



February 2023

Raise Awareness for Sarcoma

This month we acknowledge World Cancer Day (Feb. 4), International Childhood Cancer Day (Feb. 15) and Rare Disease Day (Feb. 28). All highlight and raise awareness about the challenges faced when diagnosed with cancer and especially rare cancers like sarcoma. While the incidence of cancer is declining (2023 Facts and Figures, ACS) due, in part, to increased screening and treatment options, sarcoma patients still face many obstacles.

The theme of the 2023 World Cancer Day was #Closethecaregap highlighting the inequities in cancer treatment. Insurance coverage, socioeconomic factors, gender, race, ethnicity, and age have been identified as barriers to care. With sarcoma, there are the added barriers of accessing care at a sarcoma center, few treatment options, limited clinical trial locations, and continued lack of awareness.

Although, we are making an impact, we are not where we want to be. We need to close the gap for sarcoma patients.

We hope you will join us on these days, and every day, to raise awareness for sarcoma patients and their loved ones and support research to end this disease.



Sarcoma Foundation of America
Recognizes
**International Childhood
Cancer Day**
February 15, 2023

**SARCOMA FOUNDATION OF AMERICA
RECOGNIZES
RARE DISEASE DAY**
TUESDAY FEBRUARY 28, 2023



February Webinar Spotlights Sarcoma Patient Experience

Join SFA on Rare Disease Day, Wednesday, February 28, 2023, at 6:00 pm EST for The Sarcoma Patient Journey and Perspective, a panel discussion with patients who will share their personal experience with sarcoma diagnosis, treatments, clinical trials, the challenges associated with being diagnosed with a rare cancer, and resources needed to more easily navigate their sarcoma journey. Register here: bit.ly/3RE2iEi



Research Roundup

by Dean Frohlich, PhD

In this issue, I will begin by highlighting a recent journal article in which the researchers sequenced the genomes of over 1,600 people who developed sarcoma and compared them to healthy people who did not develop sarcoma. The study's goal is to help identify mutations that predispose people to getting the disease. The publication titled "Heritable defects in telomere and mitotic function selectively predispose to sarcomas" in the journal *Science* concludes that mutations in two pathways, mitosis and telomeres, increase the risk of getting various sarcomas. This is important as it gives additional avenues for scientists to target in the treatment of sarcoma.

In addition, I would like to spotlight the results of a Phase 1 clinical trial of a new drug that inhibits a protein (MDM2) that increases in many cancer cases. The purpose of the trial was to determine the safety of the drug, determine how the drug is metabolized, and to get preliminary data on efficacy. The trial evaluated these items in many advanced tumors but, most importantly for the sarcoma community, includes a subgroup of dedifferentiated liposarcoma. The article entitled "A First-in-Human Phase I Study of Milademetan, an MDM2 Inhibitor in Patients With Advanced Liposarcoma, Solid Tumors, or Lymphomas" demonstrates that a novel dosing schedule limits adverse side effects and still demonstrates notable antitumor activity. This data has provided the rationale for a phase 3 clinical trial of Milademetan in dedifferentiated liposarcoma.

Lastly, I would like to announce that SFA is now accepting proposals for the second Last Mile Research Award. Deadline for proposals is April 3, 2023, at 5:00 pm EDT. This grant mechanism is available for sarcoma researchers and provides funding to strengthen the first resubmission of a National Institutes of Health (NIH) R01 proposal. The original R01 application must have scored in the 50th percentile or better, but outside the NIH pay line. Considerations in a funding decision will include the following: the innovation and impact of the research proposed, the financial circumstances and needs of the investigator, and the likelihood of a success in moving the proposal's score within the funding range following resubmission. The application for this grant should be within nine months from the initial R01 notification. If funded by SFA, the expectation is that funded applicants would be successfully resubmitted to the NIH. To apply, go to bit.ly/3EILptM.

Get Ready for the 2023 Stand Up to Sarcoma Gala

We're pleased to announce that the 2023 Stand Up to Sarcoma will be held on Tuesday, September 19 at Capitale in New York City. The Gala will include many of the popular features past attendees have said they enjoy plus some new and exciting sights and sounds. The evening will include presentations of SFA awards that recognize outstanding individuals in the sarcoma community. Be on the lookout for more details on this special event!

Husband and Caregiver Hits the Slopes in Memory of Lost Loved One

Doug Beck of Holladay, Utah, has been a skiing enthusiast for years. But on March 3, 2023, his 71st birthday, he will be skiing 30 kilometers for a special reason: in memory of his wife Peggy Shultz-Beck who passed away from soft tissue sarcoma in July 2022. His event Ski for Sarcoma will take place on Route 65 on the road to East Canyon in Salt Lake City.



Doug has an anonymous corporate sponsor paying for all event expenses, so 100% of the proceeds from this fundraiser will benefit the Sarcoma Foundation of America (SFA). "In March of 2022, Peggy asked me to organize a cross country ski event to benefit SFA," says Doug. "How could I possibly say no?" He has been training for his Ski for Sarcoma fundraiser for the past few months. During that time, his runs have ranged between 10 and 17 kilometers. "Not bad for an old fart," he says.



This couple's sarcoma journey began in November 2018 when Peggy was diagnosed with sarcoma in her wrist, and she began chemotherapy and radiation. What followed were dozens of surgeries and participation in a Treating to New Targets (TNT) clinical trial in Santa Monica, Calif. The trial location was hours away from their home, but the Becks made the trek 17 times to participate until doctors advised them that Peggy's sarcoma was too far advanced for the clinical trial treatment to be of any help.

In February of 2020, Peggy's arm was amputated. That's when Doug decided to retire from his Director of Sales job

with three Utah television stations to be a caregiver for his wife. "Taking care of her was the most rewarding job I've ever had," says Doug.



Prior to her sarcoma diagnosis, Peggy had been a fitness instructor for over 50 years. Her classes included aerobics,

yoga, Pilates and many more. Her employer of 29 years Sports Mall held a fundraiser in November of 2022 and placed a special plaque in the exercise studio in her memory. She was loved by her students, many of whom have already sponsored Doug's ski fundraiser.

The outpouring of support from Peggy's students, friends and family members has been overwhelming with dozens sponsoring his labor of love per kilometer skied. As of February 14, he has raised \$13,500. "She was amazing," says Doug. "She meant a lot to a lot of people."

SFA-themed Football Cleats Benefit Foundation



John Franklin-Myers of the New York Jets recently visited with Daran Pon of New York, the winning bidder of John's My Cause My Cleats auction. John presented the custom-designed cleats that reflect his support of SFA and the #sarcoma community. He also presented Daran with autographed NFL swag in thanks for his winning bid. John is an SFA Ambassador who works to build awareness in memory of his grandfather who died of sarcoma in 2011.

New Staff Join SFA



Annie Blake has joined SFA as National Director, Race to Cure Sarcoma (RTCS). She will oversee the fundraising activities to support the run/walk events which currently take place in 19 cities across the nation.

Prior to joining SFA, she was Regional Vice President for the March of Dimes, where she received the National President's Award for significant accomplishments in

fundraising, public affairs, communications, and programs. Annie also served as the Regional Director for National Events, where she led the fundraising strategies for more than 300 events, including walks/races, Galas, testimonials, and golf tournaments.

Aubrey Treese joined SFA as Development Coordinator in October 2022. In this role, she provides strategic support to the Development Department in special and community events, donor cultivation and stewardship, and online and direct mail campaigns and appeals.



Prior to joining SFA, Aubrey was the Development and Marketing Coordinator at the Mental Health Association of Frederick County, providing support to the Development Department and volunteer committees. Aubrey has held roles in several other nonprofit organizations including the Maryland Food Bank and Huntingdon House, a domestic violence agency. Aubrey holds a bachelor's degree in Health Communication from Juniata College in Huntingdon, Penn.

SFA News

Lilly Pulitzer Fundraiser Combines Fashion and Support of SFA



Visit the Lilly Pulitzer North Hills, NC, on February 25, 2023, from noon to 4 pm to show your support for SFA. Your purchases that day will benefit the foundation to the tune of 10% of sales. This event is being held in memory of Mary Grainger of Raleigh, NC, who passed away from sarcoma and was a long-time customer of Lilly Pulitzer, especially the North Hills store. Mention SFA when you shop in-store or call in your order at 919.784.9174.

New Zealander Rows His Way to Supporting SFA

Jack Walsh of Christchurch, New Zealand, is a rower with a cause! Jack has committed to rowing 50 km to support three charities, including SFA. Jack has a personal connection to sarcoma, as his cousin is currently living with the disease. He hopes the donations can further the mission to find cures and treatments for sarcoma. He's planning to do the row in mid-February.



In just 18 days, almost \$3,200 was donated to Jack's charity row, wildly surpassing the goal of \$1,500. Way to row, Jack!

MSU Student Donates to SFA in Memory of YouTube Star Technoblade

Anthony Barash, a Michigan State University (MSU) student, was selected to receive a \$200 award for his outstanding service to the community. Anthony chose to donate his award to SFA in remembrance of YouTube influencer Technoblade. Anthony will be recognized as a Spartan Volunteer Service Award Recipient on March 2, 2023 at MSU's annual University Outreach and Engagement Awards Ceremony.

More Race Locations and Dates on the Calendar

Registration is open for many of SFA's much-anticipated Race to Cure Sarcoma (RTCS) events. See the latest information below. Register at <https://www.curesarcoma.org/race/>.

- Atlanta April 15, 2023
- Boston April 23, 2023
- San Francisco May 6, 2023
- Seattle May 13, 2023
- Cleveland June 23, 2023
- Milwaukee July 8, 2023
- Washington, DC July 22, 2023
- Louisville August 25, 2023
- New Jersey August 6, 2023
- San Diego September 9, 2023
- St. Louis October 8, 2023
- Denver October 21, 2023



Race **to** *Cure*
SARCOMA

SARCOMA FOUNDATION OF AMERICA

SAVE THE DATE FOR 2023!

Atlanta - April 15
Boston - April 23
Chicago - October
Cleveland - June 24
Denver - October 21
Los Angeles - November 19
Louisville - August 26
Miami - June
Milwaukee - July 8
Nashville - October

New Jersey - August 6
New York - September
Philadelphia - September
San Diego - September 9
San Francisco - May 6
Seattle - May 13
St. Louis - October 8
Tampa - November
Washington, D.C. - July 22

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