

Looking Back, Looking Ahead

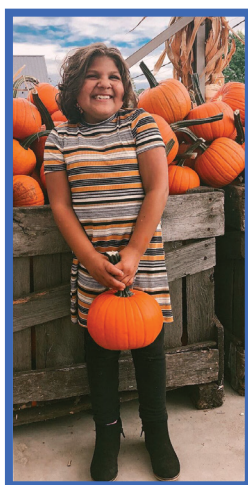
By Elise Richard

Fall 2019

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When I was first asked to write about my experience as a mother with a child who was diagnosed with leukemia, I was not sure what to share. There is so much about this experience that I have tried to forget and push past because our daughter, Sansa, has been in remission (again) for the longest amount of time since she started her treatments back in 2014 - 10 whole months in a row! At the same time, it is such a huge part of our family story, and we still see the long-term effects of her treatments every day.

The whole experience was very isolating, so the biggest message that I want to share is that you are not alone in this journey. The sleepless nights with never ending beeps from the IV machines, having to get the call that your kiddo's leukemia has come back a third time, living in the hospital for months on end, being so mad at this cruel world, not understanding why this is happening to your baby, crying in the bathroom so your kiddo doesn't see you, being so stressed that you don't even want to eat or eating so much

because it's the only thing you can do in the gosh darn hospital! It feels like everything in your world has come to a complete stop, so that you and your family can fight this, but the world keeps moving. Bills are due, other kids and pets need love and attention too, and work just keeps piling up, so you move around in a fog trying to do the best you can.

I recognize and see you, and I understand how very hard it all is to go through.

As scary and tough as every day was when we were in the middle of our war with cancer, I want to share some of the things I am so grateful for lately. Our daughter, who is 7, started first grade this year and was able to begin school on time for the first time ever. We were able to go on a couple of weeklong summer trips thanks to organizations like Cool Kids Campaign and Believe in Tomorrow. This was the first summer we were able to do that and our daughter, Sansa, was able to swim/play at the beach and didn't have to worry about getting her Hickman line infected. As tough as all of those days seemed to be and as battle worn as our family is, I have such a special appreciation for every little thing we are able to do together. I honestly was not sure if we would ever make it here, and the fear that cancer could return is always there, but I push past it because my daughter needs me now in different and new ways. She is the toughest person I have ever known, and

I am so proud of her!



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8422 Bellona Lane, Suite 102
Towson, MD 21204
p: 410.560.1770 • f: 410.560.1775
coolkidscampaign.org

Editor-In-Chief:
Melanie Kabia

Managing Editor:
Taylor Harrington

Contributing Writers:
Elise Richard, Richard Gary,
Dr. Robert Lynn, Steve O'Dell,
Renee Henry

Design:
Linda Ports

COOL KIDS CAMPAIGN STAFF:

Chris Federico
President & Founder

Janet Robinson
Director of Operations

Reneé Wooding
Director of Philanthropy

Melanie Kabia
Director of Programs and Events

Taylor Harrington
Programs & Events Coordinator

Katharina Groeger
Operations Coordinator, Charlotte

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Cancer

By Richard Gary of Poetic Views

I hope you die
Truly cease to exist
Of the things I hate
You're top of the list
You've killed my friends
And my family too
Life would be better
Without you
You make people sick
When you attack
But it inspires us all
When they fight back
So I hope you die
In every form
So a life without you
Becomes the norm
Its been on my heart
So it must be said
We'd be better off
If Cancer was dead



What Cancer Cannot Do

By: Dr. Robert L. Lynn

Cancer is so limited...
It cannot cripple love.
It cannot shatter hope.
It cannot corrode faith.
It cannot eat away peace.
It cannot destroy confidence.
It cannot kill friendship.
It cannot shut out memories.
It cannot silence courage.
It cannot reduce eternal life.
It cannot quench the Spirit.



For more inspiring poetry, visit
www.poeticviews.com, IG: poetic_views1

WHAT ARE YOU MADE OF?

by Steve O'Dell

When I was asked to write an article about our cancer journey, a part of our journey, or any specific story that I could share to hopefully encourage or empower others in a similar situation I jumped at the opportunity. Then weeks passed, the deadline came and went, and I still had writer's-block. How could I articulate something so profound, so impactful, in a manner that would be useful for others to digest in a newsletter? I wasn't at all sure how to share the raw emotions in a writing format, because there were so many emotions, but I started with a title. "What are you made of?" It was a toss-up of this and "Who do you think you are?" or "Who are you really?"

This sums it up; if you want to know who you are, who your friends are, what you and everyone around you is made of, then experience this kind of journey. If you want to find where every weakness within you might reside, then this is the journey you'll find it on. Quite frankly, this cancer journey is going to change you and everyone close to you, and the question is whether it's going to make you a stronger, better person, and family or if it is going to destroy you and everything around you? I advise the former over the latter.

This photo is of Bella, just a few short months before her diagnosis. She was a healthy, active, happy 5-year-old. I think she may have been sick a total of two times in five years.



In the spring of 2018 she started to complain, here and there, about her legs hurting, and specifically her thigh area. She would get random rashes, but that had happened before since her skin was sensitive. Then she experienced significant back pain. She was trying to "help" mommy move a bag of rice from the pantry, without her knowing it of course, and we thought maybe she pulled a muscle (as strange as that sounds for a 5-year-old). She screamed in pain and could barely walk.

Bella had some blood work done and her pediatrician thought it was odd that she had some immature white blood cells in her results, and she referred her to Johns Hopkins Hematology, but the smear looked normal and the thought was infectious disease or an auto-immune disorder. During this time Bella was on prescription

strength Naproxen just to be able to function. Her heart rate was also regularly 150. She then started to experience alarming anemia. It was when we made a visit to the hospital due to the need for a blood transfusion that many, many, more doctors became involved and we ended up in an extended stay at Johns Hopkins Children's Center to figure out the issue. After a bone marrow aspirate, and then a core sample, scans of various sorts, surgery on one tumor area in the lymph node of her neck, the results were confirmed: Bella was diagnosed with high-risk stage-4 neuroblastoma! "What the heck was that?" I thought!

It was only a matter of days before we were in treatment, and it wasn't long before hair loss was a reality. I can honestly say as fast as I have lived my life, of all the different things I've imagined, this was not among them – shaving my five-year-old little girl's head in order to avoid the unorganized hair loss. Luckily, she loved it, but it was painful for me and us, but not for her. She has the spirit to not give a crap about this type of stuff. Apparently neither did my wife with her hair! She wasn't going to let Bella do this alone. I try to pretend that is why I'm bald too!



Fast-forward (trust me at the time it will not feel like a fast-forward) through approximately 40 sessions of high-dose chemo therapy, a very high risk disease and the scariest time of my life as my daughter underwent a 13 hour surgery to remove the primary tumor around some serious arteries (it was a success but there were some scares), a bone marrow transplant that included a fairly intense bout of mucositis and colitis which had a surgeon talking out loud about the need for a possible colon removal (it didn't happen and we made it home on Christmas Eve), a month of 5 days a week radiation, and approximately 6 months of immune therapy which was around 20 sessions, and many nights in the hospital with dozens and dozens of blood and platelet transfusions! Immunotherapy presented some scary times as well with the blood pressure drops, high heart rates, very high fevers, but Bella was able to fully complete each round of EVERYTHING they threw at her!

I (dad) am writing this brief story of a harrowing journey, but don't be fooled into thinking that means I did the work. Mommy did it all. Lina saved my life when I had open-heart surgery at 36, and she saved our daughter's life with her unrelenting commitment to her care. Every minute of the hospital time over the last 18 months my wife was there, all night, morning, and afternoon, all day...every day. Every tube flush, cap change, dressing change, etc...it was mommy nurse to the rescue. This is something you really do get much better at, but it is scary at first. Hand sanitizer becomes part of the ingrained routine of everything you do, along with facemasks at all times during the cap changes (I recommend a personally purchased cloth mask with a filter, preferably two filters since I find them better for air flow), dressing changes, or at any public appearances. It is stressful because there is little room for error, little room for complacency, and the details matter. I am blessed, and proud of my wife, to say that during all the tube flushes, cap changes, dressing changes, we did not experience one infection the whole time, except one time with the PICC line before it was changed to a double-lumen Hickman. However, even that PICC line made it through two rounds of chemo which was a full 30 days longer than they typically last.



It is an article for another newsletter, but I can tell you I've learned more about leadership, courage, and what strength is from Bella than I have from any other person, source, or life experience. From three years overseas, to death, to recovery I have not experienced anything of this magnitude, but there is hope. You can get through this journey, and while it won't be easy and there will be downs, it will have its ups as well. You will meet, if you haven't already, many wonderful people on the journey. Great nurses, doctors, and technicians, but also many great volunteers and behind the scene workers like those that work hard to keep the space clean on your visits. There are so many committed individuals.

One of the most eye-opening parts of this journey for me was the way people rally for your family. This was not something I expected or even desired. I think many people enter this situation and want privacy, but after I saw Bella's face light-up on the first visit from friends of our older daughter, and all the attention that lifted her up, I knew I had to

embrace the support. It may have been uncomfortable at first, but one of the things I learned is that this isn't about me, it was about Bella. Try to always remember that when it gets tough, because it will be frustrating and it will be tiring and it will be maddening at times, and I found if you remember what this is about, then it does make it a little easier and a little smoother. I didn't know who I was when all this started, but I know who I am now. Try to draw clarity from the experiences, from your faith, and extract any of the positive things you can, however small, because your faith will serve you well at the darkest times.

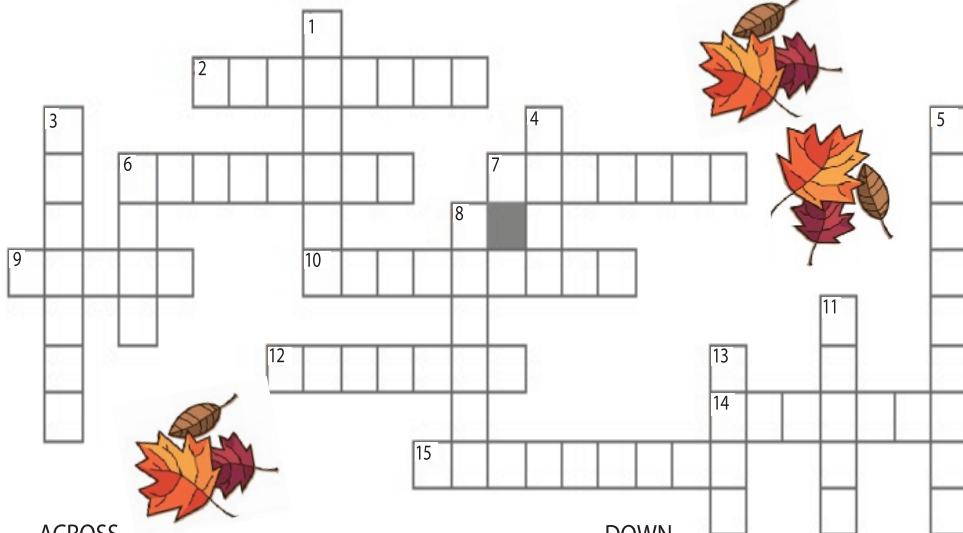
Don't give up. I say again:

WHAT ARE YOU MADE OF?



PUZZLES AND GAMES

AUTUMN CROSSWORD PUZZLE



ACROSS

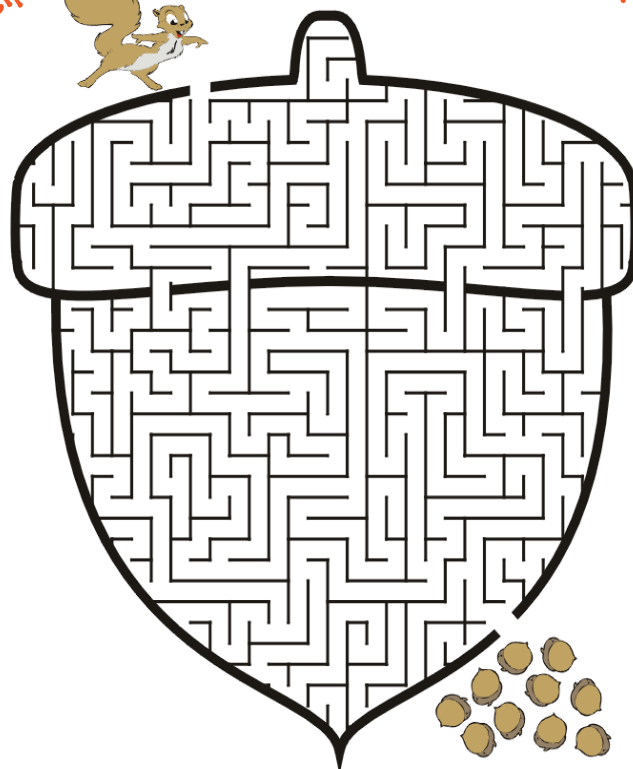
2. Last month of Autumn
6. An organized day or period of celebration
7. The process or period of gathering in crops
9. A variety of this fruit is marketed as "Autumn Glory"
10. Likes to store and eat nuts
12. Spring, Summer, Fall, Winter are the 4 _____
14. Another Autumn month
15. First month of Autumn

DOWN

1. What falls from a tree in Autumn
3. You can use it to make a pie
4. You can gather fallen leaves with this
5. Used to scare the crows from fields
6. Another name for Autumn
8. Autumn leaves color
11. Fruit of the oak tree
13. Vegetable that grows in stalks

WORDS USED: SEASONS, OCTOBER, SCARECROW, ORANGE, CORN, PUMPKIN, FALL, RAKE, LEAVES, SEPTEMBER, FESTIVAL, ACORN, SQUIRRELS, NOVEMBER, HARVEST, APPLE

Help the squirrel through the maze to find the acorns

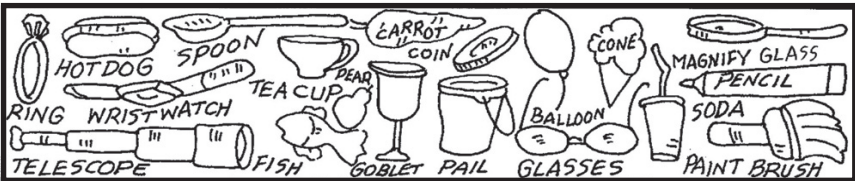
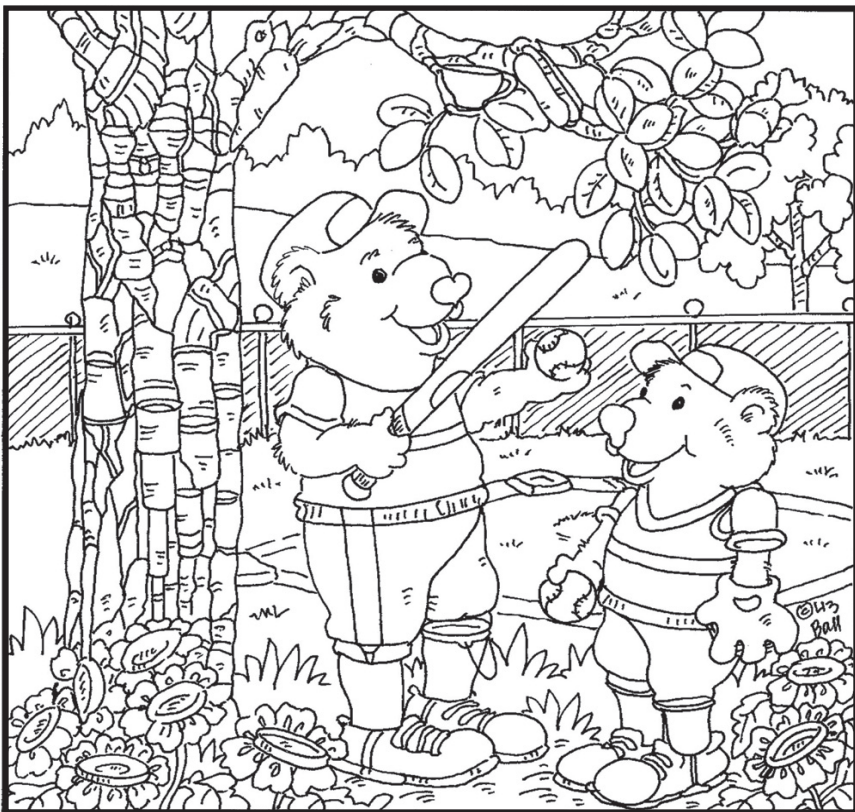


COLOR ME!



BRAIN TEASERS

CIRCLE THE HIDDEN PICTURES



FUN FALL WORD SEARCH

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

WORDS TO FIND:

- PUMPKIN
- YELLOW
- SCARECROW
- AUTUMN
- LEAVES
- SUNFLOWER
- ACORNS
- CORN
- HARVEST
- APPLES
- HAYRIDE
- RED
- THANKSGIVING
- FOOTBALL
- ORANGE



See how many words you can make out of: THANKSGIVING TURKEY



FUN FACTS!

Did you know...

Your fingernails grow faster when you are cold.

Your feet typically produce a pint of sweat every single day.

While you sleep you can't smell anything, even really, really bad or potent smells.

Your brain uses 10 watts of energy to think, and does not feel pain.



In a room with 23 other people, there is a 50% chance that two of the people in the room will share a birthday.

Of all the oxygen you breathe 20% of it is used by your brain.

The average person spends two weeks of their life waiting at traffic lights.

When you look at a bright sky and see white dots, you are looking at your blood. Those are white blood cells.

Your small intestine is the largest internal organ in your body.



Love carrots? Don't eat too many or you will turn orange.

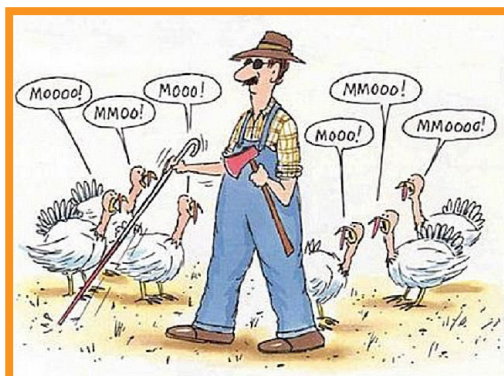
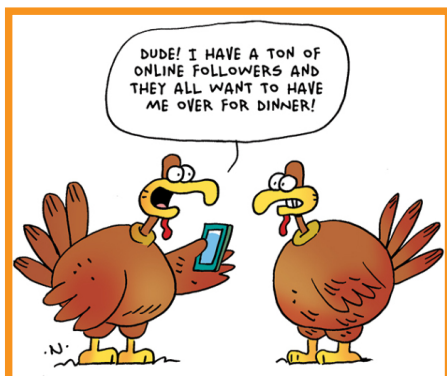
A typical cough is 60 mph, a sneeze is often faster than 100 mph.



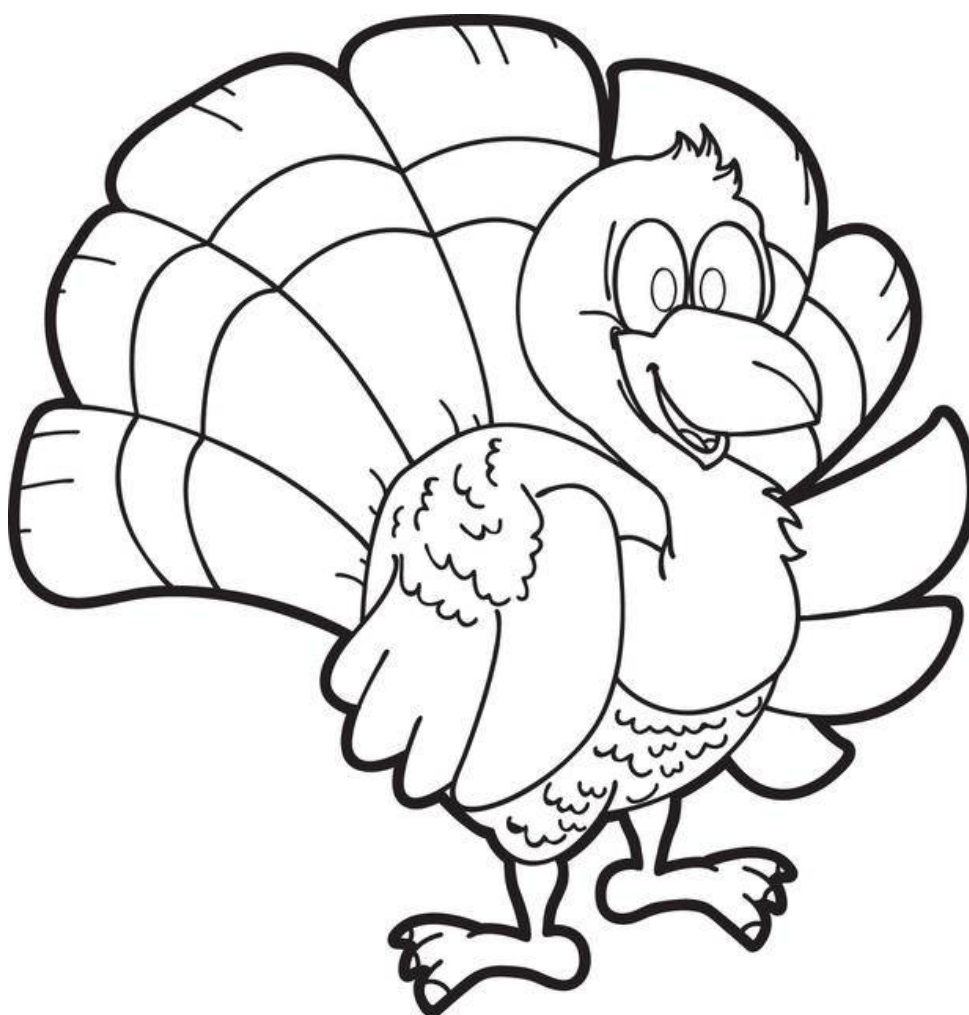
You fart on average 14 times a day, and each fart travels from your body at 7 mph.

JOCKEYS RIDDLES

TURKEY CARTOONS



COLOR ME!



HAPPY THANKSGIVING

AUTUMN RIDDLES

Q: What's the best thing to put into a pumpkin pie?

A: Your teeth

Q: Why do birds fly south in the Fall?

A: Because it's too far to walk

Q: What has ears but can't hear a thing?

A: A cornfield

Q: What reads and lives in an apple?

A: A bookworm

Q: What did one leaf say to another?

A: I'm falling for you

Q: What runs around a farm but doesn't move?

A: A fence

Q: Why did the scarecrow win a medal?

A: He was outstanding in his field

Q: How do trees get onto the internet?

A: They just LOG on

Q: What can you never eat for Thanksgiving dinner?

A: Breakfast or lunch

Q: What's the best dance to do on Thanksgiving?

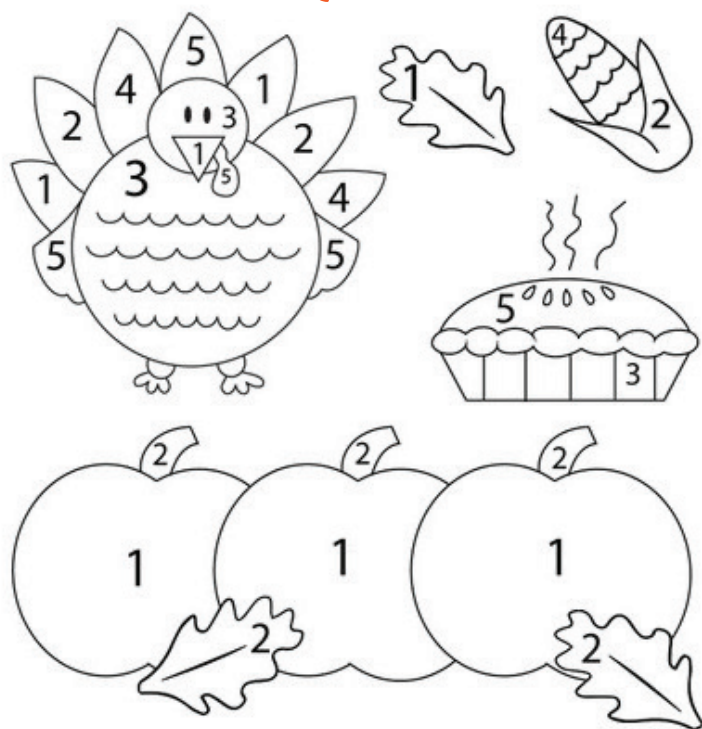
A: The turkey trot

Q: Why did the turkey join the band?

A: Because he had drumsticks

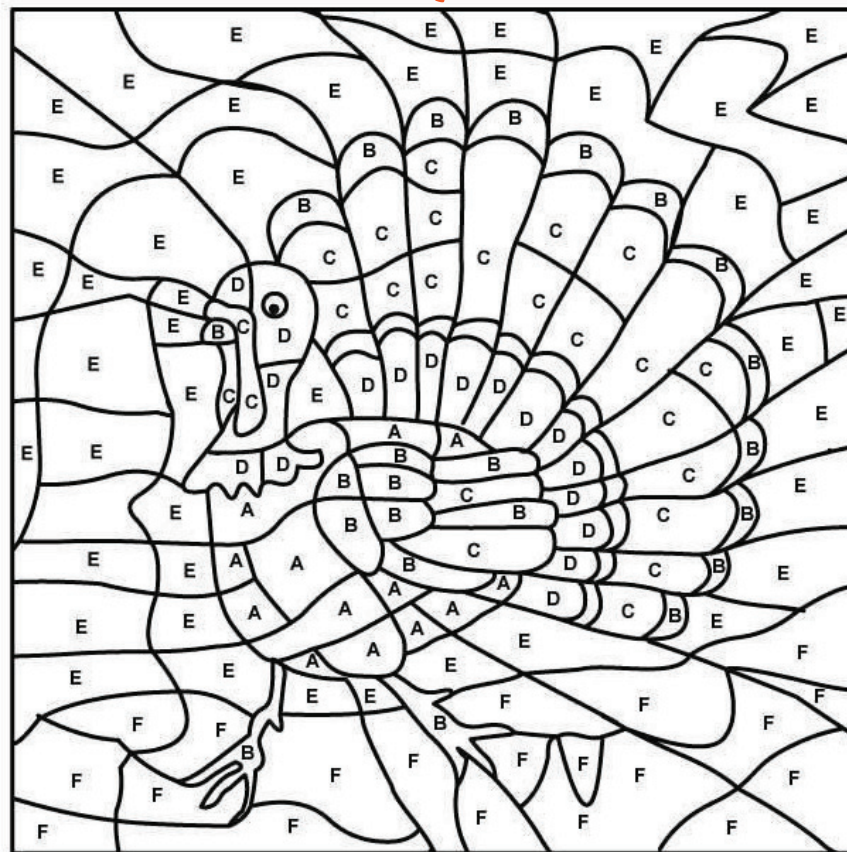
COLORING

Color by Numbers



- 1- orange 4- yellow
2- green 5- red
3- brown 6- purple

Color by Letters



- A = Brown B = Yellow C = Red
D = Orange E = Blue F = Green



THANKSGIVING

by Renee Henry



I was grumpy yesterday. Quite irritable in fact. Grumbling internally at the cold, windy weather, whinny about the crowds in the store as holiday shopping started to pick up, frustrated that my laptop is a piece of junk, and mostly complaining about the fact that I had to drive thirty minutes down to the hospital pharmacy to pick up my daughters most important chemotherapy medicine. The insurance company won't allow us to fill the prescription until we only have enough to last one day in between refills. Ugh!

So by the time I arrived at the hospital around 7 PM, I was cold, hungry and tired, after a hard day at work and fighting through the thanksgiving crowd at the grocery store. To say the least, I was not in a good mood. To top it off, I had a headache across the entire front of my head that made my eye sockets hurt.

I dragged my feet as I shuffled to the elevators and sarcastically laughed as the receptionist asked me if I knew where I was going because after a year of walking these same hospital halls with inpatient stays and clinic visits I could do it with my eyes closed. Unhappiness was spilling out of my pores like sweat as I stood in line to pick up the prescription. I complained to the pharmacy tech about the wait and unenthusiastically muttered a "thank you" as I snatched the bag and walked away.

I was wishing I was home, in my bed with the blankets over my head as I rounded the corner from the pharmacy and into the children's hospital lobby. There was an unusual crowd of about thirty people sitting and standing huddled together. It was strange because for such a sizable group it was eerily quiet. As I cautiously approached, I realized that a social worker stood in the center saying something to them in a hushed, calm and rehearsed voice. Amongst the group there were those that looked down at the ground as some looked up to the ceiling, some stood arm in arm, as others had tears streaming down their faces. They held each other in efforts to comfort and comprehend what they were being told. The look of shock, disbelief and deep grief covered their faces.

A child had passed away.

It seemed like my body started moving in slow motion as I had to walk through them to get to the elevator. Slowly weaving through their motionless huddle, it was like time was standing completely still for this family. I hung my head in shame as my earlier ingratitude was still hanging like a heavy necklace around me. There I was, grumpy about the inconvenience of having to pick up my child's medicine and they were mourning the sudden loss of their child. The sting of guilt squeezed my heart as my eyes began to fill with tears. I was jolted back to the reality that I walked out of the hospital with my child, alive and getting better with each passing day.

I had forgotten for a moment that it was my wedding anniversary and I'm lucky to have an amazing husband who truly loves me and two incredible children that I adore. I had forgotten how very blessed we have been this year as others have sacrificed and given to carry us through our child's critical illness. I had forgotten for a moment about the fun we had as a family this past weekend. It was filled with love and joy as our friends and family traveled to serve and support us. I had forgotten to be grateful...for ALL the moments we have.

As I stood outside in the cold for a few moments, I turned back to watch that mourning group of family and friends through the glass walls and I prayed for God to bring them comfort, I too grieved for their loss as I thanked God for my own daughter's life, for the gift of being a mother, a wife, a daughter, and a friend. I thanked him for the tremendous and amazing life I've been given and for having people to share it with.

I'm certainly looking forward to eating my favorite Thanksgiving dinner with our family. For taking time to be utterly grateful to God for all that's been given. We most certainly can't let this holiday go by without thanking those in our lives and pray that this holiday season you too will be reminded of all that you have!

"Enter his gates with thanksgiving and his courts with praise; give thanks to him and praise his name. For the Lord is good and his love endures forever; his faithfulness continues through all generations."

From Danielle Cook Navidi's Cookbook:
Happily Hungry: Smart Recipes for Kids with Cancer

Fluffy Mashed Potatoes with Perfect Poached Eggs

Ingredients:

2 Idaho russet potatoes (can substitute one sweet potato and one russet), peeled and cut into chunks	½ teaspoon sea salt
2 tablespoons unsalted butter	2 eggs, poached in simmering water with
1 tablespoon sour cream	1 tablespoon white vinegar

Instructions:

Put the potato chunks in a pot and cover with cold water. Bring to a boil, reduce the heat and cook until very tender when pierced with a fork, about 10 minutes. Drain well, transfer back to the pot and with an electric beater, whip the potatoes until fluffy, about 1 minute. Add the butter, sour cream and salt; whip another minute. Adjust for taste. Keep warm while you poach the eggs.

To poach eggs, bring a saucepan filled about 2/3 full of water - enough to cover the eggs - to a boil. Reduce heat to a simmer. Add the vinegar to the simmering water (this will help the egg coagulate). Crack one egg into a ramekin or small bowl and carefully slide the egg into the water. Do the same for the second egg. Cook for 3-4 minutes, making sure the water does not return to a boil. Remove with a slotted spoon, letting excess water drip into the pan. Serve on top of mashed potatoes. Serves 2.

Nutritional info: Calories: 331; Total Fat: 18; Protein: 9.5g; Carbohydrates: 34g.; Sugars: 1.6g.

Warm Roasted Potato Salad with Black Olive & Mint Pesto

Ingredients:

2 lbs. Yukon gold, red bliss or new "baby" potatoes, or a combination, unpeeled	½ cup (2 ounces) feta cheese, crumbled
¼ cup olive oil	3-4 scallions, trimmed and sliced, for garnish
	Chopped mint, for garnish

Instructions:

Heat oven to 425 degrees. Toss the potatoes with olive oil. Spread on a baking sheet and roast for 15 minutes. Toss and roast another 15 minutes, or until nicely browned and tender when pierced with a fork. While the potatoes are still hot, toss with pesto (recipe below). Garnish with scallions and chopped mint. Serve warm or room temperature. Serves 6-8.

MINT PESTO

Ingredients:

¾ cup pitted black olives (Kalamata or oil-cured Moroccan)	1 small shallot, minced
1/4 cup olive oil	1 tablespoon fresh lemon juice, more to taste
2 tablespoons lightly packed chopped fresh mint	Salt and pepper to taste

Instructions:

Put all ingredients in a food processor. Process, stopping to scrape the sides of the bowl with a rubber spatula as needed, until mixture is smooth. Adjust the taste with salt and pepper and lemon, as needed.

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Camie, Relapsed Acute Lymphoblastic Leukemia

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