

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION Going Bald for Childhood Cancer

WINTER 2015
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coolkidscampaign.org

All over the world, hundreds of thousands of people are being brave and shaving their heads for childhood cancer. Parents. siblings, family members, and friends are all stepping up for a child they know fighting cancer. These head shaving events are fundraisers for the St. Baldrick's Foundation, which is the largest private funder of childhood cancer research grants. St. Baldrick's Foundation. established in 1999, is a nonprofit committed to raising money for childhood cancer research. Its mission is to find cures for childhood cancers and to give survivors long, healthy lives.

According to St. Baldrick's Foundation, there are 9,797 fundraising events planned for 2015 and 488,274 people have committed to shaving their heads. So far in 2015, the foundation has raised \$13,243,591 with so much more coming in! Last year, St. Baldrick's raised \$38,955,025.

Since its inception, St. Baldrick's Foundation has funded 820 grants at 329 institutions in 22 countries. The first ever head shaving event was held on March 17, 2000 as part of the St. Patrick's Day Party parade at Jim Brady's Pub in Manhattan. That is why many of the St. Baldrick's head shaving fundraisers are held in the month of March. For more information or to get involved, visit www.st.baldricks.org.





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"Mom, dad, we're going to cure this!" In early February 2014, we heard those unforgettable words from our surgeon just 48 hours after Olivia's stage 4 cancer diagnosis and just one day before her emergency surgery to remove her right kidney.

But those incredibly positive and promising words were met with mixed reactions from us. I smiled immediately and raised my hand to deliver a triumphant high-five to the surgeon. But my husband, Luke, burst into tears overwhelmed with emotion from the onslaught of bad news and life-changing circumstances of the last two days.

How did our symptomless, seemingly healthy 4-year old girl with a tummy bloat and sudden loss of appetite become a Hopkins pediatric oncology inpatient? A Friday afternoon trip to the pediatrician's office had turned into a walk to the ER, a CT scan revealing a kidney tumor, an ambulance ride to Hopkins Children's Center, and multiple visits from teams of nurses, oncologists, and surgeons to our suddenly claustrophobic new inpatient room.

After days of scans and analysis to determine stage and attachment of the tumor, we were finally hearing perhaps the most promising and best news we had heard yet. The nearly two pound tumor that had taken over our daughter's right kidney and reduced its function to only 40% was operable and coming

out the following day. The cancer that had spread to her lungs could be treated with outpatient chemo and radiation, and fortunately, her brain was unscathed.

We were both perplexed, and despite the constant stream of the same information coming at both of us, we couldn't be dealing with it more differently, which was a new discovery after seven years of marriage. And thus began our emotionally dichotomous journey of Olivia's Awesome Future.

Throughout Olivia's surgery, inpatient recovery, radiation and chemotherapy treatments over the next 7 months, I, as mom, took on the role of organizing, appointment calendaring, refilling prescriptions, and anticipating answers to the tough questions from my inquisitive preschooler. Luke provided us all the emotional comfort, security, continuity, family adventures and traditions, the special father-son bonding for our 3-year old son, and most importantly, the reminders to celebrate every single milestone and victory.

I remember one of the first nights in the hospital, Luke said something like: "It's okay to feel, you know. It's important that you let yourself feel and that Olivia sees it, too." I nodded my head understanding what he was saying, but responded "I need to be strong for her, so she doesn't worry. I can reflect, feel, and



cry after she falls asleep." "Well that's not healthy," Luke said. He was right, but as a mom, I felt I had to be strong for Olivia in a different way.

I learned somewhere in life to deal with trauma and tragedy with equal parts positivity and logic. At Hopkins, when I saw my husband's emotional reactions to the information, I snapped into crisis management mode thinking I had to have laser focus attention-to-detail and absorb every morsel of information from our doctors that I thought he must be missing but wasn't.

I wanted to know and understand everything and had to work a little harder to retain and understand all of the information. I thought the more information I had, the better I could understand the root of this mystery. Moreover, I might be able to stay two steps ahead of my perplexed 4-year old who was hanging on my every word, tone, and facial expression for affirmation that everything was really as "okay" as I was repeatedly claiming it to be. My tone and feeling had to match my words. My confidence would give her assurance. I knew even if she didn't understand everything discussed and explained by the doctors at her bedside, she could certainly understand our reactions.

We also had to tell Olivia the truth. We had to be ready to tell her the truth about Wilms Tumor, the surgery, the sick cells, the needles, the hair loss, and why each of her medications in the big basket on the kitchen counter were important.

Our honesty with Olivia immediately sealed her trust in us as parents. It also gave her an education about the human body and an insatiable curiosity about cancer that she excitedly shared with her classmates, when she could attend pre-school. She had to get a new human body book for "show and share" and she demonstrated at circle time how to draw a kidney shape with her finger in the air. She assisted her Child Life Specialist and comforted other pediatric oncology kids nervous about getting their new ports accessed. Later in kindergarten this year, her bulletin board artwork professed her favorite part of her was her port "because she doesn't have to feel any needles."

In hindsight I see now that Olivia's childlike reaction, completely different from her parents' binary coping styles, was likely not because we phrased answers perfectly or upheld our weekly family farmer's market trip. We foolishly thought that our reactions and responses would shape her experience—not at all. How ironic that while I was organizing and Luke was feeling—Olivia was celebrating and living the very best of this terrible illness. The same information that gave Luke and me so much grief and anxiety only empowered her. She saw it as a wonderful opportunity

to learn about her body, share triumphs with others, and her favorite part: meet some of the best and brilliant people ever, our medical staff.

Among the many other lessons that we have learned from our courageously, awesome daughter during her cancer battle and ultimate victory is that whenever possible, we all should fight life's hardest battles with childlike optimism and resilience or be "present in the moment" as my yoga-practicing husband might say.

If you ask her, Olivia will tell you very matter-of-factly that she simply "kicked cancer's butt," but it is how she did it that makes us the proudest parents in the world.





the doctor to get checked. I had been skeptical of doing this; I was afraid the doctor would think it was ridiculous to think a baby that small was having back pain. I decided to take her. The doctor said she was doing what a normal 5 month old should and thought maybe a bit more tummy time would be helpful.

Two weeks after taking her to the doctor, I experienced a day that never ended. I will spare all the details here but try to paint the picture: My husband was traveling for work. I took three kids to run errands by myself. First, we went to the grocery store which was chaotic then to the library which was even worse! Kids were melting down crying and running away. We ended the day with ice cream at Dairy Queen with our church small group. I told my small group about the horrible day, but still remained positive because I knew tomorrow would be a new day. Leaving Dairy Queen, my two year old got his hand stuck in the van door. Our Pastor and a good friend were able to get the door open and praise God his hand was okay. After that, I finally went home to put an end to that day or so I thouaht.

Some of our dear friends and their children were staying with us for the night while they had some home remodeling taken care of. I told my friend about this terrible day and then said, "So now I keep going up to check on Cedar and make sure she's okay because I'm not sure what will happen next!" Shortly after this, Cedar woke up. While holding her, I saw that her feet were hot, red, and swollen. My friends suggested I take her to the ER; they were gracious enough to watch my boys while I did this. God had perfect timing in allowing them to be staying with us the very night my husband was out of town and my daughter needed to be rushed to the ER. After a few hours, they decided to transfer us to a nearby children's hospital.

Within 24 hours of being in the hospital, Cedar stopped moving her legs and had no pain sensations. An MRI was scheduled right away. The results revealed a tumor pressing on her spinal cord which caused her to become paralyzed. At 2 a.m. the following night, a neurologist and oncologist walked into our room. They told us they would like to perform a surgery right away to remove the portion of tumor pressing on her spinal cord in hopes of reversing her paralysis. The oncologist told us a biopsy of the tumor would be taken in order to give us an official diagnosis. I remained calm; I was so thankful we had a plan and we could heal Cedar. I had no idea what our life would look like, nor how much our lives would change due to this diagnosis.

The emergency surgery happened right away and Cedar was returned to us in the morning. The neurosurgeon felt that the surgery went well. The tumor was removed and sent off for biopsy. Her paralysis, however, was not reversed. We were told that only time would tell what movement and feeling she would have. We looked at Cedar's incision together for the first time with the surgeon. I was not prepared for this! With so many surgeries being laparoscopic and knowing the size of her tumor, I had the image of a two inch incision in my mind. Instead, I saw stitches down the entire length of my baby girl's back. It was intense. Shortly after this, I held my sweet baby for the first time after her surgery. I was so careful knowing that she had just endured major back surgery. I cradled her in my arms and prayed for her.

Next, we were given the official diagnosis: Neuroblastoma. At this time we also received Cedar's treatment plan of eight rounds of chemotherapy, which she began right away. Cedar did fantastic. Her tumor responded positively to the therapy and she finished her treatment in about six months. During that six month time span she had a few bumps in the road like an unplanned central line removal and a PICC line to replace it. She also developed an abscess on her spine where a suture had not dissolved properly; this resulted in another major back surgery. Through it all, she kept the joy she was born with and brought us more smiles than we could count.

Her brothers were terrific. They continued to adore their baby sister and her little bald head. They loved on her in the hospital and in the comfort of our own home. They now have vocabularies that include the words tumor, chemotherapy, heparin, paralyzed, orthotics, and cancer. They have had to be the most germ free boys, using sanitizer stations set up throughout our home and wearing masks when they had a cold. They watched and helped when we changed her bandages, flushed her lines, and gave her shots. Through it all, they never complained; they only supported and loved their sister. Cancer doesn't only affect the patient; it greatly impacts the lives of those around the patient. My sweet boys will have broader minds and fuller, more open hearts. They have grown tremendously through this journey.

Today Cedar is almost 2 years old. She is strong, determined and as joyful as ever. She dances, plays with babies, laughs and loves just like every little girl!

Even though we are out of treatment, our battles are not over. We go every three months for scans, we have weekly physical therapy sessions, and we are trying to figure out how to give our paralyzed toddler the most normal life we can. We don't know what tomorrow will be like; we have anxiety around every set of scans, but we are confident that God has a plan for her life. We know that she will succeed and that this is just the beginning of many obstacles she will conquer. I often turn to a quote from Scott Hamilton: "The only disability in life is a bad attitude." Life is full of ups and downs and unexpected events and trials. If we keep a positive attitude and joy in our hearts, like Cedar was born with, our lives will be much more fulfilling.



The country that put a man on the moon can

cure cancer.

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

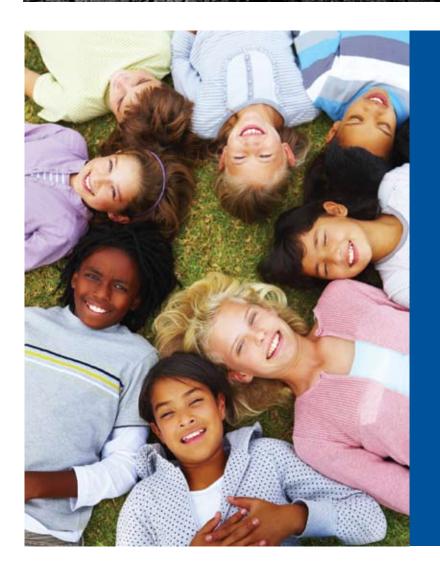
Now, President Obama has called on us to end cancer in our lifetime. America's pharmaceutical research and biotechnology companies share that goal. Today, our scientists are working on 800 new medicines to fight this deadly disease that touches so many lives.

It won't be easy, and it won't happen without a renewed emphasis on ipnovation 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.

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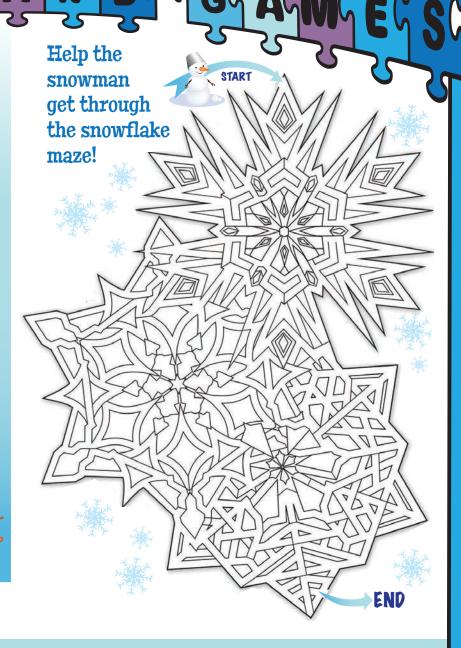
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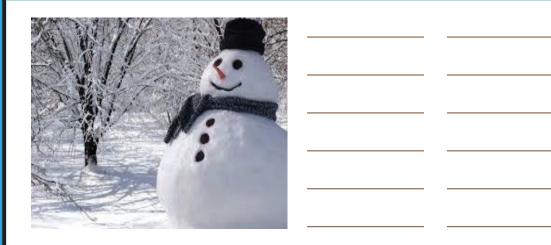
HIBERNATE MIGRATE PENGUIN POLAR BEAR SNOWFLAKE

HOT CHOCOLATE SNOWMAN **CHILLY FIREPLACE FROST**

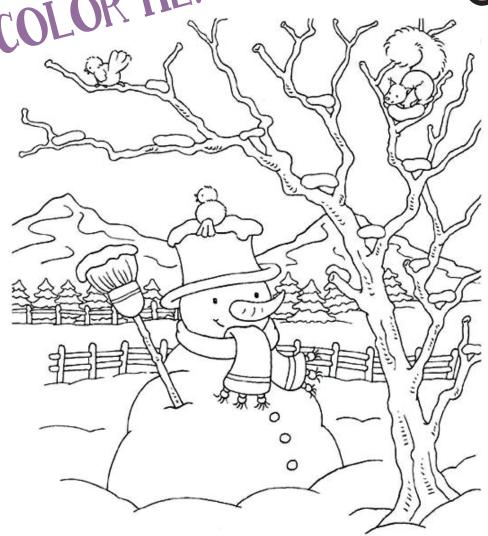


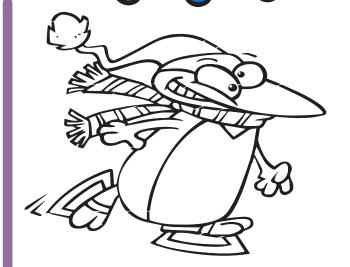


See how many words can you make out of: WINTER WONDERLAND



BYRACING THE ALSTEY







O K D O C

Place a number between 1 and 4 in each empty cell so that every row, every column and every 2x2 box contains all the numbers 1 to 4.

1	4	
4	2	
2	3	
3	1	

 $Place\ a\ number\ between\ 1\ and\ 6\ in\ each\ empty\ cell\ so\ that\ every\ row, every\ column\ and\ every\ 2x3\ box\ contains\ all\ the\ numbers\ 1\ to\ 6$

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ANSWERS:						
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MINDS BENNY DE RYS

Unscramble these WINTER words

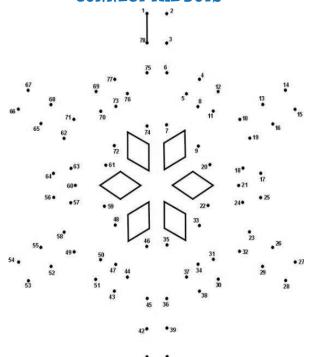
ANSWERS: 1. COLD 2. HEATER 3. COAT 4. SEASON 5. SNOW 6. 10. FREEZE 11. SNOWFLAKE 12. FROST

1. LOCD	 7. CIE	
2. ETAHER	 8. SARFC	
3. ATCO	 9. IDLAZRZB	
4. AOENSS	 10. EZREFE	
5. WOSN	11. LKNEFWSAO	

12. TRSFO

CONNECT THE DOTS

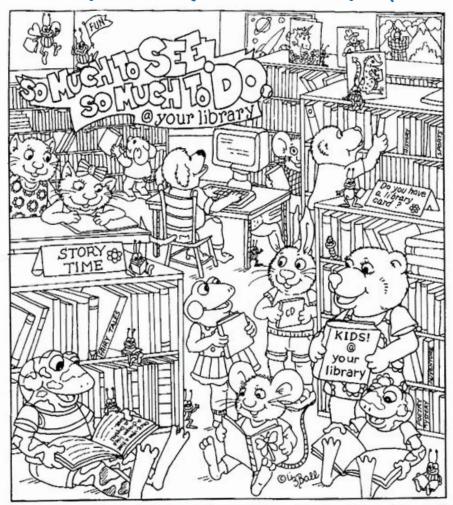
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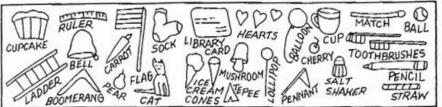


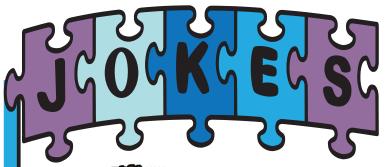
Snowflake Fun Facts for Kids

- Snow is a form of precipitation like rain and sleet.
- To snow, the temperature must be below 32 degrees.
- Snowflakes actually start as tiny ice crystals that form from water vapor that freezes in the atmosphere.
- The size of a snowflake depends on how many ice crystals connect together.
- Each snowflake is made up of about 200 ice crystals.
- Snowflakes have six sides.

After finding the hidden objects, have fun coloring this picture!











TWISTIN' THE TONGUE



What time does the wristwatch strap shop shut?



Old oily Ollie oils old oily autos



Why do bicycles fall over?

How does the ocean say hello?

Because they're two-tired!

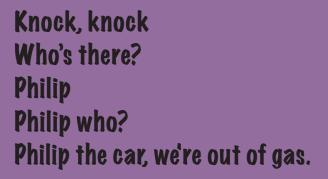
What's a boxer's favorite drink?

What kind of underwear do reporters wear?

letaind ewaN

JOKES Knock Knock

Knock, knock
Who's there?
Nun
Nun
Nun who?
Nun of your business!



Knock, knock
Who's there?
Cargo
Cargo who?
Cargo beep, beep!

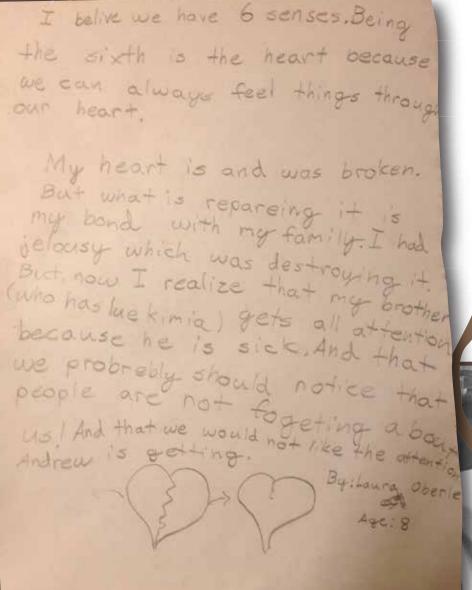


Laura's Poem

Written by Laura Oberle

Children who have a sibling with cancer are thrown into a world where they are quickly introduced to the sterility of hospitals, the helplessness of waiting, and life altering changes in their family. Having a brother or sister with cancer can be challenging in different ways. At times, siblings may feel invisible, angry, alone or even forgotten. It's important to recognize that siblings are unique and special – and that they need support, too!









JAKE'S KICKIN' IT!

CANCER PICKED THE WRONG NINJA

BY: Leah Offutt, Jake's Mom Westmister, MD

erseverance means to never give up and to face challenges head on. This is the description of our son, Jake. Jake has been training in martial arts since the age of five and is currently a second degree black belt in Taijutsu. Jake knows the true meaning of the word perseverance and is a true warrior. To his parents though, he is also a hero. Jake has had to go through some huge challenges since December 17, 2014 – challenges that none of us ever suspected. He has handled it all with dignity and a fighting spirit.

Jake has suffered from migraine headaches since the age of 6. They did not happen often but when he did get them, he would have to stay in bed and try to sleep it off. As the years went by, his migraines increased in frequency. When Jake was 10, his dad and I decided to take him to a pediatric neurologist. Our first appointment with Dr. Christopher Oakley was on December 17, 2014.

December 17, 2014 is a day that will forever be etched into our memories. It is a day that changed our lives forever. During our visit, Dr. Oakley did a physical exam and found some things that concerned him. He asked Jake to follow his finger with his right eye and his eye jumped side to side. He repeated the same

procedure on the left and his left eye jumped side to side. When he was asked to smile, only the left side of his mouth went up. When asked to raise his eyebrows, only the left brow went up. My husband and I had never noticed this before. As his parents, how could we not have noticed something so drastic? Dr. Oakley told us to go to the emergency room right away for several tests. At that point, my husband and I knew something was seriously wrong.

Jake's MRI test came back with news we were not prepared to hear. I will never forget the doctor coming in to tell us that it showed a mass on his brain stem. They put a call in to the pediatric neurosurgeons to come in to talk with us because the tumor would need to be removed. I remember the look on Jake's face and him asking if this meant he had cancer. It was an answer I couldn't give him. We wouldn't know until the tumor was out and pathology reports came back. It was going to be a very long wait.

Jake had his surgery on December 19, 2014 at Johns Hopkins Hospital performed by Dr. Jallo. Prior to his surgery, Dr. Jallo warned us that while Jake's paralysis was on his right side, when he came out of surgery, it would get worse before it got better. We were also told

that he would most likely have a breathing tube, tracheotomy, and feeding tube.

That day, Dr. Jallo was able to get 90-95% of the tumor. We were told that based on what he took out it looked like a low grade benign tumor. When we got to go see Jake, tears stung my eyes. My son did not have a breathing tube, a tracheotomy, or a feeding tube. He reached his arms out and asked for a hug. That was music to my ears. Dr. Jallo was right about the paralysis. He did not have any movement of his facial muscles. This, of course, affected his speech too. None of that mattered though because he could talk to us! He fought his way through that surgery and proved the doctors wrong!

Jake spent a total of seven days in the hospital. Once he was out, we started physical therapy and speech. He persevered through each of them and continues to do so. He had an incredibly busy schedule and yes, he complained sometimes, but he kept fighting.

We waited almost a week and a half for the pathology report to come back. We entered the meeting with the oncology team expecting to hear that it was a low grade tumor. We knew we may need to do some





chemo or radiation to make sure the rest of the tumor was destroyed, but we were not prepared for what we did hear.

Joe, Jake, and I sat in the meeting with three oncologists and a social worker. Jake's oncologists, Dr. Young and Dr. Ahsan, started from the beginning and went over what the tumor was, how it was discovered, and what the pathologist found. It turned out that his tumor is a glioma tumor and between a grade 3 and 4. It is fast growing, aggressive and hard to cure. It was our greatest fear.

To be told that your child has a very aggressive form of brain cancer was not something we were prepared to hear. I sat in the meeting taking very detailed notes while tears rolled down my cheeks. I needed to take notes because I knew once I left that room, I wouldn't remember what was said. I needed to rely on the notes I took to help me understand what the doctors were telling us. They informed us that Jake has Anaplastic Astrocytoma. He would need six weeks of radiation and chemotherapy.

Even after sitting in that meeting and feeling devastated, Jake walked out like a warrior ready for battle. This is not to say that he has not had his moments of sadness or anger, but the level of maturity that he has displayed in this situation make me look at him with so much respect. My husband and I frequently say we could never handle all that he is going through the way that he handles it. He is so inspiring to all who know him.

Jake began his radiation and chemotherapy on January 23, 2015. He had a very rough start due to the location of his tumor and his history of migraine headaches. The radiation causes swelling in his brain which unfortunately results in migraine headaches. After Jake's first treatment, he was very sick and ended up being hospitalized because he couldn't keep anything down and had a severe migraine.

Over the course of the treatment, Jake has had a few trips to the ER due to his migraines. They become severe enough that the medication we have at home doesn't work and he needs something stronger. Jake is on a steroid to help with his brain swelling and will remain on it throughout his radiation to help lessen the frequency of his migraines. The problem is that being on the steroid trades one set of problems for another. Jake is on a large number of medications for his migraines but we hope that once radiation is finished and the swelling starts to go down that we can start weaning him off some of them. For now, it is all about making him comfortable and helping him to get through this process. We have a few weeks of radiation and his first round of chemo left. We are looking forward to his first scan showing positive results from his treatments.

We have been so blessed by the community we live in and the good family and friends that we have. Many people talk about how they look up to Jake because his experience is teaching them what is important in life and to let go of the little things that have been bothering them. Jake has touched so many lives through this horrible life changing event. He has brought out the good in people, inspired others to look at things in a more positive light, and has taught others what it means to care about other people. Jake is a hero to both Joe and me. He inspires us to persevere, just as a true ninja would do.

For updates on Jake's progress you can go to http://www.caringbridge.org/visit/jakeoffutt or www.jakeskickinit.com



What is this symbol?

It is the Japanese Kanji symbol for heart and sword. It means perseverance or to never give up. Basically the meaning is that even when faced with an impossible situation you should never give up no matter what.





Ray Lewis (Baltimore Rayens retiree) makes a surprise hospital visit and cheers Jake up before his surgery.



An avid Baltimore Ravens fan, Jake is presented with an autographed Terrell Suggs photo.



COOCAREGIVER & COOKID

Victor Mazzanti is a Registered Nurse at Children's National Health Systems in Washington DC and works on the Hematology/Oncology Care Unit where he first met 11 year old Kathryn Quizhpi. Read more about both of them below!

Victor Mazzanti

Stafford, Virginia

What is your job title? What do you do? I'm a Registered Nurse at Children's National Health Systems, Washington D.C. and I take care of sick children.

Favorite part of your job? My favorite part of my job is making a difference in a child's day if even just for a moment.

Least favorite part? The least favorite part of my job is being there when a family is told their child has cancer or when a child is informed they have no other treatment options available.

What do you enjoy doing for fun? Golfing and fishing with my three sons and shopping with my wife.

Favorite movie? Against All Odds

Favorite TV show? The Voice

Favorite board game? Risk

First thing you learned to cook? Boxed spaghetti

Were you named after anyone? Yes, my dad

Beach or mountains? Beach all the way

Favorite quote? Live in the moment

What do you miss about being a kid? Being young

What is one thing on your bucket list? Travel to Lucca, Italy

Have you ever been admitted to the hospital? Never

What's the scariest thing you have ever done? Riding roller coasters

If you could have one superpower, what would it be? To live forever and never grow old.

How would you spend a million dollars? Pay off all my bills and give to people in the moment by buying them dinner, groceries, tickets, etc.

What celebrity do you admire and why? Brad Pitt because he is so giving.

If you could have dinner with one person (alive or deceased) who would it be and why? My dad because I miss him.

Kathryn Quizhpi

Chester, Maryland

What grade are you in? 5th grade

How old are you? 11 years old

If you wrote a book, what would it be about? Facing and fighting cancer

What do you want to be when you grow up? A nurse

Do you have brothers and sisters? What ages? 2 brothers – age 9 and 24, 1 sister – age 22

What do you like to do for fun? Draw

Favorite subject in school? Math

Who's your BFF? Caroline and Taylor

If you were the President of the U.S., what would you do? Help the Spanish people.

Favorite movie? Jack and Jill

Favorite TV show? Uncle Grandpa

If you were stranded on an island, what 3 things would you have with you? Clothing, camera, and family.

If you could meet someone famous, who would it be? The Rock

What question would you ask him? Can I be in a movie with you?

If you could have any superpower what would it be? To fly

Favorite ice cream and toppings? Strawberry with rainbow sprinkles

What age do you consider old? 60

Do you collect anything? SpongeBob toys

Least favorite chore? Washing clothes

If you could learn anything, what would it be? Flips

What's the scariest/craziest thing you've ever done? Going through chemotherapy.



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Myrtle's Magical Beach Vacation





Cool Kids Campaign is offering pediatric oncology families accommodations in our Myrtle Beach condo free of charge for eligible families. This program is designed to allow the families a Chance to get away from their daily routines and reconnect with each other.

> For more information, call 410-560-1770 or Visit coolkidscampaign.org



The Major League Baseball Players Association tips its cap to the



www.MLBPLAYERS.com



Send us your stuff and become a published writer or artist! Send us your stories, art, poetry, photos, and anything else you want to see in print! Email all submissions to katie@coolkidscampaign.org or mail to Cool Kids Campaign, 8422 Bellona Lane, Suite 102, Towson, MD 21204. We can't wait to hear from you!



Shop for a Cancer Fears Me® chemo cap and other Cancer Fears Me® merchandise at cancerfearsme.org



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