



Read his hero story on page 3



SPRING / SUMMER 2018



HOLD A STAND ANY TIME OF YEAR
AlexLemonade.org/Get-Involved



Wyoming Seminary Lower School in PA

ALSF MAKES LEMONADE GO A LONG WAY FOR KIDS WITH CANCER

Ever since Alex Scott first defied the odds by kicking her leg just two weeks after doctors said she may never walk again, there has been something different about her story. Alex's Lemonade Stand Foundation (ALSF) is proud of its unique start and continues to distinguish itself as a leader in the childhood cancer community. ALSF is doing more than ever to stand out and here are just a few examples:

- National Cancer Institute designation:** ALSF is the only childhood cancer organization that has been given the NCI peer-reviewed funder designation for rigorous selection of research grants. This ensures every grant dollar goes to projects that researchers believe have the best potential for impact.

- Seeing the full picture:** ALSF is unique in its approach to funding research by first identifying critical gaps and then creating programs.

- Supporting families every step of the way:** Fighting childhood cancer is incredibly expensive to the families impacted. ALSF helps families who have to travel for treatment through its Travel For Care program. ALSF also

provides resources critical to assisting families fighting childhood cancer.

- Tracing the roadmap to cures:** ALSF has always facilitated collaboration between the country's top researchers and now it is bringing them together for the "Crazy 8" initiative. Researchers will discuss and plot out the best pathways forward for finding solutions to eight childhood cancer problems. In addition to its current grant offerings, the Foundation will use this roadmap to guide future funding decisions and designate \$25 million to fund resulting projects.

- Leveraging big data:** ALSF founded the first of its kind Childhood Cancer Data Lab (CCDL). The first project is to harmonize all publicly available childhood cancer data for use by researchers. This spring, the CCDL will launch the beta version of a free tool for researchers to enhance the use of data.

Most of all, what makes ALSF different is the commitment of people like you, the dedicated donors whose passion will one day make cures possible. Thank you for continuing along this journey that Alex started.



MAKING PAR FOR THE CURE

BELLA is hitting the links to make a difference! Last year, the 8-year-old golfer out of Illinois decided to use her budding golf career to raise awareness and funds for Alex's Lemonade Stand Foundation. She signed up to be a Champion for Kids with Cancer and has already raised over \$1,200!

Bella has traveled as far as Florida and Texas and is heading to California for another tournament. She also created custom ball markers designed to raise awareness for childhood cancer research.

Champions for Kids with Cancer is a program designed for anyone who wants to make playing sports and scoring points even more meaningful by raising money for kids fight cancer.

To learn more, visit AlexsLemonade.org/KickIt



**ONE CUP
AT A TIME
CLUB**

"I feel blessed to have two healthy young boys and can't imagine how difficult it is for children battling cancer and their families. I became a (One Cup) member to help provide comfort and hope to families and children facing the unimaginable and give them the strength to keep fighting."

said Maria P. of Pasadena, CA.



As a member of the One Cup at a Time Club, supporters like Maria have made an enormous impact on families dealing with a childhood cancer diagnosis. A monthly gift in any amount is all it takes to enable ALSF to continue funding innovative childhood cancer research and give families hope for a cure.

Learn more at
AlexsLemonade.org/OneCupClub



"Don't ever give up hope. Ever."

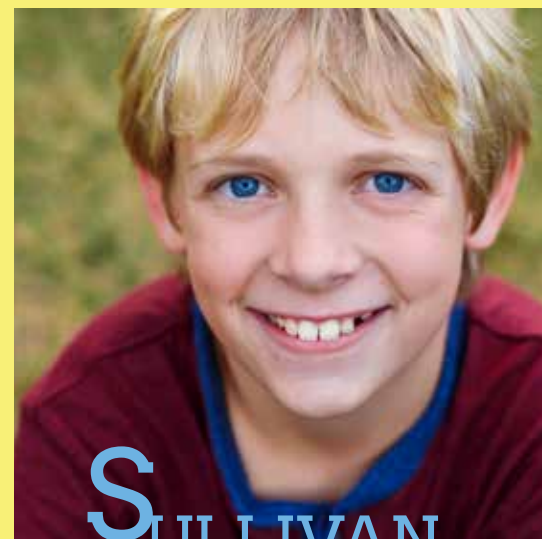
– Erin Schermerhorn, Haven's mom



**HAVEN
ANDERSON**

In 2012, at just 2 years old, Haven's family learned she had neuroblastoma, the most common cancer during infancy. Her doctors in Denver tried many different treatments in hopes of eliminating the tumor, but after five years, Haven is still fighting the disease.

Despite this, Haven approaches life with a fierce determination. She always tries new activities with a can-do attitude. Even when oncologists said she had a 0% chance of surviving this long, she is beating the odds. Now 7, Haven continues to search for a cure, with her family supporting her through participating in events for ALSF.



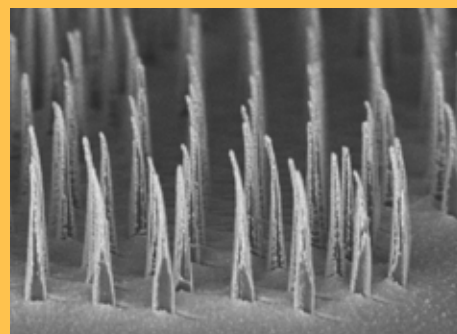
**SULLIVAN
BUTLER**

Ten year old Sullivan filled his days with Cub Scouts, triathlons and LEGOs. Then, his life took a turn when he was diagnosed with medulloblastoma, a type of pediatric brain tumor. The tumor's rapid growth forced him into immediate surgery.

After his doctors in Houston removed the golf ball-sized tumor, Sullivan required further treatment before his brain had properly healed from surgery. The procedure left Sullivan struggling with things that once came easy to him, like school or walking.

"Some things that were very easy for him before are hard now," said his father, Dan. "That's a tough thing to live with."

Today, Sullivan continues along his difficult road to recovery. Family, friends and doctors remain amazed at his progress which includes scans free of disease. While he's still adjusting to the side effects, his supportive family knows Sullivan will fight no matter what.



USING NANOTECHNOLOGY TO DELIVER CHILDHOOD CANCER TREATMENTS

Dr. Steven Jonas, of UCLA, created a potentially time-saving and cost-efficient way to deliver childhood cancer treatments using nanotechnology. His interdisciplinary team is building nanorobotic delivery drones that can administer gene and gene-editing packages directly to cells quickly, safely and for a lower

cost than current methods. For kids battling cancer, this has the potential to significantly reduce the wait time for delivery of precision medicine, like CAR T-immunotherapy, from a month to weeks.

Pictured above, these nano-sized tools are 100,000 times smaller than the thickness of a human hair.

NOVEL TREATMENT FOR HIGH GRADE GLIOMAS

Dr. Catherine Flores at the University of Florida is using her love of investigation to discover cures for childhood brain cancer. Through an ALSF Young Investigator grant and support from Northwestern Mutual, Dr. Flores focused her preliminary research on the development of a specialized immunotherapy treatment to fight high-grade gliomas. High-grade gliomas are a type of fast-growing brain tumor with poor survival rates.

The treatment starts by harvesting a child's cells and then altering them to specifically target each child's distinct brain tumor. Dr. Flores' protocol comes with minimal side effects and has the potential to lead to better outcomes for patients, while minimizing high levels of toxicity.

This spring, Dr. Flores opened a phase 1 clinical trial that tests this immunotherapy in children with high grade gliomas, the first trial of its kind for pediatric cancer. This initial trial will determine its safety and proper dosage. If successful, the hope is for this novel treatment to be applied to different types of tumors, bringing kids with cancer one step closer to a cure.

IMMUNOTHERAPY

is a type of cutting-edge cancer treatment that makes use of the body's own immune system to destroy cancer cells and keep them from returning.

ROCK STAR RESEARCHERS!

For childhood cancer researchers, publishing in a scientific journal is not just about the prestige and accomplishment. Publishing is one of the key ways scientists can collaborate and move closer to breakthroughs and cures. Here are some ALSF-funded researchers whose work has recently been published.



STEVEN DUBOIS, MD, of Dana-Farber Cancer Institute (Center of Excellence/general pediatric cancer) published in *New England Journal of Medicine* (February 2018).



STEVE JONAS, MD/PhD, of University of California Los Angeles (Young Investigator/leukemia) published in *Journal ACS Nano* (March 2018).



MICHAEL KHARAS, PhD, of Memorial Sloan Kettering Cancer Center ('A' Award/leukemia) published in *Nature* (November 2017).

Read more research stories at
AlexsLemonade.org/Blog

Did you know...

there is enough disease data at the National Institute of Health to fill up six Libraries of Congress? Unfortunately, much of that information is often written in different ways that make sense to one researcher but often times not to another. Translating that data into one consistent format so that all researchers can access and understand it is one of the jobs of the Childhood Cancer Data Lab (CCDL).

The first big data lab of its kind

dedicated to childhood cancer, ALSF will soon launch the beta version of www.Refine.bio, a tool, which is designed to collect data into one format in a central location. Researchers across the globe will be able to efficiently access and analyze this data to identify common patterns. In turn, they hope this collaborative dataset will accelerate the development of new therapies to cure childhood cancers.

To learn more about the CCDL, visit CCDataLab.org.

THE Alex's Lemonade Stand Foundation



Fighting childhood cancer, one mile at a time.

SEPTEMBER 1-30, 2018

At ALSF, we know that parents with a child fighting cancer would go a million miles to find a cure. For all kids with cancer and their families, ALSF supporters are also willing to go a million miles too in order to fund the critically needed research into less toxic treatments and more cures.

But, we need your help! This September, during Childhood Cancer Awareness Month, sign up to run, walk or ride all month long to collect one million miles and raise \$1 million and beyond!

For more information, visit TheMillionMile.org

SPONSOR SPOTLIGHT



1

If you go to dinner at **Applebee's** in Bensalem, PA, you likely will meet Charlie Donisi. Charlie has been a host at the restaurant for four years and in addition to his regular duties, he is raising awareness and funds for childhood cancer.

During his shifts, Charlie stops by every table to tell Alex's story with great

enthusiasm and ask for donations. He raised about \$5,000 of the store's \$6,000 total raised for ALSF in 2017. When asked what motivates him, he says it is his pleasure to help out a cause with such a great purpose, as Applebee's has made it part of their work culture.

"I just hope Alex is looking down from heaven with a smile on her face," he said.



Love & Lemonade

When Andy Ottenbuttel picked up Alyssa Malave for their first date, he expected a romantic night out; however Alyssa had other plans. She needed a hand with a fundraiser she was hosting for ALSF at St. Joseph's College on Long Island in New York. The couple spent the night talking, laughing and walking around hanging up giant lemon-shaped signs.

The rest, as they say, is history! Andy and Alyssa got married in September 2017 and included ALSF in their wedding celebration. In lieu of favors, they made a donation to the Foundation to help kids fighting cancer, featured a lemonade station for their guests and their officiant shared their first date story during the ceremony.



2

The Orlando Chili Cook-off, sponsored by **Northwestern Mutual**, raised over \$10,000 for ALSF in February. This is a festival that includes 100+ chili booths, food trucks, live music, games and a massive Kids Zone. Employees host an Alex's Lemonade Stand and SuperSib Emily Cartafalsa (pictured here) attended the event on behalf of ALSF.

ALSF MISSION

To change the lives of children with cancer through funding impactful research, raising awareness, supporting families, and empowering everyone to help cure childhood cancer.

HOW YOUR EVENT HELPS FIGHT CHILDHOOD CANCER



\$50

will fund one hour of research

\$400



will fund one day of research

285

ONE in 285 children in the U.S. will be diagnosed with cancer by the time they are 20 years old.

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