



Sarcoma Spotlight

July 2023

**INCREASING
AWARENESS
TO CREATE
SURVIVORS**

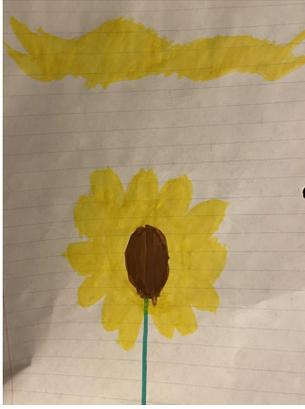


JULY IS

**SARCOMA
AWARENESS
MONTH**



Inspiring Artwork and Story Exemplifies Sarcoma Awareness Month Goal



by Brandi Felser, CEO

SFA recently received a beautiful artwork submission (at left) for Sarcoma Awareness Month from a nine-year-old boy who lost his mom to sarcoma. He included these words with the submission “I don’t want anyone else to lose their Mommy to sarcoma.” I shared his masterpiece and his message with the SFA team. And I responded to him and told him, that at SFA, we are working every day so that no one else loses their Mommy or anyone they love to sarcoma. I asked him to send us a picture of him with his mom so that we could hang it, with other pictures provided to us, on our conference room wall.

If you have attended one of our Race to Cure Sarcoma events, then you are familiar with the Wall of Hope and Remembrance. Participants bring pictures of their loved ones, family members or friends, and post the pictures on the wall with messages. We take those messages and pictures and hang them on our conference room walls. We created the Sarcoma Foundation of America Tribute Wall on Facebook as an extension of the physical wall. This is a reminder as to our why and on whose behalf we work.

The theme for the 2023 Sarcoma Awareness Month is *Increasing Awareness to Create Survivors*. Increasing survivors is something SFA works to do every day. From funding millions of dollars in research across 11 countries, providing education sessions and support for other organization’s and sarcoma center’s education initiatives, to assisting patients with clinical trial participation and matching, advocacy work to support public policies that benefit sarcoma patients, support services and materials to empower patients and of course increasing awareness. Everything we do leads to one goal, curing sarcoma, increasing survivors.

Each year, SFA works with SFA Advocate Brendan Locke to pass a resolution in the Senate officially recognizing July as Sarcoma Awareness Month. We ask the sarcoma community to join us in initiatives to amplify the needs of people diagnosed with sarcoma. We honor the survivors and remember those we have lost. Most importantly, we come together to create change.

Thank you for joining us. And thank you for supporting our work so we can support people diagnosed with sarcoma. We couldn’t do it without you.

Research Roundup

by Dean Frohlich, PhD

I am glad to be able to highlight another three studies funded in part by grants from SFA. In the first study, [“The proteomic landscape of soft tissue sarcomas,”](#) the researchers investigated the protein expression of soft tissue sarcomas from 321 adult and pediatric cases examining 11 subtypes. The results demonstrate the remarkable differences in the subtypes of soft tissue sarcomas by revealing defined subgroups based on the protein expression within the subtypes and with implications for clinical risk for patients and selection of therapies.

In the second study, [“Osteosarcoma tumors maintain intra-tumoral transcriptional heterogeneity during bone and lung colonization,”](#) investigators demonstrated that

osteosarcoma tumors continue to express a high level of different genes from cell to cell within a tumor, even when different genes are expressed as tumors metastasize to the tibia and lungs. Additionally, different tumors continue to have subpopulations of cells that express similar certain gene pathways within each environment. How these differences are regulated in osteosarcoma cells and whether differences in genomic expression bring about these differences remain unanswered but are important questions to be researched.

Lastly, in "[Single-cell profiling of alveolar rhabdomyosarcoma reveals RAS pathway inhibitors as cell-fate hijackers with therapeutic relevance](#)," the researchers used several cutting-edge techniques to demonstrate that the aggressive alveolar RMS subtype contains two cell subtypes that drive tumor growth. While chemotherapy eliminates one of these cell subtypes, it enriches the other. They then looked for drugs that may lead to better treatment options and identified a combination of two inhibitors that targets a critical cell pathway. This combination appears to inhibit tumor growth in cell culture indicating that the pathway they act on is a promising therapeutic target.

Clinical Trials Corner

This month we are highlighting a group of clinical trials that include the drug abemaciclib, which is an oral medicine that targets the proteins cyclin dependent kinase 4 and 6. Abemaciclib is currently FDA approved for treatment of certain kinds of breast cancer and researchers want to understand if this drug can extend stable disease for sarcoma patients (progression free survival). These trials are recruiting for different subtypes of sarcoma.

The first study, [SARC041](#), is for patients who are 18 and older and have recurrent and/or metastatic dedifferentiated liposarcoma. Patients will either receive abemaciclib or a placebo when they enroll, and they will not know which drug they are receiving at the time of enrollment. A patient who experiences progression of their cancer while receiving the placebo pill will be allowed to receive abemaciclib instead. There is no specific biomarker required for eligibility for this study.

The next study is for patients with [Bone and Soft Tissue Sarcoma With Cyclin-Dependent Kinase \(CDK\) Pathway Alterations](#). To be eligible for this study, patients must be 18 or older and have specific biomarkers, which can be found at the link above under "Participation Criteria." Patients with conventional chondrosarcoma, dedifferentiated chondrosarcoma, chordoma, osteosarcoma, and other soft tissue sarcomas may be eligible.

The [CAMPFIRE](#) study is for patients with Ewing's sarcoma that has recurred or did not respond to treatment. In this study, patients will receive abemaciclib in addition to chemotherapy (irinotecan and temozolamide) to see if adding abemaciclib can extend stable disease. Irinotecan and temozolamide are already used for treatment of advanced Ewing's sarcoma.

The [TAPUR](#) study (Group 17) is for soft tissue sarcoma patients age 12 and older whose tumor has not responded to standard treatments and also has an abnormal CDK4 gene. Patients ineligible for other soft tissue sarcoma trials highlighted here may qualify for the TAPUR study if CDK4 testing has been completed.

The clinical trials highlighted here cover a broad range of bone and soft tissue sarcoma subtypes. Patients interested in learning more about these studies and whether or not they qualify should talk to their doctor. Patients may also contact the investigator at the

location nearest you or your primary treatment center by following the links above under "Contacts and Locations."

Sarcoma Spotlight

Sarcoma Diagnosis Inspires Survivor's Dream to Design Homes for the Disabled

Patricia Schoolcraft is an SFA supporter who sponsored the 2022 Stand Up to Sarcoma Gala and participated in the 2023 Race to Cure Sarcoma Boston. She's also a sarcoma survivor. Patricia's journey started 40 years ago as a sophomore in college living on a remote island off the coast of Alaska. She developed pain in her pelvis along with bruising down both legs and across her abdomen. This went on for two years before she was diagnosed with sarcoma. Over the last 40 years, Patricia has had many sarcoma surgeries and recurrences, but it hasn't stopped her.



When working full-time became too much, she went back to her love of design. After taking a design class she realized that design for the disabled is extremely limited and decided that needed to change. She hopes to one day champion a fully accessible home on a hospital campus in every state. To learn more about Patricia's amazing journey, view her video [here](#).

Thank You to Our Gala Sponsors

SFA would like to thank the following generous sponsors of the 2023 Stand Up to Sarcoma Gala listed at right. SFA relies on the support of donors and friends to advance our work of funding research to find new and better therapies and, ultimately, the cure for sarcoma.

The Stand Up to Sarcoma Gala honors recipients of SFA's four international awards – the Courage Award, the Nobility in Science Award, the Vision of Hope Award, and the Compassionate Care Award.



Join the SFA community on September 19, 2023, at Capitale in New York City to honor outstanding and inspirational leaders who proudly represent SFA's important work while raising money for much-needed research.

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

SFA News

Race to Cure Sarcoma Events Featured in Health Magazine, TV Broadcast



Healthy Kansas City magazine recently published an article which highlights sarcoma and explains how SFA's Race to Cure Sarcoma series makes such a huge impact on the sarcoma community and SFA's efforts to fund research for a cure. [Read the article here.](#)

In addition, the Race to Cure Sarcoma Milwaukee was featured on Fox 6 Milwaukee on race day with a live interview with event chair and sarcoma survivor Jerry Glisch. View the interview [here.](#)

Meet Members of the SFA Race to Cure Sarcoma Marine Corps Marathon Team

The SFA Marine Corps Marathon Team is growing! We'd like to introduce you to some of its members. Other team member profiles will appear in future issues of this newsletter.



Miranda Dalecki, an oncology nurse from Millerstown, Pa., decided to be part of the Race to Cure Sarcoma Marine Corps Marathon Team as a tribute to a close friend. "I am running in memory of my dear friend and colleague Shara," says Miranda. She is excited to honor Shara's legacy through fundraising to find a cure for sarcoma.

Susie Donohue is running the MCM to raise awareness and funding for sarcoma research. "I am hoping to help fund a cure for myself and my fellow sarcoma travelers," says Susie. As a mother, she also yearns to inspire her children, showing them that even in the face of adversity, "Mama can do hard things." Susie, who resides in Oak Park, Ill., was also excited to learn her SFA marathon coach and fellow sarcoma survivor, Jacky Hunt-Broersma, shares her mantra and even has an arm tattoo that reads, "I can do hard things."

Ryan Maffei is running as a tribute to his late mother, who passed away from sarcoma five years ago. At that time Ryan, a resident of Toms River, NJ, weighed 380 pounds, but embarked on a life-changing transformation to lose weight. "I am now 200 pounds lighter and on my way to finishing my first ever marathon," says Ryan. With several half marathons already under his belt, Ryan is determined to cross the finish line of his first full marathon and honor his mother's memory in a meaningful way. Says Ryan, "She gives me the strength every day, and I am running to support sarcoma to support others like her who sadly succumbed to this disease."

Justin Reid, who lives in Greer, SC, joined the RTCS MCM Team in honor of his mother, who passed away from sarcoma in 2016. Says Justin, "I want to help support the organization that supported her during her illness." He is very excited to run and make a difference in finding a cure for sarcoma.

If you are interested in being a part of the Race to Cure Sarcoma Marine Corps Marathon Team, please email ablake@curesarcoma.org.



From left are Miranda Dalecki (l.) and friend Shara, Susie Donohue, Ryan Maffei and Justin Reid.

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:

- **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! Below are just some of the highlights of our most recent RTCS events in Cleveland and Milwaukee.

Cleveland



Milwaukee



Our Contact Information

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<http://www.curesarcoma.org>

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