

#### **OCTOBER 2024**

# An Evening of Hope: Stand Up to Sarcoma Gala Inspires and Uplifts







The Sarcoma Foundation of America's 22nd annual Stand Up to Sarcoma Gala was a night of celebration and sense of community, hope, and unwavering dedication to supporting those affected by sarcoma. Supporters, patients, caregivers and their families came together to honor those who have dedicated their work to assist people affected by sarcoma and to the survivors and patients who inspire us every day.

We are grateful to the 2024 honorees, each of whom has made a unique and significant impact in the world of sarcoma: David Fajgenbaum, MD, MBA, MSc, received the Vision of Hope Award; Cristina R. Antonescu, MD, was honored with the Nobility in Science Award; Jaclyn Cardarelli-Matte, LICSW, accepted the Compassionate Care Award. Emily Oberst, Kelly Elmlinger, and Nate Hinze were presented with the Courage Award; and Sean Cincotta received the Amira Yunis Courage Award. Their individual stories of dedication, compassion, and bravery serve as a powerful reminder of why we stand up to sarcoma. To learn more about this year's honorees click the link below.

#### **Learn About Honorees**

Actress and singer Krysta Rodriguez, who has graced both stage and screen in productions like "Halston" and "Smash" started off the evening with a heartfelt performance. During her performance, Krysta dedicated a song from "Into the Woods" a production she starred in with her friend and fellow Broadway star, Gavin Creel, who had passed from sarcoma on September 30, 2024. SAG Award-winning actress Caroline Aaron, known for her roles in "The Marvelous Mrs. Maisel" and "Ghosts," guided us through this special night of celebration featuring extraordinary honorees and recognition of important advances in sarcoma science and research.

Thank you to everyone who joined us for this unforgettable evening and to the event sponsors. Your partnership and your shared commitment to making a difference in the lives of those affected by sarcoma are what make this event so special.

Revisit memories made and view all the photos from the evening at the link below.

We hope you will join us next year for the 23<sup>rd</sup> Annual Stand Up to Sarcoma Gala.

**View Photos** 

## RESEARCH ROUNDUP

By Dean Frohlich, PhD

The first paper that I would like to highlight is "Doxorubicin—trabectedin with trabectedin maintenance in leiomyosarcoma." In it, the investigators give an update on a phase 3 clinical trial in patients with metastatic or unresectable leiomyosarcoma who had not received chemotherapy previously. Patients received either six cycles of a chemotherapy called doxorubicin alone or six cycles of doxorubicin plus another chemotherapy called trabectedin. In this combination group, trabectedin treatment was continued after the six cycles in patients who did not have disease progression. Additionally, surgery to remove residual tumor was allowed in each group after the initial six cycles of therapy. The results showed that the median overall survival was longer in the combination group compared to the doxorubicin group (33 months vs. 24 months). Additionally, as in the earlier reports, progression-free survival was longer in the combination group compared to the doxorubicin group (12 months vs. 6 months). However, there was an increase in the side effects and the percentage of patients with dose reductions of chemotherapies in patients receiving the combination therapy may be a new standard for first-line treatment in patients with advanced leiomyosarcoma.

The second study is called "The landscape of drug sensitivity and resistance in sarcoma." In this study the investigators utilized patient-derived tumor organoids (PDTOs) in which small masses of tumor are grown in culture to model sarcoma tumor behavior to determine sensitivities and resistance to different therapies. The investigators' screening pipeline tested single drugs and combinations of drugs in 97 specimens from a variety of sarcoma subtypes. Utilizing this method, they were able to identify at least one FDA-approved or NCCN-recommended effective regimen for 59% of the specimens. This study indicates that this may be a valuable method to determine to identify resistance, sensitivity patterns and provide actionable treatment information in sarcomas.

Lastly, in "MEK inhibitors lead to PDGFR pathway upregulation and sensitize tumors to RAF dimer inhibitors in NF1-deficient malignant peripheral nerve sheath tumor (MPNST)," the investigators utilize a variety of techniques to investigate how MPNST tumors become resistant to treatment with drugs that block protein called MEK (MEKi) in a cell signaling pathway involving a protein called MAPK. They found that MEKi resistance involves two additional cell signaling pathways: an increase in a protein called PDGFRβ, and increased cell signaling in the coupling of a protein called RAF. Next, they found that adding inhibitors for PDGFRβ and RAF dimers effectively decreased MPNST cell viability in vitro and animal models of MPNST. These results indicate that the combination of MEKi and PDGFR and/or RAF dimer inhibitors may be able to overcome MEKi resistance and may lead to a new therapeutic strategy for NF1- deficient MPNST patients.

## **CLINICAL TRIALS CORNER**

By Kristi Oristian, PhD

This month SFA is highlighting TINKS: a Multi-Institution Study of TGFβ Imprinted, Ex Vivo Expanded Universal Donor NK Cell Infusions As Adoptive Immunotherapy in Combination with Gemcitabine and Docetaxel in Patients with Relapsed or Refractory Pediatric Bone and Soft Tissue. This is a multi-center study for patients with childhood sarcomas that have relapsed or not responded to prior therapies. This study, sponsored by Nationwide Children's Hospital is open to children and adults ages 12 to 40 years old in the United States with relapsed or refractory osteosarcoma, Ewing sarcoma, rhabdomyosarcoma, or non-rhabdomyosarcoma soft tissue sarcoma.

Eligible patients will receive two kinds of medications: chemotherapy and a type of immune cell called "natural killer" cells imprinted for a protein called TGFβ (TGFβi NK cells). Doctors and researchers are trying to determine if adding an infusion of these NK cells to sarcoma chemotherapy can improve outcomes without too much toxicity.

Patients will receive study drugs in 21-day cycles and may receive up to 8 cycles. The drugs include Gemcitabine (GEM) by infusion into a vein on days 1 and 8, and Docetaxel (DOX) by infusion into a vein on day 8. The TGFβi NK cells will be delivered by infusion into a vein on day 12. Patients will also receive two drugs to help manage known symptoms related to treatment: dexamethasone on day 7-9 to prevent fluid retention and hypersensitivity reaction

and Peg-filgrastim (PEG-GCSF) on day 9 to help white blood cells recover and allow more chemotherapy to be given.

This study will help doctors and scientists understand if adding TGFβi NK cells to GEM/DOX chemotherapy is safe and effective.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations. Patients interested in this study should review these criteria with their doctor. To learn more about this study, talk to your doctor, contact the investigator at the <u>site</u> nearest you or your primary treatment center, or contact the <u>study</u> coordinator.

## IN THE COMMUNITY



#### Broncos' John Franklin-Myers Tackles Sarcoma with SFA Donation and Team for RTCS Denver

Denver Broncos defensive end and SFA Ambassador John Franklin-Myers has already made two sacks towards his pledge to donate to SFA for every sack he makes this season So far, he has raised \$4000 to raise sarcoma awareness and help fund research. He and the Broncos will take on the Los Angeles Chargers, New Orleans Saints, and Carolina Panthers later this October. Check out the Broncos' coming schedule here, and let's continue to cheer him on for the rest of the season!

John has also started a team for the Race to Cure Sarcoma event in Denver on October 26. His team, 98.0 JFM QB Hits, is looking for new members to help raise awareness and help fund sarcoma research. The first 15 team members registered will receive a special JFM 98.0 QB Hits t-shirt. Join his team or make a donation <a href="https://example.com/here">here</a>.

#### Golfers Tee Off for Sarcoma Awareness at Putts for Ped

The 18th Annual Putts for Ped golf tournament, held in memory of Michael John Pedrick, once again brought the community together for a day of camaraderie and support. The event fostered a spirit of togetherness, reminding participants that facing sarcoma is a shared journey. Golfers gathered at Rancocas Golf Club in Willingboro, NJ, to honor Michael's legacy and to raise money to contribute to vital research and support services for those affected by sarcoma, ensuring that Michael's memory continues to inspire hope and progress. You can view photos from the event here.





#### **Shine Bright, Do Good**

Shop for Good Online!

November 22-23 2024

Enter code **GIVEBACK-HGMOC** in your cart or at checkout on <u>kendrascott.com</u>, and 20% of your purchase will benefit SFA.

#### A Sister's Symphony: Amethyst Moye-Turner's Tribute to Angelyn

Stellar Award-winning singer, Amethyst Moye-Turner, recently released her new album, "An Amethyst Symphony." This album, six years in the making, is a tribute to her sister, Angelyn, who passed away from sarcoma in 2023. Amethyst and Angelyn had been singing together since they were young children. One track on the album, "Angels," features Angelyn. This song beautifully captures the everlasting bond between the two sisters and gives listeners an opportunity to hear them sing together once more. Amethyst recently had an album release event in Chicago which helped to raise over \$2500 for SFA in Angelyn's memory.



Listen to "Angels" and the entirety of An Amethyst Symphony.

### **SFA NEWS**

#### SFA and ACCC Partner to Share Sarcoma Resources

SFA has launched a strategic partnership with the Association of Cancer Care Centers (ACCC) to provide community oncologists, patient navigators, and other community cancer center staff with essential sarcoma information and resources. SFA developed the new online portal to help community cancer center staff better treat and support sarcoma patients and their families.

Studies show improved outcomes when people diagnosed with sarcoma are treated at a sarcoma specialty care center. However, more than a majority of sarcoma patients receive care from a community provider or facility.

Sarcoma patients seek care at community centers for a variety of reasons. Patients may lack the time, money, or ability to travel to a sarcoma specialty center on a regular basis. Cost also reduces access for patients who are uninsured, underinsured, or lack the money to pay for out-of-pocket expenses. Some patients may not know of the benefits of a sarcoma specialty center. Often, a combination of factors is involved.

SFA developed the portal's resources, which include an <u>illustrated iconographic providing a</u> basic introduction to sarcoma and common subtypes, education webinars, and a listing of

sarcoma specialty care centers across the United States, and a link to <u>SFA's Clinical Trial Matching Service</u>. Additional resources will be added in the coming months.

Visit the portal here.

#### **Meet the Newest Member of Our Team**



Claire Wang joined the Sarcoma Foundation of America in 2024 as Finance Director. She oversees SFA's finance functions, including directing and managing finances and administration to support the organization's short and long-term strategic goals.

Claire has 20+ years of experience navigating complex global business markets as an executive thought leader and financial strategist. She has extensive work experience in both the corporate and non-profit sector. Before joining SFA, Claire worked as the Head of Budgets and Financial Planning at the United Nations Foundation.



# SFA at the Forefront of Sarcoma Research

The SFA team joined leading researchers and clinicians at the ESMO Congress in Barcelona to explore the latest advancements in sarcoma treatment. SFA also co-sponsored the Strategic Advances in Sarcoma Science Meeting, which convened roughly 150 participants, including researchers, clinicians, and patient advocates, to delve into critical sarcoma topics such as genomic integrity, therapeutic resistance, and immune biology. The meeting fostered collaboration and knowledge sharing through in-depth working groups focused on complex sarcomas, epigenetics, and T-cell engineering. These events fueled our passion for improving

patient outcomes and strengthened our commitment to staying at the forefront of sarcoma research.

# Coming Soon: "Sarcoma Stories" Podcast

We're excited to announce, "Sarcoma Stories" a new podcast SFA launching in November. Sarcoma Stories will be the only podcast highlighting the journey and experiences of people living and surviving sarcoma. Each episode will feature a guest sharing their sarcoma journey, resources they found valuable and more.





**SFA Has A New Career Opportunity Available** 

**Fundraising Events Manager** 

#### Giving Tuesday is Approaching

Giving Tuesday, a global day of generosity, will be held on December 3rd. It's a time to come together and support much-needed sarcoma research. This Giving Tuesday, we invite you to join us in our mission to improve the lives of those affected by sarcoma. Your contribution, no matter the size, will support a 2025 research grant. Stay tuned for more information on how you can participate in Giving Tuesday and help us make a lasting impact.





# Calling all Federal Employees and Retirees, and all Maryland State Employees and Retirees!

The Combined Federal Campaign (CFC) and Maryland Charity Campaign (MCC) annual charitable workplace giving programs have begun, and SFA is honored to be an eligible charity! Consider including SFA in your pledge this year and help fuel our work in funding translational research to move closer to finding a cure for sarcoma. Every dollar makes a difference!

**CFC:** Get started at the official CFC giving site givecfc.org/ SFA's CFC # is: 57785.

**MCC:** Get started at the official MCC site at mcc.maryland.gov/ SFA's EIN # is: 52-2275294.

## RACE TO CURE SARCOMA ROUNDUP



Take a look at some great moments captured at our recent Race to Cure Sarcoma events!

Thank you to everyone who came out and helped raise awareness for sarcoma and supported RTCS and Sarcoma Foundation of America. Together, we're making a difference for those affected by sarcoma!







RTCS PHILLY PHOTOS

RTCS SAN DIEGO PHOTOS RTCS CHICAGO PHOTOS

#### **REMAINING 2024 DATES**

Denver - October 26

Tampa - November 2

Nashville (Virtual) - November 2

#### **SAVE THE DATE FOR 2025**

Austin - 3/22/25

Washington D.C. - 7/19/25

Atlanta - 4/5/25

Louisville - 8/9/25

South Florida - 5/17/25

Philadelphia - 9/13/25

Boston - 4/13/25 San Diego - 9/20/25

New York - 4/26/25 Chicago - 9/27/25

San Francisco - 5/3/25 New Jersey - 10/5/25

Cleveland - 6/21/25 Los Angeles - 11/9/25

Milwaukee - 7/12/25 Denver - 10/25/25

National Virtual - 7/19/25 Tampa - 11/1/25

#### Locations and Dates are Subject to Change

**Unsubscribe** 

www.curesarcoma.org

9899 Main St Ste 204 Damascus, MD 20872