



**APRIL 2024**

The first week of April is Adolescent and Young Adult (AYA) Awareness Week. In this issue, our newsletter shines a light on the AYA sarcoma community, sharing information and stories that will inform and inspire.

**SAVE THE DATE**



July 18, during Sarcoma Awareness Month, the sarcoma community will make our voices heard on Capitol Hill both in-person and virtually. If you are interested in participating, be sure to [sign up for our advocacy email list](#). We will be sharing more details and hosting a webinar detailing how you can join us to increase awareness and advocate on behalf of people diagnosed with sarcoma.

## Research Roundup

by Dean Frolich, PhD

Clinical trials frequently measure different variables that are collected at different times. These results are often published as updates which allow the investigators to provide all the results from a clinical trial in a timely manner. In the publication, "[Phase II Trial of nab-Sirolimus in Patients With Advanced Malignant Perivascular Epithelioid Cell Tumors](#)

[\(AMPECT\): Long-Term Efficacy and Safety Update](#),” the investigators provide an update from the phase II Advanced Malignant Perivascular Epithelioid Cell Tumors (AMPECT) trial (ClinicalTrials.gov identifier: NCT02494570) with nab-Sirolimus, which is an albumin-bound nanoparticle that inhibits a protein called mTOR and is intravenously administered. Nab-sirolimus is approved in the United States for the treatment of patients with locally advanced, unresectable, or metastatic malignant perivascular epithelioid cell tumor (PEComa).

In this publication, the investigators report the final efficacy and safety data 3 years after the primary analysis was completed. They confirm that the overall response rate was 38.7% with the median progression-free survival at 10.6 months. The median duration of response was 39.7 months, and the median overall survival at completion was 53.1 months. The most common treatment-related adverse events were stomatitis (82.4%) and fatigue and rash (each 61.8%). These results demonstrate the clinical benefit of nab-sirolimus in patients with advanced malignant PEComa.

In the next study, [“Sarcoma microenvironment cell states and ecosystems are associated with prognosis and predict response to immunotherapy.”](#) the researchers used EcoTyper, a machine-learning framework, to identify cell states and environments that make up sarcomas using large data sets from tumor samples from patients that can be compared with clinical annotations. Using this technique, they identified and confirmed 23 sarcoma-specific cell states. One of three distinct cell ecotypes identified is defined by a specific immune cell type called tumor-associated macrophages and another cell type called epithelial-like malignant cells was able to predict response to a type of immune therapy called immune-checkpoint inhibition which is like removing the brakes from the immune system. These results indicate a way that may allow oncologists to identify soft tissue sarcoma that may respond to immunotherapy.

Afamitresgene autoleucel (afami-cel) is an immunotherapy in which a specific kind of white blood cell called a T-cell is removed from the patient’s body and is modified to target a specific protein that is expressed on the tumor. This kind of therapy is called engineered T-cell receptor (TCR) T-cell therapy. A previous study demonstrated acceptable safety and promising efficacy in a phase 1 trial (NCT03132922).

The aim of this study, [“Afamitresgene autoleucel for advanced synovial sarcoma and myxoid round cell liposarcoma \(SPEARHEAD-1\): an international, open-label, phase 2 trial.”](#) was to further evaluate the efficacy of afami-cel for the treatment of patients expressing the specific proteins (HLA-A\*02 and MAGE-A4) in advanced synovial sarcoma or myxoid round cell liposarcoma. Patients received a single intravenous dose of afami-cel after being treated to deplete their white blood cells called lymphocytes. 52 patients with confirmed synovial sarcoma (n=44) and myxoid round cell liposarcoma (n=8) were enrolled and received afami-cel. Overall response rate was 37% overall, 39% for patients with synovial sarcoma, and 25% for patients with myxoid round cell liposarcoma. Cytokine release syndrome occurred in 71% of patients. A lower than normal level of blood cells called cytopenias were the most common grade 3 or worse adverse events (lymphopenia in 96%, neutropenia 85%, leukopenia 81% of patients). These results indicate that Afami-cel treatment resulted in durable responses in patients with HLA-A\*02 and MAGE-A4-expressing synovial sarcoma.

The last study, [“Best Overall Response-associated Signature to Doxorubicin in Soft Tissue Sarcomas: A Transcriptomic Analysis from ANNOUNCE”](#), is an exploratory analysis of tumor samples from the patients that were treated with doxorubicin in the ANNOUNCE clinical trial to identify potential predictive markers. The investigators sequenced the RNA of 259 pretreatment tumor samples to look for RNA expression patterns in tumors that responded to doxorubicin and those that did not. A best overall response-associated RNA signature to doxorubicin (REDSARC) was created by evaluating tumors with radiographic response (shrinking of the tumor measured by imaging) versus progression. The analyses indicated there was an association between the best overall response signature and histologic subtype and tumor grade. It also indicated that REDSARC was also predictive for progression-free

(PFS) and overall survival (OS). A refined 25-gene signature was identified and applied to the samples where it was predictive of PFS and OS in leiomyosarcoma, liposarcoma, and other sarcoma subtypes, but not in undifferentiated pleomorphic sarcoma. These results show that after further testing and refinement that the REDSARC signature could be used guide the use of doxorubicin in sarcomas.

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## Clinical Trials Corner

by Kristi Oristian, PhD

In support of Adolescent and Young Adult (AYA) cancer awareness, this month SFA is highlighting the [INSPIRE-AYA Study: A Multicenter Interactive Survivorship Program to Improve Healthcare Resources for Adolescent and Young Adult Cancer Survivors](#).

This study is for survivors 18 years and older who were first diagnosed with sarcoma between the ages of 15 and 39 and are within 5 years of the time of their diagnosis. Individuals must have completed active treatment for their disease and received a therapeutic intervention such as surgery, cytotoxic chemotherapy, biological or targeted agents, and/or radiation therapy. Access to email and a smartphone or internet are required.

Participants will be randomized to one of two groups. One group will receive a personalized Survivorship Care Plan (SCP) and use the Interactive Survivorship Program to Improve Healthcare Resources (INSPIRE) mobile application. In this group, patients may receive telehealth care after 1 month. In another group, survivors will receive access to a study-specific website that has links to resources for AYA survivors. After 12 months, individuals in this group will also receive a personalized SCP and access to the INSPIRE application.

Individuals must complete a baseline patient reported outcomes assessment to qualify and determine eligibility. Survivors interested in this study should [contact](#) the study director or reach out to a [site](#) near you for additional information.

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## A Story of Courage and Gratitude in His Journey Against Osteosarcoma

Sean Cincotta, a vibrant young man, faced an unexpected adversary: a diagnosis of osteosarcoma, a rare bone cancer. Undeterred by this daunting challenge, Sean's strength and determination illuminated his path as he embarked on a journey of treatment and recovery.

The battle commenced with a 14-hour complex surgery, skillfully led by Dr. Kim of Cooper University Health Care in Camden, NJ. The mission was to eradicate the sarcoma and give Sean a "bionic" shoulder and arm. The surgery was successful and was able to save the full functionality of his hand. Sean's unwavering spirit led him to embrace intensive chemotherapy, guided by Dr. Khrizman and her team at MD Anderson Cancer Center in

Camden, NJ. Together, they confronted the next phase of his fight.

Throughout this arduous journey, Sean's heart overflowed with gratitude. He reveres the unwavering dedication of his doctors—Dr. Kim, Dr. Khrizman, and their teams—who stood by him at every turn. But Sean also recognizes the pivotal role played by the Sarcoma Foundation of America and said the relentless commitment to funding research and supporting medical professionals offers hope to patients like Sean, battling this rare disease.

After an 8-month treatment journey, Sean has concluded his chemotherapy treatments and a palpable sense of hope fills the air. He acknowledges the sacrifices made by those who stood by him—doctors, family, friends, and colleagues—and could not have done it without their unwavering support and encouragement. Their steadfast support paints a brighter future for Sean.

Sean's story stands as a poignant testament to the resilience of the human spirit. It underscores the critical importance of supporting sarcoma research. By rallying behind SFA, we inch closer to a day when this rare disease becomes even rarer. Let Sean's courage ignite our collective determination to join the fight. Moreover, Sean actively contributes to SFA's mission. As part of the AYA Committee, he works tirelessly to help young sarcoma patients navigate and understand their unique journey. His firsthand experience lends invaluable insights, fostering hope and empowerment for others facing similar challenges.



Every year at the Stand Up to Sarcoma Gala, SFA awards the Compassionate Care Award to a patient navigator (clinical/nurse, community health worker, social worker in the role of a navigator) for his or her outstanding contributions to patient care, support, and education. This year's Compassionate Care Honoree is Jaclyn Cardarelli-Matte, LICSW, a licensed social worker at Massachusetts General Hospital.

Jaclyn was nominated for the Compassionate Care Award by two of her patients, Kathleena Meats and Shawnee Flynn. When asked why Jaclyn should receive this award, Kathleena's said, "Imagine being in the middle of a terrible blizzard all alone, the wind is whipping your face, you can't see anything around you, you're so cold and scared you're shaking, in what direction should you proceed, will it be the right choice, what happens if...A hand reaches out to yours and pulls you into the warmth, suddenly you're in front of a crackling fire sitting next to a friend, maybe in a rocking chair, and you start to thaw out (both physically and emotionally) as you begin to talk: this is who Jaclyn Cardarelli-Matte is to me."

Shawnee shared a similar sentiment, in her words "Jaclyn is such a huge part of each of our lives and really knows how to connect with each and every one of her patients. This is not a job to her; this is her whole life, and you know that as soon as you meet her!"

It is an important part of SFA's work to recognize the important support social workers and

navigators provide for patients and families and to highlight the lives touched. SFA is excited to recognize and honor Jaclyn Cardarelli-Matte at the 2024 Stand Up to Sarcoma Gala on October 1, 2024, for her admirable work to support and better the lives of sarcoma patients.

[Learn more](#) about the Stand Up to Sarcoma Gala and SFA's honorees.



## SFA Mourns Passing of Susan Ito

We are deeply saddened by the passing of sarcoma patient and advocate Susan Ito. Her tireless dedication to raising awareness for sarcoma left a lasting impact. Team Susan joined us for the 2023 RTCS Los Angeles to raise awareness and research funds to ease the burden on people living with sarcoma. Susan's legacy will continue through this important gathering as Team Susan will continue in her honor. Last year, ABC-7 Los Angeles shared Susan's story to help bring awareness to sarcoma. [Watch that story here.](#)

## Liposarcoma Webinar Recording and Survey

A promotional graphic for a webinar recording. The background is dark blue with yellow dotted patterns in the corners. The text 'VIRTUAL SESSION WITH THE EXPERTS' is in white, followed by 'LIPOSARCOMA' in large white letters. A yellow button says 'RECORDING NOW AVAILABLE'. Two circular portraits of speakers are shown: Raphael E Pollock, MD, PhD and Gary Schwartz, MD. Logos for SFA and Boehringer Ingelheim are at the bottom left.

**VIRTUAL SESSION WITH THE EXPERTS**  
**LIPOSARCOMA**

**RECORDING NOW AVAILABLE**

**RAPHAEL E POLLOCK, MD, PHD**  
Director, The Ohio State University  
Comprehensive Cancer Center  
Klotz Chair in Cancer Research

**GARY SCHWARTZ, MD**  
Director, Case Comprehensive Cancer Center  
Vice Dean for Oncology, School of Medicine  
Gertrude Donnelly Hess MD Professor in Oncology Research

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**SFA**  
Sarcoma Foundation of America  
Finding the cure is our focus.

In March, SFA hosted the first of an ongoing series of educational webinars focusing on specific subtypes of sarcoma. For this webinar, Raphael Pollock, MD, PhD, led a discussion placing care, diagnosis, and treatment of liposarcoma in the context of other sarcomas, while Gary Schwartz, MD, led a discussion of advances in liposarcoma treatment. Watch a recording of the webinar below and look out for our future webinars in SFA's "Subtype Series".

[WATCH WEBINAR](#)



WE WANT TO HEAR FROM YOU

# LIPOSARCOMA SURVEY

**Help inform future care decisions!**

SFA is asking liposarcoma patients to share their insights from diagnosis to treatment. This project is an important step in collecting patient experience data to be used and shared to advance treatment and care. Participants will receive the results from the project and learn about the insights found. The survey takes an estimated 30 minutes to complete. Click the button below to request a link to the survey and one will be emailed to you.

[REQUEST LINK TO SURVEY](#)

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## **Calling all AYA Sarcoma Patients and Sarcoma Caregivers!**

Are you looking for a way to connect with others who understand your journey? SFA has launched two exciting new Facebook Groups:

**[Adolescent and Young Adult \(AYA\) Sarcoma Connect:](#)**

Find support, share experiences, and build connections with other young people facing sarcoma.

**[Caregiver Sarcoma Connect:](#)**

A dedicated space for caregivers to share advice, find resources, and lean on each other for support.

Click below to join today and find your online support network!



JOIN OUR AYA GROUP



JOIN OUR CAREGIVER GROUP



## SFA Participates in our first United Airlines NYC Half Marathon

We were thrilled to be represented by a team of five dedicated runners in the United Airlines NYC Half for the first time this year. Our team successfully raised \$18,415 in support of critical sarcoma research. We're so grateful for their incredible efforts and to everyone who supported this important cause. You can read about all of our team members [here](#).



## SFA Participates in Tee Off FORE Sarcoma Fundraiser

Last month we were honored to participate in Tee Off FORE Sarcoma hosted by SFA Board of Directors member Jennifer Goodwin and the Catherine J Malatesta Foundation. Tee Off FORE Sarcoma was a fantastic day at Top Golf in Canton, MA, full of great raffles, exciting music, tasty lunch, and sunny blue skies enjoyed by friends, colleagues, family, and others hoping to make a positive impact on the sarcoma community. With more than 250 people in attendance, thanks to everyone's incredible support and generosity, Tee Off FORE Sarcoma raised \$124,000, part of which will go to support SFA's sarcoma research programs.

Congratulations to the CJM Foundation on a remarkable day of giving. We are grateful for your partnership in bringing hope and healing to the sarcoma community.



## Youtuber Pays Tribute to Technoblade

In November 2019, YouTubers Technoblade and I'm a Squid Kid engaged in "the Great Potato War," in which the two Minecraft players competed to see who could be the first to harvest 500 million potatoes. While Technoblade edged out his competitor, I'm a Squid Kid was inspired to become king of something else. This March, I'm a Squid Kid released a video detailing that new plan to honor Technoblade's legacy and raise money for SFA. That fundraiser, which is open until April 22, has raised nearly \$3,000 so far. Watch his video and learn how you can take part [here](#).



## SFA Joins Effort to Improve Treatments for Rare Diseases

On February 27th, SFA Director of Scientific Affairs Dean Frohlich, PhD, joined dozens of other rare disease patient advocates in attending an open house and special announcement in Washington, DC, following the introduction of proposed bipartisan legislation for The Promising Pathway Act. This legislation would create a rolling, real-time drug approval pathway to speed access for individuals with rare, progressive, and serious diseases without compromising patient safety or FDA's gold standard for drug approvals.



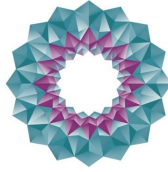
## SFA Awards Nearly \$30,000 to Support Sarcoma Research

Brandi Felser, SFA CEO, recently presented a check for close \$30,000 to support ongoing sarcoma research initiatives at City of Hope. This funding, which was raised at our Race to Cure Sarcoma Los Angeles, underscores SFA's



commitment to advancing the understanding and treatment of sarcomas.

**ESMO SARCOMA AND RARE CANCERS**  
Annual Congress



**LUGANO SWITZERLAND**  
**20-22 MARCH 2023**



## SFA at ESMO 2024: Highlights from Lugano

On March 14-16, SFA CEO Brandi Felser and Director of Scientific Affairs Dean Frohlich, PhD, attended the European Society for Medical Oncology (ESMO) Sarcoma and Rare Cancers 2024 Congress in Lugano, Switzerland. ESMO's scientific and educational program featured insights into the diagnosis, prognosis, management, and ongoing research of patients with sarcoma, with sessions on multidisciplinary expert management, targeted therapies, precision medicine, real world data, artificial intelligence, policy, and guidelines. In addition to attending the educational sessions, Felser and Frohlich met with representatives from key stakeholders from across the world to continue discussions on how we can collaborate on projects for the entire sarcoma community.

We were also proud to see SFA acknowledged during the MDM2 Session for our research support.



Sarcoma Awareness Month is almost here! Get a head start on making a difference.

- **Enter the Children's Art Contest:** Spark creativity & raise awareness!
- **Light Up Yellow for Sarcoma on July 26th:** Ask local landmarks to shine bright for sarcoma
- **Join us for Hill Day on July 18th:** The sarcoma community will make our voices heard on Capitol Hill both in-person and virtually.
- **Join the Race:** Create a team for our National Virtual or in-person Washington DC RTCS, or share photos from other RTCS races on social media.
- **Get Involved:** Get all the details about everything above and find MORE ways to help

at the link below.

LEARN MORE



Join SFA on October 1, 2024, at 583 Park Avenue in New York City for our 22nd annual fundraising gala, Stand Up to Sarcoma.

Stand Up to Sarcoma is a signature event of Sarcoma Foundation of America (SFA). The highlight of the night is our program honoring recipients of SFA's five international awards – the Courage Award, the Amira Yunis Courage Award, the Nobility in Science Award, the Vision of Hope Award, and the Compassionate Care Award.

**Join the SFA community and help make a difference in the fight against sarcoma!**

LEARN MORE, REGISTER, & SPONSOR



We're thrilled to announce that we are again partnering with the Marine Corps Marathon (MCM) and inviting you to join our team!

The MCM is a historic race that winds through Washington D.C.'s most iconic landmarks. It's a great opportunity to challenge yourself, be part of a supportive team, and see our nation's capital in a whole new way.

For more information and to register, click the link below.

We can't wait to run alongside you!

LEARN MORE AND REGISTER



Race **to** Cure  
**SARCOMA**

SARCOMA FOUNDATION OF AMERICA



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  
TAMPA - NOVEMBER 2

REGISTER FOR YOUR LOCAL RACE

**Our Contact Information**

\*{{Organization Name}}\*  
\*{{Organization Address}}\*  
\*{{Organization Phone}}\*  
\*{{Organization Website}}\*  
  
\*{{Unsubscribe}}\*

