

Summer 2019

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coolkidscampaign.org

REMISSION looks GOOD ON ME

By Noah Kabia, Age 10

In January 2016, six year old Noah was diagnosed with Acute Lymphoblastic Leukemia. He was hospitalized four times over a three and a half year treatment program, missed a total of fifteen months of school, had various blood transfusions, tests and procedures, and neurological challenges. In April, 2019 Noah turned ten and completed his chemotherapy regimen and will be able to attend school this fall for 5th grade. Through it all he has remained positive and strong. We asked Noah to reflect on parts of his cancer journey, which we share here.

When my mom first told me I have cancer I was really scared, upset and I thought maybe I am going to die. I kind of felt like I was depressed plus I just didn't feel good at all. My body hurt all the time in the beginning and I was freaking out a lot about the needle pokes and what the doctors were doing to me. A lot of my family and friends were sad and it was really confusing. I hated being in the

hospital and having to go there all the time especially on spinal tap days and I did not like the hospital food. I just really hated the whole thing.

The hardest thing was just not being able to go to school and be with friends. All the medicine was a lot to take too. There were so many pills but I got used to it after a while. I was embarrassed at times about my friends finding out that I had cancer. When I did go back to school I was afraid that I would get made fun of and sometimes I was which hurt my feelings. After missing so much time in school I hardly knew anyone when I first came back and sometimes I felt like I had no idea what I was doing or what was going on. Being bald and having a port in my chest made me feel like a weirdo. I wore a hat every day to hide. Sometimes I felt lonely and like this was going to go on forever. Sometimes I would cry.

Continued on Page 3



NOAH AND HIS FAMILY PROUDLY SPORTING THEIR CANCER FEARS ME T-SHIRTS

To order Cancer Fears Me t-shirts visit: www.coolkidscampaign.org/product/shop

OR see the order sheet on the back cover

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CONNECTION®

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My Summer Internship at *Cool Kids*

After spending a summer working for a non-profit after my sophomore year in college and recognizing the benefits of supporting local, mission based work in my hometown, it was easy for me to turn my sights towards another worthy cause. My journey with Cool Kids Campaign started in February of this year when my old intern supervisor called me to ask if I was looking for a summer job. She told me about a little non-profit headquartered in Towson, Maryland that needed help in organizing their Clubhouse over the summer and with events and administrative support duties.

Over spring break of my senior year, I stopped by the colorful Cool Kids Clubhouse and met the friendly staff. I was impressed with Cool Kids' mission to help support children with cancer, their siblings and families through academic, emotional and social programming. With my previous work, I understood the importance of having a nonprofit attitude of being willing to do whatever it takes to pitch in and help and I decided to jump on-board. Fast-forward to July of this year and I'm on the floor of the Clubhouse organizing art supplies after weeks of special event support, fundraising activities and social events for our Cool Kids. Most people would call it mundane but in mission-based work, every project has a purpose and every purpose we serve touches the lives of people directly. It's the kind of place where without true teamwork and camaraderie no one succeeds. Even in organizing art supplies, I knew I was contributing to a cause bigger than me.

To the Cool Kids team I say "Thank You!" This summer I enjoyed the opportunity of working with the staff, growing professionally and I really feel as though I contributed to a very worthy cause by "supporting the coolest kids fighting cancer!"

Best to you all!

- Sophie Seaman



REmission looks good ON ME

(continued from cover page)

A lot of good things happened too. I was treated nice by a lot of different people. I was getting presents and gifts even from people I didn't know and that was fun. I mostly liked when people just treated me like a normal kid. When I was able to be in school the nurse and my teacher really took care of me and let me rest when I needed which was a lot. Different friends came to help mom and daddy. I was also excited to count down all the months. My parents kept saying like '36 months left, 22 months left, 12 months left...and then 6 months left, 4 months and 1 month.' When my chemo was finally over I just couldn't believe it was actually done and I rang the end of chemo bell really hard! And everyone was there to celebrate with me. Like at least 30 people!

I'm really grateful to the places and people that helped me and gave me special opportunities. I got to go to Cool Kids Clubhouse and three different camps for kids with cancer and make friends with other kids like me. Oh, and different events, movies and parties too. That was actually pretty cool. Plus our family vacation to Myrtle Beach was the best ever and I can't wait to go back. I had a lot of support from my family especially my mom, dad and big sister. My family felt broken but now our puzzle pieces are put back together!

Remission to me means I'm done and I don't have to keep going to the hospital all the time. I get to be my normal self and I don't have a lot of restrictions anymore. Like all the things I couldn't do. Just people telling me 'you can't go outside, you can't play sports, you can't eat this food, you can't play with friends and you can't go to school.' Now I feel like I'm free and I can live my life. Now it's just me "Noah!"

I beat cancer! I feel like remission looks pretty good on me! That's all I have to say.

THE END



Walking On The Edge Of Life

By Lorna Mahan & Sinjin Andrukates

The world keeps moving forward
as time stands still for me,
I am the kid with Cancer,
locked in battle to be free.

For all us kids on chemo
our lives are put on hold,
As we fight to stay alive,
our chances good we're told.

Our attitude is courage
we live this life each day,
Just waiting for tomorrow,
praying cancer goes away.

Walking on the edge of life
We're never looking down,
United here in front of you,
until a cure is found.

BROKE DOWN & BUILT UP

By: Renee Henry

I don't remember how I got there but I was laying on the tightly woven Berber carpet of my bedroom floor, staring intently at the blank, tan canvas of the ceiling as if looking at an artist's masterpiece. One arm folded up and under my head while the other rested across my chest. Legs straight out and crossed at the ankles as the quiet sound of my heart beat flooded my ears and drowned out any other sounds to a dim muffle. My thoughts so deeply lost in the clouds of my mind to a point of unconsciousness. I likely could have stayed that way forever until a few rays of sunshine moved through the window and up towards my eyes. I blinked rapidly as I came back into an awareness of my own existence and the clear sounds and steady hum of the electric heater.

In the background I could barely hear my son and his Home & Hospital teacher going through his lesson for the day as they sat at the dining room table. Too far away for me to be engaged but close enough to be reminded of this routine that's been going on for the last four months. I stayed down on the ground feeling the buildup of extreme stress. Juggling my son's medical appointments, him being out of school, my work priorities and family life had gotten to me a bit (okay, maybe a lot). The onslaught of new bills, three broken cars and the challenges that come along with owning a very old home my emotions were building up. This stuff all seems to happen at once! I honestly didn't know how I was still holding up except for truly divine intervention including the family

and friends that have stepped in, once again, to help us wherever possible and the crazy, only God way that we have been cared for and often carried right through this storm.

I sat up, crossed my arms over my knees and put my head down trying to absorb my emotions. While this time has been difficult in its own way, we have survived and my son has thrived. The anxiety he was experiencing has gone, he's rested, relaxed and has made progress and neurological improvements. He's coming down off of most of his chemotherapy drugs and full of energy and excitement about the possibility of going back to school in the fall. He has been taught, tutored and tested and has held up under it all. We've had angels giving time, attention, tutoring, funding, prayers, repairs and hugs. We still have each other and this part of the journey is almost over. As I lifted my head up, I remembered that we have not been alone and I smiled. We may have been broken down but for sure we are being built back up.

"So do not fear, for I am with you; do not be dismayed, for I am your God. I will strengthen you and help you; I will uphold you with my righteous right hand."

Isaiah 41:10 NIV

PUZZLES AND GAMES

SUMMER CROSSWORD PUZZLE



Across

3. I love to build this in the sand.
4. I love to run through it and it makes me wet.
5. I have one in my backyard that I love to swim in.
6. A place that has lots of sand and water.
7. I use this to pick up sand

Down

1. The hottest time of the year.
2. I wear this to swim.
3. I like to wear these on my feet when it is hot.
5. I use this to put the sand in.

HELP THE BEE FIND THE FLOWER



HAVE FUN COLORING THIS FESTIVE FLAMINGO



CROSSWORD PUZZLE ANSWERS: Across: 3. SANDCASTLE 4. SPRINKLER 5. POOL 6. BEACH 7. SHOVEL Down: 1. SUMMER 2. SWIMSUIT 3. SANDALS 5. PAIL

BRAIN

TEACHERS

CIRCLE THE HIDDEN PICTURES



In the big picture, find these objects.



scissors



needle



crown



kite



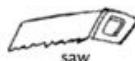
carrot



pennant



ice-cream cone



saw



tack



bowl



hockey stick



ring



teacup



button



comb



bell



snake

Summer Word Search

G	S	G	R	V	S	B	L	O	H	J	P
T	U	F	O	R	W	N	K	Q	N	P	M
M	M	H	B	Z	I	H	O	T	O	L	B
V	M	S	U	Y	M	I	P	E	I	S	U
P	E	Z	G	Z	S	S	M	G	T	S	V
F	R	K	S	M	U	E	K	B	A	P	N
L	J	N	O	B	I	S	A	L	C	C	E
N	O	I	V	T	T	S	X	M	A	H	N
N	L	V	W	S	E	A	J	U	V	M	U
D	V	P	U	B	B	L	O	O	P	X	J
X	T	G	A	J	N	G	H	G	R	S	U
U	U	L	A	B	J	N	R	C	T	F	L
A	L	X	O	A	W	U	J	I	A	T	Y
V	H	C	S	U	N	S	C	R	E	E	N
Y	P	E	R	O	S	U	N	N	Y	K	B
E	D	A	N	O	M	E	L	J	F	U	B

SUMMER
SUNNY
SUNSCREEN
POOL
LEMONADE

BEACH
SWIMSUIT
BUGS
VACATION
BASEBALL

JUNE
JULY
HOT
AUGUST
SUNGLASSES



See how many words you can make out of:
CHOCOLATE ICE CREAM SUNDAE



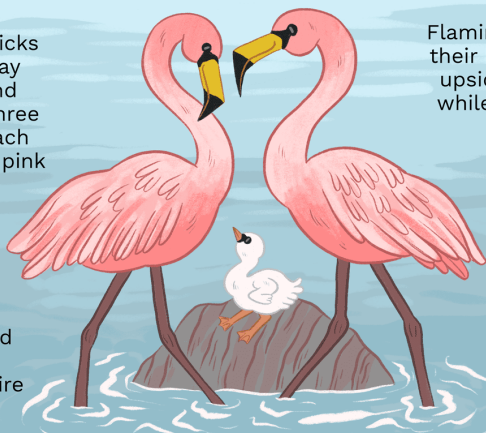
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FUN FACTS!

Fun Facts About Flamingos

Flamingo chicks are born gray or white and take up to three years to reach their mature pink

The word "flamingo" comes from the Spanish and Latin word "flamenco," which means fire



Flamingos hold their bent bills upside down while feeding

A flamingo chick's bill is small and straight

There are only 6 species of flamingos in the world

from the spruce

An adult flamingo's legs can be 30-50 inches long, which is longer than its entire body. Flamingos often stand on one leg to preserve body heat, tucking the other leg into their plumage so it is kept warm. They will alternate legs to regulate their body temperature.

CONNECT THE DOTS



The backward bending "knee" of a flamingo's leg is actually the bird's ankle. The actual knee is very close to the body and is not visible through the bird's plumage. Flamingos have a wild lifespan of 20-30 years, but in captivity have been recorded as living up to 50 years or longer. The top speed of a flamingo can be as high as 35 miles per hour.



A flock of flamingos is called a stand, colony, regiment, or flamboyance. Flamingos use these large flocks as a safety measure against predators.



Don Featherstone of Massachusetts invented the pink plastic lawn flamingo, which has been gracing lawns since 1957. These birds are still in production today and now there are more plastic flamingos in America than there are real ones.

SUNSHINE ON THE HORIZON:

Summer Spotlight with Horizon Day Camp

By Melanie Kabia



There's no such thing as a lazy summer day for the Horizon Day Camp Staff! From June through August they are busy and enthusiastically welcoming children as early as 7:00 a.m. with posters, pom poms, cheers, chants and smiles as wide as the ocean. They keep their high energy well into the heat of summer days taking care of campers often into the early evening with additional programs throughout the year... all at no cost for the families they serve, including bus transportation from across the region. Horizon Day Camp represents Maryland's only full-summer day camp for children, including siblings, who are dealing with pediatric cancer. Their camp model allows children the ability to enjoy a robust camp season, scheduling medical treatments around camp participation, while returning to the comfort of their own homes and beds each night.

Horizon Day Camp is a proud member of the Sunrise Day Camps Association. Sunrise Association, based in New York, opened its first camp in Long Island in 2006, and it seeks to open and operate free camps world-wide in communities where a need exists and the local community can support and sustain initiatives. Horizon Day Camp, located in Baltimore, is one of eight Sunrise Association camps. There are three locations in both New York and Israel Horizon Day Camp in Baltimore, and our newest camp in Atlanta. The mission of Sunrise and all of its camps is to help restore the joys of childhood for children who are dealing with pediatric cancer; this is accomplished by operating summer day camps, year-round programs, and in-hospital recreational activities. Sunrise affiliates with more than thirty renowned hospitals world-wide that are leaders in treating pediatric oncology. Now in its fourteenth year, Sunrise Association serves more than four thousand children in the hospitals, and more than two thousand children through the summer camps.

In Baltimore, Horizon is under the medical guidance of Dr. Yoram Unguru, Pediatric Hematologist/Oncologist at The Herman and Walter Samuelson Children's Hospital at Sinai, and professor at the Berman Institute of Bioethics at Johns Hopkins University. It is hosted on the beautiful campus of Boys' Latin, a private school in Baltimore City. Activities include music, arts and crafts, sports, swimming, nature activities and more. Goals include helping children develop friendships, confidence, and interpersonal skills, while enjoying the simple pleasures of childhood. Horizon Day Camp also aspires to open-up the community to the children during the summer camp and throughout the year. The Baltimore Symphony Orchestra, Maryland Science Center, American Visionary Art Museum, Baltimore Ravens, Maryland Zoo, Port Discovery, and Irvine Nature Center are among the many community groups that have visited Horizon Day Camp.

For a dynamic camp like Horizon to function without a hitch it truly takes an extraordinary staff and a leader that can bring them all together. Executive Director, Mark McElrath first joined Horizon

Day Camp in 2015 when the Sunrise Association initially launched a presence in the Baltimore area before hosting its first camp and full year of operation in 2016. Mark earned an undergraduate degree in Business Administration from Westminster College and a graduate degree in Sport Management from Slippery Rock University. He has spent the past fifteen years in Baltimore with non-profit management roles with both local and national based organizations, including Regional Director and Major Gifts Officer positions with the Make-A-Wish Foundation. He started in a development position with Horizon before assuming the Executive Director position in 2017.

Having worked in the non-profit space with cancer and children's health initiatives, Mark was immediately interested when he learned that Sunrise Association was bringing a camp and additional programming to the Baltimore area. Regarding his involvement with the camp Mark says "I most enjoy the relationships that form with all of our constituents: the children and families who benefit, volunteers, donors, the hospital personnel, our seasonal and year-round staff, and the broader community. Our mission resonates with so many people; its fun and rewarding when the community 'rows in the same direction' and gets behind our efforts to provide such special life-changing opportunities for the children we serve. We develop relationships with the campers and families, and it's enjoyable to see the kids grow and mature and see the families move beyond some of the darker times that they encounter by virtue of their cancer diagnosis. The rewarding part is knowing that Horizon Day Camp helps provide some hope, humanity at a time when they need it most. At the core of all that we do, we help provide children a normative childhood experience. Countless testimonials from parents, and children too, let us know that the offerings and opportunities that our organization provides are indeed special blessings for so many."

For children dealing with a cancer diagnosis and their families there can be so many worries and fears. Horizon Day Camp and its other sister camps work to brighten the lives of all involved by providing a community of belonging and a summer filled with sunshine. To learn more please visit www.sunriseassociation.org.





By Dasia De'Anna Kabia for my Baby Brother, Noah

I was never good at building things with my hands
Because they're always shaking
As if I'm always just awakening
From a nightmare
Fear bubbles up inside of me for what is yet to come
Fear from what tomorrow holds
Fear from the unknown

LEGO

All they ever did was frustrate me
Too many little pieces that get stuck together
Too many pieces you can lose for forever

LEGO

I never found them much fun
And there always seems to be just one
Left behind for you to step on
Creating a jolting pain
That can bring a grown man to his knees

LEGO

Is all my six-year-old brother wants for Christmas
Birthday
Everyday

LEGO

Are his paint for his pictures
He sees a perfectly congruent figure
In his head
And then he sits on his bed
With his teddy bear named Ted
And creates a world out of Legos

I wish we could trade places
Me for him, him for me
Imagine a six year old being prodded and poked
Leukemia is no joke
I sit here as the doctor spits out words like water flowing
from a sink...
I'm not listening



It makes me sick
The kind of sick that makes your body want to puke
The kind of sick you want to pause and put on mute

Mute...

I wish I could mute the sound of his pain
I wish I could silence the rain
The tears pouring down his face
I wish I could take his place
But I can't

I can't rid him from the leukemia cells which have
inhabited his life
I can't make him smile when all he wants to do is cry
I can't promise everything will be fine when that could
really be a lie
I can't make it okay
I can't make his pain go away
I can't make time go back
I can't give his immune system what it lacks
I feel useless, clueless and in the dark
I feel like I'm swimming in an ocean inhabited by sharks

I'm just a parrot repeating the same practiced response
Whose purpose is to comfort the bystander's heart
"Yes our family is well and my brother is doing fine"
I've gotten used to that well-rehearsed lie
And I wonder why when someone is sick

People pummel you with pounds of food
Perhaps they ponder your impossible predicament
Proposing the only possible way to fix it
So we push people's presents down our throats
Patting down their polite pity
Hoping for just a minute we can forget our problems
And eat a pretty treat
But as the chewing slows and our feet catch up
We are struck with the realization of our new normal

I have 11 years on my brother
I've lived 3 times the life
But I have no experience with this type of strife
This is a pop quiz I'm not prepared to take
This is a bad feeling that I just can't shake
I'm supposed to protect him
Like a pirate protects his gold
But he has cancer and all I've had is a minor cold
He knows pain beyond my comprehension
He's been through things that bring me to tears just to mention

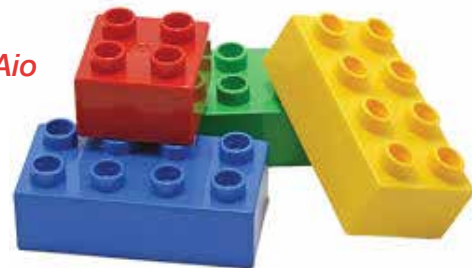
And I'm sad...

I'm sad because all I can do is sit here
Fighting back my tears
Holding on to every second of right now
As me and him, him and me
Build a ship out of Legos

SIDE BLURB:

This poem was written in 2016 by Dasia Kabia a month after her 18th birthday and her then 6 year old brother was diagnosed with Acute Lymphoblastic Leukemia (ALL) during her senior year in high school. She wanted to express her feelings and fears regarding her brothers diagnosis and used his love for Lego Toys as the focal point of the poem. Dasia gave up going away to college to be near her brother during his cancer battle. Today she is 21 years old and remains close to family and still builds Lego creations with her 10 year old little brother (see cover story).

*To View Dasia reading this spoken word piece visit
YouTube: <https://www.youtube.com/watch?v=Qv2WsVG4Aio>*



In loving Memory



Ariella



Ava

VEGAN SUMMER SMOOTHIE

Danielle Cook Navidi, author of "Happily Hungry: Smart Recipes for Kids with Cancer."

Ingredients:

½ banana
½ cup fresh or frozen blueberries
½ cup blueberry juice
¼ cup soft silken tofu
¼ cup plain or vanilla soy milk
Squeeze of lemon juice, to taste
Agave nectar, to taste

Instructions:

Process all ingredients in a blender until smooth.
Makes 1 (17-ounce) smoothie.

Nutritional info: Calories: 311; Total Fat: 5.4g; Protein: 10g; Carbohydrates: 46g.



Cool Kids CAMPAIGN®

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a published writer or artist!**

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photos, and anything else you
want to see in print!



Camie, Relapsed Acute Lymphoblastic Leukemia

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ADULT SIZES				
S	M	L	XL	2XL

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\$

\$20



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