That is what parents of sick children do - sometimes in a single day. I feel fortunate that I had front row seats to watch my parents consistently show their strength of character in times of severe heartbreak with their own son. They taught me what true resilience is and to consciously search for your blessings. With that life lesson, I looked at our tiny boy in that big hospital bed and I set a personal goal: to have fun whenever possible, even when it seems impossible. When I spoke my declaration aloud to the hospital counselor during our initial diagnosis discussion, she responded with words of shock and a “Go ahead and try, lady” look in her eyes. But it was simple to me, a child’s primary goal in life is to have fun and this would be my goal now too.

Ben’s full story on the following page.
I heard a quote the other day and it resonated with me. “Luck isn’t about getting what you want, but surviving what you don’t want.” My son survived 1,179 days of daily chemotherapy treatment. He’s happy, he’s playing sports full throttle, and he’s back in school. So, yes, we are lucky. My definition of the word luck has infinitely evolved from four years ago.

The words “Your son, Ben, has leukemia and will undergo 3.5 years of daily chemotherapy starting tomorrow” makes the floor instantly fall out from under you and the world start to spin. Our lives would forever be divided between before leukemia and after leukemia. I watched my parents care for my brother who was born with an ultimately fatal kidney disease, so I intimately knew the road we were about to travel. I naively assumed my brother paid the dues for my children in his short lived 22 years of life, but unfortunately, no one is keeping score. Our son was 5 years old and had just started Kindergarten. He would emerge from this tornado a fully formed 9 year old fourth grader. How would I make sure he becomes the person he was destined to be? How do I protect him from the pain? How can I keep him happy and not bitter? And the wheels in my brain started to turn.

Ben and I have shared some crazy funny memories during the last few years – some of which we couldn’t reveal to the nurses for fear of being kicked out of the hospital. That was the sweet spot for me – to find those moments where you have choices. Do I indulge in self-pity or do I search for the humor? Do I follow the rules or act like a total idiot? Should my son swallow his pills normally or do I playfully throw it across the room hoping it lands in his open mouth like hibachi broccoli? (Note: the latter results in many lost pills which upsets the nurses, so I wouldn’t recommend it).

I wanted to teach my son that he too has choices. Many days felt like running a marathon with broken legs, I promise you. But, selfishly, I noticed that this altered perspective created a positive shift in me as well. In turn, we were making joyful memories that would someday outshine the treacherous ones. Yes, cancer was stealing happy moments that my son so rightly deserved. But, when it wasn’t looking, we stole them right back. Now Ben and I will hear random quotes and just look at each other, smile, and hug because we share a secret.

Our latest exchange is: “Sometimes you don’t need to walk in another person’s shoes to know how they feel. Sometimes, the best thing you can do is sit beside them.” For us, that meant if Ben was able to get up between vomiting sessions and sail down the hall dancing on his IV stand, then I needed to get over my sad self and boogie down right alongside him. Ben was young and impressionable to distraction. I leveraged that advantage with overwhelming gratitude.
Since completing treatment, I can see that cancer is slowly releasing my son to be the person he’s meant to be in life. He has started hip hop dancing and he is triumphantly defying the gossip that he hears about boys who dance. I honestly don’t believe that carefree abandon would be part of his vocabulary if his life was following an unaltered path. Maybe he wouldn’t have discovered his love for music and dance if he hadn’t spent countless hours in the hospital watching his old Mom groove to the beat like a buffoon.

When his baseball team lost their first travel championship at the tender age of 8, every boy cried…except Ben. He looked at me like “oh please, are you kidding me?” He is usually the happiest, most jubilant boy on the sports field because he knows all too well the alternative. I never wanted my son to learn perspective this early in life, but it will serve him well.

I don’t want you to think that my heart is not forever broken, because it is. But, I’m leaning on my freedom of choice...

I choose to feel fortunate that my husband has a reliable job so I could leave my career and focus solely on my son’s care. I was able to catapult right by his side for the 1,000 requests of “I need you” or “Can we snuggle?” I feel grateful for the years of uninterrupted, one-on-one time with my child when healthy children were in school apart from their parents. They always say that children grow up so fast, but our experience slowed our lives down nearly to a stop. I forced myself to savor those moments even though the reason was difficult to bear. I now recognize from a single look or a crooked, nervous smile exactly what my son is feeling and what he needs... and for that gift, I am the luckiest Mom on earth.

I was able to hear “I love you” a half dozen times a day and I choose to thank cancer for that. I don’t thank cancer for much, trust me. I am choosing not to marinate in the thoughts of my son’s physical and emotional agony, the 25+ spinal taps, the gut punching setbacks and the endless hospitalizations. I am choosing to forget the names of mercaptopurine, methotrexate, cyclophosphamide, acyclovir, gentamycin, cytarabine, propofol, and all the others because I won’t need to remember them ever again. Instead, they can be replaced by Brad Pitt trivia, as God intended.

Ben was scheduled to complete his treatment on April Fools’ Day of this year, but in the spirit of the holiday, we were indeed fooled. Due to complications, he abruptly finished treatment five weeks early - on the precise day that my brother was born 47 years ago and ironically, the day my husband proposed to me. After yet another chemotherapy complication, our doctor came into the recovery room and without warning said “You’re done. No more.”

I quickly realized the aligning date of my brother’s birth and all felt right in the world again. There were 364 other days of choice, but I believe my brother laid his hands on his nephew and said “You’ve had enough. Be free.” They are eternally connected because of this shared experience and the weight of the coincidence has given me great reassurance that Ben will grow to be an old, cranky man... with an angelic uncle watching over him.

When I see my son graduate college, marry his future wife, witness the birth of his first child ...I will know that he has earned everything good in his life. That he stood tall and he is proud of himself for being a fighter. Most importantly, he will go everywhere in life knowing that his family was by his side every step of the way; that his older brother selflessly put his own needs aside every day for him; that his father was the master of distraction...and Angry Birds; and that the nurses, doctors, and friends stopped their world to care for him.

I believe Ben’s struggles will help find a cure for others and that ironically, he is the teacher and the doctors are the students. They have learned from his unique experience and these lessons will inform them how to pave an easier path for another child to live a life built around their dreams.

This was a herculean journey and people think I carried my son through it, but it was actually the opposite. My child is wiser than he should be and braver than I ever wanted him to be. He recently asked me, “Mom, you said girls will think my port scars are sexy?” and I answered, “Oh yes, Ben, they will...trust me.” My son has a triumphant story to share, and if he gets some girls along the way...well, he’s earned it.
I heard somewhere that every cancer diagnosis involves a death. God willing, not death in the literal sense of the word, but it is always the death of the life you once lived. It’s a loss of innocence, a loss of simplicity. For me, there will always be a dividing line. There was life before cancer, and now there is life after cancer.

Jackson is my firstborn. He’ll be 6 in November. My husband Jamie and I have two daughters as well, Madeleine and Finley. We were a pretty average American family until our journey with cancer began in late winter 2014. My mom, Susie, treated the entire family to an amazing trip to Walt Disney World. An hour before our flight departed, Jackson developed a massive nosebleed. It was the first one he’d ever had. It lasted for hours, and Jack was also very pale. We didn’t think much of it, since his complexion is pale anyway and it was late winter. We truly had the trip of a lifetime.

A few days after we returned home, my mom said to me, “You know, Mar. I hope Jack is ok. He just seems so pale lately.” Hearing this set off a small panic inside. I already felt in my heart that something wasn’t quite right, but hearing it from my mom prompted me to call the doctor immediately. We took Jackson in that day to see his pediatrician for blood work. The next day, March 5, 2014, our world came crashing down.

Before he even called us to alert us that something was very wrong, Dr. Surell contacted Dr. Joseph Wiley at Sinai Children’s Hospital. Jackson’s blood work was so alarming that he was pre-admitted to Sinai that morning before we even received a phone call. We rushed him to Sinai, where a bone marrow test revealed that our precious boy has Acute Lymphocytic Leukemia (ALL).

At diagnosis, Jackson was in the Low/Average Risk category. However, after his bone marrow test on Day 29 revealed that a small amount of leukemia remained, he was moved into the High Risk Category. We were absolutely crushed by those results, as they were unexpected and it meant he needed more aggressive treatment. We visit the Pediatric Oncology/Hematology Clinic at Sinai once a week for chemotherapy and treatment. In the first month of treatment alone, our skinny guy gained 50% of his body weight and he had a hard time even walking as a result of the high dose steroids he was prescribed. Since he was diagnosed seven months ago, we have spent countless nights in the hospital. Whenever he has a fever greater than 100.5, he has been admitted to the hospital. This has happened a few times.

On July 4, we were elated to learn that his bone marrow had zero percent leukemia, and that Jack was in remission! Even with remission achieved, the treatment protocol
for boys Jack’s age is three years and two months long. It has already been a long road and we are really only at the beginning. It is not easy having two demanding careers, two little girls who need us too, and a sick little guy. We are so fortunate to have my mom nearby. She helps us tremendously and we would be lost without her.

Aside from having this wicked disease, Jack is a pretty normal little boy. He absolutely loves Batman. He got the chance to meet the “Real Batman” twice, and he even got to ride in the Batmobile at Sinai’s Race For Our Kids. He was so happy! He also loves all of the other superheroes, Star Wars, Harry Potter, playing video games, and anything scary! Halloween is his favorite time of year and he loves zombies, skeletons, and vampires. He is in kindergarten this year and he’s very excited about learning to read.

From the beginning, we have been mostly honest with Jack about his diagnosis. I say mostly because there are just some things a 5 year old can’t quite understand. But he knows he has leukemia. He knows that means that something wasn’t working quite right with his blood. Steroids make him very moody, and some of the chemo makes him feel not so great. But overall he has been such a rock star. He thinks being bald is cool and makes jokes about losing his hair. For the most part, he is fine when the nurses have to access his port every week at clinic. The worst part of it for him is when they remove the tape from his chest before we leave for the day! When we learned that he was in remission, I congratulated him for kicking cancer where the sun doesn’t shine. He immediately replied, “Mom, I didn’t do it myself. Everyone helped me!”

So many wonderful things have come from this terrible diagnosis. We have met so many amazing people. The doctors, nurses, and staff at Sinai are angels in disguise. I have met so many other “cancer moms,” some of whom have become dear friends in such a short time. I am learning to slow down, and to appreciate the small moments that I used to take for granted. I have a much better perspective on life. Things that used to bother me just don't anymore. I am rediscovering a faith that I abandoned a long time ago. One of the most difficult things for me was the loss of power over my life. A cancer diagnosis means that cancer is now the boss. Though I’ve never been a fan of cardio, I decided to start running. The Cool Kids 5k in June was my very first race. I learned about the Leukemia and Lymphoma Society's Team in Training (TNT) from one of Jack’s nurses, Traci Barrett. She and I had many long conversations about it while Jack was sound asleep after receiving countless lumbar punctures in the Children’s Diagnostic Center at Sinai. Along with several friends, family, and colleagues, I will be running the Baltimore Running Festival’s half marathon on October 18. Raising money has been one small way that I’ve been able to regain some of the power this disease has stolen from me.

We have faith that Jackson will remain cancer-free, but we will never stop looking over our shoulders. We will hold our breath with every test. We know that the leukemia can come back any time. It’s terrifying when I stop and think about it, so I try not to do that. For me, keeping busy has been the best medicine. Nothing about this is easy. Having a child with cancer has rocked our world. It made me question everything. I went through all of the stages of grief. Even now, I sometimes wake up in the morning and wonder if this is really our life. Did this really happen to Jack? Why? I know that we will never know the answer. What I do know is that we were thrust into a world we never wanted to be a part of. As the saying goes, “When life hands you lemons, make lemonade.” That’s what we are trying to do, if only so our kids can see that adversity can be handled with grace and confidence.
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 300 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.

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New Medicines. New Hope.
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Cool Kids Campaign
Help mom rake the fall leaves from under the swing set. Draw the path through the maze starting at 2 and counting by 2s up to 200.

Help the lady through the turkey shaped maze to get the turkey to the dinner table.
See how many words can you make out of: PUMPKIN PIE
Unscramble these COMPUTER words

1. LBEAC
2. RRAPMOG
3. CUDTAOHP
4. UESMO
5. EOTRBO
6. IEFL
7. ENRSCNA
8. BARYKDOE
9. URNRTE
10. TIERRNP
11. ETEEDL
12. EESNRC

Find the pictures (on the right) hidden on the forest floor.

After finding the hidden objects, have fun coloring this picture!
**TWISTIN’ THE TONGUE**

Lesser leather never weathered wetter weather better.

A skunk sat on a stump and thunk the stump stunk, but the stump thunk the skunk stunk.

**HaHa! Bahahahahaha**

What is a tree’s favorite drink? Root beer.

What do you call a story about a broken pencil? Fractured.

Why did the sun go to school? To get enlightened.

Why did the canteloupe jump into the lake? It wanted to be a watermelon!

**KNOCK-KNOCK JOKES**

Knock, knock
Who’s there? Cash.
Cash who? I knew you were a nut!

Knock, knock
Who’s there? Figs.
Figs who? Figs the doorbell, it’s broken!

Knock, knock
Who’s there? King Tut.
King Tut who? King Tut-key fried chicken!
In May 2013, our 4 year old son, Jayden, had severe back pain that woke him up in the middle of the night. He would just cry and scream and lay on the couch all day and not get up. I knew that this was serious and that an active 4 year old should never have this problem, so I took him to the pediatrician immediately. We were sent home numerous times and told that he had growing pains, constipation, etc. His X-rays looked fine and his blood tests were relatively normal (only showing a slight infection).

His pain progressed and when running during T-ball, he became very stiff. I knew something more was wrong. I pushed for more testing and finally an MRI was ordered. Before Jayden even woke up from his anesthesia, I got a call from the pediatrician’s office that I needed to immediately go to Oakland Kaiser Hospital to get admitted and an oncologist would meet us there. I knew this meant bad news, and it ended up being the worst news of our lives!

I had more tests and procedures including putting a broviac catheter in to start chemotherapy and being fitted for a back brace to stabilize his spine. He needed the back brace because as the tumors shrunk and his spine lost the stability from the tumors, there was a risk of the spine collapsing and causing paralysis.

Jayden saw a steady flow of specialists, doctors, nurses, and medical students. We were informed that Kaiser was part of COG (The Children’s Oncology Group) and Jayden’s treatment would be discussed with the group to make sure he got the best treatment possible. This reassured me since his diagnosis was not very common with the presentation of tumors. We learned the extent of his treatment and that I would have to leave my job to care for him because he would not be able to attend preschool during the intense treatment. Life was about to majorly change for our family including Jayden’s siblings, Samantha and Noah.

The next few days were a complete blur. Jayden had more tests and procedures including putting a broviac catheter in to start chemotherapy and being fitted for a back brace to stabilize his spine. He needed the back brace because as the tumors shrunk and his spine lost the stability from the tumors, there was a risk of the spine collapsing and causing paralysis.

After a few days of many tests and procedures, Jayden was diagnosed with High Risk Acute Lymphoblastic Leukemia with Lymphomatous features. The Lymphomatous features were a rare presentation of Leukemia tumors or clusters. He had 3 clusters: one on his pelvis and two on his spine. The ones on his spine had caused compression fractures, which were the cause of all the back pain.
During the last week of the school year, my son, Gunner, was running a slight fever. The school nurse called and told me that he had vomited before lunch. I picked him up from school and took him to his doctor where tests for strep throat and mono came back negative. With no other symptoms present besides a low grade fever, his doctor decided to be proactive. He prescribed an antibiotic to combat mono, if by chance that was causing his fever. If the fever wasn't gone in seven days, the doctor said to bring him back in to be examined again.

During the time he was taking the antibiotics, I noticed he seemed pale. Sometimes he was playing with his sisters, but other times he didn't want to get off the couch. I thought these were common symptoms of mono. I pushed fluids to keep him hydrated and let him rest. Then on that Thursday, I noticed his fever wasn't going away and the antibiotics were almost gone. I called the doctor and told him about Gunner’s condition since our office visit. I got a message Thursday evening to call Friday morning and bring him in to the office.

At the office that Friday morning, Gunner was re-tested for strep throat and mono which both came back negative again. Blood was drawn in the office for a lab work up and a urine sample was collected. Gunner’s fever Thursday night was 102.5. Before that, it was between 99 and 100, so the spike in fever really concerned me.

Something was causing his body to try and fight, but what was it? We were sent for a chest x-ray and told the doctor would call us at home when the results were in. On our drive home, we stopped for groceries. Gunner picked out some Powerade to stay hydrated and a few snacks since he didn’t have much of an appetite.

We walked in the house. As soon as I sat the bags on the counter, the doctor called. He said Gunner’s hemoglobin and platelet counts were very low. His white blood cell count should have been 10 and it was 47,000. The doctor said to go to the ER immediately and we would be admitted to run tests and hopefully figure what was causing the fever.

We arrived at the ER and were taken back right away. Blood tests were run and the ER doctor came back quickly. I thought we were looking at pneumonia or something similar. He walked into the room and the doctor said, “My pathologist looked at the results and your son has leukemia.”

Cancer. We heard that one word that no parent ever expects or wants to hear. I was speechless. I quickly turned to my left to make sure my husband was ok and to verify that I wasn't in the midst of a horrific dream. The look on my husband’s face crushed my soul because he looked as devastated as I felt. My heart literally hurt.

We were asked which hospital we wanted to be transferred to by ambulance. We selected Dell Children's Medical Center in Austin. Within an hour, we were loaded up in the ambulance to go meet with a team of doctors and start treatment. Gunner has a big fight ahead of him.

We began the longest ride of my life down I-35 from our home hospital in Waco to the Dell Children’s Medical Center in Austin. A team of medical staff from the hospital were awaiting our arrival. Gunner was taken directly to his room.

Dr. Wells, the lead pediatric oncologist on staff, came to speak with us. He started ordering a bunch of tests. He needed to determine all prior lab results were accurate. He also was awaiting word from the pathologist to officially confirm the leukemia diagnosis.
He told us about B-cell acute lymphoblastic leukemia and m-cell acute lymphoblastic leukemia. Gunner would have one type or the other.

On that Saturday morning, Gunner would have to undergo surgery with anesthesia to determine the sub-type of his leukemia. A large needle the size of a clothes pin was inserted in the back lower hip area through the bone to extract bone marrow. The marrow held the answers to everything.

Saturday morning we sat in the pre-op area waiting for Gunner to be taken back to surgery. We all were exhausted from the day before. Tired beyond explanation from the tests and large number of hospital staff who was in and out of Gunner’s room throughout the night ensuring our baby boy was dong ok.

As we sat there, Gunner nervously said, “I wish we could get this over and done with already.” My heart broke in a million pieces. He was so brave but yet strong at the same time. I wanted to yell and scream because this situation seems horribly unfair. Why is this happening to my child or anyone else’s?

We walked with Gunner back to the stop sign and then gave him a kiss as they rolled him back to surgery. Then we waited. The procedure took about 15 minutes.

The doctor came in to talk with us. He shared his opinion that he suspected Gunner had type-b ALL or acute lymphoblastic leukemia but wanted to wait until lunch time to get the test results back to confirm his suspicions.

The next few hours we spent cuddling with Gunner. We tried to keep our minds occupied but the stakes were high. The treatment for b-type ALL is less severe than m-cell and the cure rate is very high. The treatment for the m-type is highly more intensive and the cure rate is roughly 50%.

Finally the phone rang. The doctor confirmed that Gunner indeed has b-type acute lymphoblastic leukemia. I cried big tears of joy. This was a glimmer of hope in this dark journey and one small step towards getting my baby healthy.
Michelle Vandermaas is a Child Life Specialist at Medical University of South Carolina (MUSC) Children’s Hospital. She works in pediatric hematology and oncology where she met 10 year old Samantha. Read more about both of them below!

What is your name? Michelle Vandermaas
Where do you live? Charleston, South Carolina
What is your job title? I’m a Child Life Specialist at Medical University of South Carolina (MUSC) Children’s Hospital on our inpatient hematology/oncology unit and outpatient clinic. I work with oncology patients and their families helping them cope with diagnosis, treatment, hospitalization/clinic visits through building and maintaining a supportive relationship, therapeutic play, and expressive arts.
Favorite part of your job? Getting to know children/teenagers and families.
Least favorite part? Meetings and paperwork
What does your day begin? 6:30 a.m. to get my kids ready for school.
Favorite sport to watch or play? Tennis and soccer
Do you have children? I have 2 boys, Mark and Aidan.
What do you enjoy doing for fun? Reading, running, watching my boys play soccer and tennis.
Favorite movie? Love Actually
Favorite TV show? Modern Family
Like cats or dogs? Definitely Dogs!
What’s on your IPOD? U2, Coldplay, Bastille, Ed Sheeran, Adele, ABBA, Maroon V.
Favorite book? Hunger Games, Divergent, and Harry Potter.
Favorite school subject as a kid? Science
Favorite dessert? Coffee ice cream
Favorite season? Fall and Spring
Favorite cereal? Special K and Berries
Favorite fruit? Red Grapes
What celebrity do you admire and why? Oprah and Bill Gates because they share their success with the world.
If you could have dinner with one person (alive or deceased) who and why? Mother Teresa because she was truly a saint and devoted her life to others. I would ask her to tell me all about Heaven.

What’s your name? Samantha Estes
Where do you live? Bishopville, South Carolina
What grade are you in? 5th grade
How old are you? 10 years old
If you wrote a book, what would it be about? My horses
What do you want to be when you grow up? A banker
What sports do you like? Volleyball
Do you have brothers or sisters? 1 brother, 24 years old
What do you like to do for fun? Ride horses
Favorite cereal? Frosted Flakes
Favorite snack? Goldfish
Favorite animal? Horses
Favorite subject in school? Math
Who’s your BFF? Willow Rogers
Who is your favorite celebrity? Ellen
What activities do you like for exercise? Kickball
If you were the President of the U.S., what would be your first law? No more cars…horseback riding only!
Favorite movie? Black Stallion
Favorite TV show? Good Luck Charlie
Favorite video game? Minecraft
If you were stranded on an island, what 3 things would you have with you? Mom, Dad, and a ship.
What are you most grateful for? My mom, dad, and brother.
If you were a Seven Dwarf, which one would you be? Doc because he is the smartest one.
If you could meet someone famous, who would it be? Dale Earnhardt - Do you ever get scared?
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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 910-960-1770 or visit coolkidscampaign.org
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!

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