



CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

SUMMER 2014  
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[coolkidscampaign.org](http://coolkidscampaign.org)

# NEVER GIVE UP AND FOLLOW YOUR DREAMS!



Poem by Riley Shae O'Keefe,  
16 Years Old,  
North Palm Beach, Florida  
*Diagnosed at 12 years old with  
Primary Neuroectodermal Tumor*

*Life is good, life is bad, life is fun, life is sad.  
Never give up, never stop, never return,  
'til you reach the top.  
Dreams are important to one and to all  
so you should try to stand tall.  
Always pursue the thing you want most,  
so quit standing there like you've seen a ghost.  
Quickly now because time could run out,  
to see what your dream is all about.  
It could be for good or for bad,  
to break free or to see what they had.  
For it will be the best part, of how you do the art.  
You could wish on the stars above,  
but they don't know how to teach you to love.  
For your dream is yours,  
you can keep it or share it with the world.  
I know you think it's not good enough,  
or too far to reach or too tough.  
But every dream is unique in its own little way,  
because it's yours and it's here to stay.  
So don't stop believing and never give up,  
because your dream is precious and full of love.  
So go chase it, catch it and when you're done,  
you will be happy that you had fun.  
Because you did it and now it's time,  
to come up with a new dream, you'll feel so divine.  
To learn, to laugh, to love, to cry,  
to show them all at the scene of the crime.  
That you can do it if you set your mind to it.  
**So never, never give up!***



is published by



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*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.*



# 100 Days of Love

by: **Karen Shollenberger**  
West Friendship, MD

In the fall, about a month before my bone marrow transplant, I was in the hospital for chemo. I asked one of my nurses about the rules for decorating my room while I was in for my month-long stay and eventually our conversation moved to suggestions for getting through the whole process since I was really nervous. Her biggest suggestions, based on watching countless patients before me: getting up and walking laps as much as possible and having something to look forward to each day. She said some people make paper chains and rip a piece off each day to count down the days, but I knew ripping a piece of paper was not going to keep me motivated. That night, I had trouble falling asleep because I had no idea what I was going to look forward to in the hospital.

When I found out that I had leukemia for the second time, I started a blog to keep my family and friends updated on my progress. Each update I posted was getting hundreds of views and eventually I had an idea: I would post a form on my blog, and my faithful readers could submit a message. I'd make a paper chain out of all the messages and read one each day to count down my 100 days away from home. After a bone marrow transplant, patients have to stay within 20 minutes of the hospital for a while because of the possibility of graft vs host disease, where the new marrow attacks the patient. For me, that was an apartment in Baltimore.

After I cleared the chemo and went home from the hospital, I was still trying to decide if a message chain was a good idea. I hung out with two of my friends so I asked for their opinion. I explained that I was worried I'd peek at the messages while I was putting it together, and they immediately offered to construct it for me! When I set up the form, I found a way



to email the responses to my friends instead of to me. A few weeks later, one of my friends dropped off the chain – it was amazing!

While I was inpatient and in the apartment I read a chain link each day. They had everything you can imagine: inspirational quotes, notes, jokes, funny memories, fun facts, recipes, book/movie recommendations and more. As my nurse had said, it really helped having something to look forward to, especially on the days I really didn't feel good.

Between my transplant and the end of my 100 days, I had three friends who were also getting transplants. I decided to make them countdown chains because I was enjoying mine so much. I contacted their families to see if they'd help me spread the word to get enough messages. I gave them the link to the Google Form I created and messages started flowing in. Some were anonymous because I left the name optional but everyone had something great to say. I delivered each chain to my friends in time for their day 0 (transplant day). They brightened their hospital rooms and hopefully gave them at least one smile every day.



# Want to make a chain for someone in your life?

**M**essages for my chain were gathered through my blog, but I used Google Forms to gather messages for all the chains I made. If you have a google/gmail account, it's easy! If not, there are plenty of other free form makers (or a google account is free). I've included simple directions here but for more detailed instructions and step-by-step pictures, visit the resources page of my blog:

<http://theworstbestthing.weebly.com/resources>

**1.** Go to drive.google.com. If you've never used your google drive before, it's a great resource so you can work on projects from multiple devices and even with other people, all at the same time. Anyway, near the top left, click the red "CREATE" button then click on "Form."

**2.** Name your form and choose a theme. For this example, I chose one with balloons because a bone marrow transplant is often referred to as a "new birthday." Hit "OK."

**3.** Under the form title is a space for a form description. This is where I include a description of the chain project and give people some ideas for submissions – notes, jokes, memories, etc. I've tried to keep the chains a surprise for all of my friends, so I mentioned that in the description as well.

**4.** My first question is always "Name" but I leave that optional. Some of the most inspirational quotes I received were anonymous.

**5.** Click where it says Multiple Choice (next to question type). It'll give you a bunch of form options. Choose "Text." If you want the name to be required, you can check the box below that says "Required question."

**6.** Now you need to add space for the message! Click the little arrow next to the "Add Item" box and choose "Paragraph Text." This will allow people to submit messages however long they desire. Make sure this question is marked as required!

**7.** Click on the blue "Done" button. Make sure it says "Accepting responses" along the top toolbar. Next to that is a button that says "View live form." If you click on it, you'll see what your final form looks like and you'll be able to share the URL.

**8.** From the form construction page (not the live one), you can click on "View Responses." This will take you to a spreadsheet with all of the responses.

**9.** Share the form! Consider the patients' friends from school and camp, family, neighbors, etc. When you have enough responses, click on the "Accepting responses" button and it will change to not accepting responses. If you don't get enough responses, it's pretty easy to come up with a few more jokes or quotes to include.

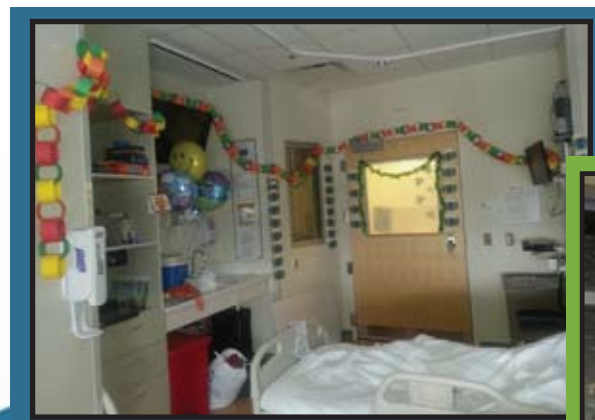
There are a few ways to put together the chains. For the first way, select the name and message columns in the excel sheet and paste them in a Word document. Print them out and cut the messages apart, then staple them on to ~2inch strips cut lengthwise on a piece of construction paper. For longer messages, you can fold up the paper.

For the second way, buy colored cardstock in the colors you want your chain links to be. Paste everything into Word just like you

would for the other method. Select only the right column and click on layout under table tools. This allows you to set the dimensions of the box. I usually made them 1.9 inches high and 7 inches wide and make the orientation of the page landscape. I cut long messages out of the document and pasted them in a separate word document to print on normal printer paper so they were easy to fold up (cardstock is too stiff to fold for really long messages).

Since I was counting down for bone marrow transplants, my chains were usually 107 days: 100 days post-transplant plus prep week. I numbered each link starting with -7 before stapling them together in order. The chain my friends made for me wasn't numbered but I thought it was a convenient way for people to keep track of what day they're on. I had extra submissions for some of my friends so I added extra links on to the end of their chain in case they had a milestone day or a tough day and needed some extra encouragement.

These chains brighten up patients' hospital rooms or bedrooms and are a daily reminder of how many people are cheering them on.





# 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.

**P/RMA**

New Medicines. New Hope.

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

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







# Stay Strong Riley

written by her mom, Teresa O'Keefe  
North Palm Beach, Florida



We all have adversities in life and Riley O'Keefe sure has had her share since she was 15 months old, but with her amazing attitude she has taken on the ultimate challenge of her life – cancer – and she will WIN!

On December 5, 2012, Riley, age 13 at the time, with a previous history of a nephrectomy (kidney removal) and scoliosis surgery, had been feeling very tired, not eating well and had been under doctors care for six months for an irregular period. We knew something more serious than “the teenager complaints” was going on when she didn't feel like going to dance class. Riley had been dancing for 11 years and never missed a class but on this day, her abdominal pain was severe enough to keep her home.

I decided to take her to our local urgent care center and within the next 24 hours we heard the worst word a parent can hear: CANCER. No one expected this outcome!! No one ever mentioned this as a possibility in the past six months of doctor visits. No one could prepare us for what would be a very long, intensive and challenging test in our lives.

After the next 24 hours, we found ourselves helicoptered down to Miami Children's Hospital from our local St. Mary's Children's Hospital with some type of cancer cells that even St. Jude had never seen! We didn't think it could be true!!! If St. Jude didn't know what type of cancer it was then who would? Riley's biopsy slides were viewed by six different sites in seven days: St. Jude, MD Anderson, Sloan Kettering, St. Mary's, Miami Children's, and Harvard University.

After seven LONG days, the doctors collectively made a decision to follow Harvard's diagnosis of PNET (Primary Neuro-ectodermal tumor) instead of Ewings Sarcoma. She had a sarcoma tumor the size of a cantaloupe in her abdominal cavity which is rare to say the least. First, it is normally only found in women, not teenagers so who would treat my daughter – an adult oncologist or a pediatric oncologist? Secondly, these cells are usually found in bones or skulls/brain. How do you treat it when it is in such an unusual area? What protocol do we use? And more importantly, will it work?

We had no choice but to stay with the pediatric oncologists because of her age and the team at Miami Children's decided to use the protocol for the treatment of Ewings Sarcoma. Our journey began on December 15, 2012. Riley had four initial rounds of chemotherapy that shrank the tumor to an operable size, an intensive 12 hour surgery at Sloan Kettering with Dr. Michael Laquaglia, and eight more rounds of chemo.

As of December 16, 2013 (one year and one day to the date of beginning chemotherapy), Riley had no evidence of disease and she has been cancer-free for a little over six months now. She has shown such strength and courage and has been a shining light to everyone around her. We are so proud of Riley. Our family encourages everyone to stay positive even during the hardest times and use that energy to promote wellness to our biggest gift: our body.



LEFT: Riley and brother, Carson  
CENTER: The Riley Family  
RIGHT: Riley's artwork





# “Cancer Can’t Win: Past to Present”

By Colin Charles Wyckoff  
Point Pleasant, New Jersey



I was 17, in the closing days of my senior year at Point Pleasant High School, when it happened. Whether I was ready or not, it came. It started as a slight stomach pain. I thought it would go away after a while but it did not; it only got worse and worse.

I started eating less and less because of it. I put my head down one day in class and my teacher sent me to the nurse. She took my temperature and - you guessed it - a high fever. It was so high that I could barely function properly. My mom picked me up from school and we drove over to a local satellite emergency room.

They ran some tests, nothing special, and they said I was good to go back home, and that they would contact us if anything showed up. We weren't home for five minutes before they called us and said to return as soon as possible.

We returned to the hospital and I felt the pain getting worse by the minute. It was tolerable up until they told me I had T-Cell Acute Lymphoblastic Leukemia, which was a rare case. It was May 9th of 2012.

The world must have stopped to give me time to let the news sink in. I thought it was all going to end right there, on that bed they had me on, but I thought about all the things I would lose if I were to give up, what life goals I would never complete.

They told me my white blood cell count (the immune system in your body) was the highest they've ever seen but by some miracle I managed to survive. From what I remember, it was over 800,000! I was transferred to Robert Wood Johnson where I underwent chemotherapy for about 15 days before I was finally released from the hospital. My doctor had a whole road map planned out for me, changing things here and there based on my reactions to certain medications. It wasn't too bad but it wasn't too good either.

It felt like a rollercoaster - one day I'd feel great, the next not so great. The routine was tolerable, up until I relapsed on June 11th of 2013.

Fate had some sort of sick sense of humor. I had been in the hospital for two birthdays in a row, the second time feeling worse than the first. Apparently the Leukemia came back in my spinal fluid, specifically around my brain, so I had very painful headaches.

My doctor informed me about a procedure called a bone marrow transplant, which would be the next big step in my treatment. The transplant would officially be the end of Leukemia, if all went well, which is why I needed the perfect donor to make it through this alive.

During the time of the donor search, my family and I started putting up flyers to support various fundraisers around town. So many people donated. Even my school had a hat fundraiser, which raised enough money to buy me an iPad!

Eventually the doctors told me they found a perfectly matched donor. I do not know his or her name, but I will be able to contact them a year after my bone marrow transplant, which occurred on November 15th of 2013.

It was very hard going through everything after transplant, even worse than when I relapsed. I was transferred to the Children's Hospital of Philadelphia (CHOP) for the transplant, and I stayed there for about 7 weeks. It felt like my whole life had to restart: learn how to eat, to walk, balance, you name it. Losing my hair wasn't fun either.

I had constant CT scans, cranial/full body radiation and I even had my appendix removed, which could have been fatal! It felt like too much, but I soldiered through it all and I am still here to tell the tale. I was discharged a couple days before Christmas; I called it my own little Christmas Miracle.

Now I'm 19 as I write this in June of 2014. I have been feeling much better day by day, getting back into my hobbies, going for checkups/treatments at CHOP, seeing friends and family, going to physical therapy, and of course, drawing, movies, gaming, making YouTube videos again.

It seems that I have a guardian watching over me, supporting me in ways I can't even explain. In addition, my girlfriend, whom I met at vocational school years ago and remained best friends with for a couple years beforehand, has been giving me so much love and support, and I am glad to have her in my life, as well as all my friends and family.

When I was a kid, I did not expect cancer to invade my life in the future. It was during my treatment that I developed a life goal for myself. I love to draw and I love visual media in many different forms. I want to be a professional animator when I grow up, and I want to see characters that I create on television. I create to inspire.

Whether my cartoon is successful or not, I want to influence. I want another kid or teenager or adult to see my works of art and be inspired to become artists in the future, even on different mediums. I want my dream to come true.

Getting diagnosed with cancer, I learned, was the best and worst thing to ever happen to me. It opened my eyes to a whole different world. I also learned life is so fragile, as it can be easily taken away. I started to appreciate life more, noticing the little things that make life worth living, and I have been more positive about everything as the years go by. I promised myself the day my life ends, I'll be sure to go with a smile.



# PUZZLES AND GAMES

## DOG WORD SEARCH

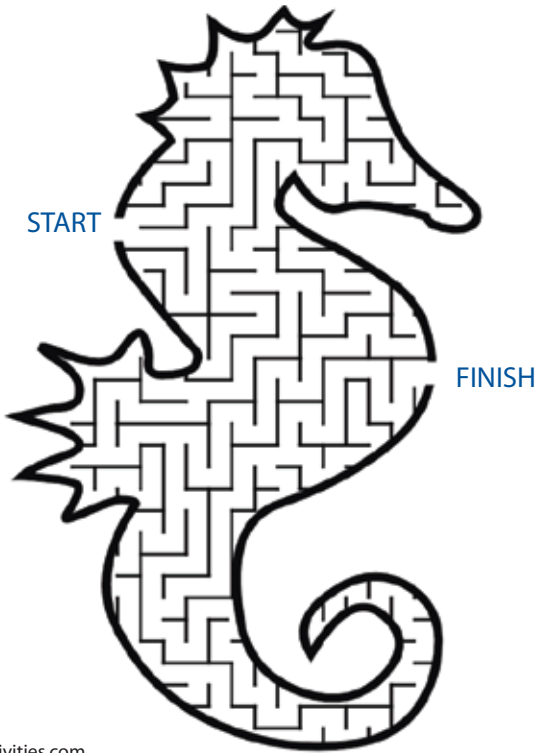
E V E N T H O U G H D O G S V  
 B A Y P P U P R Y G R E A T L  
 R Y R I N G A P P S E A R A N  
 E T R A I N I N G K C E G T H  
 E E U Y A I R E I L D R E N L  
 D T F I C G A W L A O I N O E  
 S P A D O G S H O W S N Y A A  
 T E O M Y A T I L H E A L Y S  
 E T N A C W R M H H L A D V H  
 E T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



Find these words:

- |           |       |         |          |
|-----------|-------|---------|----------|
| BARK      | FURRY | PET     | TRAINING |
| BONES     | GROWL | PLAYFUL | WAGGING  |
| BREEDS    | LEASH | PUPPY   | WALKS    |
| DOG SHOWS | LOYAL | SLOBBER | WET NOSE |
| FRIENDLY  | PAWS  | TAIL    | WHIMPER  |

Try to find your way through this seahorse shaped maze from start to finish.



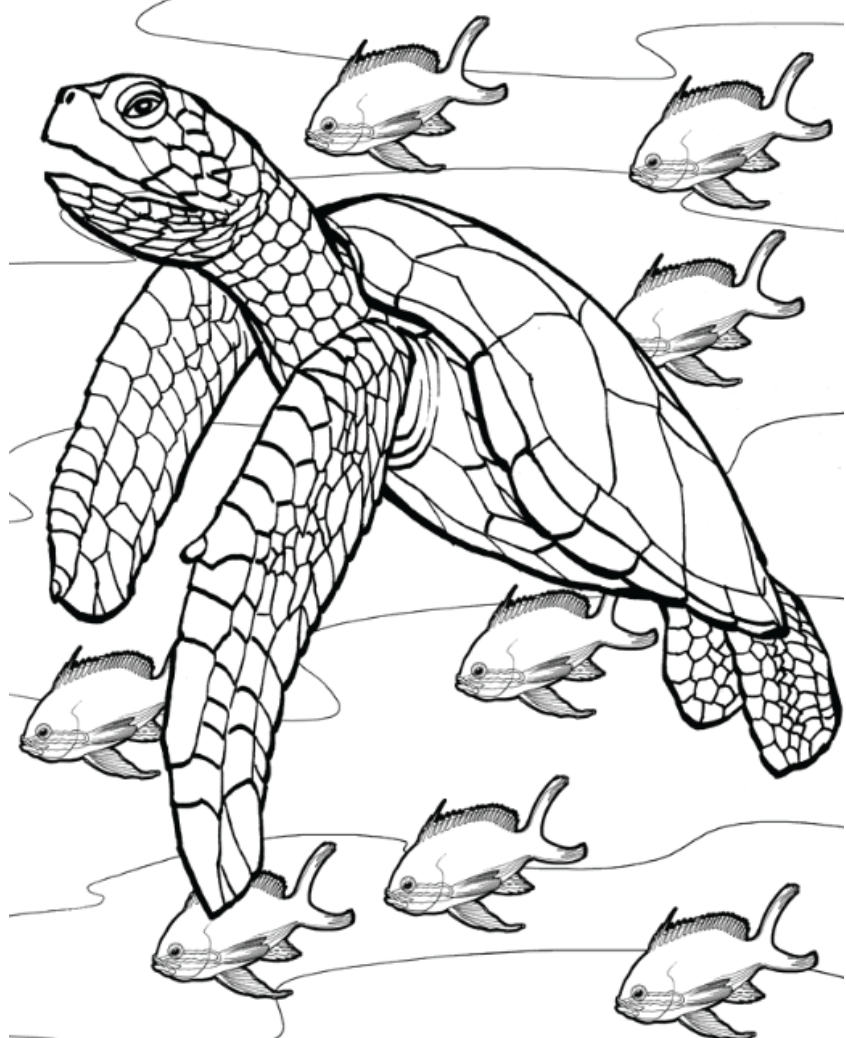
The school band needs to load their instruments onto the bus. Draw the path to the school bus starting at 5 and counting by 5s up to 500.

315	320	355	360	365	490	495			
310	325	350	345	370	485	500			
305	330	335	340	375	480				
300	295	390	385	380	475	470	465	460	455
285	290	395	400	405	410	415	430	435	450
280	275	270	265	200	195	420	425	440	445
245	250	255	260	205	190	185	180	175	170
240	225	220	215	210	95	100	105	160	165
235	230		30	35	90	85	110	155	150
			25	40	45	80	115	120	145
			20	15	50	75	70	125	140
			5	10	55	60	65	130	135

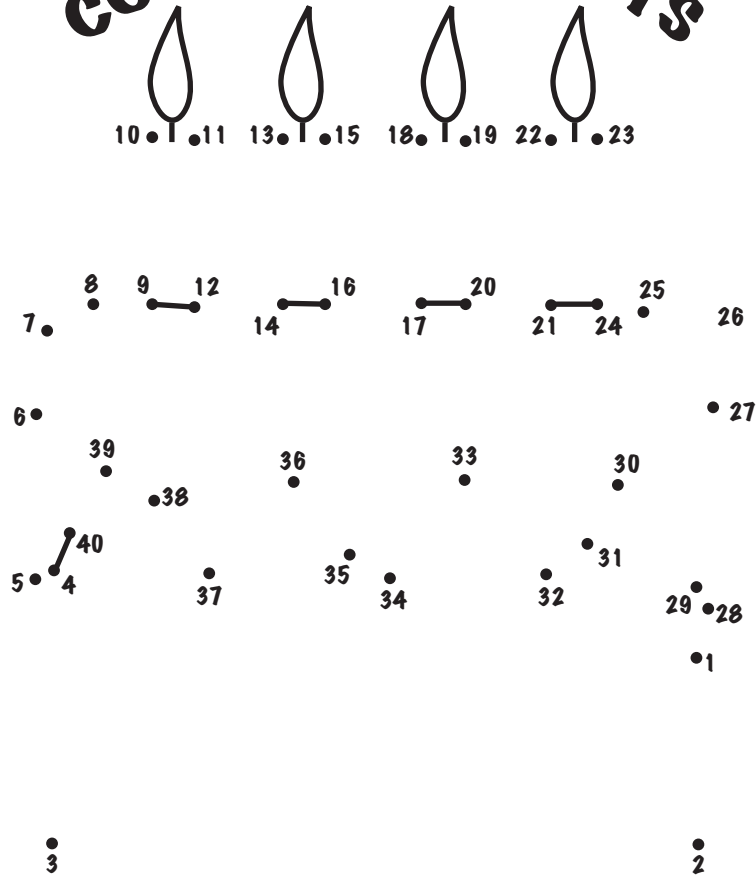
www.printactivities.com

# BRAIN TEASERS

COLOR ME



CONNECT THE DOTS



See how many words can you make out of: **BACK TO SCHOOL**






# MIND BENDERS

Unscramble these  
FRUIT & VEGGIE  
words

ANSWERS: 1. PEAR 2. PEAS 3. CORN 4. ONION 5. GRAPE  
6. CARROT 7. ORANGE 8. BROCCOLI 9. STRAWBERRY 10. GRAPEFRUIT

1. RPAE \_\_\_\_\_
2. EAP \_\_\_\_\_
3. RNCO \_\_\_\_\_
4. NOONI \_\_\_\_\_
5. PGAER \_\_\_\_\_

6. RORACT \_\_\_\_\_
7. GOARNE \_\_\_\_\_
8. CCBOROLI \_\_\_\_\_
9. RSYTRAEWBR \_\_\_\_\_
10. FGUTRPEAIR \_\_\_\_\_

FIND THE ITEMS IN THE LARGE PICTURE THAT ARE LISTED IN THE BOTTOM BOX.  
WHY NOT COLOR THE PICTURE AFTER YOU HAVE FOUND ALL THE ITEMS?



## SUDOKU

Fill in the blank squares so that each row, each column and each 3-by-3 block contain all of the digits 1 thru 9.

#1

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

#2

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

ANSWERS:

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

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

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# JOKES

# RIDDLES



## TWISTIN' THE TONGUE



You've no need to light a night-light  
On a light night like tonight, For a  
night-light's light's a slight light,  
And tonight's a night that's light.  
When a night's light, like tonight's  
light, It is really not quite right To  
light night-lights with their slight  
lights On a light night like tonight.

**LOL!**  
**HaHa!**  
Bahahaha

How do you  
organize a space  
party?

You planet early!!

How do you  
serve a smart  
hamburger?

On an honor roll!

Where are cars  
most likely to  
get flat tires?

At forks in the road!

Why was the boy  
sitting on his watch?

Because he wanted to be on time.

## KNOCK-KNOCK JOKES



**Knock, knock  
Who's there?**

**Iva.**

**Iva who?**

**Iva a sore hand from knocking!**

**Knock, knock  
Who's there?**

**Little Old Lady.**

**Little Old Lady who?**

**Wow! I didn't know you  
could yodel!**

**Knock, knock  
Who's there?**

**Roach.**

**Roach who?**

**Roach u a letter, did you get it?**



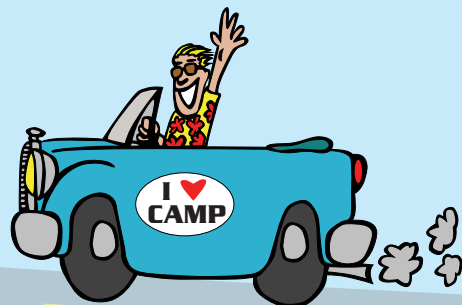
# CANCER CAMPS ACROSS THE COUNTRY

written by Karen Shollenberger, West Friendship, MD  
(Karen is currently undergoing her third treatment for leukemia)

**E**very child with cancer wants as much normalcy as possible and what is more normal than summer camp? There are dozens of pediatric oncology camps around the country that provide a normal week of summer fun with doctors on site, allowing current patients and survivors to spend time together. Some programs also include siblings, or have separate camps for the siblings and the patients.

**I**'ve been to almost ten weeks of oncology camps and they were some of the most memorable weeks of my life which is why I've returned as a counselor. Camp showed me that I'm not alone in my fight with cancer and that I have nothing to be ashamed of. During my first treatment in 2004, I tried to separate my cancer from the rest of my life and pretend it didn't exist. When I relapsed nine years later, my camp family was there for me through the entire treatment, sending me encouragement and visiting me whenever possible. I am a much happier and positive person because of everyone I met at camp and I can't imagine my life without cancer and all the amazing people I met because of my illness.

**A**ll of the camps highlighted on the following pages are free for families and accept patients from multiple hospitals. Some of them have camps or other programs in late summer or fall so there may still be time to apply. There are many more pediatric oncology camps around the country and even internationally. For locations and information, check out [cocai.org](http://cocai.org), the website for the Children's Oncology Camping Association International.



## CAMP QUALITY ILLINOIS ILLINOIS

*Interview with Mary Lockton, Executive Director. Mary has been on the board since 2004 acting as treasurer for 3 years and ED since October of 2007. Prior to joining the board, she was a companion.*

**What kind of programs do you offer for patients, siblings, and/or families?**

Patients are offered our week long camp during the summer and teen weekend in the winter. The patients and their families are invited to our reunion dinner in November, Family Day at the Chicago Wolves game and our overnight family event (for the patients not eligible to attend teen weekend) in the spring.

**What is your favorite part of camp?**

My favorite part is watching kids come out of their shells as the week goes on. Our tag line is "letting kids with cancer be kids again" and that's truly what happens.

**How many years have you had camp?**

This year will be our 20th camp in Illinois!

**What are the campers' favorite activities?**

Every year varies in activities, but they love motorcycles, Hummer and antique car rides, dances, and our almost always open ice cream tent!

**What is this year's theme?**

20 years of Camp Quality Superheroes

**What makes your camp unique?**

Our week of camp is all one on one. For every camper, we have a volunteer 'companion' paired up with them for the week. It's a great role model/friendship building experience.

**Favorite camp memory?**

There are so many things I remember from over the years. One of my favorites was watching a pinewood derby race in which campers had spent days working on making wooden derby cars in the craft room. A camper who was new that year, Sophia, was paired with a companion named Diana for the week. Sophia was a challenge. She was very shy and not at the same level as the other kids her age. Diana was her perfect match, by her side all week making sure Sophia was comfortable. When Sophia went up to race, they all cheered and cheered. Sophia's car kept making it from one race to the next. She won! The excitement in the room was unbelievable, but if you watched what was really happening, this group of kids just knew she needed encouragement and wanted so badly for her to win! Sophia's family has told us that camp has changed her life. While that is so very important to me and is reassuring to hear, I watched a room full of children teach a very valuable life lesson to others, including all of the adults in that room. Those kids, year after year, are my heroes.

Note: Camp Quality USA has camps in more than a dozen locations around the country, including Texas, Missouri, Ohio, New Jersey and more. To find one near you, visit [www.campqualityusa.org/camps](http://www.campqualityusa.org/camps)

**[WWW.CAMPQUALITYUSA.ORG/IL/](http://WWW.CAMPQUALITYUSA.ORG/IL/)**

## CAMP BOGGY CREEK FLORIDA

*Interview with Christina Champion, Marketing & Communications Specialist*

**What kind of programs do you offer for patients, siblings, and/or families?**

Camp Boggy Creek offers year-round programs to children ages 7-16 with chronic or life-threatening illnesses. There are camps in the summer in addition to extended family weekends from September through April.

**How many years have you had camp?**

Camp opened in 1996.

**What are the campers' favorite activities?**

They love them all!

**What makes your camp unique?**

The ability to serve children with serious illnesses. We have a medical facility staffed with doctors & nurses.

**Anything else you'd like to share?**

Camp Boggy Creek is free of charge to our campers and families. We rely solely on donations.

*Note: Camp Boggy Creek is part of the Serious Fun Children's Network, which has independently run camps around the world. For more information, visit [www.seriousfunnetwork.org](http://www.seriousfunnetwork.org)*

Quote: (from website) "At Camp Boggy Creek, for the first time in her life, she experienced what it is like not to be the one who is different. For the first time she was able to be a regular kid, a real part of the group—to feel like she really belonged."— Donna, Camper Mom

**WWW.BOGGYCREEK.ORG**

## CAMP SUNRISE MARYLAND

*Interview with Steve Mitchell, Director*

**What is your favorite part of camp?**

My favorite part of camp is watching the growth of the campers throughout the week. A lot of them step off the bus quite timid and hesitant and by the end of the week we can barely get them back on the bus to go home.

**What kinds of programs do you offer for patients, siblings, and/or families?**

We have a week-long camp for patients and a long weekend for siblings. In the winter, we have a reunion for everyone from both camps.

**What are the campers' favorite activities?**

To speak from a very simple point of view, I would have to say they most enjoy anything to do with the pool. Whether swimming or simply floating, pool time is a MUST. This comes as no surprise and would be a 'hit' with any kid, but for a child with cancer, the appreciation is compounded. Because of medical & treatment limitations, a visit to the pool isn't feasible at home. However, with doctors and nurses on hand to properly care for any surgical dressings or other specifics before and after swimming, the pool becomes a possibility for them again.

**What makes your camp unique?**

Camp Sunrise is unique because for the last 27 years, staffing has been 100% volunteer. We work with very generous and talented volunteers who work hard to ensure all our campers have a great week: securing donors, making plans, managing budgets, interviewing counselors and more. Camp is absolutely free for any of the campers who attend so without our volunteers, we'd be unable to keep it going.

**Favorite camp memory?**

Favorite camp memories span years and it's impossible to pick a favorite. In trying to pick a memory, the first things that come to mind are flashes of different groups of friends. I suppose I'd have to say my favorite memory is seeing kids with vastly different backgrounds forming the fastest and most solid friendships that last well into adulthood. It's a great thing to witness. How many years have you had camp? The first year of camp was 1987 and there were only 7 campers. This summer is our 28th year and we have more than 100 campers ready to attend! What is your position at camp? Director. What is this year's camp theme? Our SunSibs camp theme was Through the Ages and our Sunrise theme will be Under the Sea!

**Anything else you'd like to share about camp?**

Camp Sunrise is such a pleasure. While focus on research and cures is instrumental in saving the lives of cancer patients, Camp Sunrise focuses on giving a bit of quality back to the lives of children in treatment. It's such a great feeling to be part of a group that reminds a child, living with cancer, how to enjoy being a kid.

**WWW.HOPKINSMEDICINE.ORG/CAMPSUNRISE**





# CAMP INDEPENDENT FIREFLY NEVADA

*Interview with Melissa Cipriano, Executive Director for Candlelighters Childhood Cancer Foundation, overseeing camp operations along with the Hemophilia Foundation Executive Director.*

**What kind of programs do you offer for patients, siblings, and/or families?**  
Candlelighters Childhood Cancer Foundation offers several programs to families affected by childhood cancer. Some programs that we provide are financial assistance with rent or mortgage, utilities, co-pay reimbursements and bereavement support. Candlelighters also provides a travel program for those families that have to leave our state for treatment. Assistance with gas cards, lodging, food, and airfare is provided. Other major programs include counseling, art therapy, art education, holiday assistance, scholarships, social activities, and CAMP!

**What is your favorite part of camp?**  
The best part of camp is watching the children’s faces as they come off the bus and meet their counselors for the first time. The campers are full of excitement and hearing all the comments and giggles is music to my ears.

**How many years have you had camp?**  
This year will mark the 10th year for Candlelighters hosting a camp for children diagnosed with cancer and their siblings; however, it is our second year partnering with the Nevada Chapter of the National Hemophilia Foundation.

**What are the campers' favorite activities?**  
Zip lining, horseback riding, gaga pit, and lake front activities.

**What is this year's theme?**  
Super Heroes

**What makes your camp unique?**  
Our partnership with the Nevada Chapter of the National Hemophilia Foundation. We joined forces last year and combined our efforts to offer the best camp experience for these amazing children. We have one hematology/oncology group in Las Vegas and both of our populations see the same physicians. It just made sense for us to join efforts. Not only are we saving money by doing so, but we are also combining our camp leadership and volunteer base to create one awesome experience. We also made the difficult decision to travel out of state for our camp, but after last year’s camp, we knew it was the right decision for our camp program.

**Anything else you'd like to share?**  
Our camp program is offered to children diagnosed with cancer and their siblings, 7-17 years of age.

Quote: (from website) “It’s a time that kids can meet new friends, forget about their illness and create wonderful childhood memories.”

[WWW.HFNV.ORG/CAMP](http://WWW.HFNV.ORG/CAMP)

# CAMP OKIZU CALIFORNIA

*Interview with Katie Mahon, Program Director and Unit Leader for younger boys and girls units.*

**What kind of programs do you offer for patients, siblings, and/or families?**  
The mission of Okizu is to provide peer support, respite, mentoring, and recreational programs to meet the needs of all members of families affected by childhood cancer. During the summer, Okizu offers week-long residential camping programs for pediatric oncology patients and their siblings. In the spring and in the fall, we offer weekend-long Family Camps as well as programs for teens and young adults.

**What is your favorite part of camp?**  
My favorite part of camp is when I hear kids and parents say “me too.” You hear it when oncology patients see that other kids have scars that match their own, when siblings tell stories about having to go to their grandparents’ houses while their brother or sister was in treatment, and when parents talk about long nights in the hospital. Because peer support is such an important part of our mission, when I hear “me too” I know we are on the right track!

**How many years have you had camp?**  
2014 is the 33rd season of Camp Okizu! The first Camp Okizu program was held in 1982 and included 6 staff members and 28 campers.

**What are the campers' favorite activities?**  
We offer many traditional camp activities at Camp Okizu. Campers enjoy fishing, archery, arts and crafts, ice cream making, swimming, boating, climbing on the ropes course, etc. We recently had a water mat donated to our waterfront and it is a ton of fun!

**What is this year's theme?**  
The theme for SIBS and Oncology Camp is International Adventure! Special events will include our traditional Baseball Lunch, a Picnic in Paris, a Chinese New Year Dinner, an International Ball, and a Fiesta!

**What makes your camp unique?**  
Okizu is unique for a number of reasons. We are unique in that we serve all—members of the family in programs that are specifically for them. I also think it is unique that we continue to serve families regardless of the stage of the patient’s treatment. Families who are newly diagnosed, currently on treatment, post-treatment, and many years in remission are all welcome to attend our programs. We also welcome bereaved families to attend our programs and have two family camps and a teen and young adult program that are specifically for bereaved families. Finally, I believe we are unique because all of our programs are staffed by volunteers, over 600 each season, and more than half of our volunteers are previous campers!

[WWW.OKIZU.ORG](http://WWW.OKIZU.ORG)

# COOL KiD & COOL CAREGiVER

*Karen Duncan is a Clinical Social Worker at Mission Hospital in Asheville, North Carolina. She works in pediatric hematology and oncology which is where she met 10 year old Austen. Read more about both of them below!*

What's your name? Austen Gilreath

Where do you live? Asheville, North Carolina

What grade are you in? 6th grade

How old are you? 10 years old

If you wrote a book, what would it be about? Myself or dogs

What do you want to be when you grow up? An interventional cardiologist specializing in dogs.

What sports do you like? Soccer and softball

Do you have brothers or sisters? A twin brother, 10 years old

What do you like to do for fun? Read, hang out with friends, use electronics, watch TV, and look at pictures of dogs that I fantasize about having but can't have.

Favorite cereal? I like cornflakes, but I don't really eat cereal.

Favorite snack? Raspberries

Favorite animal? Dogs!

Favorite subject in school? Geography and math

Who's your BFF? Karleigh

Who is your favorite celebrity? Katy Perry

What activities do you like for exercise? I don't have an exact favorite. I like to run around to friends' houses, play wiffle bat baseball, and run on the treadmill.

If you were the President of the U.S., what would be your first law? Everyone in the hospital would have to have a furry legged friend with them, also known as a dog.

Favorite movie? Beauty and the Beast, Snow White, Despicable Me, and Despicable Me 2

Favorite TV show? Full House and Good Luck Charlie

Favorite video game? Mario Kart

If you were stranded on an island, what 3 things would you have with you? 1) A private jet that works, 2) a captain of that jet that can take me home, and 3) Karleigh holding a pug.

What are you most grateful for? My brother and my dad.

If you were a Seven Dwarf, which one would you be? Sleepy or Dopey. Probably Dopey because I bump into so many things I don't even know where they come from.

If you could meet someone famous, who would it be? What question would you ask? Deborah Sampson - Why would you sneak into the army as a boy?

What is your name? Karen Duncan

Where do you live? Asheville, North Carolina

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

What do you do? I help children and their families cope with their medical journey by providing compassion, offering counseling and education, and connecting them with resources.

Favorite part of your job? I meet the most amazing, inspirational people!

Least favorite part? Seeing anyone in pain.

What time does your day begin? I wake up early to walk my dogs and water my garden then arrive at work at 8:00 AM.

Favorite sport to watch or play? I love watching and playing basketball.

Do you have children? I don't have children, but I have 6 nieces and nephews and 1 great niece.

What do you enjoy doing for fun? I love gardening (flowers and food), swimming, and spending time with family and friends.

Favorite movie? Fantasia and Remember the Titans

Favorite TV show? Scooby Doo and Seinfeld

Like cats or dogs? I have two dogs – Ellis and Betty.

What's on your IPOD? Avett Brothers

Favorite book? Incidents in the Life of a Slave Girl by Harriet Jacobs

Favorite board game? Pretty Pretty Princess, Candyland, and Life

Favorite school subject as a kid? Math

Favorite dessert? Anything chocolate

Favorite season? Fall

Favorite cereal? Fruit Loops

Favorite fruit? Strawberries

What celebrity do you admire and why?

Paul David Hewson, also known as Bono of U2. He overcame adversity in his childhood, he uses his skills to promote social change, and he has been true to his values throughout time.

If you could have dinner with one person (alive or deceased) who and why? I would have dinner with my grandfather. We never met; he died before I was born. My mother has told me lots of stories about him. My family says I act like him. I'd like to see for myself.







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## Quote of the Day



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