

September is Childhood Cancer Awareness Month and World Cancer Research Day is on September 26th.



## A Month of Awareness and Progress for the Sarcoma Community

September is [Childhood Cancer Awareness Month](#). Sarcoma accounts for 15-20% of all childhood cancer diagnoses each year in the U.S. These diagnoses bring a host of challenges to children and their families. Throughout September, SFA will recognize National Childhood Cancer Awareness month with social media posts, educational content, and resources to help families with children affected by sarcoma.

We invite you to share these posts on your social media accounts, post your own messages with the hashtags [#CureSarcoma](#) and [#ChildhoodCancerAwarenessMonth](#). We also invite you to join us in raising awareness on Wednesday, September 18, for Wear Gold Day, when we encourage everyone to wear gold clothing and/or accessories in support of child sarcoma patients.

September also recognizes World Cancer Research Day on the 24th of the month. This day underscores the critical advancements in sarcoma research that have been made, are ongoing, and still need to be pursued. Both observances remind us of the importance of the work being done at Sarcoma Foundation of America, and we are eager to see what new progress can be achieved in the future.

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## Research Roundup

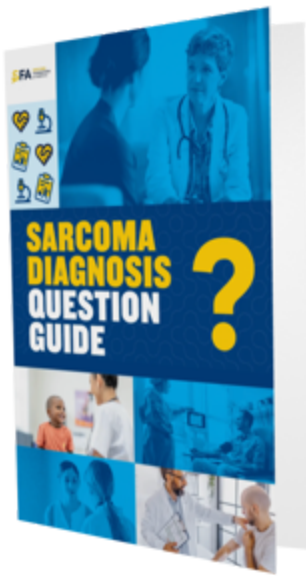
by Dean Frohlich, PhD

In the first study this month, "[Discontinuation versus continuation of imatinib in patients with advanced gastrointestinal stromal tumours \(BFR14\): exploratory long-term follow-up of an open-label, multicentre, randomised, phase 3 trial](#)", the researchers analyzed the long-term effects of stopping treatment with a drug called imatinib, a tyrosine kinase inhibitor (TKI), on the survival of patients with advanced gastrointestinal stromal tumors (GIST). This phase 3 trial, called BFR14, was carried out at 17 comprehensive cancer centers or hospitals across France. Patients with advanced GIST with a complete or partial response, or stable disease at 1 year, 3 years, and 5 years from the start of treatment were randomly assigned to either discontinuing treatment until progression or continuing treatment until disease progression. The primary endpoint was progression-free survival. Secondary endpoints included time to imatinib resistance and overall survival. The results indicated that pausing TKI treatment in non-progressing GIST patients was associated with progression, faster resistance to treatment, and decreased overall survival when compared to patient that continued TKI treatment after 3 years and 5 years of treatment. These results lead the authors to recommend not interrupting imatinib treatment in GIST patients who are not progressing and are currently taking imatinib.

Recently a protein called CDK4 has emerged as potential target for liposarcoma. In "[Role of CDK4 as prognostic biomarker in Soft Tissue Sarcoma and synergistic effect of its inhibition in dedifferentiated liposarcoma sequential treatment](#)", the researchers used a variety of techniques and models to investigate the role that CDK4 plays in a subtype of liposarcoma called dedifferentiated liposarcoma (DDLPS). In the analysis, the investigators determined that CDK4 along with another protein called MDM2 is expressed at higher than usual levels in DDLPS. However, even though CDK4 and MDM2 are located on the same chromosomal region, they are not always expressed consistently, indicating that even if MDM2 is not expressed at higher-than-normal levels that CDK4 may still be a viable treatment target. Using a DDLPS model investigators next examined the efficacy of Palbociclib, an CDK4 inhibitor, in combination or in sequential treatment with other chemotherapies. These tests showed that Palbociclib was effective when given sequentially with Lenvatinib, which inhibits a specific group of proteins called VEGFR1, VEGFR2 and VEGFR3 kinases. This early, pre-clinical study provides the rationale for the clinical applicability of sequential treatment with Palbociclib with Lenvatinib in the management of DDLPS.

Lastly, in "[HER2 antibody-drug conjugates are active against desmoplastic small round cell tumor](#)," the investigators explore the expression of a protein called ERBB2/HER2 as a target for therapy in desmoplastic small round cell tumor (DSRCT). ERBB2/HER2 expression was evaluated and found to be expressed in tumor samples and other DSRCT models. Investigators then treated multiple DSRCT models with a type of targeted therapy drug called an antibody-drug conjugate (ADC). In this case, an antibody to the ERBB2/HER2 protein is linked either to deruxtecan (T-DXd), which disrupts DNA replication causing tumor cells to die, or emtansine (T-DM1), which disrupts cell division also causing tumor cells to die. Using the ADC targets the drugs specifically to the tumor. Treatment of ERBB2/HER2-expressing DSRCT models with T-DXd or T-DM1 resulted in tumor regression. This study demonstrates that further studies are warranted utilizing ERBB2/HER2 as a therapeutic target for DSRCT and that HER2-ADCs are an option in fulfilling this need.

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## New Patient Resource- Sarcoma Discussion Guide

SFA created a discussion guide to empower patients as they navigate conversations about their diagnosis and treatment journey. With input from our patient focus group, sharing their lived experience navigating a sarcoma diagnosis, the patient voice is centered in prompting these necessary and vital conversations. This is also an excellent resource for healthcare workers to utilize for shared decision making.

This is a tool, guided by voices in the sarcoma patient community, to ensure patients have the necessary information to participate in their treatment decisions.

[DOWNLOAD GUIDE](#)



## Special Update!

Announcing Our Entertainment for the 2024 Stand Up to Sarcoma Gala – **Krysta Rodriguez**



Announcing Our MC for the 2024 Stand Up to Sarcoma Gala – **Caroline Aaron**



[LEARN MORE & REGISTER](#)



We invite you to join us at the 22<sup>nd</sup> Annual Stand Up to Sarcoma Gala on October 1, 2024, at 583 Park Avenue in New York City! Prepare to be entertained and inspired as the hilarious and talented Caroline Aaron, known for her roles in "The Marvelous Mrs. Maisel" and "21 Jump Street," takes the stage as our Master of Ceremonies. The evening will also feature a captivating performance by the versatile actress Krysta Rodriguez, whose credits span Broadway hits like "Into the Woods" and her acclaimed portrayal of Liza Minnelli in the award-winning Netflix mini-series "Halston." Join us for an unforgettable night of hope, celebration, and fundraising for sarcoma research. We can't wait to see you there!

In addition to electrifying entertainment, each year at the Gala, SFA highlights outstanding sarcoma advocates with the Courage Award and Amira Yunis Courage Award, honors a medical visionary who is advancing groundbreaking research with the Nobility in Science Award, acknowledges an organization or person providing hope to patients with the Vision of Hope Award and recognizes a Patient Navigator with the Compassionate Care Award for their outstanding contribution to patient care and support.

## We Are Thrilled to Announce Our 2024 Courage Award Recipients



We are thrilled to announce the 2024 Courage Award honorees, individuals whose personal efforts and actions in sarcoma advocacy have inspired and uplifted the sarcoma community. This year, we are proud to honor Emily Oberst and Kelly Elmlinger, both of whom recently competed in the 2024 Paris Paralympics. Emily's journey from a sarcoma diagnosis at 12 to becoming a Paralympian on Team USA's Wheelchair Basketball Team showcases her unwavering determination and passion. Kelly, who achieved the extraordinary by becoming a Paralympian on Team USA's Paratriathlon team, exemplifies the strength and perseverance needed to overcome the challenges of her diagnosis and excel as a world-class athlete. Both honorees embody the spirit of the Courage Award, demonstrating a profound commitment to creating hope and a better life for sarcoma patients and their families.

**Get your tickets and read more about them and the rest of our 2024 honorees at the link below.**

**LEARN MORE & REGISTER**





## Our Paralympic Heroes Shine Bright



The Paralympic Games have come to a close, leaving us with unforgettable memories of athleticism, determination, and the triumph of the human spirit. This year, sarcoma survivors represented the United States--and won medals--on the Men and Women's basketball teams and Para-Triathlon events. Their determination, perseverance, and athleticism illustrates the strength and resilience of the sarcoma community.

These athletes not only competed against the world's best, but they also demonstrated incredible resilience and perseverance on their personal journeys. Their dedication and unwavering spirit serve as a beacon of hope for all of us. They are living proof that with courage and determination, anything is possible.

We're thrilled to recognize the following individuals who brought home medals:

- Nate Hinze, Gold, Men's Wheelchair Basketball
- Hailey Danz, Gold, Para-Triathlon
- Emily Oberst, Silver, Women's Wheelchair Basketball
- Bailey Moody, Silver, Women's Wheelchair Basketball
- Natalie Schneider, Silver, Women's Wheelchair Basketball
- Mark Barr, Bronze, Para-Triathlon

All of the athletes have made us all incredibly proud. Their achievements remind us that within our community, we can achieve greatness. Let's continue to celebrate their victories and support them as they inspire the next generation of athletes.

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**Congratulations to our 2024 Children's Artwork Contest  
Winners**

# 2024 WINNERS



**AMBER X., AGE 4**



**HADLEY B., AGE 11**



**ROMAN G., AGE 5**

SFA is pleased to share the winners of our 2024 Children's Artwork Competition. This year, SFA received submissions from 76 young artists from six countries around the world who shared their depictions of sunflowers or yellow ribbons to raise sarcoma awareness.

Choosing three winners from this rich pool was difficult, but SFA's final selections came from Roman G., age 5, Hadley B., age 11, and Amber X, age 4. Art from these three entries, depicted below will appear on cards SFA sends throughout the holiday season.

You can see all of SFA's winning art entries at the link below.

## **View Artwork**



## **We Want to Hear From You**

If sarcoma has been a part of your life, your story can bring awareness to sarcoma and encourage others who are experiencing sarcoma in their own lives. Sharing your story can help another person feel less isolated and remind us all of the urgent need for better treatments or therapies. If you or a loved one has been impacted by sarcoma, we welcome you to share your story with us. To learn more, email [nnathan@curesarcoma.org](mailto:nnathan@curesarcoma.org) with the following information:

- Your name
- Your phone number or email
- (optional): How has sarcoma affected your life?
- (optional): Is there anything else we should know?

# SFA NEWS

## Louisville Unites: Over 800 Participants Support Sarcoma Research

The Louisville community came together in an extraordinary show of support at the Race to Cure Sarcoma, with over 800 participants joining forces to raise awareness and funds for sarcoma research. This remarkable turnout is a testament to the strength and commitment of everyone involved, from families and friends to local supporters. Through their collective efforts, the event raised over \$105,000, demonstrating the power of a united community in making a meaningful impact. Special thanks go to our dedicated committee chairs, Connie Campbell and Katie Wintergerst, whose leadership played a key role in this success.

We still have 8 races left around the country in 2024. Don't miss out on a day to come together with your local sarcoma community and help raise awareness and funds for sarcoma.

**Click your date and register now!**

### RTCS LOUISVILLE PHOTOS



[San Diego - September 21](#)

[Chicago - September 28](#)

[New Jersey - October 6](#)

[Los Angeles - October 12](#)

[Denver - October 26](#)

[Tampa - November 2](#)

[Nashville \(Virtual\) - November 2](#)



The Denver Broncos' John Franklin-Myers announced that he is donating \$1,000 to the Sarcoma Foundation of America (SFA) to support sarcoma research and awareness for every sack he makes this NFL season. The Broncos will match Franklin-Myers' donation, bringing a total of \$2,000 for every sack.

**READ THE PRESS RELEASE**



# IN THE COMMUNITY



## Team MEGcellence Surpasses Fundraising Goal!

Shaun Nerney recently ran a half marathon in honor of his girlfriend Meghan, who has been courageously facing an inoperable fibromixoid sarcoma since 2013. Meghan's strength and optimism throughout her journey have been a constant source of inspiration for Shaun. To show his support, he formed Team MEGcellence, initially setting a fundraising goal of \$5,000. To his amazement, the team surpassed expectations, raising an impressive \$8,012. Shaun describes this as the most fulfilling accomplishment of his life.

The half marathon became a powerful symbol of the love and support surrounding Meghan. Shaun was joined on the 13-mile course by his trainer, Tom, and Tom's wife, Jenalee, who ran alongside him every step of the way. The experience was made even more memorable by the enthusiastic cheers of Meghan and Shaun's mother, who led the cheering section with her trusty megaphone. Shaun's story illustrates the incredible impact that a united community, driven by love and kindness, can have in supporting those they care about.

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## Music Festival and Concert Celebrate Lives Lost to Sarcoma with Music

Two musical events in Chicago this weekend brought friends, family members, and loved ones together to celebrate lives lost to sarcoma while raising money for research and awareness. The second annual Big Heart Fest, a festival celebrating the life and joyful spirit of John "Big Johnny" O'Brien, featured multiple bands, a silent auction, and Irish themed food and drinks at "Big Johnny's" favorite location, Chief O'Neill's Pub and Restaurant. The musical acts included [Bronte Fall](#), whose lead singer Teri Bracken is Johnny's daughter. At the event, Bronte Fall performed "One More Day", a song she wrote as a tribute to her father. [Listen to that song on Spotify here.](#) The event had a record turnout and was a huge success.



That same night Amethyst Turner celebrated the release of a new album with a concert featuring a new song, "Angels ft. Angelyn," a tribute to Amethyst's sister who passed from sarcoma. Amethyst and attendees committed to giving more



than \$2500 at the event. [Read more about Amethyst and listen to her music here.](#)

# UPCOMING EVENTS



Race <sup>TO</sup> Cure  
**SARCOMA**  
SARCOMA FOUNDATION OF AMERICA

[San Diego - September 21](#)

[Denver - October 26](#)

[Chicago - September 28](#)

[Tampa - November 2](#)

[New Jersey - October 6](#)

[Nashville \(Virtual\) - November 2](#)

[Los Angeles - October 12](#)

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## Support SFA at the 2024 Marine Corps Marathon!

Sarcoma Foundation of America (SFA) is once again proud to partner with the 2024 Marine Corps Marathon (MCM) in Arlington, VA, on October 27, 2024! The deadline to join SFA at the 2024 MCM may have passed, but you can still support our team members Ashton Callahan (26.1 MCM) as well as Tyler Ross, Susie Donohue, and Jude Nosek (MCM10k).



For more details or to join [click here](#) or email [Annie Blake](#).

Stay Connected



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