

Reflecting on a Year of Progress and Looking Ahead to

2024 By Brandi Felser, CEO As we approach the end of another year, I am filled with gratitude for the incredible strides

we have made at the Sarcoma Foundation of America. Our commitment to funding research, increasing awareness, and advocating for sarcoma patients has never been

stronger. In 2023, we reached a significant milestone by awarding close to \$1 million in research funds through our SFA Research Grant Program. These grants supported twelve remarkable researchers dedicated to studying sarcoma, a cancer that arises in the body's soft tissue and bone. Each grant was meticulously peer-reviewed by members of our

Medical Advisory Board, ensuring that we fund the most promising research toward

finding a cure for sarcoma. We also awarded our first Last Mile Research Grant worth \$150,000. In total, SFA committed close to \$1.5 million to advance research. The researchers we have funded have made it their mission to develop improved treatment options for patients with sarcoma. From exploring CAR-T cell immunotherapy to investigating novel RNA sensor-based treatments, their work is paving the way for breakthroughs that could one day lead to a cure. Since the SFA's inception, we have invested more than \$20 million in sarcoma research, and we remain the leading funder of private research in the sarcoma community.

2023 also marked a record-breaking year for our Race to Cure Sarcoma series. With events held across the nation, we saw unprecedented participation from the sarcoma community, survivors, their friends, and loved ones. This year, we not only raised awareness but also created lasting, supportive connections among those whose lives have been impacted by sarcoma. The success of our National Virtual Race to Cure Sarcoma event, held on July 22, 2023, during Sarcoma Awareness Month, was particularly noteworthy as it brought together participants from all over the country to support our cause.

research and awareness for sarcoma, and our voice has been heard. We have engaged with policymakers and the public to push for better therapeutic options for sarcoma patients and to ensure that the challenges they face are recognized and addressed. Our dedication to advocacy is unwavering, and we will continue to fight for the rights and needs of the sarcoma community. As we look to 2024, we are filled with hope and determination. The new year brings with it the promise of continued progress, new partnerships, and innovative research that will bring us closer to our goal—a world without sarcoma.

Let's carry this momentum into 2024 as we continue to fight for the sarcoma community and work towards a future where this rare cancer is but a memory. Wishing you all a joyful holiday season and a prosperous New Year. **Research Roundup**

I want to extend my deepest thanks to our supporters, volunteers, and staff who have

worked tirelessly to make our achievements possible. Your dedication and generosity are

This month there are three studies that I would like to highlight. In the first titled, "Efficacy of immune checkpoint inhibitors in alveolar soft-part sarcoma: results from a retrospective worldwide registry, investigators using a worldwide registry explored the efficacy of

from adult patients diagnosed with ASPS and treated with ICI (alone or in combination with a drug that blocks certain cell signals) were retrospectively collected and analyzed. Among the 68 assessable patients, there was an overall response rate of 54.4%. After a

respectively. These results suggest that the ICI treatment provides disease control and prolonged OS in patients with advanced ASPS.

the driving forces behind our success.

median follow-up of 36 months, patients had a median progression-free survival (PFS) of 16.3 months. The 12-month and 24-month overall survival (OS) rates were 94% and 81%,

phase II study in dedifferentiated liposarcoma (DDL) and leiomyosarcoma (LMS), the combination demonstrated activity in DDL with prolonged stable disease and 2 partial responses, but not in LMS. The combination was well-tolerated with expected side effects. Follicular dendritic cell sarcoma (FDCS) is a slow-growing sarcoma, but it can result in a mortality rate as high as 20%. In the last study, "Massive parallel sequencing unveils homologous recombination deficiency in follicular dendritic cell sarcoma," the investigators sequenced the whole genome (WGS) of one patient tumor and sequenced all the genes being expressed (whole exome sequencing, WES) in additional 12 patients to identify possible mechanisms of disease and to identify possible markers of potential therapeutic significance. Results indicate a high frequency of mutations in genes that suppress tumor formation and unveiled alterations in DNA damage repair-related genes in 70% of cases. These results indicate that patients with high-stage FDCS may respond to treatment with

inhibitors to a protein called poly ADP ribose polymerase (PARP) which is involved in

Lastly, Adaptimmune Therapeutics announced completion of the next step in bringing its

other DNA repair pathways. These results provide rationale for new therapeutical

new immunotherapy for advanced synovial sarcoma to patients. By completing its

Administration (FDA) for a fami-cel, the treatment is now eligible for a Priority Review,

which would shorten the FDA's review to 8 months instead of the standard 12 months.

Submission of the BLA is supported by positive data from the SPEARHEAD-1 clinical trial,

which met its primary endpoint for efficacy. Data from the trial were recently presented at

submission of a Biologics License Application (BLA) to the U.S. Food and Drug

the Connective Tissue Oncology Society (CTOS) 2023 Annual Meeting.

approaches to improve the survival of patients.

Clinical Trials Corner by Kristi Oristian, PhD This month, SFA is highlighting a phase I/II study for adults aged 18 and older with advanced or metastatic sarcoma (excluding UPS or MFS) sponsored by <u>Tracon</u> <u>Pharmaceuticals</u>. It is investigating <u>YH001 Plus Envafolimab With or Without Doxorubicin</u> in Patients With Advanced or Metastatic Sarcoma. The study aims to determine the optimal dose of YH001 in the first part, where it is administered in combination with envafolimab with or without doxorubicin. In the second part, YH001 will be given at the recommended dose in combination with envafolimab with and/or without doxorubicin to specific sarcoma histologies, with the goal of increasing tumor cell death, particularly

treatment center, or reach out to the <u>study sponsor</u> for more information.

Webinar Hosted by SFA

Sarcoma Foundation of America is dedicated to fostering the development of innovative treatment options for those affected by sarcoma. In collaboration with the esteemed **CDRC Sarcoma Task Force**, we are excited to present a pioneering project that delves into the potential of repurposing existing medications for the benefit of sarcoma patients. This initiative is at the forefront of leveraging **real-world data**—from electronic medical records to invaluable insights shared by patients and their healthcare providers. The goal is to illuminate the path to cost-effective treatments, harnessing the power of existing drugs that, while proven safe, require further evidence to support their novel application in sarcoma therapy. Be Part of the Change: Your involvement is crucial in propelling this research forward, paving the way for new, accessible treatment avenues for the sarcoma community. **Learn More and Register Below**

rare and ultra-rare sarcomas. **Presented By:** Marco Schito, PhD DATE Executive Director of C-Path's CURE Drug Repurposing Collaboratory (CDRC) January 18th 1:00 - 2:30 EST

> Chief of the Sarcoma Medical Oncology Service at Memorial Sloan Kettering Cancer Center



LOCATION

webinar

This will be a virtual

Registration

against uterine leiomyosarcoma. Fresh from surgery and anticipating chemotherapy, Tiffany's high spirits showcased her remarkable fortitude. Her journey, marked by trials and triumphs, reveals the tenacity of the human spirit and the transformative advances of modern medicine.

In March 2014, Tiffany's unexpected diagnosis of uterine

leiomyosarcoma began, initially mistaken for a fibroid. Despite

and intense chemotherapy. A turning point came when she

enhanced strategies and vital mental health support.

and fighting with unwavering determination.

hurdles and a lack of specialized centers, she navigated surgeries

received tailored treatment from a sarcoma specialist, providing

The battle intensified as the cancer recurred in new territories.

Tiffany faced each challenge courageously, undergoing various

treatments, from chemo pills to innovative procedures. Despite a

stage four diagnosis, she defied statistics, outliving the prognosis

Tiffany's powerful mantra, "I might have cancer, but I'm not going

embodies survival, hope, and the importance of specialized care

Her narrative inspires us, showcasing the human spirit's capacity

to face life's storms. Let's spread awareness, education, and

to let cancer have me," encapsulates her spirit. Her story

and mental health support in navigating sarcoma.

sarcoma battleground.

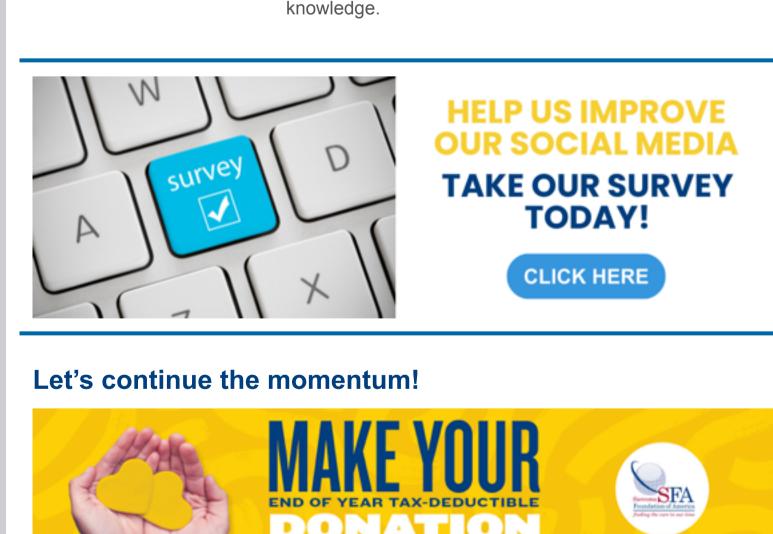
San Francisco 49ers. Check out their cleats below.

The NFL's My Cause My Cleats allows players to wear customized cleats to honor the causes they have chosen to support during Week 13 and 14 of the season. We were honored to have not one but two players representing SFA and Sarcoma during their games. John Franklin Myers, #91 on the New York Jets, and Trent Williams, #71 on the



SFA News





We are looking forward to year-end giving season, and it's not too late to continue to stand

those living with sarcoma. **Together, we have made a** *tremendous* impact! But there is

leading voice for the sarcoma community. You can make your gift in support of research,

SAME VENUE! NEW NAME!

130 BOWERY

NYC

2024 United Airlines NYC Half

We're thrilled to announce that we're an official partner for the 2024 United Airlines NYC Half! This iconic race takes place on March 17th,

an important cause, and be part of something special. You can learn

awareness, advocacy, and education at https://www.curesarcoma.org/year-end/.

beside SFA as we move forward in working to find the cure in our time. And thanks to support from friends like you, we have made significant strides toward a better life for

2024, and winds its way through the heart of New York City, from Brooklyn to Central Park. We have a limited number of spots available for runners who are passionate about our mission and want to experience this unforgettable event. Whether you're a seasoned runner or just starting out, this is a great opportunity to challenge yourself, support

BIRMINGHAM - Mar. 23

BOSTON - Apr. 28

DENVER - Oct. 26

CHICAGO - Sept. 28

CLEVELAND - June 22

Stand Up

to Sarcoma

Gala

SFA Events

OFFICIAL CHARITY PARTNER

SAVE THE DATE FOR 2024! ATLANTA - Apr. 6 **NEW JERSEY - Oct. 6**





Our advocacy efforts have been equally impactful. We have worked tirelessly to increase

by Dean Frohlich, PhD Immune checkpoint inhibitors (ICIs) in alveolar soft-part sarcoma (ASPS), an ultra-rare sarcoma. ICIs remove the "brakes" put on a patient's immune system by tumors. Data

In previous studies, a combination of ribociclib (which inhibits a protein called CDK4 that regulates cell cycles) and everolimus (which inhibits a protein called mTOR that is involved in a cell signaling pathway) has shown synergistic growth inhibition in multiple tumor models. In the second study, "SAR-096: Phase II clinical trial of ribociclib in combination with everolimus in advanced dedifferentiated liposarcoma (DDL), and

leiomyosarcoma (LMS)," investigators report that in a single arm, open label, multi-center

when combined with other medicines. YH001 is an experimental antibody targeting the CTLA-4 protein. Patients in the study will receive the trial medicine through a vein every 3 weeks,

concurrently with envafolimab and doxorubicin if assigned. This treatment may lead to

tumor shrinkage or prolonged stable disease. Doctors will monitor and collect information

on treatment-related side effects. The study aims to assess the medicine's effectiveness

requirements and prior treatment exclusions, apply. Interested patients should discuss

eligibility with their doctor or contact the study investigator at their nearest <u>site</u> or primary

for advanced or metastatic sarcoma. Additional criteria, including organ function

Join Us for a Groundbreaking Patient Engagement

Hosted by: Brandi Felser, SFA CEO Take Part in this Sarcoma Patient Partnered **Research Webinar** Our goal is to better understand the current therapies being used for

We are cordially inviting you to

our Patient Engagment Webinar

William D. Tap, MD

Tim Stuhlmiller, PhD

Cures

Lennie Woods

Sara's Cure)

Cancer Center

Defying the Odds

Tiffany presenting an

to Sarcoma Gala

Sarcoma

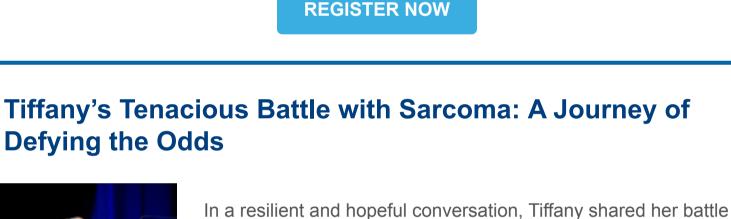
award at our Stand Up

Memorial Sloan Kettering

VP of Scientific and Medical Affairs

Executive Director and co-founder of the Clear Cell Sarcoma Foundation (formerly

PARTNERS & COLLABORATORS



support to illuminate the paths of those on similar journeys in the **NFL My Cause My Cleats Helps Bring Awareness to**



Thank you for your support—whether by sharing your "why" with friends and family, raising awareness of sarcoma and SFA, or making a donation—you made this possible. This is the transformative power of shared moments—making a direct impact in funding translational research that will lead to new therapies and bring us closer to a cure. Together, we can build off these achievements and continue to help patients, survivors, and their families.

SFA Welcomes Newest Staff Member

member of our development team. With a rich and diverse

administration, and marketing across the education, travel,

Outside of work, she's a certified yoga and barre instructor, an avid reader with over 50 books a year under her belt,

rhabdomyosarcoma survivor fuels her passion for sarcoma research and advocacy, making her a powerful voice for patients and those affected by sarcoma. Her beloved Yorkie

curesarcoma.org/year-end

Save The Date

OCTOBER 1, 2024

THE SARCOMA FOUNDATION OF AMERICA'S 22nd ANNUAL FUNDRAISER

terrier, Simba, is her constant companion, reflecting her

commitment to health, wellness, and the pursuit of

experience from both corporate and non-profit sectors.

We are thrilled to welcome Natasha, a dynamic

professional hailing from Boston, MA, as the newest

background spanning program coordination, grant

and health industries, Natasha brings a wealth of

and an outdoor enthusiast who loves hiking and snowshoeing. Natasha's personal journey as a

With the help of our supporters during this year's Giving Tuesday campaign, together, in a

single day, we raised critical funding to support a 2024 research grant!

still work to do. We must keep this momentum moving forward, and we can't do that without you! Together—patients, survivors, researchers, supporters, and advocates—we can move the needle in discovering groundbreaking cures for sarcoma. More than ever, our collective voice is important for advancing more and better treatment options that lead to a cure. Please don't let this important month pass by without making a real difference for patients and their families. The path to a cure is research - and **research is the heart of SFA**. Thank you for investing generously in saving lives as we continue our efforts to be the



NEW YORK CITY - May 4

PHILADELPHIA - Sept. 14

SAN FRANCISCO - May 11

SAN DIEGO - Sept. 21





LOS ANGELES - Oct. 12 **LOUISVILLE - Aug. 10**

MILWAUKEE - July 13 WASHINGTON, D.C. - July 20 **NATIONAL VIRTUAL - July 20** Gear up for an exciting year as our 2024 Race to Cure Sarcoma series kicks off in March with our inaugural Birmingham, AL race. These events not only help raise funds but also unite communities across the country in the fight against sarcoma. Check out the list of locations for next year, with more to come soon, along with registration info. Los Angeles RTCS Photos

Our Contact Information *{{Organization Name}}* *{{Organization Address}}* *{{Organization Phone}}* *{{Organization Website}}*

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