September 2026

A Tribute and a Call to Action

By Brandi Felser, CEO

There are people who change the way you think, lead, and show up in the world.

Katie and her children at RTCS Louisville

For me, Katie Wintergerst was one of those people.

This article reflects one of the hardest things I have had to write outside of my parents' obituaries after their cancer journeys. While many knew Katie as an advocate, colleague, mentor, and source of support, I knew her first as a friend. I recruited Katie to SFA. It took a couple of years, but I was thrilled when she finally made the leap.

I will miss her wisdom, her humor, her honesty, and our conversations. I am deeply grateful for our friendship and for everything she taught me about resilience, hope, and putting others first.

While this article begins as a tribute to Katie, it became something more as I wrote it. It became a reflection on loss, hope, and the responsibility we all have to turn those experiences into action. I hope you'll take a few minutes to read it. Whether your life has been touched by sarcoma, another cancer, or the loss of someone you love, I hope it encourages you to turn that hope into action. The work isn't finished, and each of us has a role to play in creating a better future for those who come next. Read the full tribute.

Make an impact this Childhood Cancer Awareness Month

September is Childhood Cancer Awareness Month, a time to recognize the children and families whose lives have been impacted by cancer and to raise awareness of the challenges they face.

Sarcomas account for approximately 15–20% of all childhood cancer diagnoses in the U.S. Each diagnosis brings unique challenges, affecting not only children but their families and loved ones as well.

Throughout September, SFA will recognize Childhood Cancer Awareness Month by sharing stories, educational information, and resources to help families affected by childhood sarcoma.

A sarcoma diagnosis changes a child's life in an instant. Every child deserves a future filled with possibilities, not cancer treatments. Your support can help make that future possible. Donate now.

Upcoming Education Sessions

Subtype Series: Ewing Sarcoma: Current Treatment, Emerging Research & the

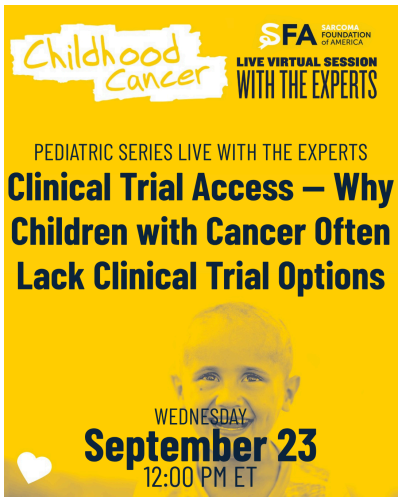
Patient Perspective

In recognition of Childhood Cancer Awareness Month, join SFA on **September 9 at 12 PM ET** for a one-hour webinar exploring Ewing sarcoma from three complementary perspectives: clinical care, emerging research, and the patient and care partner experience.

The discussion will cover how Ewing sarcoma is diagnosed and treated, including approaches for localized, metastatic, and recurrent disease; how Ewing sarcoma biology, biomarkers, disease monitoring, and emerging therapies are shaping the future of treatment; and the experiences of patients and families throughout diagnosis, treatment, recurrence, and survivorship.

Register

Pediatric Series: Clinical Trial Access — Why Children with Cancer Often Lack Clinical Trial Options



On **September 23 at 12:00 PM ET** SFA is hosting an education session exploring why children and adolescents with cancer often have fewer clinical trial opportunities than adults, particularly those with rare cancers such as sarcoma. This webinar will explore why these gaps exist, how changes in pediatric drug development and more age-inclusive clinical trial design are expanding opportunities, and what families can do to identify and access appropriate clinical trials.

The discussion will address the historical challenges that have limited pediatric cancer drug development and clinical trial participation, including small patient

populations and age-restrictive eligibility criteria; regulatory and drug-development changes aimed at improving access; and practical barriers families may face, including eligibility, timing, geography, referrals, and access to specialized centers.

Register

The Stand Up to Sarcoma Gala brings together a remarkable community of patients, survivors, families, researchers, physicians, advocates, and supporters to celebrate progress and recognize the people helping advance the sarcoma mission. It's an inspiring evening of connection, hope, and shared commitment to creating a future with better treatments and outcomes for everyone impacted by sarcoma.

We hope you'll join us for the 24th Annual Stand Up to Sarcoma Gala on **Tuesday, October 6, 2026**, at 583 Park Avenue in New York City

We're pleased to offer discounted Gala tickets for patients, survivors, and their caregiver. We hope you'll take advantage of this opportunity to celebrate with us and be part of an evening that honors your journey and the entire sarcoma community.

Meet our Nobility in Science Honoree: Shreyaskumar R. Patel, MD.

The Nobility in Science Award recognizes a visionary sarcoma researcher who has played an integral role in advancing treatments for patients.

We are proud to honor Dr. Patel with the Nobility in Science Award for his decades of dedication to sarcoma research, treatment, and the broader sarcoma community. As Medical Director of the Sarcoma Center at MD Anderson Cancer Center,

his research has focused on advancing systemic therapies for sarcomas, including gastrointestinal stromal tumors and other bone and soft-tissue tumors. Learn more about Dr. Patel.

Introducing our Vision of Hope Honoree: US WorldMeds

The Vision of Hope Award recognizes a person or organization whose actions have advanced care, treatment, or awareness for people affected by sarcoma and provided greater hope for better patient outcomes.

We are proud to honor US WorldMeds with the Vision of Hope Award for its commitment to advancing treatment options and engaging with patients and advocates throughout the development process. By incorporating the patient voice into regulatory and development efforts, US WorldMeds has helped expand therapeutic opportunities and demonstrated the meaningful impact of collaboration between industry and the sarcoma community.

Announcing our Gala Host, Jason Kravits

Guiding the evening's program, our host helps bring together the voices, stories, and impact that define this event.

Jason Kravits has appeared on stages and screens, large and small, for over 35 years. In that time, he has amassed over 100 film and TV credits, including memorable roles on Only Murders in the Building, Curb Your Enthusiasm, Young Sheldon, and Grey's Anatomy. Jason recently appeared alongside John Turturro in the stage adaptation of the Philip Roth novel Sabbath's Theater,

and as "Vice Principal Panch" in The 25th Annual Putnam County Spelling Bee.

We hope you'll join us for this special evening as we celebrate our honorees and the remarkable individuals whose courage, leadership, and dedication are helping create a brighter future for the sarcoma community.

Join us at the Gala

We understand that attending may not be possible for everyone. If you cannot join us in person, we hope you will consider making a gift in honor of the patients, survivors, and families who face sarcoma every day. Your support helps provide hope where it is needed most and fuels the progress that brings us closer to a future free from this disease.

Donate Today

Research Roundup

Highlighted Research

By Nigel Brockton, PhD

Both research studies that we highlight this month are from outside of the United States. Sarcoma is a global issue and data from other similar countries can help inform sarcoma care in the USA. The first study focuses on primary bone sarcoma (PBS), using population-based data from England. The second study addresses the unique challenges that sarcoma patients face regarding physical activity and nutrition, during and after treatment.

Primary Bone Sarcoma – Making Progress

This study revealed significant improvements in survival that have been largely driven by improvements in care delivery. Accurate population-based analyses of sarcoma incidence and survival are difficult due to the rarity and complexity of sarcoma subtypes. Existing reporting mechanisms are often restricted to classification of tumors by anatomic site and miss the detailed histology that

define sarcoma subtypes. The study by Hastings et al. analyzed 12,282 cases of PBS diagnosed in England over a 25-year period (1996 – 2020). The 2020 cut-off was used to enable five years of follow-up for all patients in the survival analyses.

There was a small but significant increase in the overall annual rates of PBS diagnosis over the study period. Chondrosarcoma (31%) was the most common subtype diagnosed, followed by osteosarcoma (28%) and then Ewing sarcoma (21%). The increase in the overall rate was likely driven by improved diagnostic techniques and changes in disease definitions. The overall increase was mainly due to increases in chondrosarcoma, particularly atypical cartilaginous tumors, a low-grade subtype of chondrosarcoma. There was a decrease in the rates of osteosarcoma diagnoses and no significant change in Ewing sarcoma rates of diagnosis.

The best news from this study is that PBS survival improved significantly overall, from 51.8% in 1998-2002 to 64.3% in 2013-2017. Improvements were reported in chondrosarcoma (66.9% to 79.4%), chordoma (54.7% to 71.3%) and osteosarcoma (41% to 58.4%). Improvements in Ewing sarcoma survival did not reach statistical significance overall but did improve for younger age groups.

Several factors likely account for these improvements. Principally, the reorganization of national sarcoma services and the establishment of specialist sarcoma centers. Given the relatively modest advances in new therapeutic agents over this period, it is encouraging improvements in care delivery were associated with such significantly better outcomes.

Incidence and survival of primary bone sarcoma diagnosed in England between 1996 and 2020; An analysis from the National Disease Registration Service. Hastings et al. Eur J Cancer. 2026 Aug 21;246:116981. https://pubmed.ncbi.nlm.nih.gov/42628139/

Nutrition and Physical Activity Challenges & Opportunities

The importance of lifestyle, particularly nutrition and physical activity, is increasingly acknowledged in cancer survivorship. However, sarcoma patients and survivors face unique challenges due to the aggressive treatments and potential physical limitations due to surgeries. Physical activity can assist recovery, reduce treatment side effects and improve health outcomes and quality of life. Similarly, adequate nutrition is essential for recovery from surgery, physical functioning and treatment tolerance.

The study by Halkett and colleagues sought to understand the lived experience of sarcoma patients, their carers and healthcare professionals. Semi-structured interviews and focus groups were conducted to assess the current perspectives regarding nutrition and physical activity among people facing sarcoma.

Five themes were identified: Physical impact of sarcoma; Uncertainty about looking after the person with sarcoma; Needing rehabilitation support; Creating a new normal; and, Physical activity and healthy diet promote psychosocial well-being. Within these themes, key aspects such as inconsistency of advice and absence of support were critical concerns. The published paper presents anonymized quotes, extracted from interviews/focus groups, that provide stark first-person accounts from patient, carer and healthcare professional perspectives.

It is clear from the participant responses, and the conclusions of the study, that sarcoma patients, carers and healthcare professional need additional support to adequately address nutrition and physical activity in the context of sarcoma treatment and beyond. The authors present a series of recommendations corresponding to each of the key themes identified. It is encouraging that people facing sarcoma recognize the value of addressing nutrition and physical activity but the gap between that demand and the provision of support is substantial. The current study should inform tangible changes in multidisciplinary care.

Physical Activity and Nutritional Supportive Care Needs Following a Sarcoma Diagnosis: Barriers and Opportunities for Rare Cancer Survivorship Care. Halkett et al. Psychooncology. 2026 Aug;35(8):e70567. https://pubmed.ncbi.nlm.nih.gov/42605703/

Clinical Trials Corner

This month, SFA is highlighting SWOG S2505 (NCT07615049), a new Phase III clinical trial comparing a shorter course of preoperative radiation therapy with the standard course for patients with stage II–IIIB resectable soft tissue sarcoma of an arm or leg. Led by SWOG Cancer Research Network, the study is expected to begin enrolling later this year.

Radiation therapy is often given before surgery for high-risk extremity soft tissue sarcoma. Standard preoperative radiation typically involves 25 treatments over approximately five weeks. In S2505, participants are randomly assigned to receive either the standard 25-treatment course or an ultra-hypofractionated course of just five treatments before undergoing surgery.

The primary goal of the study is to determine whether the five-treatment approach provides local tumor control that is not inferior to the standard 25-treatment regimen. Researchers will compare local tumor recurrence two years after treatment and will also evaluate acute wound complications and longer-term effects associated with radiation therapy.

Reducing radiation from 25 treatments to five could substantially lessen the treatment burden for patients if the shorter course is shown to provide comparable tumor control. This could be particularly meaningful for people who must travel to a specialized sarcoma center or manage work, family, transportation, and other challenges during several weeks of daily treatment.

Eligible participants must be 18 years of age or older and have biopsy-confirmed stage II–IIIB soft tissue sarcoma of an extremity that is newly diagnosed or locally recurrent, can be surgically removed, and has not spread to distant sites. Additional eligibility requirements related to previous treatment, tumor characteristics, overall health, and planned surgery also apply.

To learn more about SWOG S2505 (NCT07615049), patients and/or care partners can talk with their doctor or review the study on ClinicalTrials.gov. Patients interested in the study can follow the listing for updates as enrollment begins. If you are considering participation and need travel or financial support, you may apply for assistance from SFA.

Expanded Access to Bezuclastinib Available for Eligible Patients with GIST

Cogent Biosciences has established an Expanded Access Program (EAP) for bezuclastinib in combination with sunitinib for eligible patients with gastrointestinal stromal tumor (GIST). Expanded access, sometimes called compassionate use, provides a pathway for certain patients with serious

illnesses to receive an investigational treatment outside of a clinical trial when satisfactory treatment options are not available. Learn More.

SFA Global

A Problem in Osteosarcoma?

By Pan Pantziarka, Director of Europe Strategy and Engagement, SFA Global

Progress in sarcoma depends on developing a better understanding of the biology of the different types and subtypes of the disease. That progress is reported in articles in scientific journals - it's the core process of modern science that new results and data are published so that other scientists can replicate and build on those results. It's an incremental process that paves the way to improved understanding and from there to new avenues for clinical exploration. However, there's something worrying going on in osteosarcoma research that should be setting off alarm bells.

Journals sometimes have to 'retract' a published article - usually this is a rare occurrence, and it signals to the scientific community that the retracted paper cannot be trusted. Sometimes this is due to genuine errors in the paper, but often it signals some kind of wrong-doing - from doctored results to wholesale stealing of someone else's work or deliberate falsification of data. Generally, the rate of retractions is quite low and evenly spread across the whole spectrum of science. But that is not the case in osteosarcoma, which is showing a consistently high rate of retractions - around four or five a month. This is a tiny fraction of the total number of papers being published on osteosarcoma, but it’s higher than chondrosarcoma, another bone sarcoma, which has fewer than one a year. For another pediatric sarcoma, rhabdomyosarcoma, the number is only two in twenty years. So, this is not a problem for all sarcomas, it appears to be concentrated just in osteosarcoma.

Digging into the details is instructive and sheds some light on an underlying issue that extends way beyond this specific case. Publishing articles in journals is a key metric used in academic hiring and promotions. The incentive, from an academic career perspective, is to publish as much as you can in order to get that job or that promotion. Inevitably that creates a skewed incentive where people don't just cut corners, they go all about to game the system as much as they can. It also creates a market for unscrupulous individuals to write papers

on demand for people looking to publish without doing the work. And, in the case of osteosarcoma, it looks as if some of these people have either worked in the field before and can put together realistic results or they've built up experience in writing about osteosarcoma so that they can churn up papers quickly to people desperate to be published.

There's a cost to the activity as far as the scientific and patient communities are concerned. Firstly, detecting these papers is time-consuming and consumes resources that could be better spent elsewhere. In an analysis of retracted papers in oncology (Pantziarka & Meheus, 2019), the average time between publication and retraction was around 3.5 years - which means that data might be influencing researchers and patients for a long period of time before it's finally withdrawn. It could also be influencing other work as people try to reproduce or extend results that are worthless. Thankfully, much of the retracted work is not about clinical trials but is focused on pre-clinical work, so the negative effects are less likely to directly harm patients. There's another cost too, which is that some people might be tempted to assume that solid work is worthless because negative impressions can spill over into the field as a whole, not just on the tiny subset of unethical individuals. There is some phenomenal work being done in osteosarcoma, we should not lose sight of that.

What can be done? The simplest answer is to insist that there are sanctions associated with faking data. Where a retraction is down to actual wrong-doing rather than error, then the individuals should be penalised. Institutions should not look the other way. Longer term we, as a scientific and patient community, need to look again at how we incentivise scientific publishing. Publish at all costs is surely not the way we want to reward good science. This is an issue that SFA will be continuing to work on.

Advocacy and Engagement

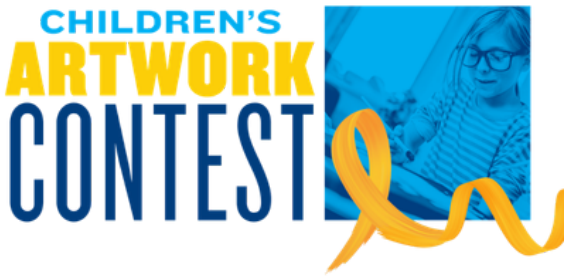
How to Talk to Kids About Rare Cancers Webinar

SFA has partnered with the Pickles Group to host a webinar and parent panel on **September 16 at 5 PM ET**. The webinar will offer practical guidance on how to talk

with children about cancer, followed by a panel of families sharing their lived experiences navigating parenthood through rare cancer. Register here.

SFA News

Thank you 2026 Children's Artwork Entries



Thank you to everyone who entered the 2026 Children's Artwork Contest. This year, SFA received submissions from many young artists from around the world who shared their depictions of sunflowers or yellow ribbons to raise sarcoma awareness. We thank everyone for their participation and sharing their talent and creativity!

Selected artwork will appear on SFA's holiday cards and will be displayed at the upcoming Stand Up to Sarcoma Gala. View all the artwork submissions.

Sarcoma Awareness Month: Turning Awareness Into Action

July's Sarcoma Awareness Month was a tremendous success—and we have all of you to thank! Together, our community turned awareness into action, helping us exceed our fundraising goal and raise **$40,373**.

This year's digital campaign brought together awareness, community engagement, and new opportunities to support SFA. Through the inaugural **Streaming for Sarcoma Campaign**, streamers on the Tiltify platform introduced sarcoma to new audiences while raising critical funds for our mission in a fun and interactive way.

"I am honored and so grateful to help spread awareness and raise money for the Sarcoma Foundation everyday through my community. Donate blood and subscribe to Technoblade!"
-Susan 🎗️ 🐖 @susanfox - Leiomyosarcoma survivor, Technoblade community moderator, and Technodad Admin

Perhaps most exciting, **170 new donors joined the SFA community** through the campaign. Every new supporter represents an opportunity to grow awareness, expand our community, and advance progress for people impacted by sarcoma.

Thank you for helping make Sarcoma Awareness Month a powerful reminder that **when we come together, awareness creates action—and action creates impact**.

In the Community

2nd Annual Jessica Rose McNamara Memorial Wine Tasting

Hosted by Jimmy and Maria McNamara, this event honors the life of their daughter, Jessica Rose, who passed away from sarcoma in July 2017. Taking place on November 14 in Unionville, Connecticut, the event will feature an evening of food and wine tasting, along with a chance to win gift raffle prizes. Thanks to the

generosity of attendees, the event raised more than $23,000 last year! Learn more about the event.

Allison's Beer Mile

Last month, Allison's Beer Mile brought together friends and family for a walk to support SFA and remember and celebrate the life of Allison McKey. This year, the event raised over $7,000 to help fund the 2026 Allison McKey Last Mile Research Award.

Race to Cure Sarcoma

Why I Race: Amethyst Turner, RTCS Chicago

My sister, Angelyn, courageously battled sarcoma with remarkable strength, resilience, and unwavering faith. Though her journey came to an end, her legacy continues to inspire me and countless others every day. In her honor, I proudly support the Sarcoma Foundation of America to ensure her story and the stories of so many others continue to bring hope, encouragement, and strength to survivors, families, and those grieving the loss of a loved one.

My involvement is rooted in a desire to turn pain into purpose through advocacy, awareness, and action. By encouraging both physical and financial support, I hope to amplify the urgent need for sarcoma research and help move us closer to better treatments and, one day, a cure. Together, we can honor every life, uplift every fighter, and give hope to those who need it most.

Sign up for SFA's 2026 Race to Cure Sarcoma events!

More than just a race, it's a chance to connect with others in the sarcoma community, recognize people living with sarcoma, honor those we've lost, and fund vital sarcoma research. Whether you walk, run, or cheer, you'll be making a difference! [Find your city and sign up today!]

Upcoming Races

- North Carolina (9/13)
- San Diego (9/19)
- Chicago (9/26)
- Tampa (10/3)
- New Jersey (10/11)
- Denver (10/24)
- Global Virtual (11/8)
- Los Angeles (11/15)

Join Our Marathon Team

Current Marathon Team Openings

- 2026 Philadelphia Marathon Weekend November 20 - 22 *(only 8k available)*
- 2027 Miami Marathon and Half Weekend January 31 *(only half marathon available)*
- 2027 Los Angeles Marathon Weekend March 5 - 7 *(only 5k available)*

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