

Connect

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Research
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Campaigning
How to get involved
with Sarcoma UK

Winter 2022



Genomics in the spotlight
Your Shout – covering issues
and stories you care about
From marathons to wedding
gifts; our amazing fundraisers



SarcomaUK
The bone & soft tissue
cancer charity



Welcome to the winter edition of Connect

As the year draws to a close, it's surprisingly hard to recall the long hot summer of 2022 and the difference from the last couple of years under Covid-19 restrictions.

Despite some challenges, I'm delighted that we have been able to press 'normal service' on so many aspects of our work, events and activities.

This issue will give you a flavour of just what we've been up to. From exciting research developments (pages six-seven) and milestone conferences (page 19) to recruiting new Trustees (page three) and a brilliant evening of comedy (page 10), it's been a busy few months.

The passing of HM Queen Elizabeth II has sparked an even greater feeling of togetherness among us all, and I'm very proud to see that the spirit of the sarcoma community is as strong as ever.

Sarcoma Awareness Month (SAM) every July is a huge awareness raising opportunity for us, and we were thrilled to have so many different aspects to our work in 2022 – our most successful month to date. With your help, we plan to build on this with some exciting plans for 2023.

What stronger sense of community can you see than the 83 amazing Sarcoma UK runners who tackled the TCS London Marathon this year (pages 16-17)? Each and every one is a hero and we couldn't be more proud of you.

The launch of our Sarcoma UK PhD Student Network this summer brought all our funded students – a total of 17 since 2016 – together (page six). Through this, they can forge valuable connections, and better understand the experience of living with sarcoma.

It was a pleasure to be able to celebrate Sarcoma UK's corporate partner The Analyst in passing £1,000,000 in cumulative donations to support our research programmes. The company's continued support and commitment over more than a decade has made a huge difference to our work (page 18).

Whatever your connection to Sarcoma UK, and however you support us, we are incredibly grateful to have you by our side.

We're always pleased to hear your feedback on *Connect* and have already started to introduce a number of changes, including a brand new page – Your Shout – which will highlight issues or stories of interest (page 15). If you have any other suggestions or comments on the magazine, we'd love to hear them. Email us at connect@sarcoma.org.uk

Thank you for helping make a better future for everyone affected by sarcoma.

Richard Davidson
Chief Executive

Inside this edition:

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From picnics to triathlons, how our dedicated supporters are making a difference.

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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.

Completing the Board – Our three new Trustees

We are very pleased that our three new Trustees will have joined the Board at Sarcoma UK by the end of 2022.

Our Board sets the long-term vision for the charity and protects our reputation and values. Their expertise and insight spans many other key areas, including strong governance and relationship building. We also look to the Board for their support of the Chief Executive, Management team and staff.

“We’re delighted to have completed our recruitment to the Board with such a wealth of experience, skills and dedication,” says Richard Davidson, Chief Executive of Sarcoma UK.

“Our Trustees are all volunteers and we never forget the important contribution that they make. I’m really looking forward to working with them all to deliver on our ambitions in 2023 and beyond.”



Fiona Cowie

Dr Fiona Cowie is a Clinical Oncologist at the Beatson West of Scotland Cancer Centre, Glasgow, specialising

in the management of adult patients with sarcomas, and children who need radiotherapy. She also undertakes the long term follow up of childhood cancer survivors.

Fiona has been actively involved in managing people affected by sarcoma for over 20 years and has been constantly learning about the many different aspects of sarcoma. She has also been involved with paediatric cancer care, Young Adult cancer care and long term follow up after treatment.

Fiona also has extensive medical panel and voluntary sector experience, including as a Duke of Edinburgh leader.

“I have used resources from Sarcoma UK over the years and have seen how valuable they are, not only to patients and families, but also to a wide range of healthcare professionals.

“I feel privileged to have been able to advocate for patients and help to ensure access to the best possible care and opinions.”



Aisha Miah

Dr Aisha Miah has spent more than a decade as Consultant Clinical Oncologist at the Sarcoma Unit,

The Royal Marsden Hospital, and is Honorary Faculty of the Division of Radiotherapy and Imaging at The Institute of Cancer Research, delivering on radiotherapy research studies for sarcoma patients. Aisha has also led on the delivery of education and training for Specialist Registrars in London and the South East as Training Programme Director for Clinical Oncology.

From a clinical perspective, she first joined the sarcoma community 10 years ago and quickly learnt the challenges in treating sarcoma and improving knowledge among health care professionals and the public. She represented Sarcoma UK as a member of the Morcellation Task and Finish Group to develop RCOG patient information leaflets and consent advice to raise awareness of uterine sarcomas.

“It has been a privilege to be part of the community observing how Sarcoma UK has evolved and transformed patients’ lives and professional perception as well as enhancing care through its policies and research programmes.

“I would hope to be able to provide some impact in further improving patient experiences and outcomes. While we are working together to help everyone,



In tribute to Gaz

Sarcoma UK was deeply saddened to hear of the loss of our friend and hero, Gareth (Gaz) Emmerson.

Gaz was a valued fundraiser, member of the Sarcoma UK community, and much, much more. Thanks to his hard work, positivity, and determination, he significantly boosted public awareness of sarcoma.

In 2021, Gaz tackled a gruelling 1,000-mile cycling challenge from

sometimes we may need to make a little more effort to provide additional support to certain groups.”



Sally Johnson

Dr Sally Johnson is an experienced NHS GP and medical leader with expertise in

clinical governance, quality improvement and the operationalisation of new clinical services.

She has 12 years of Board experience as Medical Director and Chief Medical Officer of a number of healthcare organisations that provide NHS primary care, urgent care and private telemedicine. Sally has recent leadership experience in private digital healthcare and the global Covid-19 vaccination programme.

Sally has personal experience from when a close friend was diagnosed with sarcoma. After watching her friend’s journey, Sally is keen to promote awareness of sarcoma among medical professionals to ensure early diagnosis and treatment.

“As a GP with 25 years’ experience, I recognise how hard it is to identify and refer patients at risk of relatively rare cancers; I strongly believe there is more we can and must do in primary care to increase awareness of sarcoma.

“I welcome the opportunity to work with a charity that is successfully delivering so many projects that together will improve the lives of those affected by sarcoma.”

Land’s End to John O’Groats with family and friends, despite his terminal cancer diagnosis.

He married his childhood sweetheart, Zoe, just a few days later. He then captured the hearts of the nation when he won ITV’s Pride of Britain London Fundraiser of the Year award.

Before he died in August, Gaz was determined to raise even more funds for Sarcoma UK and urged people to **donate** the cost of a pint to ‘see me out of this world.’ As *Connect* went to press, he had raised more than £140,000 with plans for further fundraising initiatives in his memory.

Our fundraising superstars

These determined supporters have given their time and energy to a veritable range of activities all in a good cause – raising much-needed funds for Sarcoma UK.



Marking their marriage in a very special way

Alice and Edward Snowdon tied the knot in July and generously asked people to make donations to Sarcoma UK to mark their wedding.

Their kindness was due to Ed having lived with a type of synovial sarcoma during his teenage years and has raised 1,983 euros to date.

“The NHS and charities such as Sarcoma UK provided fantastic support, and their care and expertise played a central role in my recovery.

“By supporting Sarcoma UK, hopefully more people can gain the help and happiness they deserve.”

We are touched by the thoughtfulness of the couple and their family and friends and wish them all the best for their married life together.



A triathlon in Tallinn – all in a day’s work for Piotr

As if a day job in sarcoma research wasn’t enough, Piotr Manasterski took on a triathlon to raise money for the charity this summer as well!

The determined athlete is a Sarcoma Research Fellow at the Institute of Genetics and Cancer in Edinburgh, undertaking research into novel drug treatments for different sarcomas.

The Tallinn Ironman 2022 involved no less than a swim of 3.8 km, 112 miles cycling and a marathon distance of running in the beautiful capital city of Estonia.

Piotr aimed to complete this incredible challenge in 11 hours, pushing himself to absolute physical and mental limits. He has already beaten his target of £500.

“As the going got very tough for me and every step became a struggle, my mind kept drifting to the lovely messages of support I received alongside the donations for Sarcoma UK. They helped me to push through the pain and finish in 11 hours and 2 minutes, just a smidge above my target of 11 hours.

“Your donations will help researchers like me and my colleagues find answers, keep the patient support line open and raise awareness to improve treatments and standards of care.”

What a feat! Thank you Piotr – take a bow!



Great British Picnic benefits from the long hot summer of 2022

The combination of the Great British Picnic and a heatwave was a tempting one, especially when the fun was all in a very good cause.

Among those who rolled out the chequered tablecloths or got friends and family together on a sunny afternoon were people like Amy Narraway. She held an amazing day in July in memory of her husband Jason Narraway at the Crown pub in Chesham raising funds for Sarcoma UK.

Natalie Denby’s event, also in July, aimed to celebrate the life of her friend Amy with all the many people she brought together. Amy died of sarcoma in September 2020. Through donations, raffle, auction and Bake Off sales a fantastic total of £6,478 was raised. Wow!

Thank you to everyone who joined in the fun and especially our Great British Picnic champions, the amazing Charlotte Beckerleg and Christine Rhodes. We are so grateful for their ongoing support.





Saddling up to launch Sarcoma Awareness Month

The prestigious Sarcoma Awareness Handicap Stakes at Chelmsford City Racecourse helped Sarcoma UK launch its major awareness month a little differently.

The race in July was named after Sarcoma UK by Noel Gulliver, a Race Day Steward at the course, with the support of Chelmsford City Racecourse. Noel first became aware of the charity when he contacted its Support Line after a sarcoma diagnosis.

"We were so excited to be at Chelmsford Races for the Sarcoma Awareness Handicap Stakes," says Kerry Reeves-Kneip, Director of Fundraising and Communications at Sarcoma UK.

"We had an amazing day speaking to attendees and raising awareness of sarcoma on race day. We are so grateful to Noel, Andy, Neil, and everyone at Chelmsford City Racecourse for facilitating this for Sarcoma Awareness Month."



Wheels on fire – the ultimate year-long challenge for Kerry

Kerry 'Kes' Pearson, from Kings Langley, Hertfordshire, is well on her way through a sporting challenge with a twist – roller skating every day for a whole year.

The challenge is to honour her mother in law, Liz, who was diagnosed with sarcoma, a rare cancer of the bone and soft tissue, in 2021 after losing her husband to a brain tumour. Very sadly, Liz passed away on 15th September 2022.

Kes has been documenting her incredible awareness raising and fundraising efforts via social media, where her Instagram account [instagram.com/kes_skates/](https://www.instagram.com/kes_skates/) has amassed over 3,200 followers.

"We are heartbroken. Raising money and raising awareness for Sarcoma UK is the only thing in my power left against this terrible disease.

"Roller skating is a release," says Kes. "Sometimes I use it to elicit joy and push the bad stuff to the bottom. Sometimes it helps me to express my feelings and cry it out. This 365 day skating challenge is my therapy."

We're wishing Kes the very best of luck for the rest of her rollerskating challenge!



Reaching for the top – a marathon and a Kilimanjaro climb

Covid has put paid to so many plans, but for one intrepid adventurer, patience finally paid off.

Father of four Chris Metcalfe was finally able to complete his 11-day Kilimanjaro trek in July this year, after two years of it being postponed.

Chris's motivation was his younger brother and best friend Rob Metcalfe. Rob, a young father with a terminal diagnosis of synovial sarcoma, passed away earlier this year.

He will be familiar to many people through his raw, impactful videos on social media and a memorable takeover of Sarcoma UK's Instagram stories.

"This was without doubt one of my greatest achievements and I am so proud I did all of this in memory of Rob and for Sarcoma UK."

And if that wasn't enough, Chris has just completed a second tough fundraising challenge - running the TCS London Marathon for Sarcoma UK this October, in a very impressive time of under five hours. Chris has so far raised an incredible £13,852. We couldn't be more grateful.



Never Forgotten Walk launches

As *Connect* went to press in November, our newest challenge was already off to a flying start.

The Never Forgotten Walk asks people to fundraise while walking 55 miles over 30 days for Sarcoma UK. The distance is especially significant as the current survival rate for bone and soft tissue cancer is 55 per cent. That's a number that the charity is desperate to change – with your help.

So far, we've been hearing lots of stories about how people are tackling this winter walk all over the country

in their own styles, whether walking, hiking or running! Many people are walking in memory or to honour a loved one during November and December.

Look out on our social media channels as to how it's all going and join in at [sarcoma.org.uk/never-forgotten/](https://www.sarcoma.org.uk/never-forgotten/)





The latest in sarcoma research – right here

From our PhD Student Network to cutting-edge projects, there's always an exciting new development on our research agenda.

A three year research project at the University of Manchester aims to personalise treatment for osteosarcoma, the most common type of bone cancer.

The £120,000 project, funded by Sarcoma UK and led by Dr Katie Finegan, will explore how different types of cells in our immune system are linked to how well osteosarcoma responds to treatment.

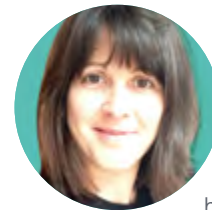
A signaling pathway that controls the cells of the immune system is also

important in how well a patient will respond to their treatment. But so far, we know very little about how this works in osteosarcoma.

The Manchester team will investigate if blocking this pathway will help show which people with osteosarcoma are most likely to respond to certain treatments – and hopefully improve their chances of survival.

Osteosarcoma often affects older children, teenagers and young adults. About 130 people are diagnosed with the disease in England each year.

Dr Katie Finegan said: "There's a real unmet need to develop new treatments for osteosarcoma, which has seen very little success for over 40 years.



Each patient's immune environment is crucial to whether they will respond well or not. Through this research we hope to understand why, which we hope will ensure each patient gets the most effective treatment for them in the future."

Applications for both our research grant rounds, our Open Grant Round and Improving Sarcoma Diagnosis call, have now closed and we will be announcing the successful projects in the Spring.



Tom and Kirsty Makin; fundraising to help our research happen

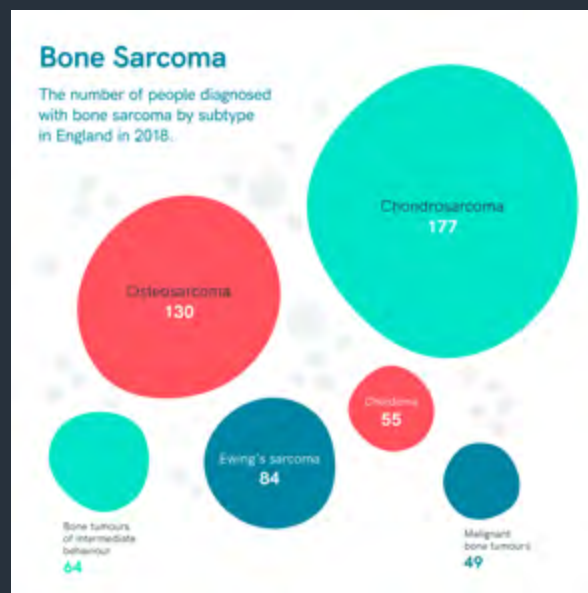
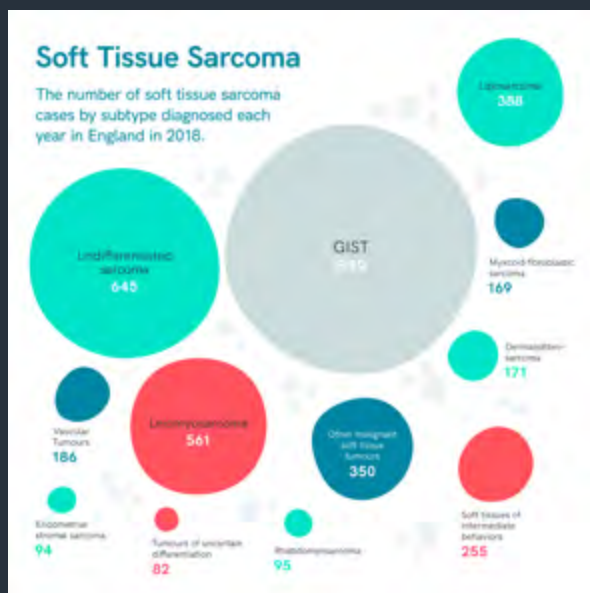
In 2019, at just 29 years old, Tom Makin of Bury, Manchester died of osteosarcoma. Thanks to his vital awareness and fundraising work, now continued by his friends and family, Sarcoma UK is able to fund research projects like this one.

"I am thrilled to hear that Sarcoma UK has been able to fund a much-needed research project, right here in my hometown of Manchester," says Tom's widow, Kirsty.

"As we know, treatments have little improved for those diagnosed with osteosarcoma, like my husband, and hope that this research is pivotal in improving treatment and outcomes for such patients.

"As just one of many that raise funds for Sarcoma UK, it is fantastic to see the money being put to such a worthwhile project. I can't wait to hear how the project develops."

(Read the story of Isobel Ball, Sarcoma UK Ambassador, who was diagnosed with osteosarcoma in 2022, on pages 12-13).



See more of the new Sarcoma infographics at twitter.com/Sarcoma_UK

Sarcoma by numbers

Our latest infographics are helping to make sense of the numbers behind the sarcoma picture.

There are over 100 different subtypes of sarcoma – so it's surprising but entirely possible that people have never met anyone with the same subtype. Even among the rarest subtypes, there are hundreds of new cases a year.

These infographics show how many people in England were diagnosed with the main subtypes of sarcoma in 2019.

Around 87% of sarcomas diagnosed – just under nine in 10 – are soft tissue sarcomas. And of the 5,138 diagnoses of sarcoma in England in 2019, 4,476 were soft tissue sarcomas.

So far, our infographics have received very positive feedback. We hope you find them useful.

You'll never work alone: our PhD Student Network in action

A big part of our research programme has been the funding of the best and brightest minds of the future in the sarcoma research community.

PhD students are early career researchers, completing a project in an unexplored area of sarcoma science under the supervision of an expert researcher. We've been able to support 17 PhD students in laboratories across the UK since 2016. The students we've funded have worked on a huge variety of areas, from exploring how osteosarcoma

interacts with our immune system, to understanding why some people become resistant to drugs.

But from speaking to students and their supervisors, we know that students get few opportunities to meet and share ideas with other students working on sarcoma. There are fewer students and projects in sarcoma research than for other cancers as it's so rare, but COVID has made it even more difficult to meet others.

We also heard that students would like to meet people affected by sarcoma and learn more about their experiences.

Our Sarcoma UK PhD Student Network, launched this summer, brings all our funded students together. Through this, they can forge valuable connections, and better understand the experience of living with sarcoma.

The launch event was attended by Sarcoma UK-funded PhD students, sarcoma researchers, and people who have been affected by sarcoma.

The event included talks from sarcoma researchers who could share advice from completing their own PhDs – Dr Nischalan Pillay, Dr Zoë Walters, and Dr Mark Elms. There were valuable insights, not only from a research standpoint but also on a personal level. The main takeaway was that everyone suffers from imposter syndrome, and this is a normal aspect of being a scientist!

"It's amazing the work that they (Sarcoma UK) do, the way that they fund research and for us to give back to someone else."

Molly McNae, a PhD student looking at Ewing's Sarcoma at the University of Leeds

Maddie Cowey and Charlotte Beckerleg spoke about their experiences of living with sarcoma, as well as their future hopes for research, diagnoses and treatments. Many of the students reported that they found this extremely motivating.

It seemed that students couldn't wait to continue these events in order to give them frequent opportunities to share their work with peers and listen to patient advocates on a more regular basis.

"We're so pleased that we were able to bring together all our funded PhD students for the first time," says Kate Quillin, Research Manager at Sarcoma UK. "It was a fantastic day filled with sarcoma science and building new connections, and a real highlight was hearing from Maddie and Charlotte, who brought home why finding the answers is so vital. Ultimately, we are helping the sarcoma researchers of the future."

Keeping the NHS and early diagnosis on the political agenda



Strength in Numbers coalition urges Government to prioritise NHS workforce planning

Sarcoma UK joined over 100 health and care organisations to ask the Government to make workforce planning a priority and commit to publishing the long-term workforce plan in full.

It has welcomed the fact that this is one of the Government's main priorities and asked for a meeting to discuss how to work together to deliver your pledge to put the NHS on a firm footing.

The Strength in Numbers coalition believes that with 6.8 million people currently on NHS waiting lists, there can be no doubt that urgent action is required to put the NHS on a firm footing.

All successful organisations do workforce planning to ensure they can meet demand - the NHS and social care system should be no exception, says the coalition.

Workforce is the key limiting factor in bringing down waiting lists and restoring timely access to care, outlines the letter sent in November.

At the time, there were 132,000 full-time equivalent vacancies in the NHS, a 25% increase from quarter four of 2021/22, and an estimated 165,000 vacant posts in social care. On average each GP looks after 16% more patients than they did in 2015.

All successful organisations do workforce planning to ensure they can meet demand - the NHS and social care system should be no exception, says the coalition.

The long-term workforce plan that the Secretary of State for Health and Social Care has re-committed to deliver is a vital opportunity to address endemic staff shortages and increase supply.

The country faces significant challenges: an ageing population, more people unable to work due to long-term sickness or reliant on long-term care, and long-standing regional and specialty shortages. But these are challenges that we can begin to address if we act now, concludes the open letter.

Early diagnosis – an update

Following our successful parliamentary events, the policy team has been working on a variety of projects focused on early diagnosis.

Healthcare professional education is key to our work. The team is also working with the University of Nottingham to create a module for undergraduate physiotherapists, as there is a lack of education among physiotherapists on sarcoma. Additionally, videos are being created for medical students to learn about sarcoma, as it often doesn't appear on medical school curriculums, or if it does, it is only for up to half a day to a day of lectures. The team is continuing to join forces with Gateway C, a free online cancer education platform, to develop a module to educate GPs on the signs and symptoms of sarcoma.

Patient empowerment is also key. Consequently, the policy team has created a resource targeted at those who are worried about symptoms but are yet to be diagnosed. Sarcoma UK is also creating self-advocacy tools, such as one on tracking and measuring lumps and bumps to encourage self-advocacy. When you search for symptoms of soft tissue sarcoma, there is very little relevant or UK-based information in the first few pages of searches, including from the main charities in this area. So Sarcoma UK is working to optimise its search engines and promotions to get information about sarcoma to the right groups.

There are currently a range of projects to improve referrals and quality of scans. In April, the first dedicated sarcoma research round which focused specifically on improving diagnosis was opened. The policy team is also commissioning specific research pieces that will hopefully work towards increasing the speed at which sarcomas are diagnosed.



“We will continue to keep up the pressure on this key issue and explore every opportunity we can to keep early diagnosis on the agenda.”

Bradley Price, Policy and Public Affairs Manager at Sarcoma UK



The 'game-changing potential' of genomics in the spotlight

Genomics could transform the future of sarcoma, but much more needs to be done to help all sarcoma patients access this, says Sarcoma UK.



The charity hosted a round table of key experts in the sarcoma field and interested parties to discuss all aspects of genomics, from progress to date to the key issues and barriers around this exciting area. It was chaired by Dr Adam Dangoor, President, British Sarcoma Group; Consultant in Medical Oncology and Chief Clinical Information Officer, Bristol Cancer Institute, University Hospitals Bristol & Weston.

The specially invited attendees at the House of Commons event, *Unlocking and Unblocking Sarcoma Genomics*, in October were able to bring their knowledge and perspectives to an area which is radically changing how we diagnose and treat cancer.

What is genomics?

Genomics is the study of a person's genes (the genome), including the interactions of those genes with each other and with the person's environment.

In this context, the genomes of the cells that make up a sarcoma tumour is of most interest, along with understanding the risk of sarcoma in a family.

The work of the sarcoma community throughout the 100,000 Genomes Project allowed sarcoma the opportunity to become a leader in this area, with it being one of few cancers to have Whole Genome Sequencing routinely commissioned on the NHS in England.

However, issues prevail across a number of areas spanning infrastructure, pathways, education, and access to data, leaving more to be done to help all sarcoma patients access genomics.

Progress in genomics research is determined by both the quality and the quantity of data. Therefore, the more sarcoma patients who contribute data, the greater the power of the data set.

One concern discussed was a lack of awareness and lack of perceived benefit by healthcare professionals. More education is needed for sarcoma clinical professionals on what genomic testing is, and how to access it, and its benefits for both the patient and the future of sarcoma.

Also, lack of collaboration is an issue; there has been very limited interaction by the NHS and Genomics England with the third sector outside of the larger players (Macmillan and Cancer Research UK) until recently.

The lack of patient and public knowledge about what genomics is and its potential also needs to be addressed.

The NHS Long Term Plan sets out a number of commitments for genomics, which are delivered through the NHS Genomics Programme. In October, the NHS Genomics Unit published the first NHS Genomics Strategy, *Accelerating Genomic Medicine in the NHS*, which sets out the ambitions and vision over the next five years for genomics in the NHS.

"We believe that genomics and personalised medicine could be one of the most exciting developments that will revolutionise our understanding and treatment of cancer," says Bradley Price, Policy and Public Affairs Manager at Sarcoma UK.

"It holds the promise of delivering serious and unparalleled improvements in cancer outcomes and the potential to radically transform the experiences of people with sarcoma and cancer more widely. However, this transformation has a number of challenges.

"The round table event was a great opportunity for people to really get under the skin of the current and future issues of genomics and share their expertise.

"We are really looking forward to taking those discussions and the recommendations forward, ultimately for maximum patient benefit."

Sarcoma UK has committed over £750,000 since 2018 to its Genomics Research Programme.



Laughing out loud in Brighton for a good cause

The South Coast's premiere multi-arts venue and listed building played host to a stellar comic evening for Sarcoma UK.

This autumn, top funny folk took to the stage at the Brighton Dome for a unique night of humour and stand-up.

An Evening of Comedy featured nine different comedians in an event spearheaded by one of our dedicated celebrity ambassadors and favourite comedians, Angela Barnes.

Angela lost her close friend and stand-up comedian Phil Jerrod to sarcoma a year before (September 2021), aged 42.

Angela had starred at the Glitter Ball earlier in 2022 not long before supporting her husband Matthew in a massive coast to coast challenge, also in memory of Phil.

Angela hosted the first half of the evening and then handed over the

comedy reins to familiar face Romesh Ranganathan for the second half.

Topics from shower gel and wedding dress shopping to lockdown hobbies and moving house went down a storm with the packed house of over 2,500 attendees.

Each and every act shared a different and poignant memory of Phil Jerrod in tribute to the Brighton-based comedian.

"We were absolutely delighted to work with Angela and such an incredible line-up of talent on this event," says Kerry Reeves-Kniep, Director of Fundraising and Communications at Sarcoma UK.

"The proof of the love and affection for Phil Jerrod was absolutely clear from both the comedians and the audience.

"We are so grateful to everyone who helped make this amazing night such a success and raise vital funds to help everyone affected by sarcoma."

Our grateful thanks to:

- Angela Barnes
- Carl Donnelly
- Joe Foster
- Kerry Godliman
- Mark Steel
- Michael Fabbri
- Romesh Ranganathan
- Seann Walsh
- Tom Allen
- Off the Kerb Productions
- Brighton Dome

55 | **30**
MILES | DAYS

NEVER FORGOTTEN WALK

NOVEMBER AND
DECEMBER 2022



The survival rate of
bone and soft tissue cancer
for 5 years plus is 55%

Together we can
change this

sarcoma.org.uk/never-forgotten

IN SUPPORT OF
**BONE & SOFT
TISSUE CANCER**

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



The one-armed bandit and Sarcoma UK Ambassador living life to the full

A rare sarcoma diagnosis and amputation hasn't stopped Isobel Ball from getting on with her life and inspiring others with her honesty and positivity.

Known first as the 'one-armed bandit' and now the 'swashbuckling chemo granny,' Isobel, 74, was diagnosed with osteosarcoma in June and is rapidly making a name for herself on social media (twitter.com/isobelball5).

Isobel, married with a son, daughter, and grandson, lives in Bury St Edmunds, Suffolk.

Around Easter this year, Isobel had been gardening when she noticed a swelling on her upper right arm, below the shoulder. A few weeks later, another swelling came up which she asked her daughter, Liz, to look at.

Dr Liz O'Riordan is no stranger to the cancer world. She is a speaker, author and storyteller who has had breast cancer twice and worked as a breast cancer surgeon at Ipswich Hospital (see box).

On Liz's advice, Isobel quickly got a face to face appointment with her GP. While he thought the problem could be tendons or muscles, he referred her to the Orthopaedic Unit at West Suffolk Hospital.

Before then, things took a different turn. In June, Isobel and her husband Keith had driven into town. While trying to go into a café, Isobel felt what was 'an almighty crack and excruciating pain' in her arm.

After Liz took her to A and E for an X-ray, an earlier appointment was made at the clinic for the following week. Her arm was now in a sling. That appointment was the first mention of cancer.

"One of the doctors told me that I had a spiral fracture, and I got up to look at the X-ray," says Isobel. "Then I heard 'and we associate this with cancer.' My first thought was - I wasn't expecting that."

Isobel was told she would be referred to a specialist hospital - the Royal National Orthopaedic Hospital in Stanmore.

There, her consultant told her that this was a rare type of bone cancer which it was very unusual to see in someone older and more common in teenagers and young people. As it was considered quite advanced, there were various options, including an amputation.

"I woke up the next morning and thought - no, let's just take it off. This was after I had seen the sarcoma specialist nurses and had what was effectively a pre-operation assessment.

"It wasn't a hard decision. I thought - let's just get rid of it.

"I didn't really feel anything - by now I had had a sling for a month, so I was getting used to how that felt."

The surgery went ahead in mid-July, with Isobel's surgeon having advised her that she thought she had made the right choice. Interestingly, his wife had already seen Isobel's Twitter feed where she had started to share her experiences.

"Before theatre, my last thought had been "I hope Keith remembers to put the bins out!"

Out of 5,138 people diagnosed every year with sarcoma in the UK, there are 662 diagnosed with bone sarcoma, of which just 200 are diagnosed with osteosarcoma.



Isobel was eventually discharged on what was then so far the hottest day of the year. Throughout, she has had 'amazing' support from her family, friends and social media followers, and describes herself post-operation as "fine, obviously. I was doing ok but obviously not up to the cleaning!"

It's been a creative time for Sarcoma UK's newest Ambassador; with a dressing on the wound, Isobel's husband devised a covering from a black bin liner and gaffer tape so she could shower.

She's also been busy baking, thanks to an ingenious way to light the gas hob, with the handle of the lighter positioned in her stomach!

As *Connect* went to press, Isobel was having six months of chemotherapy at Addenbrooke's Hospital, Cambridge, to treat two spots that had been identified in her lungs before surgery.

Her attitude has remained positive and pragmatic as she continues doing things she enjoys, including light gardening and exercise.

In September, she and husband Keith joined Liz and friends in a 5k walk for 5kyourway.org - a 'fabulous day,' rewarded by much-deserved cake.

And her 4,000 -plus Twitter followers are keen to map her milestones as well as share her fondness for cat and dog videos.

Isobel's advice to anyone facing the same choices is characteristically down-to-earth.

"It's about getting all the facts - what will be best for your body, what options you have and what will prevent the cancer coming back.

"It's not been all that challenging - I can do most things. It's about taking your time and keeping mobile. Plus I have a

lot of gadgets, thanks to Liz, and a great helper in my husband.

"I ask myself, what if I'd gone to the GP before - would he have just said that I had sprained my arm?

"In the weeks leading up to the consultant appointment, as a family, we realised that this was not good. But once we came out, it wasn't doom and gloom - there was absolutely some hope.

"I am disappointed not to be able to drive, and lose that independence, but that might be something for the future. Now I'm being positive and getting on with life as best I can."



My incredible mum - by Liz

"There aren't enough words to say how proud I am of my mum.

I felt sick when I knew that she needed the amputation - how would she cope? How would she hide it? And then I saw her tweet telling the world that she was now a one-arm bandit.

"It made me want to laugh and cry at the same time. How could she be so positive and cheery when she had just had her arm removed? But she's just carrying on living her life and has no idea how many people she is helping

by being so open and honest about her diagnosis. She really is an incredible woman.

"It has been much harder going through mum's treatment than it was for me as a cancer patient. Everything happened to me. I had no choice but to go along for the ride. But when it's someone you love - seeing them in pain, seeing the fear and worry in their eyes, knowing that as a doctor there is nothing I can do to make her better - that was hard. All I can do is be there for her when she needs me, and wait to become the daughter of the more famous mum.

"Although I'm a breast surgeon who has had breast cancer twice, I have always felt that other cancers don't

get a look in when it comes to media attention, research or fundraising.

"I have lost several close friends to sarcoma but no-one outside of our circle knew there was a month for sarcoma. All mum and I want to do is raise awareness of the symptoms of sarcoma and help Sarcoma UK to support other people and their families going through treatment. And if that means encouraging people to #BeMoreIsobel and eat chip butties and Magnum ice-creams, then I'm all for it."

Liz's latest book, a memoir called **Under the Knife**, is due for publication next summer with pre-order possible now.

How we are making a difference

Here's a snapshot of our impact in key areas such as fundraising, support and research for the year 2021/2022. We're already building on them for 2023, thanks to your help.

Total income
in 2021/2022: **£2,539,882**

£5.3 million

invested in research
projects since 2009

74

projects supported
since 2009

17

PhD students funded

10

new projects funded
in 2021/22

£997,207

awarded to research
projects in 2021/2022

20+

people affected by sarcoma
involved in reviewing
research applications

3,417

contacts from over
767 individuals to
the Support Line.

274.58

hours spent on the
telephone to the
Support Line

79%

of individuals were
new to the Support
Line this year

9 out of 10

months saw an increase in
the number of contacts to
the Support Line team

In every pound:



73p

goes into research,
information, campaigning,
support and education

27p

is spent on fundraising
activities.

Your Shout: spotlight on your issues and your stories



In the first of a regular series, Emma McCloskey recalls her sarcoma diagnosis and experiences of the sarcoma community, including co-running a Support Group.

October 2022 marks 10 years since my diagnosis with a 7.7lb sarcoma in my right thigh. I was 29 and had my whole life ahead of me, or so I thought. What followed was three and a half years of scans, treatments, poking and prodding and a lot of tears.

Immediately after diagnosis I had surgery to remove the tumour from my leg. After recovery I had 30 sessions of radiotherapy followed by a meeting with an oncologist who felt that there was no need to have chemotherapy as there was 'No Evidence of Disease.' After what felt like a lifetime, I finally breathed.

I was happy that the cancer was no longer in my body, but I was overwhelmed. While my specialist team were amazing and looked after me better than I ever imagined possible, I felt lonely.

I didn't know anyone with sarcoma, I had no one to talk to, I had no one who understood, I was angry and I was upset. My wonderful sarcoma specialist, Dr Chandrasekar, told me about the Merseyside & Cheshire Sarcoma Support Group which was run out of the Roy Castle Cancer Centre in Liverpool. I immediately wanted to go. I wanted to meet people who knew what I was going through.

I was so nervous at the first meeting. I didn't know what to expect and had lots of thoughts going round my head – do I talk, what do I say, what if I'm the only person with a walking stick, what if I fall over, what if people laugh...what if, what if, what if?

The hosts, Lesley Abraham and Rob Myers put me at ease straight away; we had tea and biscuits and well, we all just chatted. There was around 12 of us at the meeting and it was so interesting to hear every story. We all had different sub types but we all had one thing in common – sarcoma.

Most of us were treated at the Royal Liverpool University Hospital and the Clatterbridge Cancer Centre and we formed an instant connection. The meetings are held the first Tuesday of each alternate month and I soon became a regular. In September 2013 I was hit with the bombshell that my sarcoma was now in both of my lungs. I had chemotherapy and surgery which gave me a further 12 months cancer free – until I had another tumour appear on my lungs. I was utterly devastated and had to have further surgery in 2015.

The one constant throughout this time was the Support Group. There were the regulars and every so often new people would pop in and out – and soon, I became to realise that my journey

“I wanted to meet people who knew what I was going through.”

could help people. I was no longer a 'newbie' on the sarcoma scene. As time went on, I was able to support the group more by organising our very very very important Christmas lunch.

Just before lockdown, Lesley decided to take a step back and Rob asked me to assist with running the group. I was very honoured that he asked me as it's such an important support for people. Then, Covid-19 hit... lots of support groups were impacted but we wanted to see how we could continue to help people so we went virtual. We have always had good attendance but now we could reach people who couldn't make it in person by holding meetings on Zoom. We had lots of 'you are on mute,' 'your camera is off' and 'can you hear me?' but I'm pleased to say that our group quickly adapted and we are still having Zoom meetings and in person meetings two years later. We also have a WhatsApp group and we are all in touch daily.

As well as attending the group, two other people living with sarcoma asked me to be an administrator of a Facebook group they had created called 'Sarcoma Patients in the UK & Ireland.' The group is a lovely group with lots of people affected by sarcoma, whether they have had it themselves or if they have been impacted by a loved one living with it. To this day I am still an administrator and we now have more people to support!

I know support groups, whether in person, online or virtual, aren't for everyone but for some they are vital. I thoroughly enjoy being involved and helping people and long may it continue.

Please visit sarcoma.org.uk/support/support-groups/ to find your local group or an online group. We'd love to hear your ideas for future Your Shout articles so please get in touch by emailing connect@sarcoma.org.uk



#TeamSarcoma – Take a bow!

Take one iconic race and 82 determined runners. Blend with a changeable autumn day and thousands of supporters.

Then enjoy the special ingredients of the TCS London Marathon 2022 and the sheer dedication of Team Sarcoma.

We couldn't be more proud of everyone who trained so hard for one of the most incredible fundraising challenges.

Here are just a few of those heroes, each with their very own reasons for pounding the pavements for 26.2 miles of pain and glory in a good cause – raising money for Sarcoma UK.

As *Connect* went to press, the amount raised from the TCS London Marathon stood at £319,951 – smashing our target of around £240,000.

The bone costume made a welcome comeback worn by Sam Beaton in memory of Charley Peters. There were also people travelling from as far as the US and family members running together.

Our first runner (Felicity Harrison) crossed the line in 3.08.50 – one of over 42,000 on the course in October.

The marathon experience went above and beyond the race, with Sarcoma UK returning to a stand at the Excel

centre and celebrating with a post-race reception at Church House, Westminster.

Many congratulations to our amazing runners! For our fantastic photographs, thank you to Ian Randall Photography and Kois Miah. Thank you to the students at Worcester University, volunteers, and everyone who supported on social media.

“Amazing day for an amazing cause with an incredible team- I loved being a part of Team Sarcoma!”





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

Inspired by our 2022 champions? You could join them on April 23, 2023. We're with you every step of the way with personal support, fundraising materials and loads of enthusiastic advice throughout training and on the day itself.

Registration fee: £50

Sponsorship: £2,400

Our applications are now open.

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



Celebrating a life-saving £1 million partnership

A remarkable relationship spanning over a decade brought Sarcoma UK supporters together at the spectacular home and office of the Lord Mayor of London.

Mansion House, a grade II listed 18th century building which has appeared onscreen in *The Crown*, was the stunning backdrop to the celebration of the valuable partnership of Sarcoma UK and The Analyst.

The independent financial research and analysis firm has not only donated over £1 million towards the charity's vital work but become a truly valued partner and friend from its very earliest days.

At the heart of the unique partnership is Jonny Scriven. Jonny was a friend and colleague of theirs who was unfortunate to be diagnosed with a rare sarcoma, aged just 32.

When Jonny died, founder and managing partner Mark Hiley began giving a percentage of The Analyst's profits to Sarcoma UK, creating a remarkable legacy for Jonny.

Richard Davidson, Chief Executive of Sarcoma UK, told guests of the transformative impact of this relationship.

"By supporting our work, they have enabled our Support Line to respond to almost 16,000 emails, calls or texts from worried patients and their families, invested in 74 sarcoma research projects and funded 17 PhD students.

"The team at The Analyst have run marathons, cycled huge distances and even sold office furniture to raise money, on top of their annual contribution.

"But they've done so much more: they've provided advice, venues and hospitality, and during the pandemic - when all charities were suffering - they offered us early and increased support - something we're incredibly grateful for."



The Lord Mayor of London, the Right Honourable Vincent Keaveny, praised the partnership as the best example of the theme of his year in office, People with Purpose.

Dr Sandra Strauss, senior clinical lecturer and honorary consultant medical oncologist at University College London Hospital, told guests about her work - a project digging into cancer data collected by Public Health England to better understand sarcoma care - and the difference that The Analyst support has made.

Neil Madden, Chief Executive of The Analyst and Mark Hiley spoke of the motivation behind the partnership in a moving tribute to Jonny. Both ran the London marathon in 2021 for Sarcoma UK.

Our grateful thanks go to the fantastic team at The Analyst for their life-changing commitment and support, the Lord Mayor of London for kindly hosting the evening, and Ian Randall Photography.



Conference enables greater international collaboration in sarcoma care



A renowned three day event in London this autumn saw a new development in funding by Sarcoma UK for specialists.

For the very first time, the charity was able to fund and encourage clinical nurse specialists and health care professionals to attend the European Musculo-Skeletal Oncology Society Conference (EMSOS).

"We wanted to encourage and support people who were new into post, or to the profession, so to be eligible for funding, they had to have been in post for two years or less," says Sam Hackett, Sarcoma Specialist Nurse at Sarcoma UK.

"We know senior clinical nurse specialists and allied health professionals are coming up to retirement and supporting new staff is hugely important. We want them to be inspired and encouraged to stay in this field."

The high quality applications were assessed by a judging panel, including a representative with sarcoma, resulting in five nurses and two physiotherapists supported to attend. They came from across the country, including Aberdeen, Oswestry, Nottingham, Cambridge, and London.

This event was an invaluable opportunity to engage with leading and world renowned sarcoma experts, share knowledge of caring for people with sarcoma, and to also understand the science that underpins that care. The learnings will be shared with the wider sarcoma community, inspiring changes to practice and an ongoing motivation to be involved in the specialist world of sarcoma care.



Elaine Richardson works as a Macmillan Specialist Sarcoma Nurse leading in Personalised Care and Stratified Follow-up at the Robert Jones and Agnes Hunt Orthopaedic Hospital in Oswestry, Shropshire. She support patients from GP referral, through diagnosis, surgery and beyond.

"I am passionate about improving the patient experience and raising awareness to prevent delayed diagnosis.

"I applied for the opportunity to attend EMSOS to share and learn from others' experiences, and to forge relationships as I am relatively new to post. To be selected by Sarcoma UK was just fantastic and I was so proud to be supported and enabled to attend, which will enhance my knowledge and in turn that of my patients."

Tricia Moate Award Winners for 2022 – making a difference



Many congratulations to the two winners of the fourth Tricia Moate award, Nicola Day and Lucy Whiddett.

Tricia Moate worked tirelessly as a nurse and as a patient advocate for sarcoma. Sadly, she died from sarcoma in December 2018. This year's award is the fourth dedicated to her memory.

Lucy Whiddett is a Sarcoma Support Worker with the South Wales Sarcoma Service. She started the role in August 2019, which was new to the service. With the support of the nursing team, Lucy has since worked hard to make significant improvements to ensure sarcoma patients receive high quality, person-centred care and support.

"I am dedicated to my role and passionate about supporting patients and their families through the diagnostic and treatment pathway," says Lucy.

"I am over the moon to have won the award. I am really looking forward to making the most of this amazing opportunity, and using this award to its full potential to improve patient care and support."

Nicola Day is a Clinical Specialist Physiotherapist in Oncology Rehabilitation & Exercise at Addenbrooke's Hospital in Cambridge.

"I set up the 'Rehabilitation & Exercise during Addenbrooke's Cancer Treatment' (REACT) Programme in 2016 using a charity Innovation Grant to provide physiotherapy input and safe exercise opportunities to patients undergoing oncology at Cambridge University Hospitals NHS Trust," says Nicola.

"Because of my keen interest in sarcoma rehabilitation, I was concerned about the lack of physio follow up for these patients, and so applied for funding to redesign the physiotherapy and rehabilitation pathway between the hospital and the sarcoma specialist centres across the East of England Cancer Alliance."

This led to the creation of a permanently funded specialist rotational physiotherapist post for sarcoma patients within the REACT team, and the development of a patient-facing, online education class for sarcoma patients.

Sarcoma UK is grateful to Tricia's family for their ongoing support of this award.

Our Support Line opening hours

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

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

You can also text your question to 07860 058 830.



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

Our vision

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

Our mission

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

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The bone & soft tissue
cancer charity