



SUMMER 2013

CONNECTING PEDIATRIC ONCOLOGY PATIENTS THROUGHOUT THE NATION

Skype makes Cool Kids tutoring world a little smaller

One of Cool Kids Campaign's regular programs offered to kids with cancer is free tutoring here in our Cool Kids Learning Center in Towson, Md. This was designed two years ago in response to listening to families' concerns about the amount of school their children are missing during treatment and hospitalizations. Most families, already under financial strain because of the disease, are unable to hire a private tutor.

Now, thanks to Skype (a free online video and voice program between Skype users) our tutoring program is able to go national. In April, we launched our first Skype tutoring session between sixth-grader Nicolas Perez, 11, in Brooklyn, N.Y. and one of our volunteer certified math tutors, Peggy Hauf, a retired educator who teaches grades 5-8.

After a parent coordinator at Nicholas' school discovered the Cool Kids Learning Center on our Web site, it was asked if there was a similar program in New York. To our knowledge there is not, so we offered Nicolas one-on-one math tutoring sessions via Skype.

"We had been struggling to find Nicolas the additional support he needed," said Elisabeth Perez. "It seemed there was nothing available for him. I was at my wit's end. All I wanted was to have some normalcy in his school life and for him to be able to keep up with his class. Being introduced to Cool Kids Campaign has meant the world to us. It's going great! We love Peggy! She's wonderful, kind and patient."

Nicolas seems to be responding very well and looks forward to the sessions, said Hauf. "His mom says it is very helpful to him." Hauf began tutoring Nicolas once a week and Perez has since requested adding a second weekly session.

"It's as if Peggy is in the room with us!" said Perez. "We are so grateful for this program. It has touched our lives."

Hauf admits that teaching a student over the Internet is different than face to face. "I can't look over Nicolas' shoulder," she said. "He does the work, verbalizes what he's doing and then holds it up to show me." A white

board helps them both when Hauf needs to show Nicolas part of a lesson.

Although the Perez arrangement is Cool Kids Campaign's first off-site tutoring session, we hope to continue to offer online tutoring to other kids with cancer – local and nationally – to kids who may be sequestered at home so as to remain germ free or whose parents are unable to make the drive to our office.

"This is our first time trying this," said Sharon Perfetti, Executive Director of Cool Kids Campaign, "so we are experimenting. We asked Nicolas' mom for her feedback – and patience – as we figure out the best online tutoring situation."

Hauf thinks growing this program would be a fantastic benefit for children out there who need help – those who need this resource and don't find it convenient to visit the Learning Center, or those who are out-of-state. "To be able to access this help right from home is fantastic," she said.

In their next phase of off-site Skype tutoring, Cool Kids Campaign will accept five new students. If you are interested in free tutoring for your child via Skype, please contact Sharon Perfetti at sharon@coolkidscampaign.org or 410.560.1770. Before starting, you would need to register for a free Skype account on skype.com.



Nicolas Perez in Brooklyn, NY is tutored at home via Skype by a volunteer certified teacher in the Cool Kids Learning Center in Towson, Md.

IN THIS EDITION:

Princess for a lifetime **2**

Surfin' the net **5**

Living with leukemia in a 4-year-old **6**

Pull-out puzzle and games section for kids! **7**

Cancer survivor creates a flight of angels **11**

Moving forward by giving back **12**

Cool kid & cool caregiver **14**



is published by



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

Editor-In-Chief:

Sharon Perfetti
sharon@coolkidscampaign.org

Associate Editor:

Suzanne Molino Singleton
suzanne@coolkidscampaign.org

Design:

Linda Ports
LP Design, LLC
Baltimore, MD

Cool Kids Campaign Staff:

Robert Belanger
Chairman & co-founder

Chris Federico
President & co-founder

Sharon Perfetti
Executive Director &
co-founder

Kristian Sekse
Director of Development

Suzanne Molino Singleton
Marketing Coordinator

Kimmie Meissner
Board Member &
co-founder

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



2 coolkidscampaign.org

Princess for a lifetime ... because every child deserves to smile

By Tynesha Hendricks
Bronx, New York



Marisol Santiago ... the start of a beautiful thing. She was born on July 10, 2002 at nine pounds, one ounce and was a very good baby. Never cried. Later she always behaved in school. That may be why we never noticed that she was in pain. While attending preschool at age 4, Marisol slept longer at naptime than the other children. She didn't want to play or eat all of her food.

Frequent visits to the doctor told us she had a slight fever, normal for a child in school since they often get sick from other students. Take this ... and see you in two weeks. But it happened too often: the fevers, the colds, the napping.

One weekend while Marisol was visiting her dad, he noticed a bump no bigger than a mosquito bite on her right leg. It grew bigger and bigger to the size of a baseball. By the time we were scheduled for an ultrasound to question the bump, the fevers and the fatigue, it had changed from soft to rock-hard within a month. The next step was a biopsy. The ultrasound tech had no idea what was happening; he said we needed concrete results. Those came on Thanksgiving Day in November 2006. We were given the sour news that rocks your world - Your daughter has cancer. And she has to start the fight of her life to survive.

From that day on, we lived and breathed the hospital grounds and walls.

To leave became a mere visit outside to smell the roses and returning when treatments of chemo, radiation, and medicinal needles made her very sick. This continued for three long years. During that time, Marisol had different plans for us. Approaching age 5, she wanted to forget about what we were experiencing. (I say we, because as a mother, you never want to see your child suffer.)

Marisol helped to create the start of a great idea. Every costume, every makeup kit, every loud plastic shoe I could find became our new life of forgetfulness called MAKE-BELIEVE. It changed our perspective about our experience in the hospital. She became her own Super Hero! Marisol told the nurses, "Before you give me my medicine or my treatment, I need to be dressed in one of my costumes and crown." Sometimes she would say, "Please put on my makeup."

It did wonders. And became a routine. The hospital staff became well aware of Marisol Santiago. She stayed up late at night sharing her costumes and makeup. Even the boys loved the concept. They would ask, "Who are you today?" Regardless of what Marisol would wear, she was still the Princess for the Day.



After her treatments were finished, Marisol made it loud and clear what she thought – that every child deserves to smile and make memories to last a lifetime. In late 2008, we challenged ourselves to take this concept further – to dress up kids into whoever they wished to be for the day. It grew so fast that we established a not-for-profit organization called Princess for a Lifetime - dedicated to boys' and girls' happiness while enduring hospital stays.

We receive special requests from children to be dressed up as bunnies, ninjas, Sponge Bob Square Pants ... whatever they wish. Arts and crafts have been added to the agenda and we play their favorite tunes. We cater to any child suffering with an illness: cancer, sickle cell, blood disorder, Aids, chronic asthma, and others. The best medicine we have to give is the medicine of laughter, joy and happiness.

Distraction for these kids while undergoing treatment is the best gift I can give. Children

suffering an illness have no clue, no understanding of what is happening to them. They need a cheer up! Let's lend a hand to turn their frown around.

Marisol is now a 10-year-old girl in remission who prepares every gift bag and every costume request we receive for special little boys and girls ranging in age from infancy to teenagers. We include a little gift for mom and dad as well. We also organize indoor and outdoor events to cater to groups of children, and organize a gift-giving program (i.e., toys and clothing) for hospitals, homeless shelters and local churches.

My mission is to tell the world how a slight fever in my little girl went unnoticed and ended up as cancer. That changed my child's life in many ways, most importantly, to do amazing things for families battling their children's illnesses.



Tynesha Hendricks is the president and founder of Princess for a Lifetime (princessforalifetime.org). If you have kids' costumes and dress-up items to donate, please mail them to Princess for a Lifetime, 1789 Randall Avenue, Bronx NY, 10473. To become involved on their team, email princessforalifetime@yahoo.com. You can also connect with this organization on facebook, Twitter and LinkedIn.



The country that put a man on the moon can **cure cancer.**

We've always embraced big challenges in this country. It's how the world sees us. How we see ourselves.

Now, President Obama has called on us to end cancer in our lifetime. America's pharmaceutical research and biotechnology companies share that goal. Today, our scientists are working on 800 new medicines to fight this deadly disease that touches so many lives.

It won't be easy, and it won't happen without a renewed emphasis on innovation and a sustained commitment to research and development. Last year, we invested more than \$65 billion to discover and develop medicines to help patients live longer, healthier and more productive lives. Like President Obama, we believe that America's best days are ahead of us. Working together, we can do anything.

PhRMA

New Medicines. New Hope.

www.PhrMA.org

"But it ain't about how hard you hit, it's about how hard you can get hit and keep moving forward. How much you can take and keep moving forward. That's how winning is done."

~ Rocky Balboa

"I don't think of all the misery but of the beauty that still remains."

~ Anne Frank

4

coolkidscampaign.org

EVERY MOTHER WANTS
A CLEAN HOME.
**EVEN MOTHER
NATURE.**



The Cleaning Authority provides top-quality house cleaning to homeowners. We help maintain our earth through the use of Green Seal Certified® housecleaning chemicals, HEPA vacuums, and microfibers. The Cleaning Authority not only wants homeowners to feel good about their clean home, but also about the home they have helped protect by using an environmentally responsible company.

EXPERIENCE THE CLEANING AUTHORITY
DIFFERENCE. CALL TODAY FOR A FREE ESTIMATE:

866-827-0062

Visit us Online at
www.TheCleaningAuthority.com

*Available at participating franchise locations only. Franchise locations will use Green Seal Certified™ or EPA-registered cleaning products. Contact your local franchise office to determine what types of services and services are offered in your area.



Ronald McDonald House
Charities of Baltimore
is pleased to support
the Cool Kids Campaign.

www.rmhcbbaltimore.org



SURFIN' THE NET...

Have you discovered a useful or fun website to share with other families dealing with pediatric cancer? Email the link to suzanne@coolkidscampaign.org for inclusion in the next issue of Cool Kids Connection. We found a few to share with you ...



1 squirreltales.com

an uplifting and practical website to encourage and empower parents of kids with cancer when they feel the most discouraged and powerless: *You know you're the parent of a kid with cancer when ... (100 things)*



2 chemo-to-the-rescue.com

A children's book on leukemia; view and read it online!



3 mommiesofmiracles.com

Founded in April 2008 in honor of Anita's miracle and all the miraculous children who fight to defy the odds each and every day. Mommies of Miracles (MOM) has grown from a small group in Ohio to a large facebook fan page, and continues to grow. MOM is the largest online support group for moms of special needs children worldwide.



An amazing thing happens
when you give to the community.
It gives back.



At M&T Bank, we know how important it is to support those organizations that make our communities better places to live, work and grow. That's why we offer both our time and resources. What we all get in return is far more valuable.



www.mtb.com ©2009 M&T Bank. Member FDIC.

cancerfearsme.org

5

Living with leukemia in a 4-year-old

by Shane Meader, Des Moines, Iowa



It was a Wednesday evening in February 2012 when my wife Eileen and I noticed Coral's limp. It was quite minor as she was not impeded in the least of getting where she wanted to go. Thinking that it was probably growing pains in our then 3-year-old girl, we assumed it would just get better on its own.

But it did not get better. It got worse. The following Monday morning found us at her pediatrician's office. After extensive prodding, pushing and questioning, Coral's doctor admitted that he did not know what was causing her knee to hurt. He ordered x-rays and a blood test to see if those would reveal anything. He contacted us later that morning and told us we were to be at the hematology clinic at Blank Children's Hospital downtown by early afternoon.

The sign on the door read Hematology/Oncology Clinic. I knew what hematology meant but oncology was a foreign word. We were greeted warmly and shortly after, met Dr. Wendy. The next few hours demonstrated her drive for results and the skilled labor and technology at her disposal ... at a pace that was unprecedented by any previous hospital visit in my experience.

First we were sent upstairs for another blood draw. After an emotionally and physically painful procedure for Coral, we had a new blood sample and an IV on an arm board. Coral was allowed to pick out a toy. The toys were a strange component to the day, starting soon after we arrived at the clinic. Coral was showered with gifts. What is this? I wondered. Entire closets full of toys still in their packages? Hand-knitted hats?

After a few hours of tests, the day had turned into late afternoon when Dr. Wendy asked us to join her in a small examining room. Dr. Wendy sat on the rolling stool and two nurses, Natalie and Kelli, stood nearby, closing the door behind them.

"I'm not one to sugarcoat words or beat around the bush," said Dr. Wendy. "Coral has Leukemia. God is not punishing you. She is safe now."

As those few words made their way into my head, my conscience became a torrent of shock, disbelief and questioning. How can she be safe? How would you know God is not punishing us?

"How reliable is this blood count thing?" I managed to get out a question.

"It's very reliable," replied the doctor.

As simple and weak as that answer was, I felt cornered. There was nowhere to go but face the reality that Coral Blossom was stricken with a life-threatening disease - Acute Lymphoblastic Leukemia (A.L.L.). Things started falling into place in my mind: the toys, the hats, the foreign word on the clinic door. The full burden was coming to rest. Every waking moment of the next 18 hours I spent crying for our young daughter's life.

As an engineer, I soon realized that my coping mechanism was going to be learning the whys and hows of treating A.L.L. in Daddy's littlest girl. I wanted to know - needed to know - what we were doing and why. I began to ask questions of her doctors and started researching on my own. I learned at least a basic understanding that has definitely helped me, and arguably, has helped Coral. (We also have two other children: Mica, 11 and Caden, 9.)

The next few days after diagnosis were a blur of emotions, information, decisions, coordination and planning. It was a paradigm shift of life. But Dr. Wendy and everyone at the clinic carried us through the next steps, not only for treatment, but for our well-being.

The first few days in the hospital began a near endless delivery of medications by mouth. Thankfully Coral has always taken them even if she put up some resistance. Later she displayed entertaining and creative ways to resist swallowing her meds, particularly at home. In one instance as we brought meds to her while she played in the living room, she stated matter-of-factly, "Pirates don't take Bactrim."

Occasionally throughout treatment, Eileen and I would experience an intense emotional feeling that would come and go. We called it 'the knife edge.' We didn't necessarily feel it at the same time; and it meant different things to each of us. Our paradigm shift of life included having a much clearer view of what was truly important. It also revealed an ebb and flow of normal life, and life with A.L.L. A knife edge day could be when the sudden realization of Coral's diagnosis interrupts normal routine, presenting the fine emotional balance between the two.

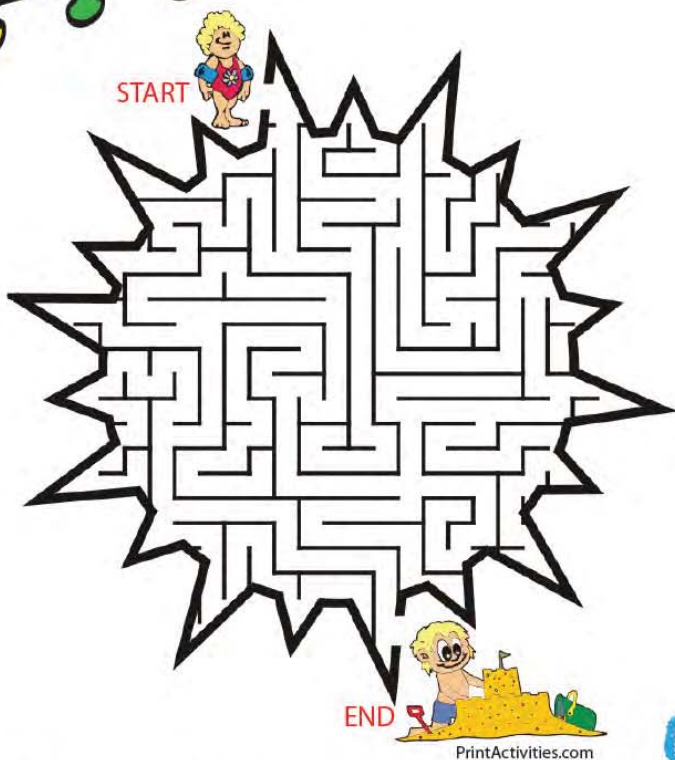
Wednesdays became our clinic day, about which Coral learned to ask almost daily. "What day is it tomorrow? Is it clinic day?"

She has never warmed up to them. Then Coral's clinic agenda became "Where's Kathy?" (Coral's Child Life professional). And sometimes the receptionist Shelley would dial Kathy's number and put Coral on the phone. "Kathy, where are you?" asked my daughter. "I want to play."

The initial news of leukemia was devastating, but good news followed soon after. The treatment was working very well and we felt a level of thankfulness that words cannot describe. For sure there have been plenty of difficult times. But for the most part Coral has remained her brilliant, quick-witted, direct self. She and her personality have played and sang through the toughest times. Currently we are in the maintenance phase of treatment and everything is going well. Coral is a happy girl who is growing quickly - like any other 4-year-old should be.



PUZZLES AND GAMES



SUMMER WORD SEARCH

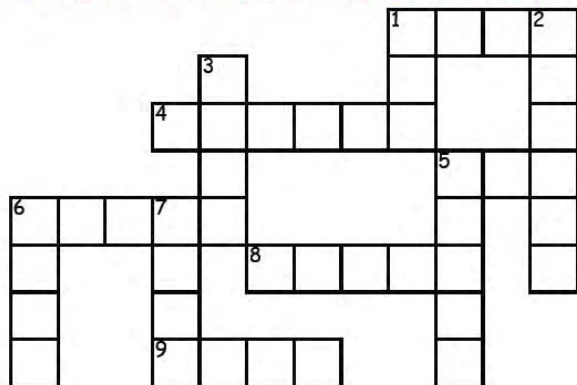
Find the summer words from the list on the left. The words can be forwards or backwards, vertical, horizontal, or diagonal. Circle each letter separately, but keep in mind that letters in each summer word may be used in more than one word. When the puzzle is completed, read the remaining letters left to right, top to bottom, to learn an interesting Summer fact.

AUGUST
BARBECUE
BASEBALL
BEACH
BIKING
GOLF
HATS
HOLIDAY
HOT
HUMID
JULY
RELAX
SANDALS
SHORTS
SOCCER
SUNBURN
SUNSCREEN
SUNTAN
SWIMMING
VACATION

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

PrintActivities.com

OPPOSITES CROSSWORD PUZZLE



Across

1. The opposite of empty
4. The opposite of summer
5. The opposite of cold
6. The opposite of black
8. The opposite of dull
9. The opposite of hate

Down

1. The opposite of near
2. The opposite of big
3. The opposite of mean
5. The opposite of sad
6. The opposite of strong
7. The opposite of short

DOWN- 1. FAR 2. LITTLE 3. NICE 5. HAPPY 6. WEAK 7. TALL
ACROSS- 1. FULL 4. WINTER 5. HOT 6. WHITE 8. SHARP 9. LOVE

ANSWERS:

abcteach.com

COLOR ME





hellokids.com

BRAIN

TEASERS

The girl is trying to catch a butterfly. Draw the path through the maze to the butterfly, starting at 1 and counting by 1s up to 100.

7	6	3	2				65	66
8	5	4	1				63	64
9	10	19	20				62	61
12	11	18	21	22	53	54	59	60
13	16	17	24	23	52	55	58	71
14	15	26	25	50	51	56	57	72
33	32	27	28	49	82	81	80	79
34	31	30	29	48	83	84	85	78
35	36	45	46	47	100		99	86
38	37	44					98	87
39	42	43					97	88
40	41						96	95
							94	93

PrintActivities.com

COLOR ME



allkidsnetwork.com

SUMMER WORDS CRYPTOGRAM PUZZLE

Crypto-families are lists of words that are encrypted or coded with a letter substitution. The two lists below have different letter encryptions. For example: "XPOQAC" is an encryption for the word "SUMMER" if X=S, P=U, Q=M, A=E, C=R, etc.

GENERAL SUMMER WORDS

DHN _____
 MWQY _____
 BDHHQ'B HWN _____
 PZVZNEHO _____
 ZWAWBN _____
 UWO _____
 IZTIFVWF _____
 XEVOEV _____
 QHOA SZYB _____
 IFZVD _____

WORDS ABOUT SUMMER FOODS

VXVEGICO _____
 GIO IBOJH IXYO _____
 PJUOBHOCXY _____
 TBNGU EJCJQ _____
 VXUJUX EJCJQ _____
 LLS EUOJF _____
 EUBJPLOBBGOE _____
 IXCOECPJ _____
 LLS BGLE _____
 LJYJY EVCGU _____



ANSWERS:
 GENERAL SUMMER WORDS
 DHN = HOT
 MWQY = JULY
 BDHHQ'B HWN = SCHOOL'S OUT
 PZVZNEHO = VACATION
 ZWAWBN = AUGUST
 UWO = FUN
 IZTIFVWF = BARBECUE
 XEVOEV = PICNIC
 QHOA SZYB = LONG DAYS
 IFZVD = BEACH
 WORDS ABOUT SUMMER FOODS
 VXVEGICO = PEPSICLE
 GIO IBOJH IXYO = ICE CREAM CONE
 PJUOBHOCXY = WATERMELON
 TBNGU EJCJQ = FRUIT SALAD
 VXUJUX EJCJQ = POTATO SALAD
 LLS EUOJF = BBQ STEAK
 EUBJPLOBBGOE = STRAWBERRIES
 IXCOECPJ = COLD SLAW
 LLS BGLE = BBQ RIBS
 LJYJY EVCGU = BANANA SPLIT

PrintActivities.com

MIND BENDERS

MAD LIBS®

Without telling what the story is about, one player asks another player to call out a word (adjective, noun, verb, etc. as needed) and fills in the blanks with those words. When all blanks are filled, the reader then reads the entire ridiculous story aloud! Guaranteed silly!

RECIPE FOR AN UPSIDE-DOWN CAKE

Here is a/an _____ (adjective) recipe for an upside-down _____ (noun).

First, preheat your _____ (noun) to _____ (number) degrees.

Then take a stick of _____ (noun) and melt it in a 10-inch

_____ (adjective) skillet over a very _____ (adjective) flame. In

a/an _____ (adjective) bowl, _____ (verb) granulated

_____ (noun) and flour, stirring the mixture _____ (adverb). Add

milk and _____ (plural noun) and beat rapidly with an electric

_____ (noun). Bake until your _____ (noun) is ready. After the cake

cools, _____ (verb) it from the _____ (noun) and turn it

upside-_____ (adjective). Serve the cake warm with _____ (past

tense verb) cream and small spoonfuls of _____ (noun) on top. Enjoy!

A VEGETABLE GARDEN

Planting a vegetable garden is not only fun, it also helps save _____ (plural

noun). You will need a piece of _____ (adjective) land at least 20 feet long

and 25 _____ (plural noun) wide. You may need a fence to keep out the

_____ (plural noun) and _____ (plural noun). As soon as the cold

weather is over, you can get out there with your _____ (noun) and plant all

kinds of _____ (plural noun). Then in a few months, you will have

homegrown corn on the _____ (noun), lovely _____ (adjective)

tomatoes with fresh green _____ (plural noun) and best of all, vine-ripened

_____ (plural noun). Homegrown _____ (plural noun) are much

more nutritious than _____ (adjective) vegetables because they contain

natural _____ (noun) and _____ (adjective) vitamins.

Unscramble these SUMMER words

1. caheb _____

2. heinnuss _____

3. blaeumrl _____

4. olpo _____

5. frta _____

6. otba _____

7. ccipin _____

8. misnwigm _____

ANSWERS: 1. beach 2. sunshine 3. umbrella 4. pool 5. raft 6. boat 7. picnic 8. swimming

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. If you use logic you can solve the puzzle without guesswork.

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

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

SOLUTION:

JOKES RIDDLES



GOOFIN' AROUND WITH THE DOC

PATIENT: Doctor! Doctor! I feel like an apple.

DOCTOR: We must get to the core of this!

PATIENT: Doctor! Doctor! Can I have a second opinion?

DOCTOR: Of course, come back tomorrow!

PATIENT: Doctor! Doctor! You have to help me out!

DOCTOR: Certainly, which way did you come in?

PATIENT: Doctor! Doctor! I feel like a pack of cards.

DOCTOR: I'll deal with you later.

RIDDLIN' AROUND!

Did Adam and Eve ever have a date?

No, but they had an apple.

What did the boy octopus say to the girl octopus?

I wanna hold your hand, hand, hand, hand, hand, hand, hand, hand.

What travels around the world but stays in one corner?

A stamp

If your aunt ran off to get married, what would you call her?

Antelope

Why did the spider cross the road?

To get to his web site

How do you make a tissue dance?

Put a little boogie in it



Knock-knock-knock all over the door jokes

Knock, knock

Who's there?

Canoe

Canoe who?

Canoe help me with my homework?



Knock, knock

Who's there?

Iva

Iva who?

Iva sore hand from knocking!

Knock, knock

Who's there?

Etch

Etch who?

Bless you!



Knock, knock

Who's there?

Henrietta

Henrietta who?

Henrietta worm that was in his apple!



Have a unique knock-knock joke or another favorite joke? Email it to suzanne@coolkidscampaign.org and we'll publish it in a future issue!

lajollamom.com

No one should fight cancer alone; Cancer survivor creates a flight of angels

By Jonny Imerman, Chicago, Illinois

I am a testicular cancer survivor. I was born in Saginaw, Michigan in 1975. When I was a baby, my parents divorced and we moved to Bloomfield Hills, a suburb of Detroit, where I attended Cranbrook Kingswood School from kindergarten through high school. After graduation, I moved to Ann Arbor, Michigan where I earned a bachelor's degree in psychology from the University of Michigan. After college, I returned to the Detroit area, working during the day while earning an MBA from Wayne State University at night.



Suddenly one Thursday morning in October 2001, my busy world came to a standstill. At 26 years old, I was diagnosed with testicular cancer. I couldn't believe it so I visited another doctor for a second opinion. He confirmed it – I had cancer. The testicle was the epicenter of the disease. I went right into surgery and my left testicle was removed.

Although the surgery went well, my visits to the doctor did not stop there. It soon became clear that the cancer had spread (metastasized) from the testicle; the disease was making its way up my body. This form of cancer was called a nonseminoma – a mixture of many different types of cancer cells, as opposed to a seminoma tumor which consists of one type of cancer cell. Nonseminomas are much more aggressive and spread much faster than their counterpart.

I knew what was next – chemotherapy – yet I did not understand what that meant. What is chemotherapy? What color is it? How will it make me feel? I called my brother and started sobbing. I could barely talk. My world was shattered. But I was not going to give up.

My oncologist told me that the treatments might make me sterile. So I went to a cryogenics laboratory to bank sperm. After that it was time to start. My chemotherapy recipe was known as BEP: Bleomycin, Etoposide and CisPlatin. My regimen included three cycles of chemotherapy each lasting three weeks. One cycle included a week of eight hours of daily chemo Monday through Friday and two weeks of two hours of chemo on Wednesdays.

The treatment weakened my body and wiped out most of my white blood cells. In fact, I was in such bad shape that the doctors were forced to delay my chemotherapy while my body recovered between cycles. In addition, it caused many side effects: throat sores, mouth sores, skin rashes, dry skin, cystic acne, extreme fatigue, hair loss, numbness in my fingers and toes, and partial hearing loss. But the most damaging side effect was a blood clot that developed in my left arm. The clot formed around my port (the medical implant used as an access point for chemo). The doctors had to remove my port, pull out most of the blood clot and then pump me with blood thinners to break up the rest. With all the side effects and delays, the chemotherapy lasted for five months.

At last, after all the treatment, I thought my fight was over. I slowly returned to my life, such as going to the gym and socializing. Although I was happy to be alive, every day was a challenge. I did not have as much energy. I looked different. I struggled to find my post-cancer identity. Just as I was getting comfortable with myself, I learned the fight was not over.

Nearly one year after chemotherapy, a routine CT scan showed four tumors along my spine. Rather than risk cutting the spine, the surgeon entered through my

stomach. He made an 11-inch incision, placed my organs to the side, and removed each tumor. The surgery lasted four hours and was successful.

Finally, I was freed from the disease and began my road to recovery. I made a vow to myself during chemotherapy. I looked at others in the oncology clinic and realized that I was different. Each day, my room was filled with family members and close friends. With so much support, I did not have a chance to lose hope.

However, in many of the other rooms, hope already seemed lost. As I walked down the hall with my chemotherapy IV-pole, I saw other people fighting cancer alone. They were lying in bed, motionless, watching television or staring in space. Their only stimulation was a nurse checking in for a minute or two on the hour. I knew this was not right and it upset me. I felt guilty because I had so many good people and positive energy around me. I made a silent promise that if I were given life after cancer, I would help these people.

So how could I help? I walked into the other rooms, one at a time, and introduced myself.

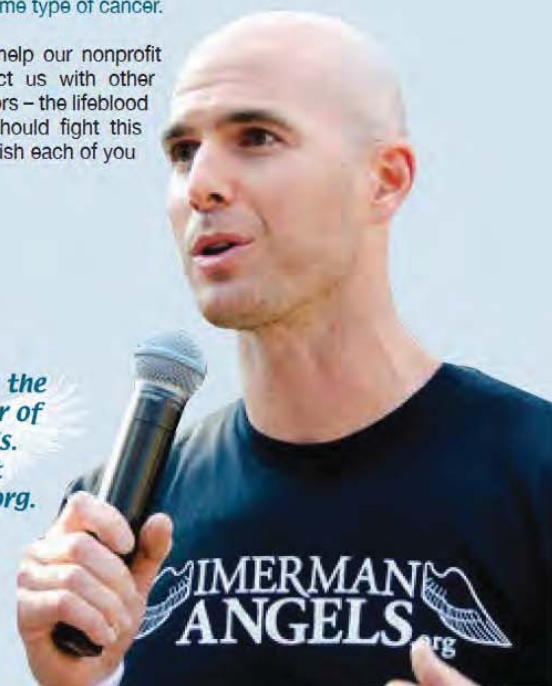
"Hey, what's up?" I said. "I'm Jonny. What's your name? I have testicular cancer. What type of cancer do you have?"

Many people were older than me; a few younger. Although they were exhausted just like me, everyone was friendly and welcomed my conversation. We shared stories, emotions, and opinions about many things in life. We each had our own type of the same disease. Some fought for themselves, others for their children, and yet others for a spouse. But no matter the motivation, we were all fighting for life. And I wanted to help them get it back.

I wondered ... what if every cancer fighter could talk with a cancer survivor? Someone who not only had beaten the same type of cancer, but who also was the same age and gender? The cancer survivor could be like an angel to that person – walking, living proof that the fighter could win, too. What an amazing connection! This is the reason I created Imerman Angels, a nonprofit organization that carefully matches a person touched by cancer with a "Mentor Angel" – someone who has fought and survived the same type of cancer.

The number one way to help our nonprofit organization is to connect us with other cancer fighters and survivors – the lifeblood of our service. No one should fight this disease alone. No one. I wish each of you well.

**Jonny Imerman is the
Executive Director of
Imerman Angels.
Learn more at
imermanangels.org.**



Moving Forward by Giving Back

Excerpted from "The View From Up Here; Your Guide to Surviving Childhood Cancer" produced by The National Children's Cancer Society - theNCCS.org | beyondthecure.org

As a cancer survivor or patient – or the parents of a child with cancer – you've faced many serious challenges. The success you've had in conquering them can make you feel powerful, hopeful and determined. So much so, that you may find yourself eager to help other cancer patients.

Many cancer survivors learn to advocate on behalf of other cancer patients and survivors. By sharing your experience with professionals, politicians and the general public, you raise awareness of childhood cancer. You have the potential to effect individual, institutional or social change. Being part of the solution can help you make sense of your health history and help you move forward.

Your experience has given you rare insight into the changes that need to be made within the community to accommodate children with cancer. Hospital policies may need to be changed, schools may need to be educated about the late effects of treatment, and employers need to be more aware of the special issues facing families dealing with cancer. You have the inside knowledge to be an effective part of the solution. Here are some ways to get involved:

- *Contact a local children's hospital to advocate for a newly diagnosed child.*
- *Get involved in current hospital policies to influence improvements.*
- *Share your cancer experience by visiting local civic groups as the guest speaker.*

- *Raise money for a charity that supports childhood cancer issues and awareness.*
- *Volunteer with nonprofits or survivorship clinics.*
- *Educate the faculty at your school about the long-term issues that survivors face.*
- *Explore resources available for survivors on college campuses and advocate for any needed accommodations.*
- *Use your voice on a legislative level to influence policies and budgets that affect survivors: contact elected officials by phone/letter/email; reach out in the community through radio stations and print media; talk to everyone around you about the issues; join an advocacy group; become familiar with the federal and state laws that affect you.*

Advocacy can be challenging and at times frustrating, yet it can also be extremely rewarding. Whatever path of advocacy you choose to pursue, you are taking a step towards healing. You are making a difference in your own life and in the lives of countless other survivors or families in the midst of the cancer journey.



The Major League Baseball Players Association tips its cap to the

**COOL KIDS
CAMPAIGN™**

for their efforts to strike out cancer!

www.MLBPLAYERS.com



Wherever you go, no matter what the weather, always bring your own sunshine.

KIDS! PARENTS! LET US PRINT YOUR STUFF!

Our goal with Cool Kids Connection is to connect families across America who are dealing with kids' cancer. This newspaper is published for you and about you ... including stories by you! Here's what we look for ...

STORIES ~ Share your experience with other kids living with cancer. Or, write about any kid-related topic at all!

ART ~ Like to draw, paint, sketch, doodle, color? Send us your artwork to publish!

POETRY ~ Express yourself through poetry: rhyme it, don't rhyme it; we'll take it happy, sad, goofy or serious!

PHOTOS ~ Introduce yourself through a photo – can be with family or friends, in the hospital, or doing your favorite thing at home!

FAVORITES ~ Share your favorite song, book, video game, app, movie, Facebook page, website or TV show ... we're listening!

JOKES/RIDDLES ~ Wanna help other kids chuckle? Share your favorite joke. Send riddles, puzzles, brain teasers, or even a word search that you made up!

COOL CAREGIVER & COOL KID ~ Each issue has a fun Q&A featuring a "cool kid" and his/her "cool caregiver" What's your favorite cereal? Do you like cats or dogs? If you were president, what would be your first law? Our list of fun questions is ready for YOU – and your favorite nurse, doctor, child life specialist or caregiver!

EMAIL submissions to
suzanne@coolkidscampaign.org.

You can also mail items to
Cool Kids Campaign, 8422 Bellona Lane, Suite
102, Towson MD 21204.

Note that we are unable to reprint copyrighted material, so be sure to send your original artwork and photos! All submission becomes the property of Cool Kids Campaign.

cancerfearsme.org

13

COOL KID



COOL CAREGIVER

Jaziel

Phoenix, Arizona

What grade are you in? **9th grade**
How old are you? **14 years old**
If you wrote a book, what would it be about?
A boy with cancer who likes to dance.
What do you want to be when you grow up?
I want to be an oncologist.
Do you enjoy playing and/or watching sports?
If so, which is your favorite? **Umm...sometimes**
Favorite team? **Cardinals Football**
Do you have brothers and sisters? **onathan (12), Erick (9) and Ian (4)**
What do you like to do for fun? **I like to use my Wii Fit.**
How do you like to help others? **I like to make people smile by doing something silly.**
Favorite cereal? **Cocoa Puffs**
Favorite snack? **Oreos**
Favorite animal? **Zebra**
Favorite subject in school? **Reading**
Who's your BFF? **Andrea Espinoza**
What activities do you like to do for exercise? **Anything, even Frisbee.**
If you were the President of the United States, what would be the first law you would make? **I would eliminate pollution by making companies work together in the same factory.**
Favorite movie? **Iron Man**
Favorite TV show? **Keeping up with the Kardashians**
Favorite video game? **Call of Duty - Black Ops**
Favorite board game? **Connect 4**
If you were stranded on an island, what 3 things would you have with you? **Food, clothes and a friend.**
What are you most grateful for? **My family and doctors.**
If you were a Seven Dwarf, which one would you be? **Happy**
If you could meet someone famous, who would it be? What question would you ask him/her first? **Niki Minaj. The first thing I would ask her is "Where the heck do you find all of your wigs?"**



Arica Dunn, BSN, RN, CPN
Gilbert, Arizona

What hospital do you work?
Phoenix Children's Hospital
What is your job title? **Registered nurse (BMT, Hematology/Oncology)**
What do you do specifically? **My job is different every day, but I always try to bring comfort to patients and their families during the good and bad days.**
Favorite part of your job? **Working with incredible families and patients while teaching and preparing them for their journey with cancer.**
Lease favorite part? **Forcing children to take medications they don't want - and giving shots!**
Favorite sport to watch and/or play? **I played softball but I love watching baseball.**
Favorite team? **Minnesota twins**
Are you married? **Single**
Do you have children? **Not yet ... hopefully some day**
What do you enjoy doing for fun? **I enjoy working out, hiking and spending time outdoors.**
Favorite movie? **Toy Story**
Favorite TV show? **The Big Bang Theory**
Cats or dogs? **Cats**
What's on your iPod? **I have a little bit of everything but truly love country music.**
Favorite book? **As a child, my mother read me Love You Forever by Robert Munsch every night, so it means a lot to me.**
Favorite board game? **Trivial Pursuit**
Favorite school subject as a kid? **Science and Math**
Favorite dessert? **Key Lime Pie**
Favorite season? **Fall - I love seeing the leaves change color.**
Favorite cereal? **Cinnamon Toast Crunch**
Favorite fruit? **Honey-crisp apples**
What celebrity do you admire and why? **Jennifer Aniston because she has done so much work for pediatric cancer research.**
If you were a Seven Dwarf, which one would you be? **Happy**
If you could have dinner with one person (alive or deceased) who and why? **My grandfather; he passed away shortly after I was born and I would love to learn so much from him.**



ARTWORK BY:

Allison K, age 7
Lutherville, Maryland

Allison created this piece of art while receiving treatment at clinic at Sinai Children's Hospital in Baltimore. Her mom said the doctors and nurses loved seeing her illustration on facebook!

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



McCormick is proud to support
Cool Kids Campaign



COOL KIDS WE LOVE



Send us YOUR photo to publish here! Email photo, name, city/state to suzanne@coolkidscampaign.org or mail to our address on page 2.

cancer fears cool kids
and The Leukemia & Lymphoma Society!

© 2013 The Leukemia & Lymphoma Society. Cancer Fears ME is a registered trademark of the Cool Kids Campaign Foundation Inc. All rights reserved.

cancerfearsme.org



sofie today
leukemia survivor

