



# Sarcoma Spotlight

**March 2020**

## **Twenty Years of the SFA**

**Twenty years later, the Sarcoma Foundation of America continues to be a voice and leader for the sarcoma community.**

Twenty years ago, before SFA, not much attention was paid to sarcoma. There were few treatment options, and no organization or institution focused on developing new therapies or expediting new treatments for patients. Sarcoma was a forgotten cancer.

Fast forward 20 years. Sarcoma awareness has substantially increased, more, though not nearly enough, therapies are available, and innovative and novel agents such as immune-oncology are beginning to be applied to sarcoma. Twenty years later, SFA continues to be a voice and leader for the sarcoma community.

[Read More](#)

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## **Advocacy Update**

### **SFA Takes Part in FDA Rare Disease Meeting**

During Rare Disease Week, SFA represented the sarcoma community at the Food and Drug Administration's (FDA) public meeting on the future of rare disease product development. The meeting brought together regulators, patients, and advocates to discuss ways to bring the patient voice into therapy



development and the importance of collaboration in the process.

During his remarks, FDA Commissioner Stephen Hahn, MD, mentioned his background treating sarcoma patients as he shared his thoughts on rare disease therapy development & patient involvement, telling the audience, "what matters to patients & families should matter to us as regulators."

A webcast of the meeting has been made available on the FDA's website at [www.fda.gov/industry/orphan-products-development-events/rare-disease-day-2020](http://www.fda.gov/industry/orphan-products-development-events/rare-disease-day-2020).

## Research Roundup

### Sarcoma Research News Highlights

- Earlier this year, the FDA approved Tazverik for the treatment of metastatic or locally advanced epithelioid sarcoma. SFA Executive Director Brandi Felser spoke with Cure Today about the approval and what it could mean for patients and for the future of sarcoma therapy development. **Read more:** [What You Need to Know About the FDA's Approval of Tazverik For Epithelioid Sarcoma](#)
- An experimental drug to be used in combination with doxorubicin for soft tissue sarcoma has been given the go head to by the FDA to begin early phase studies. The company behind the therapy refers to it as a "uniquely acting immuno-oncology drug." **Read more:** [FDA Grants IND Approval to Promising Anti-Cancer Agent Veyonda](#)
- SFA is proud to have partnered with the My Pediatric and Adult Rare Tumor (MyPART) Network, a project coordinated through the National Cancer Institute's (NCI) Center for Cancer Research (CCR). The MyPART Network is a group of patients, family members, researchers, advocates, and healthcare providers who are working together to find



treatments for childhood, teen, and young adult rare solid tumors. **Read more:** [SFA Partners with the My Pediatric and Adult Rare Tumor \(MyPART\) Network](#)

## SFA News



### Get Ready for the Race to Cure Sarcoma

SFA is gearing up for the start of our **2020 Race to Cure Sarcoma** series. Last year, people from across the U.S. came together and raised more than \$1 million for sarcoma research, making it the biggest and best year for the Race to Cure Sarcoma race series ever! Will you join the race in 2020 to help raise awareness and support sarcoma research?

Registration is now open for the Race to Cure Sarcoma in [Atlanta](#), [Baltimore](#), [Cleveland](#), [Milwaukee](#), [Denver](#) and [Louisville](#). Registration for the remaining events in 2020 will be opening soon! For more information on registration, fundraising, and sponsorship opportunities, visit [www.curesarcoma.org/race](http://www.curesarcoma.org/race). Be sure to follow the SFA on [Facebook](#), [Instagram](#), or [Twitter](#) for the latest information.

Have questions about the Race to Cure Sarcoma or an interest in serving as a volunteer? Contact us at [events@curesarcoma.org](mailto:events@curesarcoma.org).

### SFA & Flyers Fans Show Support for Oskar Lindblom

SFA has joined forces with the Philadelphia Flyers in their support of Oskar



Lindblom, the 23-year-old Flyers forward who was diagnosed with Ewing Sarcoma last December. Flyers Charities, the philanthropic arm of the team, has chosen SFA as the beneficiary of funds raised through #OskarStrong gear. Money raised will support Ewing Sarcoma research efforts.

In February, SFA took part in the Flyers Wives Carnival to raise awareness for sarcoma and to demonstrate support for Oskar. Fans at the event were encouraged to stop by the SFA booth to take an #OskarStrong selfie. The outpouring of love from the fans was amazing, with nearly 100 people taking photos for Oskar. To view the pictures from the event, visit SFA on [Facebook](#) or on [Twitter](#).



## SFA to Host 18th Annual Gala "Stand Up to Sarcoma"

The Sarcoma Foundation of America cordially invites you to attend our 18th annual gala, Stand Up to Sarcoma, to be held on May 14, 2020, in New York, NY. Stand Up to Sarcoma honors those who have battled sarcoma, as well as those who have dedicated their lives and careers to the treatment of sarcoma patients.

Congratulations to our 2020 award recipients!

### **Nobility in Science Award**

William Tap, MD, Memorial Sloan Kettering Cancer Center

### **Courage Awards**

Brandi Benson

Kara Ladd

### **Compassionate Care Award**

Robin Rawlins-Duell, ANP-BC

### **Vision of Hope Award**

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Stand Up to Sarcoma also raises money to support the SFA's work to fund innovative sarcoma research leading to the development of new and better therapies for sarcoma patients. The event will feature dinner, live entertainment, dancing, and a silent auction.

For more information on Stand Up to Sarcoma, visit [www.curesarcoma.org/nyccelebration](http://www.curesarcoma.org/nyccelebration).

## Upcoming Events

During the Month of April: [WhyWeHike - Trophy Brewing's Tap and Table Restaurant Fundraiser, Raleigh NC](#)

April 9: [WhyWeHike - Trophy Brewing State of Beer Fundraiser, Raleigh, NC](#)

April 18: [Race to Cure Sarcoma Atlanta](#)

May 9: [Race to Cure Sarcoma Baltimore](#)

May 14: [SFA's 18th Annual Gala, "Stand Up to Sarcoma," New York, NY](#)

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