

COOL KIDS CONNECTION[®]

SPRING 2014

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

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coolkidscampaign.org

Super Cam

by Julianne Page Mcneil

— Lorton, Virginia

This has been the most amazing journey that no one wants to go on. The day we were told our 19 month old baby boy had cancer, we thought the world would end. It wasn't fair. I wanted more than anything to switch places with him and take away all his pain. We knew things would never be the same.

They aren't and will never be the same. That day, I met a hero for the very first time. Our precious son, Camron, was now our SuperCam. He put on his tiny cape and started the biggest battle of our lives. He had to go through so much that no one should ever have to. And he went through all of it with that beautiful smile on his face.

Our world didn't end. Cancer isn't going to win. Everything changed BUT for the better. Each and every day became more special. Today is a gift and that's why we call it the present. Each day we live a little more, laugh a little harder, and our love grows a little stronger. We have learned to treasure every moment we have with all of our children. When they want to play just five more minutes, we suck it up and let them play. When they keep coming down the steps at bedtime, we kiss and hug our children one more time.



We have met so many amazing people along the way. There are so many good people who want to help children like Camron. People who selflessly donate their time and efforts to help families, to raise funding for research, and to raise awareness. We have met an amazing team of doctors and nurses who have dedicated their life's work to helping our children. The amazing warriors we have met and their families are so inspiring.

Cancer does not have Camron; Camron has cancer. After 2 years, 4 months, and 2 days, Camron is beating this monster. A year from now, we will finally get to celebrate NO MORE CHEMO! Until then we will continue to fight!

He's got this; he's SuperCam!





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A Gift from the Sea... 2014

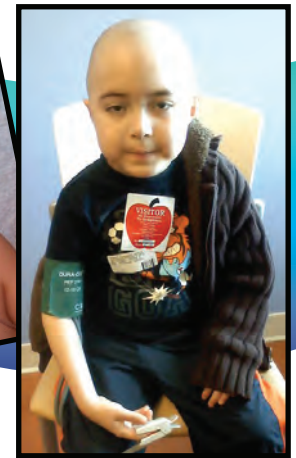


By Sarah Clarke Kleinhans and
Addison Kleinhans (9)
Broomfield, CO

Treated at Children's Hospital Colorado, Aurora, CO

Seafoam sprayed into my eyes and I felt the surfboard beneath me burst forward as I lazily draped my arm into the clear water. The sun was hot but not scorching on my back. I was blinded by its brilliant rays but no complaint came from my mouth. To my left, my husband laughed as our 12 year old daughter breezed by as if she had been born on a surfboard instead of in the snowy oceanless state of Colorado. In front of me, I watched my nine year old son carefully stand and raise his arms in triumph. His smile was so bright it contagiously lit up the faces of the surf instructors. Inside my emotions tumbled, bouncing between elation and relief, yet not without a hint of fear. Today was one of those few days in one's life that you can classify as absolutely perfect. Tomorrow, a week, a month, a year, or 10 years from now, we might have to battle the beast again yet I will draw on the strength I have gained from today being an unmatched perfect day.

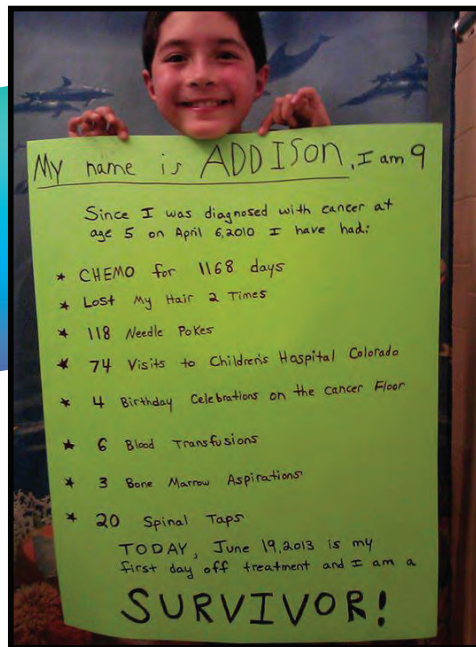
Flashback 46 months to the week of April 6, 2010. A scared and very sick 5 year old boy lies asleep, drowning in a hospital bed which appears to shrink him to an even more vulnerable size. It is a beautiful warm day outside but I know that neither I nor the little child will have much time to enjoy it anytime in the near future. Outside our room, above the nurses station is a sign reading ONCOLOGY. As my young son sleeps, there is a knock on the door. The social worker peeks her head in and quietly sneaks over to me, a handful of brochures for me to read. I hand her back the top one, "Oh, this one isn't for us, it's Make-A-Wish. That is for REALLY sick kids." Her eyes sadly met mine, her brief look of surprise masked quickly with a slight smile. "Addison's cancer diagnosis means that he is eligible for a wish. He DOES have a life threatening illness." I looked down at the smiling child hugging a dolphin on the cover and then over to the 2 inch binder containing the roadmap for his upcoming 38 months of treatment. I thanked her and she quickly exited as experience had taught her to read the cues of a parent who could handle no more information in this brand new journey.



A few days later as I sat next to Addison, his body too exhausted to play as well as bound by wires and tubes to do anything but stare at the television, I decided to start sorting through my piles of information. Once again, I found myself staring into the face of the elated child hugging the dolphin. She had no wires, obvious scars or illness as one could see from first glances. She did not appear to be the analogous "Make-A-Wish child" I had always imagined. Addison leaned over his hospital bed railing and for the first time in days, showed interest in something. "I want to do that Mommy!" I laughed and without thinking answered, "Well you can sweetie, someday...Perhaps..." Putting the brochure aside, I looked at my son and wondered how it was that suddenly my typically healthy child was eligible for a Make-A-Wish of his own.

Six months after Addison's initial diagnosis of Acute Lymphoblastic Leukemia (ALL), I found myself sitting in my kitchen with two people who would soon become our newest family members in this crazy cancer journey. Our "wish granters", Todd and Maureen, were incredible volunteers who had the wonderful "job" of helping our son decide what he wanted for his wish. Still heavily medicated on steroids and chemo, Addison was far from his former healthy self, but this boy didn't need more than a few mere seconds to explain what he wanted for a wish. "I want to go to Hawaii!" Now being so young, they had to make sure that Addison really understood what his choices were and that he might want to pick a wish that wasn't a 12 hour travel day from our home. Without a trace of reservation toward this stranger, he grabbed Maureen's hand and pulled her up the stairs when she asked him to explain why he had chosen Hawaii. When he opened the door to his tiny bedroom, the wish granters saw that this was not a wish picked on a whim.

There had been many days and nights where he pondered what it would be like to look eye to eye with a dolphin, surf on a blue sky colored wave, or discover coral in a tidepool. Addison's room was painted with an enormous ocean mural complete with blue skies, palm trees and real sand mixed into the paint to replicate the beach. A poster hung above his bed of a tropical scene so he could dream of something magical when in reality, the chemo was making him feel miserable. On Halloween afternoon, a week later, the phone rang and an excited voice filled the phone with anticipation. "Is Addison there?" Standing by my side, a very steroid bloated and bald boy stood looking up at me with curiosity swimming in his eyes. I put the phone on speaker and told the caller that he was able to hear her every word. "Well, that was one of the fastest decisions I



have witnessed. I just got out of the Make-A-Wish meeting and after we showed the photos of his room and told them of Addison's request, it was decided that his wish to Hawaii will be granted!" exclaimed Maureen.

As Addison finished his most difficult first year of treatment, we began to discuss the future trip. His immune system was expected to stay compromised but Addison's body didn't follow the norm and decided to remain even more compromised than the typical leukemia patient. His treatment would be 38 months long and his port would remain in place the entire time, putting him at greater risk for infections. We knew that it was ultimately Addison's choice as to when we would go but one day he told me that he wanted to wait until his port was out to travel. He told me he wanted to be finished with treatment and not have to worry about getting sick or having to run to the hospital with a fever. My husband and I decided that it would be a wonderful goal to help ALL of us get through some of the most difficult days, some of which were just around the corner.

One night I went into Addison's room and found him burning with fever. Terrified, I called the hospital and they told me that due to his port, I was to go to the nearest hospital immediately. Of course it was snowy and bitterly cold so we seemed to travel at a painstakingly slow, snail's pace. From the back seat, I heard a chattering little voice call out, muffled by a pile of blankets. "Mommy, I am picturing when I am all better and we are in Hawaii. That is why I am so hot right now, from the sun." Now, Addison has always had a wonderfully vivid thought process and tonight, his timing was perfect. I relaxed my white knuckle grip on the steering wheel and down the road, I swear I saw a palm tree swaying gently to calm me down. That night as the antibiotics pumped into his chest, we lay in bed discussing what we would do once we were in Hawaii. As we speculated, the hospital room was transformed into a jungle with rumbling waterfalls. Children's cries from the other rooms became tropical bird calls and the snow falling outside the window melted into white foam of crashing surf. Someday we would be finished with this crazy cancer and we could stand on the beach celebrating the fact that somehow we had survived.

On June 18, 2013, at the age of 9, Addison completed his 1168 days of chemo and his port was removed. We contacted our wish granters and told them that anytime after the new year, we would finally be ready to go on Addison's wish! Our travel date of February 1, 2014 approached quickly and soon we found ourselves digging for summer clothes in the middle of an ice storm. Two days

before our trip, as I nervously watched as the newstation warned us of an impending storm, I heard a familiar sound coming from Addison's room. Confused that I had imagined it after having heard it for over three years, I ran upstairs to find him indeed, covered in vomit. This time, not from chemo but from gastroenteritis, commonly referred to as the stomach flu. Tears rapidly followed, due to a little boy's complete and utterly heartbreaking comprehension that after all of this time, he would not be getting on a plane to go to Hawaii this week. Now never fear, a Make-A-Wish trip can be delayed but the tricky part is, it might be quite a delay before they can get everything rescheduled.

We have always tried to live by the "glass half full" philosophy so when Addison's sister Madelene and I both got sick on the exact day we were to depart, there was some pleasure in knowing that is was a good thing we weren't sitting on an airplane at that moment! Because Make-A-Wish is truly run by angels, everyone scrambled and did all they could to reschedule us and before we had time to unpack, we had a new departure date a mere three weeks from the original.

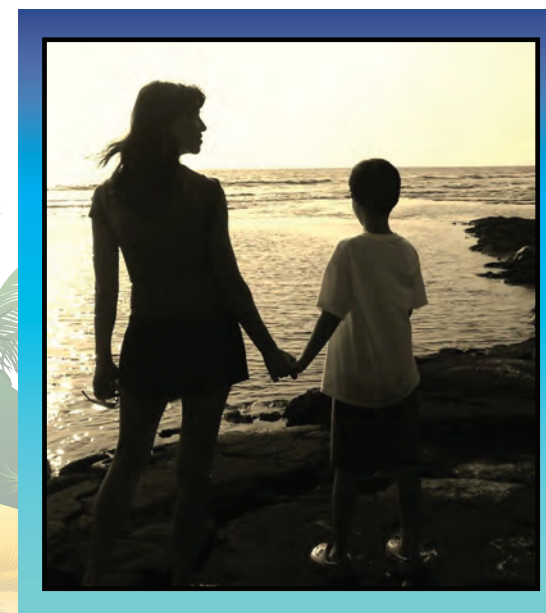
SO, here we are, back to where I started you out when you first joined me in the water. Remember? The brilliant blue sky matches the crystal clear water, filled with fish dancing beneath your surfboard? The only way to describe it is SURREAL. Even though the sun is extremely warming, my heart is so full that even a glacier couldn't chill me. Not just because we are in this magical scene, but because Addison has survived. He is far from finished but I look around and see my husband, daughter and son and realize that although we were tumbled and at moments lost in the deep, we had found our way back together as a family.

We spent the week hitting the beach at the crack of dawn and barely having the energy to crawl into our beds after days so full of adventures, there was hardly a moment to catch one's breath. None of us wanted to miss a minute. We didn't know what lay ahead for Addison healthwise and we had learned the priceless lesson of not taking a single moment for granted. We learned to surf, hiked through the islands rolling mountains, played with dolphins, attended a luau, snorkeled in the lagoon, bought fresh fruit at the farmer's market, nightswam with manta rays and Addison even helped his dad land a 101 pound

relatively rare "Big Eyed Tuna." The best part was meeting all the incredible locals who learned of our journey and welcomed us to the island with warmth and grace.

Through it all, I learned that the power of a wish is truly magical. On the last day of our vacation, we decided to go for a walk on a secluded beach that the locals had told us about. It was a sacred fishing ground many moons ago and there was even hushed talk of the island spirits gracing the land. As we silently walked along, I felt a little hand grab mine. I looked down to see a tan face, shaded by a "Nice try cancer but I am still here" hat, smiling the biggest smile I think I have ever encountered. As we turned the corner, we stopped abruptly at the sight of a row of six turtles warming themselves on the beach. Addison pulled a piece of coral out of his pocket that he had picked up on his first day. "It is time for me to throw it back because it doesn't belong to me; it belongs to the sea. I think the sea helped heal me and wash away my cancer cells." A lump caught in my throat. Our wish granters in Colorado had understood Addison's need to come here and why he wanted to wait until finishing his treatment. I realized what Addison had known all along. We weren't just leaving the island; we were leaving this chapter of his cancer behind.

As the sun began to set, he waited for the perfect wave and standing one foot in the ocean, one on the sand, threw the coral back to the sea "Goodbye cancer, thank you Hawaii!"



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



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Cool Kids Campaign





Ronald McDonald House
Charities of Baltimore
is pleased to support
the Cool Kids Campaign.

www.rmhcbbaltimore.org



SURFIN' THE NET...

Have you discovered a useful or fun website to share with other families dealing with pediatric cancer? Email the link to katie@coolkidscampaign.org for inclusion in the next issue of Cool Kids Connection. We found a few to share with you ...



1 conkerrcancer.org

ConKerr Cancer provides children with cheery pillowcases to brighten their hospital stay and a chance to learn to sew while breaking up the boredom of a hospital stay. ConKerr Cancer has delivered more than 860,000 pillowcases in just seven years to 250 hospitals throughout the country, creating 'miles of pillowcase smiles' for the children and their parents. In addition, ConKerr volunteers visit hospitals to sew with the children, breaking up the monotony of long, frightening hospital stays.



2 theblanketfairy.com

The Blanket Fairy's Mission is to make and donate as many blankets as she can to children with pediatric cancer. The Blanket Fairy follows many blogs & websites and when she sees a child that needs a lift in spirits while going thru treatment she will contact their parents to have their child go into her Sprinkle Dust Treasure Chest to pick out a blanket or any other item that may be available in there. The Blanket Fairy has very, very, soft blankets that will help children stay warm especially when they are sick. These blankets will help bring comfort to children as they go thru their treatment for cancer. The only thing The Blanket Fairy asks is that she get a picture of the child with their blanket or gift so she can post pictures on here for all the Volunteer Fairies around the world to see.



3 joyjars.negu.org/joy-jars/

JoyJars® were created by Jessica Joy Rees during her courageous 10 month fight with two brain tumors. Jessie used her JoyJars® to spread hope, joy and love to children fighting life altering medical illnesses. JoyJars® are stuffed with love and:

100% free to patients and hospitals
filled with new toys & activities
for boys and girls
ages 18 and under



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



At M&T Bank, we know how important it is to support those organizations that make our communities better places to live, work and grow. That's why we offer both our time and resources. What we all get in return is far more valuable.





Ava's Story

By Gina Rich, Los Alamitos, California



In mid-February

We noticed a bump on the top of Ava's head. We were not too surprised because Ava was always playing really rough with her older brother, Tyler. But we still checked it every day. The bump did not go away, so I took Ava to her pediatrician. Her doctor said it was a simple cyst and that we should just leave it alone. She said if it bothered her a dermatologist could remove it. I took Ava to the dermatologist and she said it was just a benign cyst. She suggested leaving it and watching to see if it changed. Even though both doctors told us it was fine, my husband and I both wanted it removed.

Friday, March 8th

It was supposed to be a simple in office procedure. I was in the room with Ava during the procedure. I watched the doctor work on her and it seemed like she was struggling. Things didn't seem right. Ava had local anesthesia and she was awake, so I had to stay calm. I saw the doctor pull something out of Ava's head. She paused and looked at it with a confused look on her face. I felt like something was wrong. She kept digging in my daughter's head and then she pulled out another piece. The doctor then asked me to leave the room. The simple procedure took three hours. The doctor called me back into the room and said that she couldn't get it all and that it wasn't what she originally thought it was. She said that she would test it and then send us the results.

Friday, March 15th

One week later, we were told they found atypical cells and that they would know more on Monday, but again they told us nothing. Ava had to go back to the doctor to get her stitches out and we were to get the results. Ava and I

waited in the waiting room while the doctor talked with Todd. For some reason, we had a bad feeling and we didn't want Ava in the room for the results. I'll never forget the look on my husband's face as he walked towards us. He tried to act normal as we drove home. Once we got home, we occupied Ava with something so Todd could share with me the results. It was Lymphoma. I'll never forget how horrible that day was; Todd felt the same way. Honestly, I felt like it had to be a terrible mistake! Ava was healthy and strong. It just didn't make sense! I started looking around for the best possible hospital. Todd and I agreed that Children's Hospital of Los Angeles would be best for Ava. I called to get her an appointment. They couldn't schedule her yet because we had to wait to find out what kind of Lymphoma she had.

Thursday, March 21st

We received the news that Ava had B cell Lymphoma. I called Children's Hospital of Los Angeles and they fit us in the next day, which happened to be the day before Ava's birthday.

Wednesday, March 27th

Ava had surgery and started chemotherapy.

Friday, April 5th

Ava was admitted for her first full dose of chemotherapy. The doctor said she would be in treatment for two years, but there would be cycles when we would not have to come in as often. He told us that she would lose her hair and that she may get sick from the chemotherapy.

January 3, 2014

Ava completed the majority of her treatment and is currently in maintenance. There were so many times when I did not know how Ava would get through all of it: many hospital stays, sickness, surgeries, chemotherapy, losing hair, being in a wheelchair, countless medications and allergic reactions. But through all of it, she didn't complain and always went along with her treatment plan.

Reflecting on the Past & Looking Towards the Future

I am so very proud of her! We're still learning to take things one day at a time. As Ava's body is healing, she still has some obstacles to overcome. Ava's goal now is to start a foundation. She wants to deliver toys to kids with cancer. Many times in the hospital, Ava had to be isolated because she was so sick and possibly contagious. Knowing how that felt, she wants to be able to bring some happiness to kids even if they can't leave their room. Ava made her first delivery of crafts and toys in January. It was the same day she was getting chemo, but she was more focused on bringing her donations. She wasn't able to visit any kids during flu season. Now that spring is coming and flu season is over, Ava will be able to fulfill her goal of delivering crafts and toys to more kids. My heart is so full of admiration for my daughter. I feel like she is truly amazing.



PUZZLES AND GAMES

MLB BASEBALL WORD SEARCH



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

MLB BASEBALL TEAMS WORD LIST

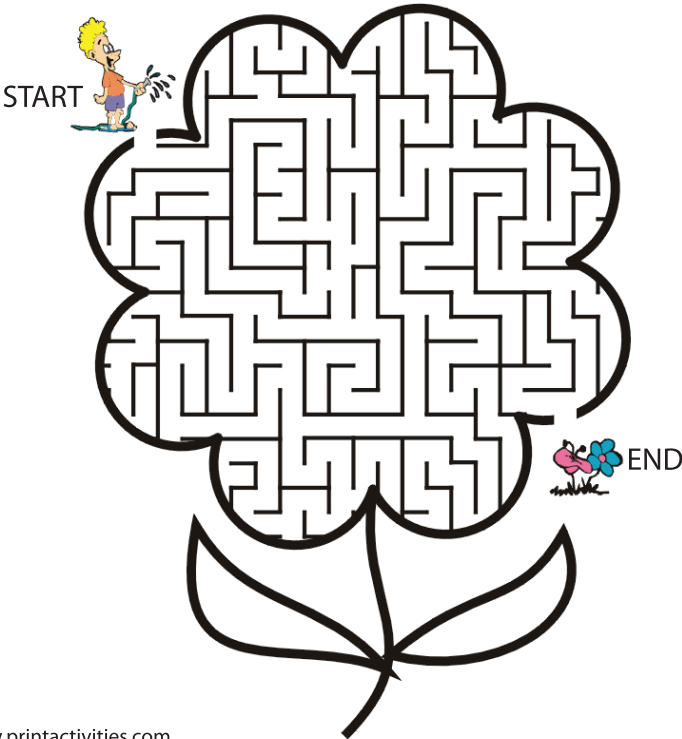
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|--------------|-----------|---------|
| ANGELS | INDIANS | RANGERS |
| ASTROS | JAYS | RAYS |
| ATHLETICS | MARINERS | RED SOX |
| BRAVES | MARLINS | REDS |
| BREWERS | METS | ROCKIES |
| CARDINALS | NATIONALS | ROYALS |
| CUBS | ORIOLES | TIGERS |
| DIAMONDBACKS | PADRES | TWINS |
| DODGERS | PHILLIES | YANKEES |
| GIANTS | PIRATES | |



The bird is looking for a tree to build it's nest this spring. Draw the path starting at 1 and counting by 1s up to 100.

87	88	89	92	93	98	99			
86	85	90	91	94	97	100			
83	84	79	78	95	96				
82	81	80	77	76	75	74	73	70	69
55	56	57	60	61	62	63	72	71	68
54	53	58	59	42	41	64	65	66	67
51	52	45	44	43	40	39	36	35	34
50	47	46	9	10	11	38	37	32	33
49	48		8	13	12	17	18	31	30
			7	14	15	16	19	28	29
			6	5	4	21	20	27	26
			1	2	3	22	23	24	25

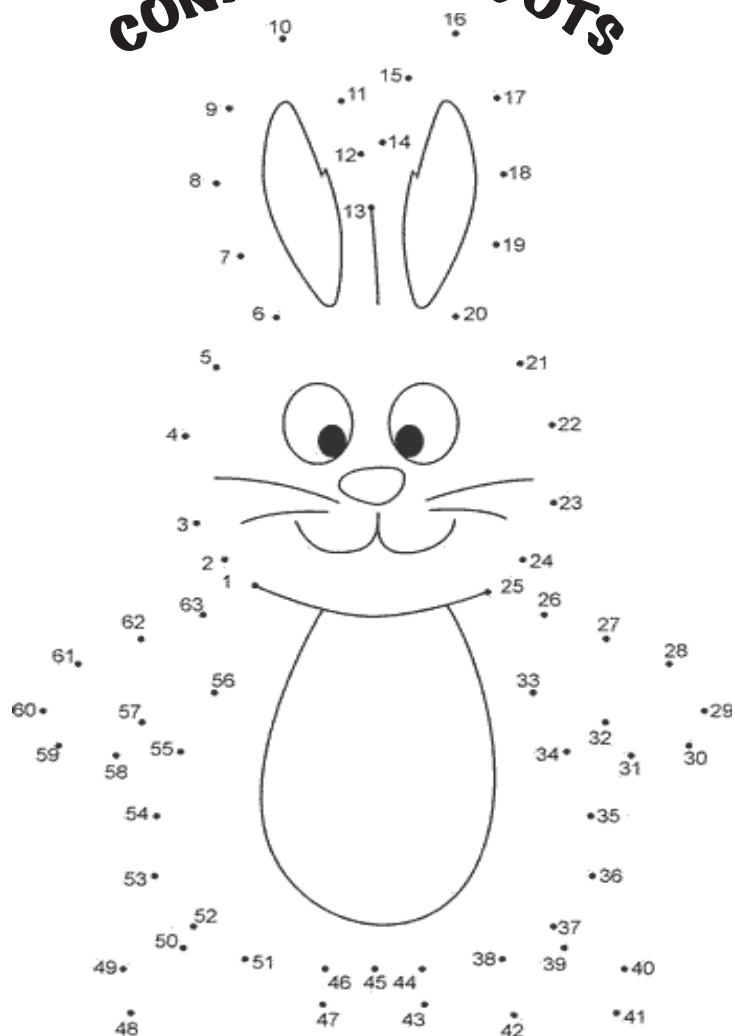
Help the boy find his way through the maze so he can water his flowers.



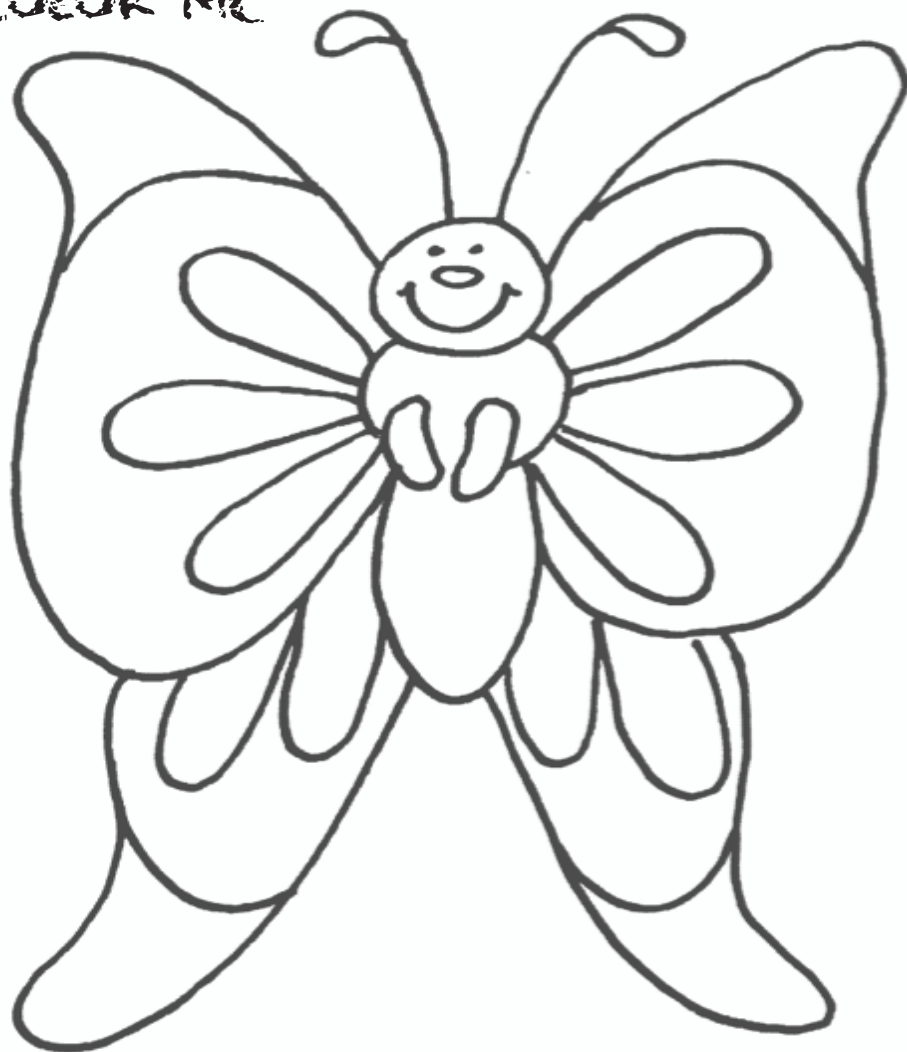
BRAIN

TEASERS

CONNECT THE DOTS



COLOR ME



www.bogglesworldesl.com



How many words can you make out of: **SHAKESPEARE**

WINTER BLENDED

Unscramble these SPRING words

1. MSOSOBL _____
2. WRAM _____
3. RBSID _____
4. OFDAIDLF _____
5. WOGR _____
6. OWESFRL _____
7. LETM _____
8. NPTAL _____
9. HCATH _____
10. IPNCCI _____

ANSWERS: 1. BLOSSOM 2. WARM 3. BIRDS 4. DAFFODIL 5. GROW
6. FLOWERS 7. MELT 8. PLANT 9. HATCH 10. PICNIC

How many koalas can you count in the picture below? Look carefully! Why not color in the picture too?



JOKES RIDDLES



TWISTIN' THE TONGUE

**If Freaky Fred Found Fifty Feet of Fruit
And Fed Forty Feet to his Friend Frank
How many Feet of Fruit did Freaky Fred Find?**

**A flea and a fly in a flue
Said the fly "Oh what should we do"
Said the flea" Let us fly
Said the fly"Let us flee"
So they flew through a flaw in the flue**

WHAT AM I?

I am hot.
I live in the sky.
I am bright. Don't look straight at me.
I disappear in the night.

THE SUN

Children
love to play with me. Don't tangle my
long string. Look up and watch me dance.
Run if you want me to fly faster.

A KITE

I am
associated with Spring. I love to hop in
the grass. I play in your vegetable garden.
My teeth are long and sharp.

A RABBIT

I live in
the water. You can drive me. I
might make you sick. Don't put a hole in
me. Tie me up when you're done.

A BOAT

KNOCK-KNOCK JOKES

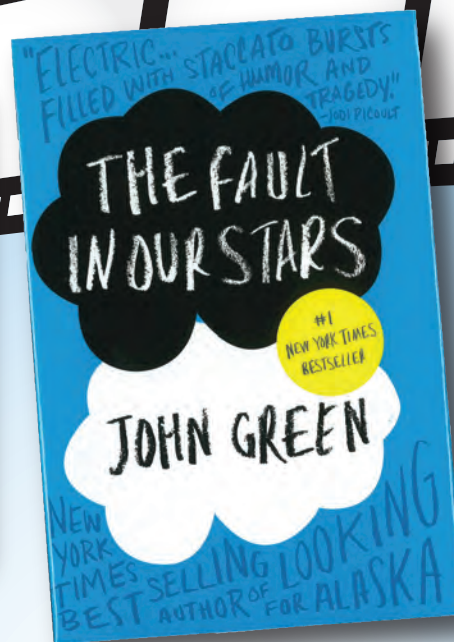


**Knock, knock
Who's there?
Wooden shoe!
Wooden shoe who?
Wooden shoe like to hear another joke?**

**Knock, knock
Who's there?
Tank!
Tank who?
You're welcome!**

**Knock, knock
Who's there?
Frank!
Frank who?
Frank you for being my friend!**

Reviews



You say you're not special because the world doesn't know about you, but that's an insult to me. I know about you.

John Green

I love you present tense

Review of The Fault in Our Stars

By: Alie Duff, 17, Carcinoid Survivor

The Fault In Our Stars, by John Green, is probably one of the most amazing books I have ever read, and I have read a lot. Hazel, the main character, is almost like a portal into my mind- a teenager who has cancer. John Green allows us to experience life with cancer along with Hazel as she tries to be strong through losing friends and the fear of leaving the ones she loves behind. It shows how much, not only Hazel, but her whole family must give up navigating cancer and taking care of her. This book has let the struggle of so many living with cancer finally be seen without any of the common one liners "they never gave up" and "they are my hero." Love, romance, and laughter are as much a part of our truth as procedures, chemo, and radiation. Sometimes you do want to give up and it's hard to always be brave. No one is perfect and that's ok just like it's ok to feel helpless as long as you keep fighting and living the life you have left just like Hazel.

Unlike many with pediatric cancer, I am now cancer free. Although, like Hazel I have met many wonderful people through a teen group my Mother made me attend at Cool Kids Campaign. Most people can only imagine what it's like to be diagnosed with cancer and even then the little details escape. Being with other teens allows us to share, or not, grieve for ourselves and others and most importantly to live the life we have been given to the fullest. *The Fault In Our Stars* is a wonderful and realistic portrayal of how cancer impacts lives and changes your perspective, but I believe that most of all it gives others the insight to see those living with cancer as more than just a diagnosis.

"My thoughts are stars - John Green,
I cannot fanthom into constellations."
The Fault in
Our Stars

Fault in Our Stars Quotes

"During the beginning of the book it talks about how Hazel doesn't like to go to her support group for kids with cancer because it's depressing. I don't agree with this at all since my "cancer friends" are some of my best friends. Everything else about this book is amazingly accurate."

Kyra McPherson, 19
Leukemia Survivor

"I agree with Kyra. Cancer was both the best and worst thing that ever happened to me. It changed a lot of things but I don't know where I would be without my "cancer friends." There's a certain connection I feel to them that a lot of people don't understand."

Tori Montanez, 16
Leukemia (AML) Survivor

"It is definitely my new favorite book. I'm currently reading it for the second time. I agree with Kyra also that everything is very accurate and I could relate to Hazel because she has to take a special "miracle" drug called Phalanxifor (not quite sure how to spell it) like I had to with Gleevec."

Emily Brooke Zimmerman, 16
Tcell A.L.L leukemia with Philadelphia Chromosome
Survivor

"I loved it because it was one of the most realistic cancer books I've ever read. Her feelings were very relatable while some books seem like the author has very little experience with cancer. Like everyone else has said, I have a connection with a lot of my cancer friends but it's from camp where we were doing normal things, not a support group where we would meet every week and talk about cancer so I think it's a little different. I never wanted to go to a support group either but I love camp. Somehow they're different in my head."

Karen Shollenberger, 19
Relapsed Leukemia
Currently in treatment



Karen had leukemia in 2004 and then relapsed in 2013 just as she was about to begin her sophomore year at Drexel University. Karen offers a unique perspective on childhood cancer. She calls cancer the “worst best thing that ever happened” to her. “Although it was a rough few years, it became such an influential part of my life that I can’t, and wouldn’t want to, imagine my life without having had cancer,” she said.

Enjoy her story on relapsing after so long and the differences between having cancer as a child from having it as a teen in this issue of the Connection and stay tuned for more in the summer and fall issues!

Relapsing After So Long; Differences In How It Affected Me

by Karen Shollenberger, West Friendship, Maryland

In August 2004, just a few weeks after my tenth birthday, I was diagnosed with Acute Lymphoblastic Leukemia. I had gone to the doctor for a normal well-child visit and she suggested some bloodwork because I had been tired and had a low fever. The next day, I was in the Hopkins emergency room. The doctors told us that I had leukemia, which I had never heard of. It wasn't until I heard the word cancer that I started to worry, since my grandma had died from cancer a few years earlier. My treatment was long but it was mostly outpatient and I rarely got fevers.

After I finished treatment in spring 2007, we all thought my cancer journey was over but this didn't stop my mom from worrying every time I didn't feel great or was tired and took a nap. Each time, I said I was fine, and I was.

As the years passed, these questions became less frequent. By the time I graduated from high school and headed off to Drexel University in 2012, they were pretty much non-existent. I had a great first year of college: I took classes I enjoyed at the times that I wanted, made some great friends, and spent a lot of time working on the student newspaper. By spring term, I was pretty tired but I attributed it to stress and just wanted summer vacation.

When I got home in June, my family headed out to Harpers Ferry, West Virginia to go hiking and show me how to get to my summer internship. During that hike, I realized something wasn't right. Sure, I hadn't been getting a lot of exercise at school but I knew I wasn't that out of shape. Not far into the hike, I felt extremely sick and exhausted and insisted on turning around, even if nobody else would. My mom looked at my eyelids, which were really pale, and decided I was anemic.

Thinking back to my diet at school, this was no surprise. Let's face it, there are limited palatable healthy food options on a college campus. I've never been a huge fan of red meat so I ate a lot of chicken. I took a multivitamin occasionally but not regularly enough to make a difference. As soon as we got home from the hike, I started taking an iron pill every day.

Two weeks later, when my family headed to Hawaii for vacation, I was feeling much better.

I did an eight mile hike one day, and even though I felt pretty sick during parts of it, I knew that two weeks earlier I hadn't even made it half a mile. Our trip was a once in a lifetime experience, though I certainly preferred the days with limited hiking.

When I got back to Maryland, I continued my internship. At the end of August, I took a day off to go to Hopkins for my annual checkup. My bloodwork showed that I was anemic, which we already knew, but I was VERY anemic. They decided I needed more tests to determine the cause, because a college student's diet would not cause a problem that bad. We headed home with a promise of a phone call to let us know what was going on.

In August 2004, I remember answering a phone call from my regular doctor and taking the phone to my mom who was out in the pool. I stood there waiting to take the phone inside, watching my mom get increasingly upset. Nine years later, my mom answered the phone when the hospital called and once again we were told to go to Hopkins as soon as possible. They had a room waiting for me. I knew right then that I had cancer again, even though the tests hadn't confirmed anything yet and they just wanted me to come in for more tests. What I didn't know was how I could have relapsed after things had been so good for so long.

As it turns out, my cancer the second time around was not technically a relapse but rather a recurrence, meaning the cancer was the same type but genetically different. I had all the right mutations for leukemia again, or as the doctors said, I won the genetic lottery twice. This is certainly not the lottery than anyone would choose to win, but that didn't change the reality. I wasn't going back to Drexel, I wasn't going to move up in the ranks at the newspaper, and I wasn't going to room with my best friend at school. Oh, and I had cancer again, but I think I cried more about school. There really are no good words to describe getting this news. It was shocking after so many healthy years and overall completely devastating.

When I was sick the first time, I hid from the doctors and pretended to be asleep whenever they came in the room and I never

got to know any other patients. I did most of my school work at home but I remember going to one event at my elementary school and having people tease me about my bandana and whether I had any hair.

In elementary school, it was a lot harder to keep in touch. None of my friends had cell phones and I didn't even have an email address. I quickly lost touch with a lot of my friends though I would hear how they were doing through the girls I kept in touch with. One of my friends called me almost every night, whether I was at home or in the hospital, and my closest friends would visit when they could.

I kept up with my 5th grade classes through Home and Hospital, which only took a few hours a week. I went back part-time for the end of the year, and it was nice to be all caught up. This time around, keeping up hasn't been so easy. Chemo knocked me down, but my bone marrow transplant knocked me down even farther. In addition, it's not as easy to tell a college that you're very sick as it is to tell an elementary school. They still want you to pay for your housing even though you physically can't be on campus. The honors college says you're going to get kicked out because you're behind on your honors requirements. They aren't sure if they can sign you up for the online classes (Drexel has a big online school) without switching you to the online program, which doesn't include your major.

Fortunately for me, my dad helped me take care of a lot of that. The system certainly isn't made for special cases. I took fall term off but started three online classes in January. I also have enough AP credits from high school that I'm still ahead of where I need to be in terms of overall credits.

While keeping up academically has been harder, keeping up socially is a lot easier now thanks to technology. Between Facebook, text messages and emails, I was incredibly overwhelmed with messages when word about my relapse/recurrence got out. It took me weeks to catch up on replies. However, I really appreciate being kept in the loop. I started a blog to keep everyone updated about my journey in one place. Thanks to Google+, I can video chat with multiple friends at once and my friends have their licenses so when they're home, it's much easier for them to visit me. There are certainly people I haven't been able to keep in touch with but nobody was mean to me this time.

I started going to camps for kids with cancer in 2008, so I know that there are lots of other people who understand what I'm going through, and I've reached out to other patients this time, something I never would have done when I was younger. Everyone in my life has been incredibly supportive; I guess because they're old enough to have a better understanding of what's going on. I still feel like I'm missing a lot at college, but I know I'll be back soon.

KIDS! PARENTS!

LET US PRINT YOUR STUFF!

Our goal with Cool Kids Connection is to connect families across America who are dealing with kids' cancer. This newspaper is published for you and about you ... including stories by you! Here's what we look for ...

STORIES ~ Share your experience with other kids living with cancer. Or, write about any kid-related topic at all!

ART ~ Like to draw, paint, sketch, doodle, color? Send us your artwork to publish!

POETRY ~ Express yourself through poetry: rhyme it, don't rhyme it; we'll take it happy, sad, goofy or serious!

PHOTOS ~ Introduce yourself through a photo – can be with family or friends, in the hospital, or doing your favorite thing at home!

FAVORITES ~ Share your favorite song, book, video game, app, movie, Facebook page, website or TV show ... we're listening!

JOKES/RIDDLES ~ Wanna help other kids chuckle? Share your favorite joke. Send riddles, puzzles, brain teasers, or even a word search that you made up!

COOL CAREGIVER & COOL KID ~ Each issue has a fun Q&A featuring a "cool kid" and his/her "cool caregiver." What's your favorite cereal? Do you like cats or dogs? If you were president, what would be your first law? Our list of fun questions is ready for YOU – and your favorite nurse, doctor, child life specialist or caregiver!

EMAIL submissions to
katie@coolkidscampaign.org.

You can also mail items to
Cool Kids Campaign, 8422 Bellona Lane
Suite 102, Towson MD 21204.

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COOL KID SHAWN



COOL KID ANTHONY

Anthony and Shawn are both 1st graders who live in New Jersey. They go to the same school and they were diagnosed with cancer around the same time. They are best friends and they spend lots of time at Children's Hospital of Philadelphia (CHOP) hanging out with their friend and Social Worker, Darlene Hammel.

Name? **Shawn**

Where do you live? **New Jersey**

Grade and age? **1st / 6**

If you wrote a book, what would it be about? **I don't know**

What do you want to be when you grow up? **Pizza maker**

Do you enjoy playing and/or watching sports? If so, which are your favorites? **Soccer**

Do you have brothers and sisters? **1 sister age 10, 1 brother age 11**

What do you like to do for fun? **Play X-box**

Favorite cereal? **Cinnamon Toast Crunch**

Favorite snack? **Slim Jims**

Favorite animal? **Snakes**

Favorite part of school? **Gym**

Who's your BFF? **Anthony**

Favorite celebrity? **Ariana Grande**

What activities do you like to do for exercise? **Nothing**

If you were president of the United States, what would be the first law you would make? **No bullying.**

Favorite movie? **Monster House**

Favorite TV show? **Tom & Jerry**

If you were stranded on an island, what 3 things would you have with you? **Video, phone, and boat.**

What are you most grateful for? **My Angry Bird stuffed animal named Chuck. He protected me and saved my life when I had to go for surgeries. He comes with me everywhere.**

If you were one of the Seven Dwarfs, which one would you be? **Happy and Grumpy. Sometimes I get grumpy because of my medications.**

If you could meet someone famous, who would it be? **Ariana Grande**

What's the first question you would ask them? **Do you wear a wig?**

Name? **Anthony**

Where do you live? **New Jersey**

Grade and age? **1st / 7**

If you wrote a book, what would it be about? **Dinosaurs**

What do you want to be when you grow up? **Army man**

Do you enjoy playing and/or watching sports? If so, which are your favorites? **Football and Basketball**

Do you have brothers and sisters? **3 sisters ages 8, 10, 37**

What do you like to do for fun? **Play outside, video games, toys and eat**

Favorite cereal? **Cinnamon Toast Crunch**

Favorite snack? **Slim Jims**

Favorite animal? **Tiger**

Favorite subject in school? **Gym**

Who's your BFF? **Shawn**

Favorite celebrity? **Strangest Death**

What activities do you like to do for exercise? **I used to lift weights before I got cancer**

If you were president of the United States, what would be the first law you would make? **No punching people in the face.**

Favorite movie? **Scream IV**

Favorite TV show? **Power Rangers**

If you were stranded on an island, what 3 things would you have with you? **Case of water, food, shelter**

What are you most grateful for? **Cake and giving people stuff**

If you were a Seven Dwarf, which one would you be? **Sleepy and Happy; I'm always happy but the medicines make me sleepy.**

If you could meet someone famous, who would it be? **Easter Bunny**

What's the first question you would ask them? **Do you lay eggs?**

COOL CAREGIVER DARLENE

Name? **Darlene Hammel, LSW**

Where do you Work? **Children's Hospital of Philadelphia (CHOP)**

Job title? **Oncology social worker**

What do you do specifically? **I assist families with children who have been diagnosed with cancer. My role is to help them overcome the challenges and obstacles they face while they are returning their children to good health. I assist families by finding financial resources, support systems in their home town, and become a great listener when they are feeling overwhelmed by the treatment and diagnosis.**

Favorite part of the job? **Meeting all the wonderful families. I am very fortunate to be with the families until their children are off treatment. I LOVE hearing the family say, "This is her / his last treatment".**

Least favorite part? **Meeting new families because it means their child has cancer.**

Time I begin? **7 A.M.**

Favorite sport to watch? **Football**

Do you have children? **I have 2 children and 3 grandchildren**

What to you enjoy doing for fun? **Jog, read and be with the family**

Favorite TV show? **NCIS / Modern Family**

Dogs or cats? **I love dogs**

What's on your iPod? **Don't have an iPod**

Favorite Book? **The Bible**

Favorite Board Game? **Pictionary**

Favorite subject in school? **Creative writing**

Favorite dessert? **Anything chocolate!!!**

Favorite season? **Fall**

Favorite cereal? **None really**

Favorite fruit? **Apples**

What celebrity do you admire and why? **Dan Cathy, CEO of Chick-fil-a. He stands by his Christian values when operating his business.**

If you could have dinner with one person (alive or deceased) whom would you choose and why? **It would have to be Jesus. I would want to know what his life was like as a small child. Lots of questions about did he play like other children his age? Did he have a "crush" on any of the little girls in his village? Lots and lots of questions**



Anthony, Darlene and Shawn draw strength from their special friendship.



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