



Connecting pediatric oncology patients throughout the nation

I Too, Want To Make A Difference

by Meredith Kelly

It has only been two months since Allison was diagnosed with Acute Lymphoblastic Leukemia (ALL). When I look back, I see how much life has been lived and how much we've learned in such a short period of time.

Today, I sit in awe, as I reflect on the last eight weeks. We've struggled through grief and acceptance, at



times the best lessons learned from my children. I can't recall a time, as a family, that we have experienced more joy and laughter. We are learning to be present, enjoying today for the gift it is. With or without cancer, this journey, life, is one day at a time.

My heart and soul fill when I recall the outpouring of love and support we have received from family, friends and our community. Never previously a parent to a child with cancer, I had no idea how people could help. "What can I do?" they want to know.

I am grateful to those who knew little things could make all the difference. A meal, offers to babysit, a diet coke or coffee when caffeine was needed, lending an ear to listen, thoughts and prayers in Caringbridge posts... simple gestures to show they care, all the while making a difference.



Now I recognize a shift within myself. As the recipient of so many gifts, out of gratitude and thanksgiving, I am seeking to give back. I know it is through giving we receive the greatest gifts. I am now searching for opportunities to make a difference.

Allison's doctors and nurses know our story. I want to know theirs. I know in doing what they do, time and again they are witness to the beauty in suffering. I ask and in hearing their stories, I am humbled. Many of them have sought to make a difference in a child's life because of how cancer has touched theirs. The beauty in their stories inspire me. They have changed, as have I,

for the better, because of this life threatening disease.

While I cannot say I am grateful for the disease in my daughter, that we battle, I am ever grateful to be where I am today, in this gift of life. I will continue to seek joy, beauty and opportunity to make a difference.

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The Cool Kids Connection is published by



8422 Bellona Lane, Suite #102

Towson, MD, 21204

Phone 410.560.1770 • Fax 410.560.1775

Editor/Cool Kids Campaign Co-Founder

Sharon Perfetti • sharon@coolkidscampaign.org

Graphic Designer

Matt Mucha • matt@hookelementaldesign.com

Contributing Writer

Molly Laurysens

Copy Editing

Jenn Marshall

Cool Kids Campaign Founders and Staff:

Robert Belanger • Chairman/Co-Founder

Chris Federico • President/Co-Founder

Sharon Perfetti • Executive Director/Co-Founder

Kimmie Meissner • Co-Founder

Kristian Sekse • Director of Development

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
www.cancerfearsme.org

Therapy Dogs Go To Heaven

by Joe Vervaecke



Elliot is a five year old, 80 pound Labradoodle who has been certified with Intermountain Therapy Animals (ITA) for three years. On Thursdays we visit the Cancer Warriors in the ICS (Immunization Compromised Services) at Primary Children's Medical Center in Salt Lake City. You can follow Elliot's visits on Facebook at: Elliot TherapyDog. In the three years of visiting we have developed relationships with several of the children and their families. I am honored that we are permitted into their lives and we value the time they share with us.

Elliot had always spent quality time with one patient in particular named Kim. She is a dear friend of ours and Elliot even appeared in several pictures on her Facebook page. Therapy dogs have a special intuitive instinct to comfort people, and after a few visits will develop deep feelings for the patient. She

was one of Elliot's favorites during past visits. After waiting for me to sanitize my hands, he would enter her room and directly step up onto her bed. Even if she was asleep or not feeling well enough for other visitors, she would leave instructions for Elliot to visit her. She would make room for him and he'd lie on her bed while she petted him for about an hour.

Yesterday we said "Good Bye" to Kim, who was losing her battle with AML leukemia. When we arrived at ICS we learned that she was actively dying and was in a coma. Her family was gathered around her bed when the nurse asked if we could visit. This would seem a rather odd request for a dog to visit a dying patient, but the staff knows Elliot and knew that he loved her. Without hesitation, her mother opened the door for us and allowed us to enter this most private moment, sharing a hug and a few tears. When Elliot entered he sensed the grief and stress, and did not step onto the bed as he normally does, but patiently stood at the side of the bed. With permission, he approached Kim who was not conscious and licked her hand. A very unusual behavior reserved for patients that are not able to pet him. She smiled and he stepped away. Before leaving he barked "Good Bye" and she twitched. We continued visiting patients, even went back to ICS to meet a new patient, but he was anxious to go home. At home,

he did not eat, but lay on the floor until we went to bed early. It took a few days for him to recover.

People often say that Elliot has a great job, gets petted and loved by all the patients, but it is rather stressful for the animals. I think it's like us going to a party and only knowing the person that we came with, and then being asked to meet and interact with all the guests, the dogs are very tired when they get home.

Meeting and getting to know the Cancer Warriors and their families have changed my life. Those kids are the bravest people that I know, we see them going through chemo and other procedures, some for several months, and enduring the side effects; but they are remarkably cheerful and pleasant even when they asked us to leave so that they can throw up. I can only imagine how much it must hurt as they battle with cancer, and when we see them connected to a pain pump, I know it has to be really awful. My heart often aches when we leave the room, and I truly believe Elliot also senses the pain.

I greatly respect the families that support the Cancer Warriors, who juggle their schedules to be with their child and continue their "normal" lives for months. They hold their child's hand and pray during the bad times, and tell stories and make plans during the good; and they lovingly comfort and encourage the other families. I am humbled to bring Elliot to the kids and help them through their hardship, even if only in a small way.

Kenzie-Covers

Kenzie-Covers have been a four year quest for Rick Levin who is a soft spoken, retired Baltimore businessman with an unassuming manner. For 30 years, he and his partner operated an avant garde urban fashion retail chain which was sold in 2006. Levin, who has no children of his own, yet still loves being around them, became involved with community outreach programs and specifically building inclusive playgrounds. Five inner city playgrounds are credited to his efforts.

With retirement and additional free time, he experienced a renewed interest in helping kids. A friend suggested he get involved with the Cool Kids Campaign.



“There are many wonderful foundations, but Cool Kids appealed to me because it was small and intimate,” Levin stated. He soon became a board member and was introduced to a 9-year old girl, MacKenzie Stuck. MacKenzie, who was diagnosed the year before with a malignant brain tumor, was undergoing her first series of chemotherapy treatments at Johns Hopkins Kimmel Cancer Center in Baltimore.

“MacKenzie was a frail, extremely feminine child dressed in pink jeans and pink shirt,” Levin recalls. “What struck me initially was that MacKenzie had decorated both her outfit and standard surgical mask with colorful sequins and rhinestones.” MacKenzie’s mom, Sue, had shared with Levin that the artwork was the result of a doctor having recently mistaken her for a boy. Later during the visit, Levin asked MacKenzie what she considered the hardest part of the cancer fight. Her answer surprised him. It wasn’t what he expected; the most difficult wasn’t missing school,

chemotherapy treatments, or the hair loss. But instead, the beautiful pink-clad child responded that the worst part was wearing the pale, bluish-green surgical mask which labeled her as, sick. He noticed that she was having trouble breathing through her self-designed mask because the sequins were weighing it down and the tiny stones caused the mask to gap on the sides. So while her efforts produced a glamorous effect, the efficacy was compromised.

MacKenzie’s creativity, however, inspired Levin to consider creating a better alternative. Having worked in the teen fashion business, he recognized the link between style and self-confidence. With MacKenzie, who prefers to be called Kenzie, as his model, Levin began with decorative bandanas to hide her thinning hair. Next, he took a conventional surgical mask and covered it with a photo of Angelina Jolie’s lower face. Kenzie was enchanted with the effect. When MacKenzie tried it on, her response was immediate...

“I feel like a movie star,” said the glowing child. The first Kenzie-Cover had been created and the response spurred Levin on to invent a product all children can wear.

Kenzie-Covers are used with an OSHA-approved N95 respirator mask which offers protection against airborne germs, pollutants and viruses. Originally developed for pediatric oncology patients, they are non-toxic, breathable, self-sticking, decorative covers which easily adhere to most facial masks. They are laboratory tested and printed with FDA-approved, water-based inks. One package contains a respirator mask as well as eight peel and stick fun, assorted covers. Children aren’t reluctant to wear them because it helps change the perception of “being sick.” “They allow the children to have fun while fighting germs,” says the beaming creator. “The original package I made expressly for Kenzie contained a mask of Tinker Bell, her favorite Disney character. However, I couldn’t mass produce

the fairy’s image because of trademark infringements.”

Besides offering sick children an escape from their painful realities, Kenzie-Covers can be custom designed to accommodate:

- hospitals and doctors’ offices
- dental hygienists
- schools and day care
- cooks and food handlers
- nail salons
- airline employees
- surgical clinics
- construction sites
- shop and sanitation workers
- landscapers
- allergy sufferers



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The covers appear in Kelli's hospital catalogue as well as Sky Mall in-flight magazine.

If you would like a free sample please email your name and address to:

freekenzie-covers@kenziecovers.com
Orders can be placed by phoning 1-888-846-9293 or their website at www.KenzieCovers.com. A portion of all profits go to help support The Cool Kids Campaign.

The Children's Miracle Network named Kenzie Stuck their 2010 miracle child. On April 27th, to celebrate her 13th birthday, the entire town of Mt. Airy, Maryland, showed up for a parade

in her honor. A video of the celebration was aired on CNN. "The community helped carry us through this ordeal," Kenzie's mom, Sue, volunteered. Hundreds turned out to support my child."

The proud teenager, who had been struggling with cancer for five years since her diagnosis, was dressed up as a sparkling, green fairy just like Tinker Bell. Sue stated that she and her daughter shared a private and fitting motto throughout her illness. The stoical little girl who loved Tinker Bell would recite to her mother "faith, trust and pixie dust. Faith in god; trust in doctors and a little bit of magic thrown in."



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teens.CanSur.vive

How a group of teens with cancer are working to help others.



Kyra became sick with Mononucleosis half way through her freshman year of high school. After about 5 months of on and off sickness, she got weaker and had to go to the doctor. Just 10 days after her 15th birthday, on May 5, 2009, her life changed when she was diagnosed with Acute Lymphoblastic Leukemia (ALL). Kyra went through intensive chemotherapy treatment for the next 9 months at Johns Hopkins Medical Center in Baltimore, Maryland. The chemotherapy made Kyra weak and since she had a compromised immune system, she needed to be very careful of illness and avoid people that may be sick. She was not strong enough to continue with school full time, but she went to school occasionally in 10th grade and had home and hospital teaching for some classes. By 11th grade, Kyra was in maintenance chemotherapy and she tried to go to school, but she wore herself down and ended up being admitted to the hospital twice before she decided to relax and wait to go back to school.

Since Kyra had missed a lot of school, she also lost touch with her classmates and friends. It was as if people, young and old, were afraid to be around her, or they weren't sure what to do. One place where kids being treated for cancer could bond was the summer camp called Camp Sunrise. These kids all speak the same cancer language and didn't mind listening to their stories about doctors, chemo, and LPs (lumbar punctures). They got to be kids and have fun. Hopkins patients attend the camp and the kids can even get chemo while at the camp. Unfortunately, this camp was only one week out of the year, so they didn't get to see each other often.

In December of 2010, Kyra invited three friends she met at Camp Sunrise for a sleepover and to decorate gingerbread houses. This was the first time they were all together outside of camp. It was wonderful to see the special bond these girls had since they all had had Leukemia. We wished there were more opportunities for them to get together. Each girl lives in a different county. We heard about

the learning center that Cool Kids was planning to start the following summer and we wanted to learn more. In February, 2011, Kyra met with Sharon Perfetti and talked about starting a support and social group for teens with cancer. There was nothing like this in the area for teens. Many of the programs are geared towards younger children.

Kyra had another sleepover with three cancer survivors and they worked on the idea of a teen group for cancer survivors. They came up with the name teens.CanSur.vive. In April, 2011, the teens.CanSur.vive group had their first meeting at the Towson Marriott, who generously donated a suite for them to have another sleepover, and a meeting room, and snacks for the next day. A couple of other teens attended the meeting and they discussed logistics and possible activities. They want to reach out to others going through treatment, so they all decorated birdhouses with a cancer theme and gave them to Hopkins to display on the pediatric oncology floors.

The teens.CanSur.vive group is blossoming. In this photo is Clarissa, Kimmie Meissner, a Cool Kids mentor to the teen group, and Kyra at a fundraiser hair cut event for Cool Kids. The girls came up with a design and decorated their shirts. Kyra and several volunteers represented teens. CanSur.vive at the finish of the Survivor Harbor 7 race in Baltimore, a race designed for survivors of a life threatening illness or condition to compete.

The first exciting event for teens. CanSur.vive was getting free tickets from the First Mariner Arena to see Rihanna. There were 3 cancer survivors and several friends that got to attend. The teen group also went



to an Orioles game in June, and Legg Mason, graciously let them use their suite. They are planning other activities, some which won't be too physically demanding so that teens currently in treatment can participate. The teens.CanSur.vive group wants to reach out to other teens so that they won't go through the journey through cancer treatment alone. If you are a teen being treated for cancer or a survivor, find teens.CanSur.vive on facebook. The group is still growing and it is open to ideas and would love to hear from you and get some input.

teens.CanSur.vive
Or email Kyra at
teens.CanSur.vive@gmail.com

Cancer as I Know it.

By Kyrilee Comeaux

You never expect the worst to happen to you. Your mind goes on vacation and says, "That won't ever happen to me." Until one day when reality catches up and it all becomes real. Throughout the two years that I was sick, I didn't know what was going on or how it was going to impact my future. The people that saved my life were there for me one hundred percent of the way and they also taught me what to expect in the future. I've been given the chance to make a difference. God saved me for a reason; to help keep everyone's mind on that vacation.

Through the months of January to March of 2001, my mom had been noticing unusual signs that my body was sending. These included red dots on my cheeks, becoming very pale, having less energy, frequent stomachaches, and much more. During this time I was only three, almost four. I was too young to understand what was going on and how to react to it. All that I can remember is that I was extremely confused, and in tons of pain.

To find out what was going on my mom decided to set an appointment on March 26th, 2001. She trusted that my pediatrician, Dr. Kamashi Neelkantan, would be able to detect what was wrong. As we all know, moms are never wrong, and as my mother was describing to Dr. Neelkantan what was happening, the air grew tight and silent. She told the doctor that every day at 2pm, I would get a fever. She would give me Motrin and it would go away until the next day at the same

time. The other noticeable symptom was that my stomach was blown up like a pregnant woman. The doctor had a look of worry in her eyes. As my mom had predicted, however, the doctor knew what to do. She took a full body workup and said she would call us in two or three days.

The next day, around 2:30pm my pediatrician made a phone call that changed my life. She told my mom that she needed to see her and my dad immediately. As my parents headed down the road with much anxiety, my grandparents stayed at home with my four month old sister and me. They were biting their nails off, they were so nervous. I still had no idea what was about to take place. When my parents sat down in the doctor's office, she gave them the news that I was diagnosed with Leukemia. Seconds after, my dad lost control, and got up and punched the doctor's wall. As my mom was calming him down and apologizing, she told the doctor to continue. The doctor then proceeded to tell my parents that Leukemia is a cancer of the bone marrow where blood cells are developed. My bone marrow cells developed abnormally and had begun to multiply quickly. They were crowding out normal bone cells and infiltrating other organs like the spleen, liver, and lymph nodes. My oversized stomach was because of the enlarged liver and spleen. The unknown red dots on my cheeks were Leukemia cells. The last thing that Leukemia did was make my body anemic. This was the cause for being so pale and having white bowel movements.

When the doctor finished, my dad called my grandparents and told them what was taking place. They packed overnight bags and rushed my sister and me to the pediatrician's office. An assistant of the doctor then led the way to Sinai Hospital. When we arrived at the hospital we met Dr. Joseph Wiley, head of the division of pediatric hematology-oncology. After we checked in, we were led to a very plain hospital room. I was given an assortment of coloring books and crayons, and then my parents were pulled aside. They were tired, scared, and depressed, but they kept going. They were told that I was to have a spinal tap to determine if I had Acute Lymphocytic Leukemia (ALL) or Acute Myelocytic Leukemia (AML). At that time ALL had an 80% to 90% survival rate. Meanwhile AML had a 50% survival rate.

After the spinal tap, the next thing on the agenda was to get an IV inserted immediately. Doing this would allow doctors to treat the symptoms right away. As you may recall, I would get a fever at 2pm every day. Because of this my mom would give me Motrin to make it go away. Unfortunately, Motrin thins the blood, which made it extraordinarily hard to insert a needle. Every time they would attempt to stick me with a needle, my veins would collapse. The nurses would put elma cream on the area where the needle would need to be inserted in order to numb the area, making it less painful. They would wait 20 minutes and then try again. They did this for several hours during the night into the morning. It was not until the early morning that they got the needle to stay in my foot.

In the late morning of Wednesday, March 28th, a spinal tap was conducted. We were later told that we were lucky. I was going to be treated for ALL instead of AML. Twenty-four hours later they put an internal port-a-catheter in my chest for surgery. This was supposed to make administering chemotherapy and other medications easier than using an IV. Towards the end of chemo, however, the port started to malfunction and was eventually removed. When the twenty-six months of treatment came to an end, I was finally in remission. This didn't come so easy though. Along with all the needles, and nasty medication, came many side effects.

The side effects included hair loss, weak leg muscles, and a thrombosis, or blood clot, formed in the brain. This blood clot was formed because of the combination of two medications. For three out of the twenty-six months, my mom had to provide me with two daily injections. The blood clot's effects became apparent one day when I awoke from a nap and began to speak gibberish and then ended my "sentence" by spitting. This was all caused because of the clot.

Even though the twenty-six months of treatment are done, I still go back every summer to make sure all of this never happens again. I am happy to report that everything is fine.

I have come to realize how blessed I am to be alive. Over the past couple of years I have met so many other people like me. They have taught me many things. I experienced meeting the most influential people, however, at a



banquet a couple of weeks ago with Ben Lanman who is a fellow cancer survivor. We were invited to a dinner party that was being hosted by Relay for Life. Relay for Life is all about raising money for cancer research. That research is then able to save lives and create more birthdays, which is what the whole banquet was all about. Besides the fact that this experience made me feel special, it also made me feel strong. The speaker that they invited shared her recent personal story with us. In it she told the audience how once you are diagnosed, you become a survivor, and from then on you stay a survivor. From that moment on, I knew I could fight for my life and accomplish anything.

Another event that Ben and I attended was on Friday March 20th 2011. Ben and I walked the survivors lap for Relay for Life at Patterson Mill High School. When we arrived, everyone had on different colored shirts. If you were a volunteer, you wore a blue shirt, you wore a white shirt if you were walking, and if you were a survivor you wore a purple shirt. Ben and I were handed a purple shirt. As Ben and I were handed our shirts, it started to downpour. It was so bad that I thought they were going to cancel. But as soon as that idea passed through my head, a rainbow soared across the sky and it was then that I knew God was going to keep everything perfect for the walk. Then the announcer called everyone over to prepare for the lap. But before they started, they had a woman speak about her adventure through cancer. She spoke about having courage, digging deep, and fighting through. She shared a quote with the crowd, "When life gives you one hundred reasons to cry, give life one thousand reasons to smile." As she was wrapping up her speech, I looked all around me



Kyra with fellow survivor, Ben.

and saw all the faces that had just lit up with smiles. The sight could have brought someone to tears. The same effect took place as we lined up for the walk. People were handing out carnations as a symbol of life. Then as the starting ribbon was cut, all the survivors became one as we walked around the track. It was the most magical event I have ever experienced.

Since May of 2001, I have met many people, learned many things, but have also wanted to give back. As I would go for treatments at Sinai, I would see a toy chest full of prizes for patients. Well, a couple of years ago, my doctor moved to another hospital right in Bel Air. In this new hospital, there wasn't a toy chest for the patients. This got me thinking, "why don't I give back and design my own treasure chest." And that's just what I did. My mom and I took a journey to Michael's and picked out the perfect box that looked just like a real treasure chest. To make it look more realistic, my godmother, god sisters, sister, and I, all decorated it make it look like a sunken treasure chest. We painted the chest a bright yellow, with jewels and pearls falling all around it. From there we packed it with assorted toys that patients could enjoy. We have received nothing but excellent reports from the office and

we hope to keep it that way. It is the greatest feeling to know that you are the reason for someone's smile.

The last thing that I'm going to talk about is what my sister, Madilynn and I do to give cancer patients hair. When I was in chemotherapy and taking medication, my hair would fall out. I was given a blonde wig to wear. I would go to the beach and people would pass by and say "I love your hair." My mom would just smile and say "thank you." Now, as



Kyra, left with her sister Madilynn

When reality sneaks up on you and everything becomes all too real, your mind is forced off its vacation. I can now put my mind back on that vacation, but aware of how to watch out for the big waves. Now that I'm cancer free, I can help people keep their mind on that vacation but also teach them how to keep watch for the waves. I know that I am extremely blessed to be alive. When remembering these times, however, I also have to give a huge thank you to my Mom, Dr. Neelkantan, and Dr. Wiley for being with me one hundred percent of the way. I love you and couldn't have done it without you. Through it all you have taught me not to take life for granted and to live it with no regrets. To live your life to the fullest and make it count. Now my next adventure is to keep everyone's mind on that vacation, without any waves.



"When life gives you one hundred reasons to cry, give life one thousand reasons to smile."

a way to say "thank you," every two years my sister and I donate our hair to Locks of Love. In order to do this your hair must be long enough to cut 10-11 inches off and still have enough hair left over. Madilynn has donated three times and I have donated twice. She donated a year ago and I gave mine almost two years ago. We both plan to keep up the tradition of giving back. I know if people didn't do this, going through chemo would be so much harder. But with thousands of people like us, we are all helping someone every day. From every patient, including me, that needed hair and has been given it, thank you from the bottom of our hearts.

Kyralee is currently 14 years old and will enter the 9th grade this fall. She enjoys playing softball and soccer and going to the beach. Kyralee is looking forward to attending Camp Sunrise in August for the first time. It is a week-long summer camp in Maryland for children who have been diagnosed with or have survived cancer.

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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.

Check out our website at www.cancerfearsme.org.

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

Editors Note: Two years ago we launched a new slogan for our Cool Kids Campaign – Cancer Fears ME! The slogan came to be after seeing the buttons “Cancer Sucks” on young cancer patients shirts. While that phrase is certainly true it just didn’t seem appropriate for the audience that was wearing them.

Cancer Fears Me came to us after years of observing that fear was the overriding emotion that many families and patients deal with while battling cancer. Fear of the unknown randomness of the very scary diagnosis of cancer. We wanted to turn around that fear and give the patient something that empowers them. And what better and simple way than Cancer Fears ME!

Shortly after developing and trademarking the slogan we had the opportunity to partner with the pharmaceutical giant, McKesson. They paid for and distributed over 15,000 Cancer Fears ME chemo caps to pediatric oncology patients across the country. Soon we were flooded with emotional photos of children proudly wearing our caps and living our slogan. It was more than we could have hoped for.

One photo in particular struck me as it crossed my desk. Little Samuel Snead who was being treated for cancer of the eye at the Children’s Hospital of Philadelphia. Something about his expression of determination at such a young age wrapped up what the Cancer Fears ME slogan was all about. I hung that photo above my desk and it has remained there for the past two years. When the opportunity was presented to us to have a billboard on 1st Mariner Arena we knew we wanted it to be perfect. But what photo to use? As usual, the answer is usually right in front of your face. Samuel became our first and only choice. And the determination that is etched on his face in the photo paid off. He is now a happy and prospering three year old. His story, as told by his mom, Sabrina, is below...



with our children and give them the opportunity to see another part of the world. We also had hope of finding a good doctor to help our son.

That Christmas as we took a family portrait, we could not find a photo out of 30 shots without a red eye and a white eye on Samuel – it was horrific. He was four months old and had yet to look at me for more than a few seconds. As I nursed and bonded with my baby, I prayed to God to let Samuel look into my eyes. But he could not see his mother.

On New Year’s Eve during a party in our home, Samuel spiked a low-grade fever. In the ER, doctors discovered he had pneumonia. Four days later at a follow-up appointment with his pediatrician, I took the opportunity to voice my concern about Samuel’s eyes. That doctor agreed that something didn’t add up. When light hit the baby’s left eye, it glowed white. She referred Samuel to an eye doctor on base.

As I picked up my contact lenses the next day, I explained my concern about the baby’s eye and asked if

On August 23, 2007, I gave birth to a sweet little boy with 10 tiny fingers and 10 tiny toes. Samuel was nothing shy of perfect in my eyes. Only two hours after delivery I noticed something was wrong – my baby was breathing rapidly as though he couldn’t catch his breath.

My best friend and I tried to convince the nurses that something was wrong – no one listened. Our concerns were brushed aside until Samuel turned purple. He was rushed to the Neonatal Intensive Care Unit where he remained for a week on oxygen and treated for

TTN, pneumonia, jaundice, and fluid in his premature lungs.

Seven days later, my husband and I brought home our baby boy. But our happiness was short-lived. A week later we noticed his eyes abnormally drifting to the sides of his head. At the baby’s six-week checkup, his doctor said it was normal. Yet this condition gradually worsened.

My neighbors and friends demanded that I seek a second opinion so Samuel visited several doctors – each saw nothing wrong. By October Samuel’s eye began to glow – it looked like a cat’s eye.

My husband serves in the United States Air Force and was transferred a month later to Anchorage, Alaska. We were thrilled to start a new life



Sam and his brother Dean



my eye doctor could look at it. He recommended we see a specialist as soon as possible. Deeply frightened, I thought that Samuel could be possibly blind, yet what I was about to hear was something that never crossed my mind.

A specialist named Dr. Shang did an ultrasound on the baby's eyes. In the left one, he showed me what looked like a ball inside. He sent me to the waiting room while he made a few phone calls. An hour later, he emerged to say that Samuel might have cancer. In disbelief, I began to black out and my body went numb. Did I hear correctly? Words cannot describe my emotions when I heard that my child had cancer. Was there a chance he might die?

I remember making three phone calls: first to my husband – I needed him there – and secondly to my mother at work. We sobbed together. Then I called a close friend and poured out my heart. We cried together as well until my phone lost its signal. Here was this precious baby boy asleep in my arms, hurting and very sick. I wished I could have taken his place. I wanted to take away his pain.

The doctor came back in as my husband arrived with our oldest son Dean. It was almost 100% certain that Samuel had Retinoblastoma. Dr. Shang scheduled him for an appointment in Philadelphia at Will's Eye Hospital. The worst was yet to come.

Samuel went through many tests – devastating to watch as a parent – although they had to be performed. He had a class D tumor in his eye (class E is the worse case, usually requiring removal of the eye); his right eye had a class A tumor. Chemo began the next day – by far the worst thing I could have



imagined putting my child through. Samuel endured six months of it and had a rocky time recovering. He stayed in the hospital more than at home.

My husband returned to Alaska while my children and I remained in Virginia to be closer to the Children's Hospital of Philadelphia (CHOP). Somehow Samuel got through it.

Samuel is now 3-years-old and in complete remission. He was able to keep both eyes and has 100% vision in his right one. Out of his left, he can see peripherally. He enjoys reading, coloring and

playing outdoors and will soon begin Pre-K.

Retinoblastoma is a rare cancer often undiagnosed. Statistics say that out of a million children worldwide, only one will be diagnosed. Oddly though, here on Dover Air Force Base, I have met two other children living with the same cancer.

Thank you for listening to Samuel's story. Let's all continue to raise cancer awareness, especially for children, and especially through such wonderful programs like the Cool Kids Campaign.

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"MAD" LIBS

The Princess and the Pea is a fairy tale written by Hans Christian Anderson in Denmark in 1835. It is believed that the story was one that he heard through spoken folk tales in his childhood. Now you have the chance to update this "ancient" story, Mad Libs style. Just ask a friend or family member to provide the missing words (don't read them the story first!). Once you have all the blanks filled in, read your new tale back to them!

Once upon a time there was a _____ (occupation) who wanted to marry a _____ (2nd occupation); but she would have to be a real _____ (2nd occupation again). He travelled all over _____ (place) to find one, but nowhere could he get what he wanted. There were plenty of _____s (2nd occupation again), but it was difficult to find out whether they were real ones. There was always something about them that was not as it should be. So he came home again and was _____ (adjective), for he would have liked very much to have a real _____ (2nd occupation again).

One evening a _____ (adjective) storm came on; there was _____ (noun) and _____ (noun), and the _____ (noun) poured down in torrents. Suddenly a _____ (verb ending in ing) was heard at the city gate, and the old king went to open it.

It was a _____ (2nd occupation again) standing out there in front of the gate. But, good gracious! What a sight the _____ (noun) and the _____ (noun) had made her look. The _____ (noun) ran down from her _____ (body part) and clothes; it ran down into the _____ (another body part) of her _____ (piece of clothing) and out again at the _____ (another piece of clothing). And yet she said that she was a real _____ (2nd occupation again).

"Well, we'll soon find that out," thought the old queen. But she said nothing, went into the _____ (room in your house), took all the bedding off the bed, and laid a _____ (type of vegetable) on the bottom; then she took _____ (number) mattresses and laid them on the _____ (same veggie), and then _____ (number) eider-down beds on top of the mattresses.

On this the _____ (2nd occupation AGAIN!) had to lie all night. In the morning she was asked how she had slept.

"Oh, very _____ (adverb)!" said she. "I had scarcely closed my _____ (body part) all night. Heaven only knows what was in the bed, but I was lying on something _____ (adjective), so that I am _____ (color) and _____ (color) all over my body. It's _____ (adjective)!"

Now they knew that she was a real _____ (2nd career choice) because she had felt the _____ (same veggie) right through the _____ (1st number from above) mattresses and the _____ (2nd number) eider-down beds.

Nobody but a real _____ (2nd occupation) could be as sensitive as that.

So the _____ (1st occupation) took her for his wife, for now he knew that he had a real _____ (2nd occupation); and the _____ (same veggie) was put in the museum, where it may still be seen, if no one has stolen it.

There, that is a true story.

The End

If you would like to compare your version with the original.....

Once upon a time there was a prince who wanted to marry a princess; but she would have to be a real princess. He travelled all over the world to find one, but nowhere could he get what he wanted. There were princesses enough, but it was difficult to find out whether they were real ones. There was always something about them that was not as it should be. So he came home again and was sad, for he would have liked very much to have a real princess.

One evening a terrible storm came on; there was thunder and lightning, and the rain poured down in torrents. Suddenly a knocking was heard at the city gate, and the old king went to open it.

It was a princess standing out there in front of the gate. But, good gracious! what a sight the rain and the wind had made her look. The water ran down from her hair and clothes; it ran down into the toes of her shoes and out again at the heels. And yet she said that she was a real princess.

“Well, we’ll soon find that out,” thought the old queen. But she said nothing, went into the bed-room, took all the bedding off the bedstead, and laid a pea on the bottom; then she took twenty mattresses and laid them on the pea, and then twenty eider-down beds on top of the mattresses.

On this the princess had to lie all night. In the morning she was asked how she had slept.

“Oh, very badly!” said she. “I have scarcely closed my eyes all night. Heaven only knows what was in the bed, but I was lying on something hard, so that I am black and blue all over my body. It’s horrible!”

Now they knew that she was a real princess because she had felt the pea right through the twenty mattresses and the twenty eider-down beds.

Nobody but a real princess could be as sensitive as that.

So the prince took her for his wife, for now he knew that he had a real princess; and the pea was put in the museum, where it may still be seen, if no one has stolen it.

There, that is a true story.

The End

Brain Teasers

Q. In and out, like the tides, I go.
Past the jaws, I move to and fro. If
you lose me, find me fast, Or else
my loss will be your last. What am I?
A. Breath

Q. What has no beginning, end or
middle and touches every continent?
A. The Ocean.

Q. What starts with E, ends with E
but usually has one letter?
A. An envelope.

Jokes

Q. What did one eye say to another?
A. Something between us smells.

Q. What drink do fighters like?
A. Fruit punch

Q. Why don't grasshoppers go to
baseball games?
A. They prefer cricket.

Q. Why did the football coach go
to the bank?

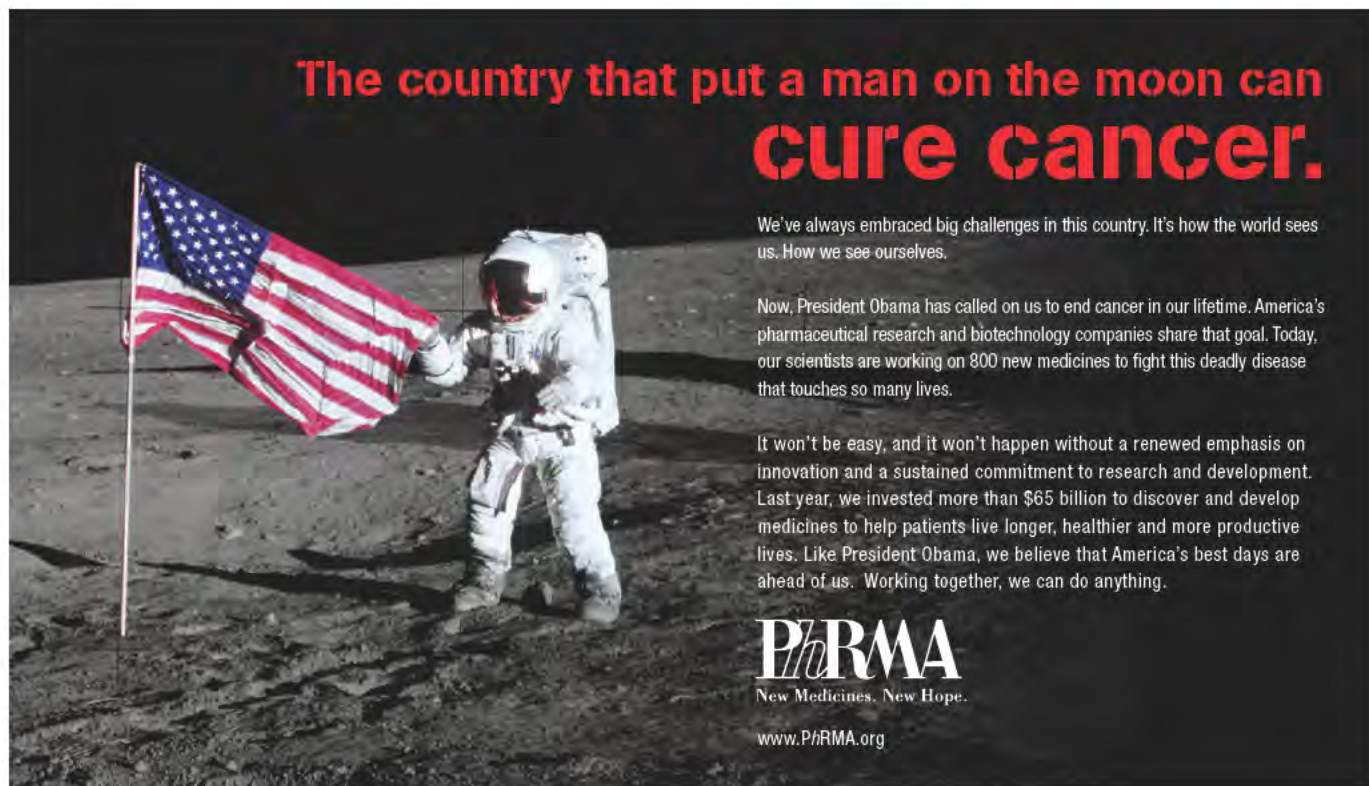
A. Because he wanted to get his
quarter back

As two caterpillars were crawling
along, a butterfly flew overhead.
One turned to the other and said,
"You'll never get me up in one of
those things!"

STUDENT: But I don't think I
deserve a zero on this exam.

TEACHER: Neither do I, but it's
the lowest mark I can give you.

A little girl goes to see the doctor.
She's got a pea in one nostril, a
grape in the other, and a string bean
stuck in her ear. She says to the
doctor, "I don't feel good." The
doctor replies, "The problem is clear
to me. You're not eating right!"



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Cool Kids & Cool Caregivers

By: Molly Lauryssens

At just three years old, Noah White is into washing clothes...and motorcycles. That's not a misprint either- he's into washing clothes! But this aspiring actor has big plans come fall when he will be attending a learning center.

Samantha Sekse might have a hard time narrowing down her favorites with questions relating to books or movies but one thing is certain- she's definitely grateful (and passionate) when it comes to her work as a registered nurse at Johns Hopkins University.

Check out this edition of Cool Kids and Cool Caregivers in this Question and Answer Series to see what these super-cool kids had to say! How would you answer these questions, what would you say?

Noah White



Where do you live?

Randallstown, MD.

How old are you?

3-years old. I just had a birthday on June 5. I'm so excited. I will be going to a learning center in the fall.

If you were to write a book what would it be about?

If I were to write a book it would be about motorcycles or washing clothes. I love to wash clothes.

Do you have a BFF?

Yes. My best friend is a girl named Sophia.

What do you like to do for fun?

I like to play sports especially soccer and basketball.

Are you a dog person or a cat person?

I like dogs and especially cats.

What makes you a Cool Kid?

I love to play, act silly, and play jokes on people.

What do you want to be when you grow up?

I think I will be a great actor because I love people, and imitate other people well.

Favorite cereal?

My favorite cereal is Fruit Loops.

Favorite movie?

My favorite movie is SpongeBob.

Favorite TV show?

Disney Channel's "Shake It Up"



What sports are you into?

My favorite game is basketball and football. I love the Baltimore Ravens.

Do you have brothers and sisters?

I have two sisters and one brother. Their names are Schone White, Jr., Niya White, and Gabrielle Swinton.

What is your favorite fruit?

My favorite fruit are watermelon and grapes.

I think I will be a great actor because I love people, and imitate other people well.

Samantha Sekse



Where do you live?
Baltimore, Maryland.

What is your title?
My title is a Nurse, A Registered Nurse if you're feeling fancy. I don't think I've ever had a title before.

What do you do?
I work as a nurse on the pediatric oncology inpatient unit at Johns Hopkins Hospital.

What is the favorite thing about your job?

This is tough to answer as there are so many favorites! I think some of my favorite things are playing games with the patients (all ages!), hearing their jokes, and being humbled every day by the strength, modesty and grace each child and family possesses at such a trying time of their life. I have learned more than I could have ever asked for or imagined I would.

What is the least favorite thing about your job?

My least favorite thing about my job is having to do throat cultures on Wednesdays. I haven't met someone yet who doesn't mind those. I also wish there was a Dunkin Donuts in the cafeteria because that coffee definitely keeps me going!

What time does your day start?

I rotate shifts as a nurse so I do both day shifts and night shifts. I either start at 7am or 7pm so I wake up at 5:30am/pm.

Favorite sports to watch?

Lacrosse and baseball (very different I know!)

Favorite sport to play?

I ran cross country, winter track and spring track throughout high school and for two years in college so this is one of my favorite sports and now cycling is my favorite.

Do you have children?

I don't have any children (yet!) I am a proud aunt to three nieces and a nephew though!

What do you like to do for fun?

I love going out to eat, playing board games and doing puzzles, cycling, kickboxing, cooking, going on trips to the beach and to visit my sisters.

Favorite movie?

My three favorite movies are: any movie with Julia Roberts, but especially Pretty Woman, then Planes, Trains and Automobiles and Away We Go.

Favorite book?

Giving Tree and The Art of Racing in the Rain.

Favorite cereal?

Cinnamon Toast Crunch

Favorite dessert?

Dove Ice Cream Bars (Dark Chocolate)

Favorite type of food?

Sushi!

Favorite board game?

The Amazing Labyrinth

Favorite card game:

I think dice games trump card games so I choose Yahtzee.

Cats or dogs?

Dogs...BIG dogs

Favorite celebrity?

Julia Roberts

Favorite season?

Fall

If you could have dinner with one person, dead or alive, who would it be and why?

I would have dinner with John Krasinski from the [television show the Office] because he's not only cute, in a charming/funny way, but I'm sure he'd be funny too.

What is on your iPod?

A group called Walk the Moon and DJ Earworm "Blame it on the Pop."

What does your ideal vacation look like?

My ideal vacation was definitely Martinique where my husband and I went on our honeymoon. Beautiful place, French-speaking, no agenda for each day, clear water beaches, hot weather, dancing at night, boat rides and snorkeling adventures, all around perfect time and place!



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