

SARCOMA SPOTLIGHT

JANUARY 2025

Closing Gaps, Improving Outcomes: Building Community Together

By Brandi Felser, CEO

Happy New Year!

2024 was quite a year for SFA and we are looking forward to 2025 and celebrating the organization's 25th year anniversary. In 2024, in addition to funding impactful research, we launched programs to increase our support and engagement with the sarcoma community: We partnered with the Association for Community Care Centers (ACCC) to provide tools and information for community oncologists. We launched a new website to increase resources for the community, and in late 2024 we launched the *Sarcoma Stories* podcast.

To date, we have released three podcast episodes and have recorded several more. Each story is unique, and we never know where the discussion will lead. But they are not just "stories". We launched this podcast to highlight the voices of the people affected by sarcoma: to better understand the challenges they face and the things that matter most to them. We also launched this podcast to help people in our community connect, share resources, or simply find someone who understands their experience. I admit, I was not sure what to expect when we decided to launch this initiative. But this podcast has turned into so much more than I imagined.

We listen to and share stories from the sarcoma community on many different platforms. Because of this, there is so much I thought I knew about the challenges, obstacles, and what is important to people navigating a sarcoma journey. But through these deeper discussions, I have been humbled, brought to tears, laughed, and most importantly educated. I have learned even more about the gaps in patient support, resources, diagnosis and treatment, some I knew about and others are new to me. A

portion of these conversations that you don't hear are the SFA team asking questions, discussing gaps and how these gaps can be filled. SFA cannot do it all, but we can bring together the right stakeholders to create changes necessary for sarcoma patients, survivors and their loved ones to thrive. These discussions, like our Race to Cure Sarcoma events, are a reminder of why SFA exists. And what drives us each day.

2025 is about building community and infrastructure to improve outcomes.

We refreshed our mission statement and strategic goals in 2024 to be intentional about addressing critical gaps to improve outcomes.

This includes improving diagnosis and treatment, patient resources and education, access to treatments and sarcoma specialty care centers, and public policy. This year, SFA will expand and increase our efforts to fund impactful research, grow awareness, engage in strategic partnerships, amplify the sarcoma voice on Capitol Hill, provide resources to empower people diagnosed to advocate and participate in their care, and work in partnership to fill gaps in diagnosis and treatments.

I hope you will continue to join us for this journey. We envision a world where no one dies from sarcoma - and we envision a world where SFA no longer needs to exist. 2025 may not be the year we put ourselves out of business, but we will continue to work toward that. #CureSarcoma



As we develop initiatives for 2025, we want to hear from you – the sarcoma community. Learn more and click below to take our surveys.

[Public Policy Survey](#): With a new session of congress beginning, let us know what advocacy priorities are most important to you.

[AYA Survey](#): If you are between the age of 18 and 40, take this short survey to help us provide support and education resources.

THE AYA SARCOMA EXPERIENCE WEBINAR



JANUARY 22, 2025



4:00 PM - 5:00 PM ET



Jackie Cardarelli-Matte
MSW, LICSW
Mass General Cancer Center



Caitlin McDonough
MSW, LICSW
Dana-Farber Cancer Institute

Join us for a webinar highlighting the Adolescent Young Adult (AYA) sarcoma experience.

A sarcoma diagnosis is devastating and imposes a significant burden on patients, survivors, and care partners, impacting all areas of their life. For the AYA population (anyone age 18 to 40), facing a sarcoma diagnosis comes with unique challenges and specific needs that require specialized care.

In this session, we discuss the challenges AYA sarcoma patients and survivors face on top of navigating cancer care, including financial wellbeing, fertility and sexual health, career navigation, and psychosocial support. Whether you are an AYA sarcoma patient, survivor, or a care partner of an AYA patient, you'll hear valuable perspectives about resources and support needed in the AYA sarcoma journey.

[REGISTER HERE](#)

**DEAR
CONGRESS**

1

**KIDS WITH
CANCER
MUST BE
THE FIRST
ORDER OF
BUSINESS
IN 2025!**



SFA Joins Effort to Prioritize Childhood Cancer in Congress

Sarcoma Foundation of America (SFA) united with 22 organizations to urge Congress to prioritize childhood cancer legislation. Together, we are calling on lawmakers to ensure children facing cancer are the first order of business in 2025.

With sarcoma accounting for 15-20% of pediatric cancers, childhood cancer advocacy is a critical part of SFA's mission, and we stand with families, patients, and fellow advocates in pushing for change that will make a difference. [Read More](#)

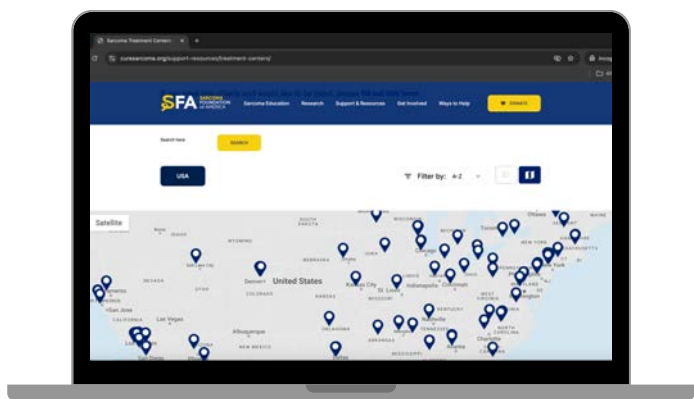
SARCOMA TREATMENT CENTERS



Sarcomas are complex, and treatment at a specialized center with a multidisciplinary team experienced in sarcoma care is crucial for the best possible outcomes. For many years, SFA has had criteria that centers must meet to be listed on our website. You can find a comprehensive list of specialized sarcoma treatment centers on our website. These centers offer access to the latest research, clinical trials, and personalized treatment plans tailored to each patient's unique needs. If you have questions about a sarcoma center, please email

programs@curesarcoma.org.

[Find a Treatment Center Near You](#)



RESEARCH ROUNDUP

By Dean Frohlich, PhD

The first article this month, "[Larotrectinib for Newly Diagnosed Infantile fibrosarcoma and Other Pediatric NTRK Fusion-Positive Solid Tumors \(Children's Oncology Group ADVL1823\)](#)," highlights a study in which larotrectinib, a drug that inhibits a specific protein called NTRK and is FDA approved for NTRK fusion-positive solid tumors that lack an good alternative treatment or have progressed after treatment in pediatric patients with NTRK Fusion-Positive tumors. In this study, called ADVL1823, larotrectinib was administered to patients with newly diagnosed tumors. Of the 33 total patients, 18 had infantile fibrosarcoma (IFS), which is a malignant fibroblastic tumor in infants, marked by rapid growth and local aggression, with rare metastasis, often featuring a fusion of the proteins ETV6 and NTRK3. Another 15 patients had other solid tumors, including other sarcoma types.

The objective response rate (ORR) within six cycles was 94% and 60% in patients with IFS and other solid tumors respectively. Two-year event-free survival (EFS) and overall survival (OS) were 82.2% and 93.8% for IFS and 80% and 93.3% for other solid tumors. Patients undergoing surgical resection of their tumor had prolonged EFS, with only 1 of 16 such patients experiencing disease progression.

These results indicate that larotrectinib is highly effective in patients with newly diagnosed NTRK fusion-positive solid tumors including IFS and should be considered for frontline therapy.

The second study, "[Maintenance therapy with trofosfamide, idarubicin and etoposide in patients with rhabdomyosarcoma and other high-risk soft tissue sarcomas \(CWS-2007-HR\): a multicentre, open-label, randomised controlled phase 3 trial](#)," was a multicenter, open-label, randomized controlled, phase 3 trial that investigated the efficacy of maintenance therapy added to standard therapy for patients with high-risk rhabdomyosarcoma and other soft tissue sarcomas.

Patients were randomized to either stop treatment (S-arm) or to receive oral maintenance therapy (M-arm) with eight 10-day courses (25 weeks) of the

chemotherapies trofosfamide idarubicin alternating with trofosfamide and etoposide. The primary outcome was event-free survival (EFS), and the secondary outcome was overall survival (OS) in the intent-to treat population.

Patients were randomly assigned to the M-arm (n = 96) or S-arm (n = 99) for a total of 195 patients. With a median follow-up of 5.2 years for surviving patients, the 3-year EFS in the M-arm was 66.9% versus 75.6% in the S-arm. 3-year OS was 82.8% in the M-arm versus 84.7% in the S-arm. Grade 3–4 adverse events were hematological in 66% of patients, febrile infections in 6%, gastrointestinal in 10%, and sensory neuropathy in 1%.

These data indicate that 25 weeks of oral maintenance therapy with trofosfamide, etoposide and idarubicin after standard therapy does not improve EFS and OS in patients with high-risk rhabdomyosarcoma and other soft tissue sarcomas.

Lastly, in "[Pazopanib in the real-world setting in soft tissue sarcomas: data from the Italian national registry](#)," investigators in Italy carried out a nationwide observational cohort study to determine the outcomes of advanced soft tissue sarcoma patients treated with pazopanib, an drug that blocks the activity of multiple proteins called tyrosine kinases. To prescribe pazopanib in Italy, the clinicians were required to complete the Italian Medicines Agency (AIFA) drug monitoring registry.

Data that was prospectively collected from a total of 1964 patients were analyzed. Data collected included the clinical characteristics, subtype, and clinical outcome. Primary outcome was time to treatment discontinuation (TTD). The most common subtypes were leiomyosarcoma (44.7%), undifferentiated sarcomas/not otherwise specified (11.5%), and synovial sarcoma (8.1%).

Overall, the median TTD was 106 days. The clinical characteristics associated with shorter TTD were Eastern Cooperative Oncology Group performance status, the number of previous lines of treatment, and prescribed dose. Additionally, in subtypes with greater than 20 patients represented in the study, there was a longer TTD in patients with malignant solitary fibrous tumor compared with undifferentiated sarcoma not otherwise specified.

This observational real-world study yielded outcomes like those reported for the trial that led to the approval of pazopanib, however includes patients with additional and more rare subtypes and indicates possible treatment differences among them.

Sarcoma Research Funding Opportunities for 2025

SFA is committed to funding research that will lead to improved treatments and outcomes for sarcoma patients. There's still time to apply for SFA's 2025 Research Grants and Last Mile Research Grant.

[SFA Research Grants](#): These grants support pre-clinical, translational, and clinical research on the etiology, molecular biology, pathogenesis, diagnosis, and treatment of human sarcomas. Funding of up to \$75,000 is available for one year.

[Last Mile Research Grant](#): This grant supports future R01 or R01-equivalent grant proposals. Funding of \$150,000 is available for one year.

The deadline to apply for both opportunities is February 3, 2025.

SFA-Funded Research Identifies Genetic Changes That Increase Risk for Some Childhood Sarcomas

SFA is proud to have directly contributed to this recently published research in the journal *Science* that has identified genetic abnormalities that increase the risk of Ewing sarcoma, osteosarcoma, and other solid tumors in children. The research found that structural variants, a less well-studied type of germline changes, contribute to the risk of solid tumors that could account for one-third of new pediatric childhood cancers.

This research was made possible by the 2021 Jay Vernon Jackson Memorial Research Award.

CLINICAL TRIALS CORNER

By Kristi Oristian, PhD

This month SFA is highlighting a [First-in-Human Trial of DS-2243a in Participants With Advanced Solid Tumors](#). This study is newly recruiting at one location in Nashville, TN with other sites anticipated to open. The trial is sponsored by Daiichi Sankyo and is open to adults ages 18 years and older in the United States with synovial sarcoma (SS) or myxoid/round cell liposarcoma (MRCLS) that are HLA-A2 positive.

Patients eligible for this trial will receive a new medicine called DS-2243a at escalating doses to help scientists and doctors determine the safety and tolerability of the medicine as well as its effectiveness at treating sarcoma. Patients eligible for this study may be monitored for up to 3 years.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations, as well as confirmation of HLA status. Patients interested in this study should review these criteria with their doctor as well as the potential clinical benefit of participation in the study. To learn more about this study, patients and/or care partners can talk to their doctor, contact the investigator at the study site, or contact the [study coordinator](#). Travel resources may be available from the study sponsor, and participating patients in need of additional support may [apply for assistance](#) from SFA.

MY SARCOMA STORY

JAMES CHARLES



In the summer of 2018, James Charles was a teenager working his first job at a ranch in Florence, Texas. A pain in his knee grew from a distraction to unmanageable pain. By the time a few weeks had passed, getting out of bed had become a struggle. James' father took him to an urgent care clinic and all James could think about was hoping he would soon be able to return to work.

The results were so unexpected that the doctor drove from the urgent care clinic to James' grandparents' house to deliver the news: James had osteosarcoma. "My mind was immediately flooded with questions like, 'What do we do now?,' 'Am I going to die?,' and 'Am I going to lose my leg?'," James remembers. "My mother, father, and my Nonnie and Papa all came to comfort me. I could see the heartbreak in their eyes. I couldn't even comprehend what had been said."

[Read James' full story here.](#)

SFA NEWS



SARCOMA STORIES

Episodes 2 & 3 Now Available

Tune in to the latest episodes of the Sarcoma Stories podcast! In episode 2, we hear from DFSP survivor Jenna Pothier about the importance of shared decision-making between patients, care partners, and medical teams. Jenna also opens up about the challenges of facing a life-changing diagnosis as a young adult, finding support, and her advocacy work. Then, in episode 3, uterine leiomyosarcoma survivor Susie Donahue shares her journey from diagnosis to treatment, highlighting the need for knowledgeable healthcare providers and patient advocacy. Susie discusses balancing work and treatment, navigating workplace disclosure, and finding strength in community. Join our Sarcoma Stories Facebook group to discuss these episodes and connect with fellow survivors and supporters.

[LISTEN NOW](#)

[FACEBOOK GROUP](#)

SFA Welcomes Jasmine Browder to Our Team

SFA is thrilled to welcome Jasmine Browder as our newest Fundraising Events Manager! She will be pivotal to the success of our Race to Cure Sarcoma events using her shared skills and experience in community events.



IN THE COMMUNITY

“Steps to Squash Sarcoma” Raises More than \$11,000

Pat Pisano recently organized the "Steps to Squash Sarcoma" fundraiser, raising over \$11,000 for Sarcoma Foundation of America! Pat is the care partner for leiomyosarcoma patient, Dina. This incredible effort supports SFA's mission to fund research, educate patients, and advocate for the sarcoma community. Thank you, Pat for your incredible effort to support SFA.

Learn about how you can get involved and help support our mission [here](#).



Pat with her group for her December 2024 fundraiser for SFA.

A LEGACY OF LOVE AND HOPE



Paul Herbert, a member of the Legacy and Sunflower Societies, has made significant contributions to SFA in honor of his late wife, Nancy Jean, who passed away in 2012 after a 13-year battle with sarcoma. He hopes to support others affected by this rare cancer and shares his deep empathy for anyone going through a similar journey.

“ I have the greatest sympathy in the world for anyone affected by sarcoma. I’ve walked that long, bitter path, and I want to help. ”

Nancy Jean’s experience with sarcoma was fraught with challenges, starting with a misdiagnosis of her tumor as benign. Her treatment involved facial surgery and reconstruction, which changed her appearance, and both Paul and Nancy Jean endured long periods of anxiety as they navigated the unpredictable path of the disease.

“ Nancy Jean was a very stoic woman. We did have the blessing of time. I wouldn’t trade the time we had together for anything, but I don’t want to relive those years either. ”

In addition to his financial contributions, Paul has actively participated in SFA events, including six Chicago-based RTCS events. In 2023, he joined SFA's team for the Marine Corps Marathon 10K, where he raised over \$7,000 and finished in the top third of his age group.

Paul remains committed to supporting SFA and believes that the foundation’s work is vital for patients with sarcoma, emphasizing the importance of providing hope and guidance to those diagnosed with the disease.

“ SFA’s work is desperately needed by patients with sarcoma. We need to be able to tell someone when they have sarcoma that there’s something that you can do. ”

THANK YOU!



Thank you for your support and commitment to our mission in 2024. We look forward to our continued partnership in the new year.

We couldn't have made such a big impact in 2024 without friends and supporters like you. From funding translational research, to education, awareness and advocacy, our community has helped lead the way in changing the sarcoma landscape.

As we enter 2025 and celebrate our 25th anniversary, we reflect on our impact as an organization. Our amazing advocates, volunteers, and other supporters have allowed us to make some amazing strides. It is also inspiring to consider our potential as we continue our mission on behalf of people affected by sarcoma.

Thank you for your support in 2024—and every single day you help to improve outcomes for people diagnosed, living with, and surviving sarcoma. We look forward to our continued partnership as we work to reach our shared goals. Together, let's change the world for people affected by sarcoma.

EVENTS

STAND UP TO SARCOMA GALA

SAVE THE DATE

Our 2025 Stand Up to Sarcoma Gala will be held in New York City at 583 Park on September 15, 2025. Stay tuned for more details.



ADVOCACY



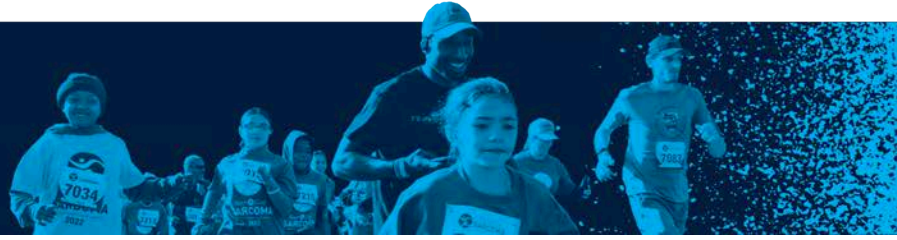
July 17
ADVOCACY DAY

July 18
EDUCATION DAY & DINNER

July 19
RACE TO CURE SARCOMA DC



[LEARN MORE AND REGISTER](#)



2025 DATES

Registration is Now Open! Register by clicking your city below.

[Austin - 03/22/25](#)

[Atlanta - 04/05/25](#)

[Boston - 04/13/25](#)

[New York - 04/26/25](#)

[San Francisco - 05/10/25](#)

[South Florida - 05/17/25](#)

[Cleveland - 06/21/25](#)

[Milwaukee - 07/12/25](#)

[National Virtual - 07/19/25](#)

[Washington D.C. - 07/19/25](#)

[Louisville - 08/09/25](#)

[Philadelphia - 09/13/25](#)

[San Diego - 09/20/25](#)

[Chicago - 09/27/25](#)

[New Jersey - 10/05/25](#)

[Sacramento - 10/11/25](#)

[Denver - 10/25/25](#)

[Nashville \(Virtual\) - 11/01/25](#)

[Tampa - 11/01/25](#)

[Los Angeles - 11/02/25](#)

Locations and Dates are Subject to Change.

Registration for Philadelphia Opening Soon.



Open Positions at SFA

[Executive Office Manager](#)

[Digital Marketing Manager](#)

[Finance Manager](#)

[Fundraising Events Manager](#)