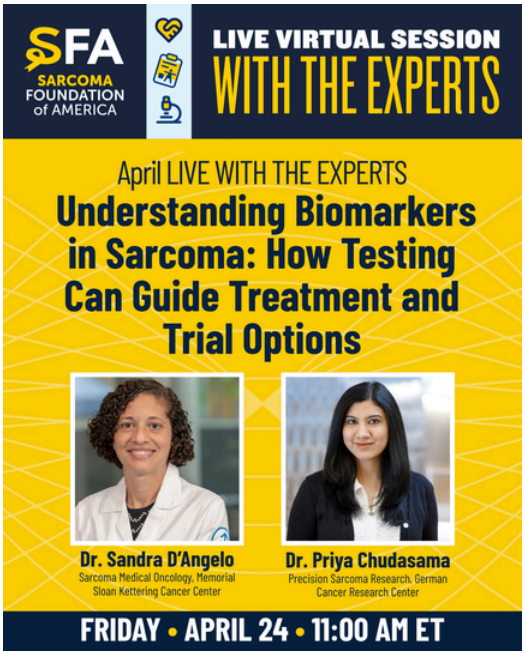
April 2026

Understanding Biomarkers in Sarcoma: How Testing Can Guide Treatment and Trial Options

Friday, April 24th at 11:00 AM ET



Join us for this educational webinar focused on biomarker testing in sarcoma. As testing becomes more integrated into patient care, understanding what biomarkers are—and how they are used—can help patients and families better navigate treatment decisions and clinical trial options.

This session will explore the different types of biomarker testing used in sarcoma, how results are interpreted, and how this information can guide personalized treatment strategies. We will also discuss how biomarkers are discovered and validated, and what they may mean for the future of sarcoma care.

Our expert speakers, Dr. Sandra D'Angelo (Sarcoma MedicalOncology, Memorial Sloan Kettering Cancer Center, New York, NY) and Dr. Priya Chudasama (Precision Sarcoma Research, German Cancer Research Center, Heidelberg, Germany), will provide both clinical and research perspectives on how biomarker testing is used today and where the field is heading.

What to Expect:

- Overview of what biomarkers are and how they are used in sarcoma care
- Explanation of common biomarker tests and how results are interpreted
- How biomarker testing can inform treatment decisions and clinical trial eligibility
- Discussion of how biomarkers are shaping the future of personalized care
- Practical guidance for discussing biomarker testing with your care team

Register here

Questions? Contact Programs@curesarcoma.org

When a Cancer Drug Is Withdrawn: Balancing Speed, Safety, and Unmet Need

In March, the targeted therapy tazemetostat (Tazverik), previously approved for certain cancers including epithelioid sarcoma, was withdrawn from all markets following new safety findings from a required confirmatory trial.

In that study, researchers observed an increased risk of secondary blood cancers in some patients receiving the drug as part of a combination regimen. Based on these findings, an independent monitoring committee determined that the risks may outweigh the benefits, leading to the decision to withdraw the drug. Tazemetostat had not been approved by regulatory agencies in Europe and was therefore not available to patients there.

This development highlights both the promise and the complexity of the accelerated approval pathway. Accelerated approval allows therapies that show early signs of benefit to reach patients more quickly, particularly in rare cancers like epithelioid sarcoma, where treatment options are limited. At the same time, these approvals require confirmatory trials to better understand long-term safety and effectiveness.

Tazemetostat had represented an important option for patients with epithelioid sarcoma, a rare and challenging disease with significant unmet need. Its withdrawal is a reminder of how difficult drug development can be in rare cancers, where small patient populations and limited treatment options create both urgency and uncertainty.

While this news may be disappointing, it also reflects an important safeguard in the system. Cancer treatments continue to be studied even after approval, and new information can lead to changes that prioritize patient safety.

For the sarcoma community, this moment also raises broader questions about how we balance speed, access, and evidence, particularly for rare cancers where patients cannot afford to wait for new options. As research continues, these conversations will remain critical to ensuring that progress is both meaningful and safe.

At SFA, we are committed to helping our community navigate these complexities by sharing not only new advances, but also the evolving evidence behind them.

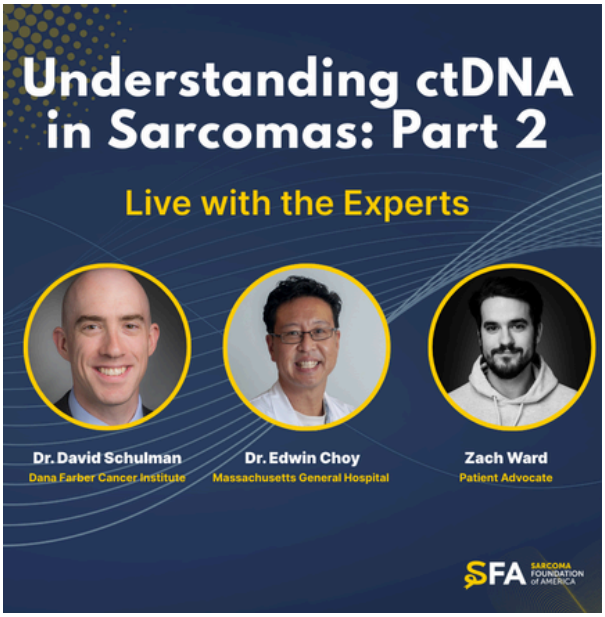
Now Available: Recordings from Recent Events

Advocacy Weekend Information Session

Learn more about Advocacy Weekend in Washington, D.C. this July. During this session, you'll hear what to expect during the 3-day event and how advocating, sharing your story, and connecting with lawmakers can help bring greater awareness, funding, and progress for sarcoma research and patient care. **Watch the recording here**.

Are you interested in registering for events held during Advocacy Weekend (July 16th-18th, 2026)? **Learn more and sign up here**.

March Live with the Experts Webinar



Building on our foundational session, An Introduction to ctDNA in Sarcoma, this next installment moves the conversation forward—addressing emerging research, practical considerations, and the real-world questions patients and clinicians are navigating today.

Watch the recording here.

Clinical Trial Matching Service

SFA offers a free clinical trial matching service through Carebox Connect to help people affected by sarcoma explore potential clinical trial options. By answering a brief set of questions about diagnosis, treatment history, and preferences, patients and caregivers can receive information about clinical trials that may be relevant to their specific situation. The platform simplifies complex eligibility criteria into easy-to-understand summaries and can connect users with study teams to learn more about participation. Users can also save their profile and receive notifications about newly available trials.

Access the Clinical Trial Finder **here** and explore more clinical trials information **here**.

RESEARCH ROUNDUP

Highlighted Research

By Dean Frohlich, PhD

This month I would like to highlight four recent publications in a variety of sarcoma subtypes. In the first publication, "**IMMUNOSARC II Master Trial: Phase II Study of Sunitinib and Nivolumab in Clear Cell Sarcoma Cohort,**" based on a previous clinical trial researchers expanded the study of a combination of drugs in the ultra-rare sarcoma called Clear Cell Sarcoma. In this Phase II clinical trial, they treated patients who were confirmed to have Clear Cell Sarcoma and were 12 to 80 years old with the combination of sunitinib, which is a drug that selectively block proteins called tyrosine kinases, and nivolumab, which releases the brakes that tumors put on patients' immune system by blocking a protein called PD-1 receptor on a specific type of immune cells called T cells. The primary end point was the 6-month progression free survival (PFS) rate with goal of having at least 10 of 23 patients' progression-free at 6 months. Twenty-three patients were evaluable for the primary end point at the cutoff. With a median follow-up of 23.0 months, the 6-month PFS rate was 50.1% with a median PFS of 6.2 months. Additionally, of the 21 patients who underwent at least 1 radiological assessment, 3 (14.3%) had a partial response, 14 (66.7%) had stable disease, and 4 (19.0%) had progressive disease. The median overall survival was 17.0 months. Additional analysis indicated that an increased expression of PD-1 was associated with better PFS. Conclusions: Additional studies are required, but these results indicate that nivolumab plus sunitinib could be useful Clear Cell Sarcoma management.

Previously, expression of a protein called HER2 had been identified as a potential target in Desmoplastic small round cell tumor (DSRCT). In the second study, "**Trastuzumab Deruxtecan Is Active in Desmoplastic Small Round Cell Tumor**," investigators used an antibody drug conjugate (ADC) called fam-trastuzumab deruxtecan (T-DXd), in which an antibody to HER2 (trastuzumab) is chemically linked to an inhibitor of a protein called topoisomerase (deruxtecan) which can kill the tumor cells. The ADC allows the deruxtecan to be targeted to the tumor increasing the concentration in the tumor while decreasing the side effects to the patient.

In this small study, the tumors of 19 DSRCT patients with DSRCT were tested by two methods for HER2 expression when possible and received off-label T-DXd. Results indicate that 9 of 17 patients with measurable disease had a partial response by RECIST criteria and the other 8 patients had stable disease. However, the responses did not correlate with either of the HER2 test results indicating that these tests are not a good biomarker for response to this drug.

These data are early and additional studies are needed and underway, but they indicate that T-DXd may be a viable option for treatment in DSRCT.

Next, in "**Safety and Efficacy of Epirubicin, Ifosfamide, and Nivolumab as First-line treatment for patients with Undifferentiated Pleomorphic Sarcoma**," investigators conducted a single-arm, phase Ib trial to determine the safety and preliminary efficacy of epirubicin (a chemotherapy that forms a complex with DNA and interrupts DNA replication), ifosfamide (a chemotherapy that works by damaging DNA and inhibiting cell replication), and nivolumab (a PD-1 receptor inhibitor as mentioned above) as first-line treatment for advanced Undifferentiated Pleomorphic Sarcoma (UPS). Only adult patients with a confirmed UPS diagnosis were eligible.

Sixteen patients were enrolled and a phase II recommended dose was determined. A preliminary objective response rate was 68.8% with a median progression free survival of 9.9 months. These results are quite early; however, the data indicate the combination of epirubicin, ifosfamide, and nivolumab is a safe and may be effective the treatment of advanced UPS.

Lastly, in "**Pleomorphic rhabdomyosarcoma, outcomes of patients with advanced disease treated with systemic agents: Retrospective study from the global pushing ultra-rare sarcomas towards hope (PUSH) consortium,**" a global consortium of investigators conducted an analysis of database records of patients confirmed to have pleomorphic rhabdomyosarcoma at 21 sarcoma centers from around the world from 2013-2023 to determine the outcomes patients treated with systemic therapies. They analyzed a total of 77 patients and found that from the start of treatment anthracycline-based treatments (chemotherapies that work through a variety of ways to stop tumor growth) had a 50% objective response rate, with median progression free survival of 5.2 months and median overall survival of 19.2 months. Gemcitabine-based treatments (a chemotherapy that interferes with DNA synthesis) had a 42% objective response rate with a median progression free survival of 3.7 months and a median overall survival of 7.8 months. Additionally, pazopanib (a drug that selectively block proteins called tyrosine kinases) had a 33% objective response rate with median progression free survival of 2.4 months and a median overall survival of 4.2 months.

Although retrospective and observational, these analyses indicate that pazopanib, and anthracycline- and gemcitabine-based regimens may have activity in patients with pleomorphic rhabdomyosarcoma. Further research is necessary and prospective validation is planned.

Clinical Trials Corner

A Phase 2 Trial of Zanzalintinib in Advanced/Metastatic Bone Sarcomas (ZAMBONE)

ZAMBONE is a Phase 2 clinical trial testing a therapy called zanzalintinib, an oral targeted therapy, in adults with advanced or metastatic bone cancers that cannot be removed with surgery or have spread to other parts of the body. This study aims to evaluate whether zanzalintinib can slow or stop cancer growth when used alone in people whose disease has worsened after standard treatments., while also identifying biomarkers that may predict benefit.

The trial includes patients with osteosarcoma, Ewing sarcoma, chondrosarcoma, and other rare bone sarcoma subtypes. Researchers will primarily measure how long patients' cancer remains stable after starting treatment, while also tracking tumor shrinkage, overall survival, and side effects. In addition, tumor samples collected before and during treatment will be analyzed to identify biomarkers that may help predict who benefits most from the drug. To join this study, participants must be 18 years or older and have a confirmed diagnosis of a bone cancer that cannot be removed by surgery or has spread to other parts of the body. Participants must have already tried at least one standard treatment for their cancer (unless no standard treatment exists), and they cannot have received more than two prior drug treatments for advanced disease.

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.

Turning Patient Experience into Progress

By Kelley Argraves, PhD

New research highlights gaps in patient experience data and why your voice matters.

A newly published study, "Burden and Unmet Needs of Liposarcoma in the United States: Patient Perspectives on the Diagnostic Journey," co-authored by Brandi Felser, Chief Executive Officer of the Sarcoma Foundation of America (SFA), highlights gaps in how the sarcoma patient experience is captured in traditional clinical data. The research provides a valuable window into the real-world patient journey from diagnosis through treatment and reinforces the importance of directly capturing patient perspectives.

The findings point to several persistent challenges, including delays in diagnosis, inconsistent awareness and use of biomarker testing, and the burden of traveling long distances to access specialized care. Patients also reported variable quality-of-life outcomes and often relied on peer communities and social platforms for information and support. Together, these insights underscore a critical gap: while clinical trials and medical records provide essential data, they do not fully reflect the lived experience of patients navigating sarcoma.

Studies like this are an important step forward, but they also highlight a key limitation. There is still not enough patient-reported data to fully understand the breadth of experiences across sarcoma subtypes. Expanding this knowledge is essential to identifying unmet needs, improving care, and guiding research and advocacy efforts in a more patient-centered direction.

Building on this momentum, SFA is preparing to relaunch its patient survey to capture a broader and more representative picture of the sarcoma journey, including diagnostic pathways, treatment decisions, access to care and clinical trials, and the day-to-day impact of living with sarcoma.

Participation will be critical. Every patient and caregiver perspective helps fill gaps that cannot be addressed through clinical data alone. If we want research, care, and policy decisions to better reflect the realities of living with sarcoma, we need to ensure those experiences are captured.

When the SFA survey relaunches, we encourage you to take part and ensure your experience is represented.

Take the SFA Patient Survey **here**. Read the full publication **here**.

SFA Global

Highlights from ESMO Sarcoma & Rare Cancers Congress 2026

By Pan Pantziarka, PhD

The ESMO Sarcoma and Rare Cancers congress took place in Lugano, Switzerland, March 12 - 14. This is an annual event that brings together doctors, research scientists, patient advocates and pharma companies from all over the world. A team from SFA attended, allowing us to keep abreast of the latest developments across the whole range of sarcoma types and subtypes. Hot topics included immunotherapy, an area that has so far produced disappointing results in many sarcomas, but which remains of intense interest. In some more common cancers immunotherapy has been a game changer, the challenge we face is how to increase the number of sarcoma patients who respond to these treatments, and to lengthen the duration of those responses. Multiple sessions touched on this, showcasing the activity that is going on in different labs and clinics.

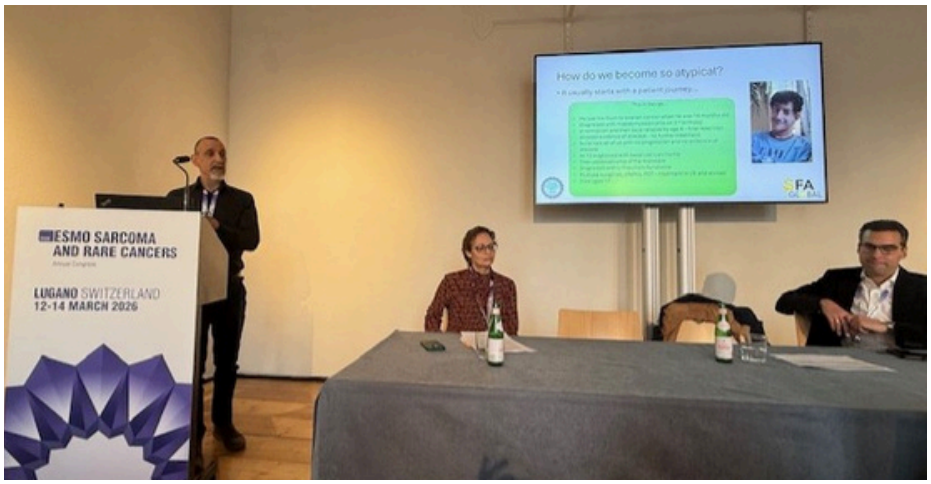
Bone sarcomas were also on the agenda - with presentations on the state of play in chondrosarcoma, osteosarcoma and Ewings sarcoma. These are all diseases where outcomes have not improved in decades. However, the encouraging thing is the scale of the work being done now. With new drugs showing promise in chondrosarcoma and Ewings sarcoma in particular. Also encouraging is the work being done on trial design, looking to streamline processes and come up with innovative ways to test new drugs.

Other major topics included liquid biopsies and tumor-agnostic therapies. The latter aims to target aspects of cancer biology that is present in multiple sarcoma types, so instead of looking at treatments on a sarcoma-by-sarcoma basis, we develop treatments that can be applied to multiple sarcomas at the same time. The idea shows great promise, but there is still a long way to go as researchers untangle the pathways of DNA damage response and other relevant mechanisms.

The congress also included a patient advocacy track, with multiple sessions and workshops during the last two days of the meeting. Topics included patient involvement in clinical trials, the value of expert centres, health technology assessment, the value of guidelines and more. These were part training but also involved discussion with health care professionals seeking to integrate the patient voice into key processes that move medicine forward. In the opening session of this patient advocacy track, I presented on a key issue for sarcoma patient advocacy - capacity. Our voice carries increasing weight with regulators, policy makers, research funders

and the research community. But to be effective we need advocates who have experience, knowledge, confidence and a willingness to ask difficult questions. My talk highlighted these needs and discussed how we can increase the number of engaged, passionate and effective patient advocates. This is a topic that SFA is working hard on, with a comprehensive Research Advocacy program in development.

The value of congresses like this one goes beyond the conference presentations themselves, it's the chance to speak directly with the clinicians and researchers face-to-face, to ask questions during the Q&A sessions and to meet with collaborators from across the globe. That's what makes such meetings valuable in moving our mission forward.



Pan Pantziarka, presenting at ESMO 2026

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.

In this episode, we sit down with Kate DeForge, who was diagnosed with undifferentiated pleomorphic sarcoma as a young adult. Kate opens up about what it's been like navigating young adulthood with sarcoma and shares the mindset and philosophy that have shaped how she lives her life since her diagnosis.

We're also joined by Kate's sister, Kristen, who offers her personal perspective on being on the sarcoma journey with a sibling. She reflects on her role in Kate's care and how she helps bring a sense of normalcy to everyday life.

It's immediately clear that Kate and Kristen are a dynamic duo. They balance one another, communicate with the unspoken understanding that only siblings share, and together tell a powerful, honest story of how sarcoma is truly a family disease. Listen here

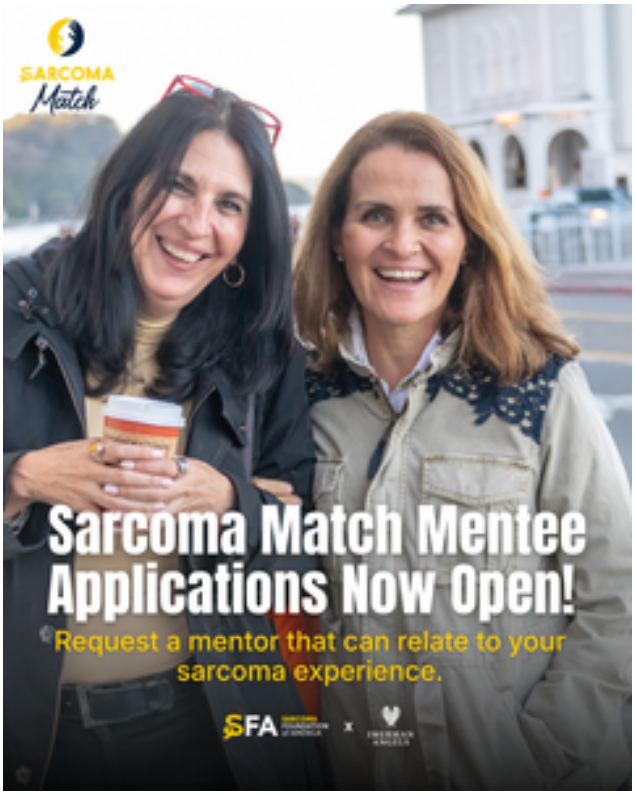
Listen to all episodes of the Sarcoma Stories podcast

Adolescent and Young Adult (AYA) Cancer Awareness Week is April 6-10

Adolescents and young adults (ages 18–39) diagnosed with sarcoma face unique challenges at a pivotal time in their lives. This AYA week we want to hear from our AYA community about their experience so we can help understand their challenges, needs, and how we can better support them.

If you are an AYA who has been diagnosed with sarcoma, please take our quick survey. Thank you! Take the survey here.

Sarcoma Match: SFA's peer-to-peer mentorship program powered by Imerman Angels



You do not have to face sarcoma alone. Through Sarcoma Match, our free peer-to-peer support program with Imerman Angels, patients, survivors, and care partners can be matched with a mentor who understands the sarcoma journey firsthand.

Through this partnership, we are working to reduce isolation and foster meaningful connections through shared experiences so that every person impacted by sarcoma has someone to turn to.

Find connection and guidance by signing up today to be matched with a mentor. If you would like to be a mentor, you can find more information here.

SFA NEWS

SFA Office Moves to Bethesda

After more than 25 years headquartered in Damascus, Maryland, SFA has relocated its offices to Bethesda. This move marks an exciting new chapter for the organization as we continue to expand our impact for people impacted by sarcoma.

Our new location places us closer to key partners in research, policy, and healthcare, strengthening our ability to advance awareness, accelerate funding for innovative research, and support patients and families nationwide.

While our physical location has changed, our mission has not. We remain steadfast in our commitment to improving outcomes for people diagnosed with sarcoma. We look forward to continuing this work from our new home and thank you for your ongoing support.

Our new address is:
Sarcoma Foundation of America
7700 Wisconsin Ave Suite 310
Bethesda, MD 20814

Please update your records accordingly. All other contact information remains the same.

Save the Date for the 2026 Stand Up to Sarcoma Gala

RACE TO CURE SARCOMA

Why I Race: Laura Groves, RTCS Boston

In May of 2024, I was diagnosed with Sclerosing Epithelioid Fibrosarcoma (SEF). I was two months postpartum after giving birth to my second baby. Being diagnosed with an ultra-rare cancer left me shocked, confused, and scared for the journey ahead. These feelings are still very prevalent today. However, over the past two years, I realized I still have a choice on how I live my life amid cancer. I've learned to focus more on what I can control. Through all the various treatments and unexpected turns, I remind myself to keep going. What fuels that mindset, are the people that love and support me everyday. My kids, my family, and friends.

Last year, when I was introduced to SFA's Race to Cure Sarcoma, I saw it as a way not only to support the sarcoma community and the critical need for research and awareness, but also a way to invite those around me into something that now has such a profound impact on my life and my family. I'm so grateful I signed up, because despite the rain, the event filled me with so many positive emotions and an overwhelming sense of gratitude and hope. I was deeply thankful for everyone who showed up, and so proud of what we were able to accomplish together through fundraising. Most importantly, it was a day of fun spent with people I love and with others who understand what it means to be impacted by sarcoma.

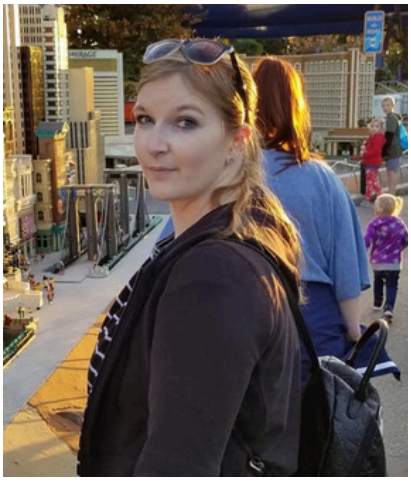
To those of you fighting sarcoma, or supporting loved ones with sarcoma, keep going!

Be part of something meaningful—join Laura at RTCS Boston on May 17th and help raise funds for sarcoma research. **Sign up here!**

Sign up For RTCS in a city near you!

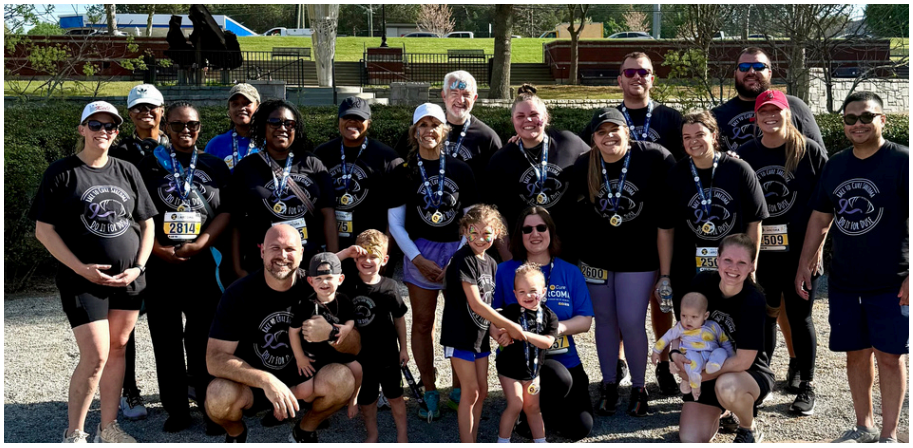
Why I Race: RTCS Atlanta

RTCS Atlanta is on Saturday, April 4th and you can still sign up! When you participate in Race to Cure Sarcoma, and donate to SFA, you are supporting more than 200,000 patients and their families who are impacted by sarcoma. Your generosity helps SFA continue to be the leading voice for the sarcoma community, enabling us to make investments in cutting-edge research and increasing sarcoma awareness. **Sign up here**!



I participate in memory of my younger sister who died from Uterine Sarcoma in 2021 at the age of 37. I want to raise awareness and funds to help others and to keep her memory alive.

-Wendy Artman



Race for Sarcoma means to me giving other families who are affected by this disease a chance to have resources, research and support to help give their loved ones the best chance at beating this disease. I am and forever with be racing in memory of my brother Matthew Van Dusen that fought with everything he had to be here for his family and friends.

-Briana Moore

Wherever You Are, You Can Race to Cure Sarcoma

The Race to Cure Sarcoma Global Virtual event allows you to participate from wherever you are. Run, walk, or move on your own schedule while raising critical funds for sarcoma research and honoring those affected by this disease. Whether you take part in your neighborhood, on a favorite trail, or on a treadmill, every step helps move us closer to better treatments and cures. Join us from around the world and help us reach our goal!

Register here to join the Global Virtual Race.

Run with Team SFA at the 2026 Marine Corps Marathon

Registration is now open to join Team SFA at the Marine Corps Marathon on October 25, 2026, in Arlington, VA. Run in support of sarcoma patients and their families while taking part in one of the nation's most iconic races.

As a proud partner of the Marine Corps Marathon, SFA's Marathon Teams have raised nearly $100,000 for sarcoma research, and we look forward to continuing that impact in 2026.

To join the team, contact Annie Blake at ablake@curesarcoma.org Runners who already have a race entry are also welcome to join Team SFA and fundraise in support of SFA's mission. Learn more

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Sign up for SFA's 2026 Race to Cure Sarcoma Events!

More than just a race, Race to Cure Sarcoma events are 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!