Carla Jannotti, our 11-year-old girl, and our family, are in the fight of our lives. It is a heartbreaking story of a promising gymnast and bright student who was diagnosed with brain cancer January 2009, and subsequently, contracted meningitis while in the hospital.

No child should have to suffer this way. No parent should have to watch it.

Due to many complications following a series of five surgeries, Carla’s once athletic body quickly lost its strength leaving her unable to walk, talk, eat and barely able to move.

Carla was taken in April to Brooks Rehabilitation Hospital in Jacksonville, Florida, in the hopes of regaining the use of her limbs. Now at home in Deltona, Florida, her condition is improving but the weight of this disease on her and the family has been extreme. Thanks to her always-positive outlook on life, an athlete’s perseverance, and overflowing encouragement and prayers from family, friends and strangers, the miracle of healing has begun.

Four months after leaving the hospital and the rehabilitation facility, Carla is now able to eat and talk, and is enjoying playing Wii for the first time. We never thought this day would come when she was able to return to the activities she had done prior to the diagnosis. Carla has never stopped smiling even on the worst of days. She is a true inspiration to all of us.

She talks about returning to gymnastics at Legacy Gymnastics in Maitland and her team and coaches await the day. I believe that with her desire and determination her dream to return to gymnastics will one day come true.

As far as Carla’s long-term plans, here it is. One day my husband and I were talking about money. Carla said, “Please don’t spend my college money.” She has every desire to live a normal life. She talks about future boyfriends, attending college, and one day having children.

Carla is a fifth-grader at Forest Lake Elementary; she loves reading and math. She loves chicken and mashed potatoes, gymnastics and rollerblading.

“I am a very determined, competitive and hard working athlete,” she said. “I love animals, especially dogs. My favorite cereal is Cinnamon Toast Crunch. My favorite movie is Wall-e.

My favorite channels are Cartoon Network and Disney Channel. I love watching soccer because my brother plays and he’s special. I have two brothers, Phillip and Alex. I love green beans.”

Carla’s best quality is that she won’t stop smiling … no matter what.
The Cool Kids Connection is a 501(c)3 non-profit pediatric oncology patients and their families.

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It’s impossible to explain cancer in 500 words or less

By Kim Haven

It is the beginning of a new year and a new decade, and the one-year anniversary of our son’s end-of-treatment for Acute Lymphoblastic Leukemia (ALL). It is a time for reflection, and as I look back on the past four-and-a-half years, I wonder how we landed at this point relatively intact — as a family and individually. This was brought home to me in a new light after I received a call from a reporter writing a story on pediatric oncology. He wanted me to provide the “steps” that an oncology family follows to get through treatment — in 500 words or less. I called several oncology mom friends and we had a great laugh over that one.

As predictable as treatment can be for standard-risk ALL, our journey was personal, as is the journey of every child who experiences cancer. It affects each family member differently. When diagnosed, our son had just turned 5 and started kindergarten. It seems that half of his life has been spent battling cancer; he is now a 9-year-old boy who happens to know more about medical procedures and protocol than most interns; can reprogram a laptop; knows which of his behaviors will illicit a violent reaction from his sister; and is quite sure he will have no use for Latin when he’s 16. In other words, it is his life experience — it’s personal.

My oldest child was 6 when my husband was diagnosed with an aggressive form of testicular cancer. His surgery, treatment and recovery lasted for almost two years, and she watched all of it with a child’s unanswerable attention — why? how? when? She accepted our answers with the same unquestioning belief she held in us when she believed we could light up traffic lights to turn them red from green.

When our son was diagnosed, she had just turned 16 — a very different age and time in her life, yet the questions remained the same — why? how? when? — although her belief in the answers was no longer there. She was incredibly angry. She walked away from the faith of others, her friends, family, and even herself. She thought if she ran far enough and felt as little as possible, she would be able to survive the sensations and reality of her brother’s cancer treatment. Now at age 20, she’s learning to make peace with God and herself. She believes that her faith has given her strength.

Our middle daughter was just weeks away from turning 17 when our son was diagnosed — history repeating itself with a sibling twist. The two always have been incredibly close, she is his confidante. Now at age 11, she still has nightmares of her brother and I leaving suddenly, yet she is a great communicator and able to talk through the fears. It was difficult for her to look ahead at times why there were different rules — his and hers, so to speak — when he was the one who looked and acted like the sick one. Always. Not to mention the attention and gifts (a somewhat unavoidable pitfall of having a cancer kid) given with good intentions and love, but not the same unquestioning belief.

Cancer can allow us to isolate ourselves by the very nature of the disease and treatment, yet we can and should reach out to each other as oncology parents. There is no one else, no matter how well they mean, who understands the same way as another parent. I have been blessed by the relationships I have gained with other moms, both in active treatment and who have traveled the road before me. I treasure the wisdom, understanding and grace as we make the community stronger as a whole. We like to think that his earlier oncology experience gave us some greater understanding and preparation. But we know that nothing prepares us for a diagnosis.

And there is nothing in 500 words or less that provides the outcome we desire. I have had the privilege, of knowing and watching some amazing everyday people walk through the craziness that is pediatric oncology; they have taught me to transform all the unanswerable, insurmountable truths we were given to turn them from red to green.

In 1978 when I was 12, my cousin died from ALL after a two-year battle. I remember when she participated in clinical trials there was a shroud of secrecy surrounding her experience (even she didn’t know about it sometimes). Being the middle child is difficult enough, but trying to find your place when the youngest has cancer and the oldest is in crisis is almost cruel. Still, she is wiser and more sensitive than most girls her age and has a true servant’s heart for those in need. She has accompanied her little brother to most appointments and procedures and has set a goal to become a counselor at a sibling camp and a Child Life Specialist — a future that would probably not be on her horizon if not for her personal journey.

My husband and I have been able to keep our marriage intact, not always given in the world of pediatric oncology. There have been times when the very fabric of our lives was beginning to tear and rip, but we were able to weather it. We stood frayed and grace, yet whole. We like to think that his earlier oncology experience gave us some greater understanding and preparation. But we know that nothing prepares us for a diagnosis.

Try to do “normal” at home whenever possible — whatever normal is for your family. And when you can’t remember normal, supply yourself with grace.

No two journeys are the same. Pediatric oncology is a tapestry of many threads and colors, and each of our children is a thread. We have seen joy and tragedy in our communities and it is this dichotomy that gives this tapestry its beautiful beauty. With the end of treatment comes the realization that the force, which has directed our lives until this point, will no longer be there. We mourn those lost and celebrate those moving onward and upward. It is who we are, who we have become, the value of our unique personal journey with its successes and failures, and allow our stories to be interwoven into the collective cloth, that we can make the community stronger as a whole. And it is only by the relationships and experiences that we have shared that the grace of God — we survived intact.

I share this journey in its messy, painful, and beautiful glory to be bound to the journey of another, who hopefully will share their story. And so on and so on, like a band of beautiful, colorfull balloons tangled together, floating higher and higher.
Welcome to Cancer Fears Me - a strong, positive mindset for those living with cancer, their support groups and caregivers.

We know fear is a dominant emotion when someone is given a diagnosis of cancer. Cancer Fears Me turns that fear around and puts you in control.

Cancer Fears Me was born after years of working with families living with cancer and recognizing how much fear this terrible disease causes. How these invading cells try to take over our bodies and our life.

Whether you are the patient, a caregiver or part of the patient’s support group of family and friends, you can show who is in control — YOU!

We have developed a line of merchandise and apparel with the Cancer Fears Me logo to help fund our programs for the Cool Kids Campaign, including the Cool Kids Connection. Show off your strong, positive attitude towards cancer!

Check out our website at www.cancerfearsmefoundation.org.

Check out our Cancer Fears Me video on YouTube! Just search for Cancer Fears Me.

At M&T Bank, we know how important it is to support those who are fighting cancer. That’s why we offer funds to let you do more than exist.

The three great essentials to achieve anything worthwhile are first, hard work; second, stick-to-itness; third, common sense.

– Thomas Edison, inventor of the light bulb

An amazing thing happens when you give to the community. It gives back.

Photo by Mitch Stringer
Animals Crossword Puzzle

ACROSS
1. Big animal that has one horn
2. This animal has a very long neck
3. Man’s best friend
4. Lives in the cold and waddles
5. Slow moving and has a shell
6. Striped animal that looks like a cat
7. Can swim under water and walk on land

DOWN
2. This animal has a long trunk
3. This animal likes to eat carrots and sugar cubes
4. This animal loves bananas
5. Some say this animal has nine lives
6. Has big ears and likes to hop
7. King of the jungle
**Riddles & Jokes**

**FATHER:** How are your grades, son?
**SON:** Under water, Dad.
**FATHER:** Under water? What do you mean?
**SON:** They’re below C level.

**Tourist:** How would you describe the rain in this part of the country?
**Local:** Little drops of water falling from the sky.

**What did Tarzan say when he heard the elephants coming?**
“Here come the elephants!”

**Why do elephants never forget?**
Because nobody ever tells them anything.

**What do you get if you cross a Cocker Spaniel with a Poodle and a rooster?**
A cockapoodledoo!

**A man rushed into the doctor’s office and shouted, “Doctor! I think I’m shrinking!” The doctor calmly responded, “Now, settle down. You’ll just have to be a little patient.”**

**Ralph:** Dad, will you do my math for me tonight?
**Dad:** No, son, it wouldn’t be right.

**Once a duck went to a restaurant and asked “Do you have any grapes?”**
The waiter replied “We do not allow ducks or other animals in this restaurant, so you’ll have to leave!” The duck went away, but came back an hour later. Again he asked “Do you have any grapes?” Again the waiter replied “I told you earlier we do not allow ducks in this restaurant. Go away! And if you come in here again, I’ll staple your feet to the floor!” An hour later, the duck returned and asked “Do you have any staples?” The waiter replied “NO!”

“Good...” said the duck, “then, do you have any grapes?”

**If corn oil comes from corn, where does baby oil come from?**

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

**Rhinoceros**

**Giraffe**

**Penguin**

**Alligator**

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If corn oil comes from corn, where does baby oil come from?
Nicholas is full of life and has a big heart that brings joy and happiness to those around him. His cheeks and bright smile can melt you away.

Nicholas was rushed to The Brooklyn Hospital Center (TBHC) in New York on September 20, 2008 with a high fever and paleness. After tests and a biopsy two days later, he was diagnosed with High Risk Acute Lymphoblastic Leukemia (ALL), a very common childhood cancer. He was 2 1/2 years old.

It was the hardest news for any parent to hear. I thought I was dreaming, that what was happening to me was too bad to be true. While listening to the doctors about his diagnosis and the intensive chemotherapy he would be going through, I just sat down in disbelief and sadness that cancer had struck my family again. I knew the courageous fight Nicholas was going to have to face.

I had lost my mother to breast cancer when I was 12 years old. She told us, “Sometimes things happen that we don’t like and you can’t blame anybody. Just have faith and pray for the best.”

After four chemo treatments and three surgeries (including removal of a mass on his stomach) and a long month of unpleasant side effects and complications, Nicholas was discharged October 17. One complication during the first cycle of chemotherapy was that Nicholas suffered a rare side effect – he developed lower extremity weakness and rigidity. He couldn’t stand up or walk on his own and could not get a good grip on his sippy cup. The doctor recommended physical and occupational therapy and a bone marrow test and on October 23 we received the good news that he was in remission.

The fourth phase of his treatment began the following year on March 16th and continued into May. Nicholas’ blood work came back good on all three counts of red and white blood cells and platelets to start his fifth cycle – an 84-day, 12-week cycle that included chemo meds, a bone marrow test and spinal taps.

In July the doctor gave Nicholas the green light for swimming classes, which he had been taking with me pre-cancer. He loves the water. He then received a pediatric walker to help build up his strength and confidence. He was determined to improve his legs and get back to walking and running alone.

Nicholas finished off the summer with five days at Sunrise Day Camp, a camp in Long Island dedicated to children with cancer. The first day Nicholas was a little nervous, yet happy to be there. He was ready for fun. The camp directors, counselors and volunteers had all good things to say about Nicholas. He had a blast! They said that Nicholas was an ambitious kid determined to beat cancer and walk again.

At the end of October, Nicholas’ doctors sent us for a second opinion at Sloan Kettering Memorial in New York City. A top cancer care hospital for kids. Sloan answered all of our questions and went into more depth about our son’s condition. We were told Nicholas would run and walk again. They had asked if we wanted to change hospitals to allow Nicholas to receive treatment at Sloan, however, we had decided to stay at TBHC – it was closer to home; our family feels comfortable with the doctors and nurses there; and they had done all the right things so far.

Four of Karen’s, an organization that helps families with kids fighting cancer, helped my family financially. Their help was a blessing. We are having difficulties paying full rent and other household needs with only one income. We have written to the majority of children’s cancer centers, associations, foundations and establishments to help us with financial assistance.

Life is funny and has a way of testing your strength, faith, family and overall character. People sometimes say a sickness of a family member can break you down and test your strength, but with a kid – your own child no less – it’s a whole different ballgame. An adult can understand and listen to doctors’ orders and defend themselves if need be, but when dealing with a sick child, it’s all about understanding, listening, strength, caring, friendship and bonding with the doctors and nurses taking care of him.

At first it was tough on my wife Adriana. A mother’s love is special and to see her son diagnosed with cancer was rough. The faith of God and the power of prayer has pulled us together to reach a goal of crushing the cancer out of our son. After Nicholas caught his mom crying several times, we set a “no crying rule.” For every family member or friend who came to visit, if they cried, Nicholas would walk over to them, speak their name, say “no crying,” and wipe away the tears with his smile.

Our family spends many hours in the hospital. Nicholas sometimes wonders why he can’t be around people. We had to explain that because of the cancer, his defense mechanisms is low and he can pick up other germs.

Nicholas’ cancer treatment will last approximately 3.5 years. Our family has been struggling since our son was diagnosed. We have been working diligently to keep the peace since this painful change in our lives. Nicholas has a daily battle as he looks to overcome leukemia. He needs daily, sometimes hourly, attention.

We are hopeful and know that he will make a full recovery. His prognosis is good. Every day is a challenge. Every day is a step forward. Meanwhile, as I see Nicholas’ positive attitude and smile, the family stays strong and together during these tough times as we struggle to remain present for him. He’s a strong fighter and with his hard work and determination, he will defeat his cancer and get his strength and power back in his legs to walk and run again. We’re happy to see his smile and confidence back knowing the challenge and fight he is going through.

Nicholas and other kids with cancer are my heroes, because no matter what struggles or sickness they’re fighting, they always wear a sweet gentle smile that brightens my day. They are our greatest inspiration to keep fighting for childhood cancer awareness and hoping for a cure.

The one thing Adriana and I have learned during this battle is how to be patient, calm, have faith, be positive and always offer a smile and a laugh, because Nicholas can feel, see and knows when one of us is down. Even though he’s a child, he has a big strong heart. It’s tough to watch what our son is experiencing, along with other kids and families we have bonded with at TBHC. We pray every day for them and Nicholas as we face the challenge together. We support each other and are strong together, and we love our children.
I started choking on the third fry and mom said, “Let’s go Josh. I’m taking you to the hospital.” There I got X-rays but they couldn’t really find anything. The doctor said they were worried. The next day the hospital called and wanted me to come back to drink milk so they could test something. When they brought me out to my mom, they said I had cancer. I saw my mom’s face. She cried and cried and went into a sort of trance; I don’t think she ever came out of it. I don’t know who called my dad but by the time he got there, the ambulance was there to take me to the Children’s Hospital of Pittsburgh. I had a tumor in my chest and I was fighting for my life. After the doctors treated it, I was able to come home – 14 days later. I got through my mouth and it closed my airway. I was then flown back to the hospital, again fighting for my life. They started me on intense chemotherapy once a week.

My cancer is now in remission. I really want to thank Dr. Ritchey, Dr. Shaw, A. Kemerer and R. Sidonio.

My Make-A-Wish trip

I made a Make-A-Wish. I really wanted to meet a few pro skateboarders like Bam Margera, Chris Cole, and Jamie Thomas, but people told me I might have to wait 3-5 years, so I chose a Make-A-Wish shopping spree on RC cars. The limo picked up my dad, my mom and me; it was really neat to ride in. Our first stop was a store in Somerset, Pennsylvania. I bought a Revo, Jato, Slayer, HPIRTRR+3 Toyota Sawyer drifting car, screwdrivers, and extra parts in case the parts break. I really had fun. That’s the one thing I never had. So I had to buy five. They are sweet.

Our next stop in the big limo was Hoss Restaurant. I ordered a big steak. We had fun. When we left Hoss, it was raining like cats and dogs. Our next stop was, of course, Walmart. I was thinking the only game system I didn’t have was Nintendo Wii. And that was it – I was happy.

Thank you Make-A-Wish.

HAPPY

in Remission

By Josh Shipley
Harry Goldstein and Erin Garner have in common that they both dig Lucky Charms. Another thing 7-year old Harry Goldstein and Clinical Social Worker Erin Garner have in common is also hard to work with kids and families when they are sad. It is also rewarding to be able to help families cope during this difficult time and see a bright future ahead!

What is your favorite thing about your job? I love being able to talk with the children about how their days are going. It is also rewarding to be able to help families cope during this difficult time and see a bright future ahead!

What do you do? I am a Social Worker in the outpatient clinic and also when they have to spend time in the hospital. I spend a lot of time talking with patients, siblings, and their families about how their hospital visits and diseases affect their regular lives.

Where do you live? I live in Baltimore now, but grew up in Delaware.

What is your favorite book? Little Women or The Secret Garden, but I just finished the Twilight movies and television, and going to Target! I also love to read books.

Do you have a BFF? Danny, 6-years old

What is your favorite movie? Ghostbusters, Home Alone, Olympic winter games-figure skating

What types of things do you like to do for exercise? Crab-walking. What is crab-walking? Walk with your hands and go backwards, running, sliding and falling. I can do push-ups, 10 or 30. If you were the President of Whoville what would be your first act as the ruler? Help the environment.

What is your favorite subject in school? Music, art & gym.

Do you have any children? Not now…maybe in a few years!

What kind of music do you listen to? Michael Jackson, Beat it.

What is your favorite sport to watch? To play? Football and baseball. Orioles and Ravens.

If you could be anything in the world when you grow up, what would it be? Baseball player

What is your favorite season? Fall

If you were stranded on a deserted island, what three things would you like to have? Water, food and juice.

What is your favorite food? Home Alone, Little Mermaid, and Father of the Bride.

What is your favorite sport to play? To Watch? Football

What is your favorite subject to study? Communication

What do you like to do for fun? I like spending time with my family and friends, watching movies and television, and going to Target! I also love to read books.

Do you have any children? Not now…maybe in a few years?

What do you like to do for fun? I like spending time with my family and friends, watching movies and television, and going to Target! I also love to read books.

Favorite cereal? Chocolate-I wish I could eat chocolate for breakfast, lunch, and dinner. We would all have dinner together: my grandfather and I would love for my grandfather to be able to see the progress in our country. Plus, everyone would be happy almost all the time. I like to clap, crawl and play. I am learning how to walk by holding on to my chemo pole!

This is my journey.

Hugs and Kisses, Campbell

Baby Campbell’s STORY

My name is Campbell Taft. I am 15 months old and I have brain cancer.

On April 2, 2009, Mommy and Daddy took me for an MRI to rule out a chance of having a glioma brain tumor. That day our lives have been forever changed. On April 7th I had my first surgery and most of the tumor had been removed. I spent two weeks in ICU at Yale New Haven Children’s Hospital in Connecticut. They took great care of me!

The tumor damaged my pituitary gland, so I must take lots of medication – maybe forever. On July 21 after a routine MRI, I had my second brain surgery. The tumor had grown back very aggressively. Chemotherapy began immediately, every week.

On my first birthday, August 14th, I had a third surgery to have a shunt put in for hydrocephalus. I am very happy almost all the time. I like to clap, crawl and play. I am learning how to walk by holding on to my chemo pole!

This is my journey.

Hugs and Kisses, Campbell

Where do you live? Owings Mills, MD

What grade are you in? First grade

How old are you? 7 years old

What is your favorite subject in school? Specials (music, media, art and gym). If you were going to write a book what would it be about? A book about sharks.

What is your favorite food? Hot dogs, plain

Do you have a BFF? Harry loves music, art & gym in school!