

SPRING/SUMMER 2020



alex

FRESHLY SQUEEZED NEWS

ALSF'S Response to the COVID-19 Pandemic

At the start of 2020, the continued dedication of supporters like you had Alex's Lemonade Stand Foundation (ALSF) poised for its most impactful year yet. Then came COVID-19, casting uncertainty over nearly everything. **One thing was certain though: more than ever, childhood cancer families needed our help.**

Families already facing the fear that accompanies a childhood cancer diagnosis had brand new dangers to navigate. Cancer treatment makes kids immunocompromised, meaning they were potentially at risk of illness if exposed to COVID-19. Many families already rely on one income, and now they were facing even greater economic uncertainty while trying to support their families.

However, thanks to our donors, ALSF was ready to address the most pressing needs in the childhood cancer community and keep research moving forward. Here's how your support helped the Foundation continue its mission and keep the safety of our supporters and heroes top of mind during the COVID-19 pandemic.

CREATING THE COVID-19 EMERGENCY FUND:

This new initiative expanded ALSF's Travel For Care program to provide grocery and travel support for families in treatment, plus extended hotel stays so kids could remain in isolation near their treatment center. Since launching in March, ALSF has provided support to more than **1,200 families.**

SHIFTING FOR DATA:

While scientific research labs ground to a halt during COVID-19, the Childhood Cancer Data Lab (CCDL) brought the power of Big Data to researchers at home. Their data refinery, refine.bio, gives researchers access to millions of pre-processed datasets online, a key resource for those with limited access to the tools they used previously. The CCDL also took their data science training workshops virtual for researchers to learn valuable new data analysis skills they could use while away from the lab.

FUNDRAISING GOES VIRTUAL:

With special events and lemonade stand fundraisers canceled out of an abundance of caution for the health and safety of ALSF supporters, the Foundation launched new ways for people to take their support online. From the Virtual End Childhood Cancer Walk/Run 5K to a Gamers for Kids with Cancer program, there are fresh, safe ways to raise funds for kids fighting cancer.

#MAKEALEXSLEMONADE:

ALSF has made lemonade out of lemons since its inception. The #MakeAlexsLemonade campaign gave supporters a chance to share how they're making the most of their extra time at home. From puzzles to pizza dough to painting, their creativity brought much-needed positivity into everyone's lives.

With your help, ALSF will continue to provide critical services for families and keep moving towards better treatments and cures. Thank you for making a difference even in the most difficult of times.

PANDEMIC

COVID-19 is a novel (or new) virus, so much of the community lacks immunity to it. It has become a pandemic because of its rapid spread.



Childhood Cancer Hero Jonathon



Participants in the Virtual End Childhood Cancer Walk/Run



The Newell Family

Fill Your Pitcher with Hope

Boris's Bracelets



ELEVEN-YEAR-OLD Boris chose to do something generous with his extra time in lockdown — make bracelets to support kids with cancer! His virtual fundraiser surpassed its \$500 goal, and he is donating all the proceeds to ALSF.

“I want to make a difference.

I want to show people who are dealing with cancer that there is hope.” — Boris

Making Masks



WHEN THE WORLD needed more masks, Gina and Sew Jo's Uncommon Threads supplied! Partnering for an online fundraiser in honor of Gina's daughter, Summer, who passed away from rhabdoid tumor in 2016, Sew Jo and her team made over 500 fabric

masks through the month of April and helped raise more than \$6,000!

Best Friends Forever

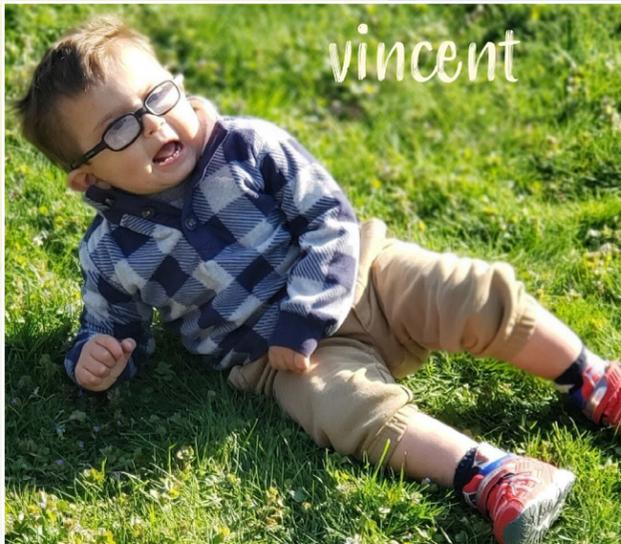


NANCY LOST HER BEST friend to leukemia when she was just 12 years old. Today, Nancy is training for the New York City Marathon as part of Team Lemon, ALSF's charity running team, to honor her best friend and all kids fighting cancer. Already, Nancy has raised more than \$2,000, and is sharing her story and the story of ALSF to inspire others to change kids' lives.

“You can't run a marathon without being 'in the now' and going that first mile. ALSF has the same approach to helping families 'in the now', 'in the next' and in the marathon of childhood cancer.” — Nancy

SOCIAL DISTANCING

Staying six feet apart, limiting large gatherings and staying home as much as possible can prevent spread of infections.



vincent

There are families across the country with kids still battling cancer, pandemic or not.

Conquering Cancer During COVID-19

VINCENT'S family calls him Vincent the Conqueror for a reason — he's crushed his treatment for atypical teratoid rhabdoid tumor (AT/RT) since he was 4 months old. Now at 2 years old, he is facing new obstacles.

In January 2020, Vincent relapsed. His family utilized ALSF's Clinical Trials Navigation program, which identified a clinical trial that could help Vincent, but a few months later, the COVID-19 pandemic struck. Soon, Vincent's weekly appointments for bloodwork, chemotherapy and various therapies halted. The community of friends and relatives his family relied on could no longer be around to assist them. Stepping out of the house was more dangerous than ever.

But Vincent's treatment can't stop. He still takes chemo at home every day. He still ventures out to get a lumbar puncture with chemo under general anesthesia every 28 days, and bloodwork every other week. His parents must primarily communicate with his neuro-oncologist via email. All his critical therapy sessions have been canceled

indefinitely. His family is afraid his future MRIs will also be canceled, or show results they cannot treat.

Vincent's family isn't the only one facing this experience. There are families across the country with kids still battling cancer, pandemic or not. Kids like Vincent are immunocompromised, meaning they are potentially at risk of illness if exposed to COVID-19, but they still need to get to treatment safely. Although some families are used to isolating themselves, physically distancing from loved ones today can feel like they're fighting alone. Vincent's family is choosing to see the positives in the current situation, from recognizing the people willing to help them, to the time they now have together — making lemonade out of lemons.

“I am most grateful for time. Our family has spent over 200 nights separated while Vincent was inpatient and all I wanted was to be home together. And now we are. I can't ask for anything more.” — Natalie, Vincent's mom

Childhood Cancer Research in a Pandemic

ALSF researchers keep science going, even under lockdown.

WITH many academic labs locked down during the COVID-19 pandemic, researchers have found ways to pivot to keep critical research moving forward.

For wet labs — biology and chemistry labs where science experiments happen — researchers moved ongoing experiments forward by designating essential personnel who could check in on the lab periodically. For institutions with clinical trials, critical treatment for children with cancer continued with precautions (and through telemedicine visits) to limit risks to staff, patients and families.

Still, the lockdown has significantly slowed research progress, so the Childhood Cancer Data Lab (CCDL), powered by ALSF, is helping the research community move forward even when they can't get to their labs. Here's how:

- 1. Making data available — anywhere, anytime — via refine.bio**
refine.bio provides researchers with access to gene expression data in one universal format that they can review and use in their projects. Access is free and available from anywhere, a useful benefit with many researchers stuck at home.
- 2. Training pediatric cancer researchers at virtual workshops**
The CCDL held virtual training workshops to give researchers who had open time on their hands the opportunity to learn data analysis skills and later, apply those newly honed techniques to analyze data resulting from their wet lab work.
- 3. Organizing the Open Pediatric Brain Tumor Atlas**
The CCDL is working to build the infrastructure of the Open Pediatric Brain Tumor Atlas. The Atlas, being built in conjunction with other researchers, includes data from 16 different research centers and samples from nearly 1,000 different pediatric brain tumor patients.

To learn more about the CCDL, visit AlexsLemonade.org/CCDL-Newsletter.

IMMUNOCOMPROMISED

Kids with cancer can be immunocompromised, meaning their immune systems are unable to fend off viruses and bacteria. Treatment for cancer can cause kids to be immunocompromised.



jake



lakelynn

Researchers Bring Treatments Closer to Home

EVEN with the spread of a new disease threatening everyone's health, treatment for kids fighting cancer can't stop. They must continue to leave the safety of their homes and travel to hospitals and treatment centers — their lives depend on it.

It hasn't been easy for kids like Jake and Lakelynn, but they are not fighting alone.

Jake was diagnosed with ependymoma in the fall of 2012. When his options for treatment were dwindling, Jake's family discovered that he qualified for a clinical trial led by Dr. Ted Johnson, an ALSF-funded researcher. Jake traveled from his home in Toronto to the trial in Augusta, Georgia, a herculean task made a little easier with the support of ALSF's Travel For Care program. In between trips to Augusta, Jake would have MRIs and bloodwork done at his home hospital. When the COVID-19 pandemic hit, and traveling was no longer safe, Dr. Johnson went above and beyond expectations, arranging for Jake's entire treatment plan to continue in Toronto.

Jake faced many relapses and complications during his fight, but today, because of the success of a recent spinal resection, Jake has no trace of a tumor left. By recommendation of Dr. Johnson and Jake's oncologist in Canada, Jake can take a break from all treatment to allow his bone marrow to recover.

Lakelynn is facing a similar situation. When doctors discovered that the sarcoma wrapped around the nerves in her arm harbored the rare NTRK gene fusion, she was put on a clinical trial that helped stabilize her cancer. Lakelynn and her family had no other option than to fly to Boston every month to receive this lifesaving treatment. But when the pandemic hit, traveling became too dangerous for Lakelynn, who was immunocompromised.

Luckily, Dr. Steven DuBois, the ALSF-funded researcher running her trial, arranged for Lakelynn to resume her treatment closer to home. Today, Lakelynn is making the much shorter, much safer trip to a local hospital.

Doctors across the country are stepping up in amazing ways to ensure kids like Jake and Lakelynn get the care they require. Their selfless efforts during this unprecedented period are keeping these families together — and saving lives.

BLOOD CELL COUNTS

White blood cell count (WBC) and absolute neutrophil count (ANC) are both blood tests used to measure the ability of the immune system to fight infection.

Partner Spotlight



Over the past eight years, Northwestern Mutual has funded a number of new ALSF initiatives to help meet the needs of childhood cancer families. In April, they continued that partnership with a commitment of more than \$100,000 to the COVID-19 emergency fund to provide families with critical support like grocery assistance and extended safe, isolated lodging near treatment centers.

V O L V O

Volvo has been a part of ALSF's mission from the very start, and they wanted to find a unique way to help out families affected by COVID-19. They launched the Volvo Virtual Grocery Run, asking supporters to donate the cost of their typical grocery store trip to ease the burden on childhood cancer families struggling to afford groceries. Volvo is matching all donations to double the impact for families in need.

Thank you to all our other partners that have helped out with COVID-19 support!

Life Has Handed You LEMONS... How Are You Making Lemonade?

In her life, Alex taught us all how to make lemonade out of lemons. To inspire hope during this pandemic, ALSF asked supporters to share moments that put a sweet smile on their faces with the hashtag #MakeAlexsLemonade. Here are some ways our supporters are turning negatives into positives!

1



Celebrating birthdays is especially difficult when you can't invite friends and family. But that didn't stop the Littlefields from chalking up their driveway for SuperSib Olive's 5th birthday drive-by bash!

2



Despite their 5-year-old son, Jaxson, relapsing earlier this year, the Butkus family has made lemonade by discovering safe ways to celebrate their time together, like driving through the tulip fields at Dalton Farms, NJ!

3



Little Penelope is really rocking it! Two years ago she was diagnosed with a brain tumor, and surgery left her with physical limitations. Her lemonade? Taking the time in lockdown to get stronger with her home physical therapy exercises!

Giving \$5 or more a month can support kids fighting cancer today, tomorrow and every year to come.



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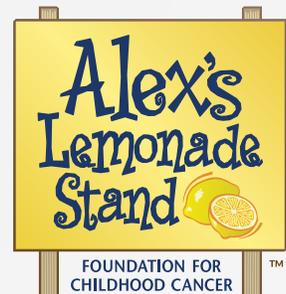


Sustain critical childhood cancer programs with your monthly gift by going to AlexsLemonade.org/One-Cup-Newsletter.



AUGUST 1ST - 9TH

Lemonade Days may have moved this year, but it also starts on an extra meaningful date: the day of Alex's passing. From virtual fundraisers to social distance-friendly events like a lemonade stand for curbside pickup, you can honor our founder's legacy of helping kids fight cancer by registering an event. Get creative, be safe and sign up at LemonadeDays.org.



AlexsLemonade.org

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