**MAY 2026**

## Tickets Now Live: Don’t Miss the 24th Annual Stand Up to Sarcoma Gala!

Tickets are now live for the Sarcoma Foundation of America’s 24th Annual Stand Up to Sarcoma Gala! Join us on October 6, 2026, at 583 Park Avenue in New York City for an inspiring evening dedicated to advancing research and improving outcomes for those affected by sarcoma.

This signature event brings together patients, families, and supporters to celebrate progress and honor remarkable leaders in the field. Don’t miss this meaningful night of community, impact, and recognition.

## SFA to Join Global Leaders at ASCO 2026

This month, SFA will attend the American Society of Clinical Oncology (ASCO) Annual Meeting in Chicago, Illinois. As a leading voice in the sarcoma community, our presence at ASCO 2026 will underscore our ongoing commitment to advancing research and improving outcomes for patients. The ASCO Annual Meeting is a premier gathering of the global oncology community, bringing together leading experts, researchers, and patient advocates to share knowledge and drive progress.

Throughout the meeting, our team will connect with patients, care partners, and medical professionals, sharing key resources such as our discussion guide and patient research survey. We will also participate in sessions focused on the latest developments in sarcoma research, helping ensure we remain closely aligned with emerging science and innovation. Our presence at ASCO 2026 will further strengthen our mission to accelerate scientific discovery and advocate for everyone impacted by sarcoma—continuing to move us closer to a future where no one dies from this disease.

## Announcing Our 2026 Compassionate Care Honoree

SFA is proud to recognize Colleen Forbes, RN, as the 2026 Compassionate Care Award honoree, to be celebrated at the 24th Annual Stand Up to Sarcoma Gala this October.

An Orthopedic Certified Registered Nurse at Duke University Hospital, Colleen serves as a Nurse

Navigator on the Orthopedic Oncology team, guiding patients and families through every step of care with personalized support. She is deeply committed to improving access to specialized, multidisciplinary care and ensuring every patient feels seen beyond their diagnosis.

Her impact extends beyond the clinic through her involvement in sarcoma awareness events, including walk/runs, golf tournaments, and patient appreciation initiatives that foster connection and advocacy.

In a patient nomination, one individual writes, ”Colleen is one of those rare individuals who is truly passionate about her work. She goes above and beyond for every patient she encounters. She takes the time to explain everything thoroughly and treats both patients and their caregivers like family. Her commitment, kindness, and unwavering compassion make her truly exceptional."

# Research Roundup

## Highlighted Research

*By Dean Frohlich, PhD*

The first study I would like to highlight this month is an update from a phase II trial of atezolizumab for patients with alveolar soft part sarcoma (ASPS) in “Atezolizumab for Alveolar Soft Part Sarcoma: A Clinical Trial Update.” Atezolizumab is an immunotherapy that “releases the brakes” that cancer cells put on a patient’s immune system and allows type of the patient’s immune cells called T cells to kill the tumor cells. This update covers an additional three years of patient observation.

In all, 53 patients with ASPS received atezolizumab. Median duration of response was revised up to 37.0 months. The overall objective response rate (ORR) was 35.8% and the median progression-free survival (mPFS) was 20.8%. ASPS results from the fusion of two genes, ASPSCR1 and TFE3, but the place in TFE3 where the genes fuse can be different and are called type 1 and type 2 depending on where the fusion is located. The fusion type was determined for 47 of the 53 patients with 41 being type 1 and 6 being type 2. Official comparisons were limited because there were too few patients however, the ORR (43.9%) and mPFS (28.3 months) were better in the 41 patients with the type 1 fusion compared to the the six patients expressing type 2 ORR (0%) and mPFS (7.5 months). More research needs to be done, but these extended results indicate atezolizumab may be useful in treating ASPS.

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Next, in “Trabectedin and low-dose irinotecan to target EWS::FLI1 in Ewing sarcoma: a phase 1/2 trial,” the investigators conducted an open-label phase 1/2 trial of trabectedin with irinotecan in 37 relapsed/refractory patients with Ewing Sarcoma (ES). ES is a bone and soft tissue sarcoma that is reliant on the fusion of two genes (EWS and FLI1). To date, no treatment has been demonstrated to inhibit the resulting fusion protein’s activity in patients. This study investigates whether trabectedin, a chemotherapy that binds to DNA and leads to the death of cancer cells, in combination with low-dose irinotecan, which inhibits a protein necessary for DNA replication can counteract the activity of the fusion protein.

The main goals of the study were to determine if the drug combination is safe, tolerable, the best dosage for future studies, and the objective response rate (ORR). Additional goals included determining the 6-month progression-free survival (PFS). The recommended phase 2 dose for trabectedin was 1.0 mg m−2 over 1 hour (day 1) and for irinotecan was 25 mg m−2 (days 2 and 4) of a 21-day cycle. The toxicities were manageable, the phase 2 ORR was 33%, and 6-month PFS was 48%. These results lay the groundwork for the development of the combination of trabectedin and irinotecan for patients with Ewing Sarcoma.

The investigators of the next study previously found that a different fusion of EWSR1 and ETS in Ewing Sarcoma (ES) is responsible for the expression of a protein abbreviated IL1RAP. The previous studies also indicated that IL1RAP may be a good immunotherapy target in ES. In “IL1RAP antibody-drug conjugates potently target primary and metastatic disease in multiple oncofusion-driven cancers," the researchers tested the efficacy of a type of immunotherapy called antibody-drug conjugates (ADCs) in ES and other gene fusion driven cancers with increased IL1RAP expression. In this case, ADCs link an antibody targeted to IL1RAP to several different drugs toxic to cancer cells to provide a more targeted delivery of the drugs. The results show that the ADCs blocked tumor growth in several nonhuman models of ES and the other cancers. These are early results, but they indicate that IL1RAP-targeting ADCs are a potential drug for IL1RAP expressing cancers including ES.

In the last study, "Multi-layered molecular profiling informs the diagnosis and targeted therapy of desmoplastic small round cell tumor," the investigators examine whether comprehensive molecular profiling can aid in diagnosis and individualized therapy in desmoplastic small round cell tumor (DSRCT), which is an ultra-rare sarcoma with few treatment options. They performed a variety of tests (whole-genome/exome, transcriptome, and DNA methylome analyses) in 30 refractory DSRCT patients and augmented those tests with protein profiling in nine of those patients. They found that in 28 of the patients (93%) received 107 molecular-based management recommendations including 17 patients (57%) who were assessed for clinical trial eligibility. Most recommendations werere informed by overexpression of various proteins including tyrosine kinases, SSTR3/5, and CLDN6. Thirteen patients (46%) received recommended therapies. Although additional studies need to be done, these results show that comprehensive molecular profiling can provide clinically actionable insights for DSRCT patients.

## Clinical Trials Corner

*By Kelley Argraves, PhD*

This month SFA is highlighting SARCO46, a Phase II clinical trial evaluating nab-sirolimus in patients with progressing or symptomatic epithelioid hemangioendothelioma (EHE), a rare vascular sarcoma. This study is currently recruiting at Dana-Farber Cancer Institute in Boston, MA, with additional sites expected to open soon across the United States. The trial is open to adults ages 18 years and older with progressing or clinically symptomatic EHE that requires systemic treatment.

Patients eligible for this trial will receive nab-sirolimus, a targeted therapy designed to block a pathway called mTOR that may help stop tumor growth. The medicine is given as an intravenous (IV) infusion on Days 1 and 8 of each 21-day cycle. Doctors and scientists are trying to determine how effective nab-sirolimus is at shrinking tumors or slowing disease progression in patients with EHE.

The primary goal of this study is to measure tumor response rate. Researchers will also evaluate progression-free survival, duration of response, and safety. There are additional eligibility and exclusion criteria, including measurable disease and minimum organ function requirements. 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 reach out to the study contact. Participating patients in need of additional travel or financial support may apply for assistance from SFA.

## AACR 2026: What We Learned and Why It Matters for the Sarcoma Community

*By Kelley Argraves, PhD*

SFA was proud to attend the 2026 Annual Meeting of the American Association for Cancer Research (AACR), one of the world's leading gatherings for cancer research, innovation, and collaboration.

AACR provides an important opportunity to stay at the forefront of scientific advances, connect with key partners across the cancer ecosystem, including researchers, industry partners, government and regulatory agencies, patients and care partners, and fellow advocacy organizations, and ensure the sarcoma community is represented in conversations shaping the future of cancer care.

*Caileen Coleman and Kelley Argraves at SFA's Booth*

This year, SFA had a presence in the Patient Advocacy Pavilion, where Caileen Coleman connected with patients, advocates, researchers, and industry partners at our booth. Meanwhile, Dean Frohlich and Kelley Argraves attended key scientific and policy-focused sessions and met with current and potential collaborators.

Among the major themes highlighted at AACR 2026 were advances in artificial intelligence (AI), circulating tumor DNA (ctDNA), immunotherapy, and antibody-drug conjugates (ADCs), all areas that have implications for the sarcoma community. We also saw the growing role of patient advocacy in research, clinical trial design, and regulatory discussions involving the FDA and NCI.

AACR is more than a scientific meeting, it is where future trends in cancer research, treatment, and policy begin to take shape. SFA's presence helps ensure the sarcoma community is represented in those conversations.

## New Study Results Offer Hope for People Living with TGCT

*By Kelley Argraves, PhD*

A new study has shown encouraging results for people living with tenosynovial giant cell tumor (TGCT), a rare tumor that can cause pain, limit movement, and damage joints. SynOx Therapeutics announced that its investigational treatment, emactuzumab, helped shrink tumors and improve symptoms in patients whose tumors could not be removed with surgery. Patients in the study also reported improvements in physical function and other quality-of-life measures.

Unlike some currently available treatments that require ongoing therapy, emactuzumab is being studied as a short-course treatment designed to provide lasting benefit. These results are especially meaningful because TGCT is often described as "benign," even though it can have a serious impact on daily life. For many people, surgery is not possible or may not fully resolve the problem.

The company plans to seek regulatory approval in 2026. If approved, emactuzumab could become a new treatment option for people living with TGCT.

## Coming Soon at ASCO 2026: New Data in Dedifferentiated Liposarcoma

We’re excited to attend the 2026 ASCO Annual Meeting, where Mark A. Dickson of Memorial Sloan Kettering Cancer Center will present new Phase 3 data on advanced dedifferentiated liposarcoma during a plenary session on May 31.

The presentation will highlight results from a Phase 3 clinical trial studying abemaciclib, a targeted therapy being evaluated for patients with advanced disease, an area where better treatment options are greatly needed.

Members of the Sarcoma Foundation of America team will attend ASCO and are looking forward to this and other exciting presentations related to sarcoma research and care.

Stay tuned for our June newsletter, where we’ll share more about the results presented at ASCO and what they may mean for patients and families.

# Advocacy and Engagement

## Stand Up for the Sarcoma Community at Advocacy Weekend

Now more than ever, the sarcoma community needs to unite and advocate for change. With the current administration proposing cuts to vital programs that support sarcoma research and patient care, it's crucial to make our voices heard.

Join SFA in Washington D.C. this July for our Advocacy Weekend. This impactful weekend will include:

**Sarcoma Community Advocacy Day:** Meet with elected officials to share your story and advocate for increased research funding and improved access to care for sarcoma patients.

**Education Day:** Learn about the drug development process and how advocacy plays a vital role in making new treatments accessible to sarcoma patients.

**Race to Cure Sarcoma:** Join us for our premier run/walk event, raising awareness and funds for sarcoma research.

**Register for Advocacy Weekend**

## Listen to the Latest Episodes of 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 10 I Pan Pantziarka

On this episode, we speak with SFA Director of Europe's Strategy and Engagement, Pan Pantziarka. While he is an incredible staff member at SFA who supports SFA's global work, he also has a sarcoma story of his own as a care partner to his son, George.

After George was diagnosed with three different primary cancers and passed in 2011, Pan quit his job in the corporate sector and found work in oncology. He is committed to making a difference using everything he can - scientific training, advocacy, and demand for change.

He speaks to us today about rare cancer predispositions, such as Li Fraumeni Syndrome, the story of George and his mother, why knowledge is power, and where he finds hope.

### Season 2 Episode 11 I Natasha Nathan

On this episode we're the sarcoma story of one of our Sarcoma Stories hosts, Tasha. Tasha has been hosting Sarcoma Stories since its inception in November 2024 and she's now sharing her story about her Embryonal Rhabdomyosarcoma diagnosis.

We also talk about some of the transitions happening at SFA with Tasha's role as she embarks on a new endeavor, starting her program - Move Anyway - while welcoming Katie Wintergerst to the podcast as co-host.

**Listen to all episodes**

# SFA News

## SFA Joins DTRF Ambassador Meeting to Highlight Patient Advocacy in Drug Development

SFA was pleased to participate in the Desmoid Tumor Research Foundation (DTRF) Ambassador meeting held in April, where CEO Brandi Felser spoke with advocates about the evolving role of patient engagement in drug development.

The meeting brought together a highly engaged group of DTRF Ambassadors, whose commitment to advancing research and supporting patients continues to be both impactful and inspiring. A highlight of the session was hearing from Zoey Morris, who co-led the meeting and shared her personal journey. Her perspective was a powerful reminder of the importance of patient voices in shaping research and care.

We are grateful to the DTRF team for the opportunity to participate and look forward to continued collaboration to strengthen patient advocacy across the sarcoma community.

# In the Community

## Learning to Live After Learning to Survive.

*By Rohini Deivasigamani*

When I was diagnosed with Stage 1 Ewing's sarcoma at 14, I remember genuinely having no emotion. It didn't make sense to me, and I didn't know

what was really coming—it almost seemed fictional, like I was being pranked. We had no family history of cancer, and I was extremely healthy and athletic, so the diagnosis felt entirely wrong and disconnected from what I thought the growing bump on my right calf was.

Looking back, though, weirdly, I took the diagnosis okay because I was the one consoling my family and reassuring everyone I would be fine, even though I had zero understanding of what cancer truly was. Ironically, I had been crying over very minimal hair loss just a few months prior to my diagnosis, yet I faced the reality of losing my entire head of thick, long black hair with sheer bravery.

Of course, my journey with sarcoma wasn't easy. There were tough decisions to make, like whether to go with radiation or surgery, if I could complete all 13 rounds of chemo, and if I could continue my education.

I was an incredibly determined and optimistic child, though. I always kept my head held high and pushed through unimaginable challenges with grace. I tried my best not to let this disease define me or stop me from achieving my goals.

However, it truly did get a little harder as I got older—both emotionally and physically. My father was also diagnosed with cancer and passed away a few months after I finished treatment. His death was a huge hit for me because it was the first time I looked at cancer differently. I experienced waves of survivor's guilt as the months of bereavement went by, but I couldn't verbalize what I was feeling at the time.

High school, inevitably, only got harder, and the pressure became more real. I tried my absolute best to conquer whatever I could despite the challenges I faced, knowing it was okay if I didn't achieve everything. Another difficult reality I had to accept after having cancer was that things would be harder for me. The reality of cancer and its consequences, coping with the loss of a parent, and navigating mental health challenges often had to be put on the back burner so I could focus on getting an A in calculus or achieving a strong SAT score—because at the end of the day, those numbers mattered for my college applications and future.

But I think that's the part that hurt the most—having to endure deeply painful life experiences at such an early age while still being expected to move forward and "do life."

Perhaps other patients and survivors can relate to this, but the stark difference in my behavior over something as trivial as hair before and after defined what was real fear versus imagined fear—and how quickly life can force you to grow into a version of yourself you never knew existed. And in many ways, that version of me is still learning how to live after learning how to survive.

## 3rd Annual Big Heart Fest Returning to Chicago

You are cordially invited to join us in Chicago in June! We are eagerly preparing for the 3rd Big Heart Fest in memory of John W. O'Brien. John passed away from Chondrosarcoma in July 2022 after a 4-year battle.

Big Heart Fest is a music festival featuring 8 live bands, plus fun live and silent auctions. Big Heart Fest celebrates Big Johnny O'Brien's Big Heart, for which he was known far and wide.

His kindness was legendary. He loved a great party and even better music, with family, friends and perhaps a pint of Guinness!

Saturday, June 13, 2026
4:00pm – 10:00pm
Chief O'Neill's Irish Pub
3741 North Elston Avenue
Chicago Illinois 60618

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## 2026 Scott Lively Memorial Charity Golf Tournament

This August, the 5th Annual Scott Lively Memorial Charity Golf Tournament returns to Bear's Best Golf Course in Atlanta, Georgia. Hosted by Scott's family and friends, the event honors Scott Lively's incredible strength and positive spirit as he faced Ewing sarcoma and later bone cancer.

Bringing together golfers and supporters, the tournament celebrates his legacy while raising funds to improve outcomes for those diagnosed with sarcoma. Participants can register to play or make a tribute gift in his memory.

Saturday, August 1, 2026
Bear's Best Atlanta
5342 Aldeburgh Dr
Suwanee, GA 30024 US

# Race to Cure Sarcoma

## Why I Race: Jenna Rogalinski, RTCS Milwaukee

Why do I race? My gut answer—to continue to fight. For 3.5 years now, I have had no evidence of disease after a grueling 2022 filled

with chemotherapy, radiation, and surgeries to combat my retroperitoneal leiomyosarcoma.

Survivorship is a complicated place to be. You're "healthy," but are you really? You still have scans a few times a year and some side effects from treatment never seem to go away. In the haze of young survivorship, it can be difficult to find direction. During treatment, my sole focus was survival. Once cancer-free, I yearned for a place to focus my intensity and drive.

SFA and the RTCS give me an outlet for my passion. Sarcoma is not defeated. We need improved sarcoma treatment, which comes from funding research. The RTCS was a heartwarming refuge for me during active treatment, and every year since, the Milwaukee community welcomes me with open arms and reminds me why I advocate and fundraise.

## 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

**RTCS**
**San Francisco**

5/9

**Register**

**RTCS Boston**

5/17

**Register**

**RTCS Global Virtual**

*Participate Anytime*

**Register**

**2026 Marine Corps Marathon**

10/25

**Join Team**

**2026 Philadelphia Marathon Weekend**

11/20 - 11/22

**Join Team**