

### We are Grateful for Your Support

At a recent group dinner, I was discussing a project that SFA is interested in launching that would include collaboration with other sarcoma organizations. While discussing, someone in the group asked why SFA would lead this project. I paused for a moment, somewhat surprised by the question. I quickly responded, "It benefits patients. People diagnosed and living with sarcoma will benefit."

Thinking on this interaction later, it occurred to me why I was surprised by the questionbecause our work and partnerships have never been about SFA. SFA was founded 23 years ago to fulfill unmet needs in sarcoma. So, whether we are funding research, educating and supporting patients, advocating on their behalf on Capitol Hill, generating awareness, or simply bringing the community together through our races, we are *always* driven by how our work will benefit people diagnosed with sarcoma. That is why SFA exists and that will continue to be our north star, our compass, our "why."

I often tell people SFA is simply a conduit. An organization that exists as a tool for the community to better the outcomes for people of all ages and subtypes living with a sarcoma diagnosis. SFA's work, and your support of our work, is on behalf of the sarcoma community and for the benefit of the sarcoma community. From our Founders to our Board Members, who have all been personally touched by sarcoma, it has never been about SFA the organization. But rather, how our work can improve outcomes for those impacted by sarcoma. In that way, when you engage with and support SFA, you are directly affecting people diagnosed with sarcoma.

We realize that finding a cure for sarcoma is a marathon, not a sprint. But we look forward to the day that SFA is out of business because people are no longer dying of sarcoma. Until that day comes, thank you for standing by us, supporting us, and sharing our mission. We are grateful for you.

I hope you have a wonderful Thanksgiving shared with family, friends, and the people who are important to you.

Branch

### **Research Roundup**

by Dean Frohlich, PhD

The first study that I would like to highlight this is month is titled "<u>Phase II trial of CDK4/6</u> inhibitor palbociclib in advanced sarcoma based on mRNA expression of CDK4/CDKN2A," This paper presents results from a single-arm, phase II trial in advanced sarcomas other than WD/DD-LPS and indicates that Palbociclib, a drug that specifically inhibits proteins called cyclin-dependent kinases 4 and 6 (CDK4/CDK6), has activity in tumors demonstrated to express *CDK4* and another protein called *CDKN2A*. The study demonstrates a promising median progression free survival and overall survival in heavily pretreated patients. These results indicate that CDK4/6 inhibitors may have a role in the treatment of advanced sarcoma patients whose tumors overexpress CDK4.

Next, I would like to highlight an analysis of patients with advanced soft tissue sarcoma, "<u>Sex-Dependent Prognosis of Patients with Advanced Soft Tissue Sarcoma</u>." The results of this study indicate that male patients may have better prognosis across histologic and molecular sarcoma subgroups than female patients. If confirmed, these results may have implications in prognostic stratification, treatment tailoring for patients, and clinical trial design.

Lastly, is a paper entitled "The interplay between neoantigens and immune cells in sarcomas treated with checkpoint inhibition." This study investigated the variables of the immune system that influence immune checkpoint inhibition (ICI) therapy resistance or immune escape. Tumors can apply "brakes" to the body's immune system, which is then not able to attack the tumor. ICI therapy allows the brakes to be released allowing the immune system to attack the tumor again. The investigators analyzed the tumors of 31 sarcoma patients treated with a specific ICI called pembrolizumab. They then used methods to investigate key immune properties, such as neoantigens (a new protein that occurs when a mutation occurs in tumor DNA) and the immune cells in the tumor. The results suggest that high quality neoantigens with specific immune cells are markers of progression-free survival (PFS). These results can inform future trials that may lead to improved outcomes for sarcoma patients treated with ICI.

### **Clinical Trials Corner**

by Kristi Oristian, PhD

This month SFA is highlighting <u>ChonDRAgon</u>, a Phase II study for adults ages 18 to 85 who have unresectable (inoperable) or metastatic conventional chondrosarcoma who have experienced progression of their tumor within 6 months prior to screening.

Patients enrolled in this study will be randomized to receive the trial medicine or a placebo control. The trial medicine, INBRX-109, is an antibody that binds to and activates a protein called DR5 (Death Receptor 5) which works within the body's own pathways to eliminate damaged or cancerous cells. If a patient is assigned to the placebo control group, and experiences progression of their tumor, they will be given the opportunity to cross over to the INBRX-109 group. Both groups will receive their treatment (or placebo) in the form of an IV infusion once every three weeks.

This study will help doctors determine if the medicine is an effective treatment option for patients with conventional chondrosarcoma. Patients interested in this study should review these criteria with their doctor. To learn more about this study, patients can talk to their doctor, contact the investigator at the <u>site</u> nearest you or your primary treatment center, or contact the <u>study sponsor</u>.

#### SFA Accepting 2024 Research Grant 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 submission deadline is 11:59 p.m. ET on February 1, 2024.

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 supporting research within the performance period.

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 SFA Grant Program aims to encourage research that results in improved therapeutic options for sarcoma patients. The SFA encourages applications in all areas of sarcoma research.

For more information or to apply, go to <u>https://www.curesarcoma.org/sarcoma-research/sfa-research-grants/</u>.

### A Journey of Resilience: Natalie's Story of Care and Advocacy in the Face of Pediatric Sarcoma



In recognition of National Family Caregivers Month, we are honored to spotlight a truly resilient caregiver, Natalie, who has navigated a tumultuous journey filled with challenges, triumphs, and ceaseless love and care for her son, Sage. A warrior in his own right, Sage battled rhabdomyosarcoma with the unwavering support of his family. He is now NED and learning to be a kid again.

For Natalie, the journey was a whirlwind of 66 weeks filled with frontline treatments, maintenance phases, and a rollercoaster of emotions. Natalie opened up about the trials they faced, sharing the raw and real aspects of being a caregiver. The physical distance from the hospital, the toll of treatments on little Sage, and the constant navigation through a labyrinth of insurance challenges were just a few of the hurdles they encountered.

Despite the hardship, Natalie found rays of hope and resilience. She spoke fondly of the times when Sage's hair began to grow back, a symbolic milestone that brought mixed emotions as they navigated the world, trying to balance normalcy with the constant underlying fragility of Sage's health.

Natalie's advocacy didn't stop at personal caregiving. With a passionate spirit, she cofounded "Chasing Rainbows," a non-profit focusing on supporting parents' mental health during their children's cancer treatments. The organization embodies Natalie's vision of providing a pillar of support for parents, ensuring they don't feel lost or alone in the tumultuous storm of pediatric cancer.

Natalie's story is a testament to the complexities and challenges caregivers face, emphasizing the need for more comprehensive support systems, mental health resources, and a community that understands and empathizes with the caregiver's journey.

Join us in celebrating the unwavering spirits of caregivers like Natalie, whose stories inspire us, reminding us of the incredible resilience and strength within the human spirit.

### **SFA Education Session Announcement**



Education Session The Sarcoma Journey Wednesday November 29, 2023

## from the Patient and Caregiver Perspective

A sarcoma diagnosis is devastating and imposes a significant burden on patients and caregivers, impacting all areas of their life. Patients often have no awareness of sarcoma prior to diagnosis; diagnosis can take years, and when diagnosed, patients often find a lack of treatment options and resources. Patients are encouraged to seek treatment with sarcoma specialists at sarcoma centers but often must travel long distances to access these centers, creating financial and other burdens on the patient. In many cases, due to its rarity, patients encounter a medical community that lacks knowledge about the disease.

In this session, patients and caregivers will share their journey with sarcoma diagnosis, treatments, and clinical trials, the challenges associated with being diagnosed with a rare cancer, and the resources needed to support their sarcoma journey. SFA honors National Family Caregivers Month and recognizes the unique role that caregivers play in each sarcoma story.

Register at the link below to join the discussion and submit any questions you have in advance. You can also submit questions through the Q&A feature during the event.



# **SFA News**

## **Putts for Ped**

The 17th Annual Putts for Ped event was a resounding success, drawing over 75 golfers to a nearly sold-out venue. Featuring a competitive putting contest, an exciting hole-in-one competition, and a raffle with over 70 items, the day held special significance as it honored the memory of Michael John Pedrick, with his family in attendance. The favorable weather added to the overall enjoyment, and a buffet dinner capped off the day by awarding prizes to the top golf teams, creating a vibrant atmosphere of camaraderie and support for a meaningful cause. The event celebrated the love of golf and highlighted the community's commitment to honoring a cherished individual and making Putts for Ped a memorable and impactful annual tradition.

### **Marine Corps Marathon Recap**



We want to thank and congratulate all SFA Marine Corps Marathon team members who ran on our team on October 29th! You showed amazing spirit, endurance, and dedication! You also helped to raise \$37,000 for sarcoma research. We are so proud of you and grateful for your support. You can read about all of the team members <u>here</u>.

### Save the Date for Giving Tuesday!



While #SFAGivingTuesday happens every Tuesday, the annual celebration of generosity will happen on **November 28, 2023**. Consider contributing to SFA on Giving Tuesday as we join together as a community to change the outcomes for people diagnosed with sarcoma. Our goal for 2023 #GivingTuesday is to raise **\$50,000**. And this year, you can amplify your impact – thanks to a generous donor, **\$25,000 of the funds raised will be matched**! Your generous donation can lead to over **\$75,000 raised** to advance the research needed to find improved treatments and a cure for sarcoma. In honor of everyone who supports this important initiative, your gift will go toward funding the 2024 Giving Tuesday Research Grant, funding translational research that will lead to new therapies and bring us closer to a cure.

Whether you donate to SFA on Giving Tuesday, promote this event and our mission through your social circles or start your own SFA fundraising campaign, please know that SFA and the sarcoma community are grateful for your support.

Don't want to wait to contribute? You can make your donation today.

### Send a Gift of Life for the Holidays

Celebrate the giving season by making a **holiday donation** in honor or memory of a loved one, friend, or colleague. By giving a gift through SFA, those who receive your best wishes will know your commitment to helping SFA fund lifesaving research, educate patients about the latest research, grow much-needed awareness, and provide hope to the sarcoma community.

What makes this holiday donation even more special is that this year's Holiday Cards feature the winning artwork from SFA's Sarcoma Awareness Month Children's Artwork Competition! Ivy and Caleb are both young artists whose lives have been touched by sarcoma. Not only is their artwork inspirational, but also the stories behind their artwork.





Ivy, 10, from California, lost a friend to sarcoma and started raising funds for the Sarcoma Foundation of America. Caleb, 9, from Virginia, lost his grandpa to sarcoma in 2018 when he was only 4.

**Donate \$25 or more, and these unique Giving Cards will be mailed to the recipient, in memory or in honor of the donation in their name.** (*The amount of your gift will not be provided.*) Please donate early to ensure your card arrives in a timely manner.

If you would like to give in honor or memory of more than one person, please email a recipient list and donation amounts to <u>development@curesarcoma.org</u>, and we will charge one credit card amount for all combined recipients.

Thank you!

### **Public Policy Committee Coming in 2024**

In the first quarter of 2024, SFA will convene a public policy committee to focus and advise on policy initiatives at the state and federal levels. The committee will provide strategic input and guidance in setting a public policy agenda to support the needs of sarcoma patients. They will plan and organize Sarcoma Advocacy Day during Sarcoma Awareness Month and represent SFA on Capitol Hill.

### Are you a Federal or Maryland State Employee or Retiree?

SFA is honored to be an eligible charity in the annual charitable workplace giving programs of the Combined Federal Campaign (CFC) and Maryland Charity Campaign (MCC) for Federal and State employees! 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.

**Federal employees:** Get started at the official CFC giving site: <u>givecfc.org/</u>. SFA's CFC # is 57785. The CFC period ends **January 15, 2024**.

**Maryland State employees:** Get started at the official MCC site at <u>mcc.maryland.gov/</u>. You'll be asked to provide SFA's EIN number, which is 52-2275294. The MCC period ends **December 11, 2023**.

Every dollar makes a difference! The heart of our mission is research and donors like you have made us the leading sarcoma research and patient advocacy organization in the country.





Los Angeles - November 19, 2023 REGISTER

### Denver





### Tampa





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