



CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

A Letter to the Governor of Maryland from a Five Year-Old

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Dear Governor Hogan,

Andrew wanted me to help him type up for you ways that he stays brave and positive while he gets chemo treatments. These tips are in Andrew's own words....

- Remember to put the numbing cream on before they give you a "pokie" (Andrew's way of saying needle stick)...it really helps a lot....
- Think of really AWESOME places you like when you get sad...like playgrounds, and favorite kid shows, Mommy and Daddy, and Hawaii....
- Learn to play video games on your tablet...they make you not focus on bad stuff when you're at the hospital all day
- Pray to God...you know He watches over all us and knows how to beat cancer...
- Listen to your favorite music like IZ's (the Hawaiian singer) Somewhere Over the Rainbow...I love rainbows, they make me happy...you can think of those things too when you're sad or not feeling so good...I drew you one....I know all the colors in order!!!
- Hug someone....like I hug my Mommy...
- Make a friend at clinic who knows how you feel and be their pen pal...like Damari and me, I text him on Mommy's phone...we are best friends now and he knows how I feel sometimes when Mommy doesn't...
- Don't forget to bring your favorite stuffed animal and blankee to the "hossible" (this is how Andrew says the word hospital)
- It's ok to cry, just make sure you have your "hugging person" with you....
- The doctors will become your friends, I didn't like them in the beginning, and they will help you...



Andrew and I hope that these little tips help you stay BRAVE and STRONG. Please know we are always here for you, praying and thinking of your journey every day. You are in the great state of Maryland with the best medical doctors on the PLANET. We are so grateful to be living here with the best medicine right at our doorstep. Thank you for not giving up and leading us Marylanders at the same time you are going through cancer treatment. You are an inspiration to my family, taking on everything that you do.

God Bless,

Andrew

Andrew Oberle (5yrs old T-Cell Leukemia)
and his Mom...Caroline Oberle





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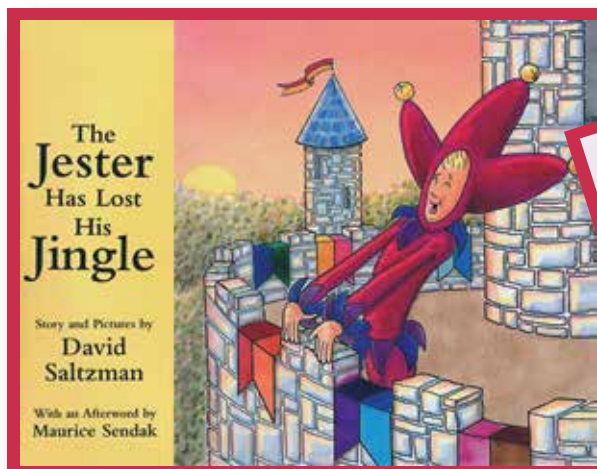
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THE JESTER'S JINGLE: Helping Kids with Cancer

By: Barbara Saltzman, The Jester's Mom



My son David never got to see his New York Times best-selling children's book between two covers. But he did see firsthand how his story brought smiles to children with cancer. And the day he experienced their joy was just the beginning.

The Jester Has Lost His Jingle was David's senior project in art and English at Yale University 26 years ago. He got the idea before his senior year when he walked into a summer school class in July, told a silly joke and no one laughed.

"Now I knew that the joke was not very funny, but nobody even smiled or said hello. They just kept to themselves and looked down at the table. My good mood soon became one of depression, rejection and disappointment," David wrote in the Author's Note to *The Jester*. "I decided to sit silently like the others, thinking to myself how quickly moods change."

"I started drawing and, as usual, did not know what I was creating, letting my hand create on its own accord. It turned out to be a very sad-looking face, humped over, trying hard to carry its own weight. I randomly added triangles to his head and, after staring at what I had just made, realized that it looked like a little jester. I added the words next to it: 'The jester has lost his jingle.'"

"And thus the Jester was born."

Those words burned themselves into David's brain. After school, he couldn't get them out of his mind, and thought that a story about a jester

who loses his jingle could be a great children's book. That night, he laid out the whole story, including rough sketches. In the fall, he returned to Yale where his professors agreed that David could turn it into a powerful children's book.

Not long after he got approval for his senior Jester project, David was diagnosed with Hodgkin's disease. That October day, our lives changed forever.

"Upon hearing the news, I went out to a patch of lawn, sat by a tree, and cried," David wrote. "As I sat there crying, I listened to my sobs, thinking how much they sounded like my laughs. And suddenly, one of the lines I had written during the previous summer popped into my head: 'Here I lie, I have a tumor...And you ask me where's my sense of humor?'"

And that was when my Jester came to me. He literally walked over to me, put his hand on my shoulder and with a concerned look said, "David, how come you're not laughing? Your cries sound just like laughs, so why not laugh instead of cry?" I thought about it for a second and then repeated the question to myself: "How come I'm not laughing?"

"So I got up from the pile of dead leaves that surrounded me, wiped my face dry of its tears and walked off laughing at how silly and scary and wonderful this world of ours is."

"He came to help me in my time of need, and my hope is that, if you let him, he will come alive within these pages and help you too."

Not long after graduating Yale with top honors in May 1989, David underwent a bone marrow transplant hoping it would eliminate the tumor taking over his lungs. While waiting in X-ray for the tumor to be analyzed, he met two little boys about 7.

“Hi, do you have cancer?” he asked, looking at their bald heads and sad faces. They nodded, yes. “I do, too,” he said. Then, as I watched, he told them the story of The Jester & Pharley, how they were banished from the kingdom when they failed to make the king laugh and went on a quest to find laughter. He told the two boys how The Jester & Pharley found laughter in the most unlikely place: in the heart of a little girl in the hospital, just like the one they were in.

The two boys listened intently to David’s every word. He took out the pad and pencil he always carried and drew a little Jester & Pharley for each to keep. “Remember that laughter’s always inside you,” he told them as they parted. They returned big smiles.

That’s when I knew that every child in the country with cancer needed a copy of David’s book. David created his story for all children, but it has special resonance for those coping with cancer. Just hearing David tell them about The Jester & Pharley brought these two little boys laughter when they needed it most. Our family promised David that we would do our best to give The Jester to all children coping with cancer.

Five years after David died, we mortgaged our home to publish *The Jester Has Lost His Jingle* ourselves. When the first copies came off the press, 10,000 were sent to hospitals for every child in the country diagnosed with cancer. Our goal as The Jester celebrates its 20th anniversary in print is to give a copy to each of the 15,700 children who will be told they have cancer in the next 12 months.

We formed the nonprofit Jester & Pharley Phund (www.thejester.org) in 2000 to extend The Jester’s reach. The Jester & Pharley Phund has developed school read-a-thons through which children across the country can join us in our mission to donate *The Jester Has Lost His Jingle* book and doll to children with cancer. To date, more than 100,000 children have read over 40 million pages to give The Jester book

and doll to ill children in their community. And our new bilingual English/Spanish edition makes it accessible to Spanish-speaking families.

David may have never seen his book between two covers, but now his witty, colorful story about self-empowerment and the laughter within us continues to find its way into the lives of children with cancer nationwide, including into care packages delivered by the Cool Kids Campaign.

Together, we are bringing The Jester’s joy to children with cancer nationwide.

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The Jester Has Lost His Jingle can be purchased on Amazon.



ONCOGRANDMA

By: Judy Horowitz Richter, Baltimore, MD
Grandmom to Ellie, almost 6 years old, Mullica Hill, New Jersey

To be a grandmother: the awe, the gratitude, the passion, the sense of connection permeates your every cell, reawakening the most visceral memories of motherhood suffused with the wonder of how fast it all went.

To be a grandmother of a child with cancer is an experience of a different caliber. My almost 6-year old granddaughter, Ellie, was diagnosed with leukemia on December 29, 2014.

After nearly 8 months of chemotherapy at one of the leading children's medical centers in the US, she is entering the 2-year "maintenance" phase which, with daily oral meds but more widely spaced chemo infusions via her port and spinal taps, promises, a more normal life for her and her family and even more importantly, a cure.

What I am sharing, in this essay, are some indelible—perhaps particularly individual-- impressions of my experience thus far and also some practical wisdom that I hope has broad application and therefore could be helpful for grandparents who enter the disorienting, tragic, and anxiety-filled world of children's cancer when their beloved grandchild is diagnosed.

When we received Ellie's diagnosis, I was already at her house, with her sisters (9 and 4) having scheduled my visit well in advance because of the winter holidays and her parents' work schedules. I first learned that Ellie would be undergoing an ultrasound and blood tests, shortly before I drove the 1 ½ hours to their house on Sunday afternoon. Notwithstanding the matter-of-fact tone of the call, I drove north on the highway, aware of a heightened, adrenaline-fueled level of alertness. I kept repeating the mantra, "treatable and curable...treatable and curable...treatable and curable..." as if keeping time with the rhythmic clashing of an ancient locomotive rather than a soundless 2009 Toyota hybrid.

Ellie was immediately hospitalized after tests revealed that she had leukemia, specifically, pre-B cell acute lymphocytic leukemia (ALL) and at nearly 6 years old, the rest of her life abruptly began.

As our family entered the labyrinth of "CancerWorld," it was soon obvious that my turnpike mantra was indeed on target: Ellie's diagnosis of ALL was statistically both treatable and curable at this point in time in a first world country with excellent medical care. But she had cancer and was facing, at best, 2 ½ years of chemotherapy. Then again, after spending time in the oncology floor's children's playroom with other families and their little ones, how mindful we all were that Ellie's particular variant of leukemia made her one of the "lucky" ones.



IMPRESSIONS FROM THOSE EARLY WEEKS:

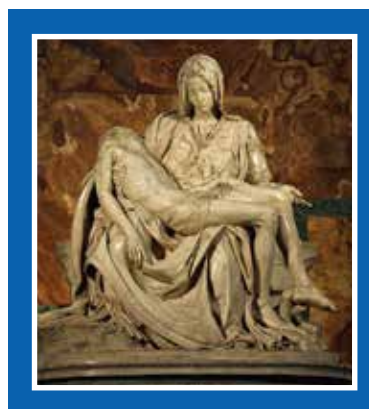
- Images of a very sick little girl alternatively sobbing and raging to be taken home as the initial “induction” phase of her treatment began. From several feet away, I viewed (with awe), the steady calmness of her parents during those early in-patient days (while once, going to the hospital chapel to cry in seclusion).
- Feeling such appreciation for the support of a “village” of the other grandparents, relatives, friends, neighbors with food, gifts, child care, car pool offers—ANYTHING that they could do to help!
- Eventually being permitted to bring the sisters to visit Ellie in the hospital; each one’s need to touch and snuggle with Ellie (carefully avoiding her n-g tube and attached IV pole) in the blessed McDonald’s Family Lounge to watch The Lion King.



- On-going awareness and gratitude for the sensitivity and kindness of the doctors, nurses, and other medical staff who were, beneath their smiling, joking faces, fierce warriors doing battle for Ellie’s life against this evil disease; the child life specialists who brought “Chemo Duck” to explain the workings of a “port” who set up a target where her elder sister and she could shoot nerf bullets at words like “cancer,” “shots,” “hospital food” (not that Ellie was eating anything), “strange people in my room poking me” (Ellie wanted to say “doctors and nurses” but the euphemism also worked...), and who explained eventual hair-loss, providing Ellie with a bald Chemotherapy Barbie.
- Ellie requesting that her adored big sister be present for the cutting of her waist-length strawberry blond locks to below-the-ear length in anticipation of the inevitable total loss of her hair.
- Realizing that this family was going to survive this crisis with strength and perspective when I overheard my daughter on the phone with her best friend—who lived hundreds of miles away—on her first night home to be with the other girls (while her husband stayed with Ellie). After describing the situation, she said to her friend, “But I can’t help thinking that somewhere there is a mother who just got news that her child was killed in an accident, who wishes she were facing what I am.”

Ellie left the hospital shortly before her 6th birthday, appearing remarkably unlike the little girl she had been prior to her diagnosis, her subsequent outpatient treatments and home routine thoroughly governed by the well-accepted medical protocols. Weak and achy, but also manic and irritable, perpetually hungry and unable to sleep at night from steroids, she demanded that her mother be by her side.

On her actual birthday, her parents tried to create a happy event at a well-loved local children’s museum with her siblings, cousins, grandparents, and aunts (one specifically in from CA), armed with hand sanitizer and hospital-strength wipes if she wanted to touch anything. For me, that day, her first in public following her discharge, was a benchmark in my acceptance/awareness of Ellie in CancerWorld: The child who skipped everywhere, bursting with life, whose waist-length red/gold curls and tiny eyeglasses never failed to turn heads, now lay, her body swollen from steroids, in a tipped-back stroller, with short and thinned hair, and medical face-mask. As I watched Ellie’s mother, my daughter, tenderly lift her from the stroller, draping her on her lap in one of the playrooms, an image of Michelangelo’s Pieta came to mind.



And so, as I was newly retired, and could not imagine anything more important—I spent the next 8 months commuting on a weekly basis between my daughter’s home and my own: 4 days there, 3 days home, typically. When I was with her, all that I wanted to do was to hold and touch Ellie. When she felt better, she loved to snuggle and I reveled in drinking in her Ellie-ness: the touching, the breathing in of her, the heft of her (which varied depending upon whether she was on steroids or at the other extreme, incapable of even keeping down water) and all the while imagining a dynamic chemical equilibrium between us with arrows both ways, the experience of Ellie-ness to me and strength, power, and health from me, draining into her.

When Ellie was well enough, she attended half-day kindergarten but could not go back to daycare. A specific schedule of in-home tutoring was established by the school—which ironically suited Ellie’s educational needs perfectly, since she was reading at a 4th grade level. It became possible for my daughter to return part time to her practice and my son-in-law was able arrange with colleagues in his practice to be available whenever necessary. (There was also significant involvement of the other grandparents.)

Depending upon her out-patient chemo schedule, Ellie would lie, with a “barf bucket” near, on the family room couch watching television. Other times, we would play checkers or other board games, and to her delight, she would honestly “cream” me; occasionally, we could go out to a department store and even have some pizza for lunch.

Without hair, Ellie attracted considerable attention, and never so much as when the child life staff at the out-patient clinic spray-painted rainbow

colors on her head, her mother and father covered her head with temporary tattoos, or when a henna artist created a magnificent (but unfortunately short-lived) cap on her head. But it is important to note that everyone who responded to her in public was unfailingly kind and loving and many tried to engage with her; some became emotional imagining the very worst possible outcome. I made it a habit to give a thumbs up gesture to those whose eyes met mine, once whispering “she’s going to be fine” to a nearly sobbing man behind us in a fast food line who had recently lost a nephew to cancer.

Although there were a number of set-backs, including several nighttime visits to the emergency room and a 5-day inpatient stay, thankfully, Ellie has been responsive to the therapeutic protocols. She and her family have made it through the initial 8 months of treatment leading to the “maintenance” phase which will continue for another 2 years. Her hair is growing back, she has begun 1st grade, and is taking gymnastics!

PRACTICAL WISDOM:

As a grandma, aware that her parents—my daughter and her husband--had received the most devastating of all possible news, and that their universe would henceforth operate under a new set of rules, my goal was to discern how my need to be deeply involved could provide the most value to them. My behavior was governed by the following articles of faith:

- This is not about me however desperately anxious I feel. Do not share your anxiety or fear with the parents. If they are so burned out or overwhelmed that they do not want to talk about “it,” set aside your desperate need to know what is happening. Action items: Attempt to totally focus on what they, not you, need to function optimally.
- Take care of yourself. Action items: In keeping with #1, turn to your friends, other family members, strangers at Starbucks (really), professional counseling. There are medications that you can take (or increase) to reduce anxiety, to help you sleep, and even, to help you get out of bed and function more effectively. A wise therapist once presented me with a very effective metaphor for appropriately prescribed, dosed, and utilized psychotropic medication: imagine putting a layer of silk to protect your skin from an impossibly itchy sweater that you must wear and cannot take off. The silk keeps you from feeling as if you want to tear your skin off, while you are still wearing the sweater. Although this may not be necessary for you, it is worth considering because it could enable you to be more helpful.
- Provide the normalcy of reasonable expectations but always with flexibility and leniency for the other children when you are the on-site grown-up. With both parents at the hospital all day during the first 2 weeks of the “induction” phase of Ellie’s treatment, and alternating coming home at night, sometimes quite late, the girls were both concerned and disoriented. Following her release, her obvious needs for parental attention typically trumped theirs. This was particularly hard on the little one, who was 4. A parental decision to increase her day care to a full week was a wise step, as she received additional attention and support from familiar staff and other parents.

With the help of the parents of fellow Girl Scouts and Hebrew School classmates, the 9 year old continued with her regular routine. And although my ostensible purpose was to be with Ellie, I was anchored at home, hopefully providing an extra measure of whatever was needed by anyone. Action items: Keep the home routines as unchanged as possible—with expectations of regressed behavior and anxiety. Provide silliness and laughter. It is also important to reassure the parents that their other children are being cared for by someone who is totally into (and enjoys) the job. Share anecdotes and details of the other children’s days that will remind them that they are raising wonderful kids who are and will be okay. Ask them to guide you in how they want you to deal with the children’s questions about their sick sibling. Try to navigate between taking over to make things work and both remembering and letting the parents know that it is still their home and their children. (This continues to be more difficult than I had expected, because I quickly adapted to the role of “responding” adult when situations occurred --having raised my own 3 girls for so many years—and so when my daughter or son-in-law are right there as “first responders,” I often hear, “I’ve got this, Mom.”)

- Visits to the hospital-- focus on whatever the parents need. Action items: Bring food for parents—delicious food from different restaurants. Be ready for reconnaissance missions to the hospital cafeteria, fancy coffee concession, food machines. With you there, your kids (the parents) can relax their vigilance a bit, knowing that their sick child continues to be enveloped in love and therefore, is “safe”—so they may be able to a break from being by the bedside or maybe take a shower. Be prepared to give up all dignity in efforts to amuse and distract your little one. For example, both of her grandfathers allowed themselves to be “made-up” by Ellie, as did I, with laughable and/or gruesome results.
- The mantra: “Just tell me what to do.” Action item: This is not martyrdom, it is intense caring. Be matter of fact and just get anything done that needs to be done, with conspicuous ease and a smile.

Living in CancerWorld has also introduced us to incredible people and service clubs. Ellie (and sometimes her sisters) received gift boxes of toys and books, hand-crafted dolls and stuffed animals, fleece blankets, exquisite cakes, offers of trips and adventures, and sleep-away camp. Any residual regional, ethnic, or otherwise categorizing smallness of heart that remained within me was purged when seeing Ellie returned from a day-long spinal tap/chemo session to find a wonderful and unsolicited mystery gift box waiting for her sent by strangers who we would never meet from distant places throughout the country.

So, the Beginning is over and we are in the Middle of Ellie’s cancer journey--albeit the more tolerable phase of “maintenance.” She and her family have become active in the pediatric cancer community, are attending social events and raising funds. Living through this has changed all of us and will continue to do so.

And the End? For me, the End is an image of Ellie, somewhere in her late ‘60’s, living a rich life of accomplishment, love, and connection, holding a precious grandchild in her lap, awash in the abundant sensations, full of joy, wonder, and gratitude at where life has taken her.

PUZZLES AND GAMES



HAPPY THANKSGIVING WORD SEARCH

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

Find these words:

THANKSGIVING	THANKFUL	STUFFING	PUMPKIN
HOLIDAY	FOOD	SALAD	PIE
FAMILY	TURKEY	BREAD	VEGETABLES
FRIENDS	POTATOES	YAM	HAM

HELP THE SQUIRREL GET TO HIS TREE



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



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

BRAIN

TEASERS

COLOR ME!



AUTUMN WORD SCRAMBLE

LAFI

KERA

NCAOR

VAHRETS

PKPIUMN

VLAEE

CSRARECOW

PPLAE

WEYLOL

GNORAE

ANSWERS: FALL, RAKE, ACORN, HARVEST, PUMPKIN, LEAVES, SCARECROW, APPLE, YELLOW, ORANGE

SUDOKU

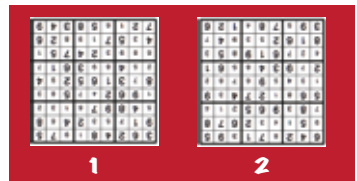
1

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

2

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

ANSWERS



MIND BENDERS

How much do YOU know about pumpkins?

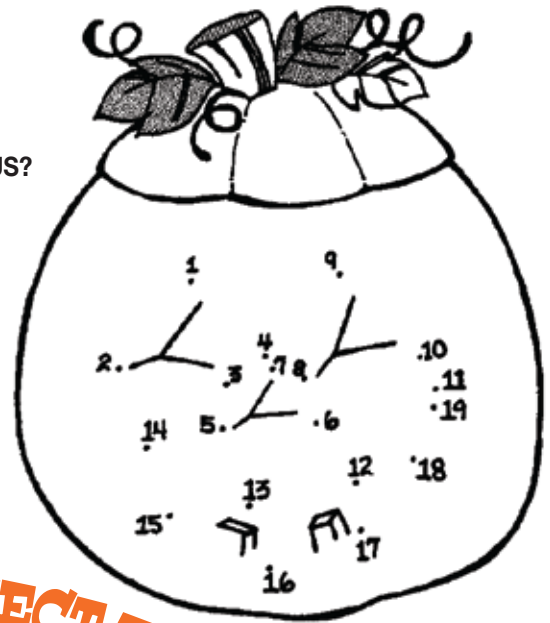
ANSWERS: 1. R. Wallace from RI grew a record holding 2,009 lbs pumpkin in 2012. 2. Top producing states are: IL, OH, PA, & CA. 3. 500 4. Fruit. Pumpkins are part of the Cucurbitaceae family, as are melons and cucumbers.

1. How much did the world's largest pumpkin weigh?

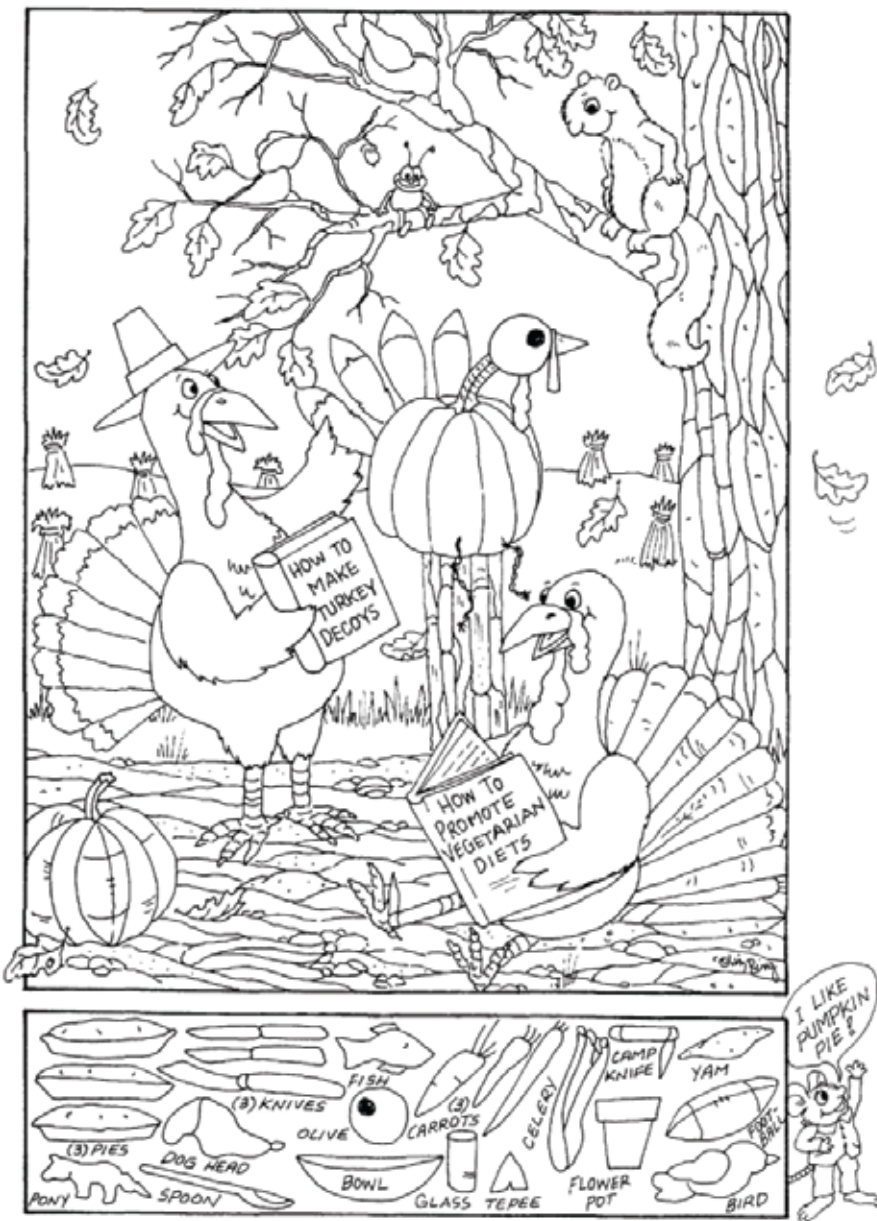
2. Which 4 states produce the most pumpkins in the US?

3. Approximately how many seeds are in a pumpkin?

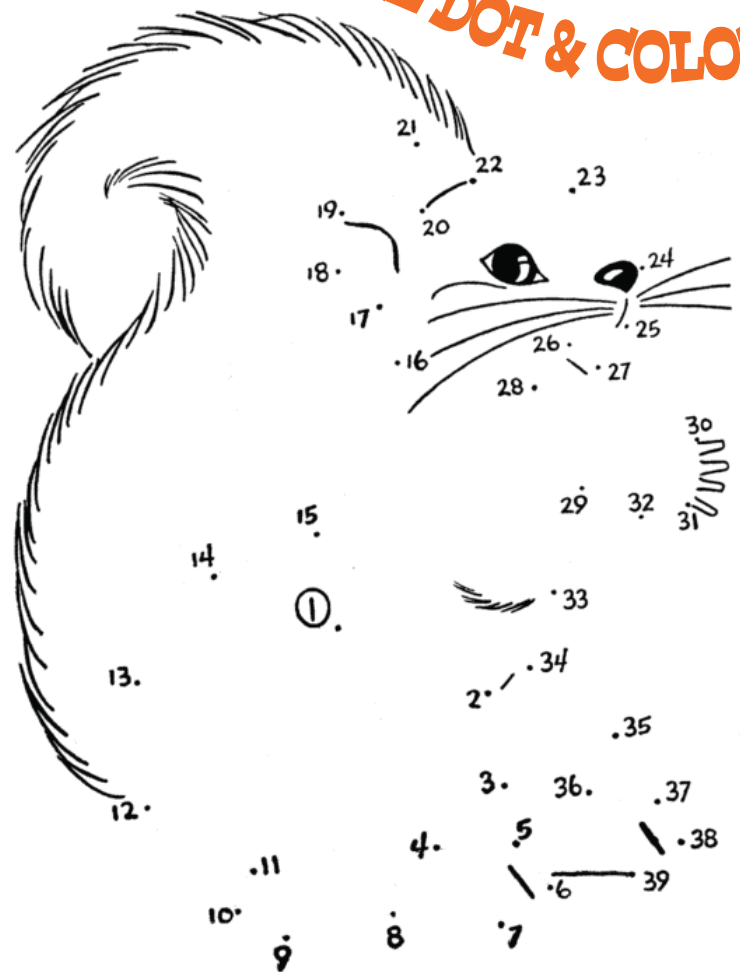
4. Are pumpkins a fruit or veggie?



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



CONNECT THE DOT & COLOR



JOKES RIDDLES



TWISTIN' THE TONGUE



Six slippery snails slid slowly seaward.



A tutor who tooted the flute
Tried to tutor two tooters to toot.
Said the two to the tutor:
"Is it harder to toot or
To tutor two tooters to toot?"

HaHa! LOL!
Bahahahahaha

What kind of music
do planets sing?

Neptune!

What kind of
bagel can fly?

A plain bagel!

Why can't you
tell a joke while
standing on ice?

It might crack up!

What goes
"tick tick woof woof"?

A watchdog!

KNOCK-KNOCK JOKES



**Knock, knock
Who's there?
Iva.
Iva who?
Iva sore hand from knocking!**

**Knock, knock
Who's there?
A little old lady.
A little old lady who?
I didn't know you could yodel!**

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

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

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SUPER HERO DAY
NOV 5 & 7

WITCHES & WIZARDS
OCTOBER 24

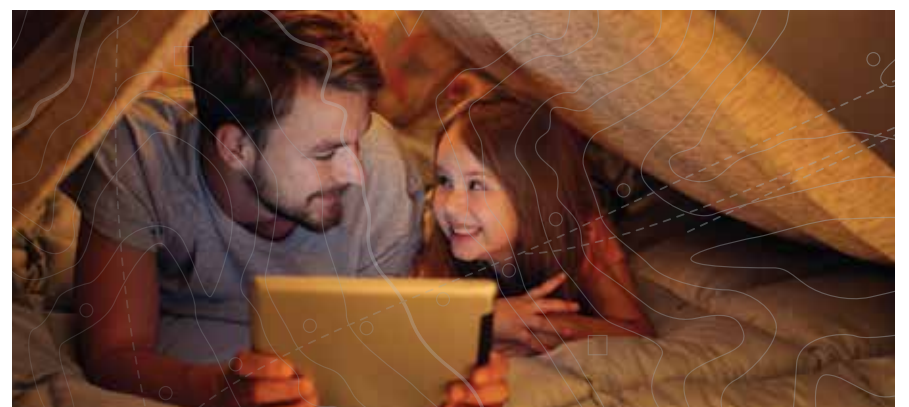
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Life of a Sibling with Retinoblastoma

By: Rebecca Furman, Towson, MD
sister of Megan, 12 year Retinoblastoma survivor

Tell me a little bit about your background and when your sister was diagnosed with cancer:

I was 7 years old, going on 8, when Megan was born. She was healthy and adorable, just like my other two little sisters. It was right around Christmas when my mom noticed Megan's eye was glowing strangely. She was 2 years old at the time and I was 12. My older brother was at the doctor's appointment where Megan was diagnosed with Retinoblastoma. It was a really scary time for my family and my parents tried to explain everything to us each in a way we would understand. They wanted to make sure we understood as much as we wanted.

What kind of relationship do you and Megan share together?

Megan is my baby sister and ONE of my favorites, because how can you really pick a favorite sister? We spend a lot of time together and have an incredible bond.

What are some things you and Megan do together in your sibling relationship?

We work out together and we recently took up running. We also spend time shopping, cooking, crafting, and running around with the dogs.

What are ways you help support Megan through her illness with cancer?

Megan has been in remission for a few years. When she was active in treatment, my siblings and I would rotate who was allowed to attend appointments with her and see what was going on with Megan's treatments. She would show us all the ins and outs of the hospital. My favorite memory was when she walked right into this little kitchenette area and just fixed herself a cup of coffee like she owned the place.

Megan knew where to go and who to talk to when she wanted to get something. She went to one appointment and they had a little baggie packed of fancy soaps and paper cups which were her favorite things at the time.

Can you talk about some ways you have helped advocate for Megan within the cancer community? (camps, organizations, events, etc.) Are you involved in helping others with cancer?

I have been a camper and a camp counselor at Camp SunSibs since Megan was diagnosed for about twelve years now. I attended support groups at various places with my other sisters. I am a member of a few Facebook groups for family members of people that have or had Retinoblastoma. I like to advocate for the siblings of individuals with cancer because they are impacted just as much, even if it is in a different way, from the cancer diagnosis.

Can you talk about an emotional time that has impacted you through Megan's journey with cancer? Have your emotions changed over the years through her journey?

When Megan was undergoing treatment, she was in a rather fragile state so my parents would take her to the emergency room for any bump or bruise. One time during my birthday party, Megan was running around with my cousins and fell and bumped her head against the sofa in the playroom. For any other child, it would mean just grab an ice pack and keep on playing but for Megan it meant my parents had to take her to the emergency room in the middle of my party. I was so upset and a little angry that they were leaving in the middle of the party before we had cake or opened presents. They were gone for what seemed like forever but was probably only a few hours. While they were gone, we had cake and ice cream. I tried really hard to wait to open my presents but my aunts and uncles were very pushy. I opened their presents slowly because I was trying to wait to open the special one from my mom. I ended up having to open it without her around. It was a handmade blanket that folded into a pillow. She worked really hard to finish the night before my party. It's been a really special blanket because it holds that memory of not having my parents or sister at my birthday.

Thinking back, I still am upset that they were not there but it is not because they missed my party; it's because I missed them while they were gone and it hurt that there was not anything I could do to help. I was always the helper personality and Megan being sick was the one thing I couldn't help with.

What are ways you practice self-care in supporting yourself as the sibling of Megan?

I share my story and try to help others in their journeys. I try to take time on a regular basis for myself and did so while she was in treatment. I took up some journaling and practiced artwork. I really got into photography when she was young and took pictures to do a photo journey of her growing up while in treatment. I've kept up the photography and still take pictures to express myself. I took up scrapbooking to showcase my pictures.

How has having a sibling with Cancer influenced you?

When Megan was sick, I learned about all kinds of ways I could help people. I learned about Child Life and knew that was what I wanted to do with my life. I want to help families like mine to get through tough times.

How old are you and Megan now and what are you both doing?

I am 24 and am a Medical Homes and Youth Healthcare Transition Assistant for Parents Place of Maryland. I work full-time, and I am in graduate school working towards becoming a Child Life Specialist. Megan is 16 going on 17 and is in high school. She goes to Camp Sunrise, which is a camp for kids who have or have had cancer, every summer.



Fall & Winter Family Retreats

Octoberfest Family Weekend Front Royal, Virginia

Octoberfest is coming and it's open to families of anyone who is under 17 years old (with preference given to those who have been treated for cancer in the past three years, and bereaved families). Come and spend Special Love's "most relaxing weekend of the year" as they celebrate the Fall Festival of Leaves in downtown Front Royal and enjoy some fun and games at the 4 -H Center. They will have their traditional camp favorites and some surprises, too. You can even ride in a parade!

Cost for the weekend is just \$25 per family (or check the scholarship box on the registration form) and covers all food, lodging, and extras. Registration forms can be found on the website. For more information about Special Love, call at 888-930-2707.

www.speciallove.org

Family Camp Burton, Texas

Family Camp was designed to meet the needs of the entire family unit as they collectively cope with the emotional roller coaster of a pediatric cancer diagnosis.

The camp creates an environment in which participants gain tools to make them stronger survivors and stronger families. It also gives parents and guardians the opportunity to witness and participate with their child or children in activities they may have thought were impossible after a cancer diagnosis. Family Camp programming allows and encourages families to spend healing time together creating treasured family memories and allows them to get to know other families who are experiencing or have experienced similar issues. It helps them find normalcy while facing the myriad of emotions that accompany a pediatric cancer diagnosis and the ensuing treatment.

For more information please contact Larry Geiger at 713-807-0191 or lgeiger@periwinklefoundation.org

www.periwinklefoundation.org

The Hole in the Wall Gang Ashford, Connecticut

Running in the fall and spring at their facility in Ashford, weekend programs continue the healing power of Camp beyond the summer months and create a memorable experience for the entire family. Families share in Camp activities and enjoy the company of other families who understand the issues they are facing.

Reach out to Camp at (860) 429.3444 or administrative office at (203) 772.0522.

www.holeinthewallgang.org

Trent's Retreat TEXAS

The Retreat itself is located along the banks of Elm Creek, one mile north of Ballinger on Farm to Market 2887. The recently completed, fully furnished, 1,200 square foot cabin can sleep eight people. It features two bedrooms with 32" televisions and DVD players, full bath with handicap accessible shower, living room with sleeper sofa, fully appointed kitchen with pots and pans, dishes, toaster, and coffee maker. The vaulted ceiling living room features a 42" television and DVD player as well as many board games, books, and DVD's. A barbeque grill is conveniently located outside.

They have included many family fun activities at the Retreat. Located along the banks of Elm Creek, fishing gear, a paddleboat, and life jackets are provided. Also on the property is a nine-hole miniature golf course, large playscape, play fort, and outdoor movie screen. Bicycles are available for the 1/2 mile nature trail or just sit on the large front porch and enjoy a beautiful sunrise as you look for nearby deer and turkey. Trent's Retreat is a place of fun for children, a place of relaxation for parents, and a place for families to be together and make special memories.

Trent's Retreat is available at no charge to pediatric cancer patients and their immediate families as well as anyone diagnosed with desmoplastic small round cell tumor (DSRCT), a very rare form of cancer that Trent battled. For information about booking a stay at Trent's Retreat, please email: misty@trentsretreat.org or call (325) 365-2103 or (325) 718-9340.

www.trentsretreat.org

Winter Family Retreat at Cathedral Pines Idaho

Enjoy cross-country skiing, snowman-building contests, snowshoeing, sledding, and creating art during a relaxing afternoon or maybe just soaking up the serene winter landscape through a frosty window of a warm cabin. The choice is yours as you join other families like yours who have been affected by cancer.

www.camprainbowgold.org

Family Camp Williams Bay, Wisconsin

Families who have a child 19 years or younger that has been diagnosed with cancer are invited to Family Camp. Family Camp in Williams Bay, Wisconsin is a fun, getaway weekend for families who have a child diagnosed with cancer. This program gives families the opportunity to bond with both each other, and with other families who have a child diagnosed with a cancer. This program is held in a safe and comfortable setting, where many participants look forward to returning as summer campers. Families stay in cabins at Conference Point Center, where games, activities, and friendships bring a much-needed respite from the medical world.

Should you have any questions please contact the Program Directors: Darryl Perkins at dperkins@onestepcamp.org or Mary Ann at mlebel@comcast.net

www.onestepcamp.org





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