My name is Zi and I am 5 years old. I was diagnosed with bone cancer in April, 2006. I just wanted to say hi! I’m from Sulpher Springs, Texas. My brother’s name is L’Kyron and my mom’s name is La-Kemya.

Connecting pediatric oncology patients throughout the nation.

Hi Everybody!

First, as co-editor of the newspaper I would like to thank Sharon Perfetti and all the people involved in getting this newspaper published. I would like to especially thank all the contributors. I have read some great poems and seen awesome artwork and I just want to thank you all!

The Cool Kids Campaign, which helps pediatric oncology patients and their families, is a very special part of my life. I began my association with the Cool Kids after the 2006 Winter Olympics. The first time that I can recall hearing the word cancer was when a friend and classmate of mine in the third grade was diagnosed. Years later my friend Kati battled bravely against this terrible monster with an incredible spirit and passion for living. She touched my heart and my life in ways that I never would have imagined. Kati has inspired me to help others fighting this disease in whatever way I can until a cure or vaccine is discovered. Currently my aunt is battling cancer and it has become even more personal. I have met some incredible kids and amazing families and hope that this newspaper will help you get to know them also.

My goal with this newspaper is that it will be a way to share and express your thoughts and feelings with each other. We welcome your creativity through art, poetry, essay, etc. and hope to provide an outlet for you as you face the challenges of your diagnosis. It will be a means of communicating for you, your friends and family to find support, hope and encouragement through others.

I hope you enjoy reading the newspaper and that it brings you enjoyment and information and in some way it makes you smile. You are all “cool kids” and I wish you health and happiness in the New Year.

Sincerely,

Kimmie Meissner

I’d like to share with you one of my favorite quotes from Helen Keller:

The best and most beautiful things in this world cannot be seen or even heard, but must be felt with the heart.

– Helen Keller

Hi my name is Kyralle!

Hi my name is Kyralle! I am here to tell you all about my life with Cancer!!!!!!!!!!!! When I was 4 years old I got diagnosed which means they found out I had Leukemia. So for my treatment I had to go all the way to Baltimore for my check-ups. My doctor’s name is Dr. Wiley. So after many years of running to the hospital at 12:00 at night I got better. I moved to a new hospital closer by. So I thought about something. There was a treasure chest at my old hospital. So I made a decision to make a treasure chest for my new hospital. It said Kyralle’s Treasure Chest for Kids!!!!!!!!!!! So with the help of my friends, my friend’s mom, my dad and sister it was beautiful!!!!!!!! Now kids can pick out his/her favorite toy and take it home to keep!!!!!!!!!!

Kyralle Comeaux was treated for ALL Leukemia at Sinai Hospital in Baltimore. She has been cancer free since May, 2003. She is pictured here with Dr. Joseph Wiley.

Photos courtesy of Mitch Stringer.
I had been a competitive figure skater for 8 years when I moved up to the Novice level. I was barely 18 years old but was having a hard time getting through my long program. It didn’t really worry me though, after all, the Novice long program is 30 seconds longer than Intermediate. I continued to run my long program twice a day, back to back, thinking my stamina would get better. But, it didn’t.

I had a cough for about a couple of months now and it was pretty consistent after running through my programs. My coach urged me to see my doctor as soon as I could because she was pretty sure I had asthma and I only had a few weeks left before competition and I still had not gotten through a whole long program. So, I finally went. My doctor was out of town that day I went in, so it was his assistant. She checked my breathing and said, “Yep, asthma. Here’s an inhaler.”

I started using my inhaler right away. My breathing didn’t get any better while I was skating. It actually got worse. It was to the point that I couldn’t even skate from one end of the rink to another. Also, I started having really bad shoulder pain but I just thought it was from the way I had been falling on my triple toe jump. My coach was getting frustrated, once again, not being able to get through a whole program, and there was only a week left in competition, so she told me to go back to the doctor to get a stronger inhaler, even though I was just there 2 weeks ago.

Within those 2 weeks, my grandma had died of a brain tumor and we had gone back to Chicago to bury her. A few days after getting back, I headed back to my doctor, along with my mom. He checked my breathing, and said I had exercised induced asthma, gave me a stronger inhaler and said he just wanted to run a chest x-ray to see if he could see what was causing my shoulder pain. He was thinking just a pinched nerve or something. I remember this day just as if it was yesterday. I was running late for my skating sessions and just wanted to go right after my X-ray and have my doctor call us with results. The nurse said we couldn’t go and that my doctor wanted to talk to us. I had no idea the results of this x-ray would change my life.

He sat us down and said there was a huge tumor on the left side of my chest and he had never seen anything like it before. I started crying, telling my mom there was so much more in life I wanted to accomplish and I didn’t want to die. My mom called my dad and my sister, and they drove to the doctors and I went through many tests that whole afternoon.

While waiting for results from the test, I felt like I just needed to be at the rink around my skating friends. After all, that’s who I spend my afternoons with and who make me feel good when I am down. So my family and I drove to the rink. I had already called my coach to let her know what was going on, so everyone at the rink already knew. They had already diagnosed it as cancer, but not sure what kind, either hodgkins lymphoma or non-hodgkins lymphoma. By 7pm, my mom received the call that was it non-hodgkins lymphoma.

That next week, I got my senior pictures taken because I had just grown my hair out really long. I got my hair cut really short right afterwards because I was going to have chemotherapy treatment for 13 months and most likely would be losing my hair. I withdrew from my skating competition that my rink was hosting but still went to the rink to cheer everyone on.

I started my first chemo treatment on June 10th, 2004. I had no idea what was in store for me and just imagined that my life for the next few years was going to be horrible. And no skating. I had no idea what I was going to do - I still wanted to be part of the skating community and competitions. My doctor knew I was a competitive figure skater and I asked him if I felt well enough if I could continue to skate. He said, of course. Well I did just that. I knew if I didn’t continue to skate through my cancer, the cancer would win. I had to keep going, even though the chemo treatments didn’t make me feel my best and my skating wasn’t the best, I felt like it was something I had to do to feel “normal.”

I had chemotherapy treatments every week for a month straight. When I was off treatment for those few weeks, I could be found at the rink - skating and coaching. I competed all season in treatment. I didn’t care that I came in last. It wasn’t about winning this season - it was about skating, and how fortunate I was to be surviving cancer and being on the ice at all with my cancer. It put a lot of things in perspective for me. I decided not to attend my first year of college since it would be hard with treatment. The
Welcome to our very first issue of the Cool Kids Connection. We are so excited to be able to put this paper together for you. As you will see, this paper is all about you and by you. Our role is strictly to bring it all together and send it out so that you can share your experiences.

We think of this first issue of the Cool Kids Connection as a work in progress. We will continue to adapt the features, articles and anything else based on what you continue to send us and what you want to see. So please, send us whatever you want that expresses how you feel and what you want to share with others.

—Kara is now 20 years old and living in Wichita, Kansas. She is working a degree in exercise science to pursue a career as a physical therapy assistant. She has been a competitive figure skater for 9 years and is currently competing at the Novice level. She also coaches at the rink when she is not skating.

I’m back, stronger than ever!

Welcome

We want to include in each issue the special ways that other kids (and some grown-ups) across the country reach out and help people they don’t even know. With all their help we are able to provide the Cool Kids Connection to you!!

Thanks to the kids in Carroll County, MD who raised $2,000 hosting a Cool Kids Café!

Thanks to the Metro Edge Skating Club in St. Louis, MO for raising $1,000 through their skate club fundraisers!

Thanks to 100 West Hair Salon in Cockeysville, MD for making us their guest bartender night beneficiary!

Thanks to the DC United Soccer Team for their soccer clinic to benefit Cool Kids Campaign!

Thanks to Lydian Financial Management!

Thanks to Under Armour for their product donations and support!

chemotherapy made me very sick every time, yet no matter how sick it got me, I knew it was saving my life.

I have been in remission for a year now. I am still skating and have completed my first year of college. I am in my sophomore year of college now and enjoying every minute of it. I am skating hard to get back to where I used to be and am glad to have my stamina back almost 100%. I have continued to coach, and most of my students compete too. I am looking forward to this new skating season and competing in Regionals my first time next season with being cancer free.

I look back on my life the past 2 years and realize how much I learned, not only with knowing more about cancer and how it works, but also about myself. I definitely know I am a stronger person with going through with what I did. And I learned to not take life for granted, because at any given moment, everything could be gone. Going through cancer was not easy, but maintaining a positive outlook on life and knowing people were out there praying for me, got me through this all. Live life to the fullest!

—Kara
My name is Zi and I am 5 years old. I was born in Sulpher Springs, Texas. My brother's name is L'Kyron and my mom's name is La-Kemya. I just wanted to say hi! I'm from Texas. I was diagnosed with bone cancer in April, 2006. My name is Kyralee!

Kyralee Comeaux was treated for ALL Leukemia at Sinai Hospital in Baltimore. She has been cancer free since April 2001. I got diagnosed which means they found cancer in my blood. Since then, I had to go all the way to Baltimore for my check-ups. My doctor's name is Dr. Carson. I would like to tell you all about my life with cancer.

I got a treasure chest at my old hospital. So I thought about something. I made a decision to make a treasure chest for my friends, my friend's mom, my dad and a sister it was beautiful!!!!!!!!! Now kids can pick out their favorite toy and take it home. I miss your sweet smile so far, far away. I wish you health and happiness in the New Year.

Sincerely,
Kimmie Meissner

Photos courtesy of Mitch Stringer.

The Origins of Love
Kids Helping Kids
Special Insert
Our Journey
Angel Poems
Cool Kids Activities

I have learned about friendship and community. I have lost some friends through this ordeal, yet I have gained many more. Our community, schools, and church have been there with us night and day. I know that I would not have been able to focus all my attention on my family if it weren't for the help and support we've been given.

I have learned how little the big things are. And how big the little things are. Even though I miss the mundane parts of "normal life" I don't miss how much time and energy was spent on trivial issues. I miss Kenzie coming in the door after school upset because of a little fight with a friend. I miss Friday's spelling, math and reading tests that seemed to occupy our time and energy on Thursday nights. I have learned that those tests are important, but blood tests and MRIs are more important, unfortunately.

I have learned how long the night hours can be. I have learned how your mind can make the scary even scarier. I have learned that life goes on. We thought our world shattered on December 2nd. I can still hear the words when the pediatrician called on the cell phone to tell us the MRI results. I can still hear Dr. Carson telling us about the surgery. I can still hear it all...

I have learned that you can't will this away, but you can focus on it and work through it. I have learned the power of prayer. I have learned that there will always be a tomorrow, and by the Grace of God, the Stuck family, all six of us, will be there facing it.

- Sue S., Maryland
Johns Hopkins Hospital

Angels
I think angels are pretty and helpful. Jesus' angels take care of us around the world.

Angel Lawrence
He has big white wings and a big smile.
He has black straight short hair like mine.
He has a white flowy white dress and flies around and helps people throw away their trash.
Angel Lawrence flies around on earth but you cannot see him. I can only see him when I'm dreaming.

By Ruben, age 9
OU Physicians Jimmy Everest Cancer Center, OK

Angels
I think angels are girls & boys & pets.
I think angels are people that aren't dead and are in trouble.
I think angels are good at parties.
I think angels are whisht because they are a spirit.
I think pet angels like to lick the other angels.
I think boy angels have bigger halos and shorter wings than girls because girl angels are prettier.
I think the bigger the halo, the naughtier the angel.
I think the bigger the wings, the nicer the angel.

By Mona M., age 6
OU Physicians Jimmy Everest Cancer Center, OK

Beautiful Angels
“Beautiful angel, won’t you come down and play. I miss your sweet smile so far, far away. Up in the heavens you fly all day long. I miss your lovable laugh, cute dance and song. You were always the one, who found the best in me. Your compassion and courage on display for all to see. Your strength and determination never left a doubt, That you were someone I could ever live without.”

“Dear little one, the truth is that I'm there, In the whisper of the wind, in the silence of a prayer. In every word you speak and everything you do, And even when you sleep, I'm right there too. My job is more important here, up in the heavens above, To watch over you and protect you and shower you with love. One day we'll be together again, but for now you just must wait, I'll be the first one you see in heaven, waiting at St. Peter's gate.”

By Jennifer W., age 20, ALL Leukemia Survivor
OU Physicians Jimmy Everest Cancer Center, OK

Angels
Angels help people.
They are beautiful.
They wear white gowns and halos above their heads.
Halos are made of something special...maybe clouds.
Angels can fly or walk on earth.
If somebody's car didn't work, maybe an angel would stop and help.
If traffic was real bad, maybe an angel would protect them.
If I was feeling real bad and couldn't get up, an angel would comfort me and help me feel better.

Angels are very helpful.

By David H., age 11
OU Physicians Jimmy Everest Cancer Center, OK

By Ruben, age 9
OU Physicians Jimmy Everest Cancer Center, OK

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- Sue S., Maryland
Johns Hopkins Hospital

Interested in being a sponsor or advertising in the next issue of the Cool Kids Connection?
If you have a business or know of a business that would appreciate helping out please send them our way. For rates and information they can contact us at
410-560-1770 or email at
sharon@bfpf.org
Believe there are Endless possibilities

so
Stay positive and
Try your best because
Rough times can
Only make us strong
So
No matter how bad it gets
NEVER
Give up!!

By: Lauren Stuck (13) and Victoria Niemeyer (13)
Los animales

Across
2. un animal que vive en el bosque, muy feróz y grande
4. un caballo que tiene rayas blancas y negras
7. es negro y blanco, le gusta el frío
8. el animal que ayuda Santa con su trineo
9. vive en las selvas, es muy feróz
10. no bebe mucho y vive en el desierto
12. vive en el agua y tiene agallas
13. tiene una bolsa para llevar sus bebes
14. dice miau

Down
1. un animal que tiene alas
3. no tiene pies, largo y flaco
4. tiene cola larga y corre muy rápido
5. es muy alto y tiene cuella larga
6. come plátanos, vive en la selva
11. un gran animal gris que tiene trompa

Ayuda Timmy encuentra lo que el necesita para construir un hombre de nieve.
Little did we know how much we would come to appreciate life and all that it has to offer.

Editor's Note: The following “story” is one family’s journey through 2006 which began with their son Ben’s cancer diagnosis and ended with his end of chemo celebration party. Ben’s mom, Sue, agreed to share her journey as well as excerpts of her actual emails that she sent out throughout the year to keep friends and family updated.

Ewing’s sarcoma. Bone cancer. That was the diagnosis we received by phone on January 4th, 2006. My precious 8-year-old Ben. What did this mean? He had started limping in October of 2005, right after we returned home from our family vacation in Disney World. First we thought he had pulled a muscle. “Lay down, rest it, put ice on it,” I said with all my motherly wisdom. After a few days of limping, we took Ben to his pediatrician’s office. An x-ray was done. It showed nothing. “Growing pains, a muscle strain, keep an eye on it,” we were told. As quickly as it came, it went away. Three weeks later it came back, a little worse this time. He complained more at night, but continued with the limp throughout the day. Motrin took the edge off. Another x-ray still showed nothing. Again, it went away. Three weeks later it was back again, much worse. It would wake him out of sleep, making him scream in pain. He started missing school. We were given a prescription for Valium, but even this remedy was short-lived. We were told it could take a few days, but with the holiday it could take longer. Waiting was awful. We didn’t want to leave the house, kept checking to make sure the phone was working. No news is good news, right? That’s what everyone would say, but it did little to comfort us.

1.4.06
Hello friends...
As promised, I will share with you the results we got this evening from Ben’s biopsy. Ben has a Ewing’s sarcoma (yes, cancer) in his hip area. It’s apparently the second most common type of cancer in children. We’re still kind of shell shocked about it, but I know the Lord will get us all through it. The doctor says it is treatable and/or curable, but we’re in for a long year of tests, chemotherapy, and possibly radiation or surgery. It will all start on Friday.

Ben does not know about this yet....and the doctors think they should be the ones to tell him since they do this kind of thing all the time and know the right things to say. Ben will be told on Friday. So, I am asking you to please not tell any of your children. I’m going to leave that up to Ben....give him the power over something....who to tell and who not to tell. I think once he knows what’s going on and it’s no longer a hush-hush kind of thing, and mommy doesn’t fall apart every time she tries to talk about it, it will be easier for all of us. It’s still very new news for Barry and I, so bear with us while we learn more about “it” and what’s in store for our family’s future. We want Ben’s life to be kept as normal as possible. He still got yelled at twice today....and I did it myself! Love you...
Sue

1.6.06
Hello friends....
Today was a good day! We’re taking the small victories where we can get them! After the bone scan and CT scan, we learned that Ben does not have cancer in any other bones or soft tissue. What a blessing that was!! Ben was so awesome today. It was such a long day and so demanding of him, but he has showed such stamina and endurance. There’s nothing like looking at your son hooked up to a bunch of machines, with his iPod on, singing “I’m Trading My Sorrows...” That’s one of his favorite songs and he sings a little too loudly when he has his earbuds in, and he kind of hums through or makes up some words when he’s not sure. It’s just so funny. He made us laugh quite a bit today, too...always the comedian. And again, we were blessed with wonderful doctors, nurses, technicians, secretaries, etc.

Ben took the news beautifully and even asked some pertinent questions. Our doctor, Dr. David Loeb, is fantastic!! He talked to Ben the whole time and explained everything in a kid-friendly way. I’m not sure just how much he understands, but I’m just so thankful now that we can all...
Our Journey...

Many blessings... solidary when the time comes as well). Daddy has decided to shave his head in easy by any means, but we had to was started. Everything moved along at were admitted to the hospital after the ble-lumen Hickman central line placed in his protocol. So much information to Ben's chest, the drugs that would make up and/or possibly surgery. We learned about need chemotherapy, possibly radiation acetabulum. We were told that he would have his tumor. It was small, located in his right hip on the area on Thursday. That was really painful for him, but he got through it. The nurse and child life specialist did a great job of preparing him for what was going to happen and how it would feel, and even used a doll to show him exactly what he could expect. They are so awesome and so loving. I started crying in the middle of it because Ben was crying and screaming and it was just so hard.....and afterward when he had calmed down the nurse and CLS did their best to comfort me as well. They are such dear, sweet people! I love you all! 

Sue

Two weeks after diagnosis Ben had a double-lumen Hickman central line placed in his chest and a bone marrow biopsy. We were admitted to the hospital after the surgery and round one of chemotherapy was started. Everything moved along at a pace, very smoothly. We were still dear in the hospital, just doing what we were told. It was up to us to make this our new normal. This was not going to be easy by any means, but we had to embrace it. Perspective set in. Perspective is everything! There are parents who lose their children in car accidents every day, or kidnappings, or any kind of tragedy. One minute their lives are moving along normally, and the next it’s forever changed! We had choices, options!! We had our son and we had hope. There are no guarantees in this life, but hope is so important. Faith, hope and a good sense of humor are key to getting through this kind of thing….just as important as a good support group of family and friends.

1.22.06

Hello friends..... (forgive me...I started typing this e-mail Saturday and have been very distracted, so I apologize for making you wait)

Ben and I returned home from the hospital last night around 8 p.m. All went well with the usual side effects of loss of appetite, vomiting, and discomfort from the surgery sites. Ben did such a good job! He is so tough! The worst part was when they changed the dressing on his central line area on Thursday. That was really painful for him, but he got through it. The nurse and child life specialist did a great job of preparing him for what was going to happen and how it would feel, and even used a doll to show him exactly what he could expect. They are so awesome and so loving. I started crying in the middle of it because Ben was crying and screaming and it was just so hard.....and afterward when he had calmed down the nurse and CLS did their best to comfort me as well. They are such dear, sweet people! I love you all!

Sue

Once home from the hospital Ben started perking up a bit more, eating more, being himself more. We came to learn that Ben would be at his best the week before the next chemo was to start. His hair started falling out. His pillow was covered with hair every morning. He and his sister thought it was the coolest thing that they could pull out without hurting. It freaked me out, and they loved it. We kept Ben's hair in a Ziploc baggie to save it.

1.30.06

Hello all...

It's good to be home! There really is no place like home, but Ben REALLY needed to be in the hospital and I'm glad we went. He received plenty of fluids and lots of tender loving care.....and got lots of uninter-

rupted rest without having to vomit. He was feeling great this evening when we were discharged. Maybe it was the bumpy ride home, but as soon as we arrived here at home he vomited again. I could just scream. He lost 13% of his body weight since his first round of chemo, so we had to meet with a dietician today. We've been instructed to treat Ben like an anorexic since his body no longer tells him he's hungry. It makes me so sad because he was such a good eater before this. Now we have to make him eat 1/4 cup of something (anything he wants) every 2 1/2 hours. Each day we increase it...1/3, 1/2 etc, up to one cup. He's scheduled to go back in to JHH for his second round of chemo on 2/8 (next week) and we have to get his body back in shape before that. His counts are climbing up, which is great, but his appetite just isn't there yet.

Oh my goodness.....this just in.....Ben actually asked for Mandarin oranges! Woo hoo.....Let's see if he eats them. I just gave him his anti-nausea medicine, so I'm going to give him a few minutes to kick in......and then we'll see if he eats. That would be AWESOME!

His spirit is still intact.....he's happy and funny and mouthy (at times). His mouth sores are no longer bothering him (as of yesterday), and he pooped (first time since two Thursdays ago). Woo hoo! He is one tough little guy! He's even come to like his central line (now that he realizes that he hasn't had to get stuck once since it was put in......and he would've gotten stuck a lot these past few days if he didn't have it). It's also not as tender anymore. I did notice some hair on his pillow this morning, so he should most likely be hairless within the next week. He's handling everything really well, though......better than I think I would if it were me.

As for the rest of the family.....Barry has really done a fantastic job of juggling us at JHH (7 trips down and back since we were admitted Saturday night) and Olivia at home and his work, not to mention all the household things that come into play. I see him even managed to send you all an update. That makes me giggle because he thought I was silly when I started this. He and Liv are out for a father/daughter dinner date and shopping for Valentines. Olivia has been absolutely wonderful throughout this whole thing so far. She's been juggled a bit from person to person at times, but she's been happy about it and has had a say in who she goes with. She is really learning a lot about compassion, too. It amazes her how much her brother misses her when she's in school or at a friend's house now. They've always played pretty well together, but now there's something extra special there. Oh, the excitement in his voice when he sees her after school or after a hospital stay.....and the way she lays next to him on the couch while they play with their video games together. It brings me to my knees.

Ok...that's all for now. I have to stop myself.....I could go on for days! At least we're home...we're happy......we're working on the boy's appetite! We love you and thank you and appreciate you! Each and every day we thank God for you and ask Him to bless each and every one of you!

love...

Sue

P.S. It was a no-go on the Mandarin oranges, but we're working on a milk-shake. Baby steps...

As March rolled around we had chemo #3 and #4. We were becoming more comfortable with the whole regimen and what to expect. With chemo #3 we left our townhouse for a 3-day stay at Hopkins and when we were discharged we came home to our new home, a single-family home that we knew we were buying for a year but hadn't really expected it to happen when it did. Actually, Barry and I were a bit like fish out of water in the new house. It would take some time getting used to.

3.5.06

Hello everyone...

So sorry it has taken me so long to get this update out to you. We are slowly settling into our new home and our internet hook up wasn't quite complete until yesterday evening.

I do have some great news...a lot of it, so I don't know where to start!

First, we had a very nice stay at JHH for Ben's treatment. He didn't have nearly as much discomfort as he did with his first round of these meds. Very little nausea, too. We were able to do homework and play and chat and he even ate a little bit. He seems to know his limit now, what he can tolerate and how much, so I just get him whatever he wanted and he did just fine.

Secondly, the MRI report came back and the soft tissue tumor is GONE!!! Woo hoo!! The bone is still involved, as they expected it would be, so we will continue with chemo as usual....but we will meet with the surgeon, radiation specialist and our doctor to talk about what our options are as to how to get rid of this. We meet with them on Wednesday at 3:45, so keep that in your prayers because we'll certainly need guidance when it comes to making a decision.

www.coolkidscampaign.org
JANUARY - MARCH 2007

To remember who I told what. Without to repeat the story over and over and try lies, teachers, school families, etc. I had was going on with Ben. It started out discomfort (like last time) in his jaw or thirdly, upon arriving home to our new house our home! some of the new neighbors have stopped by to welcome us and Ben made and delivered dinners to my family up a schedule so that someone would contacted everyone on my e-mail list and set topped Ben's updates to their families and churches. We were so blessed to have so many people praying for our family, for our Ben. We felt every one of those prayers, too. They are what carried us through! Ben received cards, gifts, letters and prayers from all over the world, from people we know and from people we have yet to meet. Prayers were being lifted up for us from all over Maryland, all over the United States, from California to Florida, all over the world, from China to the Ukraine to Germany to Namibia, Africa to Singapore to Ethiopia. One little boy affected so many people and caused them to open their hearts and pray for him—our little boy! The blessings poured down on us!

Also in March, Olivia had her Destination Imagination regional tournament. Her team placed third, so they could move on to the State Competition in April. Olivia had been such an angel through all of this. She was shuffled around a lot, woken up in the middle of the night for our ER runs, quarantined to her bedroom whenever she came down with a cold—she put up with so much. At times when she could’ve gone out to play or to a friend’s house she opted to stay in to play with Ben.

Team Ben now informed us that we had a decision to make—surgery or radiation. Just when we felt we were getting good at this whole chemo thing. We were even able to do chemo #4 as outpatient. Five days of driving back and forth to Hopkins and sitting there for 6-8 hours each day was a hassle, but getting to go home to see our family and sleep in our own beds every night made all the difference. That meant so much to Ben. He didn’t mind sitting in the clinic all day, meeting new kids, doing crafts, playing video games. We met so many great families with so many different types of cancer. It’s nice to get to talk to people who understand. Your friends and families do their best to understand, but nobody really gets it like another parent who is going through it.

The decision we had in front of us was one of the most difficult decisions we’ve ever had to make. Surgery meant removing Ben’s right hip, forever changing his body structure, the way he would walk, but also getting that cancer out of there. Radiation meant possibly killing the tumor, but maybe not all of it, and who knows what other side effects would crop up later. We met with the surgeon. We met with the radiation specialist. We hammered them with questions. The surgeon gave me the name of a family whose daughter had had a very similar surgery and said they would be willing to talk to me about it. That was very helpful. I spent two hours on the phone with this other mom. Her daughter was doing well 18 months after surgery. Barry and I were still torn. This was major, life-changing surgery. On the other hand, radiation seemed so much easier, but there was no guarantee that the whole tumor would be killed, and there was no way to know unless the tumor was removed. After a lot of discussion and a lot of prayer, we decided that surgery was the only way we could be sure that this tumor was gone. So the date was set.

It’s good to be home and to know that we’re done for now. Next, we just wait until his counts come back up. Right now, he’s upstairs giggling over something silly on TV and just being the happy boy that I know and love!

After the surgery Ben will be in a body cast for 3 months, from his chest to his toes. (YIKES!) But...the cancer will be GONE!!! He will have a 2-3 inch difference in the length of his legs, requiring us to get lifts put in his right shoe. No contact sports for him, but he will be able to play as usual once he’s recovered. He’ll go from the cast to crutches and then a cane...and he will have physical therapy to help him learn how to deal with this newness. Being eight years old, I don’t think he’ll be down for long. The 3 months in the body cast will be the hard part for him. He’ll be flat on his back for that time, so visitors will be important to him. I don’t think we’ll be going anywhere for some time, unless it’s to Hopkins....but I’m still not sure how we’re going to transport him. There’s still a lot to learn!! Just when I thought I was getting good at everything... (hee hee)

Okay, see what happens when I don’t keep up with my updates? I end up writing a short story! Again, so sorry! Bless your hearts for hanging in there with us. We feel your prayers! I do love it that is now springtime and the world is coming to life again! It warms my heart and refreshes my hope!

Love you, Sue
We had to allow Ben’s counts to come up to 1500 before surgery could take place, so we got an extra week of good days for Ben. We had a nice Easter and got to spend time with family and friends who we hadn’t seen in a while. We celebrated every chance we got. Barry and I would catch ourselves watching Ben run, jump, dance. He LOVED to dance! Would he be able to dance again with no hip? Would he be able to walk without help? This was so hard!

4.5.06
Here’s my new favorite story!

There was a man who had four sons. He wanted his sons to learn not to judge things too quickly. So he sent them each on a quest, in turn, to go and look at a pear tree that was a great distance away.

The first son went in the winter, the second in the spring, the third in summer, and the youngest son in the fall.

When they had all gone and come back, he called them together to describe what they had seen.

The first son said that the tree was ugly, had seen. The second son said they called them together to describe what they had seen. The second son said no, it was covered with green buds and full of promise.

The third son disagreed; he said it was laden with blossoms that smelled so sweet and looked so beautiful, it was the most graceful thing he had ever seen.

The last son disagreed with all of them; he said it was ripe and drooping with fruit, full of life and fulfillment.

The man then explained to his sons that they were all right, because they had each seen but only one season in the tree’s life.

He told them that you cannot judge a tree, or a person, by only one season, and that the essence of who they are and the pleasure, joy, and love that come from that life can only be measured at the end, when all the seasons are up.

If you give up when it’s winter, you will miss the promise of your spring, the beauty of your summer, fulfillment of your fall.

Moral:
Don’t let the pain of one season destroy the joy of all the rest.
Don’t judge life by one difficult season. Persevere through the difficult patches and better times are sure to come!

April 18th came. This was to be the longest day of our lives. Ben was wheeled into surgery at 9:00am. Every hour or so the surgeon would call us on the waiting room phone to let us know how things were going. They took a while getting started. Only after everything was underway did the full effect of what they were doing to my son hit me. I mean, I knew what was involved in the surgery, but I didn’t really think about what was happening to Ben until it was too late to stop it. I think God knew I would’ve taken Ben and run the other way had I thought about what they were going to have to do to him in this surgery. Nine hours later they announced that they were done. Our surgeon came out to talk to us. She had not stopped to eat, drink, or go to the bathroom the whole time in the OR. Her lips were so dry and cracked, and she looked so tired. She was incredible. I later learned that just a few years ago Ben would’ve lost his whole leg with this procedure. Our surgeon was one of the few in the country who could perform this kind of surgery and save the leg. I also was able to read the operative note a few months after the surgery and, boy, am I glad I didn’t read it any earlier. Not only was every muscle, tendon, and nerve separated and labeled, but two different saws were used to cut away my son’s bone. At one point in the surgery the flap of skin on the back of his right thigh was the only thing holding him together on that side of his body. Absolutely incredible what took place in this surgery!

No yellow cast available so I got blue! My casts were to be my home for the next 3 months.

4.19.06
Hi all,
I finally have the time to sit down and update everyone in detail about the last 36 hours, so here goes...

We got to the hospital at 7:00am with the surgery scheduled for 9:15am. After hours of waiting for the OR to be free, they were finally able to start at 11:00am. By that time the feeling of not drinking for almost 12 hours was getting to him, but he was pretty easily distracted by movies, video games and clowns doing magic tricks. I got to be with him in the OR while they put him under and I can only say that the boy had absolutely no anxiety. He needs to teach me how he does it!

Off to the waiting room... We got updates every 90 minutes which were very brief and vague (mostly saying that “Everything was going fine”). Finally at 8:00pm the surgeon came out and let us know that everything went exactly according to plans. He only lost one small muscle as a result of the bone being taken and this was assumed to be the case even prior to the surgery. Dr. Weber felt confident that the area removed encompassed all of the tumor, however we won’t know for sure for a couple of weeks. He only lost 1 unit of blood during the whole surgery which is fantastic! That meant that they could remove the breathing tubes prior to him waking up. We got to see him briefly in the PICU while he recovered and were encouraged to go home and come back in the morning.

Ben and the nurse called at 1:30am because he was in pain and a little scared. After a few consoling words, he was able to fall back asleep and did great the rest of the night. We feel very good about the level of care he got throughout the night and we actually got a few minutes of rest ourselves.

When we got to the hospital this morning he was still in the PICU, but quickly moved to the Children’s Center. He was doing fine barring pain and being annoyed with everyone poking him all the time. The Children’s Center (4th floor) is amazing. Sue has a shower in the room that she can actually use and Ben has TV and Nintendo in his entertainment center.

When I left at 12:00pm he was resting comfortably as hopefully he will do the rest of the day. They won’t try to get him up and moving around until tomorrow. He is still a little puffy from the surgery but that has already come down a considerable amount. His cast is blue for now and he will get to pick the color when he gets the next one. He was a little upset with me this morning because he asked for a yellow cast (which they don’t have). The cast is as good as can be expected. He has a slight flex to the hip and a small bend in his right knee to make it easier to transport.

All in all, we couldn’t be more happy with the way it all turned out. It pains me to see him uncomfortable in the least bit, but we are only going to be getting better from here on out. Thank you all for your prayers, meals, time, friendship and so on. We have the most amazing circle of friends we could ever ask for!

More news to come I’m sure... Barry
Can you find these Hidden Pictures?
In this big picture find the carrot, boot, toothbrush, candle, Abe Lincoln, shoe, frying pan, comb, canoe, pie, key, umbrella, sailboat, spoon, mallet, and flashlight.

En este ilustracion se puede encontrar la zanahoria, el cepillo de dientes, la candela, Abe Lincoln, el zapato, el sarten, el peine, la canoa, el pastel, el llave, el paraguas, la barco de vela, la cucharra, el mallete y la interna electrica

Doctor, doctor...

Doctor, doctor, I've a terribly sore throat. Go over to the window and stick your tongue out. Will that cure it? No, I just don't like the woman who lives across the street.

Doctor, doctor, I've broken my leg. What shall I do? Limp.

Doctor, doctor, I've developed a double heart beat since my operation. Ah, so that's where my wristwatch went!

Doctor, doctor, my aunt has a sore throat. Give her this bottle of auntie-septic.

Doctor, doctor, my eyesight is getting worse. It certainly is - this is the Post Office.

Doctor, doctor, what's the best way to stop my nose running? Stand on your head.

Doctor, doctor, when I get up in the morning, I'm always dizzy for half an hour. Try getting up half an hour later.

Doctor, doctor, will my measles be better next week? I don't like making rash promises.

Doctor, doctor, will you give me something for my head? Thanks all the same - I already have one.

Doctor, doctor, you know those pills you gave me for my stomach? What about them? They keep rolling off in the middle of the night!

Doctor, doctor Have you got something for a bad headache? Of course. Just take this hammer and hit yourself in the head. Then you'll have a bad headache.

Doctor, doctor I keep getting pains in the eye when I drink coffee. Have you tried taking the spoon out?

Doctor, doctor I keep seeing double. Please sit on the couch. Which one!

Doctor, doctor I need something to keep my falling hair in. What about a matchbox!

Doctor, doctor I've lost my memory! When did this happen? When did what happen?

Doctor, doctor, I can't stop pulling ugly faces. That's not a serious problem. Yes, but people with ugly faces don't like it.
Special thanks to the Fallston High School (Maryland) Spanish Class for contributing all the Spanish puzzles: Mary Beth Nelson (teacher), Alyssa Coonan, Shannon Folderauer, Corey Green, Leah Grothe, Samantha Hopkins, McKenzie Hull, Emily Karp, Amanda Kucharczyk, Samuel Mathis, Christopher Pappas, Stephen Ross, Brittany Rush, John Tyszkwicwicz, Caitlin Walker.

Answers

¿Quién es en Béisbol?

1. Estrellas shortstop lo que sobresale Todo. Es conocido para su atletismo en El campo.

2. Fuerte Jonron bateador, Jardín izquierda con 734 jonróns.

3. Muy atlético tirador Se puede golpear y poderrobar las bases.

4. Un embrague designo bateador. El se llama “Big Papi.”

5. Estrellas shortstop comerciado que Llega a Baltimore Orioles de Okland A’s

6. Tirador de izquierda entregado Quien tira el fuego.

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Dr. Donna Copeland, founder of the Creative Arts Program at the Children’s Cancer Hospital at The University of Texas M. D. Anderson Cancer Center once said, “What children experience during cancer treatment is very powerful. The process of creating art, music, and writing is in itself therapeutic, because it stimulates imagination, facilitates expression of feelings, and fosters feelings of well being. Transforming their experiences into art is healing and happens naturally for children.” Dr. Copeland’s philosophy led to the creation of the Creative Arts Program at the Children's Cancer Hospital which is funded by the Children's Art Project at M. D. Anderson.

The Creative Arts Program is under the direction of Dr. Martha Askins.

Ms. Janet Ruffin, facilitator of Artful Happenings, is a professional artist, arts educator, and poet. She works with patients at bedside, in clinic treatment rooms, outpatient clinic playroom, hospital playroom, teen room and Kim’s Place (social place for adolescents and young adults 15-25 years old).

She uses different mediums to inspire creativity, such as drawing, acrylic, tempera, watercolor, printmaking, digital, photography, and sculpture. Her work is primarily therapeutic and creative in these settings. In addition, Ms. Ruffin provides art education in the Children’s Cancer Hospital elementary and secondary classrooms. She uses a very diverse and engaging curriculum that educates children about the principles of art and design.

An eight week class, taught by a professional photographer with the Houston Center for Photography, is provided to the elementary and secondary students through a grant. Secondary students enroll in Art I-VI courses and receive academic credit. Students of all ages enjoy a weekly art class called ARTmoves, co-taught by Ms. Ruffin and Pi Phi volunteer Ms. Barbara King. Together, they facilitate a multimedia presentation on art history followed by an art activity related to the lesson. Other educational activities include field trips to the Museum of Fine Arts and the Houston Center for Contemporary Crafts, where children enjoy crafts classes and tour the current exhibitions and meet the artists in residence who maintain studios at the facility.

The professional writers from Writers In The Schools (WITS) (also part of the Creative Arts Program) work with the M. D. Anderson patients in the classrooms twice a week. They facilitate creative writing by presenting pictures, objects and writing samples to stimulate imagination. They expose the children to prose and various styles of poetry. The patients participate in quarterly poetry readings held at the hospital. Family members and staff are invited. Selected patients also read at a yearly program held at the Menil Museum along with select Houston area school students.

A third member of the Creative Arts Program is Michael Richardson, a Board Certified Music Therapist. Mr. Richardson provides both individual and group music therapy to pediatric patients. The children take delight in the musical, whimsical games that they play with various instruments and enjoy the beautiful harmonies that they create and orchestrate with Mr. Richardson.

Masks

Plaster gauze over plastic molds created plaster faces that were adhered to a canvas board. Patients looked at images of masks made by other people and images from art books. They were given two containers of collage materials: papers, stickers, ribbons, magazine images, old art show invitations, buttons, etc. They try to provide as many different items as possible to stimulate their creativity. After selecting their materials they painted the masks to complement their chosen items. Often the painting process changed their first vision of the surface. The final process was selecting finishing touches to glue to the mask and canvas. Rarely did they ever use all of the materials first chosen.

One of our Arabic patients is creating a mask with a veil across her face. So far all the patients and family members have loved their masks.

For more information on the Artist in Residence at MD Anderson program contact:

Janet Ruffin
Artist In Residence
jruffin@mdanderson.org
A Birds Eye View From the Blimp

By Peter Schmuck, Baltimore Sun

Whenever I watch the Super Bowl, I think of the guys in the blimp, hovering 2,000 feet above the stadium to give you the God's-eye-view of the biggest sporting event of the year.

It’s pretty cool up there. I know because I was assigned to ride the blimp and report from the sky during Super Bowl Week in 2001.

No, I didn’t watch the game from the blimp. The players really do look like ants from up there. I went along on one of the practice runs a day or two before Super Bowl XXXV, but it was a such a memorable experience that I think of the guys flying the blimp every time I see that overhead shot.

There was a time when giant blimps — called zeppelins — carried passengers across the Atlantic Ocean, but that mode of travel fell out of public favor after a giant blimp called The Hindenburg exploded as it was landing in New Jersey in 1937.

Today’s blimps are largely promotional vehicles that serve as flying billboards for large companies, and might be the safest form of travel. The helium gas now used to make them lighter than air is not flammable, and there has not been a major blimp accident since the Hindenburg tragedy nearly 70 years ago. It probably also helps the safety rating that the top speed of one of these babies is a sizzling 47 miles per hour.

I rode the Budweiser blimp at Super Bowl Week, but there also is a whole fleet of blimps owned by the Goodyear Tire Co. and a Fuji Film blimp and about 25 others around the world that also serve as floating camera platforms over big sports and entertainment venues.

On the day of the game, the blimp will carry a network crew and a high-tech (gyro-stabilized) camera. The network gets the use of the blimp for no charge other than the several times the sponsor of the blimp gets mentioned during the broadcast. The company considers that a pretty good deal, considering that other companies are paying about $2.5 million to air a 30-second commercial during the game.

Basically, the blimp is a giant gas-filled balloon with a large gondola hanging under it. There are two pilots and a passenger area, but there isn’t room for much more. The blimp I rode on didn’t even have a bathroom.

That’s no big deal if you’re going up for an hour or two, but the pilots who steer the blimp have to be airborne for up to eight hours on Super Bowl day. The event is so big that the television network devotes several hours to pre-game coverage, which includes many of those sky-shots of the stadium and the activities going on in and around it.

Of course, I asked the pilots the bathroom question, but all they would tell me was that it was “one of our trade secrets.” Turns out they just have to go back to the staging area a mile or two from the stadium and land if they need to get off the blimp for any urgent reason.

Flying the blimp may be extremely safe, but it is not easy. The pilots have to keep the airship in the right position to get the optimum shots while monitoring air traffic and adjusting to the wind. They also have to watch out for other aircraft trying to get a peek at the Super Bowl.

There are airplanes pulling banners above them and news helicopters hovering below them, all governed by air traffic rules meant to keep all of them safe and prevent an accident that could also injure people on the ground.

You probably won’t think about that when you’re watching the game and see that big overhead camera view, but it just shows how much goes into making the Super Bowl the biggest television event of the year.

— Peter Schmuck is a columnist for the Baltimore Sun who has covered 25 World Series, three Super Bowls, the Olympic Games and a variety of other major professional and college sporting events. He lives in Maryland and is one of our “go to guys” whenever we need something.

CONCERNING THE ORIGINS OF LOVE
“Cupid kissed God and that got the ball rolling.” — Julio, age 9
“One of the Greek lady gods got a crush on one of the Greek man gods, he tried to hit her with lightning and thunderbolts, but he just couldn’t get her away from him... After a while, they became the first married gods.” — Robbie, age 8

CONCERNING WHY LOVE HAPPENS BETWEEN TWO PARTICULAR PEOPLE
“One of the people has freckles and so he finds somebody else who has freckles too.” — Andrew, age 6

ON WHAT FALLING IN LOVE IS LIKE
“Like an avalanche where you have to run for your life.” — John, age 9

ON THE ROLE OF BEAUTY AND HANDSOMENESS IN LOVE
“If you want to be loved by somebody who isn’t already in your family, it doesn’t hurt to be beautiful.” — Anita C., age 8

CONFIDENTIAL OPINIONS ABOUT LOVE
“I’m in favor of love as long as it doesn’t happen when ‘Dinosaurs’ is on television.” — Jill, age 6

REFLECTIONS ON THE NATURE OF LOVE
“Love is the most important thing in the world, but baseball is pretty good too.” — Greg, age 8
“Mooshy... like puppy dogs... except puppy dogs don’t wag their tails nearly as much.” — Arnold, age 10

HOW DO PEOPLE IN LOVE TYPICALLY BEHAVE?
“They want to make sure their rings don’t fall off because they paid good money for them.” — Gavin, age 8
“They are just practicing for when they might have to walk down the aisle someday and do the holy matrimony thing.” — John, age 9

CONCERNING WHY LOVERS OFTEN HOLD HANDS
“Mooshy... like puppy dogs... except puppy dogs don’t wag their tails nearly as much.” — Arnold, age 10
Does your family have a hard time like mine, my mom cries all the time. Financially and emotionally, we stay sad. - Zi, patient at Children’s Hospital, Texas.

We have three different people to answer your question:

When I found out I had cancer in 2005, it had been a pretty rough year already. My grandma had just died of a brain tumor and then a week after we buried her, I was diagnosed with cancer. It was hard for my family especially at the beginning, but we pulled together as a family, prayed and realized that everything happens for a reason. A constant reminder for us was that God never gives us more than we can handle.

- Kara, cancer survivor

There is so much stress in the house with cancer. Everyone's lives have been so markedly changed. Nothing is easy anymore. Nothing is the same anymore. When you are upset (angry, sad), the one who feels the worst of it is the one who is safest. Kenzie takes stuff out on me, I take stuff out on Steve... No one can make the hurt/pain/stress/fear go away, and everyone shows it differently... I cry!!!

- Sue S., mother of cancer patient

When my younger sister first got diagnosed, my family was sort of in shock. The fact that my sister had a life threatening disease didn’t seem real to us. We’re a lot different now. We all cry sometimes, but that’s okay. We’ve just learned that you shouldn’t hold back and that you should live every day to the fullest. Every family goes through rough times and you should just make the most of them. Financial problems are hard to deal with because you don’t want to seem like a burden to your parents. I just help out as much as I can to help lighten the load.

- Lauren S. 14 years old, sister undergoing treatment for a brain tumor

How often do kids get any kind of Cancer?- Kyralee, former patient at Sinai Hospital, Maryland.

Dr. Wiley - Cancer is a rare occurrence in children affecting ~12,000 children under the age of 18 throughout the country each year and having an overall incidence of ~1/700 by the time they reach adulthood. This means that less than 1 in 500 children will ever get cancer. The good news is that almost 80% (8 out of 10) will be cured of their cancer with modern treatment.

Joseph M. Wiley, MD
Chief, Division of Pediatric Hematology-Oncology
The Children’s Hospital at Sinai, Baltimore, MD