



SARCOMA SPOTLIGHT

FEBRUARY 2025

Rare Disease Day, observed annually on the last day of February, is a global movement dedicated to raising awareness for millions living with rare diseases. This Rare Disease Day, SFA reaffirms its commitment to the sarcoma community, recognizing that collaboration, research, and advocacy are crucial for advancing treatments and improving lives.

SFA Launches the Sarcoma Journey Survey Research Project

SFA has developed a large-scale survey to capture the lived experience of the people affected by sarcoma to advance research and drive advocacy efforts. The survey will gather data to add greater dimension of our understanding of the impacts of sarcoma to help expedite the process of getting more approved and less toxic treatments available to patients.

Your participation is critical to ensuring the patient voice and experience is included in the sarcoma landscape. Moreover, our ability to look across subtypes for common experiences, potential treatments, and impacts can greatly advance our knowledge about sarcoma.

We created this survey to understand the patient pathways and perceptions surrounding a sarcoma journey and will share the information collected with the broader sarcoma community to improve outcomes for patients with this rare cancer.

[Learn more](#) and contribute your voice to this important research.

IRB Protocol ID 0686

RESEARCH ROUNDUP

By Dean Frolich, PhD

This month I would like to highlight three studies. The first is a clinical study in Liposarcoma and the last two include potential treatments that have the potential to move into studies involving patients in the future.

In the first paper, "[Letetresgene Autoleucel in Advanced/Metastatic Myxoid/Round Cell Liposarcoma](#)," the researchers conducted a pilot trial of an immune therapy called adoptive T-cell therapy in which immune cells called T-cells are taken from the patient and genes that make receptors that bind to proteins that are specifically expressed on the tumor are delivered to the T-cells, allowing the T-cells to attack the tumor. In this case, the new genes code for a receptor that binds to a protein called New York esophageal squamous cell carcinoma 1 (NY-ESO-1) that is expressed on myxoid/round cell liposarcoma (MRCLS).

Patients that undergo adoptive T-cell therapy must undergo a lymphodepletion regimen which prepares the body for receiving modified T-cells. In this study, 10 patients were given a reduced-dose regimen (cohort 1) and 10 patients were given the standard regimen (cohort 2). The primary end point of overall response rate (ORR) was 20% and 40%, the median duration of response was 5.3 months and 7.5 months, and median progression-free survival was 5.4 months and 8.7 months in cohorts 1 and 2, respectively.

Further studies need to be conducted, but this study indicates that lete-cel may be a promising treatment for advance metastatic myxoid/round cell liposarcoma.

Malignant peripheral nerve sheath tumor (MPNST) is a rare sarcoma that recent studies have shown have frequent and concurrent inactivating mutations in neurofibromatosis type 1 (NF1), CDKN2A, and SUZ12/EED (polycomb repressor complex 2) genes. In the second paper, "[Triple Combination of MEK, BET, and CDK Inhibitors Significantly Reduces Human Malignant Peripheral Nerve Sheath Tumors in Mouse Models](#)," the researchers used cell and mouse models of malignant peripheral nerve sheath tumor (MPNST) to systematically test combinations of inhibitors that specifically targets the loss of the above three genes.

They used cell lines to test 14 MEK inhibitors (MEKi), 11 cyclin-dependent kinase 4/6 inhibitors (CDKi), and 3 bromodomain inhibitors (BETi) by themselves and in combination. The best combinations were tested in 2 MPNST mouse models, and final combination of the three inhibitor classes was tested in the same mouse models. Combining all three classes of

inhibitors caused an average of 85% tumor shrinkage in both mouse models of MPNST. These results are early in the research process, but indicate that this combination of inhibitors may inform future clinical trials for MPNSTs.

In the last paper, "[Enhancement of anti-sarcoma immunity by NK cells engineered with mRNA for expression of a EphA2-targeted CAR](#)," the researchers used a technique similar to that of the first study to test its efficacy against cell and mouse models of several subtypes of sarcoma. In this study, instead of delivering the receptor gene into a T-cell the gene was delivered to a different kind of immune cell called a natural killer (NK) cell which is also able to kill tumor cells. In this study, the NK cell was developed to target the ephrin type-A receptor-2 (EphA2) antigen, which is expressed in various pediatric sarcomas such as osteosarcoma, Ewing sarcoma, and rhabdomyosarcoma. The EphA2-specific CAR-NK cells demonstrated increased cell killing ability against several pediatric sarcoma cell lines compared to unmodified NK cells. Additionally, EphA2-CAR-NK cells showed tumor killing activity in rhabdomyosarcoma and osteosarcoma mouse models.

Although still early, these results indicate a rationale for further evaluation of EphA2-targeted CAR-NK therapy as an option for several pediatric sarcomas.

Record-Breaking Year for Sarcoma Research Grants

The future of sarcoma research is brighter than ever! We're incredibly excited to share that we've received a record-breaking number of research grant proposals for 2025! This outpouring of interest is a powerful testament to the unwavering dedication and groundbreaking innovation within the sarcoma research community. Every proposal represents countless hours of work, fueled by the shared goal of improving the lives of those affected by sarcoma.

We extend our deepest gratitude to each and every researcher who submitted a proposal. Your commitment to advancing sarcoma care and searching for cures gives us all hope. All proposals will be reviewed by our Medical Advisory Board, and we look forward to announcing the recipients of our prestigious 2025 SFA Research Grants and Last Mile Research Grant later this year.

You can support SFA's research funding [here](#).

CLINICAL TRIALS CORNER

By Kristi Oristian, PhD

This month SFA is highlighting a [XL092 \(Zanzalintinib\) for the Treatment of Patients With Metastatic or Unresectable Leiomyosarcoma](#). This study is newly recruiting at one location in Chicago, IL at Northwestern University. The trial is open to adults ages 18 years and older in the United States with advanced leiomyosarcoma.

Patients eligible for this trial will receive a new medicine called XL092 (zanzalintinib), a type of drug called a tyrosine kinase inhibitor that interferes with cell communication and growth and may prevent tumor growth. This medicine is being developed by [Exelixis](#) and is being evaluated to treat several different kind of cancers, including sarcoma.

Patients eligible for this study will receive XL092 orally as a pill once daily on days 1-14 of each cycle. Cycles will last 14 days and will repeat as long as the patient does not experience progression of their tumor(s) or unacceptable side effects (toxicity). Patients taking the medicine will also have additional testing before enrollment and during treatment, including echocardiography, multigated acquisition scan(s), blood sample collection, and CT scan(s). Patients enrolled in this study may be monitored for up to 5 years.

There are additional eligibility and exclusion criteria, including minimum organ function requirements and prior therapy considerations, as well as confirmation of leiomyosarcoma stage. Patients interested in this study should review these criteria with their doctor as well as the potential clinical benefit of participation in the study. To learn more about this study, patients and/or care partners can talk to their doctor, contact the [investigator](#) at the study site, or contact the [study coordinator](#). Participating patients in need of additional travel support may [apply for assistance](#) from SFA.

STAND UP TO SARCOMA GALA

Mark your calendars for SFA's 23rd annual Stand Up to Sarcoma Gala on September 15 at 583 Park Avenue in New York City! This important celebration brings together patients, survivors, caregivers, researchers, and advocates to honor those making a difference in the sarcoma landscape.

Join us for an inspiring evening filled with hope, empowerment, celebration, and community. Highlights include:

- Recognition of the 2025 recipients of the Courage Awards, Nobility in Science Award, Vision of Hope Award, and the Compassionate Care Award.
- 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.
- Entertainment, a silent auction, and a live donation opportunity to join SFA in funding vital sarcoma research, education, and advocacy and make a difference in the lives of those affected by sarcoma.

Be a part of this meaningful celebration and help make a lasting impact on the sarcoma landscape. More info coming soon.

Let's Stand Up to Sarcoma together!



Recognizing Compassionate Sarcoma Care

Do you know a sarcoma patient navigator you'd like to honor? Nominate them for the 2025 SFA Compassionate Care Award!

Nurses, community health workers, and social workers who support sarcoma patients are eligible. The selected nominee will be honored at our 2025 Stand Up to Sarcoma Gala in New York City on September 15th.

Nominations are due March 7. [Learn more](#) about the award and how to nominate a navigator who's made a difference.

Dr. David Kirsch to Receive SFA's 2025 Nobility in Science Award



We are thrilled to announce that SFA is presenting its 2025 Nobility in Science Award to Dr. David Kirsch at our annual Stand Up to Sarcoma Gala on September 15th in New York City. This prestigious award recognizes researchers and doctors who have made groundbreaking contributions to sarcoma research.

Dr. David Kirsch has had an illustrious career as an internationally renowned radiation oncologist and clinician-scientist. He is an expert in the use of radiation therapy to care for patients with bone and soft tissue sarcomas and his research spans the continuum of discovery science to translational research and clinical trials.

As a Senior Scientist at Princess Margaret Cancer Centre, he leads The Kirsch Laboratory in utilizing sophisticated genetically engineered mouse models and human sarcoma cell lines to study mechanisms of tumor development and the response of cancer and normal tissues to radiation. He uses these models to develop and test novel therapeutic approaches to cancer. Dr. Kirsch also leads clinical trials for patients with sarcoma, he serves as the overall Principal Investigator for SU2C-SARC032, which demonstrated that the addition of anti-PD-1 pembrolizumab to pre-operative radiation therapy improved disease-free survival in high-risk, extremity soft tissue sarcoma patients.

Dr Kirsch currently serves as the Peter and Shelagh Godsoe Chair in Radiation Medicine, Head of the Radiation Medicine Program, and Head of the Department of Radiation Oncology at the Princess Margaret Cancer Centre, University Health Network. He is also a Professor in the Departments of Radiation Oncology and Medical Biophysics at the University of Toronto.

Join us in celebrating Dr. David Kirsch and his remarkable contributions to sarcoma research and the sarcoma community at the 2025 Stand Up to Sarcoma Gala. Together, we can make strides towards a future free from sarcoma.

SFA NEWS

Take Action: Join SFA for Advocacy Weekend 2025

Our mission is to improve outcomes for people diagnosed with sarcoma to increase the number of survivors. It centers around growing awareness about the disease, funding and advancing research, educating, and providing resources for people diagnosed with sarcoma.

Changing outcomes requires action. Together, we can push for increased research funding, better treatments, and stronger support for the sarcoma community. Take action this Sarcoma Awareness Month and join us on Capitol Hill for SFA's Advocacy Weekend, July 17th–19th. Your presence makes a difference. Let's unite as a collective sarcoma voice and advocate for the change sarcoma patients need.

Thursday, July 17th Sarcoma Community Advocacy Day

Join us for an empowering day on Capitol Hill! You'll meet with elected officials to discuss issues affecting sarcoma patients, caregivers, and families, sharing your stories to advocate for change in treatment and research.

Congressional Reception

The day concludes with a congressional reception to come together as a community with elected officials and their staff and continue the discussion about policy issues impacting sarcoma patients.



Friday, July 18th

Education Day: Understanding Drug Development for Advocacy and Education

Join us for an opportunity to learn about the pipeline from laboratory bench to patient bedside and how SFA supports the development of new and better therapies for sarcoma patients. Learn about the basic science that goes into the identification of new drug targets, preclinical and clinical trials, how these trials function and are designed, and how advocacy plays a role in making new treatments accessible to people living with sarcoma. Hear from a panel of experts from every stage of the process, have the opportunity to engage and ask questions, and leave with valuable information to help you understand the intersection between sarcoma research and advocacy.



Awards Dinner

Celebrate Advocacy Weekend and join us for a community dinner. Connect with others as we honor sarcoma advocates and our representatives who amplify our voices on Capitol Hill.

**REGISTER FOR
ADVOCACY WEEKEND**

Saturday, July 19th

2025 National Race to Cure Sarcoma, Washington D.C.

End the weekend at our premier run/walk series in the United States focusing on raising awareness and research funds for sarcoma. This takes place right at the Lincoln Memorial! Spend time at one of our nation's beautiful monuments and connect with others in the sarcoma community. Registration for the Race to Cure Sarcoma is separate from Advocacy Weekend. Registration opening soon.



New Episodes of Sarcoma Stories Available Now!



Tune in to Sarcoma Stories to hear inspiring stories from the sarcoma community.

Episode 4: The Brenneman family shares their experience navigating a spouse's sarcoma diagnosis while raising young children, finding connection after loss, and honoring their loved one's legacy.

Episode 5: Maria Pena discusses her daughter Aubrie's sarcoma journey, keeping her memory alive, and working to fulfill her daughter's bucket list. We also talk to her about efforts to bring Race to Cure Sarcoma to Austin on March 22.

Episode 6: Mike Caccioppo, diagnosed with osteosarcoma in 2021, shares his experience of being a part of the sarcoma community as well as the amputee community and how advocacy for both has become a part of his life. He also talks about parenting while navigating a sarcoma diagnosis and how he maintains an optimistic mindset through all of the challenges he's faced.

Listen to these and more inspiring episodes by following Sarcoma Stories on your favorite podcast platform! [Listen and Follow](#)



**LET YOUR VOICE
BE HEARD**

As we develop initiatives for 2025, we want to hear from you – the sarcoma community. Learn more and click below to take our surveys.

[Public Policy Survey:](#) With a new session of congress beginning, let us know what advocacy priorities are most important to you.

[AYA Survey:](#) If you are between the age of 18 and 40, take this short survey to help us provide support and education resources.

IN THE COMMUNITY

Ohio State's Jack Sawyer Raises Sarcoma Awareness During National Championship Win



Ohio State football fans have extra reason to celebrate this year's College Football Playoff National Championship victory. Defensive end Jack Sawyer helped lead the Buckeyes to a 34-23 win over Notre Dame, all while raising awareness for sarcoma.

Sawyer's dedication to the cause is deeply personal. He played the season in honor of his late friend, Jack Bennett Sawyer, who passed away from Ewings sarcoma in 2023. Throughout the season, and notably during the championship game, Sawyer wore an armband with the inscription "JBS Strong" to keep his friend's memory alive and draw attention to sarcoma.

Sawyer's efforts to raise awareness are invaluable to the sarcoma community. To learn more about Jack's story and his tribute to his friend, watch [this video](#).

EVENTS



Help support SFA with a Shop for a Cause event Sunday, February 23rd, from 12:00 pm – 6:00 pm at Lilly Pulitzer North Hills – 4321 Lassiter at North Hills Ave #105, Raleigh, NC 27609.

Shop in person and mention Sarcoma Foundation of America (SFA) at the checkout, and Lilly Pulitzer will donate 10% of proceeds to benefit SFA and our mission to improve the lives of those affected by sarcoma. Can't make it in person? Shop up to two days early via call (919) 784-9174 and mention SFA.



In Store and Phone
Orders Only
(Phone Orders Start on 2/21)

SHOP

TO SUPPORT:

Sarcoma Foundation of America

Join us at Lilly Pulitzer North Hills

Call for details: 919.784.9174

10%

OF EVENT PROCEEDS
WILL BE DONATED

February
23

2025

10:00 AM -
6:00 PM



Austin - 03/22/25
Atlanta - 04/05/25
Boston - 04/06/25
New York - 04/26/25
San Francisco - 05/10/25
South Florida - 05/17/25
Cleveland - 06/21/25
Milwaukee - 07/12/25
National Virtual - 07/19/25
Washington D.C. - 07/19/25

2025 CITIES

Louisville - 08/09/25
Philadelphia - 08/16/25
San Diego - 09/20/25
Chicago - 09/27/25
New Jersey - 10/05/25
Denver - 10/25/25
Nashville (Virtual) - 11/01/25
Tampa - 11/01/25
Los Angeles - 11/02/25
Sacramento - 11/08/25

Locations and Dates are Subject to Change.



Open Positions at SFA

[Executive Office Manager](#)

[Digital Marketing Manager](#)

[Finance Manager](#)