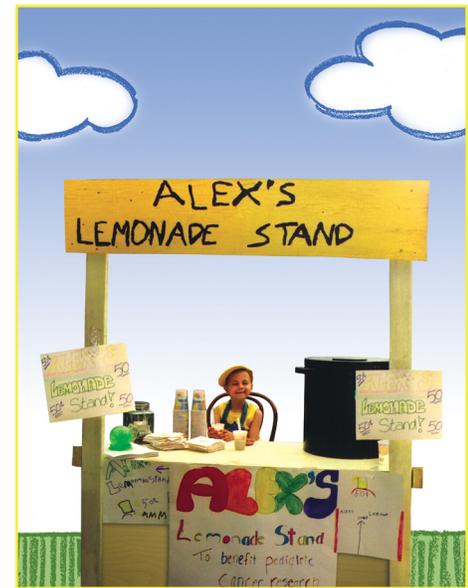


FRESHLY SQUEEZED NEWS

FALL / WINTER 2017



USING BIG DATA TO ACCELERATE CURES FOR CHILDHOOD CANCER

For years, the primary tools to combat cancer were beakers and test tubes. Now, Alex's Lemonade Stand Foundation (ALSF) is adding big data to that arsenal with the opening of our Childhood Cancer Data Lab (CCDL). The CCDL represents a holistic approach to collecting and analyzing findings from the world of childhood cancer research. Our knowledgeable team will draw upon the vast wealth of data already available while integrating discoveries from ALSF-funded researchers and many others.

Helmed by Dr. Casey Greene, who holds a PhD in computational genetics, the CCDL team will utilize their expertise in machine learning to impact the search for novel ways to approach childhood cancer cures.

With no broad, overarching solution to collecting data from across the childhood cancer community, the CCDL is uniquely suited to fill a void from analysis occurring on an institution-by-institution basis rather than data being cumulatively analyzed. The CCDL aims to eliminate that gap by building a digital platform for collecting, harmonizing and disseminating large scale data to researchers.

By creating a shared pool of data, researchers across the globe will be better equipped to contextualize and articulate the significance of their findings. And with ALSF's deep connections to institutions starting groundbreaking projects across the country, this endeavor has the opportunity to build a better knowledge base for all researchers.

"There are hundreds of projects happening across the country to combat childhood cancer, but there has never been an intuitive solution for collecting all that data," says Jay Scott, Co-Executive Director of Alex's Lemonade Stand Foundation. "The CCDL is the first of its kind in the childhood cancer space and we believe it will provide untold benefits to advancing the course of research in the field."

The CCDL represents a culmination of the past, present and future of childhood cancer research. By pulling from previous research and analyzing findings from contemporary projects, the CCDL is accelerating the path to better treatments and cures for kids fighting cancer everywhere.

[Learn more at CCDataLab.org](http://CCDataLab.org)

TWO SUPERSIBS HONOR THEIR SISTER'S MEMORY

Sisters Mia, 11, and Alba, 6, of Shawana, Wisconsin, wanted to honor the memory of their sister, Evylah, who passed away in October 2015 after battling diffuse intrinsic pontine glioma (DIPG). Mia remembers her middle sister as being strong and supportive. If Mia was sad, Evylah would make her laugh to cheer her



up. Although Alba was only 3 when Evylah passed away, she told her mom, Zoua, she remembers her relationship with her older sister. Zoua describes Evylah as loving, silly and the center of attention.

When Zoua read an ALSF email about hosting a lemonade stand, she thought it would be a great way to raise money for research while honoring the memory of Evylah. Mia and Alba, with the help of their parents, set out to raise \$400 at their lemonade stand, Evylah's Lemon Love. They hoped to raise awareness about childhood cancer and the need for research, so that other families don't have to go through what they did. The sisters more than doubled their original goal by raising over \$1,000 and hope to make their lemonade stand an annual event.

[To host your own lemonade stand, visit AlexLemonade.org/GetInvolved](http://AlexLemonade.org/GetInvolved)

FINDING CURES THROUGH CLINICAL TRIALS

Clinical trials are the result of lab study combined with extensive administrative work to build the clinical infrastructure needed to enroll patients, report findings and push treatment towards curing children. Researchers use the ALSF Infrastructure grant to hire new staff, create clinical protocols and train existing hospital personnel through phase I and II of the clinical trial process. Children who enroll in clinical trials often have relapsed disease; meaning standard treatment was not effective. Infrastructure grants make immediate impacts in the lives of these children—giving them options and hope for cures.

Children are enrolled at all phases of clinical trials. Each trial has a different goal:

Phase I trials identify the safe dosage of the drug. Phase II trials enroll more patients and continue to test dosing, while also evaluating drug effectiveness. Phases III and IV trials are larger studies which test effectiveness and study long term side effects.

Dr. Julie Park of Seattle Children's Hospital recently said – "ALSF has been instrumental in transforming the accessibility of novel cancer agents for kids with cancer. We have leveraged the infrastructure to promote training of junior faculty, those who will carry the torch for implementing clinical trials for pediatric cancer and together aim to cure pediatric cancers."

YOUR SUPPORT

makes a difference!
Please give at
AlexsLemonade.org

CLINICAL TRIALS: A FAMILY'S PERSPECTIVE

Right before Matthew turned 3-years-old, he was diagnosed with stage IV high-risk neuroblastoma. He began treatment immediately and seemed to be responding well. His parents hoped to enroll him in a stem cell transplant clinical trial. However, Matthew's cancer showed progression – thus disqualifying him from the trial.



Matthew

For children battling relapsed cancer, clinical trials can offer hope. However, clinical trials have specific requirements that must be met to ensure that researchers can safely test potential treatments. When a child's medical status changes, their treatment plan can be jeopardized.

Despite being ineligible for the clinical trial, Matthew was able to receive 18 months of treatment which included chemotherapy, radiation, immunotherapy and surgery. He stayed in remission for three and a half years. But in October 2015, when Matthew was 7, his cancer returned. Matthew had to begin his battle again. He completed treatment for a second time and is now in remission.

However, with a history of relapse, Matthew is at a higher risk of relapsing again. His parents and medical team wanted to take aggressive action and enroll him in a maintenance clinical trial.

"When your child has been in treatment for a while, you fear that you have less and less in the way of options" said Helen, Matthew's mom. "And even when your child is doing well, you keep asking yourself, 'what will I do if he relapses again?'"

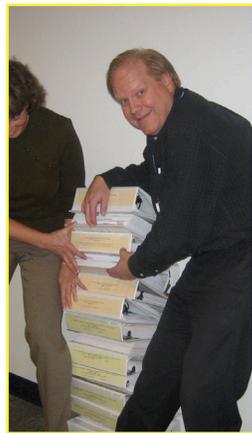
After extensive research and agonizing over the logistics of traveling far from home, Matthew began a trial at Memorial Sloane Kettering Cancer Center in New York City—1,200 miles from their home. Through their hospital social worker, the family reached out to ALSF's Travel For Care program which immediately provided support for travel and accommodations in New York City, giving the family a place to stay during his clinic visits.

Matthew is now 9 and entering 4th grade. His mother still worries for the future, but remains hopeful that this maintenance trial will keep Matthew in remission.

[Read more about family experiences in clinical trials in the ALSF blog at AlexsLemonade.org/blog.](http://AlexsLemonade.org/blog)

KILLING CANCER: ONE RESEARCHER'S CLINICAL TRIAL OFFERS HOPE TO CHILDREN BATTLING SOLID TUMORS

Viruses excel at infecting healthy cells—hijacking their normal function to feed virus growth and then eventually killing the cell. Viruses are also really good at killing cancer cells and now, Timothy Cripe, MD/PhD, from Nationwide Children's Hospital in Columbus, OH and an ALSF Phase I/II Infrastructure grantee, is harnessing their natural power to kill cancer cells in children.



The road to a clinical trial is paved with piles of data. Above, Dr. Cripe, shows the notebooks that made his trial possible.

Using a genetically-altered version of the herpes virus, Dr. Cripe's phase I clinical trial has the potential to provide a non-toxic, effective treatment for children battling relapsed extracranial solid tumors like osteosarcoma.

The treatment, called oncolytic virotherapy, converts viruses into therapeutic drugs. In the lab, the gene responsible for making the herpes virus infect healthy tissue is deleted. In the clinic, interventional radiologists map a child's tumor with CT scans and ultrasounds to guide a needle and directly inject the altered virus into the tumor. In a related study, the virus is given intravenously.

Dr. Cripe's trial was the result of years worth of work, both in the lab and in the clinical setting. Phase I of this trial is now open, with the goal of testing the safety of the drug. Phase II will test combining virotherapy with other treatments.

Unlike the more traditional chemotherapy and radiation, virotherapy does not come with harmful side effects. "We've reached the limits of chemotherapy and radiation," said Dr. Cripe. "Once we can get virotherapy treatments to work, we think they will be safe."

[Read more about Dr. Cripe's work and oncolytic virotherapy at AlexsLemonade.org/blog/oncolytic-virotherapy.](http://AlexsLemonade.org/blog/oncolytic-virotherapy)

CHILDHOOD CANCER HERO LEAVES BEHIND A RESEARCH LEGACY

Alex Podeszwa's fight against neuroblastoma started when he erupted in pain walking home from the park in 2005. That weekend, his mother Ann asked his father Dave, a pediatric orthopedic surgeon, to secure an appointment the following Monday. By the time his scans were concluded, he was diagnosed with neuroblastoma. The family braced for the worst when they discovered the disease had spread throughout his body, but wasted no time planning treatment.



Alex Podeszwa

Unfortunately, Alex wasn't improving from the initial chemotherapy, prompting a search for new options. A solution emerged at the University of Michigan — a MIBG study. A novel treatment back then, MIBG is now known for its effectiveness against neuroblastoma. Alex and his mom moved from Texas to Michigan and enrolled in the trial.

For the family, it represented a launching pad. Finally they felt like they had a legitimate shot at beating cancer. The treatment delayed Alex's cancer for a time, but it couldn't eliminate the disease. Fortunately, Alex continued to survive, but his parents knew this was only a temporary solution and they searched for new clinical trials.

In 2014, they discovered Dr. Yael Mossé's new anaplastic lymphoma kinase (ALK) inhibitor trial at The Children's Hospital of Philadelphia (CHOP). The inhibitor works by disrupting the ALK gene, a cancer-causing gene that's sometimes abnormally turned on in kids with cancer. That disruption helps prevent cancer formation. It worked well for a time, but eventually Alex's tumor stymied another trial. Resistance was becoming an increasingly apt word for Alex, both for his resilient attitude and his tumor's stubborn penchant for sticking around.

His resiliency and commitment to beating cancer extended beyond his own life though. When Alex passed away in November 2014, his family found a way to donate his cancerous cells to Dr. Patrick Reynolds' lab in Lubbock, TX.



Podeszwa Family

ALEX'S CELL LINE FLIES ON

Oftentimes childhood cancer researchers receive sub-optimal models, a problem Dr. Reynolds' Cell and Xenograft Repository aims to rectify. He developed patient-derived xenografts (PDX), which involve organically growing the remnants of a patient's tumor rather than developing it artificially. The Podeszwa family found a way to donate his cancerous cells to Dr. Patrick Reynolds' lab which has been fully funded by ALSF for the past 3 years.

Following a successful withdrawal of tumor cells safely with Dr. Reynolds, waiting was all that the lab and the family could do. After months of not seeing the cell lines grow at Dr. Reynolds' lab, Dr. Mossé offered to try.

After over a year, the cells finally grew and now this prosperous cell line remains the only ALK-resistant neuroblastoma cell line available. His cell line has presented plenty of hurdles to Dr. Mossé's lab, but they know any breakthroughs will be a significant step forward. Several of Dr. Mossé's projects utilize these cells fully including a recent clinical trial for children with relapsed neuroblastoma.

Alex's cell line was also given a name, "Fly623." His parents, Ann and Dave contemplated the name for months, deciding to commemorate their son by naming it after his love of flight and his June 23rd birthday. They know that Alex's legacy could mean cures for another child someday.

"We are beyond grateful for everything that ALSF does," said Ann. "Because we know even if our kid couldn't make it, someone else's better."



Dr. Mossé



Dr. Reynolds

ALSF CLASS NOTES:

- Preclinical studies from the lab of **Eric Raabe, MD/PhD** ('A' Award grantee 2015) at Johns Hopkins University have identified a potential new treatment for deadly atypical teratoid/rhabdoid tumors. Results were published on Neuro-Oncology's website in June 2017 in a paper co-authored with **Jeff Rubens, MD** (Young Investigator grantee 2017) also of Johns Hopkins University. The lab is moving forward with a phase I study of the drug in pediatric brain tumors.
- **Jennifer Stinson, RN/PhD** (Nurse Researcher Discovery grantee 2013) of University of Toronto developed a real-time smartphone pain management app for adolescents with cancer. Findings from usability testing were used to refine the app for ease of use and understanding, efficiency and acceptability. Next steps include piloting the app in longitudinal and multi-site studies. Stinson's findings were published in the *Journal of Pediatric Oncology Nursing* in July 2017
- **Stephen Lessnick, MD/PhD** of Ohio State University is a member of ALSF's Scientific Advisory Board and was referenced extensively in a *Nature* March 2017 article about epigenetic discoveries fueling renewed interest in Ewing's sarcoma research.
- **Iannis Aifantis, PhD** (Innovation grantee 2008, 2017 and Reach grantee 2013) of New York University School of Medicine co-authored a study showing how Vitamin C may encourage blood cancer stem cells in the bone marrow to mature and die normally, instead of multiplying to cause blood cancers. The findings were published in *Cell* in August 2017.



Eric Raabe, MD/PhD



Jennifer Stinson, RN/PhD

SPONSOR SPOTLIGHT



In July, over 1,000 Applebee's restaurants participated in their 13th annual campaign for ALSF and had their best year yet, collectively raising over \$1.3 million! Restaurants fundraised by donating a portion of lemonade sales, selling paper lemons and/or hosting other creative fundraisers like auctions, car washes, walk-a-thons, community events and more. This brings their grand total to over \$8 million since first supporting ALSF. Thank you, Applebee's!



Northwestern Mutual employees and financial professionals raised funds and awareness to find cures for children with cancer during their annual Race for Research campaign. In just over two months, Northwestern Mutual raised over \$1 million for ALSF! Thank you for your inspiration, hard work and compassion with your fundraising efforts during Race for Research and throughout the year to help kids with cancer.



In May, over 550 Five Below locations reached their goal and raised over \$1 million for ALSF! Stores fundraised by asking for donations and decorating their walls with lemon pin ups. Thank you, Five Below!



On September 10, Auntie Anne's finished their 6th annual in store fundraising campaign in support of ALSF. Guests who visited Auntie Anne's showed their support for children fighting childhood cancer by purchasing a paper pretzel ribbon icon. Guests were able to show even more support by posting a photo with their pretzel ribbon icon on social media using #auntieannes4ALSF and Auntie Anne's donated an additional \$1 to ALSF!

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MEET MORE CHILDHOOD CANCER HEROES:



Blaze, age 10, is an old soul who has been through so much in his life. Diagnosed at 3-years-old with leukemia, he has had to endure chemotherapy, radiation, a bone marrow transplant and multiple surgeries over the years. He moved to Pennsylvania from Ohio to enroll in the CART-19 study at The Children's Hospital of Philadelphia and has been in remission for almost a year. Blaze's family received assistance from ALSF's Travel For Care program in order to get Blaze to this cutting edge treatment.

To read more about Blaze, visit AlexsLemonade.org/hero/blaze-keim

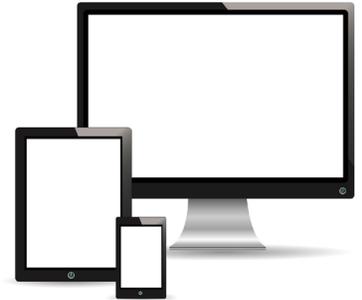


Read more about Arnav's story on our blog at AlexsLemonade.org/blog.

Arnav, age 15, is a National Honor Society member and a U.S. Junior National Cyclist who was diagnosed with osteosarcoma at the age of 14. He received chemotherapy and went through a 16-hour surgery to reconstruct his left leg. This has temporarily put the brakes on his passion for cycling, but his family says that Arnav's "relentless positivity" will see him through.

EASY EVERYDAY WAYS TO GIVE ONLINE

Did you know that while you are online shopping your purchases can benefit Alex's Lemonade Stand Foundation (ALSF)? For instance, you can log on to goodshop.com, select ALSF as your charity of choice and then shop for a cause!



Here are some other easy ways to support ALSF while shopping online:

- **Shop AmazonSmile** – Select ALSF as your charitable organization, the **AmazonSmile Foundation** will donate .5% of your eligible purchase price to us. Please note that AmazonSmile is only available through a web browser and not on the Amazon app. Visit Smile.Amazon.com for more information.
- **Support ALSF by taking a survey.** Sign up for **Survey Monkey** and 50 cents will be donated to ALSF for each brief survey you complete. Visit contribute.surveymonkey.com to get started!

No donation is too small and every penny counts when it comes to fighting childhood cancer. We know you are shopping anyway, so you may as well help kids with cancer too! For more ways to give back while shopping on-line, check out our website at AlexsLemonade.org/contribute/everyday-ways

CARS THAT CURE

Vehicle donations are another way to help raise funds and awareness for childhood cancer. We take cars, trucks, boats, ATVs, snowmobiles, motorcycles and more. When you donate a vehicle with Cars that Cure, you help fund important childhood cancer research. Please note that your donated vehicle does not need to be in working order. For more information, call toll-free (855) CAR ALSF or (855) 227-2573.



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