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

Connecting pediatric oncology patients throughout the nation.

Norman's Story

It all started with a headache and getting sick. I already had an appointment for a MRI with my doctor because I have diabetes also. The doctors saw something on my picture and told me I needed to come back in three months to have another MRI. At that MRI they discovered a tumor. They called my mom and told her over the phone and since I was in the same room I heard what the doctors said to her. I was really scared and started punching the wall, the refrigerator, everything because I was so mad. Even my sister Kayla started crying.

Soon after that I packed my stuff and my mom brought me up to the hospital and I had brain surgery. I stayed in the hospital for a little while longer and then I got to go back home with my family. At home I got cards from my class at school letting me know that they missed me. At this point I realized it was okay to be scared.

After surgery I started radiation and then I started



chemo a month after that. I still had not been back to school yet but my teachers and friends came to see me. I started to feel better than I had been because I knew that everyone was supporting me. I also started to get tutoring from Mr. Smith. Later on Kim came and tutored me.

Now I am having my last in-hospital chemo treatment. Hopefully I will be going to school soon because my tumors are gone! I can't wait to go back to school and play baseball like I was doing before all this happened.

Norman L. – age 12
Vermont Children's Hospital



SEND US YOUR STORY!

**Submissions for our next issue can
be sent to 116 Old Padonia Rd.,
Suite D, Cockeysville, MD 21030 or
emailed to sharon@bfpf.org.**

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

A note from Kimmie...

With spring upon us, it's a time to reflect on new beginnings, new hope, and miracles. As I walk along the neighborhood trail near my home, I am surrounded by the beauty around me.



*Photo by
Mitch Stringer*

The amazing blue skies, the blossoms poking through, and the brown of the past months turning to green in front of my eyes. How many of us notice the miracles that are among us in our everyday life? Why is it that it takes a monster like cancer to open our eyes and our hearts to all the possibilities in life?

Your stories and poems of inspiration as you embark on this journey of medical challenges, hope and courage has truly awakened my belief in the possibilities and the remarkable faith in mankind. It's so easy to get caught up in the everyday routines of life. As I reflect on the last four years of high school, I realize now some of the missed opportunities to get to know someone sitting next to me in class or maybe to get involved in something I was too shy or embarrassed to try. Why is it that only now as I approach graduation that I see this?

My hope for all of you as you read this edition of Cool Kids Connection, is that together we take the time to explore all that the universe has to offer, for whatever time we have on this planet, let our dreams blossom!!

Kimmie





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www.coolkidscampaign.org

The Angel Hair Foundation

How one young lady used her fight against cancer and its side effects to help others feel better about themselves

By Deborah Wright

I'll never forget the day. It was a day that changed our lives forever.

I had just finished my morning exercise class and was running errands when I got the phone call. It was my husband Rick, "Something's seriously wrong with Staci, you need to get home right away."

Staci had not been feeling well for about two weeks. She complained of headaches. We had taken her to the doctors and they gave her migraine medication. Staci was now lying on the couch not able to get up or complete a sentence; she was delirious. I held up three fingers and asked, "How many fingers am I holding up?" She could not answer! I called the doctor's office and they said "call 911 now." That was at 11:00 am. Finally at 5:30 pm, they found a tumor in her brain. We never went back home, she was admitted into the hospital and scheduled for brain surgery. How could so much have changed in one day?

After the tumor was removed we found out it was cancer. Ewings Sarcoma, bone cancer. It had started in her skull and was growing into her brain.

Staci was about to begin 10 months on intense chemotherapy and five weeks of radiation. At one of the first meetings with the doctor we were informed of all of the side effects of chemo. I cried inside, but stayed strong for Staci. Of all of the side effects she was about to face, Staci was most concerned about losing her hair. Staci was only 13 and just starting her 8th grade year in middle school. She was very active, she played soccer, ran track and snowboarded in the winter and wakeboarded in the summer. Needless to say, like most kids her age she was very conscious of her appearance.



Staci models her "angel hair."

Before Staci could even begin her first round of chemo her lung collapsed after her port was surgically implanted. A chest tube was put in and it was very painful. I felt very helpless as I watched my daughter suffer through the pain. As the pain worsened, an X-ray showed that the chest tube had moved and was causing extreme pain. Staci then had a seizure. She was scheduled for surgery to put in another chest tube. I had more than I could handle. My daughter was going through the worst time of her life. She was in extreme pain and there was nothing I could do, it was all out of my hands. Waiting for Staci to come out of the operating room seemed like an eternity. So many things went through my mind, I glanced at my husband and knew he was suffering, too. Tears welled up in my eyes, I buried my head in my hands and prayed.

Staci came out of surgery and was now ready for chemo. Our first round of chemo, which was scheduled for three days, ended up being nine days. Well, one down thirteen to go.

Staci's hair started to fall out after the second round. We asked about wigs and were given a list of wig shops in the area. We went to a couple of them and found that they just didn't work for her. Time was running out, Staci's hair was getting very thin now. She asked to go out to lunch after the second treatment, because she knew she would not want to go out anymore after her



hair fell out. At lunch she felt as if she was a “fish in a fish bowl.” She felt as if everybody was staring at her. She became depressed. She did not want to go out in public anymore and did not want to do anything.

Around that time a friend called and told me about her “hair system” and that it was the best alternative to her own hair. We were desperate and decided to give it a try. It was a Godsend.

We found a cranial prosthesis hair system that looked so real, you would never know it was not Staci's own hair. She wore the hair system all of the time. I cannot tell you how happy it made me, to see my daughter live the quality of life she was living. It proved the old adage, “If you look good, you feel good.” In between treatments, when she was not in the hospital, she was doing everything she had done before. She played soccer (she even did a header and her angel hair stayed in place!) she wakeboarded, snowboarded, went to her graduation dance, and enjoyed life. She had a great outlook on her life. At times, even she forgot it wasn't her own hair.

Staci went to the hospital with the hair system on and the doctors and nurses were surprised that her hair had not fallen out yet. Yes, even they couldn't tell it wasn't her hair!

The social worker at the hospital asked us about her angel hair. We told her all about it but when we told her the cost was about \$1,000, she shook her head because she knew most families could not afford it. I went back to Staci's room and told her this. I am so proud of her because as she was laying there in the hospital bed she said, “That's not fair, we need to help them.”

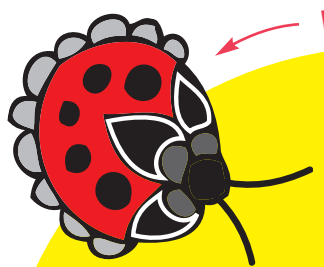
Staci's wish was to start a foundation to help other kids be able to enjoy the same benefits she did. So the Angel Hair Foundation was born to provide free cranial prosthesis (Angel Hair System) to every child in the state of Oregon who is suffering from hair loss because of treatments such as chemotherapy.

Angel Hair Systems are more comfortable than wigs. They are made from human hair and are made with specialized material, sensitive to the needs of the child and are secured on the head with adhesive. Kids can custom order the color and size and then have it cut and styled the way they like it.

Staci took a bad situation and turned it good. She tries to meet each child who receives an Angel Hair System. The kids she meets are inspired by her and she is touched by the strength of each one of them. Staci says, “I feel like there is hope for them to live normal lives while going through chemo.”

Staci is now 14 and cancer free. Even though her hair is growing and is about an inch long she still wears her “angel hair” because she feels more comfortable with it on.

If you would like more information about **Angel Hair Foundation** please call **Deborah Wright** at (541)344-5135 or email angelhairfoundation@yahoo.com. You can also visit them online at www.angelhairfoundation.org. *Staci was treated at Doernbecher Children's Hospital in Portland, OR.*



Don't count this one!

Help Us
Find the

LADYBUGS

Our ladybug friends have gotten lost inside this issue of the Cool Kids Connection. Can you help us find all six ladybugs? When you find them, email sharon@bfpf.org to be eligible to win an iPod® Shuffle. Be sure to tell us where they are hidden and your contact info in case you win!

KIDS (and Companies!) HELPING KIDS

Thanks... to **Tara S.** from **Bel Air, MD** (right) who had her birthday party gifts donated to the Cool Kids Campaign.

Thanks... to all the schools currently involved in our **Cool Kids Reading Challenge.**



Parenting a Child with a Serious Chronic Illness

By Ernest R. Katz, PhD

For a parent, nothing in life may be as traumatic as learning that your child has a serious, potentially life threatening illness like cancer, cystic fibrosis, severe sickle cell anemia, kidney or heart disease, or HIV infection. Whether the diagnosis is established prenatally, at birth, or during childhood or adolescence, parents must struggle with the shock, despair, and grief that their hopes and dreams of a perfect child are turned upside down. Fortunately, with the amazing medical advances of the last few decades have come major improvements in diagnosis, treatment, medications, and surgical techniques, altering once fatal diseases to chronic conditions that can be successfully managed. The great challenge today is how to maintain the best quality of life for the child and family in the face of often difficult and long-term treatment programs.

Maintaining normal life experiences and routines:

From the moment a parent learns their child has a serious illness, whatever the age of the child, the parenting challenge becomes how to balance a child's need for special medical attention with normal life activities. Research and clinical experience indicate that children do best when they live within a routine of love, structure, and consistent discipline. When a serious illness develops, it is only natural that parents and well-meaning family and friends shower that child with special attention, gifts, and reduced expectations for normal behaviors required from other children in the family. Although this extra attention may seem fair given the difficult life experiences the child must endure, the ill child may become overly demanding, difficult to please, and more easily upset. An ill child allowed to rule over his parents and family often thinks they must be really sick with no chance of recovery, as their parents no longer expect them to behave like the other kids in the family or community. Ongoing high-levels of special attention showered on an ill child also results in siblings feeling hurt, confused, and jealous. It is not unusual to hear brothers and sisters in this type of situation express the desire to become sick too, so that mom and dad will pay closer attention to them as well.

It can be quite challenging to help an ill child who has been treated in a very special way for an extended period of time to resume normal behaviors and expectations. It is far more productive to maintain normal family rules and expectations for behavior, with temporary modifications when necessary. This means de-emphasizing the illness as the defining aspect of a child's life, even though it is a critical part of his reality at the present time. See the whole child, including his need to continue appropriate normal activities like school, chores, and speaking nicely to others. If the illness or treatment makes it harder or impossible to do

these things as before, certainly make accommodations without abandoning the activity altogether.

The quality of life for an ill child, her parents, and siblings, are all enhanced when the family tries to maintain normal routines like bedtime, getting dressed during the day, mealtime, and communicating with friends when feeling okay. If a parent gets to a point where they feel it is impossible to maintain normal life routines for their child, they might consider consulting with a specialist in child and adolescent behavior with specialized experience in pediatric chronic illness. Your child's doctors or health care providers may be able to direct you to such individuals in your community. Always check the credentials and training of anyone you consult for expert guidance, and make sure they are experienced in situations similar to those at hand.

A difficult, but manageable challenge?

Parenting an ill child is a difficult challenge that needs to be faced with the hope that the child will experience some degree of positive growth. Even if the outcome is uncertain, we can help the child cope by focusing on what we *can* do rather than on what *cannot* be done. Parents also need to take care of themselves along the way, both emotionally and physically, or risk becoming exhausted, run down, and depressed. If parents are unable to cope, that may lead the ill child and family to feel even more hopeless about the future. Each parent handles this type of stress differently, with some seeking support of friends and neighbors, while another wants to be isolated and handle things alone. Pacing oneself and taking things "one step at a time" are not just nice sayings, but critical to long term adjustment.

Dr. Katz is the Director of the Behavioral Sciences Section at the Children's Center for Cancer and Blood Diseases, Children's Hospital Los Angeles

A Mother's Courage

My son Dustin was diagnosed with neuroblastoma at age 5 in 2004. He went through chemo, radiation and a stem cell transplant. He is now 8 and cancer free. Here is a saying I said to myself every day all day long while he was in treatment. It helped me the whole way through:

**God grant me the serenity
to accept the things I cannot
change, the courage to change the
things I can and the wisdom to
know the difference.**

Like all the other moms I wasn't dealing with things too well. But with this prayer I got through it without medication!

Pamela L., Akron, Ohio



Sound the Attack

**Mommy sounds the attack,
Daddy is the shield.**

**We will stand by Alyssa
on this battlefield.**

Lymphoma, Lymphoma go away!

**You are not wanted,
we will not let you stay.**

We will stop you dead in your tracks fast.

You will die with each chemo blast.

Doctors and nurses have your number

And will put you in a permanent slumber.

No more growing, give up the fight.

**You are no match for "earthly angels"
praying day and night.**

**Date: ___/___/___ of your death
will be recorded here.**

**From the CT/PET scans
your ugly face will disappear.**

**Bonnie M. – Mom
Alyssa M. – Daughter, age 13,
Lymphoma-Hodgkin's-Disease-Stage 2A,
starting 3rd (out of 12) week of chemo**



COOL KIDS Activities

¡PRIMAVERA! & SPRING!

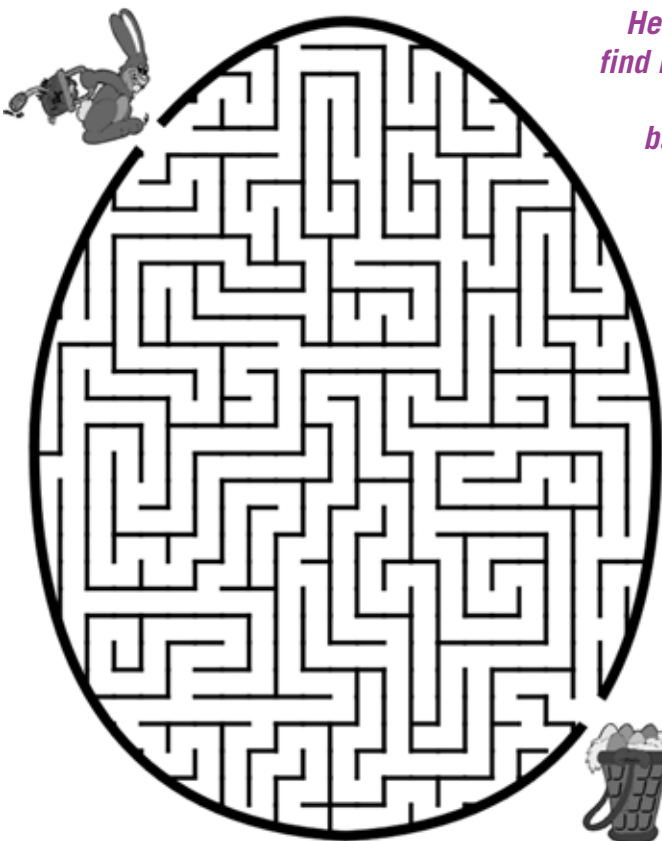
(Español) (English)

¡Busca las palabras en español e inglés! Search for both the Spanish and English words!

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

PRIMAVERA
CALOR
SOL
HIERBA
ROCÍO
FLOR
LOZANÍA
PARAGUAS
LIMPIAR
PASCUA
MADRE
LIMONADA

SPRING
WARM
SUN
GRASS
DEW
FLOWER
BLOSSOM
UMBRELLA
CLEAN
EASTER
MOTHER
LEMONADE

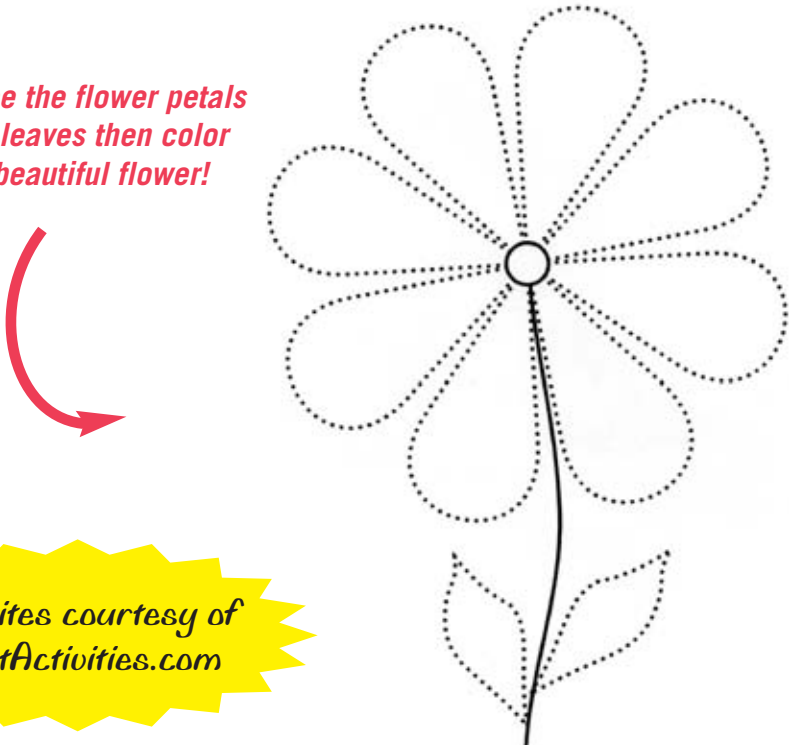


Help the Easter Bunny find his way through the maze to find a new basket for delivering the Easter eggs!

Tracé los huevos de Pascua que el conejo de Pascua que perdió en su vía luego, colorea el conejo de Pascua y decore los huevos de Pascua.

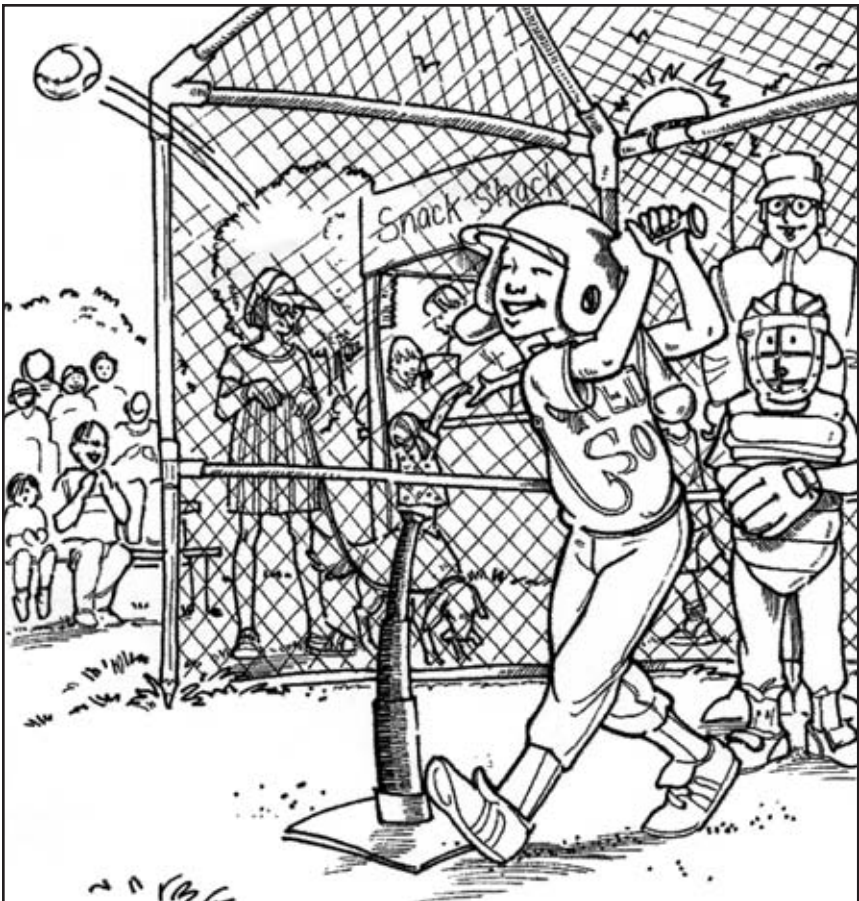


Trace the flower petals and leaves then color the beautiful flower!

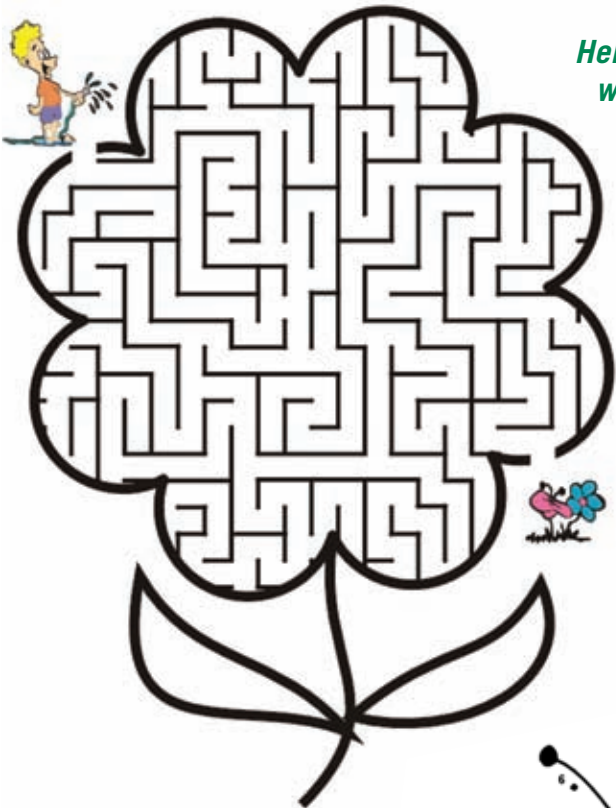


Activites courtesy of PrintActivities.com

Hidden Pictures! In this big picture find the bar of soap, toothbrush, spoon, candy cane, telescope, ice-cream cone, pencil, fishhook, apple core, mushroom, horseshoe, and hot dog. Can you find the hidden pictures?



Courtesy of Highlights



Help the the boy find his way through the flower shaped maze to find some flowers to water!

Relaciona los puntos!
Connect the dots!



Activites courtesy of
PrintActivities.com

LAUGH IT UP!

As two caterpillars were crawling along, a butterfly flew overhead. One turned to the other and said, "You'll never get me up in one of those things!"

What subject is a witch good at in school?
Spelling!

What do firemen put in their soup?
Fire crackers!

Why did the cookie go to the doctor?
Because it was feeling crummy.

What did the duck say when he bought lipstick?
Put it on my bill.

Why did the chewing gum cross the road?
It was stuck to the leg of a chicken!!!

What did the egg say to the other egg?
Let's get cracking!

What do you say to a cow that crosses in front of your car?
Mooo-ve over.

Why was the chicken afraid of the chicken?
It was a chicken.

Why did the turtle cross the road?
To get to the Shell Station!

What would you call a sleeping bull?
A bulldozer.

Why do cows have bells?
Because their horns don't work.

How can you make seven even?
Remove the "S."

Did you hear about the two silkworms who had a race?
It ended in a tie.

Why is Turtle Wax so expensive?
Because turtles have such tiny ears.

An FBI agent is interviewing a bank teller after the bank had been robbed 3 times by the same bandit. "Did you notice anything special about the man?" asks the agent. "Yes," replies the teller. "He was better dressed each time."

FATHER: How are your grades, son?
SON: Under water, Dad.
FATHER: Under water?
What do you mean?
SON: They're below C level.

STUDENT: But I don't think I deserve a zero on this exam.
TEACHER: Neither do I, but it's the lowest mark I can give you.

Why did the boy bring a ladder to school?
He thought it was a high school!

If April showers bring May flowers then what do May flowers bring?
Pilgrims!

What's in the middle of a jellyfish?
A jellybutton.

TOURIST: How would you describe the rain in this part of the country?
LOCAL: Little drops of water falling from the sky.

What did Tarzan say when he heard the elephants coming?
"Here come the elephants!"

Why did the parrot wear a raincoat?
So he could be polyunsaturated.

Why do elephants never forget?
Because nobody ever tells them anything.

How do porcupines play leapfrog?
Very carefully.

Our Journey

Editor's Note: Last issue we introduced you to the Lanman family from Bel Air, MD. Their 8-year-old son Ben was diagnosed with Ewing's Sarcoma in January 2006 following a carefree family vacation to Disney World. Now we rejoin their journey after his surgery to remove the cancerous hip bone in April 2006. (Read the first installment of their story on www.coolkidscampaign.org) This is a compilation of Ben's mom's story and her emails sent to friends and family.

After Ben's surgery in April we had a lot of adjusting to do. The shock was settling in and the initial whirlwind of prognosis, treatment schedules, and life altering options was behind us. Now we were looking at months of our new, but temporary, reality.

There were so many issues facing us. We needed to learn how to deal with a son who was going to be in a body cast for three months, our daughter Olivia was having a hard time dealing with her stress, and Ben's normally upbeat attitude was starting to show some cracks.

But there were also so many things to be thankful and hopeful about. Ben's prognosis was positive, we had a wonderful support system, and we had each other. I was even seeing how my kids were getting closer and more appreciative of each other. Something I never would have thought possible between a 10-year-old girl and 8-year-old boy!

After Ben's 12-hour surgery he stayed overnight in the Johns Hopkins PICU and was moved to the fourth floor of the Children's Center. He was still very groggy upon waking. He was uncomfortable and afraid to move. The first time he cried he could feel his belly touch the inside of the cast which made him feel like he couldn't breathe. If this body cast was going to be his wardrobe for the next three months it was going to take some getting used to. He was going to be totally dependent on everyone for everything. There were all kinds of IVs and drains coming from his hands, his central line and from inside the cast at the surgical site. He was hooked up to a pain pump that would give him a dose of medicine at timed intervals, and he could also hit a button to have it release more if needed.

For the first few days he was in and out of sleep and in and out of pain. We were glad to be in the hospital because we were close to people who knew how best to handle each situation as it arose and could teach us as well. That whole week was a blur. Physical therapists

came in the day after his surgery to get him 'up and moving.' Both of us cried through their visit. It was really hard for Ben to do what they asked of him, and it was hard for me to watch. We didn't sleep much because nights were difficult for Ben. He just wanted to roll over or scratch or just plain move, but was too afraid or too heavy to do it himself. It's amazing how much we take for granted until we can't do it for ourselves. We had many visitors, but Ben was in no mood to entertain. We were only in the hospital for a week, but in order to go home Ben needed to eat and have a bowel movement. He hadn't eaten and had barely drunk anything since the Sunday before his surgery.

A few days after surgery, a blast of pain came out of nowhere and made him scream. He had to be dosed with morphine and Oxycodone.

That knocked him out for about two hours. When he woke up he was like a brand new kid. He even ate a Ho-ho!! He ate another one on Monday. He was feeling rather adventurous, so we got him in his wheelchair and went to the playroom! It was a good day. We played games and did puzzles...and he even pooped!! That meant we could go home on Tuesday, exactly one week from his surgery!

Getting him home was quite the feat. Thank God our van has a feature where the trunk opens up and the back bench seat can flip over so the seat faces out the back of the van. We loaded Ben in this way and then slowly flipped the seat back into place. He had to wear a vest made out of seatbelts, was surrounded by pillows and his vest was hooked into the van's seatbelts. I've always been neurotic about my kids' car seats, but this made me crazy! I

sat on the floor of the van next to him while Barry drove. This worked well, but it wasn't going to work when I had to drive Ben back and forth for chemo. There was no way that I would drive for an hour while Ben laid where I couldn't reach him or get to him without pulling over, especially during chemo. If he had to be sick, which he almost always did on car trips to and from the hospital, he would choke on his own vomit. So, at that point we had to plan every outing so someone would always be in the back of the van with Ben.



Three days before surgery Ben still has fun with face paints! No time to dwell on what is ahead.

4.25.06

Hi everyone!! We're home!! We got home around 1 p.m. this afternoon. All is well...Ben is doing wonderfully! It's hard to believe that one week ago this very moment he was still in surgery! I just wanted to let you know that we're here so you'll know where to find us. I'll update you with more later. Thank you so much for the constant prayers, love and support! You guys are just awesome!

Talk to you soon! Love, Sue

We had a house full of visitors the whole week after coming home. When someone was leaving, someone else was coming up the walk to visit. It was great—just what Ben needed! It kept his spirits up, kept him distracted, and reminded him of just how special and brave everyone thought he was. His teachers, principals, classmates, our pastor and his wife, and so many friends and family came. We cherished every visit. His cast was full of signatures in no time...and that was a lot of cast! Everyone walked in looking nervous, talking in low voices—but they all left laughing and smiling. Ben didn't want anyone feeling sorry for him. He would tell jokes, show off, share funny stories and just plain make people forget that he was laying there bald and in a body cast.

Ben's school community was absolutely incredible with their outpouring of love and support. His teacher, Miss Slezak, always kept Ben in the loop as to what was

"With understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything is possible."

happening in the classroom. She wouldn't let the class forget about Ben either. She kept his desk in the same place with his name on it all year, even though everyone knew he wouldn't be back that year. She also made a DVD of every field trip, complete with a music track, and each one opened with a video clip of the kids on the bus waving and saying, "Hey Ben, we miss you. Wish you were here. Get better soon." Ben got to experience all their field trips through this DVD of pictures and video. The class also made cards for Ben for every holiday or just to say hi or get well. They made another video of each student getting up and telling a joke or two because they knew how much Ben loved to tell jokes. I didn't know whether to laugh or cry half the time while we were watching these precious kids reaching out to Ben. It moved us all. It was so good for Ben to see that his buddies remembered him and were thinking of him. His school nurse, Mrs. Kauffman, always went out of her way to stop by our house or call or e-mail to check in with us...always bringing something for Ben and spoiling him rotten! Everyone became part of our family and it meant the world to all of us!

Olivia started having some difficulties around this time. She was close to graduating from the 5th grade, which meant leaving the school she had known and loved for six years and becoming a middle schooler. I believe it was a combination of anxiety about this and the guilt that she was having so many wonderful things happen for her while her brother was having a rough time. The way he would greet her when she'd come home from school told the whole story. He missed her so much and was so glad to see her. All day was spent, "Where's Liv? When's Liv coming home?" Olivia started having 'tummy aches' each morning, saying she didn't feel well enough to go to school. The rule in our house is that if you feel poorly enough to miss school, then you must go to the doctor to get checked out. Liv was checked out and seemed fine. This went on for a few days. This was so out of character for Olivia. She

LOVED school! She did not like being absent, ever! Finally, we figured it out. Liv didn't want to leave Ben, didn't want to move on to middle school, didn't want to have fun while Ben was stuck inside, etc. Too much was going

on in her little world and she was overwhelmed. She showed no interest in leaving the house, going to school or any of the fun goings-on that only fifth graders get to experience. Bless her heart. She had put up with so much for so long and this was supposed to be her happy time. She wouldn't talk about it, only blame the way her tummy felt. Barry and I were not going to let her miss any of these experiences. It took a lot of talking and a strategy with our school counselor, but we managed to get Olivia back in school and back on track.

5.4.06

Okay gang. I've sat down here to send you all an update about 10 times, but each time I get called away or distracted by something else. I think I'm developing adult onset ADD...or I'm hanging out with Ben too much! Anyway, we're all doing just fine! This has been a great week for all of us. We've filled our day with visitors and that has been the greatest distraction for Ben. The only time he requires pain medication is before bed, and maybe once overnight, but it's more for agitation than pain. He gets uncomfortable and itchy sometimes, so we move him around a lot—from his wheelchair to the couch to the bed, etc. We've even been outside for walks in his wheelchair! Tomorrow he goes in at 6 a.m. for a cast change. They do this in the OR, so he'll be sedated. This cast that he's in now was put on right after his surgery when he was at his most swollen from all the fluids going into him. Now his body is back to normal and he's practically swimming in this cast. He's not going to be too happy in this new one because I assume it will be much tighter (now I can practically put my whole hand down inside this cast to scratch his itches). He has chosen blue with green stripes as the color for the next cast.

Overall, this whole thing has gone much more smoothly than I ever anticipated! We have been so blessed! The day of the surgery was the hardest, I think. I was okay with the whole concept of what needed to be done, but it wasn't until he was in the OR and the doors were shut that I finally thought about what they were actually doing to him in there. It took every ounce of strength not to rush in there and run away with him. It was a VERY LONG nine hours...and then they told me I couldn't stay with him overnight! ARGH! I'm glad that is in the past now and we can just concentrate on healing.

Ben's tutor has started back with his schooling this week. She's actually upstairs with him now, so that's the only reason I can sit for 10 minutes and write this! I LOVE her! He had physical therapy come to the house this week, too. We weren't able to do too much because of the way his cast is made to fit, but the new cast should allow more freedom with his good leg. We were able to support him in a standing position and have him hop a bit on the good leg...it wasn't very comfortable for him because his cast pushes on the top of his thigh and his leg is kind of splayed out to the side. He did his best, though. He is building his upper body strength by lifting soup cans like weights. He's a tough little cookie. It's almost

like this new house was made for all this to happen. His hospital bed fits perfectly in our family room (along with all his new supplies), and his wheelchair just fits to come into the room without moving any furniture.

Olivia has had some issues, but she's had a lot to put up with lately.

We think she feels guilty for having fun and doing "regular" things, so she opts out of activities (and school) so she can be with her brother more. Her stomach seems to bother her when it's time for her to go anywhere and we think she may be having stress-induced gastritis. Bless her heart! She's got a lot on her plate these days. These are her last 30 days of fifth grade, so there are lots of wonderful activities planned for her class. Thankfully, we have the greatest school community that has truly gone above and beyond for our family. It's as important to them as it is to us that Liv continues to feel special and thrive despite all that's going on in her

world. We refuse to let her miss out on any of these wonderful opportunities that are coming up! This is her time to shine! Her Destination Imagination team just won second place in their state tournament, so they will travel to Tennessee later this month for the Global finals (to compete against other kids from the U.S. as well as other countries—how cool is that?). As we speak, she is away for three days with her class to learn all about the environment and how to appreciate and protect it. It took Barry and I and half the school faculty to get her there, but we knew that getting her there was all we needed to do. Once there, we knew she'd have the time of her life! We get to see her tonight at a family campfire night and she'll be home tomorrow! I can't wait! She's such an awesome kid—and she loves her brother! Boy, does he miss her, too! They bugged and kissed and professed their love for one another before she left! It was just too much! We are so blessed!

Take good care and enjoy this beautiful day God has made for us! Love you all! Sue

Each day seemed to get a little easier. I don't know if it was easier, but we got better at handling everything. A week or so after surgery we got the pathology report. It showed NO VIABLE TUMOR!! The bone that was taken out of Ben had no living cancer in it!! That was the best news we could ever get. Not only had the chemo killed the tumor, but then it was removed! Praise God! That moment reminded me of the day after Ben was diagnosed. After driving around screaming and crying, I found myself at my church. I needed to hand this whole thing over to God because it was way bigger than me. It was a Thursday afternoon and I just showed up in the church office crying, with a



Two days after surgery Ben was pale, swollen, and afraid to move.

"He had done so well up until this point. We knew we couldn't have handled what he was going through with as much courage and strength as he had shown. We had to let him vent his frustrations and just help lead him through it."

box of tissues under my arm. They took one look at me and immediately I was surrounded by our two pastors, their wives, both church secretaries, our youth pastor, and even the cleaning lady. They all walked me to the sanctuary and came together at the altar to pray. Each one in turn said the most wonderful prayer, all different, all touching on things I hadn't even thought to pray about. So many awesome things were said. Each and every word warmed my heart like a blanket. I stopped shaking. One part of a prayer that I will never forget was, "Lord God, please hold this tumor in your mighty hand and just squeeze the life out of it." For me that day was the turning point. I went from being a sobbing mess to being filled with the most incredible peace.

5.5.06

Hello loved ones...Just a quick e-mail...I'm slightly delirious from having gotten up at 4 a.m. this morning and having spent 12 hours at Hopkins today...but all is well. Actually, all is supercalifragilisticexpialidocious!

We just got the e-mail from our surgeon that the pathology came back today from Ben's surgery. It showed NO VIABLE TUMOR!! That means that the bone that was taken out of Ben had no living cancer in it. The chemo had already killed it!! Yes, I could be sad that we took the better part of his hip when the cancer inside it was dead...BUT, we never would've known that the cancer was dead had we not taken the bone...and we couldn't take that chance.

So...it tickles me pink to say this...My son is cancer-free! Wait...let me say it again...I love the sound of it...MY SON IS CANCER-FREE!

We will continue chemotherapy until we complete all 12 sessions (today we had our fifth)...and if we stay on schedule our last chemo will be on October 2. The doctors say that this is preventative, in case there are any rogue cancer cells floating around Ben's body looking for a place to live. I totally understand this and I'm okay with it. Ben's having a bit of a rough time with the chemo he received today...and the cast change. He's a bit nauseous and his cast is tighter...not a good combination. It's okay, though...you know why? Because he's CANCER-FREE! (hee hee—I just love saying it...I'm even doing the cancer-free dance) Ben doesn't know this yet, but Liv does...and we just celebrated with big bugs and root beer floats.

So, all is well in the Lanman home...My Livi is home and safe and happy. She had a blast at Harford Glen and is so thankful that she went. My husband is safely driving on his way to work right now. I'm happily writing my e-mail update, doing my dance. And my Ben...he's sleeping soundly...and he's cancer-free!

God Bless you, each and every one! My heart is so full of thanks and love and appreciation for every single one of you. I wish you all joy and peace!

I love you so much...Sue

Ben didn't really complain of pain. Most days he didn't have any problems, but once nighttime came it was more agitation than anything else. I think all the distraction that the days brought kept him from really dwelling on how he was feeling. When night came and it was time to settle in, the 'itchies' started or the discomfort from being in the same position wore on him. It was like having an infant again, in many respects. Barry or I would scratch him, massage him, sing to him, talk calmly to him to get his mind on something else. We did everything to soothe him.

We'd ask him, "If you could go anywhere in the world right now, where would that be and what would you do there?" or "What's the first thing you want to do when this cast comes off?" We would

talk to him about his hopes and dreams.

Barry would talk to him about video games (that only a father and son can understand) and keep him distracted for a long time. We tried everything!

Some nights were better than others, but there were some very long nights. For the most part, Ben did phenomenally! His great spirit was what made it easier on us. He still kept his smile, his sense of humor. He rarely got down on himself. When he complained it was about something he felt: pain, discomfort, itchiness. We all lived with the motto that 'this is only temporary.'

Another thing we were so very thankful for was that we were able to get at-home nursing. Our nurse, Carla, would come to our home to draw Ben's blood for weekly counts. That saved us from having to tote him back and forth to Hopkins in his cast. We got really spoiled having Carla around. She was a huge blessing to have as part of Team Ben. She taught me everything about central line care to

hooking up different medicines that Ben would need through his line.

We were fortunate to stay out of the hospital for quite some time, except for when Ben had chemo. We filled our days as best we could at home. Some people thought we would go stir crazy staying home for so long, but it wasn't so bad. Some days were long and some went by rather quickly. Ben couldn't move, so I always knew where he was. I had resorted to getting a baby monitor again so that I could always hear him if he called to me—not that our house is that big, but inevitably I would go to the laundry room and have the hum of the machines drown out his calls to me that he needed to go to the bathroom or be sick, etc. His hospital bed was in our family room and I slept on the couch next to his bed. We have skylights in the family room, so even on days when we didn't get outside we had plenty of natural light and could see the clouds. We got better at going places whenever Ben's counts were high enough. We would load up and go to the library or walk in our neighborhood and look for yard sales. We really appreciated every outing so much more. The treatment Ben would get from the kids in our new neighborhood was just precious. They were so tender and sweet at first, and then they just talked to him like they would anyone else. It made him feel so good to go outside and hear all the kids say, "Hey look, Ben's coming out. Yaaay, it's Ben."

5.30.06

Hello all,

I just wanted to let you know that Ben went in for his sixth round of chemo today and is doing great. He will be in-patient this time as we didn't feel like running him back and forth for five days straight.

So far he is doing very well. He doesn't usually have too many problems with this course of drugs. If all continues to go well, he should be able to come home on Friday night!

Today marks exactly halfway through the journey in his cast AND after Friday, halfway done chemo as well! YAY! Thanks again for all of your prayers, meals and attention.

Barry

Towards the end of May Ben's good spirits started to slowly fade. His time in the cast was wearing on him. The weather was getting nicer and we could hear the kids playing outside. Neighborhood kids would pop in to show Ben a rock or a toad they had found. He loved it, but it also made him long to be with them, running, playing, getting dirty, being a 'regular' kid. There were weeks at a time when Ben couldn't have visitors because of low counts. Those long days took a toll on him. Nights were still the most difficult time for him. He was good about keeping busy throughout the day with tutoring, TV, video games, etc...but the nights brought depression, discomfort and agitation.

When his spirits would take a dive he would say things that broke our hearts, wishing he was dead, wanting to hurt the doctors for doing this to him, questioning why this was happening to him. He would



**First day home after surgery -
always the comedians, Ben and Liv
ham it up for the camera.**

vacillate between anger and sadness. We couldn't fault him for this. He had done so well up until this point. We knew we couldn't have handled what he was going through with as much courage and strength as he had shown. We had to let him vent his frustrations and just help lead him through it. There was no 'talking him down' or reasoning with him when he was in such a state. He just needed to get it out and cry himself to sleep. This was almost every night for weeks.

6.3.06

Hi again...Ben and I are home, as of 3 p.m. today. This particular chemo is the one he tolerates best...just some nausea. After being out of the hospital for so long, it was difficult for Ben to be away from home this time. I have to admit...being in Tennessee the week prior and having so much fun, and being home for only one day before going into Hopkins... it was kind of hard for me, too! I've been a bit of a whiner this week (a big apology to all those who called me while at Hopkins)! Hopefully, we won't have to do any more inpatient chemo...or have any unexpected ER visits.

There were a few surprises during this stay. The doctor who was doing rounds this week decided that Ben should be on a medication that prevents clots, since he's immobile in the cast. We were okay with that until we learned it had to be a daily injection that we'd have to give him!! He got two days worth while we were in the hospital, and it was really traumatic for him! Then, I just flat out refused it. There's too much contradiction between doctors, nurses, etc. Now I'm in a bit of a battle with them all. I am waiting to hear from "our" oncology doctor (who, by the way, didn't order this particular medication when Ben first went into the cast). Our surgeon stopped in to see us and she said she never puts kids on this medication, especially chemo kids, since it can cause bleeding (and he'd be at risk when his platelets are low). We are half way through his time in the cast, and I think he is more mobile than anyone else would be in his position. He's constantly fidgeting and moving and rolling and skooching around in that thing! I personally think he's been through enough and that this medication is unnecessary! We'll see how it goes. I have purchased it and it's sitting on my dining room table still in its bag, so I'm hoping to be able to donate it to someone who actually needs it!!

We should be going in for a cast change sometime this week or next. I should find out on Monday when we're scheduled for that. It should be an easy visit, but Ben still has to be put "under" in the OR to have it done. If anyone has any cast color recommendations, please let me know and I'll share them with Ben. He's a bit torn this time about what color(s) to choose. I did have to talk him out of one of his choices...He wanted to show his support to Livi's D.I. team by

getting a hot-pink cast with a big black X in the middle of his chest. The team's name is 'Extremely Pink'. Now that D.I. is over I think he'd just look like a big freakish super hero...and five weeks is a VERY long time!

Our next chemo is scheduled for June 19. Hopefully, this being the half-way mark with everything, it will all be downhill from here! You all have certainly made this whole experience easier for us by just being there, being so supportive and encouraging and prayerful! Bless your hearts!

Anyway, we're very happy to be home! Ben's counts will plummet this coming week, but we should be back in the swing of things the following week and hoping to get out more and/or have some visits!

*Love and blessings to all...
Sue*

Ben is the kind of kid who has always been a snuggler. From the moment he was born he would find a way to end up in my bed at night. Barry worked nights, so he slept during the daytime. Ben had a way of climbing in

bed and folding himself into you so that he just felt like a natural extension of your body. Being in this cast was particularly hard for Ben because he missed being touched more than anything. The only skin that was exposed outside of the cast was his head, shoulders and arms. All we could do was lay with him and let him wrap his arms around us. Our arms would be around him but he couldn't feel them through the cast. It was heart wrenching!

Thankfully, Ben was still Ben.

Even while in a body cast, confined to the bed or couch, he still managed to get himself into trouble. He would still aggravate Olivia or talk back to me or Barry. We learned that it is hard to

punish a child in Ben's condition, but we still needed to discipline him when he misbehaved. It's just really sad (and somewhat comical) when the only form of punishment you're left with is to take away the TV remote. It got our point across, though. We didn't have to do that too much, but sometimes it had to be done!

There was also some contention caused by Ben's lack of schedule. Because of chemo, medications, surgery and just plain laying around all day every day Ben was not tired when he was supposed to be. Olivia had to go to bed at a decent time in order to wake up

for school the next day. It seemed unfair to her that Ben got to stay up later, wake up later, watch TV and play video games, eat whatever he wanted, etc. Those are the kinds of things that caused 'bad blood' between them.

That was hard for us because we saw Olivia's point, but what could we do? We did our best to keep a 'normal' schedule for all of us, but that was thrown off so easily by any number of circumstances. For the most part the kids got along very well.

6.21.06

Hi all...Attached are two pictures of Ben in his cast. The blue cast was just removed on Thursday and replaced with the newer Patriotic cast.

He's ready for the 4th of July...wouldn't you say? It was funny...Ben first wanted orange... then decided on red, white and blue. He asked for one leg blue, one leg white and the chest to be red. I really thought he

was asking a lot of these doctors, but once they went into the OR they had a field day and created this awesome cast! They really had fun with it, and made my little guy very happy in the process!! We're going to paint some white stars on the chest just to complete the total package!

We just completed our seventh chemo as of today. He started on Monday and was unbooked at 11 o'clock today by the at-home nurse. So, now we're over the half-way mark and coming down the home stretch! Only five more to go!!! Woo hoo! Also, as of today, he only has three weeks left in his cast! Double woo hoo!!

This week has gone well so far, too. For the first time, Ben didn't get sick coming home from the hospital on Monday. Actually, he hasn't gotten sick yet with this chemo...and this is usually the worst one for him. God is so good!! Again, Ben is upstairs playing video games with Patrick, so it allows me some free time to send this update. He's been in good spirits and has even had his tutor come twice this week. She's coming again tomorrow and next week, too. He has a few hours to make up since he missed time due to hospital stays, so the school system is letting us continue until we're all caught up. Hopefully, he will continue to do well, keep his appetite and avoid those mouth and throat sores that usually accompany this chemo. So far, so good!!

We've only had a few issues at night, some worse than others...mostly agitation, itching, some pain. Ben gets a little crazy during those times, but he has really put up with a lot, being in this cast for so long! He starts freaking out between 10 and 11 and it lasts until 1-2 ish...then he finally wears out and falls asleep. It's frustrating, but it's only temporary, right? He should be better once this cast comes off for good! Next week his counts will plunge and we'll have to lay low, but hopefully he'll bounce back and have another really good



Chemo #6, always smiling!



Ben with best friend, Kieran, sharing a video game

week before chemo #8 and cast removal!! He's had such a great two weeks...it's really spoiled us all! It will stink to have to lay low again...but, again, it's only temporary!! We'll be back in full force, ready to conquer Target and church and the snowball stand once again!! We are so blessed! Thank you, my friends, for walking this path with us!!

Oh, I almost forgot! My friend, Amy, sent me this quote that she found. She said that this was my evolution with Ben's cancer, and that hope is granted by God. I LOVE IT and have to share it because it is so true!! We all know that with God all things are possible!

"With understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything is possible."

I love you! Sue

We had a lot of talks about what was going on, what we needed from each other and what things needed to change. We were all in this together and we needed to stay in touch with how everyone was feeling. It was so important that we let our thoughts and feelings be

known with each other. With so much going on around us it was easy to feel lost in the shuffle. We made every effort to keep the lines of communication open between all of us. And keeping a sense of humor proved vital. Giving ourselves permission to laugh, even when we wanted to cry, was essential.

We were getting close to the day when the cast would be removed, only three more weeks. Ben couldn't wait. We started counting down the days at this point. He had so many things he wanted to do, but I don't think he realized just how much harder it would be for him to do some of these things. We didn't know how to prepare him either. We had no idea what to expect. He had lost a considerable amount of weight and his muscles had surely atrophied from lack of use. Our heads started swirling

with a whole new set of questions...would he be able to walk? Would it hurt him to move? Could we hold him? What kind of mobility would he have? What would the difference in leg length be? We had no idea what it would feel like to not have a hip. The doctors couldn't tell us much about expectations because each patient is different in how they heal and how they handle things. We would just have to wait and see. ■

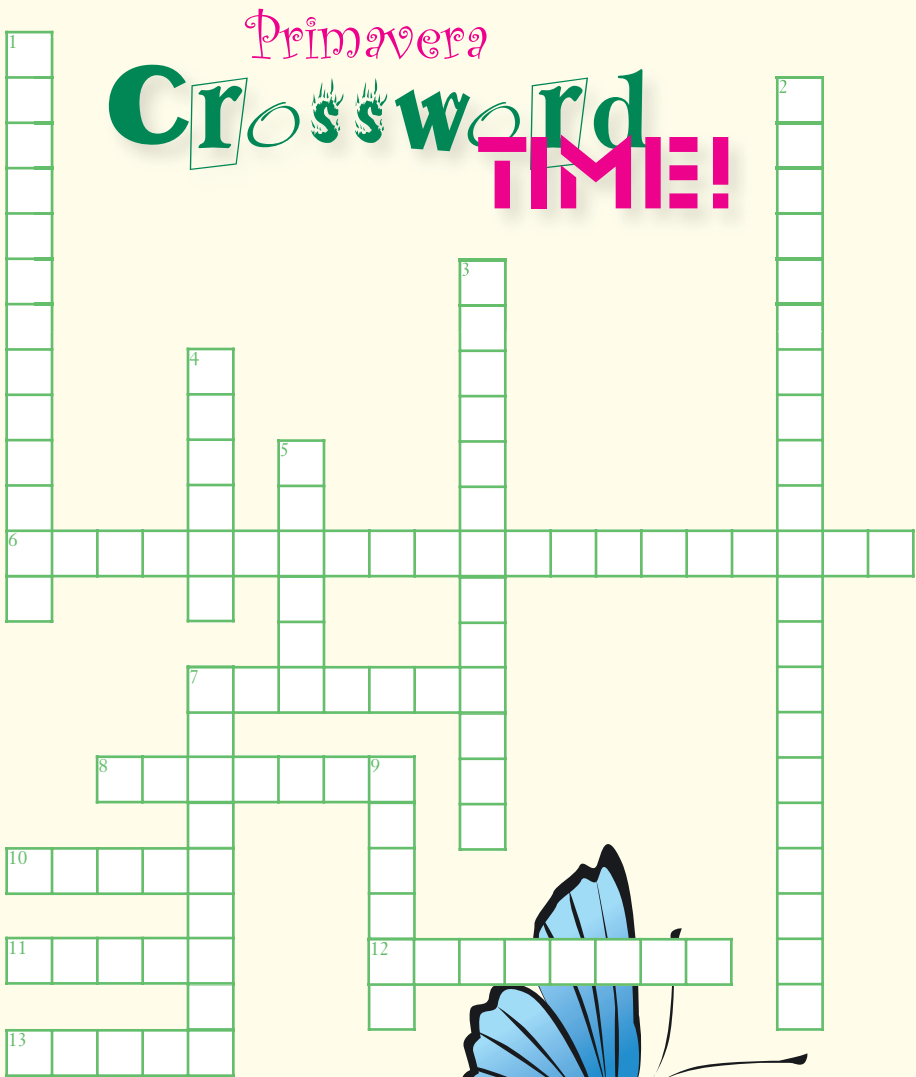
The Lanman Family story will continue in the next issue of the Cool Kids Connection. If you would like to contact them please email blanman2@comcast.net.



Brianna – age 7

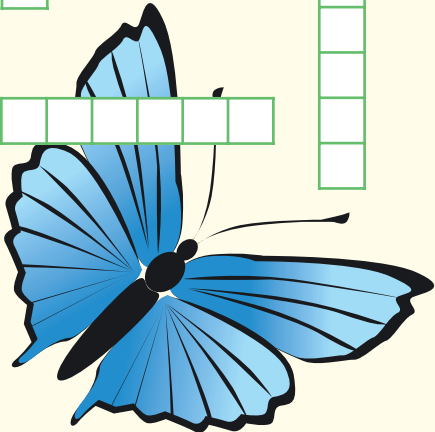
Do You Sudoku?

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



- Across
- 6. El diecisiete de Marzo
 - 7. Un día festivo de primavera
 - 8. Es un deporte popular de primavera
 - 10. Esto es que en lo se ponen huevos
 - 11. Numero once tambien contiene este
 - 12. Este es un contiene nacionalidad que se celebra el día de Santa Patricio
 - 13. Un sombrero que una Chiquita lleva a la iglesia; especialmente en pascua

- Down
- 1. El día en Mayo cuando se celebrant una de los padres
 - 2. Encanto de bueno suerte
 - 3. Este animal es un symbol de Pascua
 - 4. Las _____ crecen y tienen pétalos
 - 5. Colora durante numero cinco; hijos los buscan colora
 - 7. Los meses de Marzo, Abril, y Mayo
 - 9. Los aguaceros de Abril traen las floras de Mayo



IMPROVISAR
Escribe un nombre, verbo, o adjetivo que corresponde a los espacios. Lea su cuento creativo!

Fue una noche borrascosa y _____. _____ y yo decidimos ir a _____
_____ *adjetivo* *nombre de un amigo(a)*
_____. Tomamos el/la _____, pero lo/la rompio asi nosotros tenemos _____
_____ *restaurante* *modo de transportación*
que andar _____ kilometros a nuestro festin _____. Nosotros _____
_____ *numero* *adjetivo*
anduvimos un poco y entonces encontramos un _____ con un(a) _____
_____ *animal adjetivo*
_____. De repente, el/la _____ sin restriccion. _____
_____ *nombre* *animal previo* *verbo (pretérito él)*
<<Que extraño>> yo digo a la/el _____ a mi _____.
_____ *nombre* *dirección*
Seguimos al lado de la calle y decidimos a tomar un desvio a _____ para comprar _____
_____ *tienda*
unos/as _____ y _____ para comer en el viaje. Nosotros tenemos _____
_____ *nombre plural* *nombre plural*
_____ kilometros mas y tuvimos mucho hambre. A este tiempo fuimos calada _____
_____ *numero*
hasta los huesos pero nosotros finalmente llegamos al _____ y pedimos _____
_____ *restaurante previo*
por _____ y _____. Estabamos muy _____. Que un _____
_____ *numero comida plural* *numero refrescos* *adjetivo*
viaje _____!
_____ *adjetivo*

La Escuela de Fallston

Nuestra escuela esta en la ciudad de Fallston, cerca de Baltimore en Maryland. Es una escuela secundaria en una suburbia. Tiene 1,611 estudiantes, 155 facultad, y 41 equipos de deportes que sobresalen en muchos campeonatos de nuestro estado. Nuestros colores son anaranjado y café. Nuestra mascota es una puma y se llama “Gar.” Hay muchas clases en el departamento de espanol. Mi clase es el nivel cuatro y cinco. Nos gusta el espanol mucho y tambien nos gusta aprender.



Carros Neuvo
s do 2007
2007 Lamborghini Gallardo Spyder

Este carro tiene un motor del V-10 y 512 caballos de fuerza. Se acelera do 0 a 62 MPH en 4.3 secones. La velocidad maxima del Spyder es 195 MPH con el root echo del carro. El Spyder pesa 3462 libras y la maxima torsion do 376 libra/pie a 4500 RPM.

Photo courtesy of www.automobilemag.com



All spanish contributions were made by Fallston High School in Maryland.



Photo courtesy of www.usabasketball.com

USA Basketball

El equipo de basquetbol de los Estados Unidos, entrenado de Miguel Krzyzewski quien es tambien el coche del equipo de colegio Duke; es preparado jugar en el 2007 FIBA Calificador olimpico de America. Despues un tercer lugar final en los veranos pasados Campeonatos del Mundo, Ellos es preparado para ganar el oro. El equipo es hecho de algunos de los mrjores jugadores del NBA incluyendo los aviadores altos como Lebron James y de Dwayne Wade. Carmelo Anthony era el ejecutante superior de los equipos que conducio con 19.9 puntos un juego.

Lista Oficial

Carmelo Anthony	Kirk Hinrich	Lamar Odom
Gilber Arenas	Dwight Howard	Chris Paul
Shane Battier	LeBron James	Paul Pierce
Chauncey Billups	Antawn Jamison	Michael Redd
Chris Bosh	Joe Johnson	JJ Redick
Bruce Bowen	Shawn Marion	Luke Ridnour
Elton Brand	Brad Miller	Amare Stoudemire
Kobe Bryant	Adam Morrison	Dwayne Wade

Music Reviews

Incubus- Light Grenades: Incubus’ new album was much anticipated after their album, “A Crow Left of the Murder.” It sounds like their other albums but different in a good way. Many of the songs are acoustic and I like this change a lot! Their music seems to have matured much over the years.

La nueva album di Incubus esta muy esperado del album, “A Crow Left of the Murder.” Lo sonar como los otras albums de Incubus, pero diferente en un buen trecho. Mucho de los cantos estan acoustico, y yo me gusta mucho! La musica de este grupo ha madurado mucho durante los anos.

Beck – The Information: “The Information,” is the new album by Beck and came out shortly after his other album, “Guero.” Guero had many Hispanic and Latin influences, but this album didn’t seem to have many. “The Information,” sounds very futuristic and also a little acoustic like his past album “Sea Change.” This is some of Beck’s best music in my opinion.

“The Information,” es la nueva album de Beck, y vine cercano despues del album, “Guero.” Guero tuve muchas influencias Hispanicas, pero este album no tiene mucho. “The Information,” sonar como muy futuristico, y un poco acoustico del album, “Sea Change.” Este es la musica major de Beck, en mi opinion.

Photo by
Mitch Stringer



Hey, I Was Wondering...

This issue we received questions for our very own co-editor, World and US Figure Skating Champion, Kimmie Meissner. This made getting the answers very easy for us!

How did you get involved with skating? If you weren't a skater, what would you be?
Kara M., Kansas, 20 years old,
Non-Hodgkins Lymphoma survivor

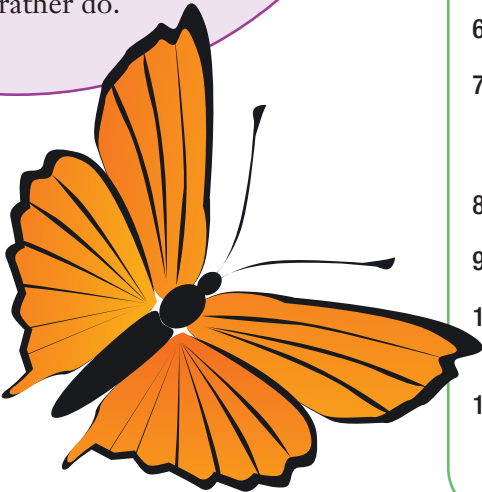
I started skating when I was 6 because one winter my backyard froze and my brothers put me in their hockey skates and I loved it! I skated all day and didn't want to stop. And plus, my brother Adam was a hockey player so I went to the rink to watch his games and I started watching the figure skaters and I knew I really wanted to pursue it.

If I wasn't a skater, what would I be? That's a good question. I'm not really sure what I would be doing because I have always wanted to skate. Through skating I have discovered the joys of giving back. I can't think of anything I would rather do.

How did it feel to win the National Skating Competition?

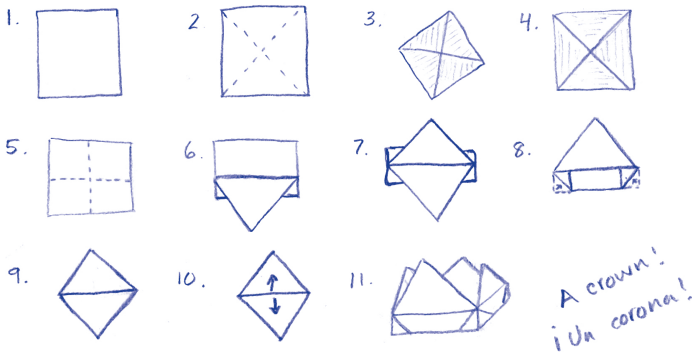
Amy M. – age 11, Glen Burnie, MD
Acute Myelogenous Leukemia

It felt great! Winning Nationals had always been a goal of mine and to be in the company of other national champs like my idols, Michelle Kwan, Peggy Fleming and Kristi Yamaguchi makes me very proud.



ORIGAMI

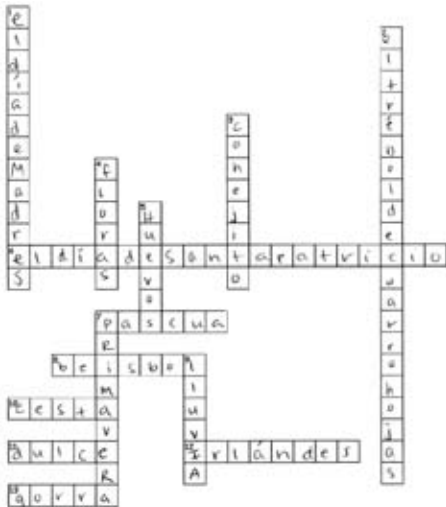
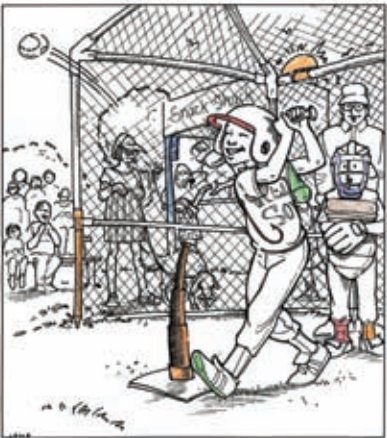
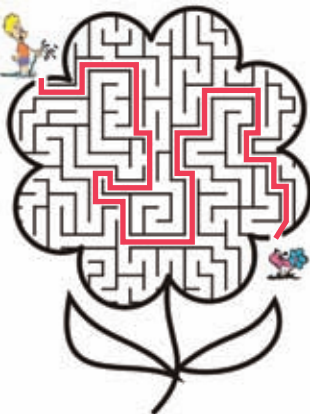
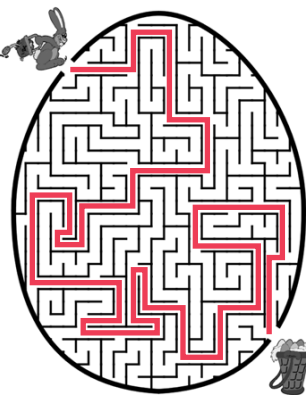
Make your own paper crown!



- 1. Start with a square piece of paper
- 2. Fold corner to corner diagonally then unfold.
- 3. Fold each corner to the middle
- 4. Turn the paper over.
- 5. Fold the bottom edge to the middle crease. Allow the triangle to pop out.
- 6. Repeat for the upper edge.
- 7. Lift up the lower triangular flap and fold in the small triangular corners.
- 8. Repeat on the upper flap.
- 9. Fold the flaps back down.
- 10. Pull the center apart to open the pocket.
- 11. Turn the model over. Pinch the corners and adjust the four points of the crown.

- 1. Empiece con un papel cuadrado.
- 2. Doble rincon a rincon en un diagonal entonces despliegue.
- 3. Doble cada rincon al medio.
- 4. De la vuelta al papel.
- 5. Doble el borde bajo al pliegue medio. Permita el triangulo.
- 6. Repite en el borde alto.
- 7. Levante la solapa triangular bajo y doble en los rincones pequenos triangulares.
- 8. Repite en la solapa alta.
- 9. Doble las solapas a bajo.
- 10. Separe el centro abrir un bosillo.
- 11. De la vuelta el modelo. Pellizce los rincones y arregle los cuatro puntos del cornona.

Puzzle Answers...



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

Pipecleaner Chain Unites Families



What value or strength could possibly come from a simple pipe-cleaner chain of hearts? Patients at the Jimmy Everest Cancer Clinic in Oklahoma City had a "pipe dream." For months patients receiving chemotherapy, children isolated in bone marrow transplant units, and families and friends had been constructing a Pipe-cleaner Dream Chain for Valentine's Day. Little hands bent and twisted simple materials into a work of wonder and hope. On Valentine's Day at OU Children's Hospital, they dreamed of seeing the complex which houses pediatric patients, their families, and their medical caregivers wrapped and bound together through the loving support of community members, standing side by side outside of the hospital and lifting a symbolic pipe-cleaner chain of heartfelt love. Something frail and beautiful illustrated the power of love, the promise of hope, and the faith that miracles are possible in our lives.

One thin connection, as the wondrous threads of a miraculously strong yet invisibly fragile spider's web, can become a lifeline for survival, when life leaves you dangling by only a thread of hope, a thread of support, a thread of information, or a thread of unity.

When the word cancer comes into your life, it changes your reality. When the word cancer is whispered fearfully in acknowledgement of the diagnosis of a child, a family must brace itself for unbridled ripples of vulnerability and uncertainty, which pulse throughout a circle of loved ones, friends, and

community. Immediately, one ugly word is personified as a slithering, deadly, and silent monster, who indiscriminately and greedily stalks the innocent. Then, the battle is on for the protection of each child, in a quest to reclaim the health and promise of childhood potential through medical intervention. In these moments of greatest challenge, patients and families at the Jimmy Everest Cancer Clinic and Children's Hospital have learned to hold hands and hearts to survive. We have learned to sow the seeds of hope, faith, love, and understanding among our little community, to help nurture fields of optimism, courage, and those positive attributes of strength essential for maximized survival through times of greatest challenge.

A chain of hearts can become the shape of your lifeline. It is the shape of hearts linked through loving care. It is the shape of hope and support through prayer chains. It is the fragile shape of a silver thread of faith, that through some miracle of sustaining power, you can somehow get through the

all together, when you have nothing else to rely on. A chain of loving support can bring light, sweetness, and encouragement into otherwise grey and fearful weeks in treatment and isolation.

A chain of hearts brings the families of cancer patients together, in support, empathy, and understanding of the other's pain. A chain of hearts binds together forever those families who have shared the experience of childhood cancer, uniting those who have fought courageously with those who continue the

challenges of the identification, implementation, successes, setbacks and new directions in a quest for the very best treatment plan possible in the care of each child. A heart is the shape of human vulnerability to the twists, curves, and changes in direction we must sometimes face in life.

A chain of hearts can get you through the tough spots. A chain of hearts can help you hold it



See below and on the facing page to find out what the kids from the Jimmy Everest Cancer Clinic have been working on lately!

ART FROM THE HEART



Kourtlyn U. – Age 12
Neuroblastoma, Bone Marrow Transplant

Zoe C. – Age 6
Acute Lymphocytic Leukemia

fight. As we learned in Kindergarten, we hold hands, linked together in strength to face life's challenges. We are here for each other. We are the lifeline, and we can get through it together, heart to heart.

For months, patients, family, and friends from the Jimmy Everest Cancer Clinic worked to construct a Pipe-cleaner Dream Chain, with which to wrap the hospital complex in Oklahoma City in a symbolic Valentine's Day Chain of Love. On that day, they were linked to one another through a fragile pipe-cleaner chain of Valentine hearts, standing together in support of those facing childhood illness, through each day of medical challenges, through each day of treatment, and through each day of improvement. United they stood, with strength, offering encouragement and loving support to each patient, family and medical caregiver, through a genuine lifeline of love. ■

LOVE
By Hope D. – age 8

*I love my brothers and my parents
more than I can tell you.
I love my grandparents and my aunts
and uncles and cousins, too.
I love my friends and have fun
when we play together.*

*Love feels like my soft squishy
pillow with the letter "D" on it.
Love feels like my doll "Pink Baby"
that I sleep with every night.*

*Love sounds like my two
little brothers laughing.
Love smells like a garden of
red roses blooming.
Love smells like chocolate chip
cookies baking in the oven.*

LOVE IS AWESOME!!!!!!

LOVE
By Brittany S.

I love my family.

I love my cousins.

*I especially love my
mommy and daddy.*

I love my doggy, Rowzer.

*And I love my friend at
church named Karis.*

LOVE
By Ethan W. – age 8

*I love God and Jesus.
I love my family and cousins.
I love my friends.
I love my dog Fluffy and
I loved my dog Seven.*

*Love feels like Jesus in my heart.
It makes my happy and proud.
It makes me feel better.
It makes me want to
jump up and down.*

*Love is the best thing in the world.
Love feels like the color red to me.
Love is beautiful. Love is fine.
Love is better.
Love is best. Love is forever.
I've got the love of Jesus
down in my heart.*

Chain of Hearts Takes Shape - One Father's Perspective

By Bobby Lehw

Nestled off to the corner of our little cancer world sits a room with small chairs and small tables obviously sized for children. Kids and adults sit here every week, cramped in the small furniture surrounded by scissors, paint and crayons making creations and helping in any way they can to offer some respite from needle-sticks, and chemotherapy, radiation and other unpleasant pokes and prods.

Recently, the glue and art work was replaced with pipe cleaners, thousands of pipe cleaners, bright colors of red, orange, blue, and yellow scattered in piles around the workroom. Bending the small metal fabric strands for weeks were tiny hands and large hands, young hands and old as they each worked toward a towering task: to create the world's largest heart-shaped pipe cleaner chain to set a new Guinness World Book Record.

The record setting goal was the idea of Kay Tangner and her army of compassionate volunteers. The idea was to stretch the chain to wrap around the new Oklahoma University Medical Center's Children's Hospital. The concept, like the courage of these young children, exceeded its original intent, wrapping around the hospital not once, but three times.

Anabel and I were invited to speak with others and participate in the ceremony. Anabel, my daughter, was diagnosed with t-cell Lymphoma just three short months after Daniel, her brother, succumbed to complications caused by neuroblastoma cancer. No

stranger to the painful and distressing world of cancer treatment, Anabel is, among others, brave and courageous. Chemotherapy, radiation, painful "back-shots" (lumbar punctures) have dominated her life in the past few years. With the help of Kay and her volunteers, the purpose of the event was to spread a little love and in doing so educate others on the struggles these children go through, helping everyone realize what valiant warriors all of these kids are. Enduring weather in the teens, newspaper reporters, media, hospital staff, volunteers and patients showed up to successfully lift the chain toward the sky at the cue of the hospital's helicopter flight around the building.

It is symbolic to think that something so ordinary as heart-shaped pipe cleaners could lift hearts and encourage others. It is not so hard to believe for those who are caring for loved ones with life-threatening illnesses.

***"They have learned lessons we would
rather not have to learn: to accept
ordinary moments for what they
really are – extraordinary gifts."***

Small things, like pipe-cleaner shaped hearts, remind us all that life in its simplest of forms should be celebrated. The children who were there knew this to be true by experience. They have had friends whom they met through treatment who have succumbed to diseases: a young teenager, David, passed away just days before the event. He was one of many who helped craft the heart-shaped chain.

Many of these kids, however, will go on to beat cancer. Maybe someday they will stumble across the Guinness World Record Book story and remember the longest heart-shaped pipe cleaner chain and smile. Maybe they will turn to their own kids and say, "see this crazy thing, I helped create it. I was there. It was 15 degrees outside, we spent months"

Our own experiences with cancer, like others, have been difficult.

***"Through it all, we realize that those
struggling with life-threatening
illnesses have learned how to not
merely survive, but to thrive."***

...even in the midst of arduous circumstances. It's what the little craft room in the middle of the cancer clinic is about. It's what heart-shaped pipe cleaner chains are about. Even if the record wouldn't have been accomplished, the children, staff and volunteers at OU's Medical Research Center are record holders: overcoming obstacles, surviving diseases and braving effects from treatment, in short, exceeding the average person's boundaries for living.

I asked Anabel on that cold blustery day, "You think if you can brave back shots and chemo, the rest of us can surely fight a little cold to lift this heart-chain," she flashed a big smile, knowing I was acknowledging her bravery and said "Absolutely." ■

Bobby and Audra Lehw
Parents of Anabel, 10-year-old cancer patient
Jimmy Everest Cancer Clinic, OK



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