Summer 2009

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Connecting Pediatric Oncology Patients Throughout The Nation

#### A Moment in Time

By Elaine "Mom-Mom" Nichols

here would be no other moment in our lives that would immobilize our heart, soul, and spirit as this one.

At this moment, July 14, 2008 at 8:49 pm, this very moment - we heard the words that silenced our world ... "Your precious little boy is sick; he has a brain tumor." My heart didn't break; it shattered into a million pieces.

I could feel every piece drop to the floor. Your Mommy and Daddy trembled with fear. Your big Pop-Pop's eves were distant, and Uncle Joe was so sad; the news was numbing for him.

Little did I know this day would change our lives forever. My beautiful little grandson, 4-yearold Aiden ... we love you more than life itself. You are the joy that fills our days, the little boy that everyone kisses the second they see him. You've pumped happiness into our hearts every minute of every day since you were born. And now with every ounce of my being, I will travel with you on this journey, and pray every day that God holds you in his arms.

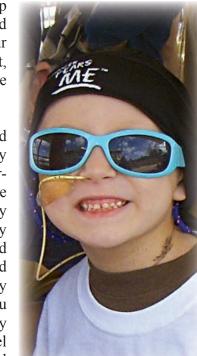
Exactly 24 hours after we learned of your tumor, you underwent brain surgery. The  $3-\frac{1}{2}$ hours waiting for our precious little boy to come out of surgery would start the roller coaster we would ride for the next year and a half. We all gathered in this little room off of the waiting

room. Your amazing surgeon, Dr. Wharf, shared the miracle of the procedure to remove the tumor, how each step was beautifully executed, and then, in his very soft spoken voice, he told us the tumor was malignant – a cancerous tumor. He could not possibly be talking about our little boy, not Aiden, who just two days ago was running, jumping, and

> playing like every other 4-year-old. I wanted to run out of the room straight to you, the littlest love of my life. I needed to touch you, to tell you everything would be okay, that Mom-Mom is here. He could not possibly be talking about our little boy, but he was.

> I knew we couldn't do this alone. We needed prayers, we needed our friends and family, and we needed God to listen to us. I've sent thousands of emails in my life, but no message would be as powerful as this. I would now reach out to our friends and family for their love, support, and most of all, their prayers. I vividly remember tears streaming down my face uncontrollably as I typed the word cancer and Aiden's name in the same

sentence. These emails would be the beginning of our lifeline, our support system, the strength we would need to get us through. Aiden's Angels was created in this very moment. Your angels will travelwithus, providing us the strength we will need every day.





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#### **COOL KIDS CAMPAIGN FOUNDERS**

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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

Aiden's "road to recovery" continues to challenge this little boy every step of the way. The results of the pathology report confirmed the type of tumor, it now had a name: medulloblastoma, the most common malignant brain tumor in children usually between the ages of 4-10 and more often in boys. Sixty percent of all childhood tumors are located in the back of the brain, as was Aiden's. Three weeks ago I had no idea what medulloblastoma was, nor could I pronounce it. Today, it is the first word I see on a page of a thousand words.

This is a very, very scary time for Aiden, and he is trying so hard to figure out what happened. He has so many questions and doesn't quite understand how he could be sick when he doesn't have any boo-boos on the outside of

<image>

Aiden and his mom-mom

his body. He asked me on the way home today, "Why am I sick Mom-Mom?" With every ounce of strength inside me, I gently responded that God chose one of the bravest little boys he knew to help other children feel better when they are sick, too.

"If you weren't sick, you would never have had a chance to meet Justin Clemens, a 5-year-old with Hodgkin's disease; or Stephen, the sick little boy in the waiting room that didn't even know how to play Monster Jam video game. Remember you helped him so he wouldn't crash Blue Thunder?" www.coolkidscampaign.org

I don't think Aiden was quite convinced. I had no real answer as this was the same question I've asked a million times since July 14th.

I've trusted God to guide us through this journey. I've always thought of myself as a caring person, but after being hit by this bolt of lightning, my eyes are open wider, my heart is ready to explode with compassion for those in need.

During the holiday season when faith in God lifts the spirit of humanity, I find myself wondering, could it be that it was not by chance Aiden was given this challenge? Rather, was he chosen? The little boy God asked to help all of us through the trying times we face in the world. To help us understand that the economy will get better, Cheerios always won't be so

expensive, and it's more than okay if your gifts this year are hugs wrapped with your arms. Trust me when I tell you that a HUG will be the best Christmas gift you will ever receive. It will last five loving seconds and fit you perfectly.

Vhy am I sick Mom-Mom?

The new year brought more challenges as Aiden continued to fight the monster. Sitting in the clinic for 6-8 hours each day gives me time to think. As I watched him get hooked up to his medicine, I reflected on the past six months. How could our precious little boy have endured six long months of fighting this disease, battling every step of the way? It became very emotional as I thought about the path Aiden had already traveled. Although we were there for each visit, it was not until I had it in print that I realized how unfair this disease is for every child with cancer. Never in my lifetime did I imagine this data would be part of my grandson's medical history: one major surgery; 12 MRI procedures (six each of brain and spinal cord); one bone marrow aspiration; spinal tap; blood transfusion; six weeks every day of radiation; three cycles, (2-3 days each) of chemotherapy and 20+ weeks of checkups/blood work. Then a half dozen times he got sick, twice he had to have his NG tube replaced, and he had kidney and hearing tests every six weeks as well.

I tried to image a healthy 5-year-old, what his chart would look like for six months: perhaps one doctor visit for a cold; maybe an ER visit for a sprain caused by jumping off the couch or wrestling with his buddy. No, Aiden's chart reads a little different.

It is without a doubt this little boy and every other child going through cancer treatments deserves all their wishes to come true.

It is now about 10 months into Aiden's journey. This week he will start his sixth cycle of chemotherapy sessions. Through it all, he continues his superhero attitude; he has no problem talking about fighting this monster. He will clench his fist and assure you he will beat his cancer! He will never cease to amaze you ... from his medical knowledge to his ability to maneuver an IV pole through the halls of CHOP (Children's Hospital of Philadelphia) like a pro.

We know this disease doesn't care about summer camp or Kindergarten, but for now, we are as happy as any proud family would be. Our little boy is scheduled for camp and registered to start school. Please keep Aiden in your prayers. Pray for clean scans, positive tests, and the strength he'll need to handle the treatments as he prepares to do what all 5-year-old boys should be doing – having fun at camp and starting Kindergarten.

Aiden is every Mom-Mom's dream; he has blessed my life in ways I had never imagined. I thought I had the hugs and kisses mastered, smothering my grandbaby with loving gestures. But not until a monster threatens the "innocence of your baby" will you know your deepest strength. My moments spent with Aiden now are filled with tighter hugs, longer kisses, many more winks, and unlimited amounts of loving stares at his beautiful little face.

Open your mind and your heart, and pray to God that he will heal our little boy and all of the children at C.H.O.P. Pray for strength for the families, and pray for yourselves, too, and thank God he has made you such compassionate and caring people.

Aiden's angels ... amazing family and friends by the very definition of the word!

#### Without leaps of imagination or dreaming, we lose the excitement of possibilities. Dreaming, after all, is a form of planning.

#### EVERY MOTHER WANTS A CLEAN HOME. EVEN MOTHER NATURE.

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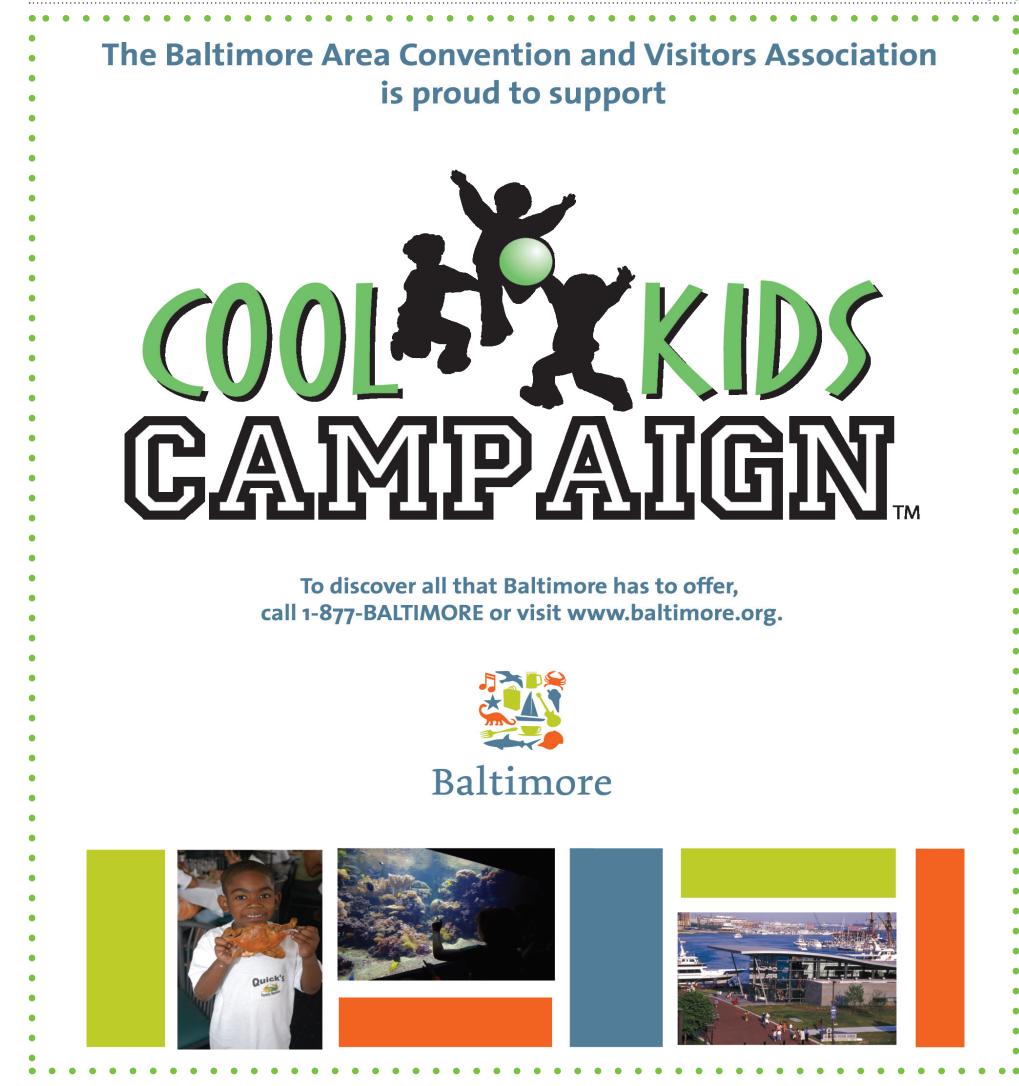


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- Gloria Steinem

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# Cancer Fears My Son Andrew

#### By Shawna Myers

y 8-year-old son Andrew started vomiting, at first every few days, then daily. He was in and out of the doctor's office for the next two months, going through a battery of tests to find the problem.

My baby – a once slender 57-pound boy – was now an emaciated 41 pounds, wasting away right before my eyes.

We awaited the results of a stomach biopsy when I was at home making dinner. Andrew was sitting in the other room.

"Mom, I see two of you," he said when he looked at me. My heart sank. The following day we were back in the doctor's office. Andrew had doctor then informed me they would be sending Andrew for a CT scan. We sat in the waiting room. I said over and over, "He's fine. I know it will come back fine." I think deep down I knew it wasn't fine. This just isn't normal.

Back in the room, the doctor came in and what he said to me will be forever etched in my mind. "We did find a tumor."

I lost it. They took me into another room and tried to calm me down. I caught a glimpse of myself in the mirror - I was unrecognizable. I have to be strong! How can this be? There is no cancer in my family. This can't be real!

The next day Andrew had surgery to remove the ping-pong ball sized tumor from the back of his brain. We waited for the surgeon to come in

## "Are you telling me my son has cancer?"

. . . . . . . . . . . . .

gotten progressively worse over the past couple of days and had to be carried in. The doctor called for the results of his biopsy – normal. I felt like I was going to pass out. This was the last hope before I asked, "Doctor, what are the chances this is neurological?"

"That's the next direction," he responded.

That night I lay in bed with my husband, reading a medical book: headache, vomiting, unsteady gait, double vision ... it sounded like Andrew. What is it?

"BRAIN TUMOR," I said through tears. It just couldn't be!

The next day we headed to Mary Bridge Children's Hospital in Tacoma, Washington. Different doctors came in and out, performing the same tests over and over. Knowing my son was very sick, but still hoping for the best, I wondered why they all kept repeating the same tests? A after surgery ... medulloblastoma was the diagnosis, an aggressive form of brain cancer. I still had to ask the surgeon, "Are you telling me my son has cancer?"

Andrew lay in the hospital bed in the Pediatric Intensive Care Unit, his head wrapped in a bandage, and tubes draining fluid from his head. This is a bad dream, I thought, please let me wake up.

A couple of weeks later Andrew was back in the hospital having a spinal tap – with good results – no detectable cells in his spinal fluid. His final diagnosis: average risk medulloblastoma.

Andrew was set to begin full cranial and full spinal radiation and chemotherapy; the radiation at UW Medical Center.

"He will not be sick the first couple of days," they said. After the first treatment, he couldn't even lift his head off the pillow. We stayed at the Ronald McDonald House, however, Andrew was too sick to enjoy the great things it offered.



I looked forward to the weekends when we traveled home to see our family. That's when I walked into the bathroom, locked the door, turned on the radio, ran the shower, and collapsed on the bathroom floor to cry. No one could hear me. At that moment, I didn't have to be strong.

Radiation was the hardest part of Andrew's treatment. He was put on a feeding tube since he was unable to keep down anything. My once vibrant blonde-haired, blue-eyed boy was slowly wasting away. He no longer was able to live as a child, but was living his life now as a cancer patient. His eyes lost their sparkle, and his hair begun to fall out in chunks.

This is cancer.

Andrew grew a little stronger with the help of the feeding tube, and began intensive chemotherapy next. He was hospitalized the first cycle, then the next two cycles as an outpatient - 48 weeks total. Andrew made it through the chemotherapy, and even attended school and participated in sports. He was very strong and never felt sorry for himself.

Andrew has now been in remission for four years. We face many obstacles from Andrew's medical battle, but he is here with us, and that is most important. Not a day goes by that I do not reflect on all he has been through. My heart aches when I hear of anyone with a cancer diagnosis.

I worry everyday for Andrew's future. I am so very proud of my son – he is my hero!



## Courageous Heroes in the Cool Kids Family By Molly Lauryssens

e've all heard the saying timing is everything. Mackenzie Stuck had obviously heard it because she has displayed the most perfect timing of all. In a small room filled with strangers and celebrity athletes, Mackenzie did not hesitate to give a much-needed hug to uplift the audience.

It happened when John Rozema was talking about the death of his son Johnny to a rare form of cancer. Mr. Rozema mentioned an anniversary date that changed his world –when Johnny first was diagnosed. The anniversary compelled Mr. Rozema to take stock of the past few years.

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"Cancer is a disease and it takes our loved ones from us, but it also gives us the opportunity to get to know that person a little better. I got to know my son very well."

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"When he was diagnosed, my life, my world came to a screeching halt," he said. "I didn't know what to do. I wasn't working at the time, doing odd jobs here and there. The only thing I knew what to do was to be a dad."

Mr. Rozema spoke from his heart; no notes in front of him as he addressed the silence. "I just wanted to be with my boy. Night and day, I didn't care, I was by his bed and I did not feel good until I was there. And oddly enough the only time I felt good was when I was in the hospital, as father and son." If a fly was around, you'd have been able to hear its wings flapping, it was so quiet. "Cancer is a disease and it takes our loved ones from us, but it also gives us the opportunity to get to know that person a little better. I got to know my son very well."

The father spoke of the courage Johnny revealed, how difficult it became at times to keep his life together. He worried not only about paying bills, but more importantly, "How am I going to keep this family together?" Ultimately, Mr. Rozema found support in the Cool Kids Campaign family. What is even more amazing is how he has turned his grief into something special – committed to volunteering for the organization because they never wavered – the same as Johnny's awesome courage.

"This is very therapeutic for me," he said, "to be able to help other families who are going through similar situations." The entire time the man spoke, it seemed at any moment he was on the verge of breaking down in tears. And who would blame him? He did an awesome job speaking of such difficult things. That is, until he mentioned Mackenzie Stuck.

"I walked in here and for the first time in 24 hours ... Mackenzie Stuck was in here with hair on her head and a big old smile. That was ..." Here, Rozema got choked up while smiling at Mackenzie seated in the front row. Her face lit up in response.

"It really brightened my day," he added. Mackenzie didn't hold back and made her way to him. A hug was just what he needed.

"Thank you," he said while holding her. It was spontaneous and beautiful. Suddenly the quiet room seemed to fill with hope and love. The courage displayed in that moment was more breathtaking than watching a million shooting stars.



BATHING SUIT

SHORTS



#### word scarce

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T SHIRT

SANDALS



A mother walked into her son's room and said cheerfully, "up, up, It's time to go to school."

The son replied, "I don't want to go to school." You have to go," the mother said.

"I hate that school. The kids are mean and rotten."

"You still have to go," exclaimed the mother.

"It's like a jungle. One fight after another. They threaten me at least 100 times a day." cried the son.

"You have to go," said the mother

"Why must I go" pleaded the son.

"Because," replied the mother, "You are the principal!"

#### FIND CHIC PHPASIC

To find the phrase fill in the blanks in words 1 through 10 with the correct missing letters to the correspondingly numbered squares in the diagram.

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Answer on page 10



Every row, column and mini-grid must contain the numbers 1 thorugh 9. Don't guess, use logic!

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Answers on page 10



Most people don't know that back in 1912, Hellmann's mayonnaise was manufactured in England. In fact, the Titanic was carrying 12,000 jars of the condiment scheduled for delivery in Vera Cruz, Mexico, which was to be the next port of call for the great ship after its stop in New York. This would have been the largest single shipment of mayonnaise ever delivered to Mexico. But as we know, the great ship did not make it to New York. The ship hit an iceberg and sank, and the cargo was forever lost. The people of Mexico, who were crazy about mayonnaise, and were eagerly awaiting its delivery, were disconsolate at the loss. Their anguish was so great, that they declared a National Day of Mourning, which they still observe to this day. The National Day of Mourning occurs each year on May 5th and is known, of course, as Sinko de Mayo. (LOL!)



Oh no, all these teen stars were in such a rush to get ready for their concerts and shows that they got themselves all mixed up! Can you help them get themselves all sorted out?

> Dylan Lovato Chace Jonas Mitchel Efron Corbin Hudgens Vanessa Gomez Vanessa Gomez Nick Osment Emily Musso Zac Sprouse Demi Bleu Selena Crawford



The best way to destroy your enemy is to make him your friend – <u>Abraham Lincoln, 16th U.S. president,</u> who brought about the emancipation of the slaves, <u>1809–1865</u>

Lots of people want to ride with you in the limo. But what you want is someone who will take the bus with you when the limo breaks down. – <u>Oprah Winfrey</u>

When you believe in a thing, believe in it all the way, implicitly and unquestionable. – <u>Walt Disney, US</u> <u>motion-picture producer, pioneer of animated</u> <u>cartoon films. 1901–1966</u>

Twenty years from now you will be more disappointed by the things you didn't do than by the ones you did. So throw off the bowlines, Sail away from the safe harbor. Catch the trade winds in your sails. Explore. Dream. – <u>Mark Twain, American humorist, writer</u> <u>and lecturer, 1835–1910</u>

Freedom is not worth having if it does not include the freedom to make mistakes. – <u>Mahatma Gandhi, Indian</u> <u>leader, internationally esteemed for his doctrine of</u> <u>nonviolent protest, 1869–1948</u>

The ultimate measure of a man is not where he stands in moments of comfort, but where he stands at times of challenge and controversy. – <u>Martin Luther King, Jr.,</u> <u>Baptist minister who led the civil-rights movement in</u> <u>the US, 1929–1968</u>

Optimism is the faith that leads to achievement. Nothing can be done without hope and confidence. No pessimist ever discovered the secret of the stars or sailed to an uncharted land or opened a new heaven to the human spirit. – <u>Helen Keller, American author and</u> <u>educator who was blind and deaf, 1880–1968</u>

Courage is the most important of all the virtues, because without courage you can't practice any other virtue consistently. You can practice any virtue erratically, but nothing consistently without courage. – <u>Maya Angelou,</u> <u>African-American poet, 1928–</u>

You can't always sit in your corner of the forest and wait for people to come to you... you have to go to them sometimes. – <u>Winnie the Pooh, the best bear ever!</u>



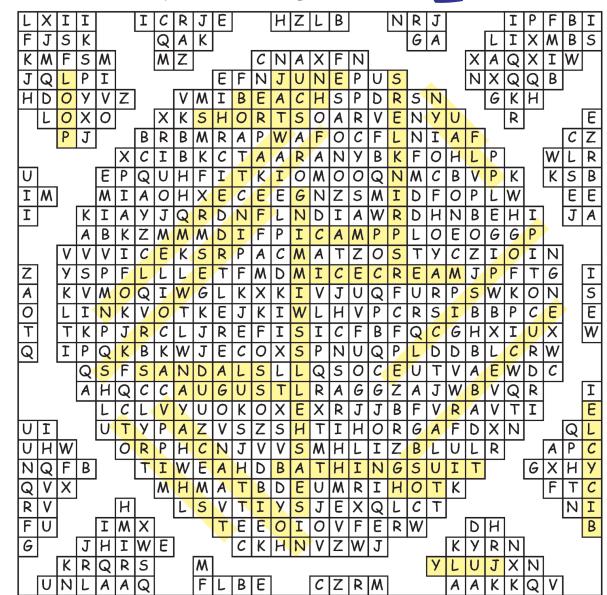
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Answers to the **COOL KIDS** Games & Trivia



Answer: Cancer Fears Me!







Answers: Dylan Sprouse Chace Crawford Mitchel Musso Corbin Bleu Vanessa Hudgens Nick Jonas Emily Osment Zac Efron Demi Lovato Selena Gomez An amazing thing happens when you give to the community. It gives back. At M&T Bank, we know how important it is to support those organizations that make our communities better places to live, work and grow. That's why we offer both our time and resources. What we all get in return is far more valuable.



- Marie Curie

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or email to sharon@bfpf.org

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

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

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## Show off your strong, positive attitude towards cancer!

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 <u>www.cancerfearsme.org.</u>
- Check out our Cancer Fears Me video on You Tube!
- Just search for Cancer Fears Me

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HAIR BY CHEMO

My 10 year old daughter, Danielle, was recently diagnosed with metastatic osteosarcoma. The hospital gave us the "Cancer Fears Me" cap and we love it. The saying has empowered us. I just wanted to thank you for your vision and creating hope for those of us who felt we had none. Because Danielle's cancer was metastatic at the time of diagnosis (20 spots on her lungs), she was given a very, very poor prognosis. After 2 rounds of chemo, those 20 spots have disappeared. She is responding incredibly well and we know in our hearts she will be triumphant. We

have had so much support from family, friends, neighbors and strangers it is overwhelming. You should feel so proud of the work that you do and the hope that you give. -- Sandra K., mother of Danielle.

e all wore our Cancer Fears Me stuff our first day at the Magic Kingdom and in the GKTW Village. Everyone asked about them. What they meant, where to get them, etc. Here are some pictures of us in our fabulous CFM gear!! - Susan D., mother of Kayla D.

> his is my daughter, Skyler, wearing her Cancer Fears Me caps during last years treatment. She put them away when her hair started growing back in January but now that it has fallen out again due to her ongoing treatment, she pulled them out again and is happily wearing them. Lately, she loves to wear them at bedtime as a nightcap!!!! -- Pamela H., mother of Skyler.

> > a strong, **positive** mindset for those **living** with cancer, their **Support** groups and caregivers

*ne likes cats: the* other prefers dogs although she's allergic. One likes Lord of the *Rings and the other* fancies Mary Poppins. When it comes to cereal, Trix tops Sofia's list, and Honey Nut Cheerios is where it's at for Christina. These girls do have one thing in common – can you figure it out? Have fun reading the Cool Kids Connection questions, and the answers from Sophia and Christina. Then think how you would answer the questions.

What other questions would you enjoy answering, too?

# Cool Kids and Cool Caregivers

### Christina J. Liu

- Where do you live? San Gabriel, CA
- What is your title? Child Life Coordinator

*What do you do?* I try to make things as easy as possible for children and their families while they are in the hospital. I give them emotional support to help them cope with the hospital experience by providing play opportunities, and explaining tests and procedures in a developmentally-appropriate manner to try to decrease their anxiety and fear of the unknown. I also support and distract children during tests and procedures and provide support to siblings and other family members.

- *What is your favorite part about your job?* Seeing a scared child smiling, laughing, and playing ... being a kid. Connecting with families and helping them through a time that can be very scary.
- Least favorite thing about your job? seeing children in pain and families grieving
- What time does your normal day start? 8:30 a.m.
- What is your favorite sport to watch? all kinds
- *To play?* swimming
- **Do you have children of your own?** not yet
- What do you like to do for fun? Hanging out with family and friends, eating, watching movies, reading and dancing
- What is your favorite movie? Lord of the Rings
- What is your favorite book? The Bible, my manual for life
- What was your favorite subject growing up? art
- Favorite cereal? Honey Nut Cheerios
- Favorite dessert? tiramisu
- Favorite kind of food? Italian
- *Favorite board game?* Apples to Apples
- Favorite card game? Nertz it's like Solitaire and Speed in one ... fast and crazy!
- Cats or dogs? definitely dogs ... but I'm allergic to them
- Favorite celebrity? Tom Hanks such a good actor
- *Favorite season?* spring
- *If you could have dinner with one person, dead or alive, who would it be and why?* Jesus I would love just to sit at His feet like Mary and listen to Him
- *What is on your iPod? If you don't have one, what CDs are in your car?* Christian worship, '50 First Dates' sound track, Ella Fitzgerald, Jack Johnson, Yo Yo Ma, and an anniversary CD my husband made



FAD STAFF

#### What do all these sentences have in common?

Madam in Eden, I'm Adam

A dog! A panic in a pagoda!

A man, a plan, a canal, Panama!

Ma is as selfless as I am.

Pull up, Eva! we're here! Wave! Pull up!

#### Stumped??

They are all palindromes, meaning they read the same front to back as they do back to front!

