



Sarcoma Spotlight

March 2023



Gala Set for September 19 in NYC

Start making plans to attend the SFA 21st annual Stand Up to Sarcoma Gala on September 19, 2023, at Capitale in New York City. Join us as we gather to honor those who are leaving their mark on the sarcoma research and treatment landscape.

The Stand Up to Sarcoma Gala is SFA's signature event honoring recipients of SFA's four international awards – the Courage Award, the Nobility in Science Award, the Vision of Hope Award, and the Compassionate Care Award.

Courage Award – honoring outstanding sarcoma advocates

Nobility in Science Award – recognizing researchers or doctors investigating groundbreaking sarcoma research

Vision of Hope Award – honoring an organization or person in recognition of the honoree's efforts to advance the care and treatment of sarcoma, bringing hope to patients and survivors

Compassionate Care Award – recognizing a patient navigator for his or her outstanding contributions to patient care, support, and education

The evening will also feature live entertainment, tasty food and libations, and an auction of exciting goodies. It's also a unique opportunity to meet and mingle with others who have been affected by sarcoma, those who are working to find treatments, and people dedicated to assisting patients during their sarcoma journey.

SFA relies on the support of donors and friends to advance our work -- funding research to find new and better therapies and, ultimately, the cure for sarcoma. We hope you will join the SFA community to honor outstanding and inspirational leaders who proudly represent SFA's important work while raising money for much-needed research.

Visit www.curesarcoma.org/nyccelebration for information on ticket purchases and sponsorship opportunities.

Research Roundup

by Dean Frohlich, PhD

This month, I would like to share with you two recently published papers that reflect the progress being made in the sarcoma research arena. Nonmetastatic Rhabdomyosarcoma in Children and Adolescents: Overall Results of the European Pediatric Soft Tissue Sarcoma Study Group RMS2005 Study is an update of an international study in which patients were allocated to four different groups: low risk (LR), standard risk (SR), high risk (HR), and very high risk (VHR) and indicates that 80% of children with nonmetastatic rhabdomyosarcoma can be long-term survivors. The study also emphasizes that early detection is key to patient outcomes.

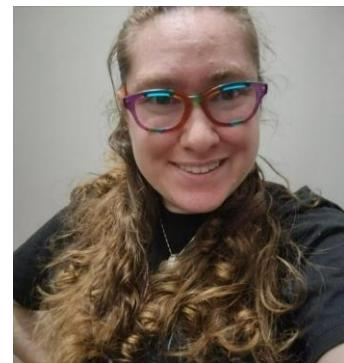
Genomic Patterns of Malignant Peripheral Nerve Sheath Tumor (MPNST) Evolution Correlate with Clinical Outcome and Are Detectable in Cell-Free DNA provides a multifaceted analysis of 95 malignant peripheral nerve sheath tumors. In doing so, the investigators have identified genomic evolutionary pathways that allow for subclassification of MPNSTs that correlate with prognosis and may lead to distinct treatments. Additionally, they have demonstrated the use of cell-free DNA as a potential way to identify MPNSTs earlier and thus improve outcomes.

Sarcoma Journey Spotlight

Sarcoma Survivor Champions Education and Advocacy

Aylat Lifshitz of Boston, Mass., began experiencing headaches and neurological symptoms between the spring and summer of 2019. Doctors initially dismissed her symptoms, but in August 2019, her health issues were finally taken seriously. An MRI was ordered, which revealed a brain metastase that led to a diagnosis of angiosarcoma. At 24 years old, Aylat began her sarcoma journey.

After receiving the news about Aylat's sarcoma diagnosis, it was another month until doctors



discovered the primary tumor on her heart and she immediately began treatment. She underwent nine rounds of systemic chemotherapy and had three separate radiations: Stereotactic Body Radiation Therapy (SBRT) to her brain resection cavity, two months of Proton Radiation to her mitral valve, and another SBRT to one of her spine metastases after chemotherapy ended. "Treatment had a lot of

ups and downs, and I had multiple dose reductions because of how my body was responding to the chemotherapy treatments. But overall, it was effective for my disease, and I have been NED (No Evidence of Disease) since July 2020," says Aylat, a special education teacher.

Through the difficult and intensive treatment, Aylat had a strong support system, including friends and family who were by her side throughout her journey. Unfortunately, the COVID pandemic did make family in-person visits challenging after her first months of treatment.

She also received therapy to help her cope with the emotions of having cancer at a young age. "I (believe) everyone diagnosed with cancer, not just sarcoma, can benefit from a therapist," says Aylat. She also finds solace in Adolescent and Young Adult (AYA) circles on social media and engaging with organizations that provide art and writing workshops and other social and emotional support for AYA patients. In addition, Aylat has found her sense of humor to be a valuable coping mechanism that helped her deal with the emotional toll of her diagnosis. "Another thing that I really gravitate towards is dark humor, which can be off-putting to some who have not experienced cancer, but for me it has been really helpful," she says.

For those newly diagnosed with sarcoma, Aylat advises getting a second opinion. "You can always get a second, third or fourth opinion, and it will not impact what your doctor thinks of you," she says. Aylat also stresses the importance of being treated at a sarcoma center, as the expertise of the staff and resources can significantly impact a patient's treatment journey. She also recommends seeking mental health support. "Don't be afraid to seek out emotional support, whether that's from the psycho-oncology team at a treatment center or a private practice. (It's) a space to process your emotions about this disease while not being afraid to impact the emotional state of someone around you," Aylat says.

Aylat's journey with sarcoma has taught her not only about the healthcare system, but also about the power of sarcoma advocacy, awareness and education. She is now a champion for improving the lives of cancer and rare disease patients through her advocacy efforts. "I have started to learn how to advocate for myself, both on a personal level, such as calling my doctors when I am concerned about a symptom," she says. "And on a larger level I share my story with others and speak to policymakers to try to influence change for cancer patients and rare disease patients like me."

SFA News

How Did They Do?

As a follow up to the February 2023 issue of Sarcoma Spotlight, we thought we would provide an update on the successes of some of our fundraising story subjects.



The Lilly Pulitzer North Hills, NC, store report their February 25, 2023 event netted \$900 to benefit SFA. The event was held in memory of Mary Grainger of Raleigh, NC, who passed away from sarcoma and was a long-time customer of Lilly Pulitzer, especially the North Hills store. Mary's friends and family posed for the picture at left.

In February, Jack Walsh of Christchurch, New Zealand, rowed his way to a \$2,000 USD donation to SFA. Jack did the fundraiser in honor of his cousin who is currently living with the disease and hopes the donations can further the mission to find cures and treatments for sarcoma.



Congrats and thanks to Doug Beck of Utah who completed his 30K Ski for Sarcoma fundraiser in early March. He raised over \$16,000 through individual donations and sponsorships in memory of his wife Peggy who passed away from sarcoma in July 2022. This extraordinary tribute was in honor of a brave lady who continued to enjoy her paddle boarding hobby despite the amputation of her arm. Doug is shown at left immediately after completing his ski fundraiser.

More Races Added to RTCS Calendar

Registration is open for many of SFA's much-anticipated Race to Cure Sarcoma (RTCS) events. See the latest information below.

- **Atlanta** April 15, 2023 [REGISTER!](#)
- **Boston** April 23, 2023 [REGISTER!](#)
- **San Francisco** May 6, 2023 [REGISTER!](#)
- **Seattle** May 13, 2023 [REGISTER!](#)
- **Cleveland** June 24, 2023 [REGISTER!](#)
- **Milwaukee** July 8, 2023 [REGISTER!](#)
- **Washington, DC** July 22, 2023 [REGISTER!](#)
- **National Virtual Race** July 22, 2023 [REGISTER!](#)
- **New Jersey** August 6, 2023 [REGISTER!](#)
- **Louisville** August 26, 2023 [REGISTER!](#)
- **Philadelphia** September 9, 2023 [REGISTER!](#)
- **San Diego** September 9, 2023 [REGISTER!](#)
- **St. Louis** October 8, 2023
- **Denver** October 21, 2023 [REGISTER!](#)
- **Los Angeles** November 19, 2023 [REGISTER!](#)

Take part in an RTCS event near you! 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!

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