SFA SARCOMA FOUNDATION of AMERICA

ONE COMMUNITY MANY VOICES REAL ACTION LASTING CHANGE

JULY IS SARCOMA AWARENESS MONTH

SARCOMA SPOTLIGHT

JULY 2025

U.S. Senate Designates July 2025 as National Sarcoma Awareness Month

The U.S. Senate has officially passed a resolution designating July 2025 as National Sarcoma Awareness Month, acknowledging sarcoma as a rare and often misdiagnosed cancer that affects both adults and children. The resolution calls for increased national awareness and encourages timely and 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, and by the countless others impacted by this disease.

ADVOCACY WEEKEND 2025

There is still time to join the sarcoma community in Washington, D.C., July 17–19 for Sarcoma Advocacy Weekend. We hope to see you at an event!

- Sarcoma Community Advocacy Day: On July 17, advocates will meet with elected officials to advocate for increased research funding and improved access to care.
- Sarcoma Education Day: On July 18, participants will learn about the drug development process and how advocacy work can help to advance this process.
- Race to Cure Sarcoma Washington, D.C.: This event will take place on July 19, concluding the weekend's events. Join us at the Lincoln Memorial as we raise much-needed research funds and awareness for sarcoma.
- Global Virtual Race to Cure Sarcoma will also begin on July 19 and run through October 1, 2025, allowing participation from anywhere. Don't have a Race to Cure Sarcoma in your area, join us for the virtual race!

Other Sarcoma Awareness Month Activities:

- Children's Artwork Contest: Children can submit artwork through July 21. The winner will be announced at the end of July and featured in SFA's newsletter and on SFA's 2025 holiday card.

- Light Up for Sarcoma: On July 25, buildings and landmarks worldwide will light up yellow for sarcoma awareness. Confirmed locations include Niagara Falls, the Rock and Roll Hall of Fame, the Twin Spires at Churchill Downs, the Tampa, FL skyline, and the Charlotte, NC skyline. Turn on your yellow lights and share pictures so we can show the world that we light up yellow for sarcoma.

- You can also show your support by purchasing a sarcoma awareness yard sign or by using images from our social media toolkit to spread the word.

Advocating for Those Who Can't: Sarcoma Advocacy Weekend

Valeria Lopez was diagnosed with Leiomyosarcoma in October 2020. She went through radiation treatment and surgery and has been free of disease since February 2023. This year, Valeria is participating in Sarcoma Advocacy Weekend from July 17-19 with the goals of increasing awareness and funding for sarcoma.

Last year, Valeria participated in Advocacy Day as well. She had just turned 34 when she was diagnosed with sarcoma and didn't realize then that she would become part of the adolescent and young adult (AYA) sarcoma community. Through the AYA community, Valeria met someone who had traveled to Washington DC to advocate for another type of cancer, who told her "I do it for those who aren't with us anymore." It was early on in Valeria's sarcoma journey, so she didn't fully appreciate this sentiment. As time went on, however, she lost people she had gotten to know to sarcoma. Sometimes it was from the same sarcoma that she had, sometimes it was to other sarcomas. She saw so much suffering. Throughout, her primary motivation remained the same: She does it for those who can't. She continues to participate in advocacy day to give voice to patients going through the relentless and awful diagnosis of sarcoma.

Valeria participated in Advocacy Day last year, which she found very empowering. This year, Valeria plans to participate in Advocacy Weekend to advocate for increased funding for trials, improved health insurance coverage, and access to telehealth, among other priorities.

YOU'RE INVITED

MONDAY
SEPTEMBER 15TH
583 PARK AVE NYC

Dinner Event
Cocktail Attire
6-10PM EST

Our 2025 Amira Yunis Courage Award Honoree

Sarcoma Foundation of America is honored to announce Andrey Ivchenko, a SAG Award-nominated actor, as the recipient of the Amira Yunis Courage Award. This award honors patients who have demonstrated strength and perseverance in their sarcoma diagnosis. We will present this award at our 23rd Stand Up to Sarcoma Gala on Monday, September 15, 2025, in New York City.

Andrey Ivchenko is a SAG Award-nominated actor best known for his unforgettable role as Grigori, the formidable villain in Season 3 of the global Netflix hit Stranger Things. He has also appeared in popular series including Lucifer, Jane the Virgin, and Counterpart alongside J.K. Simmons. In film, audiences recognize him as Red Erik in xXx: The Return of Xander Cage with Vin Diesel, and as the lead villain Perseus in the global video game phenomenon Call of Duty: Black Ops Cold War.

Born and raised in Ukraine, Andrey left his home country at 18 after completing military service. He began his acting career in Toronto after living in Europe and the Middle East. His talent and drive quickly earned him roles in series such as Falling Skies, Nikita, and Transporter: The Series. Since relocating to Los Angeles, he has continued to build a dynamic career, with recent credits including Darkness of Man opposite Jean-Claude Van Damme, The Best Man with Luke Wilson and Dolph Lundgren, and a soon-to-be-released feature film starring Ron Perlman, Stephen Dorff, and Kelsey Grammer.

In 2024, Andrey was diagnosed with a rare bone cancer known as chondrosarcoma. Following an extensive surgery that involved removing half of his pelvis and replacing it with a custom 3D-printed titanium prosthetic, along with a full hip replacement, Andrey has emerged with a powerful sense of purpose. Now in recovery, he is using his platform to raise awareness about sarcoma, honor the medical teams who saved his life, and bring hope to those navigating their own sarcoma journey.

Join us in celebrating Andrey Ivchenko 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 I would like to start by highlighting a study titled, "The role of whole-genome sequencing for guiding systemic therapy in patients with soft tissue sarcoma." In this study, the investigators looked to determine if analyzing tumors by sequencing the tumor's complete genome (WGS) can identify mutations for which there is a specific therapy already indicated or under investigation in an available clinical trial and thus, guide patient therapy in patients with soft tissue sarcoma (STS). The investigators utilized sequencing results that were in patients' electronic health records and pathology reports from clinical studies and routine tests. In all, sequencing was performed on tumors from 161 STS patients with a variety of subtypes, the most common being leiomyosarcoma (22%), undifferentiated pleomorphic sarcoma/sarcoma not otherwise specified (17%), and dedifferentiated liposarcoma (14%). At least one actionable target was found in 74 (46%) patients of which, 23 (14%) patients received matched treatment. Of those who did not receive matched treatment, non-availability of a matched treatment or lack of clinical necessity (in 17 patients) and rapid disease progression (in 10 patients) were the main reasons. Additionally, actionable targets were found more frequently in patients with complex genome sarcomas than those with simple genome sarcomas. These results indicate that it may be advantageous for patients with soft tissue sarcoma, especially those with complex genome sarcomas, to have whole-genome sequence performed on their tumors to possibly identify actionable targets.

Next, in the study, "Efficacy and safety of larotrectinib as first-line treatment for patients with TRK fusion cancer," researchers investigated the use of a drug called larotrectinib which is a highly selective inhibitor of a protein called tropomyosin receptor kinase (TRK) and is already approved for treatment of tumors with TRK fusions regardless of their subtype, however before now there has been no data on patients who have not been previously treated. In this study, the investigators studied exactly those patients. 101 patients were enrolled comprised of 14 different tumor types with the most common being non-infantile fibrosarcoma (IFS) soft tissue sarcoma (30%) and IFS (18%). The overall response rate was 77%. Median duration of response was 59 months, and progression-free survival was 61 months. These data indicate that treatment naïve patients with tumors that are TRK fusion positive that are treated with larotrectinib achieved durable responses, extended survival, and had a good safety profile.

Lastly, in "Prognostic Value of the G2 Expression Signature and MYC Overexpression in Childhood High-Grade Osteosarcoma," the investigators look to confirm and determine if the combination of two previously reported prognostic indicators are able to help identify patient survival in osteosarcoma. The first prognostic factor is the expression of a group of genes that has been called G2 and expression of these genes in osteosarcoma has been associated with unfavorable survival. The second factor is an increased expression or amplification of a gene called MYC, which has also been associated with unfavorable survival. In this study, RNA sequencing was performed on 48 patients and whole-exome sequencing was performed in 40 pediatric and adolescent patients with high-grade osteosarcoma and the gene expression signature scores, MYC amplification, and MYC expression levels were determined. Following analysis, the G2 gene expression signature and MYC overexpression, but not MYC amplification were confirmed to be associated with unfavorable survival. More studies need to be done, but these results indicate that these biomarkers may be a useful tool in determining how patients with high-grade osteosarcoma should be managed.

IN THE COMMUNITY

Why I Run: A Survivor's Commitment to the Sarcoma Community

The following was shared with us by RTCS Milwaukee committee member Jerry Glisch

In 2015, I knew little about Sarcoma cancers, like so many others. That changed for me when I found a lump in the back of my leg. I knew it wasn't supposed to be there, but I had no idea what it could be. I made an appointment, got an ultrasound, and they believed it to be a mass of blood vessels. I don't know what led me to seek another opinion, but I did. A second doctor, after an MRI, determined it was probably a nerve sheath tumor. The advice was to wait five years and reassess. That didn't sit right with me, so I got connected with a doctor at Froedtert Hospital. Shortly after, he removed the tumor. "The pathology report wasn't what we had hoped for." Those were his exact words. And just like that, I became intimately acquainted with Sarcoma. The tumor they removed was a myxoid liposarcoma. Twenty-five radiation sessions left my upper left leg badly burnt. A follow-up surgery to clear the margins left me with a long, open wound on the back of my leg for months. But I kept my leg. I survived.

It will be ten years, this year, since I found that lump. I'm a lucky one. I seemingly caught it early, and I wouldn't accept a "wait and see" treatment plan for whatever it was in my leg. So many others battling Sarcoma aren't as fortunate. My positive outcome felt like an opportunity to me.

In 2017, I ran in the inaugural Race to Cure Sarcoma Milwaukee event. I was struck by the strength and commitment of the people there, so I reached out to the Sarcoma Foundation of America. I wanted to be a part of organizing that event. I wanted to do something to help others struggling through this disease, so I joined the committee to plan the next year's event. And I've been doing it since. Each year, I hear the stories of those who battled through years of surgeries and treatments. I hear people talk about the loved ones they lost to this disease, and I feel like I have such an incredible opportunity to support this community of people, unfortunately linked by a terrible circumstance.

Not a day passes that I don't think about how fortunate I am to be here. I am forever grateful to the doctors and nurses at Froedtert, as well as my family and friends who made healing possible.

Let's end Sarcoma.

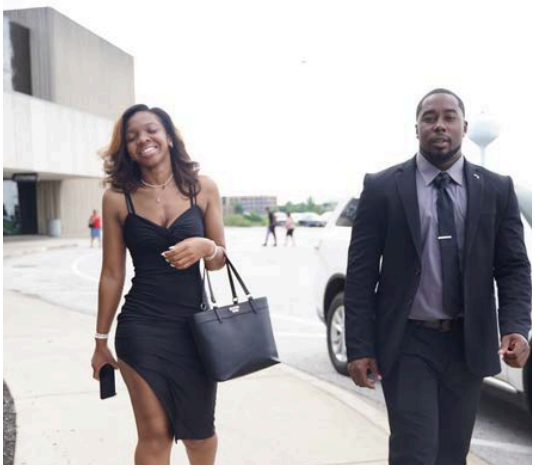
Raising Funds for Sarcoma Research

Katie Wintergerst was diagnosed with synovial sarcoma in 2018. A mom of two kids, she lives in Louisville, KY. Katie got involved with the Race to Cure Sarcoma in her city starting in 2019. The race is especially meaningful to Katie because it brings together the sarcoma community in a city that does not have a sarcoma treatment center. In essence, the race has helped to build a community around sarcoma in Louisville.

After her diagnosis in 2018, Katie was eager to get involved in sarcoma advocacy. After a quick google search, she came across the Sarcoma Foundation of America, which was planning the first inaugural Race to Cure Sarcoma event in Louisville in 2019. Excited to get involved, Katie created a race team and became a team captain and event co-chair. As the event co-chair, Katie is now instrumental in planning the event and fundraising activities. Katie helps to plan many fundraising efforts that take place throughout the year, including restaurant nights at local restaurants or jewelry sales at Kendra Scott.

Since sarcoma is a rare cancer, it doesn't receive the funding needed to make progress in finding better treatment options or a cure one day. However, progress is being made with private funding and research grants through foundations like the Sarcoma Foundation of America. Katie encourages everyone to get involved in the fight against sarcoma. "Whether you've directly been personally impacted by sarcoma or you're just looking to get involved in something, it's such a unique community and I would absolutely encourage it. We're all able to find our way through our sarcoma diagnoses and find meaning. However it is for each person, we can use our situations and stories for the better."

Breon's Sarcoma Story: Finding Strength in Sharing



Breon, a 29-year-old law enforcement officer from Illinois, discovered a mass in his foot after a work incident in May 2024. What initially seemed like a minor injury ultimately led to a synovial sarcoma diagnosis in November 2024. Faced with the difficult decision of amputation, Breon, with the unwavering support of his wife and care partner Leia, chose to proceed with the surgery.

Throughout his experience, Breon has maintained a remarkably positive outlook and a strong determination to return to his life and work. He shares his sarcoma journey

on TikTok as HeyRookie where he has found a community and offers a message of hope to others navigating similar challenges. His candid approach to sharing his story, from the physical recovery to the emotional impact on his family, has resonated with many.

Breon's journey highlights the profound impact a sarcoma diagnosis can have on an individual and their loved ones. It also underscores the importance of a strong support system, personal resilience, and the power of sharing one's story to help others.

To learn more about Breon's sarcoma story and hear his full conversation with us, listen to his episode of “Sarcoma Stories” on your favorite podcast platform and be sure to follow and turn on notifications.

The Sarcoma Shuffle: Community Steps Up

We're excited to share an update on the recent Sarcoma Shuffle, a fantastic third-party fundraiser organized by Erin and Frank Vespe!

The event was a great success, with 135 registered runners for the 5K and 10K races. Of these, 106 participants ran in person, while others joined virtually, showing widespread support for our cause. Frank delivered a powerful three-minute talk emphasizing the importance of sarcoma awareness and the mission of the Sarcoma Foundation of America.

A particularly moving moment occurred when one participant shared that she ran specifically to support SFA, as she had lost her sister to sarcoma in 2020. This personal connection reinforces the profound impact these events have on individuals within the sarcoma community. We were also encouraged to see three people inquire about making direct donations to SFA, highlighting the event's success in raising both awareness and potential support.

Erin and Frank are already looking ahead, considering ways to expand and improve the Sarcoma Shuffle if they decide to host it annually. Their enthusiasm for growing this event means even greater potential to fund research, provide resources, and advocate for people affected by sarcoma.

We extend our deepest gratitude to Erin and Frank Vespe, all the dedicated runners, and everyone who supported the Sarcoma Shuffle! Your commitment helps us work towards a world where people do not die from sarcoma.

SFA NEWS

Seeds of Hope Society Donor Spotlight: Why I Give.

In 2024, SFA launched the Seeds of Hope Society—a passionate community of sustaining givers who have committed to making recurring donations to SFA.

This month, we're spotlighting Seeds of Hope Society donor Lisa Shimel, as she shares why she gives in support of sarcoma patients, education, and advocacy:

"My husband and I choose to support SFA monthly to help SFA have a stable, reliable and known source of income to support its mission. Our donation is not substantial, but we want to support the important efforts of SFA, and we know every dollar counts. Knowing that SFA has a Charity Navigator score of 100% makes us confident our donation is put to good use.

Our son was a senior in college, studying mechanical engineering, when he discovered he had a sarcoma tumor in the lining of a nerve near his collarbone. We were so fortunate that he found it early. He carried a backpack of heavy books on a daily basis and the shoulder strap rested on the tumor, causing some pain. Initially diagnosed as a cyst, we were shocked when the lab work came back as a rare and aggressive sarcoma, a Malignant Peripheral Nerve Sheath Tumor. Following its removal, he underwent radiation while completing his studies. We have an excellent medical facility near us which has a sarcoma multidisciplinary clinic. The clinic introduced us to SFA, and we found the SFA educational resources very helpful in understanding what our son was facing. We also have a niece who has battled osteosarcoma; we donate in honor of her and of our son. My husband and I are pleased to support SFA's important work funding and advancing research, educating and providing resources for people diagnosed with sarcoma, and advocating on behalf of the community."

Thank you, Lisa, for sharing your giving story! The growing Seeds of Hope community plays a pivotal role in ensuring consistent resources that empower us to make a lasting impact. To learn more about Seeds of Hope, please click here.

Celebrating 25 Years: SFA's First Research Grants in 2003

In 2003, SFA funded the first of many exciting research grants on antisense and immunotherapy approaches. Since then, SFA has funded over 200 research grants from 137 institutions across 12 countries. SFA's investment of over $26 million in Sarcoma research has made it easier for researchers to find opportunities that advance their work.

As part of our 25th anniversary celebration, we are looking back at those early grants that SFA funded. Take a look at a clip from our very first newsletter.

THE CUTTING EDGE

Early in 2003, the SFA funded three starter grants that will explore antisense[1] and immunotherapy[2] approaches. The following are the abstracts of the first of many exciting research grants that the SFA will fund in the years to come:

Targeting the Inactivation of the MYC Oncogene to Treat Osteogenic Sarcoma

Dean Felsher, MD, PhD
Stanford School of Medicine ,Stanford University Medical Center.

Abstract:
We have found that even brief inactivation of the MYC oncogene can result in sustained regression of osteogenic sarcoma (Jain et al, Science, 2002; Weinstein, Science, 2002). Now, we propose to perform several pre-clinical studies to evaluate the effectiveness of a novel anti-sense approach for the inactivation of MYC for the treatment of osteogenic sarcoma. We will evaluate the mechanisms by which brief inactivation of MYC induces tumor regression through DNA microarrays. From these experiments, we will obtain the preliminary results necessary to subsequently conduct a clinical trial to evaluate the effectiveness of the inactivation of MYC to treat human osteogenic sarcoma.

Generating T cell Immunity to Sarcoma by Liposomal Vaccination with Sarcoma Fusion Breakpoints

Mary Jo Turk, PhD and Jose A. Guevara-Patino, MD, PhD
Memorial Sloan Kettering Cancer Center

Abstract:
We have developed a liposomal vaccine that delivers long peptides into the processing/presentation machinery of antigen presenting cells and generates outstanding cytotoxic T cell responses. We propose the use of this vaccine for generating T cell immunity to the breakpoint regions of four sarcoma-derived oncofusion proteins: EWS-ATF1, SYT-SSX, TLS-CHOP, and ASPL-TFE3. Experiments will be conducted to demonstrate that peptides within these breakpoints 1) are processed and presented by human antigen presenting cells, and 2) activate a population of cytotoxic T lymphocytes capable of killing human sarcoma cells. These studies will facilitate rapid clinical translation of four novel sarcoma vaccines.

Identification of Tumor Suppressor (LOH18CR) on Chromosome 18

Antony E. Shrimpton, PhD and Timothy A. Damron, MD
State University of New York, Upstate Medical University

Abstract:
We have identified and studied a family with familial Paget's disease of bone and Pagetoid osteosarcoma. A familial pattern is extremely unusual and indicates the presence of a putative germline mutation in a tumor suppressor gene involved in osteosarcoma. We have demonstrated loss of heterozygosity for markers located on the long arm of chromosome 18q which includes a 530 kb critical region defined by others, which is believed to contain an osteosarcoma tumor suppressor gene. We wish to sequence candidate genes, in close to this region or otherwise implicated, in order to identify a pathogenic mutation, and thus the tumor suppressor gene.

[1]Antisense drugs are small, chemically modified strands of DNA. These so-called oligonucleotides are engineered in a sequence that is exactly opposite (hence, anti) to the coding (sense) sequence of mRNA for the purpose of binding to that mRNA. Upon binding to the mRNA a duplex is formed. This duplex recruits an enzyme which degrades the mRNA portion of the duplex, thereby inhibiting the production of the intended protein. The antisense portion of the duplex is then released or further bringing to a new mRNA.

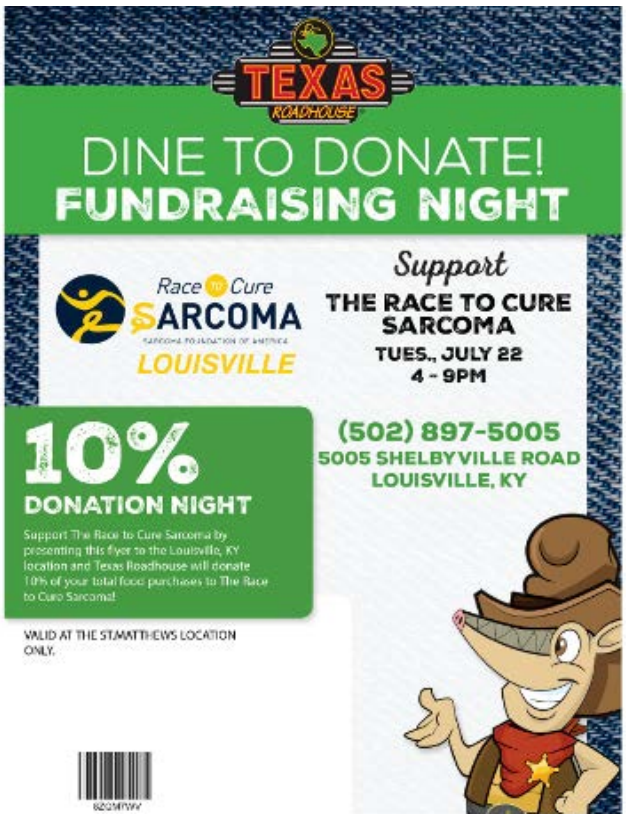
[2]Immunotherapy is the name given to cancer treatments that use the immune system to attack cancers. Immunotherapy drugs stimulate the body to respond biologically (or naturally) to cancer.

EVENTS

Upcoming Community Events

Race to Cure Sarcoma Louisville Giveback Events

In conjunction with the Race to Cure Sarcoma Louisville on August 9, 2025, there are two special giveback events providing additional ways to support the cause, we hope you will join us.



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.

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.

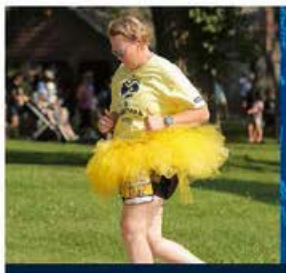
MCM 26.2
MARINE CORPS MARATHON

Race TO Cure SARCOMA
MARATHON TEAM

JOIN OUR MARINE CORPS MARATHON TEAM

LEARN MORE AND SIGN UP

Race TO Cure SARCOMA
SARCOMA FOUNDATION OF AMERICA



2025 DATES

Milwaukee July 12, 2025	**Louisville** August 9, 2025	**Chicago** September 27, 2025	**Tampa** November 1, 2025
Global Virtual July 19, 2025	**Philadelphia** August 16, 2025	**New Jersey** October 5, 2025	**Los Angeles** November 2, 2025
Washington DC July 19, 2025	**San Diego** September 20, 2025	**Denver** October 25, 2025	**Sacramento Valley** November 8, 2025