Connecting Pediatric Oncology Patients Throughout The Nation

I Play Music, NOT CANCER

By Michael C.

For 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 Game!
Ben, Luke's dad and I, yelled into our cell phones, the wind blowing so hard it rocked our car. I strained to hear my mother. “Ben is not a match,” she repeated. I was in such shock that I couldn’t even cry. My sister called our mother in shock as she took Luke to the hospital. I felt powerless to help. Moreover, it seemed like a million miles away to the D.C. area. It seemed a million miles away to the children far away from my sister and her family in Virginia. I felt like a spectator to a tragedy that was a world away. There was nothing I could do to help them rid his body of the cancer.

By Michael B.

AN UNCLE’S ULTIMATE GIFT

I talked to my husband and I felt so angry and I felt so helpless. I couldn’t even cry. I didn’t know how much that 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 to have a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled to have a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled to have a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled to have a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled to have a large tumor on his liver, later diagnosed as hepatoblastoma. He was immediately scheduled to have a large tumor on his liver, later diagnosed as hepatoblastoma. 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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.

Show off your strong, positive attitude towards cancer!

Check out our website at www.cancerfearsme.org.

Check out our Cancer Fears Me video on You Tube! Just search for Cancer Fears Me!
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.

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**WORD SEARCH**

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

**SUDOKU**

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

If you can imagine it, you can achieve it; If you can dream it, you can become it.

- William Arthur Ward

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**GHOST**

**WITCH**

**HALLOWEEN**

**CANDY**

**HAUNTED HOUSE**

**BLACK CAT**

**OCTOBER**

**PUMPKIN**

**GOBLIN**

**FALL**

Answers on page 10

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**M&T Bank**

Understanding what's important!

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.
March 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 anxiety regarding Trace’s complaints. Another sign indicating something might be wrong was a prevalent abnormal-looking vein spanning from his heart to his left arm pit.

“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.”

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 his heart to his left armpit. 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 was finished in no time, and upon his return, the lab technician asked if Trace ever received chemotherapy. “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.”

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!

In addition to letting go of my control, I had to become comfortable with the needs of my family. Once again, my independence 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, running dog, doing laundry, and 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. 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 hesitiate 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. 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, causing the nurses, and playing catch in the waiting area, were things I could focus on. Would I rather have 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! My advice is to 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 DuPont Children’s Hospital/Neonate 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.
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.

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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
somewhere 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 more. You couldn’t even pronounce, a ports-a-cath, blood and platelet transfusions, endless medical bills, lots of emergency room visits, then there it is 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. That just like that ended.

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 100% or 0 that really matters.

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 relief/relief, or the feeling of being a little last. 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 it up to being kids or flu-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 than what she actually attended. She will probably need a little extra help with her reading/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. She thought about it for a little while, and told me if she had to start taking steroids that day and after much thought decided to bring in a picture of herself before chemo and her port removed really is for the best.

We have come from, and use that feeling to move on! That!” So we must respect her feelings, realizing 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 this is just the beginning. 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! 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.

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Those who dare to fall miserably can achieve greatly. – John F. Kennedy

COOL KIDS CONNECTION  Fall 2009  www.coolkidscampaign.org

MOVING ON... ANOTHER New Normal! By Lisa G.

A CLEAN HOME.

CALL TODAY FOR A FREE ESTIMATE:
www.TheCleaningAuthority.com

The Cleaning Authority provides top-quality house cleaning to homeowners. We help keep homes clean and happy through the use of Green Seal Certified® housecleaning chemicals, HEPA vacuums, and microfiber cloth. The Cleaning Authority not only wants to make your home feel good about their clean home, but also about the home they have helped protect by using an environmentally responsible company.
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? Things is, Kane and Hoffman (and their colleagues) go to part in inspiration and motivation from music 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.

Ashley Kane

Where do you work? Flying, 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 tests, treatments, or procedures that you might need. It’s my job to help to make a clinic 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 say “no, but it’s my job to help to make a clinic appointment a little easier.
What would you do for fun? I enjoy shopping, photography, and exercising in my free time. I also have a rescued Cocker Spaniel named Freckles and a kitty (stuffed animal) named Lulu. I love to dance, sing, and go to sporting events!
What is your favorite food? I don’t really like any specific food...an unlimited supply of pizza or burgers would be great!
If you were stranded on a deserted island, what three things would you wish you had? I would need some kind of food...an unlimited supply of pizza or burgers would be great! I might have to draw straws to choose!

Michelle Hoffman

Where do you work? Elysburg, PA - home of Knoebel's Amusement Resort!
What is your title? Certified Child Life Specialist
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, make 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 your favorite sport to watch? Baseball and football the most, but I also really like watching the Olympic games because there are so many sports that you don’t get to see everyday!
What is your favorite book? Curious George Goes to the Hospital
What is your favorite subject in school? I enjoy all different kinds- some of my favorites currently on my Ipod are: David Crowder Band, 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 Kenny Chesney.
What is your favorite sport to Play? Running and biking
What is your favorite color? I’m nice and fun.
What is your favorite fruit or vegetable? I like dogs (my dog’s name is Bailey), cats (I had a cat named Jake), and I find lots of birds in my backyard.
What is your favorite cereal? Cinnamon Life
What is your favorite TV show? Superstition Peach & Mario Party on Nintendo D S
What is your favorite sport to play? Soccer & baseball
What is your favorite movie? Hotel For Dogs
What is your favorite snack? Cinnamon Life
What is your favorite author? Karma Wilson
What do you do for fun? I like to hang out with my husband/family and friends, cook, read, volunteer and do outside arts & crafts.
What is your favorite color? My favorite Disney movies are “Beauty and the Beast” and “101 Dalmations.”
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 is your favorite subject in school growing up? My favorite thing for breakfast was Waffles with fruit and sausage...
What qualities do you have that make you a Cool Kid? I'm nice and fun.
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