COOL KIDS CONNECTION®

FALL 2012

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

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# FIGHTING CANCER ONE HAIR AT A TIME

*By Matt Nichol, age 20 Warminster, PA*

Some people set up lemonade stands to raise money for cancer research. Although that is a great way to raise money, what do you learn? How does it change you as a person? Like it does when a child hears the words "You have cancer" and his/her world flips upside-down.

This is what I was thinking about when I decided to go through with this hair-raising adventure.

My friends were planning fundraisers. Even my girlfriend was organizing a lemonade stand to raise money for childhood cancer. I wanted to plan my own fundraiser – one that would take more than just a few lemons and water. I wanted to do something that would cause me to reflect – and allow others to reflect, too. I wanted to give up something ... something that many children are forced to give up after they find out they have cancer – their hair.

So I planned with Paul Matthews, father of the late Eli Seth Matthews, to have him shave my head – something that would take a lot of nerve and courage to do since I've always been self-conscious of my hair being too short. And even more so, having to go completely bald! Right then, it became a learning experience. I wanted to feel the same tension that children with cancer might experience, only they were forced to go through it without a choice. I truly felt more passion for what I was doing at that moment. I would never give up because "cancer fears me!"

I sat in the chair on the stage looking at the audience as Paul got the razor ready. Everyone looked in amazement that I was actually going to do this. The hair fell and I became light-headed due to the lack of hair. Paul continued, first creating a festive Mohawk to entertain the crowd, and then quickly erasing the rest. Then came the razor; if I was going to do this, I was going to do it right. A few minutes later he was finished.

At that point, I truly felt vulnerable since I no longer had something I cherished. I felt what I thought the children might feel when they lost their hair. I also felt pride in performing the fundraiser to the fullest. I got up from the stage and people rushed over, saying that it looked good and what a good thing I had done. Never before have I felt such a feeling that I felt then – it was indescribable. All I know was that it was over and I had given it my all.

Later that night I received a phone call – it was Paul. He said we had raised $1,360 during the four-hour event. I felt extremely happy and proud that I did my part and I hope others will do the same so they can experience these same feelings ... **one hair at a time!**

Matt Nichol, before and after his fundraising haircut.

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# What Could YOU Teach the World about Cancer?

## *Cool answers from cool kids*

*When Cool Kids Campaign launched a local project this summer called Houses of Hope: Expressing pediatric cancer through art, we sent questionnaires to kids and teens with cancer (and survivors) around Maryland. Their answers were then displayed in bios placed next to each hand-painted birdhouse exhibited in malls, hospitals, and libraries around the Baltimore-area between August and December 2012. Their answers were so inspirational and profound we wanted to share a handful:*

### What could you teach the world about cancer?

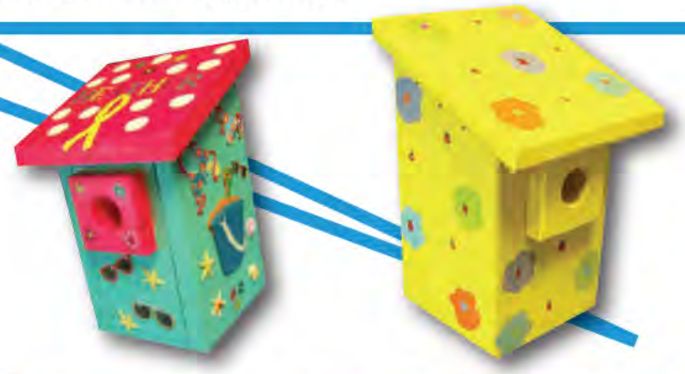
KYRA M, age 18, Forest Hill MD - Survivor, Acute Lymphoblastic Leukemia - "People take way too much for granted."

CLARISSA S, age 18, Ellicott City MD - Survivor, Acute Lymphoblastic Leukemia - "I would teach the world, especially teenagers … that when a friend or classmate is diagnosed, it's so important to support them and help them to not feel alone. Recognize that they are going through a hard time instead of pretending like nothing happened. Messaging teens through social network and email can help them feel connected."

JACOB S, age 12, Baltimore MD - Current patient, Leukemia - "That your life can change in the blink of the eye because of something like cancer, or an accident. And that we all should be thankful for every day and appreciate our lives. To always make sure that we appreciate the people in our lives who love us, and who we love, and to make sure they know how we feel."

KAREN S, age 18, West Friendship MD - Survivor, Acute Lymphoblastic Leukemia - "People with cancer are sick, but they're not contagious. They're normal and there is no need to be afraid to talk to them. After I was diagnosed, some people didn't know what to say so they didn't say anything at all, but I really appreciated any normal conversation. I didn't want to be treated differently."

MACKENZIE W, age 8, Annapolis MD - Current patient, Acute Lymphoblastic Leukemia - "That it is scary at first but you get to meet nice people and really nice nurses. It's not so scary or so bad."



## How do you maintain normalcy during treatment?

SOPHIA M, age 7, Baltimore MD - Current patient, Acute Lymphoblastic Leukemia - "I just try to be what I was like before."

GINO D, age 16, Glen Burnie MD - Current patient, Acute Myeloid Leukemia - "I have made my hospital my home with posters and games. My family and friends have seen me and everything has felt just like home."

Mom of IAN S, age 6, Bel Air MD - Current patient, Acute Lymphoblastic Leukemia - "We try to let Ian do as many normal things as possible. He goes to school, plays on sports teams, has play dates, etc. We have a wonderful community (family, church, school) that help us keep things safe for him."

BEN L, age 14, Bel Air MD - Survivor, Ewing's Sarcoma - "I don't think I kept a sense of normalcy because all of the Cool Kids and the hospital staff made me feel like a superstar."

## What hidden blessing have you found because of cancer?

BRENDAN F, age 6, Timonium MD - Current patient, Wilms Tumor - "I learned how brave, strong, and courageous I am. My family calls me their hero."

Mom of ATHENA H, age 3, Millersville MD - Current patient, Acute Lymphoblastic Leukemia - "The realization that our support system is bigger than I could have ever imagined. We have met so many new friends and been blessed by awesome resources, including Cool Kids Campaign! The care that so many unknown angels have shown for Athena and our family is just unbelievable."

ALISON D, age 16, Bel Air MD - Survivor, Carcinoid - "My closeness to my mom."

JULIANA C, age 10, Manchester MD - Current patient, Rhabdomyosarcoma - "Our family has been blessed with help from many people over the past five years; many of them were virtual strangers."

AMELIA O, age 12, Carney MD - Survivor, Acute Lymphoblastic Leukemia - "Meeting all of the people in the hospital. The security guard Gerald (he was an incredibly special person to me) and the lunch ladies. And Pharmacy – they wore gowns and hats like cafeteria folk. Camp Friendship – I am headed there soon – nine summers and still LOVE IT. The people are great! I am lucky."

## What is your overriding attitude?

MATTIE B, 15, Parkville MD - Current patient, ovarian cancer - "You just have to think there will always be a better day."

Mom of ALLISON K, age 6, Lutherville MD - Current patient, Acute Lymphoblastic Leukemia - "Accepting we are powerless over the disease is a big part of the battle. Living one day at a time and using only what we know today, allows us to experience the beauty and joy in each day."

JOCELYN P, age 4, Perry Hall MD - Current patient, Acute Lymphoblastic Leukemia - "Be happy. Be a kid."

Mom of CARA C, age 10, Baltimore MD - Current patient, Leukemia, and Downs Syndrome child - "Cara is a fighter. She is feisty and tough and a spitfire. She lives in the moment and takes each event as it comes."

## How has cancer changed you?

RICHARD K, age 17, Columbia MD - Survivor, Wilms Tumor - "I have learned a lot about loss. I am also more tolerant of differences."

AMY M, age 16, Glen Burnie MD - Survivor, Acute Myeloid Leukemia - "Yes. There is no way to go through cancer treatment and not have it change you. Cancer has made me stronger, more motivated, pushed me to reach my goals, and dream big."

BILLY H, age 11, Glen Burnie, MD - Survivor, Acute Lymphoblastic Leukemia - "Cancer didn't change me ... it made me. I love to live and I am not afraid to die."

BRANDY F, age 18, Baltimore MD - Survivor, Hodgkin's Lymphoma - "ABSOLUTELY! Cancer has made me a more accepting person. I am the girl that isn't a part of any 'group.' I have my best friend, but I also want to be friends with everyone. People who are much different than me have taught me things I would never have known. I don't judge. I accept, learn from, and enjoy being around all different people."

# 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.

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until being

STRONG

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# Surfin' the Net...

## Do you have a fun or helpful website to share with other families?

**Email the link to suzanne@coolkidscampaign.org**
**Here are several we found!**

1. **wishafish.org**
   This foundation based in Annapolis, Maryland is in their 13th season of hosting fishing excursions for sick or disabled children and their families. All 100% volunteer-based and FREE, they service PA, VA, MD, DE, and D.C.

2. **stupidcancer.com**
   The I'm Too Young for This! Cancer Foundation is a nonprofit organization that empowers young adults affected by cancer through innovative and award-winning programs and services.

3. **planetcancer.com**
   Recognizes that young adults with cancer slip into a lonely no-man's land and knows the difficulty of finding peer support. Planet Cancer exists so that no young adult will have to endure such isolation again.

4. **beadsofcourage.org**
   The Beads of Courage program is currently implemented in over 140 children's hospitals in the U.S., Canada, New Zealand, Japan and the UK. Supports over 30,000 children with their programs. Bead shopping on their site, too!

5. **Heatherbrookefoundation.org**
   Their mission is to organize and participate in the ongoing efforts in finding a permanent cure for Ewing's Sarcoma, as well as other types of cancer … educate as many as possible to increase awareness … provide assistance, information, funds and support to children with debilitating illnesses.

6. **coolkidscampaign.org/housesofhope**
   Meet 34 amazing and inspiring "cool artists" and view their Houses of Hope hand-painted birdhouses … expressing pediatric cancer through art.

# Grieving Lost Time and Innocence of Youth

**By Emily Carroll**
**Baltimore, Maryland**

It was a stunning revelation to me to acknowledge in writing how much pain I still have over my daughter Amelia's illness. I truly believed I had handled it well and moved on. What a revelation to acknowledge that I was way off base.

Don't misunderstand … I have great joy and pride in how we managed as a family to get through those 18 months of treatment and the subsequent years afterwards, waiting for the 5-year mark to come and go. There were many humorous events as well, but I think, like grieving a loved one, I need to grieve the loss. I have not allowed myself to grieve over what was lost during the process. That is not to say that I do not think about that time. Actually there have been many great conversations about that part of our lives.

You know how it goes as a mom – you have to keep moving, keep focused and rally the troops. In thinking about my first reaction when learning Amelia had cancer (March 2004; Acute Lymphoblastic Leukemia), I was devastated for about 10 minutes before entering "battle mode." Just tell me what to do, give me the list to check off, and let's get on with it. We began rolling – the army was mobilized. That's what I called us – Amelia's Army of Angels.

There is a story I relate about that first night. I had returned home with our son while Amelia's dad, David, was at Sinai Hospital with her. I remember little of that evening; however, I vividly remember being afraid to go to sleep for fear that when I awoke, Amelia would be gone. When I finally passed out, my father (who had died several years earlier) appeared to me in one of the most vivid dreams I have ever had. He put his arm around me, walked me up a lush green hill, and said, "Emily, it will be okay." Not "Amelia will die or live" … but "It will be okay. Trust God."

And I did just that. I knew in that moment that it would be okay whatever was coming at us. I am so blessed to have had that dream, and even more so, to be one of the lucky moms. Amelia is a testimony to faith, family, friends, and modern medicine. She is extraordinary; so is her brother Grayson. Their grace and love for each other, and their mental toughness, are humbling.

## THE NEED TO GRIEVE THE LOSS OF INNOCENCE

The loss of my kids' innocence kills me. Then there was my marriage, and the only house my kids knew. Plus, so much more that causes me great pain and head-shaking at my stupidity with poor choices. It certainly has made a lot of things others take for granted a real challenge for me. It is interesting to look back and recognize how in shock I really was, how much of what was done, was done on autopilot.

Being a single mom is not easy – I need lots and lots of Calgon, beach time, and even a few margaritas. However, what I have gained is so much more – well, perhaps different. And frankly, more lasting, more precious, dearer. More importantly … a deeper understanding of my faith, a responsibility to teach my kids about that faith in a real hands-on-use-it-every-day kind of way, another day to hug Amelia and Grayson, and allow her to make duct-tape boots for she and her brother.

I found myself again and I am better for it. My kids are better for it, too.

I know deep in my soul that this journey is preparing Amelia for great things – perhaps none greater than providing hope to a family fighting the fight right now! She was not your typical child then, and certainly is not now.

Just before Amelia was diagnosed her Dad and I were discussing how to channel that marble will of hers. She had been frustrating us all; my best analogy is that she is my Assateague pony – beautiful, wild, smart, and so much more. Taming the pony became our goal. Little did I know how much her tenacity would aid her in her fight against leukemia. I am convinced that her in-your-face approach was a key ingredient to her survival.

As hard as it was to watch all the procedures, such as spinal taps, they became treasured moments. A lot of love, laughter, peace, and comfort occurred during those days. I watched my daughter hold court – she is a pistol! Everyone knew her by name. We would walk into the hospital and people I had never seen before would shout out, "Hi Amelia! How are you? We are pulling for you." To this day, six years later, we see people who she knows – and I do not. Stunning.

## THE HIDDEN BLESSINGS

There are so many people placed in our paths by God who became such champions of Amelia and our family. The list is immense and humbling. They never gave up on Amelia, never treated her with anything less than Godly compassion, respect, and love. I am humbled and grateful for each and every one of them. There is no doubt in my heart that God made sure these angels would surround Amelia and so many others.

In many instances, the hidden blessings are placed in our lives long before we need them. A friendship formed during a part-time job held in college led me to the person who babysat my kids on a temporary basis; without her I would never have been able to work (my job provides our health insurance). I am a firm believer that people are placed in our lives at the right time for the right purpose. No greater proof than through Amelia's leukemia.

## MAINTAINING NORMALCY

Our church was amazing; my work place at the time (RCM&D, Inc.) and my coworkers were equally humbling. So many little things were done for us, from cooked meals to raking leaves; from hospital visits to visiting us at home when we were stuck there. The portable DVD player given to Amelia to keep in her room at Sinai Hospital was a huge help. An American Express gift card was taped to our front door one morning – that provided Christmas that year. The little things matter.

As kids, my brother Robert had a congenital heart problem which required many operations and trips to a children's hospital in Pittsburgh. That experience was God's plan for me to learn how to maintain 'normal.' My parents had four other children and were great role models for me. Robert was just one of us. Life went on. It also showed me what we do for family; what unconditional love really means. My aunts and uncles pitched in whenever needed regardless of where we were living at the time.

Fast forward to me as a parent of a diagnosed child and I was committed to making Amelia and Grayson's lives as normal as possible. As parents, we often feel less than adequate. This is one place I can say, 'I did my best and it was enough!' I have a few regrets, but overall, I did okay. We did not miss a beat. One day at a time. One crisis at a time.

I would never wish cancer on my worst enemy. BUT … I can say it changed the course of my life. It changed me forever and has enriched me beyond measure. There were so many smaller incidents that happened that would blow you away if I described them. One day perhaps I will write about all of them and relay our stories to others.

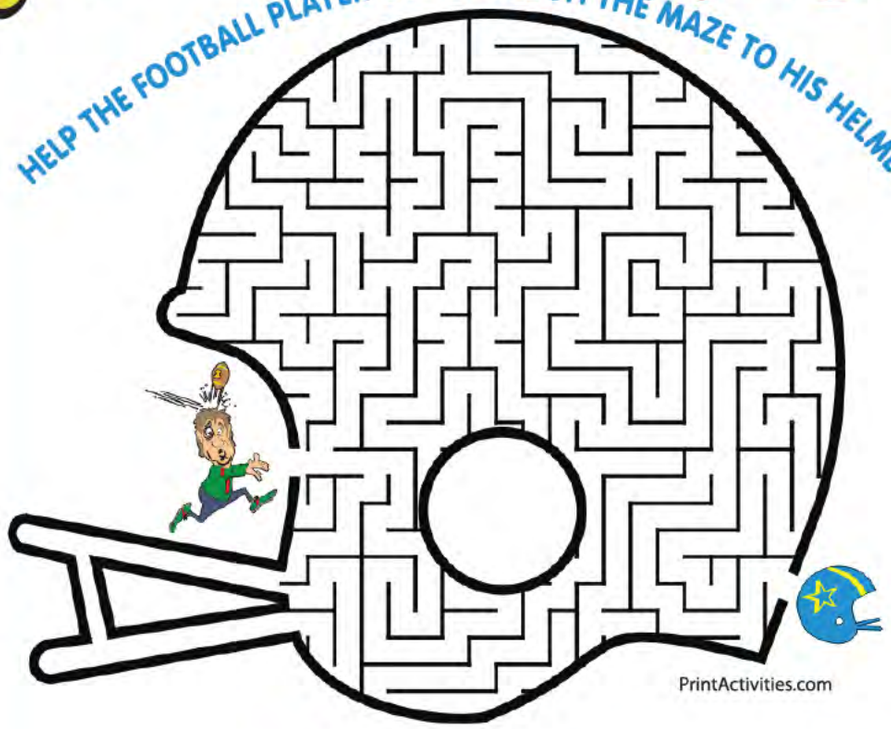
There is hope. I heard recently someone with breast cancer call it "Blessed Cancer." I understand … I truly understand.

My children and I have a strong desire to 'pay it forward' because we appreciated all that was done for us. Being a giver beats being the recipient. John Wesley said it best:

**Do all the good you can**
**By all the means you can**
**In all the ways you can**
**In all the places you can**
**At all the times you can**
**To all the people you can**
**As long as ever you can**

# PUZZLES AND GAMES

## HELP THE FOOTBALL PLAYER GET THROUGH THE MAZE TO HIS HELMET




## Hidden LEAF Challenge

How many fall leaves in any size, shape or color (NOT counting the cover or page 6) do you count throughout the newspaper? Send in your count to Cool Kids Campaign for a chance to win a Cancer Fears ME product!

Email your count to suzanne@coolkidscampaign.org with LEAF COUNT in the subject line by December 15, 2012. All correct answers will be entered into a drawing and announced in the Winter issue.

How many words can you make out of...

## HAPPY THANKSGIVING

## EASY WORD SEARCH

# HALLOWEEN

| | | |
|---|---|---|
| Costumes | Witches | Halloween |
| Candy Corn | Pumpkins | Trick-or-Treat |
| Devils | October | Chocolate |

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

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# BRAIN TEASERS

## Word Search

# ELECTION DAY

debate
election
president
vice president
electoral votes
registration
government
democracy
November
ballot
campaign
United States
convention
republican
democrat
term
vote
poll
oath

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

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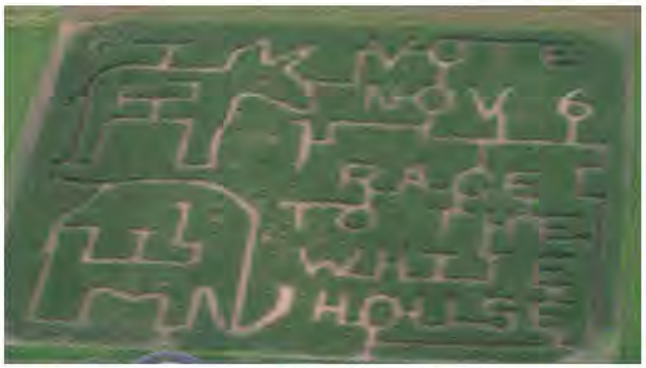

Cool corn maze in Adell, Wisconsin

patrioticpurchase.blogspot.com

Abraham Lincoln was the 16th President of the United States. He successfully led the country through its greatest internal crisis, the Civil War, preserving the Union and ending slavery.

## CAN YOU UNSCRAMBLE THE NAMES OF THESE U.S. PRESIDENTS?

1. SIGOANTHWN
2. CNLNOIL
3. NGEARA
4. EFRNJEOFS
5. AMASD
6. ETCRAR
7. EYNDKEN
8. FATT
9. DSNMIOA
10. ORONME
11. SHUB
12. XNION

ANSWERS ON PAGE 15

# MIND BENDERS

***Without telling what the story is about, one player asks another player to call out a word (adjective, noun, verb, etc. as needed) and fills in the blanks with those words. When all blanks are filled, the reader then reads the entire ridiculous story aloud! Guaranteed silly!***

"Music is the soul of the _____(noun)," said Pluto. "Music is music is music," said rapper _____(noun) I.B. Cool. These two _____ (adjective) philosophers were right on! When the beat is right, who among us hasn't felt the _____ (adjective) urge to snap his/her _____(plural part of body), stomp his/her _____(part of the body), or break out in a/an _____(adjective) _____ (noun)? There is no denying that music, whether it's a classical _____(noun) by Beethoven or a contemporary _____(noun) by the Backstreet _____(plural noun), is a/an _____(adjective) influence on our daily _____(plural noun). Music does indeed soothe the savage _____(noun) in us!

My mother loves to tell the _____(adjective) story of the day I was born. She says it was the most _____(adjective) day of her life. Mom woke up in the middle of the _____(noun), and my dad rushed her to the _____(place). When I was born, I immediately began _____('ing' verb) and _____('ing' verb), and the doctor announced, "It's a _____(noun)!" My parents _____(past tense verb) with joy. The doctor wrapped me in a soft _____(noun) and handed me to my _____(adjective) mom. I weighed _____(number) pounds and _____(number) ounces. Mom called me her _____(adjective) bundle of _____(noun) and said I was the most _____(adjective) thing she had ever seen. But I've seen the pictures, and I think I looked like a/an _____(adjective) blob!

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## Unscramble These "Fallen" Words

ANSWERS ON PAGE 15

1. S L E E V A
2. N E E W O L L A H
3. M U T U N A
4. C O C O A I P R U N
5. G I G I T S H A N K V N
6. K C A B – O T – O O L H C S (3 words)
7. P P M U K N I
8. P A P E L I N G K I C P (2 words)

Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 thru 9. If you use logic you can solve the puzzle without guesswork.

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 8 | | | 6 | | | 1 | 4 | 5 |
| | | | | | 7 | 6 | | 3 |
| | 9 | | | | | 8 | 2 | 7 |
| | 8 | | 3 | 5 | | | 1 | 4 |
| | | | | | | | | |
| 3 | 5 | | | 1 | 9 | | 8 | |
| 4 | 7 | 8 | | | | | 6 | |
| 2 | | 6 | 5 | | | | | |
| 5 | 3 | 9 | | | 1 | | | 8 |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | 6 | | | | 1 | | | 3 |
| 8 | 5 | | | 6 | 9 | 2 | | |
| | 4 | | 8 | | 3 | | 6 | 9 |
| | 7 | 6 | 1 | | 2 | | | |
| 4 | | 8 | | | | 1 | | 6 |
| | | | 6 | | 4 | 9 | 7 | |
| 5 | 9 | | 4 | | 6 | | 2 | |
| | | 2 | 3 | 9 | | | 1 | 4 |
| 3 | | | 5 | | | | 9 | |

© 2012 KrazyDad.com ANSWERS ON PAGE 15

# JOKES RIDDLES

## DONKEYIN' AROUND WITH THE DOC

**PATIENT: Doctor, doctor, I keep thinking I'm a caterpillar!**
**DOCTOR: Don't worry, you'll soon change!**

**PATIENT: Doctor, doctor, I've broken my arm in two places!**
**DOCTOR: Well don't go back there anymore!**

**PATIENT: Doctor, doctor, when I press here with my finger, it hurts. And when I press here, it hurts. And here. And here. And here also. What do you think is wrong with me?**
**DOCTOR: I think you have a broken finger!**

**PATIENT: Doctor, doctor, I keep getting a pain in my eye when I drink coffee!**
**DOCTOR: Have you tried removing the spoon from the coffee cup?**

## RIDDLIN' AROUND!

ANSWERS ON PAGE 15

1. *Which football player wears the biggest helmet?*
2. *Why couldn't the sailors play cards?*
3. *Which word in the dictionary is spelled incorrectly?*
4. *Why didn't the hotdog want to star in movies?*
5. *What does the Invisible Man drink?*
6. *Why aren't teddy bears ever hungry?*

## JOKES

(funology.com)

**Knock, knock**
**Who's there?**
**Will you remember me in a minute?**
**Yes**
**Will you remember me in a week?**
**Yes**
**Will you remember me in a year?**
**Yes**
**Knock, knock**
**Who's there?**
**You didn't remember me!**

**Knock, knock**
**Who's there?**
**Claire**
**Claire who?**
**Claire the way, I'm coming through!**

**Knock, knock**
**Who's there?**
**Nana**
**Nana who?**
**Nana your business!**

**Knock, knock**
**Who's there?**
**Ya**
**Ya who?**
**Wow, you sure are excited to see me!**

**Have a unique knock-knock joke or another favorite joke? Email it to suzanne@coolkidscampaign.org and we'll publish it in a future issue!**

# The Infamous Miss Millie

By Amanda Flamm ~ Sandy, Utah

On August 28, 2009,I delivered my second child by emergency C-section. He arrived into this world 11 weeks early. Thankfully Austin was strong. He weighed a whopping 4 pounds, 8 ounces.

Austin spent a month in the NICU – one I will never forget – a month that some days I didn't think I could physically or emotionally make it through. It was difficult to leave my new, tiny, helpless baby in a cold hospital. Of course, I knew he was in good hands ... but I am his mother. The difficulty was, I also needed to be the mother of Millie, my 4-year- old daughter. She seemed to be struggling with the adjustment of sharing my time. It had been just Millie and I at home for several years. We were – and are – best friends.

Luckily, Austin is a fighter and was able to get out of that dreaded hospital 31 days after his birth. It was amazing to feel like I had passed the most difficult trial in my life. I was so wrong. I had no idea, as I held my little man with such pride, that a horrible beast had taken hold of my daughter while I wasn't looking.

My sweet Millie hadn't been herself the first few months of being a new sister. She tried to be happy but she just wasn't. She was whiny and tired all the time. Some days she would cry for no reason. I knew something was wrong.

On December 17, 2009, my stunningly beautiful, smart and perfect little girl was diagnosed with cancer.

Cancer.

Once we knew what Amelia had, it became painfully obvious to me. I should have seen the signs. She had been extremely pale, had leg pain and unexplainable fevers, and was exhausted all the time.

I was a wreck with the traumatic arrival of my son; however, if Austin hadn't come early, I would have had a new baby right when Millie was diagnosed.

Our baby knew what was coming for our family, and he prepared us. He was – and is – "my sunshine." Austin was there to support all of us in a battle that none of us could have handled one single day sooner than when it happened.

On the very day of Millie's diagnosis, Austin was at Primary Children's Hospital as well for a follow-up appointment after having had a double hernia surgery the week before. (Just to make sure everything looked good. Thankfully, it did.) The day Austin was officially healthy was the day our world crumbled.

Millie continued to receive daily doses of chemotherapy through the start of February 2012. Unfortunately, three days after the celebration of Millie conquering cancer, we learned that she had already relapsed. Hearing "It's back" was earth shattering. Nothing can prepare you for it ... nothing. The most difficult part was telling Millie that her battle wasn't over – it had only begun and it was about to get worse.

Our girl had to endure seven more months of extremely intense chemotherapy, the likes of which her body hadn't seen before; along with eight doses of full body radiation. This was followed by a bone marrow transplant on June 22, 2012.

Millie, now 7, is still in recovery from the transplant and is doing incredibly well. She is a shining star. Because of her amazing attitude, she has been able to prove to everyone who knows her that staying positive does make a difference. Her attitude is everything. She can move mountains. She can do anything!

Miss Millie has become infamous. Her giggle is contagious, her whistle is loud, her dancing is outrageous, and her imagination is never-ending. Amelia has changed how I see the world. I am grateful to her – and will be for the rest of my life.

*Millie has won her battle in every way.*

# The Boy with the BALD Head

## By Jordan Crosser, *Clear Lake, Iowa*

As our cousins arrived, there were doors opening and the clack of shoes being kicked off in the garage. Childish giggling filled the air. A stampede like elephants sounded on the stairs. Two of them rushed to my brother Colby's side, filled with questions about his life in the military.

"Colby! Did you shoot a gun? Can you drive a plane? What's your car like? Is it cold there?" Brady and Benton's questions fired without a breath in between.

Brayton, the youngest, didn't understand the Air Force nor was interested in Colby's answers. He looked at me shyly with big green eyes, shuffled towards me, and then broke into a run with arms wide open. He grasped tightly to my neck and I leaned into his always-hospital-clean scent. I tickled him lightly, steering clear of his medical port.

"Jordy, stop! That tickles!" he said through a fit of giggles as we sat down. I asked how he was doing.

"Goooooood," replied Brayton, drawing out his o's. He tapped out a beat against the couch with his legs.

"That's good, sweetie. I haven't seen you in a while," I said.

"Yeah, not since you guys had to get shots and I didn't."

My heart sank. This little boy was 4-years-old and had already lived a life of getting poked and prodded. He had experienced more pain than some people do in a lifetime. My sweet Brayton had succumbed to leukemia. He had been referring to the blood drive we held in his name. The memory of that day is so strong …

My stomach had tied itself into a knot, pulling tighter every minute we drove closer to Nevada, Iowa from Clear Lake. My brain repeated a mantra: There's nothing to be nervous about. I've given blood before. But it was far more than the blood about which I was nervous. I had never seen a sick child. Sure, I had seen kids with fevers and cough, yet not a really sick child – not one like this. It had been eight months since I'd seen Brayton. At Christmas, he was a red-cheeked cutie who clung to my neck and begged me to play. Since then, he's been in and out of the hospital – and lost his hair.

We pulled into town and Mom stopped at a gas station. She asked if I wanted anything to eat or drink but my stomach rebelled. I stayed in the car and repeated: Don't be nervous. He's still Brayton. Mom returned upset, holding a soda and a sheet of paper. She handed me a flyer which promoted the blood drive that day at the community center in honor of a child who was battling leukemia. I glanced at the photo of a boy wearing a smile warmer than the sun. He had no hair. He stared at me. Tears rolled down my cheeks and I didn't bother to wipe them away. Brayton needed help and help I could not give him. My heart ached.

Mom and I said nothing. What could we say to make it better? Our emotions weighed down the air. She heard me crying and couldn't suppress her tears any longer. She told me softly it would be okay – a statement that neither of us truly believed.

We pulled into the parking lot at the community center. She told me to pull myself together and then go inside. I sat in the car and sobbed silently. Looking out the window, I saw boys playing soccer. They laughed as they went about their lives like nothing was wrong in the world. I felt furious, anger bubbling within. Why did they get to feel happy and have fun? Why did they get to play soccer in the sunshine on a nice day? I wanted to steal their ball and pop it. I wanted them to be as upset as me. I wanted their smiles to be replaced with tears. Then in a flash the anger was gone. It wasn't their fault – it wasn't anyone's fault. I checked my makeup in the mirror and exited the car.

As I walked up to the glass doors, the stomach knot pulled tighter. I ignored it and said hello to the people passing by. I silently thanked them for donating blood in honor of my cousin. I took a deep breath and opened the door. A blast of cold air hit my face. The slap of my flip-flops echoed in the hall as I followed the arrows to a large room. There was my mom standing near the door. This is it. I gathered all the joy I could muster, put on a smile and gave my name to the woman checking in donors. I took the clipboard and sat down. My mom approached from behind and I heard her quiet sniffles.

Like gravity, my gaze was pulled in another direction. A small boy sat on the steps, chin in his hands, and elbows on his knees. His quiet contemplation made him look wise beyond his few years. Tears welled up again and I started towards him, unsure of what to say. He stopped staring into nothing as I squatted in front of him. I gave Brayton a kiss on the forehead and said hello.

"Hey Jordy," he answered. I asked him what was wrong and he gave no reply. I picked him up and told him that all these people were here because of him and that he should feel big and important. I hoped he wouldn't see my quivering lips. He noticed the tears rolling down my face.

"What's wrong with you?" he asked. I told him my heart hurt. I didn't want to tell him the truth – that I was scared and much less brave than he. With childish naivety, Brayton asked if I needed a Band-Aid. I chuckled, "No, I'll be alright."

I returned to the line of chairs to start the paperwork. The blood donation process was nothing new; I'd done it many times. Yet this time felt different. Even though no one expected me to do this, I felt pressure from the fact that I could help other little kids with bald heads. My hand shook as I wrote. I turned in the form and waited for my name to be called. Brayton returned and reached for me to pick him up. I wrapped my arms around his tiny waist as he sat on my lap.

"Jordy, are you scared?" he asked through curious eyes. I said only a little. I said I wanted him to teach me to be brave.

"You are brave though!" he said. "You're a hero!" I looked down at this child. Every day was a constant death trap for him. I knew what he said was not quite true. There was no reason for me to be called a hero; and certainly I was not brave.

This boy was more of a hero and braver than any person I'd ever met … my boy with the bald head.

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# 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!

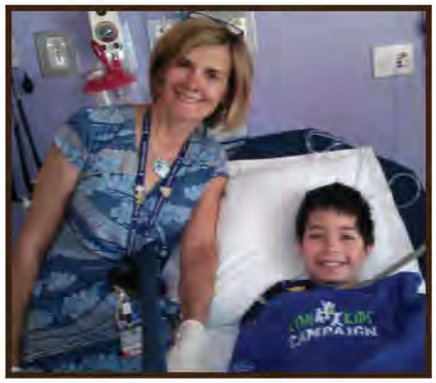
**JOKES/RIDDLES ~** Wanna help other kids chuckle? Share your favorite joke. Send riddles, puzzles, brain teasers, or even a word search that you made up!

**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**
suzanne@coolkidscampaign.org.
**You can also MAIL ITEMS to**
Cool Kids Campaign, 8422 Bellona Lane, Suite 102, Towson MD 21204.

*Note that we are unable to reprint copyrighted material, so be sure to send your original artwork and photos! All submission becomes the property of Cool Kids Campaign.*

# COOL CAREGIVER & COOL KID



## Meet Sally Aldrich,RN (Addison's nurse)

Where do you live? Denver, Colorado

In what hospital do you work? Children's Hospital Colorado

What is your job title? Primary Oncology Nurse

Favorite part of your job? I enjoy spending a lot of time with my patients.

Favorite sport to watch and/or do? I like to watch the Denver Nuggets. I enjoy skiing, snowshoeing, biking, hiking and yoga.

Favorite team? Pittsburgh Steelers

Are you married? Not currently

Do you have children? 18-year-old son

What do you like to do for fun? Outdoor activities, theatre, listening to music, spending time with friends

Favorite movie? I have many; Gone With the Wind, To Kill a Mocking Bird. I like musicals.

Favorite TV show? The Today Show; I don't watch much TV.

Do you like cats or dogs? I love dogs!

What's on your iPod? Blues, Rock 'n Roll

Favorite book? Grapes of Wrath and other John Steinbeck novels

Favorite board game? Trivial Pursuit

Favorite school subject as a kid? Reading

Favorite dessert? pie!

Favorite season? fall

Favorite cereal? Kashi

Favorite fruit? bananas, peaches, berries

If you were one of the Seven Dwarves, which would you be? Dopey

If you could have dinner with someone, who would it be? A good friend who relocated. I miss her lots.

## Meet Addison Kleinhans

Where do you live? Broomfield, Colorado (between Boulder and Denver)

What grade are you in? third

How old are you? I am 8.

If you wrote a book, what would it be about? My book would be about how dragons live and what they look like.

What do you want to be when you grow up? A veterinarian

What sports do you like? Tae Kwon Do, baseball, swimming, biking, jogging

Do you have brothers and sisters? Madelene, age 10

What do you like to do for fun? I like to cook and look at different types of rocks. I love being outside and seeing what the world is like. I LOVE ghost hunting.

Favorite cereal? Cinnamon Toast Crunch

Favorite snack? seaweed

Favorite animals? dolphins, pandas and penguins

Favorite subject in school? I love history and science. I have always been home-schooled by my mom since she, my sister, and I are professional actors. I do my homework backstage when I have a show. Sometimes I have to do the same play 30 times!

Who's your BFF? Bella. She was diagnosed a day before me with the same kind of cancer. We have gone through all of our treatments together and she sits waiting for me at the bottom of my bed after spinal taps. I hold her hand when she gets needles.

Who is your favorite celebrity? Jack Sparrow and Harry Potter

What exercise activities do you like? bike, swim, jog, use treadmill

If you were the President of the U.S., what would be your first law? Do not separate animal families.If you have a male and female dog with puppies, do not separate the puppies. They will be lonely without each other.

Favorite movie? Harry Potter

Favorite TV show? Heathcliff the Cat

Favorite video game? Mario Brothers

Favorite sport? Tae Kwon Do; it has taught me to persevere and never give up no matter how hard you try. You don't have to pass, you just have to try as hard as you can and think happy and good thoughts.

If you were stranded on an island, what 3 things would you have with you? A boat, a friend, food

What are you most grateful for? My family and all my friends who comfort me.

If you were one of the Seven Dwarves, which would you be? Sleepy, especially during my steroid week!

If you could meet someone famous, who would it be? What first question would you ask? I would meet Harry Potter. I would ask if it's hard to fly on a broomstick.

## More about Addison

The Q&A was just a glimpse of Addison! This kid could fill Connection with stories of his numerous energetic activities.

"We like to keep him active," said mom Sarah. "He travels around Colorado as guest speaker for various organizations. Before his diagnosis, he was an actor alongside of me; he worked two seasons with the Colorado Shakespeare Festival, so being in front of crowds comes naturally."

Addison was chosen Boy of the Year 2011 for Leukemia & Lymphoma Society/Rocky Mountain, which meant he traveled to schools and spoke 33 times to help raise awareness and teach others that kids with cancer are still kids! He is also a 2011-2012 Hyundai Hope on Wheels Ambassador for Denver Hyundai, which raises money for Children's Hospital Colorado Oncology. Add one more credential – Addison was Ambassador during 2010 and 2011 for Delta Delta Delta Denver through which he also did public speaking to raise money for Children's Hospital Oncology.

"He's in his third year of treatment," said Sarah, "and we often feel like the 'novelty' has worn off. People don't realize how long treatment lasts. They see him and think he is fine and forget how much illness there is when he is not out playing." However, when Sarah asks for help with an event, "The response is incredible!" she said. "My kids organize little fundraisers a few times a year to donate to organizations which have helped us."

Addison's Projects:
- Collected letters to Santa for Make-A-Wish. Macy's donated $ 2 for every letter Addison brought to them; he collected $ 9,400 for them and received letters from all seven continents
- Sells produce from their family's garden
- Designed T-shirts that say, "I do not have time for cancer"
- Through facebook (his group is 'Help Addison kick this thing!), he sells "'ghetty sauce" and jam. He uses a Cool Kids Campaign grocery bag to deliver the items to local people who make donations
- Actor in Children's Hospital Colorado staff training videos for nurses and other medical staff

# ANSWERS

**PAGE 8**

### U.S. Presidents Unscramble

1. WASHINGTON
2. LINCOLN
3. REAGAN
4. JEFFERSON
5. ADAMS
6. CARTER
7. KENNEDY
8. TAFT
9. MADISON
10. MONROE
11. BUSH
12. NIXON

**PAGE 9**

Sudoku #1

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 8 | 2 | 7 | 6 | 9 | 3 | 1 | 4 | 5 |
| 1 | 4 | 5 | 8 | 2 | 7 | 6 | 9 | 3 |
| 6 | 9 | 3 | 1 | 4 | 5 | 8 | 2 | 7 |
| 7 | 8 | 2 | 3 | 5 | 6 | 9 | 1 | 4 |
| 9 | 6 | 1 | 7 | 8 | 4 | 3 | 5 | 2 |
| 3 | 5 | 4 | 2 | 1 | 9 | 7 | 8 | 6 |
| 4 | 7 | 8 | 9 | 3 | 2 | 5 | 6 | 1 |
| 2 | 1 | 6 | 5 | 7 | 8 | 4 | 3 | 9 |
| 5 | 3 | 9 | 4 | 6 | 1 | 2 | 7 | 8 |

Sudoku #2

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 7 | 6 | 9 | 2 | 4 | 1 | 8 | 5 | 3 |
| 8 | 5 | 3 | 7 | 6 | 9 | 2 | 4 | 1 |
| 2 | 4 | 1 | 8 | 5 | 3 | 7 | 6 | 9 |
| 9 | 7 | 6 | 1 | 3 | 2 | 4 | 8 | 5 |
| 4 | 2 | 8 | 9 | 7 | 5 | 1 | 3 | 6 |
| 1 | 3 | 5 | 6 | 8 | 4 | 9 | 7 | 2 |
| 5 | 9 | 7 | 4 | 1 | 6 | 3 | 2 | 8 |
| 6 | 8 | 2 | 3 | 9 | 7 | 5 | 1 | 4 |
| 3 | 1 | 4 | 5 | 2 | 8 | 6 | 9 | 7 |

### Fallen Words Unscramble

1) leaves 2) Halloween 3) autumn 4) cornucopia 5) Thanksgiving 6) back-to-school 7) pumpkin 8) apple picking

**PAGE 10**

### Riddlin' Around

1) The one with the biggest head! 2) Because the captain was standing on the deck. 3) Incorrectly. 4) The rolls weren't good enough. 5) Evaporated milk. 6) Because they are always stuffed.

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Naturally, fear is a dominant emotion when a child is diagnosed with cancer. Our CANCER FEARS ME® slogan offers a strong, positive mindset to help turn around a child's fear and put him/her in control ... of health AND attitude! As we serve children with cancer with 100% free programs, we believe that sick or healthy ...

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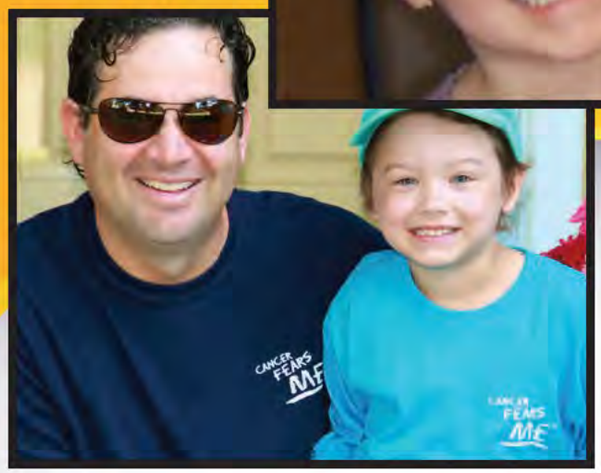

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