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COOL KIDS a division of BELANGER - FEDERICO foundation **Connection**™

Connecting pediatric oncology patients throughout the nation.

Cool Kid on a Hot Day

By Molly Lauryssens

Cool Kid Mikey T. of Glen Arm, Maryland, gave new meaning to the word "hard-hitting" on August 10th while attending the Baltimore Ravens training camp in Westminster, Maryland. At 5-years old, Mikey has been battling A.L.L. since last August. Not even the sweltering heat and humidity of August could keep him contained. No doubt, he put on his game face once he stepped onto the practice field, courtesy of the Baltimore Ravens.

Mikey was pumped. "I am super-duper ready!" he said while waiting for the Ravens to finish practicing. "I'm gonna need some safety gear." He took his best shot at a single man football sled in the end zone (a cushioned training device used for blocking and tackling).

Even though Mikey didn't have on safety gear, he still managed to "bust up" the sled while working on his technique and getting exercise. But he did more than just exercise that day. Comedian that he is, he managed to throw in a few jokes while collecting autographs and taking pictures of the players.

This Cool Kid cracked up the likes of Ravens fullback Justin Green. As Mikey and Justin posed for a picture, Mikey said to his mom, "How many more pictures are we gonna need?" Justin – and everyone around – burst out laughing.

Mikey has big plans. He hopes to play football someday. From the very beginning, he was all business. Like many Cool Kids, he was more into the action than into the watching. When the Ravens extended their practice by 20 minutes, Mikey waited patiently. At one point he commented, "This is making me hot! Let's get this show on the road."



Mikey brought up a good point: it was hotter on the field than anywhere else that day. Why? Astroturf. The bright green artificial grass is low maintenance compared to natural grass. Due to rain the previous day, the Ravens didn't practice on the regular field because it was too wet; it would have ripped apart. Unlike regular grass, astroturf holds heat. It's not unusual for it to be 10-20 degrees hotter, maybe more.

The Baltimore Ravens support many community groups during training camp. They offered group seating and a team picture to Mikey. In addition, they hosted him and his family on the field afterward when they were able to meet and greet players like Matt Stover and Corey Ivy.

Thanks Ravens for supporting the Cool Kids Campaign! ■

Mikey meets Baltimore Raven's place kicker, Matt Stover, while hanging on the sidelines during training camp.



Mikey, mom and a Raven's player. Her shirt says it all.

I don't see what's so hard about this...



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www.coolkidscampaign.org

Matt's Speech to Collegiate High School

Matthew W., age 15, was diagnosed with T-Cell ALL in November of 2006. The following is a copy of a speech he delivered to his school in April.

"Hello everybody, for those of you who don't know me, my name is Matt. I'm currently enrolled at Collegiate as a freshman, but as some of you may have noticed, I haven't exactly been attending class recently. The weekend of The Oddball Dance, I developed a nasty cough, which removed me from class for weeks. I was misdiagnosed with bronchitis, walking pneumonia, and mono until finally on November 15th they told me I had Acute Lymphoblastic Leukemia, which is cancer of the bone marrow and blood. At 15 years of age, with a 7 inch mass in my chest and a white blood cell count of around 250,000 (the normal being from 5-10 thousand), the risk that I might not recover was recorded as very high.

Fortunately, I took well to initial treatment. Within a few days I had shed 3 pounds of tumor cells, and weeks later, an examination of my bone marrow did not show one bad cell. This does not mean my treatment was over, though. In fact, the most intense phase of my treatment had not even begun.

For a while, I was receiving steady doses of chemotherapy, and doing just fine, until one admission, on January 17th, for a high dose of chemo. I had a general bad feeling about the hospital trip from the minute I woke up, and for good reason, too. On the second day of the intense treatment, the chemo caused my kidneys to fail. For days I ate no food whatsoever and was forced to lie completely still and flat while a machine cleaned my blood for me. I still haven't quite recovered from that trip.

It's very common for people to lose weight during chemo treatment, and I had already only weighed 120 pounds, but in that one week I lost 15 pounds. I was forced to go on this feeding tube almost every night since the 29th of January. So far, with the help of two

dieticians, I have successfully struggled my way back up to a good 120, and for the first time in my life, I have some fat on me. And I can tell you, it is a marvelous feeling.

I receive weekly doses of various chemicals at MCV hospital. I often feel tired and sick because of its side-effects, but it is necessary to kill the cancer. The chemicals temporarily weaken my immune system, so please, no hugs or handshakes if you see me after assembly. The chemicals also caused me to lose my hair, as you can see, but it will grow back. I try hard to keep up with school, though sometimes I can get too tired to work due to chemotherapy, and the teachers have been very helpful in allowing me to work at my limited pace.

Since November I've really been missing all of my classmates and teachers. I've received many cards, posters, prayers, hats, and other things like a basketball, a soccer jersey, a t-shirt, and a picture collage to remind me of how much caring you have in your hearts for me to get better. You have given me strength and you help me get better with your support. Yesterday, when I read the daily bulletin and saw that there happened to be an assembly today and today happens to be a Pasta Tuesday, my favorite, I knew I had to come in and surprise everyone with a quick visit.

I have to continue to finish up this school year from home, but if all goes well as it should, you can expect to see my smiling face in the halls next Fall at the beginning of the school year, as a sophomore. I really look forward to being able to be with you full-time."

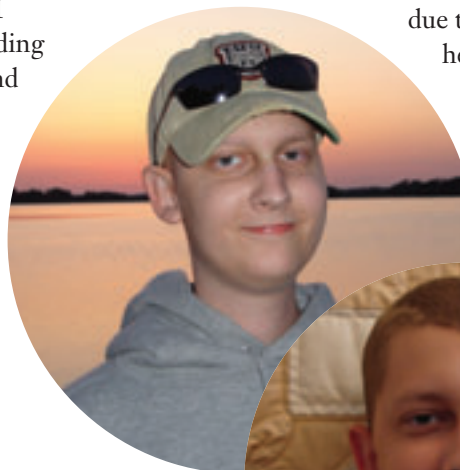
Update

by Matt's mom, Debbie W.

There have been so many blessings in Matt's life over the past 9 months. November 15, 2006 seems like just yesterday when Matt was diagnosed with T-cell ALL.

Now with the help from God, our friends and family, the great staff at the Medical College of Virginia and countless others, Matt was able to return to school on Tuesday, August 28th, 2007 to start his sophomore year at Collegiate. He now has his driver's learning permit and will be the manager of the boy's soccer team.

He will continue receiving treatment for the next couple of years and is still battling stress hyperglycemia but he can now participate in normal teenage activities. He now has his driver's learning permit and will be the manager of the Collegiate boy's soccer team. Returning to school is one more major milestone for Matt.



Enjoying a family trip.

Heading off to a school dance, nothing will keep me from my school activities.

A new school year with a bright outlook.



Dear Cool Kids,

After seeing your magazine at the treatment center where Ryan goes, we wanted to share his story with you.

Ryan was very sick for a long time and then we found out it was a brain tumor. Well, then came the treatment and then him losing his hair. He wanted to know why people stare when they should say a prayer. He said he wished he had a shirt that said, "Don't stare...say a prayer."

So we got him one. Well the nurses at the clinic, which is part of Hope Children's Hospital in Oak Lawn, Illinois wanted one like it. Not being able financially to get them all shirts, we met some friends who had just lost their son/brother from brain injuries sustained in a car accident.

They had started a foundation in his name and said that they would help us set up a website at no cost for part of the proceeds. We agreed and the RyanBoy Awareness Group was formed.

We've since gotten our own products with order forms and have been involved with fundraisers for breast cancer, Relay for Life and even our kids' school to raise money for a new playground. We're currently selling buttons (like the ones in the picture) to raise money for Hope Children's Hospital. It seems to work really well. We get them for \$1 and sell them for \$2. The hospital gets \$1 and we use our \$1 to replace the buttons. We also plan to make a donation to help build the Ronald McDonald House they're putting at the hospital.

Thank you,
The RyanBoy Awareness Group

For more information about RyanBoy Awareness Group you can visit their website at www.ryanboyag.org



Kids (and Companies!) HELPING Kids!

Thanks... to Kelly Lippenholz and her B> line of t-shirts. A % of the sales will be donated to the Cool Kids Campaign. Check them out at www.bgreaterthan.com.

Thanks... to Forest Lakes Elementary in MD. Their students reached their reading goal so the PTA donated \$500!



B> than creator, Kelly, models her B>Cancer shirt. Kelly's husband, Jeremy, models the back. Survive!

Kimmie's Angels ON ICE to benefit COOL KIDS CAMPAIGN

A hot summer night (temps over 100 degrees) set the stage for the first Kimmie's Angels on Ice, held August 25, at 1st Mariner Arena in Baltimore.

The Cool Kids Campaign Ambassador, Kimmie Meissner, was the hostess for the evening's activities, which included 13 World Class Figure Skaters performing their best routines.

The high temperatures outside were causing the ice to melt inside but the skaters didn't let that interfere with the caliber of skating that they presented to the audience. And the most important spectators were the 200 "cool kids" and their families that were the special guests that evening.

All proceeds from the event went to the Cool Kids Campaign to help publish the Cool Kids Connection as well as the Cool Kids Care Packages and to help start our Cool Kids/Cool Stuff Grant Program.

A special thanks to the skaters for understanding what kids with cancer go through and taking the time to help – Kimmie Meissner (of course!), Tanith Belbin & Ben Agosto, Jeffrey Buttle, Yuka Sato, Evan Lysacek, Michael Weiss,



Kimmie spends some time with a fan before the show.

Kimmie takes a moment to recognize the Cool Kids in the audience.

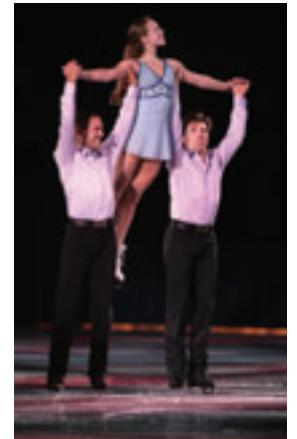
Johnny Weir, Joannie Rochette, Steven Cousins, Brooke Castile & Ben Okolski, and Jason Dungjen. With the ice skating season about to start, you can cheer on these athletes as most of them work towards the 2010 Olympics.

To see more pictures from the evening and see each performer go to our website, www.coolkidscampaign.org ■

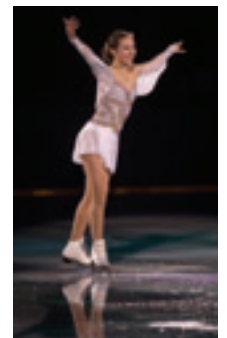
Large photos by Mitch Stringer. Other photos by Rich Dennison.



Some flowers for the evening's hostess.



The opening number included a special escort by Steven Cousins and Michael Weiss.



Taking a final bow after her "Angels" performance.

SEND US YOUR STORY!

Be a part of the next issue of the Cool Kids Connection!

Share your thoughts, feelings, fears, experiences, happiness. Our goal is to connect the pediatric oncology patients throughout the nation with each other. The Cool Kids Connection is published 4 times a year and sent to the hospitals. It is by you, for you, about you! And we need YOU to make it happen. We are looking for articles, stories, poetry, drawings, photographs, puzzles, jokes, questions...anything you want to share.

Please send your submissions by mail to:



**Cool Kids Campaign
9711 Monroe Street
Cockeysville, MD 21030**

or by email to sharon@bfpf.org

Please include all your contact information and a photo of yourself if possible. Please send only original art – we cannot use any copyrighted material. All submissions become property of the Cool Kids Campaign. This publication is offered free of charge to oncology hospitals and their patients. Funding is received through sponsors and advertisers.

For advertising information, please visit our website or email sharon@bfpf.org.

What Kimmie is thankful for... It is always good to sit down and think of all the things we are thankful for. I have met many people and had many experiences that I am very thankful for. The most important thing to me is my family. Without them I would not be where I am today, in my skating and in my life. My parents are amazing! They are very supportive and encouraging. They believe in whatever my brothers and I want to do and are behind us all the way. My brothers are great to be around. My life gets very hectic and it is relaxing to be able to come home and hang out with them. I knew that I would have to sacrifice a lot to keep up my skating, but my family has sacrificed just as much, if not more! I really love them and am so blessed to have their support and love. I am also thankful for my friends. At the Angels on Ice show, my skating friends did so well, and they were so excited to skate in front of the kids! At the show, I also had the opportunity of seeing many of the Cool Kids. I am happy to say that they are all doing very well, when just a year earlier they were so sick. It makes me unbelievably happy to see these kids with hair! I am very thankful for being able to see these transformations and being able to meet so many great people. I have been blessed with a great family and friends and I hope to continue having the opportunity to help people. So whenever you get a chance, we should all think of the people who mean the most to us and thank them for being so wonderful. Best wishes!

COOL KIDS Activities

THANKSGIVING TRIVIA

Let's see how much you know about the holiday

- 1) Thanksgiving is only celebrated in the United States. True or False?

2) The Greek Goddess of Corn is:
a) Demeter c) Ceres
b) Cornucopia d) Grainophillia

3) What is the name of the famous rock credited to where the Pilgrims first landed?

4) The Indians who were invited to the Thanksgiving feast were of the Wampanoag tribe. Who was their chief?
a. Massasoit c. Samoset
b. Pemaquid d. Squanto

5) What was the name of the ship the pilgrims came over on?

6) Who was the captain of this ship?

7) What was the original name for the pilgrims?

8) The first Thanksgiving in 1621 was believed to have lasted how many days?
a) 1 day c) 7 days
b) 3 days

9) Before being harvested, the average cranberry must bounce how many inches to be sure they aren't too ripe?
a) 1 inch c) 3 inches
b) 2 inches d) 4 inches

10) How long was the voyage from England to the New World?
a) 66 days b) 106 days c) 146 days

11) Of the original 102 pilgrims that came, approximately how many survived to celebrate the first Thanksgiving?
a) 101 b) 50 c) 10
- 12) Which of the following 3 foods that we normally do not eat today at Thanksgiving was an original food that the Pilgrims ate back in the 1600's?
a) roast beef c) ham
b) codfish

13) The Mayflower was not built to be a transportation ship for people. What was the original purpose of the Mayflower?
a) As a merchant ship to carry wine
b) As a fishing ship
c) As a ship to get spices from the Far East

14) Plymouth Rock today is as big as:
a) The size of a car engine
b) The size of the nose on a face on Mt. Rushmore
c) The size of a regular mailbox

And finally, check this out....

- 15) Which of the following were approved table manners at the first Thanksgiving?
a) to eat with your hands
b) to spit on the floor
c) to throw bones into the hearth when done
d) all of these

Puzzle Answers...

1) False - Canada celebrates a Thanksgiving also. They celebrate it on the 2nd Monday in October.
2) A - Demeter (Ceres is the Roman god of grain); 3) Plymouth Rock; 4) Massasoit; 5) Mayflower; 6) Christopher Jones; 7) Puritans; 8) B - 3 days; 9) D - 4 inches; 10) A - 66 days; 11) B - it is believed that 50% survived; 12) B - codfish; 13) A - as a merchant ship to carry wine; 14) A - about the size of a car engine. It's been cracked 3 times and each time has gotten smaller; 15) D - all of these were okay!!



Thanksgiving Word Search

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

BAKE	FEAST	PIE
COLONY	GRANDMAS	PILGRIMS
COOK	GRAVY	SNOW
CORN	HAM	STUFFING
DRESSING	INDIANS	THURSDAY
FAMILY	LEFTOVERS	TURKEY

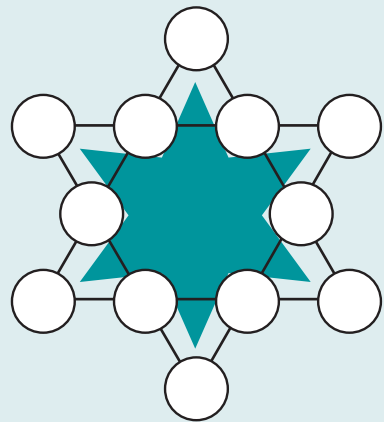
Computer Word Search

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

CD	HARDWARE	MONITOR
CHIP	INPUT	MOUSE
DISKETTE	KEYBOARD	PRINTER
FONT	LAPTOP	SOFTWARE
GAMES	MEMORY	TRACKBALL
HARD DRIVE	MODEM	

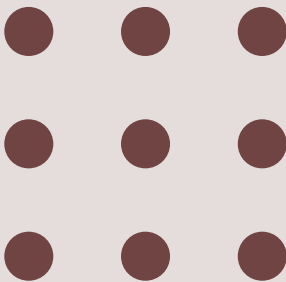
Super Number Star

The numbers 1 up to 12 must be placed in the circles of the star shown on the right. The sums of the numbers in each row, and the sum of the numbers in the six outer circles of the star, must be equal 26.

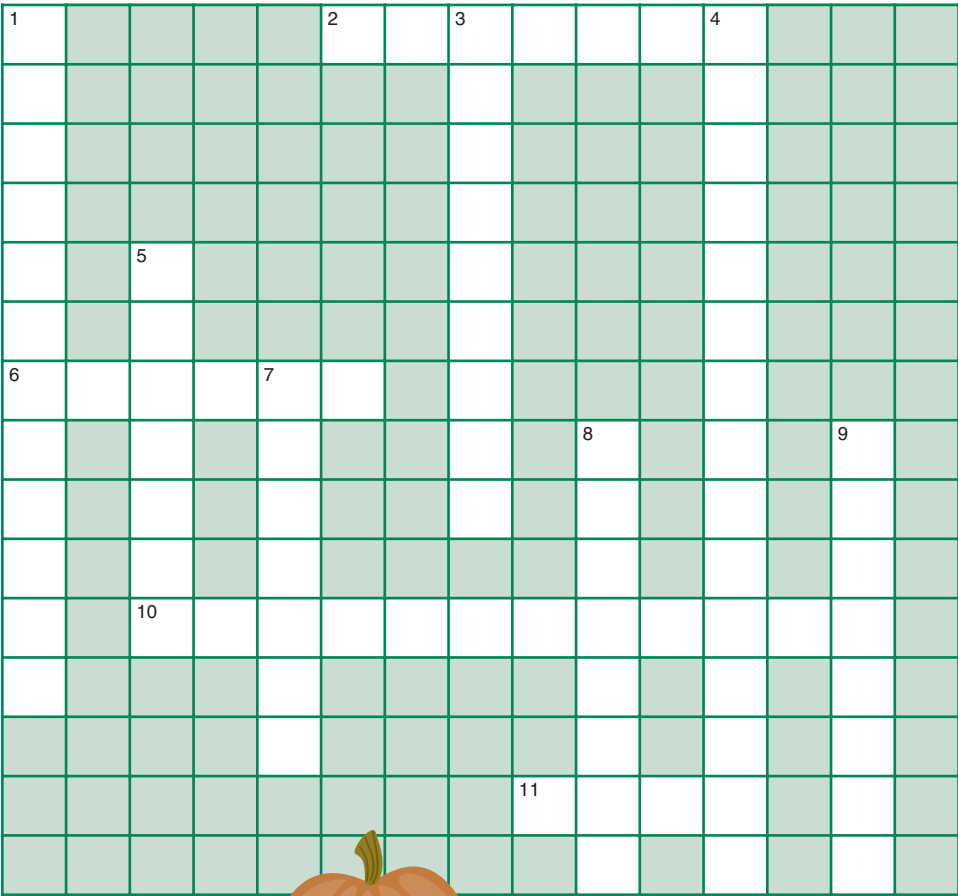


Nine Dots

Nine dots are placed in three rows of each three dots, as shown in the picture. These nine dots must be connected by four straight, connected lines (i.e. without 'lifting up the pen' in between).



The Question: How should the four lines be drawn?



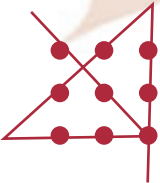
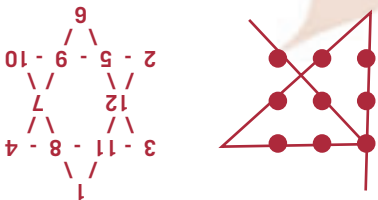
Thanksgiving Crossword

Across

- 2. This pie is a Thanksgiving favorite.
- 6. A meat served on Thanksgiving Day.
- 10. A holiday that is celebrated the fourth Thursday in November.
- 11. a yellow vegetable

Down

- 1. A boulder in Plymouth supposed to be where the Pilgrims disembarked from the Mayflower.
- 3. The name of the Pilgrim's Ship
- 4. The original people of America.
- 5. The season of gathering crops.
- 7. The country the Pilgrims came from.
- 8. The Pilgrims wanted freedom of _____.
- 9. A group of people that came over on the Mayflower



Puzzle Answers...

Text Message Quiz

Text messaging is all the rage! Cover the right hand column and test yourself or quiz the 'rents to see if they are up on the current IM and text lingo.

ABBREVIATION	WHAT IT MEANS
A3	Anytime, anyplace, anywhere
143	I love you
2G2BT	Too good to be true
404	I don't know
4COL	For crying out loud
^5	High five
BFF	Best friends forever
CU2	See you too
CD9	Code 9, meaning parents are around
COS	Because
CULA	See you later alligator
CYA	See you
DD	Dear or darling daughter
DS	Dear or darling son
G9	Genius
GR8	Great
T+	Think positive
j00r	Your
WH5	Who, what, where, when, why
WU?	What's up?
XOXOXO	Hugs and kisses
YF	Wife
YT	You there?
SYMBOLS	WHAT IT MEANS
((H))	Hugs
:-x	Kiss on the lips
:-&	Tongue tied
:-#	With braces
O:-)	I'm an angel
(:-D	Gossip, blabbermouth
@>--:--	A rose
=^.^=	A cat
:-D	Laughter

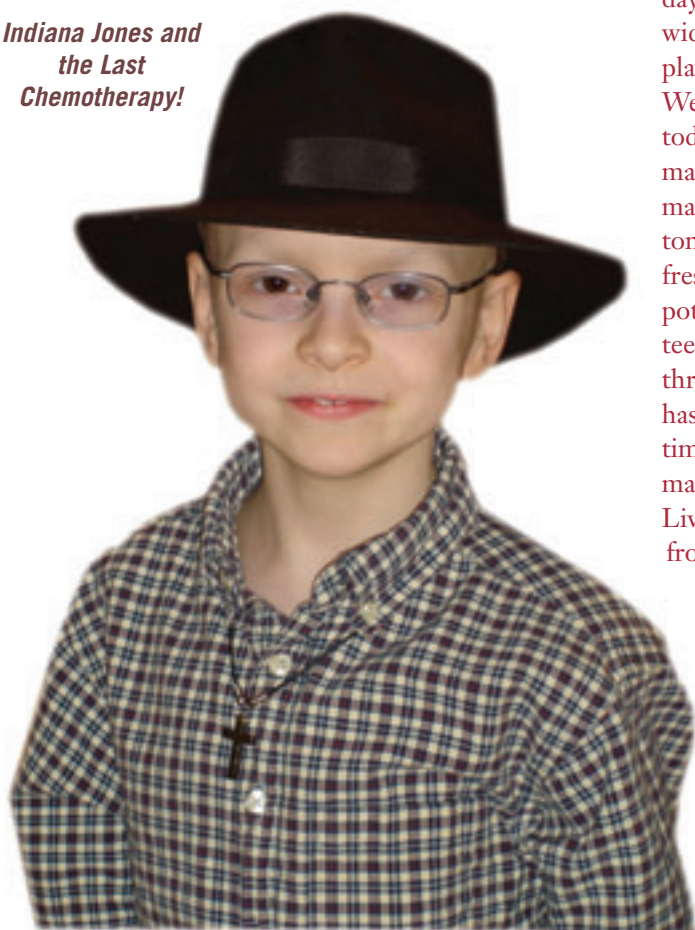
Ben's Journey

Editor's note: This is the 4th installment of Ben's Journey, one family's experience with their child's cancer diagnosis and treatment. Ben was diagnosed with Ewing's Sarcoma in January, 2006 and spent the entire year fighting the disease. Following is his journey last fall told by his mom, Sue, along with the actual emails she sent out to family and friends during that time. You can read the first 3 articles on our website, www.coolkidscampaign.org.

Before we knew it, the lazy days of summer were behind us and we found ourselves caught up in the routine of being back in school. Olivia was enjoying life as a middle-schooler and Ben was happy to have Ms. Risberg back as his home tutor for 4th grade. We were blessed to have Ms. Risberg again. She really had a way with Ben and they had formed a wonderful relationship.

We were starting to count down the number of chemos Ben had left. We had lived by numbers for the past nine months—ANC, WBC, monocytes, hematocrit, days until casts come off, etc—but this was the sweetest number yet. This upcoming chemo would be #11 out of 14, so we were down to counting on one hand! It was very exciting...combined with a pinch of scary. We were anxious to see how Ben was going to do

Indiana Jones and the Last Chemotherapy!



with these last four chemos, especially since they were going to be done without the one nasty medicine that we had come to despise. We were still taking things day by day, trying not to get too far ahead of ourselves! Don't get me wrong, we couldn't wait to put this all behind us, but after you depend on a team of doctors and nurses to steer you through each day for a whole year, you're not that eager to step back out on your own. We had come to rely on 'our team' to tell us if it was okay to go out, okay to have visitors, okay to just relax and breathe easy. It was going to be difficult to let go of that safety net.

9.20.06

Hi All...Just wanted to let you all know that chemo # 11 is now under our belt! Ben tolerated it well. This is our first time without the "red devil," so it was cause for celebration! He had a little trouble with the Cytoxan....the one that runs for an hour. It has always given him a bit of discomfort when breathing through his nose. It either burns or is very cold when he breathes in. Usually, he gets through it okay, but today was a bit of a struggle. He toughed it out, though. It was also bingo day at JH, where they have hospital-wide bingo over their TV. We always play when we're down there on Wednesdays. Ben won twice today...woo hoo! That always makes him feel good! Daddy made a wonderful dinner for us tonight...the kids' favorite (salmon, fresh green beans and smashed potatoes) and, boy, did Ben eat like a teenager! It didn't take long, but he threw it all up and was very sad. He hasn't gotten sick from chemo in a long time, so I don't know what's going on, but maybe he just ate too much. Anyway, he and Liv are happily tucked in bed, exhausted from a long day.

And, just to catch you up on what's been going on the past few days...Oh, you know there's always some kind of excitement going on around here! We were able to go to church on Sunday--Woo hoo! Ben had his friend Tim over afterward and they had a great time. Of course, as boys will do, they were antagonizing Olivia (although she is not as innocent as she looks) and before I knew it there were screams and cries. Apparently, they went down like

dominoes with Ben landing on the bottom. His right foot was hurt and he couldn't bear weight on it. He calmed down and we iced it and elevated it. It showed no signs of bruising or swelling, but he said it throbbed. We made it through Sunday night and on Monday took him to see our pediatrician. She ordered an x-ray, over which there was some debate, so we took the x-ray with us today to our orthopedic surgeon who did Ben's surgery. She reviewed the films and looked Ben over and decided it was probably a pulled Achilles tendon. So, physical therapy is on hold until he can bear weight, and he just has to stay off of it until he is ready to use it again. His cane is due to be delivered sometime in the next week or so. He was doing really well with the shoe and one crutch, so I hope his Achilles heals quickly because I'm anxious to see how he does with the cane. He's fine, though. No freaking out....I didn't, so you can't either.

And, one more thing, there is a little 3-year old girl named Rachel who had brain surgery yesterday because of a tumor that had been causing headaches. The tumor was found to be an aggressive type of cancer, and another tumor was found on her spine, for which she will have to undergo chemo and radiation to try to shrink. Please keep Rachel and her family in your prayers. I always know I can count on "my" prayer warriors. I pray her family can find the same peace that has helped carry us through this very scary time.

Blessings,

Love you guys!
Sue



Ben likes to hang out with his attending physician, Dr. David Loeb, because he wears cool shoes!

We weren't sure if we'd always have that 'black cloud' hanging over us, afraid to move forward, afraid to live freely, always afraid "it" would come back. We still had some time to wrap our heads around it all—but now we needed to focus on the moment.

We had come this far and needed to just appreciate everything we had already gotten through and be thankful that we were still standing strong, together.

It was amazing that just a few months ago Ben had his hip

totally cut out of his body. He had gone from a full body cast, to a wheelchair, to a walker, to crutches, to one crutch, to a cane, to walking with no help in just three months. We were told that it could take a year for him to be on his feet so confidently! Ben's physical therapist, Nancy, really knew how to get him moving. Believe me, he wanted it too, but it was scary and uncomfortable at times. Very few people have had this surgery, so none of us knew what to expect with Ben's

recovery. Nancy would even come to the clinic while Ben was having chemo just so he didn't miss a PT visit. She made it fun too, always bringing games and toys that would keep Ben on his feet.

We soon realized that we were starting to experience 'anniversaries' and it was a bit weird, yet very cool! We were beginning to come full circle. Ben turned 9 at the end of October. A year ago, on his 8th birthday, he was getting his first x-ray for the pain he was having in his leg. Wow...it was wonderful to not have him going through that awful pain anymore, and to know that the origin of that pain was not only killed, but removed! Woo hoo—bring on a new year! Ben's birthday was wonderful! He was surrounded by friends and had the world's coolest magician perform for them. His smile lit up the whole room. It had been a long time since he could be together with all of his friends. Two days after his birthday Ben had chemo #13....the second to last one!

10.31.06

Hey gang...

Chemo # 13 is now a memory. Yesterday went well. Thankfully it was only a one-day treatment because Ben had some weird reactions throughout the day. He did okay, but first it was a question of whether he would be able to even have the chemo. Once the counts were back and the doctors conferred, they decided to go ahead with it. They also wanted him to get a unit of blood while we were there. So, if you all recall from previous updates, this is the chemo that causes Ben to have problems with breathing through his nose. His intake of breath feels so cold that it burns and makes him very uncomfortable. This drug runs for an hour and it's only during the last half hour that this complication bothers him. (the longest half-hour in the history of half-hours)

He screams, holds his face, squishes up his nose and is just plain uncomfortable. Not thinking, I gave Ben lunch right before this all happened (a tuna fish and cheese sandwich). Anyway, once all this pain started it caused his lunch to come right back out. He was so violently sick that it caused petechiae all over his face (broken blood vessels). He recovered okay from being sick, but never looked "right" from that point on. After the chemo ended, they hooked him up to get one unit of blood. During the transfusion I pointed out to the nurse that he just didn't look right, so they did his vitals. Everything checked out okay, so we just watched him. He's never had any problems receiving blood before. This time he started getting hives. Thankfully, the blood was just about finished, so they just disconnected him from it. They normally would've treated him with Benadryl, but since he had so few hives we just watched him and they slowly went away. Overall, we got through the day. Ben did well. He wanted to go to Friendly's last night for dinner, so we did that and it was nice. That was the first time we've been out to dinner as a family in a long, long time!! Today, he still has the petechiae "mask" around his eyes and has had moments of feeling queasy, but for the most part he's doing okay.

So, to catch you up on some tidbits that have

happened since my last update...

~Ben actually rode his scooter on two separate occasions!! Once with Barry and once for his physical therapist. He had been asking to do so for a while, but we were always afraid to let him. Usually Barry is the scaredy-cat, but he took Ben out in the court while I was running errands one day.

They were so tickled with themselves when I got home and they couldn't stop talking about how well Ben did and how much fun he had.

~This past weekend was Ben's 9th birthday! He had a wonderful birthday! He was showered with cards, gifts, and plenty of love from all of his friends and family! He remembered that his 8th birthday was spent at Advanced Radiology getting his first x-ray...so it's almost like we're coming full circle now. He is very happy to be closing the chapter on age 8 and beginning anew with 9.

~Okay...lastly...we have one more chemo to go! WOO HOO! It's a five-day. It was originally scheduled for the week of Thanksgiving, meaning we would be outpatient for Monday, Tuesday and Wednesday....and then have to check inpatient for Thursday and Friday (since the clinic is closed for the holiday). That was okay by us. Whatever! We can eat turkey any day of the week...and we've learned to be thankful EVERY day of the week...so we were okay with postponing Thanksgiving.

Well, the docs apparently want to try to start chemo at a two-week interval instead of the three-week interval we've been using throughout the year. They've done



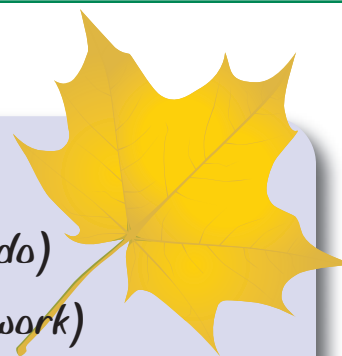
We did it!! Ben in his end of chemo shirt and Liv with her trophy for being a Super Sib!

Ben's Angel Craft

Materials needed:

- 1/8" ribbon or cord (I use blue or silver, but any color will do)
- 8 mm round bead (I use pearl or silver, but any color will work)
- #2 paperclip (also called butterfly clamp-available at Staples)
- sturdy needle

Cut a 12" strip of ribbon. Fold ribbon in half, end to end. Secure ribbon onto paperclip by putting the loop end of ribbon through the center of the paperclip, then pull the loose ends of the ribbon through the loop to tighten. Then, thread both ends of the ribbon through the hole in the bead and slide the bead down to become the "head." (this is where I use the needle to help thread and push both ends of the ribbon through the bead) Tie the ribbon into a bow or knot so it becomes a hanging ornament.



research on the two-week vs. three-week interval all year and now say that there is no difference, no harm in using a two-week interval. The benefit is that treatment is completed sooner. Ben's counts usually don't recover by the two week mark, but if they do we may just start his last chemo on the week before Thanksgiving. We just won't know until we have his counts done that day. So, stay tuned....the last chemo may start either on November 13th or November 20th....and either way we will have PLENTY to be thankful for this Thanksgiving!

I hope you are all doing well and enjoying the beautiful colors that fall has to offer. As always, thank you for your prayers, cards, meals, thoughts, calls, visits, friendship and love! We continue to be blessed each and every day, and we are so very thankful.

Love
Sue

It was hard to believe that Ben's last treatment was almost here. We were a mixed bag of emotions--and it was a BIG bag! At any given moment we could experience one or many of these emotions. It was like having a multiple personality disorder. We ran the gamut from happy to nervous, excited to uncertain, anxious to apprehensive, relieved to vulnerable, joyful to uneasy.

We were happy that the end of chemo was near, yet nervous that we'd never feel too far from this.

We were excited at the thought of getting our lives back, yet troubled that we'd never feel safe again.

We were elated that Ben was happy and healthy, yet concerned about what future effects these drugs may have on his body.

Again, we just had to step back and remember who was in charge here. All these feelings and emotions did absolutely nothing for us, except make us crazier. We put it all in God's hands and trusted Him to have a plan. After all, He had brought us this far. The only thing we had any right to feel at this point was thankful!!

11.18.06

Hello family...

Friday...an AWESOME day. Lots of friends, lots of fun. When his IV was finished today it made the ding-dong sound that it always makes, and Ben said that today it was saying, "I'm done, I'm done." The doctors, nurses, PAs, secretaries, techs, etc all gathered together and sang Happy End of Chemo to You. They gave him a big cake that said Congratulations Ben and a T-shirt that says "I Did It" and everyone from clinic signed it. Ben just beamed! It was so special! Some of his friends from clinic (who didn't have appointments that day) came in just to be there for Ben and wish him well! I

took lots of pictures that I'll post up on our site soon. It was so neat. Ben was tickled and kept singing the SpongeBob song "It's the Best Day Ever..." On the way home he called Olivia to tell her about his day, and she told us that she got her report card and made the honor roll! Then they both sang the Best Day Ever song! Ben came

home and ate four pieces of pizza and half a meatball sub....then threw it up and promptly sat down to eat the rest of the sub. He's doing just fine.

Everyone was asking how I felt. I thought I'd be over the moon, but I find myself hesitant to completely let go. Believe me, I am happy, very happy....but I also know that there are no guarantees. I think as time passes and we grow further and further from the clinic I may ease up a bit....but

***Surrounded by friends
(Amy, Griffin and Miss Tiffany)
on bingo day at clinic!***

I've also learned not to get too complacent. It's weird. We still have a long road ahead. Ben's counts were 290 Friday so he's officially neutropenic. We have to really lay low for a while. If he gets a fever we will have to check in to the hospital and stay until his counts recover. His counts may not recover until the 26th or later. Once we get through next weekend I think I'll breathe a bit easier. We've decided to postpone Thanksgiving this year. It will still be Thanksgiving, but we will just hold off on getting together with our families and having a huge meal. Nothing can stop us from giving thanks, though!! And we are overflowing with thanks to give! We are so blessed!

Right now, we're happy....all is well...the kids are playing...I'm trying to clean this house (and you wonder why my e-mails are so long....I'm avoiding cleaning). Actually, I'm just taking a break from cleaning. I did manage to find my kitchen counter under the many piles that have built up over the past week. It's all good!

I wish you all a wonderful, peaceful, safe, happy

Thanksgiving!! I give thanks each and every day for each and every one of you....and the many people you forward these updates to! God bless you!

Love,
Sue

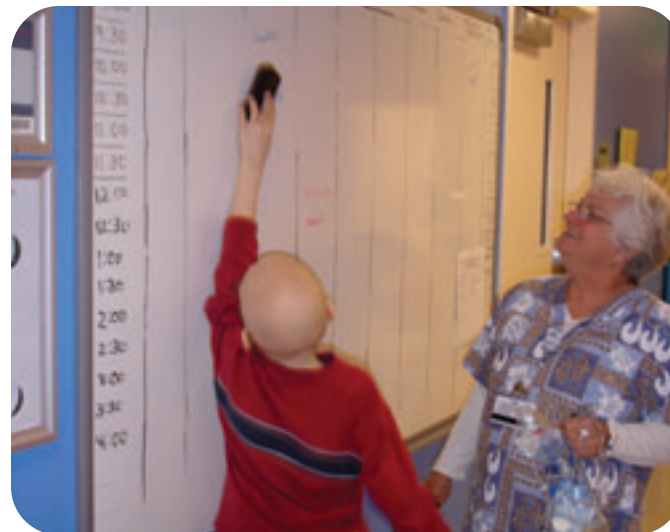
After the final round of chemo Ben's counts took a serious beating, not rebounding as quickly as we had become accustomed to because we had done chemo a week earlier than usual. I had been excited about December, thinking that we would have that whole month with good counts, able to go Christmas shopping, visiting friends, just enjoying being out with no restrictions, but we had to lay low for a few weeks longer than usual, until Ben's numbers came up. By mid-December he had 'okay' numbers, so we started venturing out. We took the Casey Cares Foundation up on their offer to see a sneak preview of the movie Charlotte's Web. Ben and Liv could even bring their friends, Maddy and Pat and Timmy. We saw friends from clinic there too, and Matt Stover, a Baltimore Raven, was there signing copies of the Charlotte's Web book and chatting with the kids. It was a great way to slowly start getting back into the world!! We were also able to start going to church regularly again!!

We wanted to do something special for everyone at the hospital who had helped us through this year, doctors, nurses, technicians, PAs, child life specialists, secretaries, etc. Liv, Ben and I racked our brains trying to come up with something that we could give everyone that wouldn't put us in the poorhouse. There were so many people who blessed us and we were determined to have something for everyone. Then, I remembered a craft we had made before that was easy, affordable and would allow us to make many. How perfect!! It was a

paperclip angel, made from a butterfly paperclip, a pearl bead and ribbon. We made over 300 and were so happy to be able to give angels to people who had been our angels. We had so many, we were even able to give them out to other patients, people in the elevator, parking lot attendants and anyone we passed along the way. We were so full of the Christmas spirit! Ben would see someone coming and say, "Mom, quick, give me another

one." People loved them! We were so blessed by the response to this simple little gift!

Right before school let out for the holiday I went to Ben's school to meet with his teacher, principal, nurse and counselor about him coming back to school. They were so great! They had continued to bless Ben and our family with visits, calls, notes, gifts, and cards the



***Nurse Shirley lets Ben erase
his name once and for all from
the patient board.***

whole time Ben was home, and now they were so excited to get a plan in place to help Ben with re-entry. None of us knew what to expect, but we were fairly certain that it would be a smooth transition. The school was ready for anything. It was so comforting to know that he was going to have so many people watching out for him, and he wouldn't even know it.

Christmas was awesome! We spent Christmas Eve with my family and Christmas afternoon with Barry's family, so we essentially packed three Christmases into two days. It was so nice to be surrounded by our families, having a meal together, going to church together, laughing together, celebrating Jesus' birthday together. Another full circle moment....last Christmas was wonderful, but had a touch of fear staining it. We had one last clinic visit scheduled for after Christmas. It would be the determining factor as to whether Ben would be able to go back to school after Christmas break, on January 3rd.

12.31.06

Hello family....

I was holding off on sending this e-mail for two reasons...one, I wanted to be able to tell you about our appointment on Wednesday...and, two, I knew it was most likely going to be my last update to you. It seems as though we've come full circle. This week last year was Ben's biopsy. We've come a long way, baby!

We had a wonderful Thanksgiving and a beautiful, truly blessed Christmas! Ben's counts took their sweet time coming up between his end of chemo and this week. I had imagined us Christmas shopping together, going out to lunch, etc. Well, it was only this week that his counts went up to a decent number. He had a heck of a time getting an ANC of over 300. Thankfully, at Wednesday's appointment his ANC was 1540! He was cleared to go back to school on Tuesday! WOO HOO! By then he should be over 2000. At 1540 he is considered "normal"...low normal...but normal. How awesome is that?! We don't even have to go back for another visit until February! We'll go back for Ben's next restaging scans (MRI, CT, bone scan, echo) and blood counts...and then his central line will be removed. I wish I could tell you in words just how blessed we all feel. God's got a plan for this boy!

Now, I know you all are thinking..."Sue, you're not going to know what to do with yourself once Ben goes back to school." Right? Well, I can assure you I will be just fine. There will be no tears shed here. This momma bird has both hands

poised and ready to shove that baby bird out of this nest and into the world again on Tuesday morning! We both need this. And I will have plenty to do to stay busy. I am looking forward to just being plain old "Mom" again.

Our baby girl (Olivia) turned 11 yesterday! She had a great day! We went to see Happy Feet and she had some friends over. It's been so nice to be able to go out again without worrying, and to have people over without dunking them in Purell first! We've done so much in the past few days and have seen so many people that I do believe we are starting to feel "normal."

It is nice to reflect back on all that this year has held and how well I think we all got through it, but I will be the first to tell you that I am SO looking forward to closing the door on 2006! 2006 will always hold bitter/sweet memories for us. It will forever be the year that cancer invaded our family...it will also forever be the year that we learned the depth and the breadth of our family and friends! We met so many wonderful people because of this experience. We learned so much. I honestly can't say it was a horrible year or even a bad year. It was definitely a full year, a busy year! It was full of blessings, too. I can say that this was the year of balance and perspective.

I do believe it was a year that has changed a lot of us forever...but not in a bad way. I have no complaints, no regrets.

I don't even know how to begin to thank you all. I must thank you for walking this road with us. It's been more like a roller coaster at times, but without you and your mighty prayers and our mighty God I don't think we would be at this wonderful place where we find ourselves right now. We know there are no guarantees in life....but we have learned to celebrate the moment...and this moment looks pretty awesome. We've learned that it does take a village and that our village starts as

close as next door and goes far across the ocean and reaches up into heaven. Your love, support, encouragement and faithful prayers have carried us this year. You have touched us in so many ways, forever

changing us. We have been brought to our knees in praise and in thanks so often this year. We have been awed, and humbled by it all. We were able to have many "It's A Wonderful Life" moments because of you. And when it came to blessings, size didn't matter...every last one was counted and not one will be forgotten...ever! I love you all so much!

Jesus has definitely had his hands full with us this year. He was always with us, leading us, holding us up, carrying us, pushing us forward, blessing us every step of the way. We felt His presence every single moment. Glory be to God...our little boy is back...healthy, happy, and going to school. He's an awesome God, a mighty God, and may He bless you and keep you in this new year. I wish you joy, peace, happiness and many, many blessings. Please continue to stay in touch.

With thanks and love, my heart is full...
Sue



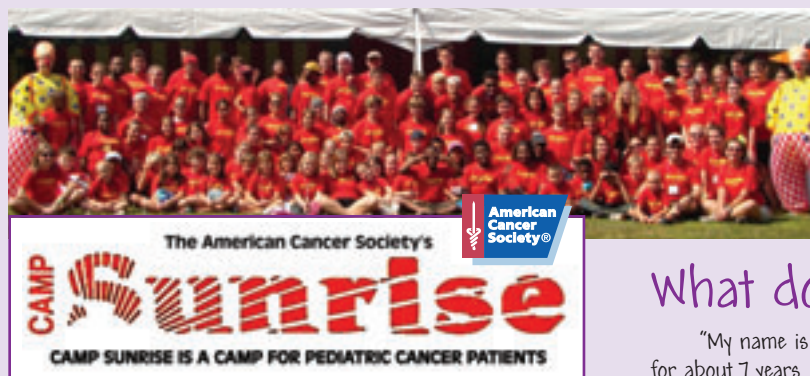
Our 2006 Christmas card. Real smiles for this Merry Christmas.

We tried to get used to the idea of Ben getting back on a school bus in a few days. Amazing how things can change so much in the blink of an eye, for better or for worse. Just one year...Last year that seemed like a lifetime. Now I'm wondering how it could be over already. Yes, at times one day could feel like an eternity, but as a whole it seems to have gone by rather quickly. All I can say is that we found blessings in each and every day along the way. We felt the prayers that went up on our behalf. We never knew what the outcome would be, and we still don't. No one does. I'm okay with that. My God has a plan...for me, for you and for Ben. That's awesome! Embrace it! He's in complete control and we're just along for the ride. Sometimes you coast along with the wind in your hair and the sun on your face, and sometimes you hold on tight and shut your eyes. No one ever said it would be easy, but the one promise He did make was that he'd be right there with you. And He was...and He is. ■

We will include Ben's update on his return to school in the next issue. If you would like to contact his family please email them at blanman2@comcast.net.



Chemo is always easier when you can clown around with friends.



By Bill Latham

I would like to let everyone know about "Camp Sunrise." The camp is free of charge and is open to any child that has been diagnosed with or recovered from cancer, no matter where you live or which hospital you are associated with. We have kids that come from New York and West Virginia as well as Maryland and the surrounding states.

Camp Sunrise is sponsored by the American Cancer Society, and is a camp for children who have been diagnosed with cancer. It is a special place where kids with cancer can simply smile, laugh and play; a place where they are not treated as "different" or "sick," a place where 4 to 18 year-olds can just be happy, fun-loving kids again.

Camp Sunrise is held for one week each August at Camp Hidden Valley. The residential camp offers older kids a traditional one-week, overnight camping experience. Activities include swimming, basketball, clowning, dancing, arts and crafts, sports, nature hikes, and much more.

These experiences are an important source of strength and support for all children. Campers walk away with team-building skills, self-confidence, friendships and memories. Campers still in treatment will receive the best care from a dedicated team of oncologists and oncology nurses 24 hours a day. The staff of volunteer counselors, from a variety of lay and medical fields, is dedicated to making the week as joyful and as normal as possible.

Sun Sibs is a program for brothers and sisters, which recognizes that siblings of children with cancer have special needs as well. To address these needs, a sibling camping weekend was developed in 1996. The Sun Sibs program meets one weekend a year, Memorial Day weekend.

When I ask my daughter, Brittney, what she thinks and likes about camp, she keeps it short and replies with: "I like swimming, dancing, playing, and making friends." Brittney will be 10 years post bone marrow transplant this January; she is a survivor of Neuroblastoma. This year was her 5th year going to camp, in December she will also turn 12. Every year she looks forward to going to camp so that she can see the many friends that she has made.

Photo from 2006 camp in which we had a circus come in for the week and the kids got to participate.

What do the campers think?

"My name is Daniel S. & I have been attending Camp Sunrise for about 7 years. Camp Sunrise is a great place to get away & forget about your illness. Every camper there has been touched by cancer & they don't look at you as being "different", it's like a big family.

I look forward to that week in August every year to see my friends and catch up on things. The staff works so hard every year to have a special event planned, so you have to go back to see what is going to happen next. The counselors

are like overgrown campers; they are helpful & like to have fun. I look forward to being a counselor & paying it forward & helping the kids have a Great experience at camp just like I have had every year. Go Camp!!!!"

By Daniel S.

Camp Sunrise.

They were words that I had heard before. They were words that I intended never to be associated with. I was very sick at the end of 18 months of Chemo. I was a thirteen

year-old girl going through treatment for medulloblastoma, or a cancerous brain tumor. I was bald and emaciated and only had energy for a few hours of sitting up in my wheel chair. Why would I ever want to go to a summer camp with other cancer freaks like myself? What would we do, play who can sit up the longest?

When I found out that my mother had signed me up to go to Camp Sunrise I was infuriated. I did everything in my power to make sure that I never set a foot in Camp Sunrise. Eventually my mom won and sent me to camp with the promise that if it was too much after two days, she would pick me up.

I found camp to be very different than I expected. Most of the campers there did not have cancer and in fact had not had it since they were very young. I also found that these normal campers accepted me for who I was in spite of my appearance and low energy level. I was warmly welcomed and instantly became friends with many of the girls in my cabin. These girls were my age and not just the little kids as I had expected. I was taken by golf cart to my different activities, instead of my usual wheelchair. The activities, such as arts and crafts, swimming, and nature, were not only normal but also a lot of fun, although I would not admit this for many months.

After spending most of my two days in the "funny farm," or hospital house, I took my mom up on her offer and left. I thought I was done with camp but I found myself repeatedly talking about camp. I told my parents of the wonderful campers and staff that I had met. I talked of the normalness of the camp and campers and how I was included in everything from activities to gossip despite my limitations. I also told my parents the most important thing about camp sunrise, acceptance. I was warmly accepted by everyone for who I was, not my cancer. I felt the unique bond that flows between all of the campers. I was included in this family, and it felt really good to be included in something again.

Camp is a great experience for anyone no matter if there are

four or forty. There are people of all ages who come to camp. I have returned to camp three times since my first year. This past year I was seventeen and a CIT, or a counselor in training. I loved working with the youngest girls cabin, but also enjoyed the free time I had to spend with my friends my own age. Camp Sunrise continues to grow every year in number and fun; and I can't wait to see what next year holds!

By Lauren M.

Lauren enjoys sharing her modeling tips with others.

My name is Katie Wilson and I am 15 years old. I was diagnosed with a brain tumor when I was 5 years old. Being young, the cancer didn't affect me too much. I really didn't know what was going on. All I knew was that I had to stay in the hospital for a couple days. One year after my cancer my mom had joined an email list for moms with kids who had cancer. She had gotten an email about a camp for kids who had cancer. It was called Camp Sunrise.

She got a little interested so she started doing research on it and was convinced that it would be a good experience for me. So that August she filled out my forms and I was off to camp. Since it was my first year and I didn't know anyone, I asked my mom and dad to drive me to the camp instead of making me ride the bus. When we got there they waited for me to get settled in before they left. That day I had met my counselors, my cabin mates, and the rest of the camp staff. It didn't seem so scary anymore. As the days went by, I was having so much fun. We went swimming, played sports, and even went bowling. It was one of the best experiences I've ever had.

That was about 8 years ago and I've been attending Camp Sunrise ever since. Each year is like the first.

There is always something new to do, and new people to meet. I've made many friends over the years and we still keep in touch today. Its like camp never really ends. I look forward to going to camp every year. I think it's a good opportunity for kids who have had cancer or who are still going through it to be able to get away from all the needles and tubes and just be a kid. I think Camp Sunrise should be introduced to all parents when their children are going through cancer so they have something great to look forward to.

By Katie W.

If you would like more info about Camp Sunrise, or you have a child interested in going to camp please call the American Cancer Society at 410-931-6850, ask for Kira Eyring. If you would like to see more pictures from this year or previous camps please go to www.campsunrisemd.com.

Hershey Characters meeting the kids.



Daniel is the one without the Hershey's syrup.



Here's Brittney singing Karaoke (she lost her hearing during treatment)



Katie and her friends before the dance.



Unexpected Opportunities

By Mrs. Myslivecek

I graduated from high school full of expectations and dreams of grand adventures after a very normal childhood. "Normal" being a life without much surprise and lots of consistency ... a good foundation to launch a career, find a husband and have a family.

Within a year, I had found Dean, who I wanted to marry. We talked of the future and having a family after our careers had been established. In two short years, we married and our family had begun – with Daniel.

We welcomed our first adventure and worked towards normal. Dean found a career after graduation and soon after, addition number two arrived. Determined to have a normal home before our family grew further, we worked fast and furious. Three years later, we had added a puppy, and Abigail; then 16 months, later David. I decided that normal really was having a few welcomed surprises along the way.

We were grateful to God for each of His blessings and moved on to child rearing, character training, church attending, healthy eating, careers, and exercise.

While performing a routine task of cutting the boys' hair, Dean accidentally clipped a mole on top of Daniel's head. We didn't know it until Daniel pointed out the swollen nodes on the back of his neck along his spine. With the help of our pediatrician, we found the clipped mole on his scalp; it had become irritated. After its removal and administration of antibiotics, the nodes returned to normal. The biopsy showed the mole was an atypical dysplastic nevus. Putting moles on a scale of 1-10, with one being normal and 10 being melanoma, atypical dysplastic nevus fell into the gray area of five.

Daniel, having an unusual amount of moles, could expect to have moles removed frequently over the course of his life and this too would be normal.

A year later in April 2004, weeks before his 14th birthday and right after finishing a week of service at Flower City Work Camp, Daniel mentioned that he had a swollen gland. That's how Daniel worked – being ill wasn't something we knew until he told us or acted out. The only way I knew he was sick was when I took him to the doctor who found a double ear infection; this had complimented teeth cutting up to age 12. I wondered what teeth he could be possibly cutting, so I expected to find strep. Silly us. I was beginning to learn that normal isn't welcomed surprises but unexpected opportunities!

That was the beginning of a grand opportunity we would not have believed if we were told. Without symptoms from the swollen gland in that area of his

neck, blood work was required. That led to surgical removal of the gland; within a week, we were facing the diagnosis of metastatic melanoma stage III – a prognosis of nine months or less.

Not knowing how to cope or where to find answers, let alone a reasonable treatment that offered hope,

Dean began to research and I began to email friends to ask for prayers. Daniel's response was, "Well, if I am going to die can I go to military school? Maybe they can send me overseas and I can help get Sadaam." To which any normal mother would respond "NO! You are too young, the army doesn't want you. I do." And I did.

"But Mom, isn't heaven better than here?"

"Well yes," I said, shivering at the reality he had accepted.

"Then I don't care when I go. I want to be happy and normal and help others before I go." Normal. What is normal? I don't know anymore. I consider myself normal and if that is what Daniel wants, being normal parents, we want to ensure his life is long and happy. In July 2004 after three surgeries, Daniel began treatment. A boot camp of another kind, one that will teach him perseverance, patience, and mature him beyond our years. We learned much from watching him march through one MRI, CT scan, IV in difficult veins, and clinical trial after another. All through a time in life when normal teens are at school, playing sports, going to proms, learning to drive, and concerning themselves with who is going where, not "what pill do I swallow next to stop this war within."

July 2005 a scan showed that our first of several attempts had failed. The cancer had spread to his hip, femur, lung and liver. We would definitely need a scan to show that, because to watch Daniel, you would think life was fine. He played soccer, went to school maintaining honor roll status, found a job, and was out with his friends. His peace and attitude of joy inspired us. The prayers that surrounded us made us able to live a life of chaos, finding only joy and peace.

August 2005 knowing we needed another clinical trial, we began researching and flying all over the country looking for the next best treatment. Daniel, being still a 'child' was not eligible for the most potent trials available, due to the risks. We began what was available, while pushing for IL2. A doctor in Colorado finally convinced the U.S. medical board that Daniel was a good candidate and to make an exception. With a clear MRI, we began traveling to Colorado monthly for grueling week long treatments. Daniel basically slept the week away as we prayed and waited.

January 2006 we found this wasn't working. Although the lesions hadn't spread to new areas, they had grown. Not until March did we find another possibility in Maryland at NCI. After two months, that no longer worked and the melanoma spread. We finally resorted to radiation. At this point, the cancer is in his lower spine and causing him pain. After many consults

with back surgeons, Daniel decided to let it go until he couldn't enjoy life and then agree to life altering surgery. We planned to finish radiation and take a new chemo pill on the road in our RV to "fish America."

Dean has the summer off from teaching and our family is avid fans of the outdoors. Daniel loves to fish for the aquatic species and has mastered the art of fly fishing. We decided to make it our mission to fish in as many states as possible while also fishing for the souls of men by assisting non-profit organizations along the way.

Normal is once again redefined as our used RV blew a transmission one state away and delayed our plans. While awaiting repairs for a week, we determine the chemo is too much for Daniel and take him off. He begins to come around and desired to continue our adventure. We fished along the way as Daniel found the energy, and made our first mission stop in Alabama to help with Katrina cleanup.

Within 24 hours and a stop at a local hospital, it was decided Daniel and I would fly home. That is where he wanted to be and we knew what kind of care he could get. Dean and the rest would drive the RV home within 24 hours. ■

EDITOR'S NOTE: Upon returning home, Daniel passed away shortly after. Here are his mom's emails after his passing.

July 11 and 13, 2006

Are things back to normal? Will they ever be? In the last year I have come to realize that things have always been normal. Normal is things going as you expect with occasional welcomed surprises. Normal is constant flow of unexpected opportunities. Daniel taught everyone he touched that life is all in how you look at it. He was a kid who always found joy in living and an adventure in the unexpected opportunities. The doctors and nurses were amazed and touched by who he was. By the grace of God may we inspire others as well.

I close with an email the day of Daniel's Celebration of Life Service. It shows you that despite our having a need to be normal, God blessed us in the midst of it and we remain forever changed.

July 16, 2006

Six months after Daniel passed away we had lost two great-grandmothers. Our youngest daughter, Abigail, was diagnosed with severe aplastic anemia the day before her 10th birthday. Just four short months later and a long February in the hospital wondering if she too would move on, we are again reminded of normal. Her treatment is working and her spirit is high. We each continue to miss and talk about Daniel. Through this all it has become evident if we continue to love and bring joy to others because of the unexpected opportunities and not despite them, you will be blessed with JOY. That, my friends, is normal.





Luke: Our Pride, Our Joy, Our Miracle Boy

By Luke's Mom (Suzanne G.)

I wrote this poem one night last week when I could not sleep thinking about all that Luke has been through this past year. This poem is dedicated to the following: Dr. Peter Phillips and the rest of the Neuro-Oncology Team, Sr. Alice (Hospital Chaplin), Kate Murphy (Luke's primary nurse), the Transplant Team, all the Doctors, Nurses, Nutritionists and Therapists that have treated Luke over this past year as well as all the clerks, environmental service attendants and volunteers. Without you all we would not be where we are today. Hope you enjoy! God Bless you all! ■

Our son, Luke Thomas Gilligan, we're so proud of him.
Writing this poem but where do I begin?

Doctor's told us it was a virus five days in a row.
But I guess as they say a mother always knows.

The ride to CHOP was nerve racking it's true.
But we never expected our worst nightmare come true.
A mass in Luke's head is what we were told.
How could it be he is just one year old?

Brain surgery one day, shunt surgery the next,
broviac placed in our beautiful baby's chest.
We look at him lie there in that hospital crib
And wonder why this happened to our precious kid.
Tests, cat scans, MRIs galore,
How much more can our baby endure?

Chemo is scheduled, it's about to arrive.
We will surely do anything for our Luke to survive.
Nausea starts with mouth sores in tow.
Our hearts break with sadness but the cancer must go.

A trip to the PICU not once, but twice.
Being back on the third floor would really be nice.
He plows through the hurdles and comes out with a grin.
With an attitude like that we know he will win.

Keep praying for our son this is all we can ask
Until this terrible time is long in the past.
We will be at his wedding and
raise a toast to him and his bride

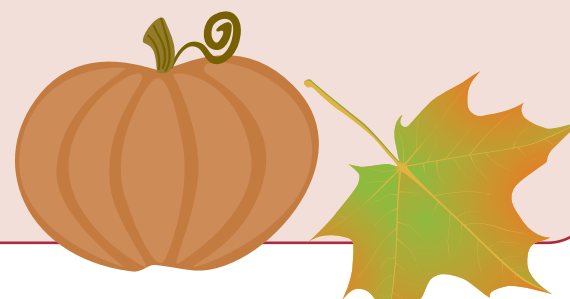
And look at each other and say "boy, what a ride."
Life is so precious; it can change on a dime
But faith in God will get you through it every time.

A big thank you to all the Doctors and Nurses at CHOP
Because of all of you Luke has made it to the top.
Special thanks to Sr. Alice, our spiritual guide.
She was a great comfort and always by our side.

Please pray for all the children and
parents in the midst of the fight.
Many of them will be our friends for life.
But remember those children who have passed away.
We will be thinking of them each and every day.
We don't know why they were taken oh so young.
But hope and pray their families stay strong.

We thank you all for your continued prayers.
It's so comforting to know so many care.
Luke's cancer is gone, the treatment is over.
It's time to go home and begin to recover.
We are packing our bags and jumping with joy.
It's time to leave the hospital with our beautiful boy.

Happy Birthday to you, Luke. You'll be turning two.
Just know Mommy and Daddy are so proud of you!



OCTOBER 13

NOVEMBER 10

DECEMBER 8

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At 6 months, Kayla received a complimentary photo session from the "Flashes of Hope" Foundation. Kayla is such a strong little baby, but her eyes dive right into your heart in this photo, which tells a story of the sadness underneath it all.



Kayla's Story

...and how you can help through the Conquer Childhood Cancer Act

By Julie W.

Our first baby girl! Life was great! My husband and I had been in love for 9 years; what could be better than expanding our family and sharing our love for a child! Our baby Kayla was born August 30, 2006. I had a great pregnancy and she was delivered with no complications. Everything was wonderful! She was so beautiful and had her daddy's big, blue eyes that would melt my heart with just a glance. I stayed home with Kayla for a couple months worth of maternity leave. It was precious time (more than I would ever know). After I went back to work, Kayla began eating less and less. She started vomiting frequently, and the pediatrician started treating for acid reflux (a common infant condition). We were changing formulas, trying different prescriptions, etc. Her check-ups and physical examinations had always been fine. She slowed down on her weight gain, but her doctor wasn't too concerned just yet.

It was 3 days before Christmas (the day before we were set to leave for our first family vacation to Baltimore to visit all of my family and Kayla would meet her Nana and Pop Pop and Aunts!). We had scheduled a trip to the pediatrician to do a weight check

on Kayla to make sure she was still gaining. Her weight was fine, but upon examining her physically, her doctor was concerned with her belly. She couldn't tell if it was just full of air, or if there might be another reason for its sudden firmness. At this point, I was so hyped up and excited to go on our trip, I really didn't think twice about it. She said she just couldn't sleep if she didn't take a step further. She ordered some blood work and even an ultrasound at a local radiology building. We left the office and it wasn't until I was sitting in the lab waiting room that I had this overwhelming fear come over me. What would I do if something was actually wrong with Kayla? I started making phone calls, just in tears with everyone. I wanted to start the prayer chain as soon as I could. Kayla was poked and had her blood drawn. While that was processing, we headed to the radiology building. It was now that I called my husband, Jason, and told him to stop what he was doing and meet me. I knew an ultrasound would show immediate images and I couldn't handle it alone. Little did I realize, this was daddy's little girl ... how should I expect him to handle it? It was a rough exam as Kayla was very hungry and very squirmy. However, they saw enough to be able to measure a 4 cm mass outside her

adrenale gland. I can't even describe the fear, pain, physical heart ache, stress, and basically literal torture that overcame us. I am confident that other parents in our situation can completely relate. It is an experience I would never wish upon even the worst of people.

Unfortunately, our story just gets worse from here and this would be the first of many "torturous" moments. We were sent to an oncologist immediately after her ultrasound. Little did we know, we would never visit her pediatrician again. This oncologist

One dreadful night when Kayla was rushed to the OR, mommy and daddy promised her anything she wanted if she came back to us! We said she would have a pony and anything else in the world. Well, she came back to us. :)

gave us the news that Kayla most likely had the malignancy called Neuroblastoma. Holding on to our last hope that this could be a benign growth was in the past. We were truly facing a nightmare. Not only did this tumor present itself as this mass outside her

After 2 weeks and 5 surgeries to try to control Kayla's bleeding, the doctors were finally able to close Kayla's open abdomen. She continued to suffer from skin irritations and extreme swelling. Kayla was 4 and a half months old. She remained on the ventilator for 3 more weeks.



How old is Kayla? She just had her first BIG birthday August 30th! She's our little princess and so smart that she knows lots of signs. Ask, "are you one?" and she'll tell you!

would show that the tumor had spread into her liver. Her liver was actually what her pediatrician was feeling

firm into her abdomen. The tumors had completely invaded it, increasing the size significantly to where it was now down into her pelvis. Both Jason and I had to hold ourselves up to keep from passing out. It was just that devastating. She wasn't even 4 months old. Merry Christmas!

Once Kayla was diagnosed, her condition continued to worsen. She was admitted the day after Christmas to obtain a biopsy of the tumor. What was supposed to be a quick, overnight trip turned into a 5 week stay on the ventilator in the PICU and 4 more weeks on the oncology floor. I didn't realize laying Kayla on the operating table December 26th would be the last time I would have her in my arms for almost a month. Kayla had developed a bleeding disorder because of the strategic positioning of this tumor in her liver. They opened her up in the OR and she had no way to clot her blood. She bled out for 2 weeks, receiving at least 100 blood/platelet transfusions. It was an absolute miracle she survived the 5 trips to the OR those couple of weeks. They also decided to begin chemotherapy even though this was NOT the conditions within which chemo should be inducted. They just had NO more options. Kayla is truly our miracle baby. She came home on oxygen and a feeding tube as she had to be completely rehabilitated after so long being unconscious. She graduated from those pretty quickly and continued to receive chemo treatments. She stopped those around May 2007. The doctors and experts expected her type of Neuroblastoma (Stage 4-S) would regress on its own. Kayla was doing awesome! She was crawling, laughing, playing, and loved being around lots of people. In July Kayla started to show symptoms again. She didn't want to eat anything, she was fussy and



Daddy, Mommy and Kayla - Here we are again, "Team Kayla" is ready for another fight with Kayla's most recent cancer progression.

didn't want to go out and she was losing weight drastically. This was NOT Kayla. After several trips back to the doctor, they discovered her tumor had progressed. We went from one CT scan in July that showed no changes to a scan and several other tests in August that showed her tumor had spread all over her body. It invaded all the cavities of her belly, her pelvis, her lymph nodes, her lungs, her bone marrow and her little bones. Once again, Jason and I became physically sick and had to jump back on this rollercoaster of pain and despair. She was now a Stage 4 Neuroblastoma patient. She was not even a year old. We are now in the middle of a high risk protocol which will include very intense chemotherapy, surgery, a bone marrow transplant and possible radiation therapy. We know we will get through this. Kayla is the strongest PERSON I know, let alone a 12 month old baby. I have full faith in her and in God that he will show his grace through Kayla.

As a first time mom, this experience can lead to so many questions. I begin thinking why didn't I know? What could I have done? What can I do now? I feel one of the most overwhelming fears of a parent of a child with cancer is that there is nothing we can do to fix them. Tylenol won't work; a cuddle and a lullaby won't make their pains go away. We aren't doctors and we have to put our faith in the experts, the research and the medicine. Kayla has an unbelievable following through CaringBridge.org (visit kaylaweber) and MySpace. A group has gathered together called "Team Kayla." We are going to do whatever we can to fight for these children while they are battling for their lives. The advances in medicine in this country are superb – some of the best in the world. However, 25% of children with cancer will still lose their fight. The number is about 25 points too high in my opinion. Cancer is the #1 disease killer of our children. These babies and adolescents are being treated with the same drugs 60 year old men and women receive. The many that do win their battle are likely to be left with lifelong complications from these treatments. There is a bill trying to make its way to a vote in Congress right now. It is called the Conquer Childhood Cancer Act of 2007. The group behind the bill is the Children's Oncology Group united with the National Childhood Cancer Foundation. They are the foremost researchers of children's cancer. We believe the children need attention on a level different from adults. They need segregated funding and grants and other aids in research. This bill will do so much for them! I will pass on giving more details and refer you to www.curesearch.org and www.myspace.com/team_kayla. CureSearch's "Reach the Day" campaign is an awesome way to get involved right online! Team Kayla can tell you more about the bill and some great ways to get in touch with your Congressmen!

Getting involved in this way is therapeutic to me. I can no longer sit back and ask, what can I do? We can do something! I urge you to get involved. We are the ones these Congressmen want to hear from. We are the ones with the voices that could help so many children dealing with this unimaginable disease! ■

*Alyssa and her
Child Life
Specialist,
Holly*



JUST IN TIME FOR THANKSGIVING...

Readers share what they are thankful for.

I am thankful for my Mom and Dad, my sister and my dog. I am thankful for my good toys, my Wii, my Webkinz, and that my counts are really high right now! I am thankful that I am not at the hospital right now!

Emily G., 5 years old

I am thankful for my parents, my sister and dog. I am thankful that my parents buy me treats, and my toys. I am thankful that my parents love me. I am thankful that my sister's Leukemia is getting better. I am thankful for my clothes and my good grades!

Allison G., 9 years old (Emily's sister)

My name is Luke D. I am from WV and I am 11 years old. I am thankful for God, I am thankful for God through Leukemia and everything else he has done for me in the past and in the future. I am definitely thankful for my mom and dad and everybody else in my family and everybody who helped us while I was sick. I am thankful for Iris my friend who has helped me a lot.

Luke D., 11 years old

My name is Alyssa G. I am eleven years old and for the last four months I have been battling cancer. When I first got diagnosed I did not know what to expect. I was scared sometimes. I didn't know that I was about to meet a dear friend and her name was Holly Senn, my Child Life Specialist. I met Holly the very first day I was in the hospital, I had to get an IV and I was scared. She said that it would be very quick and would not hurt much and she showed me how it was done. That made me less frightened. She also made sure she was always there for me from that day on whenever I had to go through a surgery or procedure. She also made sure the service dogs visited me in the hospital because she

knows how I love dogs. I'm thankful for Holly because she made a very hard time in my life a time full of fun and memories.

Alyssa G., 11 years old

There are so many things I have to be thankful for. First of all, I have to give my thanks to God for providing me the strength to carry on. When we first heard the news that our son, Matt, had leukemia, it became a life changing moment for my husband and me. We were in shock and didn't know what to expect. An instructor at the Medical College of Virginia (MCV) by the name of Marie Chapin was helping out in the Pediatric Intensive Care unit and she shared a devotional with me that basically said "In a time of crisis, we

learn the difference between believing in God and trusting him." I will always be thankful for her willingness to share the devotional with me because it helped me to focus and learn to just trust God.

I'm also thankful for the great pediatric hematology/oncology doctors (Dr. Nancy Dunn, Dr. Cliff Russell, Dr. Asad Kahn, Dr. Gita Massey, and Dr. Kamar Godder), the terrific Nurse Practitioners (Anne Mauck, Debbie Shockey and Elizabeth Hall) and the best nursing staff (Kathy Tofferi, Jill, Jennifer, Debbie and Lindsey) at the Nelson Clinic at MCV. Their willingness to share their time and knowledge while treating Matt has also been a help to our family adjusting to this life changing event. We are also thankful for the wonderful supporting staff at MCV, the nutritionists (Karen Schmidt and Sara SeagoBlanton), Dr. Matt Bitsko, Clinical Psychologist, Sister Vicki Busch, Jim Bonomo and many others. They have all touched our lives in a very positive way.

Special thanks also go out to our family and friends for all their prayers and support. This was the key to our survival. My parents came from Kentucky to stay with us for five months to help us run our household while we cared for Matt. Our daughter, Sarah, was a senior in college and was there for her brother whenever Matt needed her. Our friends from work and school brought us many

meals to help ease our life. Matt's teachers at Collegiate gave of their time to help tutor Matt and the school community kept Matt involved with visits, e-mails, cards and gifts.

We have met many people throughout this life changing event and our life has become more blessed for which we will always be thankful.

Debbie W., mother of patient



Allison & Emily



**Luke shares what he is
thankful for.**



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