



Sarcoma Spotlight

February 2022

2022 is off to a great start at SFA and we look forward to continuing and expanding our work. This year, we will continue our efforts to develop a scientific research plan that will increase our impact, with a goal of providing more rapid and targeted advancements. We plan to expand our research funding to provide more research funding and leverage current investments in sarcoma research.

Our strong education and engagement program that supports patients, family members and health care professionals will include updates and analysis of research efforts through email advisories, the SFA newsletter, and social media platforms. In addition, SFA will offer quarterly educational webinars on topics that are important to sarcoma patients and the medical community and which highlight promising research and new therapies. Our 2022 education series will launch this month.

SFA will grow our Race to Cure Sarcoma series to increase engagement within the sarcoma community and sarcoma awareness, partner with other organizations to create PSA's educating people about sarcoma subtypes and patient's needs, and offer better information and access to clinical trials.

We have already supported public policy initiatives in 2022 like the Pediatricians Accelerate Childhood Therapies Act (PACT Act), H.R. 3773/S. 1357, and the Access to Rare Indications Act (H.R. 6160). We will continue to monitor and support issues affecting the sarcoma community.

SFA's research, awareness, and advocacy efforts are essential components of our efforts to bring forward more and better therapies and information about, and access to, treatments for sarcoma patients, ultimately leading to a cure for sarcoma.

Research Roundup

In review of 2021, we would like to take this opportunity to highlight three publications, the research for which, SFA partially funded. First is a paper entitled, "[Unmasking BCL-2 Addiction in Synovial Sarcoma by Overcoming Low NOXA](#)" by Fairchild, et al. Synovial sarcoma is known to be driven in part by increased expression of the pro-survival protein called BCL-2, however synovial sarcoma has thus far proven to be resistant to BCL-2 inhibitors in pre-clinical trials. These researchers identified that increased activity of a second pro-survival protein, MCL-1, is responsible for this resistance. They demonstrated that targeting both BCL-2 and MCL-1 proves to be an effective therapeutic approach both in cell culture and animal models of synovial sarcoma. This research will have to be supported by translation into clinical trials, but offers encouragement for a possible treatment for synovial sarcoma.

Second is paper entitled, "[CD4+ T cell and M2 macrophage infiltration predict dedifferentiated liposarcoma patient outcomes](#)" by Schroeder et al. In this study, the researchers looked at previous patients to determine if specific Immune cells in the tumors of dedifferentiated liposarcoma patients treated with a type of immunotherapy called PD1 inhibitors predict clinical outcomes. They found that a certain type of white blood cell called CD4+ cells are associated with better outcomes and white blood cells called CD14 + cells and M2 macrophages are associated with worse outcomes. This indicates that future studies of these kinds of treatments may want to include immunosequencing and gene expression profiling techniques to identify which patients are likely to respond to treatment.

In the third paper, from Klemen et al. entitled, "[Long Term Follow-up and Patterns of Response, Progression and Hyperprogression in Patients after PD-1 Blockade in Advanced Sarcoma](#)", the researchers found that PD-1 blockade can

mediate durable responses in patients with advanced sarcoma. They also found that hyperprogressive disease (HPD), in which tumor growth is accelerated by treatment with checkpoint inhibitors, occurs in sarcoma at similar rates to what has been reported in other solid tumors, but patients with HPD were clinically and biologically similar to those who had progressive disease. Further research is required to determine if HPD is distinct from progressive disease and if patients with HPD should be managed differently than those with progressive disease.

Sarcoma Education Session

Join us on Rare Disease Day 2022 for the Sarcoma Foundation of America's next Live Expert Discussion:

Genomics in Sarcoma
Monday, February 28, 2022
7:00 pm EST

On Monday, February 28, SFA will host a panel of sarcoma experts who will discuss genomic testing in sarcoma treatment. Areas to be discussed include a background on genomic testing, current state of genomic testing for accurate diagnosis and identifying treatment options, and a discussion of if, and how, genomic testing may help with treatment in the future.

Registration

To join the discussion, [register here](#) and submit any questions you may have in advance. You can also submit questions through the Q&A feature during the event and anytime on social media using the hashtag #SFAResearchRoundup.

Panelists:



Compassionate Care Award

Nominate a Patient Navigator for the 2022 Compassionate Care Award!

Every day, navigators are making a difference in the lives of sarcoma patients. SFA is excited to honor these men and women with the Compassionate Care Award at the [2022 Stand Up to Sarcoma Gala](#).

The Compassionate Care Award recognizes a navigator (clinical/nurse, community health worker, or 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. Navigators assist patients from diagnosis to survivorship, helping them understand their condition and treatments as well as manage side effects; coordinate care among medical specialists; and connect patients to available community resources to overcome barriers to care. They can also help patients manage their psychosocial needs, such as work, school and home environments; relationships; mental and emotional health; and financial concerns.

SFA recognizes the important role these individuals play in the sarcoma patient journey and would like to celebrate their outstanding support of sarcoma patients.

Do you have an outstanding navigator that you think should be honored?

[Complete the nomination form here by March 31, 2022!](#)

Advocacy in Action

SFA joined the Alliance for Childhood Cancer and 19 other organizations to support the [Pediatricians Accelerate Childhood Therapies Act \(PACT Act\), H.R. 3773/S.1357](#). This bill would create a new Trans-NIH career development award focused on early-career pediatric researchers. The endorsement letter can be viewed [here](#).

We also joined The Haystack Project and other groups to support the [Access to Rare Indications Act of 2021](#). This bill will ensure that insurers look at more than just the label to decide if something is "medically necessary" for rare patients. The letter can be viewed [here](#).

The Alliance for Childhood Cancer (SFA is a Member) is hosting a **Virtual Action Day on April 28, 2022**. This important day of Action gives you an opportunity to speak with your members of Congress and their staff virtually to advocate for important childhood cancer issues before Congress. Sharing your story will ensure the voice of children with sarcoma is heard loud and clear on Capitol Hill. You can learn more or sign up [here](#).

Advocates Raising Funds for Research

Ashley Fundack describes her brother Andrew as “a local hero” who selflessly served the community as a volunteer fireman. He was the first to show and the last to leave. He was talented, dedicated, loving, and funny. According to Ashley, “Andrew was a role model for the youth, had a big heart, and would give you the shirt off of his back. He was just one of the best persons you would ever want to meet. He was a fighter and never gave up even in the toughest of times. He always had his sister’s back. He was my buddy, my best friend, and my hero.”

Five months after his 24th birthday, Andrew was diagnosed with stage four rhabdomyosarcoma. Like most families, Andrew’s never gave much thought to cancer until they were thrust into the “belly of the beast.” After multiple rounds of chemotherapy and radiation worked to get some of the cancer under control, Andrew started therapy, learned how to walk again, regained his strength and got back to some semblance of a normal life.

In January of 2018, Andrew began getting headaches and experiencing dizziness. The family then received the worst news possible- the cancer had spread to his brain. Throughout the whole ordeal Andrew never gave up. He never lost his laugh, his smile, or his contagious spirit. He passed away on February 28, 2018, at the age of 25, less than one year after his diagnosis.

When Andrew was diagnosed, his family wanted to learn as much as possible about sarcoma. They were shocked to find out how underfunded and understudied it was. They heard about SFA and Ashley knew that she needed to become a part of the Race to Cure Sarcoma committee to help raise awareness about sarcoma. “My brother was my biggest inspiration and telling his story and helping others is a way to not only honor him but to help keep his legacy alive.”



Ashley and her family were instrumental in starting the Race to Cure Sarcoma Baltimore in 2020. Though the race was virtual for its first two years, Ashley has remained a committed participant on the committee. She is excited to be part of the first in-person Baltimore race in 2022, and determined to help find the cure so other sisters don’t lose their brothers, and other parents don’t lose their children.

Race to Cure Sarcoma Series 2022

SFA is looking forward to once again hosting the [Race to Cure Sarcoma](#) events in person in 2022. It has been too long since we have been able to gather together. This year, barring any decisions out of our control due to the pandemic, all races will be hosted in person. We understand if you are uncomfortable joining us in-person for one of these events. Our National Virtual race will take place July 23rd, during Sarcoma Awareness Month, to allow the sarcoma community to participate if there is not a race close by, for community members who are uncomfortable attending in-person, or for members who are unable to make their city’s race date.

The [Race to Cure Sarcoma](#) series is important to advancing sarcoma therapies and treatments and we hope you will join us for one of these events. The series kicks off in Atlanta on April 23. [Registration](#) is open for all confirmed cities.

If you are interested in being on a committee for one of our current cities, or starting a race in your area, please reach out to us at events@curesarcoma.org.



SAVE THE DATE FOR 2022!

Atlanta - April 23	Milwaukee - July 9
Baltimore - May 21*	Nashville - October 22*
Chicago - October 29*	National Virtual - July 23
Cleveland - June 25	New Jersey - October 2
Denver - August 20	Philadelphia - September 24
Houston - September 10	Richmond - June 11
Kansas City - June 11	San Diego - September 24*
Los Angeles - November 19	San Francisco - May 21
Louisville - August 27	Tampa - November 12

*Projected date/month

Save the Date: Stand Up to Sarcoma Gala



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