



# SARCOMA SPOTLIGHT

JULY 2022



## Sarcoma Awareness Month and Beyond

*By Brandi Felser, Chief Executive Officer*

Each July, we recognize Sarcoma Awareness Month, honor patients and survivors, remember the loved ones we have lost, and raise awareness about sarcoma. We join as a community to amplify the voices and the needs of people diagnosed with sarcoma.

But many people still have never heard of sarcoma, including people newly diagnosed with the disease. In 2022, an estimated 17,000 people in the United States will be diagnosed with sarcoma, and over 7,200 people will die from this disease, 42% of diagnosed cases. And the sarcoma community continues to tackle the same issues. The need for more research funding, lack of awareness, and more and better treatment options.

It is not enough to simply raise awareness – we have to turn awareness into action.

Previously I wrote:

*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 as a community to better the lives and outcomes for sarcoma patients.*

Let's use our collective voice and take action.

What can you do?

Sign up for SFA's advocacy network and public policy committee. Let's work together to advocate for research, education and policy issues that are important to the community and will lead to more and better therapies and ultimately a cure.

Support sarcoma research funding. SFA asked the sarcoma community for feedback regarding needs in the sarcoma community. The top of the list was new therapies and ultimately the cure for sarcoma. The path to a cure is research, and research is the heart of SFA.

Join SFA, and other organizations', education sessions to become an educated advocate, and sign up to participate in research projects and collaborations.

Follow SFA on social media and share information about sarcoma, patients and actions that are being taken to reach more people, and to lift the voices of sarcoma patients and survivors.

Send us your video, story, or pictures so we can share your voice with the broader community to highlight the needs of patients and caregivers.

These are some actions we can take, together, to improve outcomes. Certainly, there is more we can do. The month of July is a time for the community to join forces, to unite to create change for the sarcoma community. But not just this month. Every month.

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Wear yellow on Wednesday, July 20 to show support for the sarcoma community.

Post your picture and why you are a sarcoma supporter. Use the hashtags:  
#curesarcoma #sarcoma #SarcomaAwarenessMonth



## Research Roundup

## Publications of Interest

By Dean Frohlich, PhD, Director of Scientific Affairs

I would like to highlight the advancement of technologies that are, or soon may be having an impact on sarcoma diagnostics and treatment. In [this paper](#), the authors discuss recent advances in tumor testing that allow for better diagnosis of sarcoma tumors, which in turn allow for a more precise treatment plan. The authors also discuss advancements in radiation therapy technologies, which allow for more precise therapies. Next, two recently published research papers ([here](#) and [here](#)) highlight the potential utility of clinical genomic profiling in the diagnosis and management of sarcomas. These insights may additionally guide development of therapeutics and lead to improved clinical outcomes. These papers discuss some of the advances that are moving sarcoma treatments forward.

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## The Last Mile Sarcoma Research Award

In support of our overall mission to fund research and increase awareness and advocacy for sarcoma patients and their families, SFA is pleased to announce that we are continuing to expand our research investment and will launch, this month, the Last Mile Sarcoma Research Award. This research funding opportunity will provide one-year grants in the amount of \$150,000, to support translational science research on the etiology, molecular biology, pathogenesis, diagnosis, and treatment of human sarcomas.

This grant mechanism is available for sarcoma researchers to provide funding to strengthen the resubmission of a National Cancer Institute NCI R01 proposal where the member is the project director and principal investigator on the application. The name "The Last Mile" is derived from the many supporters who raise funds through our Race to Cure Sarcoma (RTCS) events and Marathon teams to support sarcoma research. And as this grant mechanism suggests, we are supporting the "last mile" to assist researchers in submitting a successful R01 application.

## Advocacy In Action

SFA would like to thank [Senator Johnson \(R-WI\)](#) for re-introducing a [Senate resolution](#) designating July Sarcoma Awareness Month. We appreciate and applaud his leadership on helping the sarcoma community raise much needed awareness about this devastating disease.

The official recognition of July as Sarcoma Awareness Month aides in raising awareness about sarcoma and this increased awareness can lead to earlier diagnoses and better treatment options.

Please [contact your Senators](#) and ask them to support [Senate Resolution S.Res.694](#) and sarcoma patients and survivors.

## SFA News

Sarcoma Foundation of America in partnership with [Jordan's Dream Fund](#) is excited to announce the launch of a new grant, [Jordan's Dream Fund for Clinical Trials](#), to help assist with direct expenses related to transportation (airfare, gas, rental cars, etc.), lodging, and some medical expenses not covered by insurance and necessary for clinical trial treatment. *Applications for the grant will open in July.*



JDF JORDAN'S DREAM FUND



Jordan's Dream Fund was established in 2017 after the passing of 28-year-old Jordan Andrew Singer (1988-2017). While fighting an inspirational five-year battle with epithelioid sarcoma, Jordan befriended other survivors engaged in their own battles with sarcoma and realized that so many of their struggles are often overlooked by the larger population due to the rarity of the disease.

Jordan was extremely appreciative that he was able to receive the best care in the world, thanks to the generosity and love of his family. He had a strong support system from his adoring wife, his parents, his siblings and an extended network of family and friends. Additionally, he had the resources to pursue treatment opportunities at outside cancer centers. Without a doubt, having these options helped extend his life and bolstered his resolve to fight the disease, but he also realized that not everyone had these advantages.

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301.253.8687 • [curesarcoma.org](http://curesarcoma.org)

## Jordan's Dream Fund for Clinical Trial Participation

As the leading private funder of research in the sarcoma community, it is our goal to advance more and less toxic treatment options for sarcoma patients. To this end, it is vital that patients have access to clinical trials. Often, sarcoma patients must travel or pay out of pocket expenses to participate. SFA receives inquiries from patients of all ages, from across the country, needing assistance for information about and access to clinical trials and sarcoma specialty centers. We realize the desperate need in the sarcoma community. To assist patients with this burden, SFA is partnering with Jordan's Dream Fund to provide financial reimbursement for direct expenses related to clinical trial participation.

One of the goals of Jordan's Dream Fund is assisting patients in fighting their disease to help them realize better outcomes and live long, fulfilling lives. One way the organization is committed to doing this is by providing financial assistance so people who need help, can access the care they need.

In memory and honor of their loved one, Jordan, who passed away from epithelioid sarcoma at the age of 28, Jordan's Dream Fund is investing in the lives of sarcoma patients across the country.

Together, SFA and Jordan's Dream Fund has created a special "Jordan's Dream Fund for Clinical Trials". This fund will be used to provide financial assistance to patients diagnosed with sarcoma, so they are able to participate in clinical trials.

To qualify, patients complete an application process and once qualified, work directly with SFA to obtain the assistance needed.

Applications for this program will open later this month.

## 2022 Sarcoma Research Grant Awards

SFA has awarded almost \$1 million in research funds as part of the SFA 2022 sarcoma research funding cycle. Thanks to the dedication of our many supporters, we were able to increase our grant awards from 15 to 19. This made it possible to expand funding into many different subtypes.

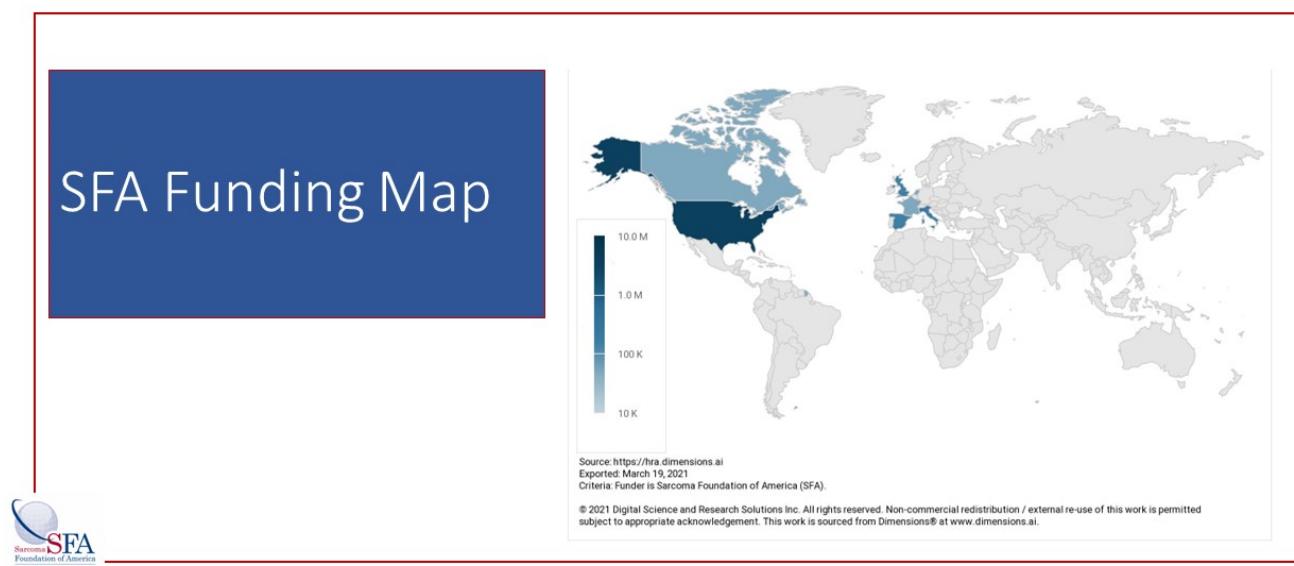
**Tumor Types:** Osteosarcoma (6), Undifferentiated Pleomorphic sarcoma (UPS) (4), Uterine Leiomyosarcoma (3), Ewing Sarcoma (2), Liposarcoma (2), Non-uterine Leiomyosarcoma (2), Alveolar Soft-Parts Sarcoma (ASPS) (1), Angiosarcoma (1), Chondrosacoma (1), Clear Cell Sarcoma (1), Fibrosarcoma (1), Mesenchymal Chondrosarcoma (1), PEComa (1), Rhabdomyosarcomas (1), Synovial Cell Sarcoma (1).

Grants were funded in **seven different countries**: United States (12), United Kingdom (2), Italy (2), Canada (1), Switzerland (1), Germany (1), Netherlands (1).

SFA is honored to support the work of the exceptional researchers that have been selected to receive a 2022 research grant award. We believe their efforts will contribute to increasing scientific understanding of sarcoma and can help lead us to advancements in the treatment of the disease. Our investment in their work is a continuation of SFA's mission to fill the research funding gap and make progress in the pursuit of discovering the cure for sarcoma.

Thank you to SFA's Medical Advisory Board Members for peer reviewing these grants and helping SFA advance important research.

Visit our [website](#) to see the 2022 grant awards and previously funded research.

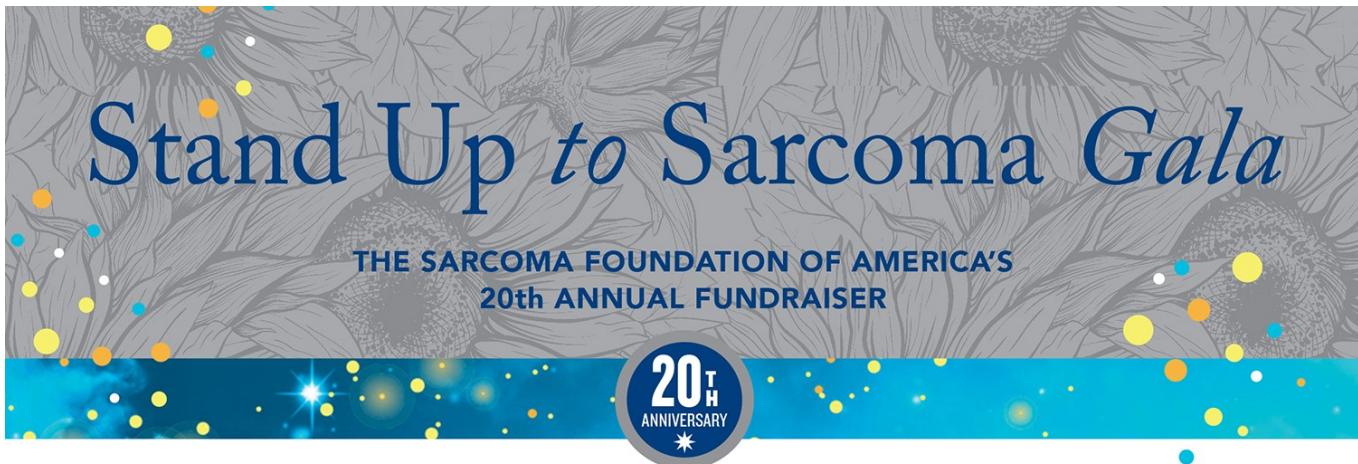


## Health Research Alliance 2022 Funding of Sarcoma Research to Date

Organization	Grants	Funding amount
Sarcoma Foundation of America (SFA)	19	\$949,000
American Cancer Society (ACS)	2	\$887,000
St. Baldrick's Foundation (SBF)	1	\$500,000
American Association For Cancer Research (AACR)	2	\$100,000



## Stand Up to Sarcoma Gala



# Save The Date

**SEPTEMBER 28, 2022**  
**EDISON BALLROOM • NEW YORK CITY**



Stand Up to Sarcoma, now in its 20th year, is the flagship event for SFA, featuring extraordinary

honorees, tributes to sarcoma cancer survivors and advocates, and recognizing important advances in science and research. The event takes place September 28 from 6:00 PM to 10:00 PM at the Edison Ballroom in Manhattan.

We sincerely hope you will join SFA in recognizing the honorees, sarcoma patients and survivors, and share in an evening of warmth and celebration as we gather attendees from coast to coast, and internationally, to join in solidarity to support sarcoma patients and survivors.

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.

SFA also awards the Compassionate Care Award to a patient navigator (clinical/nurse, community health worker, social worker in the role of a navigator) for his or her outstanding contributions to patient care, support, and education. Sarcoma is a challenging disease to navigate alone, and many sarcoma patients need additional support.

The 2022 Stand Up to Sarcoma Gala will be a hybrid event allowing guests to join in person and virtual. Funds raised from the Stand Up to Sarcoma gala will be used to support research and education

To learn more about the event or to purchase a ticket or become a sponsor, please visit [curesarcoma.org/nyccelebration](http://curesarcoma.org/nyccelebration).

## **2022 Stand Up to Sarcoma Honorees**

### **Vision of Hope Honoree**

Adaptimmune Therapeutics

### **Nobility in Science Honoree**

Crystal Mackall, MD

Ernest and Amelia Gallo Family Professor of Pediatrics and Medicine, Stanford University

### **Courage Award Honorees**

Technoblade

Todd Baron

### **Compassionate Care Honoree**

**Devon Ciampa, LCSW-C, OSW-C**

Clinical Social Worker, The Johns Hopkins Children's Center

Devon was nominated for this award by the family of Officer Spencer Butler Wiersberg. In their words "Devon understood the unique struggles Spencer was facing, both as a cancer patient and as a young adult professional. She tirelessly helped us do the behind the scenes work to benefit Spencer so that all he saw was a seamless, united front of people who love him. Devon is one of the blessings we continue to carry with us from the worst time in our lives."

# **Race to Cure Sarcoma**



## Join the sarcoma community for the National Virtual Race to Cure Sarcoma event on July 23!

During Sarcoma Awareness Month, SFA organizes a campaign to galvanize the sarcoma community and increase awareness about the disease. One of the ways we do this is by hosting the National Virtual Race to Cure Sarcoma, inviting sarcoma patients, families, friends, caregivers, and supporters to join in the effort to advocate for more and better sarcoma treatment options by participating in the race from any location they choose.

Last year, thousands of people participated and hundreds of thousands of dollars were raised in support of sarcoma research. Join us again this year to raise awareness about the needs of the sarcoma community and funds to support much needed research.

The 2022 event will take place on Saturday, July 23. Participants can walk, run, or bike, inside or outside, with family or with friends, to support sarcoma research. Even though participants may be in distant locales, this race is a chance for all to come together in spirit and honor sarcoma patients and survivors and remember the loved ones that have been lost to this devastating disease.

We will host a live virtual program on event day and will be awarding top team fundraisers and individual fundraisers, most team participation!

We invite you to be a part of this national effort and [register](#) for the National Virtual Race to Cure Sarcoma.

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### TEAM SPOTLIGHT: MILES FOR MILLIE

**Miles for Millie** joined the RTCS Atlanta for the first time this year and, boy, did they start with a bang. With 39 team members, they won the award for largest team, while bringing in close to \$1500.

After being misdiagnosed with an ear infection for over a month, eight weeks before Millie's third birthday, she was diagnosed with embryonal rhabdomyosarcoma, a soft tissue childhood cancer. An MRI confirmed that Millie had a tumor at the base of her skull and evidence of disease in her lungs.

According to Millie's doctors, the tumor was treatable and believed to be curable with prompt, aggressive chemotherapy and proton radiation. Millie started a grueling treatment regimen, the tumor had shrunk, and the news was good. Until it wasn't. On December 11, 2020, Millie's family learned that the cancer had returned and spread throughout her entire body. The family still hoped for the best and explored all avenues- clinical trials, every treatment option available and many holistic options; but, unfortunately, Millie passed away on February 8, 2021.



What motivates the family and team? Team captain and Millie's aunt, Kathleen Murray, says they are motivated by "the idea that no parent should have to hear the words – the science just isn't there yet. We've run out of options." This is why we race.

Miles for Millie has no plans to slow down! They will be participating in RTCS Nashville 2022 and hoping to bring an even bigger team to Atlanta 2023!

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# Race <sup>TO</sup> Cure **SARCOMA**

SARCOMA FOUNDATION OF AMERICA

## SAVE THE DATE FOR 2022!

Atlanta - April 23  
Baltimore - October 8  
Chicago - October 29  
Cleveland - June 25  
Denver - August 20  
Houston - September 10  
Kansas City - June 11  
Los Angeles - October 9  
Louisville - August 27  
Milwaukee - July 9

Nashville - November 5  
National Virtual - July 23  
New Jersey - October 2  
Philadelphia - September 24  
Richmond - June 11  
San Diego - September 24  
San Francisco - May 21  
St. Louis - October 9  
Tampa - November 12

[Register for an RTCS event!](#)

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