Connect

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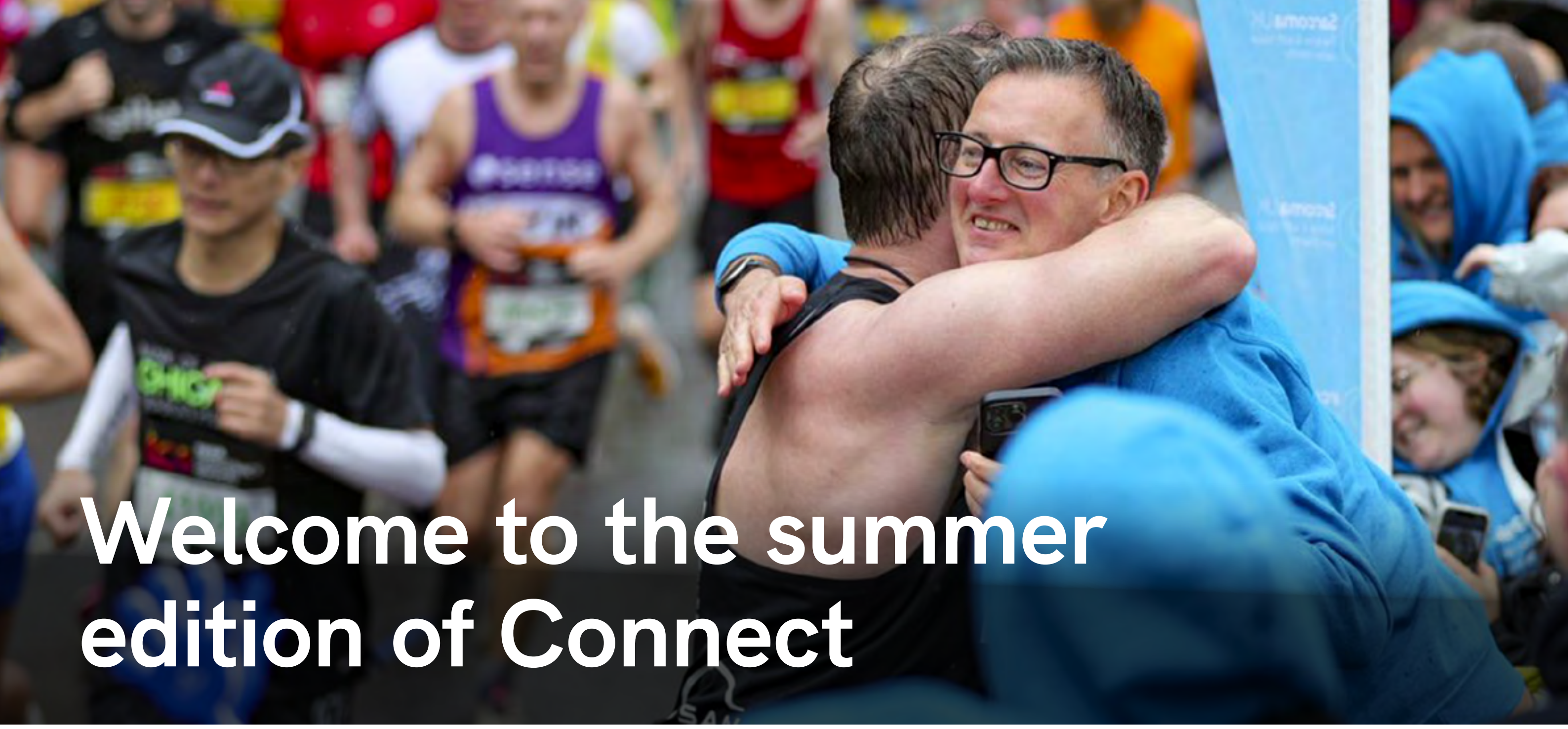
Summer 2023

Anyone for sequins? The Glitter Ball is back

Lockdown, sarcoma and me – Fiona's story

The expansion of our Support Line

Sarcoma UK
The bone & soft tissue cancer charity



Welcome to the summer edition of Connect

I'm not sure how we have reached the summer of 2023 already, but I do know that whatever the date, collaboration is at the heart of all our recent developments and achievements.

Whether you are a supporter, fundraiser, scientist, politician, or any other valued member of the sarcoma community, we have depended on your support to make our work happen.

In addition, the spirit of positivity and progress runs through this issue of *Connect* like the wording on a stick of rock. We heard about so many exciting developments in research at the influential British Sarcoma Group Conference, including work that we have supported (see opposite page).

We were delighted to engage with so many parliamentarians in Westminster and Holyrood in April when we focused on outcomes for young people and sarcoma during Teenage and Young Adult Cancer Awareness Month (page six).

Our third Glitter Ball, now a firm favourite of the social scene, was a fabulous evening which raised over £144,000 this spring (pages 10–11).

Our research programme has moved into new territory as we approach an incredible funding milestone of £1.3 million pounds for this financial year, marking 10 projects supported. And even closer to home, we are reflecting the growing importance of collaboration as we unveil the organisation's new values – the result of much input and enthusiasm from our committed staff team, who I am proud to say, embody those values every day (page 18).

Our Support Line service has gone from strength to strength since it started seven years ago and has recently expanded to cope with a growing demand, only possible thanks to your generosity (see page 19).

It was truly inspiring to see our amazing Team Sarcoma step up for the challenges of the TCS London Marathon. Over 127 dedicated runners pounded the pavements to raise around £494,000 – every single one a hero (pages 16-17).

Sarcoma Awareness Month (July) is a really important date in our calendars. Plans were still being finalised as *Connect* went to press but you can keep up with our activities and campaigns on our website and social media channels. I hope you'll join me in a new event, Cuppa & Cake, which you can hold anytime up until the end of September (page eight). What better way to get a few friends or colleagues together and support Sarcoma UK over some delicious treats?

Thank you for everything you do in helping us make a difference for those with sarcoma.

Richard Davidson

Richard Davidson
Chief Executive

Inside this edition:

Engaging with politicians and beyond
Sarcoma UK is working tirelessly to put the key sarcoma issues on the agenda.

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Your Shout
Andrew Sutton gives a personal perspective on the value of peer support.

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Team Sarcoma on track
The TCS London Marathon was back on the spring calendar complete with our 127 sarcoma heroes.

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Your greener Connect

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Please work with us, care for our environment and recycle this publication responsibly.

The British Sarcoma Group Conference 2023: a recap

Progress in sarcoma research and service delivery has never been faster, according to the annual two-day British Sarcoma Group conference.

Advances in genomics and personalised medicine, reconstruction and rehabilitation, palliative care, and updates on research and surgical developments were among the highlights of the March event in Newport, South Wales.

Sarcoma experts and community members from across the UK and beyond shared learning, inspiration and updates while celebrating the achievements of working together for better care for sarcoma patients and families.

Among the many contributions:

- Dr Brittany Siontis from the Mayo Clinic in the USA presented on the challenges and opportunities of finding new treatments for sarcoma through clinical trials. The rarity of sarcoma makes it challenging to not only ensure there are enough patients to take part, but also to engage funding sources. Dr Siontis highlighted the vital importance of collaboration, encouraging centres across the world to join together to improve outcomes for patients.
- Attendees also heard about progress on several major clinical trials. For instance, the DeFi clinical trial had very exciting results which suggest that the drug nirogacestat can improve outcomes for people with desmoid-type fibromatosis. Others included the new SARCOSight trial, which aims to improve the accuracy of surgery, and the ICONIC clinical trial, which ultimately aims to improve treatments for osteosarcoma.
- Improving the experience of patient care was a key theme throughout the conference, including the merits of increasing follow-up times as well as healthcare professionals improving how they communicate care pathways to patients.
- Innovation was also a key theme, with topics as varied as using 3D printing in surgery, new genetic testing tools, and new drugs targeting the immune system or key mutations.

Former Sarcoma UK Policy and Public Affairs Manager, Bradley Price, gave a talk on the various barriers sarcoma patients face in accessing genomic testing, and how we can help start conversations on how the research and clinical communities could tackle these barriers.

A key theme of the conference was on improving the experience of living with and beyond a sarcoma diagnosis. Ellis Lill, one of our Support Line Advisors, presented on the experiences of people with sarcoma (more on page 19).

Several new initiatives were also showcased to attendees, such as an exciting trial of ambulatory chemotherapy at UCLH, which allows patients to receive chemotherapy in an outpatient setting, giving patients more freedom as well as saving money.

Tricia Moate Award Winner 2022, Nicola Day, presented on the importance of physical activity and rehabilitation in patients with incurable cancer, and how patients could be supported in this way, before our Support Line Specialist Nurse, Sam Hackett, opened the award to new applicants.

Sarcoma UK gave several other sarcoma specialist nurses and allied health professionals from across the country (pictured above) to attend the conference through sponsorship.

"I found the '*Facing end of life*' talk by Baroness Ilora Finlay really engaging," says Laura Williams, a Clinical Nurse Specialist from the Wirral.

"It really showed the importance of early palliative care for our patients and their families. Louisa Nicoll speaking about her husband's experience was also very inspirational and will help us as professionals to be aware of and remember to ask patients what is most important to them."

"A huge thanks to Sarcoma UK for the opportunity to attend my first BSG Conference and connect with some amazing healthcare professionals," says Kelly Trigg, a Clinical Nurse Specialist from Colchester. "It was such a privilege and a pleasure."

Our dedicated fundraisers

From charity balls to golf balls and quiz nights to bake days, our amazing fundraisers have been pulling out the stops.

Headshaves and haircuts for a good cause

Two superstar fundraisers have taken their efforts to the max by losing their hair.

Schoolboy Morgan Walther-Gaby said goodbye to his hair in support of his step-mum.

So far the plucky youngster has raised over £2,000, smashing his target of £1,000, through Morgan's Brave the Shave.

Kelly Best, 25, was undergoing treatment after being diagnosed with synovial sarcoma and having major surgery.

"I want Kelly to know that if she loses her hair due to the chemo, she's not doing it along, and that I will try to understand what it feels like by losing mine too. "

Morgan was joined by his dad, Matt Gaby, who also shaved his head, and raised £1,000 for Sarcoma UK.

Meanwhile, Isla Giles chose to lose her long locks in memory of her grandad; a fitting tribute on his birthday.

Derek Giles died after a sarcoma diagnosis and his last wish was for his granddaughter Isla to undertake a unique challenge.

"It was my grandad's last wish to me to have my long hair cut, donate it to charity to make cancer patients their very own wigs and to donate the money raised to Sarcoma UK.

"My grandad was the most amazing man I know and the best grandad ever, and I feel honoured that he asked me to do this."

So far Isla has raised over £1,000 with her unique challenge.

Morgan and Isla, you are truly amazing.

Chris Martin Quiz returns with a bang

The annual Chris Martin Quiz made a popular post-pandemic return as attendees commented that the fourth one was 'the best ever.'

Chris Martin, principal private secretary to David Cameron, died of sarcoma in November 2015. His widow, BBC journalist Zoe Conway, now does everything she can to raise awareness of the disease, and funds for Sarcoma UK.

The quiz was fronted by host Ed Balls, and featured rounds by Today programme's Mishal Husain and Rob Bonnet; Shadow Chancellor, Rachel Reeves MP; former prime ministers Tony Blair and David Cameron; the King's Private Secretary, Sir Edward Young, and Baroness Liz Sugg.

Over £20,000 was raised through tickets, donations and by auction. All proceeds will go towards the **Chris Martin Fellowship**, funding Sarcoma UK's Genomics Programme with the aim of bringing about a step-change in sarcoma research.

"We are very grateful to Zoe for organising such a fantastic event in memory of Chris," says Richard Davidson, Chief Executive of Sarcoma UK.

Sarah's charity ball and best foot forward to honour husband Matt

Sarah Eborall has been fundraising in every which way for Sarcoma UK. Her husband Matt was diagnosed with a rare form of sarcoma and sadly died in March 2022, aged 39.

Sarah vowed to continue raising money and awareness to help others through sarcoma.

"He fought so long and hard against this disease and we had every hope in the world that he would beat it."

She organised a charity ball in honour of what would have been Matt's 40th birthday in February at Cottons Hotel and Spa, Cheshire, and tackled the Manchester Half in April. And since she started fundraising in 2020, Sarah has organised fundraising fairs and sales, getting her children's school Outrighton Primary School involved, and much more.

Sarah has raised an incredible £13,301 and we are so grateful for your support.

Schools in support of Sarcoma UK

Did you know that schools can make a big difference to Sarcoma UK?

Whether it is for a class, a term or even for the whole year, we are here to support your school with fundraising activities.

And if you are taking on the Duke of Edinburgh award, we can also be your assessors for your charity volunteering.

Once you complete the form at **sarcoma.org.uk/atschool** we'll be in touch. And our digital fundraising guide or physical materials will make it easy, fun and informative to get involved.

Comedian Angela Barnes braves the black chair

Our Celebrity Ambassador Angela Barnes has done us proud with her recent performance in the iconic Mastermind chair.

The comedian was up against Diarmund Gavin, Melissa Johns and Adam Fleming as they faced questions from host Clive Myrie both on their specialist subjects and a general knowledge round.

Angela's high scoring successes on Celebrity Mastermind earnt her second place and £3,000 for Sarcoma UK. Brilliant work Angela!

Jeremy hosts golf day in memory of his brother

A charity golf day at the prestigious Royal Wimbledon Golf Club in London raised a fantastic £29,386 for Sarcoma UK.

Jeremy Pilkington of Andover, Hampshire, organised the event with his sister-in-law Marissa Pilkington in honour of his late brother, Simon, who died from liposarcoma in 2019.

Jeremy's dedication to raising funds and awareness for Sarcoma UK this year doesn't end here as he and daughter, Lara, ran the Edinburgh Half Marathon for the charity on May 28. He also ran the London Marathon for Sarcoma UK in 2021.

"We are so grateful to Jeremy for organising such a fabulous event at Royal Wimbledon Golf Club to raise funds for Sarcoma UK, while raising such important awareness of sarcoma," says Kerry Reeves-Kneip, Director of Fundraising and Communications at Sarcoma UK.

"The funds raised from this event will go into funding vital research into sarcoma, offering support for anyone affected by the disease, and campaigning for better treatments."

Jeremy's charity golf day saw over 120 people attend – what an amazing event!

Tesco staff are the tops in supporting fellow worker Johnny

Big-hearted Tesco staff got together to organise a fundraiser after a fellow worker was diagnosed with osteosarcoma.

The team in Fullbridge, Maldon, have raised more than £2,300 in honour of 19-year-old team member Johnny Hughes.

He began working at the supermarket during lockdown in 2020. Johnny was diagnosed last Christmas and has been undergoing chemotherapy in London.

Johnny said: "I am lucky enough to have an amazing work family – aka 'the girls' – who have been amazingly supportive since my diagnosis."

One of 'the girls,' Michelle Jagg, hoped to raise a little money for Sarcoma UK, and also help raise awareness of sarcoma itself.

Michelle is one of the amazing Cuppa & Cake Champions with an event planned for this summer.

Johnny has urged everyone to familiarise themselves with the signs of sarcoma and to contact their GP if experiencing any symptoms.

Santa in the City – Sarcoma UK is 2023 charity partner

It's never too early to think about Christmas and we are delighted to be involved in a fantastic festive partnership.

Sarcoma UK has been announced as the 2023 Charity Partner for Santa in the City, the popular 4.5 km December run in the heart of London. You can take your pick from one of two dates – December 6 or 7 – and join hundreds of others dressed up in your full five-piece Santa suit!

Some of the Sarcoma UK team were among the runners in 2022 and this year's event promises to be even bigger and better. What better reason to get in shape through the autumn – sign up at **santainthecity.co.uk/runner-info**

Thank you to GeeWizz

Sarcoma UK is incredibly grateful for the support of GeeWizz, an amazing Suffolk-based charity.

Since 2015, GeeWizz Charitable Foundation has raised over £2 million and delivered numerous life-enhancing projects for children and young people across Suffolk with high dependency disabilities, life-limiting illness, or cancer.

"We are also hugely proud of the support we have been able to give to Sarcoma UK, an incredible charity that is so close to our hearts, funding vital research into bone and soft tissue cancer."

The difficult decision to close was taken this spring as its CEO decided to step down due to personal and family priorities.

"We are incredibly grateful for the difference that GeeWizz has made to our work through donating an amazing £162,000," says Kerry Reeves-Kniep, Director of Fundraising and Communications.

"It has been an honour to consider Sarcoma UK as part of the GeeWizz family and to see the impact of their support. We wish all of those who have delivered so much over the last few years the very best for the future."

Keeping sarcoma on the political agenda

It's been a busy start to the year for our Policy and Public Affairs team which continues to focus on the importance of early diagnosis as a priority for patients and politicians alike.

First Teenage and Young Adult Cancer Awareness Month sees politicians engage with Sarcoma UK

Over 75 MPs and MSPs met with Sarcoma UK in Westminster and Holyrood to discuss the charity's work for children, teenagers and young adults diagnosed with sarcoma.

April saw UK cancer charities come together for the first Teenage and Young Adult Cancer Awareness Month.

Sarcoma is the third most common CTYA (children, teenagers and young adults) cancer in the UK, with a child, teenager or young adult (age 0–24) being diagnosed with sarcoma every day.

Sarcomas have a worse survival rate than average for cancers affecting this age range. They are 14–16% less likely to survive for five years than the average CTYA cancer.

The House of Commons event was attended by 65 MPs, including sponsors Marion Fellows and Laura Farris, and Amy Callaghan MP, Chair of the All-Party Parliamentary Group on Children, Teenagers, and Young Adults with Cancer.

Ellie Cooper, aged 18, was diagnosed with Ewings sarcoma in 2021 and spoke of her experiences with sarcoma as a young person.

In Holyrood, there were 13 MSPs from across Scotland, including sponsors Neil Bibby, and Alex Cole-Hamilton.

Beth Keller was 22 when she was diagnosed with osteosarcoma. Beth only finished treatment in early 2023 and also spoke of her experiences.

"Cancer is different in young people. They have very different needs to older adults facing this disease, so they need a special, tailored approach to improving cancer diagnosis, treatment, care and support," says Dr Sorrel Bickley, Director of Research, Policy and Support at Sarcoma UK.

"The far-reaching impact of cancer does not end when treatment ends. Quality of life and learning to live well with cancer is vital too. The impact of a cancer diagnosis can continue for many years.

"We must raise awareness of the distinct challenges this age group face and make a difference for young people with cancer."

Life-extending GIST drug is given thumbs down by NICE committee

Sarcoma UK is disappointed that the drug ripretinib for treating advanced gastrointestinal stromal tumours (GIST) was not approved by NICE.

Ripretinib is a new drug for GIST patients with advanced disease who have had three previous treatments.

GISTs are the most common type of sarcoma and develop in the gastrointestinal tract.

"It's disappointing to hear that patients with this type of GIST cancer will not have access to ripretinib," says Dr Sorrel Bickley, Director of Research, Policy and Support at Sarcoma UK.

"For cancers like sarcoma, where the number of drugs and treatment options are already limited, access to new and effective treatments is vital."

Sarcoma UK represented the views of sarcoma patients throughout the review and gave evidence to NICE. We will continue to work with other charities, the manufacturer, and health bodies in England to find a way for patients to have routine access to this drug.

65

MPs and 13 MSPs supported Sarcoma UK's events in Westminster and Holyrood

‘Lumps and bumps’ video measures up

Sarcoma UK is helping people measure and track visible lumps and bumps with a new video.

This tool, called ‘*Measuring and tracking a lump*,’ will give them information and pictures to show their GP, enhancing their chances of referral for further tests where necessary and, ultimately, speeding up potential diagnosis.

The video features advice from a sarcoma specialist who gives expert guidance on how to measure, track and record changes to any lumps.

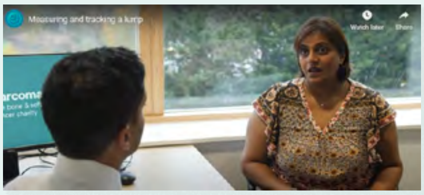
One of the symptoms of sarcoma is a growing lump, and before referral to an expert, visible lumps can change significantly.

It is not uncommon for patients to see multiple different healthcare professionals, who may not record this. And with no standard way of measuring lumps and bumps, any measurements recorded by professionals may not be consistent.

The new guidance has already been backed by MPs including Marion Fellows MP and Caroline Dinenage MP. Marion lost her husband George to sarcoma in 2018.

“I welcome Sarcoma UK’s new resource to help patients self-advocate, as well as the charity’s wider work on early diagnosis. All patients deserve the best chance at beating cancer.”

The video can be found at **youtube.com/watch?v=DqosEY0DPT0**



Sarcoma diagnosis in the spotlight at the House of Commons

An event in Westminster at the start of the year focused on the importance of **early diagnosis**, which gives anyone with sarcoma the best chance of survival.

The event was hosted by Sarcoma UK, Jess Phillips MP and Laura Farris MP, both of whom have personal connections to sarcoma.

The charity remains committed to the recommendations of its *Delays Cost Lives* report published two years ago as to how to improve the speed of diagnosis and is calling for renewed action.

Lauren Phillips, 27, from south-east London, shared her experiences at the event. Lauren’s dad Terry died of sarcoma in 2019, aged 47, and less than two months after his diagnosis.

“My dad had been experiencing pain in his left knee and a lump that was increasing in size in late 2018. He went to various doctors and was told it was a torn tendon or a ball of blood trapped underneath the knee,” says Lauren.

“When my dad was diagnosed, the doctor told him at the time that he could not give him a timeline on how long he might have left, as there was not enough research into sarcoma to know how things work. This isn’t good enough and needs to change.”

The event was attended by MPs including Marion Fellows MP, Tonia Antoniazzi MP, Taiwo Owatemi MP, and Andrew Gwynne MP.

Have a Cuppa & Cake this summer!

Boil the kettle, put on your apron, get out your china and hold a Cuppa & Cake event for Sarcoma UK.

Have a coffee morning at work, a bake sale, afternoon tea with some friends, or a glass or two of bubbly with the gang!

You will be making a big difference, helping to raise awareness of sarcoma among your friends and family and collecting vital funds to support the sarcoma community.

You can join in the fun anytime from July until September so pick your date and away you go.

Scan our QR code to sign up and find out more or go to **sarcoma.org.uk/CuppaConnect**

Cuppa & Cake

Your shout: spotlight on your issues and your stories

Bone Sarcoma Peer Support – helping others on a similar path

In the second of our series focusing on issues that matter to you, Andrew Sutton shares his experiences of connecting with others.

When I got the shock diagnosis of osteosarcoma just over three years ago, I was understandably lost. Just two months earlier, I was unaware such an illness existed. I remember spending time on Sarcoma UK's website to research what it all meant… who else could I ask? One phrase I read that day stuck with me throughout; 'sarcoma is the loneliest cancer'.

That phrase was pushed to the extreme in my case. COVID isolation protocols were enforced after the second month of my treatment, meaning that I only spoke to nurses for every five days of treatment.

Shortly after my final round of chemotherapy, I was contacted by one of those nurses to ask if I would be willing to speak to a lady that had been newly diagnosed. An initial 30-minute call with that lady turned into two hours as she got to ask her questions and I shared my experience, which all helped to address her fears. We continued to talk throughout her treatment, touching base whenever something came up and have remained in contact even after she too 'graduated' into remission.

> **"Each mentor at Bone Sarcoma Peer Support is an incredible individual."**

It was at this point I took the time to reflect on how important this had been for both of us. Why had two complete strangers created such a strong connection under the most extreme of circumstances? It all came down to a shared experience… one that we were in a unique position to relate to when no one else could. It was peer support… but how could we roll this out to benefit even more people?

I connected with a couple of other ex-cancer patients who, through their own experiences, also recognised the value of peer support. Fast forward 12 months and the team launched Bone Sarcoma Peer Support (BSPS), supported by Sarcoma UK.

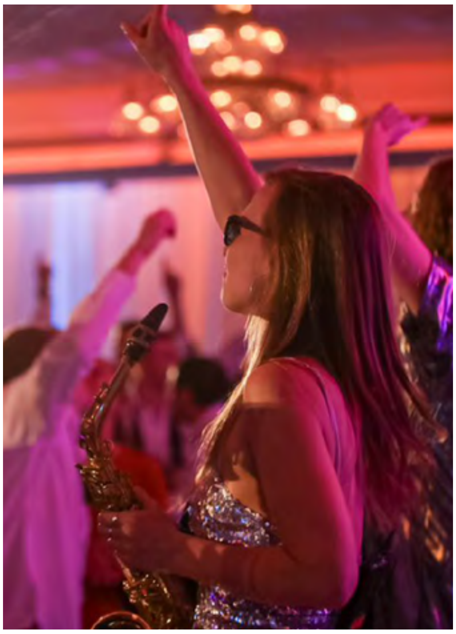
Our service matches a 'mentee' (someone needing support) with a 'mentor' (someone who can provide support) on a one-to-one basis. We collect a little information on each, trying to create the best match, including a similar diagnosis and treatment pathway. We then introduce them and do the most important thing… step back and let the conversations begin. They then decide when and how they will talk (which is usually via phone or video call but isn't restricted to that).

Each mentor at BSPS is an incredible individual. They've not only faced cancer and come out the other side, but they are willing to give their time helping others on a similar path.

We put each mentor through some training, including mental health first aid, safeguarding and listening skills, but they all possess the most important skill already… experience. And it is this experience that is invaluable to those looking for support. The opportunity to speak with someone who has been where they have. Someone who has the capacity to understand and to provide real emotional and social support and encouragement.

If you think peer support is for you (either as a mentor or mentee) you can find out more about us at **peer-support.co.uk** and apply for the service

A night to remember – Glitter Ball tops its fundraising target



Our third Glitter Ball this spring was bigger and better in every which way, thanks to the amazing sarcoma community.

The must-attend annual event in a brand new venue raised an incredible £144,000 from the generosity of 400 guests and everyone who supported the (online) auction.

Celebrity Ambassador Jake Quickenden led the talented musical line-up along with Enchorus, FullyFunktional, and DJ Teresa Wilcocks.

Singer, actor, reality TV star and presenter Jake performed a medley of songs, packing out the dancing floor at London's Marriot Hotel Grosvenor Square and receiving a standing ovation.

Sarcoma UK is very close to his heart after Jake sadly lost his brother, Oliver, to sarcoma 13 years ago, aged just 19 years old – memories he shared at the event.

"Our most successful Glitter Ball was truly a night to remember – an incredible party with a big heart and a wonderful atmosphere," says Kerry Reeves-Kneip, Director of Fundraising and Communications at Sarcoma UK.

"Jake is an amazing Ambassador for Sarcoma UK and the perfect cheerleader to inspire everyone to dig deep and support the charity while having the time of their lives.

"Thanks to the generosity of our supporters, we will make a real difference in funding vital research into sarcoma, offering support, and campaigning for better treatments."

A huge thank you to the fabulous Glitter Ball Committee – Amelia Granville, Zoe Homer-Emmerson, Emma McCloskey, Ruzin Yalchin, Paula Magus, Zoe Thompson, Jaz Thompson, James Read, Olivia Meheux and Kerry Reeves-Kneip.

We are so grateful to our volunteers – Emma Butler, Gemma Burnham-Parkes, Sofia Simpson-Wells, Amanda Osgood, Paul Osgood, Dave Read, Amy Read, Cat Ferrer-Jempson, Carly Bryan, Amy Nicoll, Hannah, Emma Delin, Jessica Hall, Steve Pollett, Natalie Donat, Carly McDonald, Darius McDonald, and Louisa Morgan.

As well as our wonderful performers, we would also like to thank our gold sponsor Rain Oncology, Diageo premium drinks, Perry's the Wedding Company and London Marriott Hotel Grosvenor Square.

Photos courtesy of Joe Gritton and Kois Miah.

Lockdown, sarcoma and me

While we all grappled with the challenges of lockdown in 2020, Fiona MacIntyre, 41, was fighting to see a doctor after finding a hard lump in her right thigh, which was eventually diagnosed as osteosarcoma. Almost three years after surgery, she's training for her first half-marathon.

Fiona, tell us your story

We all went through it in lockdown, but I was possibly having a too easy time and fate decided to contradict me.

Like everyone else I was taking my one walk a day – there was nothing else to do. Previously I'd been pretty lazy – definitely more couch potato than runner bean – and I was suddenly doing long walks regularly; five, six or seven miles.

> "I had to fight and fight and fight to get an ultrasound only after endless chasing as I wasn't a priority."

My lump was at the back of my thigh; I felt it by chance massaging it and thought it was probably due to the excess walking.

I could feel my lump below the surface but there was no redness or pain. Because I couldn't think of what I'd done to cause it – such as an insect bite or a knock – I thought, right, this is beyond my amateur diagnosis.

I thought there must be a really obvious medical reason and when researching, discovered the sarcoma advice. But I kept ignoring that in favour of the more mundane listed things. However, none of them would match my symptoms.

For example, I knew about Baker's cysts (a fluid-filled swelling at the back of the knee) as it's something triathlon runners say to keep an eye on and my grandmother had one. But they're meant to be painful and my lump was too high up. I was searching online and Google kept pushing me towards this bizarre thing called sarcoma.

I ignored a lot of the health pages but the BBC was a trusted source. A story about a nurse was scary as she found a lump which she ignored and, five weeks later, she needed an amputation of her leg. My symptoms matched exactly. And I'd run out of other things it could be.

What happened then?

This was summer and my GP was not seeing patients face to face which meant they had to take my word for it. I needed to be really specific about my symptoms, calm and focused so they wouldn't assume it was the stress of Covid. So I took photographs of the lump, and measured it, showing how it had changed. I also listed all the evidence that had made me discount the less severe options like a knot in the muscle or a cyst.

I had to do all the driving and I wasn't prepared to wait.

I had to fight and fight and fight to get an ultrasound only after endless chasing as I wasn't a priority.

I finally got an MRI in September and immediately after that was told I could go straight to have a CT scan.

It took nearly six months to get the diagnosis. By then, all the signs were pointing towards sarcoma and I'd come to terms with that.

In reality, there was no better time to go through what I went through. I had nothing else to occupy my time with, so I could dedicate myself to pushing for tests and pushing for appointments.

This felt like something I could fix, something I could take into my sphere of

> **"It's your body and your life. Know that it's okay to be assertive, to keep control of the process and not to be fobbed off."**

control. Life was really calm. If I'd found a lump a year earlier, I may not have done anything.

In terms of support, I was convinced people would tell me that it was all in my head. Friends were all going through it during lockdown and I didn't want to stress them out unnecessarily.

Lockdown gave me the chance to process it on my own terms. I deal with things by being very practical and pragmatic. So I turned it into a hypothetical exercise with four scenarios, ranging from being fine to it being cancer and I would lose my leg.

My only face to face appointment was with the consultant when my diagnosis was confirmed in November – the day before the second lockdown.

I was referred to the London Sarcoma Service and I was treated at the Royal National Orthopaedic Hospital. I didn't know Sarcoma UK existed until it was mentioned by a Macmillan nurse.

What happened after your diagnosis of osteosarcoma?

I felt like I got everything in the wrong order and dealt with the shock up front, so when I got the diagnosis it was a relief. I thought, right, I've got a plan.

My sarcoma is osteosarcoma, which is rare, but it actually is not in the bone, but in the soft tissue – also very rare – and the butt of jokes with friends. I have to be unique!

It was one month from diagnosis to the December surgery. The day the world opened up, I was going into hospital.

I was on crutches by day two – they could never find me as I was never in bed! I was chomping at the bit to get out.

I was picked up by my parents who I then stayed with in Sussex. I came out the day before my birthday, so I forced them to feed me chocolate cake!

After Christmas I was starting to go a bit stir crazy but had to prove I was self-sufficient enough on crunches to handle myself without supervision.

How did you approach your recovery?

I took no real time off work, apart from when I was in hospital. Work was a real distraction and in fact lots of people didn't know I had cancer.

I took up running as soon as I got off the crunches. My physiotherapist had talked about structured exercise and I was determined to get full use of my leg back.

I had contemplated the Couch to 5k programme but not done a single step in lockdown. I started in March and loved it. It turned into a great stress relief and it's now an integrated part of my life.

I started with 5k runs and then someone suggested 10ks and then a half marathon. With people from work, we decided to do a half marathon somewhere else. We picked Cardiff for this October as it's flat, by the sea and very pretty.

I'm probably in better shape now than ever before and at a work health check I got a green tick for exercise instead of amber!

What advice would you give to anyone else concerned about any symptoms?

It's your body and your life. Know that it's okay to be assertive, to keep control of the process and not to be fobbed off. If something is worrying you, it's important even if it turns out to be something small. Be prepared to chase and be structured rather than emotional if possible. Think about the facts when dealing with medical people – what can you say to help them do their job more effectively?

What about early diagnosis?

I really want to stress the importance of earlier diagnosis. I am still having regular check-ups and it's looking like we caught it all. I have carried on being the small percentage that bucks the trend – I feel like a fake sarcoma patient. I have a really gnarly scar on the back of my leg and make up stories about how I got it!

There's an expectation with cancer that someone else will spot it, but when you've got something rarer that isn't picked up by a regular screening, you need to chase for answers yourself. And it's worth doing. I was told how often sarcoma is misdiagnosed or people don't push for months – which makes everything more complicated when they do finally get to the right teams. So chase down those answers – even if it ends up being nothing serious.

New lumps and bumps tool from Sarcoma UK

Sarcoma UK has created a new video to help measure and track lumps and bumps, including advice from a sarcoma specialist. Read more on page six or at **youtube.com/watch?v=DqosEY0DPT0**

Our research in the spotlight

Our research programme continues to go from strength to strength, thanks to your support.

Collaboration is legacy of young filmmaker

A significant source of funding for sarcoma research in the UK is a fitting tribute to a talented young documentary filmmaker.

Sarah Burkeman was diagnosed with an undifferentiated uterine sarcoma in 2013 and passed away three years later, aged just 34.

In the hope for better treatments, Sarah gave a substantial donation in aid of sarcoma research. In her memory, her family and friends have established the Sarah Burkeman Trust (SBT).

Sarcoma UK is delighted with its collaboration with the Sarah Burkeman Trust to provide funding to several sarcoma research projects, so far supporting two key projects.

"We wish to honour our beloved Sarah's unforgettable spirit of kindness, optimism and her passion for helping people, by helping other young sufferers live the full life she so longed for herself," says Charlotte Burkeman, Sarah's sister and trustee.

The SBT has committed up to £200,000 to fund the most promising and relevant sarcoma research through Sarcoma UK in the 2022-23 financial year.

The Trust aims to fund projects in areas that have particular relevance to Sarah's own experience – gynaecological sarcomas, sarcomas that can particularly affect young people, poorly differentiated sarcomas, and projects focused on early diagnosis and immunotherapy.

> **"Collaboration truly is key to answers in research and that's why we are delighted to be working with the Sarah Burkeman Trust."**

As the first step, the Sarah Burkeman Trust has co-funded a project with Sarcoma UK at London's Institute of Cancer Research. Led by Professor Pascal Meier, this aims to explore new ways of treating undifferentiated pleomorphic sarcoma.

Treatments like chemotherapy damage cancer cells beyond repair. When this happens, the cancer cells enable a 'self-destruct' button and die – known as apoptosis. Unfortunately, cancer cells often become resistant to this process, and the treatment fails.

The project team thinks that killing sarcoma cells in a different way could make treatments like radiotherapy work better. A PhD student is investigating a different type of cell death, where the cancer cell bursts open and releases its contents. This acts a bit like a biological alarm to the patient's immune system to attack the sarcoma.

The team hopes that understanding how this works will lead us to better treatments for undifferentiated pleomorphic sarcoma and other sarcoma subtypes.

"When diagnosed, Sarah was disappointed to learn that the much-publicised cutting-edge immunotherapies offering such promise in other cancers would not have traction against her undifferentiated pleiomorphic sarcoma.

"The SBT is therefore delighted to help Sarcoma UK fund this work exploring an exciting mechanism to prime the patient's own immune system to recognise and destroy cancer cells of this and other sarcoma subtypes."

"Collaboration truly is key to answers in research and that's why we're delighted to be working with the Sarah Burkeman Trust," says Dr Sorrel Bickley, Director of Research, Policy and Support at Sarcoma UK.

"We hope that by joining forces we can accelerate research and help more people affected by sarcoma get the treatments that are so desperately needed."

Early diagnosis is focus of new projects

Sarcoma UK is funding three cutting-edge projects around early diagnosis, spanning technology to help spot gynaecological sarcomas, better genomic testing and mapping pathways to diagnosis.

Thanks to you, we've been able to commit over £300,000 to an area that is vital to ensure that patients have the best chance of survival.

Professor Maria Kyrgiou at Imperial College London will develop a piece of laser technology to help spot and treat gynaecological sarcomas, with £150,000 of funding over two years.

This uses the smoke produced through some surgical techniques, which can help tell the difference between normal tissue and the sarcoma. Although the research is at an early stage, the team hopes the technology – based on an existing tool called the iKnife – will help people with gynaecological sarcoma be diagnosed faster and earlier and improve survival rates in the future. It should also help surgeons ensure they can remove all the sarcoma the first time, avoiding multiple operations.

Secondly, a test which analyses all the genes in both sarcoma and the patient, called whole genome sequencing, can help ensure patients get the right sarcoma subtype diagnosis.

Unfortunately, there are several challenges facing the genomic testing service – including not enough scientists with the expertise to analyse the data. This means that a lot of potentially important data is being wasted. and patients aren't seeing the benefits.

£5.6 million

To date, Sarcoma UK has invested over £5.6 million into our research programme, helping us improve our understanding of sarcoma and find new and better treatments.

Thank you to everyone who has donated or supported Sarcoma UK – you're the ones making this research possible.

A project at UCLH, funded by Sarcoma UK, will create a network of scientists to upskill the sarcoma community, share knowledge and improve efficiency.

The Sarcoma Network will also train the next generation of sarcoma scientists and create an environment for continuing development.

"The generous Sarcoma UK funding facilitates pooling of knowledge, skills and effort across the NHS Genomic Service," says Professor Adrienne Flanagan. "We hope that this combined initiative increases awareness of sarcoma and will accelerate delivery of benefits for patients with sarcoma."

Finally, Sarcoma UK is commissioning new research to help understand how people are referred to specialist sarcoma services from their GP. Specialist sarcoma centres have long been under intense pressure, not only leading to long waiting times for results and diagnosis but anxiety for many patients.

> **"We hope that this combined initiative increases awareness of sarcoma and will accelerate delivery of benefits for patients with sarcoma."**

The team at University Hospital Sussex, led by Dr Nadia Mahmood and Mr John Bush, will be analysing records over the last five years to spot any trends in how each patient's referral might have related to their outcomes. They will also be exploring sources of dissatisfaction and any failures of communication between healthcare professionals and patients.

The team hopes that their results can help reduce delays in diagnosis and improve the overall experience for patients.

"We are pleased to have started our retrospective analysis of the diagnostic sarcoma service at University Hospital Sussex," say Nadia and John. "We are confident the results will positively impact the early diagnostic pathway for sarcoma patients."

"At Sarcoma UK, we hear too many stories of patients' sarcoma diagnoses being missed, often leaving them with limited treatment options," says Dr Sorrel Bickley, Director of Research, Policy and Support. "From speaking to people affected by sarcoma, we know that research to improve diagnosis is a huge priority, second only to finding new and better treatments. We hope these projects are another step in ensuring that everyone with sarcoma can get the treatment and care they need."

Birmingham showcases its sarcoma research

The team at the University of Birmingham lifted the lid to fundraisers and supporters on sarcoma research during a recent visit.

Led by Andrew Beggs, Professor of Cancer Genetics and Surgery and lead investigator on the genomics grant Sarcoma UK funds there, it was an eye-opening tour. The visit gave attendees a glimpse into the running of a world-class genomics research laboratory, showing us the importance of laboratory science of Sarcoma UK's support in understanding sarcoma better and developing new treatments.

Some of the sessions were hands-on, including getting the chance to 'feed' some real sarcoma cells in the lab, and Strawberry DNA extraction; an experiment to give participants the chance to see real DNA using only strawberries and fairy liquid.

Many thanks to Andrew and his team for the fascinating insight into sarcoma research as well as those who hosted recent visits at Manchester and the ICR.

127 Marathon heroes smash 26.2 Miles

The welcome return of the TCS London Marathon to its spring slot was one special day for the amazing runners of Team Sarcoma – our biggest ever!

Every single one had their own personal reasons for tackling the iconic race and braving a relentless training schedule throughout the winter.

From sister-in laws Lucy Woodhouse and Lizzie Drewitt to our very first PhD student Mark Elms and many more, their enthusiasm shone out alongside their bright blue vests.

Lloyd Scott MBE, a familiar London marathon face, delighted the crowds by running as Captain Scarlet – finishing his 21st race in a gruelling eight and a half hours.

Celebrity Ambassador and X-Factor finalist Jake Quickenden dug deep as he ran in the legendary bone costume in memory of his brother Oliver.

Also in a bone costume was James Nicoll, who ran alongside friend Ciaran Rigler, dressed as a penguin. James lost his dad John to osteosarcoma in 2020 and his mum Louisa is a trustee for Sarcoma UK.

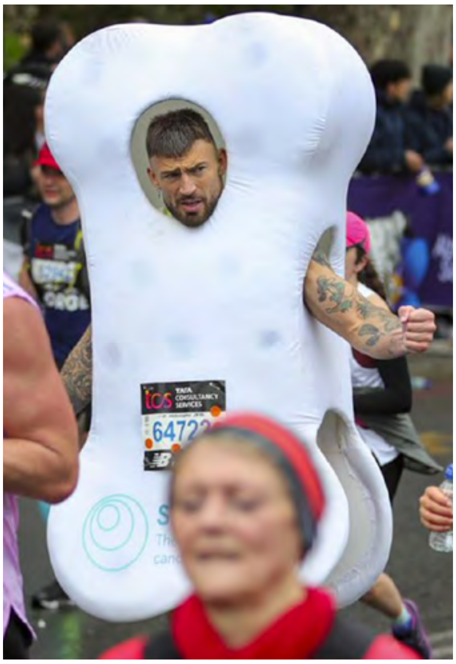
Our incredible team included everyone from big groups of family and friends to solo runners among a record-breaking 48,000 plus participants.

Despite a changeable April day, spirits remained high for celebrations at the post-race reception at Church House, Westminster.

As *Connect* went to press, the amount raised by Team Sarcoma stood at an incredible £494,000.

Many congratulations to our amazing runners – we are so proud of you all.

For our fantastic photographs, thank you to Ian Randall Photography and Kevin Richards. Thank you to the Sports and Exercise team, University of Worcester, for wonderful massages, to our incredible volunteers and cheerers, and everyone who supported us on social media.



Join Team Sarcoma and take on the world famous TCS London Marathon

Inspired by our 2023 champions? You could join them on April 21, 2024. We're with you every step of the way with personal support, fundraising materials and loads of enthusiastic advice.

Registration fee: £50

Sponsorship: £2,400

Our applications are now open.

If you have your own place, we'd love you to join us – contact **fundraising@sarcoma.org.uk**

Sarcoma Awareness Month 2023 needs you

July is the biggest date in the calendar for the sarcoma community and here's how you can join in this year, from supporting our awareness-raising campaign to fundraising and more.

Sarcoma Awareness Month activity in 2022 was our biggest yet, reaching more people than ever before. From sharing their stories and signing up to be part of our Patient Involvement Network, our supporters got behind the month in every which way.

And the opportunity to raise awareness really paid off with over 400 contacts with the Support Line in July – up 20 per cent – and a national campaign with Genomics England. Thanks to your support, our social media channels reached almost a million people, spreading the word about sarcoma and the life-changing work of Sarcoma UK.

For 2023, we want you to get involved in a bold and memorable awareness-campaign that will feature on our website and all our social media channels.

As *Connect* went to press, full details were being confirmed. However, we want to reach as many people as we possibly can with information about sarcoma, particularly those who may have never heard of us, or sarcoma before, yet may have signs and symptoms.

"From a YouGov poll, we know that 75 per cent of people have never heard of sarcoma," says Enda Guinan, Digital Communications Manager at Sarcoma UK.

"So it's important that we go back to basics by covering the key things about sarcoma, including what it is, how it can impact everyone, and the importance of early diagnosis.

"Help us spread the word this July and continue to make a difference to everyone affected by sarcoma."

Go to our website **sarcoma.org.uk** for all the latest. You can also join in the fun of our newest fundraiser, Cuppa & Cake, with details at **sarcoma.org.uk/CuppaConnect** or see page eight.

SARCOMA
AWARENESS
MONTH

+52%

Our website visits were up 52% and our social media engagement up a whopping 263% in Sarcoma Awareness Month 2022.

Our values and behaviours

We're delighted to unveil our new set of organisational values and behaviours – the principles that guide our decisions and actions.

These have been developed and updated to reflect the evolution of Sarcoma UK and to ensure we are fit for the future. Everything we do and how we do it – whether funding research, supporting patients, shining a light on sarcoma, and more – is driven by these values, hand in hand with our organisational strategy.

With your support, and our values at the heart of Sarcoma UK, we're committed to making a difference for everyone affected by sarcoma.

Our values

PIONEERING

We are leading the way to a better future for the sarcoma community

- We are bold in our ambitions to maximise our impact
- We are innovative and dynamic in our approach
- We push boundaries to transform the lives of everyone affected by sarcoma

TOGETHER

We are creating a community to make a difference for all those affected by sarcoma

- We support, encourage and learn from each other in our shared ambitions
- We connect and collaborate with others to achieve the best possible impact
- We bring everyone with us to achieve our goals

EXPERT

We use our expertise in understanding sarcoma to deliver better outcomes

- We collaborate with the best in the sarcoma community and beyond
- We amplify the voice of experience and gather evidence to make a difference
- Our professionalism is at the heart of what we do

SarcomaUK
The bone & soft tissue
cancer charity

Expanding the Support Line team

The Support Line team has gone from strength to strength since it started seven years ago, and has recently welcomed a new team member, Support Line Adviser, Ellis Lill.

Ellis, tell us about yourself

I joined Sarcoma UK at the end of September 2022. I am a radiotherapist by background and qualified in 2020 in the middle of Covid-19. I trained at Sheffield Hallam University and my first job was at St James's University Hospital in Leeds where I now live. I was then asked to join the team for paediatric radiotherapy and obviously knew about sarcoma; in fact about 80% of our paediatric radiotherapy cases were sarcoma-related.

What attracted you to the charity?

I saw the role completely by chance. I was looking on the Sarcoma UK website, researching a case that I'd never seen before, and when I saw the job description for the Support Line team, I knew that's exactly what I wanted to do. I came into healthcare for the care and compassion and had felt that time was taken away from me; I didn't have the time to spend listening to people or doing research. I feel very privileged.

What are your main responsibilities?

I work four days a week on the Support Line, covering phone calls, e-mails and texts. Carly McDonald and myself work with the Support Groups which I really enjoy. I also like taking on projects like the recent presentation at the British Sarcoma Group conference on the experiences of people with sarcoma (see page three) and possibly a new project involving clinical trials.

What have you enjoyed most so far?

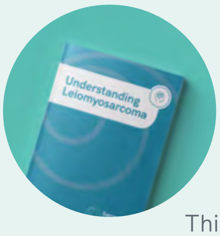
I've really enjoyed working with the whole organisation. It feels like a breath of fresh air coming to this charity. Even though there are different departments, it really feels like one big team. I've also enjoyed meeting the wider sarcoma community and doing things that I didn't think I would get the opportunity to do, like the conference.

My colleagues have been amazing – I've been very, very lucky that they are so supportive. It's always nerve-racking starting somewhere new but I feel like I've settled in really quickly, thanks to them.

What do you enjoy outside work?

I love cricket and have been playing as part of a men's team since I was eight! I also enjoy cricket coaching for children and young people aged nine to 15.

The Support Line has helped over 4,000 individuals with their concerns about sarcoma (end April 2023).



New guide to understanding leiomyosarcoma

Sarcoma UK has produced a new information booklet for anyone affected by leiomyosarcoma.

This free guide is for anyone affected by leiomyosarcoma – patients, family and friends, and healthcare professionals looking to educate patients and carers about the disease.

This booklet explains what leiomyosarcoma is, how it is diagnosed and the treatment options. You can also find out where you can go for support as well as useful space to keep diagnosis information and the details of your next hospital appointments.

Leiomyosarcoma is a type of sarcoma which develops in the smooth muscle cells, sometimes called involuntary muscles because they cause organs to contract without our control.

It is most commonly found in the limbs, the tummy, the uterus, and the retroperitoneum (deep in the abdomen and pelvis, behind the abdominal lining). Leiomyosarcoma mostly affects adults and is very rare in people under 20 years of age.

To order a free copy, or for healthcare professionals to order several copies, visit our Patient Guides page, **sarcoma.org.uk/patient-guides/**

Our Support Line opening hours

We are now open from 10 am until 3 pm, Monday to Friday.

Call us on 0808 801 0401 during these hours or leave a message and we will get back to you. If you would prefer to contact us by email, the address is **supportline@sarcoma.org.uk**

You can also text your question to **07860 058 830**.

Sarcoma UK is the only cancer charity in the UK focusing on all types of sarcoma.

Our vision

Where everyone affected by sarcoma cancer has the treatment, care and support they need.

Our mission

To ensure everyone affected by sarcoma receives the best treatment, care, information and support available and to create the treatments of the future.

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