



CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

FIGHT FOR NORMALCY

By: Shantel Randolph, Julien's mom, Baltimore, MD

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On August 26th, 2015 our lives changed forever. Our energetic, charismatic, sweet child Julien Randolph (age 5) was diagnosed with acute lymphocytic leukemia (ALL). This was a very traumatic experience for our entire family. Treatment for Julien included a two week stay in the hospital with ten days in the Intensive Care Unit, several rounds of chemotherapy, and lumbar punctures

As a very close knit family, this was a devastating blow to all of us. We wanted to protect Julien from all the pain he had to endure but knew we couldn't. We faced this new reality of hospital visits and being introduced to new words like chemotherapy and immune-compromised and new medicines and schedules for lumbar punctures; we knew our world had changed forever.

The biggest surprise of it all was how strong and courageous our little boy Julien has been so far. Through it all, Julien has remained his sweet, loveable self. He truly is our hero! What we have learned in this short period of time since he was diagnosed is to fight for the life we once had and to not let cancer be the main character in the story of our lives, especially Julien's. We had to fight for our sense of normalcy.

Once Julien came home and started feeling better, we knew we would have to make some adjustments but we were determined for him to be the 5-year-old rambunctious, energetic child he always was. We made sure we increased our family time and spent more time together doing things that brought us happiness. Whether it was playing football in the backyard or taking spontaneous trips to the beach, which is Julien's favorite, we were determined to enjoy our lives.

That is my hope for everyone reading this article. *You have to make the decision to not let cancer steal the show in your child and family's life. Make a conscious effort to enjoy every precious moment you have with your loved ones while you are fighting this battle. Even on bad days, allow yourself to have your moment but then decide to enjoy the day even if that means doing something as small as going to the store for ice cream.* We are so grateful we can surround our son with so much love and positivity. He is facing Leukemia with the will and spirit to win.

This is a three-year journey for Julien and our family. It is our belief that he will be healed, healthy, and whole. We just have to go through this chapter of his life with hope, faith, and most importantly love.





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An interview with Clarissa Schilstra

Author of: **RIDING THE CANCER COASTER**

Through her own experiences as a two-time cancer survivor, and previous teen cancer patient who faced a forty percent chance of survival, Clarissa Schilstra has learned a great deal about all of these challenges and how to cope with them. In the pages of this book, she shares those stories and strategies, in an effort to provide a guide through the emotional roller coaster that is cancer treatment and life as a cancer survivor.



What inspired you to write this survival guide for teens and young adults who have been touched by cancer?

When my leukemia relapsed, ten years after my initial diagnosis, I was thirteen years old. I had just finished seventh grade and suddenly my world was turned upside down. My relapse treatment lasted two and a half years, and during all of it I was very immunosuppressed. Therefore, I could not be in school through eighth, ninth, and half of tenth grade.

I lost many of my friends during those years, as everyone moved on, changed, and grew up. While they all finished middle school and moved on, to high school, I stayed at home, where I had a home-teacher help me keep up with my classes. I know that, during those two and a half years, I longed for a friend each and every step of the way, a friend who was a teenager with cancer like me.

I wished I knew someone dealing with the same challenges I was dealing with. I wished for someone who was one step ahead of me. I needed that person there, telling me I was not alone, that my emotions were normal, and that there were ways I could cope with everything I was feeling and all of the things I was going through. There was no such person there for guidance, no one with whom to commiserate.

I did not meet more than one or two other teens in the hospital, so it was really difficult to find someone to relate to. There was not even a book out there for guidance. When I realized the

importance of such a guide, such a book that could provide hope, support, and friendship to teens and young adults with cancer, I decided to make it my mission to create that book!

Who were some of the people who were most influential in helping you write this book?

Dr. Stephen Schimpff, a retired oncologist and former CEO of the University of Maryland Greenbaum Cancer Center, was the most influential by far! I was fortunate to meet Dr. Schimpff through neighbors who frequently brought my family dinner throughout my treatment. I was in tenth grade when I met him.

My neighbors had told Dr. Schimpff of my interest in helping other teens and young adults with cancer by writing a book, and he gladly met with me to talk about my ideas. He has been an invaluable mentor to me ever since - connecting me with resources, advising me to start a blog, and helping me get published for the first time in a book about the use of social media in healthcare environments.

Most importantly, he has spent countless hours helping me develop an outline and proposal for my book. Without his help with that, and advice regarding self-publishing on Amazon, I am quite sure I would never have been able to make this book a reality!

I also have to include my parents here, since they have been my strongest supporters. They have encouraged me to write the book for several years now, and supported me wholeheartedly when

I decided to stay home and do just that this summer. They have both spent countless hours reviewing my many drafts and advising me on how to make it better too!

What were your goals for this book?

My goals for this book are for the teenage and young adult cancer patients or survivors who read it to feel like they are not alone and that there are ways for them to cope with their experiences and adapt despite the physical, social, and emotional challenges they may face. More specifically, I hope it can help them see that it is possible to stay positive, even when life tries its best to bring them down.

What was the hardest part about writing this book?

I would say there were two “hardest parts” about writing this book. First, it was incredibly difficult to relive the more traumatic and uncomfortable parts of my cancer experience, as I wrote them down. With that, however, it was also really challenging to find out how I could write about those experiences in a way that didn’t just describe them, but went beyond that so others could learn from them and learn how to stay positive if they encounter similar experiences.

What did you enjoy most about writing this book?

The most enjoyable part about writing this book was meeting and working with some really incredible people. I reached out to Dr. Lori Wiener, a pediatric psychologist who specializes in the psychosocial needs of children and adolescents going through cancer treatment, and she generously agreed to write the foreword to my book. Her positive feedback on all I had written made me feel much more confident in the idea that my book might just meet the goals I had set for it. I was also really glad to have my good friend, Karen Shollenberger, review my manuscript and contribute some valuable advice that I think helped me make the book much better. Finally, receiving such positive reviews from Ronald R. Peterson, the President of Johns Hopkins Hospital, and Paul F. Levy, the former CEO of Beth Israel Deaconess Medical Center, was like a dream come true.

How did you get to be where you are in life today?

I can definitely say I got here today because of the people in my life.

- The unfailing support of my parents, who have always encouraged me to follow my passion;
- The unconditional love of my little brother;
- The expert care I received at Johns Hopkins Pediatric Oncology;
- The dedication to my education shown by my home teacher, Diane Baerveldt, and my teachers at Mt. Hebron High School in Ellicott City, MD;
- The invaluable guidance provided by Dr. Stephen Schimpff;
- My high school friends Sarah Niezelski, Abby Smith, and Shannon McDade, who welcomed me into their friend group when I returned to school, and helped me make my only two years of high school better than I could have ever imagined;
- And most importantly, my friends and professors at Duke University, who have shown me how to harness my life experiences to power the change I want to see in the world.



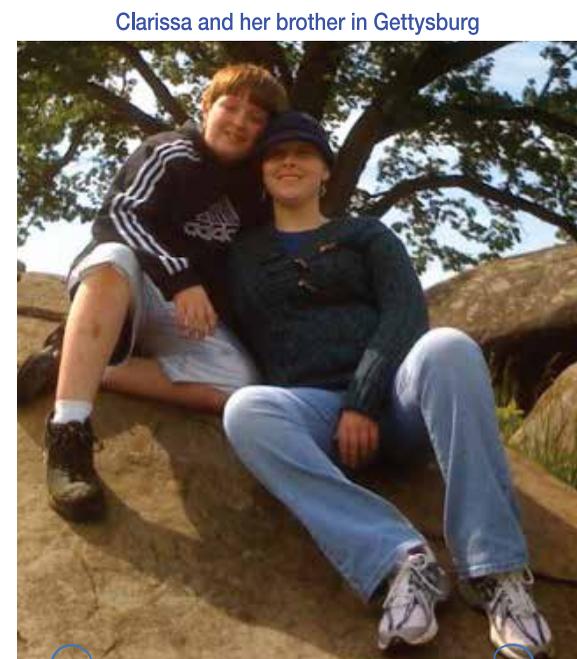
Clarissa and her dad



Clarissa's family



Clarissa's dogs were great companions



Clarissa and her brother in Gettysburg



Clarissa and Dr. Lotterman



Clarissa and Dr. Buxbaum



Clarissa and Nurse Sue



Clarissa and her mom

Things I would say to parents who have just heard the words:
"YOUR CHILD HAS CANCER"

From parents who have been through the journey



Advice from: Derrith Spitzer

mother to Ben, who was diagnosed with T-Cell Acute Lymphoblastic Leukemia in 2014 when he was 9 years old.

- Figure out what gives you control over the situation and do it. If that means asking 84 questions at each visit, do it. If that means laminating charts of your child's immunity levels, do it. And don't let anyone judge you for it.
- Make good memories every chance you get. Your child will remember those memories more than the bad. Trust me on this. Give yourself permission to have fun. The healthier you are mentally, the better caretaker you can be for your child.
- Teach your child that humor in times of true heartache will be a trait they will recycle forever.
- Dance when no one is watching.
- Roll down the windows of your car and sing your favorite song as loud as you can.
- If that doesn't work, lightly punch a wall (pillow is better). Then put "patch wall" on your husband's already long "honey do" list.
- Believe in the treatment process. Anything less allows the illness to win.
- I sought counseling toward the end of my son's treatment and told my counselor that my primary goal which was to "not worry" when my son finished his 3+ years of treatment. Her immediate response was, "that is a choice you make." I prepared myself and when the time came, I made that choice and it feels great.
- Make friends with the head nurses. It will make your experience so much lighter if you feel that you are not alone during your hospital stays or when you text them at 11:00 p.m. with questions.
- Ask the universe why this happened to your child. Then, let it go. You will never get an answer that will satisfy you.
- Lean on your friends. Don't be afraid to let go of friends that can't weather the storm alongside you. As they say, maybe they were never your friend to begin with?
- Cry when you need to, whether in private or in public, and don't feel like you have to apologize. The release would always revive me, and give me energy to continue, a little lighter emotionally than before.





Advice from: Bridget Fick

Mom to Brendan, who was diagnosed with Wilms Tumor (kidney cancer) in 2011 when he was 5 years old.

This just brought back a flood of emotions. Starting the journey is so hard. Hard to believe you will feel normal again but you will. Some tips:

- Accept help. People want to help. Take the meal when offered, let someone grocery shop, clean your house, babysit, etc.
- Remember to take some special time with the siblings. They really are impacted just as much. Set aside time for them. They are just as scared.

- The journey becomes a new "normal" and take one day at a time.
- Keep a journal of questions, fears, concerns, new families you meet, etc.



Advice from: Mary Buck

Mom to Jackson, who was diagnosed with Acute Lymphocytic Leukemia in 2014 when he was 5 years old.

- I only surrounded myself with positive. I only wanted to hear about good outcomes. I even had to block some very well meaning children's cancer organizations from my FB feed because I could not handle the occasional post about a child who didn't make it.
- I got involved. I decided to run a half marathon (even though I don't like running) to raise money for leukemia research. Having a purpose and a challenge kept me from wallowing.
- I also learned to say no. Sometimes life just got too overwhelming and we all needed a minute to breathe. I had to learn to decline invitations to some birthday parties, play dates, and evenings out with friends.

- I rediscovered my faith. Not for everyone, but it helped me tremendously.
- I made friends with other "cancer moms." Your old friends mean so well, but sometimes they just don't get it.
- I stopped sweating the small stuff. Plans will be ruined because of unexpected hospital stays. You will be rushing to the ER because of a fever instead of going out to dinner like you planned. When I learned to stop getting upset about it and just let it happen, I was much happier!
- I worked for the first nine months after diagnosis because I carried the health insurance. As soon as my husband got a job with good benefits, I quit my job as an attorney and found something that allowed me to work from home. I never wanted to be a stay at home mom, but cancer changed that. Now I get to see my kids grow and am closer to them than ever before. I am also not scrambling to find coverage at work when we find ourselves unexpectedly at the hospital. If you can swing it, having one parent at home makes life so much less stressful.



The Girl WHO FELT PAIN

By: *Jeneisha Henry,*
Osteosarcoma, 17-years-old, Baltimore, MD

I was torn. I was confused. I was sixteen years old. Two pathways stood before me: would I spend the rest of my life in fear of dying or face the biggest fight of my life? Although this choice was difficult, I already knew what I had to do. There was no way I could live in fear. I would choose to fight! I had spent the last four years of my life living in danger without knowing, and there was no way I was going back. Surgery and chemotherapy were my only choices.

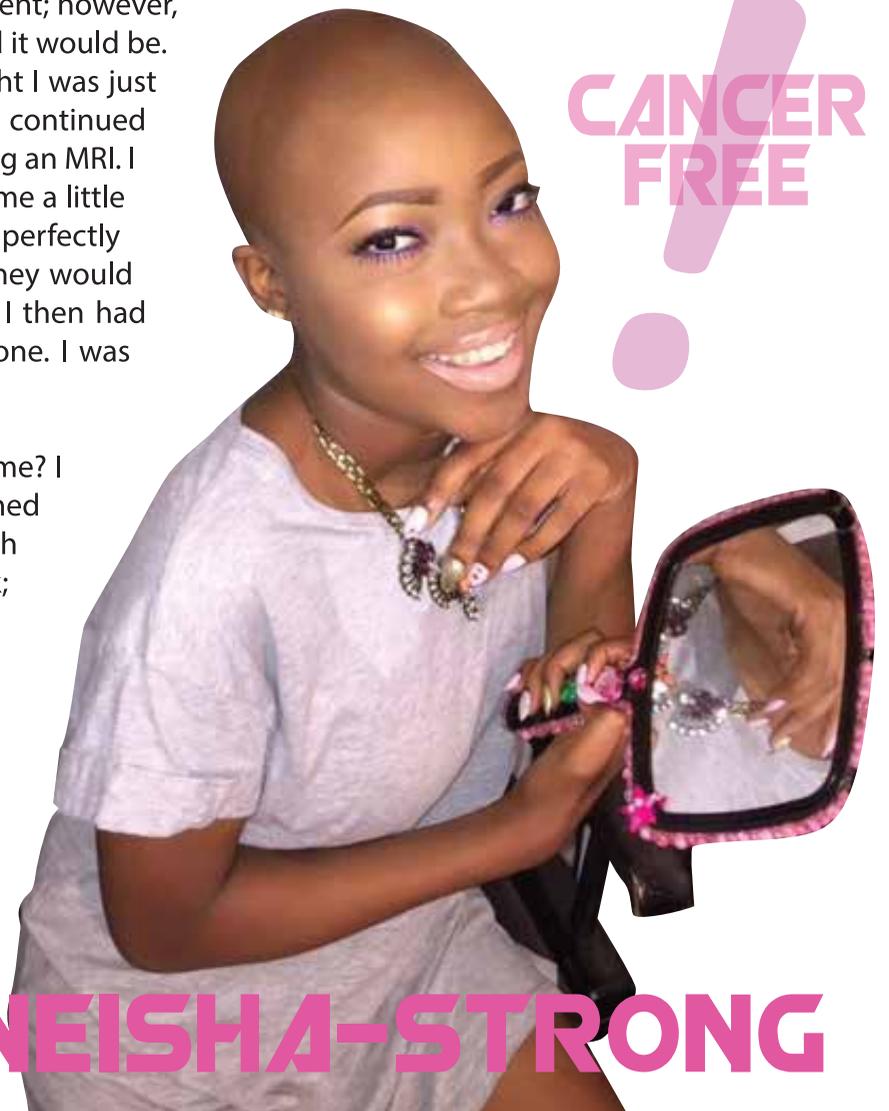
My name is Teneisha Jamila Henry. I am a seventeen-year-old Jamaican American female who lived with the kind of pain that made my eyes water and my thoughts turn to amputation. Multiple doctor visits, with prescribed medication, yielded no solution or relief. The pain in my right shoulder became overwhelming on a day to day basis.

One night, I was lying in my bed at approximately 11 p.m. when an unexpected pain shot through my right shoulder area like a lightning bolt striking a tree limb. I rushed downstairs to my dad and alerted him to what I felt. He asked me to show him where it was hurting. I placed his hand on the area, and he reminded me of an upcoming appointment. My pediatrician's diagnosis was "possible pain due to bone growth or muscle strain" from dancing during my eighth grade year.

My freshman year in high school should have been met with excitement; however, it was met with fear of the pain coming back and wondering how bad it would be. From ninth to eleventh grade, I felt frustrated because people thought I was just constantly complaining and being dramatic about the pain. The pain continued well into my eleventh grade year, so I had multiple tests done including an MRI. I took Ibuprofen, which didn't work, and used heating pads that gave me a little relief. The pain was radiating up to my neck and down to my perfectly manicured fingertips. My parents heard my cries and told me that they would not give up until we figured out where the pain was coming from. I then had another MRI which finally revealed a tumor in my right humerus bone. I was scared. The tumor could either be benign or malignant.

A biopsy determined that the tumor was malignant. I thought: Why me? I was frightened to know I had a killer in my shoulder. The test determined that it was localized. I had to choose: surgery or surgery with chemotherapy. Just surgery could result in the tumor coming back; surgery with chemotherapy could result in debilitating side effects. I chose surgery to remove the humerus and replace it with a metal prosthesis and inpatient chemotherapy. The physical side effects kept me home from school, but I continued my studies through Home and Hospital services to graduate with my class. I realize I'm Teneisha-Strong; the fight is in the attitude! The rehabilitation process has made me stronger. Most importantly, I am now cancer-free! And even though my fight is over, I have the scars to remind me of everything that I went through.

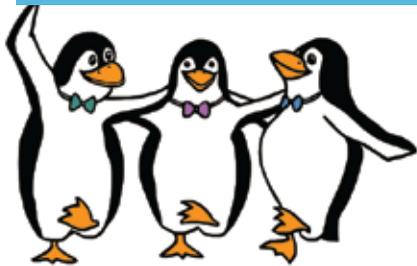
CANCER
FREE



PUZZLES AND GAMES

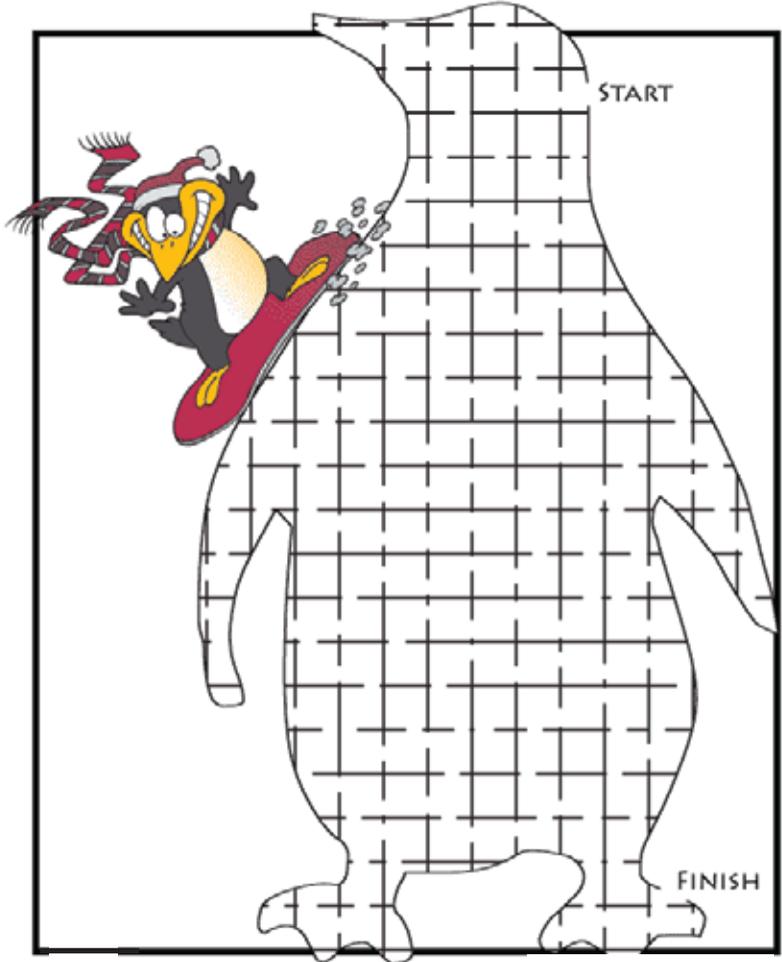
Penguin Word Search Puzzle

P E N S K C I H C G U I M N S
 A R E A B L A C K A N I D W H
 P A E L I T E F C L W I G H T
 L E S T E A T F I S H S B S I
 R D O W N F E A T H E R S O D
 S E W A H T O W C A M T L U K
 W D I T S T H B R A I N I T A
 D O W E K W A O A R S D W H A
 D O N R D S O U T H P O L E W
 L L N E E K A N N N H D B R L
 I B V T E B E C A O E I J N N
 L M Y R F I B E N T R H U E S
 O R Y U T L H U E D E R M N H
 E A M I S P Y H L E R E P O F
 T W A D D L E H E B W O R L D



- | | |
|---------------|--------------|
| ANTARCTIC | LEAP |
| BIRD | NEST |
| BLACK | ROOKERY |
| BLUBBER | SALT WATER |
| BOUNCE | SOUTH POLE |
| CHICKS | SOUTHERN |
| DON'T FLY | SWIM |
| DOWN FEATHERS | WADDLE |
| EAT FISH | WARM BLOODED |
| HEMISPHERE | WHITE |

Help the snowboarder get through the maze!

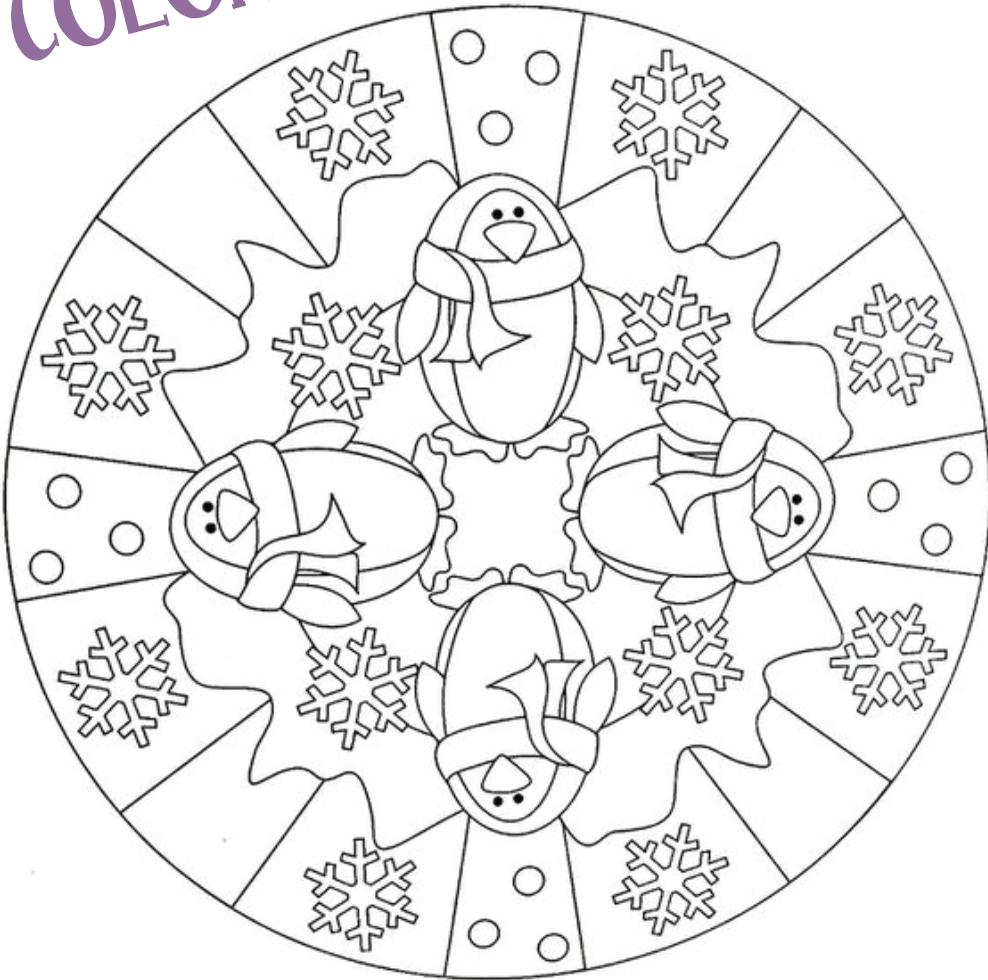


See how many words you can make out of: SNOWBOARDING

_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

BRAIN TEASERS

COLOR ME!



S
U
D
D
O
K
U

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

1

	1	4	
	4	2	
	2	3	
	3	1	

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

2

3				5
	5			2
6				1
1				3
	3			5
5				2

3

	2			4
4				2
		3	6	
		2	1	
6				3
	3			6

ANSWERS:

4	3	1	2
1	2	3	4
3	4	2	1
2	1	4	3

6	5	4	3	2	1
1	2	3	4	5	6
2	3	4	5	6	1
3	4	5	6	1	2
4	5	6	1	2	3
5	6	1	2	3	4
6	1	2	3	4	5

6	5	4	3	2	1
1	2	3	4	5	6
2	3	4	5	6	1
3	4	5	6	1	2
4	5	6	1	2	3
5	6	1	2	3	4
6	1	2	3	4	5

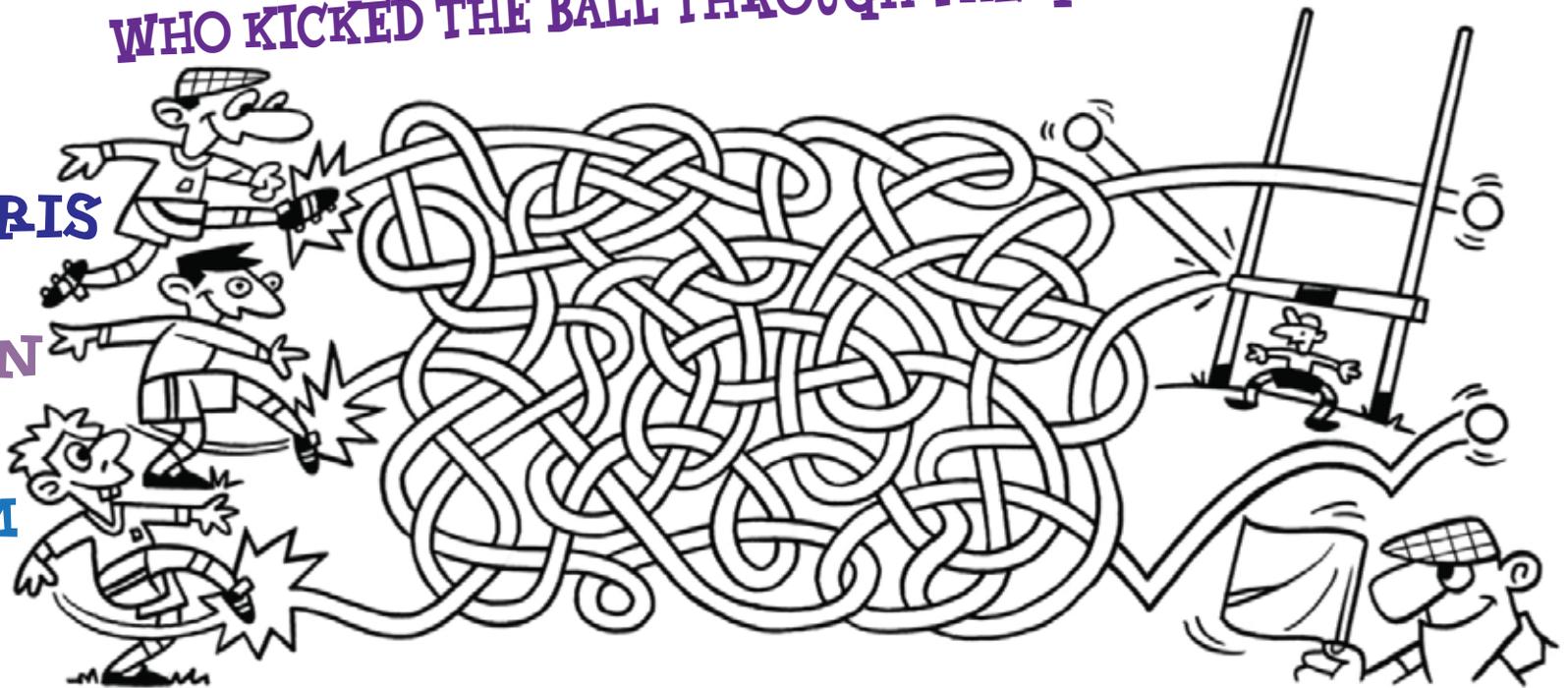
MIND BENDERS

WHO KICKED THE BALL THROUGH THE GOAL POSTS?

CHRIS

JON

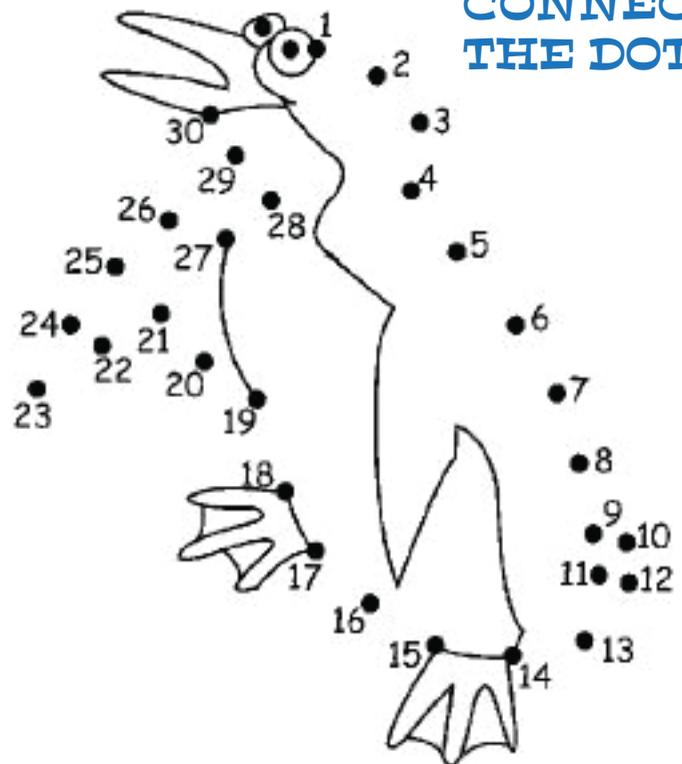
JIM



Fun Facts for Kids About PENGUINS

- ❄️ Penguins are flightless birds. While other birds have wings for flying, penguins have adapted flippers to help them swim in the water.
- ❄️ No penguins live at the North Pole. Most penguins live in the Southern Hemisphere in countries such as New Zealand, Australia, Chile, Argentina and South Africa.
- ❄️ Penguins eat a range of fish and other sealife that they catch underwater.
- ❄️ Penguin's black and white plumage serves as camouflage while swimming. The black plumage on their back is hard to see from above, while the white plumage on their front looks like the sun reflecting off the surface of the water when seen from below.

CONNECT THE DOTS



JOKES

RIDDLES



TWISTIN' THE TONGUE

Read the tongue twisters below and practice saying them.
How fast can you say it?

Fuzzy wuzzy was a bear.
Fuzzy wuzzy had no hair.
Fuzzy wuzzy wasn't very
fuzzy, was he?



How much wood would a
woodchuck chuck if a
woodchuck could chuck wood?



HaHa!
LOL!
Bahahahahaha

What's the difference
between a guitar
and a fish?

You can't tuna fish!

What do you
call a fake noodle?

An impasta

Why can't you
give Elsa a balloon?

Because she will LET IT GO!

What do you
call an alligator in
a vest?

An investigator

KNOCK-KNOCK JOKES

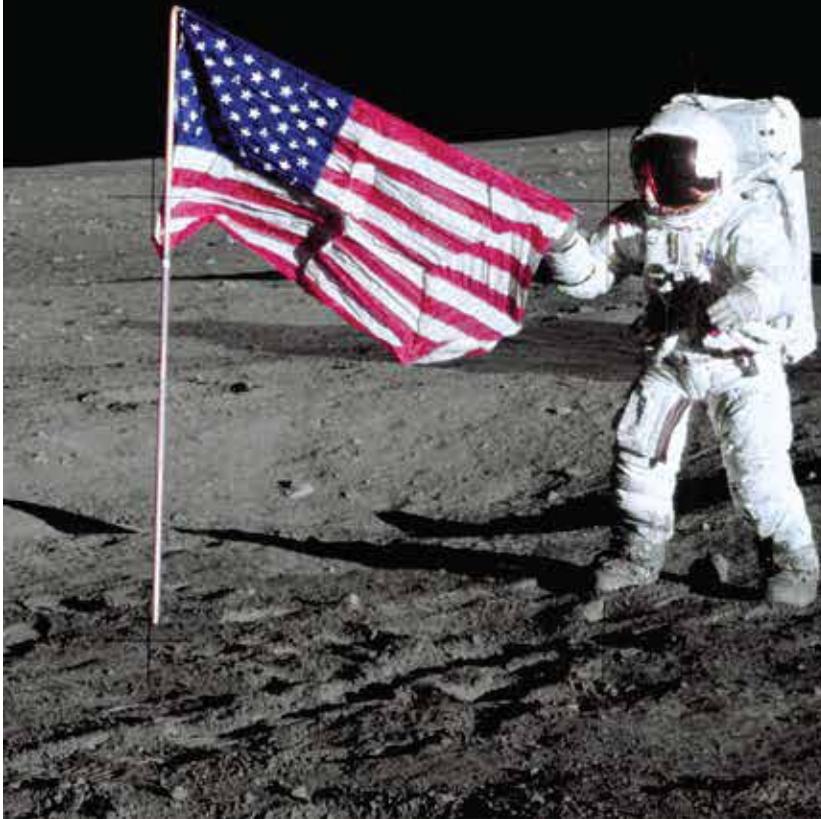


Knock, knock
Who's there?
Cows go!
Cows go who?
Cows go "moo" not "who"!

Knock, knock
Who's there?
Isabel.
Isabel who?
Isabel working?

Knock, knock
Who's there?
Alex.
Alex who?
Alex-plain later!

The country that put a man on the moon can **cure cancer.**



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

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

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

PhRMA

New Medicines. New Hope.

www.PhrMA.org

RAILROAD B&O MUSEUM

B&O RAILROAD MUSEUM

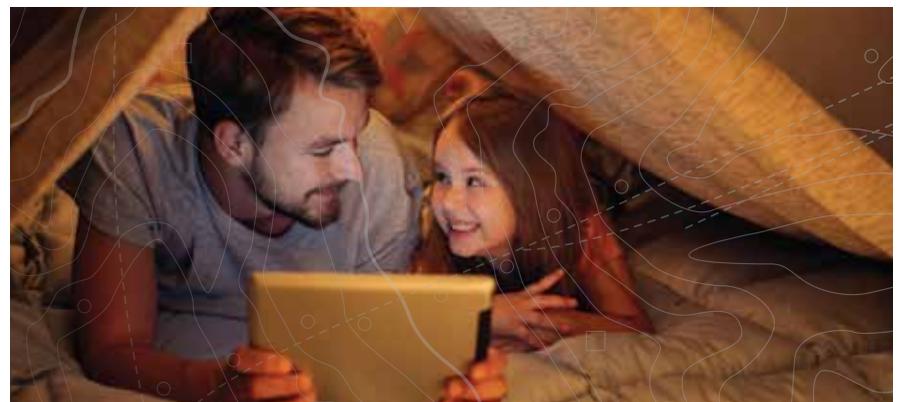
DISCOVER YOUR ADVENTURE

- STEAM POWER MONTH OCTOBER
- SUPER HERO DAY NOV 5 & 7
- WITCHES & WIZARDS OCTOBER 24
- MAGICAL HOLIDAY EXPRESS NOV 21 & 22 & NOV 30 - JAN 3
- THE POLAR EXPRESS Train Ride

CAROUSEL RIDES
SEASONAL TRAIN RIDES
INTERACTIVE KID'S EXHIBITS
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CHASE-ing Cancer Away

By: Kathy Wheatley, Chase's mom, Elkridge, MD



It's hard to believe that our #48 of the 10-12 Elkridge Hurricanes, who often led his team in tackles, was diagnosed with Pre-B Acute ALL Leukemia! Chase seemed more winded than usual when he was running the sprint drills six days a week in the August sun, but we explained it away that he was just out of shape. Chase complained of being extra tired the first week of school, but we explained it away that it was just from staying up late and sleeping in all summer.

Chase was playing football with his friends one day at recess and I noticed he was a funky shade of pale. We couldn't explain that away. We made an appointment with his pediatrician that day. His doctor read the results of Chase's blood test and advised us to go to Johns Hopkins Hospital. Three hours later, we began our "new normal" life.

Chase is a 12-year-old seventh grader. He has sisters in eighth, ninth, and tenth grades. Our family is deeply imbedded in the community and because of that, we have been overwhelmed with the outpouring of love and support from so many people. We have learned that it is so much easier to give than to receive. As Chase said to us one night, "thank you doesn't seem to be enough to say sometimes." That is so true!

We had friends, neighbors and family come to our house to clean and make repairs so that Chase could come home to a safe and clean environment. We've had friends and coworkers make meals for us. I never realized how much time shopping, planning, and cooking dinner takes. Instead of dealing with dinner, I could concentrate on Chase and his siblings.

Chase's football team chipped in and bought him an iPad to use when he's having chemo. The players wore orange ribbons on their helmets to show their support. The whole football organization donated money to our family for medical costs, gave him a picture signed by every football player and coach, and presented him with his team's Super Bowl trophy to inspire him to keep fighting.

Students and staff from his middle school held a dance and sold bracelets and t-shirts to raise money for the teen room on the Hopkins oncology floor. They were able to present a check for \$4,400 to the hospital in Chase's name.

Organizations have allowed us to attend events, bringing us together as a family to have fun and relax. We've received care packages with gifts inside for the whole family. Chase's head will never be cold, or lacking a new pillowcase to rest on, again!

Is our "new normal" life something we're glad we have? Heck no! We would love to go back to our crazy, hectic life where all of our kids were healthy. But we can't. Instead we're embracing our new crazy, hectic life.

 A life where we keep a hospital bag packed and ready to go at any time.

 A life where we have medicines, IV pumps, barf buckets, syringes, alcohol wipes, and our hospital binder in every room of our house. And we have more bags of fluid than food in the refrigerator.

 A life where hospital visitor bands are our most worn piece of jewelry.

 A life where everyone asks what his counts are before they say good morning.

 A life where we realize how blessed we are. We have family who can help us with all of our children whenever it is needed. We live thirty minutes from Johns Hopkins Hospital (unless a marathon is taking place throughout the city and we're stuck in traffic for 2 hours!) where we receive excellent care from a

knowledgeable staff. We have many caring people sending cards, positive thoughts, and prayers for our family. And we have a son who inspires us every day to greet the day with a smile and be happy for all we have.

 With all of this on our side, there's no way we won't
CHASE THIS CANCER AWAY!



MAGIC YARN PROJECT

At the Magic Yarn Project, two moms are making a huge difference in the daily lives of young cancer patients across the globe. Bree Hitchcock and Holly Christensen created a series of Disney princess themed wigs that they knit from extra soft yarn. They hope to give a bit of magic and whimsy back to young girls going through cancer treatment with the gift of princess yarn-wigs completely free of charge.



My friend remarked at how many other little girls in that hospital would love to have such a special gift as it had such an impact on her daughter's demeanor and happiness during her treatments.

These wigs are particularly special because they are made with the tender heads of young cancer patients in mind. Traditional wigs are too rough on their skin so Holly and Bree, with the help of hundreds of volunteers, are making wigs from soft acrylic yarns that are then decorated, often with a little sparkle, to resemble the hairstyles of many young girls' favorite princesses.

In her own words, Holly describes how the project came about:

"My name is Holly Christensen. I have often witnessed the scary and painful world of cancer as an oncology nurse, friend, and family member. I've always held my cancer patients very close to my heart. In 2014 upon learning that a friend's daughter had been diagnosed with cancer and would likely be in the hospital for a while, I began to think of what I could do to help bring some magic and light to this little girl's life during the trying days that I knew were ahead for her.

Knowing how difficult it would be for her to lose her beautiful blonde curls, I made her a Rapunzel yarn wig and sent it in the mail. She was overcome with joy.

I began to organize what I thought would be a small project creating a few dozen wigs to send to little cancer patients and put up a request on Facebook for yarn donations. Within hours, I was flooded with responses from around the world—mothers who wanted these wigs for their little girls who have cancer, complete strangers who wanted to help by donating money to buy yarn, professionals reaching out and requesting wigs for their hospitals

What started as a small project, has snowballed into something much bigger than I ever expected. We have been overwhelmed with the donations and desire to help that has come from all over the world.

The Magic Yarn Project was created to answer the call to bring yarn wigs to little girls and to help community members get involved in the Magic Yarn Project."

Since the project began, 180 wigs have been made and shipped to 32 states and 11 countries. These wigs are created during workshops across the country and while this fantastic pair of ladies has been able to raise a lot of funds and support for their cause they still need help.





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