



Sarcoma Spotlight

July 2020

Sarcoma Awareness Month 2020

By Brandi Felser, Executive Director

Each year, over 16,000 children, women and men are diagnosed with sarcoma and 7,000 lose their lives. Although sarcoma is considered a “rare” cancer, it is not rare to the approximately 50,000 people who are living with the disease. It is not rare to the mothers and fathers, families and friends, who have lost loved ones. Their experiences are, unfortunately, not rare.

Certainly, the adjective rare sets sarcoma apart. It means that fewer people are diagnosed with the disease. But the rare designation has more implications. It means that treatment options and research funding has lagged behind. It means the sarcoma community is smaller, with less patients to power clinical trials. The community has had to work harder to raise awareness and advocate for necessary reforms to ensure sarcoma is not left behind as novel advancements are made in the treatment of other cancers.

[Read More](#)

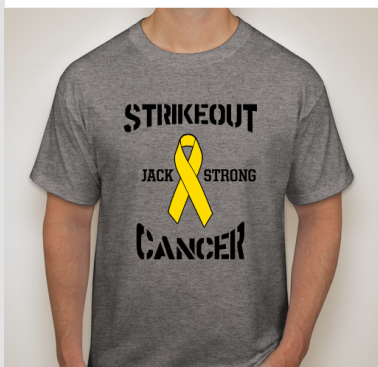
Advocates in Action

Sarcoma Advocates Take Action During Sarcoma Awareness Month

There is no time like Sarcoma Awareness Month to begin taking action and serving as an advocate for the sarcoma community! Whether you are creating awareness in your local community, raising money for research, or getting involved with sarcoma patient education, you are helping to make a difference for the thousands of people diagnosed with sarcoma each year.



One group of young advocates are using their musical talents to raise awareness and funds supporting research and advocacy. Hosting their 3rd Annual [Songs for Sarcoma](#) Concert series, these musicians began their effort when their friend was diagnosed with rhabdomyosarcoma. Due to the pandemic they have had to change from in-person concerts to posting performances online, but their resolve remains the same – to build upon the nearly \$10,000 they've raised over the years to support lifesaving medical research, patient advocacy, and awareness efforts.



Another group of young people were also inspired by a friend's diagnosis to take action. Together with a few friends, Reece H. wanted to do something special to show support for her friend Jack, who was diagnosed with osteosarcoma. Reece and friends designed a shirt using the Custom Ink fundraising site, sharing that, "we want Jack to know that he is not in this fight alone...He's always thinking of how he can help others, and now it's time for us to return the favor!" Many in the community stepped up to return that favor! They sold more than 400 shirts and raised over \$6,400 to support patients and survivors with sarcoma.

These are just two examples of people stepping up to take action. If you're looking for ways that you can be involved during Sarcoma Awareness Month, be sure to follow SFA on [Facebook](#), [Twitter](#), and [Instagram](#). Over the month of July, SFA will be posting information on how you can raise awareness and serve as an advocate. If you're looking for ways to spread awareness to your friends, family, and community, check out our new [social media toolkit](#). You'll find tips and tricks, links to shareable graphics, and sample posts to make it easier to raise awareness! Interested in hosting a virtual event or some other fundraiser? Email events@curesarcoma.org to connect with SFA staff who can help you in your efforts.

Research Roundup

SFA To Host Live Expert Chat on Latest in Sarcoma Research

Sarcoma Foundation of America
Live Expert Chat

RESEARCH REVIEW:
PROMISING RESEARCH
ADVANCEMENTS IN SARCOMA



Join SFA on Saturday, July 18, 2020, for our next Live Expert Chat on the latest insights in advancements in sarcoma research. Drs. Sujana Movva, Katherine Thornton, and Jonathan Trent will share thoughts and analysis of sarcoma research efforts that were presented during the American Society for Clinical Oncology's (ASCO) Annual Meeting in May. For more information and to register, [click here](#).

Use Your Voice to Advance Research

SFA partners with sarcoma researchers and industry to find more and better therapies for sarcoma patients. To that end, SFA is interested in learning about patient preferences for the usage of oral therapies. You do not have to currently take/or have taken an oral therapy in the past to participate in this short survey.

No identifiable personal or contact information will be shared, but survey responses will be aggregated and shared with external partners in an effort to include patient feedback in the therapy development process.

To participate in the survey, [click here](#).

Sarcoma Research News Highlights

- The University of Colorado Cancer Center highlights the projects of two 2020 Sarcoma Foundation of America grant award recipients, Drs. Breelyn Wilky and Masanori Hayashi, and their research efforts. [Read More: Two New Grants Help CU Researchers Test New Sarcoma Treatments](#)
- Gary Schwartz, MD, shares analysis of a study in metastatic sarcoma. Findings suggest a combination of nivolumab (Opdivo) and ipilimumab (Yervoy) is superior when compared with nivolumab alone. [Read More: Dr. Schwartz on the Results of the Alliance A091401 Study in Metastatic Sarcoma](#)
- R. Lori Randall, MD, talks to OncLive about the need for a multidisciplinary approach for treatment of giant cell tumor of the bone. [Read More: Randall Issues Call for Multidisciplinary Management in Giant Cell Tumor of Bone](#)



SFA News

The National Virtual Race to Cure Sarcoma is Just Around the Corner!



Excitement is building for this month's [National Virtual Race to Cure Sarcoma](#)! Although we are all miles apart, we are connected through the drive to find a cure for this disease. Join the more than 1400

people who have already signed up to be a part of this effort as we virtually gather together near and far to raise awareness and dollars to find a cure for sarcoma.

The National Virtual RTCS takes place on Saturday, July 25. SFA will be hosting live programming on race day, so be sure to follow the [National Virtual Race to Cure Sarcoma Facebook Event](#) page to take part in all of the event day programming.

To register or donate in support of the National Virtual Race to Cure Sarcoma, [click here](#).

Race to Cure Sarcoma Participant Profile: Katie Wintergerst



The Race to Cure Sarcoma is nothing without its dedicated teams and participants: patients and survivors, and the friends and families that support them.

Katie Wintergerst is a sarcoma survivor who not only participates in her local event but also takes action to advance sarcoma awareness. Katie has been part of the Race to Cure Sarcoma Louisville committee as well as represented the SFA at One Voice Against Cancer lobby days in Washington, DC, where she met with Congress to discuss the need for increased cancer research funding.

Katie's sarcoma story began in 2015 while she was pregnant with her son. She began feeling pain and cramping in her leg but chalked it up to pregnancy pains. The pain never limited her activities and would come and go so she did not give it much attention. After becoming pregnant with her second child in 2017, she began asking more questions about the pain she was feeling. After multiple conversations with her primary care physician and talks of physical therapy, Katie underwent a Venous Doppler procedure to rule out blood clots and an MRI hoping to receive answers. In 2018, Katie received an answer as the MRI revealed sarcoma in her femur and she was diagnosed with stage 3 high grade synovial sarcoma in the left adductor muscle.

Katie began the long treatment process. After chemo treatments, she began radiation to form a shell around the tumor in her leg. On October 3, 2018, surgery was performed to remove the tumor.

Katie knows all too well the challenges that come with a sarcoma diagnosis. That's why she is determined to help find an end to this disease. Not only does she advocate for more research funding, Katie started a fundraising team, "Stronger than Sarcoma," to support sarcoma awareness and sarcoma research.

We thank Katie and others like her as we all work together for a world without sarcoma. Visit our [National Virtual Race to Cure Sarcoma Facebook Event page](#) to see videos highlighting other event participants and teams.

Upcoming Events

July 25: [National Virtual Race to Cure Sarcoma Event](#)

August 15: [Race to Cure Sarcoma Denver](#)

September 13: [Race to Cure Sarcoma New Jersey](#)

September 20: [Race to Cure Sarcoma Kansas City](#)

October 2: [Stand Up to Sarcoma Gala](#)



Our Contact Information

{{Organization Name}}

{{Organization Address}}

{{Organization Phone}}

{{Organization Website}}

{{Unsubscribe}}