

The Rt Hon Victoria Atkins MP
Secretary of State Health and Social Care)
Department of Health and Social Care
39 Victoria Street
London SW1H 0EU

2nd February 2024

Dear Secretary of State,

I am writing to you ahead of World Cancer Day 2024 to highlight the importance of our work at Sarcoma UK. Sarcoma, most commonly presenting as a lump that develops in bone or soft tissue, is the third most common cancer in children, but can affect anyone at any age. At Sarcoma UK, we focus on all types of sarcomas and fund vital research, offer support for anyone affected by sarcoma, and campaign for better treatments. Around 5,300 people are diagnosed with sarcoma per year, but just 55% of patients will survive beyond five years. Like the Government, we want to see better outcomes for people with sarcoma. Please will you therefore meet with me to discuss how we can work together to make faster progress on the following key issues: (1) late diagnosis, (2) referral pathways into the NHS, (3) treatment options, and (4) support for mental health and wellbeing.

(1) DIAGNOSIS

Sarcoma is diagnosed later and has worse outcomes compared to almost every other cancer. GPs and physiotherapists are key to identifying sarcomas, but are often unaware of the symptoms, resulting in delays in diagnosis, or misdiagnosis. Patients may see their GP multiple times before their symptoms are taken seriously – 1 in 3 sarcoma patients wait over six-months to be diagnosed after their initial appointment with a healthcare professional.

At Sarcoma UK, our [Delays cost lives report \(2020\)](#) called on policy makers to make faster and more accurate diagnosis a reality for the sarcoma community. We recommended **a sarcoma education programme for healthcare professionals**, and we have since worked with our partners to:

- Develop an online and accredited sarcoma training module for GPs
- Launched an e-learning module with the University of Nottingham to help physiotherapists identify sarcomas, and
- Produced a video to ensure medical students and junior doctors have knowledge of sarcoma symptoms.

Improving early diagnosis is essential for survival. For every 1cm increase in the size of a soft-tissue sarcoma at diagnosis, there is a 3-5% decrease in the chance of cure¹.

(2) REFERRAL PATHWAYS

As soon as sarcoma is suspected, patients should be referred to one of seventeen specialist sarcoma centres across the UK to ensure they receive the best possible care. NHS England states that all sarcoma patients in England must be treated at a specialist centre; but Sarcoma UK's [National Sarcoma Survey](#) from 2020 showed this was not true for 13% of adult patients.

This is an ongoing issue as many calls to the Support Line we run, report that patient referrals are not progressing as they should. Our Support Line is staffed by highly experienced nurses and has helped people affected by sarcoma more than 20,000 times since February 2016, and receives direct

¹ [Linda's story - improving early diagnosis can save lives | Sarcoma UK](#)

referrals from eight NHS teams that feed into specialist sarcoma centres, meaning we contact individuals without them having to find us. We understand that the NHS is under tremendous pressure; but in the last year, our Support Line has had to become much more proactive to ensure that patients' referrals have been sent onto and received by the correct specialist team.

The referral pathway for a sarcoma patient varies greatly across the country. We are therefore working with clinicians to find out why this is and to properly map the referral pathways. This is crucial, as specialist centres have the expertise in this complex cancer. Diagnoses from non-specialist centres subsequently reviewed by expert pathologists resulted in a major change in diagnosis 20-30% of the time. Current data also suggests that 1-year survival post-treatment at a specialist centre compared to elsewhere increases from 88% to 92%.

(3) TREATMENTS

We do not know enough about the causes of sarcoma and how we could effectively target them with new treatments, and sarcoma tends to be underfunded by many cancer funders compared to the proportion of people affected by the disease. A lack of investment in research has led to limited treatment options for sarcoma patients, as very few new treatments are being developed. Sarcoma UK is taking steps to redress this through our own research programme – to date, we have committed over £6.5 million to over 80 research projects across the UK to date, with two-thirds (£4.28 million) invested into new and better treatments. **Urgent action is therefore needed to redress the underfunding of sarcoma research, and to increase the number of and access to new clinical trials.**

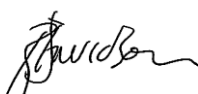
More action is also needed on genomic testing which could be game-changing for cancer in terms of diagnosis and treatment. Whilst sarcoma is one of few cancers to have Whole Genome Sequencing routinely commissioned on the NHS in England; genomic testing is not being universally offered so patients are losing out. Cancer services need to be much better integrated and coordinated. Sarcoma UK is currently running a project to identify how to address current barriers to ensure that all sarcoma patients can benefit from genomic testing.

(4) MENTAL HEALTH AND WELLBEING

Finally, we know that sarcoma has a big impact on the mental health and wellbeing of patients and their families. 90% of patients told our 2020 [National Survey](#) that their diagnosis or treatment had a negative impact on their mental health. However, 45% of patients said they were not given enough information when they were first diagnosed; and 60% said they were not given enough emotional support throughout their treatment. **Families and carers told our survey that one of the most important improvements to sarcoma services is the provision of formal emotional support.** We want to see joined-up support for the physical and mental healthcare needs of sarcoma patients and their families.

I very much look forward to hearing from you and hope you will meet with me to discuss how we can work together to deliver the progress we both want to see for sarcoma patients.

With best wishes,



Richard Davidson
Chief Executive