FRESH SQUEEZED news OF THE SEASON

AWARENESS into ACTION

Another lemonade season has come and gone and thanks to all of our supporters - it was our most successful summer to date, thank you! We look to extend this success throughout the remainder of the year to attain our goal of raising the most funds so we can give them away in the form of research grants, travel assistance and other family resources. The month of September (National Childhood Cancer Awareness Month) also provides us with an opportunity to spread the word about the need to support childhood cancer research in an effort to eradicate the disease. We look to you to help us do this by sharing the story of Alex, educating others that childhood cancer remains the leading cause of death by disease in children under the age of 15, or simply wearing our signature color - yellow.

Our hope is that as more people become aware of the disease and its implications that more people will move beyond awareness campaigns and pledge to foster actionable goals to make a difference within the childhood cancer community. We won’t stop… until there’s a cure.

SINCERELY, Liz & Jay Scott (Alex’s Parents)

Why I Support ALSF
Bailee Madison, Actress and ALSF Youth Spokesperson

Up and coming young actress Bailee Madison has shown immense support for ALSF since 2010 and hosted a number of Alex’s Lemonade Stands in Atlanta, Florida and New York City. Twelve-year-old Bailee is a shining example that you are never too young to make a difference.

Q. How did you first hear about Alex’s Lemonade Stand Foundation?
A. Through one of the ALSF volunteers, I think his name was Todd, who called us and asked if I wanted to help out at an Alex’s Lemonade Stand nearby. I will forever be grateful to him!

Q. What was it about ALSF that made you want to get involved?
A. One of the most exciting things to me about ALSF is that it’s about kids helping kids! It’s a way for the entire family, your community or friends to get together and have a day full of fun while at the same time raising money and awareness for pediatric cancer research. (Article continued on back page)
Although the majority of the donations that we receive go directly toward childhood cancer research projects, donors can also choose to support the ALSF Travel Fund that assists families with expenses related to having to travel far from home for their child’s treatment.

At 9-years-old, Alexa delos Reyes has been through it all. After being diagnosed with neurofibromatosis when she was only 2-months-old, a tumor was found in her brain just after her first birthday. She’s had chemotherapy, 6 brain surgeries, 3 port surgeries, a shunt placement and many trips to the hospital to treat infections from the ports. After all of this, due to the large size and precarious location of Alexa’s tumor (wrapped around her brain stem) it has been deemed inoperable. Running out of treatment options, Alexa and her family traveled from their home in Clackamas, Oregon to New York City to participate in a clinical trial. ALSF’s Travel Fund helped the family during their stay at the Ronald McDonald House in Manhattan and provided them with a gift card for food to cook while there. Sadly, the trial in NYC did not work for Alexa, and her tumor started to grow again. She is currently in Boston with her mom, participating in another clinical trial having to leave her dad and brother back in Oregon to continue work and school. The ALSF Travel Fund has continued to support Alexa and her family. Recently Alexa’s tumor grew and blocked her ventricles causing hydrocephalus. This rendered her totally blind and she now has a feeding tube placed directly in her stomach.

Despite all of her hardships, and being away from family for many months, Alexa always smiles, rarely complains and continues to experience the things so many little girls her age enjoy. She is a true hero.

“If it were not for Alex’s Lemonade Stand Foundation’s Travel Fund, we would not be able to get the treatment Alexa so desperately needs. It was so nice to know someone was there to help us. Thank you for making this journey so much easier to embark on.”
– Monica delos Reyes, Alexa’s Mom

Early results from a clinical trial recently found that a drug that was being used to treat lung cancer in adults (crizotinib), was found to eradicate cancer in some kids with a rare type of lymphoma (anaplastic large cell lymphoma - ALCL). For 7 out of 8 kids who had ALCL and were enrolled in the trial, there is no trace of their cancer. Better yet, crizotinib is a pill as opposed to IV chemotherapy, with minimal toxicities associated with it in spite of high dosages, and within days of taking it – it helped reduce fevers, chills and pain that some of the kids were previously experiencing.

The research team, led by Yaël Mossé, MD, Director of the Neuroblastoma Developmental Therapeutics Program at the Children’s Hospital of Philadelphia (CHOP), explains that crizotinib appears to be effective in patients that test positive for the cancer causing gene, anaplastic lymphoma kinase (ALK). Crizotinib specifically looks to disrupt this gene and, if all goes as planned, the cancer disappears. We’re thrilled to note that Alex’s Lemonade Stand Foundation had a role in this breakthrough! ALSF provided previous support to the research team that was critical for the translation of the basic research findings into a clinical trial.

Zebrafish – these black and white striped fish may seem rather unimpressive, but they are actually playing an important role in helping researchers make progress toward finding better treatments for kids with cancer. Here at ALSF, zebrafish first came to our attention when we noticed that the tiny tropical fish were being referenced as cancer models in an increasing number of ALSF research grant applications. Even as non-scientists ourselves, we couldn’t help but wonder - why zebrafish? It turns out, zebrafish's genomes and immune systems are similar in many ways to those of humans and they can easily mimic human cancers. Also, zebrafish can live 4 or 5 years, allowing scientists to study when and how the disease develops normally during the fish's lifetime as a parallel for human disease. One more bonus - the translucent fish have proteins that are fluorescent enabling scientists to watch the behaviors of cancer cells in real-time (it’s sort of like they have x-ray vision). All in all, zebrafish are an incredibly useful tool for researchers to learn more about childhood cancer and how it develops. Check out a few ALSF projects involving the slippery swimmers:

RESEARCH BREAKTHROUGH!

ONE FISH, TWO FISH, RED FISH...ZEBRAFISH?

Fish prove to be worthy bait for netting clues toward cures

Nikolaus Trede, MD, PhD, a researcher at the Huntsman Cancer Institute was awarded ALSF funding looking at a new treatment for T-cell acute lymphocytic leukemia (T-ALL), a particularly hard to treat type of childhood cancer. Dr. Trede tested the targeted treatment, Lenaldekar (LDK), and found it to be successful in treating zebrafish with T-ALL. This is even more exciting because LDK targets cancer cells (not healthy cells as with existing chemotherapy treatments) making the treatment significantly less toxic.

ALSF also recently awarded an Innovation Award grant to David Traver, PhD, of the University of California at San Diego, who is using zebrafish as a model to study pediatric leukemia. This is where the x-ray vision comes into play...Dr. Traver will model a particular form of leukemia in the zebrafish and observe how normal cells turn into leukemia. His goal is to isolate chemicals that will stop or impede this transformation and ultimately, lead to new treatments to better treat children with this type of the disease.
Ten years ago, Danny had wonderful “treatment free” year from the summer of 2011 through May 31, 2012. It was on this day that an MRI indicated that Danny’s cancer was back and growing in the original site. Although we were devastated at first, we know Danny will continue to fight and win his battle with “the beast.” He’ll receive another scan in a few months and start up chemotherapy once again.

Danny has taught us what is really important in life. He makes us laugh everyday and like that little 9-year-old ten years ago, he is living life to the fullest. He is my hero.

HOPE BERTESEN
Written by Hope Bertelsen

In 2003, when I was in seventh grade, I weighed 60 pounds, my stomach hurt all the time, and I was so weak I had trouble carrying my schoolbooks from one classroom to the next. This had started on a smaller scale when I was 7, and got worse over the years, but it took the doctors 5 years to discover what was wrong. When I became jaundiced one day, I was sent to get an ultrasound, where they discovered a mass. At 12-years-old, I went from seventh grade directly to the hospital. Within days, I was told I had neuroblastoma and immediately started IV chemotherapy.

For the next two years, I was in and out of the hospital – I had 5 rounds of IV chemo, countless surgeries, including one that lasted 13 hours, almost constant nausea, the loss of my hair and then the re-growth of my hair and then the loss of it again when I started another chemo. I had infections that put me in the PICU, and I had a stem cell transplant that very nearly killed me. My parents were told to come in and say goodbye. But somehow I pulled through all of that, and started another treatment – a radioactive treatment – that was brand new. I was one of the first people in the world to get it, and it literally made me radioactive for a week. Unfortunately, it didn’t come with any cool superpowers; but, it did destroy so much of my cancer that I was able to go on a smaller, easier maintenance treatment for a few years. I was able to graduate high school with my grade, and even attend college for a semester. Unfortunately, it did come back – I had to hold off on college to explore new treatment. But in those few years, modern medicine made huge strides. I didn’t have to go back to all the harsh IV chemos. Instead, I was able to take oral medication in the form of liquids and pills. I have been on so many experimental and new medications now that I have lost count, but they have all brought me a step closer to remission, and each one has been easier than the last. The last one was literally just three pills a day, with zero side effects.

Unfortunately, I did have to start radiation for the first time recently, but I am still hopeful. I believe that I will be well again, and when I am, I am going to help others, just like Alex. It has been over 9 years, and at 21-years-old, I am proud to say that I am still fighting, and will continue until I don’t have to anymore.
**Why I Support ALSF (cont'd from front page)**

**Bailee Madison**
Actress/ALSF Youth Spokesperson

Q. How has Alex inspired you to make a difference?
A. I've always said that you are never too young to make a difference, when I learned about Alex's story I was inspired that at such a young age she was so courageous and put others before herself. Every time I share Alex's story I'm inspired all over again.

Q. In one of your movies, “Letters to God,” you actually played a girl whose best friend was fighting cancer. Did playing this role have any impact on your decision to get involved with ALSF?
A. ABSOLUTELY!!! I was incredibly blessed to be a part of “Letters to God.” It truly changed my life.

Q. What’s your favorite thing about holding lemonade stands?
A. One of my favorite things about holding an ALSF stand is that it brings everyone together. I love watching and listening to people sharing their stories.

Q. Do you have any inside tips about how to make a yummy glass of lemonade?
A. I wish I did - our homemade lemonade is always too sour!

Q. What’s your message to other kids out there that think they might need to be a famous actress to make a difference?
A. I’m very thankful to be able to do the work I’m doing, but I believe that no matter how old you are or what you do everyone has the ability to help someone else! Just imagine how beautiful the world would be if Alex lived in all of our hearts!!

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**COOKING, RUNNING & DANCING FOR CURES!**

L.A. Loves Alex's Lemonade (Sept. 29 - Los Angeles) – L.A.'s version of a picnic featuring top chefs cooking up tastings of their dishes on the lawn of the historic Culver Studios Mansion. Childhood cancer heroes, emcee Jimmy Kimmel and musical guest Michelle Branch will help make for an entertaining and inspiring event!

Lemon: NYC (Oct. 23 – New York City) – We’re back in New York for our second Lemon: NYC, where guests enjoy a four-course, sit down dinner cooked and served by a top chef randomly assigned to each table.

NEW! Sweet Miami Lemonade (Nov. 1 – Miami) – A new culinary event featuring Miami's own Hedy Goldsmith. The event spans four private suites at the new Marlins Park with each suite featuring delicious desserts from Hedy's new cookbook, “BAKING OUT LOUD: Fun Desserts with Big Flavors” paired with signature cocktails. Satisfy your sweet tooth and help to fight childhood cancer!

The Lemon Run (Nov. 11 – Philadelphia) – A fun way to bring your family, friends and/or colleagues together for a great cause. Join us for this 5K Run/Walk and Kids’ Dash held at Memorial Hall in Fairmount Park as we look to run over childhood cancer. Register today to take advantage of a discounted pre-race registration fee!

The Lemon Ball (Jan. 12, 2013 – Philadelphia) – We’ll ring in 2013 the best way we know how - by honoring the life and legacy of Alexandra “Alex” Scott. Extend your New Year’s celebrations, tickets are now on sale!

Visit AlexsLemonade.org/alsf-special-events for more information about any of the events above.

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**SPONSOR SPOTLIGHT**

**Volvo Donates for Each New Car Sold**
As part of an ongoing program, with the purchase of every new Volvo, participating Volvo retailers will donate $10 to ALSF. This is in addition to Volvo’s ongoing stand recruitment promotion - simply recruit a new stand host and both you and the recruit receive a $25 donation.

**Pretzels for a Purpose - Auntie Anne’s**
Through October 6, guests who visit Auntie Anne’s and purchase a paper lemon icon for $1 will receive a coupon for $1 off their next purchase of any pretzel product and drink. Give and get back!

**Northwestern Mutual Joins Team Alex**
Northwestern Mutual (NWM) recently launched a national philanthropic program that benefits ALSF’s research program and our Travel Fund. NWM financial representatives and employees will support these two programs by hosting Alex’s Lemonade Stand fundraisers in their local communities. Be on the lookout in your area!

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**DONATE TODAY, HOLD A STAND, OR VISIT OUR GIFT SHOP!**

**ALEXSLEMONADE.ORG**

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