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Connecting pediatric oncology patients throughout the nation.

Cool Kid Emily and her Idol Experience

*How one Cool Kid got to
meet her American Idols*

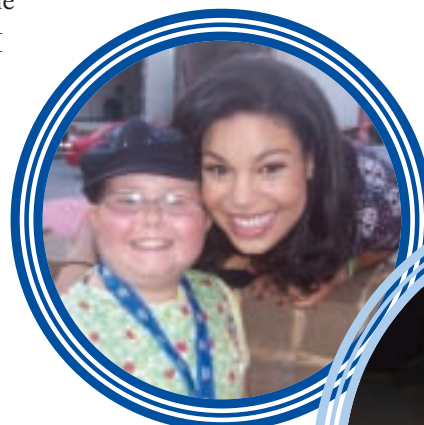


By Emily Z., Johns Hopkins Hospital, Leukemia

When American Idol was on TV, there was this one boy named Phil Stacy and when I saw him, I really wanted to meet him. So, when I got to the concert, I actually got to meet all of the idols including Phil!!!! It was a dream come true. When I went to meet the idols, 1st Mariner Arena told everybody that we could take pictures but not with them but my mom asked them and they told us to stay in the back of the line and I got to take pictures with them and with Phil!

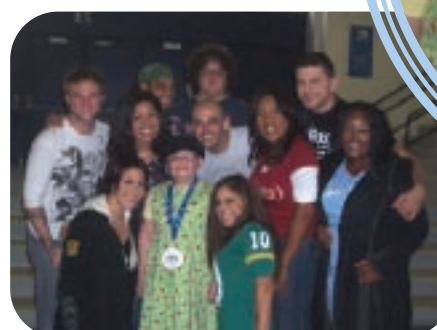
Then, after I met them, we saw them outside signing pictures for other people. I told my dad I wanted to see who was going to be outside. While they were signing autographs I heard "Emily, Emily," it was Gina, one of the idols and then after I saw Gina I saw Melinda and she was smiling and said "Hi Emily!" Then we were going to go inside to get our seats but then we heard that Jordin Sparks was on the other side and I told my parents that I wanted to get an individual picture with me and Jordin because Jordin was my second favorite on American Idol. When we finally got to Jordin, she asked me what kind of music I liked, I said Country then she told me that her and Chris Richardson were going to sing a country song and she told me that she would dedicate the song to me. To remind her, she wrote my name on the palm of her hand and then she started to sing my name. I couldn't believe it!!!!

When we got inside we sat down. I was a little worried because we had my wheelchair and we had nowhere to put it. So, my mom went down to talk to the 1st Mariner people and they said that they would move our seats near the stage so I could sit in my wheelchair. It was amazing! While the concert went on, Jordin kept her promise and she dedicated the song to me. Then, out of nowhere Gina sang her song and when she was done, she said "that was for you Emily." I was shocked!! My favorite part of the whole night was Phil Stacy dedicated a love song to me and a country song too. I loved every minute of those 2 songs. When there was a little break, two girls came up to us and introduced themselves. They were Chris Richardson's cousins. One of the girls actually has Lymphoma and she was wearing a wig because her hair was falling out. She also just heard that she has Lymphoma. It was a wonderful night!!! ■



Emily's favorite, Phil Stacey.

Jordin Sparks greets Emily.



Emily is surrounded by the American Idol cast before the concert.



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Day +434 Post Transplant, 344 Days Cancer Free!

And They Said He Wouldn't Make It...

By Janelle R., Hershey, PA

As another holiday passes I reflect on the things that have changed since last year at this time.

In the beginning of November last year Sean was fighting for his life yet again after being diagnosed with Stage 4 GVHD (Graft vs Host Disease) of the gut and the skin. At this point his skin was "melting" off of his body and blistered everywhere. His insides were almost like being eaten away from the GVHD. We had to heavily medicate him so much he did not wake for days, only to keep him comfortable and so he would not feel the pain.

The risk of infection was extremely high as his skin was raw and anything could have infected the open "wounds." This was one of the hardest times since he was diagnosed in June 2006 with AML (Acute Myelogenous Leukemia - type M2). The doctors told us that with Stage 4 GVHD most patients don't make it through and that they will do all they can to "keep him comfortable." It seemed at that point that our beautiful little boy was not going to be with us much longer.

This was not the case as our brave son fought with all his might and miraculously he pulled through and overcame his GVHD. Something the doctors could not explain...we as a family needed no

explanation...he was still with us and that's all that mattered!

Now here he is today only 1 year and a few days later!

This is why we are thankful. Sean was not supposed to live through this or his cancer or the mold in his lungs, the list goes on and on for things that he should not have lived through, but he has! I don't care how or why, all that matters to me is that he is still here in our lives! For his life I am thankful!

I am thankful for my whole family, our 4 beautiful children, our lives would not be the same without any of them! They each give something great to our family! I am so thankful for Sean (Daddy) for being my rock forever and always!

Thankful to my parents (all 4 of them) and my in-laws for supporting us through this whole thing! From day one to today all of you have been there and helped us so much! For this we are thankful, more than you will ever know!

Thankful for all of my friends, those of you who are still in contact with me and even those of you who are not. The friends who have stuck through this with me till today, I commend you! I know I was not easy to deal with throughout most of this, but you guys never gave up on me! I love you all and thank you!

All of the doctors and nurses and all the staff at Hershey Medical Center for treating my son and our family like we were your family! To us you guys are part of our family!

Thankful for all the help and support that different agencies and people have given us! Thankful for all the people who helped with fundraisers (there are too many to name!) for us it really meant a lot, everything each and every one of you have done!

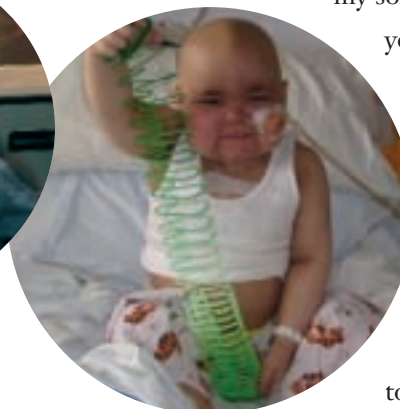


Doctor Scrubs – +42 days post transplant, October 2006. Sean gets discharged for the first time in over a month.

Sean, just one week after being diagnosed with AML, June 2006.



First major hair loss from chemo, July 2006. But it won't keep me from spiking my hair.



Easter 2007, keeping busy during treatments.

Capitol Area Head Start and Ms. Susan for being there for Sean and being understanding about his condition and all the special needs he would have in order to attend school! Thankful for Love INC for welcoming us to Hershey and allowing us to meet so many new people!

Thankful for my wonderful friend Christine! You are a Godsend and you have helped in so many ways, not just with your physical help but your words and wisdom for that I am thankful! You say how our family has touched many lives, well you my dear have definitely touched ours! Thank you Christine for all that you do!

I must end this now, as it was hard for me to reflect back on this past year and all the hardships we have endured and overcome. It took a lot for me to get my feelings down and out of my head! I feel like a weight has been lifted off of my shoulders!

Thank you to each and every one of you who follow My Bears Journey, for you we are thankful! ■

The fish was this big, I promise!



Sean's most recent picture, November 2007.

Back to school! September 2007



Kids (and Companies!) HELPing Kids!

Thanks to... Jana R. who produced a full scale skate show, Gliding for Kids Cancer, and raised over \$2,500 for the Cool Kids Campaign.

Thanks to... Barnes & Noble for their holiday book drive which brought in 677 books to be distributed through our care packages.

Thanks to... Allison G. and Alex P.! The girls made scarves and sold them to their friends at school to raise money for the Cool Kids Campaign. Allison's sister, Emily, has recently been treated for ALL.



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.



Winter Fun Depends on Where You Live

By Molly Lauryssens

Now that the holidays are over and winter is here it's time to redefine fun. Winter officially started December 22 and will end March 20. So for roughly three months how will you have fun? Will you put on your snow skis or strap on a snowboard? Will you pull out your water skis and water boards for some fun in the water? It all depends on where you live.

According to the 2008 Time Almanac, the United States is 3,676,487 square miles of which 3,537,439 square miles are dry land areas. With this mammoth area many climates are incorporated; it doesn't snow everywhere.

For instance, in the small town of Christmas, Florida the temperature in January and February can reach as high as 72. Surely they won't be using their snow gear, if they have any at all, or they'll have to travel to use it. In fact, the sunny state of Florida has seven cities that rank among the nation's top ten hottest cities.

In Michigan, in another town called Christmas you can bet you'll need snow skis and warm weather gear. People there don't have to travel far to have a white Christmas! They know what snow is all about. Christmas is located on Lake Superior and for fun they dog-sled, snowmobile and ski.

Still, when a lot of people think winter they can't help but think snow. It makes you wonder, what is a snowflake anyway? The National Snow and Ice Data Center (NSIDC) says that snowflakes are agglomerates (to collect or gather in a cluster or mass) of many snow crystals. Most snowflakes are less than one-half inch across, although in certain conditions two-inch snowflakes can form. Snowflakes form in the atmosphere and not at the surface. It can snow whether temperatures are below or above freezing.

So whether your winter includes snow or sun, don't let the colder months keep you holed up in the house. Dress appropriately for the weather and go enjoy the great outdoors!



Check it out....

Be Greater Than, an inspirational t-shirt company headquartered down the street from the Cool Kids Campaign, now has youth sizes in the B> cancer model. A percentage of each t-shirt sale is donated to the Cool Kids Campaign. Email Kelly@bgreaterthan.com for more information or check out our website at www.bgreaterthan.com

What do you want to be greater than?





COOL KIDS Activities

Pale Gail

Gail had been sick so she was feeling quite frail. Frail Gail was told by her doctor that she was cured and now hale and hearty. So hale frail Gail decided to go to the beach and get a healthy tan so she would not be pale hale frail Gail. But one day a dead whale washed up on the beach behind her home. Hale pale frail Gail could tell it had been a male, but now it was quite dead. So hale pale frail Gail's stale male whale sat outside her beach house while she thought about what to do with it.

Gail decided to see if she could sell part of the whale, so she advertised in a newspaper that the flukes were for sale. Hale pale frail Gail's stale male whale tail sale caused a lot of people to visit her house and pretty soon people had trampled a path into her back yard and on to the beach. To protect her flowers Gail decided to put up a rail along the trail to the whale. Hale pale frail Gail's stale male whale tail sale trail rail worked quite well except that one nail she used to make the rail stuck out and stuck anyone who bumped into it. Hale pale frail Gail's stale male whale tail sale trail rail impale nail was a hazard. So much so that one person sent her a letter threatening to sue if the nail was not fixed. Hale pale frail Gail's stale male whale tail sale trail rail impale nail convinced her it was time to go home from the beach.

What's in a name?

You know the names of all 50 states...but do you know where any of them come from? Here's the best information we could find on the origin of each.

ALABAMA Possibly from the Creek Indian word alibamo, meaning "we stay here."

ALASKA From the Aleutian word alakshak, which means "great lands," or "land that is not an island."

ARIZONA Taken either from the pima Indian words ali shonak, meaning "little spring," or from the Aztec word arizuma, meaning "silver-bearing."

ARKANSAS The French somehow coined it from the name of the Siouan Quapaw tribe.

CALIFORNIA According to one theory, Spanish settlers named it after a utopian society described in a popular 16th-century novel called *Serged de Esplandian*.

COLORADO Means "red" in Spanish. The name was originally applied to the Colorado River, whose waters are reddish with canyon clay.

CONNECTICUT Taken from the Mohican word kuenihtekot, which means "long river place."

DELAWARE Named after Lord De La Warr, a governor of Virginia. Originally used only to name the Delaware River.

FLORIDA Explorer Ponce de Leon named the state Pascua Florida - "flowery Easter"—on Easter Sunday in 1513.

GEORGIA Named after King George II of England, who chartered the colony in 1732.

HAWAII An English adaptation of the native word owwhyhee, which means "homeland."

IDAHO Possibly taken from the Kiowa Apache word for the Comanche Indians.

ILLINOIS The French version of the Algonquin word illini, which means "men."

INDIANA Named by English-speaking settlers because the territory was full of Indians.

IOWA The Sioux word for "beautiful land," or "one who puts to sleep."

KANSAS Taken from the Sioux word for "south wind people," their name for anyone who lived south of Sioux territory.

KENTUCKY Possibly derived from the Indian word kan-tuk-kee, meaning "dark and bloody ground." Or kan-tuc-kec, "land of green reeds", or ken-take, meaning "meadowland."

LOUISIANA Named after French King Louis XIV.

MAINE The Old French word for "province."

MARYLAND Named after Queen Henrietta Maria, wife of English King George I.

MASSACHUSETTS Named after the Massachusetts Indian tribe. Means "large hill place."

MICHIGAN Most likely from the Chippewa word, micigama, for "great water."

MINNESOTA From the Sioux word for "sky tinted" or "muddy water."

MISSISSIPPI Most likely taken from the Chippewa words mici ("great") and zibi ("river").

MISSOURI From the Algonquin word for "muddy water."

MONTANA Taken from the Latin word for "mountainous."

NEBRASKA From the Otos Indian word for "broad water."

NEVADA Means "snow-clad" in Spanish.

NEW HAMPSHIRE Capt. John Mason, one of the original colonists, named it after his English home county of Hampshire.

NEW JERSEY Named after the English Isle of Jersey.

NEW MEXICO The Spanish name for the territory north of the Rio Grande.

NEW YORK Named after the Duke of York and Albany.

NORTH AND SOUTH CAROLINA From the Latin name Carolus; named in honor of King Charles I of England.

NORTH AND SOUTH DAKOTA Taken from the Sioux word for "friend," or "ally."

OHIO Means "great," "fine," or "good river" in Iriquois.

OKLAHOMA The Choctaw word for "red man."

OREGON Possibly derived from Ouaricon-sint, the French name for the Wisconsin River.

PENNSYLVANIA Named after William Penn, Sr., the father of the colony's founder, William Penn. Means "Penn's woods."

RHODE ISLAND Named "Roode Eylandt" (Red Island) because of its red clay.

TENNESSEE Named after the Cherokee tanasi villages along the banks of the Little Tennessee River.

TEXAS Derived from the Caddo Indian word for "friend," or "ally."

UTAH Means "upper," or "higher," and was originally the name that Navajos called the Shoshone tribe.

VERMONT A combination of the French words vert ("green") and mont ("mountain").

VIRGINIA AND WEST VIRGINIA Named after Queen Elizabeth I of England, the "virgin" queen, by Sir Walter Raleigh in 1584.

WASHINGTON Named after George Washington.

WISCONSIN Taken from the Chippewa word for "grassy place."

WYOMING Derived from the Algonquin word for "large prairie place."

Brain Benders

- 1) yyy u r, yyy u b, l c u r y+y 4: __!
- 2) When is four half of five?
- 3) Why are 2008 pennies worth more than 2007 pennies?
- 4) What letter is next in this sequence?
M,A,M,J,J,A,S,O,__
- 5) What can run but never walks, has a mouth but never talks, has a head but never weeps, and has a bed but never sleeps?
- 6) What is full of holes but still holds water?
- 7) What happened in 1961 and will not happen again until 6009?
- 8) What in an automobile engine serves no purpose but without it the engine does not work?
- 9) Johnny's mother had four children. The first was April, the second was May, and the third was June. What was the name of her fourth child?
- 10) A man left home running. He ran a little and then turned left, ran the same distance and turned left again. When he got home there were two masked men. Who were they?
- 11) You are driving a bus. Four people get on, three people get off, then eight people get on and ten people get off, then six people get on and two more people get off. What color were the bus driver's eyes?

Puzzle Answers...

- 1) Wise you are, wise you be, I see you are too wise for: ME!
- 2) When it is a Roman Numeral: F(IV)E.
- 3) Because it's one more penny.
- 4) N for November
- 5) A river
- 6) A sponge
- 7) The year reads the same upside down.
- 8) Noise
- 9) Johnny!
- 10) The catcher and umpire.
- 11) Whatever color your eyes are, you are driving the bus.

Cool Kids co-founder, Kimmie Meissner, has drawn some pictures and needs you to color them in for her!



Let's see how many words you can make out of the following phrase...

Cancer Fears Me™

Ben's Journey

Through the eyes of cancer;
a brother and sister
share their experience
with the disease

An interview with Ben and Olivia Lanman

Editor's note: We have been following the journey of Ben and the Lanman family in the past four issues of Cool Kids Connection. Ben has successfully completed his treatments for Ewing's Sarcoma; he was diagnosed January 2006. To wrap up the family's journey, we asked Ben and his sister, Olivia, for their perspective on the experience.

From BEN ... a cancer survivor's perspective

Ben: I felt amazing when I finished chemo and didn't have to do it anymore. Although I would miss my friends, I was still happy that I completed what was meant to be done. I feel like I've gone through a lot and now I can do almost anything if I try my best and never give up. Although I have a limp and I can't walk as well as I used to, that hasn't changed my personality. I'm still working on trying to put on my socks and tying my shoes, but I know I will get it done because anything's easier than having cancer.

It feels amazing finally just to be able to be calm and chill out instead of going back and forth to the hospital. It was really, really hard and painful to have to go to the ER all the time when I got a fever. I feel like I have been there all the time and just want to be able to

have a cold and stay home. I kind of miss being the person that everybody knows about, but I do just want to be a normal kid – and normal kids don't get that much attention. It did help me to know how much people were praying for me and thinking about me. A lot of people care about me.

CKC: Before you were diagnosed and weren't feeling well, did you have any idea that it could be cancer?

Ben: When my leg hurt at first I thought it could be serious because my leg usually doesn't throb. It really was painful. I thought I broke my leg or something, but cancer was the last thing on my mind.

CKC: Who told you that you had cancer? Did you understand?

Ben: Dr Weber told me I had cancer. I don't remember exactly what she said, but it almost made me faint because I was scared. I knew what cancer was, kind of, but I didn't know what causes it or what would

happen to me, what it could do to me. I still have no idea where it came from, no one does. I wondered a lot why I got cancer or if I might get it again.

CKC: Did you understand how serious it was? Many times when people are given bad news, they go into denial. Their brain downplays the importance of the situation. Did you do that?

Ben: I understood it was serious, but I was about to say, "I can't handle it. I'm just a kid. I'm not supposed to have cancer at my age." It made me feel like I was about

Ben and Olivia walking the beach in Ocean City, MD.



"I used to be just a regular kid, but now I feel like I've done a lot and can do anything. It changed me in a way where I think, If I can get through cancer, I can get through anything."

to die because I was really, really scared – and I didn't feel that well when I heard it. I felt sick to my stomach. I don't think I

downplayed it at all because I couldn't get it out of my head. I felt like I would never have fun again.

CKC: At what point did you get scared?

Ben: When I first heard I had cancer I stopped being scared when I got to meet all the doctors and nurses who would help me. They were really nice and seemed like they knew what they were doing. I felt safe in their hands.

CKC: At what point did you start to feel very sick?

Ben: I didn't feel sick. I had a pain in my leg. I actually first threw up because of the chemo medicine. I would describe it as a medicine that makes your throat hurt really bad. It makes you throw up and not be able to eat for a few days, but then you'll feel better. Everything was bad about it, but I think the worse thing was the surgery. When I woke up from the surgery I wanted to scratch myself, but the body cast covered my whole body.



Christmas 2007!

CKC: What was the worst part about having cancer?

Ben: The worst part – everything was bad about it, but the chemo medicines made me feel sick. The people with central lines or the ones who have to take that medicine will know what I'm talking about.

The best part – there is not a "best" part, but the end-of-chemo party was pretty great. Even though I

met a lot of famous people, one of the best friends I met was Kimmie Meissner. She really helped me. She gave me a lot of hope. She's a very nice person.

I don't think having cancer changed me, but I do feel like I have more friends now.

CKC: Do you think having cancer changed how you handle things like stress or a problem?

Ben: I used to be just a regular kid, but now I feel like I've done a lot and can do anything. It changed me in a way where I think, "If I can get through cancer, I can get through anything – just thinking that I can accomplish anything as long as God is with me." I always knew God was with me because it's a fact. When I'm in hard times Jesus is with me and helps get me

"A smile lets them know that I'm okay and happy. I didn't want people to feel sorry for me."

"If I can get through it, you can get through it. It stinks but you'll get used to it because it's the same thing over and over again."

have to be prepared for my future. I felt a lot better just knowing that a lot of people were praying for me, even people I don't even know.

CKC: How did it feel when people stared in public at your cast and your bald head?

Ben: Most people looked at me like, "Aw, poor thing ..." and others looked at me like I was weird. My mom always said that whenever that happened to look back at them and smile. A smile lets them know that I'm okay and happy. I didn't want people to feel sorry for me. I just wanted them to think that I was a regular kid that's going through a lot, but is doing alright.

CKC: Did keeping a positive attitude during treatments help you get better faster?

Ben: Having a positive attitude did help because being positive and happy made it easier for the people around me. Being down or negative wouldn't help me or them.

CKC: If you spoke to a child who hasn't yet started chemo, how would you describe it?

Ben: After I was doing it (chemo) for a while I knew what it felt like and what to expect. You just get used to it.

CKC: What would you want other kids to know who have been recently diagnosed with cancer?

Ben: I would say that if I could get through it, you can get through it, too. It stinks, but you'll get used to it because it's the same thing over and over again. I'll pray for you and I know the doctors will



Swimming during a school trip to Tennessee.

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take good care of you because they took good care of me. I would want them to know that it is difficult getting through all that stuff, but my parents, my friends and other people I never even met were praying for me.

"I felt like giving up a lot of times, but I didn't because no one should ever give up no matter how hard things get. You just do your best."

CKC: Sometimes it's hard for adults who have never been sick to understand. What would you tell them?

Ben: I would like to tell adults that if anyone they know has cancer they should treat them with more care.

CKC: Did you ever feel like giving up?

Ben: I felt like giving up a lot of times, but I didn't because no one should ever give up no matter how hard things get. You just do your best.

All my friends helped me to feel normal and better because they played with me the same way they did before I had cancer. It was fun. They helped me through hard times. They helped me forget about the pain and being sick.

Prayer definitely works because God hears you. With God next to you, you are safe in whatever you do. I feel very lucky that I am a cancer survivor because I know that not everyone survives. I first was afraid that I would die, but then I thought, "Hey, if I die, I get to meet Jesus and all my fears would be taken away." But I'm glad I didn't die because I wouldn't have met all my friends. I met a lot of friends during chemo who I would play with at clinic. Billy and Griffin were always fun to play with

and they helped me take my mind off of chemo and being at clinic all day.

From OLIVIA ... a sibling's perspective

CKC: How did you feel when you first found out Ben had cancer?

Olivia: At first I didn't believe it. It was too scary for words.

CKC: Did you understand what it meant? Who told you?

Olivia: I didn't understand. My head was spinning. My mom told me and was just like, "Liv, we are going to beat this cancer," and I was like "WHAT!?!?"

CKC: How did Ben's cancer affect your family's home life?

Olivia: We were constantly going to and from the hospital for treatments or fevers, sometimes in the middle of the night. Sometimes I got shuffled around to different people and sometimes I got yanked out of bed in the middle of the night.



The whole family riding the OC Rocket in Ocean City, MD.



At the survivor wall in Tennessee with Liv's DI coach, Lisa Brown, also a cancer survivor.

Finally swimming again with Liv and Grannie once the central line was removed.



Look who we met in Sea World!

"Sometimes I got shuffled around to different people and sometimes I got yanked out of bed in the middle of the night."

"I did feel jealous of all the attention Ben got. I felt totally ignored."

CKC: Did friends and relatives treat you differently?

Olivia: Relatives definitely treated me differently. If Ben was in the room they would be all over him. If we were alone in the room, my relative and I, but Ben was in the house they would go to where Ben was. If it was just me and them in the house they would ask me questions about Ben. One person who didn't ignore me, though, was my cousin Kayleigh. She paid more attention to me because she understood how I felt and that I felt ignored.



It didn't seem like he would want to smile again, but it does happen!

CKC: Were you able to concentrate at school?

Olivia: School was where I could get away from it all. I got straight A's in school and my friends helped a lot by acting like nothing had ever happened; they distracted me.

CKC: People tend to pay attention to a sick child. It is normal for siblings to feel angry or jealous. Did you feel this way, and how did you deal with it?

Olivia: I did feel jealous of all the attention Ben got. I felt totally ignored, sometimes having to spend the night away from home so my parents could focus more on Ben and his medical needs. I felt like they just wanted to focus on Ben and nothing else. I wrote in a journal sometimes. Other times I talked to my cousin and friends.



Not only riding, but jumping the scooter!

CKC: How is your life different now? Have you seen anything positive come from this experience, and in how you handle stress?

Olivia: Life is fine. I know Ben is okay because he still gets on my nerves sometimes. Even though Ben doesn't have cancer anymore people still treat him differently and give him more attention. I now have a stronger bond with my family. I am still very bad at handling stress.

"Life is fine. I know Ben is okay because he still gets on my nerves sometimes."



First Day of 5th Grade!

Ben's mom, Sue, wraps up her journey as she moves into their new "normal" without hospitals, tests, and central lines being part of their everyday lives.

Hi again,

I feel so blessed to be sitting here writing this wrap up of 2007. Looking back now on 2006 seems so strange because it's getting further and further away.

Back then I don't think we ever imagined we'd feel this comfortable again. It's amazing how quickly "normal" came creeping back in. 2007 dawned with promise. Ben went back to school in January. His central line was removed in February. His hair and eyelashes slowly started coming back. We had Ben's first follow up testing in February also. All was clear, except for some stress fractures in Ben's legs which we were told not to worry about. His bones were still weak from having been in the body cast and would take some time to get back to normal. We then went back every three months for the same full day of tests and scans. It never gets easy, though. That day is always one that is treated with a little anxiety and more prayer than usual. We tend to

hold our breath until all the results come. So far so good, though. Praise God.

By spring, Ben was on his scooter and working hard to ride a bike. At first he could only do it standing up because his hip (or lack of one) didn't have the range of motion to pedal up and around. Somehow, within a month or two he was sitting down. We still don't know how he does it. Soon after, much to our dismay, he was back on his skateboard and pogo-stick. There's no stopping him! Even Dr. Weber is pretty amazed! We did a lot of vacationing in 2007, too. We went as a family this time to Knoxville, Tennessee with Olivia's Destination Imagination team when they made it to the Global Challenge. We went to Ocean City, Maryland,

thanks to Believe In Tomorrow. And we went to Give Kids the World Village in Kissimmee, Florida thanks to The Make-A-Wish Foundation. We had an incredible time everywhere we went, met some wonderful people and created some awesome memories as well! We also just loved being home, having our friends and family around, going here and there on a whim, being back in church.

We really made up for lost time this year. To look at Ben now, you'd never know what he's been through. The only clue that remains is the big shoe and the limp, but some people don't even notice that. We've learned that in a few years Ben may be able to have a procedure called an Epiphysiodesis where the growth plate in the knee of the "good" leg is drilled into to stop its growth, allowing the other leg to continue growing and catch up to the other. How amazing is that? So, one day even the big shoe will be no more. We'll see... For right now, all is well.

We have certainly learned to look at everyday problems a little differently. We don't seem to sweat the small stuff as much as we used to. Perspective is everything. We don't dwell on it, but we will never forget where we came from. We continue to be blessed every day and we continue to be thankful every moment. God is so good....all the time! Woo hoo!

Take good care, Sue

To get in touch with Sue, Olivia, or Ben you can email them at blanman2@comcast.net ■



Star Up Above

*By Jenifer K., Age 10
Leukemia, West Palm Beach, FL*

There lived a star way up above. His name was Rookie and all of the other stars made fun of Rookie. Then one night Rookie fell out of the shining sky.

Rookie was very sad and wanted to go back home! A boy was walking and heard someone crying. When he followed the sound he saw a star.

He said "Are you okay?"

"No," said the star, "I wanted to go home!"

"Where do you live?" said the boy.

"I live in the sky," said the star.

"What is your name," said the boy.

"My name is Rookie," said the star. "What is your name?"

"My name is Max."

The star started to glow. The boy said, "what is happening?"

"You make me so happy that I'm going in the sky. Thank you," said Rookie. "Don't be sad, I will watch over you."

I Wish I Was Big

*By Jenifer K., Age 10
Leukemia, West Palm Beach, FL*

There lived a fish under water. He was the only tiny fish under water and his name was Leo.

Everyone made fun of him. He was very sad and one day the shark came and he saw everyone but Leo.

Leo came to the shark and said "I bet you can't catch me." So the shark turned to Leo and said, "You want to see if I can catch you? Okay, let's see what happens if you get eaten up."

So the shark started to chase Leo. Leo was swimming so fast you couldn't see him. So the shark said, "I give up, you win, but I will come back again."

Everyone cheered to Leo and Leo said, "It's no big deal."

My Life

By Jose Garcia

I used to believe that I was never going to go to the hospital and stay there.

But now I have been hospitalized for 2 whole weeks.

I used to believe that I was never going to get surgery.

But now I have had two.

I used to believe that I was never going to need chemotherapy.

But now I get chemotherapy every week.

I used to believe that I was going to be cured in a couple of weeks.

But now I know it takes about four to six months.

I used to believe that the type of cancer I have was never going to be so painful.

But now I know that it is a hard and painful process.

Snowman
Puzzle

Created by Dani D.

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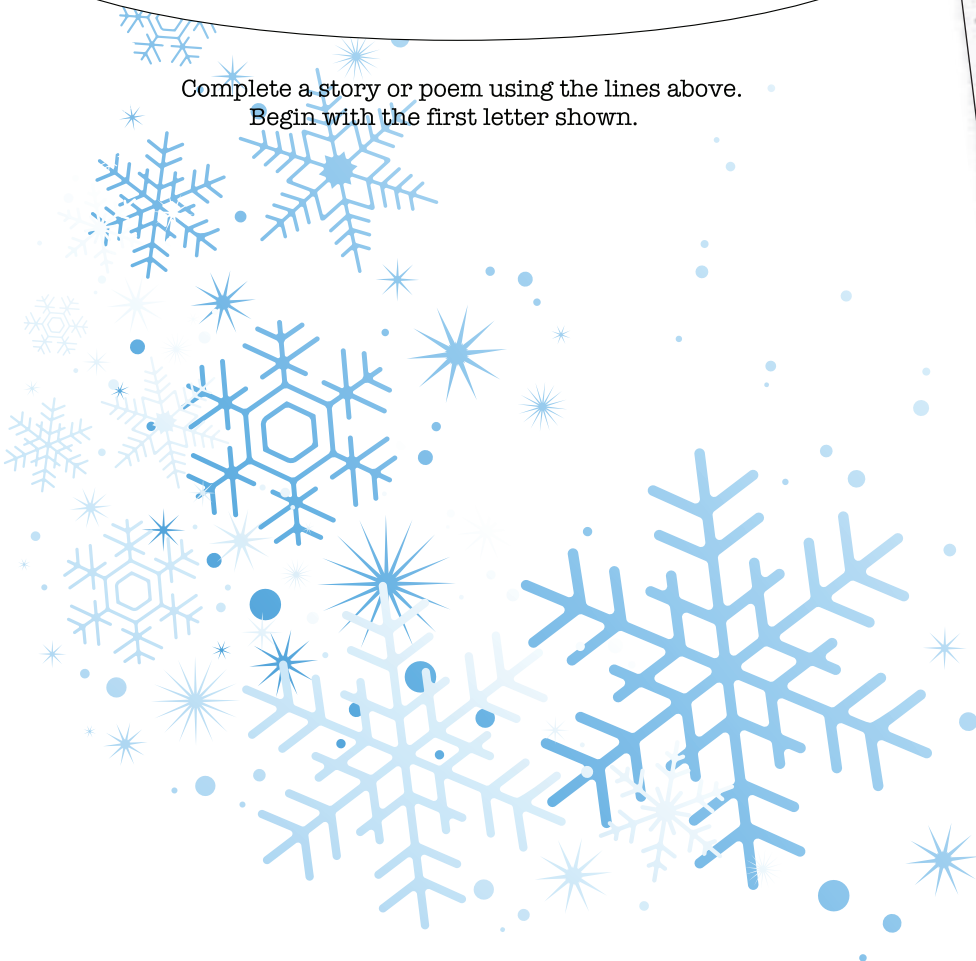
M

A

N

By

Complete a story or poem using the lines above.
Begin with the first letter shown.



Mandala

This mandala shows
my personalities. I named this
mandala "Peace" because I think
unfearness is wrong. Fear
is for leukemia, which is the
cancer my brother has. The
necklace (below) is a bravery
heart. The triangles stand for
strength. Last but not least
is the spirals, which stand
for all the twists and turns
in mine and my brother's life.



Artwork by:
Olivia Kowalski



COPING WITH A CANCER DIAGNOSIS: ADVICE ON ALL AREAS OF YOUR LIFE

Courtesy of NCI, National Cancer Institute

One of the challenges facing the family of a child who has cancer is going on with everyday life. Moving forward is not an easy task. It may be hardest during times of stress: when you find out your child has cancer, when your child is in the hospital, or when your child is suffering from the side effects of treatment.

Even when the treatments are going well, the cancer still affects each member of your family. When your child enters the hospital or goes for treatments, each member has to adjust in some way. Family members may be apart. Days of work may be missed. Brothers and sisters may feel left out. Everyone may be worried and tense.

Despite all this, family life goes on. Brothers and sisters have school and activities. Parents have jobs. It is hard to keep up with everyday activities and responsibilities while being with and caring for your child with cancer.

As the mother or father of a child who has cancer, remember that you are not alone. You can get help from many sources, such as the treatment team, which includes a social worker who can help you in dealing with your child's illness; other parents of children with cancer; support groups; or others. The information below may also be helpful for you, your child, the other children in your family, your extended family, and friends.

Your Child

Even with a diagnosis of cancer, your child still has the same needs as other young people - going to school, having friends, and enjoying things that were a part of life before cancer. You can help meet these needs by letting your child live as normal a life as possible. Some activities, however, may need to be changed at different times during treatment. After chemotherapy or radiation therapy, your child may be very tired and, therefore, need more rest. This tiredness is to be expected. Help your child find other things to do, such as new hobbies, or ask friends to come over to draw or paint.

School and Friends

Encourage your child to stay in touch with friends. Keeping contact is easier if your child can continue to go to school while being diagnosed and treated, but staying in school is not always possible. If time off from school is needed, it is best for your child to return to school as soon as possible. Children who have cancer need and like to be with others their age, and keeping up with schoolwork makes them feel good about themselves. Some cancer centers offer back-to-school programs, which may help children and classmates understand the diagnosis and know what to expect. You may ask your doctor, nurse, or child-life specialist to visit your child's classroom.

Children often worry about how their friends and classmates will act toward them, especially if they have missed a lot of school or return with obvious physical changes, such as hair loss or a missing limb. Other students are usually accepting, but they may have questions. Help your child to think of ways to answer their questions and to tell friends and classmates that they cannot "catch" the disease. Your treatment team

has had experience helping families with school. Ask them to help your child. Ask your nurse if the team or hospital has a school reentry program. Such programs send nurses to the child's classroom to talk about the child's cancer and treatment with classmates and teachers.

Your child needs to know that many people, including children, are uneasy about a serious illness. These people may act differently or say hurtful or wrong things to someone who has cancer.

You may want to talk with your child's teachers and school nurse about the disease, treatment, days missed, and any needed changes in activity. You and your family, the doctor, or members of the treatment team can explain your child's medical condition and answer questions. Teachers and other school staff may want to use this information to talk with the other students about what to expect when your child returns to school.

If your child cannot return to school right away, a home tutor may be available through the school system to help your child keep up with studies, making it easier to return to school.

To help your child and his or her siblings deal with fears and feelings, you may want to:

- Say "I love you" often.
- Assure your children that the cancer and its treatment are not punishments.
- Encourage your child or children to talk about the cancer and cancer treatment. Ask your children questions to get the conversation started. Family talks can help everyone feel less worried. Talking helps the whole family cope with the illness together.
- Tell your children that it is okay to feel sad and cry.
- Encourage activities to help your child feel more relaxed. Drawing, playing with harmless medical supplies or puppets, and role-playing may help your child feel better.

In addition, setting limits for behavior and activities is still important and even comforting to your child. But it is helpful to remember that children, like adults, have good days and bad days. Help your child feel part of normal life.

- Allow your child to make choices as long as they do not cause problems with treatment.
- Use the same rules and level of discipline as before the cancer diagnosis and treatment.
- Ask your child to continue doing regular chores around the house, when able.

Supporting Your Child

Like you, your child is likely to feel uncertain, worried, and afraid at times, but he or she may find it hard to talk about these fears and may behave differently than usual. For example, your child may become loud or bossy, be quieter than usual, have nightmares, have changes in eating habits, not do as well in school, or go back to earlier behaviors such as bedwetting or thumb-sucking.

These common behavior changes are just a few of the ones you may see. You may want to talk about such changes with the doctor, nurse, social worker, teachers, and school counselor, who have had experiences like yours.

Teenagers who have cancer have special concerns. They frequently complain that their parents try to protect them too much. Teenagers are at a stage in their lives when they are naturally trying to be their own bosses and do things for themselves, but having cancer forces them to depend on you. Giving teenagers a chance to make their own decisions and choices, when possible, will help.

You

Your child's illness will bring many changes to your life. To help you cope with these changes, you may want to consider the following suggestions:

- **Make time for yourself.** Try to do some of the things you did before your child got sick. Do not feel guilty that you need some time for yourself. Also, make a special effort to find private times to talk with your partner or those who are close to you. Do not let all your talk be about your child with cancer.
- **Prepare yourself for a lot of waiting.** Find ways to make waiting during clinic visits or while in the hospital less frustrating. Take something to read or do while your child is asleep or does not need your attention.
- **Turn to treatment staff or other resources for support.** Treatment centers have trained staff who can talk with you about your concerns. Make use of these

people for support.

- **Contact support groups.** Your treatment center can provide names of support groups at which you can meet with other parents of children who have cancer. Community resources can provide support and information. They can tell you how other parents have dealt, or are dealing, with the same types of situations you are facing.

- **Share the care of your child with your partner or others close to the family.** For example, if your child is in the hospital for a long stay, you and your partner, or friends or relatives, may want to take turns staying with your child. Letting them help will not only give each of you a break from the hospital, but it will help keep you from growing apart when one becomes more involved than the other in your child's treatment.

Brothers and Sisters

The lives of children who have a brother or sister who has cancer change a great deal. Siblings may have many different feelings about the brother or sister who has cancer and the extra attention the child receives. They may feel sorry for their sibling who is ill. Younger children may feel that they caused the cancer. Or they may believe that their own needs are being ignored.

When a child is in the hospital and is very ill, the focus is on that child. As a parent, you may not be able

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to pay as much attention to your other children as you did before. You may have to miss many of their special school or sports events. You may also use up all your energy and patience caring for your child who has cancer and not have enough energy or time to talk with your other children, play with them, or help them with their homework. It is natural, then, for siblings to be annoyed at the attention your child who has cancer is receiving.

As a result, siblings' behavior may change. They may become depressed, have headaches, or begin to have problems in school. School counselors and support groups may be able to offer you helpful advice for dealing with these issues. In addition, here are some things you can do to help your other children:

- **Talk with them about their feelings.** Talk with them about the special attention your child who has cancer is getting. Let them know that feeling mad is natural. Try to explain what is happening and why you may not be around as much as you were before.
- **Talk with them about the cancer, the treatment, and care.** Younger children's fears can be helped by knowing they couldn't have caused the illness by wishing or by spreading germs from a cold. Treatment and procedures should be explained as being helpful things and not punishments.
- **Spend time with your other children.** Try to spend some time with them doing the things they like.
- Encourage them to take part in outside activities. Make a point of noticing and praising what they do in these activities.
- **Involve them in their brother's or sister's treatment.** Let them come along with you to the clinic or hospital. Having them along will allow them to see for themselves what the hospital, clinic, and treatment are like.

- **Talk with them about questions their schoolmates and friends may ask.** Help them think of possible questions and answers so that they will feel comfortable talking about their brother's or sister's illness.

- **Ask other family members and friends to spend time with the other children in the family.** For example, an aunt or uncle might go to school events or attend important games or performances. A neighbor might help them with homework or take them on outings.

Family and Friends

A diagnosis of cancer affects not only the child, parents, and siblings, but also grandparents, other relatives, and friends. These people can support and assist you during this time.

Your employers also may need to be told about

your child's illness, so they will know why you are asking for extra time off from work. If needed, your child's doctor can write your employer to explain the situation.

You may need to tell people how to help you. Here are some ideas on how to tell them:

- Be open and honest.
- Take the lead to show others how you and your child want to be treated.
- If they are giving you too much attention, point it out.
- You may find it tiring to have to repeat details about your child's illness to many family members and friends. Ask one person to handle calls and questions. Or, develop a journal on a website such as caringbridge.org.
- It can be helpful to ask one friend or family member to be the "point person" to share with people your needs - for example, getting the wash done or shopping for groceries.

Financial and Insurance Issues

If you are like most parents of children who have cancer, you will be worried about the costs of treatment and continuing care. You want the best care but are afraid of the costs and how they will be met. You may not have health insurance. Or insurance may not cover all costs. Some insurers will not cover certain costs when a new treatment is under study.

You will need to understand the coverage that your policies offer. Here are some tips for making the most of your insurance:

- Get copies of your insurance policies and find out exactly what is covered.
- Get help if you need it to understand the policy or how to file claims if you need to. Do not be afraid to ask friends, family members, or a social worker for help. Private companies and some community organizations also offer help to deal with insurance.
- Keep careful records of all expenses and claims. Store bills and insurance forms together to make it easier at tax time.
- File claims for all covered costs. Sometimes, people do not take full advantage of their insurance, either because they do not know about a benefit or are put off by the paperwork.
- If your claim is turned down, file again. Ask your doctor to explain to the company why the services should be covered under your policy. If you are turned down again, find out if the company has an appeals process.





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