

# COOL KIDS CONNECTION<sup>®</sup>

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

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[coolkidscampaign.org](http://coolkidscampaign.org)

## THE B&O RAILROAD MUSEUM “CHOO CHOO-SES” COOL KIDS CAMPAIGN AS THEIR CHARITY OF CHOICE

All over the country, community organizations are partnering with nonprofits to benefit the people the organizations serve. In Baltimore, Maryland, the B&O Railroad Museum™ has just started a partnership with Cool Kids Campaign, a nonprofit devoted to improving the quality of life for children with cancer and their families and the publisher of the Cool Kids Connection Newspaper.

“The Museum depends a lot on the community for its support and firmly believes that we, as a responsible, cultural, and educational organization, need to give back to the community,” said Courtney B. Wilson, Executive Director. “We specifically like to partner with charities working with children since kids have such an attraction to trains.”

Each year the B&O Railroad Museum adopts a charity as part of their effort to give back to the community. Wanting to make a difference in the lives of these children and their families, the B&O Railroad Museum will offer tickets to enjoy the trains and history of the museum as well as some special family events like Day Out With Thomas and Chuggington that the museum hosts once a year.

“The B&O is a magical place for kids and we are thrilled to partner with Cool Kids Campaign to provide many meaningful and happy experiences for these kids and the families they support,” Wilson said.

\*If you are a nonprofit or a business that participates in a similar partnership, we would love to feature you in the next issue of the Cool Kids Connection Newspaper. Email [katie@coolkidscampaign.org](mailto:katie@coolkidscampaign.org) for details!

## FUN FACT:

*Six of the museum's locomotives have starred in 12 Hollywood movies:*

- Gods & Generals
- Tuck Everlasting (2002)
- Wild, Wild West (1998)
- Amistad (1997)
- Raintree County (1957)
- The Great Locomotive Chase (1956)
- The Swan (1956)
- Rock Island Trail (1950)
- Stand Up & Fight (1939)
- Wells Fargo (1937)
- The FBI Story (1959)
- The Wire (2003) HBO

The museum's spokesperson is Michael Gross, television star and Hollywood actor best known for his role as Steven Keaton in the decade log comedy “Family Ties” and Burt Gummer in the science fiction movie series and television series “Tremors.”

The B&O Railroad Museum™, a full affiliate of the Smithsonian Institution, is dedicated to the preservation and interpretation of American railroading and its impact on American society, culture and economy. The Museum is home to the oldest, most comprehensive collection of railroad artifacts in the Western Hemisphere including an unparalleled roster of 19th and 20th century railroad equipment. The 40-acre historic site is regarded as the birthplace of American Railroading and includes the 1851 Mt. Clare Station, the 1884 Baldwin Roundhouse and first mile of commercial railroad track in America. For further information on the Baltimore & Ohio Railroad Museum, please call 410-752-2490 or visit [www.borail.org](http://www.borail.org).



Andrew Oberle, 5 years old, Glen Arm, MD  
T-Cell ALL



is published by



8422 Bellona Lane, Suite 102  
Towson, MD 21204  
phone: 410.560.1770  
fax: 410.560.1775  
coolkidscampaign.org

**Editor-In-Chief:**  
Sharon Perfetti  
sharon@coolkidscampaign.org

**Managing Editor:**  
Katie Bennett Korrow

**Design:**  
Linda Ports  
LP Design, LLC  
Baltimore, MD

#### Cool Kids Campaign Staff:

**Robert Belanger**  
Chairman & co-founder

**Chris Federico**  
President & co-founder

**Sharon Perfetti**  
Executive Director &  
co-founder

**Katie Bennett Korrow**  
Community Relations  
Coordinator

**Lauren Moyer**  
Operations Coordinator

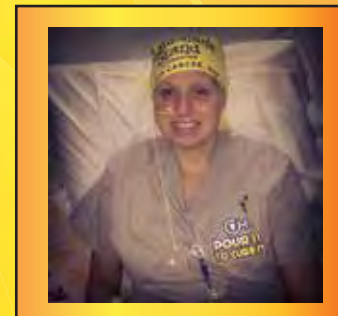
**Kimmie Meissner**  
Board Member &  
co-founder

*Cool Kids Campaign is a 501(c)(3) nonprofit organization dedicated to improving the quality of life for pediatric oncology patients and their families. This publication is offered FREE to oncology hospitals and their patients. Funding is received through sponsors and advertisers. For advertising information and rates, email sharon@coolkidscampaign.org.*



# "My Journey, My Hell, My Leukemia"

By: Brianna Gansert, 15 years old, Linwood, New Jersey  
Bilineage T-Cell Myeloid Leukemia



*You must do the things you think you cannot do.*

*~ Eleanor Roosevelt*

**M**y cancer has never been mine alone; it has affected my entire family. My mom has taken multiple leaves from work to be by my side during my many lengthy hospital stays. She takes me to and from physical therapy, home school instruction, clinic, the hospital, to my Leukemia & Lymphoma Society events and here, there, and everywhere I want/need to go.

My brother, Christian, has taken on more responsibility at home so my mom could be with me and he has stayed with me in the hospital so my mom could go back to work. He's held my hair while I've been sick, changed my hospital sheets when I've had nose bleeds, and brought his girlfriend up to the hospital so we could all have dinner together. He's taken me to clinic for chemo treatments, stayed up watching TV with me late at night when I couldn't sleep, and has been someone I could vent to when I've been frustrated.

My little brother Brandon has probably suffered more from my cancer because my mom wasn't able to be in two places at once; she couldn't be with me in the hospital and at home with him. She missed a lot of his basketball games and school functions because she was busy taking care of me in the hospital, but he understood and never made me feel bad or guilty about it. I was even able to go watch his basketball games when my absolute neutrophil count (ANC) levels were high.

Cancer is a journey of 1,000 miles but for me it feels like a million miles. My roadmap to being cancer-free has been chock-full of bumps in the road. On September 8, 2014 my mom took me to my pediatrician because I was pale, losing weight, was getting light-headed and had bruises all over my body. My doctor had my mom take me to the hospital for STAT bloodwork and within an hour I was diagnosed with leukemia. We were then sent by ambulance to the Children's Hospital of Philadelphia

(CHOP) where a few days later I had a bone marrow biopsy that showed I have a rare cancer called Bilineage T-Cell Myeloid Leukemia.

Basically I have both ALL and AML but am treated with the ALL therapy. Since my diagnosis at CHOP, not much has gone smoothly. I've had a fungal infection in my lungs, a bad reaction (mucositis) to the high dose chemo drug Methotrexate, peripheral neuropathy from the chemo drug VinCristin and an E Coli infection in my right hip- twice! And I had to undergo three separate surgeries for it. I've been in a wheelchair, on crutches, and had to learn how to get around my house without depending on everyone for everything. I've had more CT scans, MRIs, X-rays, and ultrasounds than you could shake a fist at. And I've had more blood products running through my veins that I don't know whose DNA I match anymore. Talk about taking the road less traveled!

There really is no "good" thing about having leukemia. I missed my freshman year of high school, lost all my hair (more than once!), and missed doing the things most 14-15 year old girls get to do like hanging out with their friends, going to the movies, getting mani/pedis, getting my hair done, etc.

Going out and doing things depended on my immune system, my blood counts, and my strength/weakness. If my immune system was up and I was strong enough to walk into a restaurant then I could go out to eat with my friends, but if not then they would have to come over my house to see me as I lay exhausted on my bed or couch. Nausea was/is my worst enemy. I've lost so much weight that my onco doc, Dr. Nick, is visibly concerned about my nutrition, but I can't help that I get sick from the chemo and it leaves me with no appetite. I used to be stronger than both my brothers, but now I have no muscle tone and am so weak that a stiff wind could knock me down. I hate being this weak



and I work hard at physical therapy to gain my strength back, but I also know it's a work in progress. I'm a work in progress.

The one truly awesome thing that happened because of my cancer was that Harry Styles from the band One Direction sent me a personal video message to get better. I had never been so excited before over anything- EVER! That video went viral faster than you can say "OMG" thanks to my friends. You can watch it on Youtube.

I also found out how great my community is and how they came together for me and my family. A few of my middle school teachers ran the Broad Street Run in my honor; my high school ran a 'Pennies for Patients' fundraiser for the Leukemia & Lymphoma Society in my honor. A neighboring high school found out and ran the same fundraiser in my honor and donated the proceeds to LLS. Together both schools raised over \$3,000 for blood cancer research. My friends started a team "Butterflies for Brianna" in my honor and ran/walked all night for the

American Cancer Society's 'Relay for Life' raising almost \$1,200 for cancer research. It's humbling to know the lengths that people (even complete strangers) have gone in support of me.

I am lucky and I know it. I have a great, loving family, the best friends (Jillian!) anyone could ever ask for, a close-knit community, the best onco doc (Dr. Nick aka Dr. Evageliou), and the coolest nurses (Patty, Ashley, Dave, Lexi and Erin). Like I said in the beginning: cancer has never been mine alone and the best people have helped me through the tough times as well as the good ones.

The light at the end of the tunnel for me is maintenance and yet it has remained elusive. I'm almost there but not quite. I now have to go through ten sessions of radiation treatment because Dr. Nick and all the other oncologists at CHOP think it's a good idea even though they don't have any data to support that, but my mom trusts Dr. Nick and I trust my mom. It's always been one step forward, two steps

back for me since the beginning of treatment. I still have far to go, but not as far as I once had to go. Cancer does not define me; it's just a blimp on my roadmap of life. I'm looking forward to going to the One Direction concert this summer and then back to school in September. My cancer roadmap ends in December 2016 and I'm having a party to celebrate the end of one chapter and the beginning of another. I hope through my experience with this rare leukemia and my involvement with the Leukemia & Lymphoma Society New Jersey chapter that I can bring attention to it and to other rare blood cancers because they need just as much attention as the more common leukemias do, maybe even more!

To view Brianna's One Direction greeting on **You Tube** go to:  
[www.youtube.com/watch?v=1FbSaU88C8M](http://www.youtube.com/watch?v=1FbSaU88C8M)



Along with her mom and best friend, Jillian, Brianna attended the Leukemia & Lymphoma Society Gala. Brianna was the Girl of the Year.



Brianna with her brothers Brandon (left) and Christian (right).



# Candlelighters For Children With Cancer

By: Jessica Giberson, Special Projects/Communications

When cancer interrupts a child's life, it deeply impacts the entire family. **Candlelighters For Children With Cancer** understands this and exists to support not only a child with cancer, but also each family member. Helping families in Oregon and Southwest Washington, Candlelighters offers family-focused programs and services throughout treatment and long after it is over, because the journey continues even when chemotherapy or treatment ends. We are here to support families every step of the way.

The importance of helping the whole family can be seen in the words of a Candlelighters family:

*"Candlelighters honors the fact that when a child gets diagnosed with cancer, it becomes a FAMILY disease and everyone needs something special to get through it and develop that 'new normal'. When our daughter Sammy was diagnosed with ALL at the age of 6, our older 9 year old Sydney seemed to suffer just as much, but in different ways. Being able to be involved in Candlelighters activities has been wonderfully healing for our family. Sydney got to have fun and be in the spotlight too. Sammy got to feel normal around friends that were going through something similar. We were able to cope by meeting other families and developing lifelong friendships and support systems. Candlelighters serves the WHOLE FAMILY and boy, do we appreciate that! Thank you Candlelighters for all that you do!"*

- Dennis, Michele, Sydney and Sammy  
Washougal, Washington

Candlelighters works with the two main pediatric cancer hospitals in Oregon, Doernbecher Children's Hospital and Randall Children's Hospital, to offer warm dinners and lunches, along with a food pantry and snack cart. These services are designed to feed hungry patients and parents night or day. For every newly admitted child, there is a snuggly Bedside Buddy waiting to greet them or access to our toy box. Because of the financial stresses that can come from a cancer diagnosis and cancer treatment, Candlelighters offers families emergency financial assistance to help cover bills (rent, mortgage, utilities, etc.) and gift cards to help with gas and groceries. Outside of the hospital, we build community among the families we serve through a quarterly newsletter, monthly family activities, tickets to special events, support groups and our signature annual Candlelighters Family Camp. We also provide bereavement support services, including activities, resources and funeral funds, if needed.

In order to serve families throughout the state, we have set up chapters in the Mid Willamette Valley, Central Oregon, and Southern Oregon. Candlelighters established these chapters to ensure that all families can enjoy our events and services, and feel connected.

It is very important to us that there is no charge for any Candlelighters program, service or activity—ever. Candlelighters relies on contributions from our generous donors, grants and fundraisers in order to fund our services. We are also volunteer driven, and could not do what we do without the help of our dedicated volunteers.

**To learn more about Candlelighters For Children With Cancer, please visit us at [www.4kidswithcancer.org](http://www.4kidswithcancer.org).**





# ICING SMILES

By: Cher Bork, Development Manager

National Non-Profit, Icing Smiles, is **“Baking a Difference”** for families impacted by the critical illness of a Child.

A national non-profit is creating a lot of smiles with the help of caring local bakeries all over the country. The organization, Icing Smiles, provides beautiful custom cakes and other treats for critically ill children and their families. It is through the generosity and time of the volunteer bakers (known as Sugar Angels by Icing Smiles) that over 8,500 cakes have been delivered to sick children around the country, providing happy memories and a bit of normalcy in a time of great stress.

Based in Baltimore, MD, Icing Smiles serves families in all 50 states. Founder and Executive Director, Tracy Quisenberry, understands the importance of creating beautiful memories for these children suffering from terrible disease and their families. “We understand that the simple things, like a birthday cake are luxuries to a family battling illness,” said Quisenberry. “What we provide is so much more than cake. We serve up a reason to smile.”

Families who receive these cakes are incredibly grateful that people they have never met spend hours to create something special and one of a kind for their child.

A recent message from the mom of one of the recipients says it all. “Your organization helped us celebrate our daughter beating cancer with an amazing cake. The generosity and kindness from Icing Smiles and our baker are simply wonderful. The smile it brought to Emmy’s face was priceless!”

Icing Smiles also understands the importance of recognizing siblings. Siblings are many times the unsung heroes. They miss out on many typical childhood experiences as well when a family is caring for the ill child. We want to provide them with a special memory all their own and help create a day that is just for them.

Delivering their first cake in 2010 to Violet, a beautiful 6-year-old battling brain cancer, Icing Smiles has since provided cakes to thousands of children across the country. Icing smiles, with the help of their amazing network of specialty cake bakers, delivers an average of 300 cakes each month. They are scheduled to celebrate the delivery of their 10,000th cake later this year.



## A Difference

Families can request a cake through the online application at [www.icingmiles.org/receive-smile](http://www.icingmiles.org/receive-smile).

For more information, please visit

[www.icingmiles.org](http://www.icingmiles.org) or

[www.facebook.com/icingmiles](http://www.facebook.com/icingmiles).



# 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](http://www.PhRMA.org)

McCormick is proud to support  
**Cool Kids Campaign**





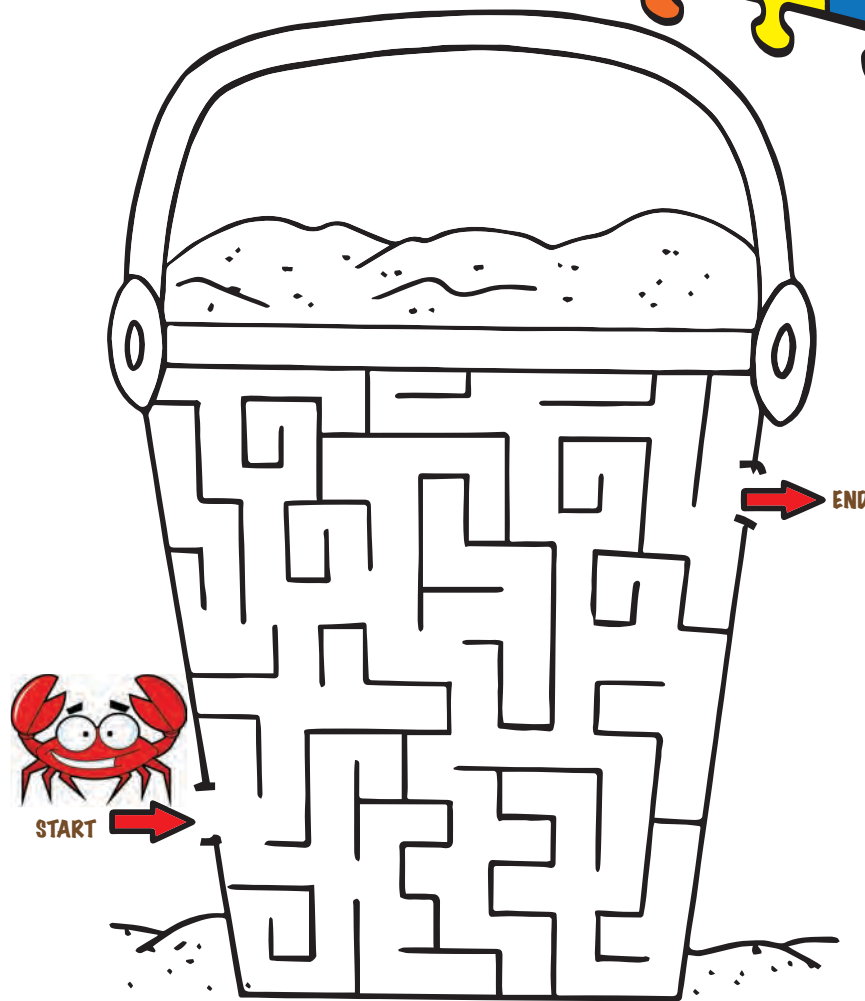
# PUZZLES AND GAMES

## SUMMER WORD SEARCH



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

AUGUST	HAT	SHORTS
BEACH	HOT	SUNBURN
BIKINI	ICE CREAM	SUNGLASSES
BOAT	JULY	SUN TAN
CAMPING	JUNE	SWIMMING
FAN	LOTION	TENT
FISHING	MOSQUITO	VACATION



Help the **CRAB** crawl through the sand bucket and then color the picture!



See how many words can you make out of:  
**SUMMER VACATION**

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

# BRAIN

DESIGN YOUR OWN FLIP FLOPS



# THE TREASURES

CONNECT  
THE DOT  
& COLOR



SUDOKU

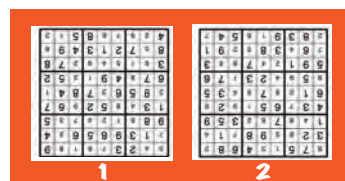
1

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

2

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

ANSWERS

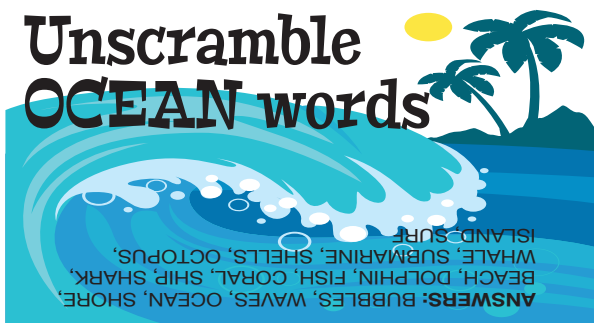




# MIND

# BENDER'S

## Unscramble OCEAN words



ANSWERS: BUBBLES, WAVES, OCEAN, SHORE, BEACH, DOLPHIN, FISH, CORAL, SHIP, SHARK, WHALE, SUBMARINE, SHELLS, OCTOPUS.

BBLSUBE \_\_\_\_\_  
VAEWS \_\_\_\_\_  
NEAOC \_\_\_\_\_  
OESRH \_\_\_\_\_  
CAHEB \_\_\_\_\_  
LDNOPHI \_\_\_\_\_  
HIFS \_\_\_\_\_  
RCOAL \_\_\_\_\_

HIPS \_\_\_\_\_  
ARHSK \_\_\_\_\_  
EWALH \_\_\_\_\_  
MAEBSURNI \_\_\_\_\_  
SLSLEH \_\_\_\_\_  
COTOSUP \_\_\_\_\_  
SLIADN \_\_\_\_\_  
FRSU \_\_\_\_\_

## Fun Facts About Dolphins



Dolphins don't need to drink like we do. Their main prey (fish and squid) contains large amounts of water and so dolphins gain water from their food.

The Killer Whale (also known as Orca) is actually a type of dolphin.

Bottlenose dolphins are the most common and well known type of dolphin.

Female dolphins are called cows, males are called bulls and young dolphins are called calves.

Dolphins live in schools or pods of up to 12 individuals.

Dolphins communicate with each other by clicking, whistling and other sounds.

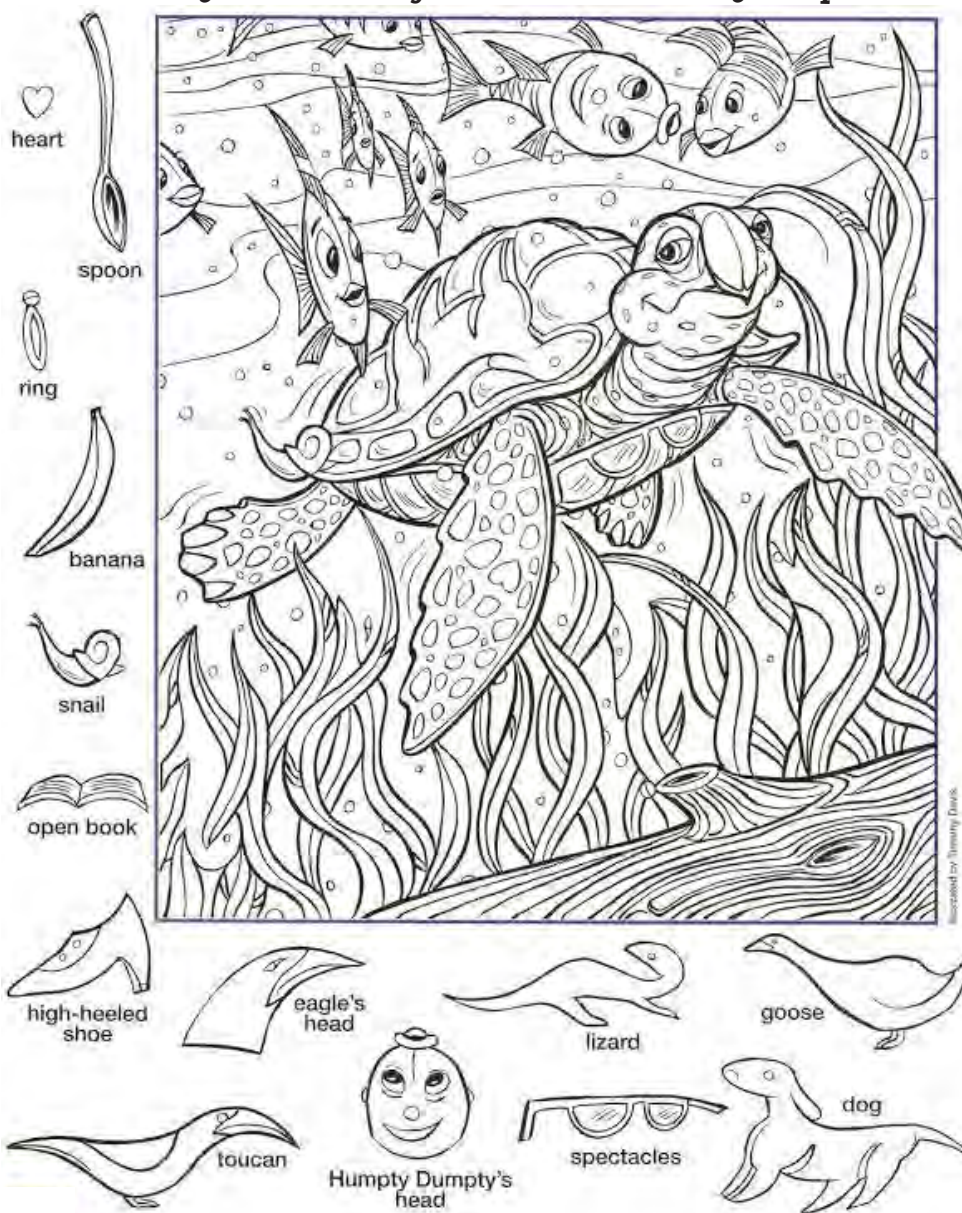
A dolphin has 2-3 times as many cells in the ear than that of a human, suggesting a superb ability to distinguish tones as well as high-frequency sound waves.

Dolphins have to be conscious to decide when to breathe. If they went into a deep sleep they would stop breathing and suffocate or drown. So, their solution is to let only one half of their brain sleep at a time. This way they get the rest they need but stay semi-conscious to continue breathing and look out for any dangers. Dolphins use a blowhole on top of their heads to breathe.

In the wild dolphins can live for a long time. Orcas may live for 70 years or more. Bottlenose dolphins can live for at least forty years. Dolphins that are kept in captivity die much earlier than those living in the wild.



After finding the hidden objects, have fun coloring this picture!



# JOKES RIDDLES



## TWISTIN' THE TONGUE



I thought a thought  
But the thought I thought  
Was not the thought  
I thought I thought.



Sam's shop stocks short  
spotted socks.

**HaHa!** LOL!  
Bahahahahaha

Where are cars  
most likely to  
get flat tires?

At forks in the road!

How do you  
organize an  
outerspace party?

You planet early!

How do hair stylists  
speed up their job?

They take short cuts!

Why does the  
Mississippi river  
see so well?

Because it has four eyes!

## KNOCK-KNOCK JOKES



**Knock, knock  
Who's there?  
Nobel.  
Knobel who?  
No bell, that's why I knocked!**

**Knock, knock  
Who's there?  
Annie.  
Annie who?  
Annie thing you can do, I can  
do better!**

**Knock, knock  
Who's there?  
Honey bee.  
Honey bee who?  
Honey bee a dear and get me  
some juice!**



# Nutritional Tips: Adjusting to Sensory Changes in your Child's Diet

By: Liz D'Alto, RD, LDN – ShopRite of Timonium, Maryland  
Elisabeth.D'Alto@wakefern.com

Nutrition plays an important role in the health of all children. They need to eat a well-balanced diet in order to keep their bodies as strong as possible, especially when fighting an illness.

Cancer and its treatments often cause changes in a child's eating habits and their desire to eat. Chemotherapy may cause various sensory changes which can affect your child's appetite, such as changes in taste and smell. Even foods they once enjoyed may now smell "off" or taste bitter or metallic causing them to eat less. Not eating can lead to an undesirable weight loss, lead to decrease in strength, and cause fatigue. Helping your child eat as well as they can is an important part of helping them through their treatment. Certain types of foods may even help alleviate some common side effects and make them feel better

**Here are several tips below that may get your child to eat more....**

- Serve foods cold or at room temperature. This can decrease the foods' tastes and smells, making them easier to tolerate.
- To reduce smells, cover drinks with lids, and have your child drink through a straw.
- Choose foods that don't need to be cooked. Raw foods typically have less of an odor than cooked. Try not to cook foods with strong odors when your child is around.
- Try using plastic flatware and glass cups and plates especially if your child has a metallic taste in his/her mouth while eating.
- Freeze fruits such as cantaloupe, grapes, oranges, and watermelon, or buy frozen blueberries and strawberries and eat them as sweet, frozen treats.
- Offer fresh vegetables when you can. These may be more visually appealing than canned or frozen ones.
- Keep food tasty. Water and meat are the two most common items that become distasteful during chemo. If your child doesn't like drinking plain water, try offering flavored water or add sliced lemon or other citrus fruits. If certain meats become difficult to enjoy, try offering other sources of protein such as eggs, low-fat dairy, beans, and fish. Or try marinating meats to make them more tender and desirable.
- Blend fresh fruits into shakes, smoothies, ice cream, or yogurt. This will help to get more protein in their diets, especially if you use Greek yogurt.
- Offer frequent small meals and snacks throughout the day, rather than three large meals. Keep nutritious snacks handy so you're prepared when hunger strikes. Try hard-boiled eggs, peanut butter, cheese, smoothies, granola bars, liquid nutritional supplements, puddings, nuts, canned tuna or chicken, or trail mix.
- Let your child eat their favorite foods any time of the day; for example if they really likes breakfast foods, let them have it for dinner.
- Get your child involved and let them help you shop and prepare the foods.
- Keep your child's mouth clean by regularly rinsing and brushing, which can help foods taste better and help promote oral health. Keep their mouth moist – don't let it get dry.

Be sure to test out this simple, refreshing recipe called the Summertime Mango Lassi. It's traditionally made with yogurt and milk, non-dairy milks and yogurt can be substituted for those with lactose intolerance. Try using soy or coconut milk and yogurt.

### Recipe for Summertime Mango Lassi

Makes 1 (17-ounce) smoothie.

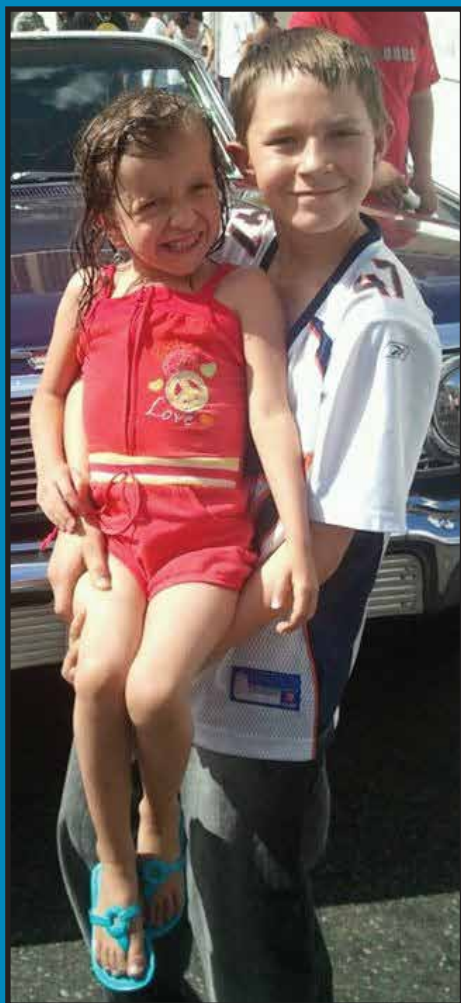


- 1 cup plain yogurt, whole milk or low fat
- 1/4 cup milk, whole or low fat
- 1 cup fresh or frozen mango chunks
- Agave nectar or honey, to taste
- Pinch of cinnamon, for garnish – optional

*Blend all ingredients until smooth. Keeps up to 24 hours in the refrigerator, re-blend before serving.*

# Fighting Angel<sup>1</sup>

By: Heather Barnes,  
Chandra's mom  
Aurora, Colorado



Chandra is a 10 year old loving, caring, happy little angel. She has a 16 year old brother (Zach) and a 14 year old sister (Jade). Her health issues started right after she was born. She was flown from Sterling to Denver for neurological issues and seizures. At the age of one, Chandra was diagnosed with Hypertrophic Cardiomyopathy (an enlarged heart). She was on medication after medication. She was constantly sick with pneumonia and bronchitis as well as chronic ear infections that led to her needing several sets of tubes being put in. She had her tonsils and her adenoids removed as well as her lingual tonsils. We were going to Denver several times a month.

Just a short time later, we were referred to genetics where we then found out Chandra has Noonan Syndrome. According to WebMD, Noonan syndrome is a common genetic disorder that is typically evident at birth (congenital). The disorder is characterized by a wide spectrum of symptoms and physical features that vary greatly in range and severity. In many affected individuals, associated abnormalities include a distinctive facial appearance, a broad or webbed neck, a low posterior hairline, a typical chest deformity and short stature.

She fought like a ROCKSTAR for six years but her heart would not last. We were then put on the transplant list at Children's Hospital in Aurora, Colorado. One of the requirements to be on this list was that you

had to live within an hour of the hospital. We lived over two hours away in Sterling, CO.

So, Chandra and I had to leave my husband and my two other children to live at Brent's Place near the hospital. They would come up on weekends to visit. We lived there for six months until flu season was outrageous and then we had to move to the Ronald McDonald House. We stayed there for another six months and then decided to rent a house so the kids had a place to run around and play and have their own rooms.

A month after we moved in (April 4, 2011 also her brother's birthday) we got the call. "We have a heart. Get here as soon as you can!" I called my husband in Sterling. He got the kids to a sitter and he headed to Aurora.

All went well with the transplant but other problems would pop up along the way. She was diagnosed with a blood disorder called Von Willebrand disease (which causes extended or excessive bleeding), sleep apnea, hearing loss (so she wears hearing aids), warts on her face and body, excessive gum tissue (so she will need to have some removed eventually), decayed teeth due to medicines, allergies, and cysts on her toe.

Chandra had started complaining of thigh pain on a Monday, and being parents of three children, we thought it would eventually go away. By Wednesday it was still there and had intensified, so I made a doctor's



appointment. They took x-rays and we went home. On Wednesday night, the doctor called and said to take her in for a MRI on Thursday because it looked like she had a fracture in her femur. Thursday morning, Chandra woke up with a bump on her forehead; it just appeared over night! It turned out to be a tumor.

After the MRI, we left the hospital and Chandra was hurting so bad that we went straight to the ER. After about three hours of waiting, they wanted more tests done. She got admitted to the hospital and after a couple days, we were told she has PTLD (Post Transplant Lympho lymphoproliferative Disease). Post-transplant lymphoproliferative disorder (PTLD) is an out-of-control growth of lymph cells which is a type of lymphoma, according to cancer.org. Chandra is now on chemo infusions every Monday followed by at home medication.

Chandra has handled all this like a champ! She fishes, swims, walks her dog, plays with family and friends and just has a good time. When she grows up, she wants to be a veterinarian or a teacher. She loves, and I mean LOVES, her dog Chewy! She has been so strong through everything and adapts to anything that comes her way. She is a fighting angel.

Everyone always asks us how we get through everything every day. To tell you the truth, we all know no other way. Chandra is the one that has carried us all through it. She shows everyone that anything is possible. We are stronger together!



# COOL CAREGIVER



# COOL KID

*Cara is a Registered Nurse at Johns Hopkins Children's Center in Baltimore, Maryland and works on the pediatric oncology inpatient floor, which is where she met 10 year old Cassidy. Read more about them below!*

## CARA (Maryland)

What is your job title? I am a Pediatric Oncology Nurse at Johns Hopkins Children's Center in Baltimore, Maryland. I take care of kids who have cancer.

What do you enjoy doing for fun? I enjoy swimming and taking my dog on walks.

Favorite Movie? *Grease*

Favorite TV show? *Big Bang Theory*

Favorite board game? *Life*. Growing up, my cousins and I would play it at every holiday gathering.

What celebrity do you admire and why? I admire Angelina Jolie because she is always bringing attention to and helping out people in poor communities throughout the world.

If you could have dinner with one person (alive or deceased) who would it be and why? It would be Kate Middleton because I want to know what it is like to be a part of the royal family.

If you could have any superpower, what would be? To transport anywhere at the snap of a finger.

How would you spend a million dollars? I would travel the world.

First thing you learned to cook? *Spaghetti and meat sauce*.

Were you named after anyone? My great-grandfathers on my Dad's side, Clay and Nathan.

Beach or mountains? *Definitely the beach!*

Favorite quote? My favorite quote is from Miley Cyrus' song "The Climb": "There's always gonna be another mountain, I'm always gonna wanna make it move, Always gonna be an uphill battle, Sometimes I'm gonna have to lose, Ain't about how fast I get there, Ain't about what's waitin' on the other side, It's the climb"

What do you miss most about being a kid? All the after school activities that I got to participate in like ice skating lessons, swim team, and dance lessons.

What is one thing on your bucket list? To go on an African Safari.  
Have you ever been admitted to the hospital? I was admitted to the hospital when I was in middle school for dehydration. Don't forget to drink plenty of water!

What's the scariest/craziest thing you've ever done? I cut my little sister's hair when we were little kids. I got in big trouble for that one!



## CASSIDY (Virginia)

What grade are you in? *5th*

How old are you? *10 years old*

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

What do you want to be when you grow up?  
*I want to be in the Olympics.*

Do you have brothers and sisters?  
*I have 1 brother and he is 18.*

What do you like to do for fun? *I like to swim for fun.*

Favorite subject in school? *Science*

Who's your BFF? *Rylee*

If you were president of the United States, what would be the first law you would make? *Kids can skip school and not get in trouble.*

Favorite movie? *Soul Surfer*

Favorite TV Show? *Zoey 101*

Favorite video game? *Sonic Race Cars*

If you were stranded on an island, what 3 things would you have with you?  
*Socks, knife, and a chicken*

If you could meet someone famous, who would it be? And what first question would you ask? *Katy Perry and I would ask how she writes all her songs.*

If you could have any superpower, what would it be? *To heal people.*

Favorite ice cream and toppings? *Mint chocolate chip and I like chocolate shaves and whipped cream and hot fudge on top.*

What age do you consider old? *50*

Do you collect anything? *Beanie Boos*

Least favorite chore? *Cleaning my room*

If you could learn anything, what would it be? *I would want to learn how to do a back handspring and a back tuck.*

What's the scariest/craziest thing you've ever done? *Have my knee replaced.*



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