

Sister Love

by Diamond Johnson & Melanie Kabia

Spring 2020 IN THIS EDITION:

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Vivacious, sunny and bright are just a few words to describe sixteen-year-old, high school junior Diamond Johnson. She aspires to major in criminal justice during college and eventually become a lawyer. Some of her favorite things are sketching, going to movies with friends and eating alfredo pasta! While Diamond doesn't have just one favorite color, because there are too many to choose from, she does have a few favorites...including her three sisters.

When Diamond was just thirteen years old and in eighth grade, one of her younger twin sisters, Logan, was diagnosed with Acute Lymphoblastic Leukemia at the age of three, the most common form of childhood cancer. Below she reflects on her experiences as a sibling of a child with cancer and the effects it had on her and her family.

Q: How did you feel when your twin sisters were born?
A: It felt brand new. I was excited for the new experience of being a big sister because I have a big sister. I was jealous because I was the baby of the family and then I found out two people were taking my spot! And maybe taking some of the attention too. Once they were born, that didn't matter. We have always been close and not even cancer changed our relationship.

Q: What do you love about being a big sister?
A: I love that I can be a role model and set a good example for them. I love spending time with them, helping them and I like seeing how their personalities are developing.

Q: How did you find out that your sibling had cancer and how did you feel?
A: Logan wasn't feeling well with an ear infection. One night she was crying so much that my mom took her to the hospital. After several test we found out she had cancer. We had to transfer to a different hospital. It seemed so unreal to me and hard to believe. When she started going through treatment and getting chemo it really hit me. I was scared for her all the time. When I saw her hair falling out and the effects of chemotherapy it made me feel depressed and helpless. There wasn't anything I could do.

Q: What were some of your fears?
A: The biggest fear I had really...I was afraid of her not making it. She had a seizure early on in the process and I was afraid of that happening again. It was scary to see.



When I would watch Logan, my older sister and I had to make sure she got her medicine. Making sure she got the correct dosage and medication was scary and a huge responsibility. There were a lot of steps and so many medications. We had to set the timer and make sure we didn't skip a step.

Q: How do you think the diagnosis affected your mom, other siblings or family members?
A: It affected the entire family. The siblings couldn't be in the hospital room so leaving after a visit was so hard. My mom had to take off work a lot and she had the extra stress of being there for Logan but also caring for my other two sisters and me. The hardest part was definitely all the separation. At different times we were all sad, scared and overwhelmed.

As a family, we were already close and stayed close through this whole situation. I think it matured Logan more. She knows a lot in terms of the cancer procedures and what was going on.

Q: What were some of the hardest things you had to watch your sister Logan go through?
A: The fevers she would get were the hardest because every single time she had a fever we had to go to the hospital and not knowing what was going to happen. Also, Logan getting bloodwork done at three years old and getting a spinal tap was really difficult to watch. Just seeing her in pain was tough.

(continued on page 11)



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A LETTER FROM THE MANAGING DIRECTOR



About a month ago, I was asked to assume the role of Managing Director of the Maryland Cool Kids Clubhouse in Honor of Ken Singleton. I was brimming with excitement for all the new plans and programs we would put in place! However, just as I moved into my new office, COVID-19 moved into all of our lives and changed everything. No longer could we gather at a Smile Celebration to honor the end of a child's medical treatment. There would be no popping popcorn and watching movies with the kids while mom and dad enjoyed a rare night out. Sadly, all of our spring fundraisers were cancelled or postponed. We could never have anticipated this level of disruption.

But even in the midst of this turmoil, there are gifts to be found. Spending time in isolation has helped me better understand what it is like for families of a child with cancer who endure much longer periods of isolation with even greater worries. Our increased understanding and empathy will no doubt influence everything we do at Cool Kids.

The cancellation of our programs and fundraisers has required us to consider how we can better reach families in a virtual environment. We've started a You Tube channel where we'll provide expert nutrition advice, healthy cooking demos and fitness content. We are partnering with small businesses to host Facebook Live shopping sprees and a fun on-line auction with great gifts for Mother's Day and graduations. We plan to start monthly Zoom calls with experts in a variety of fields who can answer questions and provide helpful advice to families of a child with cancer.

These efforts won't end when social distancing requirements are lifted – we will continue to provide on-line content as well as hosting our Clubhouse events so we can have a positive impact on as many families as possible. We invite you to follow us on Facebook, Instagram, Twitter and now You Tube to see what we are up to.

Wishing all of you health and safety and hoping you can find the gifts that are present even in these challenging times.

Warmest Wishes,

Renee Wooding

Managing Director – Cool Kids Clubhouse in Honor of Ken Singleton

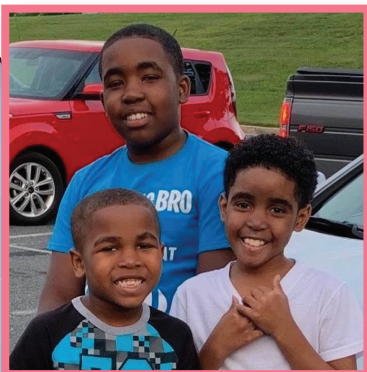


SIBLING THOUGHTS



My name is Dasia and I was 18 years old and a senior in high school when my brother was diagnosed with acute lymphoblastic leukemia. After losing one of my friends about a year before to the same type of cancer, my first thought after hearing the news was "is my brother going to die." I was afraid for him and for myself. It was hard to imagine life without him. Cancer is one of those things you wouldn't wish on any person or family, especially not a kid. However, throughout my brother's nearly four years of treatment I got to witness firsthand his strength, talent, and zeal for life. There were some pretty tough times! There was also a lot of love and generosity shown. It was a time to really focus on how much a blessing life truly is. My brother is my role model and best friend!

My name is Justin and I'm 13 years old. I remember on a nice, beautiful, Wednesday afternoon me and my family were leaving church and my parents stop to have a conversation in the car. I was worried and just wondering what they were going to say because it didn't seem normal. When my mom started to talk, she just broke down crying then I just knew it couldn't be good. They told us the news that my brother has cancer and everything in me just went in slow motion and stopped. The next thing I know is I'm crying! I look at both of my little brothers and they started crying also. We all could not believe this was true. All I could think of is "will this be the last moments with my brother."



I started to ask my parents all these questions and they were so hurt because they wanted to answer the questions, but they just couldn't. When my brother Julien found out, he didn't know what was happening to him, but he could see that it wasn't good because we all were looking so down and sad. I felt so depressed and I didn't even want to go outside or to school. All I wanted to do was hang out with both of my brothers. Even though this was the worst news I've ever gotten, I feel that this made us all stronger and helped us in so many ways. We've had the chance to meet all these wonderful people such as the Cool Kids Campaign and our summer camp staff, Horizon Day Camp. They help kids with cancer and their sisters and brothers. Me and my brothers are so thankful for these companies because they help us live regular lives again!

Tips to Help the Siblings of Your Child with Cancer

Edited by Ahuva Morris, LMSW

A cancer diagnosis has a profound effect on the entire family, especially when it is a child who is diagnosed. Children who have a sibling with cancer have various reactions.

Siblings of a child with cancer may experience a range of emotions including fear, anger, jealousy, anxiety, sadness and hopelessness related to their sister or brother's diagnosis. They are often faced with changes such as their sibling not being able to play with them as usual and their extracurricular activities getting reduced or eliminated due to parents' time constraints and focus on the child with cancer's medical care.

Here are some tips on understanding how your healthy children may feel after a sibling is diagnosed with cancer and some practical ways to support them:

Talk it through. Give your children accurate, age-appropriate information about their sibling's diagnosis as soon as possible. Don't be afraid to use the word cancer. Explain the treatment plan and how it will affect them. Remember that if you don't talk to your kids about cancer, they may come up with their own explanations, which can be even more frightening than the facts. Some children believe something they did, such as get in a fight with their sibling, caused the cancer. Let them know that nothing they did or said can cause cancer.

Answer questions as accurately as possible. Keep the lines of communication open by answering questions honestly, taking into account your children's age and prior experience with serious illness in the family. If you don't know an answer to a question, it's okay to say that you don't know and will try to find out. To maintain an honest and trusting relationship, replace statements like "everything will be okay" with "we and the doctors are doing everything we can to help your sister/brother get better."

Try to maintain normalcy whenever it is possible. Routine gives children a sense of security and helps them cope with stressful situations.

Prepare your children. Explain the treatment plan and prepare your children for physical changes their sibling may experience (for instance, hair loss, fatigue, or weight loss). Talking about appearance changes ahead of time will help reduce fear when these changes happen. Let your children know

about changes to their routine in advance (for example, "Daddy will pick you up from school instead of Mommy for a while.")

Reassure your children. Let your children know that their needs will continue to be taken care of. While your children know that you love them, they may be feeling vulnerable and need more reassurance than usual. Explain that their sister or brother needs a lot of attention right now but that does not mean you love your child with cancer more than you love them.

Acknowledge feelings. Your healthy children may feel guilty, frustrated, angry, sad or selfish for not just feeling happy they are healthy. Let your children know that you understand this is a hard time for them too and that all feelings are acceptable. Feelings are never wrong. If they want to talk about how they are feeling, hear them out. Some children won't want to verbalize how they are feeling. You can be supportive in other ways by helping them find healthy outlets such as writing, music, art or physical activity.

Identify supports. Help your children identify people they can talk to such as family members, teachers, their school guidance counselor or members of your faith community for extra support. It may be helpful to ask one of these people to look out for your well child. Pick someone the child knows and trusts and ask them if they can be there to help out if the child needs someone when you are not available.

It's a team effort. If your children express interest in being involved in their sibling's care, find ways for them to help out. Giving them age-appropriate tasks such as bringing their sibling a cup of water or an extra blanket can help them feel important and needed. Older children may be able to help out with watching their sibling or helping set up for meals.

Make time to be with the well children. While family and friends are understandably focused on caring for the child with cancer, it's important to spend time with your well children too. Having time alone with you, even in small amounts, will mean a lot and is a concrete way of conveying that they are special to you.

Support for your family. You and your children are not alone. To learn about support services such as counseling or support groups, speak to a hospital social worker or call 800-813-HOPE (4673) to speak with a CancerCare oncology social worker.

Can you find the hidden pictures?

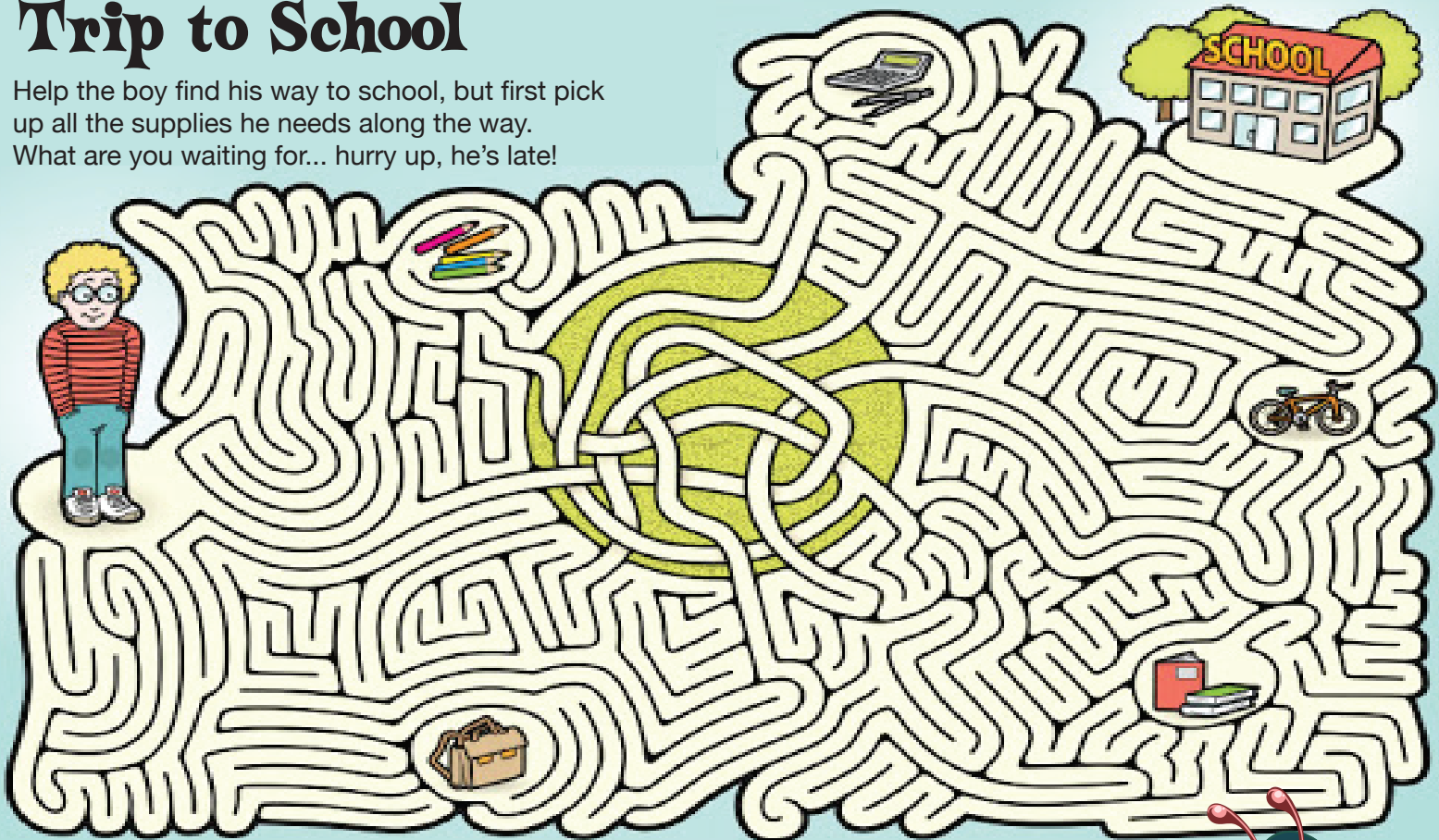


Color the bottle orange.
Color the banana yellow.
Color the toothbrush blue.
Color the boat purple.
Color the horn yellow.
Color the heart red.
Color the fish yellow.
Color the crown pink.

BRAIN TEASERS

Trip to School

Help the boy find his way to school, but first pick up all the supplies he needs along the way.
What are you waiting for... hurry up, he's late!



Unscramble these Spring words:

wyndi _____

dsalugby _____

ffoldsiad _____

elablrum _____

ecktja _____

letspa _____

mlboo _____

odeptal _____

fgsro _____

tyutfbire _____



ANSWERS: windy, ladybugs, daffodils, umbrella, jacket, petals, bloom, tadpole, frogs, butterfly

WTFUN FACTS!

SLOTHS

are popular animals these days.

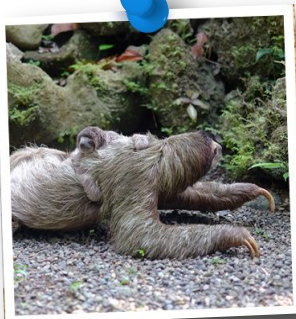
Here are some cool things that make them unique.



FACT 1:

Sloths only climb down to the bathroom once a week

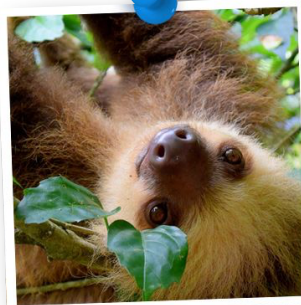
Once a week, a sloth slowly and carefully climb down from the trees to go to the bathroom on the ground! Can you imagine only going to the bathroom once a week? Scientists think there could be a few reasons why this is the case, but many believe sloths have evolved this way so they can avoid predators that hang out on the ground as much as possible.



FACT 2:

There are six species of sloth. They live in Central and South America.

All six species of sloth live in the tropical rainforests of Central and South America. There are two types: two-toed and three-toed sloths. They all mostly survive on the leaves of the trees that they hang out in. Some types of sloth have also been known to eat small insects, reptiles and birds when eating only leaves doesn't give them enough energy.



FACT 3:

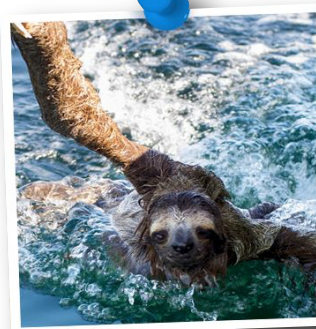
Sloths are very, very slow and only move when absolutely necessary.



Because sloths eat only leaves for the most part, they don't have a lot of energy to move quickly or very much at all. A sloth's stomach is made up of many parts that take a long time to break down the thick leaves they eat — so everything about a sloth is slow! Sloths also have much less muscle than other mammals their size. A sloth would take about five minutes to cross a small two-lane road. If you look up the word "sloth" in the dictionary, it's also a word for laziness!

FACT 4:

Even though they live upside down, sloths are surprisingly good swimmers.



Even though sloths spend most of their time hanging by their claws in trees, they are actually very good at swimming. They use their long arms and legs to paddle through the water. Sloths can actually slow their heart rate down, which also allows them to hold their breath under water for up to 40 minutes!

FACT 5:

Prehistoric sloths called Megatherium used to be the size of elephants!

About 35 million years ago there used to be a species of sloth called Megatherium. These elephant-size animals were "ground sloths," meaning they didn't live in trees like the much smaller sloths we know today. This could also be the reason why the sloths of today can swim so well — they use the instincts passed on to them from their ancestors!



JOKES

RIDDLES

JOKES ABOUT DUCKS!

What do librarians take with them when they go fishing?

Bookworms!



Q: What time does a duck wake up?

A: At the quack of dawn!

Q: What do ducks get after they eat?

A: A bill!

Q: What do you call a crate full of ducks?

A: A box of quackers!

Q: Who stole the soap?

A: The robber ducky!

Q: What do you get if you cross fireworks with a duck?

A: A firequacker!

Q: What has fangs and webbed feet?

A: Count Duckula

Q: What was the goal of the detective duck?

A: To quack the case

Q: Why was the duck put into the basketball game?

A: To make a fowl shot!

Q: What did the duck do after he read all these jokes?

A: He quacked up!

JOKES ABOUT RABBITS



Q: How do rabbits travel?

A: By hareplane.

Q: What is a bunny's motto?

A: Don't be mad, be hoppy!

Q: How do you catch a unique rabbit?

A: Unique up on it.

Q: How do you know carrots are good for your eyes?

A: Because you never see rabbits wearing glasses!

Q: What is a rabbit's favorite dance style?

A: Hip-Hop!

Q: Where do rabbits go after their wedding?

A: On their bunnymoon!

Q: What do you get if you cross a rabbit with an insect?

A: Bugs bunny

Q: What do you call a group of rabbits hopping backwards?

A: A receding hare line

Q: How can you tell which rabbits are getting old?

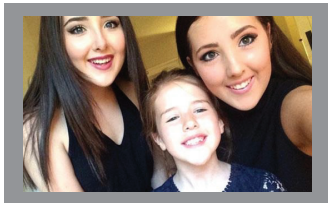
A: Look for the grey hares

Q: Why are rabbits so lucky?

A: They have four rabbit's feet?

Siblings affected by childhood cancer: 'It's one of those moments when time kind of stands still' – Meg and Beth's story

By: Carl Alexander, Cancer Research UK



Meg and Beth share the story of their younger sister Eve, who was diagnosed with Ewing's Sarcoma – a type of bone cancer – in July 2015. Eve sadly died on June 24, 2017, at age 11.

Meg and Beth remember exactly where they were when they found out about Eve's diagnosis.

"It's one of those moments when time kind of stands still for a second," says Beth. "It felt like a scene from a film. You hear about these things happening to other people, but you never think it's going to happen to you."

While Beth was at home with Eve when she started to feel pain in her hip, Meg was away from home at drama school when she heard the news. "After Dad called, he came down to Guildford to pick me up and take me home," she recalls. "It was when I got back to the house that the emotions hit. I went into Eve's room, and so many memories flooded back of us growing up together."

The storm of emotions after the news of Eve's diagnosis were hard to comprehend for Meg too. "It was a big mixture between complete and utter heartbreak and not understanding how to get my head round it. I was also angry, because I knew what a great sister I had, and I was left asking why this had to happen to our family," she says.

Eve's treatment started straight away, joining a clinical trial and being put on chemotherapy. Beth and Meg, who are now both actors, were living together in Guildford, and so were away from their family home in Corby during Eve's treatment. "Fortunately, we had each other, which made things a little easier," explains Beth.

"With the whole thing happening while we were away, that did make it quite difficult. But when we were home we'd try and lighten the load for Mum and Dad and share it between us. They could leave Eve with us because they knew we could do the extra things like taking her to the toilet in the middle of the night and making sure she didn't cry."

Staying Positive

Eve always tried to put a positive spin on what was going on, says Meg. "She even decided to call her tumor 'Monty', because she thought 'tumor' was a scary word and wanted to make it happy instead. "In her head it was clear that there was no way this thing was going to beat her. I tried to stay positive, but I think in the back of my head there was always the thought that she might not make it."

About a year into her treatment, Eve and her family were told the tumour in her hip had gone. Initially this was good news, but it turned out that cancer cells had been growing in her head too, and lumps started to form there shortly after. "That's when things started to get really hard," says Meg.

A Beautiful Smile, Then She Was Gone'

Beth had come home early from college to help her parents and because she knew she probably didn't have much time left with Eve. "It was very early that morning and my Mum woke me up because she knew Eve wasn't right. We contacted all the family members and told them to come over. Thankfully I got to spend that morning with her, which I was so grateful for."

Meg, still in Guildford, immediately came home to see Eve when she got the call from Beth. "When I arrived, I couldn't believe I managed to get there in time. She wasn't able to speak, but Mum asked if I wanted to spend some time with her. I think I had 10 minutes with her, and she couldn't talk back, but I knew she could hear me. It was like she waited for me."

"Everyone came back into the room and 2 minutes later she took a breath and her face lit up with this beautiful smile. And then she took one more breath and that was it and she was gone. "It was such a surreal moment," says Meg. "And at that point, I remember people telling me they had been heartbroken, but I don't think you can fully explain. It's like someone's physically snapped a piece of your heart off that you're never going to be able to add back on."

Coming to Terms with Loss

It's taken a long time for both sisters to come to terms with the loss of Eve. "I was almost numb to it for quite a bit," says Beth. "It was quite hard to actually let myself understand what happened."

"There have been some real ups and downs. I went to some bereavement counselling sessions and that really helped as well. Because I really do believe it's better to talk things out. It also helps to be in control and know it's okay to have those feelings and not always be yourself."

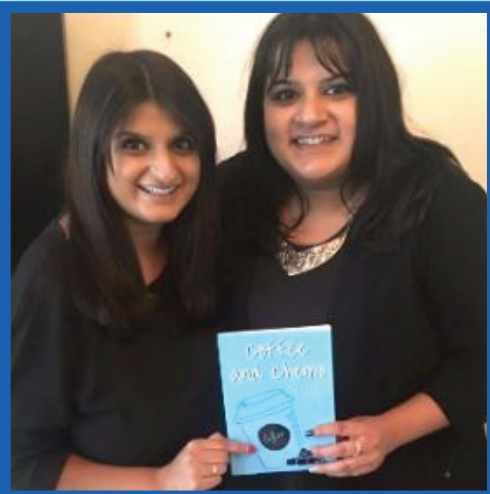
And Meg tries to use Eve in all aspects of her life. "If I go to an audition, I'll talk to her before and say: 'Hey mate, do you think I'm doing the right thing?' and just chat. I try to think what she'd do in this situation, and I think she wouldn't just sit there and do nothing. She'd get on with it. "There is a part of me still though that thinks I'm going to go back home and she's going to be sitting there on the couch and I'll hear her voice or see her face again."

Looking to the Future

Time has helped the sisters get to a point where they're now ready to look to the future, inspired by their happy sister. "I actually took some time out of the industry for a bit. Just because I didn't have the right head to go into an audition. But recently, I kind of think I've had a kick up the backside by Eve, just saying 'go and do what you want to do,'" says Meg.

And Beth agrees: "Eve supported what we do, although I think we sometimes got on her nerves with the singing and dancing!

"We're realizing now you might as well do something that makes you happy. Just go out and enjoy yourselves."



Leena Sirpal's older sister, Seema, wrote this poem for her while she was undergoing treatment for Hodgkins Lymphoma at the age of 14. The poem eventually inspired her to publish a book called **Coffee & Chemo** to help encourage others and to celebrate 10 years since her diagnosis.

*Little one, I see you lying there,
Each day in more pain, I cannot bear.
I sit by your side every day,
Sometimes not knowing what to say.
Quietly in my head, I often pray.
Wishing I could take your pain away.
Why my little sister, what did she do?
Make this a dream, don't let it be true.
I know it's not fair sis, but it won't be for long.
Just keep holding on, you have got to stay strong.
Don't give up hope, we will fight this together.
Remember God is watching over you, always and forever.*

COOL SIBLINGS WE LOVE



Kannon & Kori



Latrell & Lameia



Logan & Mya



Deyonna & Deylin



Chloe, Gracie & Bentley



The Quintero Family



Chance & Justice

Sister Love

(continued from the cover)



Q: What were the hardest things for you to deal with?

A: The hardest thing for me to deal with was holding back my emotions. I felt like I had to be okay when I was at school when I really wasn't. Trying to be strong when I didn't always feel that way. I feel like my role was to help my mother out and take care of Logan's twin sister, Raegan.

Q: Were there any good things that happened or experiences you had because of this situation?

A: Yes, different organizations like Cool Kids Campaign, Casey Cares, Horizon Day Camp and Believe in Tomorrow who provided my family with different trips, activities and experiences. It helped keep our family together and keep us close. We have some really fun memories and lots of pictures together.

Q: How do you think this situation has changed you? Does it make you see the world differently?

A: You never know what to expect. Anything can happen. I see the world as unfair at times because little kids can get cancer and they shouldn't have to go through something like that.

Q: What things do you love about Logan?

A: I love her funny little personality. She's so smart. She's very impressionable and listens and watches everything! There really is nothing like the love I have for my sisters.

Q: What advice would you give to other siblings in your situation?

A: I would tell other older siblings to try their best to be a big help to your parents, especially if you have

any other siblings to help relieve the stress. Talk to people about what you're going through and don't hold in your emotions. Let them out and ask for help when you need it. Remember that you are important too. served as an IV and chemotherapy entry point. He also had spinal fluid extracted to test for leukemia in his spine and brain. We were so thankful to learn no immature white blood cells were found.

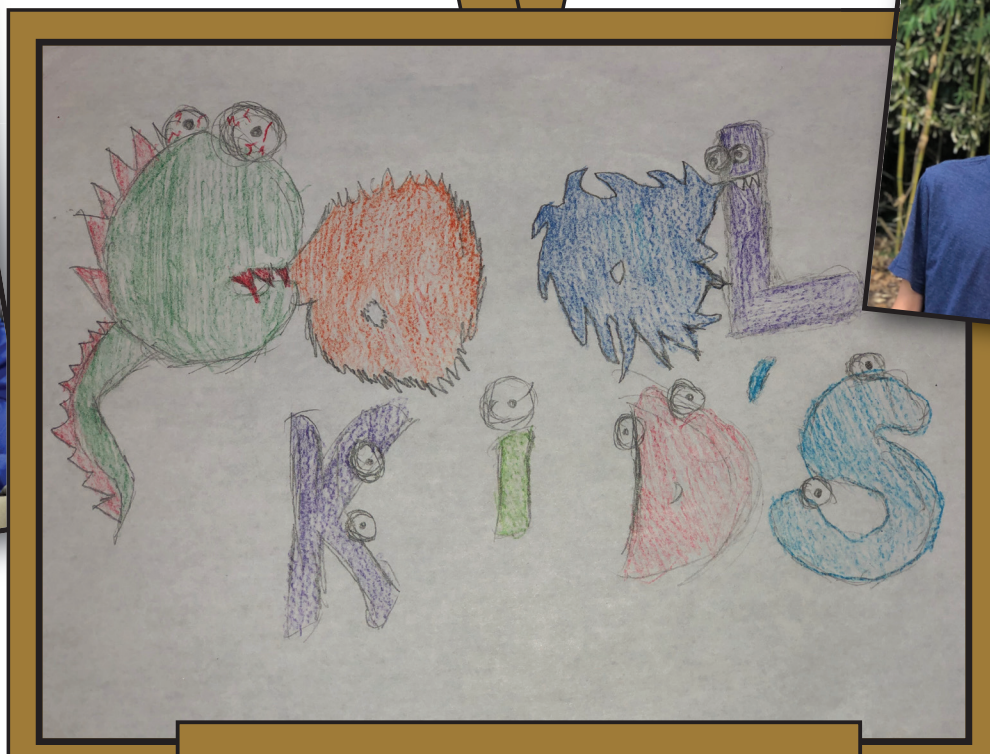
A few days later, once the doctors examined the cells, we received a treatment plan: Induction Phase (first stage, 28 days) to receive the hard-hitting chemo. Next, another spinal puncture and bone marrow biopsy to ensure there was no trace of the leukemia cells. Typically, there is no trace after the first phase ... Ethan was in remission!

Looking back, I feel like this whole cancer situation positively affected me. It made me want to be helpful and give to other families in the same situation as mine especially since I can relate.

Diamond continues to help her mom with her twin sisters as much as possible and strive towards her academic goals. She looks forward to watching her favorite Tyler Perry movies, going to prom and getting her driver's license soon.

"Thank you guys for supporting us children with cancer! No other organization does what you guys do! Y'all are one of a kind!"

~ Braydon



Braydon was diagnosed in 2015 with Acute Lymphoblastic Leukemia and is now in remission. He is in the 8th grade and enjoys wordsearch puzzles, collecting Ford model cars and is an enthusiastic Dallas Mavericks fan!



Send us your stories, art,
poetry, and photos and become
a published writer or artist!



Camie, Relapsed Acute Lymphoblastic Leukemia

Email all submissions to:
janet@coolkidscampaign.org
or mail to:
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