



Happy New Year and Thank You

by Brandi Felser, CEO

As the new year begins, I want to extend our gratitude to you. Your commitment to our mission and those diagnosed with sarcoma continues to inspire our work. We could not fulfill our mission without your support and partnership. You play a significant role in SFA's ability to fund research, advocate on behalf of the sarcoma community on Capitol Hill, provide education and resources to support sarcoma patients, and to build awareness so others can learn about and join our shared goal: to end sarcoma for everyone.

This past year, I tried to attend all our 18 Race to Cure Sarcoma events across the country. I was humbled by the people I met. People honoring their loved ones by raising funds for research or participating to increase awareness of the disease. People celebrating their survivorship, patients connecting with others who understand their journey and challenges; it was inspiring and impactful. They are a reminder to me and the SFA staff about the "why" of our organization. If you have not participated in an RTCS event, I encourage you to register for one in 2023. It is truly a sarcoma community gathering bringing people together for our shared cause.

In 2022, the organization went through a strategic planning process. Evaluating our strengths and weaknesses, identifying gaps in the sarcoma space, and planning the future for SFA. We reached out to the community, our Board of Directors, Medical Advisory Board, and other partners to tell us what we do well, what we don't, and where we should focus our efforts.

It was a long process, but what we learned is that SFA should stay the course in all components of our mission and vision. We learned we are meeting the need, but it is time to do more. Moving forward in our strategic planning, we will expand and enhance our research funding and engage in strategic partnerships to find new therapies. We will further develop ways to increase awareness about the disease and continue to lead the community in advocacy efforts. In our strategic plan, we challenge SFA to significantly expand our reach while keeping the “why” at the core of our efforts.

At this time of year, many people make resolutions to read more books, learn a new language, exercise more, or focus on better health. Everyone at SFA is amplifying our resolve on behalf of those diagnosed with sarcoma. This year, we will work to grow awareness, fund even more research, and provide resources to patients to empower them to manage their care. We want to bring the community together, partner with other organizations, and enhance ways to support patients. I know you join us in this.

I invite you to reach out to us with your ideas, thoughts, and sarcoma experiences. Let us know what would help your sarcoma experience, share your story and why you support SFA. Also, follow us on social media and comment so we can share your story, your challenges with others.

On behalf of all of us at SFA, we wish you a 2023 filled with peace and good health.

Happy New Year and we look forward to our continued partnership.

Brandi

Sarcoma Patient Journey Is Focus of Next Education Session

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.

Join SFA on Rare Disease Day, Tuesday, February 28, 2023, at 6:00 pm EST, for a panel discussion with patients who will share their personal experience with sarcoma diagnosis, treatments, clinical trials, the challenges associated with being diagnosed with a rare cancer, and resources needed to more easily navigate their sarcoma journey.

Register here:

https://us06web.zoom.us/webinar/register/WN_05W2SI3HSsyeTg3wtqizyg

Did you miss SFA's "Promising Research and Therapies in Sarcoma" session on December 7? You can watch (or re-watch) this enlightening program! bit.ly/3Wv4uzq

Research Roundup

by Dean Frohlich, PhD

To start the new year, I would like to highlight a recent publication investigating the immune environment of bone sarcomas and highlight the recent Food and Drug Administration (FDA) approval of a drug for the treatment of alveolar soft part sarcoma.

Bone sarcomas (Ewing sarcoma and osteosarcoma) are rare. Two hundred cases of Ewing sarcoma and 600 cases of osteosarcoma are reported per year in the United States, mostly in adolescents. Despite advances in immunotherapy for other cancers, treatment of bone sarcomas with immunotherapy has not been effective. In [“Ewing Sarcoma and Osteosarcoma Have Distinct Immune Signatures and Intercellular Communication Networks,”](#) Cillio et.al. describe their research into the immune cell composition of these two sarcoma types. What they find are both similarities and differences that will help inform future studies on how to treat bone cancers with immune therapies.

FDA approval of treatments for sarcoma does not come as often as we hope, so I would like to highlight that on December 9, 2022, the FDA approved atezolizumab (Tecentriq, Genentech, Inc.) for adult and pediatric patients two years of age and older with unresectable or metastatic alveolar soft part sarcoma (ASPS). ASPS is a very rare sarcoma that usually starts in the lower body, but can also begin in other parts of the body, including the arms, head, or neck. It is difficult to diagnose in the early stages because it starts as a painless lump and has often spread to other places in the body, especially the lungs.

Survivor Spotlight

Sarcoma Survivor Credits “Luck” and Outstanding Care for Cancer-free Status

Megan Gedemer of Milwaukee, Wisc., was diagnosed with a tennis ball-sized synovial sarcoma in her shoulder at twenty years old. This news came after five agonizing years of misdiagnoses including bad posture. “I had terrible range of motion, social events were becoming miserable, and nothing was worse than the pain I was in,” says Megan. “I had not slept through the night in years.”

Strange as it may seem, Megan was “excited” to receive her diagnosis. She explains that after she learned about her sarcoma “no one, including myself, could imply I was faking it, being dramatic, or seeking pain meds, anymore.”

When her treatment began, she was praised for her positive attitude and determination. Her shock and sadness coexisted with one feeling even greater than all: excitement. She was also relieved to learn that she was not “the biggest cry baby in the world.”

She first turned to the internet and Instagram to learn as much as possible about her diagnosis and interact with sarcoma survivors. She has messaged and been messaged “by patients all over the world seeking advice or just a friend.” Her



strongest connection was with Miriam who was diagnosed six months after she was, had the same subtype and was the same age. “I know from experience that finding out someone with a similar diagnosis is alive and well is so exciting. I know in my heart I gave her hope that it (the treatment) might work for her too,” says Megan. While both women were treated with the same chemotherapies, Ifosfomide and Doxorubicin, Miriam died a year later when sarcoma spread to her lungs. Every time Megan sees an Instagram post announcing the death of one of her pen pals, her thoughts turn to Miriam. “Miriam will always stick with me the most, because she was the first,” she says.

She has nothing but praise for her medical team at Froedtert & The Medical College of Wisconsin, but also has an interesting perspective on her sarcoma journey. “I have the best team anyone could ask for, and I do not wish to discredit any of their skill and heart,” she says. “But no amount of care and compassion can always save you from sarcoma. I feel that what saved me was luck. I was lucky I didn’t need to travel hours to get the best care possible. I was lucky that in the 5-7 years I had this tumor, it didn’t spread. I was lucky my tumor was located where it could be removed. I am lucky I still have an arm. And I am lucky that the one treatment option I had available worked to kill the cancer cells in my body, and not me along with it. Not everyone gets that luck.”

Megan believes that no sarcoma patient should need “luck” to survive, and that raising awareness for early detection is key. She is now over three years cancer-free and chooses to “own” her survivorship. “Sometimes I just want to leave sarcoma in the past, but I can’t,” she says. She learned that the chemotherapies used for her treatment, Doxorubicin and Ifosphomide, were developed in 1974 and 1987 respectively – the same years the Kodak camera and the Rubik’s cube hit store shelves. These treatments only have a 66% cure rate. “We didn’t stop there with breast cancer survival rates or cameras and toys for that matter either,” says Megan. “So, we shouldn’t stop there with sarcoma. We have work to do – through funding research and raising awareness for early detection, it can be done.”

NFL Star Named SFA Ambassador



We are excited to announce New York Jets’ John Franklin-Myers has been named Ambassador for SFA and the sarcoma community.

Franklin-Myers has a personal connection to the sarcoma community. The defensive end supports SFA in memory of his grandfather Billy Ray-Myers who died of sarcoma in

2011. Franklin-Myers’ past support of SFA includes his participation in the National Football League’s My Cause, My Cleats program during which he had a pair of custom cleats designed to reflect his support of SFA and auctioned them to benefit the foundation. In addition, he formed a team to participate in the 2022 New Jersey Race for the Cure. Both activities successfully built awareness of SFA’s mission and assisted with raising funds for sarcoma research grants.

“Being the voice of SFA is huge. I also learned that many who work there have lost a loved one to sarcoma,” says Franklin-Myers. “I want to raise awareness, and this is the best way of going about it.”

“The Foundation is thrilled to continue working with John in this official capacity. His ability to spotlight the importance of research for a cure is invaluable,” says SFA Chief Executive Officer Brandi Felser. “John’s support of SFA is genuinely

heartfelt and inspired by his desire to prevent other families from enduring the loss of a loved one to sarcoma.”

Dates and Locations for Some 2023 Races Are Set

Plans are underway for SFA's popular and much-anticipated Race to Cure Sarcoma (RTCS) events. As of the publication of this newsletter, nine RTCS's have confirmed dates and locations. They are:

- **Atlanta** April 15, 2023 [REGISTER!](#)
- **San Francisco** May 6, 2023 REGISTRATION OPENING SOON
- **Cleveland** June 24, 2023 [REGISTER!](#)
- **Milwaukee** July 8, 2023 [REGISTER!](#)
- **Louisville** August 25, 2023 [REGISTER!](#)
- **New Jersey** August 6, 2023 REGISTRATION OPENING SOON
- **San Diego** September 9, 2023 [REGISTER!](#)
- **St. Louis** October 8, 2023 [REGISTER!](#)
- **Denver** October 21, 2023 [REGISTER!](#)

We encourage you to take part in an RTCS event. Whether you run, walk or make a donation from the sidelines, your support makes all the difference in funding leading edge research to find a cure!



Race **TO** *Cure*
SARCOMA

SARCOMA FOUNDATION OF AMERICA

SAVE THE DATE FOR 2023!

Atlanta - April 15
Boston - April
Chicago - October
Cleveland - June 24
Denver - October 21
Los Angeles - November
Louisville - August 26
Miami - June
Milwaukee - July 8
Nashville - October

New Jersey - August 6
New York - September
Philadelphia - September
San Diego - September 9
San Francisco - May 6
Seattle - May
St. Louis - October 8
Tampa - November
Washington, D.C. - July

SFA News

SFA Fundraiser Art Becomes Holiday Standout



Creative fans of gamer Technoblade assembled an art piece that was auctioned to benefit SFA. Members of the Crane Project folded paper cranes to create the magical artwork at left.

@Cambria88 bid \$420 and took home this homage to the popular gamer and influencer. They placed a special touch on the creation by adding holiday lights which added a beautiful glow for all to see. Said the buyer, "The care, love and passion put into this piece is obvious. Plus money went to the Sarcoma Foundation of America in Technoblade's memory."

Book Club Is Well-Read in Generosity

Readers rock! Rose Bortnick of Gaithersburg, Md., recently stopped by the SFA office in Damascus, Md., to drop off check donations from her book club's holiday party.

These funds will go towards the total amount raised by her Race to Cure Sarcoma Richmond "Team Amy's A Squad." The team was formed in memory of Rose's daughter Amy Bortnick who passed away from sarcoma in 2021.



Our Contact Information

Sarcoma Foundation of America
9899 Main Street Suite 204
Damascus, MD 20872
301-253-8687
<http://www.curesarcoma.org>

Follow Us on Social Media!

