

10th Anniversary Impact Report: People Make Sarcoma UK



Sarcoma UK
The bone & soft tissue
cancer charity

10th
Anniversary

Welcome

This time marking ten years of Sarcoma UK has been like no other. Who could have predicted such challenges back in 2011 when the charity as we know it was born?



As we reflect on this milestone, there is much to be proud of. We cannot be complacent, but our progress in sarcoma research, awareness, campaigning and support has contributed to delivering on the charity's ambitions to make a difference for those who need us.

We have come a long way from our early days to advance in ways that we could never have imagined. While there simply aren't enough words to focus on every achievement, this report showcases a few of those key moments.

Here is the proof of how so many have played their part for all those affected by sarcoma. People make Sarcoma UK and it is all of you who ensured the charity continued and flourished. Even through the toughest of times, you have been behind us.

With the help of our dedicated supporters and our committed team, we can look forward with confidence to the next ten years.

Richard Davidson,
Chief Executive



10th
Anniversary

People make Sarcoma UK

The most incredible people have ensured Sarcoma UK has evolved into an organisation fit for the challenges of the last decade and more. The charity and its journey is all about those many people who have their own stories and their own unique reasons, like those featured here. Thank you to all the people who have made Sarcoma UK so far.



Roger Wilson CBE

"I am a sarcoma patient, and when I was diagnosed, there was no sarcoma patient organisation. Sarcoma UK started because I wanted to reach out to other organisations to raise awareness and fund research.

"Sarcoma UK is now a national charity and look at what has been achieved by our community. All of us. Working together. Working for each other."

Roger Wilson, founder of Sarcoma UK, who set up the Sarcoma Trust with his wife Sheelagh in the early part of the century.



Lindsey Bennister

"I've seen such a huge move forward for the sarcoma community since 2010 and it's been so wonderful to see the continued development of the charity, particularly around the area of policy and campaigns.

"I'm very optimistic about the future for research as well and I'm really excited to see the development of the genomics project. To now see that up and running is fantastic and it gives me great hope for the future."

Lindsey Bennister, Sarcoma UK Executive Director and CEO (2010 - 2018), who joined Sarcoma Trust as its very first member of staff.



Dr Karen Sisley

"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."

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.



Mel De Lacy

"I believe that in time, there will be a cure for this and other rare cancers and that we should never give up hope of finding one."

Mel del Lacy, mum, physiotherapist and dedicated fundraiser with a passion for an outdoor life and a great friend to Sarcoma UK. Mel was diagnosed with advanced metastatic leiomyosarcoma (LMS) of the uterus and passed away in 2019.



Richard Whitehead MBE

"The community spirit of sarcoma lives on. All those stories of patients are important, even those who may not still be here, and it's important to remember what we've done and the reason why we do it. We want to stop sarcoma and to have that positive impact."

Richard Whitehead, gold medal-winning athlete, longstanding supporter and first Patron of Sarcoma UK.



Ian Randall

"I'm very optimistic about the future for people affected by sarcoma. The amount of awareness about sarcoma has grown and grown and it's amazing to see."

A professional photographer and father of two sons, Ian Randall was diagnosed with Ewing's sarcoma in 2010 when he was 18 years into a career as a Fire Officer.

The story so far

The year 2021 marks the tenth anniversary of when we formally became Sarcoma UK. Here are some of the key developments in our journey.

“There was the most enormous buzz around the launch; we were doing something so significant and moving so fast.”
Karen Delin, Founder Trustee and former Chair

<div>2011</div> <div>Sarcoma UK officially launched at an event with National Cancer Director, Professor Sir Mike Richards Independent equity research firm The Analyst lends its support to Sarcoma UK</div>	<div>2012</div> <div>Sarcoma UK launches pilot Golf Ball campaign in Birmingham, aimed at raising awareness of sarcoma among GPs and the public First National Sarcoma Forum meeting for sarcoma nurses and allied healthcare professionals held in Birmingham and supported by Sarcoma UK</div>	<div>2013</div> <div>Richard Whitehead becomes first ever Patron of Sarcoma UK and receives an MBE First Sarcoma UK runner in the Virgin Money London Marathon</div>	<div>2014</div> <div>Survey and report, <i>Hidden Cancer</i>, which focused on gynaecological sarcoma, is published Launch of the nationwide ‘On the Ball’ campaign targeting GPs First <i>Understanding Sarcoma: A new patients’ guide</i> booklet published</div>	<div>2015</div> <div>NICE publishes Quality Standard for sarcoma First patient/ researcher event ‘Talking Research’ held in Manchester with Richard Whitehead First National Sarcoma Patients survey launched</div>	<div>2016</div> <div>Sarcoma UK becomes No 10 Downing Street’s Charity of the Year Launch of Support Line services</div>	<div>2017</div> <div>First Chris Martin Memorial Quiz Support Line reaches 1,000 contacts</div>	<div>2018</div> <div>Clinical trials hub established with over 3,600 page views in the first two months New sarcoma data published to help understand the disease Genomics Research Programme announced with first UK grant of £250,000</div>	<div>2019</div> <div>Sarcoma UK launches a new brand with a fresh, modern look Downing Street reception to launch the Chris Martin Fellowship Launch of NHS England Sarcoma Service Specifications Support Line extends and regulates its hours and introduces text service Publication of report, <i>The Loneliest Cancer</i>, launches Sarcoma UK’s biggest national awareness campaign</div>	<div>2020</div> <div>First parliamentary event to raise awareness of sarcoma among MPs First winners of the Tricia Moate award for allied health professionals and nurses First Glitter Ball held in London The Support Line team doubles in the face of Covid-19 Commitment to Early Diagnosis announced and first major policy campaign published with the backing of MP Jess Philips</div>	<div>2021</div> <div>Two new organisational and research strategies were launched We marked our anniversary year starting from Sarcoma Awareness Month (July) An Early Day Motion linked to Sarcoma Awareness Month was tabled by MP Marion Fellows Jake Quickenden became the first Celebrity Ambassador Team Gaz cycle ride was our biggest ever fundraiser at £116,253 and wins a Pride of Britain award – Fundraiser of the Year for the London Region</div> <div>Third genomics research grant of £250,000 awarded to the University of Southampton Sarcoma UK committed £50,000 to funding a major international clinical trial, EORTC STRASS II The 20 for 20 fundraising challenge returns for a second year An exclusive screening of the long-awaited James Bond film, No Time to Die, is held in London</div>
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Where we were... and where we are now

It's been quite a decade since Sarcoma UK officially launched in June 2011 – a single charity for sarcoma patients, carers and relatives which united the Sarcoma Trust and Sarcoma UK.

This exciting moment was marked by a glittering public launch with Professor Mike Richards and 100 guests at the London Transport Museum timed with Sarcoma Awareness Week.

Ten years on, the charity has evolved into an organisation fit for the challenges of the sarcoma community.

Since 2011, we've invested almost £4.3 million into scientific and medical research. We've helped more than 3,000 people through the Sarcoma UK Support Line. We've worked with national governing bodies, sarcoma specialist centres and many others to advocate for better and earlier treatments for people affected by sarcoma.

While we still have a huge amount to do, there is an awful lot to be proud of.

The importance of people in Sarcoma UK's evolution and achievements cannot be over-estimated. None of this would have been possible without you as part of that journey. From patients, support groups, volunteers, fundraisers and scientists, we at Sarcoma UK are looking to a future where we know we can make even more of a difference.

Never was the spirit of Sarcoma UK epitomised than in the summer of 2012. Four people representing the sarcoma community were honoured to be among the 8,000 torchbearers of the London 2012 Olympic

Torch Relay. Jordan Anderton, Paul Barden, Jo Bryant and Pippa Hatch made us very proud.

Before then, we had received our first donation from the amazing, gold-medal winning athlete Richard Whitehead MBE, who became our Patron in 2013, and continues to lend his tireless support. What better figurehead to keep inspiring us to overcoming challenges?

Our timeline (pages four – five) charts some of the many milestones of the last decade. There are the earliest days of our Support Groups online and in person and our first research grants. Other highlights are our first awareness campaign targeting GPs and the start of our links with No 10 Downing Street as we became Charity of the Year in 2016. It shows how we have continued to make an impact at the highest level through our campaigning and policy work, and for people affected by sarcoma through our expanding Support Line service.

In the midst of a pandemic, we stepped up to deliver for those who needed us most. Thanks to your support, we were able to start our anniversary year with the determination and confidence to continue and flourish.

We began 2021 with new organisational and research strategies – our road maps for the next five years to tackle sarcoma together. We know there will be challenges as well as opportunities and we need to be clear about how we will keep on track.

We have come a long way over the last decade, but we cannot afford to sit back. With your help, we can work toward a time when everyone affected by sarcoma has the treatment, care and support they need. Here's to the next ten years.



Being there for each other: the power of support groups

The value of support groups was already clear when Sarcoma UK officially launched in 2011.

Eleven local groups spanned the UK from Scotland to the South West with the first online group established in 2006, and the first face-to-face group following two years later.

Today the 16 support groups are truly a key part of the sarcoma community, whether local, (12), online (three) or via email (one).

While they are often patient-led, working with local sarcoma Clinical Nurse Specialists or doctors, all are about regular contact with people who share and understand each other's experiences.

Venues like a community hall, cancer support centre or even a pub

help to keep the meetings relaxed, with a format of whatever works for members.

"People can talk about where they are on their sarcoma journey, the football results or whatever else is topical. We don't talk about sarcoma all the time, which is a good thing," says Barry Davis, who co-runs the Sheffield group with John Beedon.

"It's not a club we want to belong to but we are where we are and it's there if people want it or need it."

The groups have done their best to keep up contact, despite the pandemic inevitably pausing face-to-face meetings or resulting in virtual Zoom or WhatsApp gatherings.

Support comes in many forms, often social. Club HQ meets annually, despite being an online group, and the East Anglia support group

usually enjoys a summer lunch and a Christmas dinner.

With the Tricia Moate award set up by the charity, the Bournemouth support group now invites all the award winners to their annual anniversary meeting which fosters the links to their founder.

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.

"They are all run very differently but united by a common purpose," says Sarah Kingsmill, Information and Support Officer at Sarcoma UK.

"As Sarcoma UK has evolved, they have been a common thread; not only part of the team but a part of our history and future."

Our fundraising heroes

Sarcoma UK has benefitted from the generosity of so many dedicated fundraisers who have gone the extra mile to undertake all sorts of personal challenges in support of our work. We couldn't be more grateful to them. Here's a snapshot of what just some of them have been up to over the last decade.



A truly Great British Picnic

Natalie Ellender knows how to host a Great British Picnic in style. She has been fundraising for Sarcoma UK since 2018, in support and memory of her friend Lisa Pidgeon, who passed away in 2019. Over the years Natalie has raised over £10,000 through triathlons, bake sales and virtual challenges. As a Great British Picnic Champion, her incredible enthusiasm was tested in the face of the pandemic as events were cancelled. Fast-forward to July 2021 and the much-awaited extravaganza finally went ahead at Sandall Park, Doncaster, raising a fantastic £5,000. 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.



James Read

James is a marathon veteran with a difference. His wife Sarah was diagnosed with sarcoma a few weeks after their honeymoon in 2015. She died in 2018, three years after her diagnosis, and James has been doing everything he can to raise awareness of sarcoma as well as fundraise for Sarcoma UK. In 2016 he ran the Virgin Money London Marathon in a giant golf ball costume to highlight sarcoma to GPs in the On the Ball awareness campaign and is still running in that outfit. His multiple runs and fundraising challenges have raised a total of £60,414.74 through Fortis in Arduis Group Fund.



The Analyst

Ten years of an incredible partnership is another very important reason to mark 2021. Thanks to a commitment from London independent equity firm The Analyst, a valuable relationship has flourished between its team and Sarcoma UK. While the business has donated more than £890,000 to date, their support has gone well beyond fundraising and awareness. The relationship is the legacy of Jonny Scriven, diagnosed with advanced sarcoma while the Analyst was being established by Managing Partner and Founder Mark Hiley. Mark and his colleague Neil Madden raised more than £5,824 by running the Virgin Money London Marathon in 2021.

Marathon heroes over the years

From one silver place in 2012 to a 35-strong team in the very first virtual race in 2020, our Virgin Money London Marathon participants never cease to amaze. Each and every one has their own story and their own motivations, united over 26.2 miles. Over the years, in blistering heat and heavy downpours, the gruelling efforts of 413 runners have raised an astonishing £1,427,667.39 (2013 - 2021).



Team Gaz

The amazing Team Gaz took the nation by storm in June 2021 when they successfully completed their challenge to cycle from one end of the country to another. The inspiration of Gareth (Gaz) Emmerson, one of the dedicated riders, was more than enough to keep those wheels spinning tirelessly from Land's End to John o'Groats. Gaz was diagnosed with sarcoma in 2014 and has now been told his cancer is terminal. Friends, family and his fiancé, Zoe, joined him in the 1,000 mile challenge - followed by the excitement of their wedding just a few days afterwards. An incredible fundraising total of more than £116,223 for Sarcoma UK is set to make a big difference to our work alongside the invaluable awareness achieved through this venture. Gaz was delighted to be named as Fundraiser of the Year for the London Region in the prestigious Pride of Britain awards.



20 for 20 - a challenge like no other

In the midst of the pandemic, fundraising needed to look a little different. Sarcoma UK supporters threw their hearts into a unique challenge which brought together 20 charities behind rare and less common cancers.

This community approach came from a desire to overcome the challenges of Covid-19 which had stopped so many fundraising events and to create something positive for everyone to join in.

Supporters could pick anything they liked based on the number 20; 20 challenges for 20 days in autumn 2020. Baking, swimming, or arts and crafts - nothing was off the agenda.

Young Harley Stradling (pictured), now aged eight, did an incredible 20 bike rides of 10km which raised over £812.94 and earned her a well-deserved silver Blue Peter Badge!

The campaign was a finalist in the Third Sector Awards for Charity Partnership of the Year and was back for 2021.



Glyn Wilmshurst

Former Chair of Trustees at Sarcoma UK Glyn Wilmshurst and his wife Katy celebrated their 25 year wedding anniversary with a difference - by aiming high. The intrepid couple climbed Mount Kilimanjaro, despite the 5,895 summit being the snowiest in 15 years and raised £4,735.



Richard Dunwoody

Former champion jockey Richard Dunwoody trekked the length of Japan - 2,000 miles - with a 20kg rucksack in 2017. He chose to fundraise and raise awareness for Sarcoma UK as his nephew George, then 21, had sarcoma. George, who had represented Great Britain at the Junior World Rowing Championships in 2014, had been diagnosed with paratesticular embryonal rhabdomyosarcoma. Richard's amazing journey - the equivalent of a marathon a day for three months - raised more than £46,708.

The Wainwright Bagger

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. Their wet and windy weekend set the fundraising bar high by raising over £7,000. What an amazing start to Sarcoma UK's fundraising adventures.

A special thank you

Alongside our many wonderful supporters who take on their own challenges big and small are our regular donors. These unsung heroes continue to change lives though their important contributions which enable us to plan for the future. Thank you to all of you.

Sarcoma research – a momentum for change

Since we awarded our very first grants in 2009, our research programme has come a long way.

Supporting the best and the brightest minds in the sarcoma research community, Sarcoma UK has funded 63 research grants, investing a total of £4.3 million. 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.

Over the last 10 years, we've invested in ground-breaking laboratory research, piecing together the biological mechanisms of sarcoma so we can identify it earlier and treat it effectively.

One of the most significant developments has been our transformational £1 million Genomics Research Programme launched in 2018; key to unlocking the secrets of sarcoma and developing new treatments. Professor Adrienne Flanagan was awarded the first £250,000 grant for a study of the world's largest collection of sarcoma samples. This study has already spurred over £2.5 million in further research funding.

Further genomics project grants have now been awarded to the University of Birmingham and the University of Southampton, using cutting-edge technology to analyse the faults in single cells and taking the first steps to translating our new genomics knowledge to the clinic. Through our core research programme, we have supported 13 PhD projects in laboratories across the UK. We've also seen many small grants go on to have a large impact. For instance, our investment of £23,000 to Professor Gonzalez de Castro at Queen's University,

Belfast, has led to the development of a new blood test that could have the potential to diagnose soft tissue sarcoma twice as effectively as current methods.

Our clinical research programme has enabled us to invest in projects which can make an immediate difference to people with sarcoma. In recognition of our founder, we launched the Roger Wilson Research Award, which supports leading clinical research projects in areas of priority for sarcoma patients. Five years on, this latest award enabled us to support the EORTC STRASS II trial, an innovative international trial improving treatment for retroperitoneal sarcoma.

As we look ahead to the next five years, our research programme will evolve for us to make the most progress for people affected by sarcoma. We will build new collaborations with other charities as well as integrating with the research community. We are already bringing patients into the heart of our research programme, to ensure that our investments truly reflect the priorities of those affected by sarcoma, including pushing for early diagnosis and better treatments.

We hope that our research funding will serve as a catalyst to unlock further sources of financial support, enabling researchers to expand their work and ultimately translate their findings into patient benefit.



63

projects/grants to date

83

papers published as a result of our research funding

40%

of our research projects to date have focused on a single sarcoma sub-type

60%

of our research projects to date have been relevant to all sarcoma sub-types

“Our supporters told us that research is their top priority. They want us to invest in hope for the future. As a link between the patient community and the scientific community, Sarcoma UK can be the catalyst for change.”

Dr Sorrel Bickley, Director of Research, Policy and Support



Mark Elms – our first PhD student

Mark Elms was one of the first students supported by Sarcoma UK when our PhD studentship programme started in 2016. His studentship was the first Sayoko Grace Robinson Studentship – an annual award of a PhD studentship in sarcoma basic science in memory of Sayoko Grace Robinson, who died of angiosarcoma in 2014. Mark is now in the final year of his PhD at the Institute of Cancer Research.

His research project set out to discover the biological features of soft tissue sarcoma to understand why some patients don't respond, or become resistant to, chemotherapy drugs such as pazopanib and regorafenib.

Mark found that for those who develop resistance to pazopanib, a different drug might be effective. To build on these important findings, he is working on understanding the molecular pathways which make people resistant to pazopanib.

Many sarcoma treatments can only work well for a short time, or not work at all for some patients. Predicting how a patient might respond to a treatment would be game-changing for sarcoma, leading to kinder, more effective treatments and less crucial time wasted.

Our early funding of genetic research

With early diagnosis a key focus for Sarcoma UK, one way of improving this is knowing who is more likely to develop sarcoma because of their genes.

In 2011, Sarcoma UK gave Dr Beatrice Seddon and Professor Ian Judson a grant of £40,000 to set up a UK arm of the International Sarcoma Kindred Study (ISKS). This initiative, first established by researchers in Australia, created a register of genetic information from people with sarcomas and their families.

Along with the UK, 20 other sites around the world contributed to ISKS. In 2016, Dr Seddon and Professor Judson were co-authors on a paper using data collected from over 1,000 people across the globe.

Their findings revealed that about half of people with sarcoma are born with genetic mutations that put them at increased risk. This major breakthrough showed for the first time that the landscape of sarcoma risk is complex, and involves the combined effect of multiple genes. They also discovered some genes that could be potential targets for treatments with new or existing drugs, potentially helping to identify the best possible treatments for individual patients and opening the door to personalised care.

Improving quality of life through technology

An initial investment from Sarcoma UK into a six-month innovative technology project has unlocked a major new avenue of research and led to additional funding.

Following treatment, many sarcoma patients can have difficulties with physical tasks such as walking or climbing stairs, often putting them at risk of poorer health. In 2012, Sarcoma UK awarded a £30,000 pilot project to Newcastle Upon Tyne Hospital to use movement tracking technologies to tackle this issue. By using video game technology linked to simple daily activities such as standing or walking, the team could explore how best to support people going through rehabilitation after surgery.

The original project has now led to almost £90,000 of further funding in how to use tracking technology in this way. Researchers hope to use this information to create new outcome measures for clinical practice and improve patients' quality of life after treatment.

Policy and Public Affairs – how we've influenced and engaged

The last decade has seen a transformation in policy and public affairs work for Sarcoma UK, stepping up a gear in recent years.

There have been many key moments of influence, resulting in improved access to treatments, better data and greater awareness among politicians.

Early diagnosis is now the biggest issue, according to those who shared their insights to inform the charity's strategy.

The commitment to campaign for earlier diagnosis – key to giving sarcoma patients the best chance of survival – kicked off in 2020 with a ground-breaking report, *Delays Cost Lives*.

"We already knew that early diagnosis was a research priority, but everyone in the sarcoma community has a role to play in helping to achieve this and transform the outlook for patients, and this report can be the catalyst for change," says Bradley Price, Policy and Public Affairs Manager at Sarcoma UK.

In 2019, there was an important advance in morcellation, thanks in part to the contribution of Sarcoma UK campaigning for women considering this as a treatment for fibroids 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.

More insight and information are paving the way for better care of sarcoma patients. Two National Sarcoma Surveys in 2015 and 2020 have helped create a valuable pool of data for understanding and influencing.

The most recent National Sarcoma Survey saw 1,117 patients, parents of young sarcoma patients, and carers add their voices to make real change to the future of sarcoma care.

In 2019, 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.

This opportunity for people to have their say and change how sarcoma is treated prompted an overwhelming response, truly demonstrating the benefit of involving patient organisations. This outlined the importance of

treatment in a sarcoma specialist centre by a sarcoma multi-disciplinary team.

Genomics is a key part of the charity's research portfolio and is also helping to inform the latest drug advances. There have been three approved drugs for sarcoma in the last decade – key developments 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 offered the chance to showcase our work and put sarcoma firmly on the agenda.

Despite the pandemic, the charity has kept up its public affairs activities, such as virtual MP meetings, webinars and an Early Day Motion in Parliament generating considerable support.

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.

"The future is about driving forward the charity's policy priorities: building on the progress in early diagnosis as well as access to the best possible treatment in specialist sarcoma centres and psychological support for those who need it," says Bradley Price.

"We have a unique opportunity with the current focus on the NHS and pressure on cancer care to raise attention to the issues that have faced sarcoma and other rare cancers for years."



Marion Fellows MP

"It is a very aggressive cancer and it is not quite so well known. A lot of people have never heard of it."

"Sarcoma is one of those things that unless you are affected by it, you can go through life knowing nothing about it."

Our decade in numbers

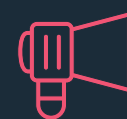
Total income: **£13,208,105.00**



£4,282,597.80
invested in research



£1,427,667.39
raised through the London Marathon

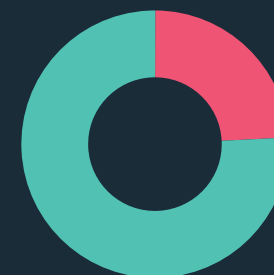


100,000
social media engagements, on average,
in a year – people actively liking, sharing,
and commenting on our posts.



12,115
contacts from more than 3,000
individuals to the Support Line

In every pound:



76p
goes into research, information,
campaigning, support and education

24p
is spent on fundraising activity,
administration and governance

Our Support Line: here when you need us

An increasing number of complex calls to the Sarcoma UK office was the motivation behind the birth of the Support Line in 2016.



The pandemic brought the toughest demands yet in March 2020 as everyone pulled together to keep telephone lines, emails and text chats open in the face of a large increase in contacts.

Confusion, changing information and anxiety were all part of their work with patients, their families and friends, as treatments and trials were paused and access to GPs limited.

The service has continually adapted its approach, grown and evolved to meet the needs of the service user, many of whom are people with sarcoma. Its breadth of knowledge has expanded through additional team members with different experiences, such as occupational therapy expertise and, most recently, a midwife with a wealth of bereavement experience.

After the first three years, the team had helped more than 1,400 individuals and gained more staff while increasing its opening hours to Monday to Friday.

A new text service began in 2019 providing a different way to access the service – more anonymous and perhaps more accessible for younger contacts. In July 2019, hours were regulated to the same every day.

It's quite a difference to when the team met 100 patients face-to-face as they went on tour as part of Sarcoma Awareness Week in 2016.

A large range of questions are covered by the small but dedicated team, ably supported by a Medical Advisory Group of clinicians.

Support, treatment, and diagnosis are consistently the three main reasons reported for contacting the Sarcoma UK Support Line which covers all type of sarcomas – soft tissue, bone and gastrointestinal stromal tumours. The team speaks to anyone in the sarcoma community, so that could be, for example, the person with sarcoma, or family, friends, GPs and hospital doctors.

The Support Line team reports that many people call because they have been told they might have sarcoma or get a letter to attend a sarcoma clinic, and they do not know sarcoma is a cancer.

Anxiety continues to be the highest disposition the team encounters, unsurprisingly in a completely unprecedented time which has affected everybody's lives.

While demand doubled within days of the Covid-19 outbreak, the busiest month the team has seen so far was March 2021. Three times as many people in the last year reported worrying symptoms (2020–2021). However, the Support Line team has enabled 25% of people to talk to their families more about sarcoma.

'The Support Line team feels that the Support Line is the beacon of what is happening in the real world for sarcoma patients,' says Helen Stradling, Support Line Manager.

'We have now spoken to more than 3,000 individuals over the five years and hear things before they get discussed as an issue nationally, which allows the charity to be at the forefront of making changes to ensure every person with sarcoma has access to the treatments they need and deserve.'

The Support Line team has collaborated with the Sarcoma UK policy team to take forward such issues as delays in surgery or access to treatments.

Cross-charity working has never been more important, demonstrated in swiftly collaborating with 22 other national cancer charities on producing advice during the pandemic.

While the true impact of the pandemic for sarcoma patients is yet to be realised, one thing is certain – the team is making a real difference.

'The Support Line team has been privileged to be able to help so many people over the last five years,' says Helen Stradling. 'We hope that we can continue to improve the service and we look forward to helping more people in the future.'

Thank you

Our sincere thanks go to everyone who makes it possible for Sarcoma UK to work towards a future where everyone affected by sarcoma has the treatment, care and support they need.

We do not receive any government funding and are fully reliant upon the generosity of our supporters.

Founder: Roger Wilson CBE

Patron: Richard Whitehead MBE

Celebrity Ambassador: Jake Quickenden

Trustees: current

Sharon Reid (Chair)

Sarah Conneally

Andy Eckles

Professor Ian Judson

Louisa Nicoll

Michael Parry

Sam Patton

Isla Robinson

Anjula Thompson

Jo Vass

Russ Wilson

Trustees: former

Karen Delin (former Chair)

Peter Jay (former Chair)

Glyn Wilmshurst (former Chair)

Lesley Abraham

Dr Jane Barrett

Professor Rob Grimer

Leigh Hibberdine

Ian Hughes

Nicky Meadows

Judith Robinson

Helen Stradling

Dr Jeff White

Sam Whittam

CEO: Richard Davidson

Former CEO: Lindsey Bennister



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Sarcoma survival rates have been very gradually increasing in the UK over the last two decades.



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