

SARCOMA SPOTLIGHT



FEBRUARY 2024

Our banner for the February newsletter honors Rare Disease Day on February 29th by combining our colors with their art theme and slogan of "Show Your Colours."

Technoblade Never Dies

Last week we received a letter that we were deeply moved by. This heartfelt letter and accompanying artwork were from Haorui Xu, a 7th-grade student at South Woods Middle School. Inspired by the NFL's "My Cause My Cleats" program, where SFA has been proudly represented by several players, and the remarkable spirit of Technoblade, Haorui has designed a pair of cleats dedicated to raising awareness about sarcoma.



Artwork by Haorui Xu

Like many, Haorui was a big fan of Technoblades and was devastated by his passing. His determination to honor Technoblade's memory reflects the courage Technoblade himself showed in battling sarcoma. His cleat design, which you can see below, will be displayed in his school and helps to bring awareness to sarcoma.

Like Haorui, your past support of SFA has raised over \$1.5 million to fund the Technoblade Memorial Research Award and has been vital in the fight against sarcoma. By standing together, inspired by the legacy of Technoblade and the dedication of young advocates like Haorui, we ensure that "Technoblade Never Dies."

Thank you for being a part of our mission to find a cure for sarcoma.

Research Roundup

by Dean Frohlich, PhD

This month I am highlighting three publications demonstrating the variety of research happening across the sarcoma landscape. The first paper is titled ["Phase II Study of Eribulin plus Pembrolizumab in Metastatic Soft Tissue Sarcomas: Clinical Outcomes and Biological Correlates."](#) In this phase II trial, the researchers investigate the safety and efficacy of a chemotherapy called eribulin in combination with an immunotherapy called pembrolizumab, which releases the "brakes" that tumors put on a patient's immune system. Eribulin inhibits the cancer cells' ability to divide, causing the tumor cells to die, and is currently approved for the treatment of liposarcomas. The study includes patients with leiomyosarcoma (LMS), liposarcoma (LPS), or other sarcoma subtypes in which anti-PD1 therapy has shown benefit, including undifferentiated pleomorphic sarcoma (UPS). The combination met the goal of greater than 60% 12-week progression-free survival in patients with LPS and was well-tolerated, but unfortunately did not meet that goal in the other subtypes. These results warrant further studies to determine if the combination is better than either drug alone for patients with LPS.

Recent research indicates that chordomas can respond to immunotherapies. In the next paper, ["Multimodal Profiling of Chordoma Immunity Reveals Distinct Immune Contextures,"](#) the researchers use a variety of methods to better understand this potential for immunotherapies as a treatment for chordoma tumors. The researchers analyzed tumor samples from 77 patients and identified two distinct groups based on the presence of a subset of white blood cells called T cells. The group with greater numbers of T cells also had higher numbers of other white blood cells. Tumors with fewer T cells also had fewer immune cells. These results provide additional evidence for chordoma tumor cells as reasonable candidates for T cell-mediated immunotherapy. While additional research is still required, this study provides further evidence for the use of immunotherapy in chordoma.

The third study, ["Neoadjuvant Chemotherapy in High-Grade Myxoid Liposarcoma: Results of the Expanded Cohort of a Randomized Trial From Italian \(ISG\), Spanish \(GEIS\), French \(FSG\), and Polish Sarcoma Groups \(PSG\),"](#) continues from previous research investigating neoadjuvant standard (S) anthracycline + ifosfamide (AI) treatment with histology tailored (HT) regimen in selected localized high-risk soft tissue sarcoma (STS). A previous trial demonstrated the superiority of the standard treatment in all STS histologies except for high-grade myxoid liposarcoma (HG-MLPS) where the treatments appeared to be equivalent. This study included additional patients with HG-MLPS to further investigate the two treatments. A total of 101 patients with HG-MLPS were randomly assigned, 45 to HT and 56 to S. At 60 months, the disease-free survival and overall survival were not significantly different, confirming that trabectedin is not inferior to AI as suggested in the original study. These results indicate that trabectedin may be an alternative to standard AI in HG-MLPS of the extremities or trunk when neoadjuvant treatment is appropriate.

Clinical Trials Corner

by Kristi Oristian, PhD

This month SFA is highlighting a study titled [CAB-AXL-ADC Safety and Efficacy Study in Adult and Adolescent Patients With Sarcoma](#). This is a multi-center, open-label, phase 1/2 study for patients with certain advanced solid tumors, including undifferentiated pleomorphic sarcoma, liposarcoma, synovial sarcoma, osteosarcoma, and ewing sarcoma. This study, sponsored by [BioAtla, Inc.](#), is open to adults and children ages 12 and older in the United States. In the first part of the study, all patients will receive the experimental drug, BA3011. In this portion of the study, doctors and researchers are trying to understand the safest and most effective dose of the drug. In a second part of the study, patients will receive BA3011 at the dose determined in phase 1 with or without PD-1 inhibitor combination therapy.

BA3011 is an experimental new medicine called a conditionally-active-biologic antibody-drug-conjugate (CAB-ADC) that targets the protein AXL. CAB-ADC is designed to take advantage of chemical properties unique to cancer cells to deliver higher concentrations of medicine directly to tumor tissue instead of healthy tissue. Researchers believe that treatment with CAB-ADC may increase tumor cell death because the many solid tumors like sarcomas overexpress AXL protein.

All patients enrolled in this study will receive CAB-ADC by infusion into a vein, and patients enrolled in groups assigned to receive anti PD-1 therapy will also receive Nivolumab by infusion into a vein.

This treatment may reduce the size of patients' tumors or extend the period of stable disease. Doctors and researchers will also collect information about treatment side effects, especially when determining the maximum tolerated dose of BA3011. This study will help determine if BA3011 is a safe and effective option for patients with sarcomas and other advanced solid tumors.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and exclusion of certain prior treatments. Patients interested in this study should review these criteria with their doctor. To learn more, talk to your provider, contact the investigator at the nearest [site](#), or contact the [study sponsor](#).

SFA Is Updating Our Sarcoma Center Database

SFA announced early last year, that as part of our ongoing efforts to support and facilitate the care of sarcoma patients throughout their sarcoma journey, SFA is working to update our 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, with the input from, and in partnership with, other organizations and the global community, 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 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.

SFA is also working with the global patient advocacy community to align with sarcoma patients and patient advocacy organizations across the globe on criteria for sarcoma centers so all sarcoma patients, regardless of location, have access to the best treatment possible.

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

Remembering Todd Barron, 2022 Courage Award Honoree: A Life Filled with Laughter, Love, and an Unwavering Spirit



Todd Barron, our 2022 Amira Yunis Courage Award recipient, was a man who embodied sunshine. His infectious smile, unwavering zest for life, and deep-seated love for his family and friends illuminated every room he entered. Todd grew up in Boca Raton, Florida, where his vibrant personality blossomed. From his early days as a fun-loving child to his successful career as a wealth management advisor, Todd left a trail of joy and generosity in his wake.

Todd's life was far from a fairy tale, however. In 2018, he was diagnosed with Ewing sarcoma, a rare and aggressive bone and soft tissue cancer. Even in the face of this immense challenge, Todd's spirit remained undimmed. He embarked on a six-year battle that showcased his extraordinary courage and resilience. He endured countless surgeries and rounds of chemotherapy and radiation, all while maintaining a positive attitude and an unwavering commitment to living life to the fullest.

Todd's fight against sarcoma wasn't just about his own survival; it was about making a difference for others. He actively participated in clinical trials, hoping his journey could pave the way for a cure. In 2022, his unwavering spirit earned him SFA's Amira Yunis Courage Award, a testament to his inspiring example.

Beyond his unwavering spirit, Todd was defined by his immense love for his family and friends. He was a devoted husband to his wife Deb, a loving father to his daughters Sarah and Lilah, and a loyal friend to countless others. Whether hosting epic parties, planning exciting adventures, or simply sharing a heartfelt conversation, Todd's infectious enthusiasm and genuine warmth made every moment with him a treasure.

Even as the cancer spread, Todd refused to let it steal his joy. He continued to travel, work, and most importantly, spend time with the people he loved. In his final days, he witnessed his daughter Sarah's Bat Mitzvah, a celebration that encapsulated Todd's life – filled with love, laughter, and the unwavering spirit that defined him.

Todd Barron's life may have been cut short, but his legacy lives on in the hearts of everyone who knew him. He was a man who faced adversity with strength and grace, who lived life to the fullest with each precious moment, and who showered his loved ones with unwavering love and support. His final message, "ALWAYS BE A GIVER," serves as a beautiful reminder of the impact he made on the world, and the inspiration he continues to offer to us all.

The Sarcoma Foundation of America mourns the loss of Todd Barron, a true champion in the fight against sarcoma. His story serves as a beacon of hope and resilience, inspiring us to cherish life, face challenges with courage, and spread the love that Todd embodied so beautifully.



SFA Honors David Fajgenbaum with the 2024 Vision of Hope Award

We're thrilled to announce that Dr. David Fajgenbaum, an acclaimed physician-scientist from the University of Pennsylvania, will receive our 2024 Vision of Hope Award at the Stand Up to Sarcoma fundraiser. This award recognizes his inspiring journey in his fight against rare diseases, including sarcoma.

Dr. Fajgenbaum's story is nothing short of incredible. While still in medical school, he was diagnosed with the rare and deadly Castleman disease. Facing multiple relapses, Fajgenbaum took his treatment into his own hands, leading a tireless search for answers. His determination paid off – he discovered an FDA-approved drug meant for another condition was life-saving for him. Now, Fajgenbaum is in fantastic health and enjoying his longest remission ever.

Dr. Fajgenbaum's powerful determination and experiences are chronicled in his bestselling memoir, "Chasing My Cure: A Doctor's Race to Turn Hope into Action." This book offers profound insights into his remarkable journey and the potential for groundbreaking medical advancements.

Inspired by his personal experience, Dr. Fajgenbaum went even further. When his uncle faced a diagnosis of metastatic angiosarcoma, he sprang into action and found promising research about immunotherapy. His quick thinking and advocacy work pioneered a treatment that has now become standard care for angiosarcoma.

This success fueled Fajgenbaum's mission to accelerate life-saving treatments for various rare diseases. He co-founded the Castleman Disease Collaborative Network, leading to 16 repurposed treatments, and co-founded Every Cure, which is dedicated to unlocking the untapped potential of existing drugs. His incredible journey has also been featured in the New York Times, TODAY Show, and others.

Dr. Fajgenbaum is the definition of a medical trailblazer, and his story will undoubtedly inspire hope in every one of us. His remarkable work shows that breakthroughs in healthcare are possible when determination meets dedication. We are deeply honored to present him with this year's Vision of Hope Award.

Stand Up to Sarcoma Gala

YOU'RE INVITED

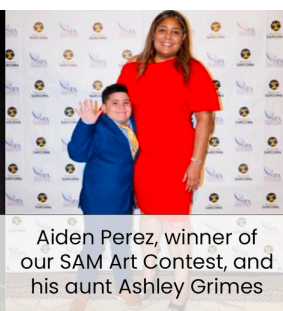
THE SARCOMA FOUNDATION OF AMERICA'S
22nd ANNUAL FUNDRAISER

Join us for SFA's 22nd annual Stand Up to Sarcoma Gala on October 1 at Capitale in New York City. Each year, we gather to honor those who are leaving their mark on the sarcoma landscape. It's also a unique opportunity to meet and mingle with others who have been affected by sarcoma, those who are working to find treatments, and people dedicated to assisting patients during their sarcoma journey. It's an evening where hope, inspiration, community and empowerment are palpable and is certainly not one to be missed!

As is the gala tradition, SFA recognizes individuals with the Courage Award who illustrate, through their personal efforts and actions, sarcoma advocacy. These individuals are patients, survivors, caregivers, and advocates who inspire others by using their platform on behalf of sarcoma patients and survivors to create hope and a better life for the sarcoma community. We also honor a researcher or doctor investigating groundbreaking research leading to new and better therapies for sarcoma patients with the Nobility in Science Award. Finally, we recognize patient navigators with the Compassionate Care Award. These international awards are the highest honor SFA bestows. Please select this [link](#) to view past honorees.



Tiffany Sontos, sarcoma patient, presenting Anjali Albanese, MSW, LSW, OSW-C with the Compassionate Care Award



Aiden Perez, winner of our SAM Art Contest, and his aunt Ashley Grimes



New York Jets' John Franklin-Myers presenting the Courage Award

Stand Up to Sarcoma, is a night of celebration and community as attendees gather from coast to coast, and internationally, to join together in solidarity to support sarcoma patients and survivors. Stand Up to Sarcoma honors those who have battled sarcoma, as well as those who have dedicated their lives and careers to the treatment of sarcoma patients. The event raises money to support much-needed research, education and advocacy efforts. In addition to the awards program, the evening includes entertainment and a silent auction.

We hope you will join us for this important celebration of the sarcoma community while raising money for much-needed research.

Visit <https://www.curesarcoma.org/standuptosarcoma/> for information on ticket purchases and sponsorship opportunities.



Race **TO** *Cure*
SARCOMA

SARCOMA FOUNDATION OF AMERICA

REGISTER NOW for the 2024 Race to Cure Sarcoma series! The series kicks off in March with our inaugural Birmingham, AL race. These events not only help raise funds for much-needed sarcoma research but also unite the sarcoma community across the country and help to raise awareness about the needs of sarcoma patients.



BIRMINGHAM - MARCH 23

ATLANTA - APRIL 6



SOUTH FLORIDA - APRIL 20

BOSTON - APRIL 21

NEW YORK - APRIL 27

SAN FRANCISCO - MAY 11

SEATTLE - JUNE 22

CLEVELAND - JUNE 22

MILWAUKEE - JULY 13

NATIONAL VIRTUAL - JULY 20

WASHINGTON D.C. - JULY 20

LOUISVILLE - AUGUST 10

PHILADELPHIA - SEPTEMBER 14

SAN DIEGO - SEPTEMBER 21

CHICAGO - SEPTEMBER 28

NEW JERSEY - OCTOBER 6

ST. LOUIS - OCTOBER 12

LOS ANGELES - OCTOBER 12

DENVER - OCTOBER 26

OFFICIAL CHARITY PARTNER



Help us celebrate SFA marathon team running in the NYC Half

Our incredible Race to Cure Sarcoma Marathon Team, including Sarah Carey, Sean Carson, RJ Coia, Irene Delagrammaticas, and Julia Lunger, will experience the bright lights of New York City on March 17th, 2024! They'll tackle 13.1 miles through iconic NYC landmarks like Times Square and Central Park, all while raising funds for life-saving sarcoma research. Learn more about our amazing team and support their efforts by clicking [here](#).

INCREASING AWARENESS TO CREATE SURVIVORS



JULY IS

SARCOMA AWARENESS MONTH



Every July, the sarcoma community comes together to acknowledge Sarcoma Awareness Month to pay tribute to those affected by sarcoma, and advocate for the needs of those living with sarcoma. It might seem far away, but we are already planning! We have so much in store, like our Children's Artwork Competition, Wear Yellow Day, a Capitol Hill Day, our National Virtual Race to Cure Sarcoma, and Light Up for Sarcoma.

This year, Light Up for Sarcoma will take place on July 26, but monuments and buildings can light up the week leading up to that or after. This program requires planning and lead time, so we are sharing information now to get as many places as possible to recognize Sarcoma Awareness Month and help bring awareness to this disease.

If you reached out in 2023 to have a monument, building, or special location in your community lit up for sarcoma, please reach out again and let us know. If you have an idea of a place to light up, you can email programs@curesarcoma.org so we can reach out. Let's light our towns yellow to bring awareness for sarcoma!

FEBRUARY 2024 DATES TO REMEMBER



February 15 - International Childhood Cancer Day - This day is an opportunity to raise awareness about childhood cancer and support children and adolescents with cancer, their loved ones and families, and remember those we have lost. Sarcomas make up about 15% of all total childhood cancers in the U.S.; treatments for many of these cancers have not advanced in the past 40 years.

February 29 - Rare Disease Day - Rare Disease Day raises awareness and support for everyone affected by rare diseases. Like many other people affected by rare diseases, people with sarcoma struggle with finding a diagnosis, feelings of isolation, and obtaining effective treatment.