

SATURDAY, AUGUST 18, 2007

Our sweet Ben has been diagnosed with a childhood cancer called Neuroblastoma. It's a tumor based cancer that starts in the systemic nervous system, often with adrenal gland cells. Ben's neuroblastoma tumor is the type that spreads quickly, and a CT scan confirmed that the cancer cells have spread from the original tumor in his abdomen to his bones and bone marrow – causing little tumors to begin forming there as well.

Because of the spreading, Ben fits into the “high-risk neuroblastoma” category. In response to this, his doctors came prepared with a plan of attack, to start immediately.

Treatment actually began on Friday, August 17th, with the placement of a Hickman line into his chest. This line has 2 tubes coming out that will be used for the administration of chemotherapy drugs as well as other necessary medicines. The first round of chemotherapy began Friday night as well. We're thankful for the quick start because we are told that chemotherapy will actually make Ben feel much better as the tumors start shrinking, alleviating some of the pain and discomfort he feels in his bones.

The treatment plan looks something like this:

- Phase 1 (6-8 months) - 6 chemotherapy rounds occurring every three weeks. Each round consists of about 3-5 days of chemo, then a recovery time at home.
- Phase 2 (3-4 months) – Higher level chemo drugs to overcome any resistance formed through Phase 1. Because of the higher levels, this phase will more than likely contain a stem-cell transplant of Ben's white-blood cells (to be taken now and frozen.) Also in this phase is a possible surgery to remove the originating tumor, as well as radiation around the tumor locations to make sure there are no cancer cells remaining.
- Phase 3 (around 6 months) – Hopefully Ben will be in remission after the first 2 phases...however, oral chemotherapy pills will be administered at home to assure the elimination of all cancer.

So, now to what really matters: How is the Towne family doing and how does Ben feel? Because of the pain medication, Ben has been sleeping through most of the days. When he wakes up, he is fairly clingy to Carin and Jeff, but usually wants to go on walks through the hallways. We've seen his personality come through as he directs people around him: “mommy carry Ben...no Daddy carry Ben...that way...no that way...go see choo choo trains” :) We are always relieved to see his personality – we are anxious to get to the point where he is feeling better.

Carin and Jeff are doing remarkably well. The hardest part was not knowing what was going on – as soon as we met with the doctors, there was a sense of relief to at least know what we are facing and how we are going to treat it.

They are very appreciative of emails, text messages, voicemails, cards sent to their house, and of course now, messages left through this caring bridge site.

Because C, J & B are supported by such a large community of family, friends and UPC family, we are asking that people wait to visit the hospital. We need to allow them some time to get adapted to this new lifestyle as well as to see how Ben responds to the treatment.

So many people have expressed the desire to help or serve in some way. As we move further along this road, there will definitely be things that come up, but for now, prayers and messages are the best way to send your well-wishes.

Thanks again, to everyone, for your encouragement and support during this difficult time. Carin and Jeff are so appreciative and feel very blessed to have all of you interested and participating in their lives.

Ben is an amazing boy and we are confident that God has good things in store – a hope and future that we can't wait to see.

MONDAY, AUGUST 20, 2007

We are so thankful that as of yesterday, the Towne family is finally in a private room at Children's. This is HUGE for Carin & Jeff. There is something just very awkward about sharing something so intimate with strangers behind a curtain. Not to mention the Star Wars videos Ben's roommate was interested in watching. At least the sound of Jaba The Hut made us all laugh at one point.

We are entering the 4th day of chemo, and are hoping for some pain alleviation soon. Ben's stubbornness and endurance came shining through last night as he did not want to sleep - even after a constant morphine drip and sleep medicine. We tried to laugh and at least recognize that a fighting spirit is a good thing...

Regarding visitors - as of now, we still ask that you hold off on coming by the hospital. We have a long road ahead of us and there will be opportunities for everyone to participate and see the Townes.

The cards, messages and signs of support have been staggering...and we are so thankful. We go by their house everyday and pick up their mail and deliver it straight to their room. We cannot thank you enough for logging on to this site, expressing your thoughts and prayers, and continuing to lift up little Ben and his parents.

Thank you.

(Kristen - Carin's sister.)

MONDAY, AUGUST 20, 2007

## *There are no words*

No words to describe the place we have found ourselves in - and no words to describe the gratitude we have felt for your outpouring of love and encouragement. Thank you.

We have been here a week and the reality and direness of Ben's illness is slowly starting to sink in. And yet, because of your prayers and the way our family has surrounded us we feel strengthened for the journey that lies ahead. Confident that when our faith fails us, yours will hold us firm.

Amidst the pain and terror there have been moments of laughter. Today while walking Ben down the hall the Children's clowns came over to try to entertain him. Upon their arrival Ben proceeded to projectile vomit numerous times. When he was finished he said, "NO! NO BALLOONS!" So while cancer tries to diminish his spirit, he will be heard loud and clear.

We look forward to hearing him for years to come.

With Thanks, Carin & Jeff

TUESDAY, AUGUST 21, 2007

*A smile*

We saw one tonight for the first time in almost two weeks. It literally took our breath away. A much needed reminder that our Ben is still here.

Tonight he will receive the fifth chemo in this first round. The next few days will be spent doing some testing and training for Jeff and me. The hope is that we might go home for a few days next week.

Thank you for your continued messages, thoughts and prayers. Please pray for protection for his body against infection.

THURSDAY, AUGUST 23, 2007

## *10 days*

10 days since the word cancer entered our lives.

10 days of not sleeping.

10 days since we have left this building.

10 days of being on a steep learning curve.

10 days of trying to comfort a child that cannot be comforted.

I can't imagine what this feels like on day 371.

Ben's body is fully experiencing the effects of the chemotherapy and cancer now. He is extremely uncomfortable, super agitated, in a lot of pain and this morning has spiked a fever. They have started antibiotics as a pre-caution.

Ben will be sedated this afternoon for a full body scan. This will be their road map for comparison in the months ahead. It will not change to course of treatment, just give them the full picture of where all the cancer has spread to.

To help us remember that he is a fighter, Ben decided to protest his continued stay here by ripping out his feeding tube today. :)

Thank you for your continued prayers.

THURSDAY, AUGUST 23, 2007

## *My Prayer*

Since Ben was a baby I have prayed the same prayer over him every night:

Dear God,

Thank you for my son.

I pray you would watch over him tonight. Protect his mind, his heart, his body and his soul. In Jesus Name, Amen.

Tonight I prayed this with fierceness. That this prayer has not been in vain. But in preparation.

SATURDAY, AUGUST 25, 2007

## *Tigger Training*

Ben has started Tigger training. He has a little stuffed tigger that has all the same new tubes and pumps that he does. Today he learned how to give Tigger medicine. The nurse thought it might be helpful to also have him help give Tigger a new feeding tube. Ben agreed to help install it and then promptly ripped it out, as he had done with his again last night. :)

He has had two blood transfusions in the last 24 hours. Once his counts come up and we finish our “at home care” training we have the potential to leave Children’s for a little bit next week. We’ll see.

SUNDAY, AUGUST 26, 2007

## *A Thank You Note*

Thank you notes are very important to me. And so it is with much grace that I ask that you accept this blanketed version of our gratitude. The amount of gifts, cards, food, and generosity has absolutely floored us. We cannot begin to tell you how encouraging it has been. Ben thinks everyday is his Birthday now because of all your wonderful and sweet gifts. A habit that we will look forward to breaking when this is all over! Jeff and I have felt warmed by your cards, emails and messages. So thank you, thank you, thank you.

Our family has been insane. They have been here at all hours of the day and would stay here at night if we let them. Washing our clothes, taking care of our every need, tending to our house, providing every meal and those needs that we don't even have the energy to think about. It is impossible to express our depth of love and gratitude.

To our friend Dr. Ken Anderson - Ben's family doctor for the past two years - for going above and beyond the version of care. For his wisdom, love, and humor.

To our fabulous bestest friends. You know who you are. We love you. Thank you. For cookies, coffee, sticker books and more.

To my mom's group. For making me laugh in the midst of so much pain and for your love from afar.

To all of those who participated in the prayer vigil this weekend across the globe. We are grateful.

To those who have posted here that we don't know. For choosing to care and taking on Ben in your thoughts and prayers.

There isn't enough stationary in print for the amount of thanks we offer. So please accept this. Thank you.

And finally to Ben. Thank you for fighting this with everything you have. For being braver than any two year old should have to be. Thank you for your smiles and kisses today. We love you with every depth of our beings. Thank you for being our son.

MONDAY, AUGUST 27, 2007

## *Fever Land*

We can't seem to stay fever free for more than a day. So far, there is no sign of infection, but they are going to continue his antibiotics and run a few more tests. In other words, I shall start finding a new paint color for our room here and possibly some better art work.

The bone scan that he took last week wasn't as conclusive as they had hoped, so we were told this morning Ben will be going in for one more either today or tomorrow. Another sedation. They know where his tumor is, and we know that there is cancer in the bones around his eyes and skull, but they aren't sure if it is anywhere else. They hope this next scan will give them a better road map as we continue treatment, especially in Phase II with radiation.

The good news though, is Ben is in a much more comfortable place. He is playing, riding bikes and much more of the boy that we know.

My cousin Becky is here with her son Jordan. Just down the hall. How is that for crappy? They are hoping to be at the end of his treatment, a doctor's appointment today at 4pm will hopefully confirm this. Please keep them in your prayers as well.

WEDNESDAY, AUGUST 29, 2007

## *Officers of Grace*

I woke up this morning incredibly discouraged. We are entering our third week here and had another sleepless worrisome night. Ben was experiencing body spasms and it was very difficult for him to sleep. I thought perhaps I should pray, yet nothing really came to mind except, "God where the \*\*\*\* are you?"

Sometimes when I don't know what to pray I just sing, it seems to come more easily. A song that our friend Dale Roth wrote has been circling through my mind for the past few days, "Hope in God":

My soul cries out to you, my heart is in despair  
 I lift my hands to heaven above.  
 Be gracious to me, Lord, and deliver me from sin,  
 Immerse me in your steadfast love.  
 Hope in God, oh my soul,  
 For the day will come again when I will praise him.  
 Hope in God, oh my soul,  
 For his faithfulness remains through the night.

A few moments later Seattle Police Officers George and Brian (who also work at UPC) paid Ben a very special visit to cheer him and bring him a police officer bear made just for him. Ben's face lit up and there were high fives given all around. In that moment I saw my son and was filled with so much gratitude for the way everyone around us is caring for and loving him. It was a moment of grace. As I walked down the hall later I thought, "I guess that is where God is. In those men."

THURSDAY, AUGUST 30, 2007

## Thursday

Thanks to all of you who have called and hoped for an update. The past few days have been busy with training and tests for us and Ben. Here are the few things we can update you on:

- Aunt Deborah came to give Ben a cute buzz cut. Uncle Steven was here to support. Luckily he still looks cute.
- His white blood cell count is finally up, which is good.
- His fever continues to ebb and flow. But now that his blood count is a bit higher they aren't as worried and our hope is that we might get to go home this weekend.
- The bone scan which was supposed to have happened earlier this week was postponed, so it will happen tomorrow in the afternoon.
- The swelling in Ben's eyes, which had been reduced after the first round of chemo has come back a bit. They are currently running some tests to try to find out why. The doctors reassured us this morning that it isn't because of the cancer, but probably more of a fluid issue.

We will try to update as soon as there is something new to report. Hopefully the next time you hear from us we will be at home!!

Thanks for your continued prayers.

Much love, Carin & Jeff

FRIDAY, AUGUST 31, 2007

## My boy

One of my favorite things to say to Ben is, "Who is my boy?" He responds enthusiastically, "BEN IS YOUR BOY!" I don't know why, but it makes me joyously happy. In a moment of sadness yesterday Jeff read my mind and said, "Carin he is still your boy."

Sometimes it is hard to remember that. The boy I had a few weeks ago who was running around our yard throwing the football is now a boy hooked up to numerous chords, who's hair has fallen out and who has a feeding tube running 24 hours a day. But he is my boy, things are just different now. It occurred to me last night that Ben is probably thinking the same thing. "That's my mom. But there is something different about her." I would like to think it is just because I have been in the same clothes for three weeks. But he knows. He is smart. And he is right.

All three of us are different than we were three weeks ago. Time will tell just exactly how.

It is good to know that some things remain the same though. Lightning McQueen, match box cars and hopefully the mercy of God.

~

Ben's bone scan will be at 3pm today. I don't think I will ever get used to handing him off to a team of doctors while remaining in a waiting room. So please pray for all of us. Thank you.

SATURDAY, SEPTEMBER 01, 2007

## *Home*

We arrived home last night around 6pm. Leaving the hospital reminded me of Tim Robbin's character at the end of Shawshank Redemption when he crawls out of the sewer tunnel and stands joyous in the pouring rain. Complete freedom.

The signs and piles of gifts that decorated our neighborhood and home welcomed us greatly. Thank you to everyone who was part of that.

It was fun to see Ben at home, playing with his toys, surrounded by his grandparents, the Husky game on. If he didn't look so different I would have thought it was all a bad dream.

We quickly learned last night that we are completely unprepared for the nursing/caring part of this journey. Setting alarms, giving various medications, and fixing feeding tubes/pumps throughout the night proved challenging. But hopefully we will find our way through all of this stuff, just as we did when we brought him home from the hospital two years ago. We were green, freaked out and unprepared to have a newborn. The same feelings hold true now. Everything is new. But it will soon be a new normal.

Thank you for continuing to hold us tightly.

TUESDAY, SEPTEMBER 04, 2007

## *Labor Day*

Jeff and I spent the weekend learning what it means more and more to care for Ben. We are making improvements as his nurses, although our appreciation for Shauna, Jana, Krysta, Elise, Megan and others at Children's has gone through the roof. We were so well cared for there.

The Townes, Headlees and Bill Zbitnoff spent much of their weekend assembling a swing set in our backyard. Thank you!

Ben spent the weekend working on some of his new toys. The train set from Aunt Kristen and Anthonie was a huge hit! Seeing him climb onto his new play set and play with his grandparents was a huge highlight for us.

Today we head into Children's for some appointments. Blood work and exams for Ben. We are hopeful to receive "good" news about his bone scan - that the cancer wasn't found in any other areas than first determined. The visit should give us a game plan as well for when we check in later this week to start round two of chemo.

It is a new week.

TUESDAY, SEPTEMBER 04, 2007

## Overwhelmed

We spent three hours at Children's today. Ben did awesome! He was such a trooper. During our time they laid out for us what the next few weeks of treatment will look like. It is going to be pretty intense.

We will check in Friday to start his second round of chemo. Following those five days they will start the process of creating and gathering his stem cells. These will be transplanted back into him later this winter when he enters "Phase Two" of his treatment. This is a complicated process, but one of the most important parts of fighting neuroblastoma.

The good news we received is that at this point there are no other bones that are infected besides his skull and his eye bones. So just his tumor, marrow and those bones. \*rolleyes\* But it was mentally helpful.

More than ever we will try to enjoy our time at home for the next two days. Ben is in great spirits today. Singing, playing, laughing and lots of smiles. On one hand we are so grateful to see him like this. On the other, it is really painful to know what he is going to have to go through in the next month - and months to come.

One day at a time.

WEDNESDAY, SEPTEMBER 05, 2007

## *Prayers for a Backpack*

Today we watched all the kids across the street on their first day of school. They were so excited, many carrying new backpacks. Ben was thrilled to see the school buses return to the neighborhood, a daily highlight for someone who loves transportation.

As I watched him with his backpack, which contains a feeding pump, ice pack and his suppliment, I prayed.

Lord let this be him. Three years from today. Excited, carrying a new backpack, one filled with good things, walking to Mrs. Anderson's class.

Please.

THURSDAY, SEPTEMBER 06, 2007

## *Delayed*

We were disappointed to find out this afternoon that Ben's second round of chemo has been delayed due to his platelet count. While we don't wish the awfulness of treatment on him, the anticipation of waiting for it to start is difficult on us.

So we will wait. And we get the sense this probably won't be the first time this happens.

Please pray throughout this weekend that when they check his counts on Monday they will be within the range that allows him to continue his treatment. Our hope now is to check into Children's on Tuesday.

Thank you.

SATURDAY, SEPTEMBER 08, 2007

## *Finding Nemo*

In the midst of cancer, we still have a two year old. He is screaming at us to, "GO TO THE HOSPITAL AND SEE NEMO!!!" Jeff said, "You want to go to the hospital?" To which Ben yelled louder, "GO SEE NEMO!!!!!!!!!!!!!!!"

We hope this means his platelets are as ready as he is.

Happy Saturday.

SUNDAY, SEPTEMBER 09, 2007

## *A Gift*

Tonight at church my beautiful and talented friends gave to us this gift. A song for Ben. For us. Written by the amazing Katie Freeze and sung by Annie Parsons and Sue Nixon.

### “Prayer for Wonders”

Well, my back's against the wall, no margin left for luck;  
 It's changing by the hour and things aren't looking up.  
 They say that mountains move if faith is big enough,  
 But I don't know the rules when hope is all you have.  
 I will pray for wonders, there ain't any other way;  
 These mountains are too high for me, so I'll look at them and say,  
 “Lord bring me to the open, to the sky that's wide and true;  
 I'll turn and see those mountains and I will think of you.”  
 There's nothing left in me, my sorrow's just begun;  
 I think of Calvary, a day without the sun;  
 They say that mountains move if faith is big enough  
 Well, I'll depend on you, your love is all I have.

~ Thank you girls. There is nothing else I can say, you have already said it all.

MONDAY, SEPTEMBER 10, 2007

## *Round Two!*

Good news today, Ben's counts are up! We will check into Children's tomorrow morning for Ben's second round of chemo to begin. It is strange to say it is "good news" to be starting chemo, but with all that lies ahead this next month we have been fairly anxious to start.

So thank you for your thoughts and prayers. We feel very encouraged today. Small steps are big now.

Please keep the Busby family in your prayers tomorrow as Jordan undergoes surgery.

WEDNESDAY, SEPTEMBER 12, 2007

## *From the Depths*

The past 24 hours have been hell. Projectile vomiting, endless crying, no sleep and trying to manage a two year old who is attached to a pole of wires. At one point last night all three of us were in tears. Hearing Ben scream from the depth of his being was the most unsettling thing we have ever experienced.

We are working with the doctors this morning to try to find the right combination of drugs that will bring him (and us) some much needed relief. His second dose of chemo will begin this afternoon.

At one point last night Jeff said to me, "I don't know how someone survives this. And if they do, what is left of them?" I don't know. For any of us.

WEDNESDAY, SEPTEMBER 12, 2007

## *He Sleeps*

I don't know if it is all your prayers or the many drugs we have pumped into Ben's system. But he is sleeping. So thank you. And thank God for drugs. A doctor reassured me earlier that all the medications he is taking for relief will not cause any problems later on for him. And as a "bonus", studies have shown that kids who have had chemo and narcotics at a young age are far less likely to use recreational drugs in the future. I told him if Ben survives this and then uses drugs of any kind I will kill him myself.

Dose 3 of 5 tomorrow.

Good night.

FRIDAY, SEPTEMBER 14, 2007

## *The Starlet Hotel*

It occurred to me last night while listening to the boy on the other side of our curtain puking that staying at Children's must be similar to a night with the Starlets - Paris, LiLo, Nicole, and Britney. Drugs, puking, all nighters, and in the end depression about where your life is. Only instead of staying in the Beverly Hilton Penthouse Suite with room service we are in a Double at Children's with a snack cart.

Ben is a trooper and is as fiesty as ever. We seem to have his nausea under control and while he doesn't feel great, he is up and about walking the halls of the hospital and giving orders. Dose 4 of 5 will start this afternoon and we are hopeful for a late Saturday discharge following Dose 5.

SATURDAY, SEPTEMBER 15, 2007

## *Biking at 5am*

Our morning started off like this:

(4 am)

Ben: "Hi Dad."

Jeff: (silent - in hopes he would go back to sleep)

Ben: "Hi Dad!"

Jeff: (silent)

Ben: "HIIIIIIIIIIII DAAAAAAAAAAAAAAD!!!"

Jeff: (silent)

Ben: "Dad, say hi BW." (his nickname)

Jeff: "Ben, shhhh, it's still nighttime."

Ben: "Ben play cars!"

By 5am we were riding a bike down the hall to much of the amusement of the night nursing staff. He is obviously feeling a lot better! :) In moments like these it is hard to believe he is so sick. But we are grateful for them (although we would prefer they started after 6am).

His final dose of chemo will be given this afternoon. Hopeful still for an early evening checkout.

SUNDAY, SEPTEMBER 16, 2007

## *A Different Bowl*

Apparently Ben does not care for our old Pyrex that Jeff has had since college. During his third session of puking today he managed to directly tell us that he preferred a "different bowl" to dispose of his stomach contents in. William and Sonoma gift cards are now being accepted.

It was a funny moment in an otherwise tough day. He is obviously not feeling well and we are hoping to get his nausea under control again. We will be at Children's every day this week in their outpatient clinic as Ben starts the stem cell harvesting process - pending he stays fever free.

TUESDAY, SEPTEMBER 18, 2007

## *Fall Harvest*

Fall is my favorite time of the year. I love the change of season. Especially when we lived in Princeton. I have never seen trees as brilliant in color as the ones in New Jersey. While walking through our neighborhood this morning it seemed fall is here. It was crisp, there was the scent of caramel apples in the air and I could see that the trees are starting to change. Sprinkled throughout all the green leaves were specs of red and yellow. The first sign that they will eventually fall, leaving the branches bare.

Bare.

I feel like that is what is happening to us, to Ben. We are being stripped. Stripped of control, stripped of life, of everything we know.

I can't help but think of the stem cells that will be taken out of Ben next week in the hopes of restoring him this winter from his high dose chemotherapy. I pray for these cells. And I pray for spring. I pray that when I see these leaves return - new and full - that we will be the same. That Ben will be restored. New and full of life.

I pray.

For renewal. For life. A new season.

THURSDAY, SEPTEMBER 20, 2007

## *Transfusions*

We spent the day at Children's in order for Ben to receive a red blood cell transfusion. He had his first one almost a month ago right after diagnosis. When they first told me that he would be having not only one, but many, many, many I felt completely terrified. After all, blood transfusions were something that only happened on ER or Grey's Anatomy in my mind. Now they almost seem routine. Almost.

As I watched the nurses hook Ben up today I looked at the bag containing the blood he was about to receive. There were a lot of technical terms on it, but the two words I recognized were "volunteer donor". In that moment I offered up my thanksgiving. For whoever that was and for the many volunteers that will be part of saving Ben's life this year.

A lot of people keep telling us that they feel helpless. That they want to do something and yet there is nothing tangible they can do. I want to tell you that you can donate blood. It is quick. It is easy. And it will save lives. Literally. It is saving Ben's as I type this.

FRIDAY, SEPTEMBER 21, 2007

## *Headed Back*

Ben has a fever. They are checking us in this afternoon. Though this is “normal” it is still super depressing. We were looking forward to a weekend at home finally. Although, really, what is a “weekend” now? All days are cancer days.

SUNDAY, SEPTEMBER 23, 2007

## *Fall Getaways*

We returned home thankfully tonight - to the latest edition of the Seattle magazine. This month's topic is "19 Great Fall Getaways". How surprised we were to find that Children's Hospital was not on the list! Jeff said it must be #20. Nevertheless, we are home. Ben handled the weekend much better than we did. Once his fever broke he was even making jokes.

*A Joke, by Ben Towne*

"Cars have trunks.

Elephants have trunks.

\*insert laughter\*

That's a good joke!"

We resume our scheduled appointments starting tomorrow, with Ben's stem cell harvest happening sometime between Tuesday and Thursday. Thanks for your prayers.

TUESDAY, SEPTEMBER 25, 2007

## Type A's

Jeff and I are both Type A's. Cancer unfortunately is not. When you are used to living by your calendar, or in Jeff's case your PDA, the "cancer schedule" can be highly frustrating. We are continuing to wait for Ben's counts to be high enough for the stem cell harvesting. The hope had been for Tuesday or Wednesday, now it is looking like he will have a possible transfusion Thursday with the stem cell harvest Friday. This bumps all of next week's "schedule" back a few days as well. For people who are organized, plan ahead and on time, it is a lesson in flexibility that we never wanted to learn.

In the meantime, Ben is hanging in there. It is difficult for us to watch him get the daily shots that are required for the harvest procedure. He cries, "No poke! No poke!" But true to his sweet nature, when finished he says, "Good job Ben." He is quickly winning all the nurses over and knows many of them now by name. And after every round of shots when walking out he cheerfully says, "See you tomorrow!" We are so proud of him. Proud to be his parents. With or without cancer.

THURSDAY, SEPTEMBER 27, 2007

## *Green Light*

We have been given the “go” for Ben’s stem cell harvest tomorrow. We will spend the day at Seattle Cancer Care Alliance where the procedure will take anywhere from 4-6 hours. The most challenging aspect will be keeping a two year old upright in a bed for the duration of that time. Wish us luck!

Many have asked if this will be painful for Ben. The answer is no. It is similar to a blood transfusion (which he received another one of today). He has two tubes coming out of his chest. They will take blood out through one, circle it through a machine, take out the stem cells, then put the blood back into him through the other tube. Pretty amazing.

Please pray that they will extract enough stem cells tomorrow. “Sometimes” it requires two days. We are really hoping and praying this can be done in one day - giving Ben (and us) the weekend off of any procedures. After 19 days straight of appointments, procedures, tests, chemo and fevers we are ready for a small break.

Thank you for your prayers. We are pressing on...

FRIDAY, SEPTEMBER 28, 2007

## *A Praise*

They were able to extract plenty of stem cells today. We could not be more grateful. Tomorrow we get the day off. No “pokes”, no tests, no procedures, no nothing. Just us. Who knows, I may even clean up around here. Wait, who am I kidding?

Thank you for your prayers. Happy Friday.

MONDAY, OCTOBER 01, 2007

## Re-Staging

In the world of theatre, if we were two months into rehearsal and needed to “re-stage” everything it would be a bad sign. However, for us and this week, we are hoping for a lot of good results.

Ben will be retested this week using all the same tests that were part of his diagnosis. He will have a CT Scan, bone scan, tissue scan and bone marrow biopsy. They do this as a bench mark - after two rounds of chemo - to see where we are at in his treatment. While it won't change the determined plan, it can hopefully give us some encouragement that it is indeed working. The results will also be part of the road mapping for the surgeons later this winter when they remove his tumor.

After a fabulous weekend at home it is hard to head back in. But today we start. The testing will be completed by next Monday with Round Three of chemo scheduled to start next Tuesday.

October here we come...

THURSDAY, OCTOBER 04, 2007

## *Trust*

While we were sitting in the Radiology Clinic yesterday I couldn't help watching one of the other mom's in the waiting room. She was holding her baby to her chest, arms clenched tight around him/her, with tears streaming down her cheeks. When they called their name, I watched her grip get tighter and her tears more abundant. And though I didn't know what the specific circumstances were around that baby's health, I knew that mother's heart. I knew what was being asked of her.

To trust.

I have been the primary caregiver in Ben's life since he was born. As a person who didn't have a lot of experience with babies, I was terrified those first few months. I had no idea what I was doing. The first day Jeff left us to go back to work I sobbed. I remember thinking, "How can he trust me to take care of him?" But slowly, together, we started to figure things out. And as my sister-in-law Deborah said to me once, "You are his mom. You will know the most about him of anyone." It was true. I slowly began to trust myself as his parent. But it didn't happen overnight. It happened over time.

One of the most challenging things about this experience thus far is that instantaneously you are required to trust people you don't even know with your child's life. Radiologists, nurses, oncologists, surgeons, fellows, technicians, anesthesiologists, and more. People you have never met. Outside of this crazy situation you would never be asked to do this. You would call, check references, talk to people, and observe someone with your child before you ever left them. But you don't have that option here. Everyday there are new procedures and new people. You look them in the eye and with your tears try to communicate that "this is my son." This is the most important job I have ever had. This is the person I have loved for the past two years with everything in my heart and soul. And I am being forced to trust you with his life. So please do your job well.

Today Ben will be sedated for a few scans and tests. Most likely it will be done by an anesthesiologist and several technicians that we have never met. And like that mother in the waiting room, tears will fall. They are tears of desperation, of fear, of love that cannot be put in words. Tears because we will be required to trust them with our child. Like it or not. I'm not sure what this says about my overall trusting of God in this – that is a topic for another day. But I trust you all to pray for us. For Ben. For those who will be taking care of him today. Thank you.

SATURDAY, OCTOBER 06, 2007

*KBye*

The Huskies are off this weekend and so are we! We get two days to ourselves to rest and relax at home - which we will cherish since next week looks to be long and exhausting.

Ben is feeling well, talking a mile a minute, incredibly active and slept through the night for the second time since this all started last night! It is so encouraging to see him doing so well and at the same time difficult to know what he will have to endure starting Monday. But until then we will enjoy our time with him and at home.

Happy Weekends to all...

The Townes

MONDAY, OCTOBER 08, 2007

## *A Long Week*

This week will be long. I wish I could magically wave my wand and it be next Sunday night.

Monday: Appointments, sedated again for bone scan.

Tuesday: Check in, all day kidney test

Wednesday - Saturday: Chemo Round Three

Both Jeff and I have been pretty discouraged. It is hard to think that this is our life. Just a couple months ago Jeff was looking forward to starting another school year and welcoming new youth staff. I was preparing to start teaching at the UW. Now, we do cancer. Not just today, or tomorrow, or this next week - but for at least a year, if not more. How did this happen? I long to take Ben to little gym, to music class, to church, the beach, to play with friends. Instead, we head to Children's.

A long week.

MONDAY, OCTOBER 08, 2007

*A Prayer, by Ben*

“Thank you God

Aunt Kristen

Dory, Nemo

The Hospital

DVD Player

Dad, Mom, Ben

Amen.”

We are thankful for him too. And the DVD player.

TUESDAY, OCTOBER 09, 2007

## *Prayers for Protection*

All cancer is awful. Neuroblastoma is one of the worst. It is a deceitful, tricky and hard to kill cancer. Basically it is sin in a cell. Because of this, Ben will be receiving some of the most hardcore chemo drugs that are available – it is the only way to fight it. Yet, the side effects are dangerous and discouraging.

The drug that Ben will receive starting tomorrow (Wednesday) is called Cisplatin. While this drug has proven in the past few years to be an extremely important drug in treating NB, it will most likely damage his hearing.  $\frac{3}{4}$  of all NB kids will suffer hearing loss - the extent to which varies depending on the child. We have been told that the “best case scenario” would be just the loss of high frequency pitches but we won’t know for another six months (approximately) what the ultimate damage has been.

First and foremost we care about Ben’s life. But this particular sacrifice has been very hard to swallow. Obviously we hope for the best, we hope for a miracle - that for some reason outside of medical science his ears are protected. Or that whatever loss there may be, it will be minimal. So we ask you to please pray for him. Please.

Besides his hearing, this drug will also make him very very sick. We have been told to expect the worst for the next 10-14 days. It is hard to know how to prepare for that. I’ve tried to tell myself that every time he throws up he will be throwing up cancer. Hopefully that will make me feel better, although I doubt it will make him feel better.

So here we go, Round Three.

Thank you for your prayers.

THURSDAY, OCTOBER 11, 2007

## *Sweet Scans*

We received very encouraging and positive results from the scans and tests Ben took last week . Here is where we stand after two rounds of chemo:

- no detection of cancer in his skull, eye bones or any other bones
- a reduction in cancerous activity in his tumor
- a significant reduction in cancer in his bone marrow
- no new cancer

We are thrilled. Obviously, he is no where close to being out of the woods, and neuroblastoma is a deceitful cancer. BUT, our oncologist Dr. Park said we should be very encouraged. Ben's body is responding to treatment!

We ask you to join us in prayer today for my cousin Becky's son Jordan. He will be having scans as well to determine the course for the rest of his treatment. This is a critical day for them.

SATURDAY, OCTOBER 13, 2007

## *A Family Affair*

We got a new roommate yesterday: Cousin Jordan! If you have to share a room here, it might as well be with family. I'm glad Jordan isn't into Kelly Clarkson like our previous roommate. Many of you have asked where you can follow Jordan's progress. Here is the link to his site: <http://bjbusby.blogspot.com/>.

We were thankful to see the Lewis family yesterday. Their son Logan is one step ahead of Ben in this process. He was diagnosed with Neuroblastoma just a few weeks before we were. They have been a source of comfort and understanding for us. You can read his updates at <http://www.loganjameslewis.com/>.

Ben's sickness started last night. We knew it would come, it was just a matter of time. He is being a total trooper as usual. We are grateful for his continued strength, humor, love and sweet manners despite it all. In the midst of having cancer he is still a two year old and wants nothing more than to play cars, build towers, sing songs and do stickers.

This afternoon he will receive his last dosage of chemo for Round Three. We are hopeful for a check out sometime tomorrow, although it will depend on how well we can keep his nausea and hydration under control in the next 24 hours.

Happy Saturday. It is Saturday right?

SUNDAY, OCTOBER 14, 2007

## Worshipping

Jeff and many of you worshipped at UPC today.

Ben worshipped the bowl.

I worshipped our laundry machine.

Round Three of chemo is finished. We are at home, although there is a strong chance we will be admitted again this week for nausea and dehydration. Obviously our hope is that he can recover quickly and we can be in our house. But nonetheless, this week is over. And we are grateful.

MONDAY, OCTOBER 15, 2007

## *Duke City*

The full effects of the Cisplatin have kicked in. Ben woke up yesterday and said, "Mmmmmm I smell good!" I guess that depends on if you like the smell of vomit or not. We will be at Children's every day this week for Ben to receive fluids and his medications through his IV - since he has thrown up everything we have given him at home. Our hope is that if we spend our days at the hospital it will keep us from spending our nights there. We'll see.

Because he is so sick right now we ask that all drop in visitors please hold off or give us a call first. It is for the protection of your clothing. (Just ask my Dad.)

For now we remain grateful that we decided to upgrade to a leather couch in our family room. I highly recommend it for quick clean up with little overall damage. A good purchase for all cancer families.

SUNDAY, OCTOBER 21, 2007

## *Mercy*

We arrived at the ER this morning around 6am. Despite our efforts to keep Ben hydrated and medicated this week - this last round of chemo has really taken it's toll. Ben is severely dehydrated, continuing to throw up, his blood counts are low and he now has a fever. He looks at us and cries as if to say, "Please make me feel better." And there is nothing we can do except cry, pray, and hold him. It is a very helpless feeling.

Needless to say it has been a long week - full of sleeplessness, anxiety and lots of laundry. In many ways we are actually thankful to be back in the hospital and hopeful that this stay over the next few days will make him feel better. He will receive a blood transfusion this afternoon - so that should help.

We pray for mercy. For Ben. For his body. For us.

TUESDAY, OCTOBER 23, 2007

## A Doctor's Report

PATIENT: BENJAMIN W. TOWNE

Age: 2

Height: 90.2 cm

Weight: 12.6 kilos and dropping

Progress:

48 hours without puking

red blood cell transfusion

platelet transfusion

Areas of Concern:

Continued fever

Severe stomach pain

Difficulty sleeping

FATHER: JEFFREY P. TOWNE

Age: 34

Height: 5'10

Weight: 180

Notes:

Continues to show immeasurable strength.

Brings level of peace and stability to patient.

*\*is currently being watched by security regarding rumors of smuggling "dad's juice" into the hospital\**

MOTHER: CARIN M. TOWNE

Age: Pleaded the 5th

Height: 5'4"

Weight: Refused Scale

Notes:

Continues to struggle heaving 8 month pregnant body out of twin hospital bed with guard rails.

A good candidate for strong narcotics.

Tendency to panic.

BABY TOWNE:

Age: 8 months

Height: n/a

Weight: n/a

Notes:

Seems actively and blissfully ignorant of current family situation.

*\*see panic note under mother's file\**

Signed,

Illegible M.D.

THURSDAY, OCTOBER 25, 2007

## *Emerging*

It has been over two weeks since Ben started Round Three of chemo and his first dose of Cisplatin. Since then his days have looked like this:

Day 1-4: Chemo

Days 4- 11: Nausea and lots of puking

Days 11-15: Fever and severe stomach pain

I hear a song coming on...."On the 15th day after chemo...cancer gave to me." \*rolleyes\*

We are relieved to report that "Ben" is finally coming back to us. His fever is gone and after a second platelet transfusion his counts are on their way up. It is painful and very difficult to watch him disappear. Two weeks of not seeing your child as you know them. But he has fought back again. Slowly. There is light up ahead.

Until the next round at least.

FRIDAY, OCTOBER 26, 2007

*A Smile*

We are home.

Ben is smiling as you can see.

Happy Weekends to all...

TUESDAY, OCTOBER 30, 2007

## *A Political Statement*

Imagine if you will...

You and your family are all packed. You head off on your “dream vacation”. When you arrive at the hotel, reception checks you in and gives you the key to your room. Only when you arrive at the room you find that there is another family there. There must be some mistake! You head back down and tell the bellmen that there is a problem. There is another family in your room. They look at you with a puzzled look. “I’m sorry, what exactly is the problem?” the bellman asks. “Well, this is probably obvious, but we would like our own room – just for our family.” He smiles. “That would be nice. Unfortunately all our rooms are full. So this is the best we can do for you right now.”

Only this isn’t a resort. It is Children’s Hospital. And instead of sharing margaritas with your new found friends you share all nighters, crying and puke. There is no beach and no pool to escape to.

As I walked through our neighborhood today and saw the meeting tonight about protesting the expansion of Children’s, I found myself extremely angry. Those who are opposed have obviously never spent a night there. Let alone 32...and counting.

We check in tomorrow for Round Four. I am anxious for Ben, anxious about what this next round of chemo will do to him and who we will get the pleasure of sharing this lovely experience with. It is too much to ask of people who are already on the brink.

I don’t often make political statements – I am an US Weekly kind of girl. But I can’t help myself.

Oh, and I love Barack Obama.

FRIDAY, NOVEMBER 02, 2007

## Round Four

Our “neighbors” were overjoyed I am sure to be woken up at 6am by a medley of Barney songs sung by Ben. Pop Goes the Weasel, I Love You, Squishy Squishy Squashy and more. Trying to tell a two year old to have a “quiet voice” is like telling me to not eat carbs right now. Impossible.

We are half way through round four of chemo. Ben is handling it fairly well although he has still gotten sick and has many moments of feeling very uncomfortable and agitated. In a moment of severe irritation last night he decided that the only thing that would make him feel better was to be naked. So he sat clothingless for awhile. I’m sure the nursing staff is thankful that has not been my mode of coping.

We are hopeful for a checkout on Saturday, pending his nausea is under control. The Busbys check in today, so we will have some cousin time until then.

SUNDAY, NOVEMBER 04, 2007

## Check

Chemo Round One - check.

Chemo Round Two - check.

Chemo Round Three - check.

Chemo Round Four - check.

We are home. Ben is doing pretty well. After the last round (devil drug), the side effects this time seem fairly mild. Every year since having Ben I curse the man (because no woman with children would ever have thought of such a crazy thing) who invented daylight savings time. This morning was no different. Ben was up at 4am - ready to celebrate this last cancer milestone.

Many have been asking us how many more rounds of chemo we have to go. Here is a cliffnote schedule:

- Chemo Round Five (in two weeks)
- (have a baby)
- Surgery to remove his tumor
- Chemo Round Six.  
(end of Phase One)

Phase Two:

- High Dose Chemo
- Stem Cell Transplant
- Radiation

Phase Three:

- 6 months of oral drugs.

So we are plugging along.

- Happy to check Round Four off the list.

TUESDAY, NOVEMBER 06, 2007

## *Ups and Downs*

The past couple days have been filled with ups and downs. Moments of fun and normalcy coupled with painful reminders of our circumstances. The joy of playing and laughing with his aunts and uncles, practicing baseball, singing and giving out hugs remind us of our boy. A last minute trip to the zoo was an awesome treat - a reminder of what life was like prior to cancer. They are not moments that are taken for granted anymore. They are like gold.

Our night ended with Ben wrenching, puking in the bath and again in his bed. There is nothing like the crying during a vomit session to quickly sober us again to his condition.

We remain thankful for the ups.

And continue to hold him close in the downs.

THURSDAY, NOVEMBER 08, 2007

## *Return to Alcatraz*

Ben spiked a fever late this afternoon, so off to the ER we went. It wasn't until 12am that they were able to get us into a room because once again there are no beds available on the SCCA floor. I thought after awhile they might wheel us into Tully's.

At 11:30pm Ben was sobbing asking to "go home" and "go to bed". You might as well have literally ripped my heart out, thrown it on the ground and ran over it with his damn IV pole.

So here we are. Another stay. Praying for no infection.

Good night or good morning rather.

FRIDAY, NOVEMBER 09, 2007

## *Post Round Four*

Ben is continuing to deal with the side effects of this last chemo. He has mucositis - an inflammation of the membranes lining his digestive track. So basically everything from his mouth to his butt hurts. Nice. He continues to throw up which is very painful because of the inflammation.

We are working with the doctors to try to regulate his pain with medication until his body is strong enough to heal itself. They are predicting we will be here until at least Sunday or Monday.

We continue to be exiled from the cancer floor due to over population. On one hand it is nice, because the rooms downstairs are bigger and brighter. On the other hand, we are severely missing the rock star oncology nurses. They are amazing. Luckily yesterday we have had visits from Shauna, Krysta, and Beckie.

Please pray for comfort, for recovery, for sleep.

Thank you.

SUNDAY, NOVEMBER 11, 2007

## WARNING: the Danger of Diaper Cream

As I have mentioned before, the cancer floor is full. So much so that there are cancer kids spread throughout the hospital in various places. We landed a room on the “general medicine” floor. It is highly frustrating to not have our oncology nurses, because even though they are very nice down here, they don’t really “do” cancer. A humorous example...

Ben is fighting a lot of things. Cancer, chemo, mucositis and now... diaper rash. Our doctor examined him yesterday and thankfully pronounced the rash nothing more than “diaper rash”. \*phew\* She said she would have some diaper cream sent down to us. Perfect.

The diaper cream arrived sometime shortly thereafter from the pharmacy. The nurse brought it in and proceeded to lock it in a safe. I said, “Would you mind leaving it on the counter so I can grab it as soon as I change his diaper?” She responded by telling me that “all prescriptions” must be in the nurses safe (which by the way I have never heard of). I said, “Even diaper cream?” Yes, even diaper cream. Apparently they wanted to oversee how much we were using.

Hmmm let’s see... Ben has stage four cancer. We give him narcotics at home. We clean the lines that run into his jugular vein. I think we can handle the diaper cream.

And by “diaper cream” I mean “Aquaphor”. It is available at Bartells or Walgreens.

~

Update: We will be here at least another few days. I’m not really sure why we are paying a mortgage.

TUESDAY, NOVEMBER 13, 2007

## Numbers

I have never been very good with numbers. In college I would “balance” my check book by going to the ATM and seeing if money would still come out. If it did, I figured I was okay (sorry Dad). I wouldn’t last five minutes working at Ernst and Young.

There are a lot of numbers involved in cancer.

Number of red blood cells

Number of platelets

Number of white blood cells

The rate at which his feeding tube is running

The number of given drugs and their dosages

The number of times he has puked

The number of days since he has pooped.

The number of eyelashes remaining.

The number of nights we have stayed here.

The number of days until we can go home.

And on really bad days, the number of kids who actually survive this diagnosis.

To say it is overwhelming is a gross understatement. Because in the end, the only numbers I really care about are these:

I only have one Ben.

And I pray One God is enough.

~

For those of you who do understand cancer numbers, we have an ANC today and his white blood cells are coming up. So hopefully his mucositis will start to taper off and we will only be here another couple days.

THURSDAY, NOVEMBER 15, 2007

## *Home*

We are home.

The hope is to be here until we check back in on Wednesday. Ben is still recovering, hopefully he will be up to full speed before the weekend is over.

SUNDAY, NOVEMBER 18, 2007

## *To family and friends of Ben,*

As you know, Ben, Carin and Jeff have been thrust into a world of cancer, one that is difficult, painful, heartbreaking and unchosen. As the Towne's navigate this challenging journey with Ben they continue to hold hope and promise for Ben's full recovery. As friends and family we all look for ways to join them in this battle. We have quickly learned how fortunate we are to have the tremendous capabilities and caring of Children's Hospital in this community. Even though neuroblastoma affects only 600 children per year, we are also blessed to have one of the nation's experts overseeing Ben's care in Dr. Julie Park. Dr. Park coordinates the care for patients with neuroblastoma at Children's Hospital. She also collaborates with researchers in outstanding children's hospitals throughout the USA to further research on neuroblastoma, study new therapies, and improve the care for this disease. As we have studied how we might better support Ben and the ongoing work, Ward and I (Ben's grandparents) and Peggy and Bob Wilkerson (Carin's aunt and uncle) have made the decision to fund an endowed chair for neuroblastoma. A "chair" gives the hospital much greater influence in retaining the brightest minds for this cancer and furthers their capacity to oversee and expand current research.

Many friends and family have also asked if there is a way they might help. Because this disease is not as prolific as other more prominent cancers, we hope to assure that further funds can be established to support exciting future and ongoing research. Almost 50% of children with neuroblastoma come out of remission. It is our hope that stronger funding could eventually help children stay disease free.

For this reason, we are setting up a "Ben Towne Pediatric Cancer Research Fund." These funds will then be given to a select committee of oncologists, under the leadership of the endowed chair recipient, to disperse to the most promising of research projects. Gifts given to the "Ben Towne Pediatric Cancer Research Fund" will be matched dollar for dollar until either February 1, 2008 or until all the matching funds are exhausted. Gifts should be sent to:

Kjell Oswald  
Director of Development  
M/S S-200  
PO Box 50020  
Seattle, WA 98145-5020

Please include a note that designates your gift for the Ben Towne Pediatric Cancer Research Fund.

We also recognize that Children's Hospital has the admirable mission to treat all children, regardless of the capacity to pay. A portion of the Towne family costs for treatment have been covered by the hospital thanks to an ongoing and generous donor community. If your preference would be to donate to the general fund for all children's care then use the same address as above and include a note designating Ben's name toward uncompensated care.

These are two options for consideration. We mention them because many of you have asked how you might help. In the meantime, please know that your support and help through prayers, cards, emails, website messages, gifts, meals, giving of blood and more, are very much appreciated.

Judy Bushnell

WEDNESDAY, NOVEMBER 21, 2007

## *A Thief*

Yesterday while Jeff was at the gym someone bashed in the window to our car and stole Ben's hospital bag full of clothes and toys. In broad daylight - at ProRobics. There are so many things wrong with this scenario I cannot even say. It's like a sick joke.

As I spent the rest of the day reveling in our "fortunate" ways, I found myself thinking that this incident is, in many ways, like cancer itself. It happens when you least expect it and in one instantaneous moment - you are shattered. The things that are of comfort and enjoyment are gone. There is no safety, fear. And like Jeff experienced, you feel like you are standing there looking at the glass all around you and asking, "how did this happen?"

It is a thief.

We check into Children's this morning to start Round Five. Once again, we will subject Ben to Cisplatin. It will take him from us for a couple of weeks. We pray again that it does not take any of his hearing. We pray for protection. We pray as we do with each round of chemo that he will return to us.

I am assuming that whoever stole our bag yesterday needed it more than we do. Someone better and more faithful than me would probably pray for them. Luckily at the end of the day, it is just stuff and glass. We can get new toys and clothes. My Dad already took the car to be repaired.

But we only have one Ben. So we covet your prayers.

~

Please pray as well today for our friend Logan. He is having surgery at 10am to remove his tumor.

SATURDAY, NOVEMBER 24, 2007

## Round Five - Update

Ben's final dose of chemotherapy for this round has just been hung. It is very surreal to watch your son sleeping peacefully knowing he is being poisoned. While it is becoming more and more "routine" it can never feel normal. Similar to our last experience with this drug, he has been in fairly good spirits until today. It is a delayed sickness. The hardest part of this stay has been that we are in "isolation" because of the bacteria infection that he continues to fight (remnants of round four). Ben feels fine from that, but it is contagious to the other kids on this floor. So he has been contained to our room for four days. If we weren't discharging tomorrow they might have to send us all three of us to the psych ward.

The plan is to go home tomorrow. We will expect to check back in later in the week once he spikes a fever and/or the level of nausea and vomiting becomes unmanageable. Until then, we will be in the outpatient clinic daily so that Ben can continue to receive fluids and anti-nausea medicines.

We are grateful to our families who have once again sustained us during this stay. Containing a two year old to a bed for four full days is an all-family task. We hope and pray that next Thanksgiving will find us in a very different place.

MONDAY, NOVEMBER 26, 2007

## Blood

Blood is a big part of our lives now. Blood counts, blood cultures, blood matching, blood transfusions – blood. To date Ben has received 15 blood transfusions and he is only four months into treatment. He has started his post-chemo downturn - violent puking throughout the night. By the end of the week he will be fairly lifeless. He will once again need blood.

So in the midst of pain and doubt this morning we offer up thanksgiving - for the Edge students and others from UPC who will donate blood today in Ben's name.

Today your donation will sustain lives.

Today your generosity will give families hope.

Today your support of us and of Ben means everything.

Thank you.

TUESDAY, NOVEMBER 27, 2007

## *Tuesday*

Ben told me this morning, "Mom, you need some coffee." He is so funny. I'm not sure coffee could touch the level of exhaustion in our house right now. But I appreciated the tip.

We ask that you please join us in prayer today for Jordan and my cousin Becky's family. He is having surgery to remove his tumor. Please pray for the surgery to be the least invasive as possible, skill for the team of doctors, and Jordan's well being. They expect it to take all day.

Thank you.

THURSDAY, NOVEMBER 29, 2007

## *Please Welcome*

Ryan Robert Towne

November 28, 2007

9:09 p.m.

6 lbs 2 oz

Initially measured at 17 ½ inches; re-measured at fathers request at 19 inches, much to the relief of Ryan's uncles.

Mother is doing well as is baby Ryan. Ben has been saying all along it would be a boy. Or a basketball. Or a dump truck. But mostly a boy. When you know, you know. He had me convinced.

Your love and prayers continue to mean a lot. Thank you.

For Carin and Ben, and now Ryan, too,

Jeff

MONDAY, DECEMBER 03, 2007

## *Time*

Time is a funny thing. Since Ben's diagnosis it feels like we have entered a cancer-warped-time zone. There is no day or night, more like 24 hour periods. Days, weeks and months in some ways seem to have flown by and at other moments stand completely and painfully still.

We are now over a week past Ben's completion of Round Five. He has spent everyday since in the outpatient clinic receiving fluids and medicines. He had a platelet transfusion on Saturday and continues to have mild vomiting, but overall is doing far better than we could have expected. He will likely receive red blood and platelets again in the next few days. And while a fever could still come about any time - causing us to return, this is the longest we have stayed out of the hospital (as in-patients) since his diagnosis - which is a very good thing since baby brother Ryan decided it was indeed HIS time to make his grand entrance.

A month early, and two weeks before his scheduled delivery, we greeted Ryan Robert on Wednesday night. The timing obviously caught us by surprise and was very stressful. And yet, he managed to come after Ben had fallen asleep for the night and before his 12am medicines needed to be given. Jeff was able to arrive at the hospital just in time to see our son be born and return home in time to care for Ben for the remainder of the night. While this was not our ideal birthing situation, we were grateful to be together for that moment.

And so it is a time of very mixed emotions.

A time of gratefulness and joy that Ryan has been given to us.

A time of anxiety and fear as Ben's surgery date approaches.

A time of survival.

A time of thankfulness to our families, who without them there is no possible way we could carry the load that has been placed on us.

And only time will tell what lies ahead for the four of us.

THURSDAY, DECEMBER 06, 2007

## *Scans*

Tomorrow (Friday) Ben will be sedated for the morning while they do his scans once again. It is one last image for the surgeons prior to Ben's surgery on the 19th. Regardless of their outcome the next step remains the same: removal of his tumor.

We are nervous. And hopeful.

Nervous because of the sedation and the results.

Hopeful that the tumor is dead.

Please keep him and us in your prayers.

Thank you.

SATURDAY, DECEMBER 08, 2007

## *Too Much*

After a long day yesterday of tests and procedures, we were ready to hear the scan results and go home. Little did we know what was in store for us.

While Ben was having his scans done yesterday to evaluate his tumor, the radiologists essentially “happened” upon a serious and potentially life threatening condition called pneumatosis. Basically what they found was that Ben has pockets of air between the lining and the wall of his intestines. There is not supposed to be air there. In a worst case scenario that air can lead to rupture. They cannot say what caused it – whether it be the chemo itself, or the side effects he has experienced following.

Ben was immediately hospitalized and will be at Children’s for approximately seven days while they monitor his condition and attempt to treat it with a heavy dose of antibiotics. His oncology team plus a surgical team will oversee the progress of the medications with daily x-rays in the hopes that after these seven days it resolves. If it does not, then they will have to surgically repair it.

In the meantime, Ben is on “gut rest”. He can have no food or drink for the week. Nothing. They will give him some nutrients through his IV, but nothing can pass through his intestines. It seems impossible. And torturous. To say we feel like we have been kicked in the gut would be a gross understatement.

The hope and prayer is that this will resolve in the next week in time for his scheduled surgery on the 19th to continue as planned. But they will not consider going in for his tumor if this is not completely resolved.

We had just begun to let ourselves get excited about a week off to be a family. We told Ben he would get to go on the ferry boat to the beach. He had been talking about it all week. As he sobbed asking to “go home” last night I cried right along with him.

It is too much.

Too much.

TUESDAY, DECEMBER 11, 2007

## Half-Way

We are half way through Ben's treatment for pneumatoxis. The doctors have been pleased with his progress as it seem the antibiotics are taking effect. A scan on Friday will hopefully confirm this and conclude this hellacious stay.

Since his diagnosis we have not faced a harder week. To deny your child food and drink is a form of torture, pure and simple. I feel like we have been stripped as parents - spiritually and emotionally. Ben will look at us with tears streaming down his face and plead, "I need something to eat!" There is no explaining to a two year old why this is happening. Nor his parents really. Second to cancer it is the most heart-wrenching thing I have experienced as a mother.

Without our families and close friends we wouldn't be making it. This is not a day to day thing. This is a twenty or thirty minute stint at a time. And getting to the end of each "day" is triumphant.

We ask please for your continued prayers. For strength. For positive scans on Friday.

FRIDAY, DECEMBER 14, 2007

*Hot Dog!*

Ben's scans were negative! The pneumatosis is resolved! We are home. Ben's first request was for a hotdog - closely followed by a donut. I have the puke bowl standing by, but so far so good.

We have so many people to thank for getting us through this week. Our parents, our siblings, Heather, Kari, Shauna, and more. For all of you. For your prayers. There were moments that I really did not think we would make it. I am so thankful that Ben will not remember any of this - though we will have a hard time forgetting.

We look forward to being a family that is all under one roof - at least for a few days. Surgery will continue as planned on Wednesday.

Ben would now like a cookie. I have a feeling I will be a waitress for the next few days. A job I will enjoy immensely.

A Very Happy Weekend to you all...

TUESDAY, DECEMBER 18, 2007

## *Surgery*

Back in August when the doctors were presenting us with Ben's diagnosis and outlining his course of treatment it seemed impossible that we would make it to this point. Yet, here we are. His surgery is tomorrow afternoon. They will remove the tumor and left adrenal gland. It is another step in a long process that will hopefully bring a cure to this horrific disease. And yet, it feels so daunting and terrifying.

Dr. Sawin will be performing the surgery. He is the Chief of Surgery at Children's. He did Ben's initial surgery to install his Hickman line. We feel very confident in and grateful for his care.

And yet, as I have expressed before, it is a forced trust. Trusting a team of people with the life of our child. So we pray. And covet your prayers. For protection, for safety, for wisdom and most of all for the removal of this mass of sin.

I asked our oncologist earlier if parents were ever allowed to view the tumor – and by “view” it I mean stab it with a knife over and over while channeling Glenn Close in *Fatal Attraction*. I just want it to die. And our son to live.

We will update as soon as possible.

Thank you.

~

An update: surgery time has been changed to 2pm.

WEDNESDAY, DECEMBER 19, 2007

## *Answered*

Our prayers have been answered. Ben's surgery was a total success. They estimated that it would take three hours and Dr. Sawin finished in an hour and fifteen minutes. The tumor was easily removed with no damage to any of the neighboring organs.

We felt surrounded by angels today. It seemed as if God ordained the people to be around us. From Candace, to Dr. Sawin, to Dr. Low and Kelly - Ben was extremely well cared for. He even had a special pre-surgery visit from his friend the puppet Eddie (who lives in the oncology outpatient clinic).

We are now working with the nursing staff and pain management team to try to make Ben as comfortable as possible. We hope for a quick and safe recovery. Then we press on to get rid of the rest of this cancer.

We are grateful for all of you. For lifting us up. For your prayers of protection. I asked Jeff earlier if he thought prayer worked. I guess I got my answer.

With Thanks, Gratitude and Relief,

C&J

FRIDAY, DECEMBER 21, 2007

## *48 Hours*

We are 48+ hours post surgery. Ben got out of bed today for the first time for a wagon ride. He looked like a little cancer prince as he laid in the wagon, propped up with pillows and was being towed all over the hospital. We followed orders closely to “turn here” and “go there”. They removed the tumor, but not his ability to direct us and everyone around here.

Many people have been asking what is next and if the removal of the tumor means Ben is cancer free. Unfortunately, it does not. As we have mentioned before, neuroblastoma is a difficult cancer to treat. Though the cancer originated in his tumor - it quickly spread through the rest of his body. So his treatment will continue and sadly get more intense. It is hard to believe that after all Ben has had to go through that the most difficult is still to come. Nonetheless, we are grateful to have this hurdle behind us.

We are hopeful for a discharge on Sunday. It will depend on how well we can manage Ben's pain. In the meantime, we will hang out with Cousin Jordan and pull our little prince around the halls of Children's.

MONDAY, DECEMBER 24, 2007

O come, O come, Emmanuel  
And ransom captive Israel  
That mourns in lonely exile here  
Until the Son of God appear  
Rejoice! Rejoice! Emmanuel  
Shall come to thee, O Israel.

O come, Thou Day-Spring, come and cheer  
Our spirits by Thine advent here  
Disperse the gloomy clouds of night  
And death's dark shadows put to flight.  
Rejoice! Rejoice! Emmanuel  
Shall come to thee, O Israel.

Merry Christmas.

From Home,  
The Townes

MONDAY, DECEMBER 31, 2007

## *A New Year*

Never in our worst nightmares could we have envisioned what 2007 would bring us. As I was transferring all our birthdays and such to my new calendar it was very surreal. I saw things in early 2007 like haircut appointments, play dates, Little Gym, vacations, rehearsals, date nights and more. After August the only thing written down were my OB appointments. The rest was blank. That is what cancer does to you. It wipes out your life. One day your calendar is full - the next day - empty.

I am not one to make resolutions. Sure I would like to lose baby weight and be chosen for the cancer mom calendar. But mostly, I just want 2008 to be over. By the end of this year Ben's treatment will be done. At least we hope so. I wonder how we will be. What will we be like as a family at the end of this year? What will our faith look like? Will we still be standing? How will we look at the world? Will we ever have a sense of normalcy again? What will it feel like to live in fear of remission?

So many fears, so many questions. And a blank calendar.

And so we pray for a new year. For strength and mercy. For restored health.

A New Year. A New Life.

SATURDAY, JANUARY 05, 2008

## Round Six

It is hard to believe that we have actually been home in our house for almost two weeks. It is the longest period of time we have spent away from the hospital since Ben's diagnosis. Reality set in yesterday though as we headed back to Children's for his pre-admit appointments. Walking through the halls seemed to knock the wind out of us. It was so familiar. And yet after finally having a break it feels extra difficult to return to cancerland. Ben feels great. As I type this he is running circles around the kitchen singing. He has been without chemo for almost six weeks and recovered very well from surgery. His laughter, joy and energy haven't been this high since July. How can he still be sick if he feels this well? How can we send him under again?

But we will. Tomorrow.

We remain grateful for your prayers. We pray specifically that the side effects of these drugs would not be as difficult as they were the first time.

TUESDAY, JANUARY 08, 2008

*For those of you who have read The Napping House...*

There is a room  
A hospital room  
Where no one is sleeping.  
And in that room there is a bed  
An uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And on that bed there is a dad  
A patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And on that dad there is a child  
A sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And on that child there are a hundred cars  
A hundred "Cars" cars  
On a sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And on those cars are three tangled tubes  
Three tangled tubes  
On a hundred cars  
On a sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And on those tubes is attached a pole  
A physically constraining pole  
Attached to three tangled tubes  
On a hundred cars  
On a sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And next to that pole is a curtain  
A thin, outdated curtain  
Next to a constraining pole  
Attached to three tangled tubes  
On a hundred cars  
On a sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And behind that curtain is a teenager.  
A video game playing teenager  
Behind a thin, outdated curtain  
Next to a constraining pole

Attached to three tangled tubes  
On a hundred cars  
On a sick child  
On a patient dad  
On an uncomfortable bed  
In a hospital room  
Where no one is sleeping.

And here at home, is a tired mom  
With a very awake newborn  
Praying for the sick child  
And the patient dad  
Because none of us are sleeping.

Goodnight. :)

WEDNESDAY, JANUARY 09, 2008

## Update

We are home. Ben has completed his sixth round of chemotherapy. We could not be more proud of him. He continues to amaze us with his endurance, strength, humor and energy. Though he has been sick, the worst of the side effects will probably take their course later this weekend or early next week. We expect to check back in for fever, transfusions and potentially mucositis again.

Until then we will thankfully check this last part of Phase One off our list. We turn our eyes rather frightfully to what lies ahead: Transplant.

Thank you for your prayers.

TUESDAY, JANUARY 15, 2008

19 & 20

We are headed into Children's today for transfusions. Ben's counts are low as expected. These will be his 19th and 20th transfusions. That is hard to believe.

Ben continues to be sick here at home but so far is fever free. We are trying not to get our hopes up that we will stay out of the hospital. But it is hard. With the addition of Ryan has come a new and even larger desire to stay out. Sleep is very little in our house, as we manage a newborn and Ben's cancer, but at least we are all together.

Even though Ben is feeling awful, his spirit remains the same. Today he insisted on picking out his own outfit. A McQueen shirt and purple Husky pants. Let's just say he won't be on Gymboree's catalog cover anytime soon. But we could not love him or his outfit more and are thankful that he continues to show such a fighting spirit.

THURSDAY, JANUARY 17, 2008

## *Earwax and the ER*

One of the more “fun” parts about having a child with cancer is how many times you get to go through the ER at Children’s Hospital. Anytime Ben spikes a fever we have to be admitted and lucky for us that usually happens after business hours. Obviously the ER is an amazing place. They save lives everyday. However, when you spend as much time in the hospital as we do, it can be highly frustrating and very often comical. It is like going through security at SeaTac airport just to get in the front door of your house. Ben gets physically examined numerous times by various interns, residents, nurses and doctors. All of whom must listen to his heart, look at his ears, push on his belly and more. And we get to answer questions like the following:

“Besides neuroblastoma is Ben in overall good health?” Yes. Besides having stage four cancer he is in excellent health.

(As he is puking) “Would you say that Ben has been experiencing nausea or vomiting?”

“Ben, on a scale from 1-10, could you rate your pain level?” Ah, no, he is 2.

“Do you have any concerns about your child’s health?” Yes. I am concerned that he will die.

But last night proved one of our most humorous ER moments so far.

Enter doctor #5...

Doctor #5: “So I have been told that Ben has a lot of earwax.” (yes, you read that right)

Me: Yes. He does. Sorry, tonight was supposed to be bath night, but obviously that is not going to happen. If you give me a q-tip, I would be happy to clean them out for you.

Doctor #5: Ohhh, no. We don’t recommend using q-tips, it could lead to infection. Would you like for me to order you a saline solution to use?

Me: No thank you. We would prefer you cure him of cancer, we can handle the ear wax.

But I digress...

Ben has a fever.

And apparently earwax.

Therefore we are back.

SUNDAY, JANUARY 20, 2008

## *A New Week - A New Phase*

We made it home with the help of Dr. Park and a class on how to give IV meds at home. It makes our med schedule a little more complicated, but since Ben's counts are still at zero and he has mucositis, he has to remain on IV antibiotics. It is amazing to think what we have learned to do in the past five months.

This week we begin the process of getting ready for Phase Two of Ben's treatment. First he will have all his scans and tests re-done. Ben will be sedated twice, have an eight hour kidney test, CT Scans, MIBG, bone marrow, EKG, a heart ultrasound, hearing test and more. It will be a tiring week for him - and us.

So here we go... Thankful for what is behind us. Scared for what lies ahead.

TUESDAY, JANUARY 22, 2008

## *Markings*

A bald head

A feeding tube

A scar on his neck where they inserted his Hickman line

A hole in his chest where two tubes now reside

A scar across his abdomen where they removed the tumor

Three holes on his back where they have extracted bone marrow

And now, hearing aides.

After Ben's hearing test today we were extremely saddened to learn that Ben has suffered "moderate" hearing loss from the chemotherapy. Following his stem cell transplant they will test him again – expecting more loss from the high dose chemo he will receive. Then he will be fitted for hearing aides.

Another mark. Another sign of just how cruel this cancer is.

TUESDAY, JANUARY 29, 2008

## *The State of Ben's Cancer*

While GWB was addressing the nation last night we were meeting with Dr. Park and Dr. Fong to receive the results of Ben's scans and tests from last week and to discuss his upcoming transplant. We received very good news! Ben's body has responded very well to treatment and he is exactly where they would want him to be at the completion of Phase One. We were obviously overjoyed and relieved to hear that.

Phase One is officially done! We hold the good news of the results in tension with what lies ahead. The remainder of the meeting was spent discussing the details of Phase Two. This will be the most difficult period of Ben's treatment. The risks are high. Yet ultimately, it will be what saves Ben's life.

We will spend the next two weeks in various appointments as we prepare for Phase Two. Ben's stem cell transplant will be overseen by Fred Hutch, so the transfer of care now begins (though it will take place at SCH). We have a tentative start date the week of February 11th.

So it is with grateful hearts that we awaken today. Grateful that Ben has done so well and grateful that last night was the last time George Bush will give a State of the Union.

THURSDAY, JANUARY 31, 2008

*Dear Friends of Ben,*

In the midst of the challenges of Ben's journey through Phase One there have also been moments of encouragement. Children's Hospital informed us last week that donations to the Ben Towne Pediatric Cancer Research Fund exceed \$100,000. They told us that this kind of response is very unusual. With matching monies, the total amount exceeds \$300,000. This immediate resource will give oncology physicians the capacity to fund promising research without normal bureaucracy or politics. And with research comes hope for more successful treatments.

We are overwhelmed by your generosity. Thank you.

Judy & Ward Bushnell

Peggy & Bob Wilkerson

FRIDAY, FEBRUARY 08, 2008

## *Transplant*

It has been a long and busy week for us - lots of appointments getting ready for Ben's stem cell transplant. It is hard to believe that this part of the treatment is before us. When we began this journey back in August it seemed so far away. And yet here we are. Though we have been through a lot to get here - this is different. And it feels different. There is a new level of fear and anxiety - as the risks are much higher.

We will check in on Tuesday to Children's for 4-6 weeks. Ben will have four days of the highest dosage of chemo they can give him without causing organ failure. The higher dose of chemo is necessary to target the "smart" neuroblastoma cells - the cells that have gone undetected in the previous scans and tests. After the four days of chemo, he will have three days of rest. Then Ben will receive his stem cell transplant. These are his cells that were harvested back in September. They have been tested and frozen and now will be given back to him to regenerate his cell structure - which will have been depleted.

From the day of transplant it will take approximately three or more weeks to recover. During this time he will be very susceptible to infection and other complications. Fever, pain and mucositis are to be expected. In rare cases there can be organ failure and fatal complications.

We remain grateful that Ben has no idea what is about to happen to him. As I write this he dancing on the couch - feeling great, full of joy. Often times it is the good moments that are the hardest. Because in the good moments we are reminded just how much we have to lose.

So until Tuesday we will be home.

Thankful to be under the same roof.

~

Because of the severity of this part of his treatment we ask that you please refrain from visiting. Thank you for understanding.

MONDAY, FEBRUARY 11, 2008

## *Into the Ark*

Recently Ben received a very special gift. A beautiful wooden ark that was made by our sweet friend Sofie in her woodshop class at school. As I watched him playing with all the animals today I wondered what Noah felt like before they went into the ark. 40 days and 40 nights trapped on a boat. Would they survive? Could they weather the storm into which they were being sent? Would God indeed meet them at the end? What would it be like on the other side? I wonder this too.

Tonight is our last night home as a family for awhile. Tomorrow we check into Children's for 4-6 weeks. There really aren't words to describe the level of fear that is consuming our minds and hearts. As Jeff and I put him to bed tonight we prayed together. That any remaining cancerous cells would be eradicated, that Ben's organs would be protected and sustained, that his hearing would not suffer anymore loss and most of all that he would be healed.

This is our son. We wish with all our hearts that we could change places with him. He has endured so much already and been so brave. It is too much to ask of such a little person. But we must ask of him again. In the hopes of healing.

So here we go...

At least there won't be any animals.

FRIDAY, FEBRUARY 15, 2008

24

I was thinking last night that we should produce a series, “24 – Cancer.” Sure Kiefer Sutherland wouldn’t be in it. And the city of Los Angeles would probably not be in danger of obliteration for the 7th time, but we could make it similar and exciting. People going crazy, toxic materials, evil cancer cells. We are up all night anyways. Perhaps we could resurrect Tony Almeda! With the writer’s strike it could be a big hit. Not.

About an hour ago they finished hanging Ben’s last bag of chemo. It will be finished in 24 hours. I simultaneously offered up praise for what it has done to the cancer and anger for what it has done to Ben. It is a strange tension. Our friend Jason Lewis asked if he could take home Logan’s last bag and burn it. Apparently there is some kind of “danger” in burning hazardous materials. Whatever. I still may try to sneak it out and torch it in the parking lot. I pray that this last dose does its job and that we never ever see a bag of poison hooked up to our son again.

The first few days have been very difficult. Ben’s level of agitation and pain are at a level we have not ever experienced. It is so hard to watch them turn your happy go lucky child into someone screaming and writhing around. There have been several moments that have left us both in tears. We have been working with the doctors to make him as comfortable as possible. They upped all his medications in their frequency and that seems to have made a difference.

Following the completion of chemo tomorrow Ben will have three days of rest, then Tuesday will be his transplant.

In the meantime, we are grateful for our favorite nurses. Being surrounded by Shauna, Jana, Chelsea and more makes a huge difference. Maybe we could do back to back series: “24 – Cancer” and “Charlie’s Chemo Nurses”. I will ponder this.

SUNDAY, FEBRUARY 17, 2008

## *Naked Candy*

No, this isn't the series sequel to "The Girls Next Door" or a new trashy series on Fox. It was Ben yesterday. In the midst of feeling awful he decided that the only thing that would make him feel better was to be naked. So he sat naked on the bed for a few hours while eating jelly bellies – much to the amusement of all. It was a relieving and humorous part of our first week here. We are thankful and amazed that in the midst of so much suffering he can still make us laugh and bring us so much joy.

TUESDAY, FEBRUARY 19, 2008

## Day 0

Today is the day. The day we have been moving towards. The day that we pray in part will ultimately lead to Ben's healing.

At approximately 2:30pm his transplant will happen. At 2:30 his own cells will be flowing back into his body. Ready to restore his marrow. Ready to fill him with life.

We will pause. We will pray. For life. For mercy. For our son.

It was impossible to know back in September what this journey would be like. As I watched the technician at Fred Hutch walk away with Ben's blood I cried. And prayed. For life. For mercy. For our son. We knew as those cells were leaving his body that they would be part of our hope. That they would come back to us in a different time and place. Since then there have been six rounds of chemo, the birth of Ryan, Ben's surgery and more. It has been a long road to get to today.

And here they are - again. But different. We are all different. We have been changed. We know what it is to live in fear. We know what it is to hold Ben close and weep at the thought of losing him. We know that even on the other side of this he will still be at risk.

And so we pray yet again. For life. For mercy. For our son.

Please pray with us.

WEDNESDAY, FEBRUARY 20, 2008

## Day 1

At 2:45pm yesterday Ben received his stem cells. The entire process only took about thirty minutes. A technician from Fred Hutch brought them in a "Back the the Future" like cooler - equipped with smoke and other special effects. After they were unfrozen, Shauna hung them up and we watched them flow into Ben. As soon as the cells began to enter his body he immediately started throwing up. (the preservative used to freeze the blood causes that reaction.) He was heavily pre-medicated so luckily he fell asleep following.

At one point Shauna said, "Ben just saved his own life." And it's true: the recent high dose chemo destroyed all of his bone marrow and from here his own stem cells will rescue his little body. The staff here will watch his organ functions very closely and manage the chemo side effects such as mucositis, nausea and fevers while guarding for infection. The next 10 - 14 days are the most critical until Ben's counts begin to turn. But every day from here on out is "positive" (day 1, day 2) signifying new life for Ben.

Thank you for your prayers and messages. There are no words for our gratitude.

SATURDAY, FEBRUARY 23, 2008

## *McQueen Jammies*

If it were not for the McQueen jammies and the cars clenched in each hand I would not recognize Ben. He is so sick. He has had a fever for almost a week now. Last night it topped off at 104. He is swollen, drugged and on oxygen. He wakes up here and there to cry and attempt to get up. But it is short lived.

The good news is that sadly, this is "normal". The doctors are pleased with how his organs are doing thus far. They expect the worst of this to last about another week - then hopefully we will begin to turn the corner.

We pray that as hard as this chemo has been on Ben that it will be harder on the cancer. That is the only thing that gives me comfort right now.

WEDNESDAY, FEBRUARY 27, 2008

## *An ANC Party!*

We were thrilled to hear today that Ben has an ANC! For those of you who aren't cancer savvy (like I was six months ago) that means his counts are on the rise. Ben has spent the past three days throwing up blood, tissue, mucus and more. It has been wretching - literally. With the rise of the white blood cells his body can begin to heal itself and bring him some relief.

It will still be another few days until he is "engrafted", meaning his new marrow is present and working. So we are not out of the woods yet, but this is a sign of life and a sign that we are moving in the right direction. Ben sensing our excitement said, "We're having a party!" That is right.

Thank you for your prayers as we continue to climb out of this pit.

~

For those interested, we are going to be part of the Children's Radio Telethon tomorrow morning. 106.1FM is hosting it on air. I will get the chance to share a brief bit about Ben's journey in the 8am hour.

SATURDAY, MARCH 01, 2008

## *Engrafted*

Today is Day 11. And we are happy to report that Ben's marrow has engrafted! It is new and restored. We hope and pray with NO CANCER!! We will probably be here about another 10-14 days as Ben continues to recover.

Since his counts began to rise so have his spirits. Last night he was up and walking for the first time and we even got some laughs out of him. Today he is playing cars, smiling and ordering us around - much more like our boy. His mouth and throat are still full of sores, so talking is minimum, but hopefully this week will bring much improvement to the mucositis.

We continue to pray for his organs, specifically his liver, as it is still at risk. But as the days go forward, the chances of damage decrease. Thank you for your continued thoughts and prayers.

From Room 68...A very happy weekend to you all.

TUESDAY, MARCH 04, 2008

## *Three Weeks*

We have been here now for three weeks. In some ways it has gone quickly, at other times it feels like we are living out the movie "Groundhog's Day". Ben continues to get better and better each day. We have been amazed by his resilience and strength. Yesterday when the doctor asked him what was in his tummy he said, "A starfish." When she asked him what a starfish says he replied, "He likes bubbles." (If you have seen the movie Nemo 50x you will get the reference.) He never ceases to make us laugh.

This week will be spent slowly weaning Ben off all the medicines that he is on and trying to get his stomach going again. The hope would be that by early next week he will be well enough to go home. Until then we will be busy managing a two year old on a pole.

We are ready to be home as a family. We miss Ryan. People keep saying things like, "You should go to Disneyland when this is over!" But all I want to do is be home, with both boys sleeping upstairs, watching American Idol. It's funny how the simple things seem so appealing now.

I pray each day that this suffering has not been for nothing. That it will bring healing. Complete healing. Now. In this lifetime.

MONDAY, MARCH 10, 2008

## *Our Rainbow*

When Noah and his family reached the other side of the flood safely God gave them a rainbow. Our rainbow came tonight in the form of pink and yellow discharge papers. The doctors deemed Ben stable, safe and ready to go home. The remainder of his recovery can now happen in our house.

Ben is currently attached to two different pumps. One feeding tube through his nose and one through his hickman line. Along with that he is on a variety of medications given every two hours around the clock. There is no rest for the weary.

But we are home.

It is almost impossible to believe that we have made it safely to the other side of transplant. This part of Ben's treatment has loomed ahead of us for six months. And now, it is over. There were moments in the past month that we didn't think we would emerge. They were so dark and so painful. Ben has endured the unimaginable. He has fought his way back once again from the depths. And for that we are overwhelmed with pride and immense gratitude.

To our families, to Shauna, to our doctors and nurses - thank you for your amazing care of us and Ben. To you all - thank you for your encouragement and prayers. On behalf of Ryan thank you to our parents, Aunt Kim, Aunt Kristen, Heather, Steph, Devon and Kari for your loving care. And to Ben... as far down as you were forced to travel does not even come close to how deeply we love you.

Up next: Radiation.

Until then....

From home,

Carin, Jeff, Ben and Ryan

SUNDAY, MARCH 16, 2008 02:08

## Rehab

Rehab is all the rage these days. It seems everyone is going. I picture these places like resorts - full of spas, gourmet chefs, and of course "therapy". What I don't picture is a two year old's bedroom. Because of the fact that Ben was on so many narcotics during and post-transplant, it has been difficult to wean his little body from them. It is sort of a mathematical equation of dosages, times and guessing. And it hasn't been going very well. While it manifests itself in celebrities with more popularity and paparazzi, in Ben it has meant waking up every :20-:30 minutes all night long, night sweats and a general heightened level of agitation and anxiety.

During the day he seems to be feeling a little better. His stomach is starting to tolerate a little formula, he is taking small sips of juice and water and he is happy to be in our house playing with his toys. Yet for as many good moments as we have, there are equally hard ones. And while Ben is getting stronger, he is still definitely recovering. We are in talks with the oncology doctors on how to make him (and us) more comfortable and hopeful that this upcoming week brings much progress.

I can see why celebrities check into said facilities for "exhaustion". Traveling the world, staying in swanky hotels, partying with your friends and getting to do exciting work... Now THAT sounds exhausting.

FRIDAY, MARCH 21, 2008

## *Good Friday*

Our Good Friday sucked. Ben woke up with a 104 fever. After spending the day in the outpatient clinic they sent us home to await the results of his blood work. Tonight they called us to say that it turned up positive for a bacterial infection and that we needed to come back. So once again we are checking in. Night #90. They expect us to be there a few days.

We never catch a break. It is just one thing after the next.

WEDNESDAY, MARCH 26, 2008

## Children's 4538

We were discharged this morning. Ben's infection is under control, but we will continue IV antibiotics from home for the next two weeks. So we now have three pumps: IV meds, IV food/fluids and our good old NG (normal feeds) tube pump.

For those who are protesting the expansion of the hospital – please know that if and when you try to take your child there and can't get admitted because there aren't enough beds, you are more than welcome to come up the street to our house. We can now administer IV drugs, IV feeds, fluids and more. We also specialize in pediatric narcotics. The only thing we can't do is surgery. Perhaps we will learn that in Phase Three.

Radiation pre-appointments start tomorrow at the UW. Ben will be sedated in the morning in order for them to make his body mold, appropriate scans and set up. Congrats to our friend Logan who is finishing up this week!

SUNDAY, MARCH 30, 2008

## Radiation

Ben starts radiation tomorrow morning. It will take place daily at the UW Medical Center for the next two and a half weeks. Ben will be sedated for each session – as there is no way to keep a two year old still and without anxiety. In preparation they have tattooed five markers on his chest and abdomen. More marks.

We are grateful to be under the care of Dr. Jay Douglas, who is not only is a wonderful doctor, but a friend and member of UPC. His comforting presence has been very reassuring to us.

We ask again for your prayers. For safety, for protection and for the complete eradication of any last remaining cancerous cells. Thank you.

WEDNESDAY, APRIL 02, 2008

## *The Hardest Role*

I have been privileged to play a variety of roles in my small acting career. But never have I played a more challenging one than “cancer mom”. To put on a smiling face when you are terrified. To sing songs and tell stories when your eyes are burning with tears that need to be released. To play games and do stickers when all you want to do is curl up on the floor in a fetal position.

Ben does not like to be sedated. He is smart. He has figured out when and how it happens. As the anesthesiologist began to infuse him today with sedative, he was screaming, “No white medicine! Don’t want it!” He hysterically cried, “Mommy lay down with me?” What is a cancer mom supposed to do? So I lied and said with a big smile, “Yep, I will be right here with you.” And then he was out. And we were escorted from the room. In there my son would lay. Alone. Without me. Without anyone – as no one can be in the radiation room.

As they closed the lead doors behind us I cried. I cried knowing that my comfort can only go so far. I cried because the accumulative days of suffering are so immense. I cried because in the end, I am only playing a supporting role. And my two year old son is the principle player.

MONDAY, APRIL 07, 2008

## *Endangered Purple Future*

Ben has completed the first half of radiation. We have six more sessions to go. Although the actual radiation process is painless and fairly quick, as previously posted, because of the sedation Ben has a lot of anxiety. He wakes up in the morning and immediately cries, "No go to UW Hospital. I don't like UW Hospital." As Huskies, it is troublesome to hear "I don't like" and "UW" in the same sentence. We hope this doesn't affect his choice of schooling or persuade him to go out of state. Perhaps this would have been another appropriate time to lie and call it University of Oregon Hospital.

He does however continue to insist on having only purple popsicles. So perhaps there is hope.

FRIDAY, APRIL 11, 2008

## *Hair*

We thought you might like an update on the Towne Family hair status:

Ryan: Currently sporting a brownish/auburn mullet with a slight comb over on top.

Jeff: Overgrown with a touch of grey in the sideburns.

Carin: After a manic plucking session there are no random greys anymore, just a burning scalp.  
and...

Ben: it is starting to grow.

TUESDAY, APRIL 15, 2008

## Radiation

Ben completed radiation this morning. 12 sessions. 12 sedations. 12 (or a few more) new cars. This officially brings us to the end of Phase Two in Ben's treatment.

We would like to say a huge thank you to Dr. Jay Douglas, Tana and the team of anesthesiologists from Children's. Your care for Ben and for us has been extraordinary.

Next up: scans, testing and Phase Three.

SUNDAY, APRIL 20, 2008

## *Once Again*

Once again Ben's scans and tests are before us. It will be a long, tiring and anxiety filled week. Based on these results, our course of treatment for Phase Three will be determined.

So once again we are asking for your prayers. For hope, for protection, for peace, for remission.

MONDAY, APRIL 28, 2008

*"There are no words. No words to describe the place  
we have found ourselves in-"*

*Monday, August 20, 2007*

Eight months later those words seem hauntingly familiar. Today we received devastating news. Ben's bone marrow still contains cancerous cells. It was as if we were back in August, being diagnosed all over again. In one phone call we were gutted. Again. Only this time it is different. Our strength is gone. Our endurance diminished. Our faith weakened. Our knowledge greater. Our options limited.

Tomorrow we will meet with our oncology team to discuss what lies ahead. Ben will undergo an intensive and experimental treatment for the next six months. It is our only hope. That, and a miracle.

FRIDAY, MAY 02, 2008

## Getting Up

There is nothing extraordinary or superhuman about what Jeff and I are doing. People say things to us all the time like, "I don't know how you are doing this." Here is the enlightened answer: We have no choice. We are doing what any other parent in our same situation would do. The only thing we can choose is to get up each day. We get up (assuming we have actually been to bed). And we care for Ben to the best of our abilities.

We met with Dr. Park on Tuesday and she was able to offer us some hope. There have been a small number of kids in Ben's same situation who have responded well to this experimental therapy. They are not promising us a cure, but there is a chance. Most families in our situation must travel to New York to receive this protocol. We are fortunate that Ben will be able to get it here - with our doctors, with our nurses, with our family around us. He will endure six months of treatment starting on the 12th. It will once again push him beyond what should ever be asked of someone so small. The main side effect will be extreme pain. Followed by nausea, vomiting, fevers, rash, hives low blood pressure and more. It will not be easy.

But we will get up. Because in the end, that is all we can do.

FRIDAY, MAY 09, 2008

## *Freedom*

For the first time in nine months – we had a break. With no appointments and Ben feeling well, we headed to our family cabin in Poulsbo for a much needed change of scenery. It is a strange thing to have not left the geographical location of our neighborhood since last year. As we drove out of our driveway Jeff and I looked at each other and said, “Are we really doing this? Do we really get to leave?” It must be how prisoners feel when they are finally paroled.

We spent four days at the beach. Ben had a so much fun. For four days he got to be just a boy – throwing rocks, looking for crabs, playing baseball and more. It was the first time since diagnosis that we have seen him without anxiety. If it were not for his feeding tube and backpack you never would have known he still has cancer. While we could not forget about cancer, for a moment it seemed cancer forgot about us. We got to be free.

As we sat through Ben’s pre-admit appointments today, our time at the beach seemed to fade to memory. Today was the first of fourteen days of shots. Sunday he will have a transfusion. Monday morning we check in and the new treatment begins. Anxiety, fear, and sadness - all the opposites of freedom, have returned. We pray that in six months, one year, two years, three years, four years, five years and more that we will know freedom again. When Ben will once again be just a boy.

MONDAY, MAY 12, 2008

## *Monday*

We are checking in this morning. The first antibody infusion is expected to start around 11am. It will go for 6-8 hours. This will be repeated daily through Thursday. Intense pain, nausea, rash, fevers and low blood pressure are expected.

Please pray that Ben would be protected.

And the cancer cells would not.

WEDNESDAY, MAY 14, 2008

## *Two Boys and a Curtain*

We are currently in the midst of Ben's third antibody infusion. Suffice to say, this has been one of our most difficult stays. The pain and agitation were so intense yesterday that we had to put seizure pads on Ben's bed in order for him not to hurt himself. They are infusing him with man made cells that are half human/half mice. These cells have been trained to essentially play PacMan in his body, seeking and destroying neuroblastoma cells. The pain comes from the fact that nerve cells have a similar protein on the surface. So his nerves are being attacked as well.

We are sharing a room with the Lewis family. It has been very comforting to us to be with them – as they understand and have been very gracious about having Ben as a screaming roommate. Logan is on round two of the antibodies. He has had 104 temp for the past two days. Last night on one side of the curtain I watched the nurses drape cold washcloths on him to try to bring him some relief. On the other side, Ben writhed around his bed screaming. It was a very surreal experience. Here are two boys, fighting the same disease, three weeks apart in diagnosis. As we all felt helpless to make either of them feel better we talked about how initially both families were told their child could have leukemia. Knowing what we know now, that would have sadly been good news.

Once again we are grateful to Shauna, Amber and Amy. For walking with us through yet another frightening time. We have one more infusion tomorrow and then they expect us to discharge on Friday for continuing recovery at home.

FRIDAY, MAY 16, 2008

## Friday

We are home. Ben has recovered well from the first round of infusions. He is back to himself and playing cars. While we are grateful to be all under the same roof again, our hearts are heavy leaving the Lewis family. Please pray for them today.

WEDNESDAY, MAY 21, 2008

## *To Battle*

I have been thinking a lot about what it means to “battle” or to “fight” cancer. The terminology used most commonly to describe the journey of cancer is difficult for me. Everyone (including myself) uses the words, “he is fighting cancer” or “she lost her battle with cancer.” What is hard about those terms is that it innately says that someone has control over the outcome of their illness. After walking with our best friends, the Wises, through Ron’s cancer, I started to resent those kinds of statements. Ron was one of the strongest, most joyful people I have ever had the privilege of knowing. No one could have fought harder or endured more. And yet ultimately it took him from us. It was out of his control.

I wish Ben’s cancer was in his control. I wish based on tenacity, determination, stubbornness and iron-will you could win. Because Ben would – hands down. A radiology nurse told us that it takes twice as much sedative to put Ben under than most kids his age. He will not just lay down and go to sleep. He fights everything. Jeff always says, “He comes out swinging.” And while we are proud of his never ending strength – because it allows us to continue treatment - it makes our days as his parents long and hard. For even though we are home, there is always something we are doing. You often hear the phrase, “pick your battles” with your kids. One of the hardest things about having a child with cancer is that we have no choice but to battle his will. Daily. The medications and daily maintenance are endless.

Yesterday we started a new drug which aims to - alongside the antibodies - work to rid Ben’s body of all MRD (minimal residual disease). The hope is that this new protocol, along with this medication, will in the end prove to be the combination that neuroblastoma can’t beat. He will be on this medication for two weeks a month through October. Administering it is proving to be a difficult challenge. It must be taken twice a day, orally. And it does not come in liquid form nor chewable tablets. After two hours last night of “choices” and “examples” – it ended with us pinning him down and gagging it down him. Swear words were dropped, tears were shed. This morning’s dose ended in Ben puking. It is so discouraging.

I am at a loss to come up with better terminology. Because it is a fight. It is a battle. One that we have been in for over nine months. Maybe by the end of this I will have found a phrase or description that sits with me better. In the meantime, the “battle” goes on. Many thanks to Aunt Kristen, Karen, Sonya, Teryn, Carla, Ashley, Maureen, Kelsey, Jenn, Katie, Carrie, Marcy, Betsy, Mollie and the Wilson family for recently putting together “Ben’s Treasure Chest” – full of “rewards” for continuing to ask a boy so small over and over to do things that he should not have to do. Each time he opens something and we see his smile – we win. At least momentarily.

WEDNESDAY, MAY 28, 2008

## *Candy Land*

As of late, Ben and I have been attempting to play Candy Land. It is a very frustrating experience for someone like me, who likes to abide by the rules, to play with a two year old who only wants to draw double purples. He will continue to draw and draw until he gets one and then exclaims enthusiastically, "two purples!" Then he proceeds to move his marker to wherever on the board he wants to. Even backwards.

Cancer Land feels a bit like this board game. Jeff and I have been playing by the rules, moving day by day, treatment by treatment, through the maze of neuroblastoma. The news last month - that after all we have been through cancer still remains in Ben's bone marrow - was like rounding the Chocolate Swamp Corner, being one draw away from the Candy Castle and unexpectedly picking the Gingerbread Man. It was as if we were sent back to the beginning in some ways. To start over. To learn a new course of treatment and new medications.

So far this treatment is very different than chemotherapy. With chemo, Ben was sick for about three weeks a month. With this new protocol, our first week of treatment was beyond hellacious, but Ben bounced back within a few days. The pills are still difficult. But other than the dosing of the medications, and some dry skin side effects (I am thinking about taking him to the Clinique counter - just to see what they would do) Ben is feeling well right now. And that is allowing us to live day to day instead of moment to moment. Next week we begin preparations for the second round of infusions. In the meantime, we get up, draw our cards and proceed. Reds, oranges, yellows, greens, lots of purples, and at times blues. Hopeful, that in the end we will still make it to the Candy Castle.

WEDNESDAY, JUNE 04, 2008

## *Boxing Cancer*

I have never understood boxing. I can't even believe it is a "sport". Punching someone in the face intentionally? For pay? Wearing flashy gross shorts, having no teeth and being awarded some superman looking belt? No compendo. I did, however, love "Million Dollar Baby". Morgan Freeman always gets me.

The premise of this current phase of treatment is to hit the remaining cancer with a variety of punches. Because neuroblastoma becomes resistant to chemotherapy in many cases, including Ben's, this phase has been constructed so that everyday something is being administered. Punches are being thrown in sequence - a left jab, followed by a straight right, followed by a left hook. A variety of forms, a variety of meds - all hoping little by little, punch by punch, to knock out the remaining cancer cells.

On Monday we finished the first two weeks of pills. A huge accomplishment. This week Ben has been hooked up to a new drug that is being infused through his Hickman line 24 hours a day for five days. We go in daily to have the bag of medicine changed out. So far he isn't feeling super great. Next week we will admit Monday morning to start the second round of antibodies. Left, right, left-right...

Oh how I continue to wish this was somehow in our control. Because despite my feelings toward boxing, and violence itself, if I were given the chance to go one on one against cancer in a ring, I would not hesitate. I would take the rage of fear that runs through my body and do whatever it took to kill it. Below the belt, to the head, from behind. We pray these drugs in combination will do the same.

SUNDAY, JUNE 08, 2008

## *Tonight*

Both our boys are asleep upstairs. For a moment, it is quiet. I don't know who will wake up first. But someone will, momentarily. Until then, this to me is peace - having both our boys asleep in the same place.

Tomorrow night will be a different story. Ryan will be here. Ben will be at the hospital. Tomorrow our hearts will be torn between two places. The joys of today will be a distant memory. The suffering will be immense.

But tonight, we are together.

WEDNESDAY, JUNE 11, 2008

## *Course Two Update*

Ben is sleeping next to me right now. And though he looks peaceful, there is anything but “peace” in his body. We are three days into the second round of antibodies. So far, everything has gone as expected: pain, low blood pressure, swelling, and high fever. They expect the fever to stay until Friday when the infusions are done.

We are thankful to be surrounded by the Lewis family, reassuring doctors, and our favorite nurses. Hopeful that the next few days will pass quickly, that the antibodies are doing their job. Praying that this suffering will not be in vain.

It looks like we will discharge on Saturday.

WEDNESDAY, JUNE 11, 2008

*Edited*

Well, we spoke too soon. There has been damage to Ben's liver due to one of the drugs he is receiving in tandem with the antibodies. This was not expected. So they turned it off early. They will continue to monitor his liver and hope to see improvement in the next few days. The antibody infusions will continue through tomorrow. Because this is an experimental treatment, they have no way of knowing how removing this drug will change the overall effectiveness. So obviously we are concerned.

I am so tired of being afraid. Fear sucks.

FRIDAY, JUNE 13, 2008

## *Our Livers*

Thank you for your prayers. Needless to say, it was a tough week. We came home today. Round Two of the antibodies is now behind us. Ben is feeling fairly well now that it is over, just some residual stomach pain and general weariness. Hopefully he will be feeling better by the end of the weekend. Monday we start two weeks of pills again.

His liver is showing improvement and they expect it to continue to heal. The doctors believe they stopped the IL2 before it caused permanent damage. We will take him in Monday for testing again and a meeting with Dr. Park. They will continue to monitor him/it and make a decision before the fourth course as to whether he will receive a reduced dosage of the IL2, or none at all. TBD.

In the meantime, the livers of his parents will probably take a hit tonight.

~

Many thanks to Shauna, Amy and Amber for their excellent care. And to our parents, Aunt Kristen, Devon and Kari for caring for Ryan this week. We are grateful.

SUNDAY, JUNE 15, 2008

## Jeff

Ever since Ben was born, he has been a “Daddy’s Boy.” I think I took him into Dr. Ken’s office monthly that first fall always thinking he had an ear infection because he was so irritable. It wasn’t until a few months had passed that I started to see a pattern: When Jeff left town, Ben was super cranky. Many times throughout his first year I would call Jeff crying at work, claim how difficult Ben was being, only to have Jeff walk in the door and Ben be all smiles. These days it is more like a running monologue... “Dad, you play cars with me? Dad you play baseball with me? Dad, you lay down with me? Dad, we ride around the block in the El Camino?” There is no one Ben loves more than his Dad.

Every father says they would lay down their life for their child. And luckily for them, that is never really put to the test. Since August though, that is exactly what Jeff has done. He has laid down his life, his job, his personal time, everything. For Ben. For us. Of the 100+ nights we have spent at Children’s Hospital, Jeff has been there for every single one of them. When I got too pregnant and uncomfortable to sleep in a hospital bed it was Jeff who forced me to go home – assuring me that he would be with him. He has been at every appointment, every meeting, every procedure, every conference, in every moment. His strength and comfort have been the rock for us all.

I cannot express my appreciation to Jeff without also finally taking the time to publicly thank our church – University Presbyterian Church. To Earl, Tim, Dave, the Pastoral Staff, the Session, the incredible staff at YMM and our congregation – there are no words for my depth of gratitude. The freedom and compassion you have shown our family is beyond measure. Because of your love and graciousness you are allowing us to walk this journey the only way we know how – as a family.

Prior to cancer I would have said Jeff was an “amazing” Dad. Yet words now do not even encompass the profound love and care he has shown. I realize that many of you are following our story because of your own admiration and respect for Jeff. For those of you who know him, nothing I have written is of any surprise to you. But at the end of the day, I am the only one who truly knows the height, the depth and the intense breadth of his devotion and sacrifice. For I have witnessed him and been with him in this terrifying valley. And so, on this Father’s Day, June 15, 2008, I offer up my thanksgiving. For the man and father that Jeff is. Praying and pleading that on this holiday, for the rest of our lives, we will give thanks for two healthy boys.

Happy Father’s Day Jeff.

Whatever “happy” means.

WEDNESDAY, JUNE 18, 2008

## *Another Week*

It is another week in Cancerland. This last round of infusions has been harder to recover from than the first one. Ben is still having residual pain, a little nausea and overall tiredness. Our doctors have commented many times that if adults were going through the treatment for neuroblastoma they would probably die (literally) or if they made it through the various treatments they would crawl into bed for days and days. Yet kids are totally different. Ben wants to play. He wants to feel well. And then becomes easily frustrated. You can watch it happen. We play, we get upset, we rest, repeat 10x daily. We are hoping the second half of the week brings improvement.

Our meeting with Dr. Park on Monday was encouraging. Ben's liver is recovering well – a Towne influence I think. ;) There will be no decisions made about the IL2 drug until we get closer to Course Four.

FRIDAY, JUNE 27, 2008

## Friday

Overall it has been a good week for Ben, minus needing his NG tube replaced after it sprung a leak. He is back to himself and feeling well.

We have had some recent care milestones that we are happy to share: Ben is finally off TPN (the IV feeds/fluids at night), he is off all narcotics (until our next stay) and after months and months of a liquid only diet - he is finally starting to eat again. Since transplant he could not stomach real food and had little, if no, interest in it. He still requires 18 hours of formula a day through his NG tube, but to hear him asking for things to eat again is very encouraging. So far his diet consists of smoked turkey, ham, hotdogs, chicken nuggets, salami, green beans, pear, strawberries, apple juice and a few crackers. Minus a little fruit, Dr. Atkins would be proud. He is only eating bites, but bites are huge to us.

We are grateful that we will have most of this next week away from the hospital and appointments. For the second time this year – we are getting out of town! We are heading again over to the family beach cabin in Poulsbo. We are looking forward to seeing Ben without anxiety, roaming the beach, playing baseball and throwing rocks in the water.

Happy 4th of July!

\*We admit for Course Three on the 7<sup>th</sup>

SUNDAY, JULY 06, 2008

### *Course Three*

This past week was perhaps the best week we have had in the entire last year. Ben was so joyful, full of laughter and life. We played on the beach, threw rocks in the Sound, looked for crabs, practiced golf, played in cars, danced, sang, participated in our 4th of July parade, experienced Ben's first fireworks and more. It was very surreal for me, since Ben and I had been over at our cabin for two weeks prior to his diagnosis last summer. It was as if time had warped somehow – like this past year had been a dream.

Sadly today we woke up to reality. Two weeks of shots have begun. We check in tomorrow at 7:30am. Course Three of the antibodies will be infused over the next four days. The tension of such impending suffering after such a wonderful week is difficult to wrap our minds and hearts around.

Once again we pray. Prayers of beggars. Begging that this treatment is working. Pleading that Ben would be protected. Dreaming of healthy days ahead at the beach.

~

Many thanks to the extended Bushnell Family. For your smiles, laughs, encouragement and of course, your cars. ;)

TUESDAY, JULY 08, 2008

10/20

Tonight we completed the 10th of the 20 antibody infusions Ben will receive. Suffice to say, the past two days have been two of the most difficult we have faced yet in this journey. The combination of extreme pain and agitation has made caring for Ben exceedingly difficult. Following such a fun and beautiful week the past 48 hours seem cruel and unjust.

After Ben finally passed out last night I laid next to him pleading over and over, "Lord do not let this suffering be in vain, Lord do not let this suffering be in vain."

We continue to beg. For mercy. For complete healing.

FRIDAY, JULY 11, 2008

*Sigh...*

Ben was discharged this morning. Our third round of the antibodies is now complete. Shots and pills will continue from home. We anticipate Ben to be recovered by the beginning of next week.

Thank you for your prayers.

THURSDAY, JULY 17, 2008

July 17th, 2008

It was three years ago today that Ben was born. Three weeks early and a total surprise. It was the day after Aunt Heather and Uncle Steven's wedding. I was going about my normal Sunday morning routine (pre-kids) – walking, reading the NYT and then grocery shopping. While pushing my cart through the QFC parking lot my water broke. It was like a scene out of a movie. Knowing what we know now about Ben's car obsession, it makes perfect sense.

At 2:34pm he arrived. Taking us by storm. Changing us forever. Opening our hearts wider than we ever thought possible. Since then, it has been a wild ride full of extremities. The highest of highs and the lowest of lows. And it has only been three years.

Happy Birthday to our sweet beloved Ben. We give thanks for you today. For your life, your joy, your love.

~

Ben is recovering well. The end of next week he has scans. More on that to follow...

THURSDAY, JULY 24, 2008

## *Distraction*

We have had a week of joyous distraction. Visits from Cousin Jules and the Tritz Family. An extravagant Birthday celebration surrounded by our family and loved ones. A trip to the beach.

We have done our best to stay upbeat and thankful. But tonight we can no longer be distracted. It is actually hard to breathe. Ben's scans are tomorrow.

Please join us in prayer.

For clear scans.

For no detectable cancer.

For hope.

~

Our full results won't be back until Wednesday or Thursday.

WEDNESDAY, JULY 30, 2008

## *Today*

Today we find ourselves where we need to be for the first time in almost a year. Ben's scans came back clear and his bone marrow biopsy negative.

What does this mean? It means that for a moment we can breathe. It means temporarily there is relief. It means that we can feel confident moving ahead in this phase of treatment. It means that today we can be cautiously hopeful.

What does this not mean? It does not mean that Ben is "cancer free." It does not mean that treatment is over. Rather, at this time there is no detectable cancer and treatment continues.

You all – our family, friends and strangers – have journeyed with us for a long time. You have been faithful to pray for us. You have been unwavering in your support. We acknowledge that there is a collective need to celebrate this news. And for that we are grateful. Please do. We are tonight. We ask though, that you also understand that this journey is not over for us. We have three long months of treatment ahead. We need Ben's scans and marrow to come back clear and negative in 3 months, 6 months, 12 months, 18 months, 24 months and into the future. The relapse rate in kids with neuroblastoma is extremely disheartening.

BUT, today we are where we need to be. Finally. So tonight, we revel in this news. We will celebrate through the weekend. Then we will turn our eyes to the 4th round of antibodies - checking in on Monday.

SUNDAY, AUGUST 03, 2008

## *Course Four*

It has been a weekend of mixed emotions. Relief - for the news we have received. Grateful - for the gift of good friends. Concern - as Ben is not feeling very well.

Ben was hooked up to the IL-2 (the drug that harmed his liver last time) all last week. He has had moments of energy, but they have been coupled with nausea and weariness. Today he received blood transfusion number 35.

Tomorrow we check in for Course Four of the antibodies. They will continue the IL-2 this week at a lesser dosage, monitoring his liver carefully. If it shows any signs of trouble as before, they will discontinue it.

As always, we are frightened by the potential risks involved in this treatment. But after last week, somewhat comforted that it seems to be working. We pray that if there are any remaining undetected cancer cells, that these last two difficult courses would eradicate them.

As you have been faithful to do, we ask once again that you would please pray for us – for Ben. Thank you.

FRIDAY, AUGUST 08, 2008

## Reminded

I have been re-reminded of a few things this week.

- This protocol is hellacious.
- Ben could not be stronger or braver.
- The nurses on the SCCA are beyond exceptional.
- We are lucky to have such supportive sustaining families.
- No one should have to share their personal hell with strangers.
- Skinny jeans do not look good on anyone, even if you are indeed skinny.
- The joy of walking out of the hospital and returning home will never get old.

THURSDAY, AUGUST 14, 2008

## *A Year*

A year.

It was a year ago tonight we heard the word “cancer” in relationship to Ben for the first time. We were told that Ben had one of two types of cancer – leukemia or neuroblastoma - though it would be a few more days before we had an official and exact diagnosis. As he lay sleeping across my chest I remember vividly looking at the doctors with rage and terror coursing through my veins. All I wanted to do was take our son and go home. But at about 10pm in a daze we were admitted to the SCCA floor. And there began our journey.

There are still days I wake up thinking this must be a dream. This can't be happening to us. To Ben. How is it possible? He was such a healthy and active little boy. But most days I can't remember what it was like before this. What did it feel like to not be afraid? What did it feel like to have freedom? To not feel this desperate - needing hope like you need water.

To say “we have been changed” or “we will never be the same” seems trite. We have been changed. And we will never be the same. How exactly that manifests itself I don't know. But it is vast, gutting, and raw. And it isn't even over. I wonder where we will be a year from now. What will it feel like? Will we be doing “normal” things? Will Ben get to be just a boy? Or will there be new levels of terror? New treatments? More hospital time? It is impossible to say. Because of the nature of this type of cancer, we only know what is in store today.

So today we look back - and we look forward. We look back on all that Ben has endured; chemo, surgery, stem cell transplant, radiation, antibody therapy and more. We are amazed by his strength, proud of his courage, and reminded of those who have surrounded us and held us together. And we look forward. Hopeful for complete and total remission. Praying for days, months and years together.

It has been a year.

Thank you for being with us.

SUNDAY, AUGUST 17, 2008

## Perks

It has been 90+ degrees in our house this weekend - and like the majority of our fellow Seattleites, we have no air conditioning. If we were not in cancerland, we would be on the Lake – swimming, getting some relief. But as it is, Ben cannot go swimming and due to the current drugs he is on he isn't really supposed to be in the sun. So in our sweltering house we remained.

In an effort to make myself feel better I decided to focus on the perks of having a child with cancer. After all, PMA heals disease right?

Here are a few:

- Solicitors leave your house very quickly when you answer the door holding a bald headed child who has a feeding tube and is holding a puke bowl.
- You don't have to cook. When your child doesn't eat... no cooking!
- If you have good insurance you actually will save money. Since you can't go anywhere, or do anything, the slush fund for Crate and Barrel really adds up!
- People expect you to look like hell. So if you merely shower, put your yoga pants back on and add some lip gloss people think you are a super model. (okay, a "plus size REI model", but you look great in their minds nonetheless)
- You have the ultimate "get out of jail free" card. So what if you have missed all holidays, birthdays, weddings, parties, and everything else you have wanted to be at? When that one thing comes along that you have always dreaded, guess what? You can't go! "Sorry, Ben has cancer."
- You have a large kitchen cupboard full of narcotics. If at some point Ben is actually off all of them, they can be sold on the black market. \*see Crate and Barrel slush fund\*
- You don't need a calendar nor an alarm clock. You don't sleep and everyday is the same! It's like Groundhog's Day!!
- Fuel prices? What fuel prices? If you only drive down the street to Children's Hospital you use no gas! We fill up our gas tank twice a year!

Luckily for us, the clouds rolled in this afternoon. Cool summer weather – another perk! And Ben is finally feeling well again.

Oh what I wouldn't give though to take a trip to somewhere that has a lovely pool. Oh wait! Children's has a rehab pool. Second floor. Perfect. I wonder if they serve margaritas?

A happy weekend to all...

MONDAY, SEPTEMBER 01, 2008

## *Course Five*

Tomorrow we check in for Ben's fifth and final antibody treatment. It is with fear, fatigue and fierceness that we enter this week. Fear as always, for the potential and known side effects. Fatigue, as caring for Ben will be difficult. Fierceness – as this is our last week of this protocol. And so over the next five days this is our prayer: that every single potentially hidden neuroblastoma cell would not just be killed - but crushed, smashed, eradicated and destroyed. One remaining cell is too many.

~

Following this week, we will have two more months of oral drugs. So our treatment will continue.

SATURDAY, SEPTEMBER 06, 2008

## *Walking Out*

We walked out of the doors of Children's Hospital this morning the same way we came in 13 months ago: the three of us – together. Only time will tell if this will actually be our last stay there. When we came through these doors for the first time last August, we carried with us a very sick two year-old. We leave today with a three year old boy. So much has changed, and so has Ben. He has grown, he is taller, his hair has gone and come again, he now knows his ABC's, numbers, shapes and colors. He knows how to ride a tricycle. He knows how to play countless video games. All things learned during the hours, days, weeks and months spent on the SCCA floor.

As we walked down the hallway, it was just the three of us. And yet it felt as if we were being carried or followed in some spiritual way by all those who have cared for, loved and sustained us these hours and days. Names, faces, images, moments flowed through my mind like a strange and distant movie. When this is all over, I shall list them by name.

In the meantime, we have now completed the final antibody treatment. At 4:28pm yesterday the final infusion was finished. No matter what happens in the future we will never have to do this again. To say that we are relieved it is over is a gross understatement. Time and time again Ben's strength, determination and humor pushed us forward. We cannot express our gratitude enough to the nurses who have walked along side us during this part of Ben's cancer journey. To Shauna, Amber, Chelsea, and Amy – thank you. Thank you for caring for all of us. For your grace, wisdom, humor and compassion. Ben could not have been in better hands.

And now we walk on. One more week of shots, two more months of oral drugs, various check ups, followed by scans in late October. Walking towards the end of treatment. Still scared. But hopeful. Thankful to be walking at all.

WEDNESDAY, SEPTEMBER 10, 2008

## *School of Bulimia*

While most of my friends have been sending their kids back to school this week, we have enrolled in the School of Bulimia. Ben being three and very very tired of things being out of his control has decided he doesn't want to take his oral meds anymore. Now that his gag reflex is "well tuned" he is puking up his pills on purpose. Since these are gel capsules and cannot be crushed, nor is the consistency that which could go down his NG tube and because he isn't eating anything orally again, we have no option but to continue to redose him over and over until each of the four pills he takes daily are down. So while we feel relieved to be done with our hospital stays, the reality that we are still very much "in this" continues. As I watched the school buses drop off kids this morning who were headed to class, I headed upstairs to start yet another load of laundry. Sigh...

A huge thank you to our Whirlpool Cabrio Washing Machine. Your strength, consistency and inability to speak have been a huge support to us this past year.

THURSDAY, SEPTEMBER 18, 2008

## *Normal*

This past week has been filled with many normal things - a baseball game, a birthday party, playing with cousins, going to the park and even haircuts! Ryan's first and Ben's first all over cut since losing his hair last fall (see picture above). Without a looming hospital stay on the calendar I have even at times begun to let my guard down - feeling as if we have made it, that the worst is now behind us. But then small reminders bring me back to reality - pills, puke, feeding pumps going off during the night, scan dates scheduled, and more. Fear seems to be held at bay for longer periods, only to rush in and catch me off guard. But I guess if we make it to the other side of this that will be our "new normal".

In the meantime, we have a few days left of oral meds then we will get a little break before starting our last scheduled dosages. Ben is feeling well and fully recovered from the final antibody treatment. He is playing hard and enjoying his time away from the hospital - getting to do normal things.

Happy Weekends to all...

MONDAY, SEPTEMBER 29, 2008

## Wishes

Now that Ben is three, he qualifies for a Make-A-Wish. We have been compiling his top wishes. So far, here is the list:

- A tummy tuck
- A Nate Berkus home makeover
- Week stay at the Ritz Carlton on Maui
- Laser hair removal for legs
- Diamond Earrings
- Private Concert with Tim and Faith
- Weekend in Paris

Oh wait....sorry....those are mine. But I'm sure, knowing how selfless Ben is, that they would be his too. We'll keep you posted on what MAW says about our application. In the meantime, Ben is getting his real wish – to be at home. We do not have an appointment at Children's for another week even. This will be our longest time away from the hospital in 14 months. And for that we are thankful. We will begin our last two weeks of oral drugs on the 6th. Until then, we continue to work on continuing issues at home – eating and sleeping. Wishing for digested meals and sleep filled nights.

SUNDAY, OCTOBER 05, 2008

## *Not One Cell*

It is hard to believe we have arrived at the last scheduled stage of treatment for Ben. It has been 14+ months. And here we are. Two weeks of oral drugs start tomorrow. Four pills a day. On one hand there is a disbelief and general numbness that we have made it to this point. On the other, as always, fear that this will not be the end.

And so as we have so many times this past year, we ask that you please join us in prayer. In hope. That with each pill swallowed, with each dose of medication, with each frustrated three year old retching – that not one cancerous cell would remain.

May this be the end. The end of treatment. The end of torturing our son. The end of cancer. The beginning of Ben's future.

Thank you.

~

Ben's scans have been scheduled for the last week of October. More to follow...

MONDAY, OCTOBER 06, 2008

## *Associated Press Release:*

### CANCER MOM GOES CRAZY

At approximately 9:00am today a cancer mom was restrained at Seattle Children's Hospital. As she was being carried off in her trademark black yoga pants witnesses said she was crying, "Those will not fit down his throat – he is three – what the \*\*\*\*?" After speaking with the pharmacist it seems that the oral drugs the cancer mom was used to gagging her child with had been recalled due to some random FDA regulation and the replacement capsules were three times as large. When asked why a drug manufacturer could not make the said capsules in a form that would actually be reasonable to dose a child with – the pharmacist replied, "We stand by these regulations as 13 cis-retinoic acid had been proven to cause severe birth defects in pregnant teenagers."

The crazy cancer mom was released on bail. Drug administration is hopeful for tomorrow – pending the tears, pleading and insistence on finding the previous size capsules SOMEWHERE in the United States comes through. To be continued...

TUESDAY, OCTOBER 07, 2008

## *Update*

Thank you to everyone who compassionately provided options for us. Thankfully the Children's pharmacy came through today - locating a batch of the previous capsules somewhere. We picked them up this afternoon and dose 1 of 28 is already down.

We now return to our mantra prayer - not one cell.

MONDAY, OCTOBER 20, 2008

## *Completed*

Six rounds of chemotherapy – check.

Surgery to remove tumor – check.

Stem cell transplant – check.

Twelve sessions of radiation – check.

Twenty antibody infusions – check.

Six courses of oral meds – check.

Ben swallowed the last two pills this afternoon. We celebrate what we know tonight. That as of 4:04pm, Ben has completed all scheduled treatment.

Now we wait. Scans will be next Wednesday.

TUESDAY, OCTOBER 28, 2008

## *Scans*

Ben's scans are tomorrow. He will be sedated at approximately 12:45pm. We are hoping to have results by Friday afternoon, but most likely they will not be in until Monday.

Our hearts plead. For complete and total remission.

THURSDAY, OCTOBER 30, 2008

## *Thursday, October 30*

Scans yesterday revealed that the cancer in Ben has aggressively progressed since the end of July. There are four new tumors – three on his brain and one on his liver.

We will be starting full brain radiation tomorrow at UW Hospital. They will do this for two weeks – in the hopes of reducing the swelling in Ben's brain and slowing the cancer from metastasizing to his other organs. In two weeks they will scan him again and from there we will make some very difficult decisions.

We are lost and in complete despair. At this time we ask that you please respect our privacy. We will not be taking visitors. Thank you.

Jeff and Carin

MONDAY, NOVEMBER 03, 2008

## *Monday, November 3rd*

Once again, we are at a loss for words.

Yesterday evening, Ben was admitted into the Intensive Care Unit at Children's Hospital. A CT scan last night and another one this morning confirmed one of the tumors in his brain has continued to grow aggressively over the last few days and even through the hours of the night.

Because of the rapid growth, the doctors confirmed that further treatment would not be effective. The decision was made to stop the radiation treatments and return home. We are continuing to monitor his pain levels and are giving him medications to keep him comfortable. Many times last night Ben told Carin not to worry and that he loves her.

Ben is now resting with his mom and dad, and is surrounded by all of his family. At this point, there is no way to determine how much time we have left with Ben...but we know that it isn't long.

Please continue to respect the family's privacy and refrain from visiting. We appreciate your thoughts and prayers.

Shauna and Kristen

FRIDAY, NOVEMBER 07, 2008

## Friday

It has been four days since we brought Ben home. We had the bittersweet relief of telling him on Monday that he is all done. There are no more hospitals and he is safe in our house. This is where he wants to be. He is surrounded by his favorite comforts and our families. He knows that he is loved.

The experience feels as if we are completely outside of our bodies and simultaneously as if our hearts are physically shattering. The pain is acute and more raw than we have ever known. It is unfathomable. But this is what we want for him now. To be done. To be free. To suffer no more.

So we are waiting, watching, and comforting him the best we can. Despairing our lives on the other side of this, longing to keep him here, yet knowing that his hours and days with us are numbered.

Thank you to everyone who participated in the prayer service on Wednesday. We are grateful.

TUESDAY, NOVEMBER 11, 2008

## *Tuesday*

It has been over a week now since we have been home. The tumor was/is growing at such a rate that our team's best guess last week was that we had but a few days. But here we are. Thankful for each day and exhausted from 24 hour cycles of care. Ben is proving yet again that his strength is beyond comprehension. He is willing himself to be here. Though he is clearly suffering and heavily drugged, our days are spent watching shows and being ordered around by him. He wants so badly to do the things he loves: play cars, tennis, baseball, golf, video games and more. Because he is too sick to do them himself, we are playing for him. He watches from the couch, or floor, instructing us "firmly", as only a three year old with brain tumors on massive amounts of drugs can do. He is too weak to walk, so when he musters the energy he crawls across the floor to get what he needs. Sheer will. We continue to talk on the phone with our care team and hospice to try to find the right combination of narcotics to meet his needs.

This is the most surreal experience. In many ways it feels like any other post-treatment period - that any day now he will begin to feel better. Yet the facts tell us that will not be the case. It is impossible to wrap our brains around this. It has all happened so quickly - and in our hearts we hoped and began to believe that he would be one of the lucky survivors. The more days we get, the more I find myself hoping for some kind of crazy miracle - the kind you hear about on TBN from women with big hair and fake eye lashes. But since God seems to have been on a year + long smoke break and I stopped using aqua net in high school - I am not counting on it. So we walk hour by hour into the unknown.

TUESDAY, NOVEMBER 18, 2008

## *6am Tennis*

Our “day” started this morning at 6am when Ben woke up and declared we must all go downstairs to the basement to play tennis. Of the three sports he loves (tennis, golf and baseball) tennis seems to be of some kind of comfort to him right now. He will tell us that sometimes he hits like Roger Federer and sometimes he is Rafael Nadal. So off we went. It was both amazing and hard to watch as he swung his racket and cried, “I can’t do it!” He is beginning to lose his balance and thus his coordination is not as it was a few weeks ago. His pain is increasing - moving into his joints. But nonetheless, he was hitting ball after ball, getting upset because he was not “smacking” them. In Ben’s world, just hitting the ball is not good enough - you must “smack it”.

It has been over two weeks now since we hijacked an ambulance from UW Hospital and came home to wait for Ben to go. He is still here obviously, fighting as hard as ever, and so are we - living a sort of “groundhog’s day” existence. We have moments each day where we can see him under the fog of cancer and narcotics, but they disappear quickly.

I guess I should be thankful for tennis at 6am. I am. But it is as sweet as it is bitter.

FRIDAY, NOVEMBER 28, 2008

## Ryan

A year ago today and month early, Ryan was born. November 28th, 2007. So much of it sadly is a blur – of chemotherapy, a terrifying infection, surgery and more. My sister Kristen drove me to the hospital, as Ben was too sick to be left without one of us. When the doctor told us that yes indeed he would be coming quickly that night, Jeff raced down to see his birth and then returned home to take care of Ben. Not exactly your ideal birthing experience. But then again, nothing in our lives has been ideal for quite some time, except maybe Ryan himself.

So many times this past year I have cursed God at the absurdity of giving us a newborn in the midst of taking care of a two/three year old with cancer. Yet, for as often as I have cursed, Ryan has made us smile. For as many times as I have wanted to crawl into a fetal position and not get up, Ryan has laughed. He has been a bright light in a very dark time in our lives. He is funny, he is coy, he is happy and at times reminds us of Ben.

I have shed so many tears in the past month - many of them on behalf of Ryan. For the great loss that he will never fully understand – the loss of his brother. A brother he will never know. A brother he will only see in pictures and on video. A brother who would have been his best friend.

Ben picked out a cake for Ryan today – “Sally” from the Cars movie. He said that someday Ryan will turn three and be a big boy just like him. We remain grateful for the time we are getting, yet each day is a rollercoaster of its own – filled with moments of joy, fear, relief, denial and dread.

Despite all that has been going on in our life and home, Ryan is growing into a healthy and happy little guy. He has been walking around our house like a drunken sailor, ignorant to all that is going on, smiling as he does, and excited to see our family who has basically raised him this year in our semi-absence. So to our families, my girl friends, and our dear Ali – thank you. Because of your love and care for Ryan he is a happy little boy – who is now one.

Happy Birthday to our sweet Ryan.

MONDAY, DECEMBER 01, 2008

## *The Polar Express*

We have been watching a lot of *The Polar Express* the past few days with Ben. As his pain continues to increase, so has his need for things to be quieter. So we have taken a break from *Cars* momentarily – to watch a calmer, more orchestrated movie - over and over. We first saw it last Thanksgiving while in the hospital and it filled me with hope in some cinematic way. That by this time next year Ben would be cancer free. That if we just believed liked that little boy in that movie we would hear those words “remission”.

Yet here we are. And “believing” for me right now is complicated. I know what I believe intellectually and theologically. But my heart is shattered - and seeing through that brokenness is impossible right now. So many desire to say something of comfort, yet nothing can comfort me from the fact that my three year old son is about to be taken. Taken. From us.

It has been my primary job the past three + years to care for him. To feed him, clothe him, bath him, to protect him. And I have done so to the best of my ability. But who will now? Who will know the things I know? That it is hard for him to wake up, he needs time. That he is lactose intolerant. That he weaves his hands in his blanket while he sleeps. That he likes the skin cut off his turkey, his waffles cut in strips, and three ice cubes in his apple juice. That he wears a 4T top, but 3T pants. He doesn't like any bubbles in his bath, and he only falls asleep after reading *Lightning McQueen* books. Who will know these things? Because he is only three. And he cannot take care of himself. So who will be taking care of him? The unknowns of the next part of his journey are so mysterious and wretched to me.

I know intellectually and theologically that I should take comfort that Ben will be pain free and with God. People have tried to remind us of that. But if I am honest I just do not know how to trust God anymore. He is a God that healed a blind man, that said “be still” and the sea stilled, who turned water into wine, who parted the Red Sea – all instantaneously. A God who raised His own Son from the dead. He could banish the cancer from Ben's body right now. But instead of parting the Red Sea, he is allowing it to close in on us. And I can see no grace, no mercy.

Even if ultimately I believe that like the children on the *Polar Express*, Ben is headed somewhere magical and extraordinary – it does little to comfort my heart. Because from my heart comes only blood and tears - pouring out with no dam whatsoever. A heart that wishes in some way it would just stop beating when Ben's does.

So I am left like that little boy, with a bell from which I can hear nothing. Wanting to believe, but there is no ring. No answer to my questions. No comfort. A scene short. And a long life ahead without my son. I hope that there are friends to go with him. And that someone knows to make his hot chocolate with soy milk.

~ Thank you to all who participated in the blood drive today in Ben's name. It meant a lot to us.

FRIDAY, DECEMBER 05, 2008

### 3 Theological Discussions

#### ANGELS

Me: Ben have you seen any angels?

Ben: (no response)

Me: Ben, have any angels been talking to you?

Ben: (no response)

Me: Let's read this book about angels. (starts reading)

Ben: Mom, I do NOT like that book. Let's read Lightning McQueen.

Me: Okay, well will you tell me if you see any angels?

Ben: (no response)

#### CHRISTMAS

Ben: ...then the polar express goes to the big Christmas tree to see King Tritan.

Me: Actually Ben, that is Santa Claus.

Ben: NO! It's King Tritan.

Me: (shrugs) Well Christmas is not just about King Tritan, it is also about Jesus.

Ben: I don't want Jesus. Tell me a story about the Gingerbread Man.

A WAVE

(I am listening to Faith Hill's "A Baby Changes Everything" on my iPod)

Ben: Mom, why are you raising your hand?

Me: (pause) I guess I am kind of ...waving.

Ben: Who are you waving to?

Me: God.

Ben: (smiles, looks around) Where is God?

Me: He is in heaven.

Ben: Where is heaven?

Me: I don't know. Some people say it is in the sky.

Ben: (looks up) I can't see him.

Me: Neither can I. But he can see you.

Ben: (smiles, looks around, slowly waves) Hi God

MONDAY, DECEMBER 08, 2008

## 5 Weeks

It has now been five weeks since we came home. There is no explanation for why Ben is still here and no time line that they can give us for how much longer we still have – as every child is different, every cancer different, and neuroblastoma rarely metastasizes to the brain in this dramatic way. So by force, we are living literally day to day.

Every day is different. Some days Ben sleeps a lot, some days he is up and playing all day. He has been extremely frustrated as of late because he has decided to try to learn to serve the tennis ball overhand “just like Roger Federer”. This would be hard for any three year old - let alone one with three brain tumors, a liver tumor, various other cancer and on a severe amount of drugs. Yet he continues to practice - the game must go on. That is Ben. There have been four different times now that we thought he was going – only to have him bounce back. To say this is an emotional rollercoaster would be a gross understatement.

As long as he is here we continue to hope in some way. But it is obvious that his pain continues to increase. With the help of our care team we are trying to keep him as comfortable as possible, but we are not always successful. We know that Ben has a very high pain tolerance, so in the moments that he cries and says his head hurts it is alarming. My original plan to sell all remaining narcotics on the black market has been given pause now that we are at a level of pain medication that could kill someone else. I am too high maintenance to be in jail. I cannot live without my Chi flat iron and various Aveda products.

I wish Ben felt well enough for us to head to Disneyland or Hawaii or something. But those memories would be mostly for us. Ben is content to be in our house with our families. As one of his favorite books reads, “My house is me and I am it. My house is where I want to be and it looks like all my dreams.” So here we are. Playing tennis, a little golf, and watching our favorite movies. Thankful and relieved to still have him with us - yet stuck in this strange form of purgatory. 5 more days, 5 more weeks, there is no way to know. Just today.

Thank you for your continued prayers.

\*disclaimer: for those of you who don't know me and have had trouble interpreting my sense of humor online, the selling drugs part is meant to be a joke. The inability to live without a Chi flat iron is not

SUNDAY, DECEMBER 14, 2008

## *Snowed*

Snow has fallen over Seattle. It is white, quiet, it is beautiful. It looks like a picture.

Cancer has metastasized into Ben's mouth this week. We can now literally see disease taking over his body. We continue to hope that the God who has shown little mercy to one so small will do so on the other side.

MONDAY, DECEMBER 15, 2008

## *A Package, A Call & A Lot of Compassion*

It has been over sixteen months now since Ben was diagnosed. Through every turn and around each corner it seems our fear has increased. And as it has, so has your compassion. I think it will take us years to comprehend all that has happened to us, to Ben. And even longer to understand the magnitude of good will that has been generously bestowed upon our son. Oh how I wish that Ben's life could be saved based on the love that has been shown to him.

Letters, cards, emails and packages have greeted us at each stage of this journey. So much so that every time a delivery comes to our house Ben believes it is for him. Today's package was for him. It was from Roger Federer's people. A signed hat, a signed picture and a card. Wide-eyed and excited Ben opened it and exclaimed, "Look what Roger Federer brought me!" I said, "Ben what do you think we should say to Roger?" He replied, "Oh, thank you Roger. Maybe next time you can come over."

Later this afternoon the surprises kept coming with a voice mail from James Blake. When Ben woke up I said, "Ben, guess who called you today! James Blake." He paused and said slowly, "James Blake who plays tennis?" We listened to the message a few times with Ben waving and saying, "Hi James Blake! Hi James Blake!"

I hesitate to share these two acts of kindness as I don't want to seem like I am exploiting Ben's illness in some way. But to me, they were representative of the body of people who have surrounded us. Of the community who has cheered him on. Of the generosity that has continuously flowed our way throughout this horrific ordeal.

This past week has brought significant changes. Ben is too weak to play tennis now. So as a substitute he sits on the couch and watches Jeff, Uncle Brian, Uncle Steven and Aunt Kristen play "Roger Federer Tennis" on the X-box. He gets to pick the players, their clothing and which venue they play in. He then cheers them on as if he was watching the actual US Open. Jeff and I plan to go to the US Open this coming year - in honor of Ben. We know that would have been his Make-A-Wish, since you cannot go to Radiator Springs. Perhaps I will get the chance to thank those men in person for the smiles they brought to Ben's face today. In the meantime, I thank all of you. For your compassion. For your generosity. For loving our son.

~

A very special thank you to all of the angels who made today's events happen. We are immensely grateful.

ETA: Ben just received a voicemail from Andy Roddick. He is sleeping, so we will look forward to his reaction tomorrow. This is amazing.

FRIDAY, DECEMBER 26, 2008

*'Meanwhile, where is God? This is one of the most disquieting symptoms. When you are happy, so happy that you have no sense of needing Him, so happy that you are tempted to feel His claims upon you as in interruption, if you remember yourself and turn to Him with gratitude and praise, you will be – or so it feels – welcomed with open arms. But go to Him when your need is desperate, when all other help is vain, and what do you find? A door slammed in your face, and a sound of bolting and double bolting on the inside. After that, silence. You may as well turn away. The longer you wait, the more emphatic the silence will become. There are no lights in the windows. It might be an empty house. Was it ever inhabited? It seemed so once. And that seeming was as strong as this. What can this mean? Why is He so present a commander in our time of prosperity and so very absent a help in time of trouble?*

*I tried to put some of these thoughts to C. this afternoon. He reminded me that the same thing seems to have happened to Christ: 'Why hast thou forsaken me?' I know. Does that make it easier to understand?*

*Not that I am (I think) in much danger of ceasing to believe in God. The real danger is of coming to believe such dreadful things about Him. The conclusion I dread is not 'So there's no God after all,' but 'So this is what God's really like. Deceive yourself no longer.'*

*C.S. Lewis – A Grief Observed*

TUESDAY, DECEMBER 30, 2008

**BENJAMIN WARD TOWNE**

**July 17, 2005 - December 30, 2008**

WEDNESDAY, DECEMBER 31, 2008

*A Memorial Service in Ben's honor*

Saturday, January 10th, 2009

2:30pm

University Presbyterian Church  
4540 15th Ave NE  
Seattle, WA 98105

In lieu of flowers remembrances may be made to:

The Ben Towne Research Fund  
Seattle Children's Hospital Foundation  
M/S S-200  
PO Box 50020  
Seattle, WA 98145

MONDAY, JANUARY 12, 2009

## *Thank you*

It is Monday morning and our house is very quiet. Ryan is napping and I sit alone in Ben's room. The emptiness is crushing. It has been two weeks. Two weeks since I have held him, since I have talked to him, since I have kissed his sweet face. The pain is intense. Our grief is raw. His absence is all-consuming. Yet we are thankful.

We are grateful to everyone who attended Ben's service on Saturday. Thank you for coming, for honoring our son and his life with joy. Thank you to so many of our friends, who travelled great distances to support us during this time. And a very special thanks to those of you who participated in the service, in song and in word - you were a gift to us.

And we thank all of you - our friends near and across the globe. For walking alongside us these past seventeen months. You have been constant in your encouragement, your prayers and your compassion. You have read our journal with bravery. Even though Ben passed on the 30th, for us his service symbolically began our new journey. It is a new life. A life without Ben. Perhaps at some point this darkness and new path will seem worth sharing publicly, but for now it feels too difficult. Even for me.

We will use this website in the future to update you on all events or activity surrounding the Ben Towne Pediatric Research Fund. Until then, as Ben said to me in a saved voicemail, "Bye Bye! See you later..."

Signing Off,

Carin and Jeff





