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**SPRING 2012** 

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**Cool Kids & Cool Caregivers** 

coolkidscampaign.org

# ECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION TAKING BLINDERS

am a dad and my hero is my son Matthew. At age 16, he has shown me the way to live. Almost three years ago, we took that call you take deep in the bowels of your home. It was not good. Matthew was diagnosed with a brain tumor; it was cancerous.

In this type of situation, we take off our blinders, and suddenly great people from all walks of life walk into ours. To name a few ... Dr. Allison Jenson at Greater Baltimore Medical Center ... Sister Rosemary at Little Sisters of the Poor ... and Dr. Joe Wiley at Sinai Hospital - maybe the most compassionate and brilliant man on the face of the Earth! Then there is Cam Cameron, Baltimore Ravens coach. Whatever Dr. Wiley did physically to help Matthew, Coach Cameron did mentally. He kept my son in the game! It would take me 23 issues of this newspaper to scratch the surface on what he has done for my son and my family. The Loyola Blakefield High School community has been tremendous. They took us in and took care of us - it is something we cannot repay. The only thing we have is to give Father Joe Pesci all the praise in the world. I cannot thank all the people who have sent letters and e-mails. Each one finds a different route to my heart. We rely on this so much to get us through each day.

Sports defined Matthew - he played football, basketball and

**By Jamie Costello** Baltimore, Maryland

baseball. If fact, shortly after his radiation treatment, he

returned with a bat in his hands, lining a shot to right field for a base hit. Dad cried that day. Double vision has forced him to hang up his glove. Now he golfs, where the ball does not move. I want to say thank you to super trainer Tim Bishop who brought back Matthew's body. Not a day goes by that Matthew isn't running or lifting. Matthew is about to get his learner's permit. From there, college. From there, his goal is to become a coach - just like Coach Cam.

Dear Cool Kids, know there is no script for life. You often have to go off the path to really find your way. Sure, you will get blue and frustrated, however, try to invite wonderful people into your heart and suddenly you'll notice a change in yours. Cancer is the cruelest challenge in life. So take off your blinders, have faith, rely on great people ... and you will get back to the script – written just for you.

Jamie Costello is a TV news anchor for ABC2 News in Baltimore.



Matt Costello (center) at the Samuelson Children's Center grand opening



## About Clarissa.

School helps teen survivor overcome emotional, social obstacles



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Cool Kids Campaign is a 501(c)(3) nonprofi t organization dedicated to improving the quality of life for pediatric oncology patients and their families.

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### I am a 17 year-old senior

at Mount Hebron High School in Ellicott City, and a two-time leukemia survivor. Leukemia is a cancer of the blood, but it can also occur in the spinal fluid, therefore, treatment for it is long – it can last almost three years. By the end of my relapse treatment, I had spent a third of my life on chemo. Including my first and second treatments, I have experienced over 400 needle sticks, 39 spinal taps, 10 days of radiation, over 40 inpatient stays, and countless outpatient visits.

The first time I was diagnosed with Acute Lymphoblastic Leukemia was at age 2. My family and I lived near Philadelphia at the time, so I went through two-and-a-half years of intense chemotherapy at the Children's Hospital of Philadelphia. Luckily I survived and I do not remember anything of that first bout with cancer. Life went on normally for eight years, with the exception of our relocation to Maryland in 2005. Blood tests had to be performed annually by my pediatrician as part of my physicals. I never once thought that the leukemia could or would come back.

However, when it relapsed on June 26, 2007 -10 years after my first diagnosis - my world came crashing down around me. I was 13. Thus began another two-and-a-half years of treatment. It was the summer before eighth grade; my life had changed drastically and I came to understand what feeling sick and tired really meant. I was admitted to Johns Hopkins Hospital and began treatment on the evening I was diagnosed. I had no idea what to expect and do not think the reality of having cancer set in until months after my diagnosis. I spent a great deal of time in the hospital; it became my second home. My doctors and nurses became my second family. They did a fantastic job of talking to me about my treatment, including me in the decision making, and treating me as a young adult. They gave me independence.

The challenge was, however, that the more time I spent in the hospital, the less time I spent at home and around my friends. Going through cancer treatment as a teenager was difficult for many reasons. Above all, I just wanted to be a normal teen – hang out with my friends, start high school with everyone else my age, and begin a new stage in my life. I wanted to go to Homecoming, join a sports team, be independent, and grow up. Unfortunately, that was not possible. In fact, my new independence was ripped right out from under me, and I could not do anything without help for almost a year into my relapse treatment.

Because I was on so much chemo, I had no immune system, so I could not go to school. I did not want to take the risk of getting an infection and having it affect my ability to stay on treatment. Therefore, I was homeschooled by a teacher supplied by the Howard County Home/Hospital Program which allowed me to complete eighth-, ninth-, and half of tenth grade. I grew more and more nervous about going back to school the longer I was out. It was not until three months after treatment part-time, as my energy allowed. Finally, at the beginning of 11th grade I was able to return full-time. Academically, socially, and emotionally, not being in school for two-and-a-half years was the biggest challenge for me.

Academically, I feel like I had a bit of an easier experience than other teens with cancer because I have always loved school and learning. Moreover, Howard County has an incredible Home/Hospital teaching system. Although my first tutor was not very good (at one point I was teaching her Algebra!), my parents asked for a teacher strong in math. The tutor in my second and third year was wonderful; she came to my house twice a week for three hours each time. However, there were times when, if I felt really sick from the chemo, we could not meet. Keeping on track was challenging, yet I worked hard and did a lot independently, both of which were key to my being able to earn straight A's on higher level classes. In fact, being a self-starter and motivated to learn was what helped me keep up with classes, so at the end of treatment, I did not have to drop back a grade. I was able to return to school, part-time at first, and exactly on track with my classmates.

Not being in school led to different social issues. There were months during which I never saw anyone my age, let alone my friends. I lost many friends over those years. As people moved on, changed, and grew up, I was stuck in time, waiting for what seemed like forever, until I was done treatment. I missed being around people my age and doing normal things. The hardest thing for me socially was that I lost the ability to feel comfortable around people my age, and I preferred (and almost still do) the company of adults. I also felt incredibly alone at times, not just because I couldn't be with my friends, but because I knew my friends could never understand what I was going through. They would talk about things that happened at school, like boyfriends and other drama that seemed

so important to them, while all I could think of was the boy I had met during one of my inpatient stays and the fact that he had just lost his battle to cancer. The difference between the issues I was dealing with, and those of my friends, made me feel at times like we lived on two different planets; it was hard for me to relate to them.

Emotionally, I have faced more challenges than I can count, most of which were caused by not being in school. I was nauseous, tired and weak beyond comprehension during much of my treatment, that it left me questioning whether or not to give up. The complete lack of social contact was downright depressing, and I had to work very hard to maintain a positive attitude. I found out later that a large percentage of teens take anti-depressant medicine to help overcome the depression they develop during treatment. I felt fortunate never to have needed those.

I managed to overcome all of these challenges with the support from my family, my doctors and nurses, and my home/hospital teacher. The six hours each week with my teacher was my social time. We shared great conversations in-between lessons, and I think it really helped me. Not only that, I used my tutoring sessions and homework to divert my attention from my emotions and the things I was unable to do. It is key, especially for teens, to use the schoolwork to give them something to accomplish, since accomplishing anything during treatment is so difficult. It also gave purpose to my endless days at home. I tried to do my best on all of my work because I knew it would affect my transition back to school. This strategy worked for me; my hard work paid off. When I returned to school, I realized that I had not fallen behind in any subjects. This made the re-entry much easier!

I now laugh every time I hear someone complain about school. NOT being in school is much worse, believe me, and it affected me socially, emotionally, and to a small extent, academically. However, I choose to look at the positive side of life. I am using my experience to help other teens through their cancer journey. I have become vice president of teens.CanSur.vive, a teen cancer support group. I write a blog on teen-cancer.com to help other young people through the emotional challenges of cancer treatment. I also speak at fundraising events for pediatric cancer research as part of my role as a Patient Ambassador for Johns Hopkins Pediatric Oncology.



### A CANCER DIAGNOSIS AFFECTS SIBLINGS, TOO

Excerpted from The National Information Center for Children and Youth with Disabilities

A child's cancer diagnosis profoundly affects the entire family. Siblings must adjust to parents and family members spending large chunks of time and attention on the sick brother or sister. The adjustment can affect the overall development of the relationship between the well sibling and the ill one, and the roles they share.

Perhaps one of the most important relationships in a child's life is a brother or sister. They begin as playmates and are many things to each other throughout life: teacher, friend, companion, protector, competitor, confidant and role model.

### HELPING SIBLINGS ADJUST

Siblings should receive as much information as they feel they need to understand their brother or sister's health needs. They should be prepared for medical procedures and hospitalization, should be included in play activities at home and in the hospital, and given strategies for coping just like everyone else involved.

If you are a sibling to a brother or sister with cancer, please consider sharing your story with others for publication in this newspaper.

Email suzanne@coolkidscampaign.org

### INCLUDING SIBLINGS IN THE EXPERIENCE

There are activities well siblings can do to feel more involved with another sibling's healthcare experience. Away from the healthcare setting, however, parents and caregivers sometimes feel they need the most help with fostering positive sibling relationships.

The responsibility doesn't have to be solely theirs. Child life specialists, nurses, social workers and other professionals can provide suggestions as well as helpful resources on how to effectively maintain a healthy balance between an ill child and his/her brothers and sisters.

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#### SEND WORKER UNDER STREE UNDER

We've discovered a splendid website called **SEND KIDS THE WORLD** ... they provide sick kids' names from around the country for people to mail 'pick me up' postcards to brighten their day. If you'd like to write to one (or more) of the kids, visit their free site! What an easy and happy way to brighten a day of a cool kid!!! Visit sendkidstheworld.com. Help to send kids the world- or at least a happy postcard.

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> M&T Bank Understanding what's important

### How does it work?

<u>**Parents</u>** can sign up their child who suffers from a life-threatening illness. The children will receive cheerful postcards from around the world.</u>

**People** can send postcards to any child listed on the website to offer an encouraging and cheerful note.

<u>**Teachers</u>** can create postcards with their students to send to any child listed on the website.</u>

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Shipping!

elcome 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.

### Check out our website at www.cancerfearsme.org

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

THE NEWLY RELEASED CANCER FEARS

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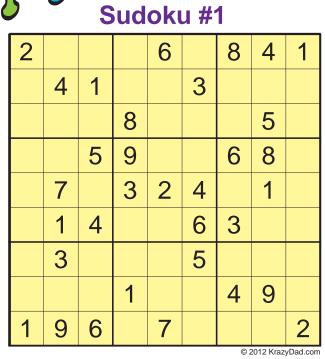
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cancerfearsme.org

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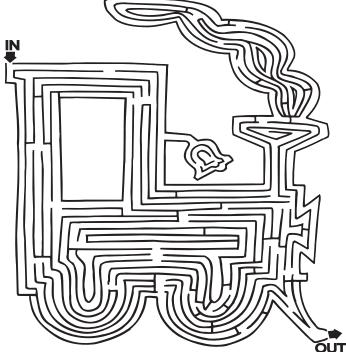
3. Why don't aliens eat clowns?

4. What do you call a fish with no eyes?

5. What do cows do for entertainment?

6. There are two cowboys in the kitchen. Which one is the real cowboy?

ANSWERS ON PAGE 9





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Originally developed for pediatric oncology patients, Kenzie-Covers<sup>®</sup> are non-toxic, breathable, self-sticking, decorative mask covers. Kenzie-Covers are laboratory-tested and printed with FDA-approved water-based inks, featuring a variety of designs to make wearing respiratory masks fun!



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	an also play by yourself! To begin, fill in the blanks below with the first words that rds into the MAD LIBS® story as prompted. It will be much funnier if you DO NOT I see whose story is the silliest!	
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# The country that put a man on the moon can **CUIE CANCEL**.

We've always embraced big challenges in this country. It's how the world sees us. How we see ourselves.

Now, President Obama has called on us to end cancer in our lifetime. America's pharmaceutical research and biotechnology companies share that goal. Today, our scientists are working on 800 new medicines to fight this deadly disease that touches so many lives.

It won't be easy, and it won't happen without a renewed emphasis on innovation and a sustained commitment to research and development. Last year, we invested more than \$65 billion to discover and develop medicines to help patients live longer, healthier and more productive lives. Like President Obama, we believe that America's best days are ahead of us. Working together, we can do anything.



# A MOM'S LESSON IN HUMILI

will never forget arriving at the hospital in Baltimore with our recently diagnosed five-and-a-half-month-old daughter. There was another mother waiting for her daughter's MRI results, and she was chatting away incessantly - animating dull stories, and trying to lure everyone around her into the conversation. Her daughter had Leukemia and the treatments seemed to have become "old hat" to her. Seemed she had already learned how to be on autopilot something at which my husband and I would be experts ourselves soon enough.

The woman stared at me for what felt like hours. We didn't exchange words and our eyes never met – but I felt her eyes on me. Her apparent attention to us was louder than her questions would have been. We were the new family on the block, so to speak. She seemed preoccupied with us, and curious about our story, however, I wanted nothing to do with her. I just wanted to go in, have the treatments for our baby, and go home. I felt extremely annoyed by this person and her intrusiveness, and I purposely found myself giving her the cold shoulder.

 ${f N}$  othing about our situation was pleasant or happy, and I could never have had such a kick in my speech as she did. Her acceptance felt wrong and somehow sinister. I was filled with a grief I had never felt before and the most traumatizing fear I had ever experienced. Worse, my eternally optimistic husband answered "I don't know" when I asked if our baby girl was going to die.

### ~ ANONYMOUS ~

 ${f 0}$ ur daughter vomited often from the chemo and it was very, very phlegmy – almost impossible to wash off our clothes. It stuck like glue. I was nursing her, and she would throw up all the milk I had to offer. I stood for hours in the bathroom at the sink in her hospital room with a toothbrush and a bar of soap, scraping off the vomit from our clothes. Then I laid them flat on the heat vent by the window to dry. There was no laundry facility available. I was just holding out for the day when I could come undone, but it wasn't any time soon.

Une day, the chatty mother showed up in the bathroom doorway as I was scraping away. I was infuriated. What in the world could this woman possibly want? I didn't want a friend in that hospital. I didn't want or need someone to feel obligated to chat with in the cafeteria. I wanted her to go away. She stood with a large garbage bag in her hands.

Give me your clothes," she said in what sounded like a bossy Jersey accent. "I live just 10 minutes from here and I am taking your clothes home to wash and dry. It's no problem. Give me your clothes." We lived more than three hours from the hospital. What she was offering to me was more than a favor; it was sanity. During those long days of treatments, she watched me. She watched me struggle and suffer as she had done. Her role now was to help someone else.

learned an amazing lesson that day, though not without great shame ... the humility, the thankfulness, the embarrassment. Mothers who have children with cancer become the ultimate fixers. We know we can do anything. We develop an unearthly strength that all other mothers think they don't possess - but they do. We become strong and privately proud. We step up to the plate because there is no alternative.

> ${f S}$ omeone once likened it to the story of the mother who lifts up a bus that is pinning her child underneath. Cancer pins down the whole family, but I lifted it off of us - with the help of God - who just might have sent someone from Jersey to me on that day.

The baby portrayed in this story is now 10 years old, living a healthy cancer-free life in Marvland.

<u></u>
MAD CLIBS HOT FUDGE SUNDAE
Making a hot fudge is as simple as one, two,
All you need are the following:
A pint of ice cream
1 jar of fudge sauce
1 cup of nuts
1 can of whipped
maraschino
Scoop the ice into a glass Pour on a gener
ous portion of hotsauce and add a heaping mound of
cream. Sprinkle with and top off with
a/an cherry. Now and enjoy!



The Major League Baseball Players Association tips its cap to the



for their efforts to strike out cancer!

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### 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 8422 Bellona Lane, Ste. 102 Towson, MD 21204

or email to sharon@coolkidscampaign.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.

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cancerfearsme.org

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### COOL CARECIVERS



Like Jake, we also enjoy getting to know new friends. How about you? Take a few minutes to get to know this Cool Kid and Cool Caregiver!



**B**altimore's Jacob Schwaab (you can call him Jake), is age 12 and a fan of Greek mythology. A social butterfly, Jake likes to get to know people and, we're told, loves talking to anyone! This summer Jake and his family are excited to be travelling to Hawaii where they will visit Pearl Harbor and the Bishop Museum and other fun stuff.

Where do you live? Baltimore What grade are you in? sixth How old are you? 12 What is your favorite subject in school? Language Arts What is your favorite food? pizza Who is your best friend? Joshua Who is your favorite celebrity (sport or entertainer)? Eddie Murphy from the movie Doctor Doolittle What do you like to do for exercise? play soccer Do you like dogs, cats, earthworms, or birds? I'm more about frogs and turtles. Do you have pets? We have a dog, Toby. He's a Golden Retriever and Yellow Lab mix. We have two cats – one is orange and named Garfield; the other is all black named Tinkerbell. What is your favorite cereal? Fruit Loops When you grow up, if you could be anything in the world, what would it be and why? A zookeeper, because I like animals.

What is your favorite movie? Percy Jackson and the Lightning Thief Favorite television show? Pokemon; I don't collect cards, though I have a lot of them. **D**r. Peter Shaw hails from Pittsburgh and is quite clearly a huge fan of rugby. (Rugby is a style of football, much like American football, and popular in England and Ireland.) Not only does he enjoy the sport, but he digs the name, too! In the Shaw household, "Rugby" is the name of their 8-month-old puppy.

Where do you live? Pittsburgh, PA

What is your title? Director of the Adolescent and Young Adult (AYA) Oncology Program, Children's Hospital of Pittsburgh of UPMC

What do you do? I am a pediatric hematologist/oncologist who cares for children and young adults from birth through 22 years old with cancer and blood disorders. I focus on ages 15-22 oncology patients to ensure they get the best care, as they often fall through the cracks of the medical system.

What is your favorite thing about your job? My patients and my colleagues.

Least favorite thing about your job? When a patient dies. What time does your normal day start? I wake up at 5:45 a.m.; I'm at work by 7:15 a.m.

What is your favorite sport to watch? Rugby

To play? Rugby and basketball

Do you have children? 3 ... 2 boys and a girl

What do you like to do for fun? Spend time with my family, play with our dog, play sports, watch sports and movies, read books, creative writing (I have written a murder mystery and a screenplay).



- What is your favorite video game? Pokemon What is your favorite sport to play? soccer What kind of music do you listen to? Movie music from Escape to Africa and Madagascar Name a song from that movie? "I Like to Move It" Do you have brothers or sisters? Samantha, age 16 What is your favorite fruit or vegetable? star fruit If you were stranded on a deserted island, what three things would you like to have? A boat, a map, and an oar.
- What are you most grateful for? My family
- What is your favorite book? The Eragon Series
- Favorite author? Christopher Paolini (The Eragon Series).

If you were one of the seven dwarfs, which one would you be? Happy



What is your favorite movie? It's hard to narrow it down to one, but maybe the original "Bad News Bears." Despite some bad language, it should be mandatory viewing for all parents and coaches of young athletes.

What is your favorite book? "The Power of One" by Bryce Courtenay What was your favorite school subject growing up? Social Studies (And in college, I was an Anthropology major.)

Favorite cereal? hot - grits; cold - Booberry

Favorite dessert? Coffee ice cream

Favorite kind of food? I eat anything, but I would say BBQ, especially ribs.

Favorite board game? Strat-O-Matic Baseball

Favorite card game? Poker

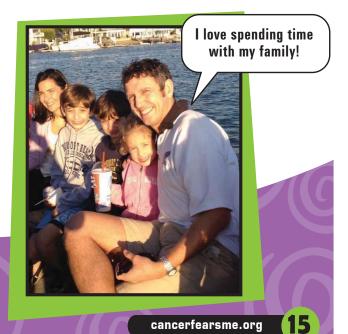
**Cats or dogs?** Dogs all the way. We have an 8-month old puppy named Rugby.

Favorite celebrity? Troy Polamalu. He is so humble and genuine. He comes unannounced to our oncology floor and hangs out with the kids for hours. No press, just him. Celebrities everywhere should take notes on how he carries himself.

Favorite season? Summer

If you could have dinner with one person, dead or alive, who would it be and why? My grandfather, Herbert Peter Lewis, who I am named after; he died just before I was born. He was an engineer and inventor, a crazy sports fan and was in the army in WWII. I hear from my mother how much I am like him. The funny thing is, he didn't like doctors. He said "MD" stood for "Mad Dogs."

What is on your iPod? I have eclectic tastes, but lately I've been listening to Foster the People, Squeeze, the Smiths, Violent Femmes, Spoon, The Who, Radiohead and Toots and the Maytals.





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