Summer 2007

COOL KIDS Connection™

a division of

BELANGER - FEDERICO foundation

Connecting pediatric oncology patients throughout the nation.

Check it out… INSIDE!

Mackenzie's Strength

Two-year-old fights neurofibromatosis

By Tammy S.

On October 6, 2003, I gave birth to a beautiful little girl we named Mackenzie. Things were great! Our family was complete with my loving husband Paul, a 6-year-old son Derek, and Mackenzie. What more could a person ask for?

I then started to notice that Mackenzie was forming brown spots on her body. I thought this was odd so I contacted our doctor. She said it was common for children to develop birth marks the first few months of their lives. Over the course of her first year, I kept a close eye on the spots but then she started vomiting almost every day. It wasn't until her 2-year checkup that I demanded an X-ray. At first they thought she might have a cyst.

Paul and I went to Strong Memorial Hospital, New York, to see the neurologist. In the waiting room my throat dropped to my feet; I was scared. No parent wants anything to happen to their children. We entered the office with MRI films. My hands were sweaty; my body was tense. The doctor said, "Your daughter has neurofibromatosis." All I remember is feeling like I wasn't in my body any longer. As much as I tried to listen, I was having a hard time concentrating. At this point, our whole life had already changed.

Over the next couple of months, we saw a series of doctors to determine the best course of action. To look at Mackenzie you would never think there was anything wrong with her. She was an energetic, curious, beautiful little girl. She acted the same as the kids I watch in her age group. It was so hard to believe this was happening to her.

Finally, it was decided that she needed brain surgery. Everyone was so wonderful and tried so hard to make this experience easier for us. I laid her on the operating table and she was so good. I was so proud of her. I held her hands and watched her slowly slip into a deep sleep as she mumbled "Mommy, Mommy" underneath her mask. I kissed her forehead and said, "Mommy's here."

We sat in the waiting room trying not to worry. I wanted so badly to hear good news but for so long we had heard nothing but bad. Hours went by as we waited and waited. After five hours the doctor walked in and we heard words of relief, "She's doing great." All we could say was, "Thank you, thank you so much!"

As we entered ICU it was a relief to see Mackenzie, but to see her head bandaged and not being able to hold her was hard. We had to be so careful and so quiet because she needed rest. Just four days later she was released - I couldn't believe it. They told us she'd

BUSES FOR BASEBALL VISITS CAMDEN YARDS

See the story on page 4

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probably be in for a week but she recovered so well, she was released sooner. The ride home was much better than the ride there. Mackenzie talked and talked until she fell asleep.

We started chemotherapy treatments in August. It was tough because we had no idea what to expect. We entered the room where she would receive her treatments and saw it was a playroom. I thought she would be stuck in a bed in a small cubicle. Instead, it was a big playroom with computers, TVs, arts and crafts, toys and an air hockey game.

The chemo isn't this ugly, thick, green stuff. It's clear and it's not scary. We were set up to do chemo once a week on Thursdays for one year.

We love the nurses who take care of Mackenzie. They all treat her so well, and us as well. They're so patient, gentle, fun, and very kid-oriented. We discussed with Mackenzie's doctor that she hadn't vomited since her surgery. He told us probably the pressure was released. It may have felt to her as if she had a horrible migraine headache constantly. Most likely, she had always felt the pressure, so she didn't know any different.

We are doing MRIs every three months, eye checks every six months and chemo until August. We just have to stay on top of things. I pray every day that in about a year I'll be telling everyone how my daughter beat cancer and couldn't be any better! She will beat this. Paul, Derek and I are here to help her. A family who sticks together can get through anything.

Mackenzie will be 4 in October. She is being treated at Strong Memorial Hospital in Rochester, New York. ■

Mackenzie and her brother, Derek

Meeting my Hero

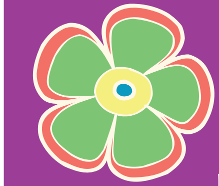
By Zachary P-D.

On Wednesday, May 23, 2007 I got to go to an Oriole game and meet some of the Orioles and interview Brian Roberts. I got to get many autographs from the players and got to meet them. After I was done interviewing Brian Roberts I gave him one of my blue "Strength Over A.L.L." bracelets and he said he would never take it off. When I gave him the bracelet he was like "wow thanks." When we were watching the game that night we could see the bracelet on his left arm while he was playing the field and batting. Ever since that night he has been wearing that bracelet all the time. I feel excited that he has been wearing the bracelet and that he has kept his promise. It was an experience that I will never forget getting to meet some of the players from the Baltimore Orioles.

Zach P-D. is being treated for AML at Sinai Hospital. He had been treated for ALL prior to this diagnosis. ■

Zach, his mom, Heather, and Baltimore Oriole, Brian Roberts

Congratulations to our Ladybug search winner, Kayla B. from Phillipsburg, NJ!! Kayla wrote, "6 ladybugs once lost, now found!" Kayla will be receiving an iPod shuffle for helping us find all our lost ladybugs.



Find the FLOWER

In this issue there are many hidden flowers, but only one exactly like this one. Can you find it? If so, please email sharon@bfpf.org. We will put all entries into a drawing for one lucky winner of an iPod shuffle. Make sure you include your name and all contact info including your address so we can send your prize if you win!

Hello, my name is Kayla B. and I found all the ladybugs in the last issue of the Cool Kids Connection! I am 13 years old from Phillipsburg, N.J. I'm a patient at The Cancer Institute of New Jersey. I was born with sickle cell disease and I also have asthma. When I am sick I stay at The Bristol-Myers Squibb Children's Hospital at Robert Wood Johnson University Hospital.

Try this...

Lateral Thinking – Can You Explain?

To answer these questions, you have to let your brain think in different ways than you may be used to. Here's an example:

Question:	A girl who was just learning to drive went down a one-way street in the wrong direction, but didn't break the law. How come?
Answer:	She was walking.

See if you can let your brain switch directions to answer these questions:

1. How can you throw a ball as hard as you can and have it come back to you, even if it doesn't hit anything, there is nothing attached to it, and no one else catches or throws it?

2. Two students are sitting on opposite sides of the same desk. There is nothing in between them but the desk. Why can't they see each other?

3. There are only two T's in Timothy Tuttle. True or false?

Answers are on page 15

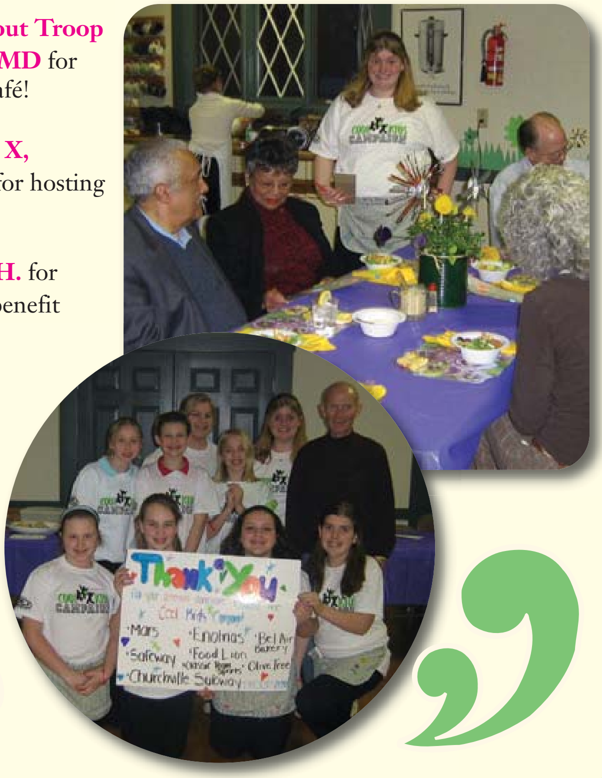
Kids (and Companies!) Helping Kids!

Thanks... to **Girl Scout Troop 2130 in Churchville, MD** for hosting a Cool Kids Café!

Thanks... to **St. Pius X, Rodgers Forge, MD** for hosting a Cool Kids Café!

Thanks... to **Jessica H.** for holding a yard sale to benefit Cool Kids!

Thanks... to **all the schools** that participated in the Cool Kids Reading Challenge!



A PERFECT NIGHT AT THE YARD

On a clear and perfect May evening, Major League Baseball Players Association (MLBPA - the organization that assists current players with grievances, salary arbitrations, and playing conditions) hosted a group of 11 pediatric oncology patients and their families to a special night at Oriole Park at Camden Yards, Baltimore, MD.

Kids from Sinai Hospital, University of Maryland Hospital for Children, and Johns Hopkins Hospital (all in Baltimore) spent time before the Orioles took on Toronto, meeting players in the clubhouse, obtaining autographs and pictures, and watching batting practice before participating in an on field check presentation with Orioles Brian Roberts and Jay Gibbons. Then it was off to the stands to scarf down hot dogs and salty popcorn as they watched the Orioles beat Toronto.

The entire evening was arranged through MLBPA Buses for Baseball, a program which provides kids throughout the U.S. and Canada a chance to attend a major league baseball game and meet professional players.

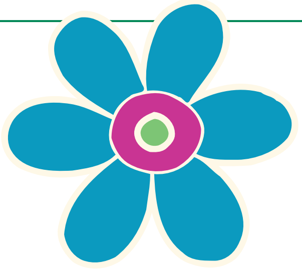
The Players Trust partners with local transit authorities and major league teams, as well as charitable organizations, in major league cities. Kids who need a reason to smile share the thrill of attending big league games together.

At the ballparks, the kids are welcomed by players who sign autographs, give away souvenirs and pose for photos. Complimentary food and soft drinks during the game are provided (in Baltimore, courtesy of Aramark), and often there's a chance to see their happy faces on the giant scoreboard. What a lasting memory on which to reflect on the bus ride home!

To date, Buses for Baseball has provided unforgettable trips to major league stadiums for over 7,000 youth from more than 167 different organizations. Root! Root! Root! for Buses for Baseball … an all-American hero for sure! ■

Photos by Mitch Stringer

COOL KIDS Activities



STATE WORD SEARCH Can you find all 50 U.S. States?

S	S	R	W	N	R	K	A	B	J	L	C	O	A	O	M	C	Y	H	A	W	A	I	I	T
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X	U	I	W	O	O	R	K	E	L	T	Y	I	L	K	N	B	C	Z	J	Z	A	F	N	C
E	T	E	K	Z	D	S	T	I	M	H	L	B	G	Y	Q	I	F	H	V	P	B	A	D	I
T	H	K	I	M	A	E	F	H	A	M	O	H	A	L	K	O	G	B	I	R	A	P	I	T
N	C	R	G	L	J	O	I	Z	C	N	I	I	A	X	T	N	C	R	U	G	L	A	A	C
F	A	N	A	X	R	M	A	S	S	A	C	H	U	S	E	T	T	S	I	B	A	G	N	E
L	R	E	M	N	S	J	E	I	L	J	R	E	A	L	R	G	B	S	J	V	Z	N	A	N
S	O	V	I	F	L	O	R	I	D	A	Q	O	S	N	M	U	I	T	J	S	T	I	X	N
O	L	A	O	D	A	R	O	L	O	C	N	X	L	P	A	I	T	K	N	K	S	S	F	O
U	I	D	O	H	A	D	I	M	Y	M	B	D	B	I	P	I	J	A	A	W	I	A	E	C
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H	A	I	N	A	V	L	Y	S	N	N	E	P	I	N	E	A	K	I	Y	S	N	O	I	G
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T	B	N	M	S	O	A	A	S	S	W	O	S	W	N	N	T	E	E	V	I	Q	I	R	Y
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Q	B	R	Q	A	P	M	A	N	F	B	Y	K	H	X	L	Y	G	J	N	R	Y	M	N	W
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ALABAMA
ALASKA
ARIZONA
ARKANSAS
CALIFORNIA
COLORADO
CONNECTICUT
DELAWARE
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HAWAII
IDAHO
ILLINOIS
INDIANA
IOWA
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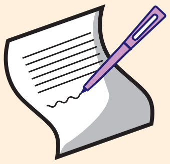
SEND US YOUR STORY!

Be a part of the next issue of the Cool Kids Connection!
Deadline for the next issue is September 1st.

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:



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or by email to sharon@bfpf.org

Please include all you 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.

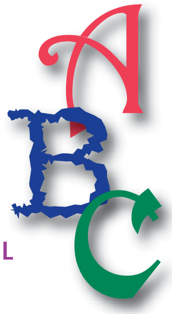
For advertising information, please visit our website or email sharon@bfpf.org.

Alphabet Challenge

Use all twenty-six letters of the alphabet to complete the following eleven words, but use each letter only once in the course of this puzzle. To keep track of which letters you use cross off the letters as you use them:

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

1. __ A __ Z
2. __ U I E __
3. __ U __ C A
4. E __ T R __
5. __ I O __ __ N
6. __ A __ __ F U L
7. __ R O __ __
8. __ E __ __ A T
9. __ __ A L A
10. __ O L A __
11. __ O R C __ P I N E



Anagram Rhyme

Will Shortz, a famous puzzlemaster, created this one: For each of the following four words, come up with another English word that uses all THE SAME letters but in a different order. The four words you come up with will rhyme with one another.

ONSET

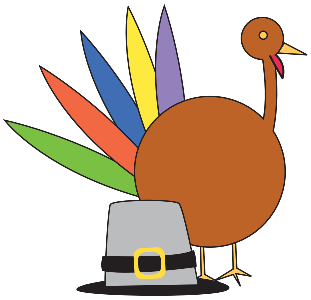
NEWS

WRONG

HORNET

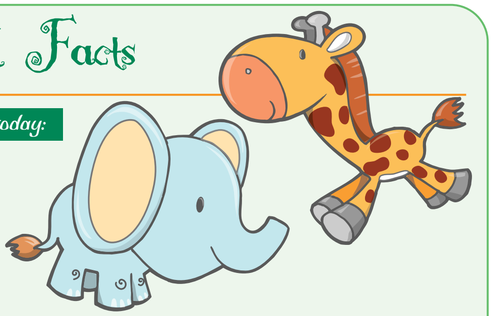
STRATEGY: Look for a pattern in the letters – what is the same in each that could rhyme?

Answers on page 15



Our next issue is coming out in the Fall, just in time for Thanksgiving. Let's celebrate together! Tell us who you are thankful for in your life. Send us who they are and why you are thankful for them. Email that to sharon@bfpf.org.

Fun Animal Facts



The 10 most popular pets in the US today:

1. Cats
2. Dogs
3. Parakeets
4. Small rodents, such as rabbits, gerbils and hamsters
5. Fish
6. Reptiles
7. Finches
8. Cockatiels
9. Canaries
10. Parrots

Habitats: Where Animals Live

Deserts (hot, dry regions)
camels, bobcats, coyotes, kangaroos, mice, Gila Monsters, scorpions, rattlesnakes

Tropical Forests (warm, humid climate)
orangutans, gibbons, leopards, tamandua anteaters, tapirs, iguanas, parrots, tarantulas

Grasslands (flat, open lands)
African elephants, kangaroos, Indian rhinoceroses, giraffes, zebras, prairie dogs, ostriches, tigers

Mountains (highlands)
yaks, snow leopards, vicunas, bighorn sheep, chinchillas, pikas, eagles, mountain goats

Polar Regions (cold climate)
polar bears, musk oxen, caribou, ermines, arctic foxes, walruses, penguins, Siberian huskies

Oceans (sea water)
whales, dolphins, seals, manatees, octopuses, stingrays, coral, starfish, lobsters

How long do animals live?

Box turtle	100 years
Human	70-80 years
Asian Elephant	40 years
Grizzly Bear	25 years
Horse	20 years
Gorilla	20 years
Polar Bear	20 years
Rhinoceros (white)	20 years
Black Bear	18 years
Lion	15 years
Lobster	15 years
Rhesus monkey	15 years
Rhinoceros (black)	15 years
Camel (Bactrian)	12 years
Cat (domestic)	12 years
Dog (domestic)	12 years
Leopard	12 years
Giraffe	10 years
Pig	10 years
Squirrel	10 years
Red Fox	7 years
Kangaroo	7 years
Chipmunk	6 years
Rabbit	5 years
Guinea pig	4 years
Mouse	3 years
Opossum	1 year

LAUGH IT UP!

When some doctors were asked to contribute to the construction of a new wing at the hospital......

- The allergists voted to scratch it.
- The anesthesiologists thought the whole idea was a gas.
- The cardiologists didn't have the heart to say no.
- The dermatologists preferred no rash moves.
- The gastroenterologists had a gut feeling about it.
- The internists thought it was a hard pill to swallow.
- The microsurgeons were thinking along the same vein.
- The neurologists thought the administration "had a lot of nerve."
- The obstetricians stated they were laboring under a misconception.
- The ophthalmologists considered the idea shortsighted
- The orthopedists issued a joint resolution.
- The otologists were deaf to the idea.
- The parasitologists said, "Well, if you encyst".
- The pathologists yelled, "Over my dead body!"
- The pediatricians said, "Grow up!"
- The plastic surgeons said, "This puts a whole new face on the matter."
- The podiatrists thought it was a big step forward.
- The proctologists said, "We are in arrears."
- The psychiatrists thought it was madness.
- The radiologists could see right through it.
- The surgeons decided to wash their hands of the whole thing.
- The urologists felt the scheme wouldn't hold water.

Ben's Journey

Editor's note: In the past two issues of Cool Kids Connection, we have chronicled one family's journey through cancer. Ben was diagnosed with Ewing's Sarcoma in January 2006 and spent the entire year fighting the disease. This is the third in a four-series journal which includes emails (in color) sent from his mom Sue to friends and family during those months. (Read the first two issues online at www.coolkidscampaign.org.) The final installment of Ben's Journey will appear in the Fall issue.

We rounded out the month of June with chemo # 7, lots of visitors, library summer reading program sign-up, and a trip to the ER for a fever. We did our usual two-day stay at the Johns Hopkins "bed and breakfast" which took us into July. We were approaching the end of Ben's time in his body cast. Ben had learned many things over these three months of confinement, about himself and others. When people look at you in pity or stare because you're different, it's best to just smile and say, "Hello." It's amazing how one simple smile can change someone's judgment. It made Ben very uncomfortable at first, but soon he learned that most people just didn't understand and were curious about why he was bald and laying in a reclining wheelchair in a body cast. Most adults looked shocked and immediately put on their best pity face. A majority of the time we were laughing or smiling, just happy to be out of the house. We tried to share that joy with everyone we met in those months. The only thing worth pitying was when I would misjudge a turn in the big wheelchair and crash Ben into a wall. That happened too often than I care to remember, but we always laughed about it. We did our best. We must've seemed like lunatics.

The 4th of July was coming up fast. We usually spend the day with Barry's family having a cookout and watching fireworks. This year we decided it would be too much for Ben. It was actually a rather uneventful day. Barry left for work as usual at 9 pm, and the kids and I settled in to watch TV. We heard popping noises outside and looked out the sliding glass doors that lead to our deck. To our amazement, we could see the local fireworks above the trees in the distance. We were very excited! I picked up Ben and said, "Let's go see some fireworks." He said, "What? Is it the 4th of July?" He never was one to pay attention to days or dates. Maybe it was because we didn't make a big deal out of it since we knew the day would be low-key. I carried Ben to the deck, body cast and all, and laid him across my lap while I sat on a deck chair. It was odd and a little unconventional, but we enjoyed it and a great memory was made.

Clowing around with my Harpo wig - What if my hair grows back like this?

7.9.06

Hello all ... Just a quick note to let you all know that we are about to embark on "the week that Ben's cast comes off!!! We start chemo #8 tomorrow, which will involve driving back and forth to Hopkins every day ... yes, it's a drag, but it is WAY better than staying in the hospital for five nights, especially since we were just there last weekend with a fever! Anyway, on Wednesday at 1:30 pm, Ben's cast will be removed once and for all! Can I get a "woo hoo?" We are all very excited about this, though I find myself rather anxiety-ridden about what to expect ... like will he be able to walk without a hip, can I hold him without hurting him, will he have pain from being so immobile for so long? Just your typical crazy mother concerns. I can't believe it's been three months since the surgery, since the cast was first put on! I'd say "time flies," but I think Ben would whack me with his cast (which he's been known to do when he's fed up with me and all my yammering about taking medicine and brushing teeth and homework, etc.) He really has endured these three months like a champ, though! Your prayers have really been felt in this family!

We had a great week this week, lots of visitors and even a shopping trip. We ventured out to buy Ben some shoes since he'll be on his feet again soon (hopefully). His feet have grown like skinny little weeds while this cast has been on. He opted on "skater shoes" which are just black Vans, but we had to walk the entire length of the mall to find orange shoelaces that he had to have. So, he's set in that regard. We even bought some boxer shorts since I don't know how he's going to feel wearing clothes again. I don't even know what size he is anymore. His weight was officially 50 lbs. without the cast at his last cast change, which was mid-June. Before cancer he was about 60 lb., so we're down ten at least. Anyway, my laundry has been a bit lighter with him in this cast, so it will be nice to fold little boy clothes again!

Another bit of exciting news, The Make-A-Wish Foundation is coming to our house on Thursday evening to meet Ben. They would like to grant him a wish! How cool is that? I'll let you all know what he chooses. I'm trying to stay out of it ... although I have dropped some hints that Mommy could really use a personal trainer! I think he would just like Mommy to be put on an island far, far away, so she would stop bugging him all the time. We've definitely had our fill of each other. Come to think of it, I wouldn't mind being on an island far, far away sometimes.

Have a great week. God bless you each and every one. I love you all!

Sue

Ben's cast removal was scheduled for Monday, July 12. We went to JH to start chemo #8 on Monday, July 10, but Ben's counts weren't high enough. They told us we could try again on Wednesday, but again we got booted. As disappointed as we were, because this would throw everything off from this point on, it was actually a blessing in disguise. There was no way Ben could have endured a week of chemotherapy and driving back and forth an hour each way for five days with the newness of having his cast off. It was great that Ben got five full days to get used to his body again before having to do chemo.

His cast came off as scheduled. All of us had been looking forward to this day for so long, like it was going to be magical in some way. We were very excited. The cast removal was done at the Johns Hopkins Outpatient Center in Dr. Weber's office. That was a nice change because up until this point all cast changes had to be done in the operating room under anesthesia. This day ended up being a little bittersweet for us. It was wonderful that Ben was finally going to be free of this cast and be mobile again, but I think we kind of expected more. Instead, it was like taking a turtle out of its protective shell. Ben looked paler, thinner, and weaker from having been in the cast for three months. This was also the first time we were able to see the actual surgical site, the scar left from where Ben's hip was removed. To see a mark like that on your baby's body is quite a shocking experience – but you quickly have to accept that it's all for the greater good. We now call it his "shark bite" because that's exactly what it looks like. He wears it like a badge of honor.

I didn't know what to bring for this day. I brought his walker, thinking he would be walking out the door on it. Ben hadn't worn clothes in three months, so I wasn't even sure if the clothes that I had for him still fit.

It was obvious that he had grown in height while in the cast, but his weight suffered from both the chemo and the cast. I wasn't sure if he would be able to tolerate elastic in his underwear or shorts, or if he would mind pants touching his leg. When that cast came off Ben was afraid to move – he froze. His knee hadn't been stretched out in three months and that was all he had wanted to do for the past few weeks – but not anymore. He was so afraid and so tender. He stayed in the same position for quite sometime. There was so much dead skin under the cast, too. There were layers on his legs that needed to be sloughed off. He thought this was really cool. On the ride home, he used his fingernail to carve the word "cool" into the dead skin on his leg. I couldn't wait to give him a real bath. He left a trail of dead skin wherever he was lying. Even the bath didn't get it all off.

Picking up Ben was something else we thought would be easier once the cast was removed. Granted, he was lighter, but he was a lot more fragile now. That cast provided all of us with such a sense of security and protection. We became so good at picking up Ben in the cast and slinging him around wherever he wanted to go. Now it took planning and maneuvering and it had to be done very slowly, with Ben whimpering from soreness and fear the whole time.

The day after his cast came off we had a visit from two wonderful ladies from the Make-A-Wish-Foundation. What a wonderful experience that was for all of us! Ben had thought long and hard about what his wish would be. Melissa and Lisa were so kind and so thoughtful. They went all out to make all of us feel special. Ben had had such a tough time lately and it was awesome to see him just beam when they told him about Make-A- Wish; it gave him something exciting to look forward to.

Kimmie Meissner signed my head...how cool is that?

7.13.06

Hello beautiful people ... I'm in a very poopy mood, so forgive me and bear with me! I know some of you are dying to know how these last few days went. Okay ... I have some good news and some not so good news. Of course, the good news is ... THE CAST IS OFF! YAAAY! The not so good news is ... Ben wishes he had it back on. BOO! He's been very stiff and uncomfortable and doesn't like moving much at all. Picking him up is quite a chore now because with the cast we had security ... and now he just whimpers and cries out if you touch him the wrong way. His actual surgical site looks good (from a doctor's standpoint ... I'm still trying to get used to that big mark on my baby) and isn't too sore ... it's mostly just the leg that hurts him. He has yet to fully bend it or stretch it out, so we don't yet know what the difference in length is between the two legs. Looks like at least one inch. It's only the first day, so I'm trying not to stress too much. I'm guilty of missing the security of the cast, too. It took all three of us (me, Barry and Liv) to get him upstairs to the tub today. He has so much dead skin that is sloughing off and I hoped that soaking may help that as well as help him relax his muscles. It was quite a workout, but afterwards he was sorer because he was so tense from the whole experience. We still have so much to learn! Physical therapy should start tomorrow. They will come to the house to begin with and then we'll graduate to a facility so Ben can work with equipment, like weights, etc. He's supposed to have PT 3-5 times a week for six weeks.

Who needs fireworks when we had our own real life flag?

More not so good news ... we got booted out of starting chemo on Monday because Ben's counts weren't high enough, so they told us to try again on Wednesday. Wednesday was the same thing, only this time his counts had fallen even lower! So, we'll go back next Monday and try again. This completely throws off our schedule a full week, so I have some serious rearranging to do with the rest of the summer (silly me for trying to schedule things anyway). Hopefully, this is not the beginning of a new pattern, but just a bump in the road. The docs did tell us that the more you're knocked down; the harder it is to bounce back. We've been spoiled because Ben's done so well up until this point. On the brighter side, it will give him some time to get used to being without the cast. I honestly couldn't imagine taking him down there every day with him being so tense and uncomfortable. Hopefully, these few days off will let him relax a bit and maybe get used to his "new body."

More good news ... Make-A-Wish came tonight ... and, boy, they are just too cool. I can't believe some of the stuff they do. They brought a gift tonight for both Ben and Liv, which was very nice. They interviewed Ben about everything from his favorite color to his favorite movie to who he'd most like to meet, etc. They asked him for two ideas for wishes ... he said to go to the Give Kids The World Village in Orlando, or to be on The Suite Life of Zack and Cody, a Disney Channel show. A friend from school (who had leukemia when she was younger) told him about her trip to the GKTW Village. The only thing he heard, and what stuck with him, was that you could eat ice cream for breakfast. It's an incredible place that really goes all out for the kids. Google it if you want to find out about it ... there's just too much to mention. As for being on the TV show, I don't know where that came from. He pulled that one out of his hat today.

We'll see what happens. We told them that if we were going to travel, we did not want to go until Ben was walking confidently, which could be a year or more. It's definitely something to look forward to. Right now, we've got to focus on getting him comfortable. Gotta run ... the boy is paging...

Love you, Bless you,

Sue

Physical therapy started two days after the cast removal. We were incredibly blessed to be assigned a physical therapist named Nancy who came to our home. We were very nervous about what to expect that first day because Ben still didn't like moving at all. He was not happy about having someone manipulate his legs and asking him to do certain exercises. He was terrified and sore and wasn't quite ready to trust Miss Nancy yet. He screamed and yelled at both of us, hurling some hurtful words. It was almost comical because this episode reassured me that Ben knows no curse words. If he had, he would've used them. Instead, he was calling us all the "bad" words he knew: stupid, pathetic, jerk, dummy. Thankfully, Nancy wasn't offended and thought our first attempt at PT went rather well. Ben was wiped out and fell asleep for three hours after her visit. Nancy came 2-3 times a week after that. To ensure that Ben continued to progress, she even came to the hospital when we were having chemo.

Ben was able to start chemo #8 on July 17. That was a five-day chemo, driving to and from JH everyday. Thankfully, Olivia was involved in a church camp each day and was able to spend time with friends afterwards until I got home. That way, Barry was able to work as usual at night, sleep during the day, and then be with us in the evenings. We continued to be so incredibly blessed each and every day with meals, visitors, friends who would call us from stores to see if we needed anything and friends who just constantly prayed for us. It made all the difference in the world.

7.19.06

Hi everyone … Just wanted to let you know that we were able to start Ben's five-day chemo on Monday, so we're halfway done for the week. It has gone well and he is tolerating it like a champ. Yesterday he had chemo from 9-2, physical therapy from 1-2 and an MRI from 3-4. It was a grueling day, but we got through it. Ben did very well with his physical therapy yesterday; unlike his first attempt at PT last Friday, (he told me he hated me for the first time ever). Anyway, he was able to stand up four times for 24 seconds each (a bargain he made with his physical therapist). She is so good with him and knows how to get the best out of him. She even told him that he could not sleep on the couch anymore unless he could walk from the hospital bed to the couch. Well, that's all she had to say ... because guess who walked with his walker from the bed to the couch last night? If he wants something bad enough, he's going to get it! It wore him out and left him sore, but he did it! We still can't really tell how much difference there is in leg length because Ben still can't fully flex that right knee. He's working on it, though, and we're seeing progress every day.

I did get some news I wasn't prepared to hear today. When the doctor sat down with me to map out the rest of Ben's treatments (chemo, scans, MRIs, CTs, blood work, etc), I found out that he actually has a total of 14 chemos scheduled, not 12 like Barry and I thought. So, we're still over halfway done, but this news was disheartening to say the least. We were so happy to have four left, but finding out we have six just really feels like a kick in the face. Ben could care less because he just takes it as it comes ... but we had told him he'd be done by his birthday (October 28), so now we have to tell him we were wrong. I feel so guilty for feeling so upset about it when I've met parents whose kids have leukemia and they are in it for 3 years ... and, of course, there are parents whose kids have been given only so many months to live. Perspective is everything! We are blessed! I truly do know it and believe it wholeheartedly, and I am so very thankful ... it's just that my hormones are out of whack and I'm finding myself slipping down more easily into a funk. No biggie ... this is just a bump in the road, right? The Lord is carrying us through. Bless his heart, He's so tired of me by now but He just keeps lifting us up and pushing us along! He's in total control and for that, I am thankful! I would be a huge quivering ball of mush by now if any of it was up to me.

Okay, so two days left of this chemo and then three weeks off. Woo hoo! (Okay, that was a half-hearted woo hoo, but what's an e-mail from me without a woo-hoo?) Please pray that Ben's counts don't suffer too much for too long and that he continues to get stronger on his feet. Thank you for being so faithful in prayer for my family. From your lips, to God's ears, to our hearts ... we ARE blessed!

Love you!
Sue

It's difficult when your expectations are dashed. We should've known by now not to have expectations or make plans. Just when you start to get complacent or feel like you've got a handle on things, something usually happens to throw you for a loop. We couldn't let this get us down, though.

At this point, we had to close ranks. We were halfway through Ben's treatment. The hardest part (surgery) was behind us. Now all we had to do was get Ben through these last few chemos and help him get stronger. Each day brought us closer to this goal. This was not going to consume our lives forever! Ben was doing just fine. He was happy, as healthy as he could be, and didn't let much get him down. He was the one taking the brunt of it all; we had no right to complain or whine.


Chemo boredom buster? Draw your own eyebrows!

7.21.06

Hi all ... Well, round #8 is complete. Only six more to go ... and, yes, I've finally wrapped my heart around it and accepted that it is what it is! If that is what it takes to have a healthy boy, then we're going to see it through. Ben is doing very well. He has only vomited once and that was this evening, mostly because if his throat feels "goopy" then that is what has to happen. He has always had a sensitive palate. He feels fine otherwise. His leg is a little achy from physical therapy today. He showed off a bit last night for our company and walked with his walker all around the family room and kitchen. He walked again for therapy today and probably overdid it a bit. He is still working on straightening that right leg, but he is so much more confident with his walker now. His therapist has put in an order for crutches, so we should be moving to the next level very soon.

We had a bit of an exciting day (to say the least) in clinic today. The fire alarm went off. We were on the eighth floor and apparently, the fire was on the ninth. Since the clinic has patients who can't be evacuated easily, we were asked to stay put until further notice. This has happened before, an "all clear" announcement came over the intercom, and everything was fine. This time we were told to get to the nearest stairwell and start moving. Since Ben is still in his wheelchair and was hooked up to chemo at the time, I had to carry him. A nurse followed close behind holding up his chemo IV. Ben does not weigh much more than 50 lbs., but carrying him is very awkward and tricky because you have to do it just right or he will scream. We made it down four flights of steps before the "all clear" announcement came. We trekked back up to the eighth floor and I sat him on a bench so I could get his wheelchair. I had held it together throughout the whole process, but once I put him down and walked away I completely fell apart. I didn't really feel it coming, and tried to do it quietly as I was walking away. My arms were shaking from having carried him so I was trying to shake them out. The whole time we had been moving downstairs I had visions of 9/11 and what it must've been like for those people ... and how serious our situation could possibly be. It was very scary. Everyone in front of us was moving so slowly and I just wanted to get out. My adrenaline was in overload and the decompression just brought forth a huge emotional tidal wave. Anyway, the nurses came after me when they realized that I was having a meltdown. They are so awesome. I was fine, really ... just being emotional ... somewhat embarrassed by the fact that my body had given in to this outburst, but I wanted to get away from Ben so he didn't have to witness his mother in this state. Once the floodgates opened, I just cried for everything I haven't let myself cry about since his treatment began. It was very cleansing and I guess I needed it. I didn't cause a scene, but I'm sure the nurses all think I'm a loon. If they hadn't figured that out by now, they got a quick lesson today. Bless their hearts ... they're all a bit nicer to me now since I've probably been labeled "fragile" or something like that.

Anyway, all in all we had a good week. I'm glad it's over and I'm sure Ben is, too. He and Liv are finally having some real quality time right now, playing their video game. We are going to venture out briefly tomorrow to see what Olivia has learned in the church camp she's been attending this week. She really enjoyed it and can't wait to show us all the "cool stuff" she learned. Then, we'll just lay low for about a week while Ben's counts fall and hopefully start to climb again and then


Dr. Emi Caywood and Ben consulting in the playroom about how to best decorate her glasses.

maybe we'll get in a week of outings and visits before the next chemo. It's all good. We are blessed.

Forgive my rollercoaster of emotions lately. I try to be positive and hopeful, but lately I find myself having some "off" days. My faith remains intact and stronger than ever (although I REALLY miss going to church), and my love for you all is, as always, overflowing. Thank you for always being my sounding board, and for continuing to encourage me with your thoughts, prayers and jokes, etc. Your prayers have overwhelmingly blessed my whole family! Please know that we pray for each of you and your families as well. I don't know what I would do without you guys!

Love you all!
Sue

We closed the door on July and happily greeted August, bringing us one month closer to the end of treatment. Ben was feeling good and doing well, so we went to see Pirates of the Caribbean II. We took six of his friends with us. That was a really fun day for him! Ben was very happy to be with his friends out in the world. He was using a walker at this point, but we still used the wheelchair for long distances. He had made such great progress. We even had the hospital bed removed from the house. August was a great month with lots of activity. We were able to do more outside of the house and we stayed busy. We had several Cool Kids activities: skating at Kimmie Meissner's Cooling Off With Kimmie party and throwing out the first pitch at the Cal Ripken Jr. World Series. Ben also had his last chemo with Doxorubicin, the worst medicine ever. He had PT in his friend Timmy's pool which was a fun change for him.

8.7.06

Hello loved ones ... I have to share this awesome day with you all! First, a little backnote: The Cool Kids Campaign put together an event for kids with cancer, so we got to meet Kimmie Meissner this weekend and skate with her at Ice World. She was absolutely precious! She even signed Ben's head! My sister Laura, niece Kayleigh, Olivia, Ben and I went together. Ben stayed in his wheelchair the whole time because I wasn't about to put him on ice without a hip. No, not ready for that yet! Anyway, Kimmie pushed him around the rink in his wheelchair and skated with Liv and Kayleigh. She took time for every child there and was so sweet. We had a blast! We were all on the news that night, maybe in the local paper this week, and Ben's head signing picture will be in a skater's magazine, too. It was just too cool for words.

Then we went to church yesterday - WOO HOO! Again, awesome day! Once I get into church it's hard to get me to leave ... I just LOVE it there! Going every three weeks just doesn't cut it ... but something's better than nothing, right? I'm thankful for the opportunity when it arises. Ben spent the whole day on his walker; he's really getting around beautifully!

Okay deep breath … on to today …we went in for chemo #9 this morning. Thankfully, we made counts, just by the skin of our teeth ... but at least we didn't get bumped again. Woo hoo! Then, we found out that Ben won a drawing contest from the last time we were in for chemo. He won first place for his picture titled "Hoping to be Walking Again Soon." They gave him a $100 gift card to Target! So, a BIG Woo hoo for Ben! That made his day.

Then ... yes, there's more (and this is the BEST part) ... while meeting with the docs to check him out, we learned that this will be his last time receiving Doxorubicin (the chemo medication they call "the red devil" because it is mean and nasty, red in color, turns his pee red, drips in for 48 hours straight, and it's also the one that causes the mouth/throat sores!. HUGE WOO HOO for that one! He has five treatments left, but getting this medicine out of the way will make his tolerating chemo so much easier! I just can't begin to tell you how incredibly happy we are about this news! I think this is Jesus' way of making the two additional chemos that much easier to bear! He's so AWESOME!

Slow going...happy to be upright! Ben's first days with a walker.

Then our physical therapist, Nancy, came to clinic and brought crutches. Ben was completely against moving away from his walker onto the crutches, but once he tried them ... he took off! Now, all he wants to do is walk. We had to leave the playroom five times, so he could rob the candy dish at the nurse's station today. He didn't care about the candy ... he just wanted an excuse to walk ... IV pole and all! Everyone at clinic is so proud of the progress he's made and has told us that they've never seen anyone improve this quickly after such invasive surgery. PTL! Woo hoo!

So, as you can see, I'm just bursting with joy! I couldn't wait to get home to tell you guys! God is so GOOD! All the time! Bless His precious heart ... He's not as tired of us as I thought He was – at least not yet!

I hope all is well with you. Enjoy the last few days of summer vacation. Thank you for continuing down this road with us ... hills, valleys, twists and turns ... blessings all the way.

I love you,
Sue

Before we knew it, it was time for school to start again. Olivia and I had a girls' day out where we shopped for back-to-school supplies and clothes, went to her school's open house and had lunch together. She was entering middle school this year and was a bit nervous about the transition. We had a nice day out together and talked about all kinds of stuff. We both needed to reconnect and just be together. That was a special day for both of us. The first day of school was due to be the first day of Ben's next chemo as well. I was not happy about not being there for Olivia's first day. Thankfully, Barry was able to be there to hear all the exciting news. I was able to hear about it later over dinner.

Chemo #10 took us into the first few days of September. We were glad to be done with a very long week. Ben began his tutoring again since he wouldn't be able to go back to school until January of 2007. He was very happy to have his same tutor from last year, Ms. Risberg. They had formed such a great relationship. She really knew how to get him going and excited about school. I saw a difference in Ben with his schooling. He really wanted to be back in school. He couldn't wait to be with his friends again! He buckled down to get his work done so he could stay on par with his classmates. I took him into school to have his school picture taken with the class. He was so happy to be back in school, even if only for a visit.

9.1.06

Hello all ...Just wanted to let you know that this week's chemo went well and Ben tolerated it all like a champ. We managed to stay relatively busy during our five 7-hour days. So now, that's 10 down, four to go! Woo hoo! Liv did really well with her first week of middle school. Sunday night was a bit rough because at 1:30 am she still couldn't get to sleep. I had to give her Benadryl (I know, I know ... bad mommy ... but the kid needed to sleep, and so did I). Anyway, she likes her teachers and is slowly acclimating to all the newness middle school brings. It was hard for her to leave the safe cocoon of elementary school, but she's a big girl now. She's a little tiny fish in a great big pond, but she's happy. I'm so proud of her! It certainly comforts me that four boys from our court come to pick her up every morning to walk to the bus stop.

Ben started walking on his own this week ... just practicing. His shoe isn't back from the "shop" yet, but his physical therapist likes to see what he can do. His gait is very quirky because of the difference in leg length, and he's got this "chicken wing" thing going on where his arms flail out as he takes a step, but he gives it his all! Bless his heart ... he really is amazing. I think that shoe, whenever it comes back, will make all the difference in the world. Whenever we're at clinic and our therapist comes to work with Ben there, all the nurses and docs cheer him on and can't believe how much he has progressed. They do little happy dances and kiss his head. He loves to show off!

Ben started a little "business" while in clinic this week. We spent most of the week in the playroom where there are all kinds of toys and arts and crafts. Pipe cleaners were the craft of choice this week. He decorated his glasses with them and they looked rather snazzy. Before we knew it, we had doctors, nurses, secretaries and PA's dropping off their glasses to have Ben decorate them. It was too funny to see all these people walking around clinic with funky looking glasses, but it made Ben feel so good. Some of the people who didn't wear glasses asked if he would do their hospital ID lanyards. It kept him busy that day. And even today, they all still had their glasses decorated. We are so blessed to be cared for by such wonderful, caring people.

I wish you all a wonderful, safe long weekend.

Blessings,

Sue

The Raven's Fan Man and the Bus Boys stop by to bring smiles to Ben and Liv.

Ben finally got his new built-up shoe on September 12. Wow, the difference that it made. It would take a while for him to get used to it, but it was nice to see him walking more evenly. He still wasn't fully extending that right leg. Chemo #11 started on 9/20. This was the first chemo without the nasty medicine. We were so excited. We couldn't wait to see how Ben would tolerate it and were so happy that he wouldn't have those awful mouth sores anymore.

9.13.06

Hello precious friends ... Let's see, where did I last leave you? Oh, the last chemo. Okay, Ben recovered well from his last chemo, tolerated it like a champ! He bottomed out without a fever and continued to keep a good appetite and great spirits. If his appetite is any indication of what we're in for when he's a teenager, we're going to need a second mortgage. Now, if only he'd gain some weight! He's still only at 50 lbs. but he's growing taller every day it seems.

We had some very interesting visitors on Sunday – The Ravens Fan Man, the Maniac, and the bus boys all drove up to our house in their big purple Ravens bus, with sirens blaring and music playing. They were all decked out in their outfits, with painted faces and everything. It was quite a sight. The kids thought it was the coolest thing in the world! The guys came out of their bus and shook the kids' hands, put Mardi Gras beads around their necks, gave out trading cards, posed for pictures, chatted, told jokes. Liv's and Ben's smiles lit up their whole faces! All the neighbors came out and it was like one big party! Too bad Barry slept through it ... since he's the only actual faithful Ravens fan in the family. We did enjoy the visit, though. It really made Ben and Liv feel special. They're a great bunch of guys who may look (and sometimes act) like lunatics, but they do a lot of charity work and have hearts the size of their beer guts! (My best girlfriend's dad from high school is The Fan Man, so I'm connected!) Ben has realized that as much as cancer stinks, it has its perks, too.

Ben is due to start chemo #11 next Wednesday, assuming his counts are good. It will be a one-day trip to Hopkins for about seven hours, so that's not bad at all. The best part is that this will be his first time having this course of meds without the dreaded "red-devil," so no more mouth sores! Big WOO HOO! I'm anxious to see how he tolerates it.

His tutor started last week, so he's chugging right along with his schoolwork, trying to stay on par with his classmates. He is very happy to have his same tutor back this year. They have a great connection, and she really knows how to get him to work. He can be a real bear sometimes, especially in the morning, but she comes right in and gets him engaged in talking and before you know it, he's working! I have seen a big difference in him this year. He actually can't wait to get back to school! He still fusses a bit now and then, but for the most part, he does his work and keeps the complaining to a minimum.

We went to Ben's school today so he could get his school picture taken with his class. That was fun! He made his rounds to say hello to some of his former teachers, his school nurse (whom he loves dearly), the janitor, and anyone else who would give him the time of day. He just loved being there! He got to see his classroom and his desk (with his name on it) that's waiting for him. He is so happy to have Miss Slezak as his teacher again this year. She moved up from third grade to fourth, and always goes above and beyond to make Ben feel like part of the class. He even sat on her stool for a while today and fielded questions from his classmates. They had some great questions: How did you get cancer? Why is your one shoe bigger than the other? What does chemo feel like? Ben did really well answering them. It just tickles and moves me how wonderfully curious and accepting these children are.

Look at me! Walking into my future...

Okay, so the big news ... Daddy took Ben to get his new shoe yesterday. It's got a Herman Munster kind of look to it, but he doesn't seem to mind. He's doing really well with it. Once he put it on and walked around for a couple minutes, we realized how much damage had been done to his little body by being without a shoe on that foot for three weeks. His back and hips are all out of whack because he would only use one crutch and basically was leaning to the left and walking tippy-toe on the right side of his body. Now his body wants to do that because it's used to that posture ... so we just have to give him some time with the new shoe and see if it evens itself out. For the most part, he's doing great! He will most likely get a cane very soon. He needs to work on his stamina and strength now. It still amazes me how far he has come in such a short time. God is working miracles in this boy! His physical therapist is amazed, too! She is another one who is so awesome with Ben. We have been so blessed by all the wonderful people in our lives. Family, old friends, new friends, doctors, nurses, therapists, teachers, church family, neighbors, surgeons, and the list goes on and on ...

Thank you so much for all you do.

Love,

Sue

The worst was now behind us, the fall would be a time to begin looking to the future and moving forward with our lives. We had so much to be grateful for and so much to look forward to. ■

The Lanman Family story will continue in the next issue of the Cool Kids Connection. If you would like to contact them please email blanman2@comcast.net.

DO YOU SUDOKU?

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6					1
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	3			5	
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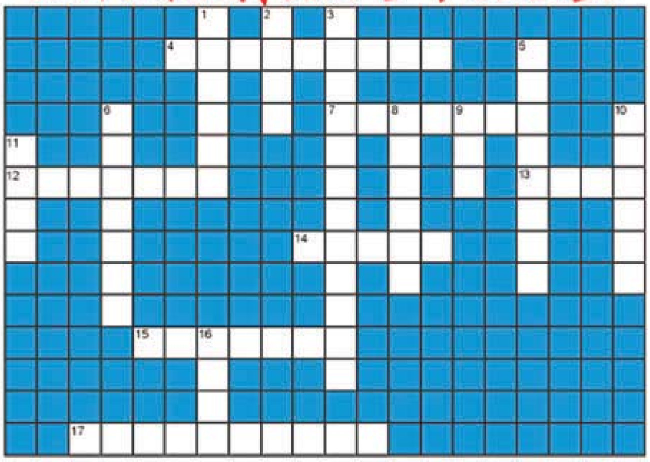
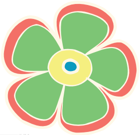
ENVIRONMENT PUZZLE





ACROSS

④ Many of our ____________ come from rain forest plants and animals.
⑦ An extreme shortage of water is called a ____________.
⑫ __________ is the ordinary pattern of weather in a region.
⑬ Putting meat leftovers in a compost heap can attract __________.
⑭ Recycling paper helps save ____________.
⑮ An animal's natural home is its ____________.
⑰ Too much heat trapped in the atmosphere is a result of the __________ effect.

DOWN

① The animal with the largest number of species on Earth is the ____________.
② More than 1,000 species of __________ may soon be extinct.
③ A word for the variety of life on Earth: ____________.
⑤ Americans use the most water in this room: ______________.
⑥ Tree experts hope to save ____________ forests from alien bugs.
⑧ Plants give off ___________, which helps people and animals breathe.
⑨ Both nitrogen and oxygen are a kind of ______________ in the air.
⑩ Oil, gas, and coal are ___________ fuels.
⑪ ____________ rain damages lakes and trees.
⑯ Incinerators __________ trash.

Q: What has a head and a foot but no arms?
A: A bed!

Q: The turtle took two chocolates to Texas, to teach Thomas to tie his shoes. How many "Ts" in that?
A: There are 2 "Ts" in "THAT!

Q: Why did the robber take a bath before he stole from the bank?
A: He wanted a clean getaway!

Q: What's the hardest part about sky diving?
A: The Ground!

Q: What has 5 eyes, is blind, goes for miles, yet bumps into nothing?
A: The Mississippi River!

Q: How many books can you put in an empty backpack?
A: One! After that it's not empty!

Q: What breaks when you say it?
A: Silence!

Q: What gets bigger and bigger as you take more away from it?
A: A hole!

Q: What gets wet the more you dry?
A: A towel!

Q: What goes through towns, up & over hills, but doesn't move?
A: The road!

Q: How many psychiatrists does it take to change a lightbulb?
A: Just one, but the lightbulb has to really want to change!

Q: What goes all around a pasture but never moves?
A: A fence!

Transitioning from treatments to school and play; It's what you've been waiting for, but how easy is it?

By Sue Stuck

"Congratulations! You did it! You're done your treatment!" Now what? After completing over 16 months of intense, weekly treatment for a malignant brain tumor, our nurses and doctors sang, "Happy End of Chemo to You," and told us they would see us in four weeks. Sounds good, doesn't it? Well, it's not quite as easy as you might think!


The shirt says it all!

When we found MacKenzie's tumor on December 2, 2005, we had taken her to a "quick" doctor's appointment over lunch and fully expected her to return to school within an hour. That was the beginning of our education in flexibility and "Plan B." Before we could even think of returning to school, MacKenzie underwent a nine-hour brain surgery, six weeks of recovery and rehab (those stinking "uncommon side effects" get you when you least expect them) and six weeks of daily radiation treatments (except for weekends, since cancer must not grow on weekends).

It wasn't until the beginning of March 2006 when we started to think about academics. Unfortunately, life had thrown us a big twist. Besides battling brain cancer, the side effects of full brain and spine radiation, and the anticipation of a year's worth of weekly chemotherapy treatments, MacKenzie still had to work on her rehab. She had an uncommon side effect from her surgery called Posterior Fossa Syndrome, which affected her ability to walk, talk, move her body, and gave her mood swings. How could we worry about school? How could we NOT worry about school?

When MacKenzie finally felt good enough, the school district provided a tutor in our home to help with schoolwork. This has been such an important part of our "educational plan." We have always experienced struggles with our kids when we tried to help them with homework. "Mommmmm, that's not how MY teacher does it!" Home schooling any of our four daughters was never in our plans, and doing it with a child who is undergoing treatment for a brain tumor AND has mood swings, as a side effect, was NOT an option.

Because of this, MacKenzie's tutor, Miss Lisa, has been an integral part of her recovery. She has a daughter the same age as MacKenzie, so she understands children, learning, attitudes and emotions. At the beginning, there were many days that MacKenzie would lay her head on the table, or even go up to her room while Lisa was trying to tutor her. Lisa always continued with a smile, a hug, and a "You can do it" attitude. She learned to nudge MacKenzie harder or back off when necessary. With her help, MacKenzie was able to finish her third grade work by the end of the summer and started working on fourth grade work at the same time as her classmates. This has been very important to her self esteem.

There has been a lot we have learned together along the way, mostly by trial and error. MacKenzie is not mentally up and running before 10 a.m., and she is fatigued after about an hour and a half of instruction. Her fine motor skills are still affected from the syndrome and the chemo, so she dictates her answers on tests and long written assignments. This also affects her processing speed, so she is allowed to take any necessary timed tests without a time limit. If she can show she knows the concept of a math worksheet after a portion of the problems, she doesn't have to complete the whole sheet.

She also seems to be having short-term memory issues, so spelling and math fact tests are out of the question. These accommodations were actually hard for me emotionally. It is hard to face that someone who has always loved school so much might have long-term struggles with academics, but we have learned to face the possible issues and not ignore them. Ignorance in the cancer world is not bliss ... face an issue as it presents itself and find the best way to overcome it!

One of the best things we have done is form a strong team, including all of MacKenzie's medical and educational caretakers. We have always had open communication between everyone, and even had MacKenzie's neuropsychologist attend her IEP (Individualized Educational Program) meeting before she returned to the classroom. At the IEP, everyone involved in MacKenzie's educational process met and wrote a plan detailing how the school would help her. They discussed issues like physical accommodations, educational goals and objectives, and standardized testing accommodations.

Having someone who is educated in, and can speak to the effects of, all that MacKenzie's brain has experienced, helped the school staff prepare for her to return. The neuropsychologist was able to address several issues that we would never have thought of to include in her written IEP. Since this is a contract between us and the school, it will be reviewed at least once a year to make sure MacKenzie is achieving appropriate goals.


MacKenzie and sister Nicki sit in on a school assembly

Before MacKenzie returned to the classroom, the school allowed me to visit each class and have an open question and answer session with the kids. I started off with a photo DVD of "MacKenzie's Journey" and a slideshow presentation teaching the kids about cancer. I wanted to address their concerns about MacKenzie's disease before they spent time with her. We talked about cancer, immune systems, changes in MacKenzie's appearance; I even showed a picture of MacKenzie's scar so the kids could look as much as they wanted without making her feel uncomfortable. Since she wasn't with me for these sessions, the kids felt comfortable asking questions. I answered them openly and honestly, and promised I would not share with MacKenzie what they had asked me. I truly believe they felt part of the team after being included in this discussion, and many of them go out of their way to help MacKenzie throughout the day.

Not everything about her transition to school has been as smooth as we would have liked. It feels to us that there is a lot of concern about "legal liability" with MacKenzie in school. What if she loses her balance and falls? What if her port gets bumped and hurt? What if? There was the suggestion that she sit on the side of the playground or in the library during recess to protect her. We have been telling her, and all of her schoolmates, that she is no different then any other child, and having her sit on the sidelines would send a different message. On a recent field trip, the administration went so far as to have a school nurse attend. Before the trip, they called to make sure she would have her wheelchair (which she hasn't had to use in months), and a blanket and pillow in case she wanted to rest. Even though we thought these measures weren't necessary, we had to do it to appease the school.


The hospital staff and Dad crowd around for a computer demonstration

At MacKenzie's IEP, we discussed that she might need help in crowded hallways because of her unsteady walk. It was written that she would take a friend as an escort and use the elevator when necessary. Unfortunately, their concern has made it so MacKenzie is not allowed to go to the bathroom without the escort. We feel MacKenzie is now strong enough and comfortable enough to follow the same routine as the rest of the students, and we don't want to interrupt other students' instruction time. The administration doesn't feel comfortable changing this without another IEP meeting. Every child is different, every cancer child is different, and every family handles transitions differently. We have discussed our plans with our doctors, and they agree that MacKenzie should participate in school activities as much as she feels comfortable doing so. MacKenzie's school has never had a student that has been through this experience, so we are testing the water. We are trying to communicate that our goal is to EMPOWER MacKenzie to be a strong individual, not ENABLE a handicap that she doesn't have!

We have learned that at MacKenzie's age, social growth is as important as academic growth. We are addressing the academics with her tutor, but because of her compromised immune system, she had limited and controlled social experiences while in treatment. If you look at the numbers, she was in treatment for 21% of her school life. We let her see friends and participate in other activities when everyone was healthy and her counts were high enough, but this doesn't allow for the normal social growth that happens on the playground and in the lunch room.

If you look back on your life, you are most likely to remember your friends and the fun times. We found that by keeping MacKenzie out of school and off the playground, we were able to get her through treatment faster. MacKenzie didn't contract a single infection or fever during her treatment, but she didn't experience the social growth that the other kids did while she was out of school. Being on the playground and having to negotiate social situations is an important life skill that is hard to duplicate. That is why, at this point, we are trying to make sure that she is at school for lunch and recess. MacKenzie has had a few close friends that have been by her side during the entire treatment, and now that she's back in school, there are more kids that want to be her friend. She has to be on the playground to experience what normal 10-year-old girls do: who's in charge, who are best friends, what games are played, which boys are cool, and most importantly, how to be friends with more then a few girls without hurting anyone's feelings.

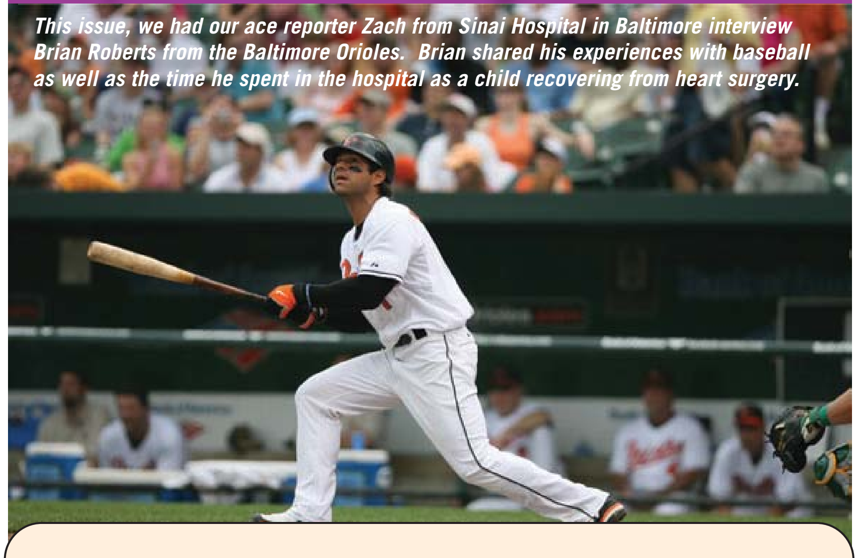
These are tough issues for most girls, so it is especially hard for MacKenzie, who hasn't had to think along these lines when she only had one or two friends over at a time. She has come home from school in tears more times then she would like, but she needs this to relearn how to handle friendships.

As a parent, you want to make life easy for your children. Childhood cancer is a lesson in how we have no control over what our children face. When MacKenzie was going through treatment, everything was scientific and driven by numbers and tests. When treatment is done, you are sent back to "normal" life to recover. Unfortunately, life is never normal again. If things go well, you learn from the experience, assimilate quickly, and move on. Sometimes the disease and the treatment can leave residual problems. This is what has happened in MacKenzie's case, but by working as a team, she will get through it and continue to love school as much as before.

MacKenzie received treatments at Johns Hopkins Hospital, Baltimore, MD, and has been transitioning back into fourth grade in Carroll County, MD. ■

Hey, I Was Wondering...

This issue, we had our ace reporter Zach from Sinai Hospital in Baltimore interview Brian Roberts from the Baltimore Orioles. Brian shared his experiences with baseball as well as the time he spent in the hospital as a child recovering from heart surgery.



Zach - How long have you been playing baseball? How old were you when you started?

Brian – I've been playing baseball about 23 years, I started when I was 5 years old.

Zach – Did you play other sports when you were young?

Brian – I played soccer and basketball until I was in high school. But then I realized I wasn't tall enough (Brian is 5'9") to really concentrate on basketball.

Zach – How did you know you wanted to concentrate on baseball?

Brian – My dad was a baseball coach so I grew up around it. I have always loved baseball, plus remember, I wasn't tall enough to play basketball.

Zach - What is most challenging about being a baseball player?

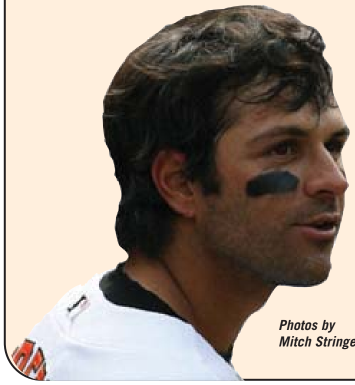
Brian – I guess playing so many games in such a short time, it gets physically grueling. Also being on the road, away from my friends and family for such long stretches.

Zach – You had heart surgery when you were a kid. What do you remember from your hospital experience?

Brian – I remember not wanting my mom to leave and not wanting to be alone. The doctors and nurses were great, they made a big difference. Since my dad was a baseball coach some of his players would visit me and that cheered me up. I do remember that it was scary.

Zach – What do you want other kids to know about your experience that would help them get through their time at the hospital?

Brian – Stay positive, focus on the good things. Don't get discouraged, focusing on the positive gets you through the hard times. And definitely lean on parents and friends. ■



Photos by
Mitch Stringer

My Loveable Big Bro

By Abigal M

A big smile from Abigal as she remembers Daniel

Hi, I am Abigal. I love to draw and spend time with my sister. I love to play with my little brother outside but that is only part of me. My other side is loving to hunt, fish, catch frogs, crayfish, minnows and get dirty! I get that from my brother Daniel. Daniel and I loved to catch the frogs in the creek at our cottage and other disgusting things in the mud. We caught snakes, shrews, crayfish and LOTS of fish. It was fun and we made a lot of memories.

Daniel taught me how to hunt and fish. My dad just sits there and helps me 'cause Daniel taught me and Dad lets me do it. I almost learned how to fly fish. That is hard. So I learned the easy way first. One time Dad helped my brother David, and Daniel helped me. It was fun. He'd tell me where to cast and then give me the pole. Then he'd pick up his pole and we would talk and fish together. I liked it. So did he. We always loved to do things together.

Daniel passed away July 12, 2006. All night Daniel couldn't go to sleep. He tried first on the couch then went to my parent's room to see if he could go to sleep there. He still couldn't and he said to my mom, "Stay right here." So she sat beside him and called Dad in to see what was the matter. Daniel tossed and turned and couldn't go to sleep. Finally, Mom said, "If you see Jesus, I know you do, you need to go to Him. You are a good boy. I love you." Then Daniel just stopped breathing. That was about 4:30 am. Dad checked his pulse and they called 911. It took them two minutes to get there. Before they got there, we called my pastor.

After they left Mom and Dad woke us up and we talked about what Daniel had gone through. Also, that he had a good life and the fun times we all had with him. He inspired others to come to know God, too. Then we went to Mom's room to say goodbye.

I remembered a few days earlier on the last part of our RV trip how Daniel would hug us, play games with us, grab our "chicken" or what you guys call thighs. He would blow kisses, too. So it was like he knew that he was going to die. That was funny to think about.

Daniel with his beloved fish

The best way I can describe my family is like a body. Daniel is the left foot, Alyssa the right foot, David is the right hand and I am the left. Mom and Dad are the eyes and God is the brain. We all need each other and we know we lost a left foot. We are not the six Mysliveceks any more because we lost a left foot. If we were a body and lost a left foot, we would have to be in a wheelchair and now we don't work right any more. But we still will always love him no matter what is in store for us. Now we are ready to move on but still not completely forget about him. NOT AT ALL!

Daniel's siblings: Alyssa (15), David (9), Abigal (10)

Daniel and I will always be best buds. He will always be a BIG part of my life. I love him so much nobody can imagine it. I love him A LOT!!

I want to get my hunting license like he did but I am only 9, almost 10, but you have to be at least 11 to hunt with a .410 or any gun! I still shoot with a BB gun and a bow. I have done that since I was 7-years-old. I am a pro ... kind of now. I can't wait any longer. I want to take after Dan the Man, MY Dan the Man. I want to wear #3 in soccer and fish and hunt. I love to do all those things and I always have. I want to hunt and fish, and play soccer just like my big brother, Daniel. ■

Puzzle Answers...

Lateral Thinking answers from page 3:

1. Throw the ball straight up in the air.
2. The two students have their backs to each other.
3. True. There are only two T's (upper case). There are also three t's (lower case).

Sudoku answers from page 12:

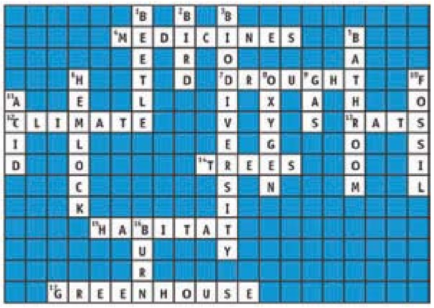
Green Squares

3	6	2	4	1	5
4	5	1	3	2	6
6	2	3	5	4	1
1	4	5	2	6	3
2	3	6	1	5	4
5	1	4	6	3	2

Yellow Squares

4	3	1	5	2	6
2	5	6	4	3	1
3	2	4	6	1	5
1	6	5	2	4	3
6	1	2	3	5	4
5	4	3	1	6	2

Crossword answers from page 12:



Anagram Rhyme answers from page 6:

STONE, SEWN, GROWN, THRONE

Alphabet Challenge answers from page 5:

1. jazz, 2. quiet, 3. yucca, 4. extra, 5. violin, 6. bashful, 7. grown, 8. defeat, 9. koala, 10. molar, 11. porcupine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