking SAUK's help to design study materials, ensure the study is acceptable to young people and their families, and help broadcast the findings of the research.

The future of spinal research in the UK and the importance of patient/public involvement (PPI)

Currently almost all the paediatric spinal centres in the UK are involved in the BASIS study and will be potential recruitment sites. At each centre there

is a Consultant Principal Investigator, and the study has certainly promoted interest in research. The British Scoliosis Society is hoping to create a 'Research Network' to encourage the enthusiasm produced by BASIS to stimulate more research into other important topics generated through the James Lind Priority Setting Partnership.

Patient involvement is crucial and recognised by the NIHR (https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf) as improving the quality and relevance of clinical research. I would encourage you all to be 'research active' whether it be by taking part in research, joining research committees, or helping to make studies better by looking at their aims, outcome measures or study information. High quality research makes a difference to the treatments we can offer.

This study is funded by the National Institute for Health Research (NIHR) Health Technology Assessment 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.



POSSIBLE EFFECTS OF TITANIUM DEBRIS

Dr Alison Tyson-Capper, Professor of Molecular Cell Biology and Dr Tom Joyce, Professor of Orthopaedic Engineering, are part of a study, funded by the British Scoliosis Research Foundation (BSRF), into what the effects of titanium debris around the spines of children with scoliosis might be.

Titanium is used in the manufacturing of growing rods such as the MAGEC spinal rods, which in April, 2020, were suspended from supply in the UK. The UK and Ireland are the only countries to have currently suspended the use of MAGEC rods.

Dr Joyce is an orthopaedic engineer and has previously worked on assessing retrieved hip and knee implants to tell what has gone right and what wrong with these implants. He was approached by a spinal surgeon to study the MAGEC implants after they were removed from patients and found that there was a substantial volume of debris from the titanium. The excess titanium debris was leading to a blackening of tissue near the rod. There was no documentation of what the adverse effect may be of this titanium wear debris and any related titanium ions because the MAGEC rods had only been used for about 10 years.

Dr Joyce, explaining why this excess debris is a concern says “Titanium is used in a lot of implants, so it generally has a positive reputation. One of the concerns we have with MAGEC rods is that the volume of wear debris that is created is huge compared with hip or knee implants.

There was another case with a type of artificial hip joint that showed that once a certain volume of metallic debris was reached, the body became sensitive to it and eventually rejected that metal implant. So, we’re seeing if there is a similar response to titanium wear from MAGEC rods.”

Dr Joyce partnered with Dr Tyson-Capper to create a research project that could assess what the biological response of titanium around the spine may be. Dr Tyson-Capper herself has a friend with scoliosis and had previously identified the biological effects of cobalt and was the first to find that there was an inflammatory response in human cells from the metal cobalt in hip and knee implants.

They aim to understand failings and identify improvements so that people can design their implants to be safe and effective and surgeons can offer the best possible rods and be equipped with the most up-to-date information about that treatment. They also want to address the need for collaboration on international standards when it comes to the best way to test spinal rods before they are implanted.



This project will have further phases but thanks to the funding supplied by the BSRF they have collected the necessary data and samples and have determined the key biomarkers that are to be assessed.

What are MAGEC rods and growing rods?

MAGEC rods were developed to be used in children with early onset scoliosis as an implant that could control the curve progression whilst allowing the spine to grow. Further growth at that age is critical for breathing and lung development. MAGEC stands for MAGnetic Expansion Control and is an alternative to the traditional growing rod.

Traditional growing rods are placed into a child's back during surgery. Because children grow so quickly, the rods need to be lengthened about every 6 months. Each time the rods are lengthened surgery is needed.

The MAGEC system combines traditional growing rods with new magnet technology. MAGEC rods are put into a child's back during operation. After that, they can be lengthened in clinic using a remote control and powerful magnets. This allows a child to grow without needing repeat operations.

On 1st April, 2020, the UK medical devices regulator, the Medicines and Healthcare products Regulatory Agency (MHRA), issued a medical device alert to all clinicians stating that they should cease implanting MAGEC spinal rods until further notice while independent interrogation is being done.



ABOUT THE BSRF

BSRF



**BRITISH
SCOLIOSIS
RESEARCH FOUNDATION**

SAUK has a sister organisation, the British Scoliosis Research Foundation (BSRF). The BSRF exists to promote research into the treatment of scoliosis in the UK.

Each year the BSRF funds research into scoliosis, and it holds an international symposium every 2 years to spread knowledge gained from research.

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

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

SCF - THANK YOU

We are grateful to all our amazing fundraisers for all their hard work over the past few months organising various events and raising an incredible amount of money for SCF. We really couldn't continue to do what we do without you, so a massive thank you!

SCOLIOSIS
CAMPAIGN
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Raising funds for
the British
Scoliosis
Research
Foundation and
the Scoliosis
Association UK

Luke Stevenson

Luke will be running the London Virgin Money Marathon in 2022 for the Scoliosis Campaign Fund.

"Scoliosis has shaped me both physically and spiritually. I had major surgery to treat my severe scoliosis when I was 14 years old which led to rods being fused to my spine. As an actor, I am running in the marathon to show that one doesn't have to be hindered by any of their physical ailments. I am also running to raise both money and awareness for scoliosis, and by running for SCF the money will go towards helping to fund research and supporting those with scoliosis and their families," said Luke.

Support Luke's fundraiser here <https://uk.virginmoneygiving.com/LukeStevensonScoliosis1994>



Donations

A huge thank you to our generous donors:

Anne Guinard
Chisha Lombe
David Jones
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Michael Robinson
Nicholas Momber
Peter Roberts
Russell Thom
Sally Jarrett

Sounds Familiar
Martin Creegan
Harry Nash
Pamela Monksfield
Susan Hudon

Fundraising

Richard Aldridge, currently on £12.50, Alpha Wolf Run

Joanne Blyth, currently on £303.75, Edinburgh Marathon

Louise Laurie, currently on £836.25, 2.6 Challenge and Machu Picchu Trek

Charlotte Brown, currently on £93.75, Cycling

Luke Stevenson, currently on £1,549.50, London Marathon 2022

Dan Oakland, currently on £678.25, Running 200k in 3 months

Laura Cole, currently on £816.25, in memory of Michael Cole

Jo Farley, currently on £240.60, Running a Virtual Half Marathon

Anton Perkins, currently on £1199.00, 2020 Virtual Marathon, 2021 London Marathon

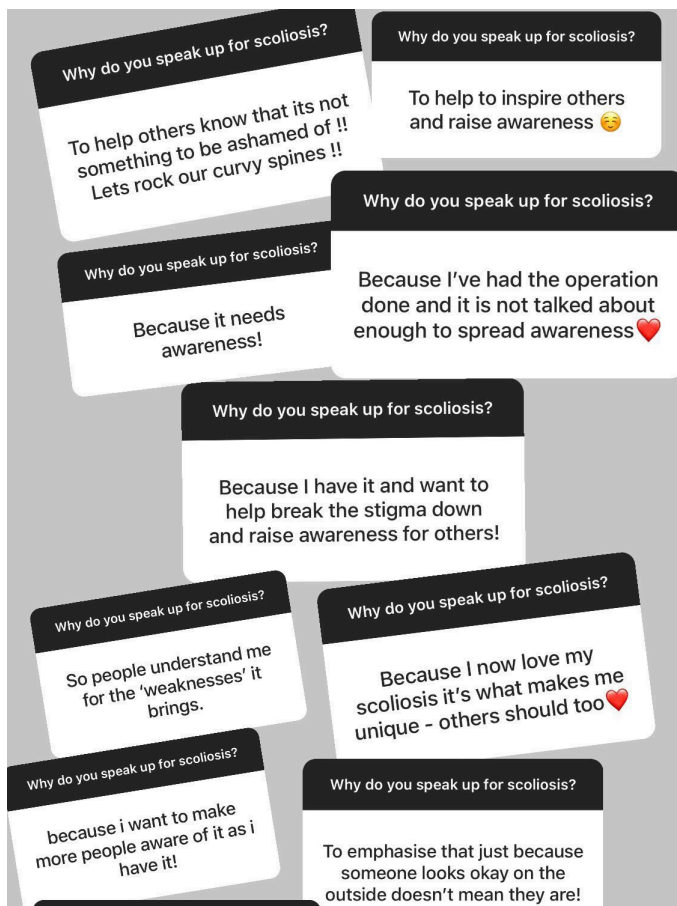
Francesca Calnan, currently on £635.00, 2020 Virtual Marathon, 2021 London Marathon

David Fisher, currently on £1,840.00, 2020 Virtual Marathon, 2021 London Marathon

Rod & Kellie Townes, currently on £2970.25, 2020 Virtual Marathon, 2021 London Marathon

Thomas Taylor, currently on £171.25, 2020 Virtual Marathon, 2021 London Marathon

Katie Goodchild, currently on £3094.73, 2020 Virtual Marathon, 2021 London Marathon



WHY DO YOU SPEAK UP FOR SCOLIOSIS?





ISAD

International Scoliosis Awareness Day
Saturday, 26th June, 2021



#BACKINGSCOLIOSIS



www.sauk.org.uk



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