



# Together we have...



Impact Report  
2022



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

# Welcome

**The year 2022 brought its own challenges for Sarcoma UK. Hot on the heels of the impact of Covid-19, the charity continued to adapt while delivering a new and ambitious strategy.**

This report highlights the impact of the charity's work and activities; a demonstrable difference that has only become a reality with everyone working together for the same outcome.

Sarcoma UK has gone from strength to strength, ending its tenth anniversary year with a growth in income and an increase in funding for world-class research.

It has continued to provide much-needed support for those affected by sarcoma. The Support Line alone helped hundreds of people – a 14 per cent increase on the previous year. The charity has transformed the experience of patients – of which I am one – with its support and information.

Although I did not know it then, my sarcoma was removed the same day Sarcoma UK officially became a charity in 2011. This was a time when good quality information for patients was woefully limited.

As a former Chair, I have seen the far-reaching impact of Sarcoma UK's work up close. With your help, I know the charity can continue to make a difference to people's lives.

**Glyn Wilmshurst**

Long-term supporter and  
Ambassador for Sarcoma UK





# Thanks to you

As we look back on 2022, it marked a time for listening and learning. Our bold strategy, shaped by your views and input, set the agenda for a year of drive and determination. A year where we had to be more agile and nimble, yet more focused long-term in what we wanted to achieve. A year where we continued to reflect on our first decade and our progress – yet a year where we set our aims high for the next five years.

I'm delighted to see the real impact we made in funding cutting-edge research, raising awareness, providing support at every step of a sarcoma journey and building partnerships in every corner of the sarcoma community. All of this only happened thanks to you and we are so grateful for your support.

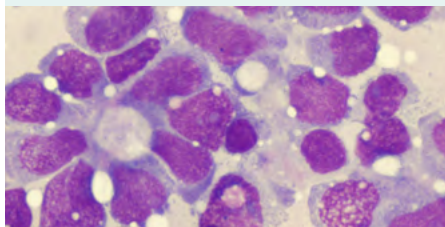
Together, we can transform the lives of everyone affected by sarcoma.



*Richard Davidson*

**Richard Davidson**  
Chief Executive of  
Sarcoma UK

**Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues.**



# Our impact and achievements

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

In delivering that pledge, we focused on four key areas outlined in our 2021–2026 strategy:

1. We will equip and empower people affected by sarcoma
2. We will fund world class research
3. We will build strong and productive relationships with healthcare professionals

4. We will work with the sarcoma community to achieve earlier, accurate diagnosis.

Given the after-effects of Covid and the financial downturn, our progress has been remarkable; an increased investment in research, patients involved in all aspects of our work, the expansion of our Support Line and our collaborations.



**“Sarcoma is so rare. Before my diagnosis, I did not even know the word sarcoma existed let alone know what it was! I want to raise awareness so that people check lumps all over their body, and not just the most talked about areas. I want more research to be conducted into sarcoma, to hopefully find a cure and to understand the disease more.”**

Geeta Patel, aged 28, was newly married and enjoying life. In 2019, she discovered a golf ball-sized lump on the back of her leg which was diagnosed as an alveolar soft part sarcoma. Following surgery and ongoing treatment, she is raising awareness of Sarcoma UK and the need for more research.

# We will equip and empower people affected by sarcoma

This year we increased our efforts to understand what patients want – and need – so it was clear how we can best make a difference. That can mean direct conversations or providing the right information and resources at the right time. Whatever the source of information and awareness, it needs to be accessible and available at every step of the sarcoma journey.

We have supported more people than ever through our Support Line, through email, telephone and texts, and are engaging more people closer to the point of diagnosis – a crucial time.

We have also worked to target and support those communities who have been harder to reach so that no-one should feel excluded from our services or resources.

**15**

**people are diagnosed with sarcoma every day in the UK.**

## How we did this →

- We responded to more people than ever before – 3,417 contacts to the Support Line team
- We were accredited with the Helpline Standard
- We gathered more insight and information from more partners
- We worked closely with the newly formed Early Diagnosis Expert Steering Group
- We were involved in and encouraged more direct referrals, such as from Swansea
- We reviewed and updated our advice and information, including our clinical trials hub and a new web page
- We hosted three well-received webinars during Sarcoma Awareness Month (July)
- We increased our contacts with people at every step of their journeys.



# We will support world class research

**Research is the key to unlocking the secrets of sarcoma – until recently a cancer that has not seen the investments that other cancers have had.**

Our dedicated five year Research Strategy, *Finding Answers through Research*, was launched in 2021. This has allowed us to shape the research agenda while being agile and flexible enough to react to changes.

Thanks to our generous supporters, we have funded more projects, large and small, and we are supporting the next generation of sarcoma researchers as well as encouraging networking and collaboration.

A major milestone was involving people affected by sarcoma in our research programme so it is better informed by their experiences and priorities.

Collaboration has been crucial in achieving our ambitions, so we have worked more closely with the scientific community to shape our research programme and priorities.



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**“I am keen to be involved in changing the landscape for sarcoma treatments and outcomes. I am here today, because people before me wanted to change the world and help people diagnosed with sarcoma. For that I’ll be forever grateful.”**

**Emma McCloskey, Research Grant lay reviewer and Support Group co-leader.**

**We awarded £997, 207 to 10 research projects**

## How we did this →

- We funded the next stage of our Genomics programme – a project at Southampton on dedifferentiated liposarcoma led by Dr Zoe Walters – for £248,398
- We awarded £50,000 to the EORTC Strauss trial – the 2020 Roger Wilson Research Award – a major international trial exploring the best treatment options for retroperitoneal sarcoma
- We laid the groundwork for the launch and first meeting of our PhD student network
- We collaborated with the Bone Cancer Research Trust (BCRT) on using national data to improve outcomes
- We chose ten projects, small and large, from applications to our first Open Grant round
- We recruited and launched our 18-strong team of Research Grant Lay Reviewers and set up our Grant Review Panel, with four people affected by sarcoma involved.
- We set up a new Research Strategy Committee, including two people affected by sarcoma
- We supported researchers to have greater patient involvement in their work
- We worked more closely with the research community, raising awareness of our work at conferences and adding our voices to influential groups such as Sarcoma Patients EuroNet (SPAGN).

## Sarcoma UK-funded study identifies numbers who missed out on surgery due to Covid-19

The international collaborative study, published in *Lancet Oncology*, found that one in seven cancer patients missed out on planned surgery as a result of lockdown.

The COVIDSurg Cancer study, part-funded by Sarcoma UK, collected data from over 20,000 patients with 15 common cancer types, including sarcoma, across 61 countries. Most patients did not suffer any short-term consequences from missing their surgery, but many will have to be more closely monitored to ensure their cancer does not spread.

Missing or delaying vital cancer treatment has hugely affected patients' mental health and quality of life. The number of patients missing out on surgery depended on the extent of the lockdown restrictions, with only 0.6% missing treatment in periods where restrictions were looser.

These results were particularly significant for sarcoma patients, for whom surgery is often the first and only line of treatment available.

# How we are making a difference

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

**Total income: £2,539,882**



**10**

new projects funded



**79%**

of individuals were new to the Support Line this year



**£997,207**

awarded to research projects



**9 out of 12**

months saw an increase in contacts to the Support Line team



**18**

people affected by sarcoma involved in reviewing research applications



**3,417**

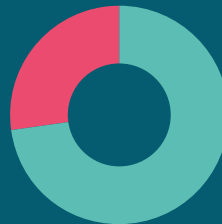
contacts from over 767 individuals to the Support Line team - up by 14 per cent



**274.58**

hours spent on the telephone to the Support Line

**In every pound:**



**73p**

goes into research, information, campaigning, support and education

**27p**

is spent on fundraising, administration and governance.



# Team Gaz

The late Gareth 'Gaz' Emmerson raised over £125,000 for Sarcoma UK since his diagnosis with Ewing's sarcoma in 2014, and boosted public awareness of sarcoma thanks to his hard work, positivity, and determination.

In June 2021 he led Team Gaz in a gruelling 1,000 mile cycling challenge from Land's End to John O'Groats, despite his terminal cancer diagnosis.

Gaz smashed his fundraising target and captured the hearts of the nation when he won ITV's Pride of Britain London Fundraiser of the Year award – an incredible legacy.

"I'm proud of a lot of things, but no more so than the work we did for Sarcoma UK," said Gaz.



"Despite it not having the happiest ending, the past eight years since I've been ill have been the best of my life, and hopefully I've shown that you can live a great life with cancer.

**"One day, hopefully soon, no one will have to go through what me and so many others have been through."**

# Gaynor Anders

Gaynor was diagnosed with synovial sarcoma in 2020, and is all too aware of the importance of early diagnosis after five years of trying to get her concerns taken seriously, despite repeated scans.



"Sarcoma UK has been simply amazing, a lifeline, a valuable source of information and guidance at a very stressful time.

"I work in clinical development and helping patients understand their options is my job. When I was diagnosed (in the middle of a pandemic), however, I went into shock and suffered paralysis of thinking. I was angry at my diagnosis having been so severely delayed and my cancer missed for so long.

**"When I couldn't think straight, Sarcoma UK provided the guidance and information I needed. Synovial sarcoma is so rare and Sarcoma UK helped me feel in some way connected to other patients fighting this horrible cancer."**

# We will build strong and productive relationships with healthcare professionals

We've made great strides in our collaborations with health professionals which benefit everyone. This year we have continued to work in partnership by engaging on consultations on guidelines, appraisal of new drugs or speeding up diagnosis.

We have facilitated networking and collaboration to encourage the sharing of best practice and ideas for improvements in the services of health professionals. This helps patients feel better equipped and more informed about their options.



Just under nine in ten sarcomas diagnosed are soft tissue sarcomas.



## How we did this →

- We joined the Cell and Gene Collective, an industry group, in preparation for cell and gene therapies
- We saw greater engagement with NICE; we sat on a NICE Task and Finish Group and discussed key issues such as the Cancer Drugs Fund and its new strategy (organisational) plus drug appraisals and leading for Cancer52 with NICE
- We met with several pharmaceutical companies to discuss future plans and collaboration
- We facilitated the SAG Chairs meeting, bringing together leaders of the Sarcoma Advisory Groups
- We awarded the third Tricia Moate Award in memory of the nurse and patient advocate
- We responded to the Government's 10 year Cancer Plan consultation, not just for Sarcoma UK but also for sector partnerships such as Cancer52, One Cancer Voice and the Children and Young People's Cancer Coalition
- We worked closely with the British Sarcoma Group and National Sarcoma Forum
- We focused on early diagnosis in our collaborative working with health professionals
- We joined seven other charities at the launch of an ambitious 10 year Cancer Plan on World Cancer Day.

## Third Tricia Moate Award

The Tricia Moate Award for 2021 went to Debbie Artis, a special sarcoma physiotherapist with the Leeds Teaching Hospitals NHS Trust, where she provides treatment at various stages of a patient's cancer journey.

Tricia Moate worked tirelessly as a nurse and as a patient advocate for sarcoma. Sadly, she died from sarcoma in December 2018 and this award is dedicated to her memory.

After the challenges of the pandemic, it was even more important to celebrate and support the work of the Allied Health Professionals and nurses working with sarcoma patients.



**Diagnosis, support and treatment remain the top three reasons for contacting the Support Line team.**



## We will work with the sarcoma community to achieve earlier, accurate diagnosis

**Since earlier diagnosis was highlighted by those involved in our strategy development, we have focused on this patient priority.**

To improve this picture, a greater awareness of sarcoma among healthcare professionals is essential. Our pledge to improve the quantity and quality of education on sarcoma for them resulted in collaborations in developing tools and resources.

We established an Early Diagnosis Expert Steering Group which has met regularly and progressed to plans for many potential projects.

Our aim to influence UK governments, the NHS and other policy makers to

improve how sarcoma is diagnosed has resulted in much greater engagement across the board, including parliamentary events and meetings in London and Scotland.

And, with research at the heart of what we do, we are working to prioritise early diagnosis for funding.

Everyone has a role in helping to achieve earlier diagnosis and we will continue to work together with the sarcoma community to make this a reality.

## How we did this →

- We collaborated and launched a GatewayC module – an accredited free education model for primary health care professionals
- We teamed up with the Bone Cancer Research Trust on medical student education
- We launched an Early Diagnosis Expert Steering Group to drive our priorities on early diagnosis through a comprehensive work plan
- We held two successful parliamentary events in Westminster and Holyrood to discuss the need for action on early diagnosis

- We met groups including the APPG on Cancer
- We achieved an early day motion in Westminster and a motion in the Scottish Parliament congratulating Sarcoma UK on its first ten years and its work
- We raised awareness of early diagnosis at conferences, including SPAGN.



## Tarli Garcha



**Tarlochan 'Tarli' Garcha discovered he had a sarcoma after going to A&E for an unrelated reason. Eventually he was diagnosed with a liposarcoma and he had surgery to remove the 10 kg tumour.**

"The doctor described the tumour as expanding like a basketball, as it had been stuck behind my kidney," says Tarli.

Now, Tarli is raising awareness of sarcoma, urging everyone to familiarise themselves with the signs and symptoms of this cancer and to contact their GP with any concerns.

The greater awareness we have of sarcoma, and the importance of early diagnosis, the more chance we have of being able to help people like Tarli when it will really make a difference.

# Raising funds and awareness to deliver our ambitions

**We will ensure we have the funds to support the charity's priorities and develop strong, diverse income streams.**

Our success in achieving a higher income for this year was set against the backdrop of the after effects and continued uncertainty of Covid, and the financial downturn.

Our fundraising successes spanned popular 'home-grown' events like our Carol Concert and the second Glitter

Ball, to legacies and challenge events and much more.

Our supporters continue to inspire us, tackling everything from the first virtual London marathon to wild swimming. Their achievements are even more remarkable as five months of this period were still under Covid restrictions.

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## Alasdair Punton



**Alasdair has supported Sarcoma UK since he lost his wife Becky, aged 28, six months on from a diagnosis of Ewing's sarcoma in 2019. Like so many sarcoma patients, Becky experienced difficulty obtaining a diagnosis, showing the importance of raising awareness.**

In 2021 Alasdair spearheaded a 24-hour relay around the North Inch in Perth which raised £5,213 - the start of even greater fundraising to come through a Group Fund. He has also raised awareness of early diagnosis by engaging with MSPs at a Scottish parliamentary event and is a Research Grant Lay Reviewer.

## How we did this →

- We held our second Glitter Ball, a sell-out event which raised over £40,000
- We benefitted from dedicated fundraisers such as Barb Kelsey's 216 mile hike and Stacey Jones's raffles and artwork sales
- We marked Christmas with our carol concert and an Oxford event, Carols, Cocktails and Canapes, which raised almost £130,000, thanks to Fiona McAlpine and Pandora Cooper-Key
- We saw the return of the campaign 20 for 20 hard on the heels of awards nominations from Charity Times and Third Sector
- We supported the October 2021 return of the London marathon and first virtual race
- We launched our first Step into Spring Facebook challenge
- We benefitted from corporate support, including David Wilson Homes, Samuel Estates and our long-term partners The Analyst
- We were inspired by Team Gaz and an epic cycle (see page nine).

## Raising awareness to make a difference

Our communications work continued to expand, whether highlighting crucial sector campaigns, championing those with personal experience of sarcoma or ensuring we target hard to reach communities.

Our first Sarcoma Awareness Month (July) saw a theme of *People Make Sarcoma UK*, fitting for our 10th anniversary year.

We are very grateful to our celebrity supporters, including our longstanding Patron Richard Whitehead MBE and our newer Ambassadors.

## How we did this →

- We supported charity-wide campaigns, including #Onecancervoice and #Researchatrisk
- Our anniversary year programme of awareness-raising had supporters at its heart, including a supporter-chosen logo
- Our awareness-raising week in July became a month, featuring webinars, social media takeovers and more diverse personal stories
- We welcomed new Celebrity Ambassadors, including sports presenter Gavin Ramjaun and comedian Angela Barnes, plus long-term supporters Sandra Dickinson and Mark Osmond
- We continued to attract celebrity support, from actor James McAvoy to footballer and author Dominic Ball
- We planned a new website to go live in spring /summer 2022.



# Thank you

Our sincere thanks go to everyone who makes it possible for Sarcoma UK to work towards a future where everyone affected by sarcoma has the treatment, care and support they need.

## Founder:

Roger Wilson CBE

## Patrons:

Richard Whitehead MBE

## Celebrity Ambassadors:

Angela Barnes  
Sandra Dickinson  
Mark Osmond  
Jake Quickenden  
Gavin Ramjaun

## Trustees

### financial year 2021/2022:

Sharon Reid (Chair)  
Sarah Conneally  
Louisa Nicoll  
Michael Parry  
Isla Robinson  
Anjula Thompson  
Jo Vass  
Andy Eckles  
Professor Ian Judson  
Sam Patton (until January 2022)  
Russ Wilson (until March 2022)



**SarcomaUK**

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cancer charity

[sarcoma.org.uk](https://www.sarcoma.org.uk)