



## **Increasing Awareness to Create Survivors**

*by Brandi Felser, CEO*

In July, I attended a funeral for a family member who passed away from osteosarcoma. His story is similar to many others. He went to the doctor complaining of pain, it was nothing. Until one morning, he got out of bed and his leg broke. The tumor had grown so big it fractured his bone. The journey began. I reflected at the funeral, and since, about his journey and the so many others' I learn about from patients and family members. I thought about what more needs to be done, and what SFA can do, to advance better outcomes for patients.

Recently, I had a conversation with someone whose brother was diagnosed with sarcoma and experienced a recurrence. His brother started a team for one of SFA's Race to Cure Sarcoma (RTCS) events and he supported his brother and SFA's research efforts through this program. As we were discussing what more can be done for sarcoma, he highlighted SFA's work to increase awareness.

One of SFA's strategic goals is to increase awareness about sarcoma and the needs of sarcoma patients. It is something we weave into the organization's programs and initiatives. The RTCS events, even the marathon teams, our communication strategies, and of course our Sarcoma Awareness Month campaigns are designed to increase awareness.

The outpouring of support for the “Light Up for Sarcoma” initiative, showcasing yard signs to draw attention to sarcoma, joining us for the RTCS events, committing to “Wear Yellow Day,” so many other things -- the sarcoma community came together to spread awareness about sarcoma during the month of July.

While we still have work to do, we need to take time to celebrate our progress. Because of you -- your support, your efforts -- we are making tremendous strides. I know we hear this in so many contexts, but we really are stronger together. I hope you will continue to join us in our work to cure sarcoma.

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## Research Roundup

*by Dean Frohlich, PhD*

[Phase II Study of Olaparib and Temozolomide for Advanced Uterine Leiomyosarcoma \(NCI Protocol 10250\)](#) is a study funded in part by SFA through the Conquer Cancer Foundation. Investigators demonstrate in a phase II trial that a combination of Olaparib (an inhibitor of a protein involved in DNA repair) and temozolomide (a drug that damages DNA) have promising activity in previously treated patients with advanced uterine leiomyosarcoma. Additional analysis showed that patient survival was increased for patients in which a different DNA repair mechanism was not working properly versus patients in which this mechanism was working properly. Additional work needs to be done with this drug combination, but these results are promising for patients with advanced uterine leiomyosarcoma.

Remodeling of the local environment by releasing proteins that support tumor growth, metastatic progression, and resistance to treatment in which a tumor resides is important for tumors to grow. In other tumors, this is done by a group of cells called cancer-associated fibroblasts (CAFs). In [Cancer-associated fibroblast-like tumor cells remodel the Ewing sarcoma tumor microenvironment](#), the investigators identified subpopulations of Ewing sarcoma cells that increase the expression and deposition proteins similarly to that of CAFs. These results indicate these cells are likely to be critical for tumor progression and may be investigated as novel targets on which to focus basic and translational cancer research efforts to develop therapeutics to integrate into Ewing sarcoma treatment regimens.

Ewing sarcoma is characterized by the fusion of two proteins such as EWS/FLI1. In another Ewing sarcoma study, [SIX1 and EWS/FLI1 co-regulate an anti-metastatic gene network in Ewing Sarcoma](#), the investigators demonstrate that another protein, SIX1, which enhances metastasis in most tumor types, decreases the likelihood of metastasis in Ewing sarcoma by co-regulating the same genes as EWS/FLI1. Like EWS/FLI1, SIX1 increases cell growth and transformation into cancer cells, but significantly inhibits cancer cell migration and invasion, and metastasis in the body. Additional studies are needed to determine the exact mechanisms leading to these characteristics in Ewing sarcoma. While drugs that inhibit SIX1 are being developed for the treatment of other tumor types, this study suggests that targeting SIX1 in Ewing sarcoma may increase metastasis and tumor progression. Additional studies on the role of SIX1 in different sarcomas are required to determine if similar results occur in similar tumor types.

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## Clinical Trials Corner

This month SFA focuses on a [ENVASARC](#): Envafohimab And Envafohimab With Ipilimumab In Patients With Undifferentiated Pleomorphic Sarcoma Or Myxofibrosarcoma. This clinical trial is available to patients with UPS or MFS who have progressed on chemotherapy and whose tumors are advanced, unresectable, or metastatic. Patients must be at least 12 years old and if enrolled in this study, will be assigned randomly into one of two groups.

One group will receive a single medicine, envafohimab, every three weeks in the form of a subcutaneous injection. The other group will receive two medicines, envafohimab as a subcutaneous injection and ipilimumab as an intravenous infusion, every three weeks. Four doses of Ipilimumab will be administered. Ipilimumab is an FDA-approved drug used for the treatment of melanoma and commonly known as Yervoy. Researchers want to understand if combining this drug with envafohimab, a new kind of anti-PDL1 antibody, will cause tumors to shrink (objective response rate).

To be eligible for this study, patients must have locally advanced or metastatic UPS or at least grade 2 MFS, have progressed on at least one line of chemotherapy, have at least one measurable tumor, have adequate organ function to handle the medicines, and meet ECOG performance status of 0 or 1. Your doctor will know how to determine if you meet these criteria. 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](#).

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## **[Paid Survey for Liposarcoma Patients Is Underway](#)**

SFA is partnering with Boehringer Ingelheim to learn about the experiences of patients living with Liposarcoma. We are currently inviting patients living with liposarcoma to participate in a paid survey to share their insights from diagnosis to treatment and everything in between. If you or someone you know is interested in applying or learning more, please click [here](#) and be sure to input "SFA" when asked how you heard about this survey opportunity.

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## **[SFA Announces 2023 Research Grant Recipients](#)**

SFA is pleased to announce the recipients of our 2023 Research Grants. Twelve grants, each worth \$50,000, have been awarded to researchers who have made it their mission to study sarcoma.

Each research proposal is reviewed by SFA's Medical Advisory Board, which recommends funding for the highest scored proposals. After the grant is awarded, SFA monitors the progress of the research, requiring an annual report to SFA's Medical Advisory Board.

[View the research grant recipients and their abstracts.](#)

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## **[AYA Advisory Group](#)**

SFA recently launched a new Adolescent and Young Adult (AYA) Advisory Group. This group will work together with SFA staff to identify priorities and needs specific to the AYA sarcoma community and develop programs to support those unique needs. This initiative reflects SFA's recognition of an unmet need in the sarcoma community to bring the AYA

community together and build on both shared and unique experiences for mutual benefit. The steering committee of AYA patients and survivors pictured below are (from l.): Sean Cincotta, Brandon Friedman, Nathan Greenberg, and Natasha Nathan. If you would like to get involved with the AYA Advisory Group, please email [programs@curesarcoma.org](mailto:programs@curesarcoma.org).



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## 2023 Nobility in Science Honoree

David M. Loeb, M.D., Ph.D., is the 2023 Nobility in Science Honoree. The Nobility in Science Award is given annually to a deserving visionary, who has taken an integral role in advancing treatments for sarcoma patients. Awardees receiving this honor have contributed in a significant way to the advancement of science, care, and treatment for sarcoma patients. This honor will be presented during SFA's Stand Up to Sarcoma Gala.



Dr. Loeb is Chief of Pediatric Hematology, Oncology and Cellular Therapy at Children's Hospital at Montefiore and a Professor of Developmental and Molecular Biology at Montefiore Einstein, both located in Bronx, NY. He is also a member of SFA's Medical Advisory Board.

He has an active translational research laboratory focused on understanding bone tumor metastasis. He is also actively involved in clinical research, including the development of radiopharmaceutical agents for the treatment of bone metastases and the development of a small molecule inhibitor of DDX3.

SFA is proud to honor Dr. Loeb for his work utilizing experimental models to investigate bone tumor metastasis in sarcoma patients. His work developing radiopharmaceutical agents and small molecule inhibitors to treat sarcomas is a shared interest of SFA, and his research has contributed significantly to the care of sarcoma patients both through his research and clinical trials.

**The Stand Up to Sarcoma Gala**, now in its 21st year, is a night of celebration and community as we gather to join in solidarity to support sarcoma patients and survivors. In addition to the Nobility in Science Award, the event highlights outstanding sarcoma advocates with the Courage Award, celebrates a patient navigator for their outstanding contributions to patient care with the Compassionate Care Award, and recognizes an organization or person providing hope to patients with the Vision of Hope Award. These international awards are the highest honor SFA bestows.

For more information about the 2023 Stand Up to Sarcoma Gala, visit the [Gala page](#).

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## SFA Is Updating Our Sarcoma Center Database

As part of our ongoing efforts to support and facilitate the care of sarcoma patients throughout their sarcoma journey, SFA is working to update its database of sarcoma centers. Because sarcomas are rare, SFA stresses the importance of receiving care from physicians and multidisciplinary treatment centers with experience treating this specific cancer.

SFA has developed [criteria](#) for inclusion in our sarcoma center certification and patient resource database. We ask Centers to meet this [criteria](#), and complete a [registration form](#). Centers currently active on the [SFA resource page](#) are also asked to complete this form to provide additional information and verify the information currently listed.

If you are a patient or caregiver, please encourage your treatment team to complete this registration so SFA can continue to offer accurate and up-to-date information to all sarcoma patients.

If you have any questions, please contact [Kristi Oristian](#). Thank you for your assistance with this important project.

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## Jordan's Dream Fund for Clinical Trials Program

SFA remains the leading private funder of research in the sarcoma community, and as part of our mission to advance more treatments with less toxic side effects for patients, we recognize the vital role of clinical trials in patients' care. Unfortunately, despite the critical nature of clinical trials to sarcoma care, sarcoma patients must often travel significant distances and pay substantial out-of-pocket expenses to participate.

In response to this unmet need in the sarcoma community, SFA has launched the Jordan's Dream Fund for Clinical Trials program to help cover out-of-pocket expenses for patients participating in clinical trials. These expenses may include airfare, gas, rental cars, parking fees, lodging, and some medical expenses related to the trial but not covered by insurance. Grants are awarded up to \$5,000.00 and are distributed four times per year.

Eligibility for Jordan's Dream Fund for Clinical Trials is dependent on adjusted gross household income and application guidelines and additional information can be found [here](#).

SFA is pleased to have made four grants in quarter two, and encourages patients and navigators to apply by September 9, 2023, for consideration in this cycle.

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## SFA Sunflower Society Blooms with Generous Donors



In July 2023, SFA created the Sunflower Society, a giving society recognizing donors who contribute \$1,000 or more to SFA over the course of the calendar year. Whether through one-time or ongoing gifts, this group of generous donors helps us continue to be the leading voice of the sarcoma community, enabling us to make important investments in research and patients and increasing sarcoma awareness.

SFA Sunflower Society members will receive exclusive information and experiences, and be invited to learn, connect, share, and see the impact they are making through the following benefits:

- Regular personal updates on the impact being made on the lives of those living with sarcoma from a dedicated SFA staff partner.
- Monthly roundup of articles of interest to the sarcoma community curated by the CEO.
- Yearly exclusive CEO update, an in-depth look at how your gift impacts the lives of sarcoma patients, caregivers, and researchers.
- Yearly update by the SFA Medical Advisory Board.
- Invitation to local in-person Sunflower Society events.
- Special recognition in SFA's annual report.
- Invitation to exclusive SFA presentations and education events.
- Sunflower Society members who donate \$10,000+ will receive two tickets to the Stand Up to Sarcoma Gala.

To learn more about the SFA Sunflower Society, click [here](#) or email [development@curesarcoma.org](mailto:development@curesarcoma.org).

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## SFA News

### Sarcoma Community Artists Help to Raise Awareness

Thank you to all who submitted artwork to our Sarcoma Awareness Month Art Contest. We received 31 submissions that came from all over the country. Not only was the artwork inspirational, but the stories behind the artwork were just as touching. The artists of the creations shown below will have their artwork displayed on various cards sent out by SFA during the holiday season and throughout the year. Congratulations to the winners whose work is shown below. From l. they are: Ivy F., Ellise, Ellie, Caleb, Alexndria and Aiden P.

You can view all of the artwork submitted [here](#).





### New Director of Operations Joins SFA Staff

Cheryl Mayes recently joined the SFA organization as Director of Operations and Human Resources. Prior to joining SFA, Cheryl was Director of Operations and Human Resources at the National Breast Cancer Coalition in Washington, DC. In her new role at SFA, she is responsible for overseeing the Foundation's general operations and managing personnel-related activities. Welcome, Cheryl!

### More Runners Join SFA Race to Cure Sarcoma Marine Corps Marathon Team

The SFA Race to Cure Sarcoma 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.



**Emma Schambers**, who lives in East Greenwich, RI, has joined the SFA Race to Cure Sarcoma Marine Corps Marathon Team in memory of her friend Catherine, who passed away in 2015. Says Emma, "Her strength during her battle with sarcoma is what inspires me to run and raise money for both awareness and research to end this terrible disease." Emma is thrilled to pay tribute to her friend and fundraise for the SFA team.

**Kristen Brenchley** of Alexandria, Va., is running for the SFA MCM Team in honor of her first husband. Says Kristen, "I am running the Marine Corps Marathon to raise funds for SFA because my first husband was diagnosed with a soft tissue sarcoma in his mid-twenties. This cause is deeply personal to me." She is excited to make a meaningful impact on sarcoma research through her participation in the marathon.



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

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## 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.

- **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 [REGISTER!](#)
- **Denver** October 21, 2023 [REGISTER!](#)
- **Tampa** November 4, 2023 [REGISTER!](#)
- **Nashville** November 5, 2023 [REGISTER!](#)
- **Los Angeles** November 19, 2023 [REGISTER!](#)

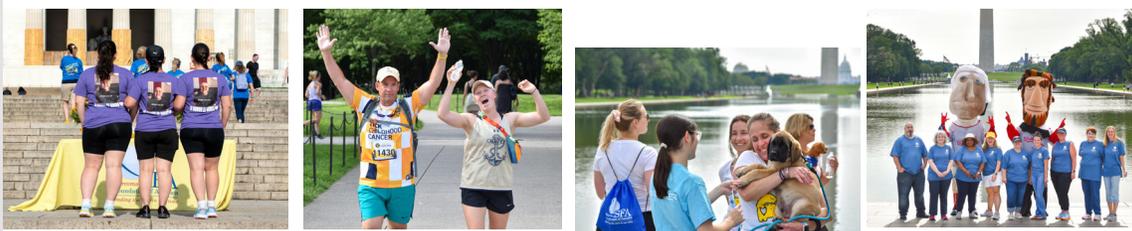
Take part in an RTCS event near you! Whether you run, walk or make a donation from the sidelines, your support makes all the difference in funding leading edge research to find a cure! Online race pages will remain open through November for those who still wish to fundraise.

During this year's National Virtual RTCS held on July 22, we more than doubled our numbers with 844 people raising over \$185,000. Over 55 teams participated across the country. Thank you to our top teams: Kate's Krew, Hoofin' It for Harp, and TR's Warriors.

Top teams at the Washington, D.C. RTCS were: Sam's Cancer Crushing Crew, Steps for Syd, and Brookie's Blessings. The inaugural DC event was marked by an enthusiastic crowd, beautiful weather and a historic backdrop, plus an appearance by the Washington Nationals' mascots "George" and "Abe" (see picture below at right).

Below are just some of the highlights of our most recent RTCS events in Washington, D.C. and the National Virtual RTCS.

## Washington, D.C.



## National Virtual



### Our Contact Information

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