

# SARCOMA SPOTLIGHT

JUNE 2025

**ONE  
COMMUNITY  
MANY VOICES  
REAL ACTION  
LASTING  
CHANGE**

**JULY IS  
SARCOMA  
AWARENESS  
MONTH**

Each year, Sarcoma Foundation of America (SFA) commemorates July as Sarcoma Awareness Month. We invite you to join SFA and the sarcoma community as we come together in raising awareness for the needs of people affected by sarcoma. **You can learn about all the ways to get involved on [Page 10](#).**

**No matter how you get involved, you are making an impact!**

## ADVOCACY WEEKEND 2025

Join Sarcoma Foundation of America in Washington, D.C., July 17–19 for [Sarcoma Advocacy Weekend](#). This impactful series of events includes Sarcoma Community Advocacy Day, a Congressional Reception honoring a Member of Congress with the Sarcoma Champion Award, an Education Day, a Dinner recognizing sarcoma advocates with the Advocacy in Action Award, and the Race to Cure Sarcoma, Washington, D.C. to close out the weekend.

### From Loss to Purpose: Liam's Advocacy Story



For Liam, advocacy isn't just about policy — it's personal.

"My family first found out about sarcoma in 2017, when my younger brother was diagnosed with osteosarcoma," he shared. "He had just turned 18, went to prom, and started treatment all in the same week." An avid Eagle Scout who loved hiking and backpacking, his brother initially noticed leg pain that led to the devastating diagnosis.

After undergoing chemotherapy, a knee replacement, and surgery on his lungs, Liam's brother was briefly in remission. But in the spring of 2019, the cancer returned. "It was terminal then," Liam said. "We thought we'd have six months to a year, but we only had three. He passed away in June 2019 — the same week I graduated college."

Tragically, sarcoma struck Liam's family a second time. In 2020, their family dog, Darla, was diagnosed with osteosarcoma. She underwent an amputation and chemotherapy, giving her another year with the family before passing away in 2023.

"Losing both of them was a cruel coincidence," Liam said. "But it's also what deepened our connection to this cause. We started participating in the Race to Cure Sarcoma in Atlanta, and I've continued in DC and Baltimore since then. It's become something that connects us as a family — and connects me to my brother."

That connection has only grown stronger through his work with the Sarcoma Foundation of America (SFA). Liam now serves on the Public Policy Advisory Committee and participated in Advocacy Day last year — an experience he found both powerful and meaningful. "Being able to meet other care partners, those who have been diagnosed, and family members — and then take those shared experiences to Capitol Hill — that was incredibly impactful," Liam said. "SFA did an amazing job preparing us. They provided materials, guidance, and made it easy to tell our stories."

He emphasized the importance of leading with your message. "You're speaking to people who are juggling many issues. It's critical to be clear, concise, and personal. There's so much power in simply sharing your story."

While some offices were more receptive than others, Liam believes every interaction matters. "Some aides were really engaged. Others said, 'We already support cancer research.' But it became clear that many didn't fully understand the unique challenges of sarcoma — or what it means to live with a rare disease. That's why education and awareness are so essential."

This year, Liam is returning for both Advocacy Weekend and the Race to Cure Sarcoma. With proposed cuts to federal cancer research funding, he believes this moment is especially urgent. "Last year, we took for granted that everyone supported cancer research," he said. "Now, even that is at risk. Our basic message — that research funding matters — is more important than ever."

For Liam, these events aren't just about action — they're about healing. "Through both races and Advocacy Day, I've met people who share stories like mine. It's helped me feel more connected to my brother. It gives meaning to our loss."

He recalled one especially moving moment. "Last year, I met someone who had osteosarcoma around the same time as my brother. Working with her through SFA has meant a lot. It's not just about that one weekend — it's given me purpose in my everyday life."

"It's powerful to realize that by sharing our stories and raising funds, we might help prevent someone else from experiencing the same loss," Liam said. "That's what keeps me involved." Join Liam and the rest of our advocacy community at [Sarcoma Advocacy Weekend](#) in Washington, DC, from July 17-19, with July 19 being our [Race to Cure Sarcoma, Washington, D.C.](#)



# STAND UP TO SARCOMA GALA

NYC  
583 PARK  
AVENUE

YOU'RE INVITED

MONDAY  
SEPTEMBER 15TH  
583 PARK AVE NYC

Dinner Event  
Cocktail Attire  
6-10PM EST

## Announcing Our 2025 Compassionate Care Honoree



Sarcoma Foundation of America is honored to announce Christina Kim, NP, of Mass General Cancer Center as the recipient of the 2025 Compassionate Care Award. This award recognizes a patient/nurse navigator for outstanding contributions to patient care, support, or education. We will present this award at our 23rd Stand Up to Sarcoma Gala on Monday, September 15, 2025, in New York City.

Christina Kim is a dedicated nurse practitioner at the Mass General Cancer Center. Her father's experience with cancer inspired her to pursue a career in nursing, earning both her bachelor's and master's degrees. For the past eight years, she has focused exclusively on the care of people diagnosed with sarcoma, providing compassionate, comprehensive support during some of their most challenging moments.

Christina was nominated for the Compassionate Care Award by her patient, Jonathan Gardner. Jonathan shared, "Christina played an essential role in my experience with Ewing Sarcoma, and her compassion, dedication, and unwavering support continue to impact my life today. One of the most memorable things Christina did for me was adapting the traditional pain scale to something that made sense to me as a person who happens to have Autism. The typical smiley face chart didn't work for me, so Christina personalized it using something I love, video games. She created a pain scale based on how long I could play video games, making it easier for me to communicate my pain levels. This thoughtful adaptation showed how much she cared about my individual needs and made my treatment less daunting."

Christina is passionate about delivering holistic, patient-centered care. She strives to address not only the medical needs of her patients but also the emotional and social dimensions of their experience. She believes that cancer care extends beyond the individual, impacting families, relationships, and all facets of life. She is committed to supporting patients and their loved ones every step of the way.

Join us in celebrating Christina Kim, NP, and her remarkable contributions to the sarcoma community at our upcoming gala. **Learn more about the gala at** <https://curesarcoma.org/stand-up-to-sarcoma-gala/>

# RESEARCH ROUNDUP

By Dean Frolich, PhD

This month, we are highlighting three studies that were published. In the first study, "[Genomic, transcriptomic, and immunogenomic landscape of over 1300 sarcomas of diverse histology subtypes](#)" the investigators performed whole exome sequencing and RNA sequencing on over 1,300 total specimens from over 1,200 patients representing 42 sarcoma subtypes. After analyzing this data, they found that there were mutations that occurred repeatedly and there was an increase in mutations in metastatic specimens compared to primary tumors. Additionally, they were able to develop estimates of immune cells in the tumors which clustered into 5 groups from low numbers to high numbers of immune cells with overall survival being lower in tumors with fewer immune cells compared to those with increased immune cells. This study encompasses a large number of specimens in a significant number of sarcoma subtypes and demonstrates that there is important information to be derived from the sequencing of tumor samples across the sarcoma landscape.

Next, in "[Phase II Study of Pexidartinib Plus Sirolimus in Unresectable Malignant Peripheral Nerve Sheath Tumors Identifies M2 Macrophage Activation](#)" the investigators studied if the combination pexidartinib, an inhibitor of a protein called colony-stimulating factor-1 receptor (CSF1R) and sirolimus, which inhibits a protein called mTOR, can inhibit tumor growth in malignant peripheral nerve sheath tumors (MPNST). The goal of using this combination is to target a type of immune cell called M2 macrophages in this sarcoma subtype. A total of 14 patients were treated during this Phase II multi-institutional study. The primary end point of progression-free survival did not improve in patients treated with the drug combination; however additional analysis indicated that in 4 out of the 5 long-term survivors the tumor had an immune-rich environment. These results indicate that additional with this combination of drugs and/or immune therapy studies need to be done in MPNST with an immune-rich environment.

The last paper, "[sarcoma](#)" is an early study in synovial sarcoma, which is an aggressive soft tissue cancer driven by a protein that is a fusion of two proteins called SS18::SSX. This fusion protein, in part, changes how chromosomal DNA is folded and regulated. One outcome of the changes is that chromosomal DNA in synovial sarcoma cells have fewer molecules called methyl groups attached to specific regions of DNA. These investigators used two methods (CRISPR/Cas9 targeting or drugs called decitabine and 5-azacytidine) to further decrease DNA methylation in cell and mouse models of synovial sarcoma. Use of these treatments also led to different proteins being expressed, including the increased expression of proteins known to suppress tumors, and immune-related genes. Although this research is very early, it demonstrates that DNMT1 inhibitors warrant further clinical investigation for synovial sarcoma.

# Revolutionizing Sarcoma Research: SFA-Funded Algorithm Enhances Genetic Analysis

We're excited to share news of a significant advancement in cancer genomics, thanks to an SFA-funded algorithm called [SAVANA](#). This innovative machine learning tool, recently highlighted in Nature Methods, is transforming how researchers detect genetic changes in cancer.

Cancer genomes are complex, and traditional analysis tools can produce misleading results. SAVANA provides a more accurate and reliable method for analyzing tumor genomes, especially with long-read sequencing data. It helps distinguish true cancer-related genomic alterations from other findings, giving us a clearer picture of the mutations that drive cancer.

This breakthrough is particularly impactful for the sarcoma community. SAVANA's capabilities will lead to a better understanding of sarcoma's genetic landscape, paving the way for more precise diagnoses and the development of targeted therapies. SFA is proud to have funded this vital research, underscoring our commitment to accelerating scientific discovery and improving outcomes for people with sarcoma.

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## Clinical Trials Corner

By Kristi Oristian, PhD

This month SFA is highlighting studies that were presented at the 2025 American Society of Clinical Oncology Annual meeting. Studies were presented at varying stages of accrual and analysis, in Phases I, II, and III and spanning multiple subtypes of sarcoma including ultra-rare subtypes. The studies highlighted below are accruing, and we encourage patients to talk to their clinical care teams and care partners about the potential risks and benefits of studies they may be eligible for.

Each study has specific eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations. Patients interested in a specific study should review these criteria with their doctor as well as the potential clinical benefit of participation in the study. To learn more about a study, patients and/or care partners can talk to their doctor, reach out to the study contact or contact the investigator at the study site nearest to them. Participating patients in need of additional travel or financial support may [apply for assistance](#) from SFA.

1. A study investigating [Hypofractionated Radiation for Preoperative Treatment of Patients with Sarcoma](#). This study is open to soft tissue sarcoma patients with tumors of the extremity and/or trunk who are 12 years of age or older.
2. [TAGGED—A phase 2 study using low dose/metronomic trabectedin, gemcitabine, and dacarbazine as 2nd/3rd/4th line therapy for advanced soft tissue sarcoma](#). This study is open to patients with advanced leiomyosarcoma who are 18 years of age or older.
3. [GALLANT: Metronomic Gemcitabine, Doxorubicin, Docetaxel and Nivolumab for Advanced Sarcoma](#). This study is open to patients 18 or older with locally advanced, unresectable, or metastatic sarcoma.
4. A study [Testing Low-Dose Common Chemotherapy \(Liposomal Doxorubicin\) in Combination With an Anti-Cancer Drug, Peposertib, in Advanced Sarcoma](#). This study is open to patients 18 and older with metastatic or unresectable leiomyosarcoma, myxofibrosarcoma [MFS], undifferentiated pleomorphic sarcoma [UPS], synovial sarcoma, or dedifferentiated liposarcoma [DDLPS] for which curative treatment is unavailable.
5. [Ivosidenib in Participants With Locally Advanced or Metastatic Conventional Chondrosarcoma Untreated or Previously Treated With 1 Systemic Treatment Regimen \(CHONQUER\)](#). This study is open to patients with locally advanced or metastatic conventional chondrosarcoma who are 18 years of age or older and have a documented IDH1 mutation.

# SFA NEWS

## SFA Welcomes Three New Staff to the Team

We're excited to expand our team at Sarcoma Foundation of America! We welcome [Danielle Carter](#) as the new Director of Communications and [Andrea Surette](#) as a Communications Manager.

Danielle joined SFA in June 2025, bringing 15 years of public health and healthcare communications experience. She previously led national communications at the CDC, focusing on vaccine safety and healthcare quality. With her Master of Public Health, Danielle will lead SFA's efforts to increase sarcoma awareness, strengthen research advocacy, and amplify the voice of the sarcoma community.

Andrea Surette, a Communications Manager, has over a decade of experience in health communications and program management, including supporting USAID-funded health programs. She holds a Master of Public Health from George Washington University.

We also welcome [Pan Pantziarka](#), Director of Europe Strategy and Engagement, who is joining us from the UK to help SFA expand its global reach. Pan has worked in oncology for nearly 15 years, following the death of his son, George, from osteosarcoma. A scientist focused on sarcoma, cancer predisposition, and drug repurposing, he is also chairman and co-founder of the UK LFS patient organization, the George Pantziarka TP53 Trust, and a co-leader of the Bone Sarcoma Alliance. He brings a PhD in computer science and machine learning.

We are thrilled to have this talented group on board to advance our mission of improving lives for people with sarcoma.

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## Our Latest Episodes of Sarcoma Stories are Live



In our latest Sarcoma Stories episodes, Dan Rubin shares how he's navigated life with Ewing sarcoma since his 2017 diagnosis. From managing treatments and clinical trials to creating a detailed tracking system, Dan opens up about staying informed, active, and hopeful—with the support of his wife, Katharine, by his side.

We also talk to Emily Oberst, one of our 2024 Courage Award honorees, about being diagnosed with Ewing sarcoma as a young teen. When she could no longer play traditional sports, Emily found a new path through wheelchair basketball—eventually competing in the 2024 Paralympics in Paris, where she won a silver medal.

[Listen now](#) and join the conversation in our [Sarcoma Stories Facebook group](#).



# SFA Engages with Global Oncology Community at ASCO 2025



SFA recently attended the 2025 American Society of Clinical Oncology (ASCO) Annual Meeting, held from May 30 to June 3 in Chicago, Illinois. As a leading voice in the sarcoma community, our participation at ASCO 2025 reinforced our commitment to advancing sarcoma research and improving patient outcomes.

The ASCO Annual Meeting is a vital platform for the global oncology community, bringing together top experts, researchers, and patient advocates. Our team engaged with patients, care partners, and medical professionals, distributing valuable information on our discussion guide and patient research survey. We also attended sessions focused on the latest advancements in sarcoma research, ensuring we remain at the forefront of scientific discovery.

Our time at ASCO included productive meetings with industry partners to learn about their ongoing clinical trials and therapies, as well as a valuable discussion with our Medical Advisory Board. Furthermore, we connected with other sarcoma advocacy organizations as part of the Sarcoma Patient Advocacy Global Network (SPAGN), strengthening our collective efforts.

Our presence at ASCO 2025 further strengthens our mission to accelerate scientific discovery and advocate for individuals affected by sarcoma. We continue to work towards a future where people do not die from sarcoma.

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## Sarcoma Community Gathers in Chicago



On May 29, 2025, Sarcoma Foundation of America hosted Mission & Momentum: An Evening of Impact in Chicago.

The event welcomed SFA supporters, partners, and community leaders for a night of reflection, connection, and forward-thinking. Brandi Felser, SFA's Chief Executive Officer, shared key organizational milestones and outlined strategic priorities for the year ahead.



This intimate gathering strengthened community bonds, provided meaningful insights, and reaffirmed our collective commitment to improving the lives of those impacted by sarcoma.

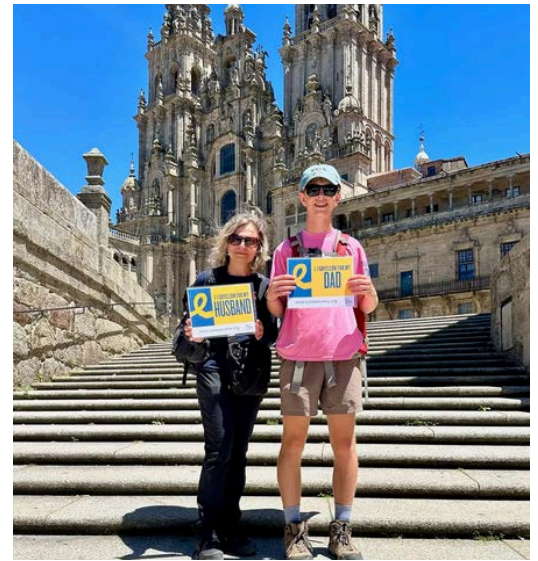
# Reflection

*Blog post from our summer intern AJ Brennaman*

We are approaching one year since the walk! That's absolutely crazy to think about!

In that year, a lot has happened. I finished high school, applied to college (I'll be attending Emory!), and have gotten much more involved with SFA.

At the beginning of the year, my family and I were asked to be the first caretaker perspective on the SFA's new podcast "Sarcoma Stories". In that episode, we spoke about my dad's diagnosis and how we adapted after he passed. It was very emotional to talk about, but hopefully it will help and give hope to another family. If you are interested in listening to the [podcast](#).



At my high school, once AP tests are over, seniors are required to complete an internship or project before graduation. I couldn't think of anything more fitting, so I got in touch with SFA and have been interning here for the past three weeks!

As someone who only saw SFA from the outside, it has been extremely interesting now knowing the inner workings of the organization. I realized that they do so much more work than most might see. Despite how much they do, each department has made time to meet with me and go over the projects they're working on.

During my time here, I've had the chance to support a few really meaningful projects. I've been helping get ready for Sarcoma Awareness Month—specifically the Light Up initiative and the Children's Art Contest. I've also worked on social media outreach, connecting with sarcoma advocates online and helping build new partnerships to expand SFA's reach.

It truly means the world to intern at SFA. With everything they've done for my family and the walk, I've made sure to do my best work.

Huge thanks to them for letting me be a part of the team, and thanks to all of you for sticking with me. Can't wait to see what this next year brings!

Check out AJ's blog [here](#).



# IN THE COMMUNITY

## Strength, Legacy, and Impact: Highlights from the SISU Open

The 2025 SISU Open took place on May 16 at Lost Marsh Golf Course in Hammond, IN, bringing together the sarcoma community in honor of Chris Langbein and his enduring spirit of perseverance.

Thanks to the incredible generosity of participants, donors, and sponsors, close to \$73,000 was raised for sarcoma research.

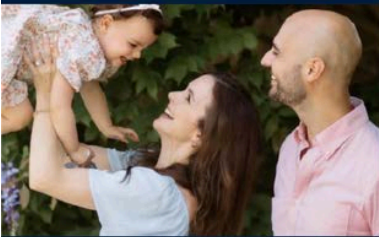
Rooted in the Finnish concept of “sisu”—extraordinary determination in the face of adversity—the event honors Chris’s legacy while supporting the Sarcoma Foundation of America’s work to advance research, explore new treatments, and save lives.

We are deeply grateful to Chris’s friends and family who made this impactful day possible.

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## Upcoming Community Events

### Cornhole Tournament & Picnic Supporting Brian



**REGISTER OR MAKE  
A TRIBUTE GIFT**

Organized by Brian’s community, this Cornhole Tournament and Picnic on July 27, 2025, at Ontario Beach Park in Rochester, NY honors his strength and resilience since his stage IV Alveolar Soft Part Sarcoma diagnosis.

### 4th Annual Scott Lively Memorial Golf Tournament



**REGISTER OR MAKE  
A TRIBUTE GIFT**

Hosted by Scott Lively’s family and friends, this memorial golf outing returns on September 20, 2025, at Bear’s Best Atlanta. The event honors Scott’s strength and spirit, bringing the community together in support of sarcoma research.

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## Baking for a Cause: A Tribute to Their Mom, Andrea



Recently, Paul Dougherty’s 9-year-old daughter, Evelyn, had an idea to hold a bake sale for sarcoma research. She and her brother, Collin, wound up raising over \$600 selling cookies and cupcakes at their stand – and decided they would like to donate all proceeds to SFA honoring the memory of their mother, Andrea. Thank you Evelyn, Collin, and Paul, for your heartfelt and meaningful fundraiser in support of advancing progress and improving the lives of people affected by sarcoma!

# EVENTS

## Ways to Participate in Sarcoma Awareness Month



### **Wear Yellow Wednesday (July 9, 2025)**

#### **2024 Photos**

Every year, members of the sarcoma community take photos of themselves, their friends and family, and even their pets wearing yellow and share them on social media. We invite you to take part in 2025.



### **Sarcoma Advocacy Weekend (July 17-19, 2025)**

#### **Learn More**

SFA invites you to join us in Washington, DC, this July for a full weekend of advocacy, learning, and our Race to Cure Sarcoma Washington, D.C..



### **Light Up for Sarcoma (July 25, 2025)**

#### **Learn More**

Every year, SFA, buildings, monuments, and other locations from across the country light up yellow in support of sarcoma awareness. Add your favorite location!



#### **Children's Artwork Competition**

Young artists are invited to join our annual children's art competition.



#### **Buy Your Sarcoma Yard Sign**

Buy a personalized yard sign to show support and raise awareness.

# Team Tara: Turning Personal Pain into Purpose at the Race to Cure Sarcoma



In late 2024, Tara, president of All Guard Alarm Systems, faced an unexpected health challenge. After weeks of testing for unexplained chest tightness and shortness of breath, doctors diagnosed her with sarcoma, a rare and often hard-to-detect cancer. "It took nearly two months just to get to that diagnosis," shared Sean, Tara's cousin. "They knew something was wrong, but sarcoma isn't something most doctors see every day. It took time, and that waiting was agonizing."

The diagnosis deeply affected Tara's colleagues at All Guard, a close-knit, family-owned business. Feeling helpless, they sought a way to show support. "We asked ourselves—what could we do?" said Kim, a longtime colleague. That's when Team Tara was formed.

The staff decided to participate in their local Race to Cure Sarcoma (RTCS) event. What began as a simple gesture grew into a significant effort. They created matching shirts, shared Tara's story, and sent fundraising links to their network. Tara was overwhelmed when she discovered their surprise. "When she saw the photos of us in Team Tara shirts and realized what we had put together, she was overwhelmed. It gave her strength."

Their efforts were remarkably successful. Through personal outreach, Team Tara raised close to \$10,000 within their immediate connections. Sean noted, "We only really tapped into our first-degree connections. We didn't even go to our broader business network or our clients. If we had used LinkedIn or shared more widely, I think we could have doubled what we raised."

The generosity of their colleagues was particularly touching. "One of the most touching things was seeing employees who don't make much give so generously," Sean said. "Some people who make \$20 an hour were donating \$200. That really shows you what kind of person Tara is and how much people care."

Tara also began sharing her experiences on a personal Instagram account. This became an outlet for her to express herself, provide updates, and connect with others facing similar challenges. "It was a good outlet," Kim explained. "Instead of having to explain everything to everyone over and over, she could post what she wanted to share—and in her own words."

Despite facing multiple rounds of chemotherapy, ongoing fluid buildup in her lungs, and a recent switch to hormone treatment, Tara remains a central motivation for the team. Her strength, humor, and humility continue to inspire everyone around her. Kim reflected, "She's incredibly strong, but this has been a challenge on every level—physically, emotionally, mentally."

Tara's path continues, and Team Tara is committed to supporting her. They are now looking into other ways to help and connect with the sarcoma community. "We want to raise more awareness, get more people talking about sarcoma, and let others know they're not alone," Sean said.

For other teams looking to fundraise, Sean and Kim offer a simple message: make it personal. Share the story. Use every tool available—text, email, social media. Remember that even small acts of support are impactful. "People just want to help. You just have to give them the opportunity. Team Tara's story is a powerful example of how community, compassion, and purpose can come together to advance the sarcoma community. Their success, built on love and genuine connection, truly drives progress."



# Scheinoff Strong: Racing for a Cure and Honoring a Legacy



*The following was shared with us by the Scheinoff family, in honor of their loved one, Richard.*

In October of 2022, Richard Scheinoff passed away from sarcoma at 62 years old. He had been on a 4-year journey with cancer, and he was still the voice of reason in our lives. His diagnosis with this aggressive form of sarcoma left us devastated. In the face of heartbreak, we found strength as a family and made it our mission to honor his legacy through action and with SFA.

Just one week before his passing, his daughter, Kimmie, and her fiancé Max Kohn, planned their wedding in just two weeks so he could be there. We made it work, and it was a day full of both joy

and sorrow, one that we'll cherish forever as a tribute to him. Now we are planning a wedding for Richard's eldest daughter, Stephanie, and his presence will be deeply missed.

The same strength drives our Team Scheinoff Strong, as we fundraise, walk, and run in the [Race to Cure Sarcoma in Philadelphia](#). Through our efforts, we hope to raise critical funds for SFA and ensure that others have more time with the people they love. This fight is deeply personal — and we are proud to stand together, racing for a cure in Richard's honor.

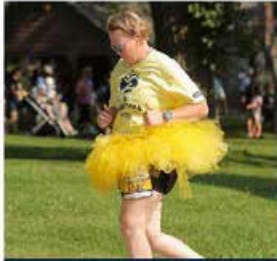


## JOIN OUR MARINE CORPS MARATHON TEAM

LEARN MORE AND SIGN UP



*Race TO Cure*  
**SARCOMA**  
SARCOMA FOUNDATION OF AMERICA



# 2025 DATES

**CLICK BELOW TO REGISTER**

**Cleveland**  
**June 21, 2025**

**Chicago**  
**September 27, 2025**

**Milwaukee**  
**July 12, 2025**

**New Jersey**  
**October 5, 2025**

**Global Virtual**  
**July 19, 2025**

**Denver**  
**October 25, 2025**

**Washington DC**  
**July 19, 2025**

**Tampa**  
**November 1, 2025**

**Louisville**  
**August 9, 2025**

**Los Angeles**  
**November 2, 2025**

**Philadelphia**  
**August 16, 2025**

**Sacramento Valley**  
**November 8, 2025**

**San Diego**  
**September 20, 2025**