SMALL STEPS, TAKING US FAR

There’s a proverb that says, “a journey of a thousand miles begins with a single step.” In our case, it all began with a single pitcher of lemonade. When our daughter Alex, a cancer patient, held her first lemonade stand, she wanted to do it so doctors could help other kids the way they helped her. Alex benefited from the experimental therapies that cancer research had made possible, and even though she was only 4, she knew how important they were and had experienced firsthand what a difference they could make. So many people have been inspired by Alex’s story and held their own lemonade stands and events that we can’t count how many cups of lemonade have been sold, but we can see how far they’ve brought us: more than 475 pediatric cancer research projects funded and research advances that are making a real difference. We have a long way to go to find cures for all childhood cancers, but there’s never been a time for more hope. This is a transformational time for childhood cancer research and your generosity and support are making an impact. We’re getting there, one cup at a time.

-Liz & Jay Scott (Alex’s Parents)

YOUR SUPPORT HELPED FUND THIS CHILDHOOD CANCER BREAKTHROUGH, FEATURED ON CBS’ 60 MINUTES!

We pride ourselves on choosing research projects strategically and funding innovative ideas that show promise with the potential to pay off in big ways down the road. Back in 2006, we gave an Innovation Award to Matthias Gromeier, MD at Duke University. Dr. Gromeier’s idea was to use the poliovirus – the same virus that caused paralysis in many people before the introduction of the polio vaccine – to fight brain tumors. He developed an engineered version of the poliovirus and used it to infect a certain type of brain tumor. The virus kills glioblastoma. It has taken many years of research for his work to go from an idea in the lab to a treatment in the clinic, but it has paid off. Some of his patients have experienced incredible results, with their tumors shrinking dramatically and even disappearing, creating hope where there was none.
If only all our meetings were this exciting!

This energetic group is “Kids for a Cure” from Lanoka Harbor, NJ. Some of the kids are barely older than Alex when she held her first stand. The group has raised more than $10,000 for childhood cancer research, and recently they came to our office to meet us and learn more about where their money goes. Learn more about our childhood cancer research projects at AlexsLemonade.org/grants

YOUR SUPPORT
makes a difference - Please give!

ADELE WHITE
Childhood Cancer Hero

Adele White’s pediatrician noticed some unusual weakness in her facial muscles, which prompted the doctor to refer her to a neurologist. To her family’s shock, an MRI revealed a lesion and Adele was diagnosed with AT/RT. Her family learned in an instant that “cancer does not discriminate and affects children even at the youngest ages.”

Adele had brain surgery which removed 60% of the tumor, radiation treatment and multiple rounds of chemotherapy. Adele is currently being cared for by the team at St. Jude’s and is on her 13th round of a drug trial to reduce tumor growth. She is “the best” traveler and patient, and has shown her family what it really means to be strong.

Adele continues to be a happy, fun, energetic 3-year-old. She recently moved to a big girl bed and welcomed a new sister to her family. Adele loves animals and is the family chicken wrangler – rounding them up from the yard to the chicken coop. She is equal parts fighter (of cancer) and lover (of life).

Information provided by Amy White, Adele’s aunt

Since Alex held her first lemonade stand, money the Foundation has raised has funded more than 475 pediatric cancer research projects at 102 top hospitals and institutions. Learn more about all of our grants at ALSFgrants.org.

Q&A with Eric Raabe, MD, PhD

Pediatric cancer researcher Dr. Eric Raabe has been in the news for his exciting discoveries regarding atypical teratoid/rhabdoid tumor (AT/RT), an aggressive and devastating childhood cancer. ALSF provided key funding for his research, paying the salary for a research assistant and the supplies needed to perform experiments. Dr. Raabe answered some questions about his work:

“I chose brain tumors because I wanted to throw myself into a research problem that was especially difficult and one that could have a high payoff for patients. Patients with brain tumors have fewer treatments available to them, because so few drugs cross into the brain. The human brain is protected from foods we eat and toxins we may ingest because of a blood-brain barrier – this prevents many cancer drugs from crossing into the brain.”

Can you describe what makes your AT/RT discovery so exciting?

AT/RT is a puzzle in that it is a very aggressive tumor, yet it has only one known mutation. The mutation that occurs is in a gene called INI1, and it is a mutation that knocks out the function of INI1. In contrast to other cancers, there isn’t anything that is obvious from the mutation studies that we can target.

What’s exciting about our studies is that we identified in AT/RT increased expression of a master genetic regulator, a gene called LIN28. This gene adjusts the expression of many other genes. LIN28 is found at high levels in normal stem cells, so having a lot of LIN28 can make these cancer cells act like stem cells – they have increased tolerance for chemotherapy and radiation therapy and they can move around (metastasize).

LIN28 may be a key driver of AT/RT cancer cell growth, invasion and resistance to therapy. So targeting LIN28 and the proteins it regulates can be the key piece for developing new therapies for AT/RT.

In simple terms (or as simple as possible!), what did you discover?

We found that a regulator of other genes, LIN28, is turned on in AT/RT cancer cells more than in the normal brain. When we take away LIN28 from these cells, they die. We also found that we can disrupt the function of other proteins that are turned on by LIN28 using drugs currently available to pediatric cancer patients. When we use these drugs, the AT/RT cancer cells also die.

What made you interested in going into the field of cancer research?

I have always been interested in biology – in particular the way that living things grow and mature. I was a neuroscience major in undergraduate and loved the complexity of the nervous system. I was also interested in medicine, so as part of my MD/PhD training, I did developmental biology research. Once I chose pediatrics for a medical profession, I found oncology to be a specialty with many challenges and also many rewards. Cancer is the process of normal development gone wrong. Cancer cells reactivate many of the programs that are needed in development. So LIN28 is a protein that is normally found in developmentally very immature cells, and cancer cells reactivate this protein – they use it to go back in time so they can become more immature cells. So cancer biology is a natural outgrowth of my interest in developmental biology.

What happens next with this project? How could it help kids with AT/RT?

The next steps are to validate the pathways downstream of LIN28 as targets. What is very exciting about this research is that we have drugs for two of the pathways that are being used in children and have good brain penetration. So we are hopeful that we will be able to validate their use in pre-clinical models and that this will then lead to clinical trials of these drugs in children with AT/RT. We also want to get smarter about targeting LIN28 directly – it is a good target because it is not usually expressed at high levels in normal cells.
WHO YOUR SUPPORT HELPS: OUR CHILDHOOD CANCER HEROES

AUSTIN DUNLAP
Information provided by Valerie Dunlap, Austin’s mom

Austin is funny, outgoing and enjoys life in the great outdoors. In the beautiful surroundings of his home in East Helena, Montana, Austin loves to go out fishing and hunting. Since age 4, he has been involved in the sports of wrestling and rodeo.

Always an active kid, it was worrying when Austin became tired and had frequent bloody noses and headaches. Finally, Austin was diagnosed with acute lymphoblastic leukemia (ALL), a type of childhood cancer.

After 3 years of chemotherapy, Austin went into remission, but just six months later he had a bloody nose that would not stop. His oncologist sent him to the ER. Within an hour came the news that Austin had relapsed.

The best treatment option was in Seattle, 600 miles away. But it was the middle of winter in Montana and Austin’s family had no money saved to travel. Desperately searching for help, Austin’s mom came across information about ALSF’s Travel Fund.

Austin’s mom said, “ALSF was amazing – it was during Christmas and she [ALSF’s Travel Fund coordinator, Shirley] gave me her cell phone number....She had the trip taken care of within days. She was amazing and helped take so much fear and stress out of us during that time.”

ALSF’s Travel Fund paid for two plane tickets to Seattle and a hotel. Austin and his parents lived in Seattle for 5 months while he had radiation, chemotherapy and a bone marrow transplant.

Happily, he is now in remission again. Austin finally got to attend his first high school activity, his senior prom, and will be graduating from high school with his classmates this June! Congratulations to Austin and his family!

THE ALSF TRAVEL FUND

Recognizing the financial burden of childhood cancer on families, our Travel Fund offers assistance to families like Austin’s who face the need to travel for childhood cancer treatment. The Travel Fund helps alleviate travel-related costs so families can focus on what really matters - their child’s health. A list of participating institutions is available at AlexsLemonade.org/travel-fund.

FEATURED HERO - LYRISSA BRAY
Information provided by Margi Bray, Lyrissa’s mom

On January 5, 2005, Lyrissa Bray, a beautiful, seemingly perfect and healthy little girl, was diagnosed with stage four, high-risk, unfavorable neuroblastoma. She was given a 30-50% chance of survival. That summer, she went into multi-system organ failure from the toxicity of the treatment. Her doctor later told her parents that Lyrissa’s survival was a “true miracle.” They learned this summer that her one remaining kidney has suffered damage from the radiation and chemo, and that she is in stage two (of five stages) of kidney disease. Despite all of that, Lyrissa is stable and thriving today!

She plays piano, volleyball and is a great artist. Her mom, Margi, says, “Somehow, some way, I hit the jackpot when I got lucky enough to be called ‘mom’ by this little hero!”

Heroes hosting stands for Alex’s Lemonade Days

Fighting childhood cancer is a big job. For Alex’s Lemonade Days, we asked 50 childhood cancer hero families – one in every state – to share their story and hold a lemonade stand to represent the many children diagnosed with cancer in their state this year. Check out all our Hero Family State Reps online at LemonadeDays.org.
FRESH LEMON LOOKS!
We’ve added new merchandise to Alex’s Shop just in time for summer lemonade season. New 2015 t-shirts (in unisex and ladies’ styles), athletic tees and more are all available online at Alex’s Shop (AlexsLemonade.org/gift-shop) or you can give us a call at (866) 333-1213 to order.

SPONSOR SPOTLIGHT
Our sponsors have found creative ways to get into the spirit of lemonade season. Visit our website for a full list of events.

Applebee’s
This year participating Applebee’s restaurants nationwide will be raising funds to help fight childhood cancer. From June 29-August 2, restaurants will raise funds for ALSF as part of the Applebee’s Serves® program. Fundraising efforts vary by location and include Applebee’s donating a portion of the sale of each lemonade (all varieties) through their Summer Squeeze® promotion to ALSF and/or selling paper lemons.

Five Below
From May 4-25, visit your local Five Below store and purchase a paper lemon to benefit ALSF. Five Below will also be donating a portion of the proceeds from Lemonade & Pink Lemonade scented nail polishes and lip balm. And be sure to take a selfie at the Selfie Stand in Five Below using #5BAlexSelfie and Five Below will donate $1 to ALSF for every photo shared.

Volvo - Win a New Car!
Buy raffle tickets for a chance to win a brand new 2015 Volvo XC60. Tickets are $25 each or a book of 10 is $200. All proceeds benefit ALSF. The winning ticket will be drawn at Alex’s “Original” Lemonade Stand on June 13, 2015, but the winner need not be in attendance to win (we’ll contact you!). To purchase tickets, call us at (866) 333-1213.

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DONATE TODAY OR GET INVOLVED!
AlexsLemonade.org

JOIN US IN FIGHTING CHILDHOOD CANCER, ONE MILE AT A TIME!
September 1-30, 2015
Childhood Cancer Awareness Month #Journey2aMillion

This September, get involved in something big – really big! To raise funds and awareness for childhood cancer, we’ve set a collective goal of going one million miles during the month of September – and we’re going to need help to reach it. Alex’s Million Mile is a virtual worldwide event and everyone logs their own miles, at their own pace, wherever they are. It’s free to sign up and you can participate on your own or with a team, by running, walking, cycling or a combo. There are no minimums – every step and dollar gets us closer to cures. Together, we are going one million miles, because curing childhood cancer is worth going the distance. Join us and sign up at AlexsMillionMile.org!

FOUNDATION SPECIAL EVENTS
Interested in showing your support and having a great time? Our special events take place in the Philadelphia area and in other cities around the country – a mix of sophisticated culinary events, athletic events and family fun.

Join us for one (or all) of our special events that truly put the fun in fundraising. A selection of our Foundation special events is below. Find out more and register at:
AlexsLemonade.org/special-events

• The Great Chefs Event - June 9, Philadelphia (Partner event with The Vetri Foundation)
• Alex Scott: A Stand for Hope Phone Bank - June 11, televised by CBS 3 and the CW Philly
• Alex’s Lemonade Days - June 12-14, nationwide
• Alex’s “Original” Lemonade Stand - June 13, Wynnewood, PA
• Freedom Ride - July 4, Independence, MO
• Lemon: Chicago - August 10, Chicago
• Alex’s Million Mile - Run. Walk. Ride - September 1-30, worldwide
• L.A. Loves Alex’s Lemonade - September 12, Los Angeles
• Lemon: NYC - October, New York
• Striking Out Childhood Cancer - October 18, Petaluma, CA
• The Lemon Run - November 8, Philadelphia and virtual

For information on sponsoring an event, contact Lisa McQuiston (lmcq@AlexsLemonade.org)