



**A sell-out stand-up comedy fundraiser wows Brighton**

**Seven cutting-edge research projects unveiled**

**Sarcoma UK goes to Downing Street**



**SarcomaUK**  
The bone & soft tissue cancer charity



# Welcome to the winter edition of Connect

This time of year is always a good one to take stock and reflect on the last few months as well as look forward to a new year.

It's been fantastic for Sarcoma UK to have had an incredibly busy summer followed by a packed autumn of events and activities, from cakes and comedy to political engagement and progress in science.

I hope you'll enjoy reading about just a few of the things we and our supporters have been up to, from heartening advances in research to Support Line developments – and more.

We are delighted that our funding for seven cutting-edge research grants smashes our £1 million target for the very first time. There's more about the exciting and diverse range of projects funded for 2022–2023 on pages four and five.

We were recently back in Brighton for a fantastic comedy night spearheaded by one of our dedicated celebrity ambassadors and favourite comedians, Angela Barnes. I'm still chuckling at the razor-sharp routines of seven different stand-ups, all to raise vital funds – more on page 11.

Also this autumn, we were honoured by a reception at No 11 Downing Street, hosted by Chancellor of the Exchequer Rt Hon Jeremy Hunt MP. Jeremy recently lost his brother Charlie to sarcoma and so knows all too well the pain and challenges of a diagnosis (see pages 16–17).

## Inside this edition:

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Read how Hristo is making a difference as a trustee.  
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At Sarcoma UK we never cease to be inspired by the dedication of our supporters in everything they set their minds to. An incredible Three Peaks Challenge this autumn in memory of Gaz Emmerson has raised more than £60,000 to date and involved 51 plucky climbers, including four Sarcoma UK staff, going above and beyond.

As *Connect* went to press, we were gearing up for our very first Shining Stars Awards ceremony at the end of November, recognising a few of those who help make the sarcoma community what it is today.

We are so grateful to everyone who has helped us in every which way this year, whether fundraising, supporting us through grant reviews, working at the coalface of science, volunteering and more. In our eyes, you are all stars.

As we approach 2024, and the second half of our organisational strategy, rest assured that we will continue to work with and for you towards a better future for everyone affected by sarcoma.

*Richard Davidson*

**Richard Davidson**  
Chief Executive

## Your greener Connect

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



# Support Group Leaders come together

It was a day to remember for the Sarcoma UK Support Groups as 16 Group Leaders got together this autumn.

The October event in Birmingham featured a packed agenda as well as valuable time in being able to meet others from all parts of the country and share their insights and experience. It was also a timely opportunity to celebrate all the hard work of the groups in supporting so many people affected by sarcoma.

As well as useful updates from different teams at Sarcoma UK, the morning featured a session on Mentoring, Buddying and Peer Support from Clinical Supervisor Jo Ham.

Andrew Sutton informed the Group Leaders about the Bone Sarcoma Peer Support service – a topic covered in the last issue of *Connect*.

Lunch was a great opportunity to talk about the morning and to catch up with old friends as well as make some new ones.

'It was brilliant to come together and recognise the dedication behind running the groups and providing valuable support to so many people,' says Carly McDonald, Support Line Advisor at Sarcoma UK who oversees the groups.

'Group Leaders really welcomed the chance to have informal discussions around the many topics they care about

as well as to share ideas and learn from the presentations.'

One Support Group Leader commented: 'It was great to meet others and hopefully we can swap and share ideas going forward.' Another participant said that it had been a great day and very informative with a great atmosphere.

For more information on the Support Groups which operate face-to-face or online, go to **About support groups | Sarcoma UK**



**"I would like to thank everyone involved who helped make the day such a success – we're really looking forward to the next one."**

**Carly McDonald,**  
Support Line Advisor  
at Sarcoma UK

# Our research progress

We're making great strides in our commitment to sarcoma research, thanks to your support.

## Biggest ever research funding will tackle major sarcoma questions

Sarcoma UK is making its biggest ever research commitment by giving the go-ahead to seven exciting and diverse projects.

And the focus on unlocking some of the leading unanswered questions in sarcoma will smash the charity's £1 million target for the very first time.

The £1.2 million funding is being driven by a desire to understand sarcoma better and develop new and kinder treatments – all thanks to everyone who has fundraised for Sarcoma UK.

Understanding ultra-rare sarcoma types is the aim of two of the new projects spanning the UK. One builds on a dedicated programme of research into clear cell sarcoma at University College London, led by Dr Nischalan Pillay. The other, thanks to a donation from

the Sarah Burkeman Trust, studies tissues from those with gynaecological sarcoma and is going ahead at the Institute of Cancer Research under Dr Paul Huang.

An international study (SAFETY trial) to evaluate the best follow up for soft tissue sarcoma will be expanded to patients in the UK thanks to almost £150,000 from Sarcoma UK. It is already open in centres in Europe and America.

Surgery and radiotherapy are key treatments for most soft tissue sarcomas, with follow-up for up to ten years to monitor for spread of the sarcoma into the lungs. But as surveillance strategies have not been well-researched and differ between centres, current guidelines are based on expert opinion, rather than evidence.

Participants in the clinical trial will be randomly allocated to one of four different treatments – CT scans or chest X-rays of different frequencies – over two years.

The team, led by Kenny Rankin at Newcastle Upon Tyne University Hospitals, plans to explore the effectiveness of these options, in terms of improved survival, any complications, and overall quality of life.

New technologies to map the features of the most common type of sarcoma are part of a project being funded at University of Southampton under

Dr Zoë Walters. Ultimately, these could be key to unlocking the most successful treatments.

Gastrointestinal Stromal Tumours (GISTs) affect over 1,000 people in the UK each year. These tumours can appear anywhere along the digestive tract but are most common in the stomach. The majority of GISTs are small, benign and relatively harmless, but for a number of patients their tumours are more aggressive and behave like cancers. They will often return after surgery, resulting in a very poor prognosis.

Improving our knowledge of which genes are activated in GIST could help develop better treatments for people whose sarcoma comes back. The team's findings will be vital to guide further, bigger, experiments in this area in the future.

'We are over the moon to be funding these new research projects, taking our all-time research commitment to over £6.3 million,' says Dr Sorrel Bickley, Director of Research, Policy and Support.

'The projects – only possible thanks to your support – were selected after a rigorous review process involving expert scientists and clinicians, as well as people affected by sarcoma.

'They will drive forward our understanding of sarcoma, from the most common to the rarest subtypes, and hopefully identify new ways of treating these cancers.'



## New test may improve outcomes for patients with a rare sarcoma

A new grant from medical research organisation LifeArc and Sarcoma UK will fund a study that could improve outcomes for patients with a rare sarcoma.

The £150,000 grant for a four-year research project at the Institute of Cancer Research, London will determine if a biomarker test is accurate in identifying those patients with soft tissue sarcomas who could best respond to a particular line of treatment.

The study, led by Dr Paul Huang and Professor Robin Jones, in collaboration with scientists at The University of Texas MD Anderson Cancer Centre, US, will also help to determine the feasibility and cost-effectiveness of incorporating the biomarker test into routine

clinical practice, as well as potentially influencing the use and availability of the targeted drug pazopanib.

Known as the KARSARC TEST, it is the first validated biomarker test that can identify long-term patient drug responses across different subtypes of soft tissue sarcoma.

The ability to identify those who will most benefit from pazopanib would offer a more cost-effective use of the treatment, as well as sparing those who will be unlikely to benefit from unnecessary side effects.

The team is seeking a commercial partner to further develop the test – and you can read about the commercial opportunity in [this brochure](#).



## Sarcoma data study reveals new and positive insights

Until now, there has been very little data available about incidence and survival of soft tissue sarcomas, despite its significance in helping to improve diagnosis and treatment.

For the first time, information about 84 subtypes of soft tissue sarcomas has been detailed, with potentially positive implications for people affected by sarcoma.

The study, led by researchers at University College London, analysed data about people diagnosed with a soft tissue sarcoma in England between 2013 and 2017.

**Incidence (how many people have been diagnosed), age at diagnosis, the route people take to diagnoses, survival, and differences due to social deprivation were all studied.**

The **analysis** found that there were 19,717 people diagnosed with soft tissue sarcoma in this period – over 3,900 a year. Soft tissue sarcoma makes up 0.8% of all cancers diagnosed. The research also uncovered new data on ultra-rare sarcomas, such as epithelioid sarcoma and alveolar soft part sarcoma, many of which have never been described in detail.

The study, published in the *International Journal of Cancer*, reveals lots of new and positive insights. For example, it suggests there has been an improvement in diagnosis for sarcoma compared to previous reports. The term 'not otherwise specified' (NOS) is used when there is too much uncertainty to make a specific sarcoma subtype diagnosis. This analysis describes just 7.2% of sarcomas as NOS, down from 20% in similar data collected between 1996 and 2010. This is likely due to advancements in molecular diagnostic tests and more specialist sarcoma pathologists, improving the accuracy of diagnosis.

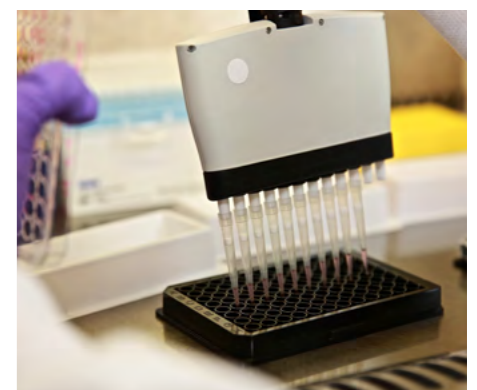
The paper also reports for the first time that social deprivation has an impact on prognosis for sarcoma. People living in more deprived areas of the UK are more likely to have a poorer outcome from

their sarcoma and are also more likely to be diagnosed after coming into A&E.

Cancers diagnosed this way are often more advanced than those caught by GP referral or screening. Although these are worrying findings, understanding people's different routes to diagnosis means that service providers can work to make treatment more equitable and accessible for everyone with sarcoma.

Sarcoma UK has compiled an interactive dashboard [here](#).

The team is working on a similar analysis of bone sarcoma. This work is being funded jointly by Sarcoma UK and the Bone Cancer Research Trust.





# Juggling recovery and working life with sarcoma

A young man whose positive approach helped him deal with a sarcoma diagnosis at 23 is now giving back to Sarcoma UK as a trustee.



## My story

‘I’m Hristo Anastasov, aged 28 and living in London. I’ve recently started a new job at McKinsey after working with Amazon for five years.

‘Four years ago (2019), I was eventually diagnosed with myxoid leiomyosarcoma (a soft tissue sarcoma) after six months. There was a lump in my upper left thigh and my initial thought was that it was a sports injury. It was around seven to eight centimetres which I could feel with my hand. It wasn’t going away so I saw my London GP after about two weeks, as it/ I was classed as a non-emergency. They said it was either some tissue or an injury but it wasn’t going to go away by itself so it should be operated on. They didn’t refer to sarcoma and I had never heard of it.

‘I was 23, an active young professional, so I was quite shocked. I luckily had private health insurance. After an ultrasound referral, I had to wait for three or four weeks. Again, the doctor said they didn’t know what it was but he could see that there was blood going through it so I was referred to another doctor.

## How I felt

‘I was fine. I never thought it would be cancer so I was probably just annoyed at all the specialists and all the time it was taking. So I went to another specialist who checked me very quickly and then referred me to another specialist – by then, my fourth doctor. I had seen a consultant at the Shard clinic who was really good. I was referred to a sarcoma specialist, but they were booked for two months so at this point I decided to go to one of their private clinics. At the initial check he said we need to operate and then three or four weeks later I was sent for a biopsy. By now it was July and this had started around January.

‘I will never forget when I was on holiday with my best friend. His brother is a doctor and so I told him about my symptoms. He said that it could be cancer – the first time I had heard about this.

“I’m not a doctor. I can’t cure people. I feel confident that I’m really contributing and giving back in the best way I can.”

## My diagnosis and treatment

‘By then I had seen four different specialists, had six appointments and no one had ever mentioned cancer. In August the consultant told me then it was a stage two sarcoma and now 10 centimetres. Back in the NHS, I was put through very quickly to University College Hospital London where my consultant was Fanel le Grange. Before surgery, I had radiotherapy at the MacMillan centre for six weeks (30 sessions).

‘I was still pretty shocked but my thinking was, how are we going to beat this, and I was really positive. With radiotherapy, I felt really bad; it was difficult to be in waiting rooms with lots of other people, some who were clearly very sick or couldn’t walk. After a couple of weeks, the skin on my leg was quite painful.

## My work

‘Amazon was very supportive and I had an occupational review through my corporate job. As I was headed for radiotherapy and needed time for my mental health, I moved to part time working. It was a very good arrangement for four hours a day and so I kept busy. One month after surgery I was working full-time again.



## My recovery

‘I followed some unconventional therapy, including fasting. I changed my eating habits, cutting out dairy, meat and cheese, and my lifestyle. A pretty big chunk of my thigh was to be cut out, although the sarcoma had shrunk to five centimetres. The doctors said yoga would be good to stretch the muscles for recovery and I was running to stay in shape for surgery. I also started meditating.

‘My surgery at the Royal National Orthopaedic Hospital in Stanmore was roughly nine months since my first symptoms. It was tough – and I spent four days in hospital when I couldn’t walk.

‘I was very mindful of my mental and my physical health. I didn’t have a physio in hospital – I was never offered one. I was given exercises but otherwise it was dealing with it yourself. I started walking very slowly and it took me two months to come back to full walking mobility. When COVID hit I was then walking my dog. I started swimming daily which was very good for my muscles, and then going to the gym and doing specific exercises. It took about 15 months.

‘Mentally it was a shock. Before COVID, I went on a silent retreat for a week in Koh Samui, Thailand. It was 16 hours a day of meditation with no phones, messages or books. This was great for my mental health. In 2021 I set myself a goal of a Tough Mudder 10K in London. This felt amazing – the cherry on top of my cake. I felt completely recovered and was able to say I am strong physically and mentally.

## My support

‘My mother was crucial after surgery. But I didn’t really tell friends apart from one, so in total, two people. It takes its toll telling other people about what you’re going through and dealing with how they feel about it.

## Sarcoma UK and me

‘No one had mentioned Sarcoma UK at all and so I found it on the internet. It was really beneficial – plenty of information and I could refer people to this to really understand what it was and what it meant.

‘In 2021 I was thinking about how I could give back, especially as there must be lots of young people in my situation. The charity posted an opening for trustees (on social media) and I thought that I’d really love to help. I know a lot about business and technology – that’s my strength. If I’d looked up the other people on the board I probably wouldn’t have applied as everyone was so impressive and older than me! I was appointed as a trustee after two rounds of interviews.

‘On the Board, I now help in particular with efficiencies of staff and I’m on the HR Committee. It has been really fulfilling and rewarding, hopefully having an impact to help lots of people going through the same thing and leveraging my skills.

‘I’m not a doctor. I can’t cure people. I feel confident that I’m really contributing and giving back in the best way I can.

‘Maybe I can help generate more funding for research and the Support Line so that more people are able to speak to them when they need to. I hope to help more people understand what sarcoma means. I also want to help people get a quicker diagnosis and to be treated faster, getting a better experience than I did.

## My advice

‘Lots! Look after your mental health as well as your physical health. But always think positively and never give up! And seek the right support for you.’



# The life-changing magic of fundraising

From climbing mountains to celebrities donating royalties, you can count on our incredible fundraisers to go the extra mile in raising money for Sarcoma UK. We are so grateful to all of you.

## TommyInnit unveiled as new Celebrity Ambassador

YouTube and Twitch sensation TommyInnit is Sarcoma UK's newest Celebrity Ambassador.

YouTuber TommyInnit, 19, who boasts an enormous 24 million subscribers across YouTube channels and tens of millions more across other social media sites, was inspired to support Sarcoma UK's work following the loss of his friend and fellow content creator Technoblade.

UK raise awareness and save lives in the future. I'm proud to be helping their mission to fund new research and offer people support, and I'd like to thank my amazing fans for their contributions too.'

'We are honoured that TommyInnit has chosen to remember Technoblade in such a powerful and positive way by becoming Sarcoma UK's newest Celebrity Ambassador,' says Richard Davidson, Sarcoma UK's Chief Executive.



Technoblade was a popular American YouTuber who rose to fame through livestreaming the video game Minecraft. He died in 2022, aged 23, after a diagnosis of stage-four sarcoma.

TommyInnit – real name Tom Simons – has raised more than £177,000 after kindly donated all of his share of advances and royalties from his bestselling book TommyInnit Says... The Quote Book. Fans of the YouTube personality have also donated nearly £3,000 directly to Sarcoma UK.

'I'd never heard of sarcoma cancer until Technoblade was diagnosed and I'm heartbroken that he's gone,' says TommyInnit.

'It's a rare cancer and it's difficult to spot the signs, so I want to help Sarcoma



## Great North Run kicks off the autumn running season

Our biggest ever team took to the streets of Newcastle and beyond to take part in the 42nd Great North Run this September.

No less than 41 runners joined over 60,000 determined others on the iconic half-marathon course.

Combined with a traditional Geordie welcome, the mixed weather of sunshine and a huge storm did nothing to stop Team Sarcoma staying on track and raising more than £15,000 to date!

With the Sarcoma UK cheer station based at mile 12, it meant that runners could get that final boost when they needed it the most.

Among those involved were Gareth Williams and John Young, a regular GNR runner and Sarcoma UK supporter, who has been organising our volunteers and finishing area cheer point every year. Gareth was running for this cause close to his heart as he had lost both his best friend John and a friend's son, Oliver, to sarcoma.

Congratulations to all the amazing runners and thank you to everyone who supported them!



## A cure for summertime blues with Cuppa & Cake

People up and down the country rose to the challenge of our new summer initiative, Cuppa & Cake.

Bunting, sweet sponges and savoury bakes were all on the menu from July to September.

Our Cuppa & Cake Champions, Michelle Jaggs, Charlotte Beckerleg and Christine Rhodes led the way. Christine's garden party raised a whopping £5,651!

'Our amazing, beautiful daughter, Hannah tragically passed away within nine months of diagnosis at the age of just 29 from synovial sarcoma.

'She held a garden party event herself to raise money for Sarcoma UK in the summer as she passed away in the September. It is very special for all of those who knew her to have this opportunity to carry on her legacy.

'Having held a successful event and started conversations around sarcoma is rewarding in itself. To then read about the research that is funded by the money we raised does help me believe that through the Cuppa & Cake event we have the potential to make a difference in Hannah's memory.'

## Where there's a will – how yours can help others

One of the most powerful ways that you can help us make a difference is by leaving a gift in your will. By doing so, you can help us get one step closer to curing sarcoma.

When you leave a gift in your will to Sarcoma UK, you help us plan and achieve our vision: where everyone affected by sarcoma cancer has the treatment, care, and support they need.

You can write or update your will for free with [bequeathed.org/](https://bequeathed.org/) SarcomaUK

Read more about the power of a legacy in our free gifts in wills brochure. Call us at 0207 856 0445 or email [legacies@sarcoma.org.uk](mailto:legacies@sarcoma.org.uk).



## Razors out alongside the spectacles for Sarcoma UK

Customers to Boots the Optician in Liverpool this August were treated to a very unusual sight – a fundraising headshave!

Fern Skelton, 24, decided to brave the shave for Sarcoma UK and a cause to which she has a close connection.

She works in healthcare and one of her long-standing patients was diagnosed with sarcoma, which is what clinched Fern's decision. In fact, her headshave was actually on the shop floor, with her patient there too.

Fern has raised a total of £903, with her amazing company willing to donate a further £500.

'Being able to do this for my patient has been such a pleasure and knowing that I have made a difference out there is just incredible,' says Fern.

A big thank you to Fern and to Boots for all their support!

## Carols or city strides – join us in December

If you fancy a pre-Christmas singsong or jog, it's not too late to join in the fun!

Sarcoma UK has been announced as the 2023 Charity Partner for Santa in the City, the popular 4.3 km run. With two dates on offer – December 6 or 7 – there will be hundreds laced up and dressed up in their cheery red outfits for a great cause.

Some of the Sarcoma UK team were among the runners last year and this year's event, starting at the Tate Modern, promises to be even bigger and better. Sign up [here](#)

If a few melodies are more your thing, why not join us for our magical Carol Concert? With seasonal music, readings and rousing carols, it will get you firmly in the festive mood.

The Carol Concert will be held on Monday December 11 (doors open at 6.30 pm), in London's St Giles in the heart of London's West End. Check out the link [here](#) for tickets.



## Move over Glastonbury – here's Party in the Drive!

The driveways of Prince Scott and his neighbour Terry Brimble were transformed into a vibrant mini festival this autumn.

From soul and disco to funk and spa, the 12-hour event in Pewsham, Wiltshire, raised almost £8,000 in aid of Sarcoma UK and other charities.

This is the third time Prince has organised this event this year in memory of his dear friend and neighbour, Tim Blythe.

The Mayor of Chippenham, Councillor Declan Baseley, was just one of the people who turned up on the driveway, dressed in ceremonial chains for the occasion.

The 2023 party was supported by Aztec Electrical, Red Squirrel Plumbing, UK Power Solutions and David Wilson Homes, where Tim Blythe worked.

And there are already plans for another fundraiser. Wow!

## A unique challenge in memory of Betty

Anna-Marie Dixon, 50, is currently well into her stride of an amazing 87 day venture.

She is aiming to cover the 300-mile distance from Stonehaven to Preston, in memory of Betty Pennington who recently died, aged 36, after renal sarcoma. This is from where Betty was brought up to where she made her family home.

Anna-Marie describes Betty as 'an amazing wife, mother to three beautiful children, talented cook and baker, a triathlete, an incredible paramedic and all-round inspiration!'

She describes the virtual challenge – between the birthdays of Betty's husband Mark and son Hamish – as one in true 'Be More Betty' style. Anna-Marie, diagnosed 15 years ago with chronic myeloid leukaemia, knew Betty through Mark after they served in the Territorial Army together.

What a story of two ordinary yet extraordinary women – wishing you all the very best, Anna-Marie.

# Shifting the balance of life after sarcoma



A diagnosis of sarcoma can be life-changing in so many ways. Nettie Wright tells how this was an opportunity to improve her work/life balance as part of her recovery.

‘In November 2017, I was diagnosed with myxoid liposarcoma – a type of sarcoma found most frequently in the limbs, and in particular the thighs. I was aged 41. The sarcoma was unusually in my left buttock and I didn’t know how treatment would affect my colon as invasive, life changing surgery was possible.

‘After 25 sessions of radiotherapy and a five and a half hour operation, the sarcoma luckily peeled away, meaning that only a small margin had to be removed. I was lucky; the treatment had been a great success with 99% of the tumour being killed by the radiotherapy. I felt extremely lucky, not only to be cancer free but also able to maintain full mobility. I appreciate that it’s not like this for everyone.

‘Before my sarcoma diagnosis I was out of the house for around 12 hours a day, five days a week. My role as a Food Technologist was stressful and high pressured. I was constantly on the go with little time for my mental and physical wellbeing. Working in the fast-paced food manufacturing industry for 20 years felt like it had finally taken its toll.

‘I was completely burned out. I really didn’t enjoy my work/life balance and felt very down and deflated before diagnosis. For all those years, I felt that I had put work first and had disregarded my health and wellbeing. My sleep patterns were poor and I really began to question if this had contributed to my sarcoma diagnosis

‘Following my recovery, I returned to work three days a week. Gradually I increased this to a four day working week. The balance was much better and I really felt like I needed this down time to enable my full recovery. In 2019, I moved jobs which reduced my daily commute from a hour was reduced to 20 minutes. My workload was more balanced, enabling me to take regular breaks and most importantly leave on time.



‘In February 2021, I got a place to run for Sarcoma UK in the London Marathon. I was ecstatic, not only to have survived sarcoma, but able to run and support Sarcoma UK. It was a real honour. However, four weeks later, my long-term partner of 24 years, Neil, died suddenly.

‘It was a really rough time, but I knew I still needed to push myself to follow my dream of running the marathon. It’s definitely what Neil would have wanted. I guess in a way, it helped me though my grief. I have always been a believer in

**“I feel that I have been given a second chance. It’s made me determined to appreciate every day.”**



physical activity helping your mental attitude and it definitely gave me focus and purpose. Despite missing Neil terribly when crossing that finish line, it was one of the best days of my life.

‘My priorities have changed. I try to be positive and happy and try not to focus on situations that are not really that important. I give 100% to work rather than 110%. In my free time, I am busy doing things that I enjoy, like DIY, walking my dogs in my beloved Derbyshire hills, paddle boarding, running and spending time with close family and friends. I have always had a lot of energy and still find it difficult to sit still but feel I have found contentment and happiness with this balance.

‘The expertise and skills of Nottingham City Hospital radiology, colorectal and plastic surgery departments saved my life. I write this with thanks to them for my life saving treatment.’

**We’d love to hear your ideas for future Your Shout articles so please get in touch by emailing [connect@sarcoma.org.uk](mailto:connect@sarcoma.org.uk)**



## Star-studded comedy evening wows Brighton

**A fabulous line up of comedians took to the stage of the Brighton Dome this autumn in aid of Sarcoma UK.**

It was a rip-roaring return for the fundraising event after a sell-out out show a year earlier in memory of stand-up comedian Phil Jerrod. He died from sarcoma two years ago in September 2021, aged just 42. Last year’s show raised more than £28,000.

Once again, the tribute to Phil was led by his close friend Angela Barnes, one of Sarcoma UK’s dedicated celebrity ambassadors. Angela is a familiar face on TV in shows such as Mock The Week and Richard Osman’s House of Games as well as on the stand-up circuit.

She is a tireless supporter of the charity, most recently coming second in the infamous (Celebrity) Mastermind chair as well as appearing on ITVx’s Tipping Point.

The evening was hosted by Romesh Ranganathan and Suzi Ruffell then took to the stage.

It was also an opportunity for the comics to share their own memories of Phil Jerrod, who had been based in Brighton, as well as adding their own takes on topics such as parenting, love and sports.

‘We were thrilled to be working with Angela, Romesh and everyone in Brighton again,’ says Kerry Reeves-Kniep, Director of Fundraising and Communications at Sarcoma UK.

‘A host of new comic stars went down an absolute storm with the packed audience and did Phil proud.

‘We are incredibly grateful to everyone who helped make this such a memorable night and raise much-needed fund to help Sarcoma UK make a difference to those affected by sarcoma.’

**Our grateful thanks to:** Angela Barnes, Jack Dee, James Ellis, Adam Hills, Jason Patterson, Suzi Ruffell, Romesh Ranganathan, Off the Kerb Productions, Brighton Dome.

**Photo credit:** Ian Randall/Sarcoma UK.



# The latest in policy and public affairs

We are keeping sarcoma on the political agenda, focusing on the priorities of patients and professionals alike.



## Concerns of 'postcode lottery' of care highlighted in major report

A recent report by the Healthcare Safety Investigation Branch (HSIB) has highlighted numerous concerns about the delivery of palliative and end of life care across England.

The investigation revealed that palliative and end of life care is 'variable and inequitable' across the NHS.

It looked at the case of Dermot – a 77-year-old patient diagnosed with myxofibrosarcoma in 2020, who received support from Sarcoma UK.

Dermot looked forward to a healthy life after surgery in May 2020. But sadly, the cancer recurred and metastasised, and he died just six months later.

'We were shocked by how quickly the cancer spread and the difficulties palliative care services had in making a difference to his suffering,' says his brother-in-law Richard.

'In his last nine months, Dermot was in contact with over ten different services. We obtained a copy of his medical notes, which were revelatory in helping us understand what happened and why.'



'It reminded us both of what happened over those difficult months and allowed us to better see how services had managed the case and their view of the situation.'

The family made a referral to HSIB because they wanted to make sure that others need not go through the same experience.

While they welcomed HSIB's national investigation and its recommendations, they believe that more learning is needed around the management of sarcoma, particularly relating to the long delay in diagnosing the recurrence and metastatic spread of Dermot's disease. Services also showed a lack of understanding of what was happening and why at the point of change in prognosis.

'During Dermot's illness, we were fortunate to come into contact with Sarcoma UK. They confirmed that Dermot's experiences were not uncommon with some types of sarcoma, and we were very grateful that they were interested in sharing our wider perspective on what services can learn about sarcoma care and the patient pathway beyond the palliative care focus of the HSIB report.'

The family is keen to encourage a wider debate on sarcoma in the context of more than just palliative services – read more [here](#).

Dr Sorrel Bickley, Director of Research, Policy, and Support at Sarcoma UK, says: 'This report sadly confirms the postcode lottery of care that many people experience when they require palliative and end of life care. We share the family's serious concerns that Dermot was unable to access the care and support he needed during a time of unrelenting difficulty and uncertainty.'

'Sarcoma UK has been advocating on behalf of Dermot's family since his diagnosis, and we share their devastation that he spent his final weeks in these distressing circumstances. We support

the HSIB's recommendations and believe these learnings have the potential to help many people receiving palliative care to have better deaths.

'We hope that NHS England will work closely with healthcare professionals and organisations like ours to ensure that people with sarcoma can find dignity, comfort and proper care throughout their palliative care.'

The family has put together their own recommendations to improve the sarcoma patient pathway. If you would like to contact them, please contact **Sarcoma UK via this email**.

## Gateway C education platform to be rolled out in Scotland

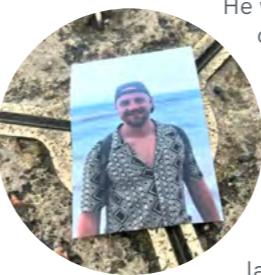
Following our early diagnosis events held in April in the UK and Scottish Parliaments, Marion Fellows MP and Dr Sorrel Bickley, our Director of Research, Policy and Support, met with the Director of NHS Education for Scotland to advocate for improved education on sarcoma for GPs in Scotland.

NHS Scotland plans to improve training for GPs in Scotland on sarcomas by offering GatewayC, a free online cancer education platform for GPs. We previously worked with Gateway C to develop a sarcoma module, launched in England and Wales in 2022, which has had strong take-up. The module should go live in Scotland in the coming months, and we will work with partners to promote its take-up by GPs.

# Team Sarcoma takes on Three Peaks and does Gaz proud

Team Sarcoma braved scary summits and the toughest of hills to climb the three highest peaks in England, Scotland and Wales in memory of Gaz Emmerson.

Gaz became heavily involved with Sarcoma UK from 2020 following his initial diagnosis of Ewing's sarcoma in 2014, relapsing in 2016. He raised more than £140,000 and was named London Fundraiser of the Year at the Pride of Britain Awards in 2021.



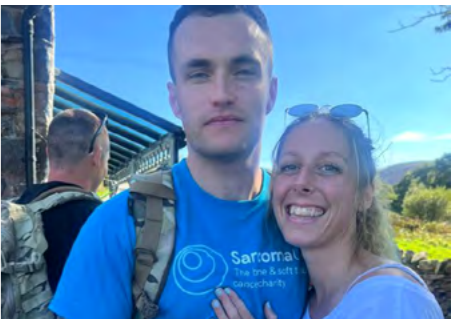
He wanted to complete the 24-hour Three Peaks Challenge for Sarcoma UK himself in 2022, but he sadly died in August last year aged 29.

Louisa Morgan, Sarcoma UK Events Manager, was taking part along with four other staff members, Kerry Reeves-Kniep, Jessica Hall, Greis Kula and Sarah Thorn:

'At 4 am on Saturday 2 September, myself and 50 others started at Ben Nevis and the famous "heart attack hill." It was incredibly tough but the views and Gaz's memory helped Team Sarcoma power through and reach the summit where Sam and Kat (pictured) got engaged!

'The next stop was Scafell Pike which we started and completed in pitch black. We were jumping across streams at the bottom and avoiding sheer drops at the top; the moonlight and songs helped us reach the top where we saw absolutely nothing thanks to the 11 pm darkness!

Once we reached the bottom the sense of relief at the bottom was huge, and it meant we had one more peak left.



With the guides repeating 'not long left now,' about 50 times, we summited Snowdon in bright sunshine. The views were absolutely breathtaking, and it was certainly worth the sore feet and wobbly legs. Around 80,000 steps and over 500 floors "climbed" later, we had completed the National Three Peaks Challenge. We were all very relieved to see a pub and comfy seats waiting for us at the bottom. It was so special to have so many people come together to remember Gaz and support everyone affected by sarcoma. '

A large, circular logo for the Glitter Ball 2024 event. The text "Glitter Ball 2024" is in a large, bold, gold font. Below it is the Sarcoma UK logo, which consists of a stylized 'S' and the text "Sarcoma UK The bone & soft tissue cancer charity". The entire logo is surrounded by a ring of gold glitter.

## Ready to sparkle all over again?

**27th April 2024**  
**London Marriott Hotel Grosvenor Square**

[@sarcoma\\_uk\\_glitter\\_ball](https://sarcoma.org.uk/glitterball)

# Spotlight on women in sarcoma science

Science and research have historically been fields reserved for men, but women have made significant and inspirational contributions to our understanding of the world. With nearly 40 of Sarcoma UK's 84 research grants led by women, sarcoma research is no different.



Dr Karen Sisley, one of Sarcoma UK's first grant holders and a Senior Lecturer in the School of Medicine and Population Health at the University of Sheffield, and Danielle Maes, a trauma and orthopaedic surgeon now undertaking a Sarcoma UK PhD studentship, tell us more about the excitement – and challenges – they face in their work.

It was during a placement for her undergraduate degree, working on drug repurposing at Glaxo Pharmaceuticals, that Dr Karen Sisley first discovered her passion for cells and genetics. 'I always liked the feeling of – and I still get it – the real buzz from doing proper research, feeling that you could go in and you might find something new,' she says. 'When I first started in cancer research, I remember thinking "I'm not sure how much I can add here" as there was so much research going on. But you come to realise that cancer is a big black box, with so many complexities. Patients who may on the face of it have exactly the same tumour may respond to it very differently.'

After she completed her PhD at the University of Sheffield, where she built her expertise in the genetics of rare cancers, Karen first turned to sarcoma research over 15 years ago. 'Some of the stuff we're now able to do is mind-blowing compared to when I first started



out. Some of the initial findings from our first Sarcoma UK grant in 2009 are still coming out now, and others are building on them and adding new meaning. It's like a jigsaw. It might be years later where you get another piece of information which gives a finding much greater significance.'

Today, Karen's research at Sheffield focuses on the genetic changes in rare cancers like sarcoma, and the effect these have on how the cancer behaves in a patient. Like many researchers, she does it simply because she loves it – but also because it's so needed. 'With Sarcoma UK, the patient interaction is so strong and you get to hear lots of people's stories. That's always a motivation to do things well. As scientists, we have to believe the work we've done is important and means something.'

**"Some of the stuff we are able to do now is mind-blowing compared to when I first started out."**

**Dr Karen Sisley, Senior Lecturer in the School of Medicine and Population Health at the University of Sheffield.**

Danielle Maes is completing her PhD alongside her clinical work as a surgeon. It was during an oncology rotation of her training in Belgium that she discovered her passion for sarcoma.

'As a surgeon, you might specialise on a joint, like the hands or feet, and not necessarily thinking about your patient's overall health. But you have to look at the health of your whole patient holistically in sarcoma,' she says. 'Sarcoma patients'



perseverance is so strong. You see them being able to live longer, continue to walk, and keep what they love most in life as the most important things.'

In her PhD research, Danielle will speak to people to help understand what works well – and less well – in follow-up in the years after sarcoma surgery. 'It feels good to write something that hasn't been written before. I think my interviews will be the first time anyone has asked patients these questions, and it will have an effect on how people are being followed up. It's a lot of their time and anxiety and disruption that goes with follow-up. I believe that four in five people do want to have sarcoma surveillance, but some don't want that uncertainty. So, in the long run, I will have helped build a very little corner of optimising sarcoma surveillance.'



# How together we are making a difference

Here's a snapshot of our impact in key areas such as fundraising, support and research for the year 2022/2023.

As we mark the half-way point of our five-year organisational strategy (2021-2026), we are delighted to have gone from strength to strength in our growth, our reach, our investment and our impact.

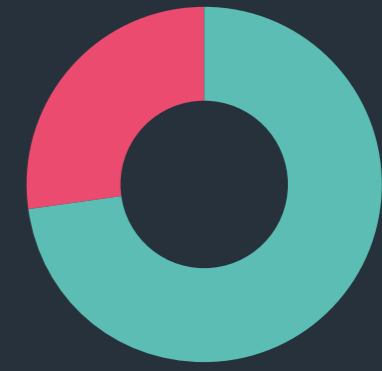
We're already building on these milestones for 2024, thanks to your help.

**Total income in 2022/2023: £2,889,367**

- Over £6 million** invested in research projects since 2009
- 76 projects** supported since 2009
- 9 new projects** funded in 2022/2023
- £1.21 million** invested in sarcoma research projects in 2022/2023 – our biggest ever amount
- Over 24 people** affected by sarcoma involved in reviewing research applications
- 4,622 contacts** to the Support Line team from 827 individuals – up by 35 per cent
- 450 hours** spent on the telephone to the Support Line
- 55 individuals** every month on average were new to the Support Line this year

- Every single month** saw an increase in the number of contacts to the Support Line team year on year
- The top three reasons** for people contacting the Support Line have changed this year; support, treatment and now advice before a potential diagnosis.

In every pound:



**73 pence** goes into research, information, campaigning, support and education

**27 pence** is spent on fundraising activities.



# Sarcoma UK in the spotlight at Downing Street

Sarcoma UK joined Chancellor of the Exchequer Rt Hon Jeremy Hunt MP in hosting a reception at the Treasury this autumn.

The Chancellor’s brother, Charlie Hunt, 53, died in August, three years after he was diagnosed with an ultra-rare form of sarcoma cancer called spindle cell sarcoma.

Sarcoma UK is spearheading efforts to fund more research into ultra-rare sarcomas. The charity has committed to raising £300,000 to invest into ultra-rare sarcoma research in 2023.

The reception was also an opportunity for guests to hear more about Sarcoma

UK and its work as well as the need for a focus into better understanding ultra-rare sarcomas.

Sarcoma UK’s Chief Executive, Richard Davidson, said: ‘It was great to meet Mr Hunt and talk about our efforts to help people with ultra-rare sarcomas, something that has touched him personally with the sad death of his brother Charlie.

‘Sarcoma UK has now set a research funding target to ensure people like Charlie Hunt, who raised almost £140,000 for our charity, have access to more effective treatments.’

Other special guests at the reception included Sheelagh and Roger Wilson

CBE, founders of Sarcoma UK; Thandi Hunt, wife of Charlie Hunt; Professor Robin Jones, Head of the Sarcoma Unit at the Royal Marsden, as well as Sarcoma UK Celebrity Ambassadors DJ Graeme Park, and YouTuber Tom Simons, aka TommyInnit.

Read about two new London projects into understanding ultra-rare sarcoma types being funded as part of the charity’s latest research commitments on page four.

Photo credit: Ian Randall/Sarcoma UK.



# First Shining Stars Awards recognises the very best of our supporters

Sarcoma UK is delighted to be holding our very first awards this winter.

As *Connect* went to press, we were gearing up for a very special event at the end of November; our Shining Stars Awards.

This is a celebration of talent, success and achievement which recognises, remembers and thanks our valued supporters from all corners of the sarcoma community.

Ten awards have been made, covering the period June 2022 – June 2023, including four which have been voted for by the public.

‘We are absolutely thrilled to be holding the Shining Stars Awards,’ says Kerry Reeves-Knief, Director of Fundraising.

‘We were overwhelmed by the strength of feeling for our dedicated supporters during the nomination process, not just in terms of the numbers of worthy submissions, but their amazing contributions. Our judging panel had the hardest of tasks!

‘The awards ceremony promises to be a wonderful evening which celebrates and showcases the very best in all areas of our work.

‘We are honoured to be holding this ceremony and would like to thank everyone involved in the many aspects of our very first awards.’

The winners and nominees of the Shining Stars Awards 2023 will be unveiled on our website at [sarcoma.org.uk](https://sarcoma.org.uk) after the ceremony.

10

Shining Star awards for the period June 2022-June 2023

4

Voted for by the public

Shining Star AWARDS

- ★ Young Sarcoma Voice of the Year (public vote)
- ★ Political Voice of the Year
- ★ Sarcoma Support Group Champions of the Year (public vote)
- ★ Sarcoma Healthcare Professionals Innovation and Excellence
- ★ Research of the Year (public vote)
- ★ Gaz Emmerson Fundraiser of the Year (public vote)
- ★ Volunteer Achievement of the Year
- ★ Partnership of the Year
- ★ Roger Wilson Inspiration Award of the Year
- ★ Lifetime Achievement Award

# Charity partnership we3can to fund research into three most common childhood cancers

Sarcoma UK is one of three leading cancer charities who have joined forces in a new collaboration to improve the lives of children diagnosed with cancer.

We3can, which is made up of Brain Tumour Research, Leukaemia UK, and Sarcoma UK, is driven by an essential mission – to make real progress in the treatment and cure of childhood cancer.

This pioneering collaboration, launched to mark the end of Childhood Cancer Awareness Month in September, is dedicated to funding research into the prevention, treatment and cure of the most common childhood cancers: brain tumours, leukaemia, and sarcomas.

We3can is inviting companies, individuals, and organisations to support this vital work, and plans to raise

funds through donations, events, and sponsorship, including opportunities to partner with the collaboration.

All funds will be split evenly among Brain Tumour Research, Leukaemia UK and Sarcoma UK.

we3can cure kids cancer

A COLLABORATION BY

Brain Tumour Research

Leukaemia UK

Sarcoma UK

‘We are delighted to announce the we3can collaboration and are committed to funding vital research to help families affected by brain tumours, leukaemia and sarcomas,’ says Dan Knowles, Chief Executive of Brain Tumour Research, Fiona Hazell, Chief Executive of Leukaemia UK, and Richard Davidson, Chief Executive of Sarcoma UK.

‘Together these three cancers make up 78% of all cancers in kids. We look forward to working with partners to accelerate world-class research into kinder, less toxic treatments for these cancers.

‘By working together, we can help save lives and ensure that more kids with cancer can have a carefree childhood and a future.’

For more information, please visit [we3can.org.uk](https://we3can.org.uk)

# Your top sarcoma concerns

Since the Sarcoma UK Support Line opened in 2016, the top reasons for people contacting the team have remain consistent – until now.

The Support Line team has seen another busy year (April 2022 – March 2023) and have supported 827 individuals with 4,622 contacts.

During this time, the top three reasons for contact have been for support, with questions about treatment and, for the first time ever, for advice before a potential diagnosis. In fact, the team has received more queries around pre-diagnosis than diagnosis.

‘This is great as we want to start conversations with people as early in the pathway as possible,’ says Helen Stradling, Support Line Manager.

‘Unfortunately, many of those in contact with us at this point tell us that their referral is not progressing in the way it should. We’ve been much more proactive chasing referrals on behalf of individuals

this year who have not been able to make contact directly, as understandably, this adds to an already stressful situation for patients and their families.

‘We know that the NHS is at breaking point and the specialist teams are stretched further than ever. But in some cases, the team has not only had to chase to ensure the referral is sent to the correct MDT (Multidisciplinary Team), but also to chase clinicians to confirm that referrals have been received.

‘The Support Line team is extremely fortunate to have links with specialist teams who are more than happy for us to make contact to ensure referrals are progressing.’

This year has seen the Support Line team further expand the direct referrals service, now offering the service to

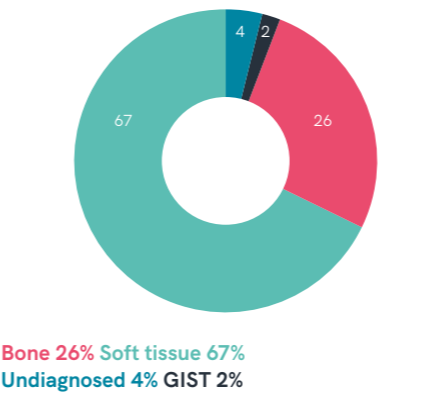
Wales, Brighton, Bournemouth, Northern Ireland, Preston, and Oswestry. In fact, referrals from the Wales team have jumped by 52%. Further expansion of this service is planned as the best way of trying to engage with those affected by sarcoma at the point of diagnosis.

Interestingly, the team has seen significant increases in queries relating to genetics and practical/financial issues.

‘Financial help for those who receive a sarcoma diagnosis, as with all cancers, is not available and this puts a huge burden on patients and their families,’ says Helen Stradling.

‘The team is excited to see what the 2023/24 year holds and to be able to continue supporting all those affected by sarcoma cancer.’

Contacts by sarcoma type



Support Line snapshot

- Since February 2016, the team has had over 20,000 contacts with more than 4,000 individuals
- The busiest month was January 2023, with nearly 500 (496) contacts – the highest number in one month
- By far the most contacts are about soft tissue sarcomas (see graph) – the most common type
- Over 50 different subtypes were included; osteosarcoma being the most common of bone sarcomas and

- liposarcoma the most common of soft tissue sarcomas
- The team expanded in January 2023, meaning 54% less people had to go through to voicemail
- This year, the SL was the main source of support for 73 per cent of respondents, up from 46 per cent.



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](mailto: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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