SFA Gala Salutes Scientific Trailblazers and Sarcoma Community Stand Outs

SFA’s Stand Up to Sarcoma Gala on September 28 marked the return of the in-person event and celebration of its 20th year. We packed the ballroom to raise money for research and much-needed sarcoma awareness. SFA's community of supporters, patients, caregivers, and families came together to honor those who have devoted their work to assisting those affected by sarcoma, and to the survivors and patients who inspire us every day. SAG Award-winning actress Caroline Aaron, one of the stars of “The Marvelous Mrs. Maisel,” was a fabulous host. The evening concluded with amazing entertainment from the Doo Wop Project.

Stand Up to Sarcoma is a flagship event for SFA, featuring extraordinary honorees, tributes to sarcoma cancer survivors and advocates, and highlights of important advances in science and research. It is a night of celebration and community that gathers attendees from coast-to-coast and internationally to support sarcoma patients and survivors.

As is tradition, SFA highlighted outstanding sarcoma advocates with the Courage Award, honored a medical visionary working to advance groundbreaking research with the Nobility in Science Award, acknowledged an organization or person providing hope to patients with the Vision of Hope Award and recognized a patient navigator with the Compassionate Care Award for her outstanding contribution to patient care and support. These international awards are the highest honors SFA bestows.

We are grateful to the 2022 Honorees and all they do to support people affected by sarcoma.

COURAGE AWARD
Technoblade
Minecraft YouTuber and Internet Personality

AMIRA YUNIS COURAGE AWARD
Todd Barron
First Vice President, Financial Advisor Morgan Stanley

COMPASSIONATE CARE AWARD
Devon Ciampa, LCSW-C, OSW-C
Clinical Social Worker, the Johns Hopkins Children's Center AYA Patient Navigator for Johns Hopkins through the Ulman Foundation

VISION OF HOPE AWARD
Adaptimmune

NOBILITY IN SCIENCE AWARD
We are grateful to everyone who joined us for this event and to the event sponsors. Their partnership is crucial to the success of the Stand Up to Sarcoma Gala and to advancing SFA’s mission, funding translational research and ultimately saving lives.

We will share the video and photos of the event soon. We hope you will join us for the 2023 Stand Up to Sarcoma Gala.

Research Roundup

by Dean Frohlich, PhD

This month, 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 Advocates for Childhood Cancer Legislation During September Hill Day

SFA visited Capitol Hill on September 13 along with the Alliance for Childhood Cancer, which represents more than 20 national patient advocacy groups and professional medical and scientific organizations. SFA staff 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. Read more about these two Acts below.

H.R. 7630/S. 4120, the Childhood Cancer STAR Reauthorization Act
On June 5, 2018, the Childhood Cancer STAR Act was signed into law – the most comprehensive childhood cancer bill in history. The STAR Act expands opportunities for childhood cancer research, improves efforts to identify and track childhood cancer incidences, and enhances the quality of life for childhood cancer survivors.

H.R. 3089/S. 1544, the Accelerating Kids' Access to Care Act
Children with cancer often require specialized care from a specific provider or facility that may not be available in their home state. Some patients face burdensome, unnecessary delays in accessing time-sensitive care, including clinical trial enrollment, outside of their home state, which can unfortunately cause a child's condition to worsen. The Accelerating Kids’ Access to Care Act reduces regulatory burdens to allow children with complex medical needs greater access to out-of-state providers who can best meet their needs.

Please consider reaching out to your House Representative or Senator and ask them to cosponsor H.R. 7630/S. 4120, the Childhood Cancer STAR Reauthorization Act, to allow STAR Act programs to continue for the next five years, and cosponsor the H.R. 3089/S. 1544, the Accelerating Kids’ Access to Care Act.

Survivor's Story

Father Shares Heartwarming Update on Daughter's Sarcoma Journey

SFA would like to share the LinkedIn post below that was shared with us and we found especially inspiring. Richard Hunter posted this story of his daughter’s sarcoma journey and three years as a survivor. This is our why.

Is this a work-related post…No. I do believe as a connection and colleague to so many of you, we should support each other whether it be through a job search or information sharing. Over the years I have seen many of my connections post about their children who have been diagnosed with some form of cancer. Many of the posts are success stories, many ask for prayers during a parent’s worst time. This is a post to all of you affected by childhood cancer, could be your child, brother, sister, friend relative, whomever.

This is my daughter Sydney, she is 14 and at age 11 came to me and said “Dad, I have this lump in my leg and I don’t know where it came from.” That lump was a Soft Tissue INI1 Deficient Myxoid Chondrosarcoma. Long word for Sarcoma, a cancer that is often found in the limbs and has a spread pattern straight to the lungs. She has been in remission for three years but every three months she must go through a series of scans to see if “it” has returned.
Why is this photo meaningful? She is shopping for her 1st Homecoming dress, of course as her Dad, I asked her “Where is the rest of it?” Look on her wrist! Those bands are her Hospital ID’s from earlier that day where she completed her quarterly cancer scans, and they came back clean. This is life with cancer, even though you beat it, it is never far away.

This is a success story and one I wish gives those going through a similar battle HOPE. You can beat IT! Your child can bounce back to have a “normal” childhood however you define that. Stay Positive and stay strong, your child looks to your face and listens to your words for reassurance. Break down in private, buy a punching bag for the garage but when you are around your child, BE that rock they need. Hardest thing you will ever do. Fight on! Never give up! Sarcoma Foundation of America CURE Childhood Cancer.

SFA News

Support SFA’s Marine Corps Marathon Team

SFA's Race to Cure Sarcoma Marathon Team will be in action on October 30, 2022, at the Marine Corps Marathon.

Our team members are SFA's Dean Frohlich, Stephanie Knappe (participating in 10K), Brian Rodriguez and Leticia Rousseve. Support our team with a donation today!

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.

SFA Accepts Grant from Neighborhood Walmart

The Walmart Community Grants Team and Facility #2551 in Mt. Airy, Md., recently selected SFA for a $1,000 grant. “We are thrilled to support your work in our communities and share your desire to provide local impact,” said a Walmart representative. The check presentation was made on October 12, 2022. We thank Walmart for their support!

Pictured at left is Walmart coach Anthony Bowins, Karen Cook, SFA development manager and Viviane Uwayo, Walmart pharmacy manager.

Giving Tuesday Returns

SFA will again be participating in Giving Tuesday on Tuesday, November 29, 2022. Traditionally held on the Tuesday after Thanksgiving, Giving Tuesday is a global generosity movement unleashing the power of people and organizations to transform their communities and the world. Please help us support our families’ journey with sarcoma and fund the much-needed research needed to find a cure.
Here’s how you can help SFA on Giving Tuesday:

- Make a donation in any amount.
- Make a donation and encourage others to do so on social media.
- Conduct a Facebook fundraiser.
- Set a goal and invite other friends and those in your network to support SFA!

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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](http://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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**SFA Closes Season with Three More Races**

There’s still time to race! The following Race to Cure Sarcoma (RTCS) events are on tap for October and November. To date, the RTCS series has raised over $800,000 this year.

- **Chicago** – October 29
- **Nashville** – November 5
- **Tampa** – November 12

We’re busy planning race event locations and dates for 2023. Watch our website and future issues of this newsletter for the latest information.

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**Our Contact Information**

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