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Connecting pediatric oncology patients throughout the nation.

A Life-Changing Event

By Megan Pavlitsa, age 11

It was just another beautiful morning of summer vacation in Lewes, Delaware. "Hi Nonnie, what's wrong? Why are you crying? Where is Connor? Where is my mom?" It was just another beautiful morning until Connor, my 2-year-old brother got sick!

This sudden sickness was a bumpy adventure and taught me a lot about life. It was only two weeks until summer came to an end, and my family was enjoying one last trip to the beach with my grandparents, Nonnie and Granddad. On

one hand, you could say this journey tore my family apart. But on the other hand, you could say it united us even more as a family and made us much stronger.

I woke up that morning looking forward to taking a relaxing ride on the motor boat and strolled down the main hallway of our beach house toward the kitchen. What I expected was far off from reality. The first glimpse of my grandmother notified me that something was wrong. With tears in her eyes, she began to tell me what happened.

"Very early in the morning, your mom took Connor to the hospital," my grandmother said.

"What's wrong with Connor?" I asked.

"When he woke up, he gagged and coughed, gagged and coughed, and your mom was concerned. She took him for help," my grandmother said. "It's probably just a bad cold.

As usual, my grandmother was wrong. Connor was one hour away from an ambulance ride that was not only going to take him to a far away children's hospital, it was also the start of a new life for my family.

After Ryan, my brother, woke up, my grandmother said we could visit Connor before he left. I sped like a tornado through the house to get dressed and we were on our way. The anxiety I had on that car ride was monstrous.

Author Megan, with siblings Connor (4) and Mackenzie (1) and Ryan (8).



Connor was diagnosed with Non-Hodgkin's Lymphoma in August, 2006 and is currently completing two years of chemotherapy.

We sprinted to Connor's room. The hospital smelled like alcohol wipes.

Connor's face was pale and he didn't have enough energy to get up and say "hi." But you can't blame him for that. I saw that he had tubes coming out from his right arm. A clear, plastic plate was wrapped around his arm like a cast. Meanwhile, my mom was on the phone with my dad who was hours away from us. As sad as it was to see him this way, it was even sadder to see him go. That day went by like no other day had, and we waited anxiously to hear how Connor was.

Finally Nonnie told us, "Your mom called. She said the doctors think Connor has pneumonia." But they were

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Cool Kids Rock at Camden Yards

By Molly Lauryssens

What do you get when you mix a bunch of Cool Kids and their families with Orioles major league baseball players and a big orange and black feathered friend in the Baltimore's auxiliary clubhouse? You get a night to remember – that goes without saying. More importantly, you get a group who refuses to quit when things look down and who are filled with hope, courage and pure determination.

Take Kenton Hartman, a 10-year-old with leukemia. When asked how everything is going for him since his diagnosis, he answered, "It's been going great. I'm done with pretty much everything. I just have to go in for checkups and get lines taken out of my chest."



When told he's a trouper, he couldn't help but agree. "Yeah, I am!" he said confidently. Kenton looks forward to simple things like hanging out with his friends this summer.

Trouper can't even begin to describe these Cool Kids.

Now consider all that the Baltimore Orioles, a team in a "rebuilding phase," has earned since June 17 – a major league lead 20 come-from-behind wins. Talk about resilient! The Orioles displayed their resilience on that night as well, coming back in the bottom of the eighth to take the lead with the help of Melvin Mora, Adam Jones and Brian Roberts. The three players, just a few hours earlier, were hobnobbing with the Cool Kids in the clubhouse. Mora hit a double to drive in Jones and Roberts to take the lead once and for all.

This took place as the Major League Baseball Players Trust hosted "Buses for Baseball." Cool Kids



and their families were invited to the Orioles vs. Houston game. The game, however, seemed to take a back seat to the festivities that took place prior to the first pitch being thrown.

After arriving by bus, the Cool Kids and company were escorted into the clubhouse and given gift bags to commemorate the occasion. They collected baseballs, Orioles hats, program books, baseball cards, and of course, Sharpie black magic markers, among other goodies. Good call to give out the Sharpies. Why? What happened next is that participating players filtered in. Baltimore's Matt Albers, Chad Bradford, Alex Cintron, Adam Jones, Melvin Mora and Brian Roberts got up close and personal with the kids and their families. The children were ecstatic as the players came in, their eyes lighting up as they put the Sharpies to good use.

Kenton was really looking forward to meeting the players, plus he knew the Orioles would pull a win. Although his all-time favorite player, Cal Ripken Jr, was not on hand, he couldn't help but gush as player after player greeted him and his family. Kenton loves playing baseball; his favorite position is catcher.

He was particularly thrilled with the baseball cards. Whenever he attends a game he adds more



to his collection. “Either I buy them or my parents buy them for me,” he said.

While most players went from table to table to say hello, Jones took root at one particular table and began signing. As the kids lined up to meet him, some turned shy. Jones’ vivacious personality put them at ease. “Don’t be shy,” he said. “I’m not going to bite you. I’m just a normal guy.”

Mikey Thurin was anything but shy. While Jones sat at the table and signed pictures, Mikey shared a story with him. “I jumped into the pool and [my tooth] disappeared when I came up.”



Jones jokingly replied, “I ain’t signing that [tooth].” Jones and the entire Thurin family broke out into a discussion about the rising rates of inflation the tooth fairy has incurred. Jones said he used to receive one dollar under his pillow – and that Mikey made out a lot better. Mikey insisted Jones sign at least 200 pictures and Jones said, “I don’t even think I have 200!”

Mekila Thompson, 9, shared a fun moment with the up and coming centerfielder.

“Mekila, that’s my best friend’s sister’s name,” he said, “it’s a pretty name!” Mekila also had a riot with the Orioles mascot, The Bird.



“The Bird is definitely crazy,” she said. Mekila didn’t predict the Orioles to be the victor on this night but she was psyched when he led the game with a lead-off single. High-fives were definitely flying among the entire group.

Five-year old Madisyn Wilson, who has mastered the world of thumb-wrestling, was a bit reluctant to converse with any players. However, through a local reporter she asked Jones to hit a homerun for her. Jones responded, “If he throws something that’s a good pitch to hit out, I’m going to try to hit it out for you.”

Jones had signed numerous pictures and left them on the table. He told the children before leaving, “Snatch everything you want.” They had no problem obliging.

It might have taken some time for some of the kids to warm up but it didn’t take much for any of the players. Before long, they were mixing in and answering questions about the game. “Will you pitch tonight?” was one common question.

“I don’t know,” said Chad Bradford. “When the phone rings and it’s my name, that’s when I go – when my name is called. Hard to say when you’re in the bullpen.”

Melvin Mora walked into the room announcing, “Sorry I’m late,” and the room erupted with laughter. He approached Mike and they began talking as Mora explained, “I’ve been getting ready for the game.”

After the players left, the Cool Kids were escorted onto the field. Their jaws dropped. Bryan Showalter, 14, appreciated the chance to pose for a picture in the Orioles on-deck circle.

“I think this is pretty cool that we get to come out here,” he said. Although Bryan is more of a soccer fan than a baseball fan, he was still stoked to see

this field of dreams. He admitted that he follows baseball only “a little.” After being on such a grand stage, perhaps he’ll start following baseball even more.

The Cool Kids weren’t the only ones lapping in the fun. Brian Roberts takes moments like this to heart.

“It’s just a fun opportunity for us to come and meet some kids that may not get that opportunity all the time,” he said earnestly. “For us as players, we are so fortunate and blessed to be able to do what we do on a daily basis.”

He’s a kid-lover for sure and enjoys the impact he has. “I love interacting with kids,” he said. “I love seeing a smile on somebody’s face who may not have had one there recently; or they are going through a hard time or may have never met a major league ball player. It’s just a great opportunity for us.”

Throughout the game, many of the Cool Kids were spotted dancing in their seats along to the stadium music. When the song played, “When you’re happy and you know it, clap your hands,” the children clapped along – an incredible sight to see.

Thanks to the Orioles and the Major League Baseball Players Trust, these families will have this moment to remember, as well as a few much-sought-after autographs and the memories and conversations that went along with them.

The Major League Baseball Players Trust, with the support of the Baltimore Orioles, is a charitable foundation created by the players to help those in need. Through the Players Trust, Major League players contribute their time, money and celebrity status to call attention to important issues affecting those in need and to help encourage others to get involved in their own communities. For additional information, visit www.mlbplayers.com. □



Chayton's journey... so far

By Lorena McCormack

Chayton has recently been diagnosed with cancer. He just turned 4 on May 19th. He has been diagnosed with one of the worst brain cancers a child can get. He is fighting it; he has an amazing sprit and so much courage. Every time I look at him I am in awe.

We never knew cancer could strike so fast or that so many children were fighting for their lives against it. It is so very tragic, while at the same time, these children are beautiful.

As parents we could never imagine something so horrible. We prepare ourselves for broken bones that might have come from playing sports, but nothing could ever prepare a parent for something like this.

Chayton has always been very healthy, super active, and very outgoing. Always a happy child to be around and very much his little brother's keeper. He is a nurturer and easily gives compassion to others. Yes, he has the heart of a lion.

Chayton has always said he wants to help others. He has definitely helped us become better people, as well as the countless lives he has touched. Watching everything he has gone through has been hard, but if by sharing our story we can help spread awareness, then maybe we can help one more person.

Everything happened really fast, from noticing him stumble on occasion, to falling over the next



few days. Of course, there are millions of excuses, he's playing too rough, he's tired, or distracted. It turned out to be so much more.

The beginning

Chayton began losing his balance around the second week in April. At first it just seemed like a mis-step or maybe he was sidetracked. By that Friday we had decided to take him to the pediatrician the following Monday, but while at his cousin's birthday party that Saturday, he kept falling for no reason and he was holding his head at a tilt. Something was wrong so we took him to the Urgent Care in Fruita.

They were very polite and calm when they told us we should take him into St. Mary's ER, and they would call ahead but we were still holding on to the thought that he had an inner ear infection.

We arrived at St. Mary's and they did a scan. When they came back into the room, they sat us down and told us they had found a mass. I still remember how long it took for those words to register. It can knock you right out of your body. In that moment, our lives were forever changed.

Dr. Hemley was on call to come in to look at the scans; she has done both of Anthony's back surgeries, so it was a relief to see her. We were expecting to hear there was a mistake but instead she was there to hold us as she said we should take him to Children's Hospital - they were prepping the flight. They would know more there what kind of mass it was and were better equipped for children with this diagnosis.

My baby took his first plane ride just hours later; he and his daddy flew into Denver. Still in shock I tried to grasp what we did know and tried to tell myself they operate on these all the time,

right? But this is my baby and this still can't be happening.

When we finally got to Denver, Chayton was in the PICU and they had done more scans. We were waiting to hear what they found. Dr. Meg came in; she had the horrible job of telling us what they did indeed find - there was a tumor in his brain stem, it is infused and it cannot be operated on. These are very rare tumors, she said, and maybe we would be able to try radiation, but there wasn't much they could do, and "I'm so sorry."

Our whole world shattered. All I could do was hold my baby and pray for time to stop. About three days later, we were moved to the seventh floor to begin radiation and if we wanted, we were offered a very small ray of medical hope - a Phase 1 clinical trial with arsenic, to work with radiation. One child with a similar diagnosis had done it and lived past 12 months. Otherwise, all we could do is radiation and hope the tumor would shrink, but this grade of tumors return 100% of the time.

We chose the clinical study, which involved three days a week - Monday, Wednesday, Friday, for infusion treatment; and we did radiation five days a week. We would go back for follow-up check-ups every two months.



During Chayton's first week, he was not responding very well to the steroids, radiation, and the other meds. The doctors gave us more bad news - they thought the tumor had grown too fast and they were not able to catch up with it. They were very sorry, but to put him through another round of treatment could cost him his life, so if we didn't, we could have maybe 72 hours left with him. They were so very sorry, they said - we barely heard a word.

They took him off the treatment meds, and then put him on a new one. It was a steady drip just to keep



him comfortable. They said at some point during his sleep he would drift away; he wasn't in any pain.

I cannot begin to describe the pain on every level you feel when you're faced with losing your child. It is tremendous. It will tear out your heart and cripple your soul; it is a very physical pain.

*Much to our amazement
we watched both of our
boys grow and mature
far beyond their years.*

Dazed, we thought about how only a few weeks earlier, Chayton was chasing his baby brother Hunter around the house, laughing and having a great time. Now he was at the point he had lost most motor skills. He could no longer walk on his own and he was barely able to eat.

We prayed for a miracle. We begged and we were heard. By Monday morning Chayton was sitting up playing video games, his eyes were clear, and he was hungry. When the doctors told us that we could try treatment again, we jumped at the chance.

Chayton has made steady progress with his treatments. He is able to stand for short periods of time and is fully aware of everything going on around him. With time he has been able to walk again and hopefully at some point he will once again be able to run and play.

We have been blessed with having a wonderful support system, an amazing family, and special friends. One of his biggest supporters has been his little brother. Hunter quickly began to participate in Chayton's recovery. Much to our amazement we watched both of our boys grow and mature far beyond their years.



We had our last treatment on June 4th. The very next day we were packed and ready to go home. We are so very thrilled to be together and to be back home; we know we still have a long road to go, but we know as a family we will travel down that road with each other.

There are a lot of changes that came with coming home. Our first priority has, and will be, being together as a family and making the most of every minute we have together. Another is in work. While we were at the hospital, we could not leave our baby's side and after being there two weeks, we received papers, Fed-Ex'd from the company Anthony was working for. They were termination papers for not returning to work in a timely manner. Included also was a bill for carrying insurance coverage for the time he was not at work. This also meant we were losing our insurance for Chayton. It was a shock and disappointment they could not wait until we got back to hand it out.

However, there have been so many amazing people who have come to our side during this very difficult time. They have graced our lives with their kindness and support. We are honored. It gives us strength and comfort – we cannot thank you all enough. Knowing that so many people care about our baby and feel for what he has, and is going through, means so much to us. It helps bring some peace. ■

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**Hi! My name is
Colby O'Neal,
I'm 8 years old,
and I am from
Deville, Louisiana.**

I sent you some pictures of me and my three sisters, Krysta-9 yrs old, & Casey-7 yrs old. Then I sent a picture of my whole family, my mom-Catrina O'Neal & Dad-David O'Neal & my sisters at the Target house # 2 in Memphis, TN. I was diagnosed with Acute Myeloid Leukemia (AML) on March 18th, 2008 at St. Jude Children's Hospital here in Memphis, TN. I am now starting my Induction #2 of chemo on Friday, April 25th, 2008. I miss my family back home a lot. I miss my little 2 lb. pekeyorkie puppy named Cola. I love St. Jude a lot, they are all very nice and try their best to make you feel as close to home as they can, away from home. My doctor, Dr. Ribeiro is an awesome doctor and a good friend, he is helping me get better. Dr. Hollywood as well is awesome. The doctors always speak when they see you and ask



how you are doing today? The nurses well they spoil all of us here as well at St. Jude Children's Hospital, they make you feel like you are family here all the time whether you see them daily or yearly they are the same. They are your family away from home. My mom & dad said we are in the best hospital in the world and they will do whatever it takes to get children better. We have hope & faith that we will beat this disease. Also my family writes about me on my website on the caringbridge.org. Mom & I read them at night to see what they wanted to say to me. I wish they could be here too. There is a lot I want to do when I can go home. I pray one day to go on professional hunts when I get better and able to go. I love to golf, hunt, fish, go camping, & love to play games on moms laptop, my PSP, & my Playstation 2. I find that's lots of fun too. My favorite things to eat are chicken pot pies, hot pockets and lots of those brownies mom buys at the store. ■

continued from cover page

wrong. Later we learned that Connor had cancer. By this time, my 2-year-old brother didn't even have the ability to walk or breathe. Connor had a tumor in between his lungs that was so big it moved his heart to the right side of his body. The tumor was wrapped around his left bronchial tube, not allowing him to breathe through his left lung. Connor had to take a medicine called chemotherapy. Most people call it chemo. This medicine, unlike any other medicine, is used to make you better but it makes you feel even worse. After a few days my brother and I were finally able to go to the hospital to see Connor. The doctor knew Connor would be in the hospital for a long time, so they made him feel at home. Within a week if you ignored the fact that you were in a hospital, you would have thought Connor was in his dream room. He had toys, movies, balloons, and stuffed animals. Best of all, he had his family and all our support. As a result of Connor being in the hospital, my family stayed in a nearby hotel called the Ronald McDonald House. It supplied dinner, breakfast, and many family-oriented activities. Although I wished I could be sleeping with Connor, it was better to be at the Ronald McDonald House close to Connor than home.

After two weeks Connor was finally able to come home. With Connor feeling better, we had the chance to look over this breathtaking experience and to reflect on how it changed our lives, and to thank many people for all their support.

My family has changed a lot throughout this experience, and this has been a very important part of not only Connor's life, but my whole family's life. This event was important because it made us realize how strong our family is. We all worked hard together to get through a time like this. This has given my family the strength to make it through any trouble and reach any goal. As a family, we were able to help Connor get through cancer, and that means a lot.

My family has talked a lot about how this experience has affected us, and changed our lives. First of all this experience has shown me the importance of respecting my brother and treating him fairly. Connor is my role model in life. As I grow up, I hope that I can be as brave as he is. This experience made my family realize how much we love Connor and each other. We now know how much family means to us. Also this experience has made me realize what is important in life and how thankful and appreciative I am of the doctors. I

hope that someday I can help others so that they can enjoy life the way they should be able to.

Another way this experience has affected me is that I try to help others. For example, my friends and I have lemonade stands to raise money for the hospital. When children go to the clinic they have to get shots, have an IV, lumbar punctures, blood taken, and bone marrow aspiration. If the children do good while having these operations done, they get a prize out of the prize bucket. How I help the hospital is by raising money to buy toys for the prize bucket. The doctors and kids appreciate all the nice toys I bring to them. The best part about raising money is when the children pick out a toy I bought. I love to see their happy faces when they get the opportunity to play with their new toys. Knowing the position that all their parents are in I am so happy to help make their day a little brighter. I am also involved in the Leukemia and Lymphoma societies' Light the Night Walk to raise money for blood cancers.

This experience has given my family many ups and downs, but most of all it has taught me the importance of my family! □

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My Son, My Superhero

By John Rozema

I grew up as a kid who loved superheroes. My favorite was Superman. A hero who was completely invincible to everything, except kryptonite. I always wished this world could have such heroes to help with all the wrongs in this world. Now that I am a father I have realized those fantasies only exist in our imaginations.

Johnny was born August 22, 1997 a healthy boy. He grew up with his older sister, Emily, and his younger brother, Luke. The three were like any other brother and sister combination – they loved to laugh and fight. Hearing both sides of this always put me on my knees in prayer to thank God for the wonderful opportunities He gave me to experience such joy and unconditional love only a father could appreciate – school, birthdays, laughs, cries, vacations, falls, and so much more that goes by in the blink of an eye.

Unfortunately on April 5, 2007 my eyes did not blink or cry when the doctors told Holly and I that Johnny had a rare form of cancer known as Burkitts Lymphoma. I thought I was in another world. I wasn't even sure if I heard the doctors

correctly. They came in and told us the news and Holly started crying. They told us to take a few minutes and would be back to answer any questions we might have. They walked out and I stared at my wife who had her head buried in my shoulder. This has to be wrong. How could this happen? How did he get this? Was I the one responsible for his disease? Did I take him somewhere I shouldn't have? What would the kids think? What would Johnny think? **WHAT IS GOING ON?**

For some reason it settled me knowing that Johnny had a name for the pain and suffering he had been going through for the past month. He came to me with a headache while we were working on his fourth-grade science project. Knowing how much Johnny hated homework, I thought he was trying to get out of his duties to the project. I told him to take some medicine and go to bed early. He did without argument. Two nights later, he woke me at four in the morning holding the bottle of children's Tylenol in his hand complaining of another headache, this time with a low-grade fever. The next day we went to the doctor's who tested him for strep throat due to redness in it and puffy glands. It came back positive. The doctor said sometimes strep can cause headaches, and prescribed antibiotics.

We went to McDonalds for lunch. I remember playing nickel hockey at the table while we waited for our meal. Johnny stayed home from school that week. The pain had gone away but the fever and general aches and pains did not. That Friday I had returned from work early and he was lying on the sofa playing Nintendo DS; his favorite thing in the world was video games. I gave him a kiss and checked him over and asked how he was feeling.

"I'm fine dad," he said. I felt comfortable with his answer and went outside to work on the house we were building. Two hours later, I walked in to get a drink and looked at Johnny. The left side of his face was completely swollen; he couldn't open his left eye. Holly and I rushed him to GBMC where he was admitted to the pediatric ICU. The next day pain set in and did not stop for two weeks. Screaming at the top of his lungs, the pain had traveled to his arms and the tops of his legs. Ice packs and heat packs didn't help at all. My son was put on I.V. pain meds.

Two days later an MRI of the head revealed a small cyst on his left temple. In the operating

room, the doctors tried to drain the cyst but had no luck draining anything from it. The following day, which included pain and screaming, they transferred Johnny to Johns Hopkins Pediatric ICU, thinking he might have a blood clot. After 24 hours of being examined by several doctors in different fields, the oncology team broke the news. The agonizing of the past month was over, yet a new pain made itself known that day – the pain of my heart breaking.

Holly and I told Emily and Luke first, at home. Johnny was pretty out of it due to a port catheter placement procedure; Uncle Chad stayed the night with him. Emily started crying. I guess being 11-years-old, her concept of the whole thing was more than I expected. Luke had total confusion written on his face. He got upset because he looked his big sister in the eyes and saw something he had never seen before – a look of fear and uncertainty. We explained everything to them, not leaving out anything. We said Johnny had a good chance of beating the cancer and would be okay. We also told them cancer was a nasty and mean disease that might also kill Johnny. Through the battle, we kept the kids up-to-date and hid nothing from them.

Children are not stupid in the slightest. They see pain and fear on parents' faces and form their own images about the parents' fears – that is not good. My goal was to fight this as a family and beat it. The next day we told Johnny he had cancer. He didn't know what it was and we explained it to him the best we could. We told him the doctors gave him an 80 percent chance of beating the cancer and that no matter what, we would not give up as long as he didn't.

I never imagined having to look one of my kids in the eye to them that they had an 80 percent chance of staying alive or being around for their



next birthday. That was the worst day a father and mother could ever have.

The doctors at Johns Hopkins were on top of their game. Having worked various fields of medicine for the past 15 years, I can say I felt very comfortable with Johnny's treatment plan. They explained to Holly and me that the small cyst on Johnny's temple was actually a tumor that had wrapped its roots around some nerves causing the swelling and partial lack of movement to his left eye. The cancer had spread to his blood system, adding a form of Leukemia. There were tumors on his kidneys, pancreas, and spinal area as well. With all this happening, the doctors were still confident they would one day receive a wedding invitation from Johnny. With this much confidence, how can anyone not feel somewhat better? One percent better.

Johnny started chemotherapy treatments immediately. He had IV chemo in his port and would also receive injections of chemo into his lower spine for five months. During his treatments



His cancer is coming back, I thought, I knew it in my heart.



in the hospital we packed up his Wii system to take with us – he was in his glory. Playing video games and watching Cartoon Network all day when no one could tell him he couldn't. Seeing him return to his old self made me more confident that this cancer was going to lose. Every test result came back with good news. I watched my son not give up, and turn into a man before my eyes. He took the good and the bad and always made the best of it. He fought all the side effects of the chemo and came out on top. He was beating something I always saw as unbeatable. When we went for the scans of different body parts, I would joke with him, saying he might get some super powers from all these tests. He'd smile and tell me to "get real." As much as I joked about it, he had already become my superhero – someone I could look up to, to find courage and bravery.

Johnny was down to his last two weeks of chemo treatments, done at home with an injection. This made him happy since he didn't have to go to the hospital to stay – only for check-ups. During those two weeks I noticed Johnny's hair starting

to grow back. My medical background kicked in and I started thinking the worst. His hair was not supposed to come back for a few months after chemo and he wasn't finished yet.

His cancer is coming back, I thought, I knew it in my heart. I talked myself out of thinking the worst; my imagination was getting the best of me. I should have listened to my imagination. At his next check up, they told us his cancer had come back and had started to grow a tumor around his aorta, constricting the flow of blood leading from the heart. This was a major setback we were told because the cancer came back during chemo treatments and they weren't sure what type of odds Johnny had. **WHAT IS GOING ON?**

He was acting like his old self – hyper, argumentative, and laughing – he even tried summer camp for cancer kids. How is this possible? Man, do I hate being right!



More chemo treatments were immediately scheduled; different types of chemo and radiation were prescribed to shrink the tumor before it cut off his blood supply. A nightmare started all over again. You would think a setback of this magnitude would drop someone's spirits. Not my son. He continued to fight with renewed enthusiasm. I couldn't believe it. Holly and I were so depressed, yet he helped keep our chins up and continued to fight.

During this setback, Make-A-Wish Foundation came to interview Johnny for his dream wish. We had asked him what he would like for a wish, and he spoke about all of us going to Disney World as a family, and flying in an airplane. He wanted his grandmothers and Uncle Chad to go with us. I couldn't promise him anything at the time, because I didn't know what Make-A-Wish was able to do.



During his interview, he was in the hospital. The interviewers came and had a good time with the children. They brought gifts and played games with them. What an awesome group of people! Johnny's interview for his wish consisted of a game of questions: "What is the one place you would love to go? Who would you love to meet? What do you want to be when you grow up? His response to the questions blew Holly and me away. He wanted to go to Disney World, he wanted to meet the Mario and Luigi characters from the video games he played, and he wanted to be Link from the popular Zelda games. After answering the questions, he had to prioritize what was most important. He wanted to meet Mario more than anything in the world.

Make-A-Wish said they would do their best. On their way out, they requested a few minutes with me in the hallway to ask how serious was Johnny's condition. That's when reality kicked in for the very first time. I had to face reality and say I didn't know; that Johnny's cancer had come back, and though he was making positive progress, I couldn't tell them if my son was going to be around for another month, or two or three.

I think that's when I snapped. I knew my son wasn't going to beat this. I started ignoring everyone and everything except Johnny and the kids – I didn't care about work anymore or the house, just my children.

With all the trips back and forth to the hospital for his treatments and check-ups, money started to become scarce. I was trying to work on my home improvement business, be a father to my children, a husband to my wife, build our home, and heal a sick boy all at the same time. Something had to give and that was my job. I found it harder and harder to concentrate on my business. I didn't feel right until I was with Johnny. Holly had a job at a bakery

but it wasn't enough. Johnny's school heard about our financial difficulties and held a few fundraisers for us. Family and friends rallied together with car washes and bake sales. People sent greeting cards with Blockbuster and Shell gift cards inside. The community prepared meals for our family. That was a blessing – to put something in the oven that didn't take away our time from the children. Hearing them all laugh together under the same roof was a feeling of peace for me. With Johnny in and out of the hospital, those times were not always there. I am still in awe to this day how much help we received from so many different people.

With the help and support from the community, I had time to think. Thinking turned into anger. WHY? Why my son? I argued with God. I became very bitter and wanted answers. I fought with God on a daily basis. I struggled to maintain my faith. Why would our Heavenly Father bestow the worst pain a father could possibly imagine upon me? I was good. I did my very best for my family. I worked two jobs to have Holly at home with the children instead of a stranger raising them. I always thanked God for blessing me with healthy children. Why was this going on now? Why couldn't He make it stop?

During my battle with God, my wife told me a story. Johnny had asked the question I had always prepared myself for – “Why me?” Johnny had just towed off after a hot bath; lying on the floor cooling off, he looked up at Holly and asked, “Why me, Mommy? Why do I have cancer?” Holly's response floored me because it was the



same response I had prepared had he asked me. Holly said, “Johnny, God gives people only what they can handle.”

Holly told me this story during my time of “Why me?” I stopped arguing with God and allowed myself to be appreciative of the time He allowed me to have with my son. I stopped feeling sorry for myself.

It was now seven months into our fight against cancer. Johnny was feeling great. He was so alive and hyper I actually had to yell at him for being too loud in the hospital room. He was so energetic playing the Wii Olympics game that the nurses had to run in because his heart monitor was reading high. They had a good chuckle when they saw Johnny working out in bed with the game. Things were going well. Then it happened again.

Johnny and I went to his clinic appointment for lab work. The results came in and I was told his chemo wasn't doing anything for him. He needed to be admitted and have more tests. This wasn't fair. I lost it and broke down in the hallway. I had to call my wife and tell her. I knew the magnitude of such news. Holly came down to the floor where Johnny's room was. The doctors asked us to speak to them in the conference room. Our nightmare became a reality – they said there was nothing left in the books for Johnny. There were other chemotherapies but nothing would help. If we wanted them to try the other chemos, they would.

My wife and I already knew we didn't want to make our son suffer any more than he had already. We said no. To this day that decision absolutely tears me apart. They gave Holly and me a few minutes alone. We held each other and comforted one another while crying, telling each other God has a greater plan and He wants Johnny now. How

was I going to tell Johnny? That's all I could think about. How was I going to be the strong father and tell my son he was going to die?

During our fight with cancer, we had always talked about God and heaven with Johnny and the kids. Their grandfather passed away a year before, so a lot of their questions were answered then. It just wasn't the same. My son, their brother, was going to heaven. I remember having a conversation with Johnny about heaven during the first few months of treatment.

“Johnny, what do you think heaven is like?” He said, “It's a place where you can go and see Pop-Pop and other dead relatives, and also thank all the people who fought in the wars.” WOW! Where did that come from? Unfortunately I will never know. But I do know that my son made me proud to be his father. There were many times before that I felt proud but that took the cake. Knowing now that my son was dying and there was no choice in the matter would he have the same feelings about heaven?

Holly and I walked into his room after our meeting with the doctors. I remember Holly sat

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*He just looked at me and
 didn't say anything. Just
 stared at me. What was I
 supposed to do?*

down next to him and wrapped Johnny in her arms and looked at me with tears in her eyes. I leaned over him on the other side and kissed his bald head and told him.

“Johnny, the doctors just gave us some bad news. Your cancer is back again and there isn't anything we can do about it this time.” He just looked at me and didn't say anything. Just stared at me. What was I supposed to do? All I could do was hug both Holly and Johnny, and cry. He had asked later when he was going to die and we told him we didn't know. That is one of those memories you wish would go away, but in the same respect, I would be losing the only adult conversation I would ever have with my son.

A week had gone by in the hospital and the staff had contacted Make-A-Wish and told them the severity of the situation. They in turn notified us they would be sending the whole family to



Disney World, including Uncle Chad and his grandmothers. This made Johnny very happy. Unfortunately Johnny started to develop some fluid on his left lung, creating an unforeseen complication which might cancel the trip. The doctors prescribed a pain medication regimen to keep him pain-free and took him to the operating room to drain his lung of the fluid. After that procedure and all the pain meds he was taking, my son was not my son anymore. He was so doped up all the time, we had trouble getting him to eat. I wasn't sure if we should go to Disney World – the trip was only two days away. The next day Johnny started to respond better to the pain meds and was more alert. I asked him if he still wanted to go and he said yes. So off we went.

Johnny was very excited to fly. I used to tell him stories of the times I was in the Air Force and how I used to fly around the world. Now it was Johnny's turn to have fun flying. He was excited during take-off and for a few minutes afterwards, then laid his head in my lap. All the excitement was making him tired. Once we arrived at Give Kids the World Resort, he took a nap. The next day he was too tired for the parks. Holly and I took Emily and Luke to Animal Kingdom wearing brave faces. Knowing this trip was about Johnny, yet him not being with us, made me and Holly miserable. We knew he was okay with his grandmothers, but it just wasn't the same. We returned after dinner and hung out with Johnny watching TV. That night Johnny climbed into bed with me and Holly. That was the last time I carried on a conversation with him.

An hour after lying in bed, Johnny started to have a panic attack. He wanted to use the bathroom. I picked him up and carried him in. It was useless, he said. He wanted to go back to bed. I picked him up and put him in our bed, and that's when it began. I could hear every breath he was taking, clear across the room. I had to call 911 because he was losing consciousness. When the ambulance arrived, I carried him out to where he passed out in my arms. Johnny was rushed to the hospital and stabilized in the emergency room. They placed a chest tube and put him on a bipap machine. (*A ventilator without the tube in the throat.*) Johnny was in the hospital for two days. A very dear friend managed to arrange a flight home for my family while I stayed behind with Johnny and waited for an air ambulance to take us back to Johns Hopkins. The next day Johnny and I came home. Johnny was in and out of consciousness. He was

relieved to be back home, but there was no more conversation, just occasional bouts of crying in pain. My mother came to relieve me at the hospital so I could go home to clean up and rest. Holly relieved Mom the next day. That following

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*Johnny made me realize
that there really are
superheroes in our world
and not just in someone's
imagination.*

• • • • •

morning Holly called to tell me I needed to come down right away. Johnny wasn't going to make it much longer. I gathered up the kids and my mother and brother and went to the hospital. When we arrived to his room I was able to give my son one last kiss on his bald head and held his hand as he passed away.

Johnny's funeral was incredible. After two days of viewings and being sad I never imagined a funeral service could be so uplifting. The arrangements were made by the parents of Johnny's school. All of Johnny's classmates sang songs including the Sponge Bob theme, his favorite TV show. His teacher, Mr. Hurley, gave a eulogy that went above and beyond anyone's expectations. He single-handedly made the worst moment of my life bearable. It was nice to hear stories about my son that I never knew. During the funeral procession to Fairview Methodist, the street workers stopped what they were doing and took their helmets off in respect for a loved one.

My son died on December 18, 2007, one week before Christmas. It was very hard to keep things upbeat for Emily and Luke. They didn't have the same enthusiasm that day. Their brother was not physically with them anymore. They both expressed to Holly and me how sad they were and we as parents held our heads high and explained that Johnny was in a place that dreams are made of. He is with God in heaven. He gets to play video games with Pop-Pop and play games we don't know about yet.

Every day I wake up and think about my son Johnny. It might be a happy thought or a sad thought, but every day I miss him. Every day Holly, Emily, and Luke miss him. His bedroom was turned into an arcade titled "Johnny's Arcade"

with a mural of characters from Mario to Sponge Bob painted on the wall. There is not a room in this house that doesn't have a picture of Johnny from some point in his life smiling at us. It will never be the same. I walk around with a feeling of something missing. I could easily stay in bed and feel sorry for myself or be angry at the world, but what good would that do for my family? We may be minus one member of the family, but we are still a family. We may have lost our son but we didn't lose what it means to be a family. Life is too short to stay hidden away. Johnny never stopped being Johnny even after he was told he was going to die. I won't stop being a father because my son lost his battle with cancer. I will become a better father because of this. My son made me proud of him, therefore, I plan on making him proud of me. There will be a time when I will be able to hold him again and when I do, it will be knowing that I did my very best in life.

Johnny made me realize that there really are superheroes in our world and not just in someone's imagination. Those heroes are the ones, like Johnny, who brave the odds no matter how grim they might be. Heroes like the families and friends who gave me the time to spend with my son. Without heroes like them I would be begging to this day for more time with my son and feeling miserable every day. I don't feel miserable. I look forward to putting one foot in front of the other. Johnny was dying and he still marched with pride and feared nothing. There will be a time when a father becomes the son and the son becomes the father. That time has come for me. My son taught me how to be who I am now.

Thank you Johnny, I love you!





Read This Brainteaser...bet you CAN!

The phaonmneel pweor of the hmuan mnid: I cdnuolt blveiee taht I cluod aulacnty uesdnatnrd waht I was rdgnieg. Aoccdrnig to a rscheearcr at Cmagbride Uinervtisy, it deosn't mttar in waht oredr the ltteers of a wrod are, the olny iprmoatnt tihng is taht the frist and lsat ltteer be in the rghit pclae.

The rset can be a taotl mses and you can sitll raed it wouthit a porbelm. Tihs is bcuseae the huamn mnid deos not raed ervey lteter by istlef, but the wrod as a wlohe. Amzanig huh?

Very Tricky Math!

- This riddle must be done in your head only – do NOT write it down.
- Take 1000 and add:
 - 40;
 - 1000;
 - 30;
 - 1000;
 - 20;
 - 1000;
 - and 10.
 - What is the new total?

Picnic Panic!

Summer is the best time for a picnic, but you seem to have your picnic items all jumbled! Unscramble each word to see what you are bringing along.

CRYHER IPE	DOAS
TTOOPA DLASA	SNAPIN
PUCS	CHEWIDANSS
DRIFE NICHKEC	SKORF
LOCE LAWS	LETKNAB
TRAMLEENOW	SLEPAP
SLEPAT	TEAMSOOT
ABDEK ABNES	BRIEFES

American Women: From Adventure to Invention

Is there a woman Edison? A female Columbus? A feminine counterpart to fast flyers Charles Lindberg and John Glenn? If so, who are they? From the list below, identify some of our most famous American women adventurers, explorers, and inventors.

Selections:

a. Amelia Earhart	e. Rear Admiral Grace Murray Hopper
b. Sacagawea	f. Sally Ride
c. Maria Mitchell	g. Isadora Duncan
d. Maya Ying Lin	h. Margaret E. Knight

1. Imagine inventing a symbol that represents the meaning of an entire war. This Asian-American architecture student did just that when she entered a design competition for a memorial for Vietnam War soldiers. Her black marble walls meet in the shape of a V and are engraved with 57,939 names. Because the walls are shiny, they reflect back the living images of relatives and friends. Who was this inventive 21-year old woman?
2. In 1932, this “First Lady of the Air” became the first woman to fly solo across the Atlantic Ocean. Fifteen hours and nineteen minutes after she left Harbour Grace, Newfoundland, she landed her flame-shooting plane in a farmer’s field in Londonderry, Ireland. Who was this female aviator who calmly explained to onlookers, “I’ve come from America?”
3. In 1943, this U.S. Naval Reserve lieutenant served her country by working on the Navy’s “Computation Project” where she learned to program the world’s first large-scale digital computer. Her contributions are still felt today. The “compiler” and COBOL, a data processing language, are her inventions. Who is this computer pioneer who satisfied her curiosity as a child by disassembling alarm clocks?
4. Did you ever wonder who invented the square-bottomed paper bag? In 1870, “Mattie,” who had been always handy with tools, developed a paper folding device as well as other practical inventions like a window sash, a clasp for robes, and a shoe cutter. Who was this “woman Edison,” as biographers call her, registering 27 patents - more than any other woman of her time?
5. This Native-American explorer whose name means “Bird Woman” served as a guide to Lewis and Clark on their famous expedition to the western United States in 1804. She knew how to survive living off the land, making the difference between the expedition’s success and failure of reaching the Pacific coast. This female “Columbus” has been honored by having a river, a peak, and a mountain pass named after her. Who is the most memorialized woman explorer in American history and was, according to Clark, “the inspiration, the genius of the occasion?”
6. This largely self-educated astronomer from Nantucket, MA discovered a new comet in 1847, and a year later, became the first woman member of the American Academy of Arts and Sciences. A public school is named after her, as well as a crater on the moon. As a professor of astronomy, she taught her students the power of observation over sophisticated tools. Who was this “explorer of the Heavens” who, colleagues claim, didn’t even own a decent telescope?
7. This California dancer and free spirit greatly influenced dance expression in the early 1900s and established training schools for children in France, Germany, and Russia. Inspired by the art of Greece, she often danced barefoot, in loose, flowing tunics and with no scenery on-stage. Her training was classical ballet, her inspiration - nature. What modern dance pioneer imitated the passing clouds and the tumultuous sea all over the world, and set the stage for fresher, more personal ways to express ideas through movement?
8. She was the first American woman to watch sixteen sunrises and sixteen sunsets every twenty-four hours. How’s that? In June, 1983, this United States astronaut became the youngest flyer and the first American woman to rocket into space. For over six days, she served as the flight engineer for the space shuttle Challenger, launching and retrieving satellites. Who is this scientist who has been stargazing ever since she was a child?

Go Green, Everyone's Doing It!

It seems everywhere we look these days, it's "green!" Recycling and caring for our planet is all the rage. Let's hope this is one trend which doesn't come and go. The more good habits we learn now, the better our world will be in the long run.

Sometimes we think we can't make a difference, yet if everyone takes a few baby steps, it adds up in a big way. And it's fun to challenge ourselves to change a few habits at a time.

These few ideas can be done daily to help the environment at home, at school, and in our neighborhoods.

- 1. Take a five-minute shower instead of a bath to save up to 2,000 gallons of water a year in your home.
- 2. Turn off the water while brushing your teeth to save two gallons of water each time.
- 3. Stop buying bottled water - up to 40% of bottled water comes from the same source as tap water; it is simply sold back to consumers at hundreds of times the cost. Producing bottles to meet Americans' demand required more than 17 million barrels of oil last year; enough fuel for more than one million U.S. cars for a year. It generated more than 2.5 million tons of carbon dioxide. Billions of bottles end in landfills annually.

- 4. Pack school lunches in reusable bags and washable containers. Use a lunch box. Buy bandanas to use as napkins. The average person generates 4.5 pounds of trash daily. Think about the amount of packaging in a single serving container of yogurt or applesauce. How much time does it take to spoon applesauce into a plastic container? You'll save money, too, buying larger sizes versus individual servings.
- 5. Use cloth towels instead of paper towels. Hang up your bath towel to reuse.
- 6. Carpool.
- 7. Just say "no" to all the bags at grocery store checkouts. Keep reusable bags in the car for grocery shopping or use a tote bag.
- 8. Plant a tree. The average tree can absorb 48 pounds of carbon dioxide a year.
- 9. Plant a garden. Go organic. It's a great way to learn about caring for the earth and living organisms. Use native plants which are accustomed to your climate.
- 10. Start a compost pile. You can make your own fertilizer and reduce waste at the same time. Your garden will thank you.
- 11. Pick up any garbage left behind at the park or soccer field or while taking a walk.
- 12. Donate old clothes and toys to be used by someone else. The average American throws away 68 pounds of clothes and fabrics a year.

- 13. Donate books to a secondhand shop, used bookstore, or a school library. Continue the cycle. Buy secondhand products whenever possible.
 - 14. Turn off the TV and computer when they are not in use.
 - 15. Turn off the lights as you exit a room. (*Listen to your mother - you've heard it your entire life!*)
 - 16. Set up recycling bins for paper, aluminum cans, glass and plastic bottles at school and home. Paper accounts for 40% of solid waste in the United States, which is about 72 million tons annually. Recycling reduces the amount of waste in landfills.
 - 17. Recycle obsolete electronic items such as computers and TVs. Americans get rid of about 130 million mobile phones every year. That's about 65,000 tons of cell phones.
 - 18. Calculate your Carbon Footprint. Reduce your impact on the environment. A Carbon Footprint measures the impact our activities have in terms of the amount of greenhouse gases we produce. You can find several online calculators at sites such as www.carbonfund.org and www.carbonfootprint.com/calculator.
- Think about your effect on the environment. What can you do to protect it? Even the simplest of steps can be profound. We all have a role to play. All you have to do is start!

- 8. f. Sally Ride
- 7. g. Isadora Duncan
- 6. c. Maria Mitchell
- 5. d. Sacagawea
- 4. h. Margaret E. Knight
- 3. e. Rear Admiral Grace Murray Hopper
- 2. a. Amelia Earhart
- 1. d. Maya Ying Lin

Answers to American Women: From Adventure to Invention

- | | |
|------------|---------------|
| Soda | Cherry Pie |
| Napkins | Potato Salad |
| Sandwiches | Cups |
| Forks | Fried Chicken |
| Blanket | Cole Slaw |
| Apples | Watermelon |
| Tomatoes | Plates |
| Frisbee | Baked Beans |

Answers to Picnic Panic

Answer to Very Tricky Math
Did you get 5000? The correct answer is 4100. Don't believe it? Check it with your calculator. The decimal sequence confuses our brain which always jumps to the highest decimals (100s instead of 10s).

SEND US YOUR STORY!

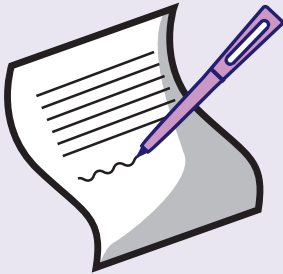
Be a part of the next issue of the Cool Kids Connection!

Share your thoughts, feelings, fears, experiences, and happiness. Our goal is to connect the pediatric oncology patients throughout the nation with each other. The Cool Kids Connection is published 4 times a year and sent to the hospitals. It is by you, for you, and about you! And we need YOU to make it happen. We are looking for articles, stories, poetry, drawings, photographs, puzzles, jokes, questions...anything you would like to share.

Please send your submissions by mail to:

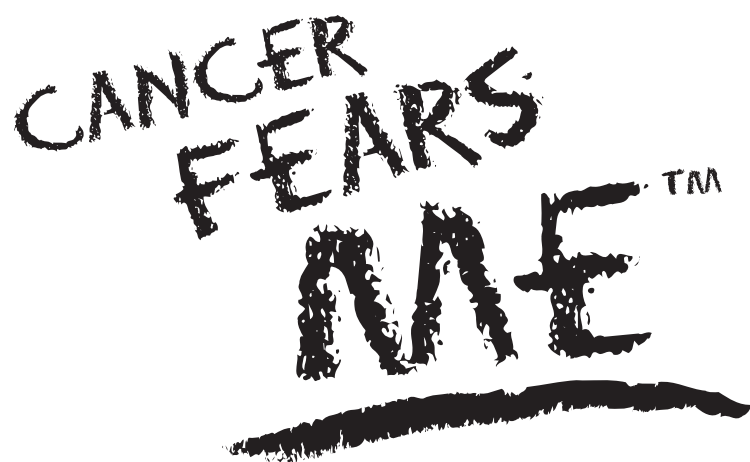
Cool Kids Campaign
9711 Monroe Street
Cockeysville, MD 21030

or email to sharon@bfpf.org



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For advertising information, please visit www.coolkidscampaign.org or email to sharon@bfpf.org



Cancer Fears Me and the Designated Patient Fundraising Program

How your family and friends can help raise money for you!

Show off your strong, positive attitude towards cancer!

Welcome to **Cancer Fears Me** - a strong, positive mindset for those living with cancer, their support groups and caregivers.

We know fear is a dominant emotion when someone is given a diagnosis of cancer. Cancer Fears Me turns that fear around and puts you in control.

Cancer Fears Me was born after years of working with families living with cancer and recognizing how much fear this terrible disease causes. How these invading cells try to take over our bodies and our life.

Whether you are the patient, a caregiver or part of the patient's support group of family and friends, you can show who is in control – YOU!

We have developed a line of merchandise and apparel with the Cancer Fears Me logo to help fund our programs for the Cool Kids Campaign, including the Cool Kids Connection.

BUT, Cancer Fears Me is also designed to directly benefit you.

Introducing, **Designated Patient Fundraising!** Through this program, your family, friends, school, anyone who supports your fight against cancer, can now sell the Cancer Fears Me gear and 25% of their sales will go directly back to you!



“ a strong, **positive** mindset
for those **living** with cancer,
their **support** groups
and caregivers ”



It's so easy. All you have to do is fill out a verification form that you are a current patient signed by an authorized personnel at your hospital. Then you will be registered with us and we will assign you a patient #. To get a verification form you can download one off our website or the Cancer Fears Me website or call us and we will send you one.

Then you or anyone you know can request the CFM catalog and order forms, hand them out to your supporters, have them place their orders with you as the designated patient, and we will send you a check for 25% of their sales.

Anyone can do this for you. And as many people as possible can do this for you. There is no limit on how much money will be sent to you and there are no restrictions on what you do with the money.

We know families living with cancer have many financial burdens. Cancer Fears Me is a way for you to directly raise money for yourself.

The remaining money is used to offset the costs of the items as well as helping the other families in need through the Cool Kids Campaign.

Anyone diagnosed with cancer is eligible, pediatric or adult oncology patients. And anyone can sell for you.

For more information or to get started with the Cancer Fears Me Designated Fundraising Program, contact Sharon Perfetti at 410.560.1770 or email at sharon@bfpf.org.

Check out our website www.cancerfearsme.org.

Cool Kids and Cool Caregivers

By Molly Lauryssens

Are you in the mood for some cabbage and ketchup or maybe some Chinese? When is the last time you read some poetry? Or how about played the card game Crazy 8's? It's summer, relaxation and fun are supposed to be in the air. It's a tall order, are you up for it? Take a moment to read what Cool Kid Ashley Lauro and Cool Caregiver Sue Kinney-Wieland like to do in their spare time as well as what they do day in and day out. In their own words, these two very special people get up close and personal with Cool Kids Connection.

Ashley Lauro

She likes old movies, cabbage and ketchup and enjoys reading poetry. She has many things in her life that she is grateful for. Ten-year old Ashley Lauro is from Roanoke, Va. and has got it going! Check out what things, she says, makes her such a Cool Kid.

What is your name? Ashley Lauro

Where do you live? Roanoke, Virginia

What grade are you in? 5th

How old are you? 10

Do you have any brothers or sisters, if so- what are their names and how old are they? Andrew, 15; Jerimiah, 17 months; Natalia, 3 weeks



What is your favorite subject in school? Science

If you were going to write a book what would it be about? Me having cancer (*acute lymphoblastic leukemia*) to let kids know what it is like.



What is your favorite food? Mashed potatoes & gravy

Do you have a BFF? Yes.

What is his/her name? Asia

Who is your favorite celebrity (sport or entertainer)?

Queen Latifah

What types of things do you like to do for exercise? Go for walks.

What qualities do you have that make you a Cool Kid? I am smart and friendly.

If you were the President of Whoville what would be your first act as the ruler? I'd make everything free.

Do you like dogs, cats, earthworms, birds? Chinchillas (check out www.chinchillaclub.com)

What is a chinchilla one might wonder? Read this excerpt from www.members.aol.com/sirchin/chininfo.htm: Chinchilla means "little chinta" a name given by the Indian tribes in their area. The chinchilla is from South America, more specifically in the countries of Argentina, Bolivia, Peru, and Chile in the high altitudes of the Andes Mountains. Their scientific name is *Chinchilla lanigera*, which means long-tailed chinchilla. Their class is Mammalia (*Mammals*), their order Rodentia (*Rodents*), and their family is called the Chinchillidae (*Chinchillas and Visachas*).

What is your favorite cereal? Trix

If you could be anything in the world, what would it be when you grow up and why? Veterinarian. I like animals.

What is your favorite movie? Pretty Woman (*Dirty Dancing is next up*), I like old movies.

Favorite television show? Baby Looney Tunes

Favorite video game to play? Mario Party

What is your favorite sport? Basketball

To watch? Do dance shows count?

What kind of music do you listen to? Hip hop, R&B.

Favorite Artist? Robin Thicke

What is your favorite fruit or vegetable? Cabbage and ketchup

If you were stranded on a deserted island, what three things would you like to have? Mashed potatoes and gravy, clothes and water

What are you most grateful for? Can name more than one thing. God, Grandma, Mom, Family, my home and all the things we have.

What is your favorite book? Favorite author? Falling Up by Shel Silverstein (*A book of poems*)

If you were one of the seven dwarfs, which one would you be? Why? Happy. There's no reason to be sad. I'm in remission and still going through chemo but when I'm done we are going on a Disney Cruise.

If you could meet and interview one famous person, who would it be and what is the first question you'd ask? Hannah Montana, What is it like being famous?

What things do you like to do in your spare time? Read, watch television and relax with my Mom.

Sue Kinney-Wieland

What is your name? Sue Kinney-Wieland

Where do you live? Omaha, Nebraska

What is your title? Peds Oncology Social Worker at Nebraska Medical Center.



What do you do? I get to meet kids who have been diagnosed with different kinds of cancer. Hopefully I help them and their families solve some of the problems that might arise because of their diagnosis.

What is your favorite thing about your job? Meeting new people from all different backgrounds.

Least favorite thing about your job? Paperwork

What time does your normal day start? About 9 a.m.

What is your favorite sport to watch? Soccer, soccer and more soccer.

To play? None!

Do you have any children of your own? Yes, we have 3. Our daughter is married. She and her husband live

in Lincoln, NE. They have a son named Max who is 10 months old. *(he might be the cutest grandchild in the whole world !!)* We also have two sons: one lives in Omaha and one lives in Chicago. They are all best friends.

What do you like to do for fun? Watch movies, get together with friends, listen to music, plant flowers, play with my grandson, spend time with my family, pretend like I can sing.

What is your favorite movie? Steel Magnolias

What is your favorite book? Right now anything by Jodi Picoult

What was your favorite subject growing up? English and Reading

Favorite cereal? I don't know if it's my favorite but I have it every morning – oatmeal !

Favorite dessert? Chocolate, chocolate, chocolate (has to be dark !)

Favorite kind of food? Chinese

Favorite board game? I'm embarrassed to say I haven't played a board game in a very long time.

Favorite card game? Crazy 8. Yes, there is a game called Crazy 8. I just finished playing it with someone who went through a stem cell transplant. I think she beat me seven games to two.

Cats or dogs? Love, love, love dogs. My favorite dog



was our dog, Tristin. He was a Black Lab. We had him for 13 years. There will never be another dog like him. We think he was part human!

Favorite celebrity? Jerry Seinfeld

Favorite season? Fall. I love the changing colors of the leaves and getting ready for winter.

If you could have dinner with one person, dead or alive, who would it be and why? I'd go out for dinner with the kids I see at work because they and their

families teach me lessons every day and remind me what is really important in life.

What is on your iPod? If you don't have one, what CD's are in your car right now? Right now on my iPod I have a little of Elton John, Harry Connick Jr., Bette Midler, Irish Tenors, and Celtic Women to name a few. I really need to update my iPod. Got any suggestions?

How often do we get to know our neighbors, really get to know them? Life is hectic and all too often we don't have the time to engage with one another.

So Cool Kids Connection is setting out to get to know you. After all, you provide us with some of the most inspirational and motivational stories. Don't be shy, we want to hear from you! Contact Sharon at sharon@bfpf.org if you would like to be interviewed for Cool Kids and Cool Caregivers for the next edition! Or of course, just send us your own article, artwork, photo or poem!

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