THE YEAR AHEAD
We want to hear from you!

While COVID is still a reality, we are optimistic about 2021 and look forward to continuing to bring the sarcoma community together and being a voice for sarcoma patients.

In December, we hosted a call with members of SFA’s Medical Advisory Board to begin the process of reviewing our research funding and developing a scientific strategic plan. As an organization, we are assessing our role in the sarcoma community and how we can be more effective and accelerate progress in sarcoma research and new therapies. There has been progress in the therapeutic environment but there is still more to do.

Last year, the Race to Cure Sarcoma events were forced to be held virtually. While that did not allow us to come together as a group, there was a silver lining. The virtual component allowed members of the community, who would not have otherwise been able to participate, to join these important events. This year, SFA plans to bring people together through the RTCS event series and is hoping to have in person events with a virtual component. The goal is to bring as many people together as would like to participate. We will leverage technology to make that happen as we did last year with all of our virtual events. We appreciate the support from the sarcoma community in 2020 as these events provide significant funding for sarcoma research.

Partnerships and collaborations with the scientific community and industry, between sarcoma focused organizations, and with advocates are important to ending this disease. That is why, SFA will develop ways to bring together the sarcoma community to help increase awareness, and also to engage with SFA on our
research and education efforts. Funding research is the heart of SFA, but we also must share information about advancements, promising research and new therapies and clinical trials. SFA will host webinars that share important information for patients.

SFA participates with several sarcoma and cancer focused groups as related to public policy. We monitor issues that are important to patients and research and we participate in lobby days and act on these issues. Advocacy surrounding issues that impact patients is important if we are going to end sarcoma. This year, SFA will help patients connect to important issues and advocate for the sarcoma community.

**SFA would like to hear from you! What are the greatest needs in the sarcoma community and what should the priorities be for 2021:** more education; increased information about clinical trials; greater opportunity to come together for advocacy? [Let us know!](#)

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**Research Roundup**

In 2020 solid progress was made in sarcoma research. In SFA’s [Research Review: Promising Research Advancements in Sarcoma](#) video, several sarcoma researchers discuss advancements in gastrointestinal stromal tumors (GIST), soft tissue sarcoma, immunotherapy in sarcoma treatment, and bone sarcoma presented at the 2020 American Society of Clinical Research Annual Meeting.

In 2020 three drugs were approved for patients with specific tumors. The first is Ayvakit (avapritinib), for adults with unresectable or metastatic GIST with a specific tumor mutation. The second is Qinlock (ripetinib), a first fourth line treatment in advanced GIST. The third is Tazverik (tazemetostat), a first treatment option specifically for patients with epithelioid sarcoma.

Continuing progress is made all the time as is demonstrated by research published within the last month. First, The FDA has agreed, based on data from previous studies in patients with Desmoid tumors, to proceed with a Phase 2/3 pivotal study for the oral gamma secretase inhibitor (GSI) AL102. The pivotal Phase 2/3 RINGSIDE study in adult and adolescent patients with desmoid tumors is expected to begin in the first half of 2021. Second, a [more recent study](#) demonstrates that progress is being made all the time in determining genetic mutations that give rise to sarcomas.

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**Jessy's Story**

Jessy Tolkan’s brother Ben passed away of Ewing’s Sarcoma in 2020. This experience had a profound impact on Jessy and her family and drove her to give back and support the sarcoma community in honor of Ben.

“I think about Ben every single day. He was my younger brother and yet from an early age, I looked up to him. He understood how to prioritize the right things - he did not sweat the small stuff. It was important to him to live a good life – to have fun and friends. This personality trait made his battle with sarcoma easier because he would not get upset about things that he could not control. He continued to have fun, see every new movie, hang out with friends. As an aside, he loved Nike – he would get a new pair of Nikes every time he got chemo. By the time of his passing, he had amassed an amazing sneaker collection!”
Jessy says Ben is best described as someone who could literally light up any room he walked into – he had such a positive and engaging personality. People were drawn to Ben for his humor and charm.

When Ben passed away, many people reached out to the family wanting to share their memories of him. He left an indelible impression on those he met.

When Ben was diagnosed with Ewing’s sarcoma the family heard about SFA from a family friend. “We were drawn to SFA because of their strong research funding program.”

When Ben died, the family was at a loss. Jessy said her family felt a responsibility to honor Ben’s memory and continue the fight to find a cure for sarcoma. They were drawn to the mission of SFA and wanted to make sure to support the organization as much as possible so other people do not experience the loss they feel as a family.

“My brother was a person of action. From the day he was diagnosed he wanted to be as assertive as possible with his care. He found the best doctors and the most aggressive treatment. As such, we wanted to be as aggressive as we can in finding a cure and funding research, education and advocacy seemed like the best way to honor Ben. Ben is no longer here to inspire us. However, critical dollars raised bring inspiration, hope and life to everyone who is battling sarcoma. As a family, we will continue to honor Ben this way for as long as possible.”

Jessy and her family participated in both the Milwaukee and National Virtual Race to Cure Sarcoma events. They have had Facebook and GoFundMe fundraisers and just recently, a Washington, DC local pizzeria and craft brewery held a joint fundraiser. The artwork from this latest event is available at livingthedream.threadless.com. Over $70,000 has been raised to date.

“My desire and commitment to find a cure to sarcoma did not die with my brother. It is the ultimate loss and ultimate pain to watch someone you love to battle this rare cancer. I feel a deep commitment to channel that energy so nobody has to experience that pain.”

SFA is grateful for supporters like Jessy and her family. We appreciate the partnership and look forward to working together to find the cure in our time. Together, we can save lives.

Tribute giving is a way to recognize, honor and celebrate people and events that are important to you by giving back to others. You can support SFA’s research, advocacy and education programs through tribute giving. For more information, please contact donate@curesarcoma.org.
We are excited to announce the dates for the 2021 Race to Cure Sarcoma series. We are planning for in person events with virtual components to allow for more participation within the sarcoma community. The virtual events in 2020 allowed more members of our community and their friends and family to join these important gatherings.

Over the past few years, these events have grown into 15 in person events and one National Virtual event that span across the nation. Last year, these events raise over $927,000 and over 4,000 people participated from across the country.

This series is a vital part of the sarcoma community because it brings together patients, survivors, family and friends to raise money to support research, education and advocacy. It bonds the community and provides a place for sarcoma patients and their families to connect with others who are going through similar situations.

Save the date for one of our many in person events or join us virtually from any location! For more information, please contact events@curesarcoma.org.

Together, we can find the cure in our time!
SAVE THE DATE!

Atlanta - June 12
Milwaukee - July 10
National Virtual - July 24
San Francisco - August 1
Louisville - August 14
Denver - August 28
Baltimore - September (TBD)
Houston - September 4
San Diego - TBD

Kansas City - September 18
New Jersey - September 19
Philadelphia - September 26
Chicago - October 16
Richmond - October 23
Cleveland - October 30
Tampa - November 6
Nashville - November 20
Los Angeles - TBD

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