

SPRING 2015
N THIS EDITION

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coolkidscampaign.org

Different diseases, different hospitals, different ages, different treatment, but two families living six miles apart found a common ground. They knew the same people, the kids swam against each other at swim meets, but they had never met. A chance meeting brought these two families together and created a friendship that defies the odds of age and diagnosis.

Both families went to the Maryland Science Center in December 2013. It was a chance meeting in the dinosaur exhibit where the families finally met and their friendships began.

"We were at this place with fishing rods and pretend fish and she had hair," Cora said. "She's my best friend."

Cora was diagnosed with Aplastic Anemia on July 21, 2011. Aplastic Anemia is a rare disease of the bone marrow with just three diagnoses for every one million people. There are only thirty children diagnosed with Aplastic Anemia in the United States per year. Essentially, Cora's body was not producing enough red blood cells, white blood cells, and platelets. The preferred treatment for Aplastic Anemia is a bone marrow transplant. Luckily, she had a very brave big brother, Andrew, who was a perfect genetic match and gave this life saving gift to his sister.

Cora received chemotherapy treatments prior to her transplant to make way for Andrew's new, healthy marrow. On September 1, 2011, Andrew underwent the surgery to harvest the marrow. It was administered to Cora on the same day. Cora was released from Johns Hopkins Hospital, stayed for a short time in a transitional living apartment, and is now a happy, healthy five year old girl. She loves the color pink, princesses, and American Girl dolls. Her illness made her wise beyond her years and gave her a sense of empathy, which has led her to help other kids going through treatment.

Emily was diagnosed with Progressive Demyelinating Encephalopathy in January of 2012. She has been seen by the best specialists in the world including NIH, the Mayo Clinic, and Children's Hospital of Philadelphia (CHOP). Emily is admitted into Sinai Hospital every four weeks for treatment. She has been hospitalized over 50 times and has received over 30 rounds of chemotherapy. The treatments include plasmapheresis, chemotherapy, and IVIG. Her team of doctors at Sinai is still trying to find a successful treatment.

She is always smiling and is an inspiration to everyone who knows her. Emily attends school at Monsignor Slade Catholic School and is in the fifth grade. She loves to swim and draw. She has been in ballet and tap since she was three years old. In the two years since the families met, a strong bond has formed for all of the kids. Cora's siblings, Andrew, 9, and Grace, 11, have become great friends with Emily's sisters, Colleen, 9, and Megan, 10. Whenever they go places together, each child gets a partner: Emily and Cora, Grace and Megan, and Andrew and Colleen. Emily's mom, Kelly, finds support in Cora's mom, Heather, who has already been through the emotions that having a sick child brings. The families lean on each other for support.

Due to treatments, Emily often doesn't feel well enough to go to school, so she visits Cora instead. The girls play together, do crafts, and swing. Emily is a great protector. She takes care of Cora, which is very important to her because she feels like everyone is always taking care of her.

"My favorite thing about Cora is her spunk and her style," Emily said. "I like to play dolls with her."

Cora visits Emily during monthly treatments at the hospital bringing happiness and sunshine to otherwise dreary days. Emily lights up when her best friend walks in the room. Cora and Emily call themselves two peas in a pod and they are perfectly matched in friendship.



Photo credit: Catherine Pelura of Catsh Photography



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

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

**Managing Editor:**Katie Bennett Korrow

Design: Linda Ports LP Design, LLC Baltimore, MD

#### **Cool Kids Campaign Staff:**

Robert Belanger Chairman & co-founder

Chris Federico
President & co-founder

Sharon Perfetti Executive Director & co-founder

Katie Bennett Korrow Community Relations Coordinator

Lauren Moyer
Operations Coordinator

Kimmie Meissner Board Member & co-founder

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# **CANCER:**The Emperor of All Maladies

THE
EMPEROR
OFACE
MALADIES
ANDORAPH DECARCE
SIDDHARTHA
MUKHERIKE

Written by: Katie Korrow
Baltimore, Maryland

Cars are driving on a dark, rainy night on what appears to be an unnamed street until a siren goes off and the camera angle switches to a walking bridge between buildings that reads: The Johns Hopkins Hospital.

"I truthfully don't remember the drive itself. It's kind of surreal," said Marcus Blair, Olivia's father. "You just don't believe it's happening to your child."

The viewer is then brought inside the hospital to the pediatric oncology inpatient care center to meet a little girl named Olivia, who is in a hospital gown hooked up to an IV pole. Olivia is 17 months old and has cancer. This is the beginning of the documentary: Cancer: The Emperor of all Maladies.

The Emperor of All Maladies, originally a book written by Siddhartha Mukherjee, was published in 2010. The book combines medical history, scientific breakthroughs, and personal stories of cancer. Mukherjee is a cancer physician, researcher, and award-winning science writer. From this brilliant book came the PBS documentary series: Cancer: The Emperor of All Maladies, which first aired March 30-April 1, 2015. It is a six hour series broken in to three parts: Magic Bullets, The Blind Men and the Elephant, and Finding the Achilles Heel. This documentary has been watched all over the country and has helped create a national discussion on cancer.

The first segment, Magic Bullets, focuses on childhood leukemia. It shares the stories of Olivia and a little boy named Luca, who is also fighting leukemia. It also highlights the history of childhood leukemia and how far treatment options have come.

Olivia is 17 months old and being treated at Johns Hopkins Hospital.

Luca was first diagnosed with rhabdomyosarcoma when he was two years old. He was treated with

high dose chemotherapy which put him into remission for two and a half years. In spring of 2013, Luca developed leukemia from his prior treatment.

"One of the reasons that this weighs on me, us, is that no one caused the rhabdomyosarcoma; it happened. But somebody caused the leukemia. The drugs we gave him caused the leukemia," said Dr. David Loeb, Director of the Musculoskeletal Tumor Program at the Johns Hopkins Kimmel Cancer Center.

The historical section of Magic Bullets begins with the story of a little boy named Robert Sandler, who was diagnosed with leukemia in 1947 when mortality rates were 100%. At the time, kids with leukemia usually died within three months of diagnosis. Robert was treated at Children's Hospital in Boston, Massachusetts by the famous Dr. Sidney Farber. On December 28, 1947, Farber injected Robert Sandler with aminopterin, which was very controversial at the time. After the injection, Robert Sandler started to get better which was the first time a leukemia patient had achieved remission. Unfortunately, Robert's leukemia came back and he passed away in 1949 shortly before his 4th birthday, but his remission was still a breakthrough in the treatment of leukemia.

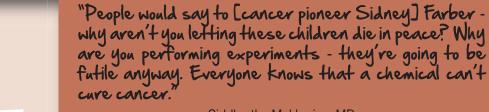
Toward the end of Magic Bullets, Karen Lord is introduced. Now an adult, Karen talks about how she was diagnosed with acute lymphoblastic leukemia in 1964 when she was 13 years old. She was treated with combination chemotherapy drugs and became one of the first children ever cured of childhood leukemia.

Little Olivia from the beginning of Magic Bullets is also in full remission.

"She's going to be 32 years old, and she's going to be proud to show her port scar," said Kelly Blair, Olivia's mom.

"When we made ward rounds, someone would say 'lenkemia' and that would be the signal to sort of shake your head - too bad - and move on. I remember one childagirl. She looked at me. "I'm dying. I'm dying. Can't you save me?"

Donald Pinkel, MD - Former Director of St. Jude Children's Hospital

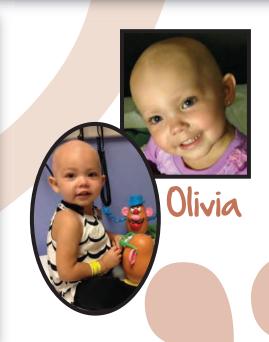


Siddhartha Mukherjee, MD

"The bone marrow where we normally produce blood is kind of like your lawn and lenkemia is like weeds so lenkemia can overtake the normal grass and kill it. So it's not enough just to mow the lawn. You've got to go and get the roots of all of the weeds and get all of the lenkemia cells out in order for the grass to be healthy again."

"What lengths are we willing to go in the attempt to cure a child? We are quite willing to push the envelope in terms of toxicity - because we know what's at stake is the rest of the child's life, you know, and that's potentially a very long life if they can be cured."

Patrick Brown, MD - Director Pediatric Leukemia, Johns Hopkins Kimmel Cancer Center





"Today, more than half-a-century after Sidney Farber's first chemotherapy trials, childhood lenkenia has a survival rate of nearly 90%. The era of bold and ceaseless experimentation - borne mostly by children - led to the most elusive of achievements. A cure."

Edward Hermann, Narrator



To watch Cancer: The Emperor of All Maladies, go to pbs.org/emperorofallmaladies.



Penrose, North Carolina

#### When you think of cancer, what's the first thing that goes through vour head?

I think of young people who have it and take forever to cure or older people who are close to death. You probably don't think of someone in high school getting cancer. That's supposed to be the time of your life -- a time to make changes, fall in love, get heartbroken, stay up late cramming for a big test, go to parties, shop, and have a social life.

As a sophomore in high school, that's what I was looking forward to, but that's not what happened. I was diagnosed with Hodgkin's Lymphoma on September 26, 2014. My life turned upside down in a day. I am hoping to be done with treatments in 2015. Originally, the doctors thought this was going to be a much longer, harsher process but with all the prayers and thoughts I received, this ended up being a short process.

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When this all started, my mom noticed a large lump on my neck that got larger during a week when I was staying after school for the in-class part of Drivers Ed. Other than the lump on my neck, nothing was out of the ordinary for me. I didn't feel different than I normally did, and I didn't have any other signs of cancer besides the large almost softball sized lump on my neck. By the end of my Driver's Ed session, my mom decided that this was not normal and we needed to go see someone. That's when it all began.

The following Saturday, we went to a doctor who ran a lot of tests for Mono, the flu, and more, all of which came back negative. He found it interesting that I was experiencing no other symptoms and even the large lump on my neck didn't hurt when he pressed on it. After that, my mom made an appointment with my family doctor, but she wasn't working on the day that I went in so I didn't get to see her. I showed up at the doctor's office not sure what to expect. Cancer never even came into my mind at the time. I mean, me having cancer? I'm in high school having the time of my life. I thought nothing could go wrong. After sitting in the office for a while, the doctor sent me to get an x-ray of my chest. She had determined that it was something to do with my lymph nodes but didn't know

After I had the x-rays done, I returned to the office and sat in the exam room while the doctor waited to get my x-rays back. When the results came back, she called my mother out into the hall. Immediately that put me on edge nothing good comes when the doctor will not talk to the patient about what is wrong. When my mom came back in to the room, I thought she was going to cry. It took me a while to get her to tell me what the doctor thought was wrong. Eventually, she said there was a possibility that I had cancer. At that moment, I think the world stopped for an instant as I took everything in. I possibly had cancer. I tried to hold back my tears and be strong but everyone has a breaking point when they just need to cry, and this time, I just needed to cry.

I was referred to a Lymphoma specialist. Of course, he wanted to be sure that I did actually have cancer and this was not just some abnormality. He ran a bunch more tests and I had a biopsy on my neck to take out a lymph node. It was the first time I'd ever undergone surgery where they put me to sleep. I was all nerves but it's not as bad as it seems, trust me. The tests on the lymph node came back positive officially diagnosing me with Hodgkin's lymphoma on September 26, 2014.

After the diagnosis, everything started blurring together. To be honest, I don't remember most of it except for the days when I got little things from school, friends, or my teachers. I remember on one really bad day, I went to school to pick up my work from the office and to my surprise there was this large poster board with tons of cards on it from my biology class. That little thing made my whole day better. I also remember receiving little gifts, cards, and care packages from both people I knew and people I didn't know who had cancer. Little things like that can really make your day when you just feel like giving up.

During chemo treatments when I was stuck at the Cancer Center, all I had was my mom at my side. She stuck with me through it all: the good, the bad, the beautiful, the ugly, and even when I started complaining about losing my hair. At first, I didn't want to lose my hair. I'm a teenage girl in high school and I thought hair defined who you are but once I lost it, I was glad I didn't have any of the hair. It's amazing once you get over the fact that you lost it. I got wigs but most importantly I got tons of hats! I love hats! I probably have more than 40.

Overall, my experience with chemo wasn't as bad as I was expecting it to be. The nurses and doctors at the Cancer Center all said I handled the chemo a lot better than I could have. I know it could have been a lot worse. At the end, I had to have another biopsy done to make sure the chemo was working and to make sure I didn't still have cancer. To my surprise, it came back negative for cancer but wow did it hurt!

In conclusion, cancer is just another chapter of my life. It's time to end that chapter and start a new one on how I overcame the fears of judgment when I went back to school and back into the real world. Cancer has its ups and downs but you just have to learn to roll with it. In the end, if anyone dares to make fun of you it's because you're stronger than them because you just went through one of the most horrible experiences of your life. If they have the nerve to say anything bad about you, they are just haters being hateful. Cancer is not something you can just fake, it's not something that you want to get, but if you have it, live your life to the fullest and don't ever look back to yesterday. Instead, look forward to tomorrow and the current time that you are living in.

Only the strongest of soldiers get the hardest of battles. If you've never had cancer, don't think you know what it feels like to have cancer. If you've had cancer, never wish for it to happen to anyone.



Rachel enjoys drawing in her spare time. She gets her inspiration from watching Anime tv shows.

# The country that put a man on the moon can

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

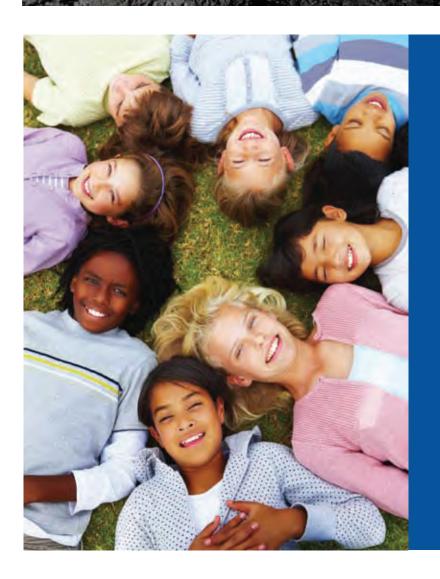
Now, President Obama has called on us to end cancer in our lifetime. America's pharmaceutical research and biotechnology companies share that goal. Today, our scientists are working on 800 new medicines to fight this deadly disease that touches so many lives.

It won't be easy, and it won't happen without a renewed emphasis on ipnovation 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



# McCormick is proud to support Cool Kids Campaign



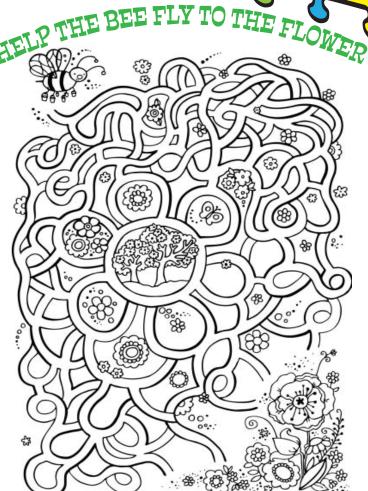
# PHUZZZLESS LAGNOD LEGANNELS

# OUTER SPACE WORD SEARCH

## FIND THESE WORDS:

booster countdown mars launch saturn jupiter atmosphere pluto capsule lander neptune satellite uranus shuttle sun astronauts moon rocket venus exploration comet gravity meteor lunar star

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



# See how many words can you make out of: APRIL SHOWERS



Complete the phrase: "April showers bring \_

11

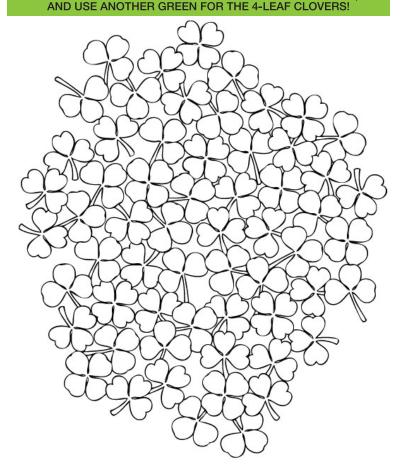
# BYRYAY







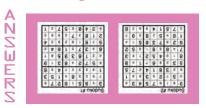
# (An YOU FIND T(n FOUR-L(AF (LOV(RS? COLOR ALL THE 3-LEAF CLOVERS ONE SHADE OF GREEN, AND USE ANOTHER GREEN FOR THE 4-LEAF CLOVERS!



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.

	4			1				8	
7	6	2	9	Tel	4				
	8	5	3	2	7		9		
6			17	4			1		
4	2						8	7	
	9			5				2	
	7		1	9	2	8	3		
			4		3	9	6	5	
9				6			2		

	8	1	6					9
4		7		9		6	8	
6	9					2		
		2	9		7		4	
	1	9				7	6	
	4		3		1	9		
		8					1	4
		4	11	2		3		7
3					9	8	2	





# NY NY DY

# Unscramble these SPRING words

WARM BUDS **PLANTING SHOWER** MOTHERS DAY FLOWERS SUNSHINE CROPS JUNE BLOSSOMS BLOOMS RAINBOW STORM **EARTH DAY** MUD RAIN WINDY

#### 

1. ETLM	_
2. DNYIW	_
3. RMTSO	_
4. RWOHSE	
5. LOBOSM	
6. DSUB	
7. SWOLFRE	_
8. NPALNGIT	
9. SMSLOBOS	
0. UDM	

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

## Fun Frog Facts for Kids

Did you know that a group of frogs is called an 'army'? (A group of toads is called a 'knot'.)

Frogs don't drink water they absorb it through their skin.

Frog bones form a ring when the frog is hibernating, just like trees do. Scientists can use these rings to figure out the age of a frog.



10. HTOMRSE AYD

#### CONNECT THE DOTS & COLOR ME!







# JYOKKE SS

# RIPORDITES



How many times can you quickly repeat these Tongue Twisters without mispronouncing the words?



Betty and Bob brought back blue balloons from the big bazaar.



Friendly Frank flips fine flapjacks.



How do you cut a wave in half?

How do you serve a smart hamburger?

lwre roe r oeU

illori honor na n

Why was the boy sitting on his watch?

What did Tennessee?

Because he wanted to be on time!

The same thing as Arkansas!

# JOKES KNOCK

Knock, knock Who's there? Some bunny Some bunny



Some bunny who?
Some bunny has been eating my carrots!

Knock, knock
Who's there?
Repeat
Repeat who?
Who, who, who...

Knock, knock
Who's there?
Lena
Lena who?
Lena little closer and I'll tell you!

# Cancer Camps Across the Country written by Natalie Page, Annapolis, MD

All of the oncology camps highlighted on the following pages are featured through COCA-I. COCA-I is an acronym for the Children's Oncology Camping Association International. COCA-I strives to strengthen the international community of camps for children with cancer and their families, according to COCA-I. They are able to achieve this goal through networking, education, and advocacy. In 2014 alone, COCA-I was honored to serve the needs of 35,500 campers. COCA-I prides itself on being able to provide the camps with resources needed to run the best possible camp. For more information on COCA-I or to learn about other oncology camps all around the world, visit www.cocai.org

### CAMP KEMO

**SOUTH CAROLINA** 

Interview with Cassandra Shea: Camp Director

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

We offer a wide variety of programs for patients and families who are treated at the Children's Center for Cancer and Blood Disorders at Palmetto Health Children's Hospitals. We have a teen group for both our oncology and sickle cell patients. We have a family weekend for oncology families, dinners, and summer camp for oncology and blood disorder patients. We also have a bereavement camp for children who have lost a sibling called Camp New Horizons. This is offered to children from North Carolina, South Carolina, and Georgia.

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

Sing-a-long time.

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

This summer will be our 36th year of Camp.

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

Our campers' favorite activities are eating, swimming, skits, arts and crafts, and playing in the fire truck.

## What are the dates for camp and what is this year's theme (if applicable)?

Camp KEMO will be held June 8-13th. Our theme for this year is Holidays.

#### What makes your camp unique?

Our camp is reserved only for our patients and their siblings. It is always a blessing to see those relationships formed at camp continue to grow when they are back at the hospital.

#### Favorite camp memory?

We had a boy who had lost his leg due to his cancer, and watching him play football at camp was absolutely amazing. He was the best player on the field and his smile was huge. Watching him be normal again, and watching the other boys interact with him like he wasn't any different is truly what camp is all about.

www.campsite.palmettohealth.org





#### Winnipegs MANITOBA

Grand

Forks

tinn

ulsa

exa

Corpus (

# Kamp KACE

# (Kids Against Cancer Everywhere) NORTH DAKOTA

Interview with Kim Belgarde: Kamp Director

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

We offer a one week residential Kamp for siblings and one week for cancer patients and their siblings. We also offer a weekend cross-country ski trip for survivors ages 15 to 22.

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

Seeing all my friends from the past year.

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

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

Water-front activities

## What are the dates for camp and what is this year's theme (if applicable)?

Provo\*

Marble

ueson\*

June 21- 26 (Charlie Brown)

#### What makes your camp unique?

Free for kampers

Mar

adific

#### Favorite camp memory?

Memorial - releasing the doves

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

Kamp is a fantastic week where kids can just be kids and not worry about being bald or sick and they have others they can relate to who are going through the same thing as they are.

#### www.kampkace.org

CAMP

Mexicali

# Camp Good Days and Special Times

Interview with Christina Woods: Camp Director

Missour

Great

elena

Falls

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

We offer week-long summer camping programs and year-round activities for children, adults, and families dealing with cancer or sickle cell anemia. We offer two weeks for children with cancer, one of which is for children from around the world (Bahamas, Germany, Antigua, Mexico, Dominican Republic, etc...) along with American kids which is called Doing A World of Good. Teddi's Team (named for the young girl who the camp was founded after) is for children ages 8-12 who have been diagnosed with cancer. Camp B&ST (Brothers & Sisters Together) is for children who have lost a parent or sibling to cancer or sickle cell anemia. Camp Childhood USA (Understanding, Support, Assistance) for children who have a parent or sibling who have been diagnosed with cancer or sickle cell anemia. We also offer a Brain Tumor Family Retreat for families in which one person has been diagnosed with a brain tumor. We also offer multiple adult oncology weekend programs. oe ca 🛪

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

The magic of Camp Good Days is bringing children together who have been through similar circumstances and have the chance to just focus on being kids again.

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

I have been involved with camp for 17 years.

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

Favorite activities for the campers, I would say, are the waterfront activities, the jumping pillow, the gaga pit, scuba diving in the pool, all-camp campfire, and pool party.

## What are the dates for camp and what is this year's theme (if applicable)?

The dates of each of our programs can be found on our website (www.campgooddays.org) and the theme for the 2015 summer is Clash of the Cabins.

#### What makes your camp unique?

I think what makes our camp unique is the fact that all of our programs are offered free of charge to anyone who qualifies. We are also unique because we have children from all over the country and from other countries who come and spend part of their summer with us.

#### Favorite camp memory?

I have way too many memories over my 17 years to pick just one!

www.campgooddays.org

## BIG SKY KIDS PROGRAM AT EAGLE MOUNT

**MONTANA** 

Interview with Jen Waters: Camp Director

St. Pa

reapol

nkato\*

hiristi.

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

Eagle Mount-Big Sky Kids offers four oncology summer camps and one reunion ski weekend for our families each calendar year.

"Spring Fling" (3/27 -29) is our annual reunion ski weekend. It's open to up to 100 former Big Sky Kids participants (former campers and their immediate family members). Activities include downhill skiing or snowboarding at Big Sky Resort, cross-country skiing, and snowshoeing at Lone Mountain Ranch, and a pizza and pool party. The only cost for the weekend is transportation to and from Bozeman.

Big Sky Adventure Camp (6/17-26) is our first oncology camp of the summer and is offered to kids between the ages of 11-18 who are still in treatment or who have just finished their treatment plus one parent each. Campers and their parents gather together in beautiful Big Sky, Montana for a full 10 days of fun in the mountains. Activities include white-water rafting, a trip to Yellowstone National Park, fishing, hiking, an overnight campout, and much more. Camp is medically supervised by both a pediatric oncologist and registered nurse(s) and is all-expense paid including travel.

Flight Camp with Summit Aviation (7/13-17) is our second camp of the summer and provides our young adult campers ages 18 and older with the opportunity to learn how to fly a plane and see the beauty of Montana from an entirely new perspective. Each of the four hand-picked participants are assigned their own Summit Aviation volunteer flight instructor, as well as their own plane for the week. Flight Camp is also an all-expense paid experience, including travel.

Camp Braveheart (7/29-8/2) is offered to children 5-10 years old, plus their immediate families. Braveheart takes place at Hyalite Youth Camp, a rustic facility located on the shores of Hyalite Reservoir just outside of Bozeman. Outdoor activities, games, campfires, crafts and special guests fill this special week with fun. Camp is medically supervised by both a pediatrician and registered nurse. The only cost is transportation to and from Bozeman.

Young Adult Retreat (8/11-19) is a retreat for young adults (ages 16-23) who have reached remission. These nine days are characterized by camping, camaraderie, and many other outdoor activities. The itinerary for YAR changes from year to year, so that returning campers are able to see many different aspects of Montana's beauty. The 2015 Young Adult Retreat will take place in and around Yellowstone National Park. It is medically supervised by a nurse and/or paramedic and the only cost is transportation to and from Bozeman.

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

The fact that people arrive at each camp as strangers and leave as one big family!

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

Big Sky Kids began in 1985, so this year is our program's 30th anniversary!

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

White-water rafting, horseback riding, kayaking, our day trip to Yellowstone National Park, our overnight campout, and of course our talent show (or un-talent show, as we like to call it).

#### What makes your camp unique?

Our relatively small camp size combined with the longer duration of some of our camps allows for everyone to leave really feeling like family! Also, I believe that the sheer number of outdoor recreational activities that we are able to provide to our campers and their families here in Montana makes our program special.

#### Favorite camp memory?

The crazy water gun fights that always happen on Lake Day during Big Sky Adventure Camp!

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

Thank you for this opportunity to share our program with others!



www.eaglemount.org

#### CAMP TA-KUM-TA

**VERMONT** 

Interview with Dennis DePaul: Camp Director

## What kind of programs do you offer for patients, siblings, and/or

Camp Ta-Kum-Ta is a year round camping experience for children between the ages of 7 and 17 who have or had cancer and are from Vermont or treated in Vermont. We are part of a large network of oncology camps globally called the Children's Oncology Camping Association International (www.cocai.org). At Camp Ta-Kum-Ta (www.takumta.org), we offer camping experiences for children in the cancer journey and their entire families. Our programs include traditional camping experiences for the summer and winter, a siblings program, a mom's weekend, and an annual reunion celebration. We have our own ropes course, a beautiful pool (shaped like a "T" for Ta-Kum-Ta), athletic fields, mountain bike trails (100+ acres), and countless activities including arts and crafts, athletics, cooking, dances (including a prom-like event), holiday specific parties, and more. During the winter months, we have cross-country skiing, snowshoeing, night hikes, and our own ice skating rink - broom ball is our favorite game on the ice! Moines

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

Camp TKT is heaven on earth! Because every child has cancer (or is in remission), the focus shifts away from their illness and children are once again just kids. We create a loving and safe environment where our children and their families can explore the realities of their cancer journey while still allowing the beautiful spirit of who they are to shine. I am often asked "isn't it a sad place?" Very simply, NO. It is the happiest, most life affirming place I have ever experienced.

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

Camp Ta-Kum-Ta has existed for a long time! We have been changing lives for 31 years (founded in 1984). We are fully funded through donations and our programs are run by volunteers.

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

There are so many! I think they truly love our "formal/prom" held during our traditional summer one-week program. With the generosity of our amazing community, we have hundreds of beautiful dresses, tuxedos, and suits. Each summer, we have 2-3 seamstresses who volunteer their time and fit the formal wear to our children's bodies (due to their treatment regiments, the body size often changes). So for one night each summer, they shine like the brightest stars in the sky! Our amazing Special Activities Team creates a magical environment for the evening that includes a formal dinner followed by a dance party.

#### What are the dates for camp and what is this year's theme (if applicable)?

Our traditional summer program will be July 26 - August 1. Our theme this year is "Game On" where we will be involved in friendly competitive activities all week (athletics, board games, costume parties, etc.)

#### What makes your camp unique?

OUR CHILDREN AND FAMILIES: We work with a very special population of children. I am so thankful to our parents for sharing their children with us knowing that for some, time is precious. OUR STAFF: All of our camp staff are volunteers with roughly a 90% return rate every year. Roughly 25% of our staff are prior campers that survived their cancer and many have been with us for all 30 years. In addition, our outstanding volunteers come from ALL OVER the United States at their own expense. They create the magic and I am inspired by their commitment, creativity, and generosity!

OUR FACILITY AND PROGRAMS: Nestled on the hillside of South Hero (an island in Lake Champlain), our facility is fully accessible and we consider differing ability in all our programs and activities. We work with children in all phases of their treatment. Our exceptional medical staff administers everything from band aids to chemo at camp!

#### Favorite camp memory?

Again, there are so many amazing memories. I remember one year we brought hot-air balloon rides to camp. We had one camper, Genina, in a wheel chair who was close to the end of her life and was more-or-less unable to participate in most of our activities (she was unable to even lift her arms). I asked the balloon folks to blow up the balloons just outside of her cabin. I could see her peeking through the window. Once they were blown up, she asked to speak with me - I happily went to her cabin. She wanted to know if she could be lifted into the balloon basket for a tethered ride. I said "OF COURSE!" We wheeled her to the balloon basket, set a folding chair in it for her to sit on and we gently lifted her up. Then woosh - we rose into the sky -Genina was smiling like a sunflower on a bright sunny day. Because Genina was so small (12 years old) she was unable to see over the side of the basket so she asked if it was ok for her to stand (I was shocked). So I turned to the other counselor in the basket with us to ask if she would help me lift her. While I was asking, this enormous cheer and clapping came from the ground. I turned around and Genina had magically pulled herself up and was standing at the edge of the basket waving to everyone below. As we fought back our own tears, we waved madly at the amazing community below and smiled brightly. It was truly a spectacular moment filled with hope and healing for all of us. I will forever be grateful for Genina and her amazing spirit.

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

harleston. Our name story! In the first year of Camp, our founders, Ted & Deb Kessler and Sheara Bilado, were talking with the children about naming our program. One of the youngest girls, Natasha, was painfully shy and really didn't know what to say. Ted loves to tease the kids so kept pushing her in a fun way and finally Natasha said, "I don't know Ted, it's just the camp "ta-come-ta." Thus, Camp Ta-Kum-Ta was born!

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