



The bone & soft tissue cancer charity

Spring 2019

Connect



Team Sarcoma goes the distance once again

Despite the heat, last year's London marathon team raised more than £250,000
Meet some of this year's runners on page 6

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Putting big ideas into practice
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Meet the new CEO
Introducing Richard Davidson

About Sarcoma UK

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments.

Sarcoma UK has helped more than 1,200 individuals who used our support services an average of three times since we launched it in February 2016.

The charity is now one of the biggest funders of sarcoma research in the UK, having invested more than £2 million to date (as of January 2019).

Our Mission

Our mission is to amplify sarcoma awareness, inspire involvement, and fund ground-breaking research to transform the lives of everyone affected by sarcoma.

What we do

- Drive awareness of sarcoma cancer.
- Find answers through funding sarcoma research.
- Provide information and support to anyone affected by sarcoma cancer.
- Campaign for better treatments and to improve standards of care.

Facts and figures about sarcoma

- Sarcoma is more common than previously thought. In 2015 there were 5,345 people diagnosed with sarcoma cancer in the UK.
- There are three main types of sarcoma: soft tissue sarcoma, bone sarcoma and gastrointestinal stromal tumours (GIST).
- Sarcoma diagnoses now make up about 1.3% of all cancer diagnoses in the UK.
- About 670 cases of bone sarcoma are diagnosed every year in the UK.
- Seven in ten (71%) sarcomas diagnosed in the UK are soft tissue sarcomas.
- The majority of people are diagnosed when their sarcoma is about the size of a large tin of baked beans (10cm).

Survival rates

- Sarcoma survival rates have been very gradually increasing over the last two decades in the UK.
- Almost eight in 10 people (78%) diagnosed with sarcoma in the UK will live up to a year.
- The average percentage of people living three years after being diagnosed with sarcoma in the UK is 64.5%.
- The five-year survival rate for sarcoma is 55%.



I would like to say a huge thank you to all of you who have helped make me feel so welcome since I joined as Chief Executive in July. Lindsey Bennister has done an incredible job for the last eight years, taking the charity from strength to strength, and I am privileged to follow in her footsteps.

I've been able to see first-hand just some of the amazing work that goes on in the Sarcoma UK family. As the dark days of winter continue, I would like to give a round of applause to all the fundraisers who are still running, cycling, baking and more to support our work. It's not long until the Virgin Money London Marathon in April. Last year the 64 strong Team Sarcoma – our biggest ever – raised a fantastic £250,000 and we can't thank you enough. You can read all about the day and some of the moving stories of people who are training so hard to achieve that 26.2 mile challenge in 2019.

Fundraising like this makes our cutting edge research possible. Dr Nischalan Pillay explains his ground breaking work to identify where sarcomas have altered a person's DNA and left a 'footprint', enabling them to pinpoint which patients will respond to specific treatments. At Aston University, Dr Richard Martin is developing a bone replacement material which kills cancer cells and encourages the growth of new bone cells.

Elsewhere in this issue we update on the progress of genomic medicine in England and how our Support team is responding to your questions with specifically developed resources.

Much has happened over the last year as you will see from the highlights of our 2017 – 2018 Impact Report. We have big plans for 2019, particularly in creating a strong brand to increase awareness of sarcoma, our income and our influence; investing in research; and increasing the information and support we offer patients and their families.

I hope you will enjoy reading Connect, especially as this is our first issue for a little while. Please get in touch with your thoughts and I look forward to meeting more of you soon.

Richard Davidson Chief Executive



@sarcoma_uk



@sarcoma_uk



Sarcoma UK



sarcomauk



Sarcoma UK

Sarcoma^{UK} PODCAST



Our podcasts are back by popular demand! The inaugural series of podcasts for Sarcoma Awareness Week 2017 paved the way for people to engage with our work through a totally different experience. Now we have a new series of podcasts coming soon around the theme of resilience.

"Resilience – the ability to recover readily"

Each of the five episodes will centre on the experience of one individual and the various aspects of their life that may involve cancer. Among the different perspectives are a young person in the Instagram age carrying on with the visible effects of cancer treatment; an active campaigner and fundraiser despite managing chronic pain as a result of cancer treatment; an activist as she campaigns for policy change after the misdiagnosis of her mother's condition.

One episode will feature Emily Travis, clinical trials participant and Sarcoma UK supporter, who represents the resilience shown by someone who has lived through three terminal diagnoses.

Our first series of podcasts dealt with some of the most frequently asked questions that are put to our Support Line team, from advice to anyone newly diagnosed with sarcoma to what happens after treatment. We hope that the second series will be equally as popular with listeners.

You can stay up to date with our podcasts and other and other sources of information or support at sarcoma.org.uk/support-information. If you do have ideas of topics we may cover in the future, share them with us at info@sarcoma.org.uk



We offer advice to anyone touched by sarcoma, whether you have just been diagnosed or someone you know is being treated for sarcoma. No question is a silly question.

**Contact our Support Line on 0808 801 0401
or email the team at supportline@sarcoma.org.uk**



**Sarcoma^{UK}
Support Line
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supportline@sarcoma.org.uk

Meet the fundraisers

From cycling the length of the country and across the channel to quiz questions and mountain summits, this dedicated bunch have been going the extra mile for everyone affected by sarcoma.



Racking those brains in memory of Chris

Politicians, journalists and celebrities teamed up for the second Chris Martin Memorial Quiz - the most recent event in memory of the Principal Private Secretary to David Cameron who died from sarcoma in 2016. Chris was passionate about raising awareness of sarcoma and his family and friends have continued his legacy. Sarcoma UK was honoured to be Number Ten Downing Street's Official Charity of the Year in 2016. The charity has now launched a Chris Martin Fellowship looking into genomics thanks to money raised from the quiz. The 2018 event raised over £21,000.

UK end to end fundraising

Sixteen year old Jonathan Radford took to his bike for a gruelling two week challenge in memory of his dad Andy who passed away from sarcoma in 2017. The teenager raised over £13,000 during the ride from Land's End to John O'Groats – and his whole family raised £18,000! Just a month earlier he was supported by cycling club The Vale of Belvoir who undertook four 25 mile challenges for sarcoma awareness. Jonathan said that his motivation for fundraising was 'so that other families don't have to go through the same thing we went through.'



The sky's the limit for The Analyst

Sarcoma UK has enjoyed support from The Analyst for a number of years thanks to Mark Hiley, Managing Partner and Founder of the London-based financial firm. Here we commemorated our partnership by presenting them with giant helium balloons spelling out the very grand fundraising total of £287,891.

Triple cycling stars

Elaine Quinn and Cathryn Walsh got themselves in a fundraising spin after Elaine's dad was diagnosed with sarcoma last year. Their incredible three stage cycle challenge took them to the New Forest, Surrey and Paris and raised over £1,500 – in just three months!



Date for your diaries

Sarcoma Awareness Week is taking place 1-7 July 2019 and the Big Picnic is happening for the third year – this time for the whole of July! We'll have more details over the coming months but keep your eyes peeled! sarcoma.org.uk/bigpicnic

High level wedding anniversary

Glyn Wilmshurst, Chair of Trustees at Sarcoma UK, and his wife Katy ditched wedding



anniversary traditions by climbing Mount Kilimanjaro to celebrate 25 years together. The 5,895 metre summit was the snowiest in 15 years but that didn't deter them unfurling the Sarcoma UK banner right there. 🌟

News

Genomic testing for sarcoma – how you could be affected

The potential to bring patients the most effective treatments faster has been given a huge boost as the NHS became the very first health service in the world to routinely offer genomic medicine. Sarcoma is one of the diseases for which patients will have the cancer's whole genome sequenced to pinpoint the whole raft of mutations that drive their growth.

The move introduced in October 2018 links hospitals across England to specialist centres which analyse and interpret patients DNA to help with diagnosis, matching patients to the best possible treatments and reducing side effects. The service is expected to generate a wealth of valuable data and enable a level playing field in the genetic testing of the future.

The pioneering 100,000 Genomes Project, which paved the way for DNA sequencing, reached its target of sequencing whole genomes from 85,000 NHS England patients in December 2018.

Sarcoma UK has produced new guidance to help answer the questions that many patients with sarcoma have for their clinician or about what this development means for them. "Our new factsheet will expand on the announcement and what it means for patients," says Claire Kelleher, Director of Information and Support. "While this development is very new, people want to know about the practicalities and how it is going to work. It benefits sarcoma patients so we wanted to explain about those as well as answer some of the tougher questions about eligibility.

"It will help patients to have a clearer picture of what is available and most likely to work for them – in short, giving more knowledge and an informed choice. At the moment it is only available in England so there

is a lack of parity with the devolved nations as well as about who will be tested. Those who have been recently diagnosed and also relapsed are eligible while others won't be ie maybe gone into palliative care. It is a real starting point and the NHS will learn a lot from the sarcoma community."

While it is early days, the Support and Information team have already had queries around genomic testing. The factsheet will be available to download on the Sarcoma UK website from February. ●

Pioneering project focuses top ten cancer research priorities

A pioneering approach to defining priorities for cancer research has led to a clear focus for the future thanks to patient and professional feedback.

The National Cancer Research Institute and the James Lind Alliance asked for your help in two UK-wide surveys which attracted more than 3,500 responses from patients, carers, health and social care professionals.

As a result, the two year-project identified 26 key questions and defined 10 top research priorities. Among those were:

- the best models for delivery of long-term cancer care
- appropriate information around cancer from diagnosis and beyond
- better co-ordination of care for those living with and beyond cancer with complex needs
- what causes fatigue and how to manage it
- psychological impact and how to support well-being
- lifestyle changes.

This is the first time that clear research priorities have been identified in this area and these findings will

Our transformational Genomic research programme aims to unlock the huge potential of the 100,000 Genomes Project. Thanks to you, we will award £250,000 to a project that brings together the best researchers using the latest technologies and the sarcoma samples collected and identified in the 100,000 Genomes Project.

shape research priorities for the years to come thanks to the thousands of people who took the time and trouble to give their views. By 2030 four million people in the UK will be living with the long-term consequences of cancer, but currently there is very little research on the problems they face and how these can be tackled. To help them live better lives, more focused research is needed. ●

NHS England consultation – the latest stage

The opportunity for anyone affected by sarcoma to have their say has now reached the next stage as their views are considered. The consultation announced by the NHS in a bid to change how sarcoma is treated welcomed responses on their wide-ranging proposals until mid-December 2018. Sarcoma UK also submitted our own views and suggestions in support of the proposed changes.

The core principles focus on making sure that sarcoma patients get the best treatment, care and access to clinical trials:

- Commissioning services to make sure that all patients are referred for treatment at a specialist sarcoma centre where outcomes are better for patients
- Ensuring the pathways for patients to reach those specialist centres are clearly defined
- Ensuring sarcoma patients treated by other teams such as children, teenagers or young adults or those living with gynaecological cancers will also be discussed and recorded by multi-disciplinary teams
- Having patients with gastrointestinal stromal tumours (GIST) or retroperitoneal sarcoma (RPI) operated on by sarcoma multi-disciplinary teams with the appropriate expertise and infrastructure for these patients.

We have been encouraged by what we have seen so far. It's a welcome sign that the NHS recognises that things need to change to give sarcoma patients access to the best care. ●



From left to right: Joe Whittall, James Quigley, Darren Steele, Vicky Smith, Róisín Gaffney, Johnny Sunderland and Emily Gasche

It's a scorcher

as Team Sarcoma smashes London Marathon

With our biggest ever team raising a fantastic £250,000, Sunday 22 April 2018 was a milestone for each and every one of our 64 amazing Sarcoma UK runners.

The Virgin Money London Marathon 2018 was officially the hottest London marathon on record. Our determined participants smashed the 26.2 mile course and their personal fundraising goals to help change the future for everyone affected by sarcoma.

The Sarcoma UK cheering squad was out in force at miles 12 and 25 to lend their support for all our runners, from first-time faces to seasoned marathoners, who braved the sweltering heat over the capital's iconic course.

As ever, we celebrated their incredible efforts after they'd crossed the finishing line with a party for well-earned hydration and a chance to reflect on their amazing achievements.

A big thank you also goes to our many volunteers who got up at the crack of dawn on a Sunday morning to cheer

our runners round the course and help look after them post-race. We couldn't do it without you!

With just a few months to go until the Virgin Money London Marathon 2019, we heard from a few dedicated runners about their reasons for going this incredible distance.

Fundraising like this makes our work possible.

Since our programme started, Sarcoma UK has awarded close to £2 million into sarcoma research. For 2018 – 2019 we have pledged a further £750,000 to expand our understanding of sarcoma!



Liam Herneman, 26

"I have decided to run the 2019 London Marathon for my mother, Julia. In March 2018, mum was diagnosed with liposarcoma, a rare cancer of connective tissue. Luckily for us, a brilliant team of surgeons from the Royal Marsden Hospital were able to successfully remove the tumour from her abdomen, saving her life.

A great deal more research is needed to understand sarcomas and improve treatments. Sarcoma UK is a friendly charity that really does deserve our support. This will be my first marathon, and I'm aiming to complete it in 4 hours."



Jo Lowe, 50

"My husband Ben was diagnosed with sarcoma in 2018 – a diagnosis that was missed during the preceding six months.

Ben used to be a professional violinist before retraining as a solicitor. He has been lead violinist of Norfolk's two main orchestras and until 2017 it was his main hobby. Unfortunately his tumour was in the left side of his chest where his violin is held and the major lifesaving surgery has meant that violin playing has had to stop. We owe his life to the Royal Brompton Hospital surgeons after we were originally told that his tumour was inoperable and incurable.

This is my first marathon! My longest previous run was 10k so hoping my body will hold out through the training."

Valerie Henney, 54

"It certainly was a tough one. I had a problem with my foot during training runs and although I was in pain nothing was going to stop me completing it. Meeting other Sarcoma runners along the route was a big help and the support of you guys and the crowd was fantastic! It was an honour to run for the Sarcoma UK team and I hope to do some more fundraising for you in the future. I know this would have meant a lot to my brother. Once again thank you for all your support and the great work you do for Sarcoma UK."

David Gallagher, 47

"I started running after my wife Lauren was diagnosed with Ewing's Sarcoma just a few weeks after we got married in 2015.

Our friends, Lauren and myself have done six marathons including two London marathons, two half marathons and a sky dive for cancer charities. Our village, New Cumnock, is a fantastic support and we have raised over £20,000 in the last two years.



Taking up the challenge of the 2019 London Marathon with my friend Andrew Ferrans, a former professional boxer, for Sarcoma UK was a must.

My wife passed away in January. Her oncologist said she was an absolute pleasure to look after and that she always put up with everything she had to go through with such a great spirit. Her self-motivation to overcome her problems was a lesson to us all.

I am so proud of her and my 13 year old daughter Ellie who wants to become an oncologist."



Team Sarcoma 2018 raised around a quarter of a million pounds – a life changing amount which will lead to more research, more support and more information for everyone affected by sarcoma.

You, too, can make a huge difference by joining Team Sarcoma if you have your own place for the 2019 Virgin Money London Marathon. Every pound raised will help our researchers in their understanding of sarcoma. With every step, you'll ensure that anyone affected by sarcoma cancer can get support and information from our Support Line nurses.

Email fundraising@sarcoma.org.uk or call 020 7250 8271.



Putting big ideas into

A passion for research into sarcoma saw a young man travel thousands of miles and badger his role models for years for research opportunities. Ten years on, Dr Nischalan Pillay is helping to transform what we know about sarcoma with help from funding from Sarcoma UK.

Dr Pillay did his medical training in South Africa, before working in Durban in the midst of the AIDS epidemic. "At that point, it was a completely demoralising situation for a doctor walking into a ward knowing that most of your patients were going to die."

This was his first link with sarcoma as many patients with AIDS develop a type of sarcoma (kaposi sarcoma) caused by a virus. Later in his training, this interest in rare cancers was stimulated when a senior colleague showed him a type of tumour arising in the nerve called a neurofibroma and encouraged Dr Pillay to give his views. While he had little idea of the clinical implications of this disease, he spent the next weekend studying a book considered the bible of sarcoma.

"That was the start of my fascination

with sarcoma and my realisation of the power of pathology," he recalls.

"In the UK, most doctors would not have experience in managing patients with sarcoma – statistics show that GPs would see perhaps one case of sarcoma during their career."

Keen to get into research, he sought out every opportunity to make his mark, including years writing to prominent figures in the field and visiting other research departments.

"Now I understand how these things work from the other side and that there simply is very little time to respond to such requests with the pressures of work in the NHS. I was lucky enough that one such person who took the time to reply was Professor Adrienne Flanagan at UCL who encouraged me to look her up if I was ever in London."

This contact led to the opportunity to visit London and attend a sarcoma multi-disciplinary team meeting. Six months later, he finally realised the dream and moved into research at University College London and the Royal National Orthopaedic Hospital.

"I had the support of role models and other people who mentored me, even though there are very few role models in the sarcoma field."

"It was a really productive time, working with amazing people, particularly with world leaders in genomics at

the Wellcome Trust Sanger Institute and publishing work in journals that at one time, even as a doctor, I really hadn't understood before."

A decade later at London's UCL Cancer Institute, Dr Pillay is focusing upon a three and a half year project funded by Sarcoma UK. The second annual award of a PhD fellowship in sarcoma basic science is in memory of Sayoko Grace Robinson who was diagnosed with angiosarcoma and died in 2014.

The £120,000 project will enable him to train a PhD student and build on his earlier work to identify where sarcoma has altered a person's DNA and left a footprint or 'mutation signature,' working with colleagues in the Francis Crick Institute and the University of San Diego, California.

"Sarcoma is fascinating in that it is not just one disease, but perhaps as many as 200 if you get really granular," explains Dr Pillay. "This makes it incredibly difficult to study."

The PhD project started in September 2018 under Dr Pillay's supervision and aims to collect all the sarcoma samples that have been sequenced by international consortia as well as those being sequenced as part of the 100,000 Genomes Project. It will bring them all together – up to 1,000 – in the largest collection of sarcoma sequencing data in one place.

"For sarcoma patients, the 100,000 Genomes Project data is fantastic – but it's still not enough, so it is necessary to partner with organisations who are happy to support and extend this work," explains Dr Pillay.

"It's always a challenge to get funding for sarcoma research"



practice



“Sarcoma is fascinating in that it is not just one disease, but perhaps as many as 200 if you get really granular.”

One of the many challenges of sarcoma, apart from being rare, is the number of sub-types. Many of the DNA mutations are effectively in just one letter of the genome sequence.

Dr Pillay uses a powerful analogy of a book to illustrate the difference with sarcoma genomes. “If you think of the genome sequence as a book, sarcoma doesn’t have mistakes in the letters but on the page, such as more than one of the same page, or a whole chapter might be missing,” he explains.

The aim is to link into data from clinical trials; the team is already talking to drug companies as they have the preliminary data at their fingertips.

“This research is so complex – it’s done with a computer rather than a pipette and is known as bioinformatics,” says Dr Pillay. “There is a global lack of pathologists and bio-

informaticians in the field of sarcoma and we desperately need more of them if we want to see the realisation of personalised medicine for sarcoma patients.

‘Ultimately, we want access to the tissue samples used in clinical trials (from drug companies) so we can prove that analysing them is beneficial.’

Long term the goal is to get funding to train clinicians – but this is no easy task.

“It’s always a challenge to get funding for sarcoma research; to have organisations like Sarcoma UK give us money cannot be over-estimated,” says Dr Pillay. “I could not possibly do this work without that support. Research needs the combination of the right people, the right place and the right time to

make it work. That time is now.” Dr Pillay is part of a consortium working to attract the interest of drug companies. “If we can find a way to repurpose existing drugs, it’s a win win – less risk for the drug companies and shows the benefits for patients with sarcoma.”

And the ultimate goal? “We want to understand why people get sarcoma and identify ways to detect it earlier and to stop it sooner. It’s not just a lack of awareness of sarcoma that is the problem – patients are being diagnosed too late.”

A groundbreaking paper is due to be published which will demonstrate how the team has pulled out the ‘footprint’ and how the disease develops. While immunotherapy has been cited as the next cancer ‘breakthrough,’ this hasn’t necessarily been in relation to sarcoma. This paper will show that up to 15 per cent of sarcoma patients could benefit from this therapy.

Dr Pillay has recent experience of sarcoma with his mother recently diagnosed with a rare type of the disease, which he says now makes his work incredibly personal. “When I see a sarcoma patient now, it takes on a new dimension. I feel a greater sense of responsibility.”

As a pathologist he works remotely from patients, often closely liaising with surgeons, radiologists and oncologists who are at the front line, and sees it as a real challenge as most patients don’t realise how crucial pathologists are to their care. However, it is mainly through his research that he meets patients who seek information or want to chat about advances in the field.

Outside the laboratory, Dr Pillay is a keen tennis player and long suffering fan of Arsenal FC since he moved to London. But his passion for health doesn’t stop at work - he takes a strong interest in all things related to artificial intelligence (AI) which he describes as a future ‘game-changer’ for clinical healthcare generally but in under-resourced regions of the world in particular. ●

Impact report 2017/18

Our first Impact Report showcases our achievements for the year, where your money went and our big plans for the future. With your support, we can do even more.



We invested almost half a million pounds (£485,176) on sarcoma research in 2017-18 with 11 projects funded



More than 440 fundraisers ran, swam, hiked, baked, dined and collected for Sarcoma UK



Our campaigning led two sarcoma drugs, olaratumab and regorafenib, to be available across the NHS in four nations



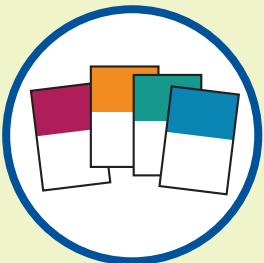
In autumn 2017, we started collating new sarcoma data (completed in Spring 2018) - crucial to our understanding of sarcoma and our focus for the future



We supported 455 individuals who contacted us on average more than three times each (totalling 1,586 contacts)



Nine in ten (90%) survey respondents told us our sarcoma information was helpful, easy to understand and helped them deal with their concerns



More than 8,400 patient information resources were distributed to specialist sarcoma centres, treatment centres and information centres across the UK



The Sarcoma UK website saw an increase of 25 per cent in users and visits



We launched the charity's Clinical Trials Hub in March 2018 with more than 3,600 page views of the hub in the first two months

The full Impact Report shows the results of our work and the value we will be adding in the coming years. You can download the full report here: sarcoma.org.uk/impact

Meet new CEO Richard Davidson

Richard Davidson joined Sarcoma UK in July from national blood cancer charity Anthony Nolan, where he was Director of Engagement, responsible for overseeing communications, fundraising and marketing. Richard has almost two decades of experience in cancer charities, notably playing a key role leading the campaign that successfully pushed for legislation on smoke-free public places in the UK while at Cancer Research UK. Our first in-depth interview with Richard reveals his initial thoughts about the charity and his ambitions for 2019.

Richard, how have the first few months been for you?

People have been incredibly welcoming and open, giving up their time to help me get up to speed. The sarcoma community is very collaborative and supportive.

What attracted you to the role?

I was approached about the role on a date which was the birthday of my late father-in-law who had died of sarcoma. When I took that phone call, I thought, 'this is fate.' I've always supported smaller, specific charities and when I worked for Cancer Research UK I was a trustee of the Small Charities Coalition. Small charities feel closer to patients and you have more opportunity to get involved and roll up your sleeves. I thought this was a role that I could get my teeth into.

What have you enjoyed most?

I've really loved meeting patients. I enjoyed a brilliant induction over the months and have met so many people, including staff, trustees and supporters. I've really welcomed the opportunity to meet patients in hospitals and support groups and hearing about what a difference the charity has made to their lives as well as some of the challenges they face.

What were your first impressions of Sarcoma UK?

The charity is very organised with very strong systems, processes and governance. Our founder, Roger Wilson and my predecessor, Lindsey

Bennister, did a great job of setting up a solid and robust charity and over the years the team has built strong foundations.

Any major surprises?

Sarcoma UK does a lot with a very small team of staff; there are just 18 of us and not much is outsourced. So I was surprised that the organisation was both lean and focused.

What's been the most bizarre thing you've been involved in at Sarcoma UK so far?

When we wanted to thank a corporate supporter for their fantastic efforts, we all took giant helium balloons with their fundraising totals on the underground. We looked like a hen party! I've also been drenched in champagne minutes before having to speak at an event when I was helping out pouring the drinks.

How would you describe the charity in three words?

Passionate, patient-focused and ambitious.

What's your leadership approach?

I hope I lead by example, and am enabling while not being too hands on.

How would your team describe you?

I hope they would say that I bring a fresh perspective and a fresh pair of eyes. I think they are looking to me to get involved in certain things. I

also bring my experience of working in bigger organisations and working in partnerships. There are things at Sarcoma UK that the charity can achieve alone and other ambitions that need partners.

What are your plans for the charity for 2019?

Growing and investing in research is high up there, especially in newer areas such as genomics. We'd also like to increase the areas of information and support that we provide to patients and their families and to raise awareness of sarcoma among health care professionals and patients. We're already making great progress in some areas but we'd like to develop others. We are also working with supporters to refresh and develop how we look and feel.

What are you looking forward to most in the next few months?

I'm looking forward to being able to articulate our ambitions and to create a strong brand to capitalise on for the future. One of the highlights will be the Virgin Money London Marathon – I absolutely love the event and I can't wait to meet our runners and supporters on the day.

You've run the London marathon – any top tips?

Just enjoy it. Get your training right and be confident in what you've done, but on the day, just enjoy it.

And finally...tell us something surprising about yourself.

I lived in Washington DC for a year, studying and working for a Senator. ●



Richard Davidson speaking at the Chris Martin Memorial Quiz

A sporting hero

Andrew Smith, aged 12, was diagnosed with osteosarcoma at the end of summer 2018 and started his treatment at University College Hospital London (UCLH) in September. Andrew continues to receive treatment there. A keen basketball player, his skills went viral when his occupational therapist tweeted a video of him playing from his chair in hospital, as on diagnosis it was not safe for him to stand. Andrew played basketball for the boys national league team in Sussex as well as both his local and school teams. We spoke to his mum, Sophie.

Could you tell us about Andrew's diagnosis?

He began suffering from knee problems in early 2018 and was referred for physio by his GP. Following improvements with his physiotherapist he was discharged in June. However, Andrew was still unable to play basketball, which is his passion, as he had ongoing discomfort. This continued during the summer when he complained of different problems, including pain around the groin, which we put down to growing pains. So I contacted his physiotherapist again and, on examination and further testing, it was discovered that Andrew had a fracture to the top of his right femur. Due to concerns around the unknown cause, we were referred to Brighton Children's Hospital, who carried out further investigations with the Royal National Orthopaedic Hospital (RNOH) in Stanmore. After a long 12 days of tests and discussions we were transferred to RNOH for a biopsy. Three days later, a telephone call confirmed our worst fears. Andrew was diagnosed with osteosarcoma (a type of bone cancer most commonly diagnosed in teenagers and young people).

How is Andrew doing now?

Andrew had a full hip replacement and the tumour removed at the end of November. The surgery was more difficult than either of us could have imagined, and he then had to spend four days in the High Dependency Unit. The therapy team at



Andrew Smith with his mum, Sophie...

...and with his brother, Tommy

Stanmore really aided his recovery and earned him an earlier discharge than was initially expected. A subsequent CT scan on his chest caused some concern and, as a result, he is now on a new chemotherapy plan, which started in

December at UCLH. It's such a brilliant hospital and we know he is in good hands. The thing that has been the hardest for Andrew to deal with is not being able to play basketball again. We have been told that he won't be able to run or play contact sport again. This is the

worst news imaginable for him, and something that he is still struggling to accept. He dreamt of being one of the first UK players to make it into the National Basketball Association (NBA). I only hope that, in time, he will be able to find a sport that gives him the level of passion that basketball did. He is very strong and determined, and has coped with this whole experience far better than I ever would.

What is Andrew like?

He's such a gorgeous boy; he's kind, considerate, caring and loving, and he totally adores his younger brother, Thomas. He's very mature and very academic. At school he loves geography, Spanish and science. He's very fashion conscious too. He loves clothes and trainers, and is incredibly fastidious about his appearance.

He's always the last one to be ready when we go out! He also loves his PlayStation and it's great that he can bring that into hospital and keep in touch with his friends. It's been brilliant for his state of mind and stops him feeling isolated. They are able to WhatsApp each other too so those friendships are still strong.

His love of basketball has got some social media attention?

Yes, his occupational therapist at UCLH, Charlotte Betteridge, has been busy tweeting about him, including videos showing his





Ron Weasley (Thomas Aldridge) comes to visit

chair basketball skills. As a result of this, the NBA in the UK sent him a bag full of goodies, including a jersey, a t-shirt and even an indoor basketball hoop so that he can play from his bed! They also tweeted a message to Andrew telling him that he was an inspiration to them all. This made him feel very proud. The latest video shows him practicing wheelchair basketball skills with his physio team. There have been so many lovely comments, including someone from a charity who has incorporated Andrew's skills into her own therapy programmes.

(Thomas Aldridge who plays Ron Weasley). That was totally amazing!


He's also been involved in designing his own Converse shoes with the Supershoes charity, which has meant sending loads of ideas of things that he likes. We're looking forward to seeing the end result.

What is the focus for you now?

Andrew is focusing on recovering from his surgery and getting through his next cycles of chemotherapy. He was able to be home for Christmas

which was just wonderful. We all totally love Christmas in our house! Thomas misses him terribly, as does my husband, and we all just wanted a quiet Christmas together. In fact Thomas requested a pyjama day so that's exactly what we did. We now need to get Andrew more mobile and on his feet, as he had to wear a hip brace when moving for six weeks after surgery. He's having physio a couple of times a day and we're trying to get him out of bed as much as possible. It's not just a question of his hip, but all the muscles in his lower body need to be mobilised as he hasn't walked since the end of August.

He is so determined, and my husband and I have been looking at different sports with him that he might want to try when he is ready. We like kayaking, which is something we can do regularly as we live near a reservoir. At the moment, it's too difficult for him to get down low enough to do this, but maybe it's something he will be able to do in the future. 🌟

 You can follow Andrew's story on twitter at [#AndrewsChairSkillz](https://twitter.com/AndrewsChairSkillz)

The hospital team at UCLH

How have other people beyond the family supported Andrew?

His school has been amazing. They held a fundraising basketball match and cake sale involving Andrew's whole year group. A Year Eight basketball match was followed by a highly contested teachers match! This raised around £700, which was boosted by the school to £1,000. The local football team that Andrew played for when he was younger also held a fundraising match and raffle, and one of his best friends shaved his head to raise money. All of this has raised around £2,500 for the ward that treats Andrew at UCLH (T11N).

Isn't Andrew a Harry Potter fan?

Andrew is Harry Potter mad! He was lucky enough to be surprised by a visit this month from one of the cast of the London stage show, Harry Potter and the Cursed Child



Research news

Clinical Trials Hub already making a difference

A clinical trials hub established by Sarcoma UK is making a big difference to patients in its first year.

For the very first time, patients and clinicians can find details of all clinical trials relating to sarcoma in one place – effectively a one stop shop for clinical trials. This ground breaking development, launched in spring 2018, is the first time that information about clinical trials for sarcoma has been integrated.

There is a need for more people to take part in more clinical trials; they are critical in developing new and more effective treatments, especially as an understanding of sarcoma lags far behind other cancers. Sarcoma UK is working to increase the number of clinical trials and has pledged over £3 million into research by 2020 with a goal of effective treatment within the next 10 years.

The clinical trials hub covers all the necessary advice, from information and advice to what they are and how to take part. The full list of current trials is regularly updated with details of where trials might be recruiting and the type of patients required.

We have already seen that this service is of value. In a snapshot poll over two-thirds of users (67%) found an appropriate clinical trials on two occasions. Encouragingly, almost all respondents (91%) said their questions had been answered. Almost half of respondents (48%) said that they were more likely to search for a clinical trial now in the future. Again, more than half of those quizzed (52%) were sarcoma patients.

Sarcoma UK was able to fund 20 per cent of applications for PhD studentships – two out of ten – in 2018.

Over the first ten months alone, the hub has been visited more than 12,100 times

"One of the main reasons we developed the hub was due to information from a national survey which asked about people's experiences right across the patient journey," says Claire Kelleher, Director of Information & Support. "The purpose was two-fold – about information but also about empowerment. Through raising awareness about clinical trials, we help people find a trial and see what it involves.

"Clinical trials are out there but people are just not necessarily asked to participate; for instance, young people are more likely to be asked. And there is also a gap in awareness about the trials. We get a lot of questions about them, but also about some of the terminology. The hub is there to help people feel empowered and to have more conversations about them.

"One of the challenges was getting information about open trials; a lot of time spent building relationships with key people to make this project happen. There are no guarantees of success with a clinical trial but it offers a chance at a stage when other options are limited. It offers hope."

Emily Travis, clinical trials participant and Sarcoma UK supporter, is currently participating in her second clinical trial. "There is definitely an element of finding out about new treatments for patients in the future. I'm currently on a Phase 1 trial of an immunotherapy - the only way the drug gets licensed for sarcoma is if there is enough data and enough people. More and more sarcoma patients can go on the drug because people like me take part in trials". ●



An 'as manufactured' glass rod as used in Dr Martin's research

Bone replacement wonder glass aims to improve patient outcomes


An investigation into bioactive glasses to replace and regenerate bone is the focus of a promising new PhD project funded by Sarcoma UK.

This study aims to build on previous work, developing a bone replacement material that kills cancer cells, encourages the growth of new bone cells and contains an antibacterial agent which reduces the risk of surgical site infection.

Survival rates of osteosarcoma are poor despite surgery, chemo or radiotherapy. As a result, safe and effective materials are needed to improve outcomes for patients, says Dr Richard Martin who will supervise the student at Aston University. Due to start in April, the work is in collaboration with the Royal Orthopaedic Hospital, Birmingham's Children's Hospital and the University of Nottingham.

New bioactive glass will provide a controlled release of key metal ions to kick start the death of tumour cells and stimulate new bone growth. The glass will contain calcium and phosphorous – the key building blocks of bone – along with gallium, a metal which is toxic to cancer cells and strontium, a known anti-microbial. These will be combined in the single glass product for bone replacement.

Dr Martin hopes to test the biodegradable materials on a range of tumours. If enough data is collected, the team will then be able to start considering clinical trials in a relatively short time. "Initial experiments have shown that these combined material specifically kill bone cancer cells while helping healthy bone cells to grow," says Dr Martin. "This study aims to evaluate the materials more rigorously as we try to progress towards human trials." ●

 You can see Dr Martin's work at www.youtube.com/watch?v=CEALpEMThjM

Support Line

Our Support & Information Team has grown with a new addition to the team at the end of last year to ensure we can keep on helping you all in the best possible way.



Joshna Hirani joined our Sarcoma Clinical Nurse Specialists in December for two days a week. As an occupational therapist she brings a new dimension to the service and an extra string to their bow. Her skills will expand the current knowledge base even further in expertise for recovery and rehabilitation and helping answer those specific queries.

Demand is growing for our independent and confidential services. We have now had more than 3,900 contacts with users and helped more than 1,200 individuals – with the average call lasting almost 30 minutes.

Fundraiser Debbie Greenway is also a user of our information and resources. She says: "Having never faced cancer within our family, hearing words like chondrosarcoma, metastasis, grade, stage, primary and secondary left me really confused. Your booklets explained all of these new words to me simply and in a way I could understand. Thank you."

Our Support Line is always here for you, no matter where you are.

- Our Support Line is independent and confidential
- We believe no question is a silly question
- We lend a listening ear
- We can point you in the right direction.

Call us on 0808 801 0401 during our opening 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 ask us anything about sarcoma, whether you are a patient, partner, carer, colleague or friend or if you have found a lump and are concerned.

If you have any feedback, please let us know as we want to constantly improve our service. ●

Our general opening hours are:

Monday 10am - 2pm
Tuesday Midday - 4pm
Wednesday 10am - 2pm
Thursday* Midday - 4pm
Friday* 10am - 2pm

*For the first Thursday and Friday of the month, we are closed on a Thursday and our Support Line hours on Friday are 9.30am – 2.30pm



The bone & soft tissue cancer charity

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If you no longer wish to receive *Connect*, contact head office at info@sarcoma.org.uk or phone 020 7250 8271

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Donate now

Breakthroughs in our understanding of sarcoma will only come through research. To date we've awarded more than £2 million to research projects that are bringing us closer to better treatments and, one day, a cure for sarcoma.

Sarcoma UK is having a real impact on people affected by sarcoma, not just through funding vital research, but through our support services, the sarcoma information we provide and by campaigning for better treatments. You can help us do even more.



Will you donate £15 a month to Sarcoma UK?

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:

Address:

Account name:

Sort code:

Account no:

I wish to set up a regular Standing Order in favour of Sarcoma UK.

Please make a first payment of £ on

and thereafter a similar payment *monthly/quarterly/annually until *further notice /the following date *please delete as appropriate

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 Date

Form B

Name:

Home address:

Postcode:

Telephone:

Email:

I have set up a regular donation to Sarcoma UK by Standing Order of £

The first payment is due and thereafter a similar payment *monthly/quarterly/annually *giftaid it*

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 Date

By signing this form you are giving consent for your personal data to be securely held, stored and used in line with our privacy policy. Visit sarcoma.org.uk/privacy-policy to read it in full.

We'd like to stay in touch with you to show how your support is helping others, share news from the sarcoma community and ways to get involved with Sarcoma UK, including new fundraising campaigns. Please sign me up to receive: Connect newsletter, four times a year by post E-news every six weeks by email.