FRESH SQUEEZED
OF THE
SEASON

A NOTE FROM LIZ & JAY
For kids and families, September is like “the other New Year.” It’s a time of new beginnings - new teachers, new classrooms and new school supplies. For us it’s a time of reflection, thinking about our daughter Alex, who lost her life to childhood cancer 11 years ago. Alex achieved so much in her life. She inspired so many people and helped make better treatments and cures for other children with cancer possible, but with each new year we can’t help but think about the milestones her classmates and friends are reaching, and how much she would have enjoyed those experiences too.

Too few people know that September is Childhood Cancer Awareness Month and that the gold ribbon is a sign of childhood cancer awareness. This fall, the childhood cancer community is urging everyone to light the world up with gold ribbons. Awareness is vital to gaining support and raising money for new treatments and ultimately, cures. Childhood cancer is the leading cause of death by disease in children in the U.S. but with your support, we’re going to change that. Thank you for being part of this effort, and for your generosity, your compassion and your leadership - you are truly creating hope for the future, so all children can have many brighter school years to come.

-Liz & Jay Scott (Alex’s Parents)

A 11-Year-Old Battles Cancer a Second Time and Fights for Others
When she was just 2, Maya Rigler battled Wilms’ tumor, a kidney cancer. After years of being cancer-free, Maya was diagnosed with a second, unrelated form of cancer. Faced with cancer for the second time, Maya, now 11, turned her thoughts to how she could help others. As she began treatment to shrink her tumor - nicknamed “Bob the Blob” - she began raising money. She has raised an astounding $167,000 and counting for ALSF and childhood cancer research!

In January, ALSF will honor Maya at The Lemon Ball as Stand Host of the Year for her exceptional fundraising and generosity. Like Alex Scott, ALSF’s founder, Maya has inspired many others to get involved in the cause. In Maya’s words, “Maybe one day we can make sure that no other kid needs to go through this stuff.” Visit Maya’s Virtual Lemonade Stand at AlexsLemonade.org/mypage/1121536

ALEX’S MILLION MILE
Our Goals: 1 Million Miles and Cures for Childhood Cancer
Every day, parents of children battling cancer travel thousands of miles for treatments. That’s why this September, Childhood Cancer Awareness Month, we’re going a million miles to raise awareness and fundraise for cures.

Last year, more than 12,000 people ran, walked or biked toward our collective goal of 1 million miles. This year we expect to exceed that. Weeks before the event began we already had more than 500 teams participating and thousands of people fundraising to fight childhood cancer. Check out our progress daily throughout September at AlexsMillionMile.org

RUN     WALK     RIDE
Matthew Mistry, MSc, POST grant recipient, The Hospital for Sick Children, Toronto. The POST program (Pediatric Oncology Student Training) is designed to attract promising graduate and medical students to the field of pediatric oncology by engaging them in research under the direction of a mentor.

Matthew Mistry’s ALSF-funded POST research project recently resulted in a prestigious publication in the *Journal of Clinical Oncology*. Mistry says, “ALSF’s support of my research project provided me with early exposure to state-of-the-art experimental techniques used to investigate the genetic origins of childhood brain tumors.”

An emerging area in cancer research is identifying genetic markers that can distinguish between an aggressive or benign clinical course of a particular tumor at initial diagnosis. Mistry recently identified two such markers in pediatric glioma. He has found that mutations in the *BRAF* gene or loss of the *CDKN2A* gene are common in an aggressive subgroup of pediatric glioma, termed secondary high-grade glioma. Interestingly, tumors harboring these specific alterations took a longer time to become malignant when compared to other secondary high-grade gliomas that did not have alterations in these genes. Importantly, these alterations could be detected at the time of first diagnosis, when the tumor was thought to be benign by pathology alone. This study could have important implications in the future treatment of childhood gliomas based on the presence or absence of these genetic markers at initial diagnosis.

“If we are able to identify early genetic changes in these cancers that predict tumor behavior in a population-based cohort, physicians could not only acquire a better understanding of disease progression, but also improve treatment planning for these patients,” Mistry said.

**HOW YOUR SUPPORT HELPS:**

Since Alex’s first lemonade stand, ALSF has funded more than 500 pediatric cancer research projects at 102 top hospitals and institutions across North America. Learn more about the grants we have made at [ALSFgrants.org](http://ALSFgrants.org)

**Expanding treatment options for children at Nationwide Children’s Hospital**

ALSF’s Phase I/II Program Infrastructure Grants help hospitals across the country build the capacity for critical Phase I and Phase II clinical trials. The grant is intended to stimulate and catalyze research efforts to speed up completion of these important and necessary studies.

Clinical trials are how researchers learn what works to treat childhood cancer. But developing and running clinical trials is expensive and complicated, and the infrastructure costs, which are vital to running these trials correctly, are not covered by patients, insurance, drug companies or other funding sources. ALSF’s Phase I/II Infrastructure Grant is a crucial source of support allowing a hospital to hire the staff required to run the trials. This may include research nurses, data managers and regulatory specialists. This critical funding accelerates the pace by which new treatments are available to children battling cancer. Dr. Timothy Cripe and his team discussed the impact that their 2013 ALSF Infrastructure Grant has had on treating children at Nationwide Children’s Hospital in Columbus, Ohio.

**Program Impact**

At Nationwide, before receiving the ALSF grant, experimental therapeutics activity was sparse.

“With the help of the grant we’ve been able to build a strong, robust, much larger and growing phase I and II experimental therapeutic program with all the right expertise in place. I would say your grant was a cornerstone to that. It helped this institution enter this arena successfully,” said Dr. Cripe.

The ALSF grant covers increased staffing in key areas, including a lead data coordinator who oversees investigator-initiated trials, quality and regulatory improvements, and a research APN (advanced practice nurse).

**How it Helps Patients**

As a result, children and families have more options for treatment. There are more studies open at Nationwide and the hospital has greater capacity to run investigator-initiated studies.

“Increased infrastructure allows our research team to better interface with patients and their families,” said Dr. Sarah O’Brien, a principal investigator at Nationwide. “For example, now we are able to have a research nurse attend our inpatient rounds on the floor every morning...The research nurse is also part of the care team. In outpatient trials, the research nurse has the time to communicate and visit with families,” which creates a better and more integrated care experience.

**New Therapies**

Among new therapies being studied at Nationwide through these clinical trials are MIBG therapy and a virus therapy. The virus approach uses an attenuated strain of live herpes virus that has been crippled so it doesn’t cause disease but can be used to attack tumors. While it is still in early stages, there are “hints of efficacy,” and this approach may turn out to be “an important part of our armamentarium,” the set of techniques available to treat childhood cancer, said Dr. Cripe.

*This Phase I/II Program Infrastructure Grant was co-funded by Flashes of Hope.*
WHO YOUR SUPPORT HELPS: Our Childhood Cancer Heroes

Childhood cancer is not just one disease. It is made up of a dozen main types and countless subtypes. To raise awareness of childhood cancer, we are honoring a child who has battled each type. Meet a few of our Gold Ribbon Representatives:

Ava Rich

Ava, a creative, sweet 11-year-old whose favorite activities include gymnastics and swimming, took her last dose of chemotherapy on July 23, 2015 after battling lymphoblastic lymphoma for 2.5 years. Her goal as a Gold Ribbon Representative is to share the importance of finding safer treatments, and to show support for all patients who feel lonely and isolated in their fight against childhood cancer.

Representative for LYMPHOBLASTIC LYMPHOMA
A form of non-Hodgkin lymphoma, lymphoblastic lymphoma is a cancer of the lymphatic system, which is part of the immune system. It occurs most often in children ages 7-11.

Ryker Wright

Ryker, a sweet baby who kept his infectious smile even through the rough times, was diagnosed with an extrarenal malignant rhabdoid tumor when he was 8 months old. Sadly, after the cancer spread quickly from his upper thigh to his lungs and liver, Ryker passed away at just 9 months old.

The Wright family hopes that one day soon, childhood cancer will receive more of the government’s funding for cancer research than the 4% currently allotted.

Representative for RHABDOID TUMOR
A malignant rhabdoid tumor is an aggressive cancer and is most often found in children under the age of two.

Jackson Dundon

Jackson was 2.5 years old when his battle with stage IV brain cancer began. Initially given a terminal diagnosis, Jackson received successful treatment and surgery and was declared cancer-free five years later. Now Jackson, a dinosaur lover and avid athlete, can finally pursue his life goal: to run as fast as a cheetah.

Representative for PNET (PRIMITIVE NEUROECTODERMAL) TUMOR
Primitive neuroectodermal tumors develop from neural crest cells and are most often found in children and young adults under the age of 25.

Ishani Sathianathan

Ishani, a happy and energetic 12-year-old who loves basketball and the San Antonio Spurs, battled rhabdomyosarcoma in her calf at the ages of 3 and 6. During both her initial diagnosis and relapse, Ishani faced surgery, a year of chemotherapy, transfusions, and four weeks of radiation. Today, Ishani is cancer-free, five years off treatment and living life to the fullest.

Representative for RHABDOMYOSARCOMA
Rhabdomyosarcoma is a tumor that occurs in striated muscle tissue and is made up of cells that typically develop into skeletal muscles. It is most commonly found in children ages 1-5.

Meet all 20 of our Gold Ribbon Reps at AlexsLemonade.org/Gold-Ribbon-Reps

Alex’s Lemonade Days - together, we did it, raising $1 million for childhood cancer research!

Alex’s Lemonade Days 2015 was an incredible weekend of lemonade, hope and fundraising for cures! A huge thank you to everyone who hosted one of the more than 2,500 lemonade stands and events from coast to coast. This year’s event was enhanced by the participation of Hero Family State Reps, families representing all the children fighting cancer in their state, who held their own lemonade stands and shared their stories. Alex’s Lemonade Days carries on Alex Scott’s challenge to the nation to help her raise $1 million for cures. Participate next June or hold your own stand any time of year!

Sign up to hold your own lemonade stand at AlexsLemonade.org/Get-Involved

Connecting Families
Families of children affected by childhood cancer gathered for ALSF’s Childhood Cancer Symposium on August 22 in Philadelphia.

This free event included sessions on topics such as survivorship care, cancer’s effect on families, coping with medical traumatic stress and empowerment through advocacy. It also served as an opportunity for families to connect with a supportive community of other childhood cancer families.
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.

- Alex's Million Mile - Run. Walk. Ride - September 1-30, worldwide
- Striking Out Childhood Cancer - October 18, Petaluma, CA
- Lemon: NYC - October 27, New York
- The Lemon Run - November 8, Philadelphia and virtually
- The Lemon Ball - January 16, Philadelphia
- Midwest Lemonade Days, June 3-4, Midwest
- Alex's Lemonade Days - June 10-12, worldwide

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

WEAR YOUR AWARENESS!
We’ve added new merchandise so you can raise awareness of childhood cancer any time of year. Our new t-shirts, socks and car magnet will spread the message wherever you go that we have to end childhood cancer! Available online at Alex’s Shop (AlexsLemonade.org/gift-shop) or you can give us a call at (866) 333-1213 to order.

2015 HOLIDAY ORNAMENT
Lily's World Record Big Lemonade Grand Stand: This holiday ornament makes a thoughtful gift and supports ALSF. Available soon!

SPONSOR SPOTLIGHT
Visit our website for a complete list of sponsors’ events.

Toys “R” Us
Toys “R” Us raised nearly $2.2 million during its fifth annual nationwide fundraising and awareness campaign. Throughout the program, Toys “R” Us encouraged social media users to show support for the cause and for Alexandra “Alex” Scott, the inspiration behind ALSF, by joining the conversation online using #Stir4ACure. Families across the U.S. joined the social media movement, sharing who or what they stir for.

Northwestern Mutual
Thousands of Northwestern Mutual employees and financial professionals raised funds and awareness to find cures for children with cancer at their annual Race for Research on July 19 in Milwaukee. Together, they collectively raised more than $515,000 in less than 2 months, which will fund 10,300 hours of childhood cancer research!

Auntie Anne’s
Auntie Anne’s is giving hope! Auntie Anne’s will be asking guests who visit their local store to “give hope” by purchasing a paper pretzel ribbon icon for $1 in the fight to end childhood cancer. As a token of appreciation, Auntie Anne’s will provide a $1 off coupon for the next purchase of any pretzel product or drink. One hundred percent of the proceeds collected through the in-store campaign will be donated to ALSF.

Red Robin
Participating Red Robin restaurants nationwide donate a portion of sales from each Freckled Lemonade beverage sold year-round as well as 100% of Freckled Lemonade proceeds from new restaurant openings the grand opening week. In 2015 alone, Red Robin has donated nearly $300,000 to ALSF.

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Alex’s “One Cup at a Time” Membership Program
BECOME A MEMBER AND JOIN THE FIGHT AGAINST CHILDHOOD CANCER!
Learn more at AlexsLemonade.org/One-Cup or call us at 610-649-3034.