

Alex's Lemonade Stand Foundation Ewing Sarcoma Impact Report



AlexsLemonade.org



Alex's Lemonade Stand Foundation (ALSF) emerged from the front yard lemonade stand of 4-year-old Alexandra "Alex" Scott, who was fighting cancer and wanted to raise money to find cures for all children with cancer. Her spirit and determination inspired others to support her cause, and when she passed away at the age of 8, she had raised \$1 million. Since then, the Foundation bearing her name has evolved into a national fundraising movement and is one of the leading funders of pediatric cancer research in the U.S. and Canada.



With Gratitude

Dear Friend,

All of us here at Alex's Lemonade Stand Foundation (ALSF) would like to sincerely thank you for your support of Alex's mission to find new treatments and cures for childhood cancers like Ewing sarcoma.

Your support is helping researchers to develop preliminary data, publish their findings, and push forward innovative treatment options. Thanks to you, we are closer to a day where no child will have to suffer from Ewing sarcoma.

We are truly honored to fight childhood cancer by your side. Thank you for being the driving force behind life-saving cures! Please don't hesitate to reach out if you need anything from us here at ALSF.

Until there's a cure,

* pr

Liz & Jay Scott Alex's Parents & Co-Executive Directors *Alex's Lemonade Stand Foundation*



Thanks to Supporters Like You



Ewing sarcoma projects (and counting) have been funded since our founding

The ALSF support is 'keeping the lights on' in the lab and making us competitive for future NIH funding." — Dr. Craig Mullen, University of Rochester





Understanding fundamental processes is critical to developing new targeted therapies. We greatly appreciate ALSF's investment in myself, my research, and my vision."

> — Dr. Genevieve Kendall, Nationwide Children's Hospital



Meet a **Ewing Sarcoma Hero**

Name: Sam Favorites: Spending his days in nature, camping or hiking

In winter 2015, Sam wiped out while skiing and injured the area encompassing his hip and groin. His parents thought that ibuprofen



might resolve what seemed like a pulled muscle. At first the pain dissipated, but between gym class and fun with friends, it soon found its way back. As the pain grew more frequent and severe, Sam was sent from doctor to doctor to discover the issue. Eventually, a biopsy with an orthopedic oncologist revealed that he had cancer, and a pediatric oncologist narrowed it down to stage IV Ewing sarcoma.

With the sarcoma metastasized to his lungs, Sam only had a 30% chance of beating his cancer, but he never gave up. He started with nine months rotating on and off with intensive chemotherapy. After that, he moved onto a month of daily radiation treatment that concentrated on his primary tumor and lungs.

He spent all of eighth grade living away from home with his extended family while his parents traded off weeks in Denver at Sam's treatment and their hometown in South Dakota. Through it all, Samuel only spent three weekends at home, but he persevered.

Today, Sam is in remission, and his family couldn't be more excited to watch him thrive. His parents are in awe of the way he's managed to put his trials behind him.

Sam's family is grateful for organizations like Alex's Lemonade Stand Foundation that give hope, courage and strength to those who need it most. They appreciate the sense of community and support amongst people fighting for a cure. Now they share Samuel's success story with others to empower those still fighting.



Research Spotlight: New Projects in Ewing Sarcoma

Radiation and the Tumor Microenvironment in an Immunocompetent Model of Ewing Sarcoma Jessica Daley, MD, Children's Hospital of Pittsburgh

When Ewing sarcoma advances and spreads to other parts of the body (metastasizes), it is very difficult to cure. Patients with metastatic Ewing sarcoma often receive radiation to help treat the cancer. During radiation therapy, the body's immune system can help attack cancer cells. However, sometime this effect is suppressed. Dr. Jessica Daley is



using her newly awarded Young Investigator Grant to understand immune cell suppression during radiation with the hope that by reactivating the immune system, she can improve treatment response. The goal of her project is to improve survival for patients with aggressive Ewing sarcoma. She is working on gathering data that will help design clinical trials for patients with aggressive Ewing sarcoma that are undergoing radiation therapy. She's especially interested in therapies that help a patient's own immune system to attack their tumors following radiation.



Impact of STAG2 loss on DNA Damage and Immunobiology in Ewing sarcoma Kelly Bailey, MD/PhD, University of Pittsburgh

Ewing sarcoma is a cancer most often diagnosed in teenagers. Scientists know that some changes in the make-up of Ewing tumors make them more likely to be aggressive and spread to other parts of the body. When Ewing sarcoma spreads to other parts of the body, like the lung, it is very

hard to cure. Radiation can directly damage tumor cells in the lungs and can also "call" immune cells into the tumor to help attack cancer cells. Dr. Kelly Bailey and her team have found that some types of aggressive Ewing sarcomas send out signals for immune cells to "go away." Dr. Bailey's Innovation Grant, awarded last year, is focused on how some aggressive Ewing tumors quiet the immune system and figuring out how to turn this effect off in order to maximize the benefit of radiation for the treatment of Ewing sarcoma that has spread to the lung. Eventually, her research will improve the outcomes of teenagers diagnosed with metastatic Ewing sarcoma.

Novel Discoveries

Glenson Samuel, MD, 2014 Young Investigator Grantee

Past ALSF awardee Dr. Glenson Samuel of Children's Mercy Kansas City was awarded a Young Investigator Grant in 2014 to monitor disease progression and response to a novel therapy in Ewing sarcoma. He was particularly looking at small particles floating outside of cells called exosomes and using these exosomes as biomarkers to monitor the disease. Dr. Samuel has made a big splash in the field of Ewing sarcoma research by understanding how exosomes could hold the key to improving outcomes in patients.

Dr. Samuel discovered that the exosomes present in the blood of patients with confirmed cases of the disease by biopsy contained specific markers that are only present in Ewing sarcoma cancer cells. Dr. Samuel's discovery gives doctors another leg up on Ewing sarcoma treatment and has the potential to allow for better diagnostics, treatment customization and long-term monitoring. The overall goal of this discovery would be to use this biomarker during therapy to help doctors see when a treatment is working (there would be less exosomes in the blood) or not working (there would be more exosomes in the blood).

After treatment, this biomarker test could be used to detect recurrence of disease before cancer cells may appear on a MRI scan. Since testing for the biomarker requires just 1/20 of a teaspoon of blood, it is noninvasive and relatively easy to add to a child's routine clinic visit. In the future, the biomarker test could make the initial diagnosis of Ewing sarcoma faster and potentially help doctors avoid the need for invasive biopsies. "There is also the potential to apply what we are learning here to other types of pediatric sarcomas," said Dr. Samuel.









Thank You

for all you do to help kids with cancer!

