Happy New Year!

2025 was a very busy year at SFA. As I type that, I find myself reflecting on John Wooden's words: *"Don't Mistake Activity With Achievement."* At SFA, this principle guides everything we do. Our focus is not simply on being busy—it's to make a meaningful impact. Every program we launch, every partnership we build, and every initiative we pursue is driven by one question: *Does this move us closer to our mission and strategic goals?*

In that spirit, I'm proud to share some of the meaningful achievements we accomplished together in 2025:

Advancing Research
Thanks to the unwavering support of our community, we increased research funding by nearly $500,000—in a year when we received a record number of proposals. Research is the path to a cure, and since our inception, SFA has remained committed to advancing studies that truly save lives.

Launching SFA Global
While we've long supported patients and research beyond the U.S, 2025 marked the official launch of SFA Global. As the largest sarcoma patient organization worldwide, we know progress requires global collaboration. We now have our first staff partner in the United Kingdom and are actively engaging the international sarcoma community to address shared challenges and opportunities.

Sarcoma Stories Podcast
Our Sarcoma Stories podcast officially launched in December 2024, but it was in 2025 that it truly gained momentum—reaching listeners on every continent except Antarctica! The feedback has been humbling, many have told us, *"I feel heard."* That sense of connection is exactly what we hoped to create. Sarcoma Stories is the only podcast dedicated entirely to the voices of those impacted by sarcoma—their journeys, triumphs, challenges, and lessons learned. It is truly inspiring.

Race to Cure Sarcoma (RTCS)
Participation in our RTCS series grew by 25% in 2025, making it our most successful year yet. These events are more than fundraisers—they are powerful gatherings of hope, remembrance, and community. Natasha from our team shared a story that captures this spirit perfectly: at her first RTCS in Boston, she stood on stage during the survivor recognition, just out of treatment, and turned to a new friend—a fellow survivor—and said, *"See you here next year."*That moment of hope and connection is what RTCS is all about.

While we celebrate these milestones, our work continues. As one of our partners recently wrote to me, *"I guess we're back in the swing of things. Looking forward to a productive year!"*
I couldn't agree more. In 2026, we will remain focused on purposeful action—initiatives that drive real change for those living with sarcoma. We have exciting new programs launching this year, and I look forward to sharing them with you soon.

Thank you for being part of this journey. Together, we are making a difference.

Warm regards,

RESEARCH ROUNDUP

Highlighted Research

By Dean Frohlich

In the first study, "Trabectedin-olaparib combination or trabectedin in advanced soft tissue sarcomas after failure of anthracycline-based treatment (TOMAS2): a randomized phase 2 study from the Italian Sarcoma Group," investigators treated patients with advanced/metastatic soft tissue sarcomas (STS) who had progressed on a kind of chemotherapy called anthracycline-based regimens with a combination of trabectedin (a different chemotherapy) and olaparib, which inhibits a protein called PARP (which helps repair DNA and the inhibition of which can cause tumor cells to die), or trabectedin alone. In all, 130 patients were enrolled in this phase 2 clinical trial. With a median follow-up of 37.4 months, the 6-month progression-free survival (PFS) was 32% for trabectedin and olaparib vs. 28% for trabectedin alone. The median PFS Was 3.9 months with trabectedin and olaparib vs. 2.9 months with trabectedin alone. The overall response rate was 12.7% vs. 7.9%, respectively. Notably, in patients with uterine leiomyosarcoma, the 12-month PFS was 42.9% with trabectedin and olaparib vs. 0% with trabectedin alone. The investigators also tested for PARP expression and found that it significantly correlated with improved PFS with trabectedin-olaparib. Although more research is needed, these results indicate that uterine leiomyosarcoma may be a good candidate for chemotherapy plus PARP inhibitor combination therapy and that PARP expression may be a biomarker to identify patients more likely to respond.

In the second study, "Metastatic Recurrence Among Adolescents and Young Adults with Cancer," investigators did a retrospective analysis of survival in 48,406 adolescent and young adults with a variety of cancers with early diagnosis vs. patients in the same age group diagnosed with metastatic disease to determine the cumulative incidence of metastatic recurrence. The investigators found that of all the patients analyzed, 9.2% had metastatic disease at diagnosis, and 9.5% had metastatic recurrence. Of the patients who were diagnosed with nonmetastatic disease, the 5-year cumulative incidence of metastatic recurrences was highest among patients with sarcoma (24.5%). They also found that the cumulative incidence of metastatic incidence increased with increasing stage at diagnosis in all cancers including sarcoma. Additionally, they found that survival after metastatic recurrence was worse than metastatic disease at diagnosis for all cancer types, except for testicular and thyroid cancers. These results highlight the importance of continued surveillance for recurrence in adolescent and young adult sarcoma patients following treatment.

Lastly, in "Inhibiting cholesterol synthesis halts rhabdomyosarcoma growth via ER stress and cell cycle arrest," researchers identified de novo cholesterol biosynthesis as a possible metabolic vulnerability in rhabdomyosarcoma (RMS). They found that stopping RMS cells from making cholesterol either with drugs or by silencing specific genes in cell culture or in a mouse model of RMS impaired the RMS cells from proliferating and activated a cell death pathway called ER stress-mediated apoptosis. They also found that when de novo cholesterol production was stopped, the addition of cholesterol did not allow the RMS cells to grow again or avoid cell death. Other analyses demonstrated that cholesterol synthesis proteins are increased in RMS tumor tissue and correlate with poor survival. These studies are very early, but they provide some evidence that targeting the de novo cholesterol synthesis pathway may be a useful therapeutic strategy for rhabdomyosarcoma.

Clinical Trials Corner

This month SFA is highlighting the TINKS trial, A Multi-Institution Study of TGFβ Imprinted, Ex Vivo Expanded Universal Donor NK Cell Infusions as Adoptive Immunotherapy in Combination With Gemcitabine and Docetaxel in Patients with Relapsed or Refractory Pediatric Bone and Soft Tissue (TINKS).

The TINKS trial, is a study testing whether adding a type of immune cell called a "natural killer" (NK) cell to standard chemotherapy (gemcitabine and docetaxel, or GEM/DOX) can improve outcomes for children with Relapsed or Refractory Pediatric Bone and Soft Tissue sarcoma that have recurred or haven't responded to previous treatments. The goal of the study is to determine the 6-month progression free survival achieved with this treatment along with measuring safety and identifying any side effects from this combined approach.

The trial is open to patients between the ages ≥ 2 years and ≤ 40 years of age and have had a relapsed or refractory osteosarcoma, Ewing sarcoma, rhabdomyosarcoma or non-rhabdomyosarcoma soft tissue sarcoma. There are additional eligibility and exclusion criteria, including minimum performance requirements and disease burden considerations. The treatment combines chemotherapy with NK cell infusions. It is given in cycles, and each cycle lasts 21 days. Patients can receive up to 8 cycles. The trial is open at 20 locations across the United States and is sponsored by the Nationwide Children's Hospital.

To learn more about this study, patients and/or care partners can talk to their doctor or reach out to the study contact. If you think you may be eligible or interested in participating and are in need of travel or financial support to do so, you may apply for assistance from SFA.

Accepting Applications: The Last Mile Sarcoma Research Award

SFA is now accepting applications for the 2026 Last Mile Sarcoma Research Award. This one-year, $150,000 grant supports sarcoma researchers seeking to strengthen the resubmission of R01 or equivalent proposals focused on advancing understanding and treatment of sarcoma. Applications are due by February 2, 2026, at 5:00 pm ET. Learn more.

SFA Global

Global Gaps in Cancer Drug Approval

By *Pan Pantziarka*

In the latest release of the cancer drugs database (https://data.tp53.org.uk/cancerdrugs.php) we can see that there are 349 drugs approved as cancer therapies globally. Of these 316 (90.5%) are approved by the FDA, in contrast 229 (65.6%) are approved in Europe by the EMA. At the previous release, in June of this year, the figures were 330 drugs in all, with FDA approvals for 298 (90.3%) and 221 (67%) approved by the EMA. Some older chemotherapy drugs pre-date the EMA and are approved at a national level rather than at a European level but even counting these the disparity between the USA and Europe is stark and not showing signs of improving. This is even more impactful for sarcoma patients, for whom fewer than 40 drugs are approved overall, and where the situation in Europe exacerbates the disparity. For example, nab-sirolimus is approved for PEComa in the US but not in Europe. Similarly, crizotinib is approved for all ages to treat ALK-positive inflammatory myofibroblastic tumor in the US, but in Europe it's not approved for adults. Tazemetostat is approved for epithelioid sarcoma in the US, but not in Europe. Even when drugs are approved, there can be a long delay between approval by the FDA and the EMA. For example, nirogacestat was first approved for desmoid tumors in November 2023 in the US, and EMA approval was granted in August 2025.

There are multiple contributing factors, not all of them under the control of the regulators. Some of these are commercial decisions, such as companies determining that European approval is a lower priority than the U.S. market. But there are also factors related to regulatory practices, differing rules on manufacturing, differing standards of evidence and so on. Oftentimes these differences are exacerbated because sarcomas are such rare diseases. For European sarcoma patients this creates a situation where they can be denied access to treatments that are available across the Atlantic.

For SFA Global, this is an area of priority. Regulation can be changed, processes improved and incentives created to equalize access to the best standard of care treatments for all sarcoma patients. Policy levers may include mutual recognition of approvals between EMA and FDA, or standardization of the processes so that the materials used in one application can easily be used for the other. Perhaps for rare diseases like sarcoma we should be talking about a joint approvals process - after all, many of the trials which provide evidence for the approval are already international trials. This also leads to broader questions on the standards of evidence needed for approvals in sarcomas - a process that is defined by what works for the most common cancers already leaves rare cancer patients disadvantaged. It is time we do better for people diagnosed with sarcoma.

ADVOCACY AND ENGAGEMENT

Listen to the Latest Episodes of Our Sarcoma Stories Podcast

In recent episodes of Sarcoma Stories, we sit down with patients, survivors, caregivers, and advocates whose experiences inspire and inform the sarcoma community. From navigating diagnosis and recovery to celebrating 25 years of progress, these conversations remind us that no one faces sarcoma alone.

Season 2 Episode 6|Crystal Malaka
We return from winter break and are joined by Crystal Malaka, a malignant peripheral nerve sheath tumor (MPNST) survivor. After receiving an initial misdiagnosis, Crystal trusted her instincts and advocated for a second opinion—one decision that ultimately led to an accurate MPNST diagnosis and life-saving care. This conversation is a powerful reminder of the importance of self-advocacy, especially within rare cancer spaces like the sarcoma community. Listen here

Listen to all episodes of the Sarcoma Stories podcast

SFA Partners with Imerman Angels on Peer Support Program

SFA is proud to announce a new one-to-one peer mentorship program powered by Imerman Angels called Sarcoma Match. Imerman Angels is a nonprofit dedicated to providing one-on-one peer support for people impacted by cancer. Matching can be based on age, gender, lifestyle, sarcoma subtype, and more to reach a simple goal: truly feeling understood by someone who has walked a similar path. Through this collaboration, patients, survivors, and care partners will be paired with 'Mentor Angels' who have faced a similar diagnosis or circumstance and can offer empathy, guidance, and hope.

We often hear how isolating a sarcoma diagnosis can be. People tell us they long to connect with someone who knows what they're going through; someone who can offer comfort and comradery as they face their diagnosis. With more than 100 subtypes of sarcoma, finding that connection can be incredibly hard. Together, SFA and Imerman Angels hope to further bring the sarcoma community together and make sure there is less isolation and more connection between those impacted by a sarcoma diagnosis.

At this time, we are only accepting mentor applications and plan to open mentee applications in the near future. Learn more

Honoring Care Partners: Reflections From the Sarcoma Community

What My Child Taught Me About Life and Courage

By Jody Hayes, Mother of Parker Hayes

Parker Hayes

Parker was just nine when he was diagnosed with Ewing's Sarcoma in his fibula—a rare bone cancer affecting only about 200 to 250 children in the United States each year. The medical details can be complex, but what truly matters is the journey he endured. The treatments for Ewing's are grueling and unchanged for decades, designed to fight the disease but often bringing immense pain and suffering in their wake. Parker was thirteen when he passed.

When I think of Parker's life, I'm struck by the lessons he left behind—lessons about pushing past our limits, about resilience born in the hardest places, and about the unbreakable strength of family. His four years fighting cancer, as brutal and unfair as they were, taught all of us who loved him how to face the inevitable with grace. He showed us how to live fully and fiercely—how to be spontaneous, silly, angry, honest, and utterly alive.

Through him, we learned that grief doesn't have to be carried in silence. We learned that speaking our pain out loud connects us, strengthens us, and reminds us that we are not alone. And perhaps the most powerful lesson of all: to move through this life without regrets, to love boldly, and to never hold back what truly matters.

Supporting a Sense of Normalcy and Finding Joy in New Traditions

When Parker began treatment, our family made a pact: we were going to hang on to as much normalcy as humanly possible. Parker had his sister, Spencer—truly each other's whole universe—and we wanted their world to feel familiar. After Parker's long chemo days and week-long inpatient stays, we needed the comfort of ordinary routines.

Never knowing if Parker would be in the hospital, if treatments would shift, or if a holiday would land at the "wrong" time, we decided to create a new tradition. We wrote the names of all the holidays on slips of paper and tossed them into a hat. On a random day, I would draw one—surprise!—and we'd celebrate.

Through this little ritual, we learned to embrace spontaneity and the simple wonder of the

moment. Every day became an opportunity for joy, laughter, and gratitude, and suddenly even the “off-season” holidays felt extra special. Parker taught us that celebration isn’t about the date on the calendar—it’s about cherishing the day you have.

The Gift

When it came time for palliative care, Parker did something extraordinary. He wrote and read our family a note, thanking us for the love, care, and support we had given him over the years. In that moment—when we were supposed to hold him up as he faced his own mortality—he became our anchor.

True to his nature, his letter was full of love, compassion, humor, and courage. Each word carried the weight of his spirit, leaving us with a rare, fragile sense of calm for the days ahead. My mother sat with him as he wrote, witnessing his grace and bravery firsthand. That simple act—his quiet, deliberate giving of strength—was a gift beyond measure, a final lesson in love, resilience, and the extraordinary courage of a remarkable child.

SFA NEWS

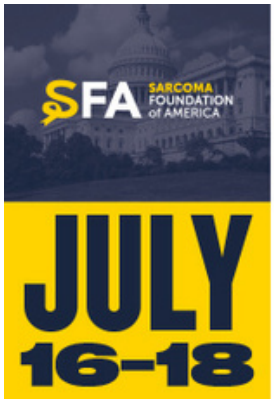
Save the Date for the 2026 Stand Up to Sarcoma Gala!

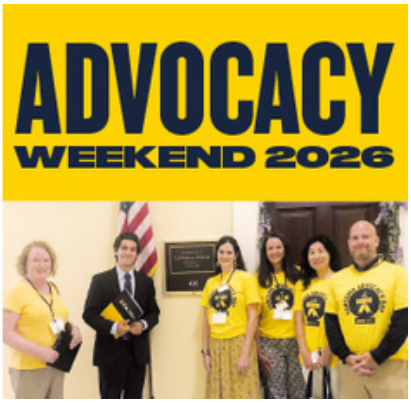
Stand Up to Sarcoma, now in its 24th year, is a night of celebration and community, bringing together the sarcoma community from across the country and around the world in solidarity to support sarcoma patients and survivors, honor our loved ones, and recognize progress.

The evening features an inspiring program where we highlight outstanding sarcoma advocates with the Courage Award, honor an investigator advancing groundbreaking research with the Nobility in Science Award, acknowledge a navigator (clinical/nurse, community health worker, or social worker in the role of a navigator) for his or her outstanding contributions to patient care and support with the Compassionate Care Award, and recognize an organization or person providing hope to patients with the Vision of Hope Award. These international awards are the highest honor SFA bestows. Mark your calendar to join us at the 2026 Stand Up to Sarcoma gala; an evening you won't forget.

Sarcoma Advocacy Weekend

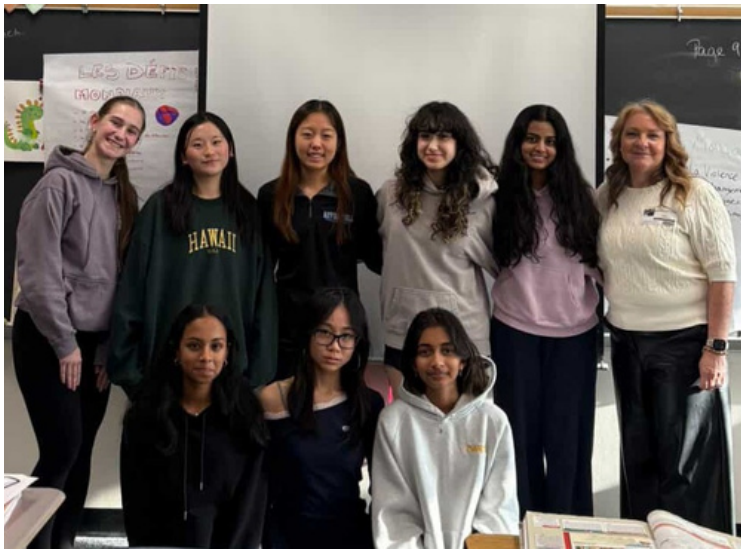
Sarcoma Awareness Month is right around the corner and so is the 2026 Sarcoma Advocacy Weekend. Mark your calendar to advocate on behalf of the sarcoma community.
Together, we can improve outcomes for people diagnosed and living with sarcoma.





In the Community

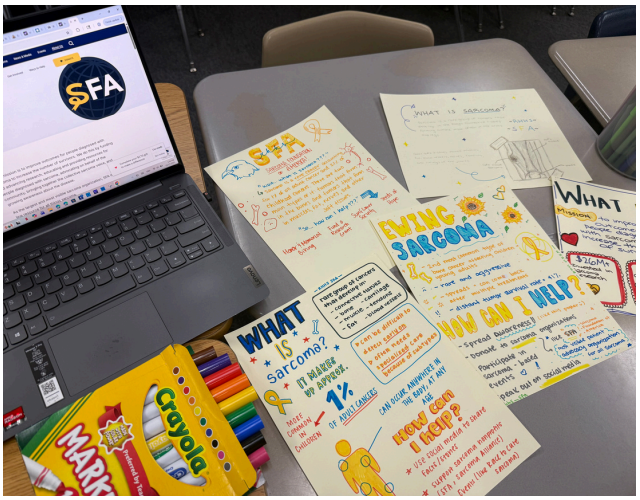
A New Generation of Sarcoma Advocates is Turning Inspiration Into Action



Lily Farnham, a high school junior in Maryland, is part of a new generation of sarcoma advocates who are turning personal inspiration into action. Lily is the founder and president of her school's Sarcoma Foundation of America (SFA) Club – an effort she started in honor of Technoblade, the video creator whose sarcoma diagnosis and death deeply impacted her and others around the world.

"I was first introduced to Technoblade's content during the COVID-19 pandemic after a friend shared his Minecraft videos. He quickly became my favorite YouTuber because of his energy and humor. His vibe was fun and he was such an uplifting spirit," Lily explained. "He did so much for the community, not just gamers but as a whole. When Techno died, I wanted to understand what happened. Learning it was sarcoma led me into researching more about the disease and I eventually discovered Sarcoma Foundation of America."

Her research into sarcoma became a big "why" in her life – why isn't there more awareness, more resources, more funding. Lily is highly involved in clubs at her school and thought starting her own and focusing her efforts towards SFA would be an impactful way to honor Technoblade, raise awareness about the disease, and support the sarcoma community. Working with a teacher sponsor to establish an SFA Club at her school, they became an official club this school year. The club already has nearly 30 students involved who meet regularly to learn about sarcoma, share educational resources, and plan fundraising and awareness activities that support the sarcoma community.



Lily's involvement with the community became even more real last July when she and her family participated in the 2025 Race to Cure Sarcoma in Washington, D.C.

“Attending the race was eye-opening for me,” she shared. “Up until that point, I was learning about it through a screen. At the race, I met patients, survivors, and families whose lives have been directly impacted by sarcoma and how it affected them, and experience that in-person. I’m really glad I got to support the community and the cause.”

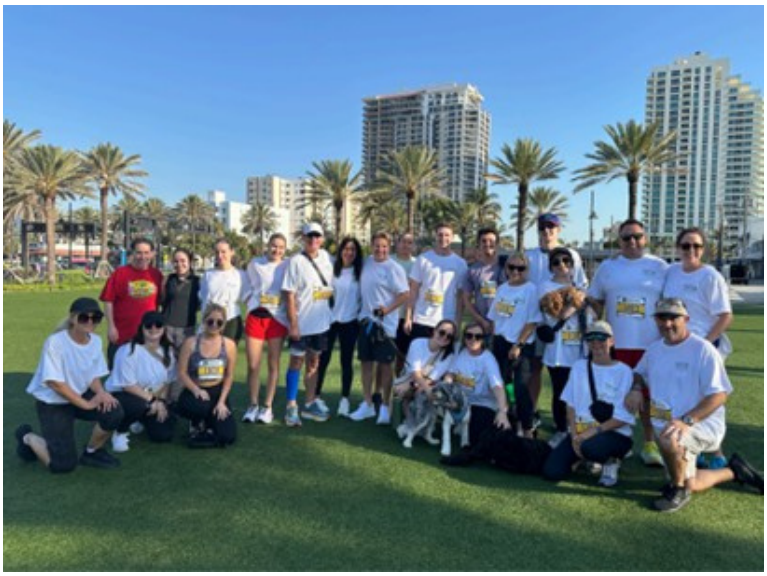
Lily hopes to bring SFA Club members with her to the 2026 Race to Cure Sarcoma Washington, D.C., on July 18th, so they too can experience the impact they are making for the sarcoma community in a more tangible way. Through her leadership and initiative, Lily is turning her “why” into action through helping bring greater awareness of sarcoma into her school community and demonstrating how students can play a meaningful role in supporting research and advocacy efforts.

RACE TO CURE SARCOMA

Why I Race: RTCS South Florida Highlight

By Marli Ehrlich, Committee Member and Team Jaclyn's Team Captain

I race with the Sarcoma Foundation of America South Florida in honor of my sister, Jaclyn. Sarcoma changed my life and my family's life forever, and being a part of this race is a way to keep my sister's spirit present while supporting research, awareness, and progress. This year marks the third annual Race to Cure Sarcoma South Florida. It continues to remind me how powerful a community is when people come together for a cause that truly matters. Racing is my way of honoring her memory while helping create hope for others.



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!

RTCS is coming to a city near you!

- South Florida — 2/7/2026
- Austin — 3/21/2026
- Atlanta — 4/4/2026
- Boston — 4/5/2026
- New York City — 4/25/2026
- San Francisco — 5/9/2026
- Cleveland — 6/20/2026
- Milwaukee — 7/11/2026
- Washington D.C. — 7/18/2026
- Louisville — 8/8/2026
- Philadelphia — 8/29/2026
- San Diego — 9/19/2026
- Chicago — 9/26/2026
- New Jersey — 10/11/2026
- Denver — 10/24/2026
- Los Angeles — 11/15/2026