Thank You and Happy Holidays
By Brandi Felser, CEO

As we near the end of 2022, I want to share a heartfelt thank you for all that you do to make a difference in the lives of those touched by sarcoma. I don’t know if Mark, Tricia, and Jack had entirely envisioned where SFA would be today. What they did know is that the sarcoma landscape needed change, and that is certainly what SFA has done.

Twenty-two years since our founding, I’m proud to say that SFA is 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.

Thanks to our many and dedicated supporters, in 2022, SFA funded 19 new research grants through our renowned grant program. These projects cover a wide range of research areas and subtypes, including rare subtypes that desperately need more support. This is an increase of $200,000 from last year totaling almost $1 million given through this program in 2022. We also funded research in seven countries: United States, United Kingdom, Italy, Canada, Switzerland, Germany, Netherlands.

We committed funding for two SPORE grants with partner institutions, and launched a new grant mechanism, The Last Mile, available for sarcoma researchers to provide funding to strengthen the resubmission of a National Cancer Institute (NCI) NCI R01 proposal thereby leveraging larger government funding. Plus, we have established a fund to assist patients participating in clinical
trials by covering expenses related to their participation and have funded our first patients.

We have built a strong and connected sarcoma community through our Race to Cure Sarcoma series through which we have raised millions for sarcoma research. We use some of these funds to directly support sarcoma centers across the country.

Our work to provide education and advocacy opportunities have brought together hundreds of people in the sarcoma community to give them information to better understand sarcoma, treatment options, clinical trials and tools to advocate for themselves and for the greater good of the community.

In 2021, and again in 2022, because of SFA's work, the Senate unanimously passed a resolution designating July Sarcoma Awareness Month. We also visited Capitol Hill as part of the Alliance for Childhood Cancer and met with representatives from the House and Senate to ask for their support to allow the Childhood Cancer STAR Act to continue for an additional five years and to ask representatives to cosponsor the Accelerating Kids’ Access to Care Act.

All truly exciting stuff.

I am honored to lead this organization. Three months after I started, the world was devastated by the COVID-19 pandemic. And I was wondering how I was going to lead this, a new organization to me, through one of the worst times in recent history. But SFA's supporters did not waiver during this turbulent time. From the people who have joined us to raise significant money for our Race to Cure Sarcoma events across the country, to patients who reach out for information, join us for sarcoma awareness month to raise the profile of the disease, to patients seeking information and participating on our education sessions, along with community oncologists, academia and industry. All of you represent SFA's dedicated group of supporters. And for that, we are both fortunate and thankful.

We often hear stories about lack of diagnosis, no treatment options, lack of advancements, lack of awareness. But we also hear stories of perseverance, courage, and putting greater advancements for sarcoma patients above everything. SFA has and will continue to accomplish many things and we never forget on whose behalf we work.

Thank you for joining us. We could not do this without you.

Happy Holidays,
Brandi

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**Experts Discuss Promising Research in Sarcoma**

Researchers are consistently making progress on new treatments and treatment combinations in treating a variety of sarcomas. Over 350 people registered to join SFA's live virtual session on Wednesday, December 7. Presenters Sandra D'Angelo, MD, Physician / Research Director Sarcoma Medical Oncology, Memorial Sloan Kettering Cancer Center, and...
Research Roundup

by Dean Frohlich, PhD

In this issue, I am highlighting two recent publications that emphasize the importance of patients in sarcoma research. The first publication, "On the road to improved outcomes by capturing leiomyosarcoma patients' views," is the result of the work of an international collaborative project that used a questionnaire to gather the views of patients, caregivers, and clinicians about the sarcoma research agenda and unmet needs from the patient’s perspective. Although this paper deals specifically with leiomyosarcoma in eight countries including the United States, the issues raised are common to many sarcoma subtypes.

The second publication, "Informed consent in clinical trials: Implementing methods to improve patient understanding in cancer research—A quality improvement initiative in a sarcoma trials unit" describes an exploratory study which demonstrated that patient education tools, including decision-aids and patient videos, can be used to help improve patient understanding of clinical trial information. Use of education tools like these will help alleviate the concerns of patients entering clinical trial and will hopefully encourage more patients considering clinical trial participation to do so.

2023 Research Proposals

SFA is now accepting proposals for pre-clinical, translational, and clinical research on the etiology, molecular biology, pathogenesis, diagnosis, and treatment of human sarcomas. The deadline for submissions is 5:00 p.m., ET, on February 1, 2023.

The SFA grants are awarded on an annual cycle from June 1 to May 31. For each awarded grant, funding of up to $50,000 in total cost is available to cover equipment, supplies and other expenses in support of research within the period of performance.

This request for proposals is in support of SFA’s overall mission to fund research and increase awareness and advocacy for sarcoma patients and their families. The goal of the SFA Grant Program is to encourage research that results in improved therapeutic options for sarcoma patients. The SFA encourages applications in all areas of sarcoma research, however the following areas of research are of particular interest: immunotherapy; omic characterization of sarcomas and definition of novel targets; omic patterns of sensitivity and resistance to existing agents; systemic therapy combinations; and gene therapy.

Learn more about applying for this grant.

SFA Tribute Wall Brings Together Sarcoma Community
To honor those who have passed away from sarcoma and to provide a forum for individuals at different stages of their sarcoma journey, SFA established the Tribute Wall on Facebook at https://www.facebook.com/groups/SFASarcomaTributeWall/.

This page allows members to share photos and memories of those lost, and post messages of support and hope for those affected by sarcoma. The genuine expressions of hope are inspiring and words of condolence are heartfelt. We encourage you to visit this page and consider joining this special group to share your story with others.

**Dedicated Marathon Team Runs to Benefit SFA**

SFA’s Race to Cure Sarcoma Marathon Team proudly represented the foundation during the Marine Corps Marathon on October 30, 2022. The day’s weather was ideal and our entire team crossed the finish line to raise funds for sarcoma research. Future marathons are in the future for our team and will be announced as they are confirmed. In the meantime, meet the selfless and committed people who are the Race to Cure Sarcoma Marathon Team.

**Dean Frohlich, PhD,** is SFA’s Director of Scientific Affairs. His reasons for racing for the team are easy to understand. For the past two years, he has been responsible for the development of SFA’s scientific strategy; SFA’s grant policies, procedures, and guidelines for applicants and reviewers; the analysis of programmatic processes and recommendations for improvement; and represented SFA at meetings with partnering organizations. He is an avid runner and has participated in numerous half marathons. This was his second marathon. Donate through his fundraising page: [https://p2p.onecause.com/mcm2022/dean-frohlich-2](https://p2p.onecause.com/mcm2022/dean-frohlich-2)

**Stephanie Knappe,** a registered nurse from Colorado, ran the 10K as a member of Race to Cure Sarcoma Marathon Team in support of her husband Frank who has been challenged by sarcoma for nearly five years. Frank has received care at the Mayo Clinic, Rochester, Minn., and most recently at the University of Colorado where he has been in a Phase I immunotherapy clinical trial. Stephanie hopes to do the marathon next year. In the past, she has run half trail marathons and other 10Ks. Says Stephanie, “We feel so fortunate, and we are committed to helping others…The science and research obviously is what can change the course of treatment for so many. That is the reason I want to participate and fundraise. I want to give back in any capacity I possibly can.”

**Brian Rodriguez,** from Chicago, Ill., ran in honor of his father-in-law Mike Cobb who passed away in July 2020 after a nine-year battle with sarcoma. “He had five
surgeries, two rounds of radiation and seemingly endless chemotherapy,” says Brian. “He was an incredible father and helped me so much along my journey.” Brian has run three previous marathons, an ultra-marathon and three half marathons. A firefighter by trade, he loves to travel with his family and is a huge dog lover. His dog Rizzo has helped him with his marathon training. Supporters at the marathon included his wife Claire, son Emmit and his mother Sharon.

Donate through his fundraising page: [https://p2p.onecause.com/mcm2022/claire-cobb](https://p2p.onecause.com/mcm2022/claire-cobb)

**Leticia Rousseve** ran in memory of her husband who in November 2014 at the age of 39 was diagnosed with one of the 75+ rare sarcomas, Desmoplastic Small Round Cell Tumor (DSRCT). He valiantly dealt with the cancer for five years with two major surgeries, endless chemotherapy, radiation and immunotherapy. Leticia and James realized early on during James’ journey that there was very little research for DSRCT and other sarcomas. Because of the lack of research and James’ incredible journey and struggle, Leticia decided she would do what she could to raise money and bring awareness of sarcomas to more friends and family. The 2022 Marine Corps Marathon is her third marathon. Says Leticia, “James was my life and my running partner. Being part of this charity, I hope to keep his memory alive now and always and hoping for more successful treatment discoveries for DSRCT and all sarcomas.”


The SFA Marathon Team is (from left) Dean Frohlich, Stephanie Knappe, Brian Rodriguez and Leticia Rousseve.

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**SFA News**

**Haunted House Scares Up Funds for SFA**

Spooky stuff and fundraising for SFA were on tap in Bethesda, Md., on October 29 when Elliott Gordon held a Haunted House event in memory of YouTube gamer Technoblade. The evening’s event raised over $600 to fund research for a cure for sarcoma. Elliott explains his reason for the fundraiser:

“A friend got me to start watching Technoblade about two years ago. Watching his videos was one of my favorite things to do on social media… I also held my first haunted house last year, although it was just for fun and not a fundraiser for anything. When Techno died, I was shocked and devastated for several days, but at first I did not think about the haunted house that we were already planning to do. Then, around a month and a half or two months ago, I decided to take donations and donate to the Sarcoma Foundation in honor of Technoblade. Now me, my family, and
some friends who were also big fans of Technoblade are going to try to raise at least 300 dollars and continue to raise more and more year after year.”

Thanks Elliot and friends!

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Your Holiday Shopping Can Benefit SFA

Mark your calendars for December 10-11, 2022. That’s when you can do some holiday shopping AND raise funds for SFA. Shop in-person at the Kendra Scott store in Bethesda Row, Bethesda, Md., or make your purchases online at www.kendrascott.com and use code GIVEBACK-CPRBK and SFA will receive 20% of the proceeds.

You’re in for a special treat if you shop the Bethesda store on December 10. From 1 to 3 pm, you can enjoy sips and sweets while you shop and learn about the Sarcoma Foundation of America and its fundraising mission to cure sarcoma. Visit the Bethesda store at 4835 Bethesda Ave., Bethesda, MD 20814. Be sure to mention SFA at the check-out counter.

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Give the Gift of Hope

Celebrate the giving season by making a holiday donation in honor or memory of a loved one, friend, or colleague. Through the SFA Holiday Giving Card donation program, those who receive your best wishes will know your commitment to helping SFA fund lifesaving research, educate patients about the latest research, grow much-needed awareness, and provide hope to the sarcoma community.

Donate $25 or more and a special Giving Card will be mailed to the recipient, memorializing your donation in their name. (The amount of your gift will not be provided.) Please donate early to ensure your card arrives in a timely manner.

If you would like to give in honor or memory of more than one person, please email a recipient list and donation amounts to donations@curesarcoma.org and we will charge one credit card amount for all combined recipients.

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Help SFA through the Combined Federal Campaign

Federal employees! The Combined Federal Campaign is on! Please consider SFA for your year-end donating. Our CFC designation number is 57785: GiveCFC.org. Not a federal employee? Your workplace may have a matching program. Check it out! Thanks to all of you for helping us find a cure for sarcoma!
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