



Lilly



Mia and SuperSib Gabriella



Garrett

WHY GO THE EXTRA MILE FOR CURES?

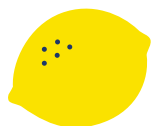
Learn the Facts about Childhood Cancer

This September, during Childhood Cancer Awareness Month, Alex's Lemonade Stand Foundation (ALSF) asked supporters to "go gold" by joining The Million Mile challenge. Participants are walking, running or riding to raise awareness and funds for better treatments and more cures all month long.

But childhood cancer does not just happen in September. Every day, families live with the uncertainty it brings through initial diagnosis, treatment, relapse and long-term side effects.

Thank you for going gold every day for children with cancer. To recognize Childhood Cancer Awareness Month, ALSF presents "the gold issue" of the newsletter. Inside, you will see how your support makes a difference.

As we all know, there is still more work to be done. Here's what you need to know about childhood cancer:



EVERY DAY IN THE UNITED STATES, 43 CHILDREN, AGES 0-19, ARE DIAGNOSED WITH CANCER. These families are immediately inducted into a club they never wished to join.

CANCER IS THE LEADING CAUSE OF DEATH BY DISEASE in American children, resulting in the death of approximately **1,800 KIDS EACH YEAR.**



Globally, **CANCER STOLE 11.5 MILLION YEARS OF HEALTHY LIFE AWAY FROM CHILDREN** in 2017. This total could be lower, if all children had equal access to care.

84% of children diagnosed with cancer are alive at least five years after diagnosis; however **THIS DOES NOT MEAN THEY ARE CURED OR FREE FROM LONG-TERM SIDE EFFECTS.**



LESS THAN 4% of the U.S. federal budget for cancer research is dedicated to childhood cancer.

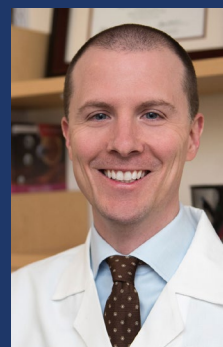
YOUR DONATIONS ARE FUNDING CRITICAL RESEARCH



ALSF-funded researcher **Dr. Michelle Monje** studies the most lethal childhood cancers: high-grade gliomas. Her study of DIPG, which currently has a 0% cure rate, has led to the discovery of genetic mutations which could be the key to treating this disease.



Dr. Yael Mossé's clinical trial for treating ALK-driven neuroblastoma using a drug called crizotinib led to a breakthrough. Crizotinib is a pill to treat cancer, instead of using traditional IV chemotherapy, and has fewer side effects for kids fighting cancer.



Using ALSF funding, **Dr. Steven Dubois** at Dana-Farber in Boston launched a clinical trial studying a precision medicine for a variety of childhood cancers that share the same genetic mutation. The result: FDA approval of Vitravki for the treatment of some types of childhood cancer.



Matteo

**CHILDHOOD CANCER
HERO MATTEO FIGHTS
WITH LOTS OF LOVE
AND LEMONADE**

From baking cookies to hosting lemonade stands, this family does it all to help fight childhood cancer.

The night before 6-month-old Matteo was diagnosed with a rare pediatric kidney cancer, his mom, Kim, stayed up late baking cookies for an upcoming lemonade stand at Power Home Remodeling to support ALSF.

The next day, Matteo's dad noticed a hard spot on Matteo's side. Kim went to the pediatrician, who immediately sent Matteo to the emergency room. A CT scan showed a mass on Matteo's kidney.

Matteo's cancer, a rare cellular congenital mesoblastic nephroma, accounts for less than

five percent of all pediatric kidney cancers.

After having the mass and one of his kidneys removed, doctors saw no evidence of disease. However, three months later a routine scan showed a new tumor in Matteo's lungs. Matteo began six months of chemotherapy and endured additional surgery to remove part of his lung.

Today, Matteo is almost two years old and cancer-free. His family, who loved ALSF before his diagnosis, has now hosted two front-yard lemonade stands and remains involved through Power Home Remodeling's corporate partnership initiative.

"Giving back to ALSF and helping fund research gives us something good to do with all the hard things cancer gave us," said Kim.



**SPEEDING DOWN
THE PATH TO CURES**

The Crazy 8 Initiative Pilot Projects are officially underway! These projects tackle the most pressing issues in the field of pediatric oncology. Thanks to the support of donors like you, grantees like Dr. Stephanie Hicks from Johns Hopkins Bloomberg School of Public Health are making steady progress.

Dr. Hicks' project emerged from the Big Data Crazy 8 group. She is working to create the tools required to analyze childhood cancer data at the single cell level.

Why is this critical? The field of childhood cancer research has long produced data that blends what is happening in all cells in a tumor together. However, this does not allow researchers to study individual cells in a tumor or in the healthy cells of a patient with cancer. In addition, different data methodologies are not always compatible across projects, which is why Dr. Hicks is developing new methods to study the data emerging from individual cells.

Dr. Hicks is currently working closely with Dr. Mariella Filbin at Dana-Farber, another Crazy 8 grantee, to study the communication between cancer cells and healthy cells in high-grade gliomas, like DIPG. Using this specific research, Dr. Hicks is creating a reproducible workflow that will allow other scientists to compare and contrast data and analyses across studies—improving efficiencies and, hopefully, the rate of discovery.

The Crazy 8 Initiative was launched by ALSF in 2018 with the purpose of creating and implementing roadmaps for cures for eight specific, hard-to-treat childhood cancers and pressing topics related to accelerating cures. This group consists of more than 90 top scientists and researchers from around the world sharing their expertise and collaborating with each other to tackle the big question: How do we find better treatments and cures for childhood cancer?



ALSF Data Scientist, Dr. Jaclyn Taroni, PhD gave a presentation at the NCI Childhood Cancer Data Initiative Symposium in Washington D.C.

**DATA SHARING CAN ACCELERATE
THE PACE OF CURES**



Science can be a secluded process. Typically, a researcher would carry out an experiment and, after several years, release the findings but keep the raw data for their own research purposes. In recent years, making experimental data available to other researchers—known as data sharing—has grown in popularity. It's also central to the ALSF Childhood Cancer Data Lab's (CCDL) mission. Just one example is the growth of refine.bio, the CCDL's data repository designed to make decades of data available to researchers for free in a streamlined, universal format. CCDL staff also stressed the importance of the practice in a recent presentation at the Childhood Cancer Data Initiative Symposium, hosted by the National Cancer Institute, where researchers and patient advocates gathered to discuss how big data could accelerate the path to cures.

Data sharing can help ensure individual experiments are reproducible by other scientists, a pivotal part of validating a project's findings. It can also help eliminate duplicative research efforts, so that every dollar is used for funding the pursuit of new treatments. Recently, ALSF became the first pediatric cancer foundation to require a data sharing plan for all funded projects. Going forward, the CCDL can use insights gleaned from these additional data sources to better identify novel traits of different childhood cancers. Your support means more data to share. That means more potential to find safer, more effective treatments for all children fighting cancer.



Kaleigh

“We are so grateful for ALSF... ALSF provides hope that cures will be found and that no child will miss treatment because of distance.”

– Jeanette, Kaleigh’s mom

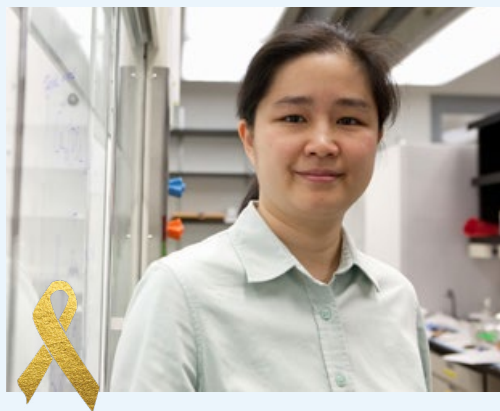
KALEIGH SEES THE WORLD AROUND HER THANKS TO YOU

Kaleigh nearly had to lose her eyes to save her life. As a newborn, Kaleigh had discoloration between her retinas and was taken to doctor after doctor for answers. Her father had bilateral retinoblastoma when he was a baby, and her parents were concerned it might’ve been passed down to her. Unfortunately, they were right. Their only plan, upon diagnosis, was to eventually remove both of her eyes.

But Kaleigh’s parents decided to get a second opinion. At a week old, Kaleigh and her family flew from Austin, TX halfway across the country to Philadelphia, PA with assistance from ALSF’s Travel for Care program. There, they met with another retina specialist who had a plan to save Kaleigh’s eyes and her life.

The next six months took Kaleigh back and forth from Texas to Children’s Hospital of Philadelphia for treatment and check-ups. And it worked. Today, Kaleigh not only has vision in both her eyes, she is also cancer-free!

3D BONE GRAFT PROVIDES SAFER OSTEOSARCOMA TREATMENT



For children who are diagnosed with bone cancers like osteosarcoma, surgical removal of tumors can improve the odds of a cure, but can also cause damage to healthy bones.

In an effort to rebuild and repair the affected bone, surgeons typically use bone grafting (the transplant of healthy bone tissue) in combination with high doses of bone morphogenetic protein (BMP) therapeutics, which are drugs that support bone development.

However, this conventional approach does

not always result in fully repaired bones, and there are some safety risks associated with the use of BMP.

The result: children are left with bones that are not strong enough to support their active lifestyle.

However, Jie Song, PhD, an ALSF grantee and Associate Professor of Orthopedics & Physical Rehabilitation at the University of Massachusetts, is getting closer to a solution that allows doctors to remove tumors and preserve a child’s quality of life. Dr. Song developed a 3D printed biodegradable synthetic bone graft that is capable of successfully attaching to healthy bone and supporting robust bone formation without the use of high-dose BMPs.

Using her ALSF Innovation grant, Dr. Song found that her synthetic bone graft successfully resulted in the formation of healthy bone 12-16 weeks after surgery. This successful outcome now has the potential to translate into safer and more effective reconstruction of bones in children with osteosarcoma, spinal cord cancer, oral cancer and other tumors in the skeleton.

Want to see the synthetic bone grafting in action? Dr. Song shared more about her project on the ALSF blog—AlexsLemonade.org/blog.

Accelerating Drug Development For Children



ALSF-funded researcher George Daley MD/PhD from the Harvard School of Medicine has taken a huge leap forward in the development of drugs to treat childhood cancer.

The promise of precision medicine as a potential cure for all types of childhood cancer brings with it the need for targeted therapeutics; but finding those highly-specialized drugs requires hours of lab work, drug development, clinical trials and the hope that ultimately the treatment will translate into a cure for children.

Using his Innovation grant, Dr. Daley was able to demonstrate that the drug-like molecules developed by his team disrupted a protein called LIN28 in the lab. LIN28 is linked to a wide variety of pediatric cancers including neuroblastoma, Wilms tumor, germ cell tumor, leukemia and pediatric brain tumors. Disrupting the protein has the potential to also disrupt cancer growth and progression.

This finding pushed Dr. Daley’s research from the investigative phase to the drug development phase and led to the formation of a biotechnology company that is dedicated to creating the drugs that will disrupt LIN28, meaning new therapies could get to kids sooner than ever before.

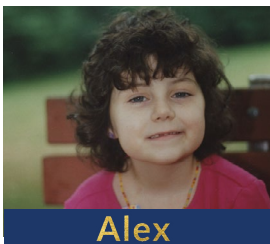
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As ALSF's Founding Sponsor, **Volvo** is always finding additional ways to give back and help kids fight cancer. This year, 20 members of Volvo Car of North America joined Team Lemon to run the Novo Nordisk New Jersey Marathon and to fundraise for ALSF. This team raised over \$13,000 which funds more than 250 hours of research!

LEAVE A LEGACY FOR CHILDHOOD CANCER RESEARCH

A Message from Liz & Jay Scott



Alex

Our daughter Alex may have only been 8 years old when she passed away, but she fit so much life into those years. Her determined spirit and her hope for a cure continues to touch countless lives - from the researchers honored with ALSF grants each year to the children we have been able to cure because of that research. Alex continues to be the inspiration behind the Foundation, and we are humbled by the fact that there are children alive today, because of her.



SuperSib Dylan with his brother and childhood cancer hero Ryan

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Northwestern Mutual employees and financial professionals raised funds and awareness to find cures for children with cancer during their annual Race for Research campaign. This year, they brought in over \$1.4 million! Thank you for your inspiration, hard work and compassion during Race for Research and throughout the year to help kids with cancer.

TOP FUNDRAISING OFFICES

- Category 1: McQuade Network Office Chicago, IL
- Category 2: Gross Network Office St. Louis, MO
- Category 3: Koch Network Office Jacksonville, FL
- Category 4: Schenkel Network Office Sioux Falls, SD

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One **Applebee's** Area Director Rallies Her Employees to Raise \$74K for Childhood Cancer Research

Across the country, 1,100 Applebee's locations raised money for ALSF in July and August. "Keep it POSITIVE, celebrate every dollar, set clear expectations, and follow up when needed. Raising money is something we look forward to and get excited about. The biggest part of why the now seven restaurants in my area perform so well is the people. They create a culture around Alex's and have dedicated employees that drive this relentlessly because of their leadership's passion. I am just the cheerleader that passes out lemon pins."

-Carrie Hellyer, Area Director of Applebee's in California. Her region increased their fundraising results from \$6,000 to \$74,000 in just three years.

Alex's story, her full and courageous life, brings up the question to all of us:

What do you want your legacy to be?



ALEXANDRA SCOTT Legacy Society

To mark the 15th anniversary of Alex's passing, ALSF launched the Alexandra Scott Legacy Society. This society recognizes and honors those who commit to ending childhood cancer as part of their life's mission. By including ALSF in your will, trust or other estate plans, you will become a member and make an impact that will last for generations to come. **For more information about the Alexandra Scott Legacy Society, please email Development@AlexsLemonade.org.**



"I was worried about Dylan more than anything and how he was going to cope [with Ryan's diagnosis]. I saw the SuperSibs program and I really wanted something that would help him,"

- Jennifer, hero mom

Have you seen our new webpage?

Visit us at AlexsLemonade.org/SuperSibs

FIGHTING CHILDHOOD CANCER, ONE CUP AT A TIME.



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