SFA SARCOMA FOUNDATION of AMERICA

SARCOMA SPOTLIGHT

September 2025

Everyone Should Have Their Best Chance

By Brandi Felser, CEO

At a recent Race to Cure Sarcoma event, one of the speakers, Michelle, a 20-year sarcoma survivor, shared her sarcoma journey. She talked about having to travel to a sarcoma center that was not close to home and uproot her family for long periods of time because, in her words, "this would give me the best chance to live." She recognized that not everyone is able to do that and said she is a "lucky one." But what she said next resonated so deeply with me, her words reflecting exactly what is at the heart of SFA and our passion to create change.

To paraphrase, she said, everyone deserves to have access to their best chance. They should not have to uproot their lives, abandon their careers, lose their homes, travel far away from their support systems, and every reason they have to keep going in order to receive lifesaving care. We know that outcomes are better when people are treated at a sarcoma specialty care center. It is estimated that less than 20% of people diagnosed with sarcoma are treated at one. But that is not a stand-alone issue.

In July as part of Sarcoma Awareness Month, SFA hosted the Sarcoma Community Advocacy Day. Sarcoma advocates from around the country met with their representatives on Capitol Hill to share the unique challenges of a sarcoma cancer journey. Accurate and timely diagnosis, access to sarcoma centers and equitable healthcare, investment in research and new therapies are all necessary to improve outcomes for people diagnosed and living with sarcoma. While approval for new sarcoma treatments has increased, we are still too far behind. And one of the most persistent challenges is the regulatory processes in place that affect rare cancers with small patient populations, like sarcoma. Twenty-five years ago, our Founders worked to change regulatory pathways for second line treatments. And they succeeded. But we have more to do.

Michelle ended with, "I see a future where everyone has access to expert sarcoma treatments close to home, where doctors have access to the knowledge and resources that they need, and where research will continue to unveil more tolerable treatment programs with less risk of mortality than newer complications and side effects so people can actually survive this thing." As I stood on the stage listening to this thoughtful sharing of a personal sarcoma journey and her vision for the future, I found myself wanting to jump up and down, literally, in agreement. These words could not better reflect SFA's mission, or my personal passion for leading SFA.

SFA's mission is to improve outcomes for people diagnosed with sarcoma. For twenty-five years SFA has been advancing that mission. SFA's roots are in funding and advancing translational research, building a pipeline of researchers, advocating for increased research funding, advancing public policies that ensure more and better treatment options and access to those options, patient advocacy that amplifies the voices of patients and supports them along their sarcoma journey, and raising awareness about sarcoma so everyone diagnosed with sarcoma has access to their best chance to live.

As we reflect on the activities of Sarcoma Awareness Month- Sarcoma Advocacy Weekend, Light Up for Sarcoma, Wear Yellow Day, and others- it is important to remember that every action taken has helped lay the groundwork for something bigger: improving outcomes for people diagnosed with sarcoma and increasing the number of survivors, ensuring lasting change, and finding the cure in our time.

Lasting change requires sustained commitment. SFA has been committed to leading change for the sarcoma community for twenty-five years, and we are not going anywhere. But your voice and support remain essential.

We are one community, with many voices, taking real action, and creating lasting change – let's continue to move forward with purpose and power, for progress. And so everyone has their best chance to live. Thank you for joining us in this movement.

This month, SFA is honoring and raising awareness of the unique needs of our pediatric sarcoma community. Founded 25 years ago by the family of a child diagnosed with sarcoma, SFA continues its mission to fund vital research, advocate for policies that prioritize sarcoma, and provide resources for families facing this rare cancer.

Behind Every Statistic Is a Child and Their Loved Ones
Sarcomas represent 15–21% of all childhood cancers, yet treatment progress has remained limited for decades. Children often face fewer clinical trials and treatment options, and even when treatment is successful, many survivors live with long-term health challenges that affect their futures and the lives of those who love them. These realities are why Childhood Cancer Awareness Month matters and why SFA has made pediatric sarcoma a priority since our beginning.

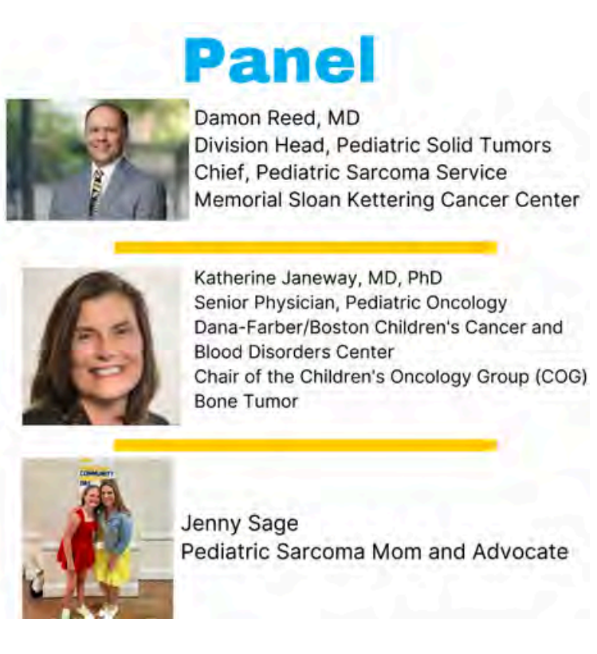
Join us to recognize CCAM This September

- **Wear Gold Day – September 18**: Post a photo with #WearGoldDay, #pediatricsarcoma, and #curesarcoma to show your support.

- **Pediatric Sarcoma Webinar – September 24, 5–6 PM ET**: Learn about the unique challenges of pediatric sarcoma care.

SARCOMA EDUCATION SESSION *with the experts*

Pediatric Sarcoma Subtype Series



Panel

Damon Reed, MD
Division Head, Pediatric Solid Tumors
Chief, Pediatric Sarcoma Service
Memorial Sloan Kettering Cancer Center

Katherine Janeway, MD, PhD
Senior Physician, Pediatric Oncology
Dana-Farber/Boston Children's Cancer and Blood Disorders Center
Chair of the Children's Oncology Group (COG) Bone Tumor

Jenny Sage
Pediatric Sarcoma Mom and Advocate

Join us as we launch our new pediatric webinar series! This informative webinar will explore the key differences between pediatric and adult sarcomas, including treatment options and the impact of receiving care at a dedicated sarcoma center versus a children's hospital.

Wednesday, September 24,
5:00PM -06:00PM ET

This session is designed for patients, families, caregivers, and healthcare professionals interested in understanding pediatric sarcoma care.

Register

23rd Annual Stand Up to Sarcoma Gala

STAND UP TO SARCOMA GALA
NYC 583 PARK AVENUE
THE SARCOMA FOUNDATION OF AMERICA'S 23rd ANNUAL FUNDRAISER
https://curesarcoma.org/stand-up-to-sarcoma-gala/

YOU'RE INVITED
MONDAY
SEPTEMBER 15TH
583 PARK AVE NYC
Dinner Event
Cocktail Attire
6-10PM EST

HONORING
COMPASSIONATE CARE AWARD
CHRISTINA KIM
NP Mass General Cancer Center
COURAGE AWARD
BILLY BRIMBLECOM JR.
CEO, Steps of Faith Foundation
AMIRA YUNIS COURAGE AWARD
ANDREY IVCHENKO
Actor, Stranger Things
NOBILITY IN SCIENCE AWARD
DAVID KIRSCH, MD, PHD.
Senior Scientist, Peter and Shelagh Godsoe Chair in Radiation Medicine
Princess Margaret Cancer Centre
VISION OF HOPE AWARD
JOHN W. O'BRIEN FAMILY FOUNDATION

There is still time to join us for the 2025 Stand Up to Sarcoma Gala.

Host Claybourne Elder from HBO's hit series *Gilded Age*, will take us through an amazing program celebrating the sarcoma community.

If you are uable to attend, you can participate in the silent auction. Browse and bid on auction items and support sarcoma research.

RESEARCH ROUNDUP

By Dean Frolich, PhD

This month I would like to highlight three recent publications. For the first study, in Ewing sarcoma (EwS) two genes (EWSR1 and FLI1) are fused together and their fusion protein causes dysregulated transcription of a range of proteins in the cell. In "Subversion of mRNA degradation pathways by EWSR1::FLI1 represents a therapeutic vulnerability in Ewing sarcoma," the researchers report that in addition to the transcriptional role the fusion protein is known best for, it also has a role in the regulation of messenger RNA (mRNA) stability. This dysregulation of mRNA, which is the RNA that cells use for a template to make proteins, contributes to tumorgenicity in a way that is separate to the transcription function. They also found that the fusion protein-mediated mRNA degradation involves another protein called HuR. This leaves EwS cells highly sensitive to the inhibition of HuR. These results are early, but indicate that targeting of the mRNA degradation pathway may be a new target in in Ewing sarcoma treatment.

Circulating tumor DNA (ctDNA) is DNA that has been shed into the bloodstream of cancer patients from their tumors. It is being used to identify and monitor other cancers, but this is not currently available for sarcoma patients. In "Droplet Digital PCR Assay for Detection and Monitoring of Universally Methylated Circulating Tumor DNA in Sarcoma Patients," investigators report an assay that may be able to identify and monitor soft tissue and bone sarcomas. The researchers were able to identify sections ctDNA that was methylated (a type of DNA modification) in patients with several different subtypes in both bone and soft tissue, but not in healthy patients. The investigators then developed a test that is able to determine if ctDNA is methylated in seven key ctDNA regions and tested the assay using blood samples from healthy patients, metastatic soft tissue sarcoma patients, and soft tissue and bone sarcoma patients currently being treated with chemotherapeutics. CtDNA was positively detected in 45% of the metastatic patients and 74% of the patients with soft tissue and bone sarcoma treated with chemotherapy across all subtypes. Also, detection of ctDNA correlated with poor overall survival in metastatic patients with soft tissue sarcoma, and increasing ctDNA during chemotherapy was associated with poor outcomes. Additional studies need to be done, but this study indicates that methylated ctDNA may be able to provide precise detection, prognostication, and monitoring of patients with sarcoma.

Lastly, in "Hyalinization-based pathologic response and immune infiltration following neoadjuvant radiotherapy with or without immune-checkpoint blockade in localized undifferentiated pleomorphic sarcoma," the researchers investigate whether the addition of immune-checkpoint blockade (ICB), in which doctors treat patients with a drug that "releases the brakes" that tumors use to stop the patient's immune system from attacking the tumor, in addition to radiation therapy can improve the outcomes of patients with undifferentiated pleomorphic sarcoma (UPS). Analysis of 68 patients with primary or locally recurrent UPS who received neoadjuvant radiation therapy with or without ICB demonstrated that the ICB group had greater tumor hyalinization (a decrease in the number of cells but with an increased amount of collagen deposited) than the non-ICB group (89% compared with 30%). In the non-ICB group, 51% of patients had a hyalinization-based pathologic response, compared to 82% in the ICB group. After 48 months, patients with a hyalinization-based pathologic response had a higher overall survival rate (100% versus 64.1%) and recurrence-free survival rate (67.1% versus 35.6%) than those who did not. These early results indicate that additional studies are warranted to investigate the role of ICB with chemotherapy and radiation therapy in UPS.

Clinical Trials Corner

By Kristi Oristian, PhD

This month SFA is highlighting TARGET-RT, Targeted Oligometastatic Radiation in Pediatric and Young Adult Patients with Soft Tissue and Bone Sarcoma. The goal of the study is to understand if the physicians can improve the overall survival of these patients by targeting metastatic sites with radiation. This study is recruiting at Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins in Baltimore, Maryland and Washington, DC. The trial is open to patients under the age of 39 with bone or soft tissue sarcoma that is metastatic and measurable.

Patients eligible for this trial may fall into one of two groups. Patients with newly diagnosed bone or soft tissue sarcoma and metastatic disease will receive consolidative radiation therapy as part of their care in addition to standard of care induction chemotherapy. This group will receive radiation to all sites of metastatic disease as well as the primary site.

Patients with progressive bone or soft tissue sarcoma and metastatic disease will receive the standard of care second line systemic therapy with radiation to at least one disease site. There are additional eligibility and exclusion criteria, including minimum performance requirements and disease burden considerations. 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 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.

SFA 2026 Research Grant Cycle is Open

The Sarcoma Foundation of America invites sarcoma researchers to submit Letters of Intent (LOIs) for research funding. Research proposals may address pre-clinical, translational, and clinical research on the etiology, molecular biology, pathogenesis, diagnosis, and treatment of human sarcomas. The SFA grant program supports our mission to fund research that results in improved therapeutic options for sarcoma patients. SFA encourages applications in ALL areas of sarcoma research.

The Competitive Letter of Intent (LOI) is designed to identify projects with the greatest scientific potential and alignment with program purpose without requiring applicants to submit a full application at the initial stage. Learn more about SFA's research funding.

SFA NEWS

2025 Sarcoma Awareness Month Children's Art Program Selections

SFA is pleased to share the artwork selected for our 2025 Children's Artwork Program. 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 in this way! Art from these seven entries, depicted below will appear on cards SFA sends throughout the holiday season and will be displayed at the upcoming Stand Up to Sarcoma Gala. View all of the artwork submission.

SFA Global Spotlight: Malaysian School Joins in on Wear Yellow Wednesday

An incredible wave of support for sarcoma awareness swept through a school in Malaysia. Led by Ti Ying, students participated in Wear Yellow Wednesday, uniting to raise awareness for #sarcoma across the globe. Their initiative, which symbolizes strength and hope, reminds us that the sarcoma community is global.

SFA GLOBAL

COMMUNITY HIGHLIGHTS

Race to Cure Sarcoma San Diego: I Race in Memory of Rae

By Maddy Ringer

Growing up Rachael Lopez-Simpson, Rae, was always drawn to dancing. She was always in theater, circus and dance classes with her siblings! Even growing up to go to school for dance and as a young adult worked at the same theater she grew up at. Rae was great humored and loved being around those who meant the most toher. You could often find her spending time watching her favorite show "Friends" or with her sisters and her nieces who she loved more than the world.As hard and she loved those she already had; Rae's heart still had more love to give. Later in life she met the love of her life who proposed to her in Hawaii in front of their whole family.

Later, Rae was diagnosed with stage 4 Synovial Sarcoma in September 2019 but that didn't stop her from having the wedding of her dreams on Halloween that same year. Over the next 2 years she fought harder than anyone could imagine. She did her best to maintain her quality of life despite having countless surgeries, receiving chemo and radiation therapies, and a below the knee amputation. She put up a courageous and valiant fight but, sadly soon after being visited by her extended family, Rachael passed away peacefully in the home she shared with her husband November 10th, 2021. Every person who had the gift of her in their lives mourned her deeply. Friends and family gathered at a Boys and Girls club she and many friends used to hang out at to celebrate her memory.

Each one of us miss her every day. SFA was Rachael's foundation of choice so in her place we continue her support and try to come to the Race to Cure Sarcoma in San Diego every year! Rachael Lopez-Simpson was so much more than just a sarcoma patient. She was a sister, wife, daughter in law, auntie and held so many other titles to countless people.

Playing with Purpose

On July 27th, the first annual Cornhole Tournament took place at Sandpiper Shelter, Ontario Beach Park in Rochester, NY, raising over $12,500! This special event was created by Brian Jaffarian and his sister Pamela Andrieu, to benefit SFA.

Brian was diagnosed with stage IV Alveolar Soft Part Sarcoma in December of 2023. Since that time, he has focused on bringing awareness and support to others affected by sarcoma. He has inspired so many people with his incredible strength and resilience.

The tournament, with close to 100 participants, isn't just about the game– it's about making a difference. The proceeds directly supported SFA and our vital work in research, advocacy, and patient support. Sarcoma is a rare and often overlooked cancer, receiving less than 1% of cancer research funding. Brian, along with his entire family, is passionate about bringing awareness and funding research to help find a cure.

Why I Give

By Jenna Pryor

In October 2015, my world changed forever. I had just started my first semester at college, then one afternoon, I got a call from my mom that shifted the next 5 years of my life – my mom, Lisa Clark, was diagnosed with cancer. Stage 4 Retroperitoneal Liposarcoma, to be exact. My mom: the health educator, wellness coach, marathon runner, and mother of four. We were heartbroken, scared, and had no clue what to do next. The lack of general knowledge about sarcoma and its treatment was shocking. We were fortunate to have access to sarcoma specialists and organizations, like SFA, that helped us make countless decisions about her care and how to move forward day by day.

Over the next 5 years, my mom underwent chemo, her lifetime max of targeted radiation therapy, clinical trials, off-label treatments, two surgeries, and countless appointments. She found a community in the sarcoma community that helped her feel less alone and take back some of her identity that was stolen by this disease.

Unfortunately, sarcoma is a persistent, relentless beast - one that my mom passed away from on July 22, 2020. She fought so hard for five long years, with the help of her doctors, surgeons, family, and friends who miss her every single day. I can't imagine how we would have made it through without SFA and other critical organizations that work every single day to improve the resources, support, and research that my family depended on.

Giving monthly is important to me because I never want a sarcoma patient or family member to not know where to go for information and support through their sarcoma journey. A cancer diagnosis is hard enough, but a rare diagnosis like sarcoma is earth-shattering. Having SFA and other sarcoma-specific resources was so helpful as my family navigated my mom's diagnosis, treatment options, and decisions. By giving to SFA every month, I can help ensure that sarcoma patients and their families don't feel like they have to face these challenges alone. I give my support in loving memory of Lisa Clark - rest in peace, Mom.

EVENTS

The 4th Annual **Scott Lively Memorial Golf Tournament** will be held on **September 20, 2025**, at Bear's Best Atlanta. Hosted by Scott's family and friends the event honors Scott Lively, whose unwavering strength demonstrated while facing Ewing sarcoma and later bone cancer continues to inspire. This outing unites golfers and supporters in his memory. Participants and supporters can register to play or make a tribute gift. Register Now

First Annual Jessica Rose McNamara Wine Tasting & Gift Raffle

This inaugural event, hosted by Jimmy and MariaMcNamara, will honor the beautiful life of their daughter, JessicaRose. Jessica was known for her compassion and was extremely soft-spoken but could capture your attention with her beautiful smile or full-bore, staccato laugh.

Jessica was diagnosed with Malignant Peripheral NerveSheath Tumors (MPNST's), a sarcoma, in the late summer/early fall of 2016 at the age of 21. And on July 27, 2017, she lost her battle to sarcoma.

This will be a special evening filled with food and wine tasting, and the opportunity to win a gift raffle prize. All proceeds from the event will benefit theSarcoma Foundation of America (SFA).

SFA is a proud partner of the 2025 Marine Corps Marathon (MCM). The MCM is celebrating its 50th year, and this event offers an experience for runners to tour the nation's most recognizable landmarks, while being supported by the men and women of the United States Marine Corps.

SFA is honored to have Neri Lopez join SFA's marathon race team. Neri is a committee memberf or the Race to Cure Sarcoma Austin event. For the first time this year she will participate in the Marine Corps Marathon, to help raise awareness and funds for SFA.

Join our Marathon Team

Race TO Cure SARCOMA MARATHON TEAM

Race TO Cure SARCOMA
SARCOMA FOUNDATION OF AMERICA

Race to Cure Sarcoma 2025 Dates:

- **San Diego 9/20**
- **Chicago 9/27**
- **New Jersey 10/5**
- **Denver 10/25**
- **Tampa 11/1**
- **Los Angeles 11/2**
- **Sacramento Valley 11/8**
-

Register now for your local race.