A NOTE FROM LIZ & JAY

Last month, August 1, marked 10 years since our daughter Alex lost her life to cancer at just 8 years of age. At times, it is hard to believe that Alex has been gone for a decade, a time span that measures longer than the years of her life itself. Even though Alex’s life was short, she did have the chance to dream big and prove that everyone is capable of making a difference in the lives of others. She dreamed of being a fashion designer (that’s her sketching fashions in the photo at top right), but she also dreamed of giving other children with cancer a precious gift - hope that they will see the milestones that she did not.

As you’ll read in this newsletter, scientists are making significant strides toward cures and exploring exciting new avenues of research that are enabling children with cancer to achieve their goals. We know we’re on the verge of more breakthroughs, and thanks to your support, will one day achieve our own milestone of finding cures for all childhood cancers, enabling us to pack up our lemonade stand and post a large “Mission Accomplished” sign on the door. We are incredibly grateful for your continued support, thank you!

Liz & Jay Scott, Alex’s Parents

SHARE THE FACTS

Need a simple way to get involved during Childhood Cancer Awareness Month, or any time of the year? Help generate awareness by educating others about the startling facts behind the need to fund childhood cancer research. We’ll share one fact a day, similar to the ones below, throughout the month of September at AlexsMillionMile.org. Spread the word through an email, on social media, or print them out and hang them on your refrigerator.

- 250 KIDS AROUND THE WORLD DIE FROM CANCER EVERY DAY APPROXIMATELY

- LESS THAN 5% OF THE FEDERAL GOVERNMENT’S TOTAL FUNDING FOR CANCER RESEARCH IS DEDICATED TO CHILDHOOD CANCERS EACH YEAR.
Stand Spotlight: Riley Gillespie
9 Years of Car Shows & Lemonade

Riley Gillespie is a 17-year-old who just entered his senior year in high school and enjoys typical teenager activities, with one big exception. Riley spends all year working on a fall fundraising event that benefits ALSF. He organizes a car show at a local middle school and is responsible for every last detail including securing cars to display, sponsors, activities, food vendors, prizes and, of course, a lemonade stand. What’s more incredible is that Riley has been doing this since he was just 8 years old.

Riley first became involved with ALSF when at the age of 6, his best friend Jeremey was diagnosed with acute lymphoblastic leukemia (ALL). Over the next three years of Jeremey’s treatment, Riley saw what his friend had to go through. When Jeremey was preparing to have his last chemotherapy treatment, Riley learned of Alex’s Lemonade Stand Foundation and decided to hold a stand to celebrate. Since Riley’s first stand, five more of his friends have fought childhood cancer. Riley realized the grim reality of cancer when in early 2009 he lost two of those friends Leah Chapman, 14 and Dayna Irwin, 15. If anything, this only made Riley’s dedication to the cause stronger enabling him to raise more than $93,000 for ALSF over the years. Kids helping kids – it’s what we’re all about.

To further recognize Riley’s contributions in the fight against childhood cancer, ALSF will be honoring him at The 2015 Lemon Ball on January 10 as the Stand Host of the Year!

YOUNG INVESTIGATORS
News from the Next Generation

Attracting and retaining the best and brightest early career scientists is of vital importance to the future of childhood cancer research. Quite simply, if we don’t have researchers looking for better treatments and cures - we’ll never find them. Enter ALSF’s Young Investigator Grants. Designed as a strategic stepping stone, these grants fill a critical need for start-up funds and encourage the most promising scientific minds to commit to the field of pediatric cancer research. Below are updates from just two Young Investigator grantees who are already making important discoveries to help children with cancer.

UNVEILING NEW THERAPEUTIC TARGETS IN AML

Fabiana Ostronoff, MD - Fred Hutchinson Cancer Research Center (Seattle, WA)

Acute myeloid leukemia (AML) is a type of cancer that affects all age groups, ranging from newborns to the elderly. Although there has been significant improvement in AML treatment, survival for adolescents and young adults (AYA) has not improved to the same extent as for children. One of the reasons for this disparity may be related to “age-specific” biomarkers found in AML. Biomarkers are molecules that may be used as prognostic indicators to see how well the body responds to a treatment for a disease.

With their funding from ALSF, Dr. Ostronoff and her colleagues set out to determine if RNA-sequencing could help them uncover specific biomarkers in children and AYA with AML. Not only did they find that RNA-sequencing is a viable tool, but the researchers are also uncovering a new class of biological markers (a genetic alteration) found in certain children and AYA with AML that cause them to be highly resistant to traditional chemotherapy.

So what’s the bottom line? By discovering a new class of biomarkers that are especially prevalent in children with AML, doctors can better identify which patients will benefit from traditional chemotherapy and moving forward – work toward developing more effective targeted therapies for children that harbor the genetic alteration.

Dr. Ostronoff’s findings were recently published in the medical journal, Blood.

DISCOVERING THE LINK BETWEEN ALL AND DOWN SYNDROME

Andrew Lane, MD, PhD - Dana-Farber Cancer Institute (Boston, MA)

Children with Down syndrome are 20 times more likely to develop acute lymphoblastic leukemia (ALL) than the general population, but for years, doctors have been unable to explain the connection between the two conditions - until now.

ALSF grantee Andrew Lane, MD, PhD, and his colleagues at Dana-Farber Cancer Institute recently uncovered that a specific gene (HMGN1) on chromosome 21 (the extra chromosome that individuals with Down syndrome have) appears to cause a group of proteins, PRC2, to shut down leading to ALL cell proliferation and growth. When the scientists “turned off” HMGN1 in the lab, allowing PRC2 to function normally, the cells stopped growing and died. Therefore, if a drug could turn off HMGN1, it could potentially stop ALL from developing in people with Down syndrome. Currently, there are no drugs that target HMGN1, but there are agents called histone demethylase inhibitors that “turn on” PRC2, which researchers suggest may cause the same anti-leukemic effect.

Dr. Lane notes that this research may also be relevant to children without Down syndrome as in many cases of pediatric ALL, the cancer cells gain an extra copy of chromosome 21, and there is a subset of pediatric ALL with a very poor prognosis that has extra copies of a piece of chromosome 21. Next steps? The researchers are now trying to better understand HMGN1 and its effect on the survival of leukemia cells.

Dr. Lane’s work was recently published in the June 2014 issue of Nature Genetics.
At Alex's Lemonade Stand Foundation, we know firsthand that cancer affects the whole family, including, and often times especially, siblings of children with cancer. These vulnerable siblings face fears and anxiety when their family is thrown into the emotional turmoil of pediatric cancer.

With a strong program already in place to recognize our childhood cancer hero families, including the siblings of children fighting cancer, ALSF is thrilled to announce our recent acquisition of the SuperSibs! program.

SuperSibs! was established in 2002 and is the only program dedicated to ensuring that siblings feel comforted, encouraged and empowered throughout their family’s battle against childhood cancer.

SuperSibs! was forced to suspend its services due to a lack of funding in late 2013, but ALSF stepped in and is dedicated to seeing the program continue and flourish.

ALSF is currently working to reinstate the SuperSibs! comfort and care program that includes sending sibling care packages. The sibling care packages will include tools that provide encouragement and support to siblings of children with cancer, as well as acknowledgement that they are also experiencing the childhood cancer journey. Additionally, the Foundation will develop a Sibling Hero Ambassador Program to help empower siblings to share their stories and raise awareness of childhood cancer and its effects on the entire family.

For more information about SuperSibs! and to be notified when we will begin to accept referrals, visit AlexsLemonade.org/SuperSibs.

WHO YOUR SUPPORT HELPS: OUR CHILDHOOD CANCER HEROES

ANTONIO GOMEZ-COLON
Information provided by Ariadna, Antonio’s Mom

Antonio, aka Tony, is a strong, positive, happy and funny boy who loves Ninja Turtles, SpongeBob and monster trucks.

The day after Thanksgiving, 7-year-old Tony woke up crying with a headache. The headache persisted and after getting sick to his stomach, his mother took him to the hospital near their home. It was here, to everyone’s shock, that Tony was diagnosed with a tumor. Tony was transferred to the Children’s Hospital of Philadelphia, and it was there that the doctors told his family that he had brain cancer.

Tony had surgery but as a result, he lost the ability to move his left side. He is now undergoing therapy and oncotherapy to help get his body moving again. Tony completed six weeks of radiation and will receive chemotherapy treatments for a year.

His family’s dream is that his horrible cancer will go away forever and that he will be able to walk again, like before, and move his left hand. They hope one day Tony will be the healthy boy he used to be.

His mom is proud of what a great boy Tony is, and how he’s kept his positive outlook and stayed tough during difficult treatments.

Meet Tony in a new video now online at AlexsLemonade.org or on our YouTube channel.

BRIANNA MERCADO
Information provided by Brianna Mercado

Brianna Mercado is a 23 year old two-time cancer survivor, professional dance artist, teacher and avid volunteer based in New York City. Her fellow dancers, friends, family and acquaintances call Brianna a warm and glowing soul, who has lived with more passion and purpose in the past 8 years than most people do in a lifetime.

Her journey is a study in contrasts, a life of serious news and playful innocence, knock-downs and get-back-ups, the deepest challenges and the greatest rewards. From surviving life-threatening bone cancer through an exhaustive battle that took her fifteenth year of life forever away, to receiving a full-ride scholarship to UC Berkeley; from pulling up California roots for the move to the Big Apple to tirelessly work to give very ill children reasons to live and fight on as a counselor at a camp for children with cancer - Brianna lives by her own credo: Go big, regardless.

Brianna was diagnosed with Ewing’s Sarcoma in June 2006 and with follicular thyroid cancer in December 2013. She is currently undergoing radiation therapy, while pursuing her dancing dreams, and the cancer is continuing to shrink every day. She believes there must be a better and less toxic way to treat and cure cancer in children and young adults, and until that day comes, she will continue to support Alex’s Lemonade Stand Foundation.

Brianna continues to spread her love and passion for life through performing, mentoring, teaching, and public speaking. She embodies her belief that inside every impossible situation there is an opportunity to be great, and no real reason to wait. If there is more to learn, someone to love, something to give, and things to do - then do them, now.
**ONE CUP AT A TIME**

What a National Lemonade Days to remember! Commemorating 10 years since Alex issued her challenge to the nation, more than 2,000 stands and events were held from coast to coast during National Lemonade Days weekend (June 6-8, 2014). Thank you to everyone who held a stand, stopped by a stand or helped to spread the word about our annual weekend of hope. Get a head start and register now for next year’s National Lemonade Days, June 12-14, 2015! Visit LemonadeDays.org.

Then and now...10 years after Alex Scott appeared on the Today Show in 2004, Liz Scott and childhood cancer hero Bridget Smith and her mom returned on June 6.

**UPCOMING SPECIAL EVENTS**

Learn about attending or supporting any of our events at AlexsLemonade.org/alsf-special-events

- **L.A. Loves Alex’s Lemonade - Sept. 20 (Los Angeles)**
  Tastings from 40+ superstar chefs at L.A.’s version of a culinary picnic.

- **Lemon: NYC - Oct. 14 (New York City)**
  Chefs are assigned to a table of guests to cook/serve meals.

- **The Lemon Run 5K Run/Walk & Kids’ Dash - Nov. 9 (Philadelphia)**
  A fun event for the entire family - virtual participants welcome!

- **The Lemon Ball - Jan. 10 (Philadelphia)**
  Our “yellow tie” gala celebrates Alex’s legacy and honors supporters.