STAND UP TO SARCOMA GALA

Mark your calendars for SFA's 23rd annual Stand Up to Sarcoma Gala on September 15 at 583 Park Avenue in New York City! This important celebration brings together patients, survivors, caregivers, researchers, and advocates to honor those making a difference in the sarcoma landscape.

Join us for an inspiring evening filled with hope, empowerment, celebration, and community. Highlights include:

Recognition of the 2025 recipients of the Courage Awards, Nobility in Science Award, Vision of Hope Award, and the Compassionate Care Award.

Unique opportunity to meet and mingle with others who have been affected by sarcoma, those who are working to find treatments, and people dedicated to assisting patients during their sarcoma journey.

Entertainment, a silent auction, and a live donation opportunity to join SFA in funding vital sarcoma research, education, and advocacy and make a difference in the lives of those affected by sarcoma.

Be a part of this meaningful celebration and help make a lasting impact on the sarcoma landscape. More info coming soon.

Let's Stand Up to Sarcoma together!

View Highlights from our 2024 Gala

Learn More and Register

RESEARCH ROUNDUP

By Dean Frolich, PhD

This month I am highlighting six studies that have been published in the last few months month. The first, "Improving Individualized Rhabdomyosarcoma Prognosis Predictions Using Somatic Molecular Biomarkers," investigates whether including additional biomarkers (measurable items that indicate what is happening in a patient's body) allows oncologists to make a more accurate prognosis in patients with rhabdomyosarcoma. In this study, investigators used clinical features and mutation data for 20 genes from 641 patients with rhabdomyosarcoma to develop three models for predicting event-free survival (EFS). The Baseline Clinical (BC) model included treatment location, age, fusion status, and risk group. The Gene Enhanced 2 (GE2) model included the BC clinical characteristics and added mutations to the genes TP53 and MYOD1. The Gene Enhanced 6 (GE6) model added mutations to the genes NF1, MET, CDKN2A, and MYCN to those included in the GE2 model. The models were then compared to determine if adding the gene mutations increased the predictive efficacy.

After analysis, the GE6 model had the best predictability compared with the BC model and GE2 model. Mutations in TP53, MYOD1, CDKN2A, MET, and MYCN were associated with worse prognosis, whereas NF1 mutation correlated with better outcomes. The investigators found that personalized prognosis predictions may suggest alternative treatment regimens compared with current treatment plans. Additional studies need to be done; however, these results indicate that the new biomarkers may Improve prognosis and treatments in rhabdomyosarcoma. These genetic biomarkers may also be used as targets for precision therapies.

In the second study, "Head-to-head evaluation of [18F]FDG PET/CT and [68Ga]Ga-HX01 PET/MR in sarcoma patients," the investigators studied two different ways to image sarcoma tumors. The first imaging method called [18F]FDG PET/CT is able to visualize glucose metabolism and the second method, more recently developed and called [68Ga]Ga-HX01 PET/MR is able to see new blood vessels being formed. Both glucose metabolism and blood vessel formation are increased in tumors. The investigators analyzed imaging data of 21 sarcoma patients who underwent both [68Ga]Ga-HX01 PET/MR and [18F]FDG PET/CT imaging on two separate days within one week of each other to determine if [68Ga]Ga-HX01 PET/MR is able to identify tumors as well as [18F]FDG PET/CT. The location, number, and image characteristics of all lesions were collected.

Upon analysis, the data indicated that [68Ga]Ga-HX01 PET/MR was as good as [18F]FDG PET/CT in detecting tumors in sarcoma patients. Although additional studies are needed, these results indicate that [68Ga]Ga-HX01 PET can augment the diagnosis of sarcomas.

In the third study, "DHX9 helicase impacts on splicing decisions by modulating U2 snRNP recruitment in Ewing sarcoma cells," the investigators study a protein which is a DNA/RNA helicase called DHX9 in Ewing sarcoma cells. This protein is involved in splicing, or joining together, of RNA so that proteins are made properly in cells. DHX9 has been shown to interact with the fusion protein that causes Ewing sarcoma and this complex then modulates how RNA is spliced. In this study, the investigators determine through a variety of techniques that, in Ewing sarcoma, DHX9 interacts with several other proteins (U2snRNP, SF3B1, and SF3A2) leading to alternative splicing which promotes cell migration and tumor invasion. These results are early, but they indicate that DHX9 may play a role in Ewing sarcoma and represent a druggable target in this sarcoma subtype.

The fourth is an update of a previously published study. "Maintenance Chemotherapy in Patients With High-Risk Rhabdomyosarcoma: Long-Term Survival Analysis of the European Paediatric Soft Tissue Sarcoma Study Group RMS 2005 Trial," is a study that began in in 2005 and was conducted by the European Pediatric Soft Tissue Sarcoma Study Group (EpSSG) that compared discontinuing therapy, which is standard treatment, with receiving an additional six 28-day cycles of a chemotherapy called vinorelbine on days 1,8, and 15 plus daily low-dose of a different chemotherapy that works in a different way called cyclophosphamide (this is the experimental treatment) in high-risk rhabdomyosarcoma (RMS). Results from the original results indicated an improved overall survival (OS), but the improvement in disease-free survival (DFS) was not statistically significant.

The analysis reported here was performed after 114 months of follow up compared to 60 months in the original report. There were 186 patients enrolled for the standard treatment and 185 for the experimental treatment. This updated analysis shows the 10-year DFS was 66.5% in with standard treatment versus 77.1% for the experimental treatment. Additionally, 10-year OS rates were 70.8% for the standard treatment and 82.9% for the experimental treatment making both measures now statistically significant. These results indicate a benefit of maintenance chemotherapy with vinorelbine and low-dose cyclophosphamide for patients with high-risk RMS.

The fifth study, "Phase 1 study of IMCnyeso, a T cell receptor bispecific ImmTAC targeting NY-ESO-1-expressing malignancies," is a phase 1 trial investigating an immunotherapy called ImmTAC (immune mobilizing monoclonal T cell receptor against cancer). This type of immunotherapy binds to a specific protein expressed by tumor cells, which then links to and activates one kind of patient immune cells (T cells). Linking the tumor cell with the T cell allows the T cells to kill the tumor cell. In this study, the ImmTAC is called IMCnyeso. The tumors of the 28 patients (20 of which had synovial sarcoma) in this study expressed the protein NY-ESO-1/LAGE-1A to which the IMCnyeso is targeted. Patients received IMCnyeso weekly intravenously (dose range: 3–300 µg). The primary objective was to identify the maximum tolerated dose (MTD) or recommended dose for a phase 2 clinical trial. Although the study was stopped before fully enrolling dose escalation, and the MTD was not identified, results indicate T cells were redirected to the tumor at doses between 30–300 µg. At these doses, preliminary efficacy includes mixed responses and a median overall survival of 12 months. Overall, these results indicate that this type of immunotherapy is well tolerated and may be effective in some subtypes of sarcoma.

The last study, "Comparison of [68Ga]Ga-Fibroblast Activation Protein Inhibitor–04 and [18F] FDG PET Imaging for Solitary Fibrous Tumor and Preliminary Application of FAP-Targeted Radiopharmaceutical Therapy," is in solitary fibrous tumor (SFT), which is a rare sarcoma that, although generally benign, has a risk of metastasis and has limited treatment options. This study compares two methods of visualizing the tumors. The experimental agent binds to a protein often found on tumor cells is denoted as [68Ga]Ga-FAPI-04) and is compared to the "gold standard " of tumor imaging which is called [18F]FDG PET/CT. Thirty-one participants with suspected recurrent or metastatic SFTs underwent both [18F]FDG and [68Ga]Ga-FAPI-04 PET/CT within 1 week of each other. The number of tumors visualized by the 2 PET/CT scans in the different organs were then compared. In a second part of the study, four patients with high [68Ga]Ga-FAPI-04 signal received single-cycle therapy of a drug that targets the same protein and contains a radioactive part in order to treat the tumors. These patients were followed up for 4 months.

The results show that [68Ga]Ga-FAPI-04 PET detected significantly more tumors than[18F]FDG. In addition, the four patients treated with the new drug tolerated it well with follow up imaging demonstrating that the patients were stable. These results indicate that [68Ga]Ga-FAPI-04 may be a promising PET agent for SFTs and that a drug targeting the same protein (called fibroblast activation protein) has treatment potential in SFT.

ESMO Sarcoma and Rare Cancers Congress 2025

SFA attended the European Society of Medical Oncology (ESMO) Sarcoma and Rare Cancers Congress 2025, held March 20–22. The Congress provided an outstanding opportunity to exchange cutting-edge research, explore innovative therapeutic approaches, and engage in collaborative discussions focused on advancing sarcoma research.

We were honored to be invited by the Scientific Committee to present our abstract, "The Patient Pathway and Impact of Sarcoma from the Patient Perspective Survey," which highlights insights from our patient survey. The program showcased the latest developments in diagnosing, treating, studying, and classifying sarcoma and rare solid tumors.

View Our Poster

FDA Approves New Treatment Option for TGCT

Exciting news for the sarcoma community! The FDA has approved Vimseltinib, a new medication offering another treatment option for tenosynovial giant cell tumor (TGCT) patients when surgery isn't feasible.

This approval brings renewed hope to those affected by TGCT, a rare and often debilitating tumor. We extend our congratulations to SFA Medical Advisory Board member Dr. William Tap for his contributions in bringing this important treatment to patients. Read the full announcement **here**.

Clinical Trials Corner

By Kristi Oristian, PhD

This month, SFA is highlighting a Phase 1/2 trial evaluating the safety and efficacy of PEEL-224 This month SFA is highlighting a Phase 1/2 Trial to Evaluate the Safety and Efficacy of PEEL-224 in Combination with Vincristine and Temozolomide in Adolescents and Young Adults with Relapsed or Refractory Sarcomas. This study is newly recruiting at three locations in Boston, MA. The trial is open to adolescents and young adults 12-49 years of age in the United States with Ewing sarcoma (EWS), Desmoplastic small round cell tumor (DSRCT) and other kinds of sarcomas.

Patients eligible for this trial will receive a new medicine called PEEL-224 in combination with two commercially available drugs, Vincristine and Temozolomide. Doctors and scientists are trying to determine how effective this combination of drugs is at treating EWS, DSRCT, and other kinds of sarcomas. This medicine is being developed by PEEL Therapeutics and is being evaluated to treat solid tumors including sarcomas.

Patients eligible for this study will receive several tests for screening and eligibility as well as imaging scans (x-rays, CT, MRI or PET scans), blood and urine tests, and electrocardiograms as part of the study. Patients will also receive study treatment for up to 34 cycles and monitored for up to one year after the last participant has received their last dose of treatment. This may involve approximately two years of treatment and one year of post-treatment monitoring.

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 combination 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 benefit of this study for them.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations, as well as histologic confirmation of sarcoma and sarcoma subtype. 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 or contact the investigator at the study site. Participating patients in need of additional travel or financial support may apply for assistance from SFA.

Share Your Story, Shape the Future of 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

ADVOCACY

A Call to Action: Make Your Voice Heard This Sarcoma Awareness Month

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.

Join Sarcoma Foundation of America (SFA) in Washington D.C. this July for our Advocacy Weekend (July 17th-19th). This impactful weekend will include:

Sarcoma Community Advocacy Day: Meet with elected officials to share your story and advocate for increased research funding and improved access to care for sarcoma patients.

Education Day: Learn about the drug development process and how advocacy plays a vital role in making new treatments accessible to sarcoma patients.

Awards Dinner: Celebrate sarcoma advocates and our representatives who amplify our voices on Capitol Hill.

National Race to Cure Sarcoma: Join us at the Lincoln Memorial for our premier run/walk event, raising awareness and funds for sarcoma research.

Together, we can make a difference. Register for SFA's Advocacy Weekend today!

Register Now

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

Find Community and Support at Sarcoma Connect

Looking for a place to connect with others in the sarcoma community? Visit Sarcoma Connect! Hosted by SFA, this group and discussion community is a platform to share experiences regarding diagnosis, treatment, clinical trials, care giving and social and emotional health related to a sarcoma diagnosis.

Unlike a Facebook Group, you do not need a social media profile to join this group and can remain anonymous if you wish. In addition to support, you'll find helpful resources like SFA's Discussion Guide, and stay informed about upcoming events, such as informative webinars.

Sign Up

Hear from the Sarcoma Community on our Podcast

SARCOMA STORIES

Looking for powerful, real stories from those impacted by sarcoma? Tune in to Sarcoma Stories, where members of the sarcoma community open up about their experiences with diagnosis, caregiving, advocacy, and hope. In our latest episode, Margaret Livermore, a leiomyosarcoma survivor and member of SFA's Public Policy Committee, reflects on her initial diagnosis, recurrence 16 years later, and the importance of self-advocacy, supporting others, and addressing health inequities that affect many in the sarcoma space.

In another recent episode, Katie Wintergerst shares her journey with synovial sarcoma as a single parent to two young children. She discusses the critical role of second opinions at sarcoma centers, her participation in early-phase clinical trials, her leadership in the Race to Cure Sarcoma Louisville, and the strength she's found through advocacy and community.

You'll also hear from Jenny Sage, a devoted care partner to her daughter, who speaks candidly about the emotional complexities of caregiving. Other episodes include Mike Cacioppo, an osteosarcoma survivor and amputee focused on resilience and optimism; Maria, who honors her daughter Aubrie's legacy while raising awareness for CIC-DUX4; and the Brenneman family, who transformed grief into purpose after the loss of their husband and father, including through a memorable journey along the Camino de Santiago. Additional voices like Susie Donohue, Jenna Pothier, and Natasha Allen round out the series with meaningful insights on navigating sarcoma, finding support, and raising awareness.

Follow Sarcoma Stories on your favorite podcast platform today.

SFA Turns 25: Celebrating Hope and Progress

This year marks a significant milestone for Sarcoma Foundation of America – our 25th anniversary! Founded in 2000, SFA emerged from the vision of parents determined to make a difference for those facing sarcoma.

Over the past two and a half decades, SFA has become a beacon of hope for the sarcoma community. We've invested millions in vital research, empowered countless patients and families with essential resources, and advocated tirelessly for policies that improve access to care.

From funding groundbreaking clinical trials to fostering a supportive community, SFA is dedicated to improving outcomes for those diagnosed with sarcoma.

Looking Ahead: A Year of Celebration

To commemorate this special anniversary, SFA has a year full of exciting events and initiatives planned. Join us for a series of events throughout July as we raise awareness and educate the public about sarcoma during Sarcoma Awareness Month. In September, celebrate with us at our annual Stand Up to Sarcoma Gala, where we'll honor those who have made a difference. And don't miss our Race to Cure Sarcoma events across the country throughout 2025, where you can participate and connect with your local sarcoma community and help raise funds for vital research. We'll also be sharing inspiring videos and stories from our founders, survivors, and others in the sarcoma community.

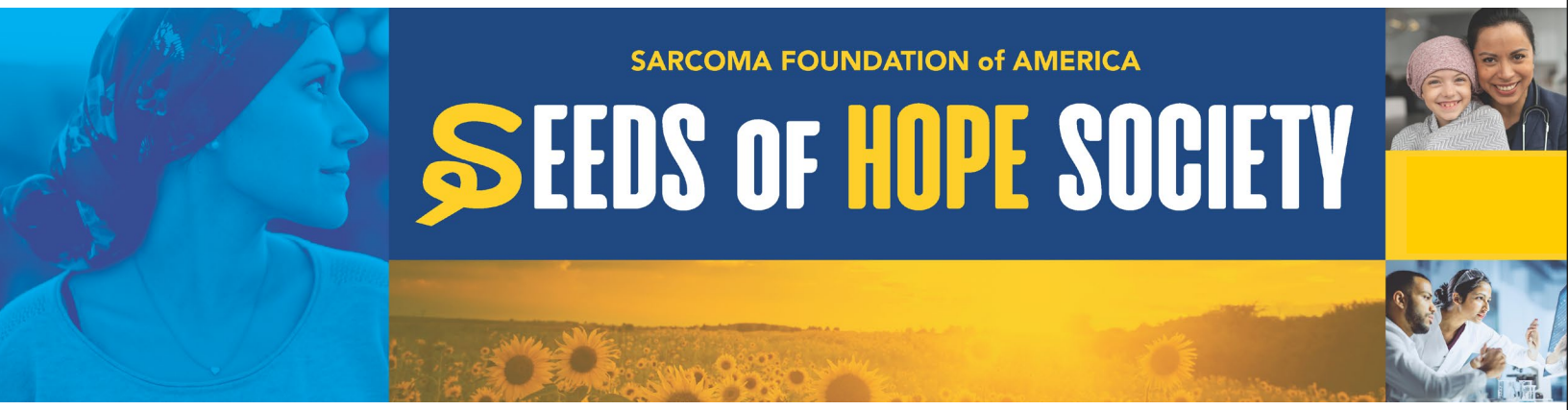
As we celebrate this milestone, we honor the strength and resilience of the sarcoma community. We also look to the future with renewed determination, knowing that together, we can create a world where sarcoma is no longer a threat.

Join us in celebrating 25 years of progress and hope. Start by taking a look back at our first SFA website and how far we have come today.

Visit our First Website **Visit our Website**

Rewatch Our Recent Webinars

Catch up on our latest sessions covering key topics in the sarcoma community. Learn how to advocate for change in our Public Policy Webinar, get expert insights on chondrosarcoma as part of our Sarcoma Subtype Education Series, and explore the unique challenges faced by Adolescent and Young Adult (AYA) sarcoma patients. Each webinar offers valuable perspectives, resources, and support—now available to watch on-demand.



Seeds of Hope Society: Growing Together to Support the Sarcoma Community

We're thrilled to share that March marked the 1-year anniversary of launching SFA's Seeds of Hope Society – a passionate community of sustaining givers who have committed to making a recurring donation to SFA. In one year, the Seeds of Hope Society has grown to a community of almost 150 active recurring donors! This growing community plays a pivotal role in ensuring consistent resources that empower us to make a lasting impact. To date, together, the Seeds of Hope community has given over $100,000 to support sarcoma research, awareness, and advocacy efforts. This is equivalent to almost two full research grants funded! This is the transformative power of shared moments—making important strides together that have an impact in helping patients, survivors, and their families.

Interested in being a part of the Seeds of Hope Society? When you stand with SFA with your recurring gift, you make a commitment to sarcoma patients and their families that they are not alone—that you are a champion they can count on through all the seasons of their lives. Every dollar makes a difference!

Here's how your monthly gift matters to those living with a sarcoma diagnosis:

- **$10 a month** supports increased awareness about the need for more research funding and treatments.
- **$25 a month** can provide education and resources for sarcoma patients to ensure they have access to the best treatment options.
- **$100 a month** can help advance research and clinical trials to realize lifesaving treatments for people diagnosed with sarcoma.

Turn your support into a flexible, convenient, and sustainable impact all year long with a recurring gift! Join the Sunflower Society

CHILDREN'S ARTWORK CONTEST

Sarcoma Foundation of America (SFA) is holding a Children's Artwork Contest to kick off Sarcoma Awareness Month this July. Submissions will be accepted through **July 21, 2025**, and the winner will be announced at the end of July. The winning entry will be featured in SFA's newsletter and appear on SFA's 2025 holiday card.

SFA SARCOMA FOUNDATION of AMERICA

ARTWORK GUIDELINES

- Artwork must incorporate a yellow ribbon and/or sunflower.
- Artwork can be any size and any medium.
- Artist must be 18 years or younger at the time the artwork is submitted.
- Submissions must be original artwork.

SUBMISSION RULES

- Artwork must be received by July 21, 2025. Artwork can be mailed to the address below or emailed to development@curesarcoma.org.
- Please include the artist's name, age, city and state of residence, and connection to sarcoma.
- Please provide an adult contact person and contact information.
- Artwork will not be returned to the artist.

07/21/25

Please mail original artwork to: **Sarcoma Foundation of America**, 9899 Main St, Ste 204, Damascus, MD 20872

Email to: **development@curesarcoma.org**

SFA reserves the right to share artwork submissions on social media, email communications, printed materials, etc. SFA will have the right to display artwork at events.

IN THE COMMUNITY

Technoblade Honored in Minecraft Movie

The new Minecraft movie includes a meaningful tribute to Technoblade, the beloved content creator who passed away from sarcoma. A recent article highlights this moment and the lasting impact he made on the gaming community. His legacy continues to inspire fans worldwide and raise awareness for sarcoma. This quiet tribute is a powerful reminder of how far-reaching one voice can be.

Navigating Sarcoma: A Care Partner's Journey and Hope

Caroline's experience with sarcoma began during the height of the COVID-19 pandemic. Her husband, Brian, who had previously been diagnosed with GIST, began experiencing persistent leg pain. In October 2020, he received a new diagnosis—spindle cell sarcoma. By then, it had already metastasized to his lungs.

They faced an emotionally taxing treatment journey that included chemotherapy, surgery, and rehab. As a care partner, Caroline played a central role—often navigating pandemic restrictions that limited hospital visitation. She stayed connected with Brian and his medical team through phone calls and virtual visits.

"The care was excellent. They considered me as the care partner," Caroline shared, emphasizing how included she felt by the medical team.

To manage the emotional toll, Caroline sought counseling and joined a couples' cancer support group. "I got so many referrals on things to do and ways to do things better from that group," she said. She also valued one-on-one sessions with a hospital social worker. "It was just so helpful," she added.

With support from family and Brian's employer, they weathered numerous hospital stays and treatments. After a period of stability, the sarcoma metastasized to Brian's brain in November 2022. He passed away on Christmas Eve that year.

Caroline now honors Brian's legacy through awareness and advocacy. She formed a team in his memory for the Race to Cure Sarcoma Boston, raising funds and awareness. "It's all about awareness," she said, hoping for increased hospital participation and sarcoma recognition, especially in smaller communities.

"Being grateful is the end result of that journey," she reflected.

To honor a loved one and support progress, consider joining a Race to Cure Sarcoma event. More than a run/walk, RTCS is a day to unite in remembrance, celebration, and commitment to research that improves lives.

EVENTS

The 2025 Race to Cure Sarcoma season is off to an incredible start!

We kicked things off in Austin, where almost 400 participants came out for the city's first-ever RTCS event, raising more than $37,000. Atlanta followed with another amazing turnout of 300+ people and over $31,000 raised. Then in Boston, more than 400 participants helped bring in an incredible $98,000+.

Altogether, that's over 1,000 participants and $165,000 raised—and we're just getting started. You can view event photos and still donate to keep the momentum going!

Austin

View Photos

Donate

Atlanta

View Photos

Donate

Boston

View Photos

Donate

Race TO Cure SARCOMA
SARCOMA FOUNDATION OF AMERICA

CLICK HERE TO SIGN UP FOR YOUR LOCAL 2025 RACE

New York - 04/26/25
San Francisco - 05/10/25
South Florida - 05/17/25
Cleveland - 06/21/25
Milwaukee - 07/12/25
National Virtual - 07/19/25
Washington D.C. - 07/19/25
Louisville - 08/09/25
Philadelphia - 08/16/25
San Diego - 09/20/25
Chicago - 09/27/25
New Jersey - 10/05/25
Denver - 10/25/25
Nashville (Virtual) - 11/01/25
Tampa - 11/01/25
Los Angeles - 11/02/25
Sacramento - 11/08/25

Registration is Now Open – 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**

Personal Fundraising Commitment:
- Marathon – $1,500
- MCM Virtual 10K – $750

There are over 200,000 patients and their families, who are impacted by sarcoma. When you join the SFA MCM race team, the funds you raise will help support critical research and provide services for those affected by this rare disease. Your impact will go beyond the finish line when you join our community of teammates from across the country as you train for this incredible event!

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