

WINTER 2014



If seven-year-old Dylan Huddleston was to meet another child who was just told s/he has cancer, he would offer this very mature advice:

"Whatever the odds are against you, never give up. Keep fighting!"

Dylan says, "If you beat this, great. Fight for your friends still battling this monster and remember those who gained their wings before their time - fight even harder for them."

These words come from a child who was told he had a one-in-four chance of beating this beast called cancer.

Our son has always enjoyed drawing, playing with Legos, and being a normal little boy. On November 6, 2012, his world was turned upside-down as he was tossed into a whirlwind that no child should ever have to experience. That was the day we discovered that Dylan had Stage 4 Undifferentiated Sarcoma.

For the next 10 months, we would be traveling and spending much time in Salt Lake City, Utah for treatments. This was time away from our family and Dylan missing most of his first grade school year.

Since the tumor in his hip was very difficult to identify, Dylan's pathology reports were submitted to two universities for further studies. They could not come up with what he had; however, one reported that there were strains of Ewings Sarcoma within the tumor they tested. Dylan also had three spots on his lungs along with cancer cells within the bone marrow.

This was hard news for us to digest as a family, since Dylan was the second family member in the same town to have been diagnosed with Ewings. His cousin J.R. was diagnosed at age 16 and passed away in January 1996 at age 20.

Our journey seemed to last forever. We had good days and some bad days. Dylan was life-flighted three times due to low blood counts and showing signs of septic shock. He was admitted multiple times for fevers and spent a total of 107 days in the hospital.

As time passed, scans were showing that treatment was working. The tumor was shrinking and the spots were going away. On May 30, 2013, Dylan finally had surgery to remove the tumor from his hip. The mass they removed was the size of a grapefruit; the tumor itself was the size of a tennis ball - and this was after shrinking it almost 70%. His bone marrow biopsy in May showed no more cancer cells. Finally in August, Dylan received the final news from his scans - he was in remission. He still had to go through 10 treatments of radiation following his scans.

Dylan, now 8 1/2, has since returned to school, having had to repeat first grade. He returned in December for his first three-month scan which showed no new activity in his lungs but he had a golf ball size tumor growing once more in his hip. Our family was shattered by the news. We have had some difficult conversations with him and he fully understands what may or may not happen this time around. Treatment began again January 7, including the start of 31 radiation treatments at the end of January.

Cancer has changed our son. It has made him more appreciative of life. Knowing that tomorrow is never a given, we take each day as it comes.

We have met some amazing families along the way and we are grateful for each and every one of them.

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Cool Kid & 14 **Cool Caregiver**

coolkidscampaign.org



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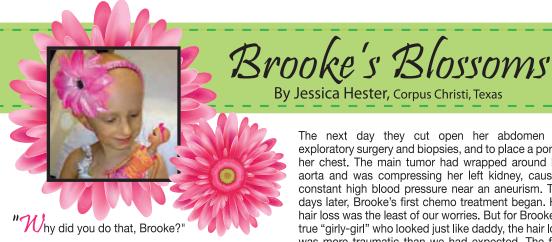
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"Because, Mom. She was staring at my head and when I gave her the flower, she smiled!"

I looked closely at my little girl and her naked, bald head. "But how did you know she wanted it when she didn't even speak English? Besides, I thought you really liked that gift?"

"I did! I loved it. But it made her happy. And that makes me happy." That conversation was in 2010, sometime between Thanksgiving and Christmas. Brooke and I were rolling her IV pole back to her room at the children's hospital after her daily physical therapy walk. She was three-and-a-half years old.

The summer of 2010 was an amazing time, one I won't forget. I had just accepted a great job in Texas working as a K-12 education consultant - and loving it. With her head full of wispy, curly brown hair, we had always referred to Brooke's hair as "wild child" hair; it often was adorned with pretty clips, bows and flowery accessories. As we whisked her off to preschool each morning from our quiet home on a large Texas ranch, Brooke was always happy, curious, and dancing; she picked wildflowers and ALWAYS smiled.

Later that fall, I was at a conference hundreds of miles from home. My husband called to tell me that Brooke had a funny but painless limp. We thought perhaps she had unknowingly sprained her leg in a dance lesson. It didn't take long for the limp to turn painful. Less than a month later, she was no longer able to attend school and spent most of her day on the couch or in bed, crying in pain. Her pediatrician presumed it was Juvenile Rheumatoid Arthritis, prescribed Advil, and put her on a specialist's waiting list.

Then came the nausea. Other over-the-counter medicine was prescribed, but the pain and nausea increased. Then our three-year-old, our tiny tough cookie who cried little, was not only entirely crippled, but also pointed to her belly button and spine to indicate how badly it hurt. We demanded a sonogram, which showed a shadow above her kidney, presumed to be a kidney stone. After more scans, tests, and an MRI, on November 18, 2010, we were told Brooke had a cancerous tumor in her belly that had metastasized throughout her lymph nodes and bones. It was Neuroblastoma at stage IV and all over her body. And it was killing our daughter hard and fast.

The next day they cut open her abdomen for exploratory surgery and biopsies, and to place a port in her chest. The main tumor had wrapped around her aorta and was compressing her left kidney, causing constant high blood pressure near an aneurism. Two days later, Brooke's first chemo treatment began. Her hair loss was the least of our worries. But for Brooke, a true "girly-girl" who looked just like daddy, the hair loss was more traumatic than we had expected. The first time wasn't as bad as the second time. A year-and-a-half later when she was almost 5-years-old, she cried as her hair fell out in clumps and she tried to put it back. The third, fourth, and fifth times were hard, too, but not as bad, because there was something special in her life that brought her an almost indescribable comfort ... blossoms.

That gift she had given the other little girl was a gigantic daisy blossom attached to a clip and headband. Since Brooke no longer had curly hair extraordinaire, there was nothing left to clip onto; a soft stretchy headband was perfect for her newly bald and sensitive skin.

Earlier, an elderly man from church had brought her fresh flowers. However, the nurses had swiftly removed them since flowers were a health hazard in pediatric oncology. Brooke had been devastated. But when she opened a care package from our neighbor, she was delighted to find large faux flowers, flowers that she could keep and wear.

I called our neighbor to tell her the story. She told me not to worry, that she would make two of each color next time - one for Brooke and one to share. Thus, was born ... Brooke's Blossoms.



Six long months later of hospitalization, we spent a single night at home. The next morning, we flew to New York City in search of a surgeon who could remove Brooke's tumor. Little did we know we would end up with a second opinion, a Neuroblastoma specialist team, and be away from home for a solid year, living in a hospitality house six blocks from the hospital. To say it was a big change from our quiet life on the ranch would be a gross understatement.

Our friends and neighbors back home decided they wanted to make more blossoms for other little girls; larger batches that they shipped to Brooke to share with other patients whom she met in the hospital from all around the world.

Eventually our little bedroom at the hospitality house was full of blossoms and materials to help keep up with the requests pouring in. By mid-2011, Brooke's Blossoms facebook page became the springboard for global requests and volunteers. A lead supplier in Montana, Halo Heaven, donated to our cause and included fun wands, fairy wings, and brightly colored fluffy ostrich feather clips.

Then came Brooke's 5th birthday wish in spring 2012. In lieu of presents, she asked for more blossoms. After her cancer had first progressed, Brooke had made a video to include on facebook and youtube. The response was incredible! Donations of materials and money poured in. Our volunteer base quadrupled. We heard from church and youth groups, Girl Scout troops, 4-H clubs, high school and ladies groups, sororities, honor societies, Junior Leagues, and independent craft shops. People liked what we were doing and wanted to help fundraise, create, and distribute. Brooke's Blossoms even received coverage in an Australian newspaper! When the Almar Princess Academy showroom in Manhattan invited her in to present a donation, that made ABC's World News!

By October 2012, we had raised enough money to file for nonprofit 501(c)(3) status with the IRS – Brooke's Blossoming Hope for Childhood Cancer Foundation – and to meet the second part of our mission: donate money to pediatric cancer research.

Watching the joy on children's faces who receive blossoms, hats and headbands is very special. Since Brooke did not want to omit boys, they also receive hats and silly squirtwater flowers. We have learned that many children with cancer do not want to wear uncomfortable, itchy wigs. They prefer fun and stylish brightly colored blossoms. Accessories are sent with a booklet that has been translated into multiple languages: English, Spanish, French, Polish, Portuguese, Russian, and Tajik.

But accessories aren't enough

Beyond sending packages, we knew that hair accessories were simply not enough. Children are dying. The statistics are staggering and heartbreaking. Drugs are made for trials and then no longer manufactured, even if they work. Kids with cancer are considered a minority population; treatments are not marketable or profitable. Never mind that cancer is the number one disease killer of children! It kills more children than HIV, diabetes, malaria and other diseases combined.

The larger cancer societies and federal government do not help much; they give less than one to four cents on the dollar to childhood cancer research. It is up to parent-led and private foundations to help. As we send out smiles, we also raise critical research dollars – a big task. While most childhood cancer foundations may choose one or the other, we choose to do both. It may be twice the work, but certainly it is also twice the hope. We have helped over 12,000 patients directly in countless hospitals across the U.S. and in 34 countries. Plus, we have raised and donated over \$20,000 (and counting!) to cutting

edge research that strives to find cures through gentler and more tolerable options. We partner with global pediatric cancer foundations and belong to a global consortium of efforts to fight this disease.

In 2013, Dell Technology flew Brooke and I to Las Vegas to present us with an award as "Inspirational Heroes of the Year." Last September, we received a proclamation from the governor of Texas. We watched our hometown of Corpus Christi glow with hearts of gold in our first annual Be Bold Glow Gold 5K Run & Walk. We have watched the awareness of pediatric cancer blossom a long way from when Brooke first handed out golden yellow "awareness blossoms" in Central Park and Times Square in 2011, yet we know there are still many who do not realize that cancer can strike any child, at any age, at any time. And that cures are needed desperately to change the outcomes.

Awareness leads to action and action leads to advocacy, on behalf of children like Brooke who fight and endure more than most adults do in a lifetime. Even in the midst of Brooke's continued fight for over three years of nonstop therapy, we turn with gratitude to our faithful and future followers and volunteers who make what we do possible ... create smiles.

Brooke's Blossoming Hope for Childhood Cancer Foundation hopes you will join in their motto: Planting Seeds of Faith, Love and Hope for Cures ... One Smile at a Time. We seek volunteers to fundraise, create, and distribute. There are many ways to help – from wherever you live. We are 100% volunteer-led and ensure that donations go directly to the fight against pediatric cancer.

We are grateful to all of our volunteers who make the foundation possible; however, not nearly as grateful as the children are – the children fighting cancer, like Brooke.

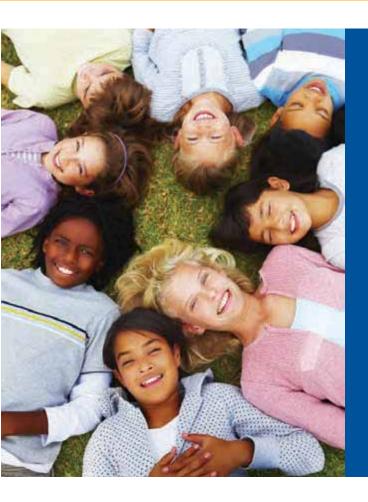






This is one of the tiles painted by various 'cool kids' who have been decorating tiles in art workshops hosted in the Cool **Kids Learning** Center and area hospitals. Each tile will be added to a large wall of tiles on permanent display at the White Marsh Mall in Baltimore, Maryland to help bring more awareness to pediatric cancer.

LET US FEATURE YOUR CHILD'S ARTWORK HERE! Submit an illustration drawn by your child with cancer to katie@coolkidscampaign.org



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KID &

COOL CARECIVER

Keith Lane Baltimore, MD

What grade are you in? Kindergarten

How old are you? 5 years old

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

What do you want to be when you grow up? I want to be a firefighter.

Do you enjoy playing and/or watching sports? Yes, football and baseball

If so, which is your favorite? Football

Do you have brothers and sisters? Two brothers, ages 6 and 10

What do you like to do for fun? Play monster trucks, ride dirt bikes, play video games, and play outside

Favorite Cereal? Apple Jacks

Favorite snack? Fruit snacks

Favorite animal? Zebra

Favorite part of school? Playing with friends.

Who's your BFF: Mekhi

What activities do you like to do for exercise: Run around

If you were president of the United States, what would be the first law you would make? I would build a house for everyone.

Favorite movie? Iron Man

Favorite TV Show? Austin and Ally on Disney channel

Favorite video game? Sonic Race Cars

Favorite Celebrity? Joe Flacco

If you were stranded on an island, what 3 things would you have with you? A reindeer, a dinosaur, and a hamburger

What are you most grateful for? My brother

If you were one of the Seven Dwarfs, which one would you be? Grumpy

If you could meet someone famous, who would it be?? Joe Flacco

What question would you ask him/her first? If he likes hamburgers



Where do you work? University of Maryland

What is your job title? Clinical Social Worker in Pediatric Hematology and Oncology

What do you do specifically? I work in Pediatric Hematology and Oncology to help patients and their families deal with tough situations. I can provide counseling, help connect them to community resources, and be supportive during a tough time.

Favorite part of job? Seeing the patients grow older and do well in school and start jobs

Least favorite part? Lots and lots of paperwork, and seeing kids who are sick

Favorite sport to watch or play? I'm clumsy, so I would rather watch... the Ravens, Maryland Men's Basketball, the Olympics, tennis

Are you married? Nope, not married

Do you have children? I don't have any children.

What do you enjoy doing for fun? I enjoy spending time with family and friends, going to movies, shopping, catching up on reality tv and Greys Anatomy, reading, and exercising.

Favorite Movie? Home Alone

Favorite TV show? Any reality TV, Parenthood, and Greys Anatomy

Favorite Book? Little Women, anything mystery or suspense

Favorite board game? Trouble

Favorite subject as a kid? Music, Social Studies (do they even call it Social Studies anymore?)

Favorite dessert? Anything chocolate and peanut butter

Favorite season? Fall

Favorite cereal? Golden Grahams

Favorite Fruit? Grapes and pineapple

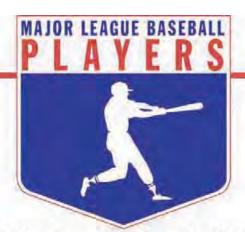
What celebrity do you admire and why? Jennifer Garner

A: We share the same last name, so maybe we are related? B: She balances her work life and family life, while not getting caught up in the drama of being famous. Also, she has done a lot of work with Save the Children, which helps children in poverty.

If you were a Seven Dwarf, which one would you be? Happy

If you could have dinner with one person (alive or deceased) who and why? It would be my grandfather, who passed away several years ago. I would love to get his perspective on life and catch him up on myself and my family.





The Major League Baseball Players Association tips its cap to the



www.MLBPLAYERS.com

Childhood cancer is more than chemo and no hair.
It's about resilience, strength, hope, courage, love, cuddles, and bravery!

VIUS! 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.

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.

BEOSSOWING BROOKE

See accompanying story on pages 2-3.

Who loved to dress up and sing to the world
Her favorite place to spend all her hours
Was out in the wind ~ and she LOVED the flowers!

But then one day her life totally changed Doctors just knew that somethin' was strange But they told her not to fret, not to worry They could fix the problem, but not in a hurry.

The medicine Brooke took made her hair ALL fall out But she didn't shout, fuss or even pout "It's okay," was all that she said As she scritched and scratched her itchy head.

Stuck inside for days on end
She longed to be back with her flowers and wind
Then one day an elderly visitor came
But nobody even remembers his name.

He was just really old ... old fashioned really And brought her flowers that made her feel silly! But the nurses came and took them away So for little Brooke that was a really sad day.

Her family and friends thought and thought (and thought some more)
To come up with a way to get her somethin' to adore Back at home a plan was devised
To give her a surprise they could take inside.

Carefully crafted, simply made Bright and colorful in any shade! Brooke opened her gift, inside it she found The BIGGEST blossom she'd ever seen around.

SO incredibly excited, she put it right on Then grabbed her mom to come right along Down the hall she danced and pranced As best she could in her pajama pants.

Right off the bat she curiously discovered
She wasn't the only child – there were SO many others
Do you know what she found peekin' in doors?
The rooms were all filled with other boys and girls!

Smilin' and healin' Brooke made new friends Some wore masks, always washed hands Then one day a lil' girl passed by She wasn't walkin' but rode a wagon inside!

When Brooke said "hello!" the other mom stopped But they spoke so differently that the girls couldn't talk Then Brooke looked right up and softly she said "Mama, why is she staring so much at my head?" "Well I think" her mom whispered quietly and low "I think she likes your flower head bow"
Then smiling and singing Brooke did something awesome She lifted her hands and she took off her blossom.

She handed it to the other girl who looked *quite* perplexed The girl looked at her mom and her mom said "si ... yes" When they got back to the room Brooke's mama then asked "Why did you give away your flower like that?" "Because she liked it and well besides It made her SO happy which makes ME happy inside."

But don't think the story stops there, **oh no, no, no!**More flowers were made by her neighbor Sunnie Jo!
More for Brooke, more to wear, more to give, more to SHARE!
Then doctors back home found the end of their rope
So Brooke went away in search of more hope.

The little country gal so simple and witty
Found herself a surgeon in BIG New York City!
Back in the hospital, in bed for weeks
She could only see sidewalks, bricks, concrete, and streets

But that didn't stop her friends back home on the ranch They made *more* blossoms! They made *more* plans! Brooke found more new friends stuck in hospital beds With little or no hair and bald little heads.

Something new was bloomin'... seeds were a sowin'
But nobody knew how far these flowers were goin'
More little friends, more little smiles
More pretty girls, then after a while ...
It began botherin' Brooke to give only to girls,
When she knew brave boys, too, all over the world
As cooler winds came with colder rainstorms
Handmade love came for both girls AND boys heads to be warm

So blossoms found buddies, more smiles to spread Brooke found some hairs popping back up on her head "So what? It's just hair," she'd say with a grin Handing out love gifts again and again.

Then when her hair fell out again it was rough But lil' Brooke said, "It's okay, hair's just stuff."

Still to this day, this love can be seen In surprised looks on faces like from old movie scenes "Really, a flower? Really, it's free?" "Really, you share them? Really, for me?"

Empowering others to be volunteers
Brooke's love will be shared for years, years, and YEARS!
Bloomin' a worldwide trail of happiness through hospital doors,
Planting seeds of Faith, Love, and Hope for cures
One smile at a time!

Facebook YOUR smile on facebook.com/BrookesBlossoms or email your smile to buddies@brookesblossoms.org. Ask to post it along with YOUR story or idea!

SECOFILIE

Avoid Getting and Spreading Germs

- Avoid close contact with people who are sick with colds and coughs. If you have one, keep your distance from others. Stay home from work, school, and errands.
- Cover your coughs and sneezes with a tissue; if no tissue is available, sneeze or cough into your upper sleeve or elbow.
- Avoid touching your eyes, nose or mouth germs spread this way!
- Clean and disinfect surfaces or objects that may be contaminated, such as bedside tables, bathroom and kitchen surfaces, and toys.
- Children and people with weakened immune systems can shed a virus longer, and might be still contagious past 5-7 days of being sick.

Practice Good Hand Hygiene

- Alcohol-based hand rubs are easier to use, take less time, and are more effective in killing bacteria than soap and water!
- Wash your hands or use hand sanitizer before eating! And after touching public areas such as handrails, water fountains, door handles, gas pumps, escalators, and ATMs. Even pets! Also wash hands after contact with body fluids, trash, raw meat, money, your car's gear shift, an open wound, and even the pen that a delivery person or clerk hands you to sign your name! (opt to use your own)
- Wash your hands rigorously with warm water and soap for at least 20 seconds or while singing 'Happy Birthday' twice through. Wash tops and palms of hands and in between fingers. Rinse well and dry. If in a public restroom, use a paper towel to turn off the faucet and to pull the door handle to exit. If no paper towel, use your sleeve or piece of clothing.

Protecting Children

- Flu vaccinations are recommended every flu season for everyone 6 months and older. It is especially important that young children and children with long-term health conditions get vaccinated.
- Caregivers of children with health conditions or children younger than 6 months old should get vaccinated.
- Keep your child home from school, day care or camp for at least 24 hours after their fever is gone without the use of a fever-reducing medicine.
- Encourage children to follow good germ prevention and hand washing!

Excerpted from websites of Johns Hopkins Hospital and Centers for Disease Control & Prevention

J404K4E4SG

RHICHERS

TWISTIN' THE TONGUE

* A big black bug bit a big black bear, and made the big black bear bleed blood.

- * You've no need to light a night-light On a light night like tonight, For a night-light's light's a slight light, And tonight's a night that's light. When a night's light, like tonight's light, It is really not quite right to light night-lights with their slight lights On a light night like tonight.
- * A skunk sat on a stump and thunk the stump stunk, but the stump thunk the skunk stunk.
- * Betty Botter had some butter, but she said, "This butter's bitter. If I bake this bitter butter, it would make my batter bitter. But a bit of better butter would make my batter better." So she bought a bit of butter, better than her bitter butter, and she baked it in her batter, and the batter was not bitter. So it was better that Betty Botter bought a bit of better butter.

WHAT AM I?

"I do not eat food. But I do enjoy a light meal every day. What am !?"

A PLANT

"Look at my apple and keep me near. Listen closely to what I say in your ear. What am I?" "I have a thousand wheels, but I do not move. What am !?"

A PARKING LOT

"Without fingers, I point. Without arms, I strike. Without feet, I run. What am I?"

A CLOCK

RIDDLIN' AROUND!

На На На На На На

- How can a man go eight days without sleep?

 He sleeps at night!
- What belongs to you but others use it more than you do?

 Your name!
- There are three houses in a straight row. One is red, one is blue, and one is white. The red house is left of the middle. The blue house is right of the middle. Where's the white house?

 Washington, D.C.

Dit's ok to be a little bottom heavy. Don't get too much one sun. Everyone nose carrors are good for you. Be a jolly, happy Soul. It takes a few extra rolls to make a good for your front yard. Remember, were all a bit flakey. Accessorize, accessorize, accessorize.



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!

A WINTER GAME BROADCAST

Hello everyone: we're broadcasting live from the American compound here at the
ski village. Unfortunately, my cohost, (male celebrity), has laryngitis
and has lost his (noun). He'll be back with us as soon as his
(noun) returns. Now to breaking (plural noun)! Sadly,
we've learned that less than 20 (plural noun) ago,
(male person in room), America's best (noun) skier and favorite to win
the Giant Slalom, suffered a life-threatening(noun) when he plum-
meted 300 (plural noun) down the side of a/an
(noun). According to the latest hospital (plural noun), he broke his
(noun), but doctors are hopeful he'll heal (adverb)
and be back on his (noun) by the end of the year. Our fervent
(plural noun) go out to this (adjective) skier and his
entire (adjective) family."
RULES FOR A SNOWBALL FIGHT
The (adjective) Winter Games Committee does not recognize snowball
(verb ending in 'ing') as an official (noun). Neverthe-
less, it has established rules and (plural noun) for the athletes who
want to throw icy (plural noun) at one another:
• Contestants can toss only one (noun) at a time, and from a distance
of not less than 25 (plural noun) away.

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All _______ (plural noun) must wear _______ (adjective) gear that

• Aiming at a/an _____ (part of the body) is not permitted. If anyone is hit

Loading a snowball with heavy (plural noun) or solid

protects their eyes, as well as their _____ (noun) and ___

below the _

(noun), that person automatically wins.

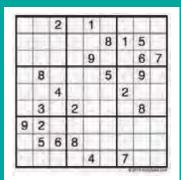
(plural noun) is _____ (adverb) forbidden. Snowball tampering will result in

__ (adjective) penalties or rejection from the _____ (noun).

1. LCOD	
2. TEAHER	
3. ATOC	
4. AOESNS	
5. WONS	
6. ICRACT	
7. CEI	
8. SRAFC	
9. IDALZRZB	
10. EZRFEE	

7. ICE 8. SCARF 9. BLIZZARD 10. FREEZE ANSWERS: 1. COLD 2. HEATER 3. COAT 4. SEASON 5. SNOW 6. ARCTIC

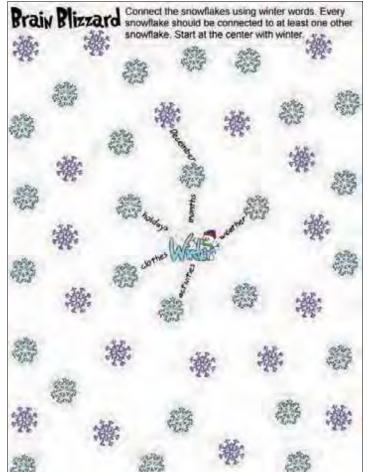
Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 thru 9. If you use logic you can solve the puzzle without guesswork.





BYRYAY

THEY ASSERTS



DLOR ME

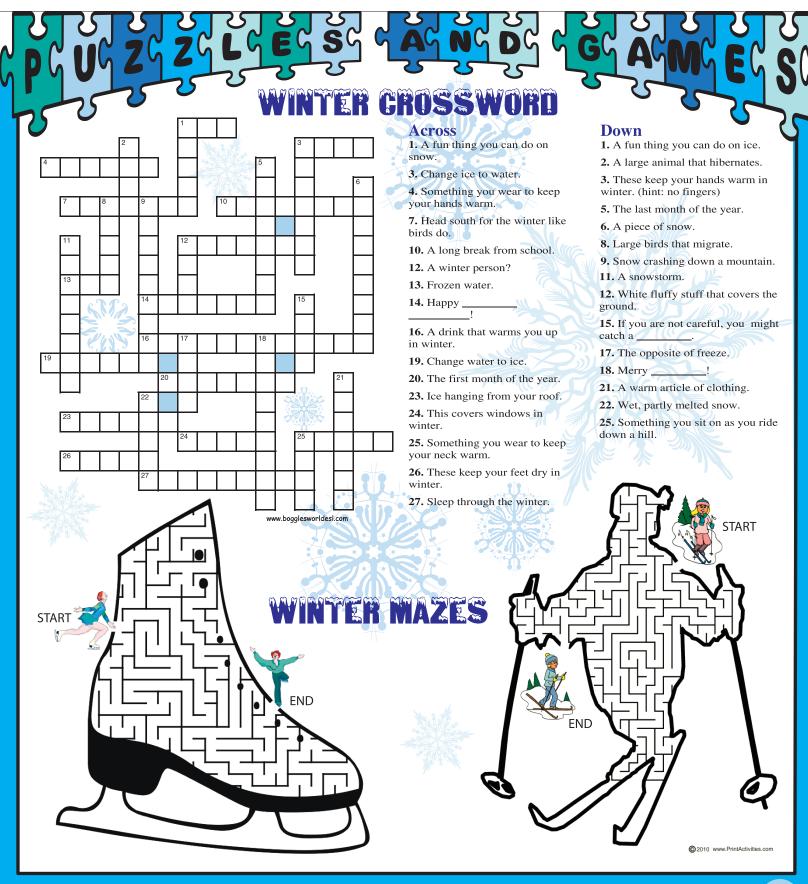


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How many words can you make out of:

HOT CHOCOLATE







Baylee's Battle



By Sharon Nichols, Phoenix, AZ

The moment has been eternally burned into my memory. I held 13-month-old Baylee in my arms, waiting for the doctors to come in. She was ghostly pale, listless, stomach distended from an enlarged liver and spleen, covered in a rash, and in need of a blood transfusion. That's when I heard the sentence that changed my family's lives forever – "We believe your daughter has a rare form of leukemia called JMML, Juvenile Myleomonocytic Leukemia, and she has a 20% chance of survival". I knew that there were only two options:

#1 – Losing the battle was not an option

#2 - Refer to option #1



Since JMML is so rare, the only treatment was a bone marrow transplant. The doctors immediately began to search the bone marrow registry, but looked at my 3-year-old son, Brody, and told me that even though there was only a 25% chance that a sibling would be a match, he should be tested. Brody ended up being a perfect match, with all factors being 100% compatible, even down to their blood type.

Baylee's and Brody's bone marrow transplant took place on November 13, 2008, one of the most terrifying days of my life. After transplant, Baylee developed Graft vs. Host Disease, where Brody's healthy white cells attacked all of the sickness in Baylee's little body. Baylee ended up in the PICU, in a medically induced coma with multi-organ failure. In the five weeks she was in a coma, she was put on dialysis, had a chest tube to

drain fluid from around her lungs, her abdomen drained to release fluid, a gallbladder drain, and a liver biopsy. There was one day when the doctors didn't expect her to make it more than two hours. It was all such a blur. It seemed like she had tubes coming out of her from everywhere imaginable.



But losing the battle was not an option. Baylee's team - our family, friends, doctors, nurses - always stayed positive and never gave up hope. We treated Baylee like she was sleeping. We would read to her, sing to her, paint her nails, and decorated her room for Christmas. And just like a Christmas miracle, Baylee's sick little body began to get better. Baylee woke herself up from her coma on the morning of December 31, 2008 by pulling out her breathing tube. Her spirit is unbreakable.

We just celebrated Baylee's 5th anniversary from transplant. Five years is a huge milestone that we've been anxiously waiting. Baylee and Brody have been asked to share their story quite a bit. When I asked them how they felt about telling their story so much, 6-year-old Baylee responded, "Mommy, we have to let kids know that it's going to be ok. Don't ever give up hope and be strong, because it's all going to be ok." So, to all families going through battles out there, don't ever give up. Stay strong because all of our children are miracles, and miracles do happen.





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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 ...



BrookesBlossoms.org

Supplies kids battling cancer who have lost their hair with headbands and hats adorned with flowers, bows, feathers and bling ... anything to help them feel special and let their divas shine through! This project is in honor of Brooke Hester in Texas. Donations accepted of supplies, handwritten messages for the kids, and of course money to purchase supplies. Email sunnie stewart@yahoo.com. Brooks Blessening Hope for Childhood Canoes Foundation

Songsoflove.org

The Songs of Love Foundation is a national nonprofit organization that creates free, personalized, original songs to uplift children and teens facing tough medical, physical or emotional challenges. Each CD is professionally produced with lyrics containing the child's name and references to his/her favorite activities, things, people, and pets. Songs are written and performed in any language in the musical style that the child likes best.

wishesandmore.org

The goal of this children's charity is to grant wishes to children with life-threatening illnesses and provide hopeful hearts, happy memories and assistance to those who love them.



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