



A Sarcoma Legacy

by Brandi Felser, CEO

It is my pleasure to share that SFA will honor our Co-Founders Mark Thornton, MD, MPH, PhD, Patricia Thornton, and John (Jack) Brooks, MD (shown from right to left), with the Sarcoma Legacy Award at the 2023 Stand Up to Sarcoma Gala awards dinner on September 19, at Capitale in New York City. As the Gala enters its 21st year, SFA is proud to honor Mark, Tricia, and Jack with this much-deserved recognition.



The spark that ignited the start of SFA was the sarcoma diagnosis of then 3-year-old Jeffrey Thornton. Grappling with Jeffrey's diagnosis, his parents found there wasn't a national patient advocacy and research organization dedicated to sarcoma patients and their families. They sought to fill that void.

Tricia had previously reached out to Jack to ask questions about a research publication that related to Jeffrey's treatment. The two exchanged emails and information. Then a serendipitous encounter at a Connective Tissue Oncology Society (CTOS) meeting brought them together. Having never met, Tricia and Mark sat next to Jack at a session. Realizing it was Jack, Tricia introduced herself. After continued conversation, and sharing a desire to change the sarcoma

landscape, the three were motivated to act not only to help treat Jeffrey's cancer but others' as well.

Twenty-three years later, SFA is now the leading private funder of research in the sarcoma community, the principal organization representing sarcoma patients' voice on Capitol Hill, and the most comprehensive patient advocacy organization representing all sarcoma patients. Because of the seed they planted, SFA has been able to invest more than \$20 million and provide funding to more than 110 institutions in 12 countries, covering all subtypes of sarcoma, over the last 23 years.

I am proud and humbled to carry the torch lit by Mark, Tricia, and Jack. I have been lucky to know them personally. Not just as Founders, but as friends, mentors, and like-minded individuals who also have a burning passion to change the outcomes for people diagnosed with sarcoma.

The three Founders of SFA have tirelessly worked to make a difference in the sarcoma community. Their passion and commitment to find treatments and a cure for sarcoma have never wavered since SFA's establishment in 2000. We are most grateful to them for leading the way in an often-overlooked and devastating disease. And I am most grateful to know them and carry on their vision.

Something that started as a serendipitous encounter at a scientific meeting, turned into a legacy that has impacted countless lives and brought the sarcoma community closer to a cure in our time.

Research Roundup

by Dean Frohlich, PhD

This month I would like to highlight two studies in ultra-rare sarcomas (sarcomas that occur in fewer than 1/1,000,000 people per year).

The first study is titled ["Epithelioid hemangio-endothelioma \(EHE\) in NETSARC: The nationwide series of 267 patients over 12 years."](#) EHE is a rare sarcoma that is frequently metastatic at diagnosis. This study describes the outcome of 267 patients with EHE in the NETSARC+ network in France for 12 years beginning in 2010. The study indicates most patients (both localized and metastatic) progressed but were still alive at 10 years. The authors conclude that in the absence of a clinical trial, anthracyclines remain a reasonable first treatment option, but better second line treatments are needed. Results also indicate that a subset of localized and disseminated EHE are life threatening, but tools to identify these patients are not available and additional studies are needed to develop them.

The second ultra-rare study is ["The landscape of alterations from 1407 ultra-rare sarcomas from the AACR GENIE database: Clinical implications."](#) In this study, researchers analyzed the genomic sequencing of 1,407 soft tissue and bone ultra-rare sarcomas from the American Association for Cancer Research (AACR) GENIE database. They found approximately a quarter of ultra-rare sarcomas have potentially clinically actionable mutations. These findings suggest that genomic sequencing of ultra-rare sarcomas has the potential to open additional treatment options for these patients. However, additional studies are needed to determine whether these genetic alterations are as predictive of responses in ultra-rare sarcomas as they are in other cancers.

Clinical Trials Update

by Kristi Oristian, PhD

We would like to share information about a new clinical trial, [Phase I trial](#) of the LSD1 inhibitor seclidemstat (SP-2577) with and without topotecan and cyclophosphamide in patients with relapsed or refractory Ewing sarcoma and select sarcomas. This study is open to patients 12 years and older who share similar chromosomal translocations (FET-family translocations).

Some patients will receive a single medicine, seclidemstat, twice daily as an oral tablet for up to 24 months or until toxicity becomes unacceptable. This will help doctors determine the maximum tolerated dose (MTD) of the new medicine on its own. Patients may also experience shrinkage of their tumor.

Another group of patients with Ewing sarcoma will receive the new medicine, seclidemstat, in combination with cyclophosphamide and topotecan for up to 24 months or until toxicity becomes unacceptable. These patients will receive seclidemstat twice daily as an oral tablet, and cyclophosphamide and topotecan on days 1-5 of a 21-day cycle. This will help doctors determine the MTD of the new medicine in combination with medicines that are already used to treat advanced Ewing sarcoma. Patients may also experience shrinkage of their tumor.

To learn more about this study, patients can talk to their doctor, contact the investigator at the [location](#) nearest you or your primary treatment center, or contact the [study sponsor](#).

September Is Childhood Cancer Awareness Month



Throughout September, SFA will recognize **National Childhood Cancer Awareness Month**, providing educational content about pediatric sarcoma and meaningful activities in which our supporters can participate to help build awareness about the disease.

During the recognition month, SFA will take to social media with posts about childhood sarcoma. Please be sure to share these posts on your social media accounts and tag #CureSarcoma and #ChildhoodCancerAwarenessMonth. Consider posting your own messages using the hashtags. On September 18, we will hold our our Wear Gold Day in recognition of the month. The

18th day of the month was selected for this awareness day as SFA officially became a charity on June 18, 2001. Everyone is encouraged to wear gold clothing and/or accessories in support of child sarcoma patients.



Clinical Trials in Sarcoma

Wednesday, September 27, 2023

6:00 pm EDT

Promoting clinical trial success through education and participation is an important strategic priority for SFA. Through our patient education, research support and industry partnerships, SFA is working to advance clinical trials in sarcoma to increase therapeutic options for sarcoma patients. Sarcoma patients face barriers related to clinical trial participation and often have limited knowledge about trials. SFA is working to overcome some of those challenges.

This session aims to help patients to better understand clinical trials, how and where to find information about trials, and when to discuss trials with their medical team. This session will also highlight trials currently recruiting in sarcoma. Panelists will be clinical trial participant and sarcoma survivor Katie Wintergerst; Richard Gorlick, MD, Division Head, Division of Pediatrics, The University of Texas MD Anderson Cancer Center; and Mrinal Gounder, MD, Sarcoma Oncologist and Memorial Sloan Kettering Cancer Center Physician Ambassador to India and Asia.

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.

SFA would like to remind patients, survivors, and caregivers to participate in our [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.

Gala Honoree Shares Her Sarcoma Journey Story

SFA's mission is to fund and advocate for more sarcoma research, encourage new and better therapy development and educate sarcoma patients. Katie Wintergerst, co-chair of SFA's Race to Cure Sarcoma Louisville committee and team captain, knows all too well this mission's importance.

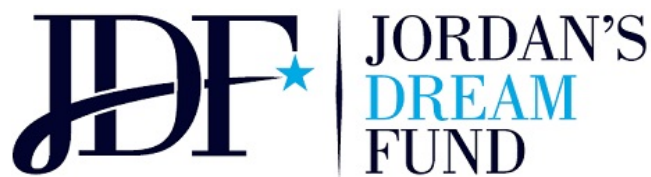
Katie's leg started bothering her while pregnant with her son in 2015. It wasn't a pain limiting her daily activity, so she assumed it was pregnancy related. In January 2017, pregnant with her daughter, she mentioned the pain to her obstetrician. The doctor said because the pain wasn't constant and didn't affect daily activities, it was probably related to her pregnancy and unlikely to be serious. But the pain persisted after her pregnancy. Katie felt a knot in her leg, and leg pains started to affect her sleep. In February 2018, Katie's general practitioner ordered a Venous Doppler to rule out blood clots. An 11cm x 12cm mass was found. An MRI, CT of her lungs, PET scan, and needle biopsy confirmed a diagnosis of sarcoma. What followed was chemotherapy, radiation, and surgery to remove the tumor in October 2018. Unfortunately, the first round of scans in March 2019 showed a suspicious spot on her lung, later confirmed to be metastatic synovial sarcoma. Katie has fought every day since to keep the sarcoma at bay, completing more rounds of chemo, SBRT, wedge resections to both lungs and immunotherapy clinical trials, and has traveled to Nashville, St. Louis, and Houston to talk to sarcoma specialists.

Following her diagnosis, Katie's reaction was like that of many other sarcoma patients: "When I was diagnosed with sarcoma in 2018, I had never heard the word before."

Sarcoma is a rare and devastating cancer, and we often hear stories about delayed diagnosis, no treatment options, and lack of advancements and awareness. But there are also stories of perseverance and courage, like Katie's.

"Being diagnosed with cancer was very eye opening. I had just created a family and was excited to experience life through their eyes. Suddenly worries that felt so heavy before no longer mattered. I am a single mom with two beautiful kids (5 and 7) who are my inspiration to fight every day. I have one clear focus, to keep fighting to watch my kids grow. Whether it be cancer or another unexpected accident, we are never guaranteed time and don't know when our last day on earth will be. Live each day to the fullest, focus on what is truly most important and keep your loved ones close."

Gala Honors Outstanding Sarcoma Community Members



Vision of Hope Award
Jordan's Dream Fund



Amira Yunis Courage Award

Katie Wintergerst

(see Katie's Sarcoma Spotlight Story above)



Courage Award

Jacky Hunt-Broersma

Our host for the Stand Up to Sarcoma Gala will be three-time Emmy® Award-winning actress and two-time Emmy-nominated director Cady McClain! Cady will lead us through this special night of celebration featuring extraordinary honorees and recognition of important advances in sarcoma science and research.

Following the awards program, Tony-, Drama Desk- and Grammy-nominated Broadway singer and actor, Max von Essen (below) will provide the evening's entertainment!

There is still time to join the SFA community on September 19, 2023, at Capitale in New York City. Join us to honor outstanding and inspirational leaders in the sarcoma community who so proudly

and effectively represent SFA's important work.

Visit the [Gala page](#) for more information on honorees, ticket purchases and sponsorship opportunities.

SFA extends its heartfelt thanks to the generous sponsors of the 2023 Stand Up to Sarcoma Gala. The support of donors and friends allows SFA to advance our work funding research to find new and better therapies and, ultimately, the cure for sarcoma.



The poster for the 2023 Stand Up to Sarcoma Gala features a blue background with yellow and white bokeh lights. The title "Stand Up to Sarcoma Gala" is written in a white serif font at the top. Below the title, the names of the sponsors are listed in a white sans-serif font, grouped by category. The categories are: HOPE SPONSORS, DISCOVERY SPONSORS, INNOVATOR SPONSORS, and BENEFACTOR SPONSORS. The names of the sponsors are listed in a white sans-serif font. The poster is framed by a vertical grey bar on the left and right sides, with the text "STAND UP TO SARCOMA GALA" written vertically in a white sans-serif font. At the bottom, the date, location, and website are listed in a white sans-serif font. The SFA logo is also present at the bottom left.

Stand Up to Sarcoma Gala

HOPE SPONSORS:

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Tuesday, September 19, 2023
Capitale • New York City
www.curesarcoma.org/nyccelebration

SFA
Sarcoma Foundation of America
Finding the cure in our time

SFA News

Putts for Ped Tournament Swings in October

Putts for Ped!

The Best Ball Scramble Golf Outing is held in memory of Michael John Pedrick. Michael was diagnosed with synovial cell sarcoma in 1999 at age 29. After radiation, surgery, and

chemotherapy, he went into remission. He lived a fruitful life for the next five years, spending time with friends and family and marrying his high school sweetheart, Jennifer, in 2005. Upon returning from his honeymoon, at his five-year checkup, it was discovered his sarcoma had returned. Unfortunately, after a courageous second battle, he passed away on July 25, 2006, at age 36.

Putts for Ped is a way for his loved ones to remember Michael, to celebrate his life, and support

For more information about the outing, to register or become a sponsor, please email jnellany@yahoo.com or bweyman@comcast.net.

Spartan Race Participation to Benefit SFA

Xochitl Strohbehn of Cliffside Park, N.J., will participate in the Tri-State New Jersey Spartan Trifecta Weekend on October 1, 2023, in Vernon, N.J. to raise funds to benefit SFA. She is taking part in the event in memory of her father who passed away in January 2018 from dedifferentiated chondrosarcoma. A Spartan Race is a series of obstacle races of varying difficulty ranging from three miles to marathon distances.

To sponsor [Xochitl](#), click here.

Support the SFA Race to Cure Sarcoma Marine Corps Marathon Team



The SFA Race to Cure Sarcoma Marine Corps Marathon Team will wave the sarcoma awareness flag when it participates in the event on October 29, 2023. As of this writing, we have 13 team members. Click [here](#) to view all team member profiles on our website.

If you are interested in sponsoring a specific team member of the SFA Race to Cure Sarcoma Marine Corps Marathon Team, please click [here](#).

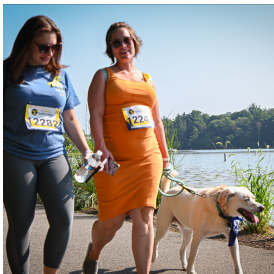
2023 RTCS Calendar

Our last seven Race to Cure Sarcoma (RTCS) events are on tap and heading to your neighborhood! RTCS events are family-friendly, fun and raise dollars for sarcoma research. See the latest information below.

- New York City September 23, 2023 [REGISTER!](#)
- Chicago October 7, 2023 [REGISTER!](#)
- St. Louis October 8, 2023 [REGISTER!](#)
- 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! Online race pages will remain open through November for those who still wish to fundraise.

New Jersey



Louisville

