

Sarcoma Spotlight

December 2020

2020: What A Year!

By Brandi Felser, Executive Director

In January of this year I wrote a blog post reflecting on my first days at the Sarcoma Foundation of America (SFA) engaging with the sarcoma community. I wrote at the time about the impression the advocates made on me as I heard the stories they shared at the December 2019 FDA Oncologic Drugs Advisory Committee meeting. I wrote then:

As someone personally affected by cancer and a seasoned cancer advocate, I am no stranger to the needs of cancer patients, survivors, and caregivers. But seeing them stand before a committee of oncologists and FDA officials to share their very personal stories served as a striking reminder of the power of patient advocacy.

I could not have asked for a better start to my time at SFA. This experience will help shape my leadership of the organization as we work to harness the power of advocacy to make changes for the thousands of sarcoma patients who need better therapies and new treatment options.

I had no idea what 2020 would bring. Now, as I reflect on the past year (and what a year it has been), those words could not ring truer. This past year has been challenging, educational, inspiring, and has brought constant change. But most important, I could not have asked for a better start to my time at SFA.

Certainly, it has been difficult to join an organization, try to learn and lead during an unprecedented (during my lifetime) pandemic. But the overwhelming support for the work of SFA from the community has been amazing. It has lifted the staff and gave us confidence in times when we were not sure how much research we would be able to fund in 2021. The response to the Race to Cure Sarcoma events, especially the July virtual race, blew us away. The dedication of so many, even while navigating through this same pandemic, gave us the drive to continue to focus on our mission to support sarcoma patients, survivors, and loved ones. We cherished the stories shared with us by so many and they provided the motivation to figure out new ways to achieve our goals so that we could continue to fund lifesaving research. Again, a striking reminder of the power of patient advocacy.

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Advocates in Action

A Powerful Sarcoma Community

Throughout 2020, SFA has highlighted patients, survivors, family members and friends on our social media channels, through our newsletters and during our events. We recognize and celebrate the important role sarcoma advocates play in advancing research and awareness that will ultimately benefit and improve the lives of sarcoma patients.

Sarcoma advocates are participating in and hosting events, sharing information, answering important questions through surveys and other projects, collaborating with researchers and industry to advance sarcoma therapies and clinical trials, and making their voices heard on Capitol Hill to advocate for policies that support sarcoma patients.

Advocates like Brendan Locke from Wisconsin who is working with his members on Capitol Hill for a resolution in the Senate designating July Sarcoma Awareness Month and others who work with sarcoma organizations to advocate for important public policies. The many sarcoma advocates that participate in the RTCS events to support research, education and awareness. The overall top teams in 2020 raised over \$258,000 to advance the cure in our time:

- Team Langbein (Chicago)- \$170,678
- Cleveland Clinic Sarcoma Program (Cleveland)- \$28,355
- Team Ryan (National Virtual RTCS)- \$23,050
- Victoria's Unicorn Warriors (Cleveland)- \$20,619
- Team Joey (Philadelphia)- \$15,817

Others who use their sarcoma experience and hold their own events or raise money and awareness in creative ways. Advocates like Lisa Lacheny who sells homemade baked goods at farmers markets in memory of her mother. Reese Huen sells t-shirts in honor of her friend Jake, Josie Naumowich who was part of our New York Gala and raises money in memory of her father, Jessy Tolkan raises money in memory of her brother and the Zach Cohen family who host a golf tournament in memory of Zach and donate the proceeds to SFA. Many advocates set up Facebook fundraisers that support research and awareness and there are many, many other ways advocates are using their experience to advocate in ways that are meaningful to them.

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Research Roundup

Advancing Sarcoma Research

Twenty years ago, the Sarcoma Foundation of America (SFA) was founded to fill an unmet need – to fund and advocate for more sarcoma research, encourage the development of new and better therapies, grow awareness, and educate sarcoma patients. Looking back at these past 20 years, we see the impact of our work.

We have harnessed resources to bring sarcoma to the frontlines, and sarcoma awareness, research, and therapies have substantially increased. SFA is proud to have been a leader in these advancements.

SFA is especially proud to have funded more than \$11 million in sarcoma research through our grant program and through collaborative research projects. These efforts have helped to uncover new insights, helping to move research from the lab to clinical trials.

In 2020 we funded fifteen new research projects and committed close to \$2 million in research dollars. Projects funded cover a wide range of research areas and subtypes, including rare subtypes that desperately need more support. For many subtypes of sarcoma, there is very little research being done and no FDA-approved product.

But we know more research dollars are needed to fund projects that improve the lives of sarcoma patients. We know we must remain laser focused on our mission because people are still being diagnosed with sarcoma. Patients still need access to

lifesaving treatments, and it is up to us to make sure they receive them.

SFA's 2021 research grant funding program to support research is [now open](#). We will invest over \$1 million to research through this program. In addition, SFA will work with the Medical Advisory Board, sarcoma research community and industry partners to develop a research agenda to identify promising research and develop funding mechanisms and collaborations to advance this science.

SFA is proud to be the leading patient advocacy organization and the largest funder of research in the sarcoma community. This past year has shined a light on how important SFA's work is to the sarcoma community and to sarcoma patients. We are committed to doing all we can to advance science that creates new and better therapies and saves lives. We hope you will continue you to join us in this important effort.

SFA News

SFA is Growing!

Two new staff members joined SFA's team recently. We are excited that they are bringing their vast experience to SFA to help us in our mission to fund sarcoma research, increase awareness and educate patients and others about sarcoma.



Christopher Vance is our new Director of Development and Communications.

Christopher has over 30 years of experience in development and fundraising with particular emphasis in health-related causes. He has a successful background in donor relations, stewardship, and revenue generation. In addition, Christopher has trained many volunteers and advocates on all aspects of development including direct mail, foundation/corporate outreach, individual donors (including major, monthly, and planned givers), and special events.

Dean Frohlich is our new Director of Scientific Affairs.

Dean has over 10 years of experience in scientific review and grant administration. He has been responsible for the development of grant policies, procedures, and guidelines for applicants and reviewers; the analysis of programmatic processes and recommendations for improvement; and represented professional organizations at meetings with partnering organizations. Prior to his work in scientific review, he conducted research in prostate cancer.



Race to Cure Sarcoma

Thank You!

We have wrapped up the "Virtual" Race to Cure Sarcoma event series for 2020. Thousands of participants raised over \$900,000 to support sarcoma patients!

Your participation in the Virtual Race to Cure Sarcoma events helps to bring us closer to the cure. It is with your support and involvement that we are able to generate awareness for sarcoma, educate and advocate for patients and raise funds for much-needed research.

You can view event day videos on our YouTube channel by clicking here:

<https://www.youtube.com/user/SarcomaFoundation/playlists>



Creating A Legacy



A charitable gift from your estate is a favored method of giving that enables you to achieve your financial goals and benefit the Sarcoma Foundation of America.

If you are considering making a bequest of a dollar amount or percentage of your estate to SFA, we recommend the following language: *I hereby give, devise and bequeath \$_____ or percent (____%) of my total estate, determined as of the date of my death, to the Sarcoma Foundation of America located at 9899 Main St #204, Damascus, MD 20872. The Sarcoma Foundation of America is a registered 501(c)(3) nonprofit organization (tax ID number is 52-2275294) and contributions are tax-deductible to the extent permitted by law.*

Please contact Christopher Vance at cvance@curesarcoma to receive your confirmation letter.

Upcoming Events

We have started to plan for 2021. Below are tentative dates for our RTCS events. We hope to have in-person events but new for next year, each event will have a live (if possible) component and a virtual component to allow for more participation. We also hope to add events in San Diego, Los Angeles and Washington, DC. If you are interested in joining the planning committee for any of these events, please email events@curesarcoma.org.



2021 Line Up

Atlanta- June (no date yet)

Milwaukee - July 10

Baltimore - August (no date yet)

San Francisco - August 1

Louisville - August 14

Denver - August 28

Houston - September 4

Kansas City - September 18

New Jersey - September 19

Philadelphia - October 2

Chicago - October 16

Richmond - October 23

Cleveland - October 30

Tampa - November 6

Nashville - November 15