

Issue 101 | Spring 2020

BACKBONE

ALICE FEVRONIA

Latest News from SAUK

The anaesthetist's role

Health play specialist's role
during hospital admission

Advice on caring for a child in
a cast

Isobel Gray Award

Fundraising, stories, and loads
more



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LATEST NEWS

Welcome to SAUK

SAUK is pleased to announce that Anne Rowlands joined the team in December, 2019, as General Manager. Anne will oversee the overall running of the charity along with our sister organisation the British Scoliosis Research Society (BSRF). Anne has previously worked as an Office Manager at Genesis Research Trust and Imperial College London for nearly 16 years. Natalie Cooper has also joined the team recently, taking over as



Communications Officer. Natalie's role focuses on delivering high-quality communications and promoting



engagement in SAUK's work to the wider community. Her time will be split between SAUK and BSRF.

Christmas cards

Thank you to everyone who bought Christmas cards from us this year. All profit made goes towards continuing the vital work we do to support people with scoliosis. The amount raised was: £1517.01

500 Club winners

1st Prize - £80 Number 146, Allison Johnson
2nd Prize - £50 Number 151, Ruth Mayorcas
3rd Prize - £30 Number 142, Nigel Shaw

Raffle winners

1st Prize - Pam Parkhouse, £2000 cheque
2nd Prize - Pete of Cardiff, Gourmet Burger Kitchen Vouchers
3rd Prize - Sandra Watson, Five Guys voucher

Volunteer photographer

SAUK is looking for a London-based volunteer photographer to help us out on an ad-hoc basis, and at fundraising events, patient meetings, photos for Backbone as and when we need it. If you would like to volunteer please contact communications@sauk.org.uk.

Coronavirus and SAUK

During the coronavirus outbreak SAUK office is only partly open, with some staff working from home and others going in for a few hours each day. However, the Helpline is working by email so if you need help email info@sauk.org.uk and someone will get back to you. This situation might change and we will keep you informed on our website.

Colour Me Krazy

SAUK is one of the charities supported by Colour Me Krazy taking place on Saturday 5th September, 2020. Colour Me Krazy is an exciting race that brings together the challenge of a 5k with a splash of colour. Please visit www.njuko.net/w/77/ for more information or to sign up!

In Memoriam, Libby Biberian

It is with great sadness that we announce that Libby Biberian has died. Libby worked for SAUK for many years and was a friend as well as a colleague. The 100 Club, which has been a great fundraiser for SAUK, was her idea, and she set it up and ran it for many years. She also answered Helpline calls and helped at regional meetings, always with a friendly smile and warm good nature. She was

a delightful person and we send our thanks and good wishes to her family at this sad time.

Brenda Luxton writes: I first met Libby at SAUK round about 1998 when she volunteered in the office to help with general enquires and to help with fundraising. Through her own scoliosis she was excellent in communicating with others who were telephoning for information, advice, and support with their journey through treatments. She was a joy to be around, and she was inspirational

and full of life, whilst still coping with her own disability.



Editors: Stephanie Clark and Anne Rowlands
 Designed by: Emily Wilson and Natalie Cooper
 Cover & Inside cover: Emily Coghlan Photography
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THE ANAESTHETIST'S ROLE

Dr Suzanne Wake, lead paediatric anaesthetist and Kevin O'Donoghue, spinal anaesthetist fellow at Nottingham University Hospitals

Anaesthetists are specialist doctors whose main role is to provide anaesthesia (putting patients to sleep) and pain management for patients undergoing surgery. After medical school and 2 years of general training, it takes 7 years and many exams to become an anaesthetist. Anaesthetists are involved in all stages of the surgical journey, including helping patients prepare for an operation and supporting their recovery afterwards. They also work outside theatres; they are part of the cardiac arrest and trauma teams and care for critically ill patients in the emergency department and on intensive care units. Provision of pain relief in labour, obstetric anaesthesia and specialist management of acute and chronic pain are other important roles. Safety and teamwork form a critical part of anaesthetic training. Whatever the hospital setting, anaesthetists are trained to deliver safe, high quality, patient-focused care.

Spinal anaesthetists have chosen to sub-specialise in this area of complex surgery, often completing further training to ensure they are experts in this field. The patient will meet their anaesthetist on the day of surgery, but many centres now invite patients to attend an outpatient assessment clinic before their operation.

Anaesthetic clinic

If a patient is called to an anaesthetic pre-operative clinic, full medical history and examination will be done. Occasionally further tests may be ordered to assess an individual's heart and lungs more closely. In some circumstances a specialist opinion may be necessary (for example, from a heart or lung specialist). A plan for regular medications and how to manage any medical problems in

the run up to surgery will then be discussed. The aim is to understand the patient's baseline function and assess if there is any way to improve the function before surgery.

All medical professions are encouraged to form decisions collaboratively with their patients, which means discussion and understanding of the risks as well as the benefits of surgery. Although anaesthetists do not take separate written consent, these discussions inform the consent process. Common areas for discussion would include the following

1) Management of bleeding

Maintaining a good blood supply and appropriate blood pressure during surgery is essential to protect the heart, brain, kidneys, and of course spinal cord. Some spinal operations can be associated with substantial bleeding. Spinal anaesthetists are experts at managing and reducing the effect of any blood loss. Common strategies include:

- Iron: if blood tests done in pre-operative assessment show low iron stores, iron supplementation in the weeks before surgery may help improve the blood count and the oxygen carrying capacity of the patient's blood. Sometimes surgery may be postponed to allow this improvement or facilitate further investigation. Iron treatment can be given as a course of tablets, or the patient may be asked to attend the hospital for intravenous treatment.

- Cell salvage: in this technique any blood that is lost during the operation is salvaged. It is washed and given back to the patient. Because it is the patient's own blood, the risks are low. Sometimes it is not available, or it is not possible to collect all lost blood and a blood transfusion may still be needed.

- Blood transfusion: patients might have to be given blood

donated by volunteers. Strict criteria are followed before the use of this limited resource. The donated blood must be matched exactly to the patient's blood type to minimise the chance of allergic-type reactions. The rigorous screening of donated blood in this country makes the risk of transmitting any infections very low. More information for patients to make an informed decision about donated blood can be found at www.nhsbt.nhs.uk.

2) Positioning

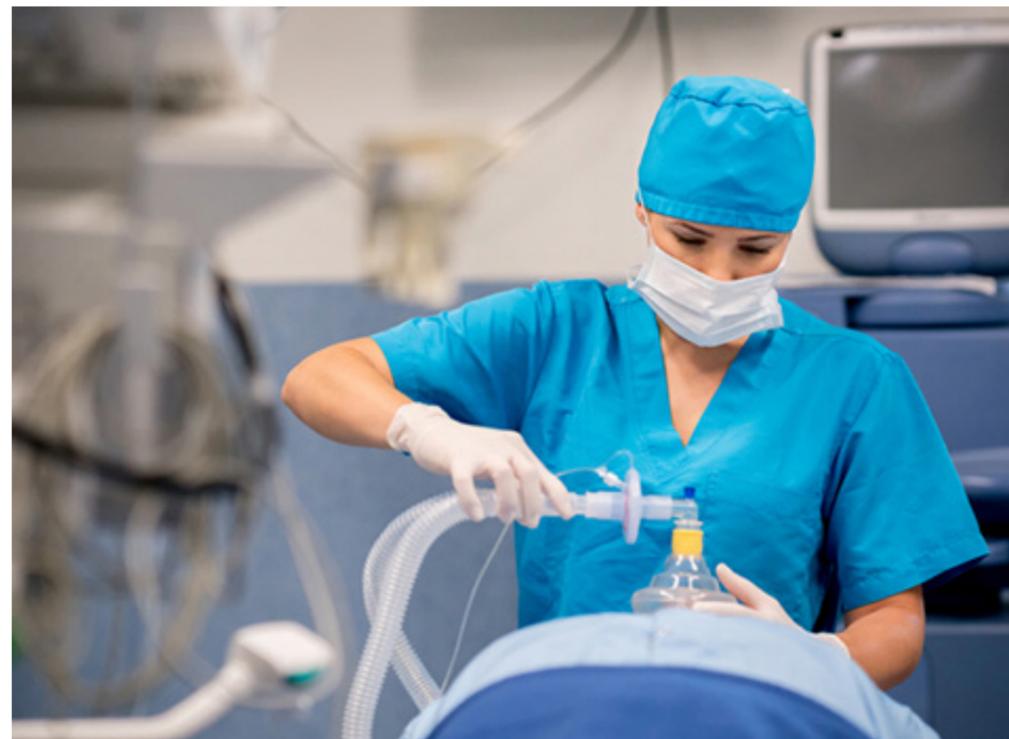
Often spinal operations are done with the patient lying on their front (prone). Patients are anaesthetised lying on their back/semi-recumbent and then turned, under anaesthesia, onto the operating table. Spinal operations can take many hours, and the patient remains in one position throughout. The theatre team are meticulous in positioning patients in a safe way. Despite this care, the duration

of surgery means that sometimes pressure marks develop on the skin where the patient rested, commonly in bony areas, including the forehead and chin, chest, hips, and knees. These marks usually settle a few days after surgery. More rarely, a pressure injury can develop that takes longer to heal. Patients often have a swollen face after long surgery, called dependent oedema, which is similar to having swollen ankles after a long journey. It will settle on its own.

A rare (one in 500 cases) complication of operations done in the prone position is post-operative visual loss. There are different causes but risk factors include certain types of positioning equipment, long surgery time, with large blood loss and low blood pressure, being male, and having diseases such as diabetes. Great care is taken to protect the face when placing a patient to ensure there is no direct pressure on the eyes. The head and neck are placed in a neutral position and kept at or above heart level where possible.

3) Spinal cord monitoring

To reduce the risk of neurological injury, some spinal operations require the spinal cord to be monitored. After anaesthesia fine needles are placed in the scalp and in some major muscle groups, which allows the neurophysiology team to check



“The theatre team are meticulous in positioning patients in a safe way”

that nerve signals can travel in both directions along the spinal cord, between the brain and the arms and legs. Both feeling (sensory) and movement (motor) nerves are tested. Should there be any alerts about potential nerve injury, all steps to optimise blood flow to the spinal cord are taken. If necessary, any straightening or instrumentation of the spine may be temporarily reversed or removed. Stretching of the spinal cord may reduce blood flow, and be the cause of the problem. Finally, if all other attempts are exhausted and spinal monitoring suggests there may still be a problem, a 'wake up test' may be needed. For this test the operation is stopped and the patient kept on their front while the anaesthetic is gradually reduced. The patient slowly wakes to a point between being awake and being fully anaesthetised. Usually, they are asked to wriggle their toes. As soon as the assessment is complete, the anaesthetic is restarted. This event is rare and usually patients have no recall of it. It is more common when the risk of spinal cord injury is increased, for example if the spinal cord is abnormal before starting surgery or if the curvature is very pronounced.

4) Pain management

Managing a patient's pain after surgery is an important part of the anaesthetist's role. Simple pain killers such as paracetamol and ibuprofen are often prescribed, together with morphine-based drugs (opioids). Treatment may be oral or intravenous, depending on the patient, the type and duration of surgery, and local practice. Common choices of these drugs include morphine, oxycodone, and sometimes fentanyl. Patient controlled analgesia (PCA) is popular because it allows individual control of intravenous opioids via a pump with a button so that the delivery of pain killers can be managed by the patient. For patients already using opioids, optimising pain relief can be more difficult and alternative pain killers such as ketamine may be considered.

The pain relief strategies available at the hospital should be discussed in detail before the operation. Medicines to help manage side-effects, such as nausea, vomiting, or constipation, should also be prescribed.

How can I prepare for my operation?

Recovery from surgery puts a lot of stress on the body. The effect of major surgery and the healing process has been likened to doing intense exercise continuously for several days. It is therefore helpful to optimise fitness before surgery.

Patients should try to stay as active as possible and try to improve their fitness. Some patients will be restricted by their curvature; however, any exercise is encouraged, such as gardening, walking the dog, using exercise bikes, or swimming. Local gyms can sometimes offer simple fitness programmes tailored to your needs.

Following a healthy balanced diet can improve surgical outcomes. Further information can be found at: www.nhs.uk/live-well/eat-well

Avoiding smoking and reducing alcohol intake is strongly recommended. As well as damaging the lungs and reducing the blood's oxygen carrying capacity, smoking is particularly bad for wound and bone healing, both of which are critical after spinal surgery.

Some people with spinal problems are in severe pain before surgery and have needed to use strong morphine-based pain killers, which can lead to tolerance to the pain-relieving properties of morphine. Minimising the use of opiates as much as possible before an operation may be beneficial.

On the day of surgery

The day has finally arrived! No doubt a mix of nervous anticipation awaits. Theatres start promptly, which unfortunately will mean an early start. There may be some waiting around so

if possible, bring a book and a family member or friend.

Depending on the planned time of surgery different fasting instructions will have been given. An empty stomach helps to prevent any regurgitation of stomach contents during anaesthesia. Being nervous can delay emptying of the stomach and so these fasting times are quite generous to reduce risks. Follow the advice given from the hospital, being careful not to fast for any longer than necessary. It is really beneficial to stay as hydrated as possible and patients waiting for surgery will be encouraged to drink water until 2 hours before their operation.

In addition to staying hydrated, another key tip is to stay as warm as possible. Bring a dressing gown or extra layers to wear whilst waiting. If asked to put on a hospital gown, then be sure to wrap up warm after this is on. You can keep these extra layers on until just before being anaesthetised. Staying warm has been shown to improve outcomes in planned surgery.

Anaesthetic room

When it is time for your surgery a member of the operating theatre team will meet you to bring you round to theatre. In the UK most people are anaesthetised in a dedicated anaesthetic room. Here you will meet the anaesthetic assistant (sometimes called an ODP) and other members of the theatre team who will complete final checks to confirm your identity, consent for surgery, and other critical information (eg, allergy status). Some people may feel anxious seeing so many new faces; however, it is important to remember that all these staff are focused on safety and making the operation a success. You may ask for a friend or relative to accompany you to the anaesthetic room, which is routine for younger patients.

Basic monitoring will be attached; ECG stickers to monitor the heart, a finger probe for oxygen saturations, and a blood pressure cuff. A cannula will be placed to allow injection of drugs for induction of anaesthesia and you will often be asked to breathe some

oxygen from a face mask. A sticker to monitor depth of anaesthesia may be placed on your forehead.

Once anaesthetised, some more advanced monitoring and usually more intravenous (IV) cannulas will be sited. An arterial line may be placed into an artery in the wrist to measure blood pressure very accurately. A blood pressure cuff can give a reading up to once every minute. An arterial line gives a blood pressure reading with every heartbeat. Occasionally the anaesthetist will discuss siting this line before induction, if closer monitoring is required. A urinary catheter is often inserted for longer operations to help drain the bladder both during and after surgery.

In theatre

When ready, the patient will be moved into the operating theatre and positioned on the operating table. Moving an anaesthetised patient is complex and requires a full team working together. Before final preparation for surgery the surgeon and anaesthetist will each do a full inspection to make sure they are both happy with the position to minimise the risks discussed earlier. The anaesthetist will typically continue to do regular inspections during the operation.

Maintaining anaesthesia

Throughout surgery unconsciousness is maintained by continuous delivery of anaesthetic agents. Some agents are inhaled via the breathing circuit, others are delivered intravenously. There will always be an anaesthetist at the bedside monitoring the patient to ensure their vital signs are within a safe range and to give medicines and fluids as appropriate. The whole team works together, led by the anaesthetist, to keep the patient safe during the different stages of surgery. The team manages the cell saver if in use and if donor blood is required, it is organised.

To monitor how anaesthetised someone is, the anaesthetist may choose to use a depth of anaesthesia

monitor. This gives extra information to help ensure the right amount of anaesthetic is delivered because too much is potentially as bad as not enough.

Recovery

Once the operation is finished patients are carefully positioned into a hospital bed, lying on their back. The delivery of anaesthetic is stopped, and the patient wakes. In anticipation of the wake up, the anaesthetist will have already administered strong pain relief and antisickness medications. The amount and type of painkiller given is individually tailored, taking into account information from the pre-operative assessment. The aim is to allow the patient to wake up as comfortable as possible, but also to avoid giving too much, which can increase risk of having side-effects such as nausea or vomiting. Patients are then moved to recovery where they will be closely monitored by their own nurse. The recovery nurse can help with 'fine tuning' of pain relief and strong painkillers, and anti-sickness medications will be prescribed for the nurses to give as necessary. The nurses work closely with the anaesthetists to ensure all medical needs are taken care of. Once patients are awake and comfortable and all vital signs are safe they will be moved to a ward or critical care location depending on both the pre-operative plan and how the operation went.

The main challenges with spinal anaesthetics relate to managing large teams, complex patient positioning, and complex surgery that can result in significant blood loss. A specialist spinal anaesthetist is an expert in managing all these problems and communicating with the highly experienced team, to help achieve the ultimate goal of safe, successful surgery. More information about anaesthesia can be found at www.rcoa.ac.uk/patient-information.

HILL, PEDDER, AND MINNS FUND

Andrew Minns was a founding SAUK member and Trustee. He left money to SAUK to set up a fund to support those affected by scoliosis. In 2018, Mrs Patricia Hill and Mrs Daphne Pedder, long time members and supporters of SAUK, passed away and left SAUK funds. Part of their legacy has been added to the Andrew Minns fund to create the Hill, Pedder, and Minns fund. This fund is used to support as many people as possible.

Who can apply?

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

Emily Haynes

Emily was diagnosed with a major double curve scoliosis at the end of summer, 2019, after complaining of a bad back. Her GP referred Emily to the Royal National Orthopaedic Hospital (RNOH) and the first thing her surgeon did was X-ray her back. Emily was



Emily Haynes with Buzz in January 2019

operated on in October that year and has made an amazing recovery and much quicker than could ever have been imagined. Her whole team at RNOH were amazing and the family cannot thank them enough for all their help, support and reassurance throughout this journey. When Emily came home her family kept their promise to get her a puppy – Buzz. To aid Emily with her studies she was awarded £500 from the Hill, Pedder, and Minns Fund. Emily had been struggling to sit at her desk and take notes so the money awarded has been put towards a laptop and iPad that will enable her to work more freely and not restricted to a desk.

EMILY COGHLAN



Emily is a documentary photographer, artist, and researcher. After studying history for her undergraduate degree and documentary photography at masters level, she is now considering pursuing a PhD in the arts, in relation to medical, historical, and patient-based perspectives of scoliosis. Emily's recent MA project entitled 'Witches' Broom' explores historical treatments of scoliosis, her own experience of spinal fusion surgery, and parallels between horticulture and orthopaedics, based on archival imagery and text, sculpture, and photography, and can be seen on her website: www.emilycoghlan.com/witches-broom. This project considers how we have arrived at contemporary medical understandings of the condition, and questions what is 'normal'.

Emily is hoping to expand this project in new directions and include others' experiences. Please get in contact if you: - have had treatment for scoliosis and are interested in sharing your experience - are researching scoliosis in higher education - may know of any potential funding sources for PhD level study on scoliosis from an arts and humanities perspective - are an artist or writer working on/researching an area of scoliosis, orthopaedics or health and are interested in collaborating.

Please contact Emily directly at eh_coghlan@yahoo.com

Alice FEVRONIA



Photo credit: Emily Coghlan

In the Autumn of 2019, Alice Fevronia made it all the way to the final of the tenth series of the Great British Bake Off. This was the pinnacle of a journey that started when she was diagnosed with scoliosis at age 16.

'I was just looking in the mirror one day and I thought I didn't look quite right,' Alice tells me when I ask her how she first thought she may have scoliosis. Alice was an enthusiastic athlete in her teenage years, training three or four times a week and racing every weekend. It's this level of fitness that initially helped her realise there was something wrong. She had noticed that she had started to get out of breath more than before. It was then her physical appearance that caused her some concerns, 'I just remember looking at my ribs and thinking they stick out quite a lot and they're not what I would want them to be like.' She arranged an

appointment with her GP who suggested physiotherapy but Alice and her parents weren't satisfied with this advice so sought a second opinion. The second opinion said that she had a condition called scoliosis, hers was a 50 degree 'S' shaped curve, and she was in need of an

"I just remember looking at my ribs and thinking they stick out quite a lot and they're not what I would want them to be like"

operation. This diagnosis came as a shock. 'I'd never really heard of scoliosis before. I may have heard of having a curved spine but I hadn't heard of scoliosis and didn't know anyone else who'd had it.' She found out afterwards that her godmother had had a scoliosis operation in her youth, but this was years before Alice was born.

The inevitable day of the operation came and Alice was understandably terrified, 'I'm not good with needles at the best of times and I remember being terrified of the general anaesthetic.' Alice's surgeon was going to fuse four vertebrae in her lumbar region and this correction would leave the top curve to self-correct. It was quite a complicated operation in which a chest drain was inserted, a rib was removed to use as a bone graft, a lung was deflated, and her diaphragm was cut. Her father joked that a car crash may have been less invasive. She was in intensive care for 24 hours and then spent a further 7 days in hospital before she was able to return home.

Alice was off school for 9 weeks to recover and then she spent 6 months in a brace. It was this period that she found the most difficult and is very open about how badly she coped mentally, 'I did find the experience traumatic. I did get incredibly

sad and I struggled mentally.' Alice was advised to avoid transport as much as possible and signed off physical exercise for a year. She had gone from exercising four or five times a week and competing in athletic competitions to being effectively house bound. This was the time when she discovered baking. Alice said she had to find things to do that weren't active and baking was something she would do to take her mind off things. Even now she still finds it quite therapeutic, definitely not when she was in the Bake Off tent but usually it allows her to 'zone out and go into [her] own little world.' Reflecting on that period she says she felt very isolated and bored, and baking was something she could do to escape daytime TV and then share the finished result with her friends when they came to visit after school.

When it was time for Alice to return to school her friends were incredibly supportive. They always carried her bags for her since she wasn't allowed to carry anything over 1 kilogram in weight. But the brace was a struggle, 'when they said brace, I had in mind a corset-type thing... but mine was skin-coloured, thick plastic, and sheepskin lined.' Alice became self-conscious so started to try and wear baggy clothes to make the brace less obvious but the main struggle for her was how hot the brace made her, 'everyone else was dozing on their desks and I was sat bolt upright.' The summer months were hard, especially with the added pressure of her GCSEs. Aside from her friends not many people

Photos courtesy of Alice's Instagram: @alice.fevronia



understood what had happened to Alice so she organised a non-uniform day and an assembly to explain her condition and stop the curious glances in the corridors. Day to day now Alice said she rarely thinks about scoliosis. She does get the occasional twinges or a bit of pain and now as she's getting older is starting to make sure she's more careful with her back. Since being on the Great British Bake Off

"I thought that I was always going to be in pain or it would always be a problem and that's just not the case"

she's had people contact her to ask advice about their own scoliosis diagnosis. Their concerns were all the concerns Alice had, missing school or work, worried about not seeing their friends, and so on. Alice says it's just about 'finding things you can do and setting little goals week by week, organising a few nice things to look forward to.' The most important thing she has learnt is to be proud of her scar, and she wants other people to feel the same. She said that when she was 16 she could never have imagined how she would feel now, 'I thought that I was always going to be in pain or it would always be a problem and that's just not the case', after all her scoliosis diagnosis led her to one of her greatest passions.

Appearing on this series of the Great British Bake Off was actually Alice's



second attempt to be on the show. There is a long process that starts with an online application form where you list what you can bake and then there are various interview and taste testing stages. Alice said she entered like you would enter a lottery, 'I never thought I would get on but there's nothing to lose.' As she was progressing further through the application process it dawned on her that this was looking a lot more like a realistic prospect. Looking back now on the whole experience Alice says she can appreciate it more, 'at the time I was still trying to take it all in.' She agrees with the judge's decision and says the best person won, 'David knows so much about the science of baking, if anyone had a question, he would answer it.' She says being on the show was a 'pinch yourself moment' and everyone involved was lovely.

It's been a bit of a whirlwind year for Alice so she is just taking things one step at a time. Since finishing the Great British Bake Off Alice is still teaching, juggling this alongside baking activities. She says ideally she'd like to keep combining teaching and baking, maybe even teaching baking one day but for now she is still teaching geography and bringing in the occasional treat for her class.

Keep up with Alice and her work on:

 @alice.fevronia

 @alicefevronia

Interview and article by Emily Wilson, past Communications Officer for Scoliosis Association UK.



SAUK DONATIONS

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

Flora Johnson, Daniel Sclare, Jennifer Vanstone, Neil Warren, D Jeanes, William Tulip, Marina Jakovleva, Emma Richardson, Heather Roberts, Helen Wilkins, Adetomike Adeniji, Victoria Margeson, David Crittall, Kirsten Palmer, Natalie Malcolm, Holly Painter, Jason Thompson, Anne Carman, Jill Cordingley, Karen Bell, Nicola Briggs, B Crompton, Stephen Gerwitz, Tim Underwood, Nicola Wilkinson, Joanna Parker, Joanne Ward, Simone Dunsheath, Jackie Baulf, Thomas Cunningham, Elizabeth Morath, Ian Churchward, Sarah Latham, Frances Booth, Sheena Lucas, Iain Matthews, Margaret France, Mingxi Zhang, Karen Reding, Andrew Knapp, Nina Corrin, Kath Wharton, Gilly Cox, Martin Bourne, APS Legal and Associates, Lorne Dryer, Hannah Lerwill, Yvonne Matthews, Mica Gooding, Douglas Rew, Ruth Mayorcas, Kirsten Mackey, Ceri Jones, Christopher Church, John Francis, Sandra Cooksey, Charlotte Merrills, Barbara Sinclair, Michaela George, Declan Dowling, Margaret Owens, Elwyn Davies, Denie Randle, Pauline Riccobono, Jodie Mangham, Diane Marriot, Fleur Bateman-Martin, Tracy Hart, Julie Barber, Deborah Willshaw, Chris Dunsheath, Joanne Daniels, Claire Ridgeon, Claire Prescott, Gavin Warrington, Susan Cripps, Paul Gilheany, Zoe Rex, Sarah Parker, Tom Corless, Kim Farmer, Steven Lewis, Lisa Hennessy, Lauren Downard, S V Llewellyn, Gwynfa Llewellyn, Michael Fairfield, Sarah McCann, Kathryn Mackney, Katie Ward, Susan Wingrove, Richard Llewellyn, Mr Johal, John Fawcett, Barbara Dobrovolskiy, Thomas Rolf, Michael Elshaw, Timothy Ross, Donna

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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.

£15 was received in memory of [Peter Roberts](#)

£727 was received in memory of [Joyce Batley](#)

£15 was received in memory of [Shane Keyte](#)

£325 was received in memory of [Judy Finch](#)

£105 was received in memory of [Eric Pask](#)

£505 was received in memory of [Mrs. Patterson](#)

£723 was received in memory of [Raymond George Pollard](#)

£199 was received in memory of [Paul Henry Moody](#)

£125 was received in memory of [Robert Mark Berwick](#)

£50 was received from [Andrew Predeth](#) in memory of his late wife [Christine](#)

£328 was received in memory of [Philippa Preston](#)

£79 was received in memory of [Elizabeth Fraser](#)

£100 was received in memory of [Isobel Gray](#)

Special Mention

£3000 was received from [The Sir James Reckitt Charity](#)

Long time SAUK member [Judy Finch](#) kindly left SAUK a £100 legacy

[Rohan Day](#) made a generous donation of £250

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.



Freya walked the Pennine Way, also know as the backbone to Britain, to raise money for charity

[Eugenie Kamas](#) raised £2255 to celebrate her 50th birthday

[Brian Warsop](#) completed the Chesterfield Half Marathon and raised £301

[Collin Wallace](#) completed the Survival Challenge and raised £521

[Anthony Martin](#) raised £674 through Freemason Fundraising

[Alison Barnes](#) raised £125 with fundraising activities at the Hollybush Garden centre

[Laura Campbell](#) has been swimming the length of the English Channel in her local pool and has raised £140

[Darren Raybould](#) raised £548 by getting a Scoliosis support tattoo

[Helen Rayner](#) has raised £340 through her London Marathon fundraiser

[Denise Mott](#) is running 1200 miles this year and has raised £175 to be split with SAUK

[Thomas Taylor](#) has raised £171 through his London Marathon fundraiser



Nathalie Van Der Weide hosted a bake sale to raise funds for SAUK

[Jonny Driver](#) has raised £1080 through his London Marathon fundraiser

[Linda Bryant](#) has raised £527 by baring her back as a model for sketching scoliosis

[Cecelia Jane](#) raised £15

[Waitrose](#) raised £325 with a box in their store

[Notley High School](#) raised £182 by fundraising

[Granite House](#) held an event and raised £67

[Kath Mottram's daughter](#) held a bake sale and raised £50

[Farmors 6th form students](#) completed the three peaks challenge and raised £500 for SAUK

[Gemma Beer](#) raised £112 with a quiz night

[Wolverton Trinity Lodge](#) raised £674 for SAUK

[Mewies Solicitors](#) raised £54 with fundraising activities

[The Rotary Club of Romsey](#) raised £129.14 with their Walk The Testway fundraiser

[Sarah Young](#) held a fundraising pub quiz for SAUK and raised a fantastic £581

[The Brighstone Christmas Tree Festival](#) raised £50 via SAUK member Stephanie Stanley

VIRTUAL FUNDRAISING

Until we can meet again in person, the options for fundraising have been limited because get togethers and outdoor activities should be avoided. There are, however, so many ways that you can become a virtual fundraiser. Fundraising online not only gives you a fun activity to do but also can create new opportunities for online connections while supporting us to continue the important work we do. Below are a few ideas to get you started. Please let us know if you need any help. Good luck to you all!

- Online pub quizzes: We may not be able to go to the pub but we can keep the friendly competition of a pub quiz alive in our own homes. Get your friends to invite their friends and before you know it, you have a whole host of virtual quizzers to donate to your cause (and they get a great night out of it too.)
- Online bingo: Again, this could be a regular event. Email out some cards; use a random number generator and revise that bingo lingo!
- Live Streams: Set yourself a weird and wonderful challenge and use Zoom or Facebook to broadcast it live. Shave it; Dye it; Eat it; Let your imagination go wild!
- Use your own skills: Teach yoga, offer musical instrument coaching, create art or knitwear, host language-speaking lessons, use the skills you already have to bring in those donations, and teach your friends something new!
- Virtual challenges: Use this opportunity to get fit by challenging yourself to some at-home exercises. How many flights of stairs can you climb? How long can you use a skipping rope or hula hoop for?
- Grow a crazy beard or moustache: Use your time in lockdown to grow out that beard, develop a curly moustache, perfect that goatee making yourself look slightly ridiculous is always a great way to get in those donations from friends and family.
- Raise awareness online: Share your fundraising page on Facebook, as well as background about SAUK's mission, and remind people of your own story and the reasons why you're fundraising. SAUK needs your help!

SAUK Fundraiser of the Year

Zygi Kamasa

We are delighted to award Zygi Kamasa Fundraiser of the Year. Scoliosis has played an important part in the lives of the Kamasa family and has affected the family of four in different ways.

On the occasion of the Zygi's 50th birthday, he asked that all presents be donations towards SAUK, which ended up raising an incredible £2255. SAUK is very grateful for this donation and the support of the Kamasa family. These funds have helped SAUK to provide information and support to individuals and families affected by scoliosis across the UK through the Helpline.

Zygi underwent scoliosis surgery in 1986 when he was 17 years old so he knew what the road ahead looked like for his daughter when they spotted her scoliosis when she was 8 years old. She wore a brace from the age of 10, which was difficult and became increasingly so as she entered teenage years. Unfortunately, her scoliosis worsened so when her curve increased to over 50 degrees the decision was that she had to undergo spinal fusion surgery. She is now, thankfully, fully recovered.

"It was wonderful to raise awareness and include all our family and friends in the fundraising and to know that the donations went towards a cause close to our hearts," said Zygi's wife Eugenie.

Facebook fundraisers

Zoe Widdowson	Rosanna Berrows	Lorraine Wilson	Jessica Larcombe	Charlotte Dodd
Toni Cummings	Richard Collins	Lizzy Rowland	Jade Booth	Celia Middleton
Tina Wilson	Richard Aldridge	Lisa Richardson	Helz Chapman	Catherine Smith
Tia Deacon	Prianka Kumari Mistry	Libby Marriott	Hayley Hughes	Caitriona Currie
Tammy Copus	Paris Brown	Laura Campbell	Hannah Challis	Belinda Tricker
Ioana Trif	Olivia Bowes	Laura Hornsey	Gemma Hutsby	Ashleigh Alexandra
Sophie Ingman	Nomes McHugh	Lara Callow	Gary Parks	Arriane Johns
Sophie Bryan	Niamh Dunn	Kirsty Hemmings	Gareth David	Amy Croft
Sharon-Lesley Minta	Tinka Domaracka	Kimberly Fox	Emma Reed Hillen	Amelia Fisher
Shannon Landers	Mike Burns	Katie Stevenson	Emma Sims	Amanda Beers
Shannon Wallis	Michelle Holbrook	Julie Harding	Emily Skinner	Alice Yare
Sam Jarrold	Mia Cheetham	Joy McGeown	Eddie Lowe	Alexandra Cox
Sammi Power	Ma Ryam	Jo Schiff	Danni Pentecost	Alanna Roberts
Ruth Driver	Maria Mackay	Jorja Sehmbi	Claire Shreeves	Adrianna Kinsella-Davies
Ruby Williams	Maria Kouli	Jodie Mangham	Chloe Hammond	Abby McAlley
Ross Taylor	Maisy Fay	Jessica Sayer	Chloe Manley	



Evie gave a talk about scoliosis to her Brownies pack

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

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

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

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

REGIONAL REPRESENTATIVE UPDATES

Martin Symons and Ellen Ross, East England Regional Representatives

Park Radio (Diss)

Park Radio has chosen Scoliosis Association UK as one of their nominated charities for 2020, so invited Martin and Ellen along to talk more in depth about the charity and about the condition live on radio on 13th January. Ellen and Martin are looking forward to working with the radio throughout the year to raise vital funds and raise more awareness of scoliosis and the important work done by SAUK. They will keep us updated throughout the year.



Martin and Ellen at the Park Radio studio



Norfolk Makers Festival

Norfolk Makers Festival was another very successful event where Ellen Ross, Martin Symons, and Linda Bryant were selected by budding artists with the aim to raise awareness of the condition and the charity. Linda Bryant and Martin Symons chose to bare their backs for the event to show off their curves and scars.



Linda Bryant being sketched



Linda, Martin and Ellen at the Festival

Tereza Hayek, North Wales Regional Representative

Presentation to Newport Girls' High School Austen's House Charity Scheme

In November Tereza visited Newport Girls' High School to give a presentation about scoliosis and SAUK's work because the school had chosen SAUK as their charity of the year.

Last year they raised £627.52 for their chosen charity and are hoping to surpass that total this year. The donation will be made at the end of the 2019/2020 academic year.



Sketch of Martin



Sketch of Ellen

LEICESTER PATIENT MEETING



I attended the SAUK patient meeting in Leicester on the 12th October, 2019, in my role as one of the Midlands Regional Representatives; it was my first time attending such a meeting, and I was a bit unsure about what to expect and what the day would entail! We met at the Richard III Visitor Centre, where I was introduced to the day's speakers: the Nottingham/Leicester scoliosis specialist surgeons, Mr Grevitt, Mr Sell, and Mr Yoon.

After this opportunity to chat, we listened to some talks from the surgeons about scoliosis, focusing on the background and types of scoliosis: adolescent idiopathic scoliosis, early onset scoliosis, and syndromal, neuromuscular, and congenital scoliosis. These were all very educational and the surgeons explained the symptoms and management of scoliosis clearly. We then heard from another speaker, Professor Gordon Campbell, who told us the story of Richard III's discovery and how he was kept in Leicester (despite claims from several other cities)!

After lunch, Ann Marriott spoke to us about her role as a scoliosis specialist nurse and the support she provides to patients and their families, particularly around the practical side of what happens when people with scoliosis have surgical treatment. We then had a talk from Suzanne Wake, a specialist anaesthetist who manages patients before, during, and after spinal fusion surgery, about her



job and how she can support patients and their families. (See page 4 for an account of her talk.)

We also formed groups and discussed our concerns and questions relating to scoliosis, which were split into several key themes – it was great to get some clear advice or to just discuss with other members our concerns.

There was also an opportunity to ask questions: discussion revolved around future treatment options for scoliosis (eg, vertebral body tethering), activity restrictions post-op (depending on the patient and specific situation, people should have no restrictions post-op), and having epidurals (should not be a problem after surgery since the rods are in a different part of the spine).

Overall, it was a fascinating day with several key take-home points about the reality of different management options and dispelling some key myths about scoliosis and spinal fusion surgery. It was great to meet everyone, and I look forward to attending more meetings in the future!

Emma Ponyton-Smith,
Midlands Regional
Representative

BT Young Scientist & Technology Exhibition 2020

Back in late November, 2019, SAUK was approached by a teacher in Northern Ireland who asked if we could share her student Eliana's project with our members so she could gather some information on what it's like for adolescents living with scoliosis. This project was going to be Eliana's contribution to the BT Young Scientist & Technology Exhibition 2020. We shared this survey on our Facebook page and Eliana received a great response, so thank you to all our wonderful members who took part! Eliana has written a report to let us know how she got on at the Exhibition.

My name is Eliana Campbell and I am from Donegal in the North-West of Ireland. I recently completed a science project on scoliosis for the BT Young Scientist & Technology Exhibition in Dublin, Ireland. My project was titled 'A qualitative analysis of the quality of life experiences of post-primary students with Adolescent Idiopathic Scoliosis (AIS).'

I chose my topic because I have AIS myself. I was diagnosed in April, 2016, and I had spinal surgery in July, 2018. I now have two metal rods and 22 metal screws in my spine. Obviously AIS has had a major effect on my life as I can no longer play sports, I can't carry a school bag, etc. Having AIS inspired my

Eliana with the Irish Minister for Education Joe McHugh



project and the aim of my project was to really see if or how other teenagers' experiences were similar to mine and to see how they were affected in their daily lives - to give those with AIS a voice to tell the world how they feel.

I began by identifying four areas of interest that I thought would be affected in daily life: 1 school life, 2 home life, 3 strengths or attributes participants felt they gained as a result of AIS, and 4 how they feel their life differs from those of the same age who don't have AIS.

To find teenagers to participate I contacted national and international scoliosis support groups including SAUK. In total I had 11 participants from around the world (Ireland 5, UK 3, USA 3). This was an ideal number because qualitative analysis usually requires around a dozen or so responses.

I analysed my responses and found that school and home life is affected in many ways. 'Pain as a barrier to learning' was the biggest subtheme found in this category with 8 of the 11 participants reporting that pain distracts them in class, and causes a loss of focus and of course absence. There was also a 'Loss of friendship/social interaction as a result of a lack of awareness, support, and understanding of others', which displays the need for there to be a general understanding of the condition among the public. A few participants were even bullied because they had the condition and wanted to 'change; become invisible' and blend into the crowd. Finally, there was a major 'loss of sporting and physical activity' due to a loss of mobility with teenagers having to give up their livelihoods, which is absolutely heartbreaking.

However, there are positive attributes; participants feel as if they have more resilience and a generally more empowered attitude towards life, filled with determination. For example, they want to prove people wrong about their stereotypical associations with the condition. There is an amazing 'change in outlook' too among participants.



Eliana with Fianna Fáil leader Micheál Martin

Having gone through the battle with scoliosis has really put their life in perspective, making difficulties more trivial (feeling like they can get through anything) and that they no longer bother about the small stuff. The participants found they had empathy for others because their experience made them realise that you never know what someone else is going through. I had such an incredible time taking part in the BT Young Scientist & Technology Exhibition. I got to gain new skills by having to complete a scientific write-up and presentation. Having to stand up and present my project in front of anyone who comes by is definitely out of my comfort zone but this experience has greatly increased my confidence.

I met Joe McHugh, Minister for Education, who actually referred to my project in a TV and radio interview, and unbelievably in the opening ceremony. Micheál Martin, Fianna Fáil leader, also talked to me about my project. I met so many amazing people and made friends for life who have similar interests to me. Taking part was a lot of work, and at times I was in pain during the exhibition itself from having to sit/stand too long, but it just shows that even with scoliosis, anything is possible.

HEALTH PLAY SPECIALIST'S ROLE DURING HOSPITAL ADMISSION

By Gail Manning
Registered Health Play Specialist
Northwick Park Hospital



A registered health play specialist uses therapeutic play to support children and young people during a hospital visit, whether inpatient or outpatient, and they can also work in hospices or in the community setting. We work with children and young people to help them cope while in hospital and to understand the 'what and why' of their experience.

To become a health play specialist, you must undertake a 2 year healthcare play specialism foundation degree. The degree covers areas such as the child, family and society, play and recreation, enhancing resilience, promoting health and wellbeing, policy and procedure, leadership and management, health in children and young people, and child development. The course is split between a practical placement and academic study. 200 hours each year are spent working with a mentor (who is a registered specialist and has been practising for at least 2 years).

Throughout the first year the student observes their mentor working and has to pass set competencies. In the 2nd year the student has to put into practice what they have learnt in the first year. To qualify you have to pass both the academic assignments and the practical competencies. Throughout the 2 years the student attends university 1 day a week for lectures and completes several assignments per year. Each element of the course has to be passed for you to qualify. The course is intensive and you need to be self-

motivated.

I undertook my practical training at the Royal National Orthopaedic Hospital (RNOH), Stanmore, and my academic study at Nescot College in conjunction with the University of West London. The RNOH is recognised as a national centre of excellence for the treatment of acute and neuromusculoskeletal conditions in children and young people, and therefore I was very fortunate to be able to train in such a specialised setting. At the RNOH many of the patients I worked with were being treated for scoliosis, which meant working with young children through to adolescents. Some children had been attending appointments at the hospital for many years and others were dealing with the sudden diagnosis of scoliosis in their teenage years. Therefore, the treatment they received varied, from bracing changes every 6 months to spinal operations.

Each health play specialist is unique in the way they work. We all have our own specialties and working practice but we practice under a professional code of conduct set out by the National Association of Health Play Specialist (NAHPS) and Healthcare Play Specialist Education Trust (HPSET). The play specialist may work in a team with a play worker. The play worker is qualified in childcare and offers a supporting role by providing activities, assisting with planning, supporting patients, and working with the multidisciplinary team.

The play specialist's role is varied and no 2 days are the same because

each patient we meet is different and will have unique needs. The play specialist alters their approach depending on the patient's age, developmental stage, needs, family structure, culture, and treatment. They will take their time to get to know the patient and build up trust, so that throughout the patient's stay they have someone to lean on.

When a child is faced with a diagnosis of scoliosis there is a great deal of information to digest, which can be both emotionally and physically challenging. So how can the play specialist help? Play is essential to normalise the daunting experience of illness for children of all ages. It comes in many forms, and we as the play specialist will adapt our approach to the individual's needs. I find that once I begin talking to adolescent patients they are keen to have information explained to them and often open up about their worries. It is important that we don't assume as children turn into teenagers that they don't need our support.

The play specialist can use therapeutic play to prepare the child for surgery, bracing, MRI scanning, or other procedures they may have during their stay in hospital. Real medical equipment, books, videos, adapted dolls, and role play can be used during these preparation sessions. What? Why? Children in Hospital (2019) have produced a range of videos for children of all ages to help them prepare for their hospital stay. I regularly use them and they are very well received.

Preparation gives the child time to work through anxieties or worries



Breathing star, copingskillsforkids.com

and learn coping strategies. It gives them a safe space to express how they are feeling. Simple devices such as a breathing star can be very helpful (coping skills for kids. com 2017). Play preparation helps children understand their illness and treatment, it enables clarity and dispels misconceptions and untruths. Play enables an expression of feelings and increases the ability to cope. Through preparation children and young people can attain a better understanding of those involved in their care, can build up trusting relationships, and can speed their recovery. During preparation children and young people can voice their worries. The play specialist can explain in age appropriate language what is going to happen stage by stage. Preparation also enables parents to ask practical questions, such as where do I wait? Can I stay with them until they go to sleep? Will I be there when they wake?

Work has been published about the needs of children to gather information when undergoing a clinical procedure. Children want to know if it's going to hurt. In our role we always tell the children the truth. We need children to trust us, so when having a blood test or a cannula we will tell the child it will hurt but not for long. Children like to build up a picture in their head of how the situation will unfold. Who will be there in the room? Where will I sit? Will I be scared? Can my mum/dad be with me? What can I do to make it easier? By having this information, they build up strategies to help them cope and they know what to expect during the procedure.

We work with the multidisciplinary

team, so we can share concerns with the team and ensure they are aware of a patient's specific needs. We also share ideas to make the whole experience less stressful and making the children and young people more in control of what is happening.

During pre-assessment appointments patients can sometimes visit the ward. The play specialist will usually show them around, which is a valuable opportunity to build a picture of the environment they will be staying in and who will be involved in their care. When the patient meets the play specialist for the first time, they will get to know them and explain how they can assist during the stay.

Distraction is a further example of the play specialist's therapeutic role. This role can be in the form of play, singing, books, games, or whatever suits the individual in question. One of the most popular distractions with adolescents is their phone and I always get a smile out of them when I tell them they can 'snapchat' their journey to theatre. During recovery the play specialist will be able to give support and offer distractions from boredom and discomfort. You may be surprised by the amount of activities you can achieve from a hospital bed, painting, cooking, slime, card games, and many more.

Syringe and cannula painting



“Play preparation helps children understand their illness and treatment, it enables clarity and dispels misconceptions and untruths”

As part of the recovery from a spinal operation, time spent sitting in a chair is increased steadily, which can be challenging because it's not comfortable. The play specialist can help to make the time go quicker by engaging in an activity with the patient.

Postprocedural play allows the patient to talk through their experience. What went well and what was challenging. Younger children enjoy playing with medical equipment and a soft toy, enabling them to re-enact what they have been through. They will often talk about how they felt and what scared them. By playing through these scary experiences they can come to terms with why it happened. Older patients can be angry or frustrated about why this has happened to them or anxious about school work or their social lives. We can support them by listening and sharing their concerns with the relevant people. We can direct them to support services such as the Scoliosis Association

UK, which has a network of others with scoliosis, telling stories of their journey. While training we encourage many patients to join us in the playroom where they could meet others going through similar journeys. For the younger children who having a brace fitted for the first time or having one replaced we will plaster their toy so that it looks like them, which helps them relate to what's happening to them and enables them to play through their experience.

A day in the life of a health play specialist begins with a handover, which allows us to see who is on the ward, who is having surgery that day, and how patients have been overnight. The play specialist will then aim to see all the patients who are on the morning list for surgery. They will begin by finding out how the patient is feeling and how much information they know. They can then break down the

Patient making rice crispy cakes during bed rest



procedure stage by stage, ensuring the patient understands and has them time to ask questions. They will discuss who will be looking after them, and what to expect on their return to the ward and the following days. If the patient is anxious about a particular stage the play specialist will go through the stage with them and offer coping mechanism to help them through; they can even accompany them to theatre if needed. Throughout the day the play specialist will be supporting children and their families through normalising play, and they will support patients with play preparation, distraction, and post procedural play. They will be involved with playing games, making slime, cooking, reading, crafts, the list goes on! They may also have administrative jobs such as emails to answer, events to organise, attending safeguarding, and multidisciplinary team meetings, training sessions, creating wall displays, ensuring toys are fit for use and cleaned regularly, auditing their work, and updating play plans for long-term patients.

As a newly qualified play specialist in my first role, I love my job. It is incredibly rewarding, especially having the opportunity to help children and young people every day to cope with challenging and scary experiences. I try to bring fun and laughter to the ward, and aim to reduce anxiety for the whole



Creating a plaster cast on a doll's leg

family. I support the doctors, nurses, and other health professionals, with the aim of making the ward a happy, welcoming place. Children attending hospital often have no idea what is going to happen or why. The environment is unfamiliar and clinical and there are lots of strangers asking questions and looking at the patient's body, which can be a stressful and anxious time for parents too in that they may have had long journeys, had to organise time off work and childcare, and be worried about their child's health. Having a play specialist on the ward helps everyone to feel more secure. We aim to be relaxed and friendly, offering familiar activities and reducing anxieties.

Exercising with Scoliosis

Regional Representative for East England, Martin Symons has found his love of exercising and being active again thanks to the support he's had from physiotherapist Scott Rowbotham. Martin has a keen interest in promoting sport for disabled people - in particular, outdoor pursuits and adventures such as climbing, cycling, and canoeing, however ambitious!



Martin in his Boma



Martin on his coast to coast challenge

The Client

I was born with Klippel Feil Syndrome which is a rare skeletal abnormality characterised by abnormal fusion of two or more vertebrae. Features include a short, webbed neck, restricted mobility of the upper spine, and low hairline. I have severe kyphoscoliosis. I also have a growth hormone deficiency and aplastic anaemia. I saw an orthopaedic surgeon throughout my childhood, until I was 18 when I was discharged. The decision was not to do surgery because I wasn't having any problems.

I was a very physically active person up to my early 30's and did horse riding, walking, rock climbing, and canoeing until I had respiratory failure caused by pneumonia in 2001. This was my way of keeping fit and mobile as

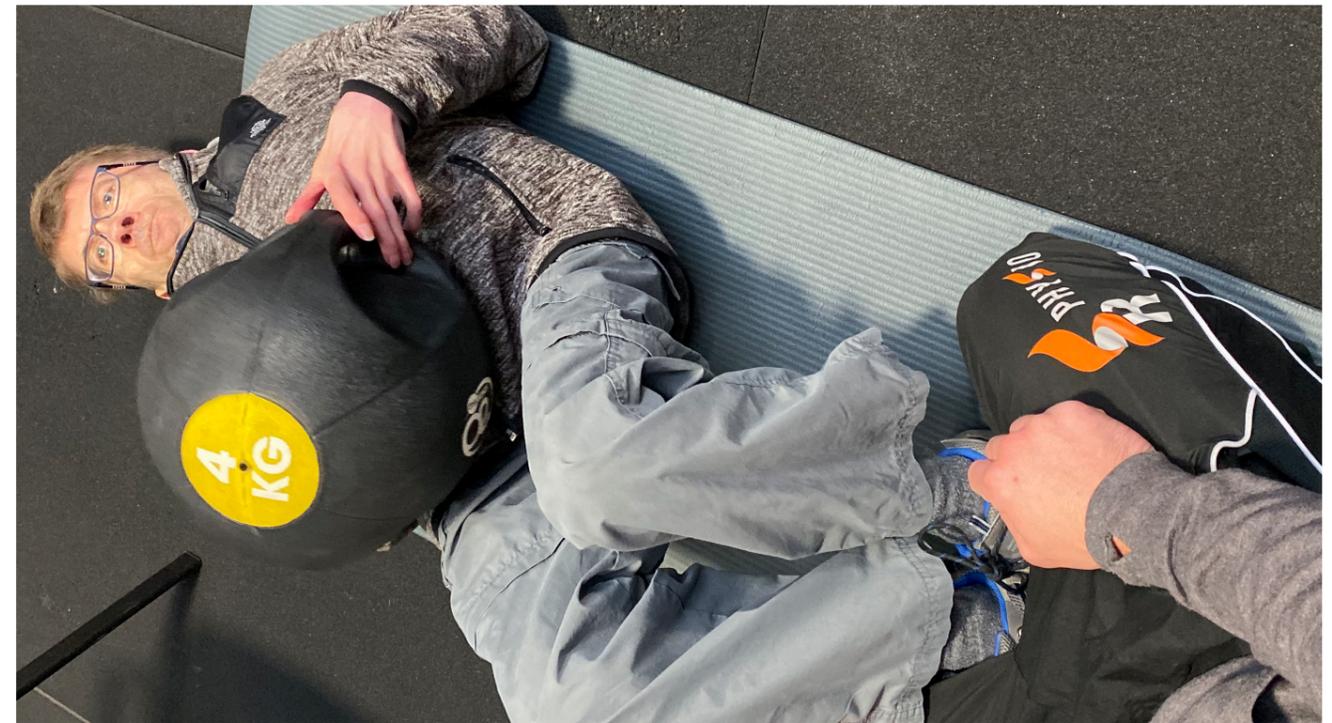
well as fulfilling my love for outdoor pursuits. After I was ill I lost a lot of muscle tone and was quite weak. I had to learn to walk again because of the 6 weeks I spent in the intensive care unit.

5 years ago, I was referred to the scoliosis team at the Norfolk and Norwich University Hospital because I noticed my scoliosis was getting worse. The strange thing is that unlike the stories you hear from others who have scoliosis, I don't get much pain. As a result, there was nothing they could do because of everything else I had wrong. If they did, they'd have to break my spine in several places and I'd be in the hospital for weeks if I survived the operation. It was agreed that the best thing was to have a mould made for my wheelchair. The priority was now to

maintain the mobility I have left.

Massage therapy is the one thing that works for me, both physically and mentally as well as being relaxing. I've been to the gym on the odd occasion but not really worked out. I saw a physiotherapist once but like all NHS physiotherapy you only get 6 weeks and I didn't keep up the exercises. It was a motivational thing – or lack of.

Last September I found out about a charity in Norwich called Able2B. It provides sessions such as boxing and other activities for disabled people. I booked a consultation with a physiotherapist Scott. I then started a weekly session of what is not I believe your conventional physiotherapy. This is like going to the gym but with a



personal trainer who would work with you for an hour. You do have to pay, but you have to decide what's important. In November I saw my respiratory consultant and because my spirometer test showed that it was the best since 2015, he encouraged me to continue.

The Physiotherapist

My name is Scott Rowbotham and I am a specialist physiotherapist and director of SR Physio who works with adults and children with long term conditions. Because of my background in sport, and having a degree in sports rehabilitation, I take great pleasure and try to focus my time in helping everybody exercise. Scoliosis has been a condition I have particularly enjoyed helping people to manage.

I have helped people with scoliosis improve their confidence to participate in exercise and physical activity, and to reassure them that they can exercise and that under the correct supervision it is safe to do so. Both physical function and respiratory function are of paramount importance for all with scoliosis and therefore exercise must be promoted in any way, no matter how small or intense.

If it is difficult for people with scoliosis to access suitable physical activity then home exercise programmes are also an excellent way to prevent discomfort from inactivity, maintain muscle strength, range of movement, and comfortable sitting and standing postures.

I am now fortunate to help run Able2B gym – as one of the four volunteer directors I take great pride in working at a unique setting where exercise classes and 1:1 exercise sessions are adapted for all individuals. We have proven that aerobic exercise (exercise focused on the cardiac and respiratory system) and anaerobic exercise (short bursts of exercise for muscle development and strength) can be done by all.

My top tips for exercise:

1. Little and often. We know that simply walking is very beneficial for a multitude of markers for health and can prevent sedentary behaviours that can be very detrimental to us. Trying to exercise in short bursts will feel more achievable, less daunting, and less strenuous, making it far easier to convert it into a habit for long term benefit.

2. Do what you enjoy (or hate the least). If you choose something you think you will enjoy or have enjoyed previously it will make it much more likely that you will consistently take part in physical activity.

3. Make it social. Not only will it make you feel guilty if you don't turn up to see your friend, team, etc. but also social interaction with physical activity is proven to have excellent benefits for mental health and wellbeing, and therefore is a fantastic venture for all.

4. Seek professional advice. Exercise can be very daunting, particularly for those who may have not had an easy journey through physical education, with peers and teachers potentially not understanding their needs or how to adapt to them. Medical professionals can signpost you to appropriate places where you can exercise and what form of exercise.

5. Set yourself a goal. A goal will give you a focus that currently may not seem achievable but given time and consistency can be achieved and will maintain motivation in your pursuit to exercise.

Taking care of a child in a cast

Emma's son Bertie was born with a 34 degree curve, which is regarded as severe in someone so young, and had progressed to 55 degrees before casting was advised. After 22 months in a cast his curve has reduced to 30 degrees. Emma shares her advice for taking care of a child in a cast.

Introduction

When Bertie was born, I instinctively knew something wasn't quite right with his back. Babies are so scrunched up when they're born that I was hoping it was just that and not something more serious. He had all the standard baby checks and everything came back as normal so I tried to put it out of my mind. When he was 12 weeks old, he was admitted to hospital with an infection. One of the nurses who took him for a lumbar puncture asked if I was aware of any problems with his back – I wasn't. When the consultant came to see us, I asked her to have a look at Bertie's back – I was petrified but knew it was the right thing to do. There was no going back and I had no idea what may happen. She examined Bertie and I heard the word scoliosis for the first time – his suspected diagnosis. I had heard of the condition but had no idea about what it really was and what it meant for the future.

When we first saw the spinal surgeon, we were told to watch and wait until Bertie turned one as they were hoping his spine might correct itself as he grew. When we returned, we were told that



Emma, Bertie and Eva

his curve had not corrected and had in fact progressed. He was measured for and fitted with a removable brace at the age of 14 months.

Fast forward to January, 2018, when Bertie was 18 months old and I was given the news I was dreading; Bertie would be upgraded from a removable brace to a permanent plaster cast jacket (POP) jacket. His curve had progressed again. I was shocked, worried, upset, panicked - a whole range of emotions. I had no idea what to expect. How would he cope? How would I cope? What effect was this going to have on us? Nappies, clothing, washing - what was I going to do?

I started researching but since casting is fairly rare, I struggled to find the answers I was looking for. Our casting journey so far has been a massive learning curve for Bertie and I, as well as his older sister Eva (who is 5 years old) and we're still learning as we go along.

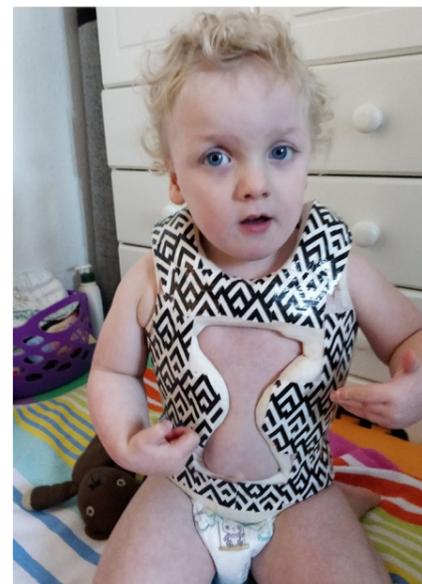
Casting Process – what happens?

We arrived on the ward at the Royal National Orthopaedic Hospital in Stanmore at 7am the day of casting. Bertie was checked over by the nurses, paediatricians, the spinal team, and anaesthetists. He's usually first on the theatre list because of his age and we usually head down to theatre about 9am as soon as we've consented to the procedure.

I stay with Bertie as he's put to sleep in my arms, I then hand him over to the anaesthetist and leave theatre. This

is when I head to the restaurant for breakfast - usually a fry up - it's the only thing I look forward to on casting day! It's a long and busy day so I've realised to eat in peace whilst you have the chance is the best thing to do, plus it takes my mind off things whilst he's under anaesthetic.

Whilst in theatre Bertie is put in traction (a big metal frame that looks a bit medieval) and his spine is manipulated into a better position. He is then wrapped in Plaster of Paris. The cast looks like a vest, it has shoulder straps, is solid all the way down the back, has a cut out for his tummy and chest and goes down to the tops of his thighs. The process normally takes between 1 ½ and 2 hours but can vary and is longer if he is also having an MRI/CT scan. Once he's in recovery the nurses take me down to meet him and as soon as they're happy with his observations and breathing we are taken back up to the ward. He then has



Bertie with his old casts

regular observations - every 15 minutes for the first hour then hourly after that. He can eat and drink as soon as he's ready and this is monitored by the nurses. Once he has passed urine his canula is taken out.

Then it's off to plaster theatre for the team to check that the cast is fitting correctly and it's not irritating his skin. We check that he can sit up unaided and often the cast needs trimming a bit at that point to enable him to do so properly. They can also flare out the cast if needed and I usually ask them to do this around his tummy and chest hole. Finally, we go for an X-ray to check his spine is in the correct position in the cast. Once this is all completed – usually around 5pm - we are discharged and can go home.

Advice & Tips

The biggest challenge with casting is keeping the cast dry and clean. If the cast gets wet it can alter the shape and therefore affect its viability. If it ever gets damaged it has to be removed and replaced, with the same long process in hospital – it is stressful and time consuming.

There are various tips I've picked

up on our casting journey so far – mostly through trial and error. I always buy a size up on tops because they have to go over the top of the cast. A larger size isn't always necessary for trousers; I find if the trousers have a stretchy waist the same size is normally ok. The casts can vary in size and shape so I tend to go shopping soon after a cast fitting rather than before.

I buy nappies with extra absorbency and size up for nighttime. I put them on under the cast and tuck them up as far as it will go. When Bertie was younger and passing urine more frequently at night, I would tuck a reversed nappy around the belly bar for extra protection. For our first cast I was told by the plaster team to set alarms throughout the night to check his nappy. I did this for the first cast and some way through the second but then I stopped because I was exhausted and had realised by then that he would generally pass urine just before he woke up! In the case of a tummy upset I will tuck an extra nappy up the inside of the cast as far up the back as I can get it.

I always buy bibs with waterproof backing for eating/drinking, I also find neckerchief bibs handy to ensure no crumbs fall inside the cast

(in winter I tend to automatically put a neckerchief bib on with his clothes first thing in the morning and leave it on). I use a painting bib for any messy play but honestly, I try to avoid messy play altogether. Activities like this can damage the cast - especially if he's only just had one applied. I also use duct tape to give the cast an extra layer of protection, especially since the tape is waterproof.

If I suspect any crumbs have fallen down the inside the cast, I floss it with a pair of tights. I will floss occasionally anyway; Bertie loves it but I have to be careful not to overdo it as his skin is very sensitive underneath the cast and the last thing you want is any sores developing.

Items I can't do without:

- Waterproof bibs
- Duct tape
- All in one rainsuit/ waterproof (we also have to be very careful when out in the rain, especially if it's torrential)
- Bodysuits with poppers under the groin (this helps to keep the nappies in place)

Washing is extremely tricky; Bertie is obviously not allowed a bath when he's in the cast so I have to wash his hair at the kitchen sink! I layer a waterproof bib, children's hairdressing cape and towel over his cast, then lay him on the kitchen draining board supporting his neck over the sink, I then wash his hair using a sponge and bowl of water. I then twizzle him round and let him dip his feet in the bowl (he's learnt not to splash too much) and sponge his arms and legs. In between washes I have Nilaqua towel-off shampoo and body wash, which are excellent for a quick and easy freshen up.

In the summer the heat can be really tough on Bertie. The cast acts as a lot of layers so I have to keep him as cool as possible. I looked into buying a cooling vest but they

Helpful resources

I've found a few forums on Facebook helpful, such as a couple of American-based groups which have the most information about casting.

- Parents of Scoliosis Children UK – this group is mainly used by parents of teenagers going through the surgery stage
- Congenital Scoliosis Support!
- Early Onset Scoliosis and Mehta Casting



“the strength my son shows dealing with it all constantly amazes me”

are very expensive so I came up with my own invention - a swim vest with removable floats that I replaced with medical gel ice packs. It works a treat and Bertie loves wearing his special vest.

Adjusting

Bertie took about a week to adjust to his first cast. He was very grumpy initially but adjusted much more quickly than I anticipated. Each subsequent cast takes about 2 days to adjust to normal. His balance can be quite off whilst he gets used to the new shape and weight of each cast. Bertie has additional medical diagnoses and was unable to walk before his casting journey began. Now at the age of 3 ½ he has started to take independent steps although he is still very wobbly and is unable to walk on uneven surfaces.

Although the cast stops him from doing certain things, he has managed to still do most 'normal' activities like climbing up on everything at home! I try not to stop him from doing things but there are restrictions on certain activities, he's not allowed to go on bouncy castles or trampolines.

Because he's so off balance I have to be constantly aware of his surroundings - if he falls, he falls hard and could really hurt himself. I also have to be careful of other children around him in case he falls on them, which could really hurt them because of the weight of the cast (each one weighs between 1 ½ and 2 kgs!) and the fact the cast is solid - I'm constantly covered in bruises!

Sleeping

I've not noticed a huge change in his

sleep since we started our casting journey. To begin with he was clearly uncomfortable overnight and the regular checks on his nappy disturbed him. He has sleep apnoea and some ear/nose/ and throat issues so often has disturbed nights anyway. I was advised it may help to switch to a memory foam mattress but I didn't find this necessary and was concerned that with the weight of his cast he may find it difficult to roll over in his sleep if he sunk into the mattress.

Summary

At the start of our scoliosis journey, Bertie's curve was 34 degrees (severe in someone so young), and as we started our casting journey his curve had progressed to 55 degrees. All his X-rays so far have been lying down since he can't stand for long enough, which means his curves readings are probably better than if he was standing. Bertie has been casted for 22 months so far and he is now holding at about 30 degrees in cast but he is yet to have an out of cast X-ray. It's been quite the journey for myself, Bertie, and Eva and I know this is just the beginning. I know it's the best thing for Bertie but it's hard. It's difficult not knowing what the future holds and that's the worst thing about scoliosis, it's so unpredictable and everyone's situation is different. The thing is, when you're a parent going through this, it is so tough but the strength my son shows dealing with it all constantly amazes me.

If anyone would like to contact me, please let SAUK know and they can pass on my details.

Emma Elliott

Mehta casting for infantile scoliosis - a parent's perspective

Donna and Jody's baby, Charlie, was just 3 ½ months old when he was diagnosed with infantile scoliosis. They waited anxiously for another 3 months to see if his scoliosis would self-resolve, but unfortunately it was progressive. They have shared their insight into the casting process and treatment with us.

Finding out that our tiny little baby had a potentially life-threatening condition was absolutely devastating... Charlie was just 3 ½ months old when he was diagnosed with Infantile scoliosis. There was an 80-90% chance that his curve could self-resolve, so we hoped and prayed that the odds were in his favour. We were advised by the consultant to wait and watch for the next 3 months.

Unfortunately, the second X-ray 3 months later revealed that Charlie was in the 10-20% of cases that were progressive. At just 7 months old Charlie's curve was at 42 degrees. Charlie required treatment immediately. As parents we were so scared. We were afraid of the unknown, and what lay ahead for Charlie. We were told



that Charlie needed to go into a plaster jacket immediately. The aim of this jacket was to try to hold the curve until Charlie would be old enough to assess the need for spinal surgery.

“Charlie never let anything get in his way”

After many days and nights of tears, we began to research and discovered a treatment that could potentially correct the curve in Charlie's spine, instead of just holding it. We contacted Shriners Hospital for Children in Philadelphia, and Charlie was soon accepted for treatment using Mehta's Growth Guidance Casting (MGCC). During the first 2 years of life the human body grows at an extremely rapid rate. MGCC harnesses this vigorous natural growth as the corrective force and creates the possibility for young spines to grow straight three dimensionally.

At just 9 months old Charlie received his first Mehta cast under general anaesthetic. I won't lie... it was a huge adjustment for not only Charlie, but for us as parents too. Charlie had no idea why his little torso was wrapped in hard plaster. It was now up to us as

Charlie's parents to help him adjust and make him as comfortable as possible. Those first few days and nights were rough. Charlie cried, and we cried with him. But after those initial few days it soon

became apparent that Charlie had accepted his new 'norm'! Yes, life is different for a child in a plaster cast, but I can assure you, it certainly won't hold them back! Charlie had 12 Mehta casts over 26 months, and he never let anything get in his way!

Waking up in the recovery room, Charlie was always upset. He had a brand new cast in a colour of his choice and the team at Shriners quickly tidied the cast up, ensuring there were no rough edges that would irritate his skin. We always kept a bib on him in case he was sick after coming around from the anaesthetic so this kept him and the cast clean until we got him dressed. We always made sure to check the cast over thoroughly before we left, just in case any adjustments needed to be made.

After Charlie got his first cast, we wanted to make sure he had a car seat that was comfortable. Each

“Cast life is challenging but it’s doable”

child and their cast is unique, and what car seat may work for one, may not work for another so I would definitely recommend waiting until after the first cast is applied before deciding on a car seat. We chose the Cybex Sirona car seat which fitted him perfectly, and we’ve had it for 4 years now!

Charlie learned to crawl in cast and he learned to walk in cast. I was always nervous for the first few days of each cast, because he could be a little off balance. With each new cast he had applied, he had a new centre of gravity. And once he adjusted to that his balance was perfect, and then I could relax a little more.

When we got back home after each trip, we got Duct tape and decorated Charlie’s casts. This made them a bit more fun and colourful, and it also made them wipeable too - this was great, especially with a messy toddler! At mealtimes, we always used Bumpkin bibs on Charlie, so as not to get any crumbs or food underneath the cast and to keep him clean. We



always had to be extra careful that nothing got in below the cast. In the event of this happening, unnoticed by us, it could cause skin irritation or breakdown. In some extreme cases, skin breakdown can lead to extra time out of cast, which therefore delays treatment. Thankfully throughout our 26 months of casting we never had any unwanted objects in below the cast, nor skin breakdown either.

At times, Charlie would get itchy and loved getting his back scratched but we just couldn’t reach down and scratch his back, so we had to improvise. We cut the leg from a pair of fine ladies tights, and threaded this underneath the cast. Charlie lay on his belly while I ‘flossed’ the material up and down. This helped to relieve any itch that Charlie had, and it also removed any crumbs and dirt that were under the cast. Charlie absolutely loved this too!

Bath times were not always fun. When Charlie was little, it took two of us to bath him. I held him in my arms while Jody washed his hair and body. Poor Charlie screamed every time, and over time, he developed a fear of the water. As he got older and heavier, we washed him at the kitchen sink. We rolled a towel up and put it under his neck so we could wash his hair, again he hated this. But we tried to make it as fun as possible with all sorts of bath toys. We sometimes let him sit on a chair in the bath so he could splash his feet and play. But with the cast, we had to be so careful not to get the cast wet. Any water near the cast could compromise its integrity.

Charlie’s casts were changed every 8 weeks under general anaesthetic.

Tips:

- Duct tape is great for decorating the cast but is also useful for making it wipeable
- Bumpkin bibs are great for making sure crumbs don’t get under the cast during meal times
- A pair of tights threaded underneath the cast is a great back scratcher and way to get out any crumbs that may have fallen down
- During the break between cast changes Aquaphor was great for soothing the skin
- Feeding little and often meant Charlie’s stomach didn’t expand too much under the restriction of the cast
- Using two nappies, one tucked under the cast and one over to hold the other in place meant we were mostly accident-free

We removed the cast 48 hours before he was due to get his new one, and then he was allowed to take a proper bubble bath. We applied lots of Aquaphor to help take any redness or bruising out of his skin, and to prepare it for the next cast.

Over the 26 months that Charlie was in cast, he developed very strong little legs. He used his legs a lot to get up and down from the floor. His movement around his torso was restricted, and he couldn’t twist left or right, or bend forward or back. His flexibility and range of motion was limited but he adapted, and did things using the range of movement he had.

Charlie was always a fussy feeder. He never really wanted to eat. But with being in cast, we had to feed him little and often. His little tummy was restricted by the plaster, so he couldn’t eat very much, and if he did eat too much his little belly would swell making



him uncomfortable.

I never thought I’d say this, but we are lucky here in Northern Ireland that our summers aren’t too hot! While Charlie was in cast, we had to make sure that he didn’t overheat. He wore fewer layers than his siblings during the warm weather because too many layers could cause him to overheat. If it did get too hot, we just kept him indoors. But thankfully there weren’t too many days like that, and he was still able to get outside and play with his brothers and sister.

Charlie was still in nappies while he was in casts, which was something completely new to me, and I had to try and figure out what would work best for him to keep him clean and dry, and to keep the nappy on. It took a bit of trial and error before I finally mastered what would work for us for the next 26 months. I always changed Charlie on my knee and we used two nappies: a small size, which I took the sticky tabs off the sides and tucked under the belly bar at the front and under

the back of the cast. Then I used the next size up nappy, and put it on over the top of the smaller nappy, and over the outside of the cast, and this held the smaller nappy in place. It wasn’t just a straightforward nappy change, but it worked for us, and thankfully we didn’t have many accidents over the 26 months.

Before Charlie began his casting journey, we were scared and afraid of the unknown, and of course it’s only natural to feel that way. But Charlie adapted to life in a plaster cast like a true warrior and we as a family adapted with him. Cast life is challenging but it’s doable!

Each unique Mehta cast that Charlie had applied, allowed his little heart and lungs to grow and fully develop. It held his little spine straight, and guided it to grow straight. Mehta casting saved Charlie’s life.

You can follow Charlie’s journey on Facebook: @Charlie’sJourneywithInfantileScoliosis.

Editor’s note. This technique was developed and practised by the late Miss Min Mehta, FRCS, at RNOH, Stanmore. Min was a long time Trustee of SAUK and is much missed by us and the many patients she cared for.



Donna Ferris

ISOBEL GRAY AWARD

Ellen Ross and Martin Symons

The Isobel Gray Memorial Award is presented each year to a person, or persons, who have made an extraordinary contribution to the work SAUK does. This year is no exception and we are delighted to award Martin Symons and Ellen Ross the Isobel Gray Award for 2020. Martin and Ellen are two of our East England Regional Representatives and are somewhat of a dream team!

Ellen has been a Regional Representative for just over 2 years now and has thoroughly enjoyed her time volunteering. Ellen said, 'I have so much passion and this amazing charity is really close to my heart. I am immensely proud of what we have achieved so far. It's truly been an honour to represent SAUK and I'm looking forward to seeing what the future holds.'

Martin has been a Regional Representative for some years now, raising awareness through word of mouth and other networks he belongs to.

In July, 2019, Martin undertook a 10th Anniversary ride across England using an all terrain wheelchair called a boma and raised £400 for SAUK.

In January, 2020, Ellen and Martin went live on Park Radio (Diss) to talk about SAUK and how important it is to continue raising awareness and funds. The radio station has chosen SAUK as one of their nominated charities for this year, which is incredible. Ellen and Martin will be working with them throughout the year with the aim of raising much needed awareness and funds.

In February, 2019, Ellen and Martin attended the Norfolk



Martin and Ellen with their Isobel Gray Award certificates

Makers Festival where they were sketched by members of the public and spoke about the work SAUK does. It was such a success that they attended the event again in February, 2020.

Watch this space to see where Ellen and Martin's journey takes them next!



Ellen (right) and Martin (middle) at Park Radio



Martin (middle) with his boma and support team during his Coast to Coast Challenge. (See page 20)

ROLL OF HONOUR



Calum Park

Nominated by Leigh Park

Calum is 16 years old and was born with congenital scoliosis with multiple abnormal vertebrae. He was also born with a learning disability, delayed speech, and stunted growth/premature puberty. We tried to keep life as normal as possible for Calum growing up but it was difficult since we had no support in respect of his scoliosis.

Unfortunately, his spine deteriorated and he developed kyphosis. He got involved in a programme called 'Straight to Swimming'. During this time at the scoliosis swimming club he not only pushes himself with his swimming, but also he has reassured other kids who have been newly diagnosed. Calum was placed on the 'urgent' waiting list in May, 2017, but he still waited a full year for surgery. During this time the kyphosis doubled, leading to breathing issues, severe pain, depression, and bullying. He again battled on and still helped other kids.

In May, 2018, Calum had his surgery. He was in the theatre for 10 hours and unfortunately he had multiple signal loss. They stopped the operation and he had to lie flat and

still for 7 days with only his screws in place. This was difficult, but he tried to smile through the pain and constant vomiting. Calum then went back to theatre and had his rods inserted. The problem was that the rods were bent around his severe kyphosis and he has now been left with 4 of his 16 screws very prominent and is only 5 foot fully grown. His lack of sleep drains him throughout the day, and he only gets relief from discomfort, muscle, and pressure pain by having a long bath every night. This routine also helps his brain to 'switch off'.

He has accepted what has happened to him and still continues to be a support to others. We are part of a support group called Scoliosis Support Belfast, and we meet up with other patients and kids for coffee and treats. We both support these frightened families starting their journey.

My wee warrior is amazing, but he doesn't even realise how brave he actually is. He pushes himself to attend Mencap a few nights per week, even though he is exhausted. He is loved by so many people and is very, very special.



Tilly Richards

Nominated by Lisa Richards

My daughter Tilly Richards is 13 years old. Tilly had the surgery in June. She has struggled with recovery but is so strong. The hurdles that have been thrown at her have made her so determined to get through this time. She has gone back to school and has been an inspiration to her school friends and family. Tilly raised over £200 before her surgery for SAUK. She wanted to make sure she could have the surgery operation and know she has helped a little for other boys/girls in the same situation. It is such an amazing achievement to get through this treatment and encourage others that they can do it too and stay positive. I'm so, so proud.

Kate Mottram

Nominated by Kath Mottram

My daughter Kate has had severe congenital postural scoliosis. She has struggled every day of her life with what we thought was global development delay. She has endured years and years of physiotherapy to help her learn to sit up and walk, from when she was an infant. We saw specialists time and time again to figure out why Kate was struggling so much, especially with her physical development. Her doctors just put it down to a delay in her development, but the specialist couldn't tell us why Kate wasn't hitting her milestones.

At 11 months old, Kate still had a bad head lag and she didn't sit up until she was 16 months old. We were also told that Kate wouldn't ever walk or talk or even recognise us as her parents. Kate has always found life a challenge, but she never gave up. She did learn to walk when she was 3 years old, speech came later. Then when she was 11 years old her spine began to curve and she ended up with an 85 degree curvature, and that was back in 1999.

She had her 11-hour operation early in August, 2000, just days before her 12th birthday, to insert two titanium rods down her spine to stabilise the scoliosis. She was in hospital a week and a half, and it was one of the hardest things that Kate's Dad and I have had to cope with. We had just had our second baby daughter who was only 7 weeks old when Kate had her surgery.

The month before Kate's operation was so stressful. Each week we noticed that she was getting weaker and she was so fragile. She couldn't eat without being sick. Her weight plummeted to under 5 stone before her major surgery. Kate also has Asperger's Syndrome, which was made worse by all the stress and pain that she was experiencing.

Now, 19 years later, she still suffers greatly with pain and unfortunately, not all her spine could be straightened. Her right shoulder blade is very prominent compared with her left side. But thanks to her spinal surgeon, she is still here for us! We now know it was the scoliosis that caused Kate to struggle so much as a baby, but her surgeon saved her life.

As a family, we are all so extremely proud of all that Kate has achieved. She is a wonderful daughter and sister, kind, wonderful, and gentle, and we love her to bits.

Gabriella Winton

Nominated by Angela Winton

After being diagnosed in September, 2018, and subsequently operated on in December 2018, it meant that my daughter – 13 at the time – had to give up her place at SNAGS (Scottish National Age Group) Swimming Competition. Only the best swimmers from all over Scotland qualify and she was gutted at having

to pull out.

However, by July, 2019, she was back training – starting with a week's swim camp at Lanzarote. She then completed her first gala 11 months after surgery and won a Bronze Medal in 100-metre breaststroke!

I believe my daughter deserves this recognition because she has shown that anything is possible – despite major, life changing surgery, you can still go back to doing everything you could before – and hopefully be an inspiration to anyone going through a similar experience.



Lyla Copeland

Nominated by Belinda Copeland

I would like to nominate my 12-year-old daughter Lyla.; she was diagnosed with scoliosis in February last year presenting a 79 degree curve. We were referred to the Royal National Orthopaedic Hospital in Stanmore, where we went for surgery, but the operation had to be deferred because activity was lost because of a problem identified by spine monitoring. She was very sick the next few days and was blue lighted to Great Ormond Street where a surgical team was waiting to bring her to surgery. It turns out that her stomach had been punctured twice during the spinal fusion, so she was in ICU for 2 days on a ventilator before going to her own room on the ward.

The following week she was back in surgery again and 4 weeks later we are still here but things have improved, and we hope to go home to Northern Ireland next week. It's been a complete nightmare and she has been through so much but has already greatly improved and is stronger than she will ever know.



Lucy Thompson

Nominated by Marianne Thompson

My daughter Lucy Thompson was diagnosed with adolescent idiopathic scoliosis in August, 2017. This year on 6th February she had aAnterior sSpinal fFusion at Bristol Children's Hospital. She has a fantastic positive attitude which that has boosted her recovery to no end. She has worked so hard to catch up at school, I am so very proud of her.



Jake Tomkiss

Nominated by Rebecca Rainbow, Joanne Tomkiss, Sally-Ann Burton, Lane Tomkiss and Carol Tomkiss

Rebecca Rainbow - Jake is an incredible boy who shows outstanding courage every single



day. Jake visits his dad in the workplace and is a confident, kind, and caring little boy to anybody he comes in contact with. He understands that his treatment for scoliosis provides limitations, but he continuously challenges the norm with the aspirations he has. Jake is a fighter, and an inspiration to any other child with scoliosis. Jake – your dad is so proud of you and speaks fondly of your bravery and achievements every single day.

Joanne Tomkiss- Since a very young age my son has been fighting so many complex health conditions. He was first seen about his scoliosis when he was 18 months old and at that time, the doctors decided to just keep a close eye and review. Jake's scoliosis deteriorated rapidly, and he was given his first spinal brace at the age of 2 years. We went for regular checks until 14th February, 2017, when it appeared that the brace was no longer supporting him. He was taken into a ward on this day and was taken to theatre to have a plaster of Paris cast fitted.

It was apparent within a matter of hours that this wasn't going to work for Jake. He couldn't stand up let alone walk and he was tilting to one side. The decision was that he would need to have surgery a lot sooner than planned. After lengthy chats

with the scoliosis team we opted for the Trolley system and this was scheduled for 10th October, 2017, just 3 days after his 4th birthday. Jake underwent his 12 hour operation as planned but had complications during surgery. This surgery sadly failed and by August, 2018, just 2 weeks after his dad and I got married, we were back for operation number two, this time for Magec rods. This operation has been successful so far and we will continue to keep our fingers crossed. Jake has been the most incredible, brave, happy little boy throughout everything he has faced. He continues to make us proud every day and no matter what he faces, he continues to do it with a smile on his face and an amazing amount of bravery for someone so little.

I think Jake deserves this award for all the above and for the amount of care he gives for other people who go through different situations. He may be only 6 now but his bravery and his positive attitude are what has helped get him through this tough time and I am a super proud mummy. We still have a very long road to face but we will continue to do this together.

Sally-Ann Burton - Jake has had to have several corrective operations already, one of them life threatening. I have scoliosis myself

and understand the complications and pain management related to this condition. Jake is always smiling and tries to make the best of each day.

Lane Tomkiss - Jake is 6 years old and has already had two operations on his spine. He is a brave little lad who doesn't let it get him down even when he's restricted in what games he can play with his friends.

Carol Tomkiss- Jake is only 6 years old and has had several operations on his back, but he never lets it get him down. He's always smiling even though he can't do a lot of things that other boys his age can do. He is a very brave little boy.



Morgan Elshaw

Nominated by Melanie Elshaw

Morgan was so brave when she found out she had Chiari 1 malformation and had decompression surgery in June, 2019. She had cerebrospinal fluid (CSF) leakage and went back into hospital on two more occasions and back into theatre.

She has been a true inspiration and has committed herself to catching up on her studies since she is in year 11 and has her GCSEs this year. For the future, Morgan's ambition is to perform on the West End stage, because musical theatre is her passion. Unfortunately, her dancing, singing, and acting have had to stop temporarily whilst she is recovering. She is a very determined and focused young lady and will continue to work hard to achieve her goals in life.

About the BSRF



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

Each year the BSRF funds research into scoliosis, and it holds an international symposium every 2 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.

New research

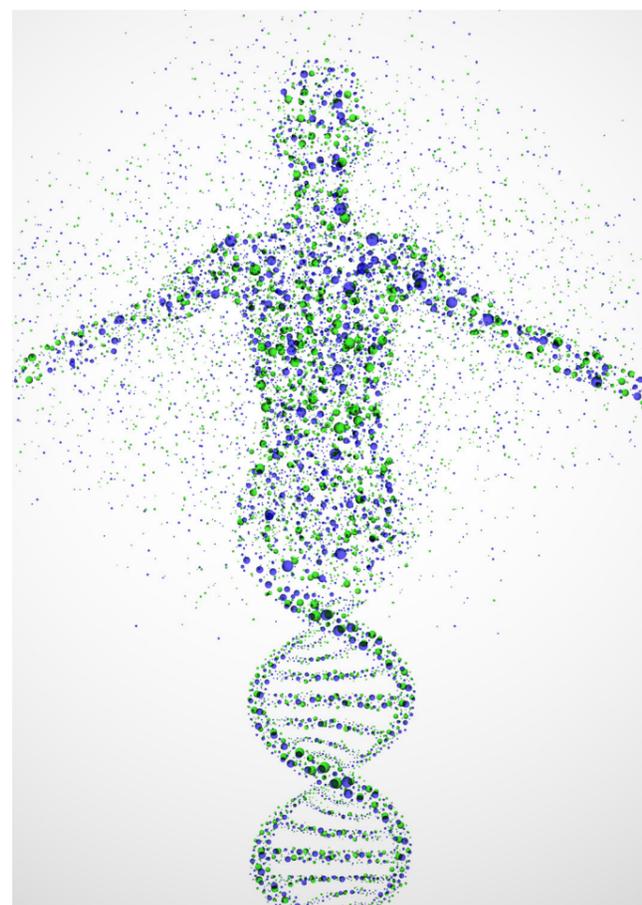
BSRF has invested donated funds into some exciting new research projects for 2020. One of those is a project by Lisa Graham Wiesener & Paul Toner from Queen's University, Belfast. This study aims to engage with patients with scoliosis, family members, and healthcare professionals to generate a comprehensive and meaningful long list of candidate outcomes for spinal surgery.

Stephen Joel Lewis and Nasir Quaraishi from Queen's Medical centre, Nottingham, also received a grant to develop research into understanding and managing intraoperative neuromonitoring (IONM) changes during surgery for scoliosis. Much controversy exists in managing IONM changes. The aims of this research are to determine whether patterns of spinal cord injury could be detected through IONM changes, distinguish causes related to perfusion versus direct trauma, observe effects of interventions done in response to changes, and establish evidence-based algorithms in managing IONM alerts.

Judith Meakin and Andrew Clarke from the University of Exeter aim to assess shape differences between scoliotic and normal vertebrae with their grant. This project builds on previous BSRF funded work to develop reliable methods for comprehensively characterising vertebral shape. They hypothesise that they will identify novel differences that they can subsequently use to understand initiation and progression of scoliosis.

Scoliosis Priority Setting Partnership

In 2019, we completed the Scoliosis Priority Setting Partnership from which we 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.



SCF - THANK YOU

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



Donations

A huge thank you to our generous donors:

- Vicki Morrison
- Dr Duncan Wilkins
- Antonia Phillips
- Eughim Chua
- Elaine Mayall
- Caroline Lane
- Tracey Gumbrell
- Carole Taylor



Fundraising

Aimee Templeman skydived at age 15 and raised £921

Marie Zorab complete the Birmingham Great Run and raised £700

Richard Aldridge completed the alpha wolf run and raised £12

Colin Wallace completed the Survival Challenge and ran a raffle raising £642

David Fisher is part of the SCF London Marathon team and has raised £950

Kellie & Rod Townes are part of the SCF London Marathon team and have raised £2537

Shaun Lawrence completed the Washington Forge Rotary Swimathon raising £100

Anton Perkins is part of the SCF London

Marathon team and has raised £1199

Felicity Price's daughter did a Bake Sale and raised £319

Katie Goodchild is part of the SCF London Marathon team and has raised £1078

Louise Laurie is doing the Manchester Marathon and a Machu Picchu trek and has raised £441

Gemma Russell is doing the Great Bristol 10K and has raised £378

Francesca Calnan is part of the SCF London Marathon team and has raised £509

Adam Chilton is part of the SCF London Marathon team and has raised £82

Haydn and Ashleigh Davies are doing the Eastbourne Triathlon and have raised £408



MORGAN'S STORY

Morgan Elshaw was diagnosed in December 2017 with Adolescent Idiopathic Scoliosis which came as a huge shock to her and her family. She shares her journey from diagnosis to recovery in the hope it will reassure others that they can get through this too.

Morgan Elshaw was diagnosed in December, 2017, with adolescent idiopathic scoliosis, which came as a huge shock to her and her family. She shares her journey from diagnosis to recovery in the hope it will reassure others that they can get through this trial too.

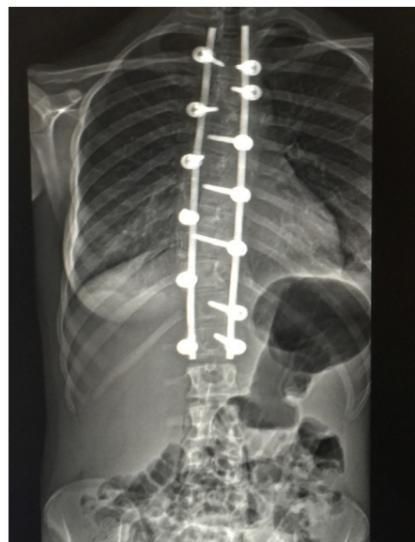
In December, 2017, I was diagnosed with adolescent idiopathic scoliosis (AIS). I hadn't presented any symptoms apart from my right shoulder being higher than my left, and over time my right shoulder blade became more prominent and clothes didn't always fit me very well. Initially my mum took me to see a physiotherapist who told me there was nothing they could do and that I needed a hospital referral. After meeting my spinal consultant at Sheffield Children's Hospital (SCH), I was told I had a 52 degree idiopathic spinal curve, meaning there was no reason for why I had it.

Throughout 2018 I was monitored every few months but by November

surgery was the only option because my curve had increased by 5 degrees. I was absolutely devastated, my ambition is to have a career in performing arts, especially musical theatre, and I knew that working towards my dream would have to stop for a while. However, my parents and I agreed it was the best option for the future and a date was set for June, 2019.

In December, 2018, I had an MRI scan and in March, 2019, I was referred to a neurosurgeon because something had been identified on the MRI. I was told that I had Chiari 1 malformation and needed decompression surgery before spinal fusion surgery. The neurosurgeon explained that the cerebellar tonsils at the base of my brain had extended into my spinal canal and this was restricting the flow of spinal fluid. It was a complete shock to us all, again I had not had any symptoms and this surgery would delay spinal fusion by 3 months so that I had time to recover. The date was arranged for 5th June.

Morgan's spinal X-rays before and after surgery



From March onwards time flew, I was busy with studying and with my dancing even competing up to a few days before I was admitted to hospital. On arrival at the SCH theatre admissions, my parents and I had a meeting with the neurosurgeon and various other medical staff. I was then handed my gown to change into and it wasn't long before I was taken to the anaesthetic room. The hardest part was leaving my parents. I cried so much but the anaesthetic soon started working and I fell asleep. I woke up on the ward and my recovery was reasonable despite some sickness, in fact I was only in hospital for 4 days and by 9th June I was home. However, because I had leakage of the cerebrospinal fluid, I returned to hospital twice. The final time I was in theatre for a lumbar puncture and more stitches. Overall, I had been in hospital a total of 3 weeks which we hadn't expected. Since this was the first time I had been in hospital, it all came as quite a shock. At home I recovered slowly, and gradually life settled down again although it was far from 'normal' for me as I was unable to carry on with all the performing arts classes I was used to.

In August, we had more hospital appointments with the neurosurgeon to ensure that the decompression surgery had been successful and a pre-op for the spinal fusion surgery. It was hard to believe from the X-rays that the curve of my spine was so pronounced. The consultant explained that he would be inserting two titanium rods and screws to fix the curve in the thoracic area of my back and that it would never move again! The consultant



was aware of my career ambitions, so he would not be operating on the lower part of my spine because this would enable me to have some flexibility, although somewhat reduced. The date for spinal fusion was arranged for 1st October and I felt more anxious this time after the setbacks I had experienced with the first operation.

On the morning of my operation I was given a pre-med to relax me, it took effect almost immediately. I can't remember anything from that point onwards until I woke up afterwards and I was very emotional. I was in theatre for 5 ½ hours and around 2 hours in the anaesthetic room being prepared before surgery. My recovery was straightforward and I followed the advice from the medical staff who looked after me. The following Saturday I felt so relieved to be allowed home.

I am currently still recovering and had my 8 week post-op review with my spinal consultant at the end of November. I saw the X-ray post-op and it is amazing because I now have two titanium rods and

13 screws in my back. The curve in my spine was 65 degrees pre-op and now it is 21 degrees! I still have some pain in my shoulder blades and numbness in my back but I have been told that because of the nature of the surgery and the amount of pushing and pulling that was done to straighten my spine this is to be expected. During the operation the consultant lifted my rib cage slightly and spaced out my ribs a little too! Unfortunately, I have been having headaches which I never had before the decompression surgery, but again the neurosurgeon has told me that these should settle in time.

I returned to school part-time in December and combining this with home study I am gradually increasing my hours so that I am back full-time, although some access arrangements have had to be made in school. I am continuing to work hard as I have my GCSEs in the summer. I have improved dramatically and from now on it is onwards and upwards as I start to return to dance and continue with my performing arts studies to achieve my dream.

My journey has been a very emotional one and it has taken a long time for me to feel able to speak about it but now I want to raise more awareness about Chiari 1 malformation and scoliosis. When I was diagnosed with Chiari 1 malformation in particular, the support was minimal and I didn't know anyone who had undergone both operations and wanted to pursue a career in the performing arts. I felt apprehensive and anxious; I had never been in hospital before and didn't really know what to expect. I am now actively trying to raise more awareness about these conditions and am therefore looking to raise funds for the charities close to my heart, please see my Just Giving page: www.justgiving.com/crowdfunding/morgan-elshaw.

It would mean a lot to me if my story was heard because I would really like to share my own personal journey and to reassure others that they can get through this, even though it seems like a long road ahead. My mum started a blog as soon as I went into hospital which gives further information and is aimed at giving some support to parents who may be in the same situation as ourselves. If anyone would like to read more about my journey the blog address is <https://it-is-what-it-is.co.uk>

Finally, I entered a UK Miss Galaxy pageant competition (www.galaxypageantsuk.com) and I am through to the final! The ethos of the competition is about accepting who you are and being yourself, so I am looking to raise more awareness. I will compete against other contestants around my age from all over the UK. I am proud to be Miss Teen Nottinghamshire Galaxy. I am also a semi-finalist for Miss Teen Great Britain 2020 which takes place later this year.

Morgan Elshaw

ISAD

International Scoliosis Awareness Day
Saturday, 27th June 2020



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