

Alex's Lemonade Stand



FOUNDATION FOR CHILDHOOD CANCER

TM

FRESH SQUEEZED NEWS OF THE SEASON

FALL/WINTER 2016

MAKING LEMONADE AND CREATING CHANGE

Another fun and successful summer lemonade season has come and gone. The leaves will soon change in Philadelphia (where we are based) and the cooler weather will arrive. With these seasonal changes, we are also seeing change take place in the childhood cancer community every day. In this newsletter, you will about read how the funds you raised allow both young investigators and expert innovators to bring about better treatments and cures. Take time to read about some of the results of their research efforts and what the future holds. **It is your donations that make this all possible!**

To facilitate more change, we will continue to focus on filling gaps in funding and resources. We have always grown ALSF's programs not by looking at what is currently happening and trying to do more of the same, but by looking at what is **not** happening and ask how we can make it happen.

As you know, September is Childhood Cancer Awareness Month and it is our job to keep spreading the word about the need for more research. Childhood cancer is still the leading cause of death by disease in children in the U.S., but with your continued support, we will change this together.

Until there's a cure,

Liz & Jay Scott (Alex's Parents)

CENTERS OF EXCELLENCE GRANT PROGRAMS FOCUS ON NOVEL TARGETED CHILDHOOD CANCER THERAPIES

The ALSF Centers of Excellence (COE) program currently funds four leading childhood cancer institutions: Dana-Farber/Boston Children's Cancer and Blood Disorders Center, Children's Hospital of Philadelphia, Texas Children's Cancer Center/Baylor College of Medicine, and University of California San Francisco. Institutions funded by the Centers of Excellence grant are expected to develop new therapeutics, conduct Phase I and Phase II clinical trials of highly innovative therapies and train the best and brightest investigators in developmental therapeutics and cancer pharmacology.

Dr. Steve Dubois of Dana-Farber/Boston Children's Cancer and Blood Disorders Center explained, this ALSF program is a major investment in the promise of novel targeted therapies for children with cancer. "We are already starting to see returns on this investment and expect even more progress over the next 5-10 years. Very soon, we will also activate a new Phase I clinical trial that will be led by our institution, but will be open at the other ALSF COEs. This grant mechanism has therefore encouraged new collaboration between the four leading centers. The COE Grant provides another source of funds to support the infrastructure of our experimental therapeutics program. This infrastructure allows us to open trials we would not otherwise be able to open and choose trials based upon the best science and not finances." To learn more, visit our website at AlexsLemonade.org and search for Center of Excellence Grants.



ALEX'S
MILLION
MILE



1 MONTH.
1 CAUSE.
1 MILLION
MILES.

SEPTEMBER
IS CHILDHOOD
CANCER
AWARENESS
MONTH



Every day, parents of children battling cancer travel thousands of miles for treatments. From September 1-30, we are going a million miles to raise awareness and fundraise for cures.

Last year, more than 15,000 people logged miles and raised money for childhood cancer research. This year we're doing it again! To find a cure for childhood cancer, we are raising a million dollars by going the distance. We hope you will join us by running, walking or riding to exceed one million miles all month long!

Anyone can join and there is no minimum mileage or fundraising requirements. Every mile and every dollar helps! If you are already on an Alex's Million Mile team or have made a donation to this campaign, we thank you for your support!

Check out our daily progress during the month of September at AlexsMillionMile.org or on our Facebook page at [Facebook.com/AlexsMillionMile](https://www.facebook.com/AlexsMillionMile).

WHO WE ARE HELPING: OUR CHILDHOOD CANCER FAMILIES

Childhood cancer hero Kaela Cruz and her SuperSib brother Anton are close siblings who are both continuing Alex's legacy of finding a cure for childhood cancer, one cup at a time.

Together with their parents, the Cruz siblings are Hero Family Ambassadors for ALSF and are participating in Alex's Million Mile this September. Running, walking and riding miles is more than just a way to get closer to a cure—it is a true testament to the strength and determination of the Cruz family.



Kaela Cruz

Meet Kaela Cruz, Hero

Kaela lost her leg to osteosarcoma, the most common type of childhood bone cancer, in January 2007, just before her 5th birthday. As part of her treatment, Kaela had an above the knee amputation of her left leg. Her treatment lasted 13 months.

Today, Kaela is a budding paralympic athlete and a member of the North Jersey Navigators Paralympic Sports Club. At the 2016 Junior Nationals in Wisconsin, she received eight 1st place medals, one 2nd place medal in track and field, and another medal in swimming. She continues to shine in school too, as an A+ honor roll student.

"Kaela is our inspiration. Her strength and determination shows us that no matter what the obstacle, you never give up. Not ever." said her father, Matt.



Anton Cruz

Meet Anton Cruz, SuperSib

Anton is 13 years old and started 8th grade in September.

He is an active and accomplished teenager. He has a black belt in Tae Kwon Do, loves drawing, video games, Japanese anime, rock climbing, dancing and instructional videos.

When Kaela was in treatment, Anton was always there by her side. Donna and Matt, Kaela and Anton's parents, included him every step of the way. During her treatment, Anton constantly encouraged Kaela to do her best.

"Anton helped Kaela build more confidence just by playing and being her little brother. It created a strong bond between them," said Matt.

[Read about Kaela's story in her own words at AlexsLemonade.org/blog](http://AlexsLemonade.org/blog)

YOUR SUPPORT
makes a difference - Please give!

PRESTIGIOUS JOURNAL *NATURE* FEATURES MAJOR WORK BY ALSF RESEARCHERS

In July 2016, ALSF Grantees Drs. George Daley and John Powers had an article published in the highly prestigious scientific journal, *Nature*, titled "*Multiple Mechanisms Disrupt the Let-7 MicroRNA Family in Neuroblastoma.*" Dr. John Powers received a Young Investigator (YI) Grant in 2012 to study with mentor Dr.



Dr. George Daley

Dr. John Powers

George Daley at Dana-Farber/Boston Children's Cancer and Blood Disorders Center. The YI funded project led to the publishing of this paper. Three time Innovation Grantee (2009, 2011 and 2016), Dr. George Daley spoke with us about the article:

ALSF: Can you explain the recently published article in simple terms?

GD: Well, I think in a nutshell the core of this project is the idea that there is a common mechanism of what we call the pathophysiology – a sort of common set of molecular principals that explains, essentially, a large percentage of neuroblastoma. What we previously knew about neuroblastoma was that the hybrid, highly aggressive forms had a super high expression of the oncogene, MYCN. We found MYCN is super high in part because it's helping to sponge this microRNA, let-7. Let-7 is best known as a tumor suppressor and is being inactivated by MYCN.

The next thing you know John [Powers] my post doc says "Well, if we look at the different classes of neuroblastoma, there's still another unfavorable prognostic class." It turns out when he looked at the question, he found where the major let-7 genes are located. So boom, the second piece fell into place.

The third piece, which was really the reason we got into this in the first place and was what ALSF originally funded us to study, was the LIN28 protein being the major negative regulator of let-7. So you have three different novel mechanisms all focused on inactivating let-7. The reason that's important is that it focuses the therapeutic strategy. One of the goals in the future of therapeutics has got to be restoring let-7 and there are various strategies for doing that.

ALSF: Where do you go from here? What's next for you?

GD: Wonderfully, we've just been awarded an Innovation (grant) from ALSF to follow up on some of this work. I think we're in a position where we may be able to, with the help of ALSF, come up with a novel therapeutic. So that would obviously be super exciting.

ALSF: What did you find interesting or surprising?

GD: A really fun thing for me to share is that, even though I'm at [Boston] Children's, I'm trained as an adult hematologist/oncologist. I had traditionally been working on adult leukemia. When I came here, we sort of made this observation about LIN28, almost by accident. So, we wrote a grant [proposal] to ALSF to study germ cell tumors. It ended up that the models we developed with the grant from ALSF didn't get germ cell tumors, it got another pediatric tumor called Wilms' tumor. The next thing you know we're studying Wilms' tumor. Then, we're studying neuroblastoma. In a very, very short stretch of time, catalyzed by funding from ALSF, we've got two major projects and multiple major papers on pediatric cancers. Its really been exciting for us!

IN THEIR OWN WORDS...

Since 2015, ALSF awarded 50 Pediatric Oncology Student Training grants, 22 Young Investigator grants and 3 'A' awards to pediatric cancer researchers around the country. Here is what some researchers had to say about what it felt like to receive a grant from ALSF and what it means to the advancement of their projects.

Dr. Mark Chiang, MD, PhD

University of Michigan

Young Investigator Recipient (2011); Innovation Grant Recipient (2016)

"We are grateful to Alex's Lemonade Stand Foundation (ALSF) for their support of our research. This support will help us make important advances to overcome the challenges for developing more effective and less toxic therapies for pediatric leukemia. This grant also helps us acquire major support from the National Cancer Institute (NCI). Early stage investigators like myself have questioned whether to pursue pediatric cancer research given the current funding shortages. Thus, the funding from ALSF comes at a critical time to establish a new, young laboratory committed to finding better treatments for pediatric cancer. As a physician-scientist who actively treats patients with leukemia, I am well poised and eager to translate our findings to the bedside."

Dr. Chiang is currently generating additional preliminary data to investigate a promising but understudied gene that is critical for leukemic cell growth.



Emily Theisen, PhD

Emily Theisen, PhD

Research Institute at Nationwide Children's Hospital

Young Investigator Recipient (2016)

"By prioritizing questions relevant to pediatric malignancies, Alex's Lemonade Stand Foundation enables young investigators to pursue routes of inquiry more impactful to patient care. The mechanisms which cause pediatric cancer not only matter to our young patients, but also illuminate the ways in which biology is

altered in other diseases, and must not be overlooked. These research pursuits, while important, do not often garner the same level of government support as other major diseases. Support from ALSF, during my early career, enhanced my ability to pursue these pressing questions and fostered my independent research career focus on pediatric cancer."

Dr. Theisen is currently researching how the driver of an aggressive childhood bone tumor manipulates other normal proteins. This type of hijacking allows cancer cells to thrive at the expense of normal cells. Fundamental understanding of these manipulations and knowing whether misguided proteins are targetable will lead to better therapeutic strategies for these young patients.

C. Russell Cruz, MD, PhD

Children's Research Institute

'A' Award Recipient

"Research support is critical to any beginning investigator and I feel especially privileged that a foundation as respected and as inspiring as Alex's Lemonade Stand Foundation has chosen my proposal as one of its award recipients. I have met successful scientists who have grown as investigators through the help of ALSF, and it is my hope that I follow their great examples."

Dr. Cruz is a recent recipient of the 'A' award which is designed for early independent scientists who want to establish a career in pediatric oncology research. Dr. Cruz is currently studying a group of cells called natural killer cells (NK cells). He wants to use cord blood as a source of the NK cells because it is readily available at multiple cord blood banks around the world. He also proposes to arm these NK cells so they can withstand the harmful effects of the cancer environment. This work will pave the way for the use of these novel cell therapies for brain cancer in children.



C. Russell Cruz, MD, PhD

STAND SPOTLIGHT:

AN EXCEPTIONAL SCHOOL SERVES OVER 1,300 CUPS OF LEMONADE FOR ALSF



Schools have always been strong supporters for ALSF. When teachers, students, staff and parents come together, amazing things happen!

Southwest Elementary School, in Clemmons, NC, is no different. Southwest's exceptional children's classrooms raised more than \$14,000 for childhood cancer research over the past 5 years!

In June, the school held their 5th annual lemonade stand and served over 1,300 cups of lemonade (raising \$5,500). Students in the exceptional children's classrooms (Preschool EC, Readiness, Core 1 and Core 2) use the annual lemonade stand to learn about helping others in need while working on social, math, language and functional communication skills.

Southwest teachers embraced all the educational benefits and lessons that come from hosting a lemonade stand.

Boys and girls at the school organized, planned and advertised the event. Teachers showed the students how to sequence the steps necessary to make the lemonade. The students also practiced addition and subtraction skills with money. The boys and girls also flexed their functional communication skills by asking visitors to buy cups of lemonade.

"Our students and staff have such BIG hearts to help others, which is truly what this event was all about," said Maria Vernon, a speech-language pathologist at Southwest and volunteer organizer of their ALSF lemonade stands.

Southwest Elementary School plans on continuing their annual lemonade stand tradition for years to come.

Want to learn more about how to get your school involved? ALSF has great resources for teachers, parents and students. Head over to our website: AlexsLemonade.org/Schools, to learn more!



INTRODUCING ALSF'S FIRST COOKBOOK!

This Fall, look for the new ALSF Cookbook in our gift shop. Featuring over 35 recipes from world-renown chefs and stunning photography, the book will be available just in time for holiday shopping and 100% of the proceeds goes towards our mission-fighting childhood cancer, one recipe at a time!

SPONSOR SPOTLIGHT



NWM Sioux Falls

Northwestern Mutual
Northwestern Mutual employees and financial professionals participated in the company's annual Race for Research to raise awareness and funds for childhood cancer research. Northwestern Mutual raised an incredible \$775,000 in less than two months for

ALSF. Thank you for your hard work, dedication and creativity around your fundraising efforts during Race for Research and year-round.

Applebee's

This past July, over 1,000 Applebee's restaurants participated in their 11th annual campaign for ALSF collectively raising nearly \$1.2 million! Restaurants fundraised by donating a portion of the sale of each lemonade sold, guests purchasing paper lemons and/or hosting other creative fundraisers like car washes, carnivals, karaoke nights and more. This brings their grand total to over \$7 million since first supporting ALSF. Thank you, Applebee's!

Auntie Anne's

From July 18 through September 11, Auntie Anne's hosted their 5th annual in-store fundraising campaign to support ALSF. Guests who visited Auntie Anne's showed their support for children fighting childhood cancer by purchasing a paper pretzel ribbon icon for \$1. Guests who purchased an icon were given a coupon for \$1 off their next purchase.

Rita's Italian Ice

From June 27 through July 24, more than 600 Rita's locations asked guests to donate \$1 for a paper lemon to raise money for "Rita's Fund of Hope," a Travel for Care endowment that helps families with children battling cancer travel to their children's treatment. Heroes in 7 states spent the day at their local Rita's store serving as Chief Ice Makers.

ALEX'S LEMONADE STAND FOUNDATION

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ALSF PLANS FOR BIOINFORMATICS LAB TO ADVANCE THE PACE OF CHILDHOOD CANCER RESEARCH



ALSF recently announced that our organization will open a state-of-the-art bioinformatics lab and use 'big data' to advance the pace of childhood cancer research. This was announced by Liz Scott, co-executive director of ALSF and Alex's mom, when she attended the National Cancer Moonshot Summit in June in Washington, D.C., hosted by Vice-President Joe Biden and Dr. Jill Biden.

The bioinformatics lab will utilize data scientists, computer scientists, bio-informaticians, computational biologists and other scientists to analyze and decipher the huge amount of childhood cancer data generated in research facilities across the country. The first informatics lab of its kind, discoveries will be shared to inform more research, find targets and develop new cures. By leveraging data, it will be a resource for ALSF funded researchers to access first rate analysis of their data to further enhance their ability to accelerate cures.

"We are excited to be able to harness the power of big data and open the ALSF Data Lab," said Jay Scott, co-executive director and Alex's dad. "Currently, the childhood cancer research community does not have a non-affiliated center to objectively analyze existing science and look for patterns to share with scientists. This is a true privilege to be able to offer this resource to the community and ultimately advance the pace of finding cures. We anticipate this new model of improving research to be up and running in the next 12 to 18 months."

JOIN US FOR

The 11th Annual

LEMON BALL

January 14, 2017, Philadelphia, PA

Presented by Applebee's, Northwestern Mutual and Volvo

Join us for our "yellow tie" gala at the Philadelphia Marriott Downtown!

FOUNDATION EVENTS

Want to show your support and have a great time? Our special events take place 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/alsf-special-events

- **L.A. Loves Alex's Lemonade** - September 10, Los Angeles, CA
- **Lemon: NYC** - October 4, New York, NY
- **Striking Out Childhood Cancer** - October 16, Petaluma, CA
- **The Lemon Climb** - October 22, Boston, MA and virtual
- **The Lemon Run** - November 13, Philadelphia, PA and virtual

For information on sponsoring an event, contact Jay Scott (Jay@AlexsLemonade.org)

DONATE TODAY OR GET INVOLVED!

ALEXSLEMONADE.ORG