

Sarcoma: An Urgent Rare Cancer Priority

Sarcoma is a rare and often aggressive form of cancer that affects both children and adults. In 2026, an estimated 17,000 Americans will be diagnosed with sarcoma and more than 7,000 will die from the disease. Sarcoma accounts for approximately 15–20% of all childhood cancer diagnoses, making it one of the leading causes of cancer-related death among children and adolescents in the United States.

Despite its significant impact, sarcoma remains underrepresented in research, drug development, and public policy discussions because it accounts for only about 1% of adult cancers. Sarcoma is not a single disease, but a collection of more than 100 distinct subtypes, many of which have no FDA-approved therapies specifically indicated for their treatment. As a result, patients are often treated with decades-old therapies that may not adequately address the unique biology of their disease. The rarity and complexity of sarcoma also contribute to significant diagnostic challenges. Patients frequently experience delays in diagnosis due to limited awareness and the difficulty of recognizing rare cancers. These delays can span months or even years, often resulting in diagnosis at a later stage when the disease is more difficult to treat. For patients with metastatic sarcoma, outcomes remain poor, with survival rates remaining unacceptably low.

Individuals living with sarcoma face unique clinical, financial, and geographic challenges throughout diagnosis, treatment, survivorship, and end-of-life care. Yet the needs of rare cancer patients are often overlooked in federal policymaking. Increased investment in research, expanded access to specialized care, and policies that address the unique barriers faced by rare cancer patients are essential to improving outcomes.

The Sarcoma Foundation of America (SFA) and the broader sarcoma community respectfully urge Congress to support the following legislative priorities to advance research, improve access to care, and ensure that patients affected by sarcoma are not left behind.

Legislative Ask #1

Protect Funding for Research Investments in Sarcoma. We urge Congress to protect and support robust federal investments in biomedical and cancer research by funding:

NIH at \$47.3 billion

NCI at \$7.46 billion

ARPA-H at \$1.5 billion in sustained funding

Legislative Ask #2

We urge Congress to support and advance the Clinical Trial Modernization Act (S. 4440 / H.R. 3521).

Legislative Ask #3

We urge Congress to support policies that preserve and permanently expand telehealth access, including the CONNECT for Health Act (H.R. 4206 / S. 1261) and the Telehealth Modernization Act (H.R. 5081 / S. 2709).

Legislative Ask #4

We urge Congress to support and advance the Comprehensive Cancer Survivorship Act (H.R. 8839).