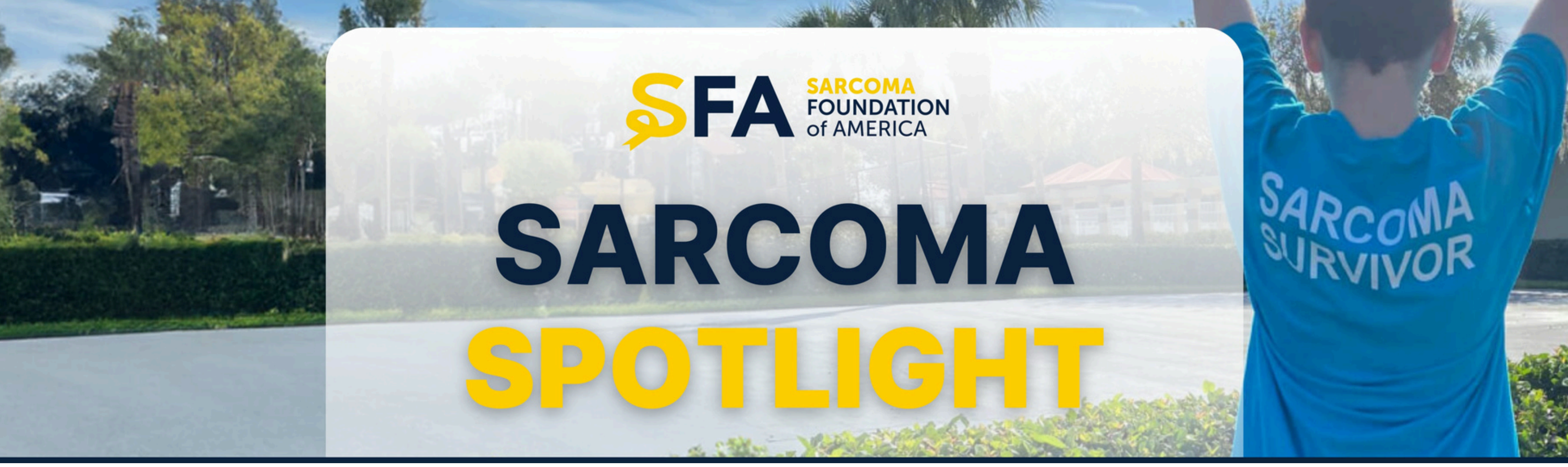

SFA SARCOMA FOUNDATION of AMERICA

SARCOMA SPOTLIGHT

Championing Better Treatments and Outcomes for People with Sarcoma

Brandi Felser, CEO

Last month SFA hosted our annual Stand Up to Sarcoma Gala. Once again, it was an impactful event filled with meaningful discussion, opportunities for new connections, and celebrating progress. Like our Race to Cure Sarcoma events, the gala brings together diverse members of the sarcoma community. Listening to the journeys of the patients and survivors and applauding the work of our honorees always connects me to why SFA's mission is so important.

Our mission is to improve outcomes for people diagnosed and living with sarcoma.
Our entire organization is passionate, and laser focused on achieving that mission. A central focus is advancing new and better treatment options. While we are the largest funder of research in the sarcoma community, that is only part of the equation. Not only are clinical trials often treatment for many sarcoma subtypes, but they are also necessary to advance therapy approvals. That's why SFA works closely with our industry partners to provide the patient voice, share information with patients and facilitate access through our Jordan's Dream Fund program to advance clinical trials.

In the last several years, we have seen increased options for sarcoma clinical trials and increased FDA approvals, some for rare subtypes. But we have also seen many potential therapies fail. Either because they did not show efficacy or because of barriers rare cancers encounter.

We appreciate the investment from industry in a rare cancer like sarcoma and we encourage more. But the reality is, the rarity of sarcoma poses challenges other cancers do not face and industry investment alone will not fix that. Aside from the challenges associated with traveling to sarcoma centers for expert treatment, a limited number of trials, and open trials have limited sites. Current regulatory processes create barriers to FDA approvals and industry investment.

There is currently no single effective approval pathway for rare cancers like sarcoma. Realizing better and less toxic therapy options must include working closely with legislators and regulatory bodies to develop and implement fit for purpose approval pathways, recognizing that more than one approach may be needed. We, the sarcoma community, must have a voice in the creation of these processes. SFA is leading the way in ensuring our voice is amplified in the places where decisions are being made. Our Sarcoma Advocacy Day is one part of ensuring our voices are represented. We also work behind the scenes with other organizations, policy makers, and public policy experts to insert the voice of the sarcoma community, so we are not left behind.

Earlier this year, I participated in a roundtable that produced a whitepaper with recommendations to lawmakers on how we can improve the regulatory process for rare cancers like sarcoma. This paper has been provided to our lawmakers on capitol hill with ongoing discussions about how we can affect necessary changes. We recently submitted formal comments to the FDA in response to their draft guidance to industry on *Approaches to Assessment of Overall Survival in Oncology Clinical Trials*. Our position is clear; this guidance, if not framed with rare cancers, like sarcoma, in mind, could significantly impact the potential for new sarcoma treatments to be developed It is necessary that the sarcoma, and rare cancer, voice is included.

As the largest sarcoma organization representing all subtypes of sarcoma, we understand the strategies necessary to improve outcomes. We will not stop until there are better, less toxic, and more accessible treatments for every person diagnosed with sarcoma. Our mission is clear, and we remain fully committed to making meaningful progress.

A Night of Celebration and Community: The 23rd Annual Stand Up to Sarcoma Gala

On Monday, September 15, Sarcoma Foundation of America (SFA) proudly hosted its 23rd Annual Stand Up to Sarcoma Gala, an unforgettable evening filled with celebration, community, hope, and unwavering dedication to supporting those whose lives have been affected by sarcoma.

Supporters, patients, caregivers, and families came together to honor those who have devoted their lives to helping people impacted by sarcoma and to pay tribute to the survivors and patients who inspire us every day. The evening highlighted the strength of our community and the importance of raising awareness and funding to advance research.

Guests were treated to an incredible performance by Tony Award-winning, Emmy and Grammy-nominated actor, singer, writer, and producer Annaleigh Ashford**,** currently starring in the Paramount+ Original Series *Happy Face*. She kicked off the night with a lively audience-participation song, inviting the crowd to sing and drum along with her, creating a moment of unity and laughter that set the tone of the entire night.

Serving as master of ceremonies was Claybourne Elder, a Grammy, SAG Award, Drama Desk, and Lucille Lortel–nominated actor currently appearing as John Adams on HBO's hit series *The Gilded Age*. With warmth and charisma, his presence made the evening flow seamlessly, allowing everyone to focus on what mattered most our shared mission to stand up to sarcoma.

We were deeply honored to recognize this year's distinguished awardees, each of whom has made a unique and lasting impact in the fight against sarcoma:

- **David Kirsch, MD, PhD** – *Nobility in Science Award*
- **The John W. O'Brien Family Foundation** – *Vision of Hope Award*
- **Christina Kim, NP** – *Compassionate Care Award*
- **Billy Brimblecom, Jr.** – *Courage Award*
- **Andrey Ivchenko** – *Amira Yunis Courage Award*

Their stories of compassion, dedication, and bravery serve as powerful reminders of why we continue to stand up to sarcoma together. Learn more about this year's honorees.

We extend our heartfelt gratitude to everyone who joined us for this special night and to our generous event sponsors. Your commitment makes it possible for SFA to advance research, support patients and families, and fuel hope for a brighter future. Relive the evening! View photos from the Gala.

Mark your calendars—we hope you will join us for the 24th Annual Stand Up to Sarcoma Gala on October 5, 2026, at 583 Park Avenue, New York City.

Thank you to our generous sponsors.

November Live with the Experts

Understanding ctDNA in Sarcomas
Monday, November 3, 2025
9:00 am EST

Our Expert Panelists:

Dr. Herbert Loong
The Chinese University of Hong Kong

Dr. David Shulman
Dana Farber Cancer Institute

Edwin Choy, MD, PhD
Massachusetts General Hospital

Join us for an in-depth discussion with sarcoma experts on circulating tumor DNA (ctDNA) — what it is, how it’s being used in oncology, and what current research is uncovering about its role in sarcomas.

To join the discussion, register here and submit any questions you may have in advance. You can also submit questions through the Q&A feature during the event and anytime on social media using the hashtag #SFAResearchRoundup.

RESEARCH ROUNDUP

Highlighted Research

Each month, SFA highlights recently published work that is helping scientists uncover new insights into sarcoma and explore potential therapies. These studies represent important steps along the path to better treatments and improved outcomes.

Using Cell Maps to Explore Potential Ewing Sarcoma Therapies

The first paper "KC1036, a multi-kinase inhibitor with anti-angiogenic activity, can effectively suppress the tumor growth of Ewing sarcoma," attempts to map the cell-to-cell communications in Ewing sarcoma (ES) and use this map to identify potential new therapies. They used a technique called single-cell RNA sequencing (scRNA-seq) data analysis to determine how the cells within the ES tumor microenvironment (TMA) communicated with each other. The analysis indicated that multi-kinase anti-angiogenic inhibitors may be effective against ES. The investigators then tested a novel multi-kinase inhibitor, KC1036, in ES cancer cell lines and mouse models of ES. The first mouse model uses an ES cell line implanted in a mouse and the second uses cells from a patient's tumor implanted into the mouse. In both cases the drug of interest is then used to determine efficacy against the implanted tumors. The results of these series of experiments indicate that KC1046 may be effective against ES. These are early results, and many additional studies are needed, but they indicate that this multi-kinase inhibitor may be a therapeutic option in ES.

The Role of Next-Generation Sequencing in Sarcoma Diagnosis and Treatment

There are many different subtypes of sarcoma with early and accurate diagnosis being very important in the development of a treatment plan for the patient. The next study, "Exploring the impact of NGS on diagnostics and treatment of sarcoma: insights from real-world data across multiple institutions in Europe," investigates the potential benefit of next-generation sequencing (NGS), a technique used to determine the changes in tumor DNA, in real-world situations across multiple countries in Europe to guide diagnosis and treatment strategy. The investigators analyzed 694 samples from six sarcoma-expert institutions in three countries: Greece, Poland, and Spain. They identified 90 different sarcoma histological subtypes. In 8.9% (62) patients, NGS resulted in a change in the diagnosis. NGS panels used for this purpose were able to identify multiple genetic alterations. 19.5% or 135 were actionable according to an FDA approved human genetic variant database called OncoKB, and four other alterations (0.6%) were actionable in disagreement with OncoKB. These results indicate that it is important to work with a sarcoma-expert pathologist and that next-generation DNA sequences may be useful in the diagnosis and the determination of therapeutic options in sarcoma.

Potential Biomarkers Linked to Sarcoma Immunotherapy Response

Tumors can activate the brakes on a patient's immune system. One type of immunotherapy called immune checkpoint inhibition (ICI) can release those brakes and allow a patient's immune system to attack their tumor. This type of immunotherapy is not very effective in sarcoma, however, in "High transposable element expression in sarcomas is associated with increased immune infiltrates and improved outcomes including after immunotherapy," the investigators are trying to determine how the effectiveness of ICIs can be increased and to determine in which patients it will be effective. They did this by determining whether the expression of transposable elements (TEs), which are DNA segments that when expressed can stimulate antitumor immunity, but are modified in many tumors so that they are not expressed.

Using a machine learning technique (lasso-penalized logistic regression), they analyzed DNA expression from several ICI studies to determine if TE and other gene expression can predict immune infiltration of sarcoma tumors. They found that expression of TEs and a protein called Ikaros family zinc finger 1 (IKZF1), which regulates how DNA interacts with other proteins, were important in the ability of ICI therapeutics effectiveness. In addition, they found that TE and IKZF1 expression positively correlated with improved clinical outcomes and overall survival.

These results, although early, indicate that further study is needed in the use of TE and IKZF1 expression as potential biomarkers of ICI treatment outcomes and as therapeutic targets in sarcoma.

Clinical Trials Corner

This month SFA is highlighting METTSEO, the metastatic Ewing's trial testing schedule enhancement to improve outcomes. This study is newly recruiting at Moffitt Cancer Center, with 16 additional locations opening across the United States. The trial is open to patients at least one year of age with widely metastatic Ewing sarcoma or metastatic CIC-rearranged sarcoma.

Patients eligible for this trial will receive a different approach to chemotherapy treatment that is designed to attack different populations of cancer cells as the cells adapt in response to treatment. In this approach, the first phase of treatment uses medicines intended to kill the majority of the cancer cells, and a series of follow up medicines target residual cells that may have escaped the first phase. The last phase is extended treatment with a combination of medicines as part of maintenance chemotherapy. Doctors and scientists are trying to understand if this unique and phased approach to chemotherapy is tolerable to patients, and if it improves survival for these exceptionally high-risk patients.

This is a phase 1 trial, which means that doctors are learning whether administering the medications used in this study in this way is a safe and tolerable option for patients. All of the medicines in this study are chemotherapies already used to treat patients with Ewing sarcoma.

These medicines include vincristine, doxorubicin, cyclophosphamide, ifosfamide, actinomycin, irinotecan, cabozantinib, topotecan, temozolomide, and etoposide.

Patients should talk to their clinical care teams and care partners about the potential risks and benefits of this study for them, as well as their goals during and after treatment.
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 or reach out to the study contact. Participating patients in need of additional travel or financial support are encouraged to apply for assistance from SFA.

Research Spotlight: Motivated by the Search for a Cure

The John O'Brien Family Foundation Research Award, established in memory of John O'Brien, funded a 2024 Sarcoma Foundation of America (SFA) Research Grant awarded to Michael W. Stacey, PhD, Research Associate Professor at the Frank Reidy Research Center for Bioelectrics at Old Dominion University (ODU). His project, "Mitochondrial Epigenetic Processes and Transfers in Chondrosarcoma Cancers with Mutant IDH2," explores how sarcoma cells can alter their surroundings to survive and spread.

This award is part of SFA's research fund program, which allows families, individuals, and organizations to establish funds in honor or memory of a loved one or to support research into specific sarcoma subtypes. These restricted funds leverage SFA's competitive grantmaking process to fuel innovative projects and ensure donor priorities make a lasting impact.

New Insights into How Sarcoma Spreads

Chondrosarcoma, the second most common form of bone cancer, can carry a mutation (IDH2) that produces a cancer-causing chemical inside the cell's mitochondria, the part of the cell that generates energy. Dr. Stacey and his team asked an important question: Can these altered mitochondria move from cancer cells into nearby healthy cells, and if so, what happens next? The research showed that the answer is yes. Mutated mitochondria can transfer into normal cells, reducing their ability to produce energy and even changing their DNA so that the cells begin to behave more like tumors. This finding suggests that sarcoma may hijack surrounding healthy cells, creating an environment that helps the cancer grow and spread.

Turning Discovery into Progress

These discoveries are opening new possibilities for therapies that do not just attack the tumor itself but also protect surrounding cells from being taken over.

The work has already resulted in three manuscripts in preparation, two National Institutes of Health (NIH) grant applications, and a collaboration with engineers at ODU to study how tumors change their environment and how to block that process.

"Rare cancers are devastating and resistant to therapy. Without SFA support, it would have been nearly impossible to generate the data needed to attract NIH funding. The importance of SFA cannot be overstated," Dr. Stacey shared. "I like to feel I have contributed toward helping patients with these devastating cancers. To be part of a global team working toward a cure is what motivates me."

SFA's Commitment to Advancing Research

At the 2025 Stand Up to Sarcoma Gala, the John W. O'Brien Family Foundation received the Vision of Hope Award in recognition of their commitment to advancing sarcoma awareness, research, and patient support. Founded in 2023 after John O'Brien's passing from chondrosarcoma, the foundation is led by his wife, Pat, and their four children. In her remarks at the Gala, Pat O'Brien shared that realizing the dream of funding groundbreaking research had always been at the heart of the family's mission.

Your support makes a difference. Learn how you can fund a research grant and help advance life-saving treatments for people diagnosed with sarcoma.

Pat O'Brien accepts the Vision of Hope Award from SFA's Natasha Nathan.

Apply Now: 2026 SFA Research Grants

We are now accepting applications for the 2026 Research Grant Cycle. These grants provide up to $75,000 to support new ideas that could lead to better treatments and outcomes for people with sarcoma.

Letters of Intent are due November 6, 2025. Learn more.

ADVOCACY & ENGAGEMENT

Recognizing Childhood Cancer Awareness Month

September was Childhood Cancer Awareness Month, a time to raise awareness of the unique needs of children and families impacted by sarcoma. Sarcomas make up 15–21% of all childhood cancers, yet treatment progress has been limited, and many survivors continue to face long-term challenges. These realities are why SFA has made pediatric sarcoma a priority since our founding 25 years ago. As part of that commitment, we share the story of Jason, a high school student and sarcoma survivor whose journey reflects strength, resilience, and hope.

Faces Behind the Ribbon: Jason McGrew

At age two, Jason's limp was first thought to be growing pains. When the symptoms returned with a fever, further testing at Stanford Children's Hospital revealed Ewing sarcoma. Thankfully, the cancer had not spread, and Jason underwent chemotherapy and a rotationplasty amputation to remove the tumor.

Jason does not remember much about treatment, but he has lived with its effects his whole life. His prosthetic leg has required more medical care than most of his peers, yet it has also allowed him to stay active, play sports, and pursue hobbies like reading, writing, and violin. Now in high school, Jason plans to attend college and hopes to earn a PhD in mathematics.

Being a survivor has also shaped Jason's goals toward advocacy. He volunteers with the amputee and cancer survivor communities and wants to be part of the support systems that every patient and family deserves.

Jason reminds us that every childhood cancer survivor faces unique challenges, but that survivors can still stand together in advocacy and hope. To kids and families facing sarcoma today, he offers this encouragement: "*There are people out there who are completely willing to support you. You do not have to go through this by yourself*."

No one goes through a sarcoma journey alone. Share your story and inspire others.

SFA NEWS

New Director of Research Engagement

Missy Tursiella, PhD

SFA is excited to announce that Melissa (Missy) Tursiella, PhD, joined us in September as our new Director of Research and Engagement. Missy has more than seven years of experience managing federal biomedical research portfolios. As a Science Officer and later Program Manager for the Congressionally Directed Medical Research Programs (2018–2025), she oversaw the full research grant cycle, from investment strategy to application review, and led the launch of a high-visibility biomedical research program. She also worked closely with patients, advocates, and scientific experts to shape program priorities.

Missy earned her BS in Biology from the University of the Sciences in Philadelphia and her PhD in Microbiology and Immunology from the Pennsylvania State University College of Medicine, where she studied DNA virus–induced tumorigenesis. She completed postdoctoral fellowships at Pennsylvania State and at the U.S. Army Medical Research Institute of Infectious Diseases, focusing on DNA tumor viruses and biodefense pathogens.

Support SFA Through Workplace Giving

Calling all Federal and Maryland State employees and retirees! The Combined Federal Campaign (CFC) and Maryland Charity Campaign (MCC) annual charitable workplace giving programs have begun, and SFA is thrilled to announce our participation and listing as an eligible charity. Consider including SFA in your pledge this year and help fuel our work in funding translational research to improve outcomes for sarcoma patients. Every dollar makes a difference! Learn More About Workplace Giving with SFA

- **CFC:** Federal employees and retirees can find us in the charity list this fall with SFA’s code 57785.
- **MCC:** Maryland State employees and retirees can find us in the charity list using SFA’s EIN #: 522275294.

SFA Launches Pediatric Sarcoma Webinar Series

The first session in SFA's new pediatric webinar series explores the key differences between pediatric and adult sarcomas. Expert panelists Damon Reed, MD; Katherine Janeway, MD, PhD; and care partner and advocate Jenny Sage shared insights on treatment options, the importance of specialized care, and the unique challenges faced by children and families affected by sarcoma. View the recording.

Listen to the Latest Episodes of Our Sarcoma Stories Podcast

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

Episode 16 | Andrey Ivchenko: Strength, Self-Advocacy, and Recovery
Actor Andrey Ivchenko—known for Stranger Things and Call of Duty—shares his experience with chondrosarcoma, from misdiagnosis to recovery after an extensive hemipelvectomy. His story underscores the power of self-advocacy, care-partner support, and continued research in rare cancers.

Episode 15 | SFA Founders: 25 Years of Impact
In honor of SFA's 25th anniversary, founders Mark Thornton, Tricia Thornton, and Jack Brooks reflect on how a family's determination grew into the largest private funder of sarcoma research—and what they envision for the community's future.

Episode 14 | Breon and Leia Glass: A Powerhouse Team
Breon Glass, a 29-year-old synovial sarcoma survivor and law-enforcement officer, and his wife Leia share their journey through diagnosis, amputation, and recovery. Together they highlight the strength of partnership, the value of research, and the importance of living fully after a sarcoma diagnosis.

Listen to all episodes of the Sarcoma Stories podcast

Join the Team at SFA!

As SFA continues to grow, we’re expanding our team to help advance research, raise awareness, and improve outcomes for everyone affected by sarcoma.

We’re currently hiring for several key roles, including:

- Director of Advancement
- Development Manager
- Fundraising Events Manager

If you or someone you know is passionate about making a difference in the sarcoma community, we’d love to connect. View current openings on LinkedIn
Questions? Email info@curesarcoma.org

IN THE COMMUNITY

19th Annual Pub for Peds

On October 3, family and friends gathered at Rancocas Golf Club for the annual Putts for Ped golf outing in memory of Michael John Pedrick. The gathering brought loved ones together to celebrate Michael's life while raising funds to support the Sarcoma Foundation of America. Organized by SFA Board Member Jennifer Nellany, who helped establish Putts for Ped with family and friends to honor her late husband's memory, the event continues to celebrate Michael's legacy and make a lasting impact in the fight against sarcoma.

Scott Lively Memorial Golf Tournament

On September 20, the 4th Annual Scott Lively Memorial Golf Tournament was held at Bear's Best Atlanta in honor of Scott's life and legacy. Hosted by his brother, Ryan, and mother, Kathy, the event brought together family, friends, and supporters to raise funds and awareness for sarcoma research. The Lively family continues to honor Scott by turning their loss into impact, helping advance the search for better treatments and a cure.

The 2024 tournament raised more than $42,000, bringing the total to over $143,000 raised in four years for sarcoma research. In 2025, Jeffrey A. Toretsky, MD, of Georgetown University received the Scott Lively Memorial Research Award, a $75,000 grant in support of his research on Ewing sarcoma.

RACE TO CURE SARCOMA

Chicago Community Rallies and Exceeds Fundraising Goal

On Saturday, September 27, more than 765 members of the Chicago sarcoma community gathered at Diversey Harbor for the largest Race to Cure Sarcoma Chicago yet. Survivors, caregivers, and supporters came together to raise vital funds and awareness, with 37 fundraising teams helping bring in more than $94,000 to support those impacted by sarcoma. This milestone event reflects the incredible passion and dedication of the Chicago community.

RTCS Chicago Team Highlight

Team Kimme, led by Kimme's brother Mark Capulong, is a shining example of love and legacy in action. At our recent Chicago donor event, Mark and his mother shared heartfelt stories about Kimme that reflected her resilience, joy, and pride. This year marked the family's 5th Race to Cure Sarcoma, and their 2nd without Kimme physically present. Team Kimme was honored with the Largest Team award at RTCS Chicago 2025, bringing together 84 members in her memory. Through the team, the family continues to honor Kimme's life by raising awareness, funds, and community support.

Team Kimme at RTCS Chicago 2025

RTCS Chicago Team Member Highlight

Annie Solis, RTCS Chicago 2025

Annie Solis is a dedicated member of the Race to Cure Sarcoma Chicago committee who leads with passion and purpose. Each year, she builds one of the largest teams at the race, rallying friends, family, and community members to make a meaningful impact. This year, her team Steph's Support Squad was the top fundraising team, raising more than $10,000 in support of sarcoma research and patient programs.

Annie runs in honor of her mother, Stephanie Solis, who is living with leiomyosarcoma and currently participating in a clinical trial funded by an SFA grant. Stephanie was also a guest speaker at this year's event, where she shared her story and experience with leiomyosarcoma, inspiring everyone in attendance.

In her first year as a committee member, Annie has already made an incredible impact as a leader for RTCS Chicago.

RTCS Philadelphia Participant Highlight

Dr. Arianne Missimer is a physical therapist, dietitian, functional medicine practitioner, and founder of The Movement Paradigm, whose personal journey as a stage 3 liposarcoma survivor has made her a powerful advocate in the sarcoma community.

Diagnosed in 2015 just before her wedding, she endured chemotherapy, radiation, and surgery while refusing to let cancer define her—training for and ultimately competing on American Ninja Warrior (!!!) during treatment.

Now celebrating 10 years cancer-free, she shares her story through her TEDx talk Challenge Accepted and her book Rise Up, while also fundraising for Race to Cure Sarcoma. Her work as a speaker, author, and integrative health leader continues to inspire patients and professionals alike, offering hope and empowerment rooted in movement, mindset, and resilience.

Dr. Arianne Missimer, RTCS Philly 2025

Join Us for the Final Races to Cure Sarcoma of 2025!

There are only three Race to Cure Sarcoma events left this year — and there's still time to be part of the movement to raise awareness and funds for sarcoma research. Don't miss your chance to join the community, honor loved ones and make an impact. Register today!

Join us:
October 25-Denver, Colorado
November 1-Tampa, Florida
November 2– Los Angeles, California