July 2026

Many Voices. Real Action. Lasting Change.

July is Sarcoma Awareness Month, and as we begin this important month, I first want to express my sincere gratitude to U.S. Senator Ron Johnson for once again championing the Sarcoma Awareness Month Resolution in the Senate. Having leaders in Congress who recognize the unique challenges facing the sarcoma community and are willing to shine a light on our needs is incredibly important. We are grateful for advocates who help ensure our voices are heard.

As I reflect on this year's Sarcoma Awareness Month theme "**Many Voices. Real Action. Lasting Change.**" I'm reminded of what makes this community so remarkable.

Sarcoma is not one disease. It is many subtypes, many diagnoses, many experiences, and many individual journeys. Yet despite our differences, we are

united by a common goal: creating lasting change and improving outcomes for everyone affected by sarcoma.

But lasting change doesn't happen on its own. It requires action.

At the Sarcoma Foundation of America, our action is focused on what matters most:

Education. Every person diagnosed with sarcoma deserves access to reliable information, meaningful participation in their care, and medical professionals equipped to treat sarcoma wherever patients receive care.

Advocacy. We work to bring together the collective voice of the sarcoma community, representing all sarcoma subtypes—to advance policies and priorities that improve outcomes and quality of life.

Research. We are committed to building a strong pipeline of innovative research that will lead to more effective, less toxic treatment options and, ultimately, better futures for patients and families.

SFA is proud to be the leading organization representing all sarcoma subtypes and driving efforts to create lasting change. But the truth is, we cannot do it alone.

Our greatest strength has always been our collective voice.

Every action matters. The big things and the small things. Clicking "share" or “like” on a social media post. Wearing yellow. Displaying a yard sign. Participating in an event. Starting a fundraiser to support research. Asking a local landmark, business, or community space to light up yellow in honor and memory of those impacted by sarcoma.

These actions may seem small on their own, but together they create something powerful. Together, they raise awareness. Together, they amplify our message. Together, they move us closer to the change we all want to see.

That is how lasting change happens, not through one voice, but through many voices coming together with purpose and determination.

I hope you'll join us this month and throughout the year. Every voice matters. Every action counts. And when we stand together as one sarcoma community, there is no limit to what we can accomplish.

The tide is rising, and SFA is proud to lead the charge.

With gratitude,

Get Involved with Sarcoma Awareness Month

July is Sarcoma Awareness Month, a time for the sarcoma community to come together to raise awareness, advocate for better therapies, and support everyone impacted by this rare cancer.

In 2026, the U.S. Senate unanimously passed a resolution designating July as National Sarcoma Awareness Month, recognizing sarcoma as a rare and often misdiagnosed cancer that affects both adults and children. The resolution calls for increased national awareness and encourages timely, accurate diagnosis and treatment.

This recognition is a meaningful moment for the sarcoma community. It was inspired in part by the life and legacy of Melissa Locke, who died from synovial sarcoma in 2017 at the age of 38, as well as the countless others impacted by this disease. Melissa's husband, Brendan, has continued to share her story and advocate for greater sarcoma awareness, including efforts to help establish July as National Sarcoma Awareness Month.

Every voice matters — and together, we can influence policy, raise awareness, and improve outcomes for people affected by sarcoma.

Throughout July, we'll share ways you can get involved to raise awareness about sarcoma and help advance meaningful progress in research, treatment, and support for those affected. No matter how sarcoma has touched your life, there is a place for you to join the movement.

Every voice matters. Every action counts. Together, we are creating meaningful momentum toward progress in awareness, support, and research. Thank you for joining us!

Sarcoma Awareness Month Events:

- All Month: Streaming for Sarcoma
- July 8: Wear Yellow Wednesday
- July 11: Race to Cure Sarcoma Milwaukee
- July 15–18: Sarcoma Community Advocacy Weekend
- July 18: Race to Cure Sarcoma Washington, D.C.
- July 18: Race to Cure Sarcoma Global Virtual
- July 21: Children's Artwork Contest submissions due
- July 24: Light Up for Sarcoma

Learn More and Get Involved

It's Not Too Late to Join the Sarcoma Community at Advocacy Weekend 2026

2025 Advocates

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

It's not too late to register and join SFA in Washington D.C. July 15-18 for Sarcoma Advocacy Weekend. This impactful weekend will include:

- **Congressional Reception 7/15:** Spend the evening with members of Congress, legislative staff, sarcoma patients, advocates, and medical professionals to raise awareness and foster meaningful dialogue about our key policy priorities. The reception will take place from 5-7PM at the Rayburn House Office Building. Light refreshments will be served.
- **Sarcoma Community Advocacy Day 7/16:** Join us as we flood The Hill with yellow to meet with elected officials and share your story to advocate for increased research funding and improved access to care for sarcoma patients. We have headquarters for the day at the Cannon House Office Building and will begin and end the day in this space. Breakfast and lunch will be served, and the space will be available throughout the day for you to take breaks between meetings.
- **Education Day 7/17:** Gain an insider's view of how new sarcoma treatments move from discovery to patients. Hear directly from leaders in research, government, industry, and advocacy as they discuss drug development, clinical trials, regulatory engagement, research funding, and the growing role of patient advocates in shaping the future of sarcoma care. Interactive discussions and small group sessions will provide practical insights on how advocates can make a meaningful impact. Can't make it to Washington D.C. but still want to participate in education day. Register to join virtually here!
- **Race to Cure Sarcoma 7/18:** Join sarcoma patients, survivors, caregivers, advocates, researchers, clinicians, and supporters for SFA's signature run/walk event. Whether you run, walk, cheer, or participate in honor of someone affected by sarcoma, you'll help raise awareness, celebrate resilience, and support critical research efforts. Race entry will be covered by SFA for anyone joining us for other Advocacy Weekend events (discount code to be provided). Participants are encouraged to set-up a team and fundraise to support SFA's mission of research, education and advocacy.

To register for Advocacy Weekend please visit our website and complete the registration form.

Research Roundup

FDA Grants Full Approval to Tecelra® for Advanced Synovial Sarcoma

The U.S. Food and Drug Administration (FDA) has granted full approval to Tecelra® (afamitresgene autoleucel, afami-cel) for eligible patients 12 years of age and older with synovial sarcoma that cannot be removed with surgery or has spread to other parts of the body and has progressed following chemotherapy.

Tecelra first received accelerated approval in 2024. Full approval means the FDA has reviewed additional clinical evidence confirming the treatment's benefits, moving it from accelerated to traditional approval. The expanded approval also includes adolescents as young as 12 years of age, making Tecelra the first engineered T-cell therapy approved for children with a solid tumor.

Tecelra is a personalized immune cell therapy that uses a patient's own T cells to recognize and attack cancer. A patient's T cells are collected and genetically modified to recognize a protein called MAGE-A4 that is found on some synovial sarcoma tumors. The modified cells are then returned to the patient, where they help the immune system identify and destroy cancer cells. Not every patient with synovial sarcoma is eligible for this treatment. Patients must have tumors that express the MAGE-A4 protein and have a specific inherited immune system marker called HLA-A*02. Testing for both biomarkers is required before treatment can be considered.

The FDA based its decision on results from the Phase 2 SPEARHEAD-1 trial. Nearly 44% of patients whose advanced synovial sarcoma had progressed after chemotherapy experienced tumor shrinkage after treatment with Tecelra, and some responses lasted two years or longer. By comparison, studies of other treatment options for patients with previously treated advanced synovial sarcoma have found response rates that have generally been below 15%, helping put these results into perspective. [NB1.1][NB1.2][KA1.3]As with other cellular therapies, Tecelra carries important risks, including cytokine release syndrome (CRS), and treatment requires close monitoring at a specialized treatment center following infusion.

What This Means for Patients

Full FDA approval provides greater confidence that this therapy offers meaningful benefit for appropriately selected patients with advanced synovial sarcoma. It also reinforces the growing importance of biomarker testing, since determining both MAGE-A4 expression and HLA type is essential to identifying patients who may benefit. Patients with advanced synovial sarcoma who have not undergone this testing should consider discussing it with their healthcare team. While not everyone will be eligible for Tecelra, this approval represents another important step forward in expanding treatment options for people living with synovial sarcoma.

Highlighted Research

By Nigel Brockton, PhD

Every month, researchers answer more questions about sarcoma, and we try to share some highlights of those advances here. The two studies below illustrate very different but important insights. The first addresses the potential impact of common, non-cancer medications, on immunotherapy outcomes. The second described an elegant approach to potentially enhance responses to immunotherapy in tumors that are typically resistant.

Managing Many Medications

Concomitant medications are medications taken during the same period of another medication. Almost all cancer patients receive medications in addition to the primary therapy for their cancer, either for the management of pre-existing chronic conditions or for symptom management. Concomitant medications can influence the outcomes of immunotherapy in other solid tumors, but this new study has investigated the impact on immunotherapy in patients with advanced or metastatic sarcoma.

The research team pooled seven existing clinical trials to examine 321 sarcoma patients with an average of four years follow-up in a range of sarcoma subtypes. Anti-infective, such as antibiotics and antivirals, were associated with shorter progression -free survival (PFS) and the use of vitamins/minerals/supplements/ herbal products was associated with longer PFS. No class of medications was significantly associated with objective response rate (the observable impact of the therapy on tumor burden) or therapy-related adverse events.

The timing of anti-infective therapy, during active immunotherapy treatment, was particularly linked to poorer outcomes. This insight could help clinicians schedule treatment around the administration of other necessary therapies. The authors caution that the observed impact of vitamin/supplement use could potentially simply reflect other patient factors such as nutritional and socioeconomic status rather than a direct effect of the supplements.

*Concomitant Medication Effects on Immunotherapy Outcomes in Sarcoma: A Pooled Post Hoc Analysis of Seven Phase II Trials*Shahnam et al., Cancer Medicine15, no. 6 (2026): e72066 https://doi.org/10.1002/cam4.72066.

CRISPR activation STINGing Sarcomas

Immunotherapy has yielded disappointing treatment outcomes in many soft tissue sarcomas. Immunotherapy requires that immune cells infiltrate into the tumor and recognize tumor cells as foreign or dangerous. Unfortunately, immune infiltration into soft tissue sarcomas is lower than observed in immunotherapy-responsive cancers.

Godsk and colleagues discovered that immune cell infiltration into tumors was correlated with the presence of the STING (Stimulator of Interferon Genes) pathway in soft tissue sarcomas, in a newly established cohort of 120 patients.

The team then used a system called CRISPR activation to restore STING signaling in soft tissue sarcoma cells. CRISPR is a DNA editing technique for which the Nobel Prize was awarded in 2020. However, CRISPR activation is a new approach that has not yet been tested in humans. Godsk used lipid nanoparticle (LNP)–mediated delivery of CRISPR activation to reactivate STING signaling and promote T cell recognition and tumor cell killing in laboratory tests of sarcoma cells.

Together, these results show that controlled activation of STING in immune “cold” tumors can enhance immune infiltration and tumor cell killing. Targeting STING through CRISPR activation may represent a promising therapeutic strategy for soft tissue sarcoma.

Restoring STING expression in soft tissue sarcoma increases activation and function of tumor infiltrating lymphocytes Godsk et al., Cancer Immunology, Immunotherapy, (2026). https://doi.org/10.1007/s00262-026-04455-3

Clinical Trials Corner

DS-2243a for Synovial Sarcoma, Myxoid/Round Cell Liposarcoma and Other Advanced Cancers

A new Phase 1 clinical trial is evaluating DS-2243a, an investigational immunotherapy designed to target cancers that express a protein called NY-ESO-1. Researchers are studying whether the treatment is safe and whether it may help control tumor growth in people with advanced cancers.

The study is enrolling adults with advanced or metastatic synovial sarcoma, myxoid/round cell liposarcoma, certain types of non-small cell lung cancer, and urothelial (bladder) cancer. Participants must also be positive for HLA-A2, a genetic marker required for the treatment to recognize cancer cells. While the study is open to people with a variety of advanced cancers, one expansion cohort is specifically enrolling patients with synovial sarcoma and myxoid/round cell liposarcoma. These sarcoma-specific groups will help researchers better understand how the treatment performs in these rare cancers.

This first-in-human Phase 1 study will evaluate the safety of DS-2243a, determine the recommended dose for future studies, and look for early signs of anti-tumor activity. Researchers will also measure outcomes such as response rate, progression-free survival, and overall survival. The trial is currently recruiting at sites in the United States and internationally. U.S. locations include Dana-Farber Cancer Institute in Boston, Memorial Sloan Kettering Cancer Center in New York, and Sarah Cannon Research Institute in Nashville.

Patients interested in learning more about the study can visit ClinicalTrials.gov (NCT06644755) or contact the study team at CTRinfo_us@daiichisankyo.com. Participating patients in need of additional travel or financial support may apply for assistance from SFA.

SFA Global

Why Sarcoma Awareness Matters: Expanding Knowledge, Access, and Advocacy

By Pan Pantziarka

As July is sarcoma awareness month, we can reflect on why it's necessary to have focus on awareness. A key question we have to ask is awareness for whom? There are many answers to this - depending on who the person is, where they are located and what their background is. For example, sarcoma patients need to be aware of things like access to specialized sarcoma care. We all know that sarcomas are rare, and in some cases ultra-rare, so being treated in a centre that has experience of treating sarcomas can make a difference in quality of care and in treatment outcomes. Access to such care is not always easy - it often involves travel, expense and additional levels of stress. In places like Europe, access to sarcoma specialized centres varies by country, with some countries having very few or no sarcoma specialists. In low and middle-income countries this is often the default case - for example a study published in the journal Bone and Joint Open last year reported on access to sarcoma centres by region and found that while in Europe the proportion with access was 54% and in Australasia 63%, in North America it was 37% and Asia 33%, whereas for Latin America and the Middle East it was 14% and in Africa it was 0%. The overall global figure was 40%, which is too low but also masks the disparity of access.

The awareness question is also key when thinking of family doctors, emergency room physicians, nurses and others who the first points of contact for sarcoma patients on their diagnostic journey are often. The rates of misdiagnosis for sarcomas are high, and of course the effects can be serious - from receiving incorrect treatments to long delays and multiple investigations before the correct diagnosis is made. These delays can have serious long-term impacts; therefore it's of high importance that sarcoma awareness is raised with the non-specialist medical community as a matter of urgency. Organizations like SFA plays a key role here, but so can individual sarcoma patients play a part in educating people on what sarcoma is and how it first presents itself as a problem.

Awareness raising with policymakers is also essential in addressing some of the challenges that the sarcoma community faces. Advocacy weekend is a great example of this - please sign up to take part in this important activity. So many of the issues that we face - lack of research funding, difficulties in drug

approvals, clinical trial regulations that disadvantage rare cancers and so can be changed - we just need to convince policymakers that it's important. The same challenges exist globally; it is not just an issue that is unique to one part of the world.

Finally, as sarcoma advocates, we also need to raise our own levels of awareness. Our voice is increasingly being sought to provide input to research questions, regulatory changes, pharma company developments and more. To maximise the power of our input, to increase our reach, we need to be be knowledgeable, considered and able to generalise beyond our individual experiences. To this end SFA is developing a comprehensive research advocate training program. We are working with leading experts from within the sarcoma community to build a program that promises to empower the next generation of sarcoma patient advocates.

Advocacy and Engagement

Supporting Policies That Advance Sarcoma Research and Patient Care

Every year, policymakers and federal agencies make decisions that can directly affect how quickly new treatments are developed, how patients access testing and care, and how rare cancer communities are represented in healthcare policy discussions. As part of its commitment to improving outcomes for people affected by sarcoma, SFA recently submitted comments to the U.S. Food and Drug Administration (FDA) and the Centers for Medicare & Medicaid Services (CMS) on issues that directly affect treatment development, diagnostic testing, and patient access to care.

Expanding Treatment Opportunities Through Drug Repurposing
SFA provided comments to the FDA regarding opportunities to repurpose existing FDA-approved drugs for diseases with significant unmet medical need. For many sarcoma subtypes, treatment options remain limited, and some have no therapies specifically approved for their disease. Traditional drug development can be especially challenging in rare cancers because patient populations are small and clinical trials are often difficult to conduct. SFA encouraged the FDA to prioritize rare cancers when evaluating drug

repurposing opportunities and to consider evidence generated through investigator-initiated studies, academic research programs, natural history studies, patient registries, and real-world data. These sources of evidence are often critical in rare diseases where large clinical trials may not be feasible. By supporting innovative regulatory approaches and recognizing the value of real-world evidence, drug repurposing may help shorten development timelines, reduce costs, and bring new treatment options to patients faster.

Improving Access to Biomarker and Diagnostic Testing

SFA also submitted comments to CMS regarding prior authorization requirements and access to laboratory and biomarker testing. For sarcoma patients, timely testing is often essential for diagnosis, treatment planning, disease monitoring, and identification of clinical trial opportunities. Delays in obtaining approval for medically necessary testing can postpone important treatment decisions and create additional emotional and financial burdens for patients and families. In its comments, SFA urged CMS to adopt patient-centered policies that reduce delays, eliminate unnecessary repeat testing, and prevent patients from being penalized because of administrative barriers. SFA also recommended expedited review pathways for time-sensitive oncology testing and safeguards to protect patients from unexpected financial burdens caused by processing delays.

Advocacy in Action

Rare cancer patients face unique challenges that are often overlooked in broader healthcare policy discussions. Through its advocacy efforts with federal agencies and policymakers, SFA works to ensure that the experiences and needs of the sarcoma community are represented when decisions are made that affect research, testing, treatment access, and patient care. These recent comments are one example of how SFA brings the patient voice directly to decision-makers and advocates for policies that support better outcomes for people living with sarcoma. Advocacy extends beyond Capitol Hill. Every patient, caregiver, clinician, and supporter has a role to play in advancing policies that accelerate research, improve access to care, and expand treatment options for people living with sarcoma. Together, we can help ensure that the voices of the sarcoma community continue to shape the future of cancer research and care.

Listen to the Latest Episodes of Sarcoma Stories Podcast

In recent episodes of Sarcoma Stories, we sit down with patients, survivors, caregivers, and advocates whose experiences inspire and inform the sarcoma community. From navigating diagnosis and recovery to celebrating 25 years of progress, these conversations remind us that no one faces sarcoma alone. Listen wherever you get your podcasts.

Season 2, Episode 14 I Rohini Deivasigamani

In this episode, we're joined by Rohini Deivasigamani, a 25-year-old from New Jersey who was diagnosed with Ewing sarcoma at 14 years old. Now, a decade later, she reflects on her journey from teenage cancer patient to young adult survivor and shares how time and perspective have shaped the way she processes that experience.

Rohini shares not only about her own diagnosis and treatment, but also about her father's cancer diagnosis, which came shortly after hers. She discusses how her understanding of what they both endured has evolved over the years and the lasting impact those experiences have had on her life. Ten years after completing active treatment, she offers a real look at what survivorship means, the challenges and growth that come with it, and how she continues to navigate life beyond treatment.

Season 2, Episode 15 I Brendan Locke

In honor of Sarcoma Awareness Month, Brendan Locke shares the sarcoma journey of his wife, Melissa Locke. Brendan and Melissa have been vital in the advocacy work to get July nationally recognized as Sarcoma Awareness Month and you'll hear the origin story of how they first brought this to their elected officials in partnership with SFA.

Through emotional reflections on Melissa's journey, we discuss why the visibility for sarcoma through a dedicated month is so important and talk about the hope we share that this platform may lead to the funding needed to achieve better treatment options for sarcoma patients.

We are so grateful to Brendan for sitting down with us and have this conversation, and also to Melissa - for all she did for the sarcoma community, and all she continues to inspire through the hope she held. Hope that cannot be extinguished by death.

Listen to all episodes

SFA News

Nurse Appreciation Campaign Raises More Than $14,000 to Honor Sarcoma Nurses

Thank you to everyone who supported our Nurse Appreciation Campaign during National Nurses Month in May. Together, you helped raise more than **$14,000**, exceeding our fundraising goal and honoring the nurses who make a difference in the lives of sarcoma patients and families every day. Through tribute donations, supporters recognized these often-unsung heroes while helping advance SFA's mission. We are grateful for your generosity and for joining us in celebrating the compassion, dedication, and expertise of nurses throughout the sarcoma community.

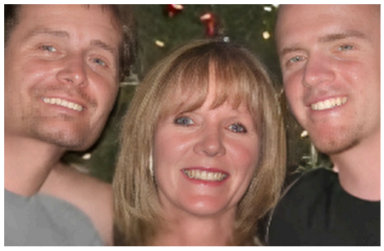
In the Community

Sarcomathon 2026

Join Sarcomathon 2026 on Saturday, July 11, hosted by the Sarcoma Lab at University of Massachusetts Chan Medical School in recognition of Sarcoma Awareness Month.

This virtual event will feature a full day of livestreamed sarcoma research, discussions, Q&As with scientists, research demonstrations, and seminars. Register at tinyurl.com/Sarcomathon2026

2026 Scott Lively Memorial Charity Golf Tournament



Hosted by Scott Lively's friends and family, this memorial golf outing returns on August 1, 2026, at Bears Best Atlanta. Bringing together the community, the tournament celebrates his legacy while raising funds to improve outcomes for those diagnosed with sarcoma. Participants can register to play or make a tribute gift in his memory.

Mitch Kurtz Memorial 2nd Annual Hockey Game

Friends and family of Mitch Kurtz will come together for a memorial hockey game on August 1, 2026, from 5–7 PM at Inwood Ice Arena in Joliet, IL. The event will honor Mitch's life, celebrate his memory, and raise awareness for leiomyosarcoma. Support the event by making a tribute gift here.

Allison's Beer Mile

21st Annual Marcia Brodsky Cure Sarcoma Golf Outing

Allison's Beer Mile returns on Saturday, August 1, 2026 at 5:00 PM at the David and Debbie Meiss farm in Gridley, IL. Join for a run and walk in support of SFA to honor and celebrate the life of Allison McKey.

The 21st Annual Marcia Brodsky Cure Sarcoma Golf Outing will take place on August 7, 2026, at Wind Watch Golf Club in Hauppauge, NY. Hosted by the Brodsky family, this annual charity event brings the community together in support of sarcoma research and treatment, honoring Marcia Brodsky's legacy.

Race to Cure Sarcoma

RTCS Expands to North Carolina in September 2026

SFA is excited to bring Race to Cure Sarcoma (RTCS) to North Carolina for the first time! In partnership with Duke Cancer Institute, RTCS North Carolina will take place on September 13 at WakeMed Soccer Park.

Each year, RTCS events bring together patients, survivors, families, friends, and supporters from around the world, creating moments of connection, remembrance, and hope while raising critical funds for sarcoma research.

We are looking forward to welcoming the North Carolina community into the RTCS family and growing this incredible movement together.

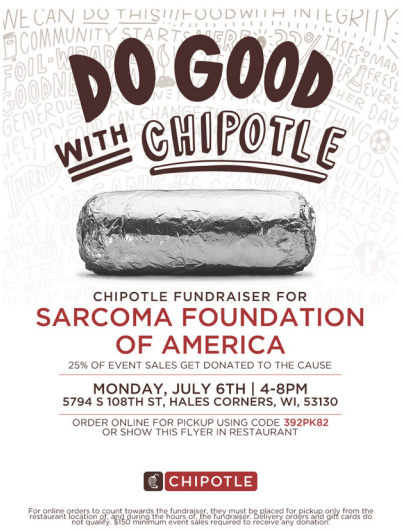
Register or show your support here.

Why I Race: Peggy Huhn, RTCS Milwaukee

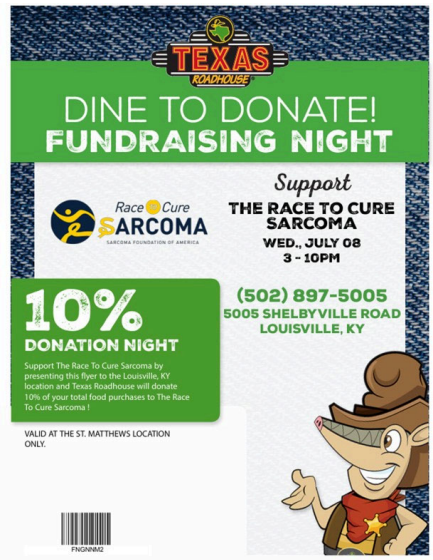
My name is Peggy Huhn. I am a 5 1/2 year Sarcoma Survivor!!!! On February 10, 2021, I was diagnosed with myxofibrosarcoma, a mass within my right hamstring. What has followed are years of treatments including chemotherapies, radiation, immunotherapies, surgeries, ablations and ultimately an amputation of my right leg at the hip in January of 2025. Just when we thought we had this all handled, I learned that it had returned, this time metastasized to my chest … but I am still here!!

I think that is what drives me the most to create our team of “Fork Wanda” for this year’s Race to Cure Sarcoma. I have wanted to participate the last 2 years, but treatments had been preventing me from getting going! On the year anniversary of my amputation (January 23) I was in chemotherapy and my nurse, Lysbeth, told me she was part of the committee … it was a sign! I knew I wanted to do something to commemorate my amputation, Lysbeth was in front of me, and I was once again in the chemo chair …. This was it!!! Because … I am still here!!! And this is my opportunity to raise awareness, fundraise for the cause and …. to celebrate! My team continues to grow, our goal is huge!!! 100 people and $10,000 and we are almost there!

RTCS Giveback Events



RTCS Milwaukee



RTCS Louisville

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

More than just a race, it's a chance to connect with others in the sarcoma community, recognize people living with sarcoma, honor those we've lost, and fund vital sarcoma research. Whether you walk, run, or cheer, you'll be making a difference! Find your city and sign up today!

Upcoming Races

RTCS Milwaukee

7/11

Register

RTCS Washington DC

7/18

Register

RTCS Global Virtual

Register by 7/18

Register

Marine Corps Marathon

10/25

Register

Philadelphia Marathon Weekend

11/20 - 11/22

Register

Los Angeles Marathon Weekend

3/5/2027 - 3/7/2027

Register