

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

Every new treatment begins with research. Supporting research means accelerating breakthroughs and giving patients more opportunities for longer, healthier lives. Research funding creates hope for patients with few options.

Key Benefits for the Sarcoma Community:

- Advance research into rare sarcoma subtypes.
- Support development of new therapies and treatment approaches.
- Expand access to clinical trials for sarcoma patients.
- Improve survival and quality of life for current and future sarcoma patients.
- Ensure that rare cancers are not left behind in the nation's cancer research agenda.

For the sarcoma community, federal research funding is not an abstract budget item, it is the pathway to new treatments, better outcomes, and ultimately cures. Because sarcoma is a rare and complex cancer that receives only a small fraction of overall cancer research funding, continued federal investment is essential to ensure that patients have access to scientific advances, innovative clinical trials, and the hope that comes from a robust research pipeline. For patients with sarcoma, these investments are especially critical. Sarcoma is a rare and highly complex cancer comprising more than 100 distinct subtypes. Because each subtype affects relatively small numbers of patients, sarcoma research often struggles to attract the same level of private-sector investment and research attention as more common cancers. Federal funding helps fill this gap, driving discoveries that improve outcomes and create new treatment options for patients with few alternatives.

Why Research Funding Matters for Sarcoma

1. Sarcoma Is Rare, but the Need Is Great: Sarcoma accounts for only a small percentage of adult cancers, yet it includes dozens of biologically distinct diseases that affect both children and adults. The rarity of sarcoma creates significant research challenges: smaller patient populations, fewer clinical trials, limited commercial incentives, slower drug development, less available research funding compared with common cancers. As a result, many sarcoma subtypes still have limited treatment options and poor outcomes, particularly for patients with metastatic or recurrent disease. Federal research investment is often the primary driver of discovery in rare cancers such as sarcoma.

2. NIH Funding Fuels Basic and Translational Research: The NIH supports the foundational science that leads to new treatments and cures. For sarcoma patients, continued NIH investment is essential to understand rare sarcoma subtypes, identify new therapeutic targets, develop innovative treatment strategies, and improve outcomes through precision medicine.

3. NCI Is the Engine of Cancer Research: NCI funding directly supports sarcoma clinical trials, rare cancer research initiatives, and pediatric and adult sarcoma research. For rare cancers like sarcoma, NCI funding is often the difference between a study moving forward or never happening at all. For many sarcoma patients, especially those with advanced disease, clinical trials represent the best hope for effective treatment.

Legislative Ask #2

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

Supporting the Clinical Trial Modernization Act means supporting parity, innovation, and hope for families facing rare cancers like sarcoma.

Key Benefits for the Sarcoma Community:

- Reduce financial barriers to clinical trial participation.
- Increase enrollment in rare cancer clinical trials.
- Encourage use of digital health technologies that reduce the burden of travel.
- Accelerate development of new therapies for rare cancers such as sarcoma.

The Clinical Trial Modernization Act (S. 4440 / H.R. 3521) is bipartisan legislation designed to remove financial and logistical barriers that prevent patients from participating in clinical trials. The bill authorizes federal support for community-based trial outreach, allows sponsors to help cover patient expenses related to clinical trial participation, supports the use of digital health technologies, and provides limited tax relief for clinical trial compensation.

For patients with sarcoma, a rare and often aggressive cancer comprising more than 100 subtypes, clinical trials are not simply research opportunities, clinical trials are frequently the only option for treatment. However, because sarcoma patients often must travel long distances to specialized centers, participation costs can be prohibitive. By removing unnecessary financial and logistical obstacles, this legislation will help ensure that patients can access clinical trials based on medical need rather than their ZIP code or financial circumstances.

Why Sarcoma Patients Need This Bill

1. Sarcoma and Rare Cancer Patients Depend on Clinical Trials: Unlike common cancers, sarcoma affects a relatively small number of patients, making it difficult for researchers to enroll enough participants to advance new treatments. Clinical trials are essential for developing therapies for rare cancers, yet many promising studies struggle to recruit sufficient numbers of patients. The Clinical Trial Modernization Act would help increase enrollment by reducing the financial burden associated with participation and expanding outreach efforts to underserved populations.

2. Travel Costs Are a Significant Barrier: Sarcoma care is concentrated in specialized academic cancer centers. Many patients must travel hundreds of miles and sometimes across state lines to access clinical trials. Families often face expenses such as airfare or mileage; hotel stays; meals; parking; lost wages from time away from work. The bill allows clinical trial sponsors to provide financial assistance for these costs without triggering federal anti-kickback concerns. This makes it easier for patients to participate regardless of where they live. For rare cancers, geography should not determine whether a patient can access a potentially lifesaving treatment.

3. Digital Health Technologies Can Reduce Patient Burden: The legislation permits the provision of digital health technologies that help patients participate in trials remotely. This can reduce the number of in-person visits required and lessen travel demands for patients with rare cancers who live far from specialty centers. For sarcoma patients undergoing intensive treatment, remote participation tools can help maintain access while minimizing disruption to daily life.

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).

Supporting telehealth means supporting access to existing treatments, quality patient care, and access to sarcoma expertise regardless of where a patient lives. It ensures that patients and families can focus on treatment and recovery instead of barriers that too often stand between patients and the specialized care they need.

Key Benefits for the Sarcoma Community

- Improve access to sarcoma specialists and specialty cancer centers.
- Support second opinions and multidisciplinary treatment planning.
- Ensure patients can receive quality care without repeated long-distance travel.

Telehealth has become an essential component of cancer care, allowing patients to consult with specialists, receive follow-up care, review imaging and pathology results, participate in multidisciplinary care planning, and access supportive services without the burden of travel. Medicare telehealth flexibilities have been extended through December 31, 2027, but many of these policies remain temporary and require permanent legislative action.

For patients with sarcoma, a rare and complex cancer that often requires treatment at highly specialized centers, telehealth is not a convenience; it is a lifeline. Because sarcoma expertise is concentrated in a limited number of specialty cancer centers, many patients must travel long distances for consultations and ongoing care. Telehealth helps bridge that gap, reducing financial, geographic, and logistical barriers while ensuring access to expert care. Telehealth helps remove unnecessary barriers to care by allowing patients to consult with sarcoma specialists, receive follow-up care, participate in multidisciplinary treatment planning, and access supportive services without the financial and physical burden of frequent travel.

Why Telehealth Matters for the Sarcoma Community

1. Sarcoma Specialists Are Limited and Concentrated at Specialty Centers: For rare cancers like sarcoma, virtual access to expertise can mean faster diagnosis, more appropriate treatment decisions, and better outcomes. Studies show outcomes are better when patients are treated by multidisciplinary teams that have sarcoma-specific expertise. Unfortunately, these specialists are often only available at major academic medical centers. Telehealth allows patients to obtain expert second opinions, consult with sarcoma specialists, review pathology and imaging results, participate in multidisciplinary treatment planning, receive follow-up care closer to home. Telehealth eliminates geographic restrictions and allows patients to receive care from home, helping ensure that access to expert cancer care is not determined by ZIP code.

2. Telehealth Reduces Travel Burdens and Financial Hardship: Without telehealth, many patients must repeatedly travel several hours—or even across multiple states—to receive specialty care. Sarcoma patients often face substantial costs associated with accessing specialized care, including transportation, lodging, parking, meals, missed work for patients and caregivers. Telehealth can reduce the number of in-person visits while maintaining high-quality care, helping families save both time and money. This is especially important for patients undergoing active treatment, surveillance imaging, or long-term follow-up.

Legislative Ask #4

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

No survivor should have to navigate the lifelong impact of sarcoma without the resources, support systems, and coordinated care they need to thrive.

Sarcoma survivors often face unique challenges because of the rarity and complexity of their disease. Many survivors require lifelong surveillance imaging, management of treatment-related disabilities, rehabilitation and physical therapy, ongoing monitoring for recurrence, screening for secondary malignancies, access to specialty survivorship programs.

Key Benefits for the Sarcoma Community

- Improve survivorship care planning and coordination.
- Improve management of late and long-term treatment effects.
- Support workforce participation and quality of life.
- Improve transitions from active treatment to long-term survivorship care.
- Ensure that rare cancer survivors receive support beyond treatment completion.

The Lainie Jones Comprehensive Cancer Survivorship Act (CCSA) of 2026 (H.R. 8839) is bipartisan legislation designed to address the long-term physical, emotional, financial, and practical challenges faced by cancer survivors from diagnosis through the remainder of their lives. The legislation seeks to establish a national standard for survivorship care, improve care coordination, support patient navigation, expand survivorship research, strengthen workforce assistance programs, and improve quality of life and health outcomes for cancer survivors. This legislation addresses critical gaps in survivorship care by improving care planning, patient navigation, workforce support, research, and care coordination.

For sarcoma survivors, the challenges do not end when treatment ends. Survivors often face lifelong physical, emotional, financial, and medical consequences that require ongoing support, monitoring, and access to specialized care. For individuals affected by sarcoma, survivorship is often a lifelong journey. Many survivors continue to face intensive surveillance, late effects of treatment, secondary cancers, physical disabilities, mental health challenges, fertility concerns, employment disruptions, and ongoing financial burdens long after active treatment has ended.

Why Sarcoma Patients Need This Bill

1. Survivorship Begins at Diagnosis: Sarcoma survivorship does not begin when treatment ends, it begins at diagnosis and continues throughout a survivor's lifetime. For sarcoma patients, who often require years of monitoring and specialty follow-up, coordinated survivorship care is essential to achieving the best possible outcomes.

2. Sarcoma Survivors Face Significant Long-Term Health Effects: Many sarcoma survivors experience long-term complications related to surgery, chemotherapy, radiation, or other treatments, including: chronic pain, mobility limitations, lymphedema, cardiac complications, secondary cancers, fatigue and cognitive challenges, and mental health concerns. The legislation supports development of survivorship care standards and programs that help patients identify, monitor, and manage these late and long-term effects.

3. Improved Care Planning and Care Coordination: Many cancer survivors struggle to transition between oncology care and primary care after treatment. For sarcoma survivors who frequently receive care from multiple specialists, care coordination can reduce gaps in care and improve quality of life.

4. Support for Patient Navigation: Navigating survivorship can be overwhelming. Survivors often must manage multiple specialists, insurance issues, rehabilitation services, imaging schedules, and supportive care needs. The bill includes provisions to strengthen survivorship navigation programs that help patients and families access the care and resources they need throughout the sarcoma journey.

5. Workforce and Employment Protections: Sarcoma often impacts a survivor's ability to work during and after treatment. Long-term side effects can create ongoing employment challenges. The legislation includes workforce assistance initiatives that help survivors re-enter or remain in the workforce while managing the lasting effects of treatment. This is particularly important for adolescent and young adult sarcoma survivors, who may experience disruptions to education, career development, and financial stability