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Sarcoma UK
The bone & soft tissue cancer charity

Welcome to the winter edition of Connect

While this time of year can bring a slower pace, you'll see from these pages that we've only stepped up a gear in our commitment to those affected by sarcoma.

Our *Don't Delay* campaign for Sarcoma Awareness Month focused on the urgent need for early diagnosis, with personal stories that struck a chord with people across the UK. I make no apology for us continuing to highlight this issue and build on the campaign's success in raising awareness, particularly among audiences who have been harder to reach (see page eight).

We have reached an incredible milestone in our research investment, as ten new and innovative projects are given the green light this year with funding of £1.4 million. I'm hugely excited about the potential of this programme and the collaborations which are helping to make it possible – read more on pages 12–13.

Working with others is what we do best – and that applies to everyone in the sarcoma community. I'm delighted that our Involvement Network is going from strength to strength with close to 150 dedicated members who help us shape all aspects of our work and share their stories.

We are thrilled to benefit from the support of celebrities who go above and beyond in raising our profile. Footballer and author Dominic Ball, opera singer Mark Llewellyn Evans and TV presenter Charlene White have recently been announced as Celebrity Ambassadors and we couldn't be more grateful for their time and talents (see page 17).

It is with profound sadness that we learnt of the death of Pandora Cooper-Key. Pandora was an extraordinary individual whose impact on Sarcoma UK and the wider community cannot be overstated, particularly through raising more than £130,000 through a memorable carol concert at Christ Church Cathedral in Oxford.

This time of year is a golden opportunity to do something for and with others or remember loved ones. Whether you are enjoying a singsong at our own Carol Concert on December 10 or striding round the streets of London in a Santa outfit (see page five), you can be sure that your support is very much appreciated.

Wishing you all the very best for 2025 and our heartfelt thanks for everything you do for the sarcoma community.

Richard Davidson

Richard Davidson
Chief Executive

Inside this edition:

sarcoma.org.uk

Your greener Connect

Sarcoma UK is committed to looking after the environment. This publication is printed using paper sourced from well-managed sustainable forests and non-toxic ink. All resources are distributed with a minimum amount of shipping and recyclable packaging where possible.

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

Shining Star Awards are back – even bigger and better

It's the second year of our Shining Star Awards. As Connect went to press, the excitement was building for this very special event at London's Mansion House on Tuesday November 26.

And this year there are even more opportunities for recognition with an extra award at the ceremony hosted by TV presenter and Sarcoma UK Celebrity Ambassador Charlene White.

Ten awards cover the period June 2023–June 2024, including three which were chosen by you. They are:

- ★ The Gaz Emmerson Sarcoma Fundraiser of the Year for someone who has been an outstanding fundraiser for Sarcoma UK
- ★ Sarcoma Support Group Champion of the Year for a support group or individual in a support group who has made an outstanding contribution
- ★ Young Sarcoma Voice of the Year for a young person who has done something outstanding to raise awareness, provide support, raise funds or be an advocate.

Those selected by a judging panel are:

- ★ Political Voice of the Year
- ★ Sarcoma Healthcare Professional of the Year
- ★ Sarcoma Research of the Year
- ★ Volunteer Achievement of the Year
- ★ Partnership of the Year
- ★ Roger Wilson Inspiration Award
- ★ Charlie Hunt Group Fundraisers of the Year.

'We couldn't be more delighted to see the return of our Shining Star Awards,' says Kerry Reeves-Kneip, Director of Fundraising and Communications.

'It did not seem possible to improve on the amazing achievements and number of nominations for our very first awards – but somehow, our incredible supporters have outdone themselves yet again.

'So much is being done by so many people and organisations. This is our way to shine a light to thank, recognise, remember and engage those in the sarcoma community.

'We are honoured to be holding the ceremony at Mansion House and would like to thank host Charlene White as well as everyone involved in the many aspects of our awards.'

The winners and nominees of the Shining Star Awards 2024 will be unveiled at **sarcoma.org.uk/shiningstar** after the ceremony.

Tricia Moate Award winner from CNS team in Brighton

Sarcoma UK is delighted to announce Sarah Randall as the winner of this year's Tricia Moate Award 2024.

Sarah is a Clinical Nurse Specialist at the Royal Sussex County Hospital in Brighton. She was instrumental in establishing a Sarcoma CNS team at the hospital trust, having gained temporary funding from Surrey and Sussex Cancer Alliance.

As part of this award, Sarcoma UK sponsors allied health professionals (AHPs) and nurses involved in the care of sarcoma patients to attend next year's British Sarcoma Group (BSG) conference.

The award is in memory of Tricia Moate who worked tirelessly as a nurse and patient advocate for sarcoma before she died from sarcoma in 2018.

Sarah joins a host of worthy winners for the award, first given in 2020. The conference would bring networking and education opportunities, Sarah said. She believes knowledge gained at the event will enable her to draw up robust standards and guidelines for local services that feed into specialist centres – the ultimate aim is for these standards to be adopted by sarcoma networks across the country.

Her role involves providing information and support for patients on the diagnostic pathway; running nurse-led clinics for sarcoma patients; communicating with specialist sarcoma centres to provide seamless support for patients and ensuring all organisations involved in care have relevant up-to-date information and that patients remain 'in the loop' at all times.

Sarah also supports oncology clinics and provides ongoing support, information and advice for sarcoma patients in the hospital's catchment area. As well as leadership to junior staff members within the sarcoma and wider cancer CNS team, she is the lead for service development in sarcoma services at University Hospitals Sussex NHS Foundation Trust.

Sarah is an advocate of Sarcoma UK's work. 'I often push Sarcoma UK's Support Line and website to patients. I tell them, "if you are going to look things up on the internet, go to the Sarcoma UK website as sarcoma is very specialist and very rare."'

Every which way of fundraising for Sarcoma UK

From a crochet marathon to a world-famous road race, our wonderful fundraisers and their supporters continue to amaze us. Thank you all.

Three Peaks for Ryan? No problem!

The relatives of Ryan Balra from Buckinghamshire, who lived with osteosarcoma for eight years, pulled out all the stops to take part in the Three Peaks Challenge.

Ryan, just 24, faced his condition with incredible composure, continuing his education and supporting others throughout his treatment. His family wanted to carry forward his spirit of resilience and determination to honour his memory and raise funds for Sarcoma UK.

The 24-hour challenge in August saw the 17-strong team climb the highest mountains in England, Scotland, and Wales and smash their target of £20,000.

Needles at the ready for a heartwarming knitting and crochet fundraiser

A hobby was turned into hope for a father and husband who was undergoing his second surgery for sarcoma as well as raising awareness and funds.

Rachael Allen of Newark embarked on a 12-hour crochet marathon for her father Trevor who had surgery the same week.

Rachael and mum Tana were stationed outside the Co-op in Farnsfield to crochet and knit blankets. These were donated to Nottingham City Hospital where Trevor is being treated for spindle cell sarcoma.

'The first time we were told Dad had sarcoma was horrendous. Then we thought things were getting back to normal but now we are back at square one. To be told he has sarcoma a second time left us stunned,' says Rachael.

The family's creative challenge smashed their original target of £250 to raise an incredible £1,840.

'Crocheting and knitting is something we both like and I've not seen anyone else do this as a fundraiser. We are trying to turn our horrible situation into something positive and raise funds that will help other families who are going through the same thing.'

Help drive tomorrow's scientific breakthroughs and sponsor a scientist

Investing in research is our most powerful tool when finding a cure for sarcoma – and you can be part of this.

Could you give a monthly gift to go towards funding our innovative and inspiring sarcoma research? Your regular donation will go towards our research fund and help us plan for our future projects.

Your consistent support ensures cutting-edge programmes across the UK can push forward, accelerating discoveries far beyond the laboratory, which could save countless lives.

From as little as £1 a month, you can set up a regular gift by direct debit at **sarcoma.org.uk/sponsor-a-scientist** or scan the QR code here.

Sponsor a scientist today and help us rewrite the story of sarcoma.

Scan the QR code to set up your regular gift. **sarcoma.org.uk/sponsor-a-scientist**

> "We are so proud of everyone who took part in the Great North Run this autumn and raised more than £33,000."

A beautiful necklace with a special memory

Sarcoma UK is thrilled to announce a new partnership with Remember, a unique jewellery company that specialises in beautiful, discreet keepsakes. The exquisite pieces, known as Stanhopes, allow wearers to carry a miniature treasured photograph, hidden within an elegant necklace.

This collaboration offers a meaningful way to commemorate loved ones or memories, while also contributing to Sarcoma UK's vital work. The company was founded by Ollie Richer, a history enthusiast with a passion for memory and remembrance.

For every Stanhope necklace bought using the code SARCOMA, Remember will donate 20% of the proceeds to Sarcoma UK. The buyer will also receive a £5 discount. Visit **remember.co.uk**

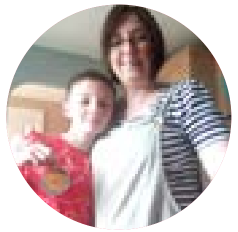
Getting into the team spirit with a virtual 5km

Hats off to the Tumour Team at the RJAH Hospital, Oswestry who all completed a Virtual 5km Challenge during Sarcoma Awareness Month.

'It was so super fun,' says Elaine Richardson, Macmillan Sarcoma Clinical Nurse Specialist, Montgomery Unit.

'We had about 60 runners and walkers of all ages!! People had entered from London to the Midlands and many from the local area.'

Quite a few shared the glory at the local Henley Wood park run with a competition for the best decorated race number.



Participants in the Montgomery team who were game to run, walk, roll or stroll in July raised a fantastic £664.

Get festive with a singsong or a Santa run

Christmas isn't Christmas without a carol concert – or a showstopping red costume! It's not too late to join us on Tuesday 10 December at London's St Giles-in-the-Fields for 7pm.

Everything is set for a fabulous evening of Christmas carols, festive readings and a myriad of special performances hosted by the ever popular Sarcoma UK Celebrity Ambassador Mark Llewelyn Evans. Tickets at **sarcoma.org.uk/get-involved/carol-concert/**

If you are after a great incentive to be festive season fit, look no further than Santa in the City!

Sarcoma UK is delighted to be the Charity Partner for the 3.5km race in December for the second year. Hundreds of runners, including staff and trustees from Sarcoma UK, had a ball in their seasonal outfits and you can join them.

Sign up for races in London (Dec 4 or 5) or Tunbridge Wells (Dec 7) at **santainthecity.co.uk**

Our biggest ever team takes on the Great North Run

An amazing 55 runners braved the half-marathon route from Newcastle to South Shields in September, all for a very special cause.

Our biggest ever Team Sarcoma joined a record number of runners all competing in the iconic Great North Run. And their months of training paid off with a collective total of more than £33,000 raised for Sarcoma UK.

Among the dedicated team were first timers and Great North Run regulars, family groups and friends.

Joel Tierney took part for the second year running, after his friend Lydia was misdiagnosed at the age of 21. This was later found to be a rare sarcoma – a Phyllodes tumour.

'The charity continues to fund research to prevent misdiagnosis and offered Lydia and her family lots of support during a difficult time.'

Three generations of the same family ran to raise awareness of the cancer that grandfather of ten and Sarcoma UK Ambassador John Young experienced.

Wife Sue, also a charity Ambassador, (John's step-daughter) Dr Vivienne Heaton, 48, and grand-daughter Lily Heaton, 21.

Steve Tostdevine was a fit and active 77-year-old. But within weeks of discovering a small lump on his thigh, he died from liposarcoma.

His wife June led a team of seven, running in Steve's memory and raising awareness and funds for Sarcoma UK.

A huge congratulations and thank you to our incredible Team Sarcoma, volunteer cheering squad, all those who lent their support, and our volunteer photographer Ed Spooner. It is a truly amazing event – even in the rain!

The latest in policy and public affairs

How our team is highlighting the issues that matter to the sarcoma community and building relationships with policy makers

State of the Nation review kicks off with a bang

This autumn, the Policy and Public Affairs team kicked off a major new project: our State of the Nation review of sarcoma services and treatment across the UK spanning England, Scotland, Wales and Northern Ireland. This ambitious project aims to get a thorough picture of how the NHS is looking after people with sarcoma, including what's working well, and where things could be better. We will be seeking the views and experiences of people affected by sarcoma, and those working in the NHS, as well as from government, researchers and other charities.

This project will gather evidence about the many issues in sarcoma care, such as government health policy and how the NHS is organised. It will also look into some of the key concerns that our supporters have told us matter most to them, such as early diagnosis, being seen by a specialist sarcoma centre, research into new and better treatments, and joined-up support for mental health and wellbeing.

> "This review will help us make the case for change in sarcoma services and treatment to the governments and the NHS across the four nations."

We are incredibly grateful that our review is being expertly supported by an Advisory Group – half of the people involved in the group have been affected by sarcoma, and half are healthcare professionals working in the NHS. Together they represent almost every part of the UK. The group first met in September and will use its expertise to advise us on how best to run the review and what evidence we should gather. We will meet with them throughout the project as we receive evidence and develop our findings and recommendations on what's working well and what needs to be improved. This will help us produce a report and action plan to make the case for change to the governments and NHS across the four nations.

More details about this project and how you can contribute are shown at **sarcoma.org.uk/SOTN** and shared on social media.

New Parliament, new connections

Since the General Election in July, the policy team has begun forging relationships with policy makers in the new government and Parliament.

After the summer break, we wrote to the new Secretary of State for Health and Social Care, the Rt Hon Wes Streeting MP, highlighting the need for urgent action on sarcoma. As Shadow Health Secretary, Wes Streeting advocated for earlier diagnosis of cancer. We also wrote to new Junior Health Ministers responsible for cancer prevention and cancer care. We are seeking meetings with the new Ministerial team and stressed the need for action on early diagnosis of sarcoma, better education for primary healthcare professionals, and more effective referral pathways to specialist centres.

We also plan to raise the need for more funding for research into sarcoma and new treatments with the new Secretary of State for Science and Innovation, the Rt Hon Peter Kyle MP, who leads this department responsible for science, research and development. We will highlight the need for faster action to make sure there is equal access to genomic testing for people with sarcoma, which can improve patient care, lead to more precise sarcoma diagnoses and enable more targeted treatment. We will also raise the issue of sarcoma in Parliament with the new intake of MPs and the Committees who hold the government to account on their promises to improve the NHS and cancer care. We'll also be arranging events in the devolved Parliaments as part of our ongoing efforts to increase our knowledge and presence in all four nations.

One Cancer Voice

In September, the Policy and Public Affairs team attended an event by One Cancer Voice, a coalition of over 50 charities working on behalf of the one in two people who will get cancer in their lifetime. The event gave Sarcoma UK a chance to discuss how to influence the new UK Government on cancer policy and NHS delivery, and to work with many other cancer organisations, such as Cancer Research UK, Young Lives vs Cancer, MacMillan, and Cancer52, which represents people with rare and less common cancers. Key opportunities include the new government's proposal for a Ten-Year Health Plan for the NHS and findings from an independent investigation by Lord Darzi, a Consultant Surgeon at Imperial College Hospital NHS Trust and The Royal Marsden NHS Trust. The investigation was commissioned by the new Health Secretary into the NHS in England, finding that cancer care still lags behind other countries, as well as considering how to address the unique needs of children and young people with cancer.

The event also included a discussion with a former Special Advisor to the previous Government on how to effectively engage ministers and departments on our policy priorities, with valuable insight on the inside workings of the Health Department. The afternoon was a timely and highly informative event, serving as a reminder that the new government's focus on NHS reform and clinical research is a window of opportunity to make real change for people affected by sarcoma.

Radiating light after darkness

After several weeks of high intensity proton beam radiation to treat his skull base chordoma tumour, David Ly turned his mask into a work of art.

'I remember the feeling of complete and utter darkness. I was strapped down with a hard plastic mask moulded to my head and with only small holes to breathe through. For about an hour a day, five days a week, up to nine weeks, this was my routine. One false move and I could lose my vision forever (or so I thought). A giant two-storey machine circled around my head, delivering an unfathomable amount of radiation to tiny spots of residual tumour. I wanted to turn this dark and horrible experience into something bright and positive.

'My journey started in 2020, just as Covid-19 spread and lockdowns changed us all forever. I had just turned 40 when I started to get some strange intermittent double vision. I had never had a major illness before or even been admitted to hospital. So I didn't think anything of it until a fortuitous trip to the optician started a year of hospital treatments and anxious phone calls. A 23mm suspected chordoma was on the base of my skull, a one in a million bone sarcoma pushing against my pituitary gland and likely blocking a cranial nerve.

'It took six agonising months with two endoscopic surgeries and a craniotomy to debulk most of the tumour and get enough margin to be accepted into the Proton Beam Therapy Programme. I'm so thankful to the neurosurgery team at the National Hospital for Neurology and Neurosurgery for their magician's work.

> A chordoma is a bone sarcoma that develops in the cartilage cells – they make up 37 per cent of all bone sarcomas.

'Proton Beam Therapy (PBT) is a radiotherapy that uses a beam of high energy protons to treat specific types of cancer like chordoma. There are just over 100 specialised centres in the world that can do this. We're fortunate to now have two centres in the UK, at The Christie Hospital in Manchester and UCLH in London.

'When I started PBT in December 2020 at The Christie, there was so much debate about wearing facemasks to protect against Covid-19. And there I was, with this customised mask that could help extend my life. So I wanted to shine a positive light on the mask and reflect its positive energy.

'Fortunately I found Paul O'Farrell, an East London-based artist and costume designer, who helped me turn this vision into something real and beautiful.

'The glitter represents those invisible protons circling around my head. The 'hair' is the positive energy hopefully putting the beast to rest for good. It's warrior armour – a literal reflection and reminder of what I went through.

'I realise that for some the mask can also be a negative trigger, and that's OK too. I was fortunate that I didn't get too claustrophobic and my side effects were manageable. I have so much empathy for the children and young adults who must endure it.

'There is a national charity that works with children to paint masks, but I haven't found anything similar for adults. One day I hope to collect photos of all these beautiful masks from patients of all ages for display.

'My hope is that this helps brighten up someone's journey and shows them that there will be light at the end of the tunnel.'

David Ly is a member of the Sarcoma UK Patient Involvement Network, a Chordoma Foundation and Chordoma UK Ambassador and a Bone Sarcoma Peer Mentor.

Sarcoma Awareness Month campaign drives home 'Don't Delay' call

Did you see our July campaign on early diagnosis? This year's activity reached more people than ever before.

From media coverage to digital engagement, this awareness-raising initiative was a massive success in highlighting the importance of 'don't delay' when it comes to sarcoma.

Here's a snapshot of our impact across the board:

- 265 media mentions in July, spanning national, regional and specialist media
- Potential audience reach of 4.11 billion
- 5,646 views of our Sarcoma Awareness Month (SAM) website page
- A 53 per cent increase in overall website traffic compared to June
- Total social media followers grew to over 34,000
- Billboards in London, Birmingham, Manchester, Liverpool, Bradford, Swindon potentially seen by 1.65 million people
- Over 30 supporters who participated in our campaign photoshoot
- 251 SAM packs with key information sent out to organisations and healthcare professionals.

This year's campaign built on the success of 2023's *Does Size Matter?* initiative and was a fantastic opportunity for everyone to get involved.

'Our *Don't Delay* campaign has reached an incredible amount of people this summer with remarkable engagement across the board,' says Enda Guinan, Digital Communications Manager at Sarcoma UK.

'In particular, the personal stories shared by Darrell, Jake, Kripa, and Rhadika really struck a chord in highlighting the importance of early diagnosis.

'There's a long way to go and we will continue to work toward the day when the word sarcoma is immediately recognised for the devastating disease it is and the need for swift action.'

A young colleague inspires bank staff to fundraise in her memory

Employees at the London branch of German bank Berenberg have raised £85,000 for Sarcoma UK in memory of a colleague.

Lily-Rose Bury joined the UK office of Berenberg on their graduate programme in 2021. Two months later, she died aged 20 as a result of sarcoma cancer diagnosed during her third year at university.

A small lump on the side of her foot grew significantly over a few months. Lily-Rose was diagnosed with rhabdomyosarcoma which had already spread to other parts of her body.

Despite this, she finished her physics degree, achieved a first-class grade, and began working at Berenberg.

Four staff members – David Mortlock, Laura Janssens, David Hogg, and James Burt – ran 25km over 1,000m of elevation in the Lake District to raise money for Sarcoma UK. They have contributed £85,000 to the fund in Lily's name, now at almost £154,000.

Berenberg has long been involved with golf and some famous golf names such as Gary Player, Tom Watson, Fred Couples and Mark O'Meara donated.

'We all still think of Lily-Rose and her courage,' says Laura Janssens. 'Given her diagnosis and the horrible illness she was fighting, to have achieved a first-class degree and started her career in banking was a remarkable achievement. It is hard to comprehend the magnitude of what she went through, but she would never let it define her.'

'Lily-Rose Bury was a remarkable young woman whose courage and resilience in the face of sarcoma moved us all,' says Sarah Thorn, Philanthropy and Partnerships Manager at Sarcoma UK.

'This generous donation from Berenberg employees in her name will fuel breakthroughs in research and treatment, ensuring other young lives are not tragically cut short.'

Donate to Lily-Rose's fund at **justgiving.com/campaign/lily-rose-bury-fund**

Sarcoma UK has funded a project looking at rhabdomyosarcoma – It looked at why rhabdomyosarcoma cells can resist treatment and will hopefully result in new treatments.

Rhabdomyosarcoma develops in the skeletal or voluntary muscles of the body. There are an average of 112 cases of rhabdomyosarcoma diagnosed every year in England – less than three per cent of all soft tissue sarcomas.

How a life-saving partnership transformed the future of Sarcoma UK

Ever since the charity's inception, it has been fortunate to benefit from the support of one company – The Analyst. Even during the tough times of Covid, the financial independent research house saw them offer much-needed early and increased support.

Recognition of that collaboration, now spanning over 12 years, came with one of the first Shining Star Awards for Partnership of the Year, accepted by Founder and CEO Mark Hiley.

The motivation was Jonny Scriven, a co-founder and friend of Mark's. Jonny was diagnosed with a rare sarcoma, PNET (Primitive neuroectodermal tumour) aged just 32 and died a year later in 2011.

Since 2012, The Analyst has generously given Sarcoma UK a percentage of profits that would have gone to Jonny. But the commitment has now evolved far beyond the annual funding support, currently £1.1 million.

Based in Clapham and started as a blog, Mark describes The Analyst as 'small in our industry but we've gone past being a startup.' He was delighted to receive the award on behalf of the company, now with more than 20 staff, in recognition of a remarkable legacy.

'It was so special to be at Downing St. All the awards were a good reminder of just how many people do amazing things. It was great to be able to go back to the team and explain how much it means.'

His personal commitment has seen him run the London Marathon for Sarcoma UK twice, this spring wearing a bone costume.

'That was fun. I'd done the training so I knew I could get round OK and there is a really good energy with the crowds when you're wearing a costume. Towards the end my body started to break down. It took a while to recover.'

The Analyst colleagues have also run the marathon, with Mark's wife Sam having tackled RideLondon 100. The company has sold old IT equipment and gave the money to Sarcoma UK.

> **"They are not only the charity's biggest donor but also a truly valuable partner and friend to Sarcoma UK."**
>
> **Richard Davidson, Chief Executive of Sarcoma UK**

The sustained partnership allows the charity to make long term investments, says Mark. 'It's amazing how it has added up! We build our support into the budget – it's not just an end of year decision.

'It's part of how we run the company – part of our mission and ethos. The charity is like a stakeholder in the business. I know everyone there so well; the way they do business really aligns with our values.'

His proudest moments have been the tangible outcomes. 'It's been seeing the money going into long term research, and when we were able to add extra people to the Support Line when they really needed them.

'Raising £1 million for the partnership and having everybody there to celebrate (an event at Mansion House) was pretty special.'

The partnership is a major driver for Mark. 'Delivering it year after year and growing it also drives the main ambition for the business. It's all wrapped up into the same thing.'

And he is full of praise for Sarcoma UK. 'The problem is so big but the charity is so small. It really punches above its weight. But its impact is also disproportionate to its size. With other, bigger charities, our support would get lost in the mix. It feels like it makes a real difference.'

As for the future, there may be another marathon and a possible world record attempt for a human body part costume. Watch this space!

Thank you to everyone at The Analyst for your incredible support.

Our year in numbers 2023–2024

You can see at a glance just how we are making a difference in vital areas of areas such as fundraising, support and research.

We are delighted to continue to advance in our research investment, the people who we can help, the numbers of the public that we reach and more.

Thanks to your support, we're already building on our impact for 2025.

5,088
contacts to the Support Line team from 1,077 individuals – up by 30%

£3,840,681
Total income in 2023/2024

545.23 hours
spent on the phone

£8 million+
invested in research projects since 2009

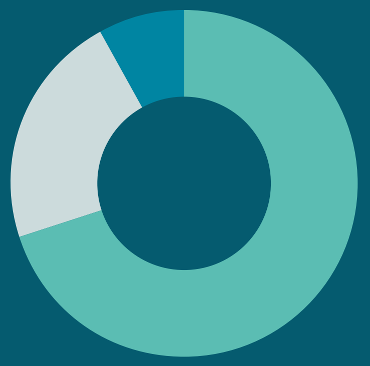
8/12 months
saw an increase in contacts to the Support Line team year-on-year

98
projects supported since 2009

265
media mentions in Sarcoma Awareness Month for our *Don't Delay* campaign

14
new projects funded in 2023/2024

For every pound we receive:



70p
is invested in research, information, campaigning, support and education

22p
is spent on fundraising activities

8p
is allocated to reserves to support our mission in the coming year

£1.53 million
invested in sarcoma research projects in 2023/2024 – our biggest ever amount

26+
people affected by sarcoma involved in reviewing research applications

The latest in research

We are accelerating progress in sarcoma diagnosis and treatment, thanks to you.

Research investment tops £8 million with 10 new grants

Ten new and innovative research projects are to be funded by Sarcoma UK – with collaboration the key to a bigger investment than ever before.

And the announcement of the latest grant round means that the charity's total research commitment will be over £8 million since its very first grants in 2009.

Sarcoma UK is delighted to be collaborating with the Sarah Burkeman Trust and GIST Cancer UK on specific grants, enabling more funds for this important research.

Grants have been awarded to top institutions across the country in Newcastle, Southampton, Birmingham and London ranging from around £49,000 to £149,000.

These ten projects aim to further understanding of sarcoma, unlock the potential for better and more personalised treatments, and improve quality of life for those with sarcoma.

Key themes include investigating new treatments harnessing the immune system to fight cancer and discovering who will benefit most from which treatment.

Scientists will learn more about the interactions between cancer cells and healthy cells, how this affects the way sarcoma develops and how to prevent this.

Other projects will focus on the patient experience and how care and support can be improved to ensure the best possible quality of life for people with sarcoma.

'We are thrilled to be committing over £1.4 million across ten important and innovative projects, with focus on investigating new and better treatments, and gaining deeper knowledge of sarcoma with the aim of improving outcomes, quality of life and personalising care,' says Dr Sorrel Bickley, Director of Research, Policy and Support at Sarcoma UK.

'We are delighted to be collaborating with GIST Cancer UK and the Sarah Burkeman Trust. Together we can accelerate progress in sarcoma diagnosis and treatment.

'This programme would not be possible without the generosity of our supporters and we are hugely grateful for their time and donations.'

The new funded projects revealed:

Investigating markers on cells in leiomyosarcoma for precision medicine led by Dr Paul Huang at the Institute of Cancer Research

Reactivating the immune system to tackle osteosarcoma that has spread to the lungs led by Professor Agi Grigoriadis at King's College London (in collaboration with the Sarah Burkeman Trust)

Identifying the 'Achilles heel' of a genetic change in GIST to design better treatments led by Professor Sarah McClelland at Bart's Cancer Institute (in collaboration with GIST Cancer UK)

Understanding what helps and hinders children with sarcoma be physically active after treatment led by Dr Morven Brown at the University of Newcastle

'Sleeping cells': preventing resistance to chemotherapy in osteosarcoma led by Dr Lucia Cottone at University College London

Understanding how Kaposi's sarcoma responds to immunotherapies led by Professor David Pinato at Imperial College London

Engineering on a microscopic scale: mimicking how leiomyosarcoma spreads in the body led by Professor Darryl Overby at Imperial College London

Making better models of liposarcoma led by Dr Zoe Walters at the University of Southampton

Reassurance or anxiety – how does the intensity of monitoring for sarcoma after surgery impact patients' quality of life and survival? Led by Dr Laura Magill at the Birmingham Centre for Observational and Prospective Studies (BiCOPS)

Using the power of a supercomputer to improve outcomes in GIST led by Dr Dean Bryant at the University of Southampton (in collaboration with GIST Cancer UK).

Two new projects:

Reactivating the immune system to tackle osteosarcoma that has spread to the lungs

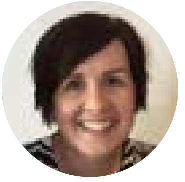
Osteosarcoma is one of the most common types of primary bone cancer, but treatments have not significantly advanced for decades. Outcomes can be especially poor when the sarcoma has spread to the lungs.

To develop better treatments, we need to understand how tumour cells spread and grow in the lungs. This is the focus of Professor Agri Grigoriadis at King's College London, awarded £50,000.

Cancer cells can hijack key immune cells which can make chemotherapy less effective. By understanding the specific ways osteosarcoma cells do this, researchers can create a way to reverse it and kick-start the body's own defence system, enhancing the effects of chemotherapy.

Understanding what helps and hinders children with sarcoma be physically active after treatment

Adolescent and young adult sarcoma survivors are less physically active than non-cancer peers, and often to peers with different cancer types. There is also a lack of support to help them engage in physical activity.



This £49,746 project led by Dr Morven Brown at Newcastle University will speak to childhood, adolescent and young adult sarcoma survivors to understand their barriers to physical activity, gain knowledge of the physical activity they need and want, and identify relevant behaviour change techniques to increase engagement in physical activity. This will inform the development of an intervention to support and improve levels of physical activity, with the ultimate aim of reducing poor health.

Getting to know you – our PhD students

Our recent PhD Student Network Meeting was a day packed with debate and discussions.

Students from locations ranging from Oxford and Sheffield to London and Birmingham joined Professor Janet Shipley of the Institute of Cancer Research and Clair Lupton from our Involvement Network.

Clair kindly shared her experience with sarcoma and offered advice to the students when considering the lay perspective and involvement in grant applications.

The regular meeting provided an invaluable opportunity for our students to share their groundbreaking research, discuss the future of sarcoma treatment, and gain insight into the experiences of those living with sarcoma, as well as the importance of patient voice in research.

A core principle of Sarcoma UK's research strategy, *Finding Answers through Research*, is to develop the next generation of research leaders. The charity proudly supports PhD projects in labs across the UK, but this commitment goes beyond funding, as this long-term opportunity in connecting them as a valuable student network demonstrates.

'It was a wonderful day, with lots of useful discussions and interesting questions about the variety of projects and paths the students can take next,' says Kate Quillin, Research Manager at Sarcoma UK.

'Thanks to your support, we are funding PhD students who are dedicated to uncovering the answers that could lead to the sarcoma treatments of the future.'

> "Thank you so much for organising. I thought it was a really useful event and Clair was fantastic."
>
> **Matthew Marzetti.**

The impact of Sarcoma UK research; a UK-led initiative to personalise sarcoma treatment

The Sarcoma Genomics England Clinical Interpretation Partnership (GeCIP) led by Professor Adrienne Flanagan analysed sarcoma samples to identify genetic markers associated with different types of sarcomas.

At the time of funding, this represented the largest amount – £250,000 – Sarcoma UK had so far invested in a single project (as reported in *Connect* Summer 2019).

£250,000

The largest amount Sarcoma UK had then invested in a single project

They found correlations between clinical and genetic features and patient outcomes and concluded that genetic testing at diagnosis can help guide clinical monitoring and prognosis. In chondrosarcoma, the team at UCL found a group of mutations that could aid more accurate prognosis if investigated at diagnosis. In adamantinoma the team gathered data to make this one of the most comprehensive studies of this unique sarcoma subtype.

The team optimised techniques such as a long-read sequencing, resulting in improved turnaround times for the delivery of whole genome data in the clinical setting. To date, this work has led to the publication of 14 papers and secured over £2.75 million of further funding to continue this impactful work.

Amelie's story – five years on

In 2019, Connect featured little Amelie Callanan who had had her leg amputated, just days before her sixth birthday, after a diagnosis of Ewing's sarcoma, chemotherapy and surgery.

Today, Amelie's determination and zest for life remains unchanged. She appeared onscreen at this year's Glitter Ball and is one of the nominees for the Young Sarcoma Voice of the Year 2024 at the Shining Star Awards.

We caught up with mum Emma to hear all about Amelie, aged 11, starting secondary school and with big sporting ambitions for the Paralympics.

All change

The last five years have seen a few changes. The family moved house in Surrey and had a new addition, Ted aged three, who Amelie is 'really good with.' Amelie started a new school and her passion for sports remains undimmed.

A great friend to Amelie was Amputee Bear, a cuddly teddy bear with an amputation and a glamorous tutu. At the time, Amelie was passionate about ballet and this was an easy way for her to relate to what was happening.

'She was only five, so she didn't really understand the word cancer. She had some questions but she didn't really know what to ask because she wasn't quite aware of the enormity of the situation.'

'I didn't really know what it was, and then everyone was trying to explain it to me, but I didn't really understand,' says Amelie.

Diagnosis

'Amelie was experiencing pain in her leg which went away after three to four months and then we noticed swelling. We took her to the doctors and at that point they were very quiet as there was clearly a problem.

'That point of diagnosis was a total shock. Even to GPs, it sounded like something that wasn't very common.'

Amelie had the best possible treatment, but the tumour had also spread to both her lungs.

'We were then told there would be two options - a rod or an amputation. And about a minute later, he said it's gone to both her lungs. You just want to scream - I did scream. Your whole world just falls apart.'

Amelie's treatment worked very effectively in reducing the tumour and eliminating the sarcoma from her lungs before the amputation.

'The doctor said to us - we treat to cure. And we latched onto that.'

Before the amputation above her knee, Amelie worked with physiotherapists at University College London Hospitals. They had a teddy bear which Amelie already loved.

'They amputated the bear, put a dressing on and put a tutu on the bear. It was to try to help her understand what was going to happen, and that she was going to come out the other side - and carry on being Amelie.

'They turned it into, like a mini Amelie, wearing a ballet dress.

'She had the surgery, she was lying in the bed and almost from then, it was a huge sense of relief. Her leg is gone but so is the cancer. And Amelie, she's still our little girl.'

Within a few months, Amelie was bouncing on the trampoline and back on a scooter. The hospital school was also vital for the family.

'They helped Amelie to gain confidence, feel normal and gave her a sense of routine. But they challenged her too.'

Amelie still has Amputee Bear and loves dancing and performing for her mum with her younger sister Georgia, aged eight.

And despite school life being 'full on,' she's thrown herself into different sports. She is rowing weekly with Paralympian double gold medallist Rachel Morris who is 'a bit of a role model.' As well as loving skiing, swimming, football, tennis and netball, Amelie is horse riding once a fortnight.

At the time of this interview, Amelie was really excited about the Paralympics and interested in 'her' categories. She was also settling into her first year at secondary school – at first nervous but looking forward to wearing a blazer!

> "I want to be like a Paralympian. I'd like to swim the channel and raise money for sarcoma."
>
> **Amelie Callanan**

How does it feel to look back?

'It seems weird – in some ways it feels like a life that didn't really happen. It sounds ridiculously naive but I didn't think you could get cancer in your bones. It didn't even cross my mind.

'My perception of cancer was that you would have a really poorly child and Amelie just wasn't that child. So it was quite a shock to us when we got that diagnosis.

'It felt really lonely at the beginning because I'd never heard of it. No one that I spoke to had really heard of it. And it's scary when you just don't know what it is you are dealing with.

> "At the beginning, you just get through each stage, and we've moved away from that."
>
> **Emma Callanan, Amelie's mum**

Sarcoma UK and us

The family's involvement with Sarcoma UK has increased over the years since the 'bit of a blur' around diagnosis.

'At the time, there was only one information source and it was all really helpful, really useful and easy to read.

'Sarcoma UK has helped us feel really supported as a family, to feel that there are people looking out for us and that we're not alone They have stayed in touch, checking in on us and encouraging us.'

What would you say to other parents in a similar situation?

'Your children are amazing and will find inner strength you didn't think was possible. But it's your child's journey, no one else's so try not to compare yours to others. People REALLY want to help, so don't be afraid to lean on people and tell them how to help. You need to be assertive, advocate and fight for your child.'

Amelie today

Five years on, Amelie's most recent of her regular scans was all OK.

'I want to be like a Paralympian. I'd like to swim the channel and raise money for sarcoma,' says Amelie.

'Something that stands out is Amelie's level of determination and grit - I'm not just saying that as her mother. People who know Amelie say she's got something really special - it's what got her through her illness, but it's that drive that gets her through every single day.

'I just feel so proud of her because there's nothing that she's not going to do.'

The Sarcoma Parents Support Group which meets virtually has been running since March 2024. It was founded by Kate Munday-Hoctor after her daughter Amber's experience with synovial sarcoma. More information about all groups can be found at **sarcoma.org.uk/support/support-groups/find-a-support-group/online-support-groups/**

Sixth Support Group Leaders day generates ideas and insight

The annual get together of Support Group Leaders in Birmingham was a great opportunity for collaboration and creative thinking as well as conversation.

Always a valuable way to share insights and experience, the autumn day had a packed programme but also time to catch up on how the year has been going for the different groups, both online and face to face.

As in previous years, the main aim of the day was to bring the Support Group Leaders together to share ideas, discuss challenges and successes and plan the way forward for the growth and development of the groups.

It was a pleasure to welcome Roger Wilson CBE, Founder of Sarcoma UK, and his wife Sheelagh. Roger fascinated the attendees with his presentation on the journey and role of the Sarcoma Patient Advocacy Global Network (SPAGN).

All the debates and discussion of the day were this year captured in a highly creative way thanks to Caroline, a talented illustrator from the company Inky Thinking.

As well as useful updates from all areas of work of the Sarcoma UK team, with Community Fundraising Manager Emily Williams also present, the morning focused heavily on small group work.

Leaders were encouraged to discuss topics important to them and to ask questions to gather ideas to further develop their group.

> **“Very, very informative, inspiring and relaxed.”**
>
> **Support Group Leader**

‘It was great to be back together at the Priory Rooms with some familiar faces and welcome some newer members,’ says Carly McDonald, Support Line Advisor at Sarcoma UK who oversees the groups alongside Support Line colleague Ellis Lill.

‘Hearing first-hand from people about how they support those affected with sarcoma and sharing their different ideas always brings home how important the network is.

‘Having Caroline from Inky Thinking was a definite talking point as well! We’ve already come away with some great ideas about the next day so we can’t wait to see everyone next year.’

For more information on the Support Groups which operate face-to-face or online, go to **sarcoma.org.uk/support/support-groups/**

Hold the front page for our Celebrity Ambassadors

It’s been a busy time on the celebrity front with new faces and daring challenges helping to shine a light on sarcoma.

Opera singer Mark Llewelyn Evans and footballer Dominic Ball have both become Celebrity Ambassadors for Sarcoma UK.

And ITV Loose Women presenter Charlene White has become the latest of our amazing high-profile supporters. She is set to host the Glitter Ball in 2025 as well as the second Shining Stars Awards.

Mark, whose father died from sarcoma cancer, has been a good friend of the charity for some years. He hosted last year’s inaugural Shining Star Awards, our Carol Concert and a live auction at the Glitter Ball this April.

The Welsh baritone’s long and successful career has seen him sing at international opera houses, in films and before Six Nations rugby matches.

Footballer Dominic Ball has become a Celebrity Ambassador in a deeply personal mission – to honour the legacy of his best friend Spencer McCall, who died from Ewing’s sarcoma at just 24 years old.

Dominic, recently signed to Leyton Orient, has played for clubs including Ipswich, Glasgow Rangers, QPR, Aberdeen, and Rotherham United. He is donating proceeds from his debut book, *From Winning Teams to Broken Dreams*, to Sarcoma UK.

‘We are truly honoured to officially welcome Charlene, Dominic and Mark to the charity,’ says Kerry Reeves-Kneip, Director of Fundraising and Communications at Sarcoma UK.

‘They are all passionate about raising awareness of sarcoma, raising funds for research, and helping to make a positive difference to the sarcoma community.

‘We look forward to working closely with them as we push forward for better outcomes for those affected by sarcoma.’

Jake takes to the Masterchef kitchen just months after fundraising walk and abseil

Reality TV star Jake Quickenden has been out and about in several ways to support Sarcoma UK.

This autumn he was rattling pots and pans on Celebrity MasterChef all the way to the semi-final.

In May, he joined a man who walked 100 miles in 36 hours from Liverpool to Skipton in memory of his brother. Jake walked the entire route alongside Chris Metcalfe, from Skipton, who was fundraising for Sarcoma UK.

Jake lost his brother, Oliver, aged 19, to osteosarcoma in 2012 while Chris lost his brother Rob Metcalfe in 2022, four years after he was diagnosed with synovial sarcoma.

‘My feet may be sore but it was worth every step to walk 100 miles for Sarcoma UK in memory of my brother Rob – and fantastic to be joined by Sarcoma UK Ambassador Jake Quickenden, who is such a great supporter of this charity,’ says Chris. ‘One thing myself and Jake found ourselves saying while walking is that we were doing this because we had the choice to do a 100-mile walk – Rob and Oliver don’t.’

Daredevil Jake also helped to kick off Sarcoma Awareness Month by abseiling 300 ft down a London skyscraper. He joined Aaron Hoctor, Tom Knight, Marty Munday and Kieran Vincett in the challenge organised with support from the Lloyds Foundation Global Community Engagement team.

We are so grateful for everything you do Jake – and can’t wait to see what you get up to next!

Recognising three decades of sarcoma care

It is hard to overstate the influence of Professor Ian Judson in the sarcoma world and the development of Sarcoma UK. His dedication over more than thirty years spans medical oncology, clinical trials, drug development, international research, teaching and more.

With well over 300 published papers and thousands of patients having been in his care, Ian was a worthy winner of the Lifetime Achievement Award at the first Shining Star Awards. He is a Sarcoma UK Ambassador.

Ian, how did you feel about the Lifetime Achievement award?

I was delighted and rather humbled. When it was presented (at this year's British Sarcoma Conference), I was surrounded by friends from the UK and professional colleagues which made it very special.

What inspired you to go into this field?

It was almost by chance. A previous mentor was one of the pioneers of medical oncology – Eve Wiltshaw (first medical director of The Royal Marsden Hospital). Her diverse practice included sarcoma. When Eve retired, her practice was being 'farmed out' to three new consultants, of which I was one at The Royal Marsden Hospital. I wasn't terribly busy so I took on sarcoma.

I had always thought that sarcoma didn't have a lot of good treatments and that I would be able to put people into phase one clinical trials (first stage of developing new drugs). I didn't then appreciate the diversity and complexity of sarcoma.

If you enjoy phase one trials, you're constantly being challenged. And sarcoma is just like that. It repays a lifetime of study. So it was a great fit.

Another happy accident was in my work on imatinib – a drug for GIST (gastrointestinal stromal tumour). I was in the right place at the right time.

> **"This is a huge honour, and deeply appreciated…I have been involved in sarcoma care since 1991 and the way the field has changed in that time is astonishing."**

I also led a new EORTC (European Organisation for Research and Treatment of Cancer) study to try and answer a fundamental question in chemotherapy about using a single agent or combination therapy. For sarcoma there can be a long list of issues. The study did show that a single agent would work to keep tumours smaller, if not impact survival rates.

A time of massive change.

There has been huge change from when there were two drugs only. Outcomes are considerably better than 15 to 20 years ago and some of the new drugs can make a big impact without all the side effects.

The frustration is that they're not always available on the NHS. NICE (National Institute for Care and Health Excellence) do a good job and have a thorough approvals process but it is not always understandable.

What about Sarcoma UK?

Roger Wilson CBE (Founder of Sarcoma UK) started the newsletter; the next step was the development of a patient support group. Roger very graciously said publicly that it was my idea that this was what we needed. I am not convinced, but I'll accept the compliment! We worked together to create Sarcoma UK and develop it from a patient support group to a larger charity that would support research

The progress of the charity is tremendous. I've had a long association with Sarcoma UK, having been Chair of the Scientific Advisory Group and then on the Board. It has been reassuring and quite wonderful to see the charity continue to flourish.

How about future ambitions?

Something which also occupies me as a Trustee at St Christopher's Hospice is that we don't reach all the people we should. White middle-class people remain our biggest users. This needs more work to try and understand the barriers. This is what I'm passionate about. I have learned in the hospice sector that some fears about authority and institutions may be deeply embedded in some ethnic minority groups and this can be a real problem.

Ian, thank you so much for everything you have done for the charity and those affected by sarcoma.

Your sarcoma reasons for contacting our Support Line

It's been another busy year for our experts on the Sarcoma UK Support Line. Here's the lowdown on why the team is so in demand and their future plans.

This year, the team had 5,088 contacts with 1,077 individuals – an amazing 30 per cent increase in the number of people.

'As we aim to help as many people affected by sarcoma, to see such an increase is encouraging,' explains Helen Stradling, Support Line Manager at Sarcoma UK.

The top three reasons for people getting in touch have remained the same; for support, with questions about treatment and for advice before a potential diagnosis.

'The support given to those who contact the Support Line is mainly emotional. Communication and information is not always clear or forthcoming, which leaves people anxious and unsure of what is happening. Being able to reassure people that things are happening in the background is key.'

When people contact the team to talk about treatments, it is usually treatment options that they want to discuss. This can be at diagnosis, at a time of recurrence or metastatic spread, and when people are told there are no further options.

Understandably, individuals can be very distressed and often the team need to explain why there are so few options available.

People can be desperate and will ask about accessing treatments that are costly or not evidence-based, says Helen.

'We are very clear that we can only endorse treatments that are clinically safe and effective.'

It is the second year in a row when pre-diagnosis advice appears in the top three reasons for getting in touch – a time which can be particularly scary and sometimes hard to navigate.

A lack of communication causes the most anxiety, coupled with the fact that people may not have heard of sarcoma before, and they turn to Google.

'This year we are focusing on how people are contacting the team and why so we can see if there is anything further we can be doing to make getting in touch easier or promoting the Support Line.'

Interestingly, the use of telephone has increased by 11 per cent, and email is down by 13 per cent, while text and social media have increased by one per cent.

The team has continued to actively engage with the expanding local sarcoma support groups network, now with nine teams using the direct referrals system.

While the Support Line team is small, the staff have big ambitions. These include enhancing their collaborations with charities as well as expanding both individual contacts and the direct referrals.

'The team looks forward to what is to come, seeing how much more we can achieve and helping to support anybody affected by sarcoma.'

Photography exhibition focuses on experiences of bone cancer

Close to the Bone was proudly supported by Sarcoma UK and Bone Cancer Research Trust in London after a successful unveiling in Glasgow in the spring.

This inspiring collection by Caroline Seymour captured the intimate journeys of bone cancer patients, showing that no one faces this diagnosis alone. It was held at the Royal College of Surgeons of England in late summer.

Did you know?

- The Support Line opened on February 8, 2016 and has gone from strength to strength.
- To date, the team have had over 25,000 contacts with more than 5,000 individuals including a couple right from the start.
- The team spent 48.45 hours on the phone to one individual this year!
- Wednesday was the busiest day of the week for contacts and Friday the quietest.
- Five contacts is the average number per individual.
- Direct referrals started from the teams in Plymouth and Aberdeen, in addition to accepting referrals from support group leaders.

Our Support Line opening hours

We are 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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