



Read his hero story inside



OUR FOUNDER
ALEXANDRA "ALEX" SCOTT

SUMMER 2019



FIGHTING CHILDHOOD CANCER, ONE INNOVATION AT A TIME

Thanks to your support, Alex's Lemonade Stand Foundation (ALSF) is able to accelerate cures by being innovators in the childhood cancer community. Innovation has always been at the forefront of our work ethic, starting with ALSF's Founder, Alex Scott. Her out-of-the-box thinking evolved into her front yard lemonade stand to help kids like her. In that spirit, ALSF has always tried to find the best way forward, searching for new ways to fill the gaps in both research and family services.

So, just how do we innovate? Let us show you the ways...

1. **THE CRAZY 8 INITIATIVE** – ALSF has always been about collaborating and working together to find cures. This is why in the summer of 2018, we launched the Crazy 8 Initiative. We brought together researchers and scientists from around the world to share their expertise in eight childhood cancer challenges and tackle the biggest question of all: how can we find better treatments and cures for children with cancer?

2. **CHILDHOOD CANCER DATA LAB** – The Childhood Cancer Data Lab (CCDL) is the first lab of its kind dedicated to childhood cancer research. By leveraging data, the CCDL is a valuable resource for researchers to access first-rate analysis of their data to further enhance their ability to accelerate cures. Training is now available in several cities for researchers to learn basic data science skills to enhance their work.
3. **PEER-REVIEWED GRANTS PROGRAM** – ALSF's rigorous grant selection process is recognized by the National Cancer Institute as the sole pediatric cancer organization granted their Peer Reviewed Funder designation.
4. **QUALITY FAMILY SERVICES** – Having a child with cancer is one of the most difficult situations a family can face. Your support allows us to help these families through tough times, including with financial assistance so children can travel to reach potentially lifesaving cures and sibling support.
5. **CROSSING THE FINISH LINE TO CURES** – Our Centers of Excellence and Bio-Therapeutics Grants ensure that researchers can push their discoveries from the lab to the clinic by funding the infrastructure and securing lab needs for clinical trials.

We couldn't do any of the above without the incredible support we receive from YOU. Whether you make a donation, participate in an event, join our monthly giving program or are involved in other ways, we are incredibly grateful for your dedication to our mission. We hope you enjoy reading this newsletter and learning more about where the money goes to put an end to childhood cancer.



CYCLING TOWARD CURES: ACROSS AMERICA IN 30 DAYS

It takes determination and stamina to cycle cross-country in a month. Luckily, the Fraylick brothers have those qualities in spades. As Perry and Keenan Fraylick travel coast to coast in June, they hope to raise money for childhood cancer research and spread awareness across the nation.

The brothers were inspired by the story of Tyler Trent, a former student at Purdue, where Keenan is the race director of the Triathlon Club. Tyler fought a long battle with osteosarcoma, during which he raised awareness for pediatric cancer and asked people to donate money for more research. Next thing the brothers knew, they were connected to a coach with Champions for Kids with Cancer, a fundraising program from ALSF, and began taking pledges per mile traveled. The rubber has only just met the road, and the brothers have already surpassed their goal of \$10,000.

Perry's memories of growing up help to fuel his conviction. "We want to do anything we can to prevent cancer from continuing to rob kids of their childhood," he said.

Champions for Kids with Cancer is a program designed for anyone who wants to make playing sports even more meaningful by raising money for kids fighting cancer. To learn more, visit ALSFchampions.org.

Abbi

HERO

“Cancer treatment is so much better than what my mom had because of folks like ALSF helping raise money to improve outcomes for kids.”

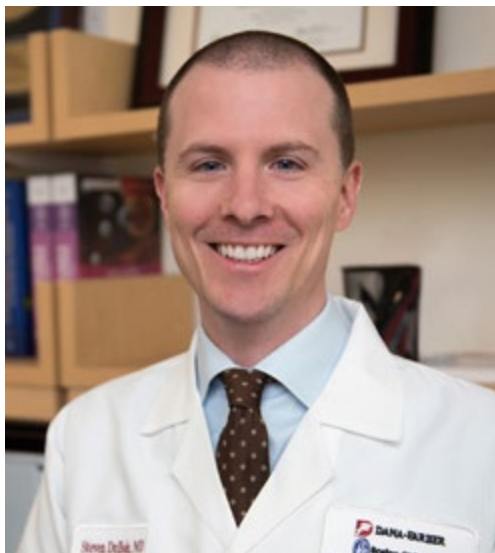
– Becky, Abbi’s mom

Abbi has seen the movie *Frozen* nearly 100 times, while her grandmother Cheryl was more familiar with being frozen as a kid throughout her Michigan upbringing. Despite being born decades apart, their childhoods have one experience in common: both were diagnosed with cancer.

But while Abbi’s grandmother remembers her cancer treatment as a harrowing and lonely experience, Abbi’s battle has been different. Back when Cheryl was diagnosed, there weren’t many treatment options available, nor places to administer the treatment. She spent six months at a hospital far from her home and

family. While Cheryl beat the odds and has been cancer-free for 50 years, the radiation treatments that saved her life created long-term health problems.

Today, Abbi’s treatment for embryonal rhabdomyosarcoma is more precise, more widely available and causes fewer side effects. With her family at her side, 4-year-old Abbi exudes joy despite her many hardships already. With the deep impact the disease has had on Abbi’s family, they’re now raising money for research to ensure it doesn’t affect families in the decades to come.



BREAKTHROUGH: Targeted Therapy for Pediatric Cancers Gets FDA Approval

The FDA recently approved a new pediatric cancer drug thanks, in part, to ALSF-funded research. A clinical trial, led by Dr. Steven DuBois at Dana-Farber Cancer Institute, showed that the drug Vitakvi (also known as larotrectinib) was an effective treatment for several types of pediatric cancers when a certain biomarker is present.

This is only the second time the FDA has approved a drug based on the presence of a biomarker for a specific type of cancer.

In Dr. DuBois’ trial, over 75-percent of patients treated with larotrectinib responded positively to the drug, and their tumors either shrank or disappeared. Each of the children

in the larotrectinib trial had cancers that had the NTRK gene-fusion present. NTRK occurs when genes fuse together abnormally, resulting in the growth of abnormal cells, which become cancer. While NTRK fusions are rare, it does occur across a range of cancer types including infantile fibrosarcoma, soft-tissue sarcoma and thyroid cancers.

The trial was held at multiple sites, including Dana-Farber Cancer Institute, which ALSF funds through its Center of Excellence (COE) program.

Read more about this breakthrough at AlexsLemonade.org/Blog.

The Roadmap to Cures: ALSF’s Crazy 8 Initiative



Last September, over 90 all-star researchers gathered in Philadelphia to kick off the Crazy 8 Initiative, ALSF’s one-of-a-kind action plan to address the most pressing issues in childhood cancer.

Following the meeting, ALSF committed \$25 million to support large scale collaboration projects to make significant progress within

the next 5 years in eight focus areas: big data, clinical trials, embryonal brain tumors, fusion negative sarcoma, fusion positive sarcoma, leukemia, neuroblastoma and high-grade gliomas. So far, thanks to supporters like you, ALSF has awarded nearly \$1 million to 10 pilot projects related to this initiative.

“When you put the right people together, you will foster groundbreaking synergy,” said Dr. Nada Jabado, from McGill University, who co-chairs the Crazy 8 Initiative with Dr. John Maris from Children’s Hospital of Philadelphia.

Dr. Jabado also serves as a team member on the high grade glioma Crazy 8 group, bringing her expertise in histone mutations that appear in high grade pediatric brain tumors and may be the key to cures. That group’s pilot project, co-funded with the Robert Connor Dawes Foundation and Northwestern Mutual, will study the cell identity changes that take place within the microenvironment of high grade gliomas, like DIPG. Researchers aim to better understand these deadly tumors and develop more effective therapeutics to improve outcomes for children.

ROCKSTAR RESEARCHERS



Dr. Marie Bleakley, (ALSF Bio-Therapeutic Impact grantee) from Fred Hutchinson Cancer Research Center, is leading the phase I clinical trial of an adaptive immunotherapy to treat leukemia that has relapsed after stem cell transplantation failed. Dr. Bleakley’s trial uses altered T cells to target a protein called “HA-1” which is found on the surface of leukemic cells in some patients. *Dr. Bleakley’s grant is co-funded by Cure4Cam Childhood Cancer Foundation and Marshall County Childhood Cancer Awareness Corporation*



Jeroen Roose, PhD, (ALSF Innovation grantee) from the University of California San Francisco, developed a drug-screening tool that helps doctors identify targeted therapies that while inadequate on their own, when used in combination could kill non-responsive cancers. The screening technique is described in the April 9 edition of the journal *Cell Reports*.

Kabir

HERO

"I truly believe the future of cancer treatment is in research and funding; it's the only way to advance this science for those in need."

– Bhavika, Kabir's mom

Cancer has become all too common a term in Kabir's family. The disease impacted his aunt, his second cousin and even his dog. Then, it hit him too. A theme-park enthusiast, 6-year-old Kabir couldn't have expected his own childhood to resemble a roller coaster ride when doctors diagnosed him with acute lymphoblastic leukemia (ALL). First, Kabir's mom Bhavika and Kabir uprooted their life, moving from their home to a location closer to the hospital in case of an emergency.

Months later, Kabir's brother Ayaan and his father Mangee came too. Ayaan and Kabir may squabble like typical siblings, but their

deep bond helps power their parents through this ordeal.

Everyone was excited when his treatment finished in May 2019, but they don't see that as the end of their fight. They want to help others too. Kabir even turned his My Little Pony-themed birthday party into a fundraiser for other kids with cancer by supporting ALSF.

**Read more hero stories at
AlexsLemonade.org/heroes**



CCDL's Dr. Jaclyn Taroni instructing ALSF-funded researcher Dr. Jim Amatruda

Researchers Gain New Skills to Advance their Discoveries

Lindsey felt frustrated. As a postdoctoral fellow at The University of Minnesota, her funding is reliant on grants to sustain her work. However, her latest grant application ran into a brick wall when a reviewer claimed her concept — investigating gene expression differences between sexes — was too risky, saying there wasn't enough data to back it up. Lindsey disagreed, she just didn't have the means to demonstrate it.

So, she started taking programming courses to learn those skills and tools. Then, she discovered the data science training workshop from the Childhood Cancer Data Lab (CCDL). The CCDL is the first informatics lab of its kind that accelerates the pace of finding cures for childhood cancers. When Lindsey heard about this opportunity, she flew to the hands-on

session in Houston, learned basic data analysis and came home with a starter kit of code she could manipulate using her own research.

Bingo!

Now, she can use these takeaways to supplement her application and demonstrate the validity of her research to a reviewer. Three days of training and suddenly, funding feels much, much closer. "It seriously could be career-changing," says Lindsey.

The CCDL will lead three additional data science workshops this year in Chicago, Philadelphia and San Francisco, helping researchers accelerate their work for kids with cancer.

Learn more at CCDataLab.org



Impactful ALSF-Funded Research Results in Immunotherapy for Relapsed Neuroblastoma Patients

ALSF-funded researcher Drs. Andras Heczey and Leonid Metelitsa made huge leaps forward in the search for cures for relapsed high-risk or refractory neuroblastoma. Dr. Heczey shared the groundbreaking success story of a child enrolled in a phase I clinical trial for GD2-CAR NKT cell immunotherapy, co-funded by an ALSF Bio-Therapeutics Grant and run by Texas Children's Cancer Center and Center for Cell and Gene Therapy at Baylor College of Medicine.

The trial makes use of the child's own Natural Killer T-cells (NKTs) which were extracted, genetically-modified, replicated and injected back into him. He had advanced disease in several areas of his body, and like most patients battling relapsed neuroblastoma, he had been through several unsuccessful treatments and was close to exhausting all options.

After a four-week follow-up, his tumor disappeared and a second tumor significantly shrank in size.

"Without the support of the Alex's Lemonade Stand Foundation, this first in-human clinical study of Natural Killer T Cells may not have been possible. These promising initial results inspire hope for children with neuroblastoma," said Dr. Heczey.

Dr. Heczey's grant is co-funded by Cure4Cam Childhood Cancer Foundation, Tap Cancer Out and Turn It Gold.



CARS THAT CURE

Donate your Vehicle for Childhood Cancer!
Call (855) CAR ALSF or (855) 227-2573

SPONSOR SPOTLIGHT



When "Auntie" Anne Beiler started her pretzel stand, she said, "Caring for other people is the purpose of Auntie Anne's."



More than 30 years later, that commitment to giving back continues to motivate the company and drive its commitment to Alex's Lemonade Stand Foundation (ALSF). Since 2011, Auntie Anne's has raised more than \$4.2 million for ALSF through its annual in-store fundraising campaigns, coin canister donations, local event collaboration and the company's annual C.A.R.E.S. Golf Tournament. This year's annual in-store fundraising campaign is slated for **July 22 - September 15**. Guests can donate \$1 to ALSF by purchasing a lemon icon and in return receive \$1 off their next visit.



At Power Home Remodeling, caring is a daily practice. It's a core value and ingrained in their DNA. So is happiness. Every June,

Power joins us in the fight for a cure by dedicating 30 days to raising funds via payroll donations, lemonade stands, fundraisers and even playing kickball! With the rallying cry of 'Care to Smile', Power is challenging their people to care more, smile more, and fight more to help end childhood cancer for good.

five BELOW

Congrats to Five Below for putting the "squeeze" on childhood cancer! Throughout their May campaign, customers made a donation of \$1, \$3 or \$5 to ALSF for a paper lemon. Five Below has been a proud partner of ALSF and has so far raised over \$5.5 million in the fight against pediatric cancer.

For \$10 a month, you will help support lifesaving childhood cancer research.



Join the **One Cup at a Time Club** to give monthly.

AlexsLemonade.org/one-cup

Childhood cancer hero, Caroline, age 6



Thanks to you -

Lemonade Days was a sweet success. Thanks for helping us raise much needed funds for childhood cancer research.



THE Alex's Lemonade Stand Foundation **MILLION MILE**

Fighting childhood cancer, one mile at a time.

How far would you go for safer treatments and more cures for kids with cancer?

This September, join The Million Mile and go the distance during Childhood Cancer Awareness Month. Whether you are a runner or a walker, a biker or a swimmer, your miles can help ALSF raise awareness and funds for critically-needed research.

For more information, visit TheMillionMile.org

ALSF MISSION

To change the lives of children with cancer through funding impactful research, raising awareness, supporting families, and empowering everyone to help cure childhood cancer.





HOW YOUR DONATIONS HELP FIGHT CHILDHOOD CANCER



will fund one hour of research



will fund one day of research

EVERY DAY, 
36 
KIDS 
 ARE DIAGNOSED 
 WITH CANCER IN THE U.S.

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