

BACKBONE



SAUK announces a new Royal Patron

Scoliosis and Pregnancy

Scoliosis and Mental Health

Celebrating Curves:
Online Life Drawing

SAUK funds new e-learning
module for GPs

Coming to the Spinal Clinic

Fundraising, stories, and loads more

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THE SCOLIOSIS ASSOCIATION UK IS DELIGHTED TO ANNOUNCE A NEW ROYAL PATRON

We are pleased to announce that Her Royal Highness Princess Eugenie has agreed to become the Royal Patron of the Scoliosis Association UK.

HRH Princess Eugenie's own personal story has been an inspiration to many of us and our families who are affected by scoliosis. We know that she will not only relate to the work that SAUK does in supporting those with scoliosis and their families and raise awareness of scoliosis, but also help to raise the profile of the charity and expand its appeal and its message.

Stephanie Clark, co-founder and chair of SAUK, says 'I am absolutely delighted and grateful that Princess Eugenie is to be our Royal Patron. Her bravery and experience make this a very personal decision, and will continue to offer encouragement to the many people of all ages who are struggling to come to terms with their scoliosis.'



LATEST NEWS

Caroline Freedman is a personal trainer with scoliosis and now an author, having written a book called 'The Scoliosis Handbook of Safe and Effective Exercises Pre and Post Surgery'. This book is filled with advice about exercise Do's and Don'ts before and after surgery (and if you don't need surgery), pregnancy and scoliosis, and a chapter with helpful tips, covering how to sit in an airline seat and feel comfortable, sports to avoid, what to wear under and over a brace, and more.

Stephanie Clark, our Chair of Trustees at SAUK, said "Caroline has produced a beautifully written and clearly understandable guide to exercise for people with scoliosis, always emphasising that individual needs vary and that people should be guided by their physician. I can heartily recommend people with scoliosis of all ages read it." The Scoliosis Handbook of Safe and Effective Exercises Pre and Post Surgery by Caroline Freedman is available to purchase in the UK from Amazon UK (Please use Amazon Smile and choose Scoliosis Association UK as your charity) and Waterstones now!

THE SCOLIOSIS HANDBOOK

OF SAFE AND EFFECTIVE EXERCISES
PRE AND POST SURGERY



We are excited to welcome Emily Gibson to the team as our Fundraising Officer. Emily has a background in leading a high performing student fundraising organisation, as well as taking part in many personal fundraising events, and endeavours. Her role at SAUK is to answer enquiries about fundraising events, help to organise events and provide support for individuals fundraising for us.



Invitation to Participate in the **SCOLI Study**

*A survey about Adolescent Idiopathic
Scoliosis & Wellbeing*

We are inviting young people with **Adolescent Idiopathic Scoliosis** (aged 12-21, who have not previously had spinal fusion surgery) to fill in a survey about their scoliosis and their wellbeing. Findings will help to inform scoliosis services & supports.

The survey can be completed at home and is open to those in **Ireland & the UK**. Participants will receive a gift voucher to thank them for their time.

- For more information & to take part please contact Gillian at gillian.motyer@ucdconnect.ie or +353(85)2165385, who will send you a link for the study via email.



We're here to talk - SAUK provides a Helpline so that people can call or email the friendly SAUK team for advice, support, or just someone to talk to.

Whether you want general guidance or advice or just to talk things through; the SAUK team are here to lend a listening ear. We receive calls from people who have just been diagnosed, worried parents, people who have lived with scoliosis for many years, and many others.

You can call us on 0208 964 1166 or if you prefer email info@sauk.org.uk and we will always get back to you.

NEW SAUK TRUSTEES



Colin Nnadi

Mr Nnadi was appointed Consultant Orthopaedic Spine Surgeon at the Oxford University Hospitals NHS Trust in 2008. He was locum Consultant Spine Surgeon at the Queens Medical Centre, Nottingham, before taking up his Oxford post.

Mr Nnadi has a special interest in Paediatric deformity and is a member of the British Scoliosis Society, European Spine Society, and Scoliosis Research Society. He has published a book on Early Onset Scoliosis. He is also on the editorial board of the European Spine Journal.

He has been Chief investigator for two National trials – The Magnetic Growth rods trial in Early Onset Scoliosis and the K Spine system for Adolescent Idiopathic Scoliosis. He is a regular faculty member at international conferences on paediatric spinal surgery.



Leia Clancy

Leia has a background in fundraising and now works in the Not-for-Profit practice of the UK's biggest executive search firm. She works on a range of senior appointments across the sector with a particular focus on income generation.

She was diagnosed with severe scoliosis when she was 13 and had both bracing and corrective surgery. Given the long term effect of the condition, she has since become a committed advocate for scoliosis awareness, appearing in publications such as Cosmopolitan UK and projects like Behind The Scars.



Rachel Levene

Rachel is a mother of two and a GP in London. She was diagnosed with scoliosis aged 2 years and her first surgery was when she was 8. She had spinal fusion and Harrington rod instrumentation in 1974. She was under the care of the wonderful Mr Charles Manning until well into her teens and has never really left the RNOH. Over the years she has received incredible care from Departments of Orthopaedics, Metabolic Medicine, the Pain Clinic, and Physiotherapy Dept. She remembers very clearly her time as an inpatient in the 1960's and 1970's and is happy to witness the advances in the physical and emotional care of patients today. She feels passionately about the psychological effects of scoliosis and the importance of body positivity, not just for people with scoliosis but also for anyone with a visible physical difference. In her spare time she loves baking and crafting. She lives in London but her heart is split between Newcastle and Cornwall.

SCOLIOSIS AND PREGNANCY

Anita Simonds, Professor of Respiratory & Sleep Medicine, Royal Brompton & Harefield NHS Foundation Trust and Catheirne Nelson-Piercy, Professor of Obstetric Medicine and Consultant Obstetric Physician, Guy's & St Thomas' NHS Foundation Trust

Idiopathic scoliosis is fairly common in young girls, many of whom plan to have children at some point in their lives. The effects of scoliosis on the back, the pelvis, and in some cases the respiratory system, frequently prompt the question from a prospective parent: "What are the risks of pregnancy?"

The short answer is that in most cases there will be few if any problems, but those mothers-to-be who have the disorder understandably have a lot of questions about the effect their scoliosis can have on them and their child. These concerns can be about the health risks of pregnancy to a mother with scoliosis and whether there will be any obstetric problems during the pregnancy or birth. Many prospective mothers are anxious that they could pass scoliosis on to their children, and whether the condition could pose a risk to carrying the child to term or cause difficulties in delivery. And, naturally, parents also worry about the effect that becoming pregnant could have on their body in general and curve in particular.

The commonest type of scoliosis is the idiopathic form, which becomes apparent during the adolescent growth spurt at around the age of 10–14 years. By this stage the development of the lungs and heart is complete, and apart from a mild degree of restricted lung capacity, individuals with adolescent-onset scoliosis rarely encounter breathing problems during pregnancy or as they get older.

In some people who are born with scoliosis (congenital type), or in whom the scoliosis is associated with a neuromuscular condition, such as muscular dystrophy or poliomyelitis, lung size may be more severely restricted because the lungs haven't had room to grow. Breathing will also be affected if the muscles that expand the rib cage are weak.

A useful way to assess lung size is to measure vital capacity with a simple blowing test — this measures the total amount of air that can be actively expelled from the lungs after taking in maximum breath. If the vital capacity is less than 50% of what is predicted, a full review by a respiratory specialist is advisable.

However, evidence suggests that as long as the vital capacity exceeds about 1 litre the outcome will probably be good. Indeed, recent successful pregnancies have been achieved in individuals with a vital capacity of about 600 millilitres (0.6 litre), provided that they received respiratory support. Below this lung size problems with a reduction in oxygen level (hypoxaemia) can occur. Low oxygen levels characteristically worsen on exertion and during sleep, and may be accompanied by a rise in the concentration of waste gas (carbon dioxide).

A low oxygen level is harmful to the growing baby and can also lead to heart strain in the mother. Fortunately,

this situation is rare, and monitoring of oxygen levels can be easily done during exercise and at night. In very few cases with severe scoliosis, respiratory support at night can be provided by a small breathing machine. This is called non-invasive ventilation. Non-invasive ventilation is needed only in a few patients — usually those with a vital capacity of less than 1 litre and/or weak muscles. Provided that this breathing support is used and carefully monitored, successful outcomes for mother and baby can be achieved.

Sometimes an early-onset scoliosis will be associated with a congenital heart defect (eg, hole in the heart). Heart problems will nearly always be detected in childhood and corrected where necessary. However, to ensure



that there are no heart problems, an ECG (electrocardiograph) and echocardiogram (an ultrasound scan) of the heart can be done.

Provided that the oxygen level of the mother is fine and heart function is good there should be no threat to the growth of the baby, and the enlarging uterus easily adapts to the shape of the mother. Idiopathic scoliosis is probably inherited on multiple genes. Although idiopathic scoliosis sometimes runs in families, this is not common, so parents can be reasonably reassured that the risk of the baby developing scoliosis is low.

It is important to remember that most people with adolescent onset scoliosis will not have a low vital capacity or heart problems. Simple breathing tests can check on lung function and if there is any query about this your GP can refer you to a respiratory specialist.

There are exciting new developments in genetics, but it is not yet possible to provide a screening test for scoliosis. Ultrasound scans of the baby will of course check overall growth, including



“Most people with adolescent onset scoliosis will not have a low vital capacity or heart problems.”

spinal development. The exception to this are some of the congenital forms of scoliosis, which are associated with conditions such as neurofibromatosis, and with some types of myopathy and muscular dystrophy. These do run from generation to generation, and some conditions can be detected prenatally. Genetic counselling services exist in all regions of the UK and any individual with concerns can be referred for advice by their GP or hospital specialist.

Large hormonal changes occur during pregnancy with an increase in oestrogen, progesterone, and relaxing. These hormones help to loosen the ligaments of the pelvis and lower spine to ease the birth of the baby. Although concerns have been raised that hormonal fluctuations could lead to progression of a spinal curvature, most studies are reassuring on this point, suggesting that changes in the degree of scoliosis are slight, provided that the curvature is stable at the outset of pregnancy.

Some degree of breathlessness is common from the early months of pregnancy in all women. This shortness of breath is partly caused by the rise in progesterone, which stimulates breathing by increasing the depth of each breath. Blood volume also increases. These normal physiological changes are well tolerated and only likely to prove a problem if the vital capacity is low or heart function is compromised.

Around 80% of people will have

some sort of back pain in their life so it is no surprise that many pregnant women experience discomfort as a result of the strain put on their back. As the baby grows, the additional burden affects the mother's posture and the abdominal muscles work hard to maintain neutral posture. The abdominal muscles stretch as the baby grows, lessening their effectiveness in maintaining neutral, usual, posture, and consequently additional strain is placed on the muscles that run parallel to the spine. As with scoliosis outside pregnancy—and back health in general—keeping the core strong and maintaining a reasonable level of fitness will help to alleviate back pain in pregnancy.

In some women with more severe scoliosis early / preterm delivery (less than 37 weeks gestation) is necessary because the effect of the growing baby and uterus on the mother's breathing means that the woman becomes uncomfortably short of breath even with the help of non-invasive ventilation. Also, in some women the baby does not lie head down but transverse (across the abdomen) making a Caesarean birth necessary.

It is always sensible to discuss the management of labour in advance with the midwife, GP, obstetrician, and anaesthetist.

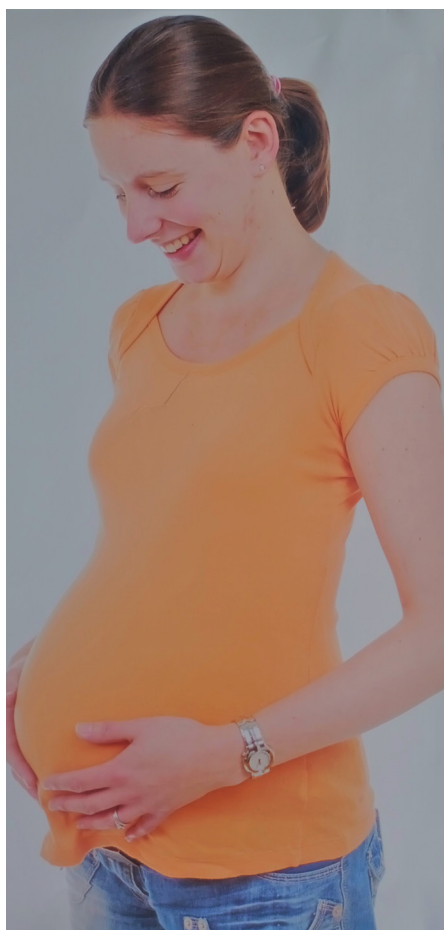
Comfortable positioning—the position adopted during labour and delivery is crucial for the comfort of the spine, and long immobilisation is unhelpful. The

most comfortable position (a relative term!) will, of course, vary between individuals.

Epidural pain relief may be able to be used during labour. However, epidural insertion can be challenging, particularly in women with severe scoliosis or in those who have had corrective surgery with metal rods and fusion. In these individuals, it may be more difficult to locate the right place for the regional / spinal / epidural anaesthetic or produce an even spread of this agent. Indeed, in some patients, epidural insertion might not be possible and other options for pain relief during labour should be considered. It is therefore important to have an early assessment and discussion with your obstetric anaesthetist to enable pain relief for labour to be individualised. Some women might require a caesarean section, and again it is vital to have an early discussion with your obstetric anaesthetist about the most appropriate type of anaesthetic.

The good news is that it has been known for many years that the outcome of pregnancy in scoliosis is generally good. A survey, carried out by Dr Phillip Zorab and Dr David Siegler, of 118 pregnancies in 64 women with scoliosis found that no serious medical problems were encountered. 17% of mothers reported increased breathlessness and 21% had increased back pain but found it tolerable. A normal delivery was achieved in most women with only 17% requiring a caesarean section for obstetric reasons.

More recently in a study of 142 pregnancies in women who had been treated with corrective scoliosis surgery there was a slightly higher proportion



Helen pregnant after fusion surgery

who had a caesarean section compared with the general population, but the rates of complications in pregnancy and delivery were no higher than in the general population and the offspring were healthy. About 40% of mothers developed low back pain during pregnancy but this had resolved by 3 months after delivery in most. A survey of cases of mostly idiopathic scoliosis in India published in 2010 again shows a higher caesarean rate than in individuals without a scoliosis but there were no major problems with the mothers' health.

These results justify an optimistic outlook in the main. However, individuals with congenital or early-onset scoliosis, and those with muscle weakness, breathlessness before pregnancy, or heart problems, should always seek medical advice.

In recent years at the Royal Brompton Hospital, several mothers with quite severe scoliosis have been supported throughout pregnancy with good results, and only a few have been advised to avoid pregnancy. Pre-pregnancy counselling is an excellent idea for all people contemplating pregnancy and is especially relevant to those with scoliosis. It is for this reason that the Royal Brompton/ Queen Charlotte's/ Hammersmith/ St Thomas' Hospitals in London run a pre-pregnancy counselling service. Here, the individual relevance of the above considerations can be discussed in detail, and advice given about sensible health measures, vitamin and folate supplementation, posture, and exercise. In addition, the management of any coexisting problems such as asthma, hayfever, indigestion, or diabetes can be optimised, in order to give both mother and baby the best chance.

Editors note:

For more information on local pregnancy counselling services speak to your GP.

At any point if you feel unsure or have questions, please contact SAUK and one of the friendly Helpline staff will help to alleviate any concerns or fears that you may have. SAUK also has a fantastic network of members and volunteers who are happy to talk to you about their experiences of pregnancy with their scoliosis. SAUK exists to ensure that you should never feel alone during your scoliosis journey.

PREGNANCY AFTER FUSION

At the time I was diagnosed with idiopathic scoliosis in 1995, when I was 14, and when I underwent subsequent corrective surgery in July, 1997, aged 16, the question of pregnancy and birth was not top of my list of considerations. In fact, I don't think it was anywhere on my list!!

Fast forward 8 years and my husband and I decided to try for a baby. I contacted my surgeon to ask if there was anything I should be taking into consideration or anything I should be aware of so that I was fully prepared. He advised that there was absolutely no reason why I should not be able to experience a perfectly normal pregnancy and birth. This gave me the confidence to embark on this new chapter.

My husband and I welcomed Max into the world (bang on due date!) in June ,2008, and he was followed by Sam in March, 2011. Both pregnancies were very straightforward. I experienced no significant back pain or discomfort. I carried both comfortably and continued to be very mobile throughout. I was looked after via 'shared care' which meant I had the usual appointments with the community midwife, but I also was overseen by a consultant. This was as much because of my fusion as it was my previous two miscarriages (before Max's arrival).

During both pregnancies, an appointment was scheduled with an anaesthetist because of my surgical history. This was a very useful discussion. She advised, both times (I was obviously a little more clued up the second time!) that they would not

be able to administer an epidural for two reasons: 1) the fusion meant that I would not be able to bend and separate the vertebrae for them to site the needle, 2) the scar tissue would make it difficult for them to locate the right place to administer the drug. In the event of needing a caesarean, I would have to have a general anaesthetic. She did mention that there would be the possibility of giving a slightly stronger painkiller than normal to bridge the gap if needed.

Armed with this knowledge I was perfectly happy that I knew the hospital would be fully up to date and that I knew what I could and couldn't have. I did still make sure I wrote in capital letters all over my notes 'CAN'T HAVE

AN EPIDURAL!!!!

Both of my boys laboured well without any complications, and I had both boys naturally without any pain relief. With Max, I did experience some continuous lower back pain for which they recommended the pool – it was a game-changer and definitely something I would recommend! The midwife was very attentive, checking with me frequently how the pain was. Sam arrived too quickly for them to even finish filling the bath!

It's worth casting your mind a little further forward to post-pregnancy too. I knew our three door sporty number wasn't going to cut it when I was trying to put a baby in a rear-facing car-seat in the back. I can't twist! So we ended up changing our car to a five door so that it was easier to get a baby in and out. The weight of your pram, ease of putting up, taking down and handle height were all factors we assessed when buying. It sounds pedantic but when you think how much time you're going to be spending doing it, it really will make a difference, I promise!

There is not a lot of discussion around pregnancy and scoliosis, so as with all of my scoliosis experience, I always aim to be open and honest, in the hope that it helps make someone else's journey that little bit lighter. SAUK provides invaluable support during these times. I wish I had known about them sooner!

**Helen Gardner, Central England
Regional Representative**



Helen admiring her 'bump'

SCOLIOSIS & MENTAL HEALTH

Mental health has become a hot topic in recent years and rightly so, with more prevalence in the media, more funding for support and less stigma, all of which has opened the door for more people to talk about it. We all have mental health just like we all have physical health, but physical health issues in life, like a scoliosis diagnosis, surgery, or bracing, can affect us mentally too, and this side of scoliosis is rarely talked about.

Anxiety is an extremely common issue among adults, children, and young people. It is normal to be anxious in life, such as before an exam, job interview, starting a new job or school, or having major surgery! Talking to someone about your anxiety is a great way to ease your nerves, and talking to parents, friends, family or even your surgeon can help you start to rationalise some of those worries. However, at times with scoliosis, it might seem that parents or friends just don't understand, or it might be hard to talk, and that's ok too.

Most often scoliosis is diagnosed between the ages of 10 and 15 years, and the average

age of curve progression is thought to be 11.7 years of age in the USA. Alongside that, 50% of mental health problems are established by age 14, and 75% by age 24. Adolescence is a difficult time for many reasons, especially when you've just been diagnosed with scoliosis. During puberty, our brain goes through a lot of changes, making it a time when mental health issues might develop. The rational, logical part of our brain develops more slowly than the fight/flight, fear response part of our brain, meaning in our teen years we find it harder to rationalise things in the way adults might. Because we can't rationalise, we might start to worry and add worries about a diagnosis we have never heard of, and about surgery, being different from our peers, having to wear a brace, coupled with all the usual things that bother us when we are teenagers, such as exams, relationships and school. It is easy to see how mental health and a diagnosis such as scoliosis go hand-in-hand. So, what can we do about it? Firstly, if you are struggling, please seek help from your GP or local mental health services. Don't be put off by the thought of long waitlists either, many GPs can sign post to charities or services that can help you in

the meantime. Below are some general strategies and things you can do that may or may not help when you feel worried.

Writing worries down: writing our thoughts and worries down can help them to seem simpler and more concrete, and to stop them flying round our head. You might want to go a step further and after writing them down, by categorising them. There are two types of worry that we can categorise our thoughts into - practical and hypothetical. Practical worries are those we can do something about, such as what do I take to hospital with me? Will my parents be able to stay? I'm worried about sports after surgery, can I still play football, tennis, can I still go to dance class? These are worries we can do something about - asking for help from your surgeon, a friend, someone who's had the surgery, a nurse, or worker at the hospital, etc. The other type of worries are hypothetical worries. These are worries we can't control or change - for example, what if surgery goes wrong? What if my curvature has increased? What if I'm in pain after surgery? What if the morphine makes me sick? What if the anesthetic doesn't work?! While some of these we



might be able to ask for reassurance about, ultimately there's nothing we can do to control them. The best technique for such concerns is distraction. Our brain can't do two things at once, so find something to entertain yourself; a TV show, a podcast, a puzzle, a game, or exercise.

Other techniques are as easy as breathing. When we feel anxious, our brain sets off a fight/flight response. This is a response that stems from evolution and keeps us safe, it prepares us to either fight the danger, or run away from it. Our modern-day anxieties often can't be fought or run from, leaving us just feeling anxious. By slowing our breathing, we fight against this fight/flight response, and turn it off. Breathing techniques can involve counting our breathes in and out, using our hand to do a technique called 'five finger breathing', which can slow our breaths down. YouTube has useful videos of this technique - hold one hand out, fingers spread wide, and with the index finger of your other hand, trace up and down each finger, around your hand, breathing in as you move up and out as you move down each finger. Or we can use grounding techniques, which bring us back to reality and remind us of our surroundings rather than letting ourselves to get lost in our thoughts. A common method is thinking about five things we can see, four things we can touch, three things we can hear, two things we can smell, and one thing we can taste. These techniques may be useful before an appointment, before going to hospital, even right before surgery, or for anything in life that feels stressful and overwhelming.

I also love using glitter jars with the young people I work with and encouraging them to make their own. Glitter jars are like a snow globe of glitter. When you shake them up, they can represent our brain when we feel anxious and worried - hundreds of thoughts swirling at once, unable to focus on one specific thing, as the glitter starts to settle and slow, we can also breathe deeply and settle our brains the same way the glitter settles, these are a great aid to take with you to hospital, or use in recovery, or have in your bedroom to watch as you

fall asleep. They are incredibly easy to make and can be used alongside the grounding or breathing techniques.

Another common mental illness in adolescents is depression, or low mood. Low mood often occurs when we are unable to get enjoyment out of things we love, or when we stop doing things we enjoy. For someone with scoliosis, it may be that they start to feel low because

“Hold one hand out, fingers spread wide, and with the index finger of your other hand, trace up and down each finger, around your hand, breathing in as you move up and out as you move down each finger.”

they stop doing things they enjoy, be it because they've just had surgery and can't participate at the moment, or they have been told their hobby isn't ideal for someone with scoliosis. Either way, low mood can feel tough, and scoliosis doesn't help. Sometimes limiting ourselves to lying on the sofa or in bed only reinforces that low mood, and sometimes because of pain we can't go out and do the activities we want to. Usually, this is a short-term issue, and after surgery and recovery, most of us can go back to sports, dance, and hobbies we enjoy, but in the meantime, maybe try thinking about what matters to you. Maybe make a list of things that you find important and want to do, and see if these can be done during your recovery to make it an easier journey - i.e., texting and reaching out to friends, visiting or having family visit you, learning a new language or a new skill, sewing, drawing, or reading, making videos, TikToks, writing a blog, or making a scrapbook. Having a plan of activities that you want to do can help make recovery a little easier, and maybe a little less boring!

As someone who has experienced scoliosis surgery and is embracing a career in mental health, I have developed my own ideas of what might be helpful, but these are suggestions only and they may work for some people and not others. We're all different, and we all handle our scoliosis and our diagnosis in our own unique

ways - with different types of exercise we enjoy, whether we feel comfortable playing contact sports, using painkillers, going to physiotherapy, choosing not to have surgery, being braced. We all have our own things that we feel comfortable doing. That is the same when it comes to protecting our mental health. Find what works for you and only you, whether that is watching a film or going out for a run, playing with your dog, cat, or rabbit, or taking a long relaxing bath. Most importantly, reach out and talk. I guarantee any worries you have about scoliosis, other people with scoliosis have experienced those worries too! Follow my Instagram @scoliosisters_uk for more mental health tips, quotes, and stories.

Glitter jar recipe

1 jar – glass or plastic
Water
Glitter
Clear glue
Food colouring (optional)

- 1) Fill your jar about half full with warm water**
- 2) Add a long squeeze of clear glue - the more glue you add, the slower the glitter will fall**
- 3) Then sprinkle in your glitter and food colouring if you want the water to be coloured too, but this is optional.**
- 4) Fill to top with water, leaving a small gap.**
- 5) Screw the lid on, and shake. At this point, add more glue or glitter if needed.**
- 6) Once happy, fill to the very top with water, then screw closed, you can glue the lid on if you wish!**

Victoria Steele, Children's
Wellbeing Practitioner

Scoliosis and me



My name is Charlotte and I am 27 years old. In 2007 I had spinal fusion surgery to correct my scoliosis. Although I felt pretty prepared physically for the operation, nothing could have prepared me for the mental health side of things. Initially I was ok, I just wanted to focus on recovering, but then I started struggling with extreme anxiety and panic attacks which was frightening at 15 years old.

For many years, I tried to block this out until at 22/23 I had Cognitive Behaviour Therapy and Counselling. Blocking my emotions and feelings out was not good, and I found myself in an ambulance going to A&E because I had a horrendous panic attack. I found that the therapy really helped. I was able to offload more to a stranger than I would with family and friends. Over the next few years though I gradually began to open up to people about how I felt. I would tell others to not be afraid to reach out to people and not to push away the ones you love, they want to help you and be there through your scoliosis journey. It's okay to cry. What each and every one of us goes through with scoliosis IS a huge deal. Keep connected with the people who love you and lean on them for support.

DO THE THINGS YOU LOVE! Focus on the things you're good at, take up a new hobby. Don't lose sight of yourself. Get out walking, listen to music, learn an instrument, immerse yourself in a book – there are so many things you

can do but the most important is to keep talking, no matter how you feel. I decided to set up a scoliosis support group in 2020 so I could help others affected by the condition and ensure that no matter what, they weren't alone. Although Covid-19 happened, I didn't let this stop me and moved the support group online and set up a blog on Instagram. My best advice for people in a similar situation is to talk about the way you feel, to friends, family, your GP, just make sure you reach out because you'll feel so much better for it. Don't keep things hidden away and please remember no one will think any less of you.

**Charlotte Dodd, Midlands England
Regional Representative**

10 years with scoliosis, yet it wasn't until this year that I truly felt comfortable about my journey. From countless physiotherapy sessions to X-ray scans, I eventually had my spinal fusion surgery. Back then, I felt helpless and lost.

My constant battles against body insecurities and scoliosis started with avoiding full-length mirrors and becoming anxious about what to wear to hide my disfigured body. I dropped out of classes because of the physical pain, yet, unknowingly, it was also down to my mental health being...well not so healthy.

Although surgery brought some hope, my hospital experience ended up pretty distressful. Plus, because of admin errors, I was only informed about my surgery just a day before. Post-surgery, plenty of challenges awaited me including adapting to physical inflexibilities and falling behind at school. Above all, my mental health deteriorated. Yet was I the only one experiencing this? Well the answer is NO! And that's something I wish I had known back then. Scoliosis can affect your mental health just as much as the physical difficulties, and you are definitely not alone in this.

And here are some of the things I did to help myself overcome everything:

- Writing! I poured out



all my thoughts as a way of releasing and unloading burdens.

- Listening to podcasts about mental wellbeing and scoliosis really allowed me to understand how to manage and mentally prepare myself.

- Giving myself daily positive reminders or small milestones to work towards, even if it means getting out of my comfort zone, such as not being afraid to wear tops revealing my scar and actively talking to others about scoliosis.

- I attended counselling sessions (with both positive and negative experiences).

- Joining SAUK! I met a great community where we can share our concerns and openly discuss our experiences in a safe environment.

Fast forward to now, I joined SAUK as a Regional Representative and even started blogging about my scoliosis experience. I also have a strong passion for patient advocacy and am working in MedComms to become a Patient Engagement Writer. Overall, scoliosis has become an empowering part of me and I hope my experience can help shed some light to you.

**Vicky Wong, South West England
Regional Representative**

Separating Fact from Fiction – a SAUK information sheet

· Having scoliosis doesn't mean that a child cannot do sport or PE (physical education). People should try to keep fit and active to keep the back muscles strong. Always check with a specialist about what sports can be done after surgical correction or during treatment for a spinal curvature.

· Having metalwork in your spine will not necessarily set off the detection system at airports. Even if the detectors do activate, the airport security guards will be able to see your scar and it won't cause a problem. You do not need a letter from a doctor.

· Scoliosis cannot be prevented. It is not caused by carrying heavy school bags or anything a child or parent did or did not do. In most cases scoliosis is idiopathic, which means there is no known cause.

· Scoliosis can worsen very quickly during adolescence because the child is growing fast at this time. As a parent you shouldn't blame yourself for not spotting the curvature sooner. Your child's scoliosis will probably have developed very quickly and can seem to appear out of nowhere. What might have been a straight spine a few weeks before may suddenly show signs of curving.

· After surgery many people think that they cannot take part in activities such as horse riding, sky diving, and contact sports. Most patients will be able to do these things in time. However, it is very important to check with your specialist to make sure you are back to full health before taking part in such activities.

· With all surgery there are risks, and with spinal

surgery there is a very small chance of paralysis. The important thing to remember is that paralysis happens very rarely. The scoliosis specialists weigh up all the pros and cons. If they think the risks are too great they won't do the operation.

· Just because you are diagnosed with scoliosis does not mean you will need to have an operation. If the curve is very big or growing very quickly surgery might be recommended. However, many people simply need to have their spine checked regularly to make sure the curve isn't getting bigger.

· At the moment, spinal surgery is the only proven way of treating scoliosis and correcting spinal curvature, except in the case of very young children and some types of smaller curves, for whom bracing or casting can be useful. Treatments such as physiotherapy and exercise routines can help with pain and improve posture and flexibility but will not reduce the size of a curve or slow down worsening of the curve (progression).



I'm a scoli warrior - a poem by Cassie Clarke

I had a curve in my spine
Now it's fine
I had a lot of pain
Now there's no rain
I had anxiety and was scared
Now I do things that I didn't dare

I'm a scoli warrior

I went to have a operation
Now I feel new sensations
I struggled at first
Now it might hurt
I used to be small
Now I'm really tall

I'm a scoli warrior

I have metal rods
Now I'm uniquely odd (in a good way)
I stand out from the crowd
Nothing can stop me now

I'm a scoli warrior

I went home on day four
It's still a bit sore
It's better than being in bed
I get to see my family and friends
I'm a scoli warrior
Remember, YOU CAN DO THIS!

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 of providing support and information for people with scoliosis and raising awareness.

Kayleigh Meek
Katherine Miller
Martin Bourne
Karen Brace
Christina Bolger
Anna Negri
Susan Pratt
Catherine Richards
Delyth Stow
Arieta Visoka
Sara Essalmi
P D Aherne
Leo Emmerson
Justin Farquhar
S Roberts
Philippa Smith
Tracey Bone
Lisa Camm-Keyte
Kimberley Briggs
Vivian Doan
Lola Rose Freer
Sarah Geldart
Colette Gilkes
Amanda Jones
Coralie O'Gorman
Hannah O'Gorman
Jojo O'Gorman
Guiliana Parodi
Jennifer Robson
Ealish Swift
Sue Willmington
Ronan McGirr
Lindsay Stanley
Belinda Bradley
Rachel Carr
James Little
Ian Churchward
Peter Grosch
Camilla Seckin
Clare Paleit
Glynn Snelling
Leah Whitehouse
Rebecca Lyon
Sharon Howard
Sian Stott

Matthew Court
Veronica Skelton
Susan Darby
Dalia Zwick
Sue Willmington
Ross Bruce
Hannah O'Gorman
Barbara Hulme
Amy Marsh
Jennifer Vanstone
John Fawcett
Barbara Sinclair
Daniel Harrison
Felicia Penalver
Lauren Downard
Abbie Blake
Chisha Lombe
Kathryn Mackey
A L Headford
Maria Webb
Karen Trainor
Eva Butterly
Jolene Green
Cecelia Jane
Kristen Barrow
Dawn Bate
Vivienne Green
Julia Pallant

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.

£115 was received in memory of

[Libby Biberian](#)

£15.00 was received in memory of [Mr Beverley Brown](#)

£2125.50 was received in memory of [Eric Howard Pask](#)

£170.70 was received in memory of [Mary Sybil Thirza Threlfall](#)

£387.50 was received in memory of [George Anthony Court](#)

£190 was received in memory of

[Zoe Louise Underwood](#)

£50 was received in memory of

[Lynette Kay Broomhead](#)

£410 was received in memory of Janet Potter

£50 was received in memory of

[Judy Finch](#)

£105 was received in memory of

[Mr Hipwell](#)

£150 was received in memory of

[Katherine Guy](#)

£140 was received in memory of [Christine Predeth & her dad Stanley Richardson](#)

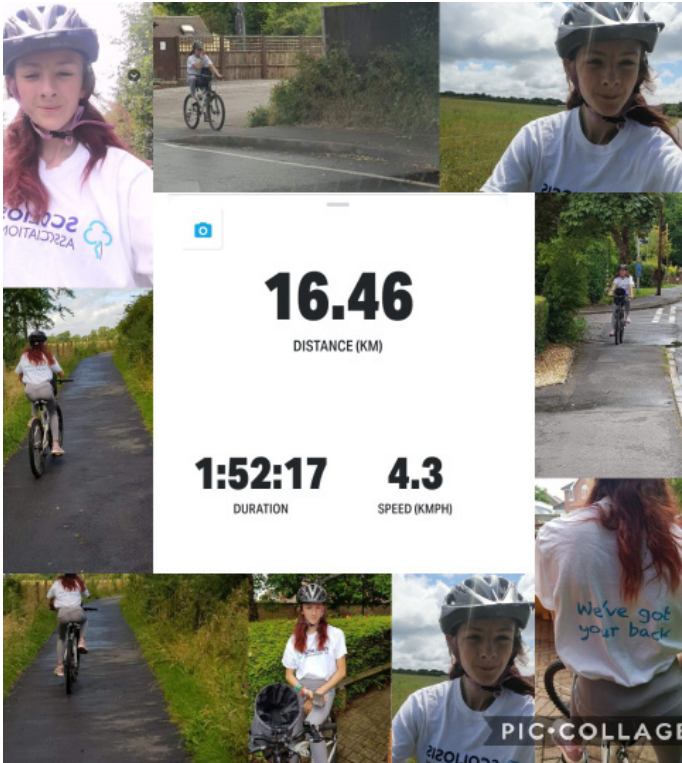
Legacy

SAUK received a total of £12,291.42 from the legacy of Dorothy Sharp.

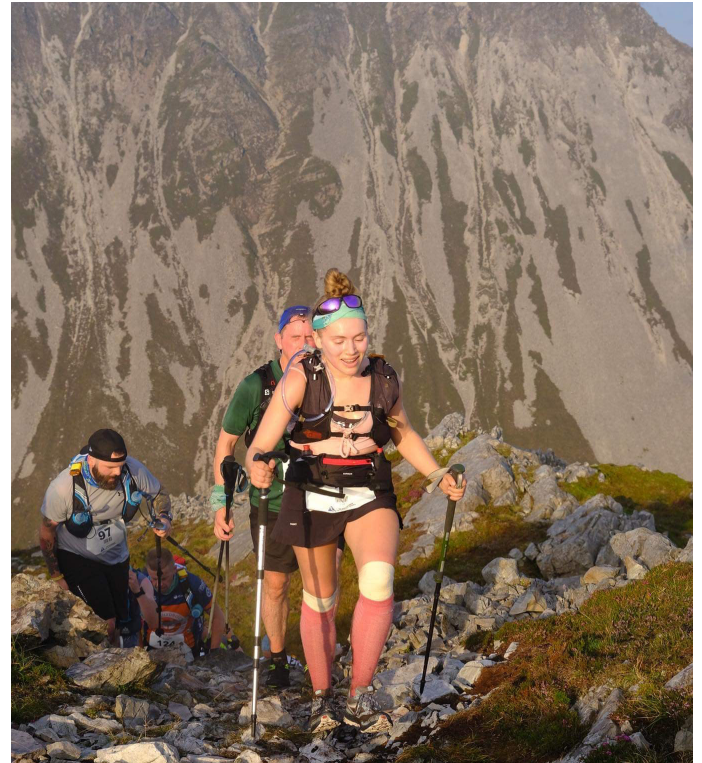
Dorothy's nephew David spoke about his Aunt, saying "Dorothy had scoliosis for many years. She never made a fuss about it although it gave her obvious pain and limited her mobility. She finished her days where she started in Doncaster and is sadly missed by her family. Dorothy enjoyed life and spent time living in London where she worked for a concrete company. In retirement she moved to Stroud and North Yorkshire before returning to Doncaster."

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.



Abbie challenged herself to do a sponsored cycle



Eva Butterly taking on the Kerry Way Ultra Nite challenge to raise funds for SAUK

[Linda Bryant](#), 'Bare My Back', £527.50

[Kevin Mcken](#), 'The 26.2 Garden Challenge', £543

[Sally Traill](#), 'The 2.6 Challenge', £494.06

[Helen Gardner](#), 'The 2.6 Challenge', £378

[Christine Nixon](#), 'The 2.6 Challenge' – 26 Countries in 2.6 days', £350

[Pauline Jones](#), 'The 2.6 Challenge', £161

[Abbie Blake](#), 'Cycling 10 miles and doing much much more', £350

[Ellen Ross](#), 'Online Fundraising Event', £461.50

[Ann Liebeck](#), 'Performing Online at The Space UK', £105

[Jeanette Henry](#) raised £12 with the sale of her home-made jewellery

[Dawn Bate](#) of Gingers Hair Studio raised £200 with a book sale

[Alex Marchant](#) donated £620, the royalties of Grant Me The Carving of My Name, an anthology of Ricardian short fiction.

[Sarah Cole](#), £131.25 for making face coverings

Facebook Fundraisers

Sarah Patricia Metcalfe, Theresa Kirk, Caitlin MacLeod, Tina Steer, Neeyce Huggins, Ann Liebeck, Sophie Blackwell, Courtney Edwards, Hope Collins, Alex Elizabeth, Karen Watson, Martin Symons, Taylor Made Beauty, Paul Chandler, Neil Dallison, Rawden Enever Leala Jacobs, Sarah O'Gorman, Beth Lewis, Slade Stevens, Lucy Erica Munroe, Bev Beasley, Jantil Moon, Wendy Haren, Steve Davenport, Lindsey Metherell, Jemma-Leigh Benham, Sophie Emmings, Freya O'Rourke, Stephanie Clark, Aniela Stevenson, Tamsin Smith, Louise Pascoe, Olivia Wilkes, Lucy Poll, Donnie Swain, Austin Ikponmwosa. Becky Smart, Olivia Weston, Nicki Moore, Hope Ridgley, Kirsty Jones, Ian Renton, Raj Jaiya, Morgan Kendall, Ethan James, Rhys Evans, Geraint Bradley, Efan Williams, Nick Francis, Claudine Cassidy, Bethan Phillips, Kyra Chamberlain, Dawn Victoria Edwards, David Rundell, Selina Green, Sam Spearing, Vikki Evan Stubbs, Marc Barnes Jaqueline Lusat

FUNDRAISING FAQs

Who can I fundraise for? Can I fundraise for both SAUK and SCF?

- The answer is yes, you can fundraise for both SAUK and SCF. SCF stands for the Scoliosis Campaign Fund. By fundraising for SCF, 50% of funds will be given to Scoliosis Association UK (SAUK), with the other 50% given to the British Scoliosis Research Foundation (BSRF). You can also choose to just donate to SAUK, if you wish.

How can I fundraise online?

- Fundraising online is really easy! To set up a fundraising page, head to Virgin Money Giving, click 'fundraisers' > 'create a page'. Or visit <https://uk.virginmoneygiving.com/fundraiser-portal/userSignIn>.
- You can also go to Virgin Money Giving, click 'make a donation' > search for SAUK or SCF > make a one-off donation or set up a monthly donation.
- You can also set up a Facebook Birthday Fundraiser for SAUK!

How do I set up a fundraising page?

- Head to Virgin Money Giving, click 'fundraisers' > 'create a page'. Or visit <https://uk.virginmoneygiving.com/fundraiser-portal/userSignIn>

Do I need to set up a fundraising page?

- You don't need to set up a fundraising page, but it is recommended as it's one of the easiest ways to keep track of everything you fundraise. You can also add offline donations to your page (such as cheques and cash).

How do I send you my cash donations?

- You can pay in your fundraising by heading to Virgin Money Giving > Make a Donation
- Alternatively, you can send us a cheque payable to either: 'Scoliosis Association UK' or 'Scoliosis Campaign Fund', both at Unit 4 Ivebury Court, 325 Latimer Road, London, W10 6RA.

How does my fundraising impact SAUK? How will my money raised be used?

- SAUK raises money to support people with scoliosis and their families and raise awareness of scoliosis. Your money is also used to run the Helpline, which is an invaluable resource to support people. The money from SCF is also used for these purposes, as well as to fund research, through the BSRF, into finding the causes of scoliosis and treatments to improve quality of life for patients.

Do I need to be 18 years old to fundraise?

- No! You can be any age to fundraise.

Can I still fundraise during Covid-19?

- Yes! There are plenty of ways to virtually fundraise! If you'd like more information please contact us by email at fundraising@sauk.org.uk or info@scoliosiscampaignfund.org.uk. You can also telephone us on 020 8960 5343

Will I receive any materials to help with my fundraising?

- We will send you a Fundraising Pack! This includes: a t-shirt, posters, fundraising pack, sponsor sheets, Backbone magazine, balloons, and an information leaflet

What fundraising event is right for me?

- We have many different events going on throughout the year, such as marathons, cycle challenges, raffles, and many more. Have a look out for the events we promote or look on our website/social media for inspiration to start your own fundraising event.

How can I advertise and promote my event?

- We can help with advertising/promoting your event – just email us at fundraising@sauk.org.uk or info@scoliosiscampaignfund.org.uk. It's great to start by advertising on your social media and sending links to friends.



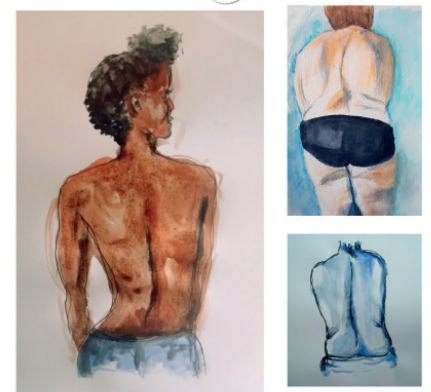
SAUK ONLINE SHOP

Check out our online shop and show off your support of SAUK by rocking our merchandise! The tote bags are a brand new addition, featuring a spine illustration by Hannah Webb.



We can't believe it's time for Christmas Cards either! We have a sale on last year's cards, and two great new ones for 2020. All cards come in a pack of 10 and are available from our Christmas shop online or by returning the form on the back of this magazine. Card prices range from £2.50 - £3.50 a pack.

We are also selling a limited edition 2021 A4 wall calendar featuring drawings from the Celebrating Curves life drawing events. Get yours now from our online shop for £8.



2021 Calendar
'Celebrating Curves'



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



[/ScoliosisAssociationUK](https://www.facebook.com/ScoliosisAssociationUK)



[@ScoliosisUK](https://twitter.com/ScoliosisUK)



[scoliosis_association_uk](https://www.instagram.com/scoliosis_association_uk)

INTERNATIONAL SCOLIOSIS AWARENESS DAY

We missed celebrating in person this year's International Scoliosis Awareness Day but we still managed to make a splash on social media with some great online events lasting the whole month of June. Thank you to anyone who attended the online events, started a fundraiser, or used the opportunity to talk about your scoliosis to raise awareness.

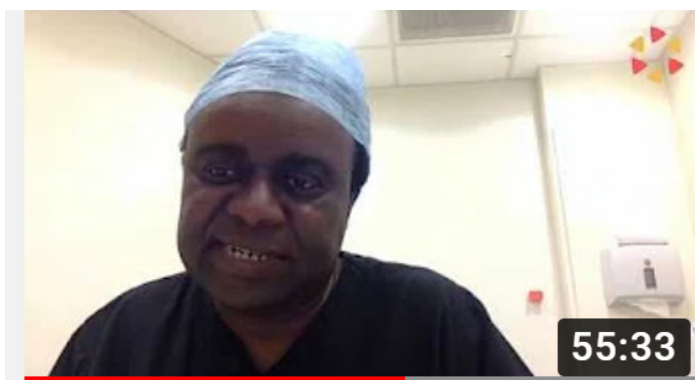
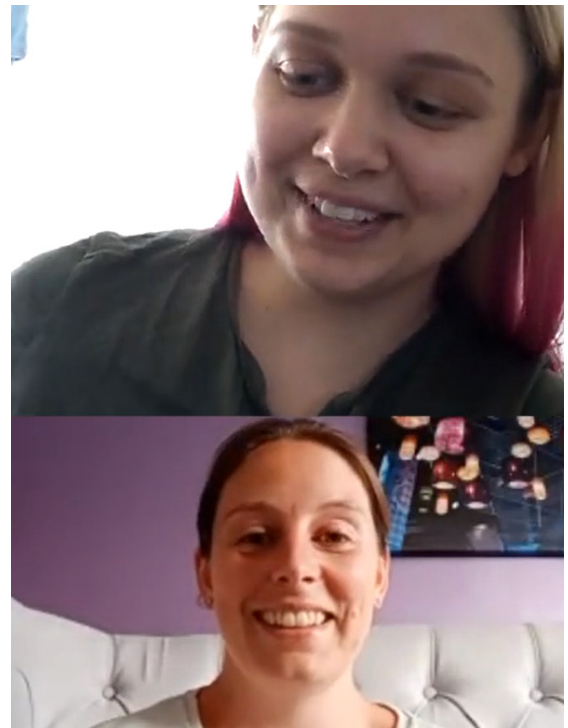
It was a day to celebrate how far you've come in your scoliosis journeys and a day to celebrate the community you've found amongst others affected by scoliosis. It was a day to raise awareness about the condition so that others out there know you have their backs and it was a day to show the public that you may be bent but you are not broken.

We want to thank our terrific Regional Representatives in particular for making this ISAD special. East England representative Martin and Ellen had event after event, starting with their first ever podcast – "Talking Scoliosis". The open and honest chat between the two about their scoliosis experiences and the support they've found thanks to SAUK was published on our social media channels and can still be watched on YouTube. On the big day the dynamic duo also held two Zoom events that also served as fundraisers so that after many months of lockdown, people could still gather virtually in their own homes to celebrate.

This year ISAD was celebrated all month long thanks to a campaign to fill our social media feeds with creative images that represented scoliosis. We had dozens of people send us artwork, photos, and poems. These were shared on social media over the month of June, to the delight of many.

We were delighted to have a special guest for ISAD – Colin Nnadi, an orthopedic surgeon at the Oxford University Hospitals NHS Trust and one of SAUK's newest Trustees. Colin held a live virtual Q&A session and spent the hour answering so many of your questions. We hope you were able to catch it live; it was very informative! If you missed it, you can still watch it on our YouTube channel – Scoliosis Association UK.

Charlotte Dodd, representing Midland England also got on board with video. She was featured on our SAUK Instagram page in live videos talking about her own scoliosis experience and interviewing others about theirs.



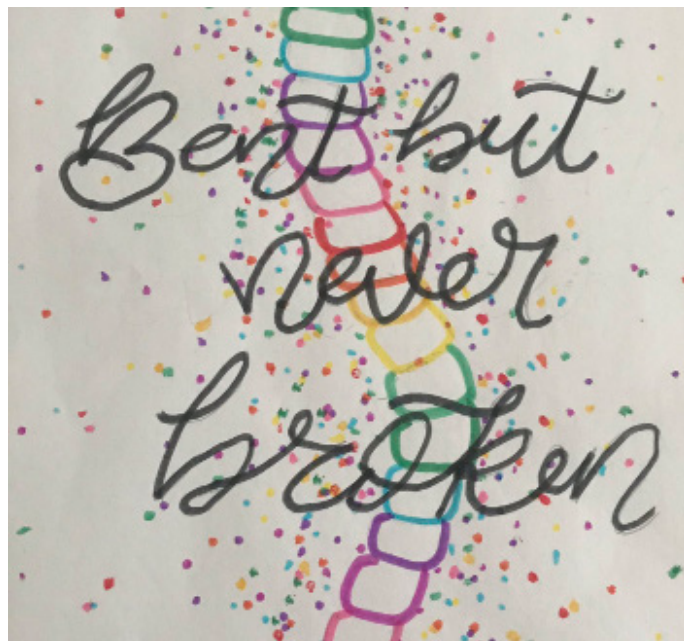
Scoliosis Q&A with Colin



Talking scoliosis



Estelle Huntley



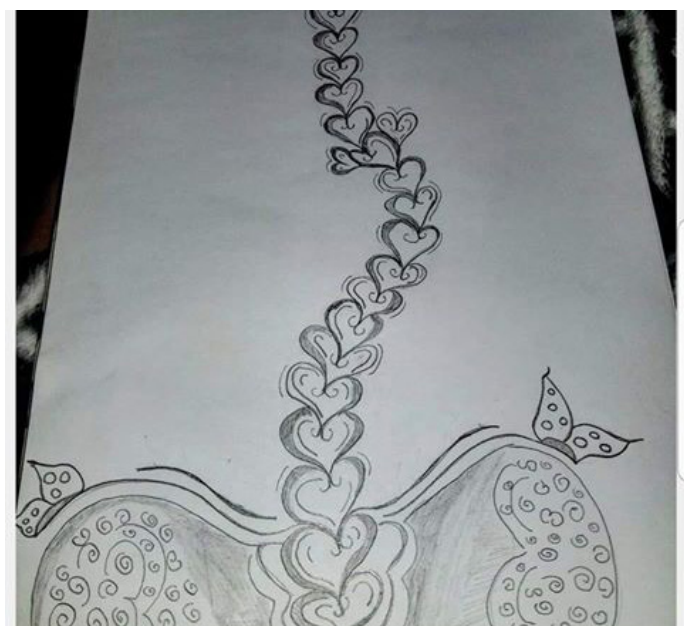
Sandra Brown



Grace Halton



Ciara Aloisia Nic Oscair



Rember Knippa



Sophie Maw

CELEBRATING CURVES ONLINE LIFE DRAWING

To celebrate International Scoliosis Awareness Day, Sarah O’Gormon wanted to remind people of the beauty of curves and scars through a unique online life drawing session to celebrate people with scoliosis. Several of our brave and beautiful Regional Representatives volunteered to be the models to showcase different shapes, sizes, curves, and scars. Each model sat for a few different poses that showed off what made them unique while a class of people from around the world sketched them. Each model introduced themselves and it was a great opportunity to learn about scoliosis and raise awareness and just a great reason to get creative!

The first session was such a success that Sarah threw a second one a month later and had even more people join the class, with new models who were inspired to bare their backs. Not only did these events raise awareness of scoliosis but they also raised funds for

SAUK. It was a free event but Sarah asked people to donate if they could and we are so grateful for the generosity they all showed.

Lou Williamson is one of those models who also happens to be a SAUK Regional Representative for the East & West Scotland region. She saw the call out for models and surprised herself most of all by saying yes. It was a bold move for her and she made it even more so worth her while by starting a fundraiser for SAUK that raised over £800!

“I am/was extremely body conscious and even my own Mum could not believe I had signed up to do the life drawing. I have always covered up and only a few of my close friends have seen me in as little as a swimming costume. However, at 45 I decided that if I couldn’t show others that I could accept myself for who I am, how could I really go on representing SAUK. I told myself that if I

announced to friends that I was doing this and could raise £100 for the charity, then I would not then back out. I would have to be a model if only to save face. A few hours after my Facebook post I’d raised £300. The total kept growing and growing until I raised over £800 via the Ko-Fi site! I was nervous but after I felt somewhat empowered!” said Lou.

Out of this experience the models even got some pretty fantastic sketches of themselves. We have included a few of them in this magazine but the full albums can be found on our Facebook page. Thank you to everyone who attended - you are some seriously talented individuals!

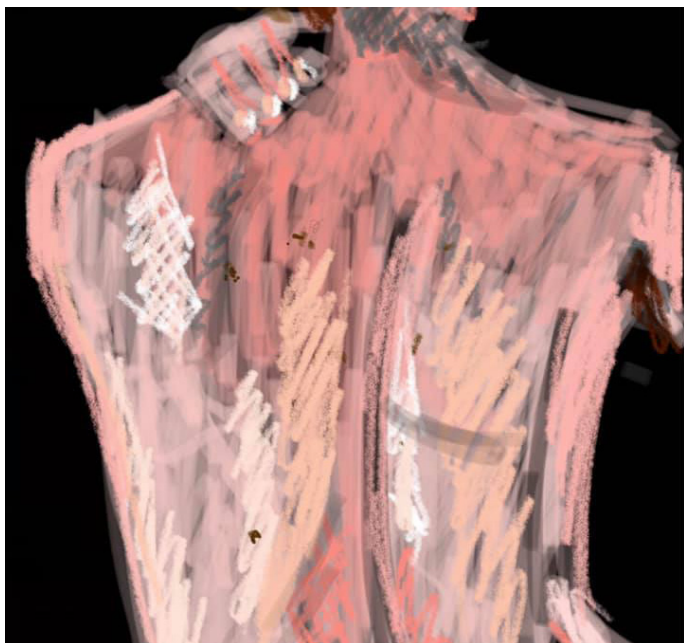
Thank you most of all to Sarah O’Gormon who made this event a reality and has inspired so many people to look at the things that make us unique, like an artist sketching a masterpiece.



Sue Willmington



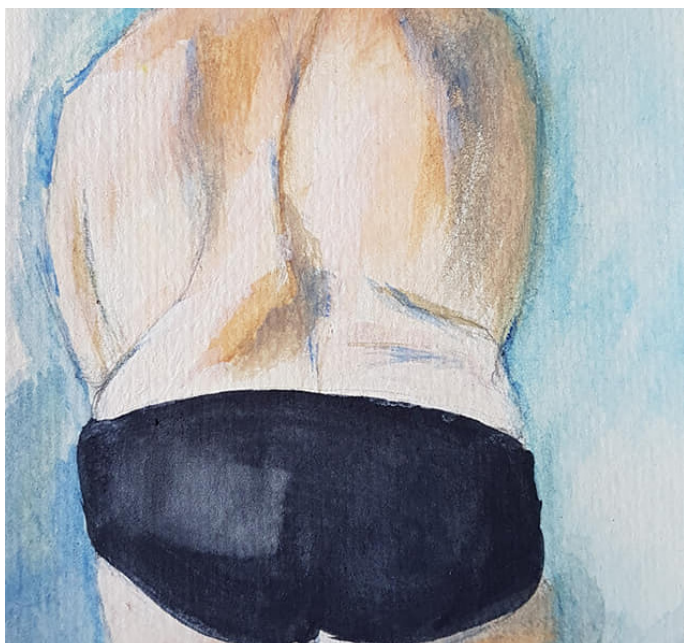
JoJo O’Gorman



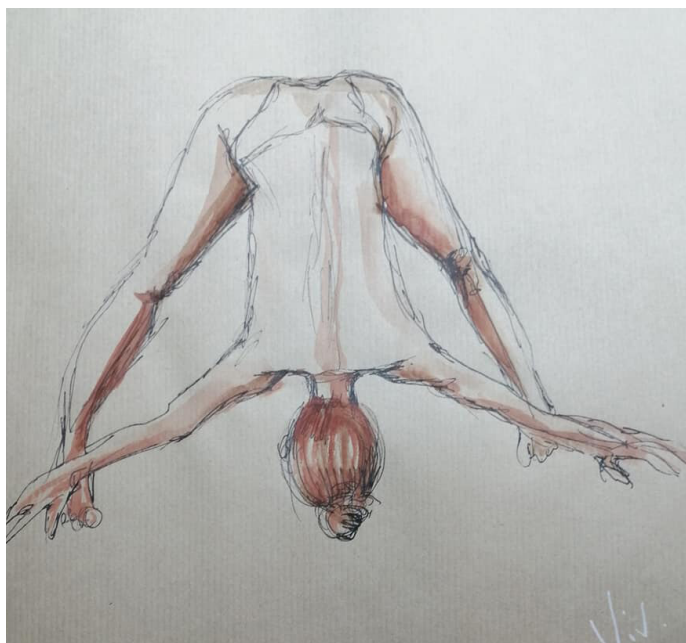
Kimberley Ann Briggs



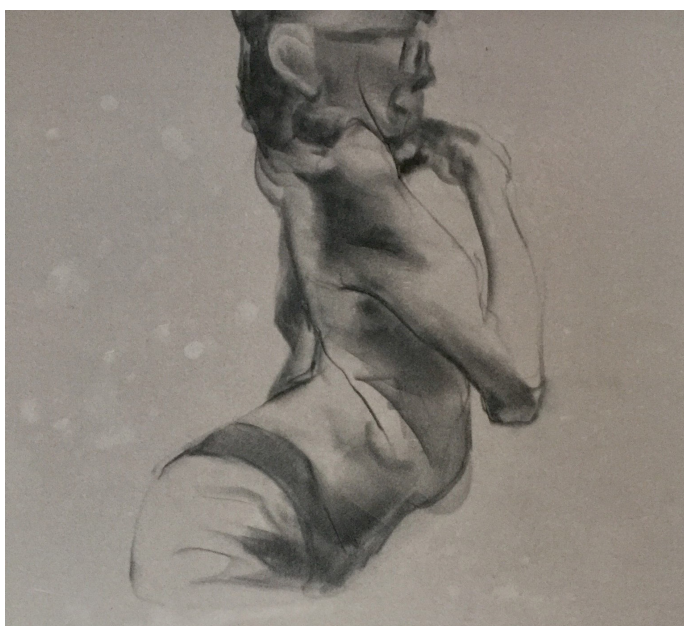
Hannah Schwartz



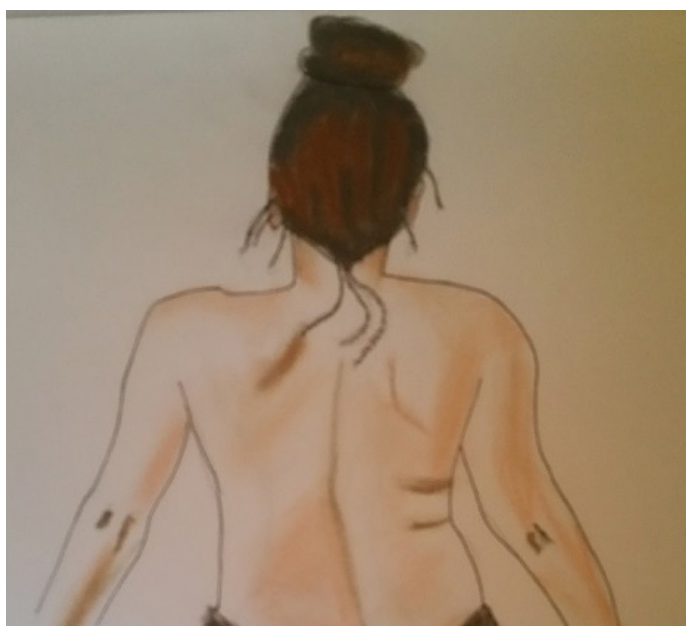
Mary Bradley



Sarah O'Gorman



Kirsty Whiten



Barbara Hulme

Life in a turtle shell

First things first, my name is Gemma and I live in the UK with my parents and two sisters. I am 16 years old and I want to go into a career in healthcare. I enjoy reading, crocheting, volunteering, and baking. I am originally from Italy and moved to England when I was 10 years old. I had scoliosis diagnosed at birth as part of another medical condition. I currently wear a hard-plastic back brace for 22 hours a day, and have done so for 3 years and counting.

I decided to write this blog to help other teenagers with scoliosis and/or a back brace to feel confident and supported in their journey for a straighter spine. I want to share my story and experience as well as the tips and tricks that I learnt along the way living in my turtle shell.

When I was told that I had to wear a back brace at age 13 in Year 8, I was very stressed and scared. I knew that getting a back brace was the best thing for my spine to avoid surgery, so I agreed. On my next hospital appointment, the technician started the process to make my brace. First, I was sent for X-rays to see my curve and then a plaster cast mould to make the brace in my size. I was very lucky and got to choose a colour or pattern to put on my brace and I choose a pink background with small rabbits. Then I went to have my new back brace fitted and edited. Finally, I took my back-brace home, on a 2-hour

train ride, for the first time.

I became very self-aware and wondered about my appearance and clothes. Knowing what to wear as a teenager with a back brace can be hard because there is a big stigma around body image anyway, but I promise it will get better with experience.

First thing you will need is a vest of some sort (such as a cotton vest or thermal vest) to use underneath your back brace because it can get uncomfortable or painful because the brace can stick to the skin. Then, if you plan to wear your knickers above your back brace (I prefer to keep them underneath), it might be helpful to invest in a size bigger. When wearing tops start by wearing naturally loose clothing such as toddlers (which are my favourite) or jumpers or one size bigger tops such as t-shirts or anything that makes you feel comfortable. For

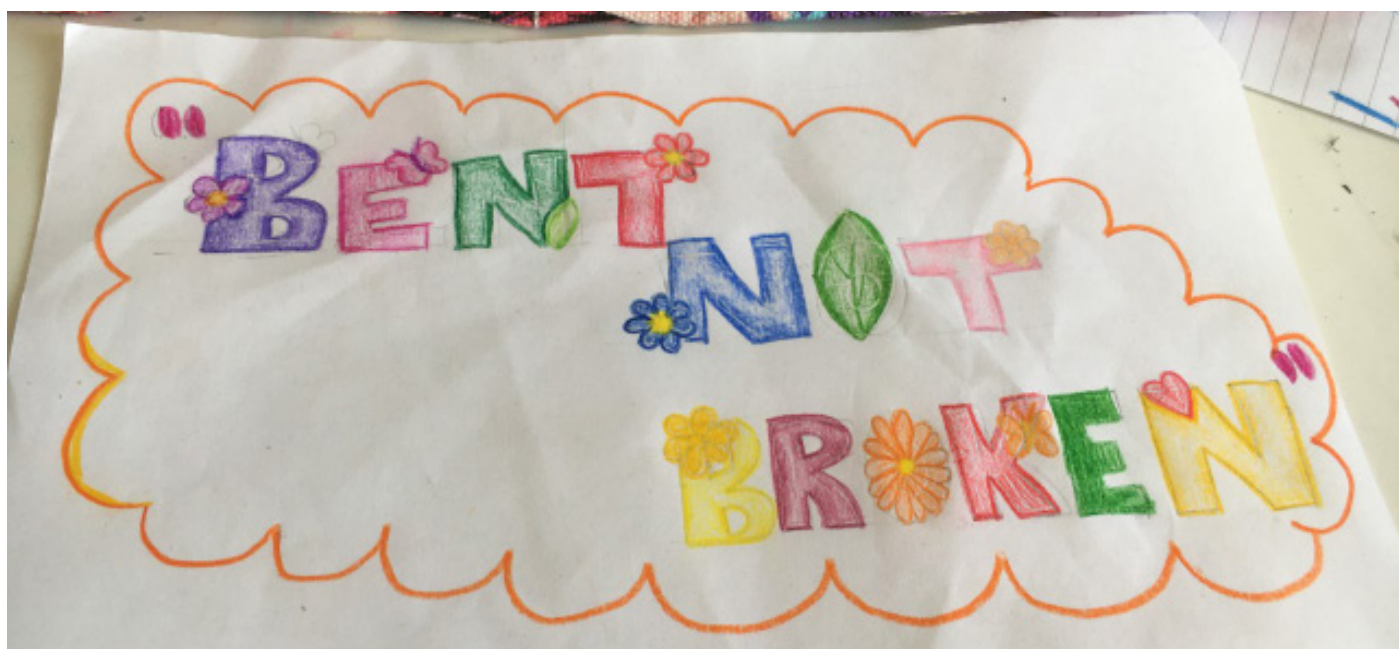
trousers or shorts, I would recommend getting a size bigger, possibly with adjustable elastic so that they can fit comfortably over your brace. As you become more comfortable in your brace, you will probably start wearing less loose clothing, but this will come slowly and gradually.

It can be difficult at first to wear the back brace because it's probably uncomfortable and a bit sore. One way that you can relieve the soreness is to put some oil or cream on your back to help take away some of the friction and hydrate your back, which should make it feel less sore. If you are in pain, you should always contact a healthcare professional because the brace may be wrong or too small and therefore no longer effective. I have recently started physiotherapy because I have had pain in my back, and it has really helped me relieve some of that pain. Remember to speak to your doctor about this and they will refer to the right people.

It is important though that you wear it for the right number of hours (22 hours for me) so that it's most effective. Having a routine can help you to be constant in the number of hours you keep it on for. For example, if you go to bed at around 10 pm every night, then you could take the back brace off at 8 pm and put it back on before going to sleep. If you do exercise during the day, you could track the time you spend without the brace and subtract it from the usual hours without it.

Sleeping in the brace can be tricky and it does take some getting used to. You make feel more comfortable sleeping on or supported by lots of





pillows. Also, if you wear a bra, I find it more comfortable to wear one at night with the brace since it's a little painful without it. Going to the toilet with the brace can take a little longer, because you can choose to take the brace off or keep it on.

When telling friends remember to choose friends who are trustworthy and will support you. If one of your friends reacts badly or is mean to you about it, that friend isn't worthy of your friendship. When people ask or make remarks about your back brace, you have two choices - you can either ignore them or explain to them what it is and why you need it, and both are good responses. You are stronger than people's perceptions and your real friends will stick by you no matter what. If you feel bullied or unsafe you should always tell a trusted adult such as a parent or teacher. At school, certain adjustments may make you feel more comfortable such as using a lift (if available) and a having a locker to store your books can be helpful so you don't have to carry a heavy load on your back. You may struggle to bend down especially from seated so it's helpful to ask people to pick up pens you drop. You may want to discuss this with your school nurse, SENCO (Special Educational Needs Coordinator) or head of year/house.

After receiving your back brace, you will probably need to be closely monitored by your doctor, technician, and scoliosis nurse. Remember to ask and talk about any concerns you may have to the healthcare professional. You may have follow-up appointments every 6 months or a year where you might get an X-ray to check how your curve is progressing and have your back brace adjusted. I have had so many X-rays in the past 3 years that the radiographers at the hospital remember me and know me by name! As you grow, you will probably need new braces, which is normal; I have had three braces in 3 years.

I wanted to share some of the fun stuff you can do on you back brace too. You can:

- Use it like a drum to make some lovely music or annoy people
- Use it as a portable whiteboard to draw on and take notes
- Lie on your back with your legs above the floor pretending you are a turtle
- Be bulletproof in battle- I don't know where this could be useful, but still
- Fool people that someone is at the door by knocking on your brace - this is funny

· Always stay warm in the winter because I find the brace to be very insulating in the cold and wet English winter

3 years after receiving my first back brace I am more confident and comfortable with my scoliosis. A lot has changed in that time. I have grown (not a lot in height) for a small year 8 to a loud and strong Year 11. I am no longer scared or embarrassed if my back brace shows through my clothes, and I have a strong team of friends supporting me through this. I am excited for the next few years of my life as I finish my A-Levels and progress to university or an apprenticeship. I hope that my back brace works out and my curve stabilises as I stop growing so I don't need surgery. But I now know that I will not let scoliosis hold me back and I can reach my goals. I have scoliosis, but I am so much more than my scoliosis. I am Gemma and I am proud to be a SCOLIOSIS WARRIOR. I wish all who are starting this journey or are in the middle of this journey the best of luck. I will leave you with this quote.

"Always remember that you are Braver than you believe, Stronger than you seem and Smarter than you think, you are a SCOLIOSIS WARRIOR"

Gemma Sarigu

SAUK funds new e-learning module for GPs

For people living in the UK, the first step to accessing healthcare usually means a trip to see their GP. This means GPs have an important role in identifying people with possible scoliosis, organising tests to confirm this diagnosis, and arranging an onward referral to a specialist when necessary.

Scoliosis is a common condition; for example, it is estimated that between 2% and 3% of children aged between 10 and 16 years old will have a spinal curvature of 10% or more, and many adults will also be affected. However, a spinal curvature may not always be obvious in the early stages and not all GPs will be experienced in assessing for a spinal curvature.

Raising awareness of scoliosis among GPs and helping to keep practising doctors' knowledge of scoliosis diagnosis and treatment up to date is therefore important to help ensure that people with scoliosis receive the best care possible. Previous SAUK campaigns raising awareness about scoliosis among GPs and other healthcare professionals working in the community have been well received. However, SAUK has not

run a dedicated campaign focused on raising awareness of scoliosis among healthcare professionals for around 20 years, making it high time for an update.

Legacy funding

In 2018, SAUK received over £60,000 as a legacy fund from Patricia Hill. The Trustees considered a range of possible options in terms of how best to use this money. For some time the SAUK team had been hoping to run a project that would build the skill and confidence of GPs and healthcare professionals in primary care working with people with scoliosis. Patricia's very generous donation provided SAUK with the opportunity to realise this wish and undertake a high-profile national project aimed at educating community healthcare professionals about scoliosis.

Deciding how to reach GPs

For GPs and other healthcare professionals, keeping knowledge up to date is done through a process of Continuing Professional Development (CPD). Online education modules are one popular and important component of CPD as they allow people to target their learning at areas in need of development or areas of interest and get educational credit for this work.

Following discussions with regional GP leads, we approached the Royal College of General Practitioners (RCGP) and agreed to fund a new dedicated e-learning module focused on scoliosis in childhood. The RCGP is the leading body supporting GPs in the UK, with over 53,000 members. The college has an established team working on education for GPs

Learning Assessment

Pre-Course Assessment

Click here to attempt this quiz

Average Score:
58.25%
Based on 40 attempts.

Post-Course Assessment

Click here to attempt this quiz

Average Score:
93.33%
Based on 27 attempts.

Navigation

Home

Portfolio

My courses

Courses

Scoliosis

This half-hour module aims to update GPs about scoliosis, a common orthopaedic condition in childhood which benefits from early recognition. The module uses a case-study approach to discuss the clinical assessment of a patient presenting with possible scoliosis as well as how to investigate in primary care, when to refer and the possible approaches that might be taken in secondary care.

0%

CPD*: 0.5 credit

*This course is 30 minutes in duration, worth a minimum of 0.5 credit. You are encouraged to reflect on any impact that this module has had on your practice and claim the actual time to complete and reflect on the course for your CPD log.

Your progress ?

1. Pre Course Assessment

2. Scoliosis

3. Post Course Assessment

An example of the content from the RCGP e-learning module

and their e-learning platform has been accessed by around 110,000 healthcare professionals working in primary care, including GPs and GPs in training. Each day, the online learning platform receives around 30,000 views. Working in partnership with the RCGP gave SAUK the unique opportunity to offer our education module to this large national audience.

Developing the e-learning module

Charities, such as SAUK, work in partnership with the RCGP to develop educational content. The funding SAUK gives to the college covers the costs of an experienced team of doctors who write the content for the module as well as a wider team who develop the visual and interactive content and others who promote the finished material.

Work began on developing the module in the autumn of 2019. SAUK outlined the intended title, objectives, and scope of the module as well as the key messages we felt were important to raise. SAUK put together an experienced team with a mix of different backgrounds to try and represent the voices of different stakeholder groups, including our members. The SAUK team was led by Nick Jones, a GP, and included Carol Richards and Susannah Kraft,

Trustees with personal or family experience of scoliosis, as well as Colin Nnadi, a Trustee who is an orthopaedic surgeon with a special interest in scoliosis.

The RCGP appointed an experienced author, Dr Dirk Pilat, who leads on creating e-learning modules for the college. Creating the e-learning module has been a collaborative effort. Through team meetings, shared ideas, and two rounds of written reviews, the module developed and flourished into a thorough, engaging, and comprehensive learning platform. The module was completed in August, 2020, and is now up and running on the RCGP platform.

What does the module look like and what is included?

The module aims to help GPs to assess patients with scoliosis, and to recognise who needs referral and in what time frame. It also provides information on how best to treat and support people with scoliosis through diagnosis and long-term follow-up, considering both their physical and mental health as well as the psychological impact a diagnosis can have on the family.

The module begins with a quiz which also helps people reflect on what they already know about scoliosis, which also helps people

to identify areas where they feel less certain. Throughout the module itself there is a mixture of slides demonstrating examination techniques, X-rays, or other clinical images, and interactive quizzes and questions to keep the learner interested and engaged. There are also case studies, which play out imagined scenarios in which the learner follows a patient's journey from the point of diagnosis through follow-up. At the end of the module there is another quiz so that people can see what they have learned and help consolidate the new knowledge.

What happens next?

The module is now live with new learners taking advantage and accessing the module every day. However, completing the module isn't the end of the story. The RCGP has a dedicated team who will continue to promote the content to their national and international audience, through email, social media, and their host website. Information on engagement and interest in the module will be periodically fed back to SAUK so we can track engagement and understand the value of the module we've helped create. In coming years there will be opportunities to update and amend the review, with the aim of to keep this relevant to doctors as practice changes.

Dr Nick Jones, SAUK Trustee

An example of the content from the RCGP e-learning module

Cobb Angle

The Cobb angle is named after the American orthopaedic surgeon John Robert Cobb (1903–1967) and is used to measure curvatures of the vertebral column such as scoliosis and traumatic deformities.

If referring a patient who has had an x-ray, it is useful to mention the Cobb angle in the referral letter. One of the benefits of arranging an x-ray at the time of referral is that, if appropriate, it can be repeated when the patient is seen and this will tell the consultant if there has been progression of the Cobb angle between referral and first appointment. This information can guide decisions on the urgency of treatment versus a watch and wait approach.



Mother Daughter Bond

My scoliosis journey with my daughter started just over 5 years ago, when Emily was diagnosed by chance. At this time, I wasn't even aware of the condition, so felt very worried and apprehensive about the future.

Emily was in year 6 when she had her first consultation with the specialist, and X-rays showed that she already had a 60 degree curve. Bracing was not an option so the only choice was a spinal fusion to correct the curve. As a parent, I felt upset and guilty, wishing I had noticed sooner; there was a whole mixture of emotions.

After an MRI scan and her final consultation, Emily had her spinal fusion on the first of August. It was such a worrying time but the nurses and doctors were fantastic. Her operation lasted for 6 hours, then the next 2 days were spent in the high-dependency unit, which was heart-breaking to see her in so much pain. The physiotherapists soon got her up and slowly Emily started to walk a little further every day, and then mastering stairs. It was hard to believe that just a week after her operation she would walk out of the hospital and be 2 inches taller!

Her recovery went well, with good and bad days. 5 weeks after her operation she started high school, full time with all her friends – she was so determined to be there on day one with everyone. Although Emily was unable to do sports for a year after her operation, her check-ups were all positive and going in the right direction.

Since Emily was only partly fused the consultant mentioned that there may be the possibility that the lower part of her spine would curve as she got older and she may need a further fusion. Unfortunately for Emily this was the case, so she was scheduled for her second fusion in 2019. However, before her operation she managed to complete her Duke of Edinburgh award with her friends, which was such a great achievement and a very proud mum moment.

When your child is diagnosed with scoliosis, as a parent it can be such a worrying time, not knowing all the facts, what questions to ask the consultant, what to expect when your child goes into hospital, and most of all it can feel a really lonely time. It's nice to know that there are people

out there that know exactly what you are going through and can offer the support to reach out to when you need it most.

Christine Davidson

In July, Katie celebrated the 6 year anniversary since her operation to correct her scoliosis. She has been able to achieve so much since then and is currently studying musical theatre at the school of her dreams, Emil Dales School of Performing Arts. Katie continues to look after her body, and has massages to help with aches here and there. She is so happy to be able to continue her ambition of performing and while it's not always easy, she is advancing well.

Katie says that looking back over the last 6 years is surreal.

She says, "Admiring how far I have come and looking at what I have been able to achieve is still something that amazes me every day. Hearing that I was going to need surgery was such a shock (as I was only diagnosed 6 months beforehand) and I immediately panicked that it would affect my performing. I remember crying straight away. Eventually, the pain was so severe that I was wheelchair bound, which meant that dancing after surgery was more likely than dancing without the surgery! So we took the leap and pursued with surgery. Recovery wasn't easy but by 7 months I was back performing a dance solo on stage with minor restrictions.

Occasionally (and mainly at the start of a new school year after having a summer holidays) I can get lower back pain where my fusion finishes and my 'normal' spine begins (L3). This is solved within a few weeks of doing my clinical Pilates exercises and having





sports massages. Although this can be frustrating times to have to sit out of a few classes, when I look at the bigger picture and reflect on how much I am still able to do, this frustration quickly subsides.

Our days at Emil Dale Academy are intense and physical and 95% of the time my back is completely able to withstand the strain with the occasional massage and heat pack to help any niggles.

I previously worried that colleges would be fearful of accepting me because of my few limitations (no back bends, low arabesque, no contractions, etc) but this really wasn't the case at all. All three of my schools/ colleges have been completely understanding and so supportive of my situation, which I couldn't be more thankful for.

This isn't to say the past 6 years have been easy; recovery and rehabilitation to get back to the standard I was previously at took time and hard work. But I was determined, and I did it. I might not be able to do a backbend or have my arabesque as high as it used

to be, but I look at all the other things I am able to do and am so grateful to still be doing them. My main advice would be to not give up. Everyone always says it, but it really is true. I would also recommend speaking to someone if you feel overwhelmed by the idea of surgery or after you've had the surgery done. It can be a really big thing to process and talking about it can really help. You will get there, and it's so important to take a step back sometimes and reflect on everything and admire how much you are already achieving and how far you've come."

Katie's mother Wendy said "we know having this surgery is such a worry for parents and the people who have to go through the operation, particularly when they are active and have a passion for an activity. To be able to see that this could continue for Katie will hopefully bring encouragement and hope to many."

Wendy reflects on when Katie was diagnosed and quickly taken in for surgery. "When we had made the decision to go ahead with surgery we had so many unanswered questions in our minds. Would she be able to

dance at high level or even at all? How would she be able to move her body? Would her pain go? How would she manage with metal rods in her back? It was a worrying time for us all as a family.

During her year of rehab doing clinical Pilates and easing herself back into dance classes, Katie's passion and love for her performing took over and it was a relief to see her happiness return. With our support, positivity, and encouragement, and Katie's determination to move forward, her progress that started as baby steps started to flow as her muscle memory took over. Katie has shown it's possible to dance at a degree level, so we encourage everybody to not give up just because you have a fused spine. Scoliosis has given Katie strength and resilience, which is invaluable for her industry. And given me a daughter to be proud of!"

Katie & Wendy Towner

Coming to Spinal Clinic

One of the recently completed research projects that SAUK's sister charity, the British Scoliosis Research Foundation funded is Edge Hill University's research into "Improving young people's engagement during spinal consultations", led by Professor Lucy Bray, with colleagues from Alder Hey Children's Hospital

This research project was undertaken to collaboratively create a consultation guide for young people with adolescent idiopathic scoliosis.

Researcher Lucy Bray is a children's nurse by trade, working with children and young people undergoing surgery and procedures. She is passionate about children being informed, prepared, and involved in decisions and choices about their healthcare. She made contact with the BSRF because the team knew there was a need to develop resources to help empower children and young people with scoliosis to have a voice and participate in their healthcare consultations.

"Sometimes as adults we can try to protect children and young people from difficult conversations, or they can become excluded when complicated language is used. There is increasing evidence that if we involve young people in consultations in a meaningful way, then this is really valuable to them and can result in less anxiety and worry and more understanding of what is happening," said Professor Bray.

Workshops were held separately with ten young

people (aged 14-16 years) with scoliosis and eleven parents. The groups took part in creative activities to explore what it was like coming to a spinal clinic in order to create the content and format of the Coming to Spinal Clinic resource. These workshops showed that many of the young people and parents had felt anxious and worried when they had attended spinal clinic for their first appointment and that they had struggled to ask questions and gain information during the consultation.

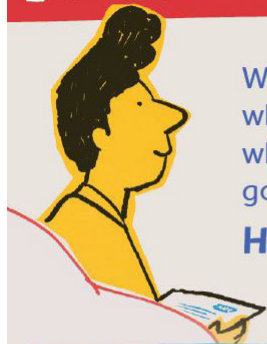
The young people thought that colourful and engaging information in the form of an animation and a paper 'prep sheet' would help other young patients to prepare for a clinic appointment. This prep sheet gives suggested questions that a young people could ask during their appointment and provides room for them to write down the answers and their own questions. Having a physical paper reminder of the questions that they want to ask aims to help the young patients remember their questions and to give them the confidence to speak up and show that they want to take part in the clinic consultation. Professor Bray commented that everyone has been in a consultation

Coming to Spinal Clinic Hints & Tips

If your child has an appointment at the spinal clinic, there are lots of ways you can help make the experience better. Here are some suggestions developed with the help of parents of children with scoliosis.



IDEAS FOR QUESTIONS



We asked other young people who have been to spinal clinic what they thought would be good questions to ask.

Here's what they said...

Why has this happened to me?

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What does my X-ray show?

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Which treatment is best for me?

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where they leave and then think, uhh I forgot to ask this or I can't remember what they said about that. Appointments are often busy and young patients have had a new diagnosis with lifelong consequences, so it's a lot for them to take in. The parents have many questions they need to ask, the consultant has a considerable amount of information they need to share, and the young person can often have a lot of thoughts whirling around in their head, and it can be difficult to articulate those thoughts into questions

Because this resource has been made for young people, by young people, we hope it will empower them to ask questions in clinic, gain the information they need to understand their own health condition and become involved in the decisions being made.

One surprising thing for the researchers about this project was that they thought they were just creating a resource for young people, but it became apparent throughout the project that parents could also

struggle to get involved with clinic consultations. Parents were keen to have their own information leaflet as part of the resource, with key information to help them support their child when they came to the clinic. The young people with scoliosis participated throughout the project, giving feedback and investing time to make sure the resource was as right as possible. They and the parents discussed how they had enjoyed meeting other young people with scoliosis and their parents and having the opportunity to discuss their experiences with other families who had 'been there'.

This project shows that together we can learn more about scoliosis and find ways to continually improve the experience of receiving treatment for scoliosis.

The 'Coming to Spinal Clinic' resource is freely available and accessible to watch and download on

<https://www.edgehill.ac.uk/comingtospinalclinic/>

Your spinal clinic appointment will be full of new information, so it can help to think about what you want to know before you come. This prep sheet is designed to help you think about what you want to ask or find out about when you are there. You might find it helpful to work through it with your mum, dad or carer.

REMEMBER

It's **your** back, so it's important **you** know about things. But it's still **your** choice to ask questions or not.

Breakage London



Breakage London™ is a 'social good' clothing brand, specialising in premium apparel that is designed to empower people with scoliosis. 20% of profits from all garments sold go to Scoliosis Association UK to support us to continue providing advice, support, and information to people - affected by scoliosis and their families and raise awareness of scoliosis among health professionals and the general public.

Scoliosis makes the process of buying clothing challenging, particularly if you are trying to disguise scars from surgery or wear a body brace beneath. That is why the core product offering of Breakage London is simple: upper body garments in modern streetwear styles, designed to accommodate unique scoliosis bodies, featuring designs that celebrate scoliosis; all in an attempt to spread awareness of the condition.

The company's founder (Dan Ayers, 26) was diagnosed with scoliosis when he was 15 years old, and he had spinal fusion surgery in September, 2010, when he was 16. 10 years on, he founded Breakage London to remind people that scoliosis is not the end of the story, it is only the beginning.

Speaking about the design process, Dan explains "I always knew from the beginning that I wanted the core design to be on the back of the garments, rather than the front, because I wanted people to feel empowered and wear their scoliosis proudly". The 'asymmetrical line' design on the back of the garments visually reflects the asymmetrical skeleton of a scoliosis body, but they also have a deeper meaning.

premium apparel, designed by people with scoliosis, for people with scoliosis.



According to Dan, the design is inspired by Kintsugi (金継ぎ) which translates to mean “golden joinery”. Kintsugi is the ancient Japanese art of repairing broken pottery by mending the areas of breakage with gold lacquer. As a philosophy, Kintsugi treats the breakage and repair as part of the history of the object, and something to celebrate, rather than disguise. The imperfections in the pottery make the object even more beautiful and unique than it was before. That is precisely why the “breakage” design is on the back of the garments rather than the front, because scoliosis should be celebrated as a tale of triumph and resilience, not disguised as something to be embarrassed of.

Breakage London launched its first collection, entitled ‘Halcyon’, in July, 2020. Following the success of Halcyon, they launched their second collection, entitled ‘Bloom’ shortly afterwards in September, 2020.



According to Dan, the limited edition “Bloom” design was inspired by the symbol of a flower bursting through the concrete. The flower growing through the cracks represents thriving in the face of adversity and against all odds, which Dan felt is something that many people dealing with scoliosis can relate to. “There are no straight lines in nature, everything is perfectly imperfect, and that’s what makes it so beautiful”, he says. “Society constantly tells us that we should strive for perfection, particularly when it comes to our bodies, and just because my body will never be ‘perfect’ by society’s standards, doesn’t make my body any less of a miracle... I’m perfectly imperfect just the way I am”.

Bloom Collection

September 2020



Breakage London is on a journey, Dan says. Each new collection that is released represents a new chapter, and each new chapter looks at the scoliosis experience through a different lens. Chapter 1 was ‘Halcyon’, and was about acceptance and finding peace with your scoliosis; Chapter 2 was ‘Bloom’, and was about personal growth and thriving despite scoliosis; Chapter 3... will be revealed very soon, says Dan. He gave us no hints.

Be the first to find out about future releases by following the story as it evolves on the brand’s Instagram channel (below). For more information on the brand, or to purchase items from the collections, head over to the brand’s website (below).

 @breakagelondon

www.breakagelondon.com

For all media, partnerships or personal enquiries, please contact:

dan@breakagelondon.com

About the BSRF



SAUK has a sister organisation, the British Scoliosis Research Foundation (BSRF). The BSRF exists to promote research into the treatment and cause 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.

Scoliosis Priority Setting Partnership

The Scoliosis Priority Setting Partnership identified the most common unanswered questions about the diagnosis and management of scoliosis put forward by patients, family members, and medical carers. We hope that these findings will inform future research to align with what matters most to those directly affected.

The James Lind Alliance (JLA) Scoliosis Priority Setting Partnership has agreed the following Top 12 priorities for research:

1. What are the best strategies for reducing or preventing the curve from getting worse, combining treatment and self-management approaches to avoid the need for surgery?
2. How is quality of life affected by scoliosis and its treatment? How can we measure this in ways that are meaningful to patients?
3. Could surgical procedures be improved to become less invasive, reduce scarring and increase flexibility?
4. What are the long-term outcomes and side-effects of surgery?
5. How likely is scoliosis to get worse over time, either with or without treatment? Should people be monitored?
6. What is the best method of imaging scoliosis that also reduces exposure to radiation?
7. Which type of brace (eg, rigid or dynamic) is most effective in the treatment of (a) early onset scoliosis and (b) adolescent idiopathic scoliosis?
8. What forms of postural care are most effective (standing frames, seats, sleep suits & wheelchairs) for managing early onset, neuromuscular, and syndromic

scoliosis?

9. If scoliosis is diagnosed earlier, does this change the choice of treatment and/or lead to better outcomes?
10. How are the psychological effects (including on body image) of diagnosis and treatment best managed?
11. Can the instrumentation (rods/ implants etc) cause harm in the short or long term?
12. How is scoliosis affected by hormonal changes in women (puberty, pregnancy and the menopause) and does this have implications for treatment using HRT?

History of BSRF

BSRF was formed in 1973 and was formerly known as the Phillip Zorab Scoliosis Research Fund.

Dr Zorab was a chest physician at the Brompton Hospital, London, specialising in respiratory problems caused by scoliosis. He was very interested in research into the condition and was the first person to organise international symposia on the subject in the 1960s and 1970s. These brought together many physicians and surgeons who had children and adults with scoliosis in their care. The symposia stimulated new research into scoliosis worldwide. Dr Zorab died in 1983 but the BSRF continues his work.

Since its inception, the BSRF has strived to stimulate high quality research into scoliosis. It continues to hold the international symposia and continues to offer grants year on year for research into different aspects of scoliosis.

SCF - THANK YOU

We are grateful to all our amazing fundraisers for all their hard work over the past few months in 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!

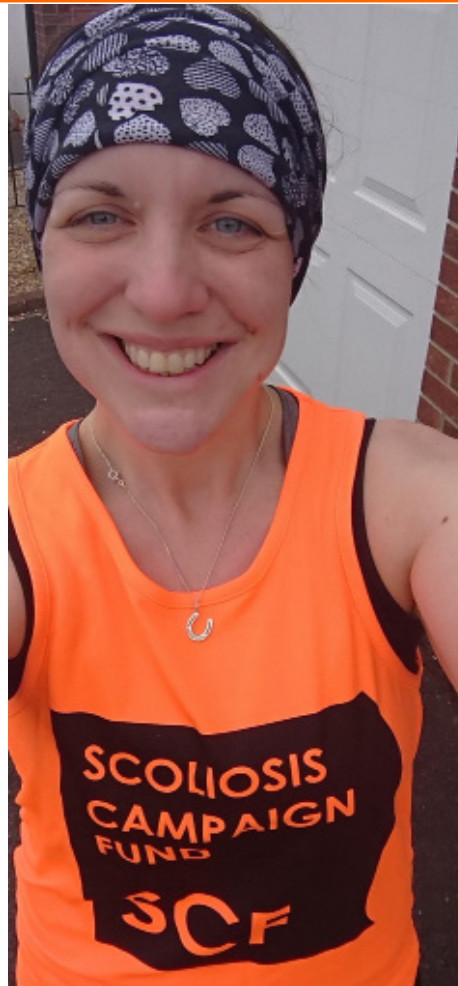
SCOLIOSIS
CAMPAIGN
FUND

SCF

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



David taking on the 30 mile Peak District walk challenge to raise money for the Scoliosis Campaign Fund.



Gemma ran the virtual Bristol 10K after COVID-19 cancelled the original marathon-

Donations

A huge thank you to our generous donors:

Andrew Halstead
Jean Hornbuckle
Maria Senner
Michael Robinson
David Smith
Andrew Gray
Nicholas Momber
Mrs J Westley-Smith
Sandy Kennedy
Susan Newnham
Chisha Lombe

Fundraising

Aimee Templeman skydived at age 15 and raised £921
Chantelle McGarry, 'Scoliosis Awareness Month 2020', £1,010.31
Melissa Milne, 'My Fundraising Page', £251.25
Steve Hicks, 'BazHicks CptnMonty', £1,576.53
Laura Price, 'Team Price', £928.75
Keira & Zac Pearce - £200 for doing Evendons Lockdown Puzzle Trail

Scoliosis Campaign Fund (SCF) raises money to support people with scoliosis and their families, and funds research into finding the causes of scoliosis and treatments to improve quality of life for patients.

SCF is a joint fundraising venture between the Scoliosis Association UK (SAUK) and British Scoliosis Research Foundation (BSRF). All money raised is divided equally between the two charities.

There is still little knowledge or understanding of scoliosis, which can make it difficult for people to access the care and information that they need and can leave them feeling isolated and unsure where to turn.

SCF allows SAUK to continue to provide advice, support, and information to people affected by scoliosis and their

families. SAUK also works to raise awareness of scoliosis among health professionals and the general public.

SCF also raises funds to allow BSRF to continue financing research to discover the cause(s) of scoliosis and develop treatments to improve the quality of life for those who live with the condition.

Research has led to huge advancements in scoliosis treatments over the years allowing patients to better manage their condition and enjoy much improved quality of life.

Whatever amount you raise; you're helping to fund our essential work.

23 YEARS LATER

Helen Gardner is a SAUK Regional Representative in the Central England Region who uses her experience of having had fusion surgery 23 years ago to support others going through this now, telling them what to expect and showing them that there is light at the end of the tunnel. This is her story told through blog entries that cover certain points in her life. You can find Helen on Instagram @helen_scoliosisrep

Entry 1

My journey began in 1995 when I was 14. I was on a shopping trip for the family summer holiday when my sister noticed my right shoulder blade was sticking out when I was trying on swimming costumes. Being a teenager, I shrugged it off but when we got home my mum took me to see a family friend down the road who happened to be a nurse. She asked me to do what I now know as the forward-bend test and immediately told us I had scoliosis and we should go to the doctor.

I had no idea what she was talking about and the time between this and the first visit to the consultant is a bit of a blur. I remember waiting in the waiting room and going for X-rays. What I remember most is the overwhelming feeling of shock, confusion, and bewilderment at what I was seeing on the X-rays. How on earth does that happen?! How can that be there in me and I haven't known about it?!

Entry 2

After my diagnosis of adolescent

idiopathic scoliosis, I think I and my family were in shock. I'm sure (although they never said it to me) my parents wondered why they hadn't noticed. In truth, it can creep up quietly and rapidly and typically with this type the patient is in their teens, not likely to be parading around hardly clothed in front of their parents!

I was fitted for a brace, which I was expected to wear 23 hours a day. All the time, everything inside you is trying to fight against this new, horrible experience - you don't want to be there but at the same time you resign yourself to having to go through it. I was so worried about what people would think at school that it became quite traumatic and a point of friction. I told only a few very close friends about my diagnosis. I didn't want to be bullied, to be labelled as some sort of freak, or laughed at. I suppose I was struggling myself to come to terms with this new me.

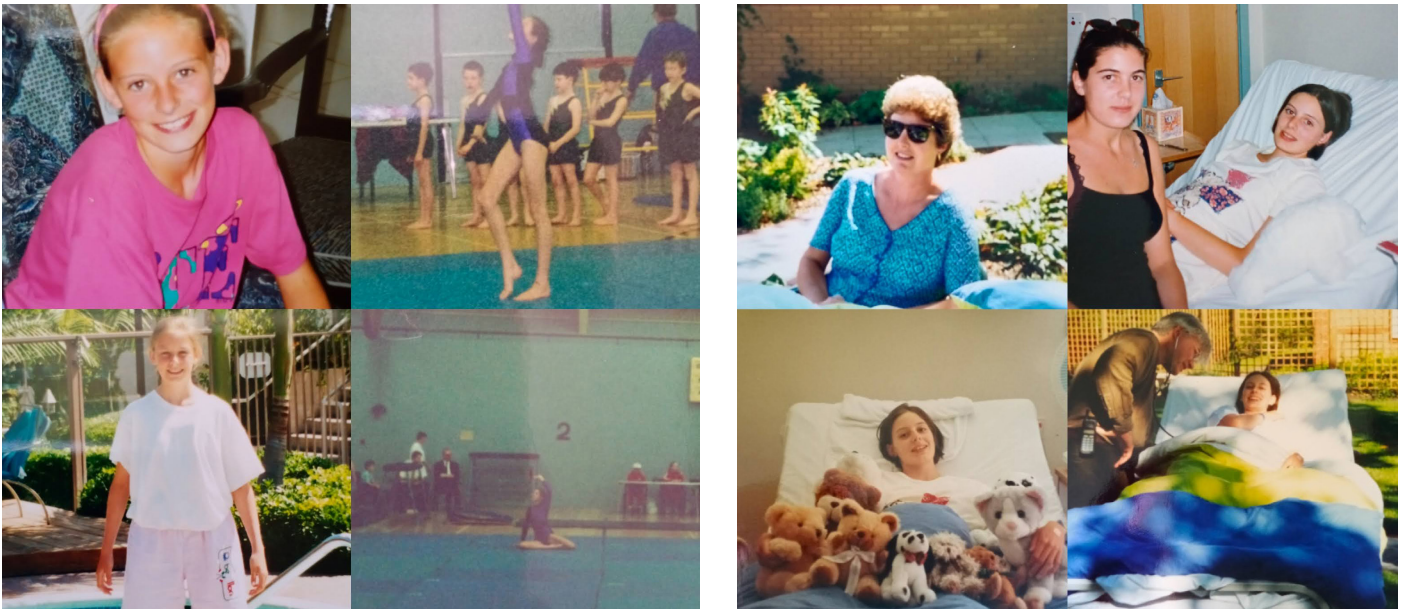
Entry 3

Having been wearing a Boston brace

for nearly 16 months and with the degree of the curve hovering around 60, I made the decision with my parents to have the surgery. They were a huge source of amazing support. I can't imagine how hard it must have been for them to watch their child have to contemplate risks of paralysis and other significant complications.

Entry 4

The night before the operation I was feeling a mixture of apprehension, nerves, and fear. A room had been prepared for my mum so she could stay at the hospital, but I remember asking her to stay with me until I fell asleep. I woke up suddenly, very early in a state of quiet panic, frightened about what was about to happen. I drifted back off and then when I awoke again, I was strangely calm, perhaps numb. I took the pre-med and waited to be taken to theatre. As I was wheeled down, I remember an emotional embrace with my dad outside the anaesthetics room. I am told about the moment they wanted to make sure I could move my toes and apparently I tried to



get up, thank goodness I was too dozy to remember!! The operation had taken 13 hours during which the surgeons removed ribs, collapsed a lung, manually straightened my spine, attached numerous screws and two titanium rods and applied the bone material to help hold it in its new position. I was told to think of the metal as scaffolding.

Entry 5

The first week I was not allowed out of bed. I ached, a lot, and having to lie and not move yourself was limiting.



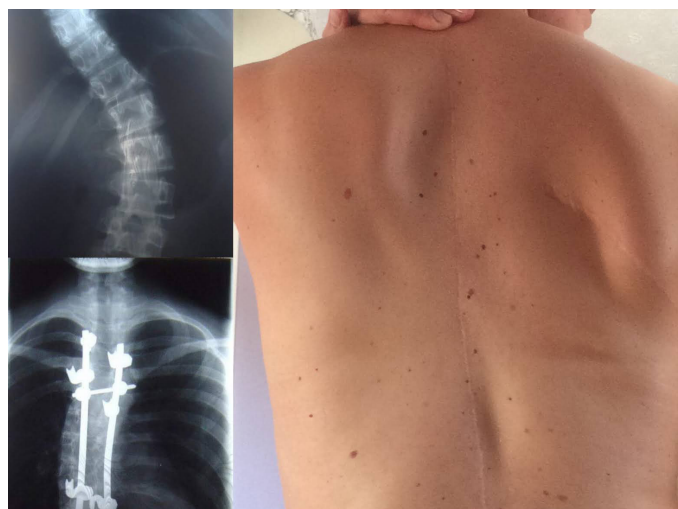
Every time I coughed or breathed deeply or laughed, I was reminded of the immensely invasive nature of the surgery. I had to do breathing exercises to up the lung function. I had to do physio in bed to restore the muscles that had wasted from being immobile for so long. To push myself back up caused more pain and so I would have to call for the nurse every time to help move me back up. These day-to-day activities suddenly became impossible to do on my own. The loss of dignity was inevitable, not something anyone wishes to relinquish, but at 16 it's certainly not something you expect!!

My family were a light in the darkness every day. They made it more bearable. I have memories of them all being there whenever they could. My grandad came to sit and play cards sometimes. My dad would come on the way home from work and we would watch telly. He'd help me to and from the little kitchen to

make a hot chocolate and get some steps in once I was allowed up. That first time I got up was like I was doing it for the first time ever. I felt incredibly heavy, I managed to get round the bed and was exhausted. I was so breathless. My best friend would come and sit with me, chatting then I would fall asleep mid conversation.

Entry 6

After 2 weeks in hospital, I was on my way home. It was about a 45 minute journey, the longest I had been sat



upright since the operation. I felt every single bump, but it was so good to be going home. Mum and dad had set up a sun lounger daybed for me in the lounge so I had somewhere slightly firmer than the sofa to lie. I was discharged with exercises to do, and was advised how to get out of bed (roll onto your side and rise up - still do it now mostly!!). I still needed a lot of help, so mum helped me shower and wash my hair since I couldn't lift my arms up high enough. It's like going back to the beginning. It was just so nice to be home, in my space, with all the home comforts and a feeling like I was on the next phase of the recovery. By September, I went back to school full time. My friends were great at carrying my bags for me and the following Easter I managed the school American Exchange trip to New Jersey. Flights, bus trips, unfamiliar beds, etc. We had an overnight stay in a hotel with a pool. I asked my friend to check how my back looked in my

swimming costume. This would be the first time that I had exposed it, in particular in front of my classmates, I was really self-conscious but she was so lovely and encouraging that I soon forgot. I have never looked back since.

Entry 7

I'm almost 23 years post op and I'm still learning about the effects of my scoliosis. I have aches and pains from being fused for so long but am 100% certain I would not have the quality of life I do now if I hadn't had the

surgery. I had, and continue to have, incredible love and support from my family and friends (some who have been with me right through). I believe my experience with scoliosis has enabled me to deal with other considerable challenges I have faced in the form of miscarriages, breast cancer, and a law degree (just graduated last year with a first.) It makes you determined and strong but I have frustrations and sadness at times as I still reconcile with it all in my head. I wanted to be involved with SAUK to help others and raise awareness. Now, I have a fabulous husband, two handsome, funny, and crazy boys, and awesome parents and sisters. Don't ever underestimate the power of you, and always share - you might just be the light at the end of someone's tunnel.

Helen Gardner, Central England
Regional Representative

CHRISTMAS CARDS 2020

No.	Title	Dimensions (mm)	Price per pack of 10	Number of packs	Price
1	Snowy Fall Candles	126 x 126	£3.50		
2	We Three Kings	126 x 126	£3.50		
3	Nordic Woodland SALE	126 x 126	£2.50		

Postage and packaging

For orders of 1 pack please add £1.00

For orders of 2 packs please add £1.35

For orders of 3 packs please add £1.89

For orders of 4 packs please add £2.00

For orders of 5 packs please add £2.90

For orders of 6 - 10 packs please add £5.00

Total price

Post & packaging

Optional donation

Overall total

Please send completed order forms together with your cheque, made payable to 'SAUK', to: Scoliosis Association UK, 4 Ivebury Court, 325 Latimer Road, London, W10 6RA.

Your details (in block capitals)

Address and postcode:

Name:

Telephone:

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