

# Sarcoma Foundation of America

*Annual Report 2019*





# AR19

## A MESSAGE FROM SARCOMA FOUNDATION OF AMERICA LEADERSHIP

Dear Friends,

Thanks to your support, in 2019 we advanced our work in fostering and funding research, growing awareness, and educating patients and others about sarcoma research, therapies and clinical trials. We broadened the Race to Cure Sarcoma series, an important event for the sarcoma community as it brings together survivors, family members and friends to connect and raise awareness about sarcoma.

We realized our highest single funding of sarcoma research in a single year, investing \$2 million to find new and better therapies for sarcoma patients. This investment funded 15 grants through our grant program, sponsored a Career Development Award and a Young Investigator Award through the Conquer Cancer Foundation, committed money to support translational research from a clinical trial in partnership with Duke University Medical Center, and invested nearly \$500,000 to support other sarcoma organizations/centers in advancing their missions.

SFA testified at an FDA public meeting in support of Tazemetostat, the first therapy for epithelioid sarcoma, and this advocacy effort played a role in its June 2020 FDA approval. Additionally, we continue to partner with industry by making our community aware of new and exciting treatments for sarcoma and encouraging patients to participate in their clinical trials.

We offered education conferences, became an official advocacy partner to NCI's My Pediatric Adult Rare Tumor (MyPart) Network, sent advocates to Capitol Hill to advocate for more research funding for rare and childhood cancers.

There is more detail throughout this report as to SFA's programs and 2019 accomplishments. I hope you are as proud as I am of our work on behalf of sarcoma patients, and I hope you will continue to stand with us as we continue to work to conquer sarcoma.

Sincerely,

*Mark Thornton*

**MARK THORNTON, MD, PhD**  
*President, Board of Directors*

The mission of the Sarcoma Foundation of America (SFA) is to advocate for sarcoma patients by funding research and by increasing awareness about the disease. The organization raises money to privately fund grants for sarcoma researchers and conducts education and advocacy efforts on behalf of sarcoma patients.



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# Advancing Our Mission

## RESEARCH

With a goal of finding the cure for sarcoma in our time, research and new therapy development is at the core of SFA's mission. In 2019, SFA invested more than \$2 million in sarcoma research, making it the single biggest year for research funding in the organization's history. SFA prioritizes investing in innovative research and fills the funding gap that may leave many of these projects unrealized. This work solidifies our position as one of the leading funders of sarcoma research in the United States.

## SARCOMA RESEARCH GRANT PROGRAM

In 2019, SFA funded 15 research awards through our Sarcoma Research Grant Program. These awards supported researchers at institutions throughout the United States and internationally. The awards also reflected an increased focus on immunotherapy in sarcoma. You can see all of the grants awarded in 2019 and previously on SFA's website [www.curesarcoma.org/research](http://www.curesarcoma.org/research).

## MULTI-YEAR AWARDS FOCUSED ON UTERINE LEIOMYOSARCOMA

Building on our investment in research in this highly aggressive subtype of sarcoma, SFA continued funding two multi-year projects in uterine leiomyosarcoma (ULMS). Conducted by researchers at Memorial Sloan Kettering Cancer Center and at Stanford University, these two projects combined total \$1.25 million in funding for ULMS.

## COLLABORATIVE RESEARCH

SFA makes it a priority to join forces with other organizations who share a common interest in investing in sarcoma research. In 2019, SFA once again sponsored a Career Development Award through the [Conquer Cancer Foundation](#), the charitable arm of the [American Society for Clinical Oncology](#). This award supported the work of Matthew Ingham, MD, of the New York-Presbyterian and Columbia University Irving Medical Center. SFA also provided \$100,000 to support a trial sponsored by SARC and led by David Kirsch, MD, of Duke University. SFA's funds helped support a correlative component of the trial looking at adding immunotherapy to standard of care radiation and surgery for dedifferentiated liposarcoma and undifferentiated pleomorphic sarcoma.

## RESEARCH LAB SUPPORT THROUGH THE RACE TO CURE SARCOMA

A portion of funds raised through the Race to Cure Sarcoma series are provided to partner sarcoma centers to support their research efforts. In 2019, SFA awarded nearly \$500,000 to sarcoma labs at 10 institutions.



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## *Advancing Our Mission*

### **EDUCATION, ENGAGEMENT & ADVOCACY**

SFA believes that having an educated, engaged, and empowered patient community is one of the keys to facilitating progress in sarcoma research and treatment. In 2019, SFA's programming included educating patients, survivors, and caregivers and representing their needs with legislative, regulatory, and industry stakeholders.

### **EDUCATION**

SFA supported educational conferences at sarcoma centers featuring sessions by sarcoma experts on topics related to treatment, clinical trials, advancements in therapy, and mental health issues for patients. SFA also contributed to educating patients by providing updates and analysis of research efforts to the sarcoma community through email advisories, the SFA newsletter, and social media platforms.

### **ENGAGEMENT**

SFA served as a representative of the sarcoma patient voice at meetings, conferences, and in cancer and rare disease coalitions. Over the course of 2019, SFA engaged with other important stakeholders at, among other events, the American Society of Clinical Oncology's annual meeting, the National Organization for Rare Disorder's yearly meeting, and the National Institutes of Health's Rare Disease Day conference, which for the first time had a focused track on rare cancers with a significant focus on sarcoma.

SFA also became an advocacy partner for the National Cancer Institute's My Pediatric Adult Rare Tumor (MyPart) Network. MyPart Network is a group of patients, family members, researchers, advocates, and healthcare providers working together to find treatments for childhood, teen, and young adult rare solid tumor, and includes several subtypes of sarcoma. The study follows people over the course of their disease to learn how these tumors develop and to discover treatments.

### **ADVOCACY**

As a patient advocacy organization, the SFA takes every opportunity to engage with those who have an influence over sarcoma research and drug development. In December, SFA took part in a meeting of the Food and Drug Administration's (FDA) Oncologic Drugs Advisory Committee meeting regarding the application for Epizyme's epithelioid sarcoma therapy, tazemetostat. In addition to submitting public comments

for the record, SFA's Executive Director, Brandi Felser, delivered a public statement at the meeting urging the committee to recommend approval of the therapy. The committee did recommend approval and in January the FDA approved tazemetostat, making it the first therapy approved for epithelioid sarcoma.

SFA not only serves as an advocate on behalf of the sarcoma community, we also work to ensure that patients and survivors play a significant role in advocating for change. Former Rep. Sean Duffy (R-WI) introduced a resolution officially recognizing July as Sarcoma Awareness Month. Rep. Duffy was inspired to take up this issue thanks in large part to one of our active grassroots advocates.

SFA provided scholarships to advocates to travel to Washington, D.C. to participate in action day events to bring attention to issues impacting sarcoma patients and their families, including federal funding for cancer research. Advocates were a part of both the Alliance for Childhood Cancer's Action Days and the One Voice Against Cancer Lobby Day.



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## Advancing Our Mission

### EVENTS

#### RACE TO CURE SARCOMA SERIES

The Race to Cure Sarcoma is the premier run/walk series in the United States focused on raising awareness and research funds for sarcoma. Sarcoma patients, survivors, their friends and loved ones come together as a community to support innovative research for better treatments and an end to sarcoma. Partnering with local treatment and research facilities in

cities across the United States, SFA raises money to fund research on both the local and national levels. The Race to Cure Sarcoma also creates awareness for the disease and helps to promote a sense of community among those whose lives have been impacted by sarcoma.

The 2019 Race to Cure Sarcoma series showed exceptional growth. A new event was started in Louisville, Kentucky and the existing events

surpassed their 2019 goals. Overall over 7,000 people participated in the Race to Cure Sarcoma (RTCS) events across the country and we raised over \$1,000,000. We also received increased requests to bring the series to new cities and will add two new cities to the lineup in 2020.

#### 18TH ANNUAL NEW YORK GALA

The Stand Up to Sarcoma event builds upon SFA's mission by establishing connections among sarcoma patients and survivors, their families, and the medical community. The SFA relies on the devotion and support of donors and friends to make this important evening a success in raising funds for our mission.

Each year the SFA recognizes individuals who have battled sarcoma and those who have dedicated themselves to making a difference for sarcoma patients and their families. In 2019, Serena Burla, Connor Chin, Kennedy Cobble, Nicholas Dubrul, Amanda Levine, and Alexandros Souris were recognized with the Courage Award for their advocacy work in the sarcoma community. We were proud to honor Patrick J. Boland, MD, FRCS(I), FACS with the Nobility in Science Award and Roberta Sales with the Compassionate Care Award in honor of their devotion and care to the sarcoma patients they serve.

Amira Yunis was honored with the Vision of Hope Award. The Vision of Hope Award is presented to a person or organization whose achievements provide increased hope for better

patient outcomes. Awardees receiving this honor have contributed in a significant way to the advancement of care, treatment, and hope for sarcoma patients.

#### SARCOMA PATIENTS AND FAMILIES SUPPORTING SARCOMA

Our lifesaving work would not be possible without sarcoma community members across the country who give their time and talent to activities that support our mission. Their efforts help us to fund innovative research, educate patients, survivors and family members and raise awareness about the needs of the sarcoma community. With countless ways to engage and raise critical funds they are truly making a difference. SFA is thankful for the many supporters across the country who raise money through events, birthday celebrations, memorial pages and other activities.

#### Some highlights of these are:

Many families and groups host golf tournaments to support SFA and sarcoma research, education and awareness. Fifteen golf tournaments were held in 2019 and many are annual events such as the 2nd Annual Zach Cohen Golf Tournament raised over \$190,000 and NFL player Jared Goff participated in the "My Cause My Cleats" campaign in memory of Zach and the 15th annual golf tournament held in memory of Marcia Brodsky hosted by her son Mike.

Our "Raise Your Way" page has allowed supporters to create their own fundraiser and track their donations. One of these events was called "Family



Night at the Fairgrounds". A high school senior who lost her brother to sarcoma decided to use her senior service project to raise money for SFA. She hosted an event at a local fairground where she created games, activities, and donated all of the proceeds to this event in memory of her brother, raising over \$8,000.

- "Strike Out Sarcoma", put on by SFA and Onkois. This event brought in over \$10,000 and took place at the New Jersey Somerset Patriots baseball field. It was an evening

dedicated to sarcoma awareness at the ballpark. This was a continuation on the long-standing relationship between SFA and Onkois that stemmed from their previous involvement in the Race to Cure Sarcoma Virtual events.

#### **OUTREACH FOR AWARENESS**

The Sarcoma Awareness Month PSA aired in late June and all of July 2019. More than 200 stations ran the PSA, with a total of more than 11,000 airings. Based on assumed audience sizes it is estimated that the airings

reached more than 16 million listeners. The "Sarcoma Heroes" PSA started airing on radio stations throughout the US in August 2019. More than 300 stations ran the PSA, with a total of more than 33,000 airings. Based on assumed audience sizes it is estimated that the airings reached more than 41 million listeners. SFA staff and representatives spoke at important sarcoma education events and were highlighted for the National Football League's "My Cause My Cleats" efforts for the third year. The "My Cause My Cleats" is a campaign that is hosted

by the NFL each year. Players are able to pick a nonprofit that they would like to highlight on their cleat design. The player's cleats are then auctioned off and the proceeds are donated to the chosen nonprofit.

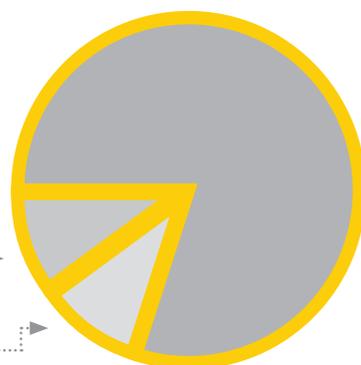
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## FINANCIALS

### FUNCTIONAL EXPENSES

|                  |                    |
|------------------|--------------------|
| PROGRAM          | \$ 2,637,111 (80%) |
| MGMT AND GENERAL | 343,493 (10%)      |
| FUNDRAISING      | 334,457 (10%)      |

TOTAL \$ 331,5061



### ASSETS

#### Current assets

|  |              |
|--|--------------|
| Cash and cash equivalents  | \$ 1,678,101 |
| Contributions receivable, net of allowance for doubtful accounts of \$25,000 | 160,357      |
| Prepaid Expenses   | 53,149       |

TOTAL CURRENT ASSETS \$ 1,891,607

#### Property and equipment

|                              |           |
|------------------------------|-----------|
| Leasehold improvements       | \$ 78,190 |
| Machinery and equipment      | 34,262    |
| Furniture                    | 13,443    |
| Website                      | 39,000    |
| Total property and equipment | 164,895   |
| Accumulated depreciation     | (68,467)  |

NET PROPERTY AND EQUIPMENT \$ 96,428

Investments \$ 5,371,823

#### Other assets

|                    |        |
|--------------------|--------|
| Donated jewelry    | 10,000 |
| Deposits           | 5,466  |
| Total other assets | 15,466 |

TOTAL ASSETS \$ 7,375,324

# Your Support

### LIABILITIES

|                                   |            |
|-----------------------------------|------------|
| Current liabilities               |            |
| Grants payable                    | \$ 774,265 |
| Accounts Payable                  | 38,188     |
| Accrued Expenses                  | 51,541     |
| Deferred lease incentive, current | 10,546     |

TOTAL CURRENT LIABILITIES \$ 874,540

#### Long term liabilities

|                                      |           |
|--------------------------------------|-----------|
| Deferred lease incentive, noncurrent | \$ 55,367 |
|--------------------------------------|-----------|

TOTAL LIABILITIES \$ 929,907

### NET ASSETS

|                                       |              |
|---------------------------------------|--------------|
| Without donor restrictions            |              |
| Designated by the board               | \$ 1,118,245 |
| Designated by the board for endowment | 312,567      |
| Total designated by the board         | 1,430,812    |
| Undesignated                          | 2,637,445    |
| Total without donor restrictions      | 4,068,257    |
| With donor restrictions               | 2,377,160    |

TOTAL NET ASSETS \$ 6,445,417

TOTAL LIABILITIES AND NET ASSETS \$ 7,375,324

### REVENUE

|   |              |
|---|--------------|
| Grants and contributions  | \$ 1,273,503 |
| Special events net of costs of direct benefits to donors (2,534,938 -489,209) | 2,045,729    |
| Investment gain   | 636,240      |
| Other   | 13,772       |

TOTAL REVENUE \$ 3,969,244



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