CHECK OUT What's Inside

2 - 3

An Uncle's Ultimate Gift

Cancer Fears Me

6-/

Cool Kids Trivia, Games & More

How A Walk Through Her Son's Cancer Transformed One Mother

A Note from Mya

12-13

Moving On... Another "New Normal!"

14-15

Cool Kids & Cool Caregivers



Connecting Pediatric Oncology Patients Throughout The Nation

I Play Music, NOT CANCER

By Michael C.

Tor most of my life, I've lived with only my mother. In grade school, Mom knew I would do well, so she expected me to do the best that I could. Along with my friends – who lived in similar situations – I learned how to work hard and use my natural talents to get to the top of the class. This was how our world went, and as we grew older, the challenges and expectations grew as well. We knew that college (still a long way off) was the ultimate goal of the educational system. I worked hard, not because I thought it would lead to more personal glory, but because I wanted to reflect the values instilled in me as a child.

I have been playing music as long as I can remember, whether singing in the car, playing in the middle school band, or recording in my basement studio. The idea that I can be successful in whatever I desire

has led me to do something which I dreamed of as a child – produce and record albums. At age 9, I wrote clarinet music; at 12, I wrote pieces for lone vocal and guitar. Now I enjoy arranging pieces with many different instruments. My achievement in music owes to the idea that I can achieve in anything I desire - even writing and producing whole albums of my songs.

On December 28, 2008, I first heard the word rhabdomyosarcoma.

A day earlier I had a biopsy of a mass behind my eye, and an MRI. During the first few days I was plagued by thoughts about my mortality, but by the first meeting with the oncologist (to whom I owe

my life), I was ready to start treatment and beat this unpleasant and metastatic development in my life. I had been able to do everything else I desired – why couldn't I beat cancer? The more time I spent caring for my health, the better I felt! To ease my distress during radiation, I had to spend much time with head and neck hygiene, and with chemotherapy came a barrage of important pills and medications. Even though my diagnosis wasn't optimal: stage IV metastatic alveolar rhabdomyosarcoma that had spread to the lymph node and bone marrow, by late April 2009, the tumor had shrunk so much that it didn't show up on the MRI.

Since that day in April, I've never had a doubt that if the cancer recurs, I can beat it again. If I get a secondary cancer – I know I can beat that, too! I fought cancer the same way I make music – by working at it and believing that nothing is impossible.

> I think I'm going to be making music for a long time.

> > Mike is in the 12th grade and plans to attend Carnegie Mellon to study computer science and music. He has been undergoing treatment for rhabdomyosarcoma at Johns Hopkins since the beginning of 2009. You can hear his music and download it for free from www.grenaders.info.

Mike on the field at the Raven's



The Cool Kids Connection is published quarterly by



9711 Monroe Street Cockeysville, MD 21030 1.866.979.1770 • 410.560.1770 Fax 410.560.1775

Editor/Cool Kids Co-Founder

Sharon Perfetti sharon@coolkidscampaign.org

Editor/Cool Kids Co-Founder
Kimmie Meissner

Advisor and MomJudy Meissner

Graphic Designer/Page Layout
Megan McClintock

Contributing Writers
Molly Lauryssens

Copy Editing

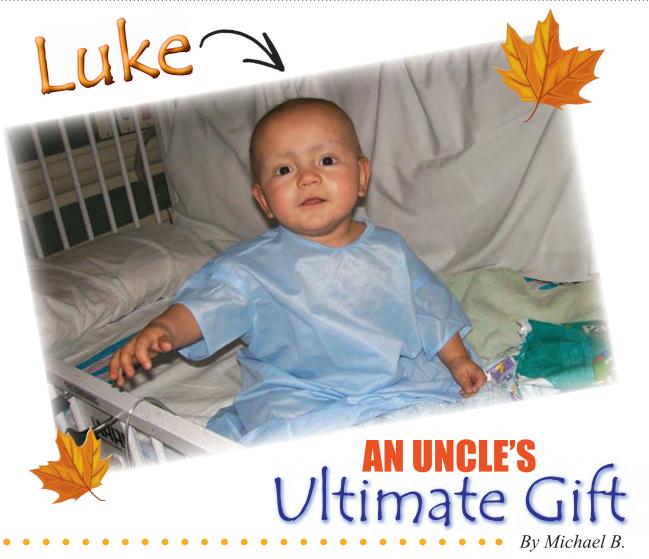
Suzanne Molino Singleton www.snippetsinspiration.com

COOL KIDS CAMPAIGN FOUNDERS

Chris Federico
Rob Belanger
Sharon Perfetti
Kimmie Meissner

The Cool Kids Campaign is a 501(c)3 non-profit devoted to improving the quality of life for pediatric oncology patients and their families

www.coolkidscampaign.org



"Can you say that again?"

I yelled into my cell phone, the wind blowing so hard it rocked my car. I strained to hear my mother

"Ben is not a match," she repeated. I was in the Target parking lot when my mom had called to relay that my brother-in-law Ben was not a match for my nephew Luke's imminent liver transplant.

I paused for a second. "Can I test to see if I'm a match?" I asked. I didn't know how much that call would change my life.

It was at Luke's 6-month "well baby" checkup that his doctor felt a hard area on his abdomen. My sister called our mother in shock as she took Luke to the Inova Loudoun Hospital for an ultrasound. That was a defining day in all of our lives. Luke had a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled for treatment and chemotherapy at Fairfax Hospital in Virginia, where he underwent four rounds of chemotherapy. He had a liver biopsy

and a central line placed into his chest to administer the drug. That was the first of many challenges and trials for this little boy.

Luke's tumor, it was discovered, was wrapped around a vessel on his liver. As he continued round after round of chemo, the tumor did not shrink or move away from the vessel as the doctors had hoped. Now it seemed that shrinking and removing the tumor was not an option; they would have to remove his entire liver to ensure they rid his body of the cancer.

Luke would need a new liver. Ben, Luke's dad and one of the kindest people I have ever met, immediately volunteered to donate a portion of his. It didn't surprise me. It was very difficult to hear this news. My family in Reno, Nevada lives far away from my sister and her family in the D.C. area. It seemed a million miles away and I felt powerless to help. Moreover, it seemed so unfair that such a tiny boy should have to go through so much.

As Luke's treatment progressed, my sister and I spoke often, talking more in those few months

than we had in the last 10 years. Luke became very ill during the chemo and it seemed cruel he had to experience it just to have a transplant anyway. I was so proud of my sister's strength and courage to fight this thing head on. If it had happened to my daughter – only eight months older – I might not have been able to handle it, yet I guess as a parent, you do what you have to do

Every time my sister and brother-in-law heard more bad news they turned to each other and their faith in God to confront each problem.

It was early November when I received the news that Ben was not a match and that they would have to find another donor. Using a donor meant one of two options: Luke would have to wait for an organ donor, a sad thing in itself because it meant someone else had to lose a loved one. There was also no guarantee one would arrive in time, nor a guarantee it would mesh. The other option was to find a living donor. I decided it was in my cards to do this for my sister and her family. I wanted to help and this was the way I could. As a blood relative, my liver had a better chance of not being rejected. I flew to Virginia early on Thanksgiving morning; it was the first time I had met Luke, and I held him that night for the first time. I looked at him in awe and had the feeling he was going to be very important someday.

I began the testing the next day, exhausting and painful, but the doctors and nurses at Georgetown were incredible and helped me to feel at ease. We were still waiting for an organ donor, which never seemed to come through. Finally, I was deemed as an excellent candidate to donate. The surgeon from the transplant team asked what day I wanted to donate; I told him the sooner the better and asked if it could be done that week. Everyone agreed that Friday, December 5 would be the best time.

In surgery, my last thoughts before sedation were with my wife and 19-month-old daughter back home in Reno.

Luke's surgeons were able to remove the entire tumor with the liver, but found the tumor had spread up the vena cava. It was very lucky they had decided to do the surgery earlier than expected; otherwise it may have been too late. Luke pulled through like the hero he is, but had to return the next day for more, which turned out okay as well.

I had been a soldier for over 10 years and a fitness trainer, so I had expected to recover quickly and return home within a week. I did not realize how difficult my recovery was going to be, much longer and more painful than I had anticipated. But I was persistent and pushed myself to get strong enough to leave the hospital so I could be home by Christmas. On my last day, I was able to visit Luke in the PICU. He was attached to so many machines and tubes it was dizzying, and had been placed in an artificial coma to keep his new liver stabilized. He had excess fluid in his lungs and the doctors struggled to strike a balance. Every time they tried to remove fluid, his blood pressure dropped to a dangerously low level. The doctors and nurses were incredible and worked diligently to get him stabilized and healthy.

Walking through the Transplant Center at Georgetown was an experience like no other; the children there are superheroes. I had such a feeling of admiration for their fearlessness and solidarity. I visited the hospital three more times before flying home and each time I became more and more in awe of these super heroes and their parents.

trips to the hospital, infections, and many medications to administer at home. I also had a few complications, which ensued in another hospital stay and a trip back to Georgetown. But I made it through – we both did.

I now feel a connection to Luke that I hope will remain for many years. He's too young to know it, but he probably helped me more than I helped him. I saw a strength I have never seen before – in my family, in the parents and children of PICU, in the other donors I met, and in myself. You never know how strong a person you are until you've been tested. It's amazing what you find out about yourself.

No one can do this alone. They call it battling cancer for a reason. I declared war the day I asked if I could potentially donate, and I helped Luke win one battle, yet there are many more out there.

I'm just getting started.

Luke is now an active little boy who is walking and talking and trying to keep up with his 5 year old brother. He also welcomed twin brothers in May!



4 COOL KIDS CONNECTION Fall 2009 www.coolkidscampaign.org



w.coolkidscampaign.org COOL KIDS CONNECTION Fall

The Baltimore Area Convention and Visitors Association is proud to support

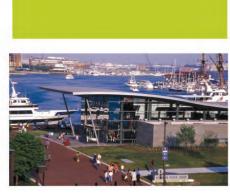


To discover all that Baltimore has to offer, call 1-877-BALTIMORE or visit www.baltimore.org.



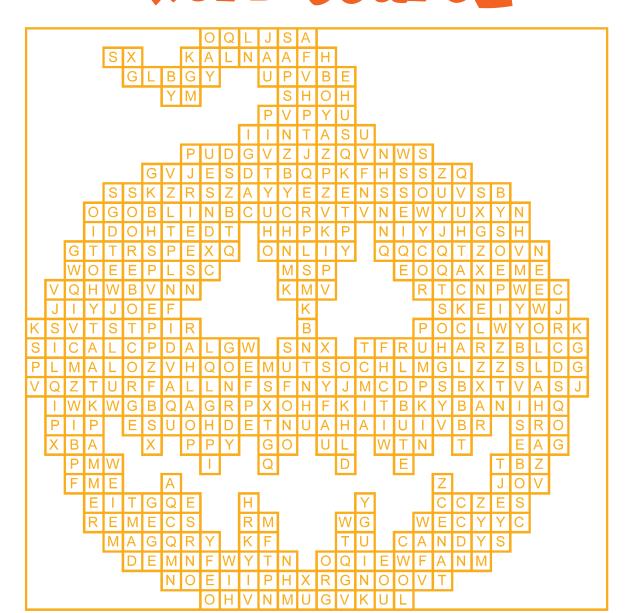








WORD SCARCE



GHOST BATS OCTOBER

WITCH **PUMPKIN GOBLIN**

HALLOWEEN COSTUME **FALL**

CANDY SPIDER

BLACK CAT

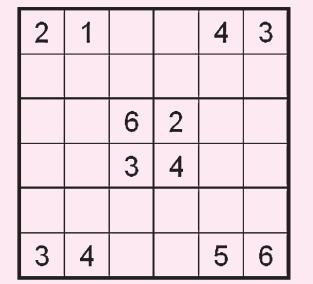
Answers on page 10

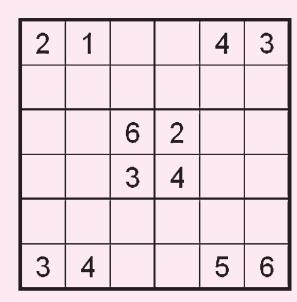


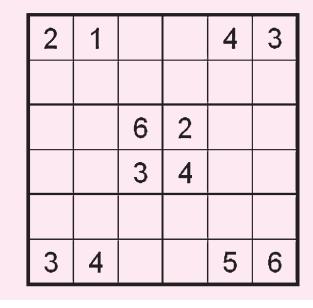
- Q. What has two hands but can't clap?
- A. A clock!
- Q. How do you tell when a clock is hungry?
- A. It goes back for seconds!
- Why did the clock scratch?
- Because it had ticks!
- Q. What happens when you annoy a clock?
- A. It gets ticked off!
- Q. What dog always knows the time?
- A. A watch dog!
- Q. What time is the best time to go
- A. Tooth-hirty!
- Q. Why did the girl sit on her watch?
- She wanted to be on time!
- Q. How do you know if your clock is crazy?
- A. It goes cuckoo!
- What did the digital clock say to the mother clock?
- A. Look Ma! No hands!
- Q. Why do you have to be careful at sun rise and sunset?
- A. Because day breaks and night falls!
- HAUNTED HOUSE Q. What time was it when the elephant sat on the clock?
 - A. Time to get a new clock!



Every row, column and mini-grid must contain the numbers 1 through 9.







If you can imagine it,



COOL KIDS CONNECTION Fall 2009 7

An amazing thing happens when you give to the community. It gives back.



At M&T Bank, we know how important it is to support those organizations that make our communities better places to live, work and grow. That's why we offer both our time and resources. What we all get in return is far more valuable.





HOW A WALK THROUGH HER SON'S CANCER



arch 8, 2008 had to be the longest day of my life. What began as a cheerful Sunday morning tickling my 7-year-old son, ended in utter disbelief. Trace had just recovered from the flu, and had been sleeping on the living room couch to be closer to our bedroom. He had complained of chest discomfort for several days, so I called the pediatrician. My only explanation for his discomfort was the fact that the flu had developed into pneumonia.

The doctor examined Trace and declared that everything was clear – ears, throat, lungs. However, he sensed my uneasiness regarding Trace's complaints. Another sign indicating something might be wrong was a prevalent abnormal-looking vein spanning from his heart to his left armpit.

"You don't seem settled with this exam," said the pediatrician. "You know your child far better than I do, so let's head over to the hospital to take X-rays."

Trace was finished in no time, and upon his release, the lab technician asked if Trace ever had any heart problems. I answered no without a second thought. No sooner did we walk into the house when the telephone rang; it was the doctor explaining that an abnormality had been revealed on one of the X-rays, with instructions to return to the hospital the following Monday for a CT scan.

Transformed One Mother

As my Mama Bear instinct kicked in, I demanded we immediately return to the hospital for the scan. I was not about to wait until Monday and was surely not going to allow my insurance company's prior approval take precedence over my baby!

The CT scan was extremely traumatic for Trace; the technicians demanded he lay completely still. However, every time he lay down, he began to gasp for air as if he were choking. My husband and I attributed this to stress and trauma. Finally, the scan was complete and as we headed to our car, my cell phone rang – it was our pediatrician. Trace had a tumor the size of a baseball in front of his heart, pushing on his airway and compromising his oxygen supply.

He said he would make arrangements with A.I. DuPont Hospital in Wilmington, Delaware, to have Trace admitted to the emergency room immediately. I was stunned, dumbfounded, and scared beyond belief, and yet I had to maintain my composure to ensure I did not project my feelings and emotions onto my son. The two-hour drive was full of apprehension, anger, doubt, disbelief, stress, and an undeniable amount of sadness because of the unknown.

One year and five months has transpired

seizures, rashes, emotional breakdowns, and anger outbursts. At the same time, we have grown stronger spiritually, have learned to cherish each and every memory as simple as it may be, have found joy in the midst of pain, have learned to be transparent with others when it comes to needs, and have grown to be better parents.

Having our lives turned completely upside down within a matter of hours was traumatic for our entire family. As a type "A" personality, I try to run the household with structure and organization. The first thing I was forced to come to grips with is that my calendar, structure, and planned events had to be set aside immediately. There was no event more important than the well-being and care of my son. I resigned from my job as a seventh- and eighth-grade Language Arts and History teacher to be at my son's bedside 24 hours a day. I did not have a choice in the matter. I had to let go and allow individuals to come into my classroom. The school's principal and the pastor of the affiliated church offered to continue teaching for me.

As a mother, I share this because others in similar situations need to know it's okay to let everything else take the back burner. I found it extremely difficult to walk away from the career I dearly love, but I am thankful for those in my

I was stunned, dumbfounded, and scared beyond belief, and yet I had to maintain my composure to ensure I did not project my feelings and emotions onto my son.

since that emotionally charged day. The journey has been long and tiresome, but the battle is being valiantly fought and our mighty warrior is winning! Trace was diagnosed a few days after his biopsy with non-Hodgkin's T-cell lymphoblastic lymphoma. His treatment protocol spans for two years and he has seven months left of chemotherapy and steroids. We have endured high and low counts, infections,

life who stepped up to the plate to meet the needs of my students. I realize I was blessed beyond belief to have that kind of support system in my workplace. In addition, it made more sense financially for my husband to continue working while I became the primary caregiver. Every situation is different for every family, but the important message here is to "let go" and allow others to become your support system.

In addition to letting go of my career, I had to become vocal with the needs of my family. Once again, my independent personality struggled with this concept. I received more e-mails, phone calls, and text messages than you can imagine from people wanting to help in some way. There were offers to watch our 5-year-old son while I was at the hospital and my husband at work, dinner offers, housecleaning, errand running, dog sitting, and laundry. I was overwhelmed by people willing to assist our family; I had become so accustomed to doing everything myself. I repeatedly told everyone we were fine, but the offers did not stop. It finally hit me – people just wanted to feel needed and know they are making a difference. So I allowed friends to clean my house and do the laundry. All kinds of people babysat for us and stopped by to let our dogs outside. When we arrived home, I didn't have to cook for a month because dinner arrived at least three nights a week.

Looking back, the lesson I learned was to fulfill the desires of others and allow them to fill a need. Now, I don't hesitate to ask friends or family for help when I need it the most. More importantly, I learned that those who love me the most want to express their love in many different ways.

More than anything else is my growth throughout this entire ordeal. My advice to anyone faced with adversity of any kind is to open your heart, listen intently to those around you, and never compromise your morals and beliefs. In the process, you may grow personally and spiritually into a new person. Although this may not be easy for some to comprehend, I never compromised on my morals and beliefs and remained continually and constantly comforted. Wherever you find comfort, seek that place and remain still to sort out the flood of emotions inside of you.

My last bit of wisdom deals directly with my role as a parent. Becoming a better parent as a result of this ordeal did not come easily at the beginning of the roller coaster ride. I had to first realize and begin believing that what was happening to my son was no fault of my own. As parents, I believe we have an instinct to automatically take ownership of whatever happens to our children – we feel completely responsible. Taking the time to work through the process of understanding that this situation was

100% completely out of my control was the first step in my growth as a better parent. At first, I wanted to analyze the things we had exposed our child to, in hopes of figuring out the cause of the cancer. I have to be honest – these hours were wasted moments I could have put to better use.

Once I stopped dwelling on the reasons, I concentrated on simply making memories with my son – playing Uno, completing word puzzles, watching movies, reading "Get Well" cards, building Legos, teasing the nurses, and playing catch in the waiting area, were things I could focus on. Would I have rather been home with a healthy child doing nothing? Absolutely! But, making these simplistic memories were a huge part of the healing process for me as a parent.

There are so many other lessons I have learned in being forced to deal with the unexpected, and I look forward to the new lessons I am sure to learn in the remaining months of this journey. As

a family, we are learning to live again with a sense of normalcy in our household. We simply take one day at a time and deal with every situation the best way we know how. Yes, some days are far better than others! We believe that after every storm, God provides a rainbow. In December, Trace will once again become a big brother, making him the oldest of three boys. This just goes to show you that rainbows come in many forms!

Blessings and love to all.

Trace is being treated at AI DuPont Children's Hospital/Nemours in Wilmington, Delaware. He is expected to have a 100% full recovery and his last treatment is scheduled for March of 2010. He decided to return to school this year and is in the 4th grade at Salisbury Christian School in Salisbury, Maryland.



COOL KIDS CONNECTION Fall 2009 9



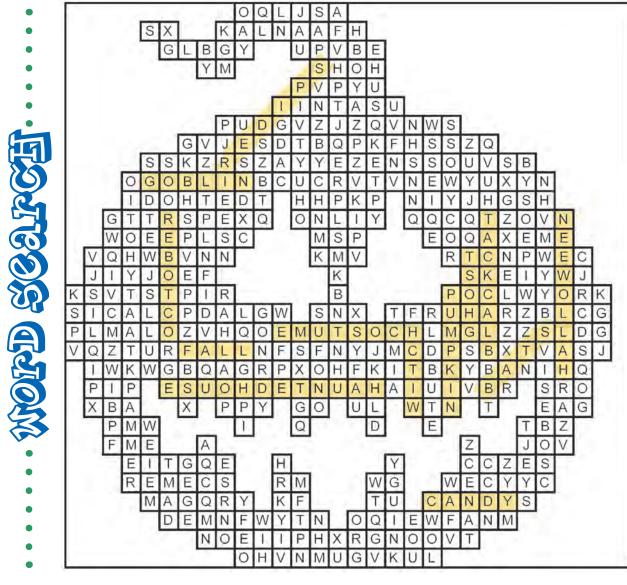
10 COOL KIDS CONNECTION Fall 2009 www.coolkidscampaign.org COOL KIDS CONNECTION Fall 2009 11 www.coolkidscampaign.org

3 5 6

5	6	1	2	4	5	3
	4	3	5	6	1	2
0	5	2	6	1	3	4
A	3	4	1	2	6	5
13	1	5	4	3	2	6
SS.	2	6	3	5	4	1

5	2	1	6	4	3
6	4	က	2	5	1
3	1	4	5	6	2
2	5	6	1	3	4
4	6	2	3	1	5
1	3	5	4	2	6

Games, Trivia & More ANSWERS



Share Your Passion & donate

to our cause with your everyday purchases.

We've partnered with Capital One® Card Lab Connect to bring you our newest fundraising program, which helps us earn money effortlessly every day!

Just carry one of our custom credit cards (it comes with a competitive rate and no annual fee), and 1% of purchases made with the card will be donated to our organization. We'll also receive a \$25 bonus donation when you make your first purchase. And not only will you be donating to our cause with each purchase you make, you'll be helping to spread the word when people see your unique card, designed specifically for our organization.



Hi my name is Mya

I am 7 years old and I have cancer. In 2007 I found out that I had Lymphoma and then this August I was told I now have Leukemia. I will transfer from the Valerie Fund at Monmouth Medical Center in New Jersey to the Childrens Hospital of Philadelphia (CHOP) in Pennsylvania, as soon as they find me a bone marrow donor.

While I was waiting, I found this thing called oovoo. It is a free website that allows you to video teleconference anyone. The site is http://www.oovoo.com It seems kind of cool being on a camera talking to your friends while I am in the hospital and they are home. I have a computer in my hospital room, that has a webcam and Internet. That is all you need to use it. You can talk to six people at the same time.

I think it is a great site for kids with cancer, since many times we can't leave the hospital, and sometimes we can't have our friends visit either. But I am always able to talk to them and even see them using my computer. My mom also likes it, because anyone that wants to talk to me on Oovoo has to send her an email first and ask if they can be added to my contact list. Only people in my contact list can see and talk to me on Oovoo. You should try it!

Mya Terry Oakhurst, NJ

Send us YOUR Story!

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

> Please send your submissions by mail to:

Cool Kids Campaign 9711 Monroe Street Cockeysville, MD 21030

or email to sharon@bfpf.org

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 include all of your contact information and a photo of yourself if possible. Please send only original art - we cannot use any copyrighted material. All submissions become property of the Cool Kids Campaign. This publication is offered free of charge to oncology hospitals and their patients. Funding is received through sponsors and advertisers.

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

12 COOL KIDS CONNECTION Fall 2009 COOL KIDS CONNECTION Fall 2009 13 www.coolkidscampaign.org www.coolkidscampaign.org

MOVING ON... ANOTHER "New Normal!"

omewhere in the beginning of this, well let's call it a journey, I remember a lot of people telling us that we would get used to this "new normal" life. And indeed, a new normal it was. Our "normal" lives included 11 hospital admissions, countless trips to clinic, hair loss, many, many medications (some I still can't even pronounce), a port-a-cath, blood and platelet transfusions, endless medical bills, lots of emergency room visits, then throw in a little worry and fear... and this was our "new normal." Yet, somehow we did adjust to our life as being parents of a daughter with Leukemia. In fact, we dove in feet first. We researched and read, joined a support group, started a team to walk for Leukemia, supported other pediatric oncology groups, we made new friends, and tried along the way to make Emily's life as "normal" as possible. Our family went through 26 months of what most parents consider their worst nightmare. Then just like that it ends...

Our journey began on June 8th, 2007. We had noticed for several weeks that things were just not right with Emily. She was only 5 years old, but was constantly tired, pale, and in the final week she began limping. After extensive leg x-rays, it was the blood tests (looking for what we were thinking could be Lyme's disease) that confirmed the devastating news. The diagnosis was Acute Lymphoblastic Leukemia. As the weeks stretched on, we were told of her exact kind of cancer, and we were relieved to find out that she was considered low-risk, making her chance of relapse in the smallest category. However, all cancer families know there is no number that defines our child. For us it is either 100% or 0 that really matters.

The first 8 months were the hardest. It was absolutely heart-wrenching to watch Emily go through chemo and its side-effects. Our family tried to keep as positive about it as we could. After all, being angry or resentful would benefit no one. When Emily finally began the maintenance phase of treatment allowing her to return to



challenges to be faced. School was a balancing act, and Emily was sick frequently. Being immune-suppressed from the chemo, left her at risk for infections. The transition was emotional as well, she could tell even in Kindergarten that she was different from the rest of the kids. having hardly any hair certainly didn't help. We made the best out of the remaining year and a half, though we found it almost impossible to plan things as we never knew if she was going to feel well enough to attend whatever plans we had made. Even traveling often became a source of frustration, most of the time Emily would end up running a fever, and we would be in search of the closest ER. Through it all, we kept telling

part was over. However, there were still many

As a family, we decided on celebrating the end of this milestone with a party. We felt it was the best way to thank our supportive group for their love and help they had unconditionally given us. Emily chose a pool party, and over 100 friends

ourselves that it would all be over soon enough,

and we could hardly believe the moment when

it was time to start counting down the final days

until the end of chemo.

and family joined us to commemorate the end of her chemotherapy. Gone would be the days of lumbar punctures, medicine, and frequent hospital stays. It seemed almost too good to be

Emily has taken this new chapter in her life, just as in stride as all the others. She seems neither happy or sad that it is over. Through it all, getting her to share her emotions and feelings has always been a challenge. I sometimes even feel that she actually doesn't quite get the fact that it really is over. The morning of her one month post-treatment check-up, she asked me if she had to start taking steroids that day (usually part of the normal monthly cycle of her medicine schedule). I had to remind her that she was all done with medicine! She is also fearful to have her port removed. It has become like a friend to her, saving her from what would have been countless needle sticks. Emily has also expressed her concern over missing her doctor and nurse, who she has become very fond of. We reassured her that over the next year, she would still go to clinic for check ups, and that having her port removed really is for the best.

Where does this leave us, her parents? The feelings are mixed, there is relief, joy, and there is also the strange feeling like something is missing. It is almost like the feeling you have the day after Christmas. You spend so much time preparing and stressing over details, and then when it is over there is a feeling of bewilderment, or the feeling of being a little lost. We also have a little feeling of worry. Every bruise, illness, or leg pain will probably always arise concern and suspicion. Gone for us is the carefree ability to chalk up these regular-type symptoms to normal childhood issues.

Another aspect is the need to keep a close eye on Emily's progress at school. During Kindergarten and First grade she almost missed more time in school then what she actually attended. She will probably need a little extra help from a tutor in math, where she shows the biggest gap in her academic progress. We also will pay close attention to her social skills and developmental progress. Whether we could help it or not, she has become a little too accustomed to getting what she wants, when she wants it!

Already we have seen a remarkable difference in Emily's energy level. And more fascinating is her strong feeling and desire to put it all behind her. On one of the first days of school this year, her teacher had asked the children to fill a bag with things on a checklist. One of the items was to represent a very important event in their lives. I suggested to Emily to bring in a picture of her in the hospital, or something that she could use to share her story of surviving cancer. "No way," she said, "I don't want them to know about that!" So we must respect her feelings, realizing that even at 8 years old, all people handle their emotions differently. It seems Emily is really ready to move on!

Our long-term goal as a family is to continue to support the organizations out there that help make life a little better for families of cancer patients. It is very motivating to see the many foundations that are out there that have been started by families whose lives have been touched by cancer. This "pay-it-forward" attitude is inspiring, and I imagine very cathartic to families like us. I hope to never forget where we have come from, and use that feeling to put something positive on what was a deeply emotional and trying time for all of us.

Through the last two years we have been told how strong we are, and how well we handled all of this. Meeting so many other oncology families, I believe we are ALL strong-we have no choice! We have no idea what the future holds for us, especially Emily. We can only hope that she stays in remission forever. We can only hope that one day a cure is found so that no child must give up some, or all of their

childhood. As the 26 months drew to an end, we knew that she certainly couldn't stay on chemo forever. Though taking her off chemo meant a new worry. This is a new stage in our lives with Emily, who is now a cancer survivor. We must realize that the time has come to see her as that. It is like pushing the baby bird out of the nest to see if she can fly on her own. Knowing our little bird, we just know she can do it!

Those who dare to fail miserably can achieve greatly.



maintain our earth through the use of Green Seal Certified® housecleaning chemicals, HEPA vacuums, and microfibers. The Cleaning Authority not only wants homeowners to feel good about their clean home, but also about the home they have helped protect by using an environmentally responsible company.

EXPERIENCE THE CLEANING AUTHORITY DIFFERENCE, CALL TODAY FOR A FREE ESTIMATE:

866-827-0062 Visit us Online at www.TheCleaningAuthority.com

14 COOL KIDS CONNECTION Fall 2009 www.coolkidscampaign.org COOL KIDS CONNECTION Fall 2009 15 www.coolkidscampaign.org

Cool Kids AND Cool Caregivers

It's no wonder four-year old Brooke Mulford of Salisbury, MD wants to be a Child Life specialist someday. After seeing what these cool caregivers- Ashley Kane and Michelle Hoffman-share about what they do, who can blame her? Thing is, Kane and Hoffman seem to get their inspiration and motivation from people just like Brooke. So without further ado, check out this installment of Cool Kids/Cool Caregivers and you'll see just how cool these participants really are.



Where do you live? Elysburg, PA - home of Knoebel's Amusement Resort!

What is your title? Certified Child Life Specialist

What do you do? I work in the outpatient pediatric hematology/oncology clinic. My job is to support our patients and families during their clinic appointments. Sometimes, my job involves lots of play-video games, board games, arts & crafts, and lots more. Other times, my job is to help to explain everything that is happening in clinic whether it's about your diagnosis or about tests, procedures, or treatments that you might need. It's my job to make your appointment a little better!

What's the most favorite thing about your job? Besides helping kids have fun during clinic appointments, one of my favorite things to do is to help kids get through something they are really afraid of. It's definitely OK to be scared, and it's even OK to cry, but it's my job to help kids be a little less afraid and realize just how brave they really are!! I love when kids can say "Wow! I did it!" It makes me feel great!

Least favorite thing about your job? I don't like seeing anyone have to get needles...I wish there was a better "needle-free" way of doing things but until that day comes, I just remember that my job is to help make the needles a little easier.

What time does your normal day start? 8am

What is your favorite sport to watch? I like to watch baseball and football the most, but I also really like to watch the Olympic games because there are so many sports that you don't get to see everyday!

Play? My favorite sport to participate in is swimming-I swam on a team since elementary school! It's a great workout and tons of fun. I especially like relay races because you get to swim with your teammates!

What do you like to do for fun? I enjoy shopping, photography, and exercising in my free time. I also have a rescued Cocker Spaniel named Freckles and a miniature lop rabbit named Baylee who keep me busy. I am getting my Master's degree which means that I am also a student and go to class (and I even have homework!). I encourage the kids who are reading the Cool Kids Connection to get involved and rely on support. I volunteer at summer camps for kids with special healthcare needs and diagnoses, and I help to coordinate a group for teenage oncology patients called Keymo Teenz. The group gets together to go rock climbing, to the movies, or to an amusement park to just spend time together since everyone has been through similar experiences.

What is your favorite movie? I have lots of favorite movies but one movie that always makes me laugh is Madagascar! I especially like the scenes where all of the jungle animals dance!

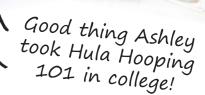
What is your favorite book? Riding the Bus with My Sister by Rachel Simon. I like the Harry Potter movies but the books are just too many pages for me!! What was your favorite subject in school growing up? Science, especially biology-even though it was a lot of new information to learn!! **Favorite thing for breakfast?** French toast

If you were stranded on a deserted island, what three things would you wish you had? 1. Someone to keep me company!! 2. A radio or some music so that I could dance around or sing 3. Because I don't really like seafood, I would need some kind of food...an unlimited supply of pizza or burgers would be great! If you could have dinner with one person, who would it be and why? There would be a big toss up between the Genie from Aladdin because he could grant me three wishes OR Jack Black because he's a great actor and extremely funny! I might have to draw straws to choose!

What kind of music do you like? I like all kinds of music because the patients I work with listen to such different music. I can go from listening to Hannah Montana, to the Jonas Brothers, to country music stars, or just the popular music on the radio! My iPod is a mix of everything but I really like Jason Mraz and the Dave Matthews Band.

Do you have children? No but maybe someday!







Where do you live? Salisbury, MD

What grade are you in? Pre-K 4year olds

How old are you? 4

What is your favorite subject in school? Playing games & Arts & Crafts

If you were going to write a book what would it be about? Puppies

What is vour favorite food? Salmon, steak & scallops

Do you have a BFF? Jordan & Greyson

Who is your favorite celebrity (sport or entertainer)? Air Bud

What types of things do you like to do for exercise? Yoga, soccer, walk my puppy

What qualities do you have that make you a Cool Kid? I'm nice and fun.

If you were the President of Whoville what would be your first act as the ruler? To help them.

Do you like dogs, cats, earthworms, birds? I like dogs (my dogs name is Bailey), cats (I had a cat named

Lulu) & birds- (Mommy & I feed lots of birds in our backyard)

What is your favorite cereal? Cinnamon Life

If you could be anything in the world, what would you be when you grow up? To be a nurse or a child life specialist or work with my Mommy.

What is your favorite movie? Hotel For Dogs

Favorite television show? Special Agent Oso & Wipeout

What is your favorite video game to play? Super Princess Peach & Mario Party on Nintendo D S

What is your favorite sport to Play? Soccer & baseball To Watch? Soccer

What kind of music do you listen to? My Songs of Love song written for me, James Taylor & reggae music

Do you have any brothers or sisters? No

What is your favorite fruit or vegetable? Avocados & strawberries

If you were stranded on a deserted island, what three things would you like to have? My blankie,

A Littlest Pet Shop, my Lulu kitty (stuffed animal)

What are you most grateful for? My Mommy & Daddy and my friends.

What is your favorite book? Curious George Goes to the Hospital

Favorite author? Karma Wilson





Where do you live? Fort Wayne, IN

What is your title? Pediatric Outpatient Clinic Social Worker

What do you do? I meet with all patients and families when kids are newly diagnosed with cancer and then on an ongoing basis for when they have questions or needs during clinic appointments and hospitalizations. I meet with them to provide support and discuss resources, making referrals when appropriate. Some of the other things I assist families with are financial/ insurance problems, emotional issues, discharge planning and school concerns.

What is the most favorite thing about your joh? Celebrating big and small things with our kids (off-chemo parties, good reports, holidays, etc.) and going to their schools for school talks when they are ready to transition back to school. **Least favorite thing about your job?** Dealing with difficult policies, insurance companies and agencies. I get frustrated when there aren't enough resources to help the patients and families who need them most. I often wish I had a magic wand! What time does your normal day start? 8:00am on Mondays and Fridays when we have morning report, 8:30 on the others since I often have to stay late.

What is your favorite sport to watch? OSU football since I grew up in Ohio- go Bucks! Play? Running and biking What do you like to do for fun? I like to hang out with my husband/family and friends, cook, read, volunteer and do outside

What is your favorite movie? My favorite Disney movies are-"Beauty and the Beast" and "101 Dalmatians." What is your favorite book? I read so much it's hard to pick one, but two good books I just read this summer were "The Shack" and "My Sister's Keeper."

What was your favorite subject in school growing up? History

Favorite thing for breakfast? Waffles with fruit and sausage

If you were stranded on a deserted island, what three things would you wish you had? running shoes, Bible and chapstick If you could have dinner with one person, who would it be and why? President Obama since we're at the brink of so much reform and I think he's an inspiring leader. Like most of America, I'd like to hear more about his health care policy proposals. What kind of music do you like? all different kinds- some of my favorites currently on my Ipod are: David Crowder Band, U2, Matt Wertz, Coldplay, Jon McLaughlin and Metavari.

Do you have children? not yet

www.coolkidscampaign.org COOL KIDS CONNECTION Fall 2009 16

