



CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

Spring 2019

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coolkidscampaign.org

THE HEALING POWER OF ART

Kids & Art Foundation is a nonprofit organization that believes that art can help heal the amazing spirits that are touched by cancer. We see that happening in front of our eyes every time we bring our art experiences in the outpatient waiting rooms at Lucile Packard Children's Hospital at Stanford and at UCSF Benioff Children's Hospital. Our program provides psycho-social support to the pediatric cancer patient, sibling, and care circle during all phases of their cancer journey. We focus on the whole child in treatment and not just the diagnosis.

For 10 years, we have teamed up professional artists with families facing pediatric cancer for free art experiences at Bay Area hospitals and unique art destinations for creativity. Together we use art as healing to empower, encourage, and create memorable experiences.

Art has the power to create control when there is none. Find meaning in chaos and be the owner of your story. We would like to take this opportunity to encourage you (the reader) to look around and find some beauty in your surroundings. How about asking for some blank sheets of paper and a pencil? Take a look around the room. What object can you use to draw a circle with? How about the bottom of a water bottle? Draw two or three circles that overlap. Then make doodles, shade or scribble inside

the shapes you've made. Does it look like an animal? A face? Abstract geometric art? Let your imagination take over and ask everyone who interacts with you in your hospital room or wherever you are, to give a name to what you have created. Let the fun begin...

Being creative can be a wonderful way to pass the time, forget your troubles, give you a sense of freedom. It is a relaxing outlet that can improve how you feel about the challenges you are facing. Art (of any kind) can make you feel calmer and less anxious too. When you feel scared, bored, or fed up, try creating a little space for art. It can bring comfort, joy, and lift your spirits. We hope it makes you smile, laugh, and make a bad day better. This is what we like to call the healing power of art because being creative can change how you feel in lots of positive ways.

We know firsthand that Cancer Sucks and it's no fun going in and out of the hospital. Take that anger, that frustration, that fear, that anxiety, and add words to it, color it, tear it in small pieces and put it back together and breathe as you marvel at what you recreated.

Kids & Art hopes these activities will brighten your day. Remember, cancer sucks. Art heals!

TO FIND OUT MORE ABOUT OUR ORGANIZATION, PLEASE GO TO:
KIDSANDART.ORG

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Check us out on social media:



WE'RE TOUGH, WE'RE WINNERS, WE'RE COOL

by Meaghan Kilner

There's ways in which all of us are alike,
We've all faced things we never wanted to.
But whether your name's Susie or it's Mike,
It's often pretty easy to feel blue.

When cancer comes a-knocking, don't be scared,
Together we can face the ugly beast.
Nurses and doctors work together paired,
So we can have a celebration feast.

Treatment can be terribly tough, I know,
But keep on pushing on, keep your chin up.
We're fighting the beast back, each blow-by blow,
And one day we will win the victory cup.

We may be only kids, but don't be fooled:
We're tough and strong; we're winners, and we're cool!



WHAT CANCER CANNOT DO

Author Unknown

**It cannot cripple love.
It cannot shatter hope.
It cannot corrode faith.
It cannot eat away peace.
It cannot destroy confidence.
It cannot kill friendship.
It cannot shut out memories.
It cannot silence courage.
It cannot reduce eternal life.
It cannot quench the Spirit.**



Thank You!

THANK YOU FROM BROOKE

Brooklynn affectionately known as 'Brooke' is a 5-year-old sass-a-frass. Brooke was diagnosed with T Cell Leukemia in March of 2017. She is a typical five-year-old girly girl. Loving all things nails, glitter, and pink. She loves to play with her 6-month-old sister as well as swimming. Even throughout the toughest parts of treatment, Brooke remained her normal energetic fun self. She is now in long-term maintenance and so far, when they say, "this is the easy part" that is so true! So, if you are in the trenches of treatment there is a light at the end of the tunnel, I promise. Brooke is living proof of that. During many of those tough times, we had Cool Kids, offering comfort and support to both Brooke and her siblings. Thanks to Cool Kids, my children always felt like 'normal' kids. As parents, we all crave a sense of normalcy and that is exactly what Cook Kids did for us.

Brittany – Brooklynn's Mom



THANK YOU FROM EUNICE KIM

As a person who has always been healthy; it was a huge shock when I heard that I was diagnosed with cancer at a young age and it became the toughest times that my family and I had to go through. During this time, I had the blessing of having the support of my friends and community to alleviate some of the different hardships. I will never forget the support that I have received but what was shocking to me was the amount of encouragement and support I had received from complete strangers.

It is hard enough to be generous to those you are close with but I was blown away at the generosity of strangers and I believe it has shaped my personal outlook on life. One of the driving forces that made Brown Advisory the place I wanted to work is that it is involved in the community. After a short time at the firm, it was clear that a special group of people surrounded me. There has never been a shortage of opportunities to help the community and different organizations in need and I learned early on how important the Cool Kids Campaign was to the firm, which lined up perfectly with my personal life experience.

Once the holidays started, multiple groups at the firm were collecting gifts and donations for their respective organizations. There was an initial fear of not being able to collect the allotted amount of gifts but I was quickly proven wrong. The colleagues at Brown Advisory were so eager to donate gifts and gift cards and there was an overflow of generosity that I was able to witness. It was just another reminder of how fortunate I am to work for a firm that is always looking for ways to be an encouragement to others, even if they are complete strangers.



A SURVIVOR

by Valerie Edgar, Survivor Kyle Edgar's mom

If you are reading this newsletter and this article, there is no doubt your family has been touched by childhood cancer. Therefore, you know how devastating it is to hear the news that your child has a life-threatening disease and will have to undergo extensive treatment. That is where our family was last year - when my 18-year-old son Kyle officially got the diagnosis of Osteosarcoma on March 2, one day and nine years since we lost his grandma and my mom to cancer. From day one, my son was courageous and took it in stride. While on our long drive south to withdraw him and pack up his dorm room at the University of South Carolina on March 3, he stated that he was glad he had it instead of his friend who did not have health insurance and needed a running scholarship for college. To this day, I am still surprised with his magnanimous statement. A few days later, we learned that it had spread from his right leg to both his lungs. It was almost worse than the first diagnosis because it made the disease seem even more diabolical.

We started treatment at the University of Maryland Medical Center and they were extremely kind. We switched to Johns Hopkins because they have a specialty Sarcoma Center. Because the disease primarily strikes children, Kyle was treated in the Pediatric Unit. Therefore, my 6 foot 1 inch young man was one of their bigger "kids." We are eternally grateful to Hopkins - for the best doctors and surgeons - and the BEST nurses ever. Kyle rang the bell for the end of chemo on December 7, 2018. He wanted to have the most people at a bell ringing ever and in fact, we had so many people we had to move to the Great Room and then the lobby.

During the 10 months of treatment, the outpouring of support from friends, coworkers and family was tremendous. People prayed and wanted to help and many made meals and gave gift certificates for restaurants and carry out, as well as purchased movies since all of his chemo had to be in-patient. Lots of down time to kill. We watched the entire Game of Thrones seven seasons, twice, and many more movies. We were very lucky that Kyle did not get ill from the chemotherapy. So his energy remained relatively high and when he was not in treatment, he was bored. Friends came to visit and he did as much as he could. As one friend put it, he "put cancer in the corner." His positive attitude made a difference and he never asked "why me?" Therefore, cancer fears him all right - because he never doubted he would beat it! We gave away nearly 1,000 #Kylestrong and Beat Cancer! Yellow wristbands for those supporting him to make cancer fear him!

His friends supported him from day one and continued to visit him at the hospital until the very last day, which was good because he got tired of seeing me all the time in the 10' x 10' room. A shout out to Forever Fearless for bringing "real food" on Friday nights. Kyle did not eat much of the hospital food - we had to bring in food from home or carryout.

Several organizations only provide support up to 18 years old. Therefore, my "big kid" fell into a young adult category - and there are no "make a wish" opportunities for that age group. There is an organization for young adults called the Ulman Foundation - he was able to attend a few meetings in between treatments and as a survivor will again be able to attend. In addition, he applied for a scholarship with them towards college since he plans to return this fall!

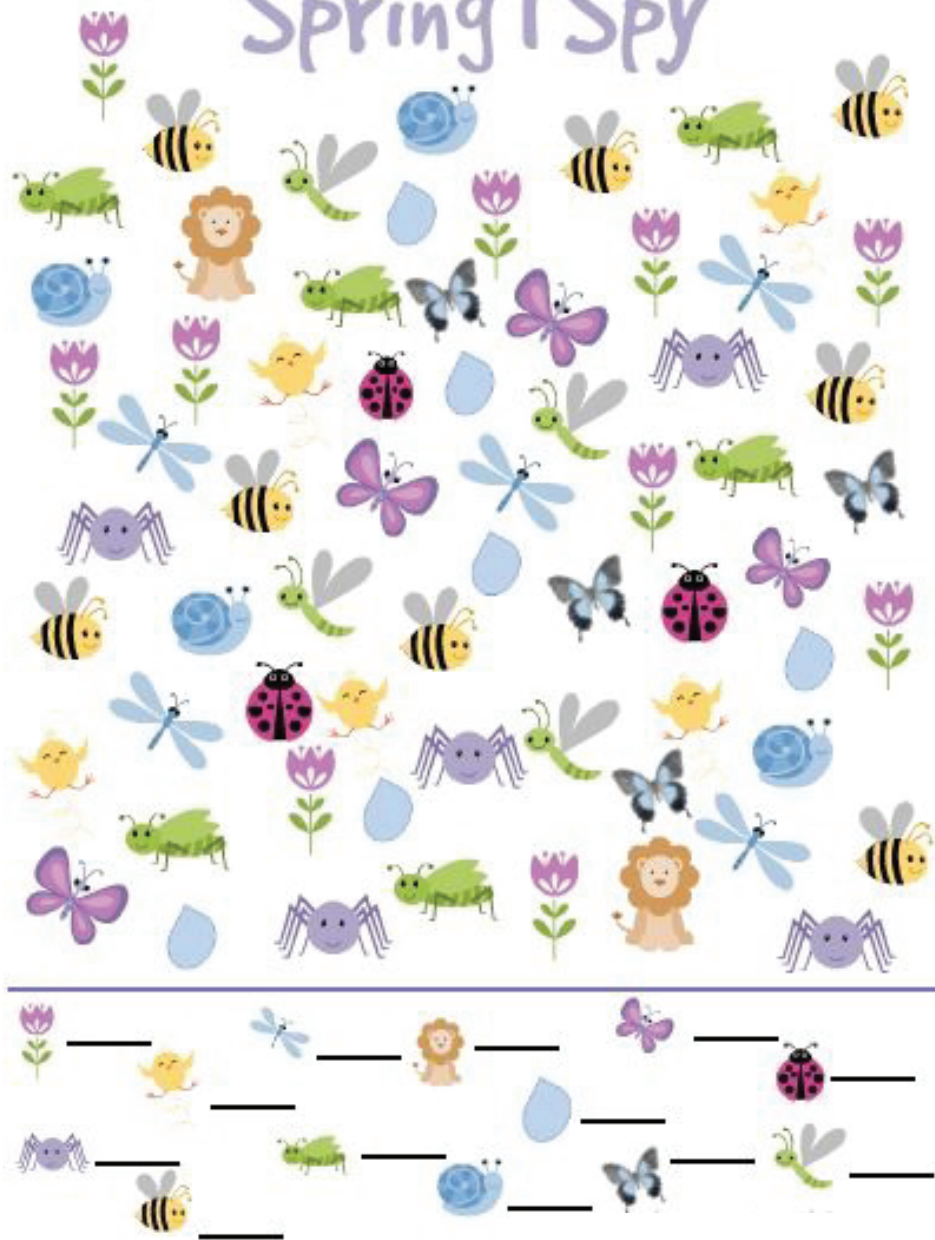
One thing that struck me with these organizations, is that often the people involved are not only committed, they are often family of survivors or survivors themselves. It seems like only those who have been through this truly understand. I am so incredibly grateful for meeting another mom of a young woman with Osteosarcoma in the family lounge - she connected all the moms of the kids with Osteo and we keep in touch to this day. We support each other and are able to ask questions about treatments and symptoms of problems - it was the best coping mechanism. I knew I could turn to these women - #Osteomoms - for anything. We cheer for each other's kids and we are sad when there are setbacks, and we pray. As you continue your journey, do not be afraid to talk to other families -- you could very well learn some important information or get answers to questions you forgot to ask the doctors. You could even develop lasting friendships that will help you along the way. In addition, do not be afraid to ask for help. That is why great organizations like Cool Kids exist - to help you and your family through a journey that is likely your biggest challenge ever.



PUZZLES AND GAMES

HOW MANY CAN YOU FIND?

Spring I Spy



COLOR THE BUTTERFLY & TULIPS

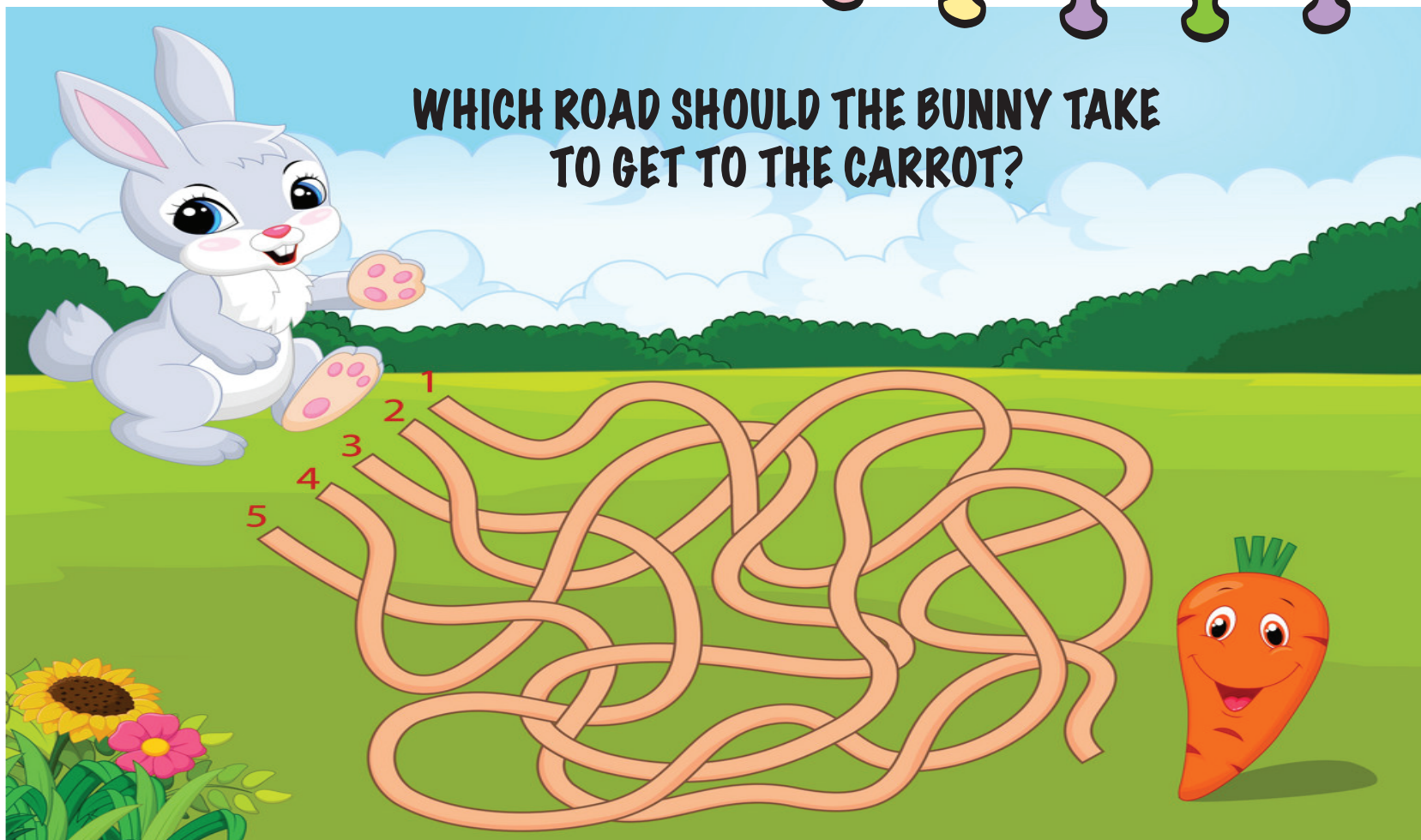


SPRING WORD SCRAMBLE

MOLNGIBO _____	ODRUOTOS _____	TIEK _____
NEUSNSIH _____	ERGNE _____	HCKCI _____
SLPTIU _____	NWOARBI _____	FUBTRYTLE _____
AINR _____	ILSO _____	RLMAELBU _____

ANSWERS: BLOOMING, SUNSHINE, TULIPS, RAIN, OUTDOORS, GREEN, RAINBOW, SOIL, KITE, CHICK, BUTTERFLY, UMBRELLA

BRAIN TEASERS

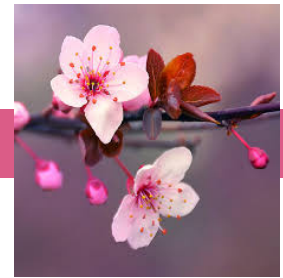


See how many words can you make out of:
MONARCH BUTTERFLY



WE FUN FACTS!

ALL ABOUT CHERRY BLOSSOMS



There's more to these pretty flowers than meets the eye!

There are 200 different varieties of cherry blossom.

Cherry blossoms are Japan's national flower. Known as "sakura" in Japanese, these pale blooms are a symbol of more than just spring — they stand for renewal and hope.

U.S. cherry blossom trees date back to 1912. Japan sent the trees to the U.S. to represent goodwill. In 1915, we reciprocated by sending flowering dogwood trees to Japan.

The top perfume in the U.S. is Bath and Body Works' Japanese Cherry Blossom. Thirty million units of the mixture of cherry blossoms, crisp pears, mimosa petals, and sweet sandalwood are sold each year.

In the U.S., we most often associate cherry blossoms with our nation's capital. National landmarks surrounded by spring flowers attract visitors to Washington, D.C.'s Tidal Basin each spring.

Neither D.C. nor Japan hold the title of "Cherry Blossom Capital of the World." Rather, it's Macon, Georgia, which is home to 300,000 Yoshino cherry blossom trees.

While cherry blossom season usually lasts about a month, from the time the first to the last tree blooms, each individual tree may only flower for about a week. Trees usually live for 30 to 40 years.



Jefferson Monument, Washington, DC



Mt. Fuji, Japan

JOKES RIDDLES

SPRING RIDDLES

Q: Does February like March?

A: No, but April May

Q: When do monkeys fall from the sky?

A: During APE-ril showers

Q: What do you call a rabbit with flees?

A: Bugs Bunny

Q: How excited was the gardener about spring?

A: So excited he wet his plants.

Q: What goes up when the rain goes down?

A: Umbrellas

Q: What's Irish and comes out in Spring?

A: Paddy O'Furniture

Q: Why did Cinderella get kicked off the baseball team?

A: She always ran away from the ball.

**Created by one of
our Cool Kids: Mia
Cochran.**



Sharing Your Life With Cancer

a blog by Tamsyn Kiely

The day you are told your child has cancer is the most unnatural day of any parents' life. From that day forward, nothing is the same, your life and the life of your child is changed forever. The days that follow are surreal and just as unnatural as the day your baby was diagnosed, because from that day forward...

You share your life with cancer....

A life partner you never expected to have, never would want, and most certainly would never want in your child's life. A big shadow in every moment of every day in your life. A reminder that your life can be turned upside down in an instant.

Waking up that morning, I knew something big was going to happen. My husband and I had already decided the day before that our son needed to go to the doctor again. We were not happy with previous answers that his leg pain was growing pains. I knew there was something wrong and the pains were not just growing pains, it was something else. I just did not know what.

I was not prepared to be told he has leukemia. I was not prepared to travel 700kms away from our home the very next morning. I was not prepared to leave our daughter behind without really being able to tell her anything. I was not prepared for my baby boy to undergo his first anesthetic, his first surgery (to have his port in), his first lumbar puncture (first of many), a bone marrow aspirate and his first chemotherapy treatment all within 72 hours of being told he had leukemia.

There are so many things along this journey that I was not prepared for, some bad and some good. I would like to take this moment to focus on the good:

I was not prepared for the strength and courage that I saw in not only my son, but also every other child with cancer we have come to know and have seen in our days at the hospital.

I was not prepared for the hallways of the hospital, once so scary; to become familiar and comforting as the hospital became our second home.

I was not prepared to meet amazing nurses, who go above and beyond to make this journey as happy and smooth as they could, for not only the children but the families as well.

I was not prepared for the new relationships that I have formed along the way, new friends we will have for a lifetime.

I was not prepared for the profound positive effect this journey would have on my relationship with my husband and kids.

I was not prepared to receive so many blessings during the hardest time of our lives to this point.

Being on this journey has taught me so much; so much about myself, my wonderful husband, and my kids. I have learned many lessons from our own personal journey, and from the experiences of other people.

The biggest lesson I have learned is that life is truly a gift. You are not given any more than you can handle. There is a lesson to be learned in everything that happens in your life. Sometimes you don't know what that lesson is until later on, and sometimes the lesson is as clear as day. Sometimes the lessons are hard to learn, and the situation is hard to accept. What life has dealt you is truly heart breaking and life can be cruel.

Sharing your life with cancer reminds you that there is a lesson in everything. Sharing your life with cancer reminds you to embrace every day, cherish the ones in your life that bring happiness, and bring your own sunshine wherever you go.



ABOUT THE WRITER

Tamsyn Kiely is a 30-year-old mother of two who has been in Queensland, Australia with her husband and children for 7 years. Moving to Australia changed their lives and they have never been happier. Tamsyn is passionate about creating a healthy, positive and happy environment for children and teaching them about the good in the world, no matter what happens in life. Tamsyn has been caring full time for her son since he was diagnosed with Acute Lymphoblastic Leukemia in Feb 2014. She has learned a lot about Childhood Cancer and plans on using her experience to educate others about Childhood Cancer and all it involves. Through her experience, Tamsyn has also realized how to pursue her passion for helping others.

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Smiling While Sending Hope



*M*y name is Katie Haynes. I am 19 years old and am from Youngsville, North Carolina. I have many chronic illnesses, including POTS, EDS Type 3, MCAS, AMPS, IBS, and Alopecia. Even before getting sick, it has always been a big mission of mine to make an impact on other people's lives. I am making this mission come alive by creating toy drives, comfort packages, awareness videos and sending VOGMASK® to people. I have participated in toy drives and comfort bags for Duke Children's and UNC Children's Hospitals, and I also helped at the Ronald McDonald House of Durham, NC and Ronald McDonald House of Falls Church, VA. I love making an impact on others' lives, and I hope to help many more people in the future! That is why I am here today sharing this story. Thank you for being here and reading my story, and for your interest in making kids' days a little brighter! Your support helps a lot and allows these kids and teens affected by chronic illnesses feel a little more at ease!

I love being able to bring joy to kids and teens as they face big obstacles in their lives, whether it be chemotherapy treatment, a transplant surgery, or other health challenges. For about 5 years, I have participated in a variety of projects for children with chronic illness, and I have also sponsored local families in need. In December of 2017, I launched a project where I send packages and masks to people fighting chronic illness. I also created a Facebook page to help the growth of my project in January of 2018 (Smiling While Sending Hope). In August of 2018, I also began sending sensory packages for individuals with special needs. There are also teens in the area and at the hospitals whom I meet and give packages and/or masks to.

This is my long-term goal: to grow and make a bigger impact each year. I find people's stories that speak to me and post them in online groups, so that I am able to send more mask packages. Due to expenses, and since I want to meet each of the warriors, I prefer to send my packages locally. I was inspired to start this and to get involved about 7 years ago when Paxton, a little boy at my church, passed away. Not long after his passing, I helped with a toy drive called "Presents for Paxton" for UNC Hospital. A few years later, I went on a camping trip and met a girl named Skyla Rippey. She has a rare blood disorder called Diamond Black-Fan Anemia. Skyla and I have gotten to know each other very well, and are now good friends. When I found out that she was receiving care at one of my local hospitals, I started going with her to appointments and began to do research on childhood illnesses. After that, I began workshops and gave presentations to share with others what I had learned.

My goal with this project is to bring smiles to people's faces and to spread awareness of the many illnesses and diseases young individuals face. I want to move away from focusing solely on the illnesses and instead show others that those with chronic illnesses are not as different from everyone else. They can do everything you can do; they may just have to learn to adapt in certain ways.

Thank you for reading about my projects, what I do, and how I started!

Katie



Bringing a smile to teens and young adults eyes

COOL KIDS WE L♥VE

*Send us your stuff and become a
published writer or artist!*

*Send us your stories, art, poetry,
photos, and anything else you
want to see in print!*

*Email all submissions to
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or mail to:*

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Towson, MD 21204.*



TYLER



STELLA



LOGAN

Children are at the heart of our care

From pediatric medicine to specialty care,
the Herman & Walter Samuelson
Children's Hospital at Sinai offers exceptional
care and support for children and their families.
lifebridgehealth.org/childrenshospital



A LifeBridge Health Center

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Children's
HOSPITAL AT SINAI



Cool Kids CAMPAIGN®

Learn About Our Club House



Cami, Relapsed Acute Lymphoblastic Leukemia

**Helping kids with pediatric cancer and their families
is what Cool Kids Campaign is all about.**

In our Learning Center, we focus on the academic, social and emotional needs of children living with cancer.

Our programs include one on one tutoring, Mommy & Me for the little ones with cancer, Super Sibs to focus on the issues of the siblings and a Teen Club for patients and survivors.

All Cool Kids Campaign programs are free to families and children living with (or survivors of) pediatric cancer.

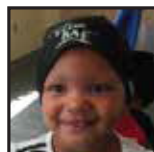
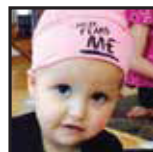
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