SFA SARCOMA FOUNDATION of AMERICA

SARCOMA SPOTLIGHT

MAY 2025

STAND UP TO SARCOMA GALA

Don't miss an unforgettable evening, join us at our 23rd annual Stand Up to Sarcoma Gala on September 15, 2025, at 583 Park Avenue in New York City. This special evening brings our community together—from individuals affected by sarcoma and their care partners to researchers and advocates—to honor inspiring achievements and support SFA's vital research, education, and advocacy.

The evening will feature the presentation of the 2025 Courage Awards, Nobility in Science Award, Vision of Hope Award, and the Compassionate Care Award. It's an opportunity to connect with people dedicated to improving outcomes for those with sarcoma, enjoy entertainment, and contribute through our silent auction and live donation.

Be part of this special gathering. Your support helps make a difference. Further details and registration will be available soon. Let's Stand Up to Sarcoma together!

2025 Courage Award

We are thrilled to announce the 2025 Courage Award honoree; this award recognizes individuals whose personal efforts and actions in sarcoma advocacy have inspired and uplifted the sarcoma community. This year, we are proud to honor Billy Brimblecom, Jr. Billy's journey from diagnosis to helping restore amputees' mobility with state-of-the-art prosthetics through the Steps of Faith Foundation is an inspiration and provides hope to the thousands of men, women, and children diagnosed with sarcoma each year.

Billy embodies the spirit of the Courage Award, demonstrating a profound commitment to creating hope and a better life for sarcoma patients and their families.

Get your tickets and read more about Billy.

RESEARCH ROUNDUP

By Dean Frolich, PhD

This month I will be highlighting 3 publications. The first is a guideline update and the other two feature advances in synovial sarcoma research.

In the first publication, “Bone Cancer, Version 2.2025, NCCN Clinical Practice Guidelines In Oncology,” the National Cancer Center Network (NCCN) provides an update to its consensus and evidence-based framework for the workup, management, and surveillance of local and recurrent/metastatic bone cancers. With additions to the multiple ways that bone sarcomas can be treated today, it is important for patients and oncologists to be knowledgeable of what the latest data indicate are the most effective ways to treat these sarcomas. All patients need to be treated individually, and these guidelines may not be the most effective treatment for all patients, but the guidelines are a good platform on which to base the discussion of bone cancer patients’ treatment.

The second publication, “Pharmacologic degradation of WDR5 suppresses oncogenic activities of SS18::SSX and provides a therapeutic of synovial sarcoma,” describes a study in which the investigators used a variety of techniques to identify that a protein called WDR5 is important for synovial sarcoma growth in both cell culture and in a mouse model. They found that WDR5, which had previously been found to change DNA expression by modifying the DNA, interacts with the fusion protein (SS18::SSX) that is found in most patients with synovial sarcoma. They then used a molecule that causes WDR5 to be broken down in the cells to determine that decreased levels of this protein inhibits synovial sarcoma cell growth once again in both cell culture and a mouse model. This is an early study, but it indicates a possible new target in synovial sarcoma.

The last study, “Autologous T cell therapy for PRAME+ advanced solid tumors in HLA-A*02+ patients: a phase 1 trial,” is an early report from phase 1 clinical trial investigating a type of immunotherapy called T cell receptor (TCR)-engineered T cells. T cells are a type of white blood cell, and in this therapy, a patients own T cells are removed and then modified so that they attack a specific protein made by the tumor. Here the protein being targeted is called preferentially expressed antigen in melanoma (PRAME), which is found in synovial sarcoma in addition to melanoma and other solid tumors. In addition to PRAME having to be made by the tumor, the patient needs to have a specific immune HLA type (HLA-A*02). This is how the immune system recognizes foreign cells (or in this case tumor cells) compared a patient’s own cells and is different among patients.

The main purpose of this study is to determine the safety, tolerability, and maximum tolerated dose (MTD) and/or recommended dose for extension. The secondary purposes include tumor response as well as duration of response. A total of 40 patients including 8 synovial sarcoma patients were enrolled in the phase 1a dose escalation and the phase 1b dose extension groups. Overall, the treatment was determined to be safe, and the MTD was not reached. Of the 41 patients receiving treatment, severe cytokine release syndrome was observed in 2 of 41 (4.9%) patients receiving treatment, and severe neurotoxicity did not occur. An overall response rate of patients with confirmed response of 28.9% (11/38) was observed with a median duration of response of 4.4 months across multiple cancers including synovial sarcoma. Overall, this early analysis showed that this therapy demonstrated acceptable safety and promising anti-tumor activity including synovial sarcoma and warrant the further studies being planned for this treatment.

Clinical Trials Corner

By Kristi Oristian, PhD

This month SFA is highlighting ADCElerate1, a First-in-human, Phase 1/2, Multicenter, Open-label, Dose Escalation and Expansion Study to Evaluate the Safety, Pharmacokinetics, and Antitumor Activity of ADCE-D01, a Humanized Anti-human uPARAP Antibody Linked to a Topoisomerase I Inhibitor, in Patients With Metastatic and/or Unresectable Soft Tissue Sarcoma. This study is newly recruiting at eight locations in the United States, Belgium, France, Germany and the UK. The trial is open to adults 18 years and older with soft tissue sarcoma that is metastatic and/or unresectable and with a life expectancy of at least three months.

Patients eligible for this trial will receive a new medicine called ADCE-D01. Doctors and scientists are trying to determine the safety, tolerability, and optimal dose of this medicine in patients with advanced soft tissue sarcomas. This medicine is being developed by Adcendo ApS and is one of a class of drugs called antibody-drug-conjugate (ADC) therapies. This kind of therapy uses an antibody linked to a drug to deliver medicine more precisely to tumor tissue with less toxicity to healthy tissue. ADCE-D01 is a medicine that uses an antibody to the protein uPARAP, which is more highly expressed in tumor tissue than normal tissue, to deliver the drug deruxetecan to tumor cells.

This is a phase 1/2 trial, which means that some patients (phase 1) will receive an escalating (increasing) dose of the trial medications to determine the safe and tolerable dose of the drug and some patients (phase 2) will receive the dose of medication that was determined to be the safest and most tolerable dose of medication to determine if it is effective. Patients should talk to their clinical care teams and care partners about the potential risks and benefits of this study for them.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations. Patients interested in this study should review these criteria with their doctor as well as the potential clinical benefit of participation in the study. To learn more about this study, patients and/or care partners can talk to their doctor, 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.

Advancing Sarcoma Science: Celebrating National Cancer Research Month

May is National Cancer Research Month, recognizing the dedicated scientists and clinicians advancing diagnostics, treatments, and care for people affected by cancer. Research is fundamental to the Sarcoma Foundation of America (SFA) mission. Your support helps fuel progress in understanding and addressing sarcoma:

SFA's Research Investment: Since 2000, SFA has invested over $26 million through more than 230 grants, supporting sarcoma research at institutions globally.

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Leading Private Funder: As the leading private funder of research in the sarcoma community, SFA grants have generated significant additional funding, led to numerous publications, supported clinical trials, and resulted in patents, amplifying the impact of our initial investment.

Understanding Patient Experiences: SFA developed the "Patient Pathway and Impact of Sarcoma from the Perspective of Patients Questionnaire" (Sarcoma Journey Survey; IRB Protocol ID 0686) to better understand the lived experiences of people with sarcoma and their care partners.

Learn more about our research initiatives and consider making a gift this month to help accelerate the next discovery.

Thank you for supporting the research that moves us closer to improving outcomes for people diagnosed with sarcoma.

Contribute to Research Elevating Patient Voices in Sarcoma Care

SFA has developed a large-scale survey to capture the lived experience of the people affected by sarcoma to advance research and drive advocacy efforts. The survey will gather data to add greater dimension of our understanding of the impacts of sarcoma to help expedite the process of getting more approved and less toxic treatments available to patients.

Your participation is critical to ensuring the patient voice and experience is included in the sarcoma landscape. Moreover, our ability to look across subtypes for common experiences, potential treatments, and impacts can greatly advance our knowledge about sarcoma.

We created this survey to understand the patient pathways and perceptions surrounding a sarcoma journey and will share the information collected with the broader sarcoma community to improve outcomes for patients with this rare cancer.

Learn more and contribute your voice to this important research.

IRB Protocol ID 0686

Learn More

ADVOCACY

Your Voice Matters: Join SFA for Advocacy Weekend

On a recent Sarcoma Stories podcast episode, care partner Jenny Sage shared her daughter Gracie's story and spoke passionately about advocacy. Reflecting on SFA's Hill Day, Jenny called the experience "powerful," emphasizing that "advocacy is really where we're going to create change."

Her words resonate strongly today. As potential changes could impact sarcoma research funding and patient support, uniting our community voice is essential. Jenny believes everyone can contribute, urging listeners to "just do something"—whether sharing a post, volunteering time, or joining larger efforts.

Jenny also shared the realities of limited treatment options for pediatric sarcoma, noting many therapies are decades old with serious long-term effects. "What people don't understand is... these kids end up with long-term major health implications," she explained. This highlights the urgent need for research into new, more effective treatments – a critical goal SFA pursues through funding and advocacy efforts like Advocacy Weekend.

One powerful way to make an impact is by participating in SFA's Advocacy Weekend 2025, happening July 17th-19th in Washington D.C. This event includes our Sarcoma Community Advocacy Day, where we meet directly with legislators and their staff. As Jenny noted, "I hope that we can encourage people to come and join us because that movement is really what's going to change... access for sarcoma patients."

Join the movement. Help improve outcomes for people diagnosed with sarcoma.

Register for Advocacy Weekend

Listen to the Podcast

Your Voice Matters: Shape SFA's Public Policy Priorities

As we plan our advocacy initiatives for 2025, we want to hear from you! Share your thoughts on the public policy issues that matter most to the sarcoma community by taking our short survey.

With a new session of Congress beginning, your input will help us prioritize our advocacy efforts and ensure we're effectively representing the needs of sarcoma patients, families, and caregivers.

Click here to take the survey and make your voice heard!

SFA NEWS

Listen to the Latest Sarcoma Stories & Join the Conversation

Stay connected with the sarcoma community through the Sarcoma Stories podcast. Recent episodes feature insightful conversations, including Shaun Nerney discussing his experience as a care partner for his fiancée living with fibromyxoid sarcoma, and we also speak with Brian Fugger, a synovial sarcoma survivor of 20 years. Brian shares his perspective on what the sarcoma landscape looked like 20 years ago at the time of his diagnosis, taking us through his treatment journey and how his marathon running has been an outlet for him to not only give back to the sarcoma community, but also reclaim his life. Tune in wherever you get your podcasts to hear these stories and then join the conversation with other listeners in our dedicated Sarcoma Stories Podcast Discussion Group on Facebook to share your thoughts on the latest episodes.

Follow Sarcoma Stories **Join our Facebook Group**

Celebrating 25 Years: Share Your SFA Photos & Memories!

This year, Sarcoma Foundation of America marks a significant milestone – 25 years dedicated to improving outcomes for people diagnosed with sarcoma. Since our founding in 2000, SFA has grown alongside the community we serve, funding vital research, providing education and resources, and advocating on behalf of patients and their families.

As part of our anniversary celebration, we are creating a special timeline to highlight key moments and milestones from the past quarter-century. Alongside this timeline, we are collecting photographs and memories from throughout SFA's 25 years to help document our shared history, and we need your help!

Do you have photos or recollections from past Race to Cure Sarcoma events, Stand Up to Sarcoma Galas, advocacy days, or other SFA-related activities? We invite you to share these visual memories and stories with us. Your contributions help tell the story of our shared commitment, the progress made, and the strength of the sarcoma community.

Please submit your photos and memories by emailing them to commsdept@curesarcoma.org.

Help us build a rich archive celebrating 25 years of community and progress. Thank you for being an essential part of SFA's history and its future.

IN THE COMMUNITY

An Inspiring Path: Taylor Hosey Ray's Experience with Sarcoma and Nursing

This May, join SFA in celebrating and raising sarcoma voices. In observance of Women's Health Month, International Nurses Week, and National Hospital Week, we're honored to share the story of sarcoma survivor and nurse, Taylor Hosey Ray.

Taylor Hosey Ray was just six weeks away from completing her nursing degree when she was diagnosed with Ewing Sarcoma on the bottom of her foot. Her path in nursing took an unexpected turn as she transitioned from student to patient. Demonstrating unwavering determination, she continued her education remotely while simultaneously undergoing intensive chemotherapy.

Taylor's determination was tested once again when, after completing the initial rounds of chemotherapy and scans, she faced a life-altering decision between three distinct treatment options. Seeking the best path forward for both her health and her future as a nurse, she consulted extensively with her orthopedic surgeon, asked numerous questions, and worked closely with physical therapists to evaluate her options.

After careful deliberation, Taylor chose to undergo a below-knee amputation, a decision that offered the lowest risk of local recurrence while maximizing her mobility. Throughout this challenging period—navigating difficult decisions, undergoing surgery, and completing chemotherapy—she remained steadfast in her goals. Despite these obstacles, she successfully graduated from nursing school and passed the NCLEX examination on her first attempt.

Today, Taylor stands in the same operating room as an oncology OR nurse, where she once lay as a patient nearly 2 years ago, working alongside the very orthopedic surgeon who performed her amputation.

"Working in the OR with oncology surgeons is so incredible. Their work is invaluable, and intricate, and they are usually operating on patients on the biggest day of their lives. Seeing patients who may have sarcoma, and getting to be a part of their care and a part of their story makes it all worth it...I feel so lucky to go to work everyday, and be on the other side."

Taylor's journey from patient to healthcare professional and colleague is a testament to the efforts and dedication of doctors and healthcare professionals and the impact of leading-edge sarcoma research.

Advancing Sarcoma Efforts on All Fronts: A Conversation with Dr. Kurt Weiss

In the world of sarcoma research and treatment, few voices carry the resonance and authenticity of Dr. Kurt Weiss—a surgeon, scientist, and survivor. In a recent conversation, Dr. Weiss opened up about the challenges, hopes, and evolving science in the world of these rare and complex group of cancers.

"We're finally figuring this out," Dr. Weiss said, referring to the recent momentum in sarcoma research, particularly around immunotherapy and newly emerging ADCs (antibody-drug-conjugates). He highlighted the success of combining checkpoint inhibitors with radiation in the SARC32 trial—a strategy that was once just an educated guess but is now yielding real results. "It works. And it's just... such an exciting time," he emphasized.

But this momentum, he warns, is dangerously close to stalling. "Now is when we're going to make the funding for a super rare disease even harder than it already is?" His frustration stems from proposed changes to indirect costs—funds that institutions rely on to keep research infrastructure running. These are not the flashy research dollars that fund experiments; they're what pay for electricity, lab maintenance, data storage, and even toilet paper at the cancer center.

"There is tremendous understanding that in directs are sort of the lifeblood of academic institutions," Dr. Weiss explained. "You can't just apply sweeping changes and expect large university systems to figure it out." Instead, he advocated for a phased and transparent approach.

This isn't just about dollars and cents. It's about equity and continuity in scientific discovery. Dr. Weiss explained how in directs from his more recently successful colleagues helped keep his lab afloat during leaner years: "That money wasn't just for them—it kept the lights on for me too. And now that I've had some success, it's my turn to pay it forward."

He underscored the collaborative nature of science: "Unless you're one of the rare few with 30 years of uninterrupted NIH funding, you rely on the system working together. That's how academic science survives."

Dr. Weiss's identity as a sarcoma survivor only sharpens his urgency. When asked if he approaches sarcoma more as a surgeon, scientist, or survivor, he replied: "Every organization has to have a heart, a gut, and a brain. My heart is the survivor bit. My gut is the surgeon. And my brain is the scientist."

For Dr. Weiss, research is not an abstract pursuit—it's personal. "My life was saved by an investigational treatment," he said. "If I weren't doing this, there'd be something wrong with me."

His ultimate mission? Tackling metastatic disease. "We're failing the same patients all the time," he said. "If we can make sarcoma a local disease that just affects your arm, leg, pelvis, or retroperitoneum—and doesn't go to your lungs and try to kill you—that's the same as a cure."

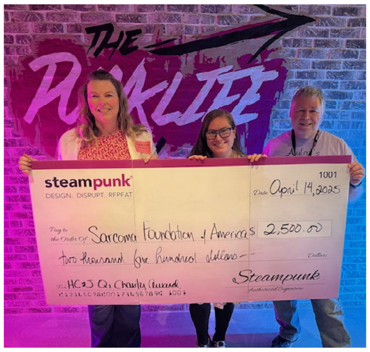
For Dr. Weiss, the work is urgent, but it's also filled with hope. "It's a super exciting time to be a sarcoma investigator," he said. "We're asking and answering questions we couldn't before." Despite the progress, the threat of lost funding weighs heavily. "This is not a great time to be declaring war on academia," he said.

His message to the sarcoma community is clear: "Let's put our foot on the gas. Let's figure out metastatic biology. That's where we can make the biggest difference."

Celebrating Dr. Crystal L. Mackall's Breakthrough in Cancer Immunology

SFA congratulates Dr. Crystal L. Mackall, MD, FAACR—former member of our Medical Advisory Board—on receiving the AACR–Cancer Research Institute Lloyd J. Old Award in Cancer Immunology. We were proud to honor her as our 2022 Nobility in Science award recipient at the Stand Up to Sarcoma Gala, recognizing her pioneering CAR T-cell research and her leadership in translating immunology discoveries into clinical trials for sarcoma patients.

Steampunk's Generosity Fuels Sarcoma Research



This April, SFA was honored to be selected to receive a $2,500 donation from Steampunk, based in Virginia.

Each quarter, Steampunk employees nominate and advocate for their favorite charities, with a company-wide vote determining the recipient. SFA was nominated by Kobi Lifshitz, whose daughter, Aylat, is a sarcoma survivor, a dedicated member of the Race to Cure Sarcoma Boston planning committee and an active participant in the National Race to Cure Sarcoma.

We are incredibly grateful to Kobi for his nomination and for supporting our mission to advance research, increase awareness, and support patients and families impacted by sarcoma.

An Evening of Impact: SFA's Mission & Momentum in NYC

On April 22, 2025, SFA hosted Mission & Momentum: An Evening of Impact at One Vanderbilt in New York City.

The event brought together SFA supporters, partners, and community leaders for an evening dedicated to celebrating progress and looking ahead. Brandi Felser, SFA Chief Executive Officer, provided an update on organizational achievements and outlined strategic goals for 2025. Dr. William D. Tap, SFA Medical Advisory Board member, discussed the current state and future directions of sarcoma research.

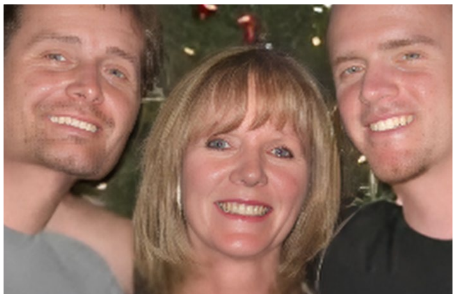
This intimate gathering fostered community connections, offered critical insights, and reaffirmed our shared commitment to improving the lives of those affected by sarcoma.

Community Events Honor Loved Ones, Support Sarcoma Progress

Sarcoma Foundation of America is grateful for the dedicated communities across the country organizing events in honor of loved ones, with proceeds advancing our shared mission. We invite you to learn more about these upcoming third-party events:

The Sisu Open Honoring Chris Langbein: Friends of Chris Langbein host The Sisu Open golf outing on Friday, May 16, 2025, at Lost Marsh Golf Course in Hammond, Indiana. What began as an annual gathering of college friends evolved into this event named for "Sisu," the Finnish concept of steadfast resolve that defined Chris's spirit. This year's event continues to honor his legacy. Participants and supporters can register to play or make a tribute gift at: https://runsignup.com/TicketEvent/TheSisuOpen

4th Annual Scott Lively Memorial Golf Tournament: Hosted by Scott's family and friends, this memorial golf tournament returns on Saturday, September 20, 2025, at Bear's Best Atlanta in Suwanee, GA. The event honors Scott Lively, whose unwavering strength demonstrated while facing Ewing sarcoma and later bone cancer continues to inspire. This outing unites golfers and supporters in his memory. Participants and supporters can register to play or make a tribute gift via the event page: https://runsignup.com/TicketEvent/ScottLivelyMemorial



Cornhole Tournament & Picnic Supporting Brian: Organized by his community, this Cornhole Tournament and Picnic on July 27, 2025, at Sandpiper Shelter, Ontario Beach Park (Rochester, NY), supports Brian. The gathering honors Brian's incredible strength and resilience since his diagnosis with stage IV Alveolar Soft Part Sarcoma in December 2023. Participants and supporters can register to participate or make a donation via the event registration page: https://runsignup.com/TicketEvent/CornholeTournamentAndPicnic

Your involvement in these events helps keep the legacies of Chris and Scott alive, shows meaningful support for Brian, and fuels Sarcoma Foundation of America's critical work in funding research, providing patient education, and advocating for better outcomes for everyone affected by sarcoma.

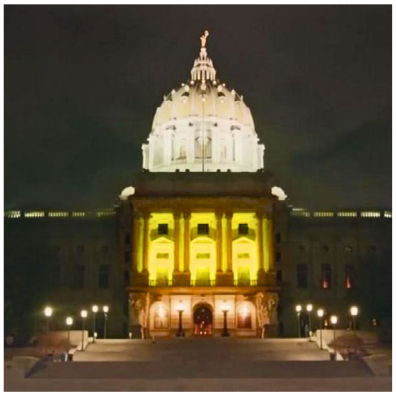
EVENTS

Get Ready: July is Sarcoma Awareness Month!

Every July, Sarcoma Foundation of America (SFA) and the sarcoma community come together to raise awareness and support people affected by sarcoma. Learn about our plans and how you can make this Sarcoma Awareness Month one to remember as we work towards our mission to improve outcomes for those diagnosed.

Throughout July, there are many ways to get involved and make a difference:

Wear Yellow Wednesday (July 9, 2025): Show your support by wearing yellow, the official color for sarcoma awareness. On July 9th, take photos of yourself, friends, family, and even pets wearing yellow and share them on social media to help spread the word!



Light Up for Sarcoma (July 25, 2025): Help illuminate the country in yellow! On July 25th, SFA, buildings, and monuments across the country will light up yellow. Encourage prominent locations in your area to join by reaching out directly to building management or local officials via email or official request forms. Let's make skylines glow yellow for the sarcoma community!

Children’s Artwork Competition: Young artists are invited to join our annual children’s art competition. Encourage young artists affected by sarcoma to express themselves. Go here to find more info.

Yard Signs: Help spread awareness by putting a yard sign in your yard. We have a variety of signs to help show your support. **(Coming Soon)**

Sarcoma Advocacy Weekend (July 17-19, 2025): Join us in Washington, DC, for a full weekend of advocacy and learning.

Find info and more ways to engage during Sarcoma Awareness Month on our website:

Sarcoma Awarness Month

Let's work together this July to increase understanding, support patients and their care partners, and bring the community together.

Race TO Cure
SARCOMA
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CLICK HERE TO SIGN UP FOR YOUR LOCAL 2025 RACE

South Florida - 05/17
Cleveland - 06/21
Milwaukee - 07/12
Global Virtual - 07/19
Washington D.C. - 07/19

Louisville - 08/09
Philadelphia - 08/16
San Diego - 09/20
Chicago - 09/27
New Jersey - 10/05

Denver - 10/25
Tampa - 11/01
Los Angeles - 11/02
Sacramento - 11/08

The 2025 Race to Cure Sarcoma season rolled into New York City on April 26 at Rockefeller Park, where more than 180 supporters joined together and raised over $23,000 toward our $50,000 goal. If you weren't able to make it—or if you'd like to help us surpass our target—there's still time to donate and fuel progress for everyone affected by sarcoma.

New York

View Photos

Donate

Join Our SFA Marathon Team Today!

MCM 26.2
MARINE CORPS MARATHON

Sarcoma Foundation of America (SFA) is a proud partner of the 2025 Marine Corps Marathon (MCM). The MCM is celebrating its 50th year, and this event offers an experience for runners to tour the nation's most recognizable landmarks, while being supported by the men and women of the United States Marine Corps. We invite you to join us in Arlington, VA on October 26, 2025.

As part of the 2025 SFA MCM race team you will receive the following perks:

- Guaranteed entry to the 2025 Marathon or MCM Virtual 10K
- Custom MCM marathon shirt and swag bag
- Personal fundraising page dedicated staff to support you
- Complimentary registration

If you are interested in joining our SFA MCM race team, please register using the links below.

Register for MCM Marathon

Register for Virtual MCM 10K

For full race details visit the MCM website or contact Annie Blake at ablake@curesarcoma.org.