



# Sarcoma Spotlight

May 2023

## May Is Cancer Research Awareness Month



SFA is proud to participate in recognizing **National Cancer Research Month**. This month highlights the importance of life-saving research to the millions of people around the world affected by cancer.

Join us in support of this awareness month as we focus on the significance of advancing sarcoma research and supporting patients and their families. This month is an important moment to unite our voices against sarcoma.

Sarcoma is a rare and aggressive cancer, and research is critical to finding new treatments and improving outcomes for those affected by sarcoma. At SFA, we're committed to funding innovative research to advance the fight against sarcoma. In fact, in the past 22 years, SFA has funded over 200 sarcoma research grants, totaling over \$14 million invested in sarcoma research. Our grant recipients have gone on to develop new treatments and therapies that have improved the lives of countless sarcoma patients.

In 2022, 19 new research grants were funded through SFA's grant program totaling nearly \$1 million. Check out our 2022 awardees and their sarcoma research [here](#). At SFA, we're committed to funding meritorious research projects across the spectrum of sarcoma subtypes. Learn more about subtypes [here](#).

We hope you will consider [a gift to SFA](#) and make a difference for patients, caregivers, and their families. Your thoughtful donation will fuel research, and support those affected by sarcoma during the most difficult times.

# Research Roundup

by Dean Frohlich, PhD

I am extremely pleased to tell you that the first three studies discussed below were funded in part by grants from SFA.

The first study “Epigenetic Control of Translation Checkpoint and Tumor Progression via RUVBL1-EEF1A1 Axis” identifies a protein that could be a potential new drug target in Ewing sarcoma. The investigators show that decreasing levels of this protein, which is involved in epigenetic pathways that can help control which genes are expressed, and an inhibiting another important protein, decreases the rate at which cancer cells grow in the lab. This is an early study, but it indicates that this is a possible combination therapy in Ewing sarcoma.

[“The M6A Reader YTHDC1 and the RNA Helicase DDX5 Control the Production of Rhabdomyosarcoma-Enriched circRNAs”](#) investigates how a new biologically active class of RNA (circRNA) impacts the creation of tumors in rhabdomyosarcoma. They identify a pathway where the creation of circRNAs relies on the interaction between a protein called YTHDC1 and the RNA helicase (DDX5). This study indicates that the decrease of YTHDC1/DDX5 reduces cell growth and that they may act in the initiation of rhabdomyosarcoma tumors. Future work must be done to determine how they correlate with tumor onset and progression; however, the inhibition of the pathway could become an interesting therapeutic approach.

The next study [“Structurally Complex Osteosarcoma Genomes Exhibit Limited Heterogeneity within Individual Tumors Across Evolutionary Time”](#) looked at osteosarcoma, which is an aggressive cancer with a high chromosomal complexity meaning that there are large parts of the genome that are either deleted or copied. There are different hypotheses as to how this occurs, and this study further examined whether the complexity comes from constant evolution of chromosomal mutations or from early multiple mutations followed by stable maintenance of an abnormal genome. These investigators sequenced over 12,000 individual tumor cells from different patients at diagnosis and upon relapse. The data indicate that the latter may be the case. These results have implications for diagnosis, biomarker assessment, and mechanisms of resistance.

Lastly, I want to highlight a phase 3 trial for a new drug to treat Desmoid tumors, [Nirogacestat, a Gamma-Secretase Inhibitor for Desmoid Tumor](#). This study found that Nirogacestat was associated with better outcomes as measured by multiple criteria in adults with progressing desmoid tumors with mostly low-grade adverse events.

## Clinical Trial Participation in Sarcoma

A strategic focus for SFA is clinical trial support and participation. We often receive questions from patients and family members about clinical trial participation and options. This has led us to develop programs and initiatives to better support patients.

In response to this need, we created a [page](#) on the SFA website for clinical trial listings. While the list is by no means exhaustive currently, our goal is to grow this page, provide an updated trial matching site, and relieve the burden of clinicaltrials.gov.

Last year, we launched SFA’s [Jordan’s Dream Fund](#) for clinical trial participation. This fund provides up to \$5,000 to patients participating in clinical trials who need assistance with travel, accommodations, and other expenses associated with clinical trial participation.

In July, during Sarcoma Awareness Month SFA will host a session on clinical trial participation, when to start talking about trials, and how to engage in shared decision making with your medical provider when evaluating a trial.

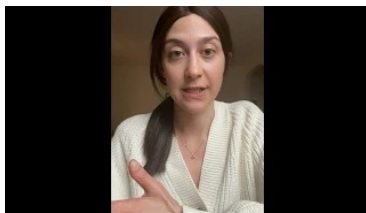
SFA works to grow awareness about the sarcoma trials available to patients through industry partners. We provide information about clinical trials through our social media platforms, and we will begin to include information in our monthly Sarcoma Spotlight newsletter.

We partner with sarcoma researchers and industry to find more and better therapies for sarcoma patients. We also work to advocate for and develop programs in collaboration with our strategic partners to overcome barriers to participation in clinical trials. To that end, SFA is interested in learning about patient experiences related to clinical trials.

That's why we are asking patients, survivors, and caregivers to participate in this [Clinical Trials in Sarcoma survey](#). The purpose of this survey is to identify barriers to and facilitators of clinical trial participation. We would like to [hear from you](#) so we can better understand how we can help to relieve some of these barriers and better support patients on their sarcoma journey.

### *Survivor Journey Spotlight*

## **A Courageous Patient's Story in Her Own Words**



Natasha "Tasha" Nathan is the team captain for Tasha's Team at the Race to Cure Sarcoma Boston and a sarcoma survivor. She was diagnosed with rhabdomyosarcoma in March 2022. Tasha's story teaches us that advocating for yourself and being persistent is necessary when you know something is not right with your body. Hear her story in her own words [here](#).

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## **Philadelphia Area Social Worker to Receive SFA Compassionate Care Award**

Every year at the Stand Up to Sarcoma Gala, SFA awards the Compassionate Care Award to a patient navigator (clinical/nurse, community health worker, social worker in the role of a navigator) for his or her outstanding contributions to patient care, support, and education. This year's Compassionate Care Awardee is Anjali Albanese, MSW, LSW, OSW-C. Anjali is a licensed social worker with Fox Chase Cancer Center in Philadelphia, Penn. She received her master's degree in Social Work from the School of Social Work at Rutgers, The State University of New Jersey, and her bachelor's in Psychology from Montclair State University.



Anjali was nominated for the Compassionate Care Award by her patient Tiffany Sontos and her coworker Stephanie Greco. When asked why Anjali should receive this award Tiffany said, "I have learned how to fly with broken wings, and I have Anjali to thank, because she is one of my biggest cheerleaders, she is my navigator through the healthcare system and most importantly she sees me as a person not just a number. Anjali truly is and will always be my angel on earth." All too often, it is easy to get caught up in the moment seemingly "just doing my job" not always realizing the lives touched by the important support social workers provide for patients and families. There is no doubt there are many other patients like Tiffany who share her sentiment. For this, SFA is excited to recognize and honor Anjali Albanese for her admirable work to support and better the lives of sarcoma patients at the 2023 Stand Up to Sarcoma Gala at Capitale in New York City.





Join SFA for a Sarcoma Community Event on Sunday, June 11, 2023, from 11:00 am to 3:00 pm, at James Driver Park in Houston, Texas. The day's program will feature comments by sarcoma survivors, sarcoma physicians, and SFA staff. A BBQ picnic lunch will be provided as well as kids' activities including a face painter, balloon artist and bounce house.

The event's scheduled special guest will be SFA Ambassador John Franklin-Myers of the New York Jets who is also a Texas native. John has been a long-time supporter of SFA and has been affected by sarcoma as his grandfather died from the disease in 2011.

"We're so pleased to bring this special program to Houston," says SFA CEO Brandi Fraser. "It's a unique opportunity to bring together sarcoma patients, survivors, their friends and loved ones to create lasting connections and build awareness of the disease."

There is no cost for the event, but pre-registration is required for each person attending. Be sure to [register](#) by June 8, 2023.

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## SFA News

### New Members for SFA Board

SFA is pleased to welcome Jennifer Nellany and Bruce I. March to its Board of Directors.



**Jennifer Nellany** of New York, NY, is the general counsel of Kushner Companies, a diversified real estate company headquartered in New York City. She received her legal degree in taxation from the New York University School of Law. Prior to joining the SFA board, Nellany was board president of the Sarcoma Alliance in Mill Valley, Calif.

**Bruce I. March** of Fort Lauderdale, Fla., also recently joined the SFA Board of Directors. March is a partner at Greenberg Traurig in Fort Lauderdale, Fla. He received his juris doctor degree in 1987 from the New York University School of Law and specializes in merger and acquisition issues.



## Join the SFA Marine Corps Marathon Team

SFA is an official charity partner of the 2023 Marine Corps Marathon (MCM). The event will take place on October 29, 2023, in Arlington, Virginia and around the Nation's Capital. We have been awarded 50 entries to the marathon, 20 entries to the 10K and 5 entries to the 50K.



SFA will cover the cost of registration for each participant in the race. In return, each racer will be asked to raise \$2,500 and required to raise \$600 to participate in the marathon or 50K and \$250 for the 10K. You will receive an official SFA MCM t-shirt, your own fundraising page, and access to tips and tricks along the way to assist with ensuring your fundraising efforts are successful. You will also have access to a running coach, Jacky Hunt-Broersma, who will be there to help you along the way with a training plan and monthly online meetings. Jacky is one of the most accomplished adaptive ultramarathoners around, an endurance coach, mom, and Ewing's sarcoma survivor.

If you are interested in being a part of the Race to Cure Sarcoma Marine Corps Marathon Team, please email [kcook@curesarcoma.org](mailto:kcook@curesarcoma.org).

## Get Ready for Sarcoma Awareness in July

July is Sarcoma Awareness Month and SFA is already planning activities to raise awareness about sarcoma and the needs of sarcoma patients. We have initiatives planned over the course of July and we want you to save some dates!

**The Annual "Wear Yellow Day"** - On Wednesday, July 12 we invite the sarcoma community to join us in wearing yellow, take a picture and post it to your social media and SFA's social media to help us raise awareness.

**Light Up for Sarcoma** - On Sunday, July 16, we are requesting monuments across the country to be lit up yellow for sarcoma awareness. Is there a "monument" or building in your area that can be lit up? Let SFA know or make the request so we can put it on our list. Email [programs@curesarcoma.org](mailto:programs@curesarcoma.org).

**Sarcoma Awareness Yard Signs** - Place a sign in your yard throughout July in honor of Sarcoma Awareness month. The annual yard signs for sarcoma awareness month can be purchased directly from our website and shipped to you.

**National Virtual Race to Cure Sarcoma** - On Saturday, July 22 patients, survivors, friends and family from across the country will join us live in [Washington, DC](#) and [virtually](#) across the country to raise awareness and research funds for sarcoma. If you do not have a race in your city, or you cannot join one this year, we hope you will participate in the National Virtual event.

Be sure to follow us on social media and our Sarcoma Spotlight newsletter to stay updated on all of the activities we have planned.

## SFA Welcomes New Staff Members

We are pleased to introduce three new employees to the SFA staff:



**Sandy Lombardo** has joined SFA as Director of Finance and Administration. She is responsible for overseeing the fiscal activities of the association as well as various human resources activities. Her previous experience includes ten years as Director of Finance/Controller for the Association for Manufacturing Technology in McLean, Va. Lombardo received her bachelor's degree in Finance from Towson University in Towson, Md.

**Kristianne Oristian, PhD**, recently joined the SFA staff as Program Manager, Engagement and Research. Her duties include assisting in the development and coordination of the organization's patient engagement and education efforts and supporting SFA's research programs. Prior to working for SFA, Oristian completed her Postdoctoral research at Duke in the laboratory of Dr. David Kirsch in the Department of Radiation Oncology-Cancer Biology. She earned a PhD in Pharmacology from Duke University and her bachelor's degree in Biochemistry from Elon University in Elon, N.C.



The new Fundraising Event Manager for SFA is **Shelby Ostrander**. She previously worked in the Corporate Development and Events Department of Head for the Cure Foundation in Kansas City, Mo. She is responsible for assisting with the management of various SFA fundraising events including the Race to Cure Sarcoma. Ostrander received her bachelor's degree in Events and Conference Management from the University of Missouri in Columbia, Mo.

## Calling All Young Artists!

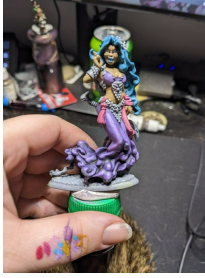
SFA is holding a [Children's Artwork Competition](#) to kick off Sarcoma Awareness Month this July. Submissions will be accepted through June 25, 2023, and the winner will be announced at the end of July. The winning entry will be featured in SFA's newsletter and appear on SFA's 2023 holiday card. [Review the contest rules and guidelines.](#)



## SFA Supporters Raising Awareness and Research Funds

In Sacramento, Calif., 13-year-old **Triune Cantoneros (I.)**, an 8th grader at Saint Ignatius Parish School, raised funds for SFA through a school community service program, The Arrupe Project. Students were asked to choose a non-profit organization to raise funds for throughout the school year.

He raised over \$1,300 by selling macarons and cinnamon rolls during a school open house. He also spoke to as many people as he could about sarcoma and the importance of research. Way to go, Triune!



**Callisandra, Countess Cider of the Apple Orchards** (Twitter handle) live streamed on her painting reaper miniatures (l.) and requested donations to benefit SFA from her viewers. The fundraiser was held in memory of her brother Mat who died from sarcoma in 2018. She raised \$2,235.69! This is her third successful fundraiser to benefit SFA. Thanks for your commitment to SFA, Callisandra!

In April, the **Scott Lively Memorial Event** raised over \$27,000 through a golfing fundraiser held at the Bears Best Atlanta Golf Club in Suwanee, GA. The event was held in memory of Scott Lively who died of Ewing sarcoma in 2014. SFA is so grateful for Scott's family's ongoing support.



Two students from **Rohan Woods School in St. Louis** designed a service project around philanthropy and in memory of their favorite YouTuber, Technoblade. They ran a lemonade stand to coincide with the school's testing period and provided a refreshing treat for students who were done testing early. All proceeds were donated to SFA. Great job, Louis (r.) and Liam (l.) on giving back to SFA and the sarcoma community!

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## Full 2023 RTCS Calendar

Register for the Race to Cure Sarcoma (RTCS) events in your neighborhood! RTCS are family-friendly, fun and raise dollars for sarcoma research. See the latest information below.

- **Cleveland** June 24, 2023 [REGISTER!](#)
- **Milwaukee** July 8, 2023 [REGISTER!](#)
- **Washington, DC** July 22, 2023 [REGISTER!](#)
- **National Virtual Race** July 22, 2023 [REGISTER!](#)
- **New Jersey** August 6, 2023 [REGISTER!](#)
- **Louisville** August 26, 2023 [REGISTER!](#)
- **Philadelphia** September 9, 2023 [REGISTER!](#)
- **San Diego** September 9, 2023 [REGISTER!](#)
- **New York City** September 23, 2023 [REGISTER!](#)
- **Chicago** October 7, 2023 [REGISTER!](#)
- **St. Louis** October 8, 2023 Registration coming soon!
- **Denver** October 21, 2023 [REGISTER!](#)
- **Tampa** November 4, 2023 [REGISTER!](#)
- **Nashville** November 5, 2023 [REGISTER!](#)
- **Los Angeles** November 19, 2023 [REGISTER!](#)

Take part in an RTCS event near you! Whether you run, walk or make a donation from the sidelines, your support makes all the difference in funding leading edge research to find a cure!

Check out some of the highlights from recent races below.



## Atlanta



## Boston



## San Francisco







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