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,

Thanks to your thoughtful support, we have been able to find new discoveries for childhood cancer treatment. ALSF-funded researchers continue to develop breakthrough treatments, lead new clinical trials, and publish their findings in peer-reviewed journals. Thanks to you, we were able to make this progress, which has positively impacted the lives of children with cancers like Ewing sarcoma.

Our daughter, Alexandra "Alex" Scott, believed that if we all worked together, we could cure childhood cancer. That idea of collaboration is what inspired others to help her reach her $1 million fundraising goal. Her idea is the reason we are able to do what we do now. We are always amazed at what can be accomplished when you bring people together. ALSF, scientists, and you — we're all coming together for one common goal: to cure childhood cancer. Thank you for all you do in the fight against childhood cancer.

Until there are cures for all kids,

Liz & Jay Scott  
Alex's Parents & Co-Executive Directors  
Alex's Lemonade Stand Foundation
The 'high-risk, high-reward' studies that ALSF supported are some of the very studies that best represent me, our science, and serve as the platform for the work we have ongoing and propose for the future. It doesn’t escape me that the support from ALSF has been instrumental, and I extend my deep appreciation to ALSF for supporting our science from the very beginning.”
— Dr. Cigall Kadoch, Dana-Farber Cancer Institute

ALSF helped launch my research program 10 years ago and has supported my lab at every step along the way. Their investment in childhood cancer research has transformed the field and nurtured the development of a generation of childhood cancer researchers.” — Dr. Michelle Monje, Stanford University School of Medicine
Dr. Robin Parihar of Baylor College of Medicine is using his 2021 'A' Award Grant to better understand how the tumor environment of pediatric solid tumors like Ewing sarcoma decreases natural killer (NK) cell immune activity. These findings could be broadly applied to enhance NK cell immunotherapies in general. To address the inability NK cells have to survive, multiply, and stay activated to fight tumors, Dr. Parihar and his team have modified NK cells by genetic engineering technology in two unique ways that keep NK cells switched ‘on’ within the harsh tumor environment. They added an activating signal and deleted an inhibitory signal specifically within NK cells that should safely and durably maintain their activity. The team hypothesizes that these uniquely co-modified NK cells armed with a tumor-targeting protein called a chimeric antigen receptor (CAR) will multiply, survive, and kill cancer cells in the tumor environments of otherwise resistant childhood solid tumors. They will test these NK cells' ability to kill tumors in laboratory models of the tumor environment developed in their lab, and ultimately in children with advanced solid tumors. Dr. Parihar expects their findings would have the potential to increase response rates in future clinical trials of CAR-NK cells.

The Potential of Bromodomain Inhibitors in Ewing Sarcoma

Dr. Shireen Ganapathi of Seattle Children’s Hospital is using her 2021 Young Investigator Grant to improve therapies for adolescents and young adults with Ewing sarcoma who present with multiple tumors at diagnosis (metastatic) or have recurrence of their disease following initial treatment. The goal of her research is to identify different targeted drugs that can be safely used in combination and effectively treat high-risk Ewing sarcoma patients. Dr. Ganapathi and her team are trying to answer questions such as why certain tumors present in multiple sites, or why certain tumors are resistant to the treatments that they give. Bromodomain and extraterminal domain protein (BET) inhibitors are a class of drugs that alter a specific tumor’s ability to turn on genes that are critical for its survival and propagation. Many tumors show striking results with BET inhibitors in the lab, but, like many agents, are not curative alone. Dr. Ganapathi’s research will identify efficacious drug combination strategies with the BET inhibitor, BMS-986158, with a future goal of translating the most successful combinations to high-risk patients, and identify how Ewing sarcoma can escape BET inhibition to identify additional targets for treatment.
Thanks to you, we have been able to fund outstanding research, leading towards breakthroughs and cures. Read through some of our recently funded research projects in Ewing sarcoma below.

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<th>INSTITUTION / PRINCIPAL INVESTIGATOR(S)</th>
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<td>Exploiting the Potential of Bromodomain Inhibitors in Ewing Sarcoma</td>
<td>Seattle Children's Hospital / Shireen Ganapathi, MD</td>
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<td>Turning Killers into THINKers: TME Hostility-Impervious NK Cells for Treating Neuroblastoma and Sarcoma</td>
<td>Baylor College of Medicine / Robin Parihar, MD/PhD</td>
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<td>Stapled Peptide PROTAC: A 3-in-1 Treatment for Pediatric Solid Tumors</td>
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Click here to see a complete list of ALSF-funded projects in Ewing sarcoma
Meet Childhood Cancer Heroes

Malina was a normal toddler when she gradually stopped walking. Her parents took her to the doctor and emergency room repeatedly. They were told that Malina was being stubborn and acting out. An emergency MRI finally revealed that Malina had a mass in her spine, pushing on her nerves and cutting off all function from the waist down. Within an hour Malina, who was just 19 months old, was being prepped for spine surgery. Shortly after, Malina was diagnosed with Ewing Sarcoma. Her family enrolled her in a study led by ALSF-funded researcher Dr. Glen Samuel at Children’s Mercy Kansas City.

Each clinic visit, Malina gives one extra vial of blood. Dr. Samuel is using the sample to study the biomarkers of Ewing sarcoma that might make detection of reoccurring disease quicker and less invasive. Today, Malina is 5 years old and cancer-free. She recently was able to visit the lab where Dr. Samuel is studying Ewing sarcoma and see how her participation is making a difference for other children.

Jacob is a kid who knows how to keep his chin up. At 3 years old, he’s shown a lifetime’s worth of courage battling Ewing sarcoma. One night, Jacob climbed out of his crib and fell on his left arm. The next day he was experiencing neck pain, but a trip to urgent care suggested he had nothing more than a pulled muscle. The pain persisted, but again, the emergency room X-rays showed nothing out of the ordinary. It wasn’t until he stopped wanting to use both arms that the pediatrician sent him for a CT scan. This time, they found a mass in his neck, and Jacob was diagnosed with Ewing sarcoma.

The mass was putting pressure on his nerves, causing him to lose function in his arms. He received surgery to remove the tumor, but with half the tumor wrapped around his spinal cord, they could only extract 40-50% of what was visible. Additionally, Jacob endured chemotherapy and six weeks of proton radiation. Today, Jacob is in remission, and his whole family is so proud of how far he’s come!
Thank You
for all you do to help kids with cancer!