

SFA Gears Up for Sarcoma Awareness Month



July is Sarcoma Awareness Month and SFA has planned a variety of activities to raise awareness about sarcoma and the needs of sarcoma patients. The month's theme is "Increasing Awareness to Create Survivors." 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, taking a picture and posting it to your social media. Send your picture to SFA and we'll post it, too!

Light Up for Sarcoma - We are asking monuments and landmarks across the country to light up in yellow for sarcoma awareness on Sunday, July 16. 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 <u>programs@curesarcoma.org</u>.

Sarcoma Awareness Month Yard Signs - Place a sign in your yard throughout July in recognition of Sarcoma Awareness Month. These signs can be purchased from our store 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 the Washington, DC area 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.

Twitter Chats - We're also planning Twitter Chats with sarcoma physicians who will field your questions and pass along important information for the sarcoma community. You don't want to miss that!

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

Research Roundup

by Dean Frohlich, PhD

This month I would like to highlight several recent publications that demonstrate new approaches researchers are using to develop new therapeutics for sarcoma. These studies are early in the development process, but demonstrate new and innovative methods to treat this difficult-to-treat disease.

In the study "Combination of protein and cell internalization SELEX identifies a potential RNA therapeutic and delivery platform to treat EphA2-expressing tumors," investigators target the EphA2 receptor tyrosine kinase which is overexpressed in many solid tumors including Ewing sarcoma. The investigators used a novel bioinformatics approach to identify an RNA aptamer (short sequences of artificial RNA that bind a specific target molecule) that binds the EphA2 receptor strongly and disrupts its ability to function. In a mouse model of spontaneous metastasis for Ewing sarcoma, the aptamer slowed primary tumor growth and significantly reduced the number of lung metastases.

The second study, "Proteasome Inhibition Sensitizes Liposarcoma to MDM2 Inhibition with Nutlin-3 by Activating the ATF4/CHOP Stress Response Pathway," investigates a new drug combination in liposarcoma. It demonstrates that inhibiting the cancer cells' proteasome, which degrades proteins, in combination with MDM2 inhibition, which is frequently overexpressed in liposarcoma, activates a cellular stress response to induce apoptosis (a type of cell suicide), providing a potential therapeutic approach to this soft tissue sarcoma.

The third study is "A new treatment for sarcoma extracted from combination of miRNA deregulation and gene association rules." These investigators study how identifying a list of common downregulated microRNAs (miRNAs) in sarcoma can be used to design potential treatments. These miRNAs regulate the expression of a large number of genes, many of which are differently regulated in sarcoma. First, they were able to use miRNAs to identify biomarkers of metastases and then identify new individual or combined treatments, with drugs related to each gene. Using one of these drug combinations, they observed a reduced tumor size in mice, suggesting a potential new treatment.

Clinical Trials Corner

SFA would like to introduce a new addition to the Sarcoma Spotlight newsletter, where we will highlight sarcoma clinical trials..

The first trial "Brightline-1," is for people diagnosed with dedifferentiated liposarcoma who are 18 years of age or older. In this trial, patients will receive either doxorubicin or a new medicine called BI 907828. Doxorubicin is already used to treat sarcomas including liposarcoma, and doctors are interested in learning if BI 907828 offers improved progression-free survival over doxorubicin. For patients, this means stable disease for a longer period of time.

BI 907828 is a type of medicine called an MDM2 inhibitor, which is designed to block the function of the protein MDM2. Studies have shown MDM2 is protein that significantly impacts the growth of dedifferentiated liposarcoma cells. People diagnosed with dedifferentiated liposarcoma who choose to participate in this study will either take BI 907828 as a tablet or receive doxorubicin as an infusion in a vein.

Patients interested in participating in this trial should talk to their doctor. More information can be found at clinicaltrials.gov, NCT05218499 or https://brightline-1.researchstudytrial.com/.

Embracing Life After Diagnosis and Advocating for Sarcoma Research and Awareness

Kate DeForge underwent open heart surgery. That is not something most people are thankful for, but for Kate, it led to an unexpected discovery: a cardiac sarcoma diagnosis that may not have been found for a very long time otherwise. At 37 years old, and after recovering from heart surgery, Kate began her journey with sarcoma. One of Kate's biggest struggles has been managing her sarcoma treatment alongside a mechanical valve she received during heart surgery. A mechanical valve is a type of heart valve made with materials like titanium and carbon. The presence of the mechanical valve complicates her sarcoma treatment and necessitates careful monitoring of her platelet levels.



During chemotherapy, there can be a temporary drop in various blood cell counts, including platelets. In Kate's case, she needs to be on an anticoagulant to help prevent blood clots for the rest of her life. "Once they [platelets] hit 50,000, I have to get off my anticoagulant and go on heparin drips, so it's led to a lot more in-patient visits on top of my treatment," says Kate.

Despite these challenges, Kate has been able to maintain a positive attitude and appreciate the little things in life that she once took for granted. Being in a hospital room for long periods for sarcoma treatment has made Kate realize how much she previously overlooked. She now embraces everyday experiences, something that she could not do while in isolation during treatments. She also drew parallels between the isolation she experienced during the nadir phase of cancer treatment to the sense of quarantine experienced during the COVID-19 pandemic. When a patient is in nadir, this means their blood cell count has reached the lowest point during a treatment cycle. "You know, as a cancer patient, when you're in nadir, you can't be around anyone, and it feels like you're in quarantine all over again," says Kate.

One thing that has been vital throughout Kate's journey has been her support system. She credits her big family, friends, and wife as the people who have given her unwavering support during her recovery and treatments. "I've been lucky that I've had tons and tons of support throughout this whole journey, which has been great," says Kate. Kate also emphasizes the important role her wife played in recovering from her heart surgery. "My wife is my number one caretaker. She drives me to my appointments and cared for me when I was recovering, since I couldn't use my arms at all, dress myself, bathe, drive, cook, or even take the dog out."

Kate's experience with sarcoma has also influenced her perception of the importance of sarcoma research and awareness. "In my case, I have an incredibly rare cardiac sarcoma. What I'm learning is we have no protocol, as it's not studied enough because there are not enough cases, which is a good thing, but not a good thing for people that actually do have it," says Kate. She also highlights how her journey has been a learning experience for her and her doctors. Each treatment cycle brings new insights, guiding adjustments, and improvements. Thus, sarcoma research holds great significance for Kate and others with cardiac sarcoma, as it paves the way for enhanced understanding and better treatment outcomes.

SFA News

Final Days to Enter Children's Artwork Competition



Kids 18 years old and under have until July 10 to submit their original artwork to SFA for our <u>Children's Artwork Competition</u> to kick off Sarcoma Awareness Month this July, and the winner will be announced at the end of the month. The winning entry will be featured in SFA's newsletter and appear on SFA's 2023 holiday card. Emailed submissions will now be accepted. Review the contest rules and guidelines.

Join the SFA Marine Corps Marathon Team

The clock is ticking toward the deadline to join the SFA 2023 Marine Corps Marathon (MCM) Team. 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 Team t-shirt, your own fundraising page, and access to tips and tricks along the way to help make your fundraising efforts 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.



Family Raises Funds in Memory of Lost Loved One

Our thanks go to the Dante Luca Foundation for raising awareness and funds for SFA and sarcoma research, in memory of Dante Luca Martorella. Dante passed away at 21 years old after an 11-month battle with rhabdomyosarcoma. Dante's family—Alessandra, Damian, Tricia, Stephania, and Cristiana—organized a birthday celebration at a local pub in memory of Dante with over 40 auction baskets and a 50/50 raffle, with proceeds benefitting SFA. SFA staff were honored to be invited to attend this celebration of Dante's life and the work his family is doing to support sarcoma research.

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.

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!
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!

Looking for an additional way to support the RTCS and its participants? Buy a Spotlight Sign in honor or memory of a person affected by sarcoma. The sign will be placed along the course of the RTCS of your choice, and can be a real motivator for runners and walkers. Up to three photos can be submitted for the sign. Please be sure to email photos and team name to events@curesarcoma.org as soon as possible to ensure sign will be available on event day!

Our Contact Information Sarcoma Foundation of America 9899 Main Street Suite 204 Damascus, MD 20872 301-253-8687 http://www.curesarcoma.org

Follow Us on Social Media!









