

## Check it out... INSIDE!

**The Torino Classroom**  
page 2

**Surviving & Thriving**  
page 4

**Jesse's  
Continuing Journey**  
page 6

**Mykel' Story**  
page 7

**Samuel's Story**  
page 8

**Cool Kids  
Activities**  
page 10

**Cancer Fears Me™**  
page 13

**Cool Kids and  
Cool Caregivers**  
page 14

# COOL KIDS Connection™

Connecting pediatric oncology patients throughout the nation.

## Looking Back

By Olivia Lanman

When I was 10, my 8 year old brother, Ben, was diagnosed with Ewings Sarcoma. When he first started complaining of pain I thought he was exaggerating because the doctors couldn't find anything wrong on the x-rays. An MRI finally revealed that something was there. A biopsy told us that that something was cancer. I was really scared because I thought I might lose my brother. In the end he was fine, but it took a lot of hospital trips, patience and prayer. Without even one of those things he wouldn't be the happy, healthy, annoying little brother he is today.

Looking back now, that was a hard time to go through, but it taught me a lot. It taught me to appreciate every moment of life and not to take anything for granted. It taught me not to sweat the small stuff and to never give up. I realized how much I loved and needed my brother and that, even though we fight, we belong together.

School was my escape, my place to get away from it all. There I could be just plain Olivia. I wasn't just Ben's sister. (At least not to my friends.) It really aggravated me when people would come up to me and I would be expecting a conversation, but they would say, "Hey Liv, how's Ben? How's his chemo going? When does his

body cast come off?" (He had a body cast on for 3 months after his hip was removed.) It was like I wasn't even there. They'd look right past me and center the conversation around Ben. It frustrated me at the time, but now I understand that they were just trying to be thoughtful. I felt guilty because I thought I was acting selfish, but my mom told me I shouldn't feel that way, that I deserve peoples' attention too.

It also bugged both me and Ben when people would stare and look at him with pity. Sure, they saw a pale, bald, little boy in a body cast and a reclining wheelchair, but there was so much more to him than that. We didn't feel sorry for him and he didn't feel sorry for himself, so why should they? People should just smile and say hello.

Now, three years later, Ben is 11. He can do everything any 11 year old boy can do. I could tell you that he is back to being his normal, annoying self but, truth is, he never really stopped.

If I had to give advice to other kids who have a brother or sister with cancer I would say: Stay strong in your faith and trust that whatever you're going through is part of God's plan. You are exactly where you're supposed to be.



*Olivia is now 13 and in 8th grade. Her brother Ben is a healthy 11 year old and was treated at Johns Hopkins hospital in Baltimore, MD.*



The Cool Kids Connection is published quarterly by



9711 Monroe Street  
Cockeysville, MD 21030  
410.560.1770 • Fax 410.560.1775

Editor/Cool Kids Co-Founder  
Sharon Perfetti  
sharon@bfpf.org

Editor/Cool Kids Co-Founder  
Kimmie Meissner

Advisor and Mom  
Judy Meissner

Graphics & Layout  
John Eiben

Contributing Writers  
Molly Lauryssens  
Kelli Anders

Copy Editing  
Suzanne Molino Singleton  
www.suzannesingleton.com

#### COOL KIDS CAMPAIGN FOUNDERS

Chris Federico

Rob Belanger

Sharon Perfetti

*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](http://www.coolkidscampaign.org)



Lenny Ware

## THE TORINO CLASSROOM

A really cool new program for the Cool Kids in Las Vegas, NV is the Torino Classroom at Sunrise Children's Hospital.

Created by the Nevada Childhood Cancer Foundation and sponsored jointly by the Torino Foundation, Sunrise Children's Hospital, and the Clark County School District, the Torino Classroom was started in June 2008 and is the first educational program of its kind in the State of Nevada.

Cool Kids, Kindergarten to Grade 12, attend regular classes every day, Monday through Friday, while they receive treatment for their illness and stay up with their regular class schedule at school. Torino Classroom is located on the fifth floor at Sunrise Children's Hospital, right in the Pediatric Oncology Department.

Lenny Ware, the Torino Classroom teacher, is pretty cool too. He is a former football star for the University of Nevada Las Vegas Runnin' Rebels, where he earned his masters degree in education, and he also played for the Tennessee Titans of the National Football League and the Las Vegas Gladiators of the Arena Football League.

Say Hi to these Cool Kids who are students in Torino Classroom. They wrote these essays for their English class:

#### Torino Classroom Essay 1 – Thomas

Hi! My name is Thomas and I'm 10 years old. I was diagnosed with ALL Leukemia December 26, 2007. I have been diagnosed for a year now. Hopefully, I'm going to be able to go to school again.

Leukemia has impacted my education emotionally because I think that my friends are learning more than me. I miss being in a classroom instead of having a home-bound teacher come to my house. I have to do all the work at home and there's nobody to help me.



Thomas



The Torino Classroom has helped me conquer my challenges by meeting new friends and helping me with my studies. It also helps me because it makes me feel like I'm in a real classroom. I probably wouldn't be learning the same things my other friends are learning.

### Torino Classroom Essay 2 – Jaslyn S.

Hi, everyone! My name is Jaslyn S.

I have sickle cell disease and Junior Rheumatoid Arthritis (JRA). It's been really tough for me to be successful in school having sickle and JRA because I am sick a lot and I miss school because I am in the hospital a lot.

Since I'm in the hospital, I've missed out on a lot of school dances, seeing my friends every day, going to parties, my school work, joining after school activities, going to fun class field trips and going to concerts.



The Nevada Childhood Cancer Foundation and the Torino Classroom helped me overcome my challenges by giving me a chance to learn and do work while I'm in the hospital and helping me on work that I needed and tutoring me. It also has helped me by being in class with other students. That gave me a chance to make friends who have similar challenges to my own and with people who understand what I'm going through with my illnesses.

I am very grateful for the Nevada Childhood Cancer Foundation and the Torino Classroom program and I give them a big Thanks!

### Torino Classroom Essay 3 – Valerie Cruz

Hi! My name is Valerie. I am 16 years old. On September 14, 2007, I was diagnosed with a stage



4 brain tumor when I was 15. A week after my surgery, I began radiation and chemotherapy. A month later, I stopped radiation. But, I have been doing chemotherapy for a year so far. During radiation, I lost all my hair.

While doing chemo, I missed a lot of school. Since I missed so much school, I didn't see a lot of my friends and I missed out on being a normal teenager. Not going to school was very hard for me. I had a lot of bad grades and I lost a lot of friends.

Nevada Childhood Cancer Foundation and Torino Classroom helped me with my education. I am now 10 credits ahead and am being awarded Student of the Year.

I am very thankful to have everyone from NCCF and Mr. Lenny Ware help me with my struggle in my education.

### Torino Classroom Essay 4 – Tealan Mitchell

Hi! I'm Tealan Mitchell. On May 7, 2008, I was diagnosed with AML Leukemia cancer. That moment was pure devastation. This cancer is not like others. It is very, very severe.



I thought life was over for me. No more school, no more friends, family and teachers. I thought I would never be able to go back and correct a lot of things I said to people who are important to me.

This diagnosis impacted my education by missing days in school, not seeing my friends, not being able to get in touch with them. That hurt because I thought everybody forgot me and I was just another face in the crowd.

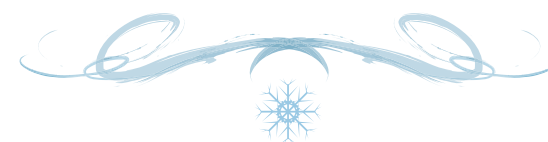
There were times my own father grew scared because I was in so much pain I couldn't talk. Turning his face as I lay there in pain, I open my eyes and see him in the doorway, his back turned toward me. To see his pain as a father and me the child only made the pain worse.



There are not enough words to explain how the homebound Nevada Childhood Cancer Foundation and the Torino Classroom helped me get through and overcome my educational challenges. I was scared I was not going to be able to graduate with my class.

But, Mr. Lenny Ware came in my room with homebound books and said, "Let's start school." From that moment, I knew for a fact I was going to graduate with my class. I made two As, two Bs and two Cs for the first quarter and I intend on graduating with a 4.0 GPA.

*For more information on The Torino Classroom contact the Nevada Childhood Cancer Foundation at 702.735.8434, [www.nvccf.org](http://www.nvccf.org).*





# Surviving & Thriving



By Annette Hagy

Aaron Matthew Hagy was born on June 20, 1990, our second child and second son, just 20 months younger than older brother, Trey. Upon that first wondrous mother's inspection in the hospital bed, he was perfect – pink and sweet and beautiful. My boys and I were living with my parents in Ohio because my husband, Rick, an officer in the Navy, was scheduled to attend several different training schools in different locations in just a couple of months. The next weeks were just as normal as they could be and filled with the excitement and newness of our baby boy and trying to get into a routine with a baby and a toddler.

Before chemo started.



When Aaron was about 8 weeks old, I noticed that one of his eyelids wasn't opening all the way and his pupils weren't the same size. I pointed it out to my mom. Was it possible that it had been that way all along and I hadn't noticed? But we both agreed that this was something new and we needed to have it checked out by the pediatrician, who said that it might be an infection of some kind, but we needed to follow up with an ophthalmologist.

This was all happening just before moving to Newport, Rhode Island, where Rick would spend 10 months at the Naval War College. Shortly after getting settled in Newport, we took Aaron to the eye doctor who ordered an MRI. We traveled



Mid-way through his chemo treatments...

to Boston for the MRI, and when the doctor talked to us afterwards, he went over some of the possibilities that could be causing the drooping of his eye known as "ptosis" (the first of many terms we would learn in the coming months). He did mention that it could be a tumor, but I barely let my ears hear that possibility and told myself that it was an infection, and we went on our way.

When the phone rang at 10:00 p.m. that same night and I heard the doctor's voice, I was filled with dread. The MRI had revealed a mass and we were to report to the hospital first thing the next morning for further tests. From that point on, everything went fuzzy and dreamlike, as we went through the motions of gathering what we would need for our hospital stay.

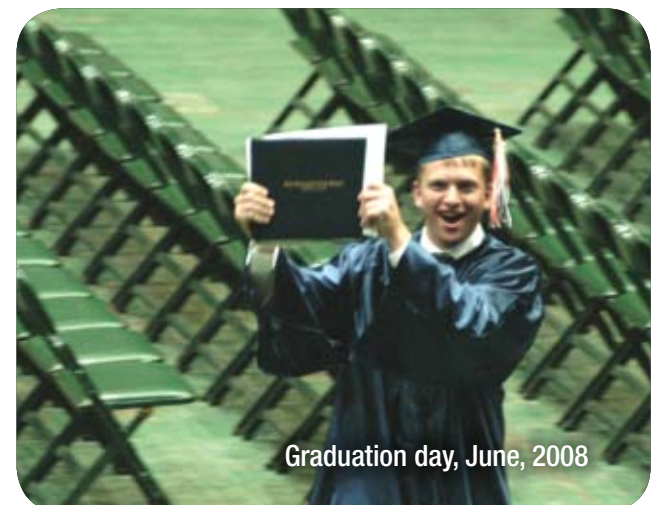
Within just a couple of days, Aaron was scheduled for surgery to remove the mass that was wrapped around both the carotid and subclavian arteries. The tumor was pressing against a nerve that controlled his eyelid. We learned that this was called Horner's Syndrome. The doctors weren't hopeful that they would be able to remove all of the mass because of its location, but after surgery, they were practically jumping for joy. Thankfully, the tumor was encapsulated and they were able to remove the entire tumor that could be seen by the naked eye. The biopsy came back and the diagnosis was Stage 1 Neuroblastoma. But the doctors were so hopeful that they said that there was a 99.9% chance there would never be a recurrence.

Aaron made an amazing recovery from his surgery and soon we were back into our routine with our little family and were making our once monthly trips to Boston for a chest x-ray and bloodwork, plus a CT scan every other month. He also had several other tests to make sure the cancer wasn't showing up somewhere else. Just as this was

becoming somewhat routine, at about the six-month post-operative point, the x-ray tech called us back for a retake. The dreamlike fog was back with a vengeance and my mother's instinct knew that something was wrong. Sure enough, there was another tumor – at the same spot as before.

This time, along with scheduling the surgery, it was decided that Aaron would begin chemotherapy after recovering from the operation. Back came the fog as we learned all about having a central line placed in his little body. Things were happening way too fast – the nurses were so calm about this and we didn't seem to have a choice in anything. We wanted to slow down and take things one step at a time, but that wasn't going to happen. We just had to plunge ahead and learn about all the things we needed to do to get through this and to be there for Aaron. He was only 9 months old and was about to have his second surgery! We didn't have time to process it and looked to the other moms and dads in the hospital and took strength and advice from them. Aaron's surgery was a success, and once again the entire tumor was removed. This time, I was unable to be assured that things would be OK and was filled with the fear of the unknown. Would we again be facing another recurrence?

Shortly before Aaron's first birthday, he began the first of his chemo treatments that would last six months. His protocol was pretty aggressive, with 7 different drugs, the names of which would be engrained in my memory forever. I wondered what it felt like to him – could he actually feel the drugs entering his body? The effects of that first treatment were frightening. Aaron couldn't keep anything down. He was hoarse from crying and throwing up and I couldn't imagine how he was going to survive this! And to top it off, Rick was scheduled for another training program – this time



Graduation day, June, 2008





Aaron and Mark Isabelle (age 7) with the necklace that Aaron gave him.

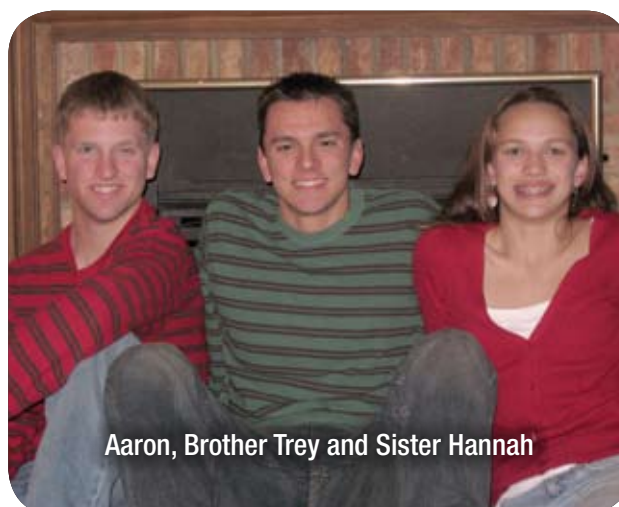
in Norfolk, Virginia. We decided that the boys and I would move back to Ohio to stay with my parents again, so that they could help me with the boys. I couldn't imagine leaving the security of the wonderful doctors and nurses at New England Medical Center, but they helped us connect with the Cleveland Clinic and assured us that Aaron would be in very capable hands there. How right they were! When it was time for his second chemo treatment, now at Cleveland Clinic, Aaron was given Zofran, a new anti-nausea drug which had just been approved by the FDA. I waited and watched, expecting a repeat performance of round number one. It never happened! He threw up maybe once or twice, but that was it! Zofran was a miracle drug in my eyes, as Aaron hardly appeared sick at all! He would still get sick from the chemo, but he bounced back each time – the difference with the Zofran was like night and day.

The next months would bring the expected plunge in white cell counts, fevers and infections after almost every treatment. The daily rituals were just a part of our routine. His line had to be flushed, using all the sterile precautions with masks and gloves and the endless washing of hands. The infections still came – right along with my guilt about perhaps not doing something right. I soon learned that with virtually no white blood count, he was almost certain to have infections. I also learned that we could avoid the 10-day hospital stay if I learned how to administer his antibiotics at home. I could do that?? That turned out to be a Godsend since Aaron didn't have to be stuck in a hospital room, but it was also a stressful responsibility! Keeping track of several different antibiotics and when to give them was a 24-hour-a day job, but it also gave us the gift of having Aaron at home with us. Rick and I talked frequently on the phone and he came to visit as much as he could. With his support and that of my parents and extended family and friends during that time it made it possible to get through those months.

Aaron's treatments ended just before Christmas, 1991, when he was just 18 months old. Realizing what he had endured in that short amount of time broke my heart, but we were starting down a new path. He would have monthly checks again, with x-rays, CT scans and the occasional MRI to make sure he was still cancer free. Those appointments were never easy, the memory of that one time when we were called back in to take another x-ray came flooding back each time. But we never had to do another retake.

Little by little, the tests became a little less frequent – which always was both a welcome and scary step away from the security blanket of just making sure the cancerous cells had not returned. When Aaron was just 6 1/2 years old, we reached the 5-year post-chemo point, and we hesitantly celebrated that wonderful milestone. During those five years, Aaron was healthy, active, funny and growing up with no memory of all he had been through. He knew he had a big scar just along his shoulder blade where the surgeons went in both times, and he knew that he had to go to the oncology clinic every so often and have his "blood taken out and be very brave." And he knew that he had had cancer when he was a baby. When he was 3 1/2, we all welcomed little sister, Hannah into the world, who was adored by her brothers. When Aaron was four, he had the privilege of being the official starter for an American Cancer Society running event and felt very proud to blow the whistle for the start of the race.

Aaron is now 18 years old, and is a freshman attending Clarion University in Pennsylvania. He still has his droopy eyelid and isn't sure that he wants to have it fixed. He feels that it has become a part of who he is. We still go together for his annual follow-up appointments which usually just include bloodwork. He has an echo-cardiogram



Aaron, Brother Trey and Sister Hannah

every other year to check for long-term effects of one of his chemo drugs. Thankfully, these tests have all been normal, and he has been cancer free for 17 years. Even after all of these years the follow-up appointments are still difficult for me. Understandably, we are not worried about cancer on a daily basis anymore, but when those appointments come around, the memories come back very clearly.



High school senior picture

I know that not all victims of childhood cancer get to have the happy outcome that Aaron has had and I am so very grateful that he is healthy today. I am also heartbroken for the endless number of children and families who continue to battle the many forms of this terrible disease. Our very dear friend, 7-year-old Mark Isabelle, who was featured in a recent Connection issue, is bravely and successfully fighting leukemia now. Aaron and Mark have a special connection of their own, and Aaron couldn't wait to give Mark the heart necklace that he was given at his last appointment. I am amazed at the strides that have been made in cancer research since Aaron was a baby. I continue to pray that the ongoing study and knowledge of our wonderful and talented oncology researchers will soon find the cures so that more and more of our children can survive cancer.

I pray that by hearing more stories like Aaron's, children with cancer and their parents will have that glimmer of hope and be strengthened and comforted with the knowledge that there are many survivor stories out there – more and more each day.

*Aaron's follow-up care is provided by Walter Reed Army Medical Center.*



By Marion Leimbach

We have had legal guardianship over our grandson Jesse since he was 5. His mother and father are also in his life, but my husband and I have taken over the responsibility of raising him.

Jesse has been in chemotherapy for over two years. When he was 13 he noticed a little bump near his ribs, two days before our Alaskan cruise. I told him we would check it when we returned from vacation; we were all excited to go.

After a great trip with our grandchildren, we made an appointment for Jesse to see the doctor. They took an X-ray and he went home. To our surprise, the doctor called and wanted him to have a CT scan the next day, so we made an appointment with a surgeon. It was a tumor on his rib and it needed to be biopsied. The pediatric oncologist called us the day before the appointment with the surgeon and spoke to us about the tumor. From everything going on, I knew what they suspected – a cancerous tumor.

As far as symptoms, there weren't many. In previous months, he had some pain in his side when breathing hard, and a few times, he was sent home from school because of a fever and not feeling well. He was getting ready to play Youth Football for the Rocklin Thunders again and had a physical exam in May where he mentioned the side pains to the doctor, who thought it was probably growing pains.

Jesse's biopsy was in July 2006; they knew it was cancer. What type we did not know for sure, but the surgeon, Dr. DuBois, thought it was Ewing's Sarcoma. My grandson was then hospitalized and had to be tested to see if the cancer was only in the ribs or in the bone marrow as well. After the results indicated it was definitely Ewing's Sarcoma, chemo treatments began.

You can imagine how shocked we all were! I instantly used the computer to learn exactly what Ewing's Sarcoma was. I cried reading over the information, and how it had become cancer in my Jesse. We were all devastated.

Jesse had to be home-schooled during eighth and ninth grade, and his internal clock became off. He stayed up late and slept well into the morning, sometimes into the afternoon. Weekends were his social time and we thank his wonderful friends and family for being so supportive.

After several weeks of treatment, Jesse had surgery to remove the tumor, along with two ribs. It was very painful for him, pain like he had never experienced. He recuperated well though – he is some boy!

We had many questions for the doctors and still have questions. We belong to Kaiser Permanente and the pediatric doctors there are wonderful and very knowledgeable. Jesse's treatment was to last 10 months. He tolerated it very well, with no real

pain or stomach problems, mainly just the loss of his hair which grows back, thank God.

We were sure he would receive a clean bill of health after the next CT scan. To our surprise, the cancer spread into his blood stream and lungs. There were several nodules in both lungs. This was not good; treatment was to continue.

Jesse, being the kid he is, didn't seem to mind going through further treatment. In the last year, he has tried several, most which did not work. The last several months he has been receiving a treatment which has slowed the growth of some of the tumors. This cancer can be really stubborn!

A few months ago, he said the back of his head hurt. The doctor checked it and found another tumor growing out of his skull into his brain – they decided on radiation. Jesse went through three weeks of it, and lost the hair across his head, but the radiation took care of that tumor.

He is still in chemotherapy and living a fairly normal life now. Finally he is back to school, has a girlfriend and is learning how to drive with a learner's permit. He gets good grades and his friends are there for him. Jesse recently turned 16 and is looking forward to getting his driver's license.

We all take this one day at a time and are very pleased Jesse is doing well under such unpleasant events. He still wants to play sports and will try out for the basketball team; he'd like to play football next year for his high school. His goal and dream in life is to play for the NFL – that's what he strives for.

The cancer to him is just a setback and he says he will go no matter what. He is a big football fan and made a wish with Make-a-Wish to attend the Pro-Bowl football game in Hawaii last February. He met face-to-face with many of the players – a dream come true. I know my grandson won't ever forget that trip; we won't either!

Jesse has not shown much anger for this disease and has been very positive throughout. He has helped us with his courage and his determination to accomplish all he wants to accomplish. We will try to always support him in what he wants to do and help him as much as we can to make it happen.

*Jesse is being treated at Sacramento Kaiser Permanente Pediatric Oncology by Doctors Jolly, Kiley and Adams.*



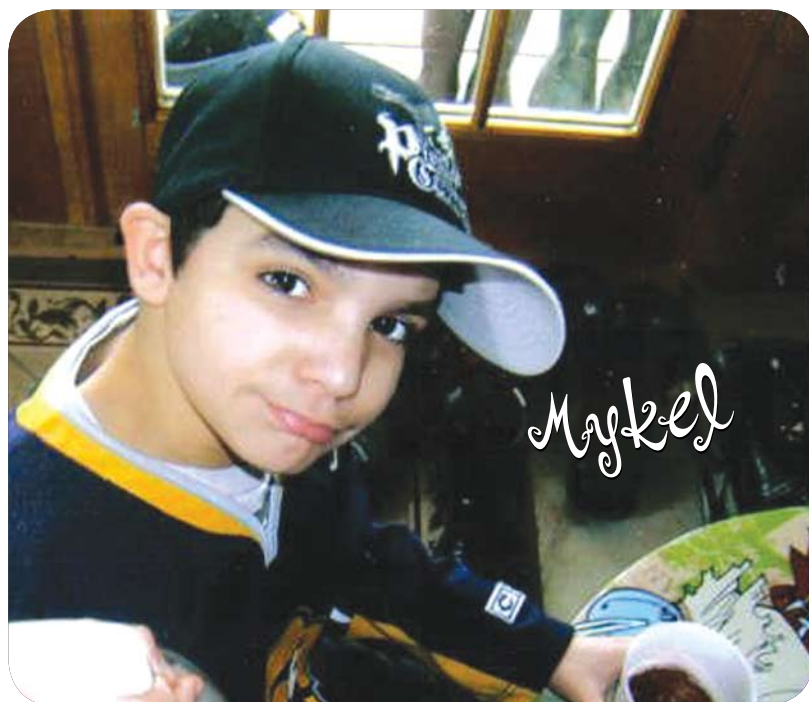


# Mykel's story

in his own words...

My name is Mykel Ruffini. I am 10 years old and was playing in gym at school. I hurt my side. I was in a lot of pain so my mom and dad took me to the hospital. Then I was sent to Children's Hospital. They did a cat scan for the second time and found a huge mass on my kidney. Then I was in ICU because I tore a little bit of my mass so I was bleeding internally. Then they took good care of me so I went home. Then I had a biopsy on November 6th. On November 11th I went to Roswell to find out I have a Wilms Tumor Stage 3 so I have to get chemo for 12 weeks then see if it shrunk. If so they will have to take my kidney and tumor out then have radiation and chemo for 6 months. So that is my story. I love your slogan Cancer Fears Me!

*Mykel is being treated at Roswell Park Cancer Institute in Buffalo, NY.*



CANCER  
FEARS  
ME™

APPAREL & ACCESSORIES

[www.cancerfearsme.org](http://www.cancerfearsme.org)

“Life is an opportunity, benefit from it.

Life is beauty, admire it.

Life is bliss, taste it.

Life is a dream, realize it.

Life is a challenge, meet it.

Life is a duty, complete it.

Life is a game, play it.

Life is a promise, fulfill it.

Life is sorrow, overcome it.

Life is a song, sing it.

Life is a struggle, accept it.

Life is a tragedy, confront it.

Life is an adventure, dare it.

Life is luck, make it.

Life is too precious, do not destroy it.

Life is life, fight for it.”

*Mother Teresa*

WE SUPPORT THE  
COOL KIDS CAMPAIGN.  
BECAUSE THEY'RE  
OUR KIDS, TOO.

A strong community is a vibrant, living thing. The more we all participate in it, the more it grows. Which is why we're happy, and honored, to participate in any way we can.

1-888-TOP-BANK  
PROVBANK.COM



Member FDIC

**Provident**  
BANK

Serving the Community Since 1886

*Just the right size for you to grow.*

# Samuel's Story

By Sabrina Snead

On August 23, 2007, I gave birth to a precious baby boy named Samuel. In my eyes he was perfect.

Little did I know Samuel was a very sick baby. He stayed in my recovery room for two hours after delivery and I immediately noticed something was wrong when my best friend brought it to my attention. Samuel was breathing rapidly as though he could not catch his breath. My friend and I tried to convince the nurses that something was wrong but no one listened. I begged for someone to help my son but no one took my concerns into consideration.

After two prolonged hours, Samuel turned purple. This alarmed the nurses who rushed him to the NICU where he remained for a week. He was put on 100% oxygen and treated for TTN, pneumonia, jaundice, fluid in the lungs, and premature lungs.

On August 30, my husband and I were able to bring our baby boy home. When Samuel was two weeks old we noticed his eyes drifted in the direction of his ears. I knew some infants have lazy eyes, but his seemed abnormal. At his six-week checkup, I mentioned this to the doctor who said it was normal. It gradually worsened. My neighbors and close friends demanded I seek a second opinion; it wasn't getting better and it was very noticeable.



I took Samuel to doctor after doctor who each said this was normal. One doctor even told me I was paranoid and overreacting, and nothing was wrong with my son's eyes. He said if there was a problem, he could not refer the baby to an eye doctor until he was four months old.

In October Samuel's eye began to glow – it looked almost like a cat eye. This frightened my husband and me, because deep down we knew something was wrong and it bothered us that no doctor would take into consideration that I am a mother of two other children, and I was worried.

In November my family and I packed up our home and drove to Alaska. My husband serves in the United States Air Force and he was transferred to Elmendorf AFB in Anchorage. We were thrilled to be starting a new life with our children and give them the opportunity to see a new side of the world. At last I had hope of finding a good doctor to help our son see.

In December we wanted to take our Christmas photo but it was unsuccessful. With a total of 30 shots we could not find one where Samuel did not have a red eye and a white eye. It was horrific. I had a sick feeling in my stomach that something was truly wrong and knew I was not overreacting.

Samuel was then four months old and had yet to look at me for more than two seconds. As I nursed and bonded with him, I'd pray, "Lord, please let him look into my eyes. I want to see him look me in the eyes." But Samuel could not see me.

It's the little things we take for granted. You never think things like this will happen to you or your loved ones. On New Year's Eve, Samuel spiked a low grade fever. I wanted to leave in the middle of our

party to take him to the ER. My husband pleaded with me to stay home and give it another day.

But that was not an option. Something kept telling me to take him. Thankfully I did, because we found out he had pneumonia, and because of it, we were able to get a full diagnosis. Four days after being treated, the baby had a follow-up appointment with the pediatrician. She said he was better, and I voiced my concerns about Samuel's eyes. She agreed things didn't add up. He had yet to make eye contact and his eyes still were facing toward his ears. He continued to have a red and white eye in photos, and when light hit his left eye in a certain way, it would glow white – it was very scary.

The doctor put in a referral for him to see the eye doctor on base. The next day, I had to pick up my contact lenses. My whole family went along for a family day out. I was still very bothered about my son's symptoms and was crying out for help. In desperation to find hope, I explained my concerns to my eye doctor's secretary. I asked if Dr. Powell could look at Samuel. Within five minutes, she checked him, but did not say much other than we needed to urgently call first thing Monday morning to see an eye doctor.



I was frightened deeply and knew Samuel was possibly blind, which explained why he could not see me. Yet what I was about to hear was something that never crossed my mind. I woke up 9 a.m. Monday morning and called the eye doctor in the hospital. Samuel's referral had not cleared yet, so I was denied an appointment. Five minutes after hanging up, I received a call from Dr. Powell who had personally made Samuel an appointment. We headed there right away.





Dr. Shang did an ultrasound on Samuel's eyes, indicating the right eye looked good but when he got to the left eye, he showed me what looked like a ball inside. I had no idea what I was looking at, and to be honest I had no idea what it could be.



He sent me to the waiting room and said he needed to make a few phone calls. An hour passed before Dr. Shang emerged. I don't remember much of what was said, other than he thought Samuel may have cancer. I began to black out and my entire body went numb. All this time I had been telling doctors something was wrong with my son, yet they all insisted he was fine and thought I was an over-paranoid mother. Why a doctor would not listen to a mother and her concerns, I will never know. A mother always knows her child – it's what God gives us – to help us nurture our children and take care of them. That's what mothers do – we take care of our babies and that is exactly what I was doing.

I was in disbelief; I could not believe what I had just heard. I sobbed as Dr. Shang continued to make phone calls to get Samuel help. I remember making three phone calls after I heard the news: first to my husband ... I was so numb inside I do not remember a single word he said once I told him the news. I just needed him there to keep me strong for Samuel.

Here this precious baby boy slept in my arms and he is hurting and very sick. I wished I could have taken his place and taken away his pain. My mom was working and could not talk, but I insisted she speak with me, as I broke the news to her. She sobbed as well. Then I called a close friend and poured my heart out.

We cried together until my phone lost its signal. I just needed someone to talk to. I knew I had to stay strong for my little guy.

The doctor came back in as my husband was arriving with our oldest son, Dean. He explained to us he was 99.9% sure Samuel had retinoblastoma and scheduled us to go to Philadelphia in two days to see Dr. Shields at Will's Eye Hospital. Once again we packed and flew halfway across the world. A whole day of flying, and the worse was yet to come.

Samuel went through many tests devastating to me as a parent, although it had to be done. He had a class D tumor in his left eye, class E being the worst case, requiring removal of the eye. His right eye had a class A tumor.

The next day the baby began extensive amounts of chemo. This, by far, was the worse thing I could have ever imagined having to put my child through. Words cannot begin to describe the emotions I felt when hearing my child had cancer and there was a chance he may die. It's a part of life no one likes to think about.

Samuel endured six months of chemo. He had a rocky time recovering. He stayed in the hospital more than at home. My husband returned to Alaska while my children and I remained in Virginia to be closer to CHOPS (Children's Hospital of Philadelphia). It was long, but he got through it and we were right there with him.

Today I am happy to say Samuel is in remission and is growing healthy and strong. At 16 months

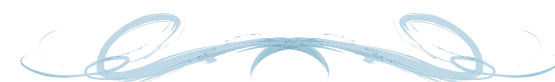
old, we are happy to have him looking us in the eyes, speaking to us, and calling us by names: Momma, Dadda or daddy, and Bubba, or as he likes to say, "Deeeeeaaaannnn."



The one thing I can say as a parent is to never take life for granted. Count your blessings. Thank God every day for being healthy and alive. And something I'd like to say on Samuel's part...there is nothing better than cars, food, milk, and a good ole' "baba."

God bless and thank you for taking the time to read about Samuel Snead and his journey with cancer...and how he kicked cancer in the butt FOR LIFE!!

*Samuel has been treated at Wills Eye Hospital and Children's Hospital of Philadelphia.*



## 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 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](http://www.coolkidscampaign.org) or email to [sharon@bfpf.org](mailto:sharon@bfpf.org)

Please send your submissions by mail to:  
**Cool Kids Campaign**  
9711 Monroe Street  
Cockeysville, MD 21030  
or email to [sharon@bfpf.org](mailto:sharon@bfpf.org)



COOL KIDS

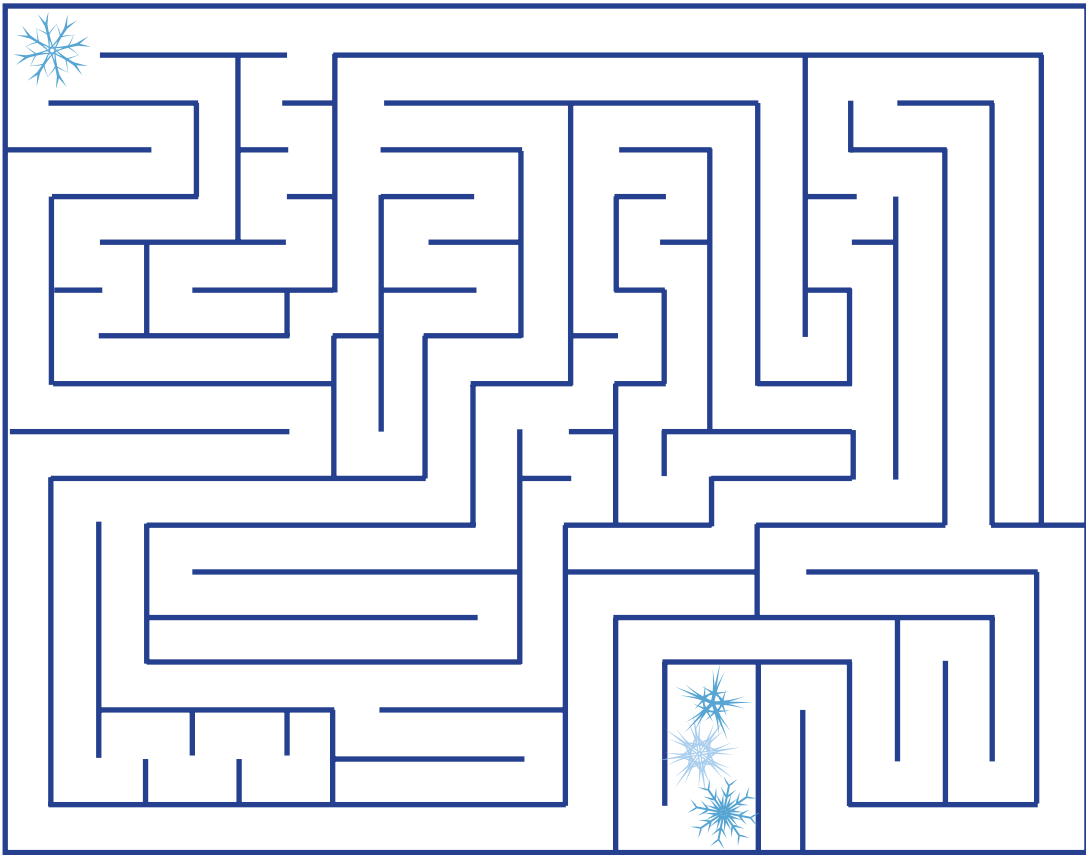
ACTIVITIES

Trivia Quiz

- Q: When is the first day of winter in North America- November 21<sup>st</sup>, December 21<sup>st</sup>, or January 21<sup>st</sup>?
- A: December 21<sup>st</sup>, this day is also referred to as winter solstice, the shortest day of the year.
- Q: What winter sport uses sticks and pucks to play?
- A: Hockey. It is the most popular sport in North America. Each year the winner of the NHL Championship takes home the Stanley Cup, a trophy that has been around since 1927!
- Q: Where was the first ice hotel built – United States, Iceland or Sweden?
- A: Sweden. The most famous ice hotel was built in Sweden over 15 years ago. It has rooms full of beds made of ice and snow.
- Q: What is unique about snowflakes?
- A: No two are ever exactly the same! While most of them have six sides and form in the clouds with water and ice, each one is unique in size and shape.
- Q: How many people in the world live in cold Arctic places – 1 million, 2 million or 4 million?
- A: More than 4 million people live in the Arctic regions of Alaska, Canada, Greenland, northern Scandinavia and Siberia.
- Q: Who invented the snowmobile- John F. Kennedy, Henry Ford or Joseph-Armand Bombardier?
- A: Joseph-Armand Bombardier from Quebec, Canada invented the modern snowmobile in 1959. Snowmobiles are great to ride around in snow and ice because they don't need roads.

How many snowflakes can you find in this issue of the Cool Kids Connection?

Help the snowflake find its friends...



- Q: What does a polar bear use to catch food, its ears, nose or eyes?
- A: Its nose. The polar bear relies on its sense of smell to catch food. These arctic bears can smell a seal up to 20 miles away.
- Q: Where do monarch butterflies fly off for the winter, Mexico, Spain or France?
- A: Monarch butterflies spend the cold winter in the warmer climates of Mexico. They huddle and sleep on thin branches and start migrating north again in the spring.
- Q: What is an igloo made out of – snow, white bricks or wood and ice?
- A: Igloo is the Inuit word for shelter. This shelter is made from blocks of snow that are cut to form the shape of a dome. Window holes are cut in the igloo so light can come in.
- Q: What does Groundhog Day represent?
- A: The halfway point of winter. Legend has it that each year on February 2<sup>nd</sup>, a groundhog wakes up from a sleepy winter to look for his shadow. If he sees it, he comes out for the spring but if he doesn't, he goes back to sleep!





# A play on words

Picabo (*pronounced peekaboo*) Street apparently came into a lot of money because of her Olympic performance in skiing. Rather than spend it on herself, she showed a lot of character by donating it to a local hospital. The primary facility the hospital needed was a retrofit of the Intensive Care Unit, so in her honor, the hospital board is going to name the new unit, "Picabo, I.C.U."

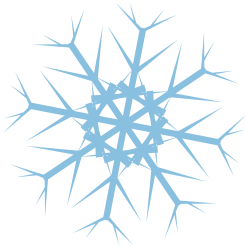


# Word Search

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



# Jokes



Q: Where do polar bears vote?  
A: The North Poll.  
Q: Where do snowmen go to dance?  
A: A snowball.  
Q: What do you get when you cross a snowman with a vampire?  
A: Frostbite.  
Q: What do you sing at a snowman's birthday party?  
A: Freeze a jolly good fellow.  
Q: Why don't mountains get cold in the winter?  
A: Because they wear snow caps.



BLACK ICE  
BLIZZARD  
BOOTS  
CARNIVAL  
CHRISTMAS  
COLD  
EGG NOG  
FIREPLACE  
FIREWOOD  
FOG  
FREEZE  
FROST  
GLOVES  
HAIL  
HEADBAND  
HIBERNATION  
HOCKEY  
HOLIDAYS  
ICE FISHING  
ICICLES  
KNIT CAP  
LONG UNDERWEAR  
MITTENS  
OLYMPICS  
PARKA  
SCARF  
SEASON  
SKATES  
SKI DOO  
SKI PANTS  
SKIING  
SLED  
SLEET  
SLIPPERY  
SNOW CASTLE  
SNOW PLOW  
SNOW SHOVEL  
SNOW TIRES  
SNOWBALL  
SNOWBOARD  
SNOWFLAKE  
SNOWMAN  
SNOWSHOES  
SOLSTICE  
SOUP  
STEW  
STORM  
SWEATSHIRT  
TOBOGGAN  
VACATION  
WIND CHILL  
WOOL SOCKS

The Baltimore Area Convention and Visitors Association  
is proud to support

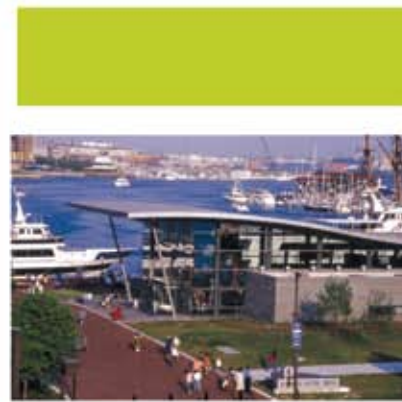
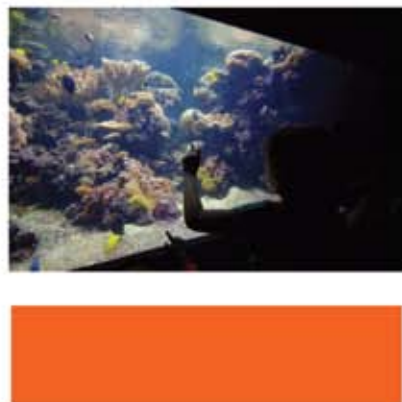


# COOL KIDS CAMPAIGN™

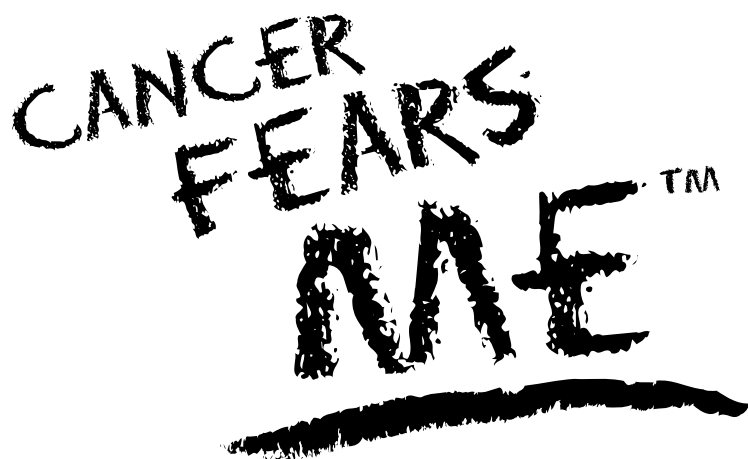
To discover all that Baltimore has to offer,  
call 1-877-BALTIMORE or visit [www.baltimore.org](http://www.baltimore.org).



Baltimore







### 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.



I'd like to share my son's picture wearing this CFM cap. He is 11 years old and was diagnosed in June of this year with a type of brain cancer called a non-germinomatous germ cell tumor. He is completely finished with chemo and he has responded very well to treatment thus far. The doctor says the tumor is barely visible in the MRI and he feels strongly that surgery may not be necessary. My son, Ben, will have radiation as part of the final treatment.

He is doing so well, not even chemo keeps him down! He's out on his skateboard, hanging out with other boys his age right after chemo. I seriously believe that cancer fears him!

April K., Tennessee



Ben is being treated at St. Jude Children's Hospital.

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

Hello my name is Cortney. I have been through the most difficult year of my life. My four year old was diagnosed with JMML, a rare form of leukemia that affects less than 1% of all childhood cancers. We underwent a bone marrow transplant April 24<sup>th</sup>, 2008. We had many bumps in the road, but we are now home. She was given a hat with your logo, and wow, she and I felt so powerful when she wore it. For Christmas this year our family has chosen to give gift bags to all the children battling cancer in the hospital. I would love to order them all chemo caps to put in them. Thank you for creating such a powerful logo!

Cortney G., Missouri



Cortney's daughter Lanie was treated at Cincinnati Children's Hospital.



Check out our website [www.cancerfearsme.org](http://www.cancerfearsme.org)



# Cool Kids and Cool Caregivers

By Molly Lauryssens

She is a cereal connoisseur and loves all kinds of animals, except worms because they are “yucky.” She can belt out jumping jacks for fun and is a fan of Hannah Montana. Her name is Mya Terry and she is definitely a Cool Kid.

His name is Matthew Eggen, but you can call him “Matty” and his favorite cereal is Captain Crunch. He lives in Baltimore and has the distinct honor of working with families who are dealing with a cancer diagnosis.

Take some time to get to know this Cool Kid and Cool Caregiver. Do you have anything in common?

## Mya Terry



**What is your name?** Mya Terry

**Where do you live?** Oakhurst, New Jersey

**What grade are you in?** First Grade

**How old are you?** 6-years old

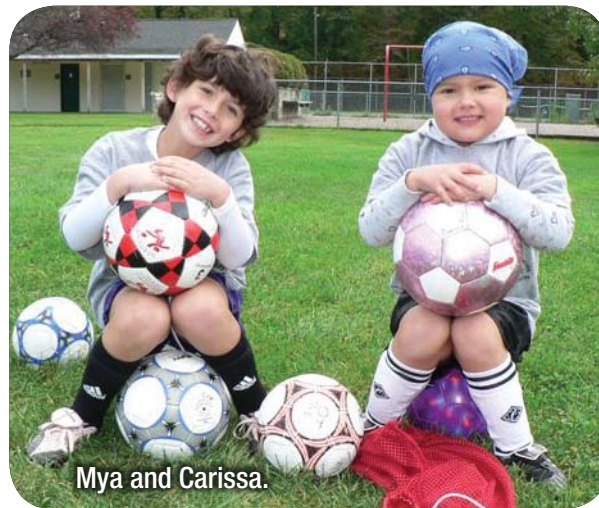
**What is your favorite subject in school?** Math

**If you were going to write a book what would it be about?** It would be about a doggie and kitty, because I like dogs and cats.



**What is your favorite food?** Hamburger helper

**What is your favorite food from Christmas Day?** Hot chocolate and macaroni and cheese.



**Do you have a BFF?** Two- Samantha and Serenna

**Who is your favorite celebrity (sport or entertainer)?** Hannah Montana and on the radio I think I like Chris Brown, he sings love songs and cool songs.

**What types of things do you like to do for exercise?** Jumping jacks. Sometimes I do 20.

**What qualities do you have that make you a Cool Kid?** Soccer makes me a cool kid, because I like kicking the ball and stuff.

**If you were the President of Whoville what would be your first act as the ruler?** Just make me a president.

**Do you like dogs, cats, earthworms, birds?** Dolphins. Worms are too yucky. I like some birds too.

**What is your favorite cereal?** Fruit Loops, Cocoa Puffs, I like a lot of different cereal.

**If you could be anything in the world, what would it be when you grow up and why?** I would be a veterinarian because I like all types of animals.

**What is your favorite movie?** The Scooby-Dooby Doo Movie

**Favorite television show?** Naked Brothers Band

**What is your favorite video game to play?** The Goosebumps on Wii.

**What is your favorite sport?** Soccer

**What kind of music do you listen to?** Hannah Montana

**Do you have any brothers or sisters, if so- what are their names?** Michael Terry

**What is your favorite fruit or vegetable?** I like carrots and broccoli and peaches.

**If you were stranded on a deserted island, what three things would you like to have?** Food, my cousins and all my pets.

**What are you most grateful for?** My cousins, Alex and Kenny.

**What is your favorite book?** I like all the Goosebumps books.

**Favorite author?** R.L. Stine

**If you were one of the seven dwarfs, which one would you be?** Why? I don't know.

**If you could meet and interview one famous person, who would it be? And what is the first question you'd ask?** Jonas Brothers; I would ask how do you play your music?

## Matthew Eggen

**Name:** Matthew Eggen, but my friends call me “Matty.”

**Where do you live?** Baltimore, MD

**What is your title?** Clinical Social Worker – Pediatric Oncology – Johns Hopkins Hospital

**What do you do?** I get to assist families with the transition to the world of cancer. I help the entire family cope, adjust and navigate their way through “Planet Cancer.” While the doctors focus on



curing the patient, I assist with families. Fixing the patient is great, this is the goal of treatment, but if families disintegrate due to this illness then the family becomes ill. I assist with keeping the family including the parents and siblings, healthy.

**What is your favorite thing about your job?** As much as I never want to meet the families I work with – I would prefer they didn't have cancer – I enjoy working with the varieties of people I do. Cancer has a way of really mucking up lives and I am amazed at the strength not only of the patients I work with but the parents and siblings. Parents tell me that this isn't strength, it's responsibility;



but I see it as amazing because patients and families didn't know how strong they were before this and then they have to manage it.

**Least favorite thing about your job?** The understanding that the families are negotiating the realization of cancer and as much as I want to I simply cannot fathom what that would feel like.

**What time does your normal day start?** 8 a.m.

**What is your favorite sport to watch?** Baseball, any level.

**To play?** Tennis or Golf

**Do you have any children of your own?** No

**What do you like to do for fun?** Spend time with my girlfriend Kate, hike, get lost and find our way home.

**What is your favorite movie?** The Shawshank Redemption

**What is your favorite book?** The Giving Tree, it was my mom's and grandmother's favorite too.

**What was your favorite subject growing up?** Recess, still is.

**Favorite cereal?** Captain Crunch

**Favorite dessert?** Little Debbie Nutty Bars

**Favorite kind of food?** In & Out Burger



**Favorite board game?** Trivial Pursuit

**Favorite card game?** Spades or hearts

**What is your favorite food during the holidays?** Lefsa. It is a Norwegian potato dish that looks like a tortilla. I haven't had it since I left California, I miss it.

**Cats or dogs?** We have two cats, Emma and Jasper.

**Favorite celebrity?** I know Aaron Eckhart and Christy Turlington volunteer at Camp Okizu, a camp in northern California for siblings of and kids with cancer, so they are pretty cool in my book.

**Favorite season?** Spring

**If you could have dinner with one person, dead or alive, who would it be and why?** My mother, she died in 1986 of cancer, I was 10.

**What is on your iPod? If you don't have one, what CD's are in your car right now?** Explosions in the Sky, Chevelle, Collective Soul, Al Green and the always popular Pink Floyd.

**What are you most thankful for?** My family would laugh at me for this but I will say my family. I moved to the east coast a few years ago and since then haven't been as close to them. But at the end of the day I know I have them and they have me. Without family, doing the kind of work I do, "life"

would be unreasonable. For the families I work with, cancer puts a real strain on the word "family." I think I understand this more and more everyday, knowing that my family is so far away. I am thankful for my health, for the health of my family, and the health of the families I work with.

**A**re you interested in being profiled, or know someone who should be, in one of the upcoming editions of the Cool Kids Connection? Please contact Sharon Perfetti at [sharon@bfpf.org](mailto:sharon@bfpf.org).



**“I take nothing for granted. I now have only good days, or great days.”**

*Lance Armstrong*

**“I have heard there are troubles of more than one kind. Some come from ahead and some come from behind. But I've bought a big bat. I'm all ready you see. Now my troubles are going to have troubles with me!”**

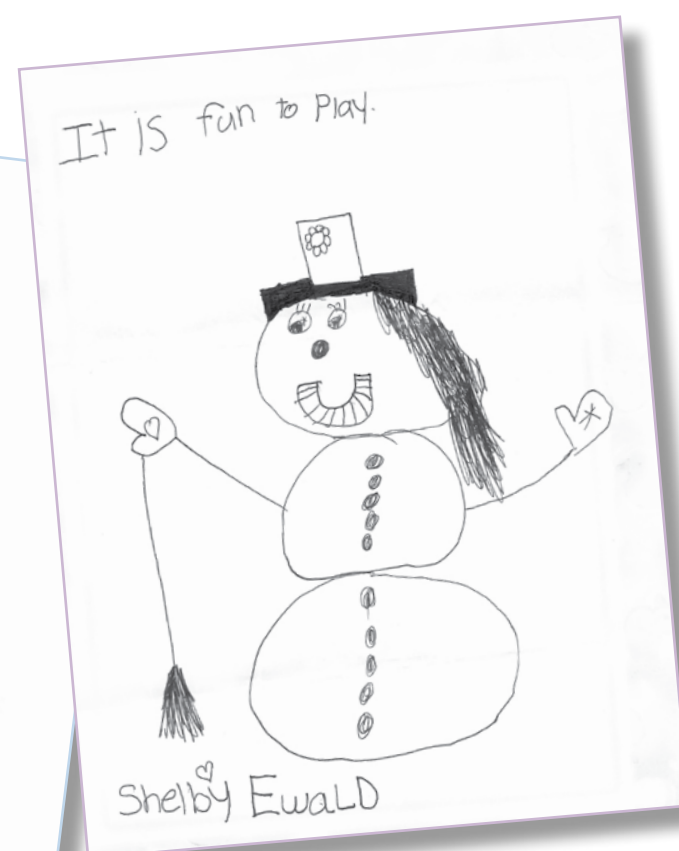
*Dr. Seuss*



## Shelby Ewald

Shelby was treated for Acute Lymphoblastic Leukemia at Roswell Park Cancer Institute.

After a year of treatment Shelby is now in 2nd grade and is currently in remission.





The Dunkin' way to pay.



AMERICA RUNS ON DUNKIN' SM



Proud Sponsor of

