“We’ve been honoured to support Sarcoma UK as the Downing Street Charity of the Year”

Theresa May, Prime Minister
Welcome to the first Connect of 2017! We have lots of real stories, news, updates from last year and information about exciting upcoming events, including the infamous London Marathon in April. We’ll be along the route cheering on over 40 runners who are all raising funds so that Sarcoma UK can continue to provide expert support to the sarcoma community, and find a cure through our research programme. Each runner has their own reason for running, so we caught up with Linzi, on page 6, to hear her wonderful memories of husband Matt who inspired her to take on this challenge.

We’re also proud to launch our Annual Review (see opposite page) where you can read about our achievements and exactly how your donations have been used as part of our commitment to transparency and honesty.

You might also wonder why Theresa May is on the cover? The Prime Minister held a special reception for us, to transform the landscape for sarcoma. It was an honour to introduce the Prime Minister to so many of the sarcoma community, and to have the chance to talk to MPs and people of influence who can help take the sarcoma agenda forward. Read more about the spectacular evening on page 11.

Here’s to a 2017 filled with more ground-breaking developments.

Lindsey Bennister Chief Executive

The most common sarcoma sub-types are:

**Soft tissue sarcomas**

- Leiomyosarcoma
- Fibroblastic sarcoma
- Liposarcoma
- Gastrointestinal stromal tumour (GIST)
- Kaposi’s sarcoma (KS)
- Angiosarcoma
- Malignant peripheral nerve sheath tumour (MPNST)
- Synovial sarcoma
- Rhabdomyosarcoma

**Bone sarcomas**

- Chondrosarcoma
- Osteosarcoma
- Ewing’s sarcoma
- Chordoma
Annual Report 2015/16

Our latest Annual Report is where you can read about our achievements for the year, how we used your donations and our plans for the future.

- Our online GP education module 'Lumps, Bumps and Sarcomas' was successfully completed 3,300 times.
- We had face-to-face contact with over 500 GPs at five education events.
- We sent out 760 'On the Ball' GP awareness packs.
- We distributed 4,500 patient information booklets, an increase of 33%.
- We provided support and information by telephone and email to over 300 people.
- We provided face-to-face support and information to 550 people at 25 events.
- We hit the £1 million milestone in research funding, with 23 projects funded.
- Our media work reached an audience of 37.6 million, through 264 media mentions.
- 10 Downing Street's Great British Bake-Off for Sarcoma UK reached over 1.75 million via social media.

We exceeded the £1 million milestone in our research funding during 2015/16, having invested in 23 high quality projects since 2011 (read about three of them on page 8). We also launched our new Support Line, which is for every single person affected by sarcoma.

Download the full report from sarcoma.org.uk/SUKAR2015-16
Sing, dance, cycle and run like Santa!

Our loyal fundraisers have been very busy as usual; here’s what you’ve been up to. From festive races in London to riding bikes in Spain, there’s nothing you won’t try once.

**Runners smash Royal Parks Half Marathon**

#TeamSarcoma took on the Royal Parks Half, and smashed it! The runners completed the race in the beautiful scenery of some of London’s best known Royal Parks. They even had time to wave and smile as they went past the Sarcoma UK cheering station at mile 10! A special shout out to Dean – who took on the whole race dressed in a leopard print suit. Snazzy.

**Dancing to the beat**

Sinead, Kerry and Chessie Folwell organised a fantastic ‘Zumbathon’, in support of their mum. Over the course of the day, the group danced their way to raising over £5,000!

**Sing for Sarcoma UK**

A charity choral concert organised by the three sons of Cambridge college porter Charlie Banwell – Alex, Adam and Sebastian – has raised over £3,500. Alex also sings in Eton’s close harmony group, The Incognitos. “Earlier this year I was diagnosed with a large tumour,” says Charlie. “Thanks to Sarcoma UK’s Support Line, I was referred to a sarcoma specialist centre in London and my 5kg tumour was removed at the Royal Free Hospital. I was very lucky and I have made a complete recovery. I am incredibly grateful for the help and advice we received from Sarcoma UK.”

**Ride for a reason**

To remember his wife, Anna, Paul Seddon took on the 790km ‘Camino de Santiago’ – the ancient pilgrim’s route from France to Santiago de Compostela in Spain. It was a monumental challenge for Paul, who completed the cycle ride in rugged terrain and raised over £1,600 for Sarcoma UK.

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Run, Santas, Run!
A team of 28 jolly Santas took on the fun Santa Run in London’s Victoria Park on 4 December 2016. The team was made up of staff from 10 Downing Street, as well as friends and family of sarcoma patients (and Sarcoma UK staff). Taking on either the five or 10 kilometre course, this festive bunch raised over £2,600 for Sarcoma UK!

Marathon madness with Nessie
Tammy completed the Loch Ness Marathon with fellow Sarcoma UK runner James. They met for the first time on the start line and motivated each other through the tough course, crossing the finish line together in just under five hours. Tammy ran in support of her daughter, and raised over £2,000.

JustGiving Award for Carey Lander
Camera Obscura band member Carey Lander was awarded a posthumous Special Recognition Award at the JustGiving Awards on 22 November 2016 because of the record-breaking amount of money she raised for Sarcoma UK, after being diagnosed with osteosarcoma. Carey was a very private person, but she launched her JustGiving page in August 2015 so that “in the future... children don’t have to undergo such awful treatment and have a better chance of survival”. Our Chief Executive Lindsey Bennister said: “Her legacy will live on through the research we have been able to invest in.”
“I’m running the London Marathon for Matt”

Linzi Deane, 26, from Essex, knew she couldn’t back out when an email dropped into her inbox confirming her place in the London Marathon 2017. She is running in memory of her husband, Matt; this is her story.

“I always wanted to run a marathon but it’s something I always put off, thinking ‘I’ll sign up next year’. I used to do cross-country when I was younger, although I wouldn’t say I was very good, I never won! So, although I wouldn’t class myself as a runner, I guess all that is about to change…

“It was April last year that the thought seriously crossed my mind. My husband, Matt, was in hospital at the time and a few of our friends were running the London Marathon. I mentioned in passing to him that I always wanted to run one, and he said to me to stop just saying it and sign up! And that’s how I ended up here!

“That attitude sums up Matt, he was very motivated and hard working. Matt was 23 when he started getting pains in his arm, and like I imagine many young people would, he just put it down to muscle strains from being active. The pains came and went over a number of months, sometimes worse than others, and looking back I wish he’d gone to his GP sooner. He was diagnosed with Ewing’s sarcoma in 2013, by which time his tumour was 10cm. Over the course of the next three years, Matt went through radiotherapy, chemotherapy at UCLH and three operations. Matt remained positive throughout his treatment, determined to continue working, travelling and living as “normal” a life as possible.

“Right now, I am just concentrating on ramping up my fitness regime – I am already turning down invitations to the pub! I have bought some new trainers and I have managed to complete an 11-mile run. Considering I had only ever run 5k, I am pretty pleased with myself. My marathon training plan truly began in January and I’ll sign up to some races, including a half marathon. My top tip is to listen to podcasts on longer runs, they keep your mind occupied – particularly comedy ones which take your mind off the pain!

“I wouldn’t say I’m excited about the marathon – yet – but my friends and family will be there to cheer me on. Matt’s sister is pregnant; her baby is due in March, so I hope I can get a little Sarcoma UK Babygro for my youngest cheerleader! Let’s hope my training continues to go to plan, and I look forward to sharing my marathon story with everyone once I have crossed the finish line…wish me luck!”

Visit Linzi’s JustGiving page: justgiving.com/Linzi-Deane

Cheer on #TeamSarcoma

Our London Marathon team is inspirational – and we’re not just talking about the runners. The day wouldn’t be the same without the volunteers who give it their all at our cheering stations to help the runners through one of the biggest challenges of their lives. Join us on Sunday 23 April 2017 at:

- Mile 12 – Jamaica Road, Bermondsey SE16 4RT from 9am-2pm
- Mile 25 – Cleopatra’s Needle, Embankment from 9am-4.30pm

Contact Kat at fundraising@sarcoma.org.uk for more information.
Fundraiser focus: Gina Long MBE

When her daughter was diagnosed with sarcoma, legendary fundraiser Gina Long knew she wanted to raise a large amount of money for Sarcoma UK by organising a special, truly memorable event that people would donate generously to...

"Tuesday 24 September 2013 is a day I will never forget. It was the day sarcoma came into our lives.

"My beautiful daughter Alexandra (Ali) was just 23 years old when she was diagnosed with a Myxoid Liposarcoma after a very large lump was found on the inside of her knee and inner thigh. Naturally, it was a difficult time for our close family, but one that ultimately had a happy ending.

"Ali was under the care of a Sarcoma Specialist Centre, The Royal Marsden. I write this story just weeks after Ali, now 26, has arrived in New Zealand on her travels with her boyfriend, Ben. I am delighted to say she is flourishing. Seeing Ali go through this ordeal at such a tender age made me realise I wanted to make a bigger difference.

"As an active charity campaigner and fundraiser for more than 40 years, I knew I had to do more! It is why I have become so passionate about raising funds for Sarcoma UK, through GeeWizz – a charitable foundation that I set up. I want to make a direct difference to anyone affected by sarcoma, to those who are sharing a similar experience to us.

"I knew I wanted my first GeeWizz event to be a big one. In the end, we organised two huge fundraisers running virtually simultaneously: the Ultimate Charity Auction (which ran from Saturday 22 October – Sunday 6 November 2016) and the Secret Garden Ball on Friday 14 October 2016.

"The online auction captured the imagination of the world through the sale of unique items and experiences, including a one-to-one training session with Sarcoma UK’s Patron, Richard Whitehead MBE, a VIP Manchester United experience and a sailing trip around the British Virgin Islands on a luxury catamaran.

"The auction is always great fun, with yelps of delight often heard from me as I put the phone down on a donor offering me a true money-can’t-buy experience. The last few hours are always a mixture of excitement, pride and sheer joy.

"A whopping £106,000 was raised – and Sarcoma UK was one of the four beneficiaries. I know this will help sarcoma researchers search for better treatments, and ensure the Support Line nurses can offer personal support to anyone who needs it.

"Prior to the auction starting, we also held our very first GeeWizz Secret Garden Ball. The black-tie ball had sold out four months before the big event.

"Having already gained the support of Terry Butcher, former England professional footballer and manager, and William van Cutsem, a close friend of Prince William, we were thrilled to attract similar high-profile names to the evening with support from former England cricketer Graeme Swann, Suffolk operatic star Laura Wright (who performed beautifully), and popular television presenter Chris Hollins acting as the MC for the evening.

"In attendance that evening was courageous Suffolk teenager Kim Sale who has Ewing’s sarcoma. She’s now focusing on her GCSEs, but sports-mad Kim has mentioned the possibility of competing in a future Paralympics – and it was wonderful to be able to raise enough to fund her first sports blade. The night raised more than £83,000 – all this was done from a farm office in the middle of Suffolk countryside, where I sit next to my farmer husband, Andrew.

"With a small but brilliant team behind me, I was so proud to be able to present Sarcoma UK with a cheque for over £57,000 from GeeWizz and I look forward to supporting their amazing work in the future.”

To find out more about Myxoid Liposarcoma and Ewing’s sarcoma, visit sarcoma.org.uk/sarcoma-types
Research highlights

Wow, what a year! Sarcoma UK exceeded the £1 million milestone in research breakthroughs are being made.

New drug combination could target resistance to sarcoma drug

Scientists have identified a new combination of drugs that could be effective in treating advanced sarcoma that is resistant to pazopanib (a type of treatment for advanced soft tissue sarcoma).

The research team led by Dr Paul Huang at the Institute of Cancer Research, identified particular proteins that are involved in the development of this resistance. In a trial, they have tested out a new combination of drugs on these proteins and found a combination of drugs that successfully targets the resistance.

This research project, co-funded by Sarcoma UK, could lead to more effective and personalised treatments for sarcoma.

“We look forward to the outcomes of the trial and more effective treatments for sarcoma patients. The Sarcoma UK research programme is helping to find answers sooner.”

Sarah McDonald, Sarcoma UK’s Director of Research

Breakthrough in chordoma research

Chordoma is a type of bone sarcoma with limited treatment options. This project, led by Professor Adrienne Flanagan at University College London Hospitals, tested a number of compounds on chordoma cells to see whether the compounds affected the cell’s growth rate or caused the cells to die. The testing identified four compounds that showed potential and these will now go into a clinical trial to investigate their potential as a new type of treatment for chordoma.

This research project, co-funded by Sarcoma UK, could lead to a new treatment for chordoma.

“We thank you to Sarcoma UK for contributing funds for this vital research to find potential treatments for chordoma. We are excited about the prospect of a drug trial for patients with few treatment options.”

Professor Adrienne Flanagan, Clinical lead for the diagnostic pathology service for the London Sarcoma Service

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Professor Adrienne Flanagan, Clinical lead for the diagnostic pathology service for the London Sarcoma Service

sarcoma.org.uk
from 2016

Research highlights from 2016

Wow, what a year! Sarcoma UK exceeded the £1 million milestone in research funding. These three Sarcoma UK-funded research projects show what breakthroughs are being made.

Discovery in the genetics of sarcoma

Testing the genes of people with rare cancers like sarcoma could uncover what’s known as “cancer families”. The testing can pick out genetic mistakes that are hidden within their family tree that makes them more susceptible to being diagnosed with cancer. This phenomenon can be seen in families where many family members have been affected by cancer – sometimes the same type, sometimes many different types of cancer, depending on the gene involved. It’s down to inherited cancer-causing mutations in the gene.

A team of researchers from the UK are part of an international project looking at this phenomenon and the link to sarcoma in families with multiple cancers. So far, the research has found that over half of the people with sarcoma they have tested were born with a mutation in at least one gene that is known to increase the risk of cancer.

Knowing when families carry genes which increase their risk of cancer will help as family members can be offered genetic counselling and screening.

“This study gives us the most detailed picture yet of the genetics of sarcoma patients.”

Professor Winette van der Graaf, Professor of Personalised Oncology at The Institute of Cancer Research

Check our website, sarcoma.org.uk, for news stories and sarcoma breakthroughs as and when they happen. Also make sure you sign up to our mailing list to receive our e-news, which goes out every six weeks.
Sarcoma UK’s Support Line

Not everyone understands sarcoma. We do. Our Support Line helps hundreds of people affected by sarcoma – like you – who may have questions about diagnosis or treatment.

Sarcoma UK Support Line is here for every person affected by sarcoma.

It has been one year since we were able to launch our national Support Line, thanks to your donations. In 12 months, our expert Support Line nurses have helped almost 1,000 patients, carers, family members or friends of someone with sarcoma. We are here for everyone worried about sarcoma.

No question is a silly question.

Don’t be shy in asking us anything on your mind about sarcoma. You’re not alone and lots of people are also probably thinking of that question too. We’ve worked in the world of sarcoma a long time and nothing phases us. Here are some of the most common questions we’ve received this year. They may have even crossed your mind too.

“I have sarcoma but I don’t really know what that is?”

We know that not many people have heard of sarcoma. Sarcomas are cancers that develop in your bone and soft tissue. There are over 100 different subtypes – some of which are difficult to get your tongue around. That’s why we are here. With over 20 years’ nursing experience in the sarcoma field, we can help you understand your specific type of sarcoma, what happens next and what is happening right now.

“Where should I be treated?”

Anyone with suspected sarcoma should be cared for in a sarcoma specialist centre. These are UK-wide. Here, you will meet your Multidisciplinary Team (MDT) that may include a surgeon, oncologist and a sarcoma specialist nurse. We have seen the work of sarcoma MDTs at first hand and we have strong links with all of the sarcoma specialist centres. We can point you in the right direction to find yours.

“How do I cope with the side effects of treatment?”

Like many others, you might experience a range of side effects during and after your treatment. We can discuss your diet and nutrition during chemotherapy or even find the right type of rehabilitation available for you. We can help you devise a plan to manage your symptoms.

“What clinical trials are available?”

Clinical trials look at new drugs or combinations of drugs to treat sarcoma. We can give you advice on what questions to ask to take part in a clinical trial or where to find one.

Visit our website for our opening hours: sarcoma.org.uk/sarcoma-uk-support-line

“Thank you, just being able to talk to someone who knows about sarcoma is so helpful. Nobody understands it like you do.”
PM hosts Sarcoma UK reception

Prime Minister Theresa May, MPs, patients, carers, health professionals, researchers, and Sarcoma UK supporters came together to transform the landscape for sarcoma.

Wow, what a night! Monday 28 November 2016 will go down in Sarcoma UK history. It was the evening that Prime Minister Theresa May held a reception at 10 Downing Street in our honour, a culmination of a very special and year-long partnership.

As we announced in our spring 2016 issue of Connect, Sarcoma UK was No 10’s official charity of the year in memory of Chris Martin, who was the Principal Private Secretary to former Prime Minister David Cameron.

November’s reception was about giving Sarcoma UK an opportunity to speak with a clear voice – to people of influence, to funders and to the wider sarcoma community on the issues that the charity cares about.

Our Chief Executive, Lindsey Bennister, spent time talking to the Secretary of State for Health, Jeremy Hunt MP, about the experiences of sarcoma patients within the NHS and many of our guests took the opportunity to talk personally to the Prime Minister during the evening.

Dr Sarah Wollaston MP, Chair of the Health Select Committee and a former GP, engaged with our guests around early diagnosis of sarcoma and learned about the work the charity does to support GPs to recognise the signs and symptoms of sarcoma. We were also honoured to meet Sir Paul Nurse, Chief Executive of the Francis Crick Institute; Cally Palmer CBE, the National Cancer Director and Chief Executive of the Royal Marsden Hospital; and Dr Jonathan Fielden, Director of Specialised Commissioning at NHS England.

Our Patron, Richard Whitehead MBE’s achievements were officially recognised during the evening, highlighting his ‘40 marathons in 40 days’ challenge, with the Prime Minister presenting him with a Point of Light Award for his services to Sarcoma UK: an award for outstanding volunteers who make the country a better place.

The reception paves the way for more research breakthroughs in 2017, and we would like to thank No 10 for their dedication, hard-work and commitment in putting the spotlight on sarcoma.

Sarcoma UK’s pledge

Ten people are diagnosed with sarcoma every day in the UK. We have pledged to invest over £3 million into sarcoma research by 2020 with the aim of finding effective treatment for the disease within the next 10 years; we currently invest £500,000 a year into this research.

View more on our website: sarcoma.org.uk/No10
No 10 Reception

Craig Gerrand, Sarcoma UK-funded researcher; Prof Adrienne Flanagan; Dr Jonathan Fielden

Sir Paul Nurse, Director of the Francis Crick Institute; our Patron, Richard Whitehead MBE

Glyn Wilmshurst, Trustee, Sarcoma UK; Lindsey Bennister, Chief Executive, Sarcoma UK; Theresa May, Prime Minister
Our Patron, Richard Whitehead MBE; Theresa May, Prime Minister; Pippa Hatch

Lindsey Bennister, Chief Executive, Sarcoma UK; Jeremy Hunt MP, Secretary of State for Health

Prof Ian Judson, Trustee, Sarcoma UK; Paul Huang, Sarcoma UK-funded researcher
A day at the museum

Nine-year-old Alex made friends with archaeologist Dr Max Pinarello on Twitter…they both have sarcoma and they both share a love of dinosaurs, archaeology and museums. We caught up with the boys on a special day out at the Natural History Museum in November 2016.

Alex Goodwin, 9, lives near the Warwickshire and Leicestershire border, with his dad, Jeff, mum, Maria, and his little sister, Sophia, 4

"I was told I had cancer at the beginning of June last year. It was just after my birthday, so I was nine years old. But I remember feeling poorly at Christmas time and I was misdiagnosed, which means I was poorly but they thought I was ill with something else.

"I felt quite strange when I found out I had sarcoma. It’s horrible because I feel poorly and weak. My Mummy and Daddy explained to me what was wrong, along with the doctor, too. When I am in hospital, I have all the nice nurses around me looking after me. And my Mummy and Daddy, too, of course. I also find that all my Twitter friends help, as they send me messages of encouragement and support.

"I am interested in nature and history, so learning about those things makes me happy. I love sharks and dinosaurs and birds of prey. I’m training to be a falconer and I have some owls called Murray and Mango and they make me happy, too.

"I met Dr Max on Twitter, he was one of my first followers. We talk about history, archaeology and natural history. He is very clever about lots of things, but he likes Egyptology best. I loved our day out at the museum, we saw some really interesting things like meteorites and a piece of the moon! I loved the dinosaurs too, but my favourite part of the day was just hanging out with my friend Dr Max. We will be friends forever, because we talk a lot and he knows lots of interesting things."

Alex is currently having treatment in America. Follow his journey on Twitter @alexs_journey

Archaeologist, Dr Max Pinarello lives in London with his wife and baby daughter

"I have Myxoid Liposarcoma. I had a lump in my leg for a year or so, and I just ignored it, thinking it was a muscle strain. Eventually my GP sent me to a sarcoma specialist. My wife was actually six months pregnant when I was first diagnosed and I am now the proud father of a baby girl.

"I have had an operation to remove the tumour, and I am also undergoing radiotherapy. Suddenly I was thrown into a new world, and it is the support of my friends and family that has got me through. Cancer changes your life, it has made me very open and honest. That is so important, you can’t be shy, you have to talk about everything. That is why I like to help other people, people like Alex.

"It was on my first day of radiotherapy at the Royal Marsden that Alex sent me some words of encouragement on Twitter, he must have found me as I mentioned #sarcoma. That is how our friendship started. I would often tweet him things to cheer him up, like pictures of animals or funny things about Batman.

"Then one day Alex tweeted me saying that he was coming to London and asked if I would give him a tour of the Natural History Museum. He told me that he wanted to be a scientist one day.
I talk to Alex about his sarcoma, too, but I don’t want to overwhelm him, I am just here for him if he needs me. I know he prefers to talk about history and dinosaurs and I hope I can inspire him. I often think of Alex and how well he deals with everything, he just nine years old and an absolute inspiration.”

Follow Max on Twitter, @DrMaxishere

With special thanks to Patrology Curator Epifanio Vaccaro and Assistant Curator Meteorites Natasha Almeida from The Natural History Museum for allowing us to go behind the scenes, and see a 4.567 billion year old meteorite (older than the Earth!) and a piece of the moon.
More and more Sarcoma UK supporters are making a monthly donation. Will you join them?

Many patients have never heard of sarcoma until they are diagnosed themselves. At a time like this, speaking to somebody who understands what you are going through is vital. Sarcoma UK’s Support Line gives every patient access to a Sarcoma Specialist Nurse for independent and confidential advice.

Will you donate £15 a month to give every sarcoma patient a listening ear?

sarcoma.org.uk/donate

Thank you!

I’d like every patient affected by sarcoma to get the support they need.

To register, please fill out both forms. Form A should be returned directly to your bank (or you may be able to do this online), and Form B to us at: Sarcoma UK, 49-51 East Road, London, N1 6AH. Form B notifies us that you have set up a standing order gift and allows us, if applicable, to claim Gift Aid from your donations.

Form A

To the Manager: [Bank name]
Address: [Postcode]
Account name: [Account no.]
Sort code: [Bank name]
Account no.: [Date]

I wish to set up a regular Standing Order in favour of Sarcoma UK.
Please make a first payment of £ [payee] on [date] and thereafter a similar payment *monthly/quarterly/annually until *further notice /the following date [Payee: Sarcoma UK Sort code: 40-52-40 Account no: 00019763 Bank: CAF Bank Ltd Branch: 25 Kings Hill Avenue, West Malling, Kent ME19 4JQ Signed: [Signature] Date: [Date]

I have set up a regular donation to Sarcoma UK by Standing Order of £ [Name: First name Last name] *please delete as appropriate

Form B

I want to Gift Aid this donation and any donations I make in the future or have made in the past 4 years to Sarcoma UK. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. Please notify the charity if you: want to cancel this declaration, change your name or home address, no longer pay sufficient tax on your income and/or capital gains. If you pay income tax at the higher or additional rate and want to receive additional tax relief due to you, you must include all your Gift Aid donations on your Self-Assessment tax return, or ask HM Revenue & Customs to adjust your tax code.

Signed: [Signature] Date: [Date]

Code: SU1171