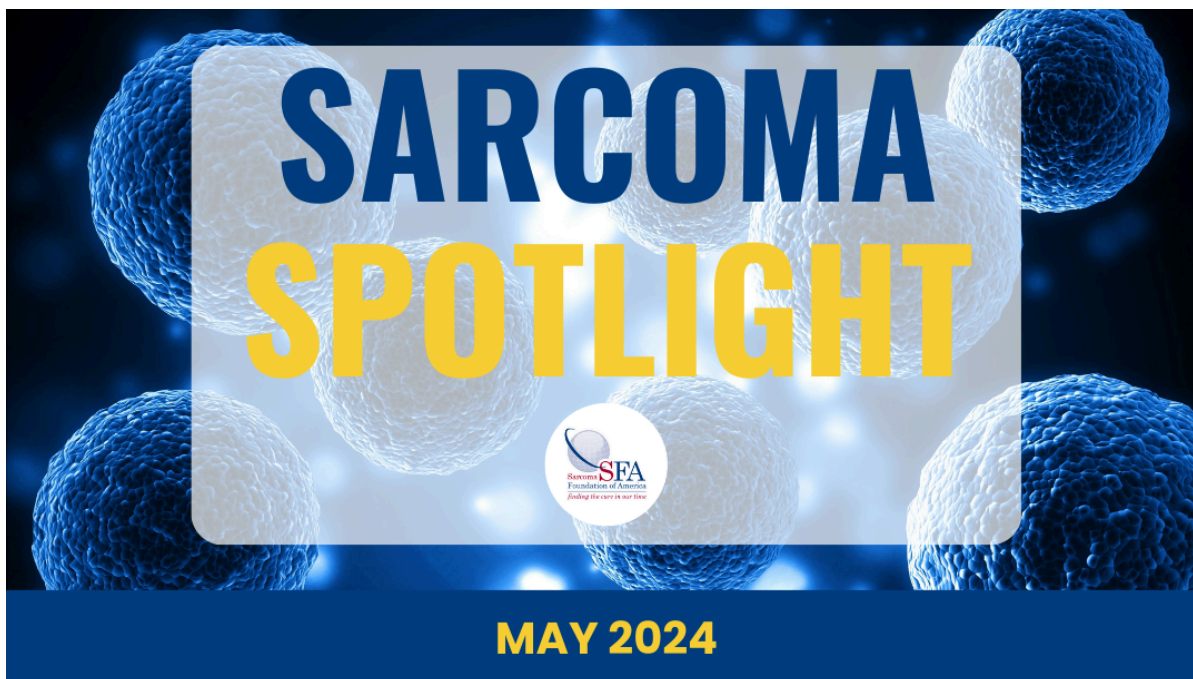


National Cancer Research Month, observed every May, provides a platform to raise awareness about the critical role research plays in enhancing our knowledge of sarcoma and developing more effective treatments for this rare form of cancer.



**HILL  
DAY**  
**INFORMATION  
SESSION  
WEBINAR**

**MAY 16<sup>TH</sup>  
4:00 PM ET**



## Join Us for a Sarcoma Hill Day Info Session Today at 4pm ET

Sarcoma Hill Day is scheduled for **July 18, 2024**. This event brings together sarcoma advocates from across the nation to educate Members of Congress about the challenges faced by the sarcoma community.

As a participant, you will have the unique opportunity to meet with elected officials and their staff to discuss issues that directly impact sarcoma patients, caregivers, and their families. This is your chance to share your stories, experiences, and concerns and to advocate for meaningful change in sarcoma treatment and research.

If you are interested in participating, join us for a webinar on **May 16 at 4:00 PM ET** to get more information and details. You do not have to be registered for Hill Day to participate in this webinar. We will provide a snapshot of the day, the process for appointments, and other details. This is a webinar meant to answer any questions about what participating in the Sarcoma Hill Day entails. A recording of the webinar will be shared with people who are unable to attend the event.

If you choose to participate in Hill Day, SFA will host further webinars to equip you with the knowledge and tools needed to effectively communicate with your representatives. We hope you will join us to make a difference for people affected by sarcoma.

**Register for the Sarcoma Hill Day 2024  
Info Session on Thursday, May 16th**

**Register for Hill Day 2024 on  
July 18th**

**REGISTER NOW**

**REGISTER NOW**

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## Research Roundup

by Dean Frohlich, PhD

The past month saw the publication of several impactful studies, five of which I am sharing today. The first two studies emphasize the growing importance of genome sequencing and identification of molecular targets. Current sarcoma subtype identification is based on a process called immunohistochemistry. This method of identification is often challenging even for experienced pathologists and involves identifying sarcoma subtypes using cell morphology and the presence of specific proteins expressed by tumor cells. Using genome sequencing and identifying molecular targets offers the potential to identify subtypes more precisely and easily, ultimately improving treatment.

The first study I'm sharing today illustrates how a technique known as whole-genome and whole-transcriptome sequencing (WGTS) can aid in tumor classification and patient treatment. In "[Comprehensive Genomic Profiling Alters Clinical Diagnoses in a Significant Fraction of Tumors Suspicious of Sarcoma](#)," the investigators used WGTS in routine diagnostics of 200 soft-tissue and bone tumors. Based on the WGTS results 7% (13/197) of the diagnoses were reclassified. In malignant tumors, the investigators found variants that were relevant to treatment in 15% of cases. This study indicates that WGTS can help clarify tumor classification and help identify molecular targets for treatment for a significant number of sarcoma patients.

A second important study emerging this month also highlights how molecular profiling can provide more accurate diagnosis and tailored treatments for patients with rare tumors. This study focused on embryonal rhabdomyosarcoma (ERMS). Mutations in the NF1 tumor suppressor gene are the second most common genetic event in ERMS. NF1 alterations also are also responsible for the pathogenesis of most malignant triton tumors (MTT).

In the study, the researchers analyzed the clinicopathologic and molecular features of NF1-mutant compared to NF1-associated to better understand their pathogenesis. The researchers found that although both tumors can have similar morphologic and clinical features, their genomic landscapes are different. This distinction can be helpful for making a diagnosis in challenging cases. They found that patients with NF1-mutant RMS had better outcomes than patients with NF1-associated MTT. The 5-year survival rate was 70% for patients with NF1-mutant RMS compared to 33% for patients with NF1-associated MTT.

The next study of note identified a new potential therapeutic avenue for desmoplastic small round cell tumors (DSRCT). DSRCT are a type of aggressive, pediatric sarcoma characterized by the EWSR1:WT1 fusion oncogene and with a 5-year survival rate of 15-25%. In this study, "[Comprehensive Transcriptomic Analysis of EWSR1:WT1 Targets Identifies CDK4/6 Inhibitors as an Effective Therapy for Desmoplastic Small Round Cell Tumors](#)," investigators determined that the fusion stimulated tumor cell growth in a specific cell pathway called the cyclin D-CDK4/6-RB axis. Additional studies indicated that treatment with the CDK4/6 inhibitor Palbociclib reduced cell growth in two DSRCT models. Additional

studies need to be conducted, but this study supports clinical investigation of Palbociclib for treating DSRCT.

The fourth study I'm discussing this month also involves a new possible therapeutic strategy, this time for alveolar soft part sarcoma (ASPS), a sarcoma known to be driven by the ASPSCR1::TFE3 fusion. In [ASPSCR1::TFE3 Drives Alveolar Soft Part Sarcoma by Inducing Targetable Transcriptional Programs](#), the investigators strive to gain a better understanding of the mechanisms by which the fusion drives cancer growth and help identify potential therapeutic targets. They determined that the ASPSCR1:TFE3 fusion regulated essential cell programs involved in cell proliferation, angiogenesis, and mitochondrial biology. They also found that the fusion increased cell proliferation by increasing levels of a protein called cyclin D1. They found that inhibition of cyclin D1 signaling decreased cell growth and when combined with inhibition of another protein called CDK4/6, it led to tumor growth in a model of ASPS. These results indicate a possible therapeutic strategy for ASPS.

The last study I'm discussing this month identifies a specific protein called HER2 as a target for future therapies for sarcoma. The study, "[Autologous HER2-specific CAR T cells after lymphodepletion for advanced sarcoma: a phase 1 trial](#)," is a prospective, interventional phase 1 study for patients with advanced sarcoma. Each patient had a type of white blood cell called a T cell removed from their bodies. The T cells were then modified to be able to attach to HER2, becoming HER2 CAR T cells and were then infused back into the patients. This study had two objectives. The primary outcome was to assess the safety of one dose of HER2 CAR T cells. The secondary outcome was to determine if this process provoked any antitumor response. Thirteen patients were treated. HER2 CAR T cells expanded after 19 of 21 infusions. Most patients had some adverse effects with severity depending on the dosage. Antitumor activity was observed with clinical benefit in 50% of patients treated.

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## Clinical Trials Corner

by Kristi Oristian, PhD

In support of Women's Health Week, SFA is highlighting A Randomized Phase 2/3 [study](#) of Olaparib Plus Temozolomide Versus Investigator's Choice for the Treatment of Patients With Advanced Uterine Leiomyosarcoma After Progression on Prior Chemotherapy.

This study is for patients 18 years and older with histologically confirmed uterine leiomyosarcoma (uLMS) that is metastatic or locally advanced and surgically unresectable.

The study consists of two treatment arms. In the first arm, patients receive temozolomide and olaparib on days 1-7 of each cycle. In the second arm, patients receive trabectedin or pazopanib.

In both arms, cycles repeat every 21 days if tolerated, and the cancer does not progress. Patients will have imaging and blood draws to monitor their cancer.

Patients must have at least one measurable lesion (tumor). Eligibility requires prior progression on, or intolerance to, at least two prior types of systemic therapy for advanced uLMS, with one being an anthracycline. Patients may have had one study drug previously but not both. Additional inclusion and exclusion criteria apply. Your care team will know how to determine if you meet these criteria.

Patients interested in this study should talk to their care team or reach out to a [site](#) near you for additional information.

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## Running for the “coolest, funniest, friendliest human being ever” – Marli Ehrlich shares her story

Marli Ehrlich is a committee member who ran in the inaugural [Race to Cure Sarcoma South Florida](#) to honor her sister Jaclyn, who passed away in 2021 from Ewing sarcoma. Marli described Jaclyn as “a crazy good soccer player and the coolest, funniest, friendliest human being ever” whose memory still fills her with pride and inspiration.

Jaclyn’s cancer appeared in the fall of 2019. Jaclyn, a high school junior at the time, fell during a soccer game near her home in New Jersey. Thinking it was a torn muscle, she started seeing a physical therapist but kept on with her life as usual. A few weeks later, Jaclyn fell again, but was unable to stand afterwards. Her parents took her to a hospital in Philadelphia, where an x-ray revealed a tumor in her leg and diagnosed her with Ewing sarcoma.

Marli heard the news about her younger sister’s diagnosis while studying for a final exam at the University of Central Florida. “I had an exam the next day, and I wanted to be there as fast as possible. I texted Jaclyn saying ‘I’m getting on a plane five minutes ago,’ but Jaclyn told me, ‘don’t you dare miss that exam. Finish everything that you’ve worked toward, and do it for me. Then you can come home,’” Marli recalls.

Jaclyn’s treatment began with surgery to remove the tumor in her leg, and she also started chemotherapy. A follow-up medical visit found the cancer had metastasized to Jaclyn’s lungs. “It was a come and go cycle,” Marli explains. “Tumors would get smaller but then new spots would come up. That’s when she started doing clinical trials and radiation.”

[Read More.](#)

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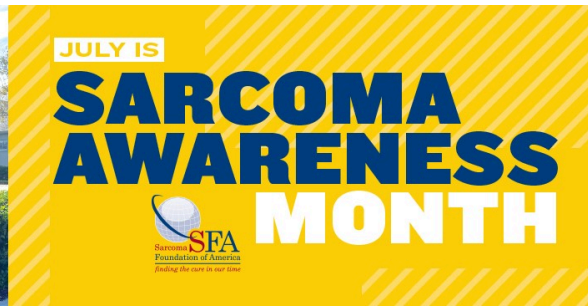
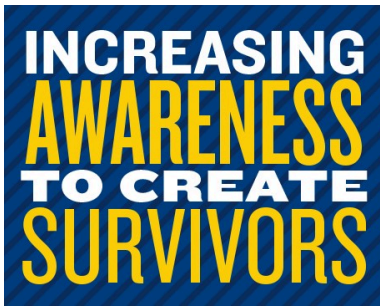
## SFA Shares Previous Educational Webinars for National Cancer Research Month

Sarcoma Foundation of America’s ongoing educational webinar series is a great resource for anyone interested in learning about sarcoma. These sessions bring together key stakeholders to discuss the leading treatments and developments of living with sarcoma or sarcoma research.

For National Cancer Research Month, SFA is highlighting recordings of some of our webinars that share how sarcoma research is leading to improved treatments and promising new therapeutic approaches. Watch them at the links below or look out for our next scheduled webinar, which will review findings from the American Society Clinical Oncology’s (ASCO) 2024 meeting, this June.

**Click the images below to watch the webinars.**





**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



## Pharos Athletic Club Raises Funds for Cancer Research at 2nd Annual Olympic Weightlifting Meet

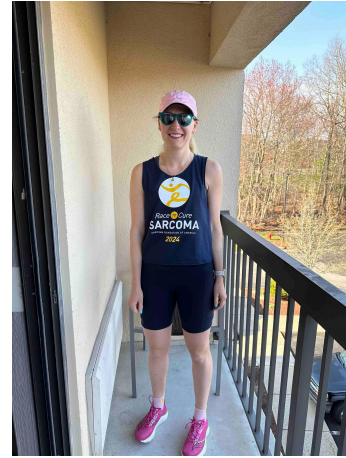
Pharos Athletic Club - Echo Park hosted its 2nd Annual Olympic Weightlifting Meet on Saturday, April 27th, raising funds for cancer research. The event, organized by cancer survivor and Pharos Athletic Club coach Robin Reader, showcased the strength and dedication of our members while supporting a vital cause.

We are incredibly grateful for the support and dedication shown by all participants and contributors in this event, which plays a crucial role in advancing cancer research.



## Boston Marathon

We may not have had an official team at the Boston Marathon this year, but SFA was proudly represented thanks to the amazing Mary Grace Manganolo! Inspired by a friend who survived sarcoma, Mary Grace ran the full 26.2 miles in 3 hours and 19 minutes. Thank you, Mary Grace, for bringing sarcoma awareness to such a major event.



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## Sarcoma Survivor Raises \$1,100 at Wedding



Brian Fugere, a sarcoma survivor and Sarcoma Foundation of America's 2009 Courage Award recipient, recently celebrated his wedding to his bride, Angie, in a heartwarming ceremony. During the wedding, the couple decided to dedicate their money dance to raise funds for a cause close to their hearts. Thanks to the generosity of their friends and family, Brian and Angie raised an impressive \$1,100 during their wedding celebration, showcasing their creativity and generosity in using their special day to give back to the sarcoma community and continuing Brian's inspiring journey as a sarcoma survivor dedicated to raising awareness and funds for sarcoma research.



## SFA Attends Rare Disease Spring Forum

by Dean Frohlich, PhD

The National Community Oncology Dispensing Association held their Spring Forum on April 3-5 in Dallas. I was privileged to participate on a panel titled, "Rare Disease in Focus: Medically Integrated Approaches and Impact on the Patient Journey." The panel discussed many topics regarding challenges in navigating rare malignancies with an emphasis on desmoid tumors. This included difficulties in navigating the healthcare system and diagnosis. Additionally, we discussed how medically integrated teams including physicians and pharmacists along with services provided by patient advocacy groups can improve patient



outcomes. We also discussed the value of patient education and the roles that each member of a medically integrated team and patient advocacy plays.

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## What Makes an Effective Sarcoma ‘Specialist Center’? New Research Has the Answers

SFA is proud to have contributed to a new research article to help guide patients and health care facilities understand what makes a sarcoma "specialist center". The paper, led by the Sarcoma Patient Advocacy Global Network (SPAGN), and includes SFA and sarcoma specialists and experts, outlines characteristics defining a sarcoma specialist center or network for sarcoma treatment.

SFA's [sarcoma specialty center criteria](#) (developed in partnership with patient advocacy organizations) acted as a starting platform for this paper. This paper will help both sarcoma patients identify centers for care and guide priorities for establishing effective care centers that can improve patient outcomes. SFA CEO Brandi Felser contributed to the paper, which [appears in the latest issue of \*Cancers\*](#).



## SFA Has New Career Opportunities Available

[Race to Cure Sarcoma Development Coordinator](#)

[Executive Office Coordinator](#)

[Finance Director](#)







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](#)



# EVENT PHOTOS



ATLANTA



SOUTH  
FLORIDA



BOSTON



NEW YORK  
CITY



## Race <sup>to</sup> Cure SARCOMA

SARCOMA FOUNDATION OF AMERICA

- [Seattle - June 22](#)
- [Cleveland - June 30](#)
- [Milwaukee - July 13](#)
- [Washington DC - July 20](#)
- [National Virtual - July 20](#)
- [Louisville - August 10](#)
- [Philadelphia - September 14](#)

- [San Diego - September 21](#)
- [Chicago - September 28](#)
- [New Jersey - October 6](#)
- [Los Angeles - October 12](#)
- [St Louis - October 12](#)
- [Denver - October 26](#)
- [Tampa - November 2](#)

### Our Contact Information

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- \*{{Organization Address}}\*
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- \*{{Organization Website}}\*

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