August 2026

More Than Awareness

By Brandi Felser, CEO

This past Sarcoma Awareness Month was a special one.

We came together not only to raise awareness about sarcoma, but to strengthen and celebrate our community. People from all over the world participated, and as strange as it may sound, I felt more connected to the sarcoma community than ever before. Even though we were spread across continents and time zones, the world somehow felt a little smaller.

But we did more than raise awareness. We took action.

Together, we made sure our voices were heard on Capitol Hill, where decisions are made that can have life-changing and life-saving impacts for people affected by sarcoma and other rare cancers. Our advocacy community grew, and many familiar faces returned for Advocacy Weekend. We held more meetings, built more relationships, and shared more stories than ever before.

During Education Day, we learned about the drug development process and explored the barriers that continue to slow progress in sarcoma research and treatment. We heard perspectives from patients, researchers, industry leaders, and government agencies, and discussed how advocates can work alongside the FDA, NCI, DOD Congressionally Directed Medical Research Programs, industry partners, and members of Congress to create meaningful change. We then closed out the month by coming together at the National Race to Cure Sarcoma.

By every measure, Sarcoma Awareness Month 2026 was a success. But that is not what stays with me. What stays with me are the stories.

I had the privilege of partnering with two advocates as we met with members of Kentucky's congressional delegation and their staff. Both had lost a child to sarcoma. They shared the challenges they faced seeking specialized care, the limitations of available treatments, the financial burden of traveling out of state, and the obstacles of navigating insurance coverage while trying to secure the best possible care for their loved one.

Their stories echoed so many others that were shared throughout the weekend. One advocate, who attended our very first Advocacy Weekend and continues to join us year after year, spoke about the many surgeries he has endured throughout his sarcoma journey. Every story moved me. Every journey left an impression. Every person carried a

reason for being there, a deeply personal "why."

And I carry those stories with me, alongside my own and alongside the countless stories I have heard from members of our community around the world.

At the National Race to Cure Sarcoma in Washington, D.C., we celebrated survivors as we do at every Race to Cure Sarcoma event. I had the honor of calling their names as they were recognized. I met survivors, family members, and friends. I listened to pieces of their journeys and told them I looked forward to seeing them again next year, and every year after that. A few days later, I received an email from one of the survivors.

I saw it shortly after it arrived, but I wanted to take time to reflect on it before responding because I was deeply humbled by the words she shared.

In part, she wrote:

"As a survivor, I know what it means to have people who show up for this community with care and persistence. The passion you bring to this work is not lost on those of us who have lived it. You are helping people feel less alone, and you are helping to save lives."

I shared the email with my family and sat with it for some time before responding. Her words meant more than I can adequately express.

Because the truth is, I sincerely hope that everyone affected

by sarcoma feels less alone, not just during Sarcoma Awareness Month, but every day of the year. I hope our community knows there are people, many people, who are committed to improving outcomes and supporting patients and families through every stage of the journey.

I am simply one of many who have the privilege of being part of that effort. I do not take that responsibility lightly.

Every conversation, every story, and every person I meet reminds me of what is at stake and why this work matters so much. Meeting patients, survivors, caregivers, family members, researchers, medical professionals, and advocates is both inspiring and grounding. Their strength, perseverance, and perspective are powerful reminders of why we continue pushing forward.

The truth is that this community has given me far more than I could ever give back. I have had the privilege of knowing extraordinary patients, survivors, caregivers, researchers, medical professionals, and advocates whose courage and determination inspire me every day.

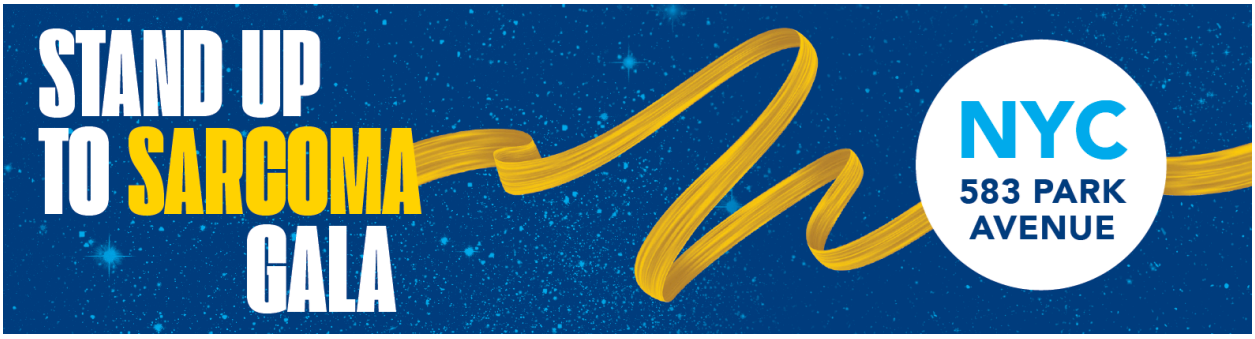
Thank you for sharing your journey with me and SFA. Thank you for lending your voice, your story, and your reason for showing up. Whatever your "why" may be, you help make this community stronger.

As we look ahead, I hope you'll join us at our Stand Up to Sarcoma Gala. It is more than a fundraiser. It is an opportunity to come together, celebrate progress, honor those we have

lost, recognize the strength of survivors, and deepen the connections that make this community so special. It is a chance to stand alongside others who understand this journey and recommit ourselves to the work that still lies ahead.

Together, we will celebrate. Together, we will remember. And together, we will continue creating the change that people affected by sarcoma deserve.

Join us at the Stand Up to Sarcoma Gala!



The 2026 Stand Up to Sarcoma Gala will be held on Tuesday, October 6th from 6:00PM to 10:00PM at 583 Park Avenue in New York City.

Join us for an unforgettable evening of inspiration and impact as we recognize extraordinary individuals and organizations who are advancing the sarcoma community through advocacy, compassion, and innovation in science and

research.

The gala will feature an elegant evening of dining, entertainment, and powerful stories from those whose lives have been touched by sarcoma. Together, we will honor the strength of survivors, remember loved ones, and raise essential funds that accelerate research and provide support for patients everywhere.

Celebrating a Courage Award Honoree

The SFA Courage Award honors individuals who illustrate outstanding commitment to sarcoma advocacy through their personal efforts and actions. Honorees include patients, survivors, care partners, and advocates who have demonstrated strength and perseverance throughout their personal experience with a sarcoma journey. By using their voices and platforms to raise awareness, these individuals are making a meaningful difference for sarcoma patients, survivors, their families, and the sarcoma community.

This year, we are proud to honor **Jerry Glisch**, whose unwavering dedication to the sarcoma community exemplifies the spirit of this award. As a sarcoma survivor, advocate, and dedicated member of the Race to Cure Sarcoma Milwaukee committee since 2017, Jerry has elevated awareness by securing valuable

media coverage while also generating critical funding to advance much-needed sarcoma research. His commitment is making a meaningful difference for patients and families affected by this rare cancer.

Don't miss this special night of celebration, purpose, and community. Your support and presence help fuel our mission and bring us one step closer to finding a cure for sarcoma. Reserve your seat today before it's too late and join us in celebrating Jerry and all our outstanding honorees!

Support the 24th Annual Stand Up to Sarcoma Gala: purchase tickets, sponsor, donate, or place a program ad today.

Research Roundup

FDA Accepts NDA for Varegacestat in Adults with Progressing Desmoid Tumors

The U.S. Food and Drug Administration (FDA) has accepted the New Drug Application (NDA) for varegacestat, an investigational oral gamma secretase inhibitor, for the treatment of adults with progressing desmoid tumors.

The NDA is supported by results from the Phase 3 RINGSIDE trial, the largest randomized study conducted in patients with progressing desmoid tumors. Patients receiving varegacestat

experienced significant improvements in pain, with benefits observed as early as four weeks and a median tumor volume reduction of 83%.

What this means for patients: FDA acceptance of the NDA means there is a potential new treatment option for adults with progressing desmoid tumors. If approved, it would expand the available treatment options for patients living with this rare disease.

Highlighted Research

By Nigel Brockton, PhD

We do not often highlight review articles in our newsletter, but review articles are an important way for researchers to "take stock" of the current research and focus attention on important issues or gaps in research. In the first paper highlighted below, the authors contrast the research on how cancers spread. Focusing on the differences between sarcomas and more common types of cancer can provide valuable insights into disease control and therapeutic priorities.

Sarcomas are Different

Sarcomas arise from mesenchymal cells which form the body's connective tissues like bone, muscle, fat, and cartilage and account for only ~1% of overall cancer cases. Carcinomas arise from epithelial cells lining body surfaces and internal organs and include the most common types of cancer such as lung, breast colorectal and prostate cancer. The vast majority of global cancer research is focused on cancers arising from epithelial origins and the recent review by Chevalier and colleagues highlights that many insights and assumptions, derived from research on carcinomas, cannot be directly applied to sarcomas, particularly when attempting to understand how and when sarcomas can spread (metastasize) In addition, the diversity of sarcoma subtypes mean that even when this distinction between cells of origin is acknowledged, there is no “one-size-fits-all” solution to understanding sarcoma metastasis. Focusing on the unique biology of sarcoma subtypes may offer an opportunity to identify potential vulnerabilities to targeted treatment approaches.

Sarcoma metastasis: distinct biological principles beyond the carcinoma paradigm. Chevalier et al. Cancer Metastasis Reviews, 2026 Jul 20;45(3):48. https://doi.org/10.1007/s10555-026-10360-z

Molecular Trapping

The second publication highlights the potential vulnerability of Ewing sarcoma to Cyclin-dependent Kinase 8 (CDK8) inhibition. Ewing sarcomas are driven by a characteristic chromosomal defect, the EWSR1::FLI1 chromosomal

translocation. This defect creates a fusion protein that drives gene expression and tumor formation. McGinnis and colleagues conducted high-throughput screening of a library of small molecules in patient-derived Ewing sarcoma cell lines. Several of the active molecules were similar to known Cyclin-dependent Kinase 8 (CDK8) inhibitors. CDK8 inhibition is a promising therapeutic target for a range of common malignancies, with several investigation drugs currently being evaluated Further probing of the mechanisms responsible revealed that these CDK8 inhibitors exerted their effect on the proliferation by “trapping” the gene expression machinery on the DNA. Gene expression requires alternating cycles of binding and release of this cellular machinery, so by trapping the expression machinery, the genes activated by the rogue machinery are silenced. Although this research is at an early phase, the targeting of the CDK8 inhibitors to the EWSR1::FLI1 gene expression could offer a novel therapeutic vulnerability for the treatment of Ewing sarcoma.

CDK8 inhibition induces Mediator trapping and impairment of the EWSR1::FLI1 transcriptional program in Ewing sarcoma. McGinnis et al. (2026) In press.
https://pubmed.ncbi.nlm.nih.gov/42447057/

Clinical Trials Corner

By Kelley Argraves, PhD

This month, SFA is highlighting URSa-1, a Phase II clinical trial evaluating pembrolizumab in adults with five ultra-rare sarcoma subtypes: pleomorphic liposarcoma, perivascular epithelioid cell tumor (PEComa), epithelioid sarcoma, CIC-rearranged sarcoma, and sclerosing epithelioid fibrosarcoma/low-grade fibromyxoid sarcoma. The study is sponsored by Memorial Sloan Kettering Cancer Center and is currently recruiting at Memorial Sloan Kettering locations in New York and New Jersey.

Pembrolizumab is an immunotherapy that blocks PD-1, a protein that normally helps keep the immune system from becoming overactive. By blocking PD-1, pembrolizumab may help immune cells recognize and attack cancer cells. Participants receive pembrolizumab through an intravenous infusion once every six weeks for up to eight treatment cycles, provided the disease does not progress and the treatment does not cause unacceptable side effects. Imaging and blood samples will be collected throughout the study to monitor response and explore how the immune system responds to treatment.

The primary goal of the study is to determine whether pembrolizumab shows activity against these ultra-rare sarcoma subtypes. Researchers will evaluate tumor response at 12 weeks, along with treatment safety and other signs of clinical activity. The study will also examine whether immune markers measured in blood and features identified through imaging may be associated with treatment response.

Eligible participants must be 18 years of age or older and have one of the included sarcoma subtypes that is recurrent or metastatic and not considered curable by other means. Participants must have measurable disease and generally must have experienced disease progression following one to three prior lines of treatment. Patients who have previously received PD-1, PD-L1, PD-L2, or certain other immune-checkpoint therapies are not eligible. Additional eligibility requirements related to prior treatments, overall health, organ function, and medical history also apply.

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 need travel or financial support to do so, you may apply for assistance from SFA.

SFA Global

New Drug Approval Framework in UK?

The traditional model of drug development leads from pre-clinical studies in a lab, to animal studies, to early phase studies where the drug is tested on people to see if it's safe, then to see if it's effective and finally to large, randomised trials where it is compared to an alternative to see if it leads

to improved outcomes. It's a model that has produced tremendous advances in many diseases, including many cancers. However, it's a model that doesn't work so well for rarer diseases, including most sarcomas. When patient numbers are low, where the commercial returns are unclear or where the understanding of disease biology is poor, the standard path often leads nowhere. These problems are well-known to the patient community, to doctors and researchers, and increasingly they are being recognised by medicines regulators like the FDA, the European Medicines Agency (EMA) and others.

The SFA, as part of the PUSH (Pushing Ultra-rare Sarcomas beyond Hope) consortium, has engaged with both the FDA and the EMA on these issues. At the EMA a number of workshops on ultra-rare sarcomas have been conducted where key issues, such as trial design, the use of real-world data and trial end-points have been explored. The ultimate goal of these processes, as with the standard drug development path, is to get drugs for sarcomas approved and made available to the patients that would benefit.

The Medicines and Healthcare products Regulatory Agency (MHRA) is the UK regulator, and it too has been looking at this issue of how to get drugs approved for rarer diseases. The solution it has proposed is called The Rare Disease Therapies Regulatory Framework, and the heart of it is a new form of drug approval called the Investigational Marketing Authorisation (IMA). This combines approval of the drug to be

administered to patients with aspects of a clinical trial and continuous data collection. Periodic reviews are part of the process, so the regulators are checking the efficacy and safety of the drug as part of the IMA, as well as enabling scientific advice and other feedback mechanisms to guide the development. Eventually, as the data matures and the benefits are confirmed the IMA can lead into a standard drug approval.

In terms of evidence generation, the proposal emphasises patient-centricity, openness to innovative study designs and the use of real-world evidence. The approach is explicitly more flexible than the standard development pathways that apply in more common settings.

In many respects this corresponds to some of the things that PUSH is doing in its studies – continuous data collection, learning from every patient, early and regular interactions with regulators. The IMA and PUSH approaches are complementary – both are addressing the same underlying issues and coming up with similar strategies to reach the same ultimate end. At the moment the IMA is still at the proposal stage, so we have to wait to see whether it moves to implementation – for us at the SFA it represents a clear advance that other regulators should be taking note of.

Advocacy and Engagement

SFA Expands Its Public Policy Advocacy for the Sarcoma Community

By Kelley Argraves

Public policy decisions can directly affect sarcoma research, access to testing and treatment, clinical trial opportunities, and the development of new therapies. In recent months, the Sarcoma Foundation of America has increased its engagement with federal agencies to ensure that the needs of people affected by sarcoma are represented as these policies are developed.

SFA submitted comments to the Centers for Medicare & Medicaid Services regarding prior authorization requirements for medically necessary laboratory and biomarker testing. For people with sarcoma, timely testing may be essential to confirming a diagnosis, selecting treatment, monitoring disease, and identifying clinical trial opportunities. SFA urged CMS to prevent timing-based denials and unnecessary repeat testing, establish expedited review pathways for time-sensitive oncology testing, allow appropriate retroactive

authorizations, and protect patients from financial liability when delays result from administrative processing issues beyond their control.

SFA has also worked at the state level to protect access to biomarker testing. In Maryland, where state law requires coverage of medically necessary biomarker testing, SFA joined more than 35 advocacy organizations in calling on insurers to comply fully with the law. SFA also sent an action alert to members of the Maryland sarcoma community explaining how to report delays or denials and raise concerns about enforcement of these patient protections.

SFA also responded to the Food and Drug Administration's request for information on drug repurposing. Because many sarcoma subtypes have few or no specifically approved therapies, evaluating existing medicines for new uses may offer an important route to expanding treatment options. SFA encouraged the FDA to prioritize rare cancers and consider evidence from investigator-initiated studies, academic research, patient registries, natural-history studies, multi-institutional collaborations, and real-world data—particularly when conventional large clinical trials are not feasible. SFA also emphasized the importance of involving patients, clinicians, researchers, and disease-specific advocacy organizations in identifying promising opportunities.

In a separate submission supporting the Haystack Project citizen petition, SFA encouraged the FDA to adopt scientifically rigorous but appropriately flexible approaches to

evidence generation in rare and ultra-rare diseases. The comments highlighted innovative trial designs, external controls, natural-history comparisons, real-world evidence, and outcomes that reflect what matters most to patients. SFA made clear that regulatory flexibility does not mean lowering standards for safety or effectiveness; rather, it recognizes that strong evidence may need to be generated differently when patient populations are extremely small and biologically diverse.

SFA also commented on proposed revisions to federal grant regulations. The Foundation urged the Office of Management and Budget to preserve independent, merit-based scientific review; maintain stable and predictable support for ongoing research; protect the research infrastructure that rare cancers depend upon; and avoid policies that could unnecessarily limit international scientific collaboration. Rare cancer research often relies on long-term studies, patient registries, tissue repositories, shared data resources, clinical trial networks, and collaboration across institutions and countries. Disruptions to this ecosystem can delay research progress and the development of new treatments.

These federal policy efforts are complemented by SFA's annual Advocacy Weekend. Advocates receive education about research, drug development, access to care, and the policymaking process before bringing the priorities of the sarcoma community directly to congressional offices. Together, regulatory engagement and grassroots advocacy

help ensure that the perspectives of patients, caregivers, clinicians, researchers, and advocates inform decisions that shape the future of sarcoma care.

Through this growing body of work, SFA is advocating for policies that reduce barriers to care, strengthen rare cancer research, encourage innovation, and accelerate the development of better treatments for people living with sarcoma.

Listen to the Latest Episode of Sarcoma Stories Podcast

Season 2, Episode 16 I Ken Cleary

Ken Cleary, an angiosarcoma survivor and amputee. Ken describes the journey to diagnosis, how he made the decision to go forward with an amputation as his frontline treatment, and how he has adapted to life afterward. Ken's reflections on his experience are honest and inspiring - his perspective both grounding and motivating.

Of the many topics we discuss, we talk at length about the trust Ken put in his care team while making extremely difficult decisions, and how they have helped him through more than just his treatment. His team made such a profound impact that Ken nominated his nurse, Colleen Forbes, to receive SFA's 2026 Compassionate Care Award, which she will be honored with at the 2026 Stand Up to Sarcoma Gala in October.

SFA News

Join Our Team!

SFA is growing our team, and we're looking for passionate, dedicated individuals who want to make a meaningful impact for the sarcoma community.

We're currently hiring for several positions:

- Director of Engagement and Advocacy
- Engagement and Advocacy Program Manager
- Fundraising Events Manager
- Finance and Administration Manager

Whether you're passionate about advocacy, community engagement, fundraising, or nonprofit operations, there's an opportunity to put your skills toward a mission that matters.

Explore all of our current openings and learn more about each position and how to apply here.

Create Your Estate Plan During Make-A-Will Month

Have you been putting off creating or updating your will? August is National Make-A-Will Month – a perfect opportunity to take an important step in planning for your future and gaining peace of mind for yourself and your loved ones.

Including the Sarcoma Foundation of America in your estate plan is a meaningful way to leave a lasting legacy for the sarcoma community. Through planned giving, you can help advance critical sarcoma research, support patients and families, and contribute to a future where no one dies from sarcoma. Planned gifts may also offer valuable tax and financial benefits while helping you achieve your long-term goals.

This Make-A-Will Month, we invite you to set aside time to create or update your legal will and consider how your legacy can make a difference for generations to come. Visit our website for information on planned giving.

This message is for informational purposes only, and is not intended to provide, and should not be relied on for, tax, legal or accounting advice. You should consult your own tax, legal and

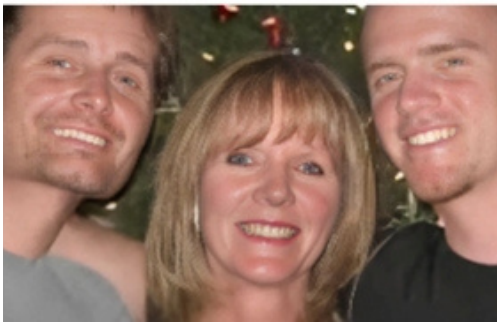
accounting advisors before engaging in any charitable giving plan.

In the Community

Our Hearts Beat for Sarcoma

On July 25, Jordan Farrell hosted a Zumba masterclass benefiting RTCS North Carolina in partnership with the Duke Cancer Institute. Inspired by her mother's journey with leiomyosarcoma, the event brought the community together and raised $1,200!

Scott Lively Memorial Golf Tournament



Hosted by Scott Lively's friends and family, this memorial golf outing took place on August 1, at Bears Best Atlanta. The community celebrated Scott's legacy while raising funds to improve outcomes for those diagnosed with sarcoma.

Mitch Kurtz Memorial 2nd Annual Hockey Game

Friends and family of Mitch Kurtz came together on August 1 at Inwood Ice Arena in Joliet, Illinois, for a memorial hockey game to honor Mitch's life, celebrate his memory, and raise awareness for leiomyosarcoma.

Allison's Beer Mile 2026

Allison’s Beer Mile returned on August 1 in Gridley, Illinois, with a run and walk benefiting SFA in honor and celebration of the life of Allison McKey.

Race to Cure Sarcoma

Why I Race: Helen Johnson, RTCS North Carolina

Helen Johnson identifies as a New Yorker and a North Carolinian, a coffee lover and a dessert enthusiast, an insanely proud wife to Conor and lucky mom to Nell and May, and a cancer survivor. She began experiencing tenderness in her left ankle in 2023, during the third trimester of her pregnancy with Nell.

After many doctor's visits, x-rays, and MRIs, plus a second pregnancy with May, she was diagnosed with myxofibrosarcoma in August 2025. On September 5, 2025, she underwent surgery to remove the lower part of her leg.

Since then, she's been cancer-clear and hyper-focused on her recovery, acclimating to life with a prosthesis, and trying to practice gratitude for every step and every toddler snuggle. She is forever indebted to her incredible care team with her doctor at the helm—whom she considers life-saver, genius, and friend for life.

Race to Cure Sarcoma North Carolina is One Month Away!

We're excited to welcome the North Carolina sarcoma community to the 1st Race to Cure Sarcoma North Carolina on September 13 at WakeMed Soccer Park in Cary, presented in partnership with Duke Cancer Institute.

Whether you're walking in honor of a loved one or yourself, celebrating a survivor, remembering someone you've lost, or supporting the search for better treatments, your participation helps fuel lifesaving sarcoma research and brings our community together.

There is still time to register, start a team, join an existing team, or show your support. Every participant and every dollar raised helps move us closer to better outcomes for everyone affected by sarcoma.

We can't wait to see our newest Race to Cure Sarcoma community come together this September. Register today and be part of this exciting first race!

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

- Louisville (8/8)
- Philadelphia (8/29)
- North Carolina (9/13)
- San Diego (9/19)
- Chicago (9/26)
- New Jersey (10/11)
- North Carolina (9/13)
- Denver (10/24)
- Los Angeles (11/15)