

Connect

Latest news
Research
Support
Campaigning
How to get involved
with Sarcoma UK

Winter 2021



Our 10 year anniversary edition:

**How we've changed the
landscape for sarcoma research**

**Our Pride of Britain award
winner Gaz**

**The Virgin Money London
Marathon is back -
our 2021 superstars**



SarcomaUK
The bone & soft tissue
cancer charity

10th
Anniversary



Welcome to the winter edition of Connect

We are starting to move on from the 'back to school' feeling of autumn as the festive season approaches.

We have never been more delighted for some – if not all – elements of normality, whether catching up with colleagues in the office, or the return of some of the events and personal challenges that were hit hard last year.

The Virgin Money London Marathon is always special, but this year felt even more remarkable for us and our amazing 116-strong team, including 46 virtual runners. Their dedication and determination on a sunny October Sunday remains a constant inspiration with the potential for transforming lives, thanks to their impressive fundraising – over £400,000 to date (pages four to five).

This issue is not just about 2021, but our last decade as we mark our tenth anniversary year. So we've been looking back at some highlights, from our research achievements to date to the importance of Sarcoma Awareness Weeks – and a month – to our community (page 16).

Our anniversary theme is *People make Sarcoma UK* and this issue is full of remarkable people and their stories. We were absolutely delighted when Gaz Emmerson won Fundraiser of the Year for the London Region of the Pride of Britain awards. Raising more than £116,223 this summer by a 1,000 mile cycle

ride, no-one could have been more worthy of such recognition (page 14). Thank you to every one of our fundraisers, including my sister Jo, who tackled the Great North Run this year.

It's not too late to join in the 20 for 20 challenge – back by popular demand after its debut last year. The impact of this fundraising collaboration has been such that it reached the final of the Third Sector Awards 2021 in the category of Charity Partnership of the Year. There's really no limit as to what you can do (page nine) so why not give it a go?

If you've wondered how we use our income, the experiences of two very different users of the Support Line, now five years old, help underline its real impact on those who need us (pages 18-19).

Thank you to all of you – the people that make Sarcoma UK – who show your support in so many different ways. You mean that we can continue to build on the progress of the last ten years and make a difference to those with sarcoma.

Richard Davidson
Chief Executive

Inside this edition:

Five years of support
Two people share their different experiences of how the Support Line helped them.
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007 helps raise funds
A very special film screening has helped kick-start our 10th anniversary year.
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How we've changed the landscape through our funding – thanks to you.
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Your greener Connect

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

Our decade in numbers

These are some of the key figures that show our impact over the last decade and the last financial year (2020–2021) in fundraising, research, support and awareness raising.

Total raised over the last ten years: **£13,208,105.00**

£4,282,597.80

committed in research funding

63

research grants awarded

13

PhD students funded

£1,427,667.39

raised through London Marathon

413

runners of the London Marathon from 2013 to 2021

2

awareness raising campaigns

11

drugs and treatments we've been involved in

12,115

contacts from over 3,000 individuals to the Support Line (November 2021)

77%

of contacts were new to the Support Line (2020–21)

85

sarcoma information resources, including 33 dedicated factsheets and information booklets

2

National awareness polls with YouGov – these established that 75% of UK population don't know what sarcoma is

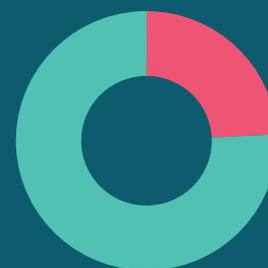
+3.5 million

impressions (3,533,765) on our social media platforms in the last 12 months

100,000

social media engagements in a year on average

In every pound:



76p

goes into research, information, campaigning, support and education

24p

is spent on fundraising activity, administration and governance

Team Sarcoma is back on track for marathon

With a virtual team and a London event, Sunday October 3 2021 was memorable for each and every one of our 116 amazing Team Sarcoma runners.

Our dedicated champions smashed those 26.2 miles and their personal fundraising targets to make a difference in this most special year for the charity.

Up and down the country, 46 virtual runners completed their own races in their own locations for their own unique reasons.

In London, the enthusiastic Sarcoma UK cheering squad got our 70 runners round, despite the changeable weather of sunshine and showers.

A post-race reception at Church House Westminster saw celebrations, reunions and much-needed sports massages. Another milestone was Sarcoma UK's first time hosting a stand at the Excel Centre – a fantastic opportunity to meet our runners.

Ben Bate set a new Guinness World Record for Fastest Marathon Dressed as a Body Part (male runner), with a time of 03:49:14.

As well as the record books, Ben made it onto the BBC TV coverage of the day while Rhino Man Gavin Metson, running for the second year, was featured on BBC Newsround and CBBC.

Many congratulations to all our superstar runners who have raised an incredible £400,000 plus (including 2020 fundraising) – you are simply the best.

A big thank you goes to the volunteer cheer squads, Zac and sports therapy students from the University of Worcester, and Ian Randall and Sam Rockman for photography.



Ten years of 26.2 miles

- 2012** One silver place
- 2015** 24 people raised over £80,000
- 2017** 45 runners raised over £135,000
- 2018** 64-strong team who raised £250,000
- 2019** 68 runners raising over £260,000
- 2020** First ever virtual race in October with 35 runners who raised £300,000 to date



Team Kennedy

Jo Kennedy went the distance in Kent with her children Olli and Rachel, plus Rachel's boyfriend Liam, as Team Kennedy. Their motivation was Jo's husband Fraser who died from sarcoma in 2019.

"None of us are seasoned runners so we have a long way to go to be able to run 26 miles," said Jo before the race.

"Very tough virtual run along the Kent coast but very thankful for the opportunity of running for Sarcoma UK and proud of our achievements! We had a great day."

Team Kennedy has raised £2,160 for Sarcoma UK – thank you!



Mark Hiley and Neil Madden – The Analyst

The 26.2 miles completed by Mark Hiley and Neil Madden is just the latest commitment in ten years of support from independent equity firm The Analyst. Mark is Managing Partner and Founder, and Neil is Partner & CEO.

This incredible partnership was the legacy of Jonny Scriven, diagnosed with advanced sarcoma while The Analyst was being established by Mark, and has gone from strength to strength. Their support, beyond fundraising and awareness, has seen a valuable relationship flourish between its team and Sarcoma UK.

"I really enjoyed the day. It really brings home just what a difference the organisation and supporters make," says Mark.

"At times it took my breath away seeing the charities and stories on the run."

Mark and Neil have so far raised £5,824 from the marathon, The Analyst having donated more than £890,000 to Sarcoma UK to date. We are so grateful for everything they do.





Photos by Ian Randall
ianrandallphotography.co.uk



Rob Uren

Rob Uren ran for Sarcoma UK after experiencing first-hand the different that the charity can make in terms of support and information. He was diagnosed in April 2020 with an epitheloid sarcoma and has been cancer-free for over a year. Eighteen months on, he's conquered the London marathon and raised over £4,000.

"Just want to say thanks to Louisa and Enda and everyone at Sarcoma UK London Marathon Club 2021 for all of your support along the way - you guys are awesome. I'd love to do it all again!"

Rob has said that the voice of clarity and reason provided by the Support Line was invaluable at a time when Google was the only real source of information.



Team Tom

The dedicated team were hoping to raise £100,000 from the 2021 Virgin Money London Marathon, after taking part in the first ever virtual race in 2020.

Kirsty Makin and friends ran in memory of her husband Tom who died of osteosarcoma in 2019 aged just 29 years old.

Team Tom's line-up was Luke, Juke, Ryan, Ashleigh, Fliss, Kirsty and Ben, fresh for the success of their virtual marathon in 2020. The team powered through their target to raise over £103,000 - and still counting.

"Thank you to the whole team for organising the cheer stations and after party!" said Kirsty on behalf of Team Tom.

"It was really emotional for us to clap each of the runners into the room knowing they have been on a similar path to us. Heartbreaking and inspiring all at the same time!"

"So proud of Tom's Team for completing the London Marathon in memory of my best mate Tom Makin. We miss him every day," said Luke Drogan.



Oli Corri and Charlotte Hallgren

Oli and his sister Charlotte ran in London in memory of their sister Phoebe. Oli originally signed up to do the 2020 marathon, and Charlotte started to join him during his training so also took part.

"Witnessing the extraordinary bravery and strength that Phoebe showed every day inspired us to try and accomplish something that we thought was totally beyond our reach.

"We like to think that Phoebe didn't lose her fight against sarcoma. She just passed the baton onto us."

Phoebe Omerod-Goss died in 2019, aged 24, after a year-long battle with retroperitoneal sarcoma.

"Massive well done to everyone for yesterday and for all the money raised, was so lovely getting to meet some of you on the course. So proud of being part of this team."



Team Steph

Team Steph comprised of nine women - Jan Cornell's two daughters and two nieces, one of whom completed the 26.2 miles with five friends.

Their motivation was Jan's daughter, Stephanie Darling, who died in 2019 from angiosarcoma of the heart, but had herself completed the London marathon, aged 26.

They chose four different marathon routes. Daughter Deb ran the London Marathon in a brilliant three hours and 44 minutes while her sister Ali ran a route which took her past all of the places that were dear to Steph.

Niece Lizzie walked a huge circle in and around Chelmsford Town while the other niece, Irena, and her five friends (pictured) walked the coastal path from Benfleet to Shoeburyness - and back again.

"It was bright, sunny, windy and showery weather but as with many other occasions where we have celebrated Steph's life, the rain lashed down and a wonderful rainbow appeared!" says Jan Cornell.

To date, Team Steph has raised £10,900.00 for Sarcoma UK - a fantastic contribution and achievement by all.

Our progress in Policy and Public Affairs

It's been a few years of change for Sarcoma UK's policy and public affairs focus, with a growing team dedicated to focusing on key issues.

The last decade has seen improved access to treatments, better data and greater awareness among politicians. However, there is still plenty to be done.

Early diagnosis is now the biggest issue, with the charity determined to achieve change in this area that is so critical for the sarcoma community.

The commitment to campaign for earlier diagnosis – key to giving sarcoma patients the best chance of survival – led to the publication of a milestone report, *Delays Cost Lives*, in 2020.

Now the Policy and Public Affairs team has expanded in recognition of the importance of this issue.

As part of the new organisational strategy commitment to early diagnosis, we will soon be welcoming an Early Diagnosis Officer, who will focus on bringing the sarcoma community together to improve the speed and accuracy of the diagnosis of sarcomas.

This role will look to change the health system, working on projects across all areas of the sarcoma diagnostic pathway with internal and external stakeholders.

In 2019, there was an important advance in morcellation, which is when tissue such as the uterus or fibroids is cut into small pieces to be removed more easily. This was partly thanks to the contribution of Sarcoma UK campaigning for women considering this as a treatment to have the information they need.

Revised guidance from the Royal College of Obstetricians and Gynaecologists now covers consent as well as new information for patients about the procedure and the risks as well as treatment options.

In August, NICE published new morcellation guidelines which further ensure that patients (and their families and carers, as appropriate) are given adequate information about the procedure's safety and efficacy, and understand any uncertainties. This includes signposting to our collaboration with the Royal College of Obstetricians and Gynaecologists.

"We welcome this guidance and are also very happy that our call for more research into outcomes of this procedure has been followed," says Bradley Price, Policy and Public Affairs Manager.

The more insight and information about sarcoma patients, the better the potential for understanding and influencing. The most recent National Sarcoma Survey saw 1,117 patients, parents of young sarcoma patients and carers add their voices for change to the future of sarcoma care.

The NHS England Sarcoma Service Specification in 2019 heralded the first time that all sarcoma services were commissioned to deliver the same level of care to patients across England. An overwhelming response truly demonstrated

the benefit of involving patient organisations. This outlined the importance of treatment in a sarcoma specialist centre by a sarcoma multi-disciplinary team.

Three approved drugs for sarcoma in the last decade are largely thanks to patient representations by Sarcoma UK.

Larotrectinib and entrectinib were both approved for use in England and Wales in 2020. These are 'histology-independent drugs' which target tumours based on their genetic make-up rather than where they are in the body. Trabectedin was approved in 2010 by NICE and thanks to input from Sarcoma UK, was recently made available for routine use in Scotland.

In 2020, Sarcoma UK's first parliamentary event helped showcase our work and put sarcoma firmly on the agenda. Recent public affairs activities such as virtual MPs meetings, webinars and a well-supported Early Day Motion in Parliament this summer have continued despite challenging times.

Partnership working remains key, campaigning with others in One Cancer Voice to put cancer patients at the centre of the pandemic recovery plans and the #NeverMoreNeeded campaign calling for more support for charities to keep going.

Now the future is about driving forward the charity's policy priorities and maximising the spotlight on the NHS and cancer care as never before.



Baroness Sugg runs the Virgin Money London Marathon

Liz Sugg joined our team in memory of her friend and colleague Chris Martin. Former principal private secretary to David Cameron, Chris passed away in November 2015 after a sarcoma diagnosis. His legacy has been a strong connection for the charity with Downing Street, including Sarcoma UK becoming Charity of the Year for No 10. Liz raised more than £7,000 – amazing work!

It's all about community – the enduring essence of support groups

The pandemic took the challenges faced by those affected by sarcoma to new heights.



However, the enduring spirit of the Sarcoma Support groups – local, email or online – ensures that community remains at their heart.

Eleven local groups spanned the UK from Scotland to the South West when Sarcoma UK as we know it officially launched in 2011.

The first online group was established in 2006, and the first face-to-face group followed two years later. Today the 16 support groups are truly part of the sarcoma community, whether local, (12), online (three) or via email (one).

Most sarcoma support groups are patient-led, working closely with local sarcoma Clinical Nurse Specialists or doctors. What unites them is regular contact with people who share and understand each other's experiences, in a variety of venues.

Some members particularly embrace the concepts of 'support' and 'community' as the most beneficial aspects for them, according to Sarcoma UK.

The down-to-earth, friendly people don't have all the answers but they can provide understanding, compassion or even just a cuppa and a biscuit!

Since the pandemic, groups have been meeting virtually, if at all. As Connect went to press, they were hoping that some face-to-face meetings may be happening soon, even before Christmas. Support comes in many forms, often social.

“Whether someone visits a group once or is a regular member, they take something away with them and feel a little less alone.”



That community feel also flows across the different groups. Wherever and however they operate, friendships and networks have flourished beyond the formal elements.

Even at the first Support Group Leaders networking event/workshop in 2019, it quickly became clear that leaders could gain a lot from sharing best practice and learning from each another.

This feeling has only developed over time as they have seen each other more, with a successful virtual get-together in June 2021.

Sarcoma UK is due to host another Support Group Leader event in 2022. It is hoped that this will provide another opportunity to demonstrate the value of peer support.

The groups are run independently but supported by Sarcoma UK. Newer groups benefit from the experience of more established members, especially at network days, as well as sharing friendship and best practice.

The Gynae Sarcoma email support group was formed some years ago by Shirley Collings, branching off from the main sarcoma email group. It was felt that groups of women may feel less comfortable talking in person about personal issues that were specific to gynaecological sarcomas.

“The email group might not have numerous emails on a regular basis, but this does not hinder the warm, friendly feeling among the email group. We know we can post a question at any time and there will be someone who can understand and reply to the email for support or advice,” says Karen Delin, one of the leaders of the group.

Recently, the group relaunched on a different platform, transferring smoothly from Groupspace to Groups.io in April.

“This gave everyone a chance to log on, write a post and update everyone with how they are doing. Although there has been no other activity, it is just the knowledge that there are people out there to touch base with and ask for help.”

Karen runs the London Sarcoma Support Group, which continues to meet monthly on Zoom.

“There has been a huge benefit to Zoom meetings during Covid restrictions, allowing us to maintain a support network, especially when people can feel very isolated during lockdown. They have been a real help for those that may not be able to travel due to undergoing treatments, or time constraints. When we can meet face-to-face, maybe we will look at alternate months of meeting in person and on Zoom to support everyone we can.”

The best of the best – our fundraisers over the years

These heroes really know the meaning of a challenge. Over the last ten years, they have tackled just about everything you can think of and tested themselves to the limit. All these fundraisers have made a difference for those affected by sarcoma. Here's a handful of the charity's many highlights. Thank you all.



Birthdays with a difference for Barb

A triathlon for a birthday celebration? No problem at all for Barb Kelsey and friends. To mark her 65th birthday, they took on a triathlon involving swimming 65 lengths, cycling 65 miles and walking the Isle of Wight coastal path raising a fantastic £4,191 for Sarcoma UK.

Rewind five years and the challenge for Barb's 60th was a gruelling 216 mile hike. From Robin Hood's Bay to St Bees, the coast-to-coast adventure over two weeks raised £6,000.

Long-time fundraiser Barb supports us as part of Team ULegend in memory of her son-in-law, Andrew Wheddon. They have been raising money for the past nine years through the campaign begun by Andy and so far have raised an amazing £69,338.14, smashing their £65,000 target.



The incredible impact of Emily Travis

Emily Travis has had a huge impact on Sarcoma UK in all respects. Diagnosed with leiomyosarcoma in 2014, she supported us as a dedicated fundraiser, superb communicator and all-round awareness raiser.

In 2018, Emily, from Marlborough, Wiltshire, helped to organise a charity ball which raised over £13,000 thanks to the support of the local community. Tickets for the Town Hall event were snapped up within 24 hours. Even this summer, she shared her experiences of clinical trials during a webinar for Sarcoma Awareness Month weeks before her death. Emily, you continue to inspire us.



Carey Lander and Camera Obscura

Carey Lander was diagnosed with osteosarcoma in her leg in 2011. That didn't stop her travelling and playing keyboard with the Scottish indie pop outfit Camera Obscura.

The Glasgow musician was determined to do all she could to raise funds and awareness for Sarcoma UK, along with the band. Before her death in 2015, Carey's Campaign had surpassed all expectations beyond her £50,000 target and become the single biggest campaign in the charity's history. The fundraising continued in her memory, eventually topping £168,000 after worldwide support.

Carey was given a posthumous award – Special Recognition Award – at the Justgiving awards in 2016 which was accepted by her mum Eileen Lander. By speaking out and raising funds, Carey changed the sarcoma landscape significantly and was a groundbreaking supporter for Sarcoma UK.





Sunflowers for sarcoma

Most of us wouldn't be up for a 150 mile walk from Birmingham to London. But tackling this dressed as sunflowers? That was the mammoth challenge pals Dean Horwood and Jack Singleton completed this spring as they walked and wild camped along the canal route.

Their inspiration was Dean's wife Michelle, who lost her two year battle with sarcoma in 2020 aged 44. An incredible £12,100 has been raised to date, more than doubling the original target. What an achievement!

20 for 20 – back by popular demand

In autumn 2020, Sarcoma UK supporters stepped up for a unique fundraising challenge that brought together 20 rare and less common cancers.

Now it's back again by popular demand after helping to create something positive that everyone could take part in during the toughest times of the pandemic

The charities asked supporters to take on 20 challenges for 20 days, picking anything they liked based on the number 20. Together, these organisations exist to support and improve the lives of over 87,000 people every year diagnosed with rare and common cancers.

Nothing was off the agenda and the creativity we witnessed knew no bounds – indoor or outdoor, alone or with friends, you name it.

The campaign has such an impact that it was a finalist for a prestigious award – Charity Partnership of the year – at the Third Sector Awards 2021.

This year, everyone is just as enthusiastic, and coming up with new challenges – for instance, walking 5k over 20 days, or doing 20 sit-ups for 20 days!

Thank you to everyone who completed their own 20 for 20 challenge in 2020, and everyone who they inspired to go for it this year...it's not too late to join in [here](#).



James runs for mum

James Abrahams had chalked up over 71 marathons, give or take a few ultras, by summer 2020 when the pandemic derailed his running plans. Long-standing fundraiser James has taken on a number of different running events for our charity in memory of his mum, Karen Abrahams, and raised £2,800. He's also taken part in online quizzes to raise money for good causes. With events cancelled in 2020, James signed up for a virtual running challenge of 1,000 km to keep up his running motivation.

This autumn he completed no less than his 75th marathon in Chester – a course he had previously tackled in 2018. This most recent race was just a couple of weeks after completing an ultra challenge – the picturesque Chiltern 50.

We are so grateful for James' ongoing support – keep on running!



Sleeping under the stars for Sarcoma UK

Easter eggs were certainly earned by Ethan, Rory, Reece and Joel who took on a very different challenge in March 2021. Inspired by young Max Woosey who camped out for a year in his garden from the first lockdown, the brothers took to the great outdoors to raise money for Sarcoma UK. The Williams Boys Easter Holiday Camp Out raised £1,185 for the charity which was close to their hearts; their mum's cousin and goddaughter Phoebe passed away aged 24 after a year-long battle with retroperitoneal sarcoma. Who knew you could sleep out on a trampoline and in a playhouse as well as tents? What an amazing adventure.

The Wainwright Bagger – where it all began

The very first fundraising event of the new charity in 2011 involved not just a determined climbing team, but a dog. The Wainwright Bagger involved scaling seven named Wainwrights in the Lake District and the formidable Scafell Pike, the highest mountain in England. Sarcoma UK's fundraising challenges got off to a flying start with the £7,000 raised.



We've been expecting you, Mr Bond

The wait was over this autumn as *No Time to Die* finally hit the big screens – but Sarcoma UK got there first!

A select group of supporters were in for a treat as they got to see this year's must-watch movie even earlier than the official release date.

The exclusive screening of Daniel Craig's last adventures was thanks to their generous support of the charity and a musical link between sarcoma and the legendary James Bond movies.

The event came about due to the kindness and legacy of Derek Watkins, his widow Wendy and a friendship with Bond producer Barbara Broccoli.

Derek Watkins died in 2013 after a two-year battle with synovial sarcoma. An esteemed trumpeter who had played on every one of the 23 James Bond soundtracks from *Dr No* to *Skyfall*, Derek was recognised by his fellow professionals as the finest lead player of his generation.

Derek and his family had already supported Sarcoma UK through a fundraising campaign before his death. Wendy Watkins and granddaughter Carys who attended the screening were carrying on his legacy.

Richard Davidson, CEO of Sarcoma UK, challenged supporters to "one last mission – if you choose to accept it. We need to raise awareness of sarcoma symptoms and encourage people to go back to their doctors to get diagnosed."

Guests, including long-term supporters from the charity Geewhizz, enjoyed the film at NBC Universal Studios cinema in London's West End with dinner in the Bloomsbury Hotel.

As the charity's first event in 18 months, it kicked off the ten year celebrations and has raised over £30,000 for Sarcoma UK.

Richard Whitehead MBE clinches silver medal in Tokyo

Our Patron, Richard Whitehead, never ceases to inspire us.

In Tokyo this summer for the postponed Paralympics 2020, Richard took silver in the men's 200 metres T61 race, passing the baton to teenage Ntando Mahlangu from South Africa.

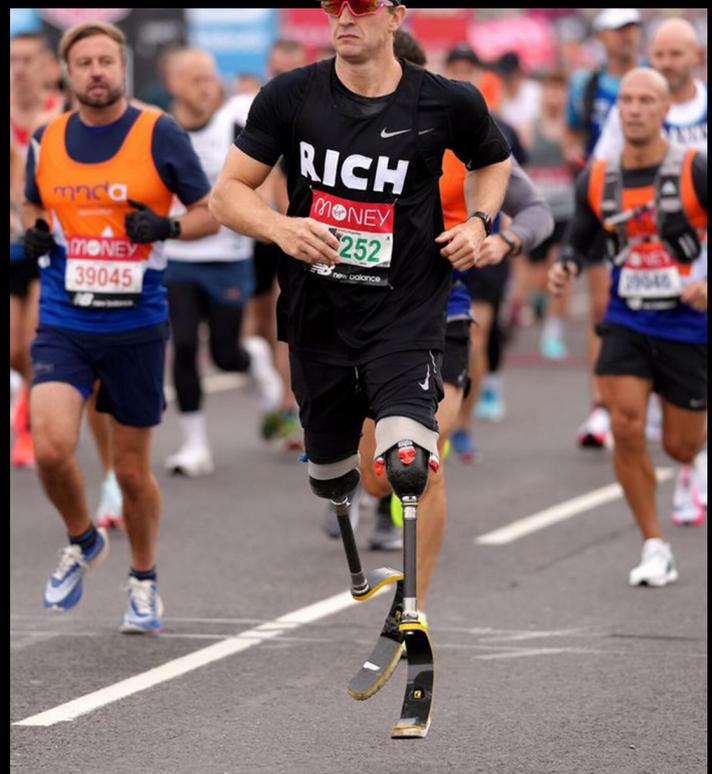
Richard's successes in the Paralympics are legendary, having achieved gold medals in Rio and London in the T42 200 metre races, and his legacy for other athletes cannot be over-estimated.

Despite having a raft of incredible achievements under his belt, Richard has always been hugely committed to Sarcoma UK and the sarcoma community from before he became a Patron in 2013.

Even before his Paralympian race, the champion took time to record a special video message for Sarcoma UK supporters on a day off from training.

Richard also sent a good luck video to Team Sarcoma runners in October's Virgin Money London Marathon. He delighted spectators by his own race – an experience he said 'made him feel like a rock star' – and finished in an incredible three hours and 33 minutes.

Richard, we couldn't be prouder to have you as our Patron.



How you can help us change lives

Sarcoma UK does not receive government funding and so relies on your generous donations. Our regular donors are unsung heroes who change lives through enabling us to plan for the future. John is one of them.



John Coles has been donating monthly to Sarcoma UK for more than four years. His support was inspired by the memory of his beloved wife Eleanor.

Eleanor was 51 when she died in 2017 from a soft tissue sarcoma which affected her abdomen. The couple had been married for 23 years after they met while John was on a business trip to Singapore.

“Eleanor had a strong Buddhist faith and making donations is a key element of Buddhism,” reflects John.

“I remember reading information from Sarcoma UK about the high mortality rate of sarcoma and the fact that this has not improved for decades.

“To me, that suggests there is insufficient research into sarcoma, its causes and treatments. Because sarcoma is not as common, or not as well-known, as other cancers, it does not get the same recognition and funding.”

After Eleanor’s death, John was motivated to find a new purpose in his life. He left his career in the aerospace industry and started his own travel company, **Kew Bridge Travel**.

“Eleanor and I enjoyed many travels, so I felt that the project was inspired by our time together.

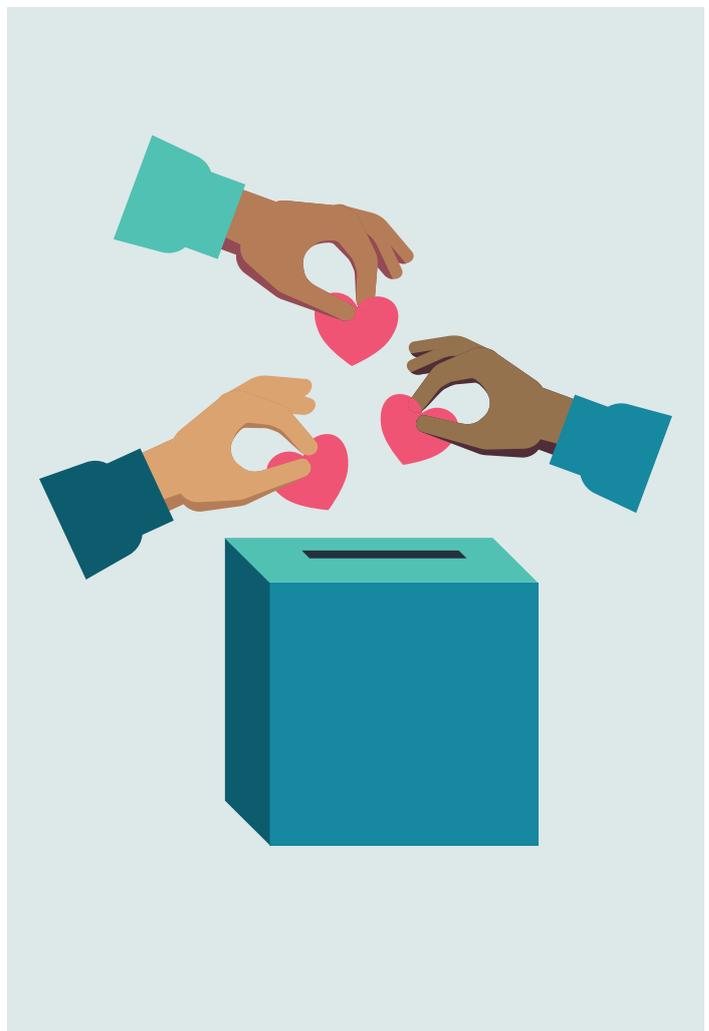
“I then thought to bring these two elements together and commit to donating 5% of profit from each client’s holiday to Sarcoma UK.

“I hope my contribution will help fund research, and mentioning Sarcoma UK on my company website will help raise awareness of the charity and its vital work.”

Thanks to people like John, we can continue our work and ensure everyone affected by sarcoma receives the best treatment, care, information and support available, and to continue to invest in treatments of the future.

We can’t thank you enough for your incredible support, which will transform the lives of everyone affected by sarcoma.

“Because sarcoma is not as common, or not as well-known, as other cancers, it does not get the same recognition and funding.”



Join our club of regular donors with a few simple steps on the website or call our team on **020 7250 8271**

Talking ten years of sarcoma research

The first ten years of the Sarcoma UK research programme have brought some remarkable achievements since our first research grants were awarded. Here we explore the key themes and programme highlights.



The last decade has seen Sarcoma UK invest in ground-breaking laboratory research, piecing together the biological mechanisms of sarcoma so we can identify it earlier and treat it effectively.

A major milestone was our £1 million Genomics Research Programme launched in 2018; key to unlocking the secrets of sarcoma and developing new treatments.

The first £250,000 grant was awarded to Professor Adrienne Flanagan for a study of the world's largest collection of genomic data from sarcoma samples. Further genomics project grants went to researchers at the University of Birmingham and the University of Southampton (see opposite page) who use cutting-edge technology to provide crucial knowledge about faults in single genes that lead to sarcoma and move towards translating this to new treatments.

“Now is the time to capitalise on our unique position and our research achievements to deliver on our ambitions. We will continue to push forward and translate progress in our understanding of sarcoma into improving treatments and, ultimately, making a difference to people’s lives.”

Dr Sorrel Bickley, Director of Research, Policy and Support

It's been heartening to see many of our smaller grants go on to have a large impact. In 2014, we awarded £31,000 to Dr Paul Huang at the Institute of Cancer Research to explore why patients develop resistance to the sarcoma drug pazopanib. Paul, along with PhD student Mark Elms, has built on this work with a second £120,000 grant, and found that a different drug, dasatanib, can be given to those who are resistant to pazopanib.

Our core research programme has enabled us to support thirteen PhD students in laboratories across the UK.

Our clinical research programme focuses on projects which can make an immediate difference to people with sarcoma. The Roger Wilson Research Award supports leading clinical research projects in areas of priority for sarcoma patients. Five years on, this enabled us to support the EORTC STRASS II trial, an innovative international trial improving treatment for retroperitoneal sarcoma.

As Connect goes to press, our latest grant rounds are in full swing. As well as the final round of our Genomics Research Programme, we have welcomed applications for projects exploring any kind of sarcoma research via our Open Grant Round. Applications are currently being peer reviewed by external sarcoma experts, who will ensure that only those of the highest scientific quality are funded.

This year, we have introduced Research Grant Lay Reviewers into our research programme. With personal experience of sarcoma, they have volunteered to help us identify the research questions which are most important and relevant to patients.

Thanks to our support for the best and the brightest minds in the sarcoma research community, substantial grants, major new trials and new treatments have all demonstrated advances in science at a time when supporters have told us that research is their top priority.

The next ten years will see our research programme evolve even further to make the most progress for people affected by sarcoma. We will build new collaborations with other charities and promote further integration with the research community. As we look to the future, with patients even more at the heart of our research programme, we will broaden our horizons to build an even more ambitious research programme to achieve real change for people affected by sarcoma.

“Research is at the heart of everything we do. It has never been more important for us to keep pace with scientific advances so we can make the biggest possible difference to all those affected by sarcoma.”

Richard Davidson, Chief Executive



Karen Sisley – an early grant holder

Dr Karen Sisley was awarded one of Sarcoma UK’s first research grants in 2009 and is now a member of the charity’s Research Advisory Committee.

She is a Senior Lecturer at the Department of Oncology at the University of Sheffield with a specialisation in sarcomas and an interest in rare tumours.

Karen’s three-year project identified for the first time the genomic differences which define certain sarcoma subtypes. The success of this basic science project led to new sarcoma cell lines being developed and supplied to other international academic institutions. Cell lines are vital for creating a simple model of sarcoma for scientists to see how the cells respond to drugs in the laboratory. The cell lines created by the team are more reliable and realistic than earlier ones, so researchers can better assess how drugs might perform in patients and develop effective treatments for sarcoma.

“The support of Sarcoma UK was absolutely crucial in my research being able to generate further understanding about genetics and the potential for new treatments. It has been incredible to see how the charity’s ambitious research programme has gone from strength to strength with the potential for making a difference to people’s lives.”



Our third genomics research grant

This year we announced the third of four grants as part of our flagship Genomics Research Programme, which will see Sarcoma UK invest a total of £1 million in genomic research.

The £250,000 grant for a new project led by Dr Zoë Walters at the University of Southampton will explore the genomics of dedifferentiated liposarcoma, a particularly aggressive subtype of soft tissue sarcoma.

Current treatments for dedifferentiated liposarcoma can be ineffective, with debilitating side effects. Dr Walters and her team will take genetic information from patient tumour data to identify specific genes which play a part in the development of dedifferentiated liposarcoma. This knowledge will then allow them to target these genes with drugs, and explore if there can be a more effective treatment.

Genomic research like this will provide crucial answers about sarcoma, and push us forward to finding better treatments.

Interestingly, Zoë Walters was part of a team awarded one of the very first grants made by Sarcoma UK for a one year project at the Institute of Cancer Research.

10 YEARS OF SARCOMA RESEARCH:

63
research grants awarded

100+
presentations and workshop sessions by our grant holders to date

£4,282,597.80
committed in research funding

83
papers published as a result of our research funding



Go Gaz! Hero pedals his way into national awards

Gareth 'Gaz' Emmerson is something special. Not only has he achieved a gruelling 1,000 mile fundraising challenge and got married days after, he has now been recognised for his phenomenal work with a top award.

Eight years ago, Gaz, now 28, from Shrewsbury, was diagnosed with Ewing's Sarcoma. In November 2020 he found out his cancer had returned for a fourth time. But a terminal diagnosis has not stopped him wanting to make a difference to others.

When he decided to create a bucket list of all the things he wanted to achieve, there was a big ambition for Sarcoma UK – to raise as much money as possible to help those in the future with this condition.

"I wanted to find a focus, something positive – you've got all this negativity around scans and cancer," says Gaz.

Gaz set out to cycle 1,000 miles in 12 days, as part of an eight-strong team of close family and friends.

Team Gaz Emmerson biked from Land's End to John O'Groats in June, raising an incredible £115,853.

After training while going through chemotherapy, the ride certainly pushed

him to his limits – injuring his knee on day two. But there was incredible support for his team as they hit the headlines and raised awareness of Sarcoma UK.

"It's been special to do it with a close group – we push each other. I tried to zone out for a lot of it and just think, I'm doing this, I've got to keep going."

In October, Gaz was delighted to be announced as the winner of the prestigious award of Pride of Britain Fundraiser for London ITV Region. His story featured on ITV News and promoted a renewed interest in both his challenge and the charity.

The Daily Mirror's Pride of Britain Awards is the biggest awards show of its kind on British TV and was screened on ITV in November.

"A huge thanks to Sarcoma UK for the nomination," says Gaz. "I genuinely couldn't have picked a better charity to fundraise for."

"I couldn't be prouder of Team Gaz Emmerson's fundraising total and everything that came after my decision to do the bike ride."

Gaz certainly doesn't do things by halves. Just a week after the cycle, he and fiancée Zoe – part of the team – got married at the Eden Project. And if that wasn't enough, he's now setting his sights on the next fundraising target for 2022 with an even bigger team.

"It takes a really remarkable person to get a terminal cancer diagnosis and immediately channel everything into doing something positive for other people," says wife Zoe Homer-Emmerson.

"We know very sadly that the great research Sarcoma UK is funding isn't going to benefit Gaz because of time, but it will benefit the children, the young adults and the teenagers who are diagnosed with his type of cancer in years to come."

Thank you

"We really couldn't keep on doing the work that we do without people like Gaz," says Kerry Reeves-Kniep, Director of Fundraising and Communications at Sarcoma UK.

"The phenomenal amount that Team Gaz has raised has really enabled us to keep our investment in research and support going. There is no doubt that all that he and his team have done will save lives."

"We are so grateful to Team Gaz and everyone who supported their amazing fundraising challenge in so many different ways."

Our Founder Roger Wilson CBE - then and now



Today's Sarcoma UK owes its existence to Roger Wilson. Roger was diagnosed with a soft tissue sarcoma in 1999. Three years later, he started work on what has now become Sarcoma UK with his wife Sheelagh. In 2011 he led the handover of Sarcoma UK and its associated charity, the Sarcoma Trust, in a restructuring before the official launch of Sarcoma UK as we know it today.

The journey began in 2002 when Roger joined the NCRI Sarcoma Clinical Studies Group. Since then his interest in patient advocacy and cancer research have spanned involvement in NICE guidance, the British Sarcoma Group and Sarcoma Patients Euronet (SPAEN), of which Roger has been president since the start. Sarcoma UK has named an annual research award after him (see page 12).

How does it feel to reach this 10 year milestone?

I'm delighted to be alive! I deliberately took a step back in 2011, when the official launch of Sarcoma UK was being planned. I was approaching 65 and thought I should take it a bit easier. It didn't quite work out as planned, especially with recurrences and other health considerations.

It's not easy stepping back; some people make a serious mistake by not doing so. It felt like a bit of foresight and wisdom. I look back and think 'thank god I did.'

What are you most pleased about for Sarcoma UK?

It was a great delight to hear that we were going to start a telephone helpline (Support Line) in 2016. I knew way back that was a service that was needed.

I was punching the air as if I had scored a goal. They have done an amazing job. That's the signature event that stands out.

How about your CBE in 2011?

This was completely out of the blue. I came home one evening to open the envelope and my jaw dropped. I had no idea that this was going on. I was deeply flattered by the steps taken by those in the sarcoma community. And I met the Queen!

How were you impacted by the pandemic?

Because of my disability Sheelagh travels with me - we have a 'well-worked system.' We'd been in Europe just three weeks before lockdown and it was a slightly weird world to come back to. But the growth of Zoom, for instance, has meant that I have more routine involvement as a patient than I would be able to have otherwise. I'm leading on patient involvement in three clinical trials and am involved with other studies too.

"As a patient, I am impatient; I want things to change, and change rapidly."

What else are you focusing on?

At SPAEN, we're developing a closer relationship with the Connective Tissue Oncology Society (CTOS), based in North America - the international association of sarcoma clinical researchers. We are developing a robust plan for how patient groups worldwide can work together with specialists on the research agenda. It focuses on how we can agree on priorities and how we can talk positively together about research issues and our experiences.

What are your hopes for the sarcoma community?

At SPAEN, we set out to create partnerships with professionals and now have significant relationships in Europe and the US.

We want to make this truly worldwide. We can talk together, agree our challenges and respect our differences. The best, maybe the only, way we will move the sarcoma agenda forward is by working together internationally.

And for Sarcoma UK?

I would really like to see a sustainable funding structure so that whatever we might be hit with in the future, the core organisation can be kept in place with committed people competent to rebuild as necessary.

Richard Davidson (CEO of Sarcoma UK) and the Trustees have done a stunning job during the pandemic by taking a cool, hard look at what needed to be done and where we wanted to be. So my hope for the future is a secure organisation with a focus on sarcoma.

Sarcoma Awareness Week – ringing the changes

From photo awareness campaigns and picnics to social media takeovers and supporter fundraising, Sarcoma Awareness Weeks – and one month – have looked very different over the years. Here’s a few of the highlights.

It was such a key moment for the sarcoma community that the official launch of Sarcoma UK was timed with Sarcoma Awareness Week (SAW) in June 2011.

An inspiring film called ‘All in it together – living with sarcoma,’ was premiered at the launch and featured real life experiences of living with sarcoma.

By 2012, the week was firmly in the calendar, with a creative awareness campaign targeting GPs with golf balls piloted in Birmingham.

 The charity also called on people to support a photo awareness campaign, ‘All in it together – the many faces of sarcoma.’ The result was a website montage of anybody touched by sarcoma.

Sarcoma UK’s tireless supporters were out in force; a 570 mile trek by Guy Hinton along Italy’s Via Francigena raised more than £10,000. Twenty Kent Police Probationers tackled a variety of fundraising challenges after a close friend and colleague was diagnosed with sarcoma.

In 2013, a new campaign encouraged people to share their stories as well as photos. Sarcoma Voices – calling for people to speak out – was born to help raise awareness and improve services.

A new national learning initiative to raise awareness of sarcoma among medical students and trainee doctors was developed by the Royal Liverpool and Broadgreen University Hospitals NHS Trust.

The On the Ball campaign, focusing on early diagnosis and information for GPs, went national in SAW 2014 with a launch including Patron Richard Whitehead MBE. Ultimately, 1,600 GPs received information packs and golf balls – almost three times the initial target!



An event with the charity’s researchers and scientists discussing their vital work, Talking Research, kick-started SAW 2015 and was attended by 130 people.

A poll in 2015 around awareness of sarcoma revealed 53 per cent of people had not heard of sarcoma and was the basis for renewed efforts to spread the word.

A film ‘What is Sarcoma?’ and an online photo exhibition ‘Sarcoma and You’ made SAW 2016 the most successful yet. The film was viewed 10,000 times.



In 2017, supporters were urged to join in a new initiative, the Big Picnic. This year also saw the launch of the Sarcoma UK podcast series – five episodes based on the most frequently asked questions to the Support Line.

Our impact was growing as SAW 2018 saw more than 850,000 people reached through social media plus 35 pieces of media coverage

In 2019, a Downing St reception launched the Sarcoma UK Genomics Research Programme.

Even though 2020 was like no other year, the Great British Picnic carried on, now running from May until October.

In 2021, SAW became a month and launched a year of events to mark the charity’s 10th anniversary. Under the theme *People make Sarcoma UK*, those who have been here since the beginning and those along the way were in the spotlight.

People were encouraged to ask their MP for a meeting to talk about sarcoma. There was also a digital time capsule and social media takeovers by patients and scientists.

Whatever 2022 brings, it’s clear that an awareness date – week or month – is here to stay for the sarcoma community.



A truly Great British Picnic

Seasoned fundraiser and Great British Picnic Champion Natalie Ellender has been fundraising for Sarcoma UK since 2018, in support and memory of her friend Lisa Pidgeon, who passed away in 2019.

But her dedication was tested in the pandemic as events were cancelled. Finally, a much-awaited extravaganza went ahead at Sandall Park, Doncaster, raising a fantastic £5,000, in July 2021. There were rides, stalls and even a mini Crufts-style dog show! We are so grateful to Natalie and Lisa’s family and friends for their support.





Sarcoma UK
The bone & soft tissue
cancer charity

10th
Anniversary



Christmas Carol Concert

AN EVENING OF CHRISTMAS CAROLS, FESTIVE READINGS
AND SOLO PERFORMANCES IN AID OF SARCOMA UK

sarcoma.org.uk/christmas21



ST PAUL'S
CHURCH
COVENT GARDEN

Wednesday 8 December

The Actor's Church, Bedford Street,
Covent Garden, London WC2E 9ED

020 7836 5221

www.actorschurch.org



Adapting and evolving – five years of support

Since 2016, the Support Line Service has grown and evolved to meet the needs of its users. We hear from two people with very different experiences of sarcoma about what the service has meant to them.



“From the very first time, I was talking to someone who knew not only my condition, but also the teams treating me and the procedures. I had never heard of sarcoma. My whole life was thrown upside down and I was in a spin.”

Lisa’s story

Lisa Hall, 58, lives in Elstow, Bedfordshire with her husband who is a farmer. In 2019, she was diagnosed with an aggressive form of de-differentiated chondrosarcoma. Following a limb salvage operation, further recurrences eventually meant the only option was major surgery, removing her left arm and shoulder.

She first heard about Sarcoma UK’s Support Line via Macmillan, among information that she’d been given at her first consultation but ‘didn’t want to look at.’

“From the very first time, I was talking to someone who knew not only my condition, but also the teams treating me and the procedures.

“I had never heard of sarcoma. My whole life was thrown upside down and I was in a spin.”

Lisa considers herself a strong person who has supported other people through different cancers, but found that others, too, had no idea about sarcoma.

“My friends and family were fantastic, but it hit them hard as well. For me, talking to someone outside them, who was being practical, answering my questions and providing reassurance about the procedures, was invaluable.

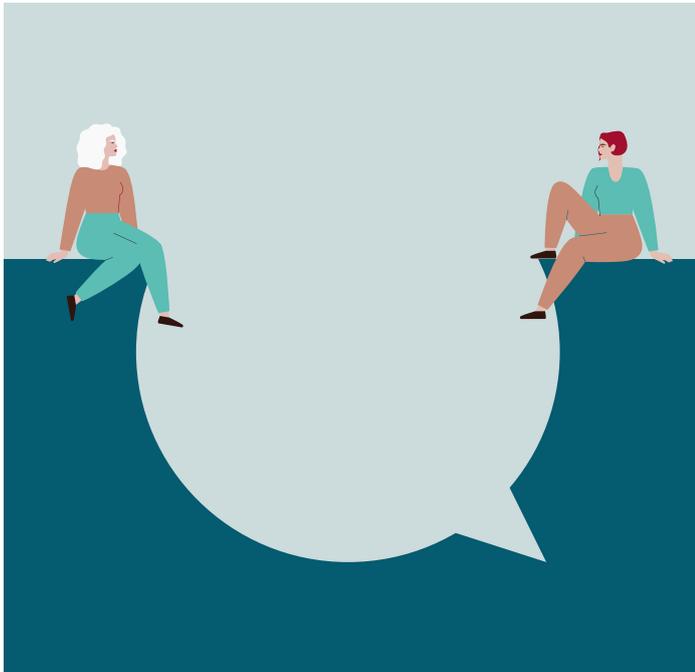
“I needed a shred of hope. I felt that if I am going through all this, I can find something. I was in freefall.

“Sam and Helen have so much experience (as sarcoma specialist nurses on the Support Line), and I didn’t feel so isolated. Acceptance is key; with my amputation, they were fantastic, reassuring me about the team, and how fit and well I was for the surgery.”

Lisa has remained in contact and is now involved with the charity in other ways, such as the recent Scanxiety study, and a webinar for Sarcoma Awareness Month.

Her advice to others facing a similar situation is to contact the Support Line.

“It is the most important support I have ever had. I don’t think I would be as I am without them. They really got me through those vital first few days and months.”



“I just didn’t know where to turn. It was easier to talk to someone who knew what they were talking about. I picked up the phone and spoke to Helen. She’s the most wonderful person. Sometimes we speak and sometimes we email.”

Elizabeth’s story

Elizabeth Baker, 59, is a mother of two with one grandson, aged seven. She lives in Huddersfield and works part-time in her family business.

She first came into contact with the Support Line when her daughter Charlotte, now 31, was diagnosed with a very rare sarcoma – extraskeletal giant cell osteosarcoma – for which she underwent surgery and chemotherapy three years ago.

The first time the family had heard of sarcoma was when Charlotte was first referred to a specialist clinic. A Google search came up with the Support Line details.

“I just didn’t know where to turn. It was easier to talk to someone who knew what they were talking about.

“I picked up the phone and spoke to Helen. She’s the most wonderful person. Sometimes we speak and sometimes we email.

“I’ve also spoken to her colleagues. It all flows – you never have to explain again who you are.

“I wanted to know as much about sarcoma as I could, and Helen explained everything to me in simple terms for someone not from a medical field. It was just someone saying, look, we are here for you, which has made all the difference.

“I do feel as if Helen has been a friend. She is so kind. I’d love to meet her someday.”

Elizabeth found that all the conversations have been useful, whether around diagnosis, or at different stages of the sarcoma journey.

“When you have a daughter and a grandson, bobbing along nicely, and this happens – my head went ‘boom’. Some people don’t have families to help them – who do you turn to then?

“For me it’s the right thing. I think I would have really struggled without it.

“The fear never really goes away, but the Support Line helps you take a step back, one step at a time.”

Our milestones 2016–2021

- An increasing number of complex calls to the Sarcoma UK office was the motivation behind the birth of the Support Line
- A new text service began in 2019
- While demand doubled within days of Covid-19, March 2021 was the busiest month to date
- We have had 12,115 contacts from over 3,000 individuals in five years
- Support, treatment, and diagnosis are the three main reasons for contact
- 2021 has brought new developments such as Zoom sessions on specific topics and health and wellbeing days
- The team speaks to anyone in the sarcoma community, for example, the person with sarcoma, or family, friends, GPs and hospital doctors
- The Support Line team has enabled 25% of people to talk to their families more about sarcoma.



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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