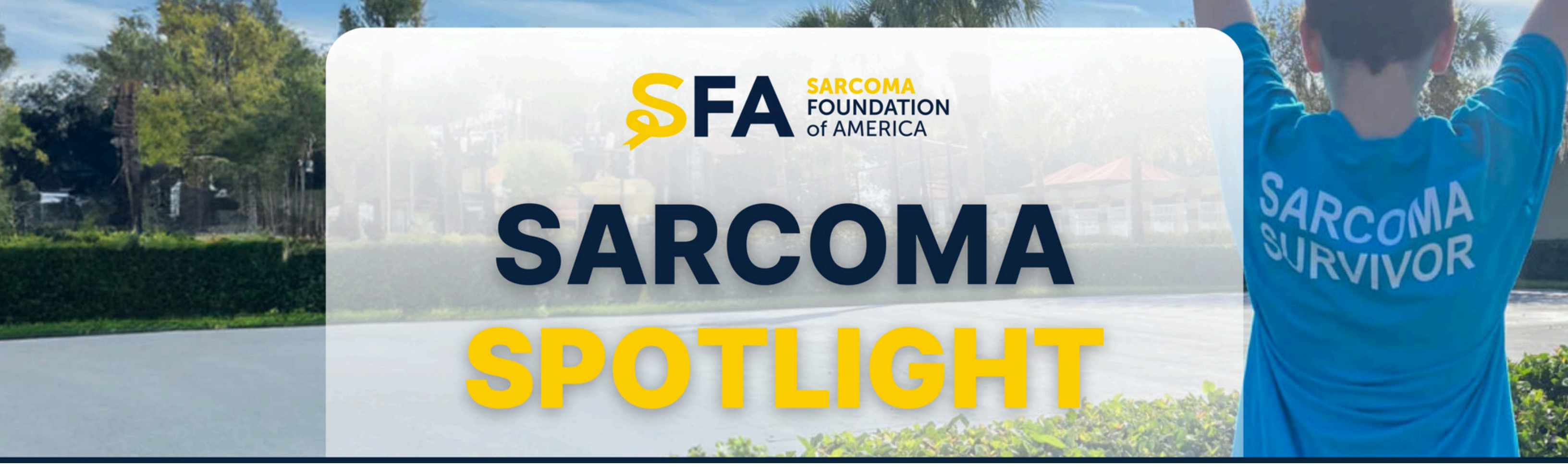

SFA SARCOMA FOUNDATION of AMERICA

SARCOMA SPOTLIGHT

A Giant in the Sarcoma Community

Brandi Felser, CEO

The sarcoma community recently lost a giant in the field and a valued member of SFA's Medical Advisory Board. Brian van Tine, MD. PhD was among the first to welcome me to SFA and the broader sarcoma community. Just last year, he sent me a note that simply read, "In case no one has told you lately, I think you are doing an amazing job." That gesture reflected who he was—always supportive, generous with his time, and deeply committed to advancing progress in sarcoma research. He was always willing to answer questions, provide counsel in times when the path was not clear, and share his brilliance on how we can make progress in research. Words cannot fully capture his contributions to SFA and his leadership across the sarcoma community. His passing leaves a profound gap—not only for me personally, but for SFA and the entire field.

At the 2025 Connective Tissue Oncology Society (CTOS) Annual Meeting—the global gathering for sarcoma research—CTOS honored Brian while also celebrating the Society's 30th anniversary. As I reflect on that milestone, I realize that for 25 of those years, SFA has been an integral part of the community's growth, research advancements, and progress. When our founders first envisioned SFA at a CTOS meeting, sarcoma research funding was scarce, and few scientists pursued careers in the field. Many were told, "You can't make a career out of sarcoma."

From the beginning, SFA recognized the need to invest in developing a pipeline of investigators to drive research forward. We funded young investigator and career development awards to ensure that talented scientists who desired to invest their talents in sarcoma had a path to dedicate their work to improving outcomes for sarcoma patients.

At our 2023 Stand Up to Sarcoma Gala, Dr. Loeb, our Nobility in Science honoree, said, "I would not have had a career if it weren't for SFA." We hear that often. Over the past 25 years, SFA has invested tens of millions of dollars in research and generated even greater impact through seed grants, large multi-year awards, and advocacy for increased funding We have played a important role in moving the field closer to the goal of curing sarcoma—or at least ensuring that no one dies from it.

Brian received his first SFA grant in 2011, around the time he started working at Washington University, through our Race to Cure Sarcoma series. He continued to receive support in subsequent years. He was often pitching me research ideas, impressing upon me the importance of our role in the sarcoma community- our role in advancing science and challenged me to think strategically about how SFA could expand its impact.

He encouraged bold action, often saying SFA should "take the lead" in bringing others together to drive progress. He often pushed me to tackle initiatives I was hesitant to take on but he felt needed to be done to realize progress. While we did not always agree, I deeply valued and appreciated his vision, his candor, and his unwavering dedication to patients.

I will greatly miss his counsel and candor, his big personality, low voice when he would often be presenting groundbreaking research at sarcoma meetings. I remain profoundly grateful for the wisdom he shared, his dedication to the patients, and the inspiration he provided. Brian was, truly, a giant among giants. As he reminded me more than once, "SFA is a leader—and must be." We will continue to honor that charge and carry his and the SFA legacy forward.

Giving Tuesday

We understand that you get many requests for support for Giving Tuesday. **Your gift to SFA on Tuesday, December 2, 2025, for GivingTuesday**, a global day of giving, can help save lives. Your support will fund the 2026 Giving Tuesday Research Grant, funding translational research that will lead to new therapies and bring us closer to a cure.

Once again, this year, your impact will go even further – thanks to a generous donor, **$25,000 of the funds** raised will be matched! Your generous donation can lead to over **$75,000 raised** to advance the research needed to find improved treatments and a cure for sarcoma.

We hope you will join us in our work to ensure people diagnosed and living with sarcoma have access to more and less toxic treatment options.

Thank you for your support and thank you for always standing with us!

RESEARCH ROUNDUP

Highlighted Research

New Study Identifies High-Risk Subgroup in Localized Ewing Sarcoma

This month I would like to start by highlighting an Ewing sarcoma study. Entitled "Molecular Characterization Informs Prognosis in Patients With Localized Ewing Sarcoma: A Report From the Children's Oncology Group," this study looks to identify subgroups within localized Ewing sarcoma (EWS) that are associated with treatment response or resistance. The investigators analyzed clinical and molecular traits from 351 patients with localized EWS. DNA sequencing was performed to identify common EWS gene fusions, changes in the number of copies of specific segments of DNA in the genome called recurrent copy number alterations (CNAs), and mutations in two different proteins called TP53 and STAG2. EWS fusions were identified in 282 (80.3%) patients. Pathogenic TP53 mutations were identified in 14 of 277 (5.1%) patients and STAG2 mutations in 21 of 277 (7.6%) patients. A total of 63.1% of patients were found to have recurrent CNAs. Upon analysis, patients with TP53 mutation had an increased incidence of relapse (5-year cumulative incidence of relapse of 43%) compared to patients without TP53 mutation (22%), STAG2 mutations had in increase in relapse (53%) compared to those without (21%), as did patients with recurrent CNAs (30%) compared to those without (16%). When analysis was performed on multiple characteristics at the same time, STAG2 mutation was the only molecular biomarker that remained prognostic. These results indicate that localized EWS patients with STAG mutations are a high-risk population and treatment strategies may need to take this into account.

Long-Term Nirogacestat Treatment Shows Sustained Benefit in Desmoid Tumors

In the second study, "Efficacy and Safety of Long-Term Continuous Nirogacestat Treatment in Adults With Desmoid Tumors: Results From the DeFi Trial," investigators share the results of long-term treatment of patients with desmoid tumors (DT) with the selective gamma secretase inhibitor, nirogacestat. The primary analysis of nirogacestat showed significant improvement versus placebo in progression-free survival (PFS), objective response rate (ORR), and patient-reported outcomes (PRO) in adult patients with progressing DT. This report follows on the previous analysis with long-term nirogacestat efficacy and safety. End points included PFS and ORR, PRO, and safety. The median duration of treatment was 33.6 months. Median PFS was not reached. The ORR with up to 4 years of nirogacestat treatment was 45.7% (32 of 70 patients with DT), this includes three additional partial and three additional complete responses since the primary analysis. Tumor sizes continued to decrease in patients, and frequently reported treatment-emergent adverse events (TEAEs) decreased with time. These results provide a better understanding of the long-term benefit of nirogacestat in patients with progressing DT and may help inform treatment decisions to improve patient care.

Study Identifies New Antibody-Drug Conjugate Targets in Soft Tissue Sarcomas

The last study looks to take advantage of a relatively recent technology called antibody-drug conjugates to enhance sarcoma treatment. They combine a therapeutic that is toxic to cells, whether they are cancer cells or normal, healthy cells with a monoclonal antibody that is specific for a tumor antigen via a linker molecule. The goal is to deliver a chemotherapy selectively to cancer cells expressing the target antigen. In, "Expression of antibody–drug conjugate targets in soft tissue sarcomas," the researchers analyzed the expression of 62 targets and 60 genes in 1664 primary tumors in a variety of soft tissue sarcoma (STS) subtypes. Expression was compared to that of 7414 normal tissue sample. Expression of the targets were mixed across and within all STS types, but all types expressed multiple targets. The high target overexpression rate in some STS types suggested numerous new therapeutic opportunities. Additionally, the expression of target along with targets of several other therapies was demonstrated in several subtypes which indicates the possibility of combination therapies. Although early, these results indicate the possibility of multiple opportunities for the use of ADCs in soft tissue sarcomas.

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.

Now Available: November Live with the Experts Recording

The recording of our November Live with the Experts session, Understanding ctDNA in Sarcomas, is now available. This in-depth discussion explores what circulating tumor DNA (ctDNA) is, how it's being used in oncology, and what current research reveals about its potential role in sarcomas. Watch the full discussion.

Our Expert Panelists:

Dr. Herbert Loong
The Chinese University of Hong Kong

Dr. David Shulman
Dana Farber Cancer Institute

Edwin Choy, MD, PhD
Massachusetts General Hospital

SFA Global

FOSTERing Change in Osteosarcoma

By Pan Pantziarka

Osteosarcoma is a sarcomas where standard treatments have not changed in decades. It is the most common bone sarcoma in children and young people but can also impact older adults. It is desperately in need of new treatment options, which is the main focus of the FOSTER consortium. FOSTER stands for Fight OSteosarcoma Through European Research - and it represents the coming together of doctors, researchers and patient advocates from across 19 European countries to focus on all aspects of the disease - from basic biology through to clinical trials and long-term outcomes for survivors.

In September, I attended the two-day in-person meeting of FOSTER in Warsaw, Poland, representing SFA and the parent/patient voice. The FOSTER CabOs trial has been a main focus of the consortium to this point. It's a large multi-country trial to test the addition of a drug called cabozantinib to the end of first line treatment to see if it can delay or reduce the number of patients who develop recurrence. It has been a major achievement to get the trial designed and funded, including donation of the drug and placebo from the pharma company . Patient advocates have been involved all along the way, from the initial discussions on the trial design to taking part in discussions with the European drug regulator (EMA) to talking with the drug company.

The trial is about to open for recruitment and already the conversation is about how we can use the trial as a platform to ask additional questions - like can we test something new for those patients who do get a recurrence, or is there something we could add in to those patients who are in a high risk group? The trial is already being viewed as a jumping off point to evolve into a place to explore more questions. And always there's a consistent focus on learning everything we can from patients who join the trial. This positive approach is now attracting attention from outside of Europe - perhaps the time will come when it's a truly global collaboration and FOSTER can stand for Fight OSteosarcoma Through Effective Research.

PUSH Collaboration Expands Global Effort with New Website

SFA is proud to announce the launch of the new Pushing Ultra-Rare Sarcomas Beyond Hope (PUSH) website. SFA serves as the administrator of this global collaboration, which connects clinicians, scientists, and patient advocates to accelerate research and improve care for people with ultra-rare sarcomas.

Through focused working groups, PUSH brings together people, data, and ideas to advance treatment development and knowledge-sharing worldwide. Visit the new website to learn more about its mission and current initiatives and to find out how to get involved.

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 4 | Living Loudly: A Conversation with Joel and Amanda Stetler
In this episode, we sit down with Joel and Amanda Stetler, a couple from California navigating life with Joel's low-grade fibromyxoid sarcoma. Over the ten years since his diagnosis, they have built a full and vibrant life — raising three children, advancing careers, and embracing their shared motto to "live loudly."

Joel and Amanda share both the patient and care partner perspectives on the long road to diagnosis, the honest conversations they've had along the way, and how they continue to find balance, meaning, and connection in the midst of uncertainty.

Season 2 Episode 3 |Living Beyond "Benign": A Conversation with Chris Barry
In this episode, Chris Barry, a desmoid tumor survivor, rare disease patient, dad, and civil engineer from the San Francisco Bay Area, shares his experience living with familial adenomatous polyposis (FAP) and a large desmoid tumor. His journey has included chemotherapy, major surgeries, and an intestinal transplant.

Chris talks about the challenges of living with a diagnosis often called "benign" and how that label can be misleading for desmoid tumor patients. He also discusses how his experiences have shaped his perspective and inspired him to become involved in the sarcoma community to support and advocate for others.

Listen to all episodes of the Sarcoma Stories podcast

Honoring Sarcoma Care Partners

November is a time to recognize the care partners who walk alongside loved ones facing sarcoma. They manage appointments, track treatments, ask hard questions, and bring comfort in the most difficult moments. Their strength and constant presence make an immeasurable difference. This month, we honor every care partner whose love and perseverance helps carry families through the sarcoma journey.

Below, we share perspectives from care partners and those wishing to honor the people who have supported them along the way. Thank you to everyone who shared their stories with us.

Sharing Care Partner's Perspectives

I'm Grateful for Every Moment We Shared

Jennifer Goodwin

Being the caregiver for a child with stage 4 cancer is not one job, but many. When my daughter Catherine was diagnosed with epithelioid sarcoma at 16, our lives changed overnight. I became her advocate, nurse, and constant companion through months of chemotherapy, radiation, and hospital stays. Each day was filled with decisions, medications, and managing pain, but also small moments together — singing in the car, talking about life, and finding connection in the midst of chaos.

Caregiving for Catherine taught me more about strength and love than I ever thought possible. While we lost her far too soon, I remain proud of her courage and grace, and grateful for every moment we shared.

My hope is that by sharing our story, others understand the depth of what caregivers face and the importance of finding compassion and support along the way.

The Goodwin Family

My Daughter's Love Continues to Carry Me

Sabina Allen

Being Natasha’s care partner was one of the greatest gifts of my life. She was so independent and knew exactly what she wanted and what to ask for. Caring for her taught me something new every day about love, patience, and strength.

What stands out most to me is Natasha’s relentless desire to live and her determination to complete her bucket list. Even when she was struggling, she thought of others. She wanted to help people feel less alone by sharing her story and was always there for everyone in her life. Her courage to face every treatment and clinical trial with strength and hope showed who she truly was. I still have a hard time speaking about her in the past tense because she feels so present. Her love, her strength, and her passion continue to carry me.

To anyone beginning their care partner journey, give yourself grace. You are doing the best you can. Accept help when it is offered and focus on the people who show up for you. It is okay to not be okay, and every day will be different.

I also wish someone had told us early on to talk about end-of-life planning. Even when you believe your loved one will pull through, it is important to have those conversations and protect their wishes and legacy.

Being a care partner is a full-time job, not just physically but emotionally. If you do not have the energy to check in with others, that is okay. You are giving everything you have to someone you love.

Sabina and Natasha Allen, Japan 2025

Staying Calm Amidst the Chaos

Emily Mancewicz

Emily Mancewicz and Matt Hymel

As a healthcare provider, balancing my professional knowledge with the role of caregiver to my fiancé has been a challenge. I feel the pressure of every clinical decision with my understanding of current research, and having to use that information to make the best choice for our unique sarcoma situation.

The hardest moment for me was flying home after our third second opinion. Each visit brought conflicting recommendations, and the uncertainty was overwhelming. Ultimately, the decision on how to proceed with treatment is my partner's decision, and I support him completely. We are currently undergoing AIM chemotherapy after heavily weighing our options.

Being a care partner means being available for appointments, helping manage side effects at home, and trying to maintain some sense of normalcy. We've been fortunate to receive help in so many forms from friends and family in our 'village' — this is something you should never have to experience alone. It is hard, but it has also deepened our connection and our gratitude. After everything we've faced so far this year, we are so excited to move into a new chapter next year, and look forward to our wedding!

Honoring Our Care Partners

The Rock of Our Little Family

Carrie Carpunk

I was diagnosed with synovial sarcoma in the gastric wall at the age of 35. I had been married for 14 years and we had a 9-year-old daughter that was born with spina bifida. Upon diagnosis, my husband turned into caretaker mode. He was with me at all appointments, and to date has only missed a handful. He was there to help me out of bed after surgery, to help with baths, to help pull my pants up when I couldn't bend. He carried it all. I was self-employed at the time, so he literally carried it all. When I was diagnosed, there were very few treatment options, so my oncologist, Dr Brian VanTine, kept a close eye on me and hoped that we saw no reoccurrence. I am so thankful for my husband through this journey. He has been the rock of our little family.

The Carpunk Family

I Couldn't Have Picked Someone Better Than You, Mom, to Support Me

Jonathan Gardner

Nancy and Jonathan Gardner

When I was going through treatment for Ewing's Sarcoma, my main caregiver was my mom, Nancy Gardner. My mom was there for me through everything, every appointment, every conversation, she helped me navigate different situations, she picked me up when I was down in the dumps and supported me in every moment when I felt like giving up. She helped me navigate complicated medical situations, comforted me when I was anxious or in pain, and reminded me that I was still me, even when cancer tried to take that away. My mom still supports me in different ways and I am lucky to have her.

There are two moments that may seem small to others, but to me, they meant everything. The first was when I was in the hospital waiting for radiation. My mom said, "You know we're near a shopping area I used to take you and your brother to when you were little, it has a really good pizza place and Newbury Comics. Want to go?" I was down for it since I was in need of some new mangas so we went, got pizza, and walked around Newbury Comics. Honestly, thanks to her idea I got to feel normal for a bit like I didn't have a tumor in me. I was just, well, me before the treatment looking for my next read, having fun and of course eating some good pizza along the way.

The second story I want to share was one of my days off from treatment. I was down in the dumps again. I just got off a hard week of treatment, and my mother wanted to do something to help. She asked if me, and my father would want to go to the beach. We both were good with it. We went on a drive to a small beach. We just sat watching the waves. We talked about some of my favorite things like pro wrestling and video games and things to look forward to. We even talked a bit about life. We went into the water for a second and it just felt normal.

There are plenty more I can share about my journey and how my mother helped me. These 2 small moments remind me there was hope and that I was going to get through my cancer, and I did thanks to many people, but especially my mother. I will leave you with something I said to my mom a little after my treatment was done. When I was in the fox hole known as my cancer treatments I couldn't have picked someone better than you mom to support me. I love you mom, thank you for everything!

My Caregiver, My Partner, My Hero

The Survivor, Anonymous

We have been fighting Leiomyosarcoma for nearly 12 years and my caregiver has been by my side every step of the way. He's been my cheerleader, my nurse, my guiding light and my best friend. This battle is hard for the survivor and watching someone you love to go through this....sigh.....I cannot imagine.

He pushes me in all the best ways, he supports me always and he validates me when it's so, so scary. He is my taxi driver for all and any appointments. He's my advocate when standing up for myself and fighting for the best and right care feels too hard. He is my chef and my food delivery driver, keeping me well fed (too well actually) when I am in the hospital and getting me whatever food I need/want/can stomach while on chemo. He is my nurse (both in and out of hospital). And he is my support the whole way.

He has watched (many times) as I'm wheeled away to surgery, fearing the outcome. He sat next to me when listening to the treatment plan. He's read the reports and researched all the things. He is the most stable part in all of this because I know he is always there for me.

He works, he takes care of himself and he struggles. Finding the right support as a caregiver is not easy. This is a long hard road, and he just keeps going. I will never be able to express my gratitude for all he does for me. And for him, I keep fighting.

SFA NEWS

Introducing Our New Staff Members

Director of Engagement and Advocacy

Katie Wintergerst

Katie Wintergerst has been active with SFA since 2018 when she was diagnosed with synovial sarcoma. She has served as co-chair of the Louisville SFA Race to Cure Sarcoma since 2020. Katie has brought significant attention to sarcoma, SFA and RTCS. Her enthusiastic support of SFA amidst her personal sarcoma journey is a testament to her strength and tenacity.

Outside of work Katie enjoys spending time with her family and traveling.

Communications Coordinator

Kayla Highbaugh manages SFA's social media presence and supports the organization's efforts to raise awareness of sarcoma, share impactful stories, and advance its mission to fund research and find a cure. With a background in nonprofit communications and digital engagement, Kayla brings creativity and compassion to her work, helping connect and uplift the sarcoma community.

Outside of work, she enjoys traveling, exploring new coffee shops, and spending time with loved ones.

Kayla Highbaugh

Communications Manager

Stacy Coppess

Stacy Coppess brings over a decade of health communications expertise to SFA. Prior to joining SFA, Stacy was a communication specialist at National Institutes of Health, where she authored plain language content reaching millions of people annually. At the National Institute on Drug Abuse, she translated complex scientific research into educational materials, managed public inquiry systems, and developed SEO-optimized content strategies.

Earlier, as Health Information Librarian at the National Library of Medicine, she served as product manager for medical test information and coordinated social media efforts for MedlinePlus.gov. She is skilled in creating evidence-based health communications that empower patients and families.

Support SFA Through Workplace Giving

Calling all Federal and Maryland State employees and retirees! The Combined Federal Campaign (CFC) and Maryland Charity Campaign (MCC) annual charitable workplace giving programs have begun, and SFA is thrilled to announce our participation and listing as an eligible charity. Consider including SFA in your pledge this year and help fuel our work in funding translational research to improve outcomes for sarcoma patients. Every dollar makes a difference! Learn More About Workplace Giving with SFA

- **CFC:** Federal employees and retirees can find us in the charity list this fall with SFA's code 57785.
- **MCC:** Maryland State employees and retirees can find us in the charity list using SFA's EIN #: 522275294.

Join the Team at SFA!

As SFA continues to grow, we're expanding our team to help advance research, raise awareness, and improve outcomes for everyone affected by sarcoma. If you or someone you know is passionate about making a difference in the sarcoma community, we'd love to connect. Questions? Email hr@curesarcoma.org

- Director-of-Advancement-Vacancy-Announcement-2025.pdf
- Development-Manager-Position-Announcement-2025.pdf

RACE TO CURE SARCOMA

Finding Strength and Support Through the Sarcoma Community

When Emma Mayer awoke one morning in October 2024 with tingling and numbness in her left arm and hand, she never imagined it would be the beginning of her sarcoma journey. After discovering a deep mass near her neck, she was diagnosed with Undifferentiated Pleomorphic Sarcoma (UPS), a particularly rare and complex form of soft tissue sarcoma, made even more complicated by its location in the head and neck.

Emma Mayer

Determined to seek expert care, Emma transitioned to “straight” Medicare to access a nationally recognized sarcoma center. Although she initially hoped surgery might be possible, she faced the difficult reality that removing the tumor would mean losing full use of her left arm. Instead, her UCLA sarcoma team pursued radiation followed by immunotherapy, offering a treatment plan tailored to her specific case.

The journey has been challenging, both physically and emotionally, but Emma remains deeply grateful for her UCLA healthcare team, her support network of family and friends, and organizations like SFA that provide connection and community.

On November 2, Emma joined the Race to Cure Sarcoma Los Angeles to raise awareness and support for others impacted by this rare disease. “Whatever the future holds, and despite the trials to be faced, we will continue to face this together,” she says.

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, celebrate 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! See all dates and sign up!

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
- North Carolina — 9/19/2026
- San Diego — 9/19/2026
- Chicago — 9/26/2026
- New Jersey — 10/11/2026
- Denver — 10/24/2026
- Los Angeles — 11/1/2026

Spread the word: Invite friends, family, and colleagues to join your team. Each person who joins RTCS helps to grow the sarcoma community and raise more money for research.

https://curesarcoma.org/race-to-cure-sarcoma/