



SARCOMA SPOTLIGHT

April 2021

Sarcoma Advocacy

By Brandi Felser, CEO

Advocating on behalf of those impacted by sarcoma has been a core principle of the Sarcoma Foundation of America's mission since the organization was founded in 2001. The SFA continues to be actively engaged in the public policy arena, urging legislators and regulators to place a high priority on rare cancer research, drug development, and access to quality patient care. We are also actively engaged in coalitions like the Alliance for Childhood Cancer, the Cancer Leadership Council, One Voice Against Cancer and many others where we actively engage in advocacy letters to Members, action items and Advocacy Days.

April is National Minority Health Month (NMHM), a time to raise awareness about health disparities. In sarcoma, as other diseases, data shows that health outcomes are worse for minorities and those in a lower socioeconomic status, who often are metastatic at diagnosis. The role of health insurance, or lack thereof, has an impact on health outcomes in sarcoma.¹

I often see posts on Facebook groups and receive emails sent to SFA describing patients and family members who run into barriers accessing treatment and needed tests, treatment denied by the insurance company, or patients stating they simply cannot afford a particular treatment and need financial assistance. A sarcoma diagnosis is especially challenging because patients are encouraged to obtain treatment at a sarcoma center and to be treated by a sarcoma specialist. Many patients

have to travel to a center and unfortunately, not all patients have the financial resources to do so. Many patients and families suffer the financial toxicity of a sarcoma diagnosis and must choose between treatment and daily needs.

When I started at SFA, I saw, in different places, sarcoma referred to as the “forgotten cancer”. I also saw many sarcoma advocates disagree with that term. Regardless of the language, sarcoma is disadvantaged. Sarcoma lacks research funding, awareness, and treatment options. Patients need access to healthcare and the few treatment options that do exist. The cost of treatment, lack of access to healthcare, and access to clinical trials are all on a long list of barriers to getting treatment necessary to overcome a sarcoma diagnosis.

In every survey SFA has done asking the community about priorities and needs, research funding is at the top of the list. As we conduct our scientific landscape analysis, it is becoming increasingly clear that sarcoma is being left behind in research funding. Rare does not mean less important, it just means fewer voices.

As I wrote in an article in July 2020:

Although rare means there are fewer voices, it does not mean that collectively our voice is not powerful. It does not mean that we do not have the power and strength as a community to bring about increased awareness, more and better treatment options, leading to a cure for sarcoma.

There are many issues important to sarcoma patients and family members, researchers, and medical professionals in our community. Let’s come together to address these issues and advocate for better outcomes for sarcoma patients.

To that end, **SFA is hosting a virtual Advocacy Day July 21, during Sarcoma Awareness Month**. If you would like to be a part of this day, and other actions we take on issues important to the sarcoma community, please sign up [here](#) so we can communicate with you and keep you updated. We are also organizing a public policy strategy stakeholder committee to assist with establishing public policy priorities and planning for the Advocacy Day. If you are interested in learning more about the committee, please [sign up](#) and SFA staff will reach out with more information.

Together, the sarcoma community can make our voices heard and educate our lawmakers and others on the needs of our community. Together, we can advance the priorities of the sarcoma community.

1: <https://pubmed.ncbi.nlm.nih.gov/31838786/> <https://pubmed.ncbi.nlm.nih.gov/29078908/>
<https://cebp.aacrjournals.org/content/29/11/2141.abstract> <https://onlinelibrary.wiley.com/doi/abs/10.1002/pbc.28708>

SFA's Impact

SFA began funding sarcoma research in 2004 with 3 grants of \$25,000 each. That seed has grown into more than \$12 million in research funding. At the start of 2021, SFA began a deep dive analysis into the impact of our work.

The analysis began on grants awarded from 2013-2020. Over this timeframe, the SFA Research Grants Program alone gave more than \$4.4 million to over 85 grants. Although researchers are encouraged to

investigate any of the numerous types of sarcoma, 15 different sarcomas have been funded with Osteosarcoma, Ewing's Sarcoma, Synovial Sarcoma, and Rhabdomyosarcoma the most frequently funded. This gives us good insight into outreach we may need to do to find ways to encourage and support research in other sarcoma subtypes.

Our reach is international! SFA funds mostly in the United States, however, we have also been successful in funding high-quality sarcoma research internationally with grants awarded to investigators in Italy, Spain, the United Kingdom, Canada, France, and the Netherlands.

SFA's Research Grant Program is only one way we support sarcoma research. We also provide support through the Conquer Cancer Foundation (ASCO), local cancer centers, and other sarcoma organizations. The Race to Cure Sarcoma event series provides the bulk of our research funding so we share these successes with the many sarcoma community members and their family and friends who have contributed to advancing sarcoma research.

We will continue to analyze our research funding as part of our scientific strategic plan and we will continue to update you on the impact of your support and how SFA's research funding making a difference!

Stand Up to Sarcoma Gala: Courage Award Honoree

Team Langbein

Team Langbein is a group of friends, family and colleagues of Chris and Becky Langbein who have come together and rallied around Chris after he received his diagnosis of sarcoma. Through raising awareness, advocating for enhanced treatments and funding important research, their goal is to eradicate sarcoma so no other family has to go through what the Langbeins are experiencing. Team Langbein is mostly known for its fundraising success supporting the Chicago Race to Cure Sarcoma event. Since 2018, they have raised nearly \$500,000 that has been used to support the Sarcoma Foundation of America's (SFA) research activities. Said Dave Hales, spokesperson for Team Langbein, "We want to ensure that we are supporting an important health issue that doesn't receive enough funding because of its lower prevalence."

"We are proud to accept this award not just in recognition of our fundraising efforts but also our activities to further SFA's message and continuing to educate the public on what sarcoma is and why it is so critical for more funding. We hope our lofty goals inspire other RTCS teams to help further the cause to fight this disease."

Stand Up to Sarcoma is the flagship event for SFA, featuring extraordinary honorees, tributes to sarcoma cancer survivors and advocates, and recognizing important advances in science and research.

Each year the event highlights outstanding sarcoma advocates with the Courage Award, honors a researcher or doctor advancing groundbreaking research with the Nobility in Science Award and recognizes an organization or person providing hope to patients with the Vision of Hope Award. These international awards are the highest honor SFA bestows and are awarded each year at the Stand Up to Sarcoma Gala in New York City.

Courage Award honorees illustrate, through their personal efforts and actions, sarcoma advocacy. These individuals are patients, survivors, caregivers, and advocates who inspire others by using their platform on behalf of sarcoma patients and survivors to create hope and a better life for the sarcoma community. Many do not think they have done something special but who have inspired others and are making a difference for

sarcoma patients and their families. The Courage Award honors patients who have demonstrated strength and perseverance in their sarcoma diagnosis.

For more information on the New York Gala, please visit <https://www.curesarcoma.org/nyccelebration/>.

RTCS Fundraising Summit



Join us for a special one-hour video chat to discuss how some of the most successful teams raise funds for the Race to Cure Sarcoma (RTCS) events.

On Saturday, May 15th, 2:00 pm EST, the Sarcoma Foundation of America will be hosting a fundraising summit and we are inviting you to listen, ask questions, make suggestions on the best way to raise funds, increase team participation and enlarge your event committee for the RTCS.

Guest speakers include:

- * Lisa Lacheny from RTCS Atlanta
- * Connie Campbell from RTCS Louisville
- * Katie Wintergerst from RTCS Louisville
- * Shannon Corrubia from RTCS New Jersey

[Click here to register!](#)

RTCS Events



*Race **TO** Cure*
SARCOMA
SARCOMA FOUNDATION OF AMERICA

REGISTER TODAY!

Atlanta- June 12
Milwaukee - July 10
National Virtual - July 24
San Francisco - August 1
Louisville - August 14
Denver - August 28
Baltimore - September (TBD)
Kansas City - September 18

New Jersey - September 19
Philadelphia - September 26
San Diego - October 2
Chicago - October 16
Richmond - October 23
Cleveland - October 30
Tampa - November 6
Los Angeles - November 7
Nashville - November 20

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