

Passage from: Johanna's "CarePage"

5/21/08

Wednesday - 7 incredibly jam-packed months have lapsed since my last update, time flies when you're having a good, healthy life, right?!

Today, Johanna had her "health-visit" to the Jimmy Fund Clinic again (her last one was on 2/20th) - the usual routine: blood drawn with multiple tears - this time, from her arm which was numbed so, it wasn't too bad, blood pressure, height, weight (ahemmm, we're working hard on that jelly-belly!) - all are fine according to Dr. Degar - we'll see her again in 3 months on 8/27/08! We took a long sigh of joyful relief, as with every fearful visit comes that familiar feeling of dread - what if...

I thought it was time to write. Forgive me if this gets too emotional - we've all been to hell and back afterall.

It was one year ago, 5/21/07 (so hard to believe), when Johanna began her first round of chemotherapy to begin a perilous battle against Burkitt's Lymphoma. Michael and I seldom talk of the day (5/19/07) that we were told that our sweetheart was being assaulted by Burkitt's Lymphoma - cancer. It was very tough, sad, devastating. I remember screaming, wailing. I was so confused and hurt by the fact that God would do this to her, to us - I had tried for so long to have her; through the medical miracle of fertility treatments and also through a heavenly miracle, we were given a gorgeous, precious daughter. Why would a loving God then subject our child to this horror? I thought I'd literally die of a broken heart that day. To be strong was probably the most difficult thing to do - Michael and I nearly collapsed from the sheer helplessness of it all...but we had to be strong for Johanna. She needed to see in our eyes that we believed her strength and ours would beat this cancer. And so, she did.

Today, Johanna looks and feels fantastic. Her energy is absolutely boundless. Her hair has grown back so beautifully - as if it's a gift - a lighter brown than before, very curly, with blonde highlights! Her outlook on life is that of any 8-year-old - wonder at every sunrise and sunset and at everything in between! We often ask Johanna what she thinks of her ordeal, really because we are just so amazed by her - she usually just shrugs, says "I didn't like the medicine, but, I'm all better, and the hospital people were so nice" - she often asks to visit 6-North which we plan to do again very soon, she wants to bring lots of gifts to everyone! We admire her ability to put it all behind, do only children possess that?? For her, it must be behind her, as there is so much ahead - her victory over her cancer will define part of her personality forever, but it will not stop her. I seem to carry the weight of her battle against the "grancer-bug" around with me everywhere I go - for me, I don't want to shed it...part of me feels that suppressing it would be a victory for the cancer in a way, as though I was accepting it. No way do I want to accept it - I will continue to be vigilant (yet uneasy) with every sniffle, ache, splinter, bugbite, bruise, moan, tear, broken nail, hair-out-of-place - you name it! It's so true - you can never watch your children too closely!

Since I last wrote, so much of life has happened!! Last November, Johanna had her wish of going to Disney World granted by the wonderful Make-A-Wish Foundation of Massachusetts and Give-Kids-the-World-Village. Words can never express how absolutely fantastic this trip was! Special angels from the MAWF, Marcela, Cara and Lauren, showered her with gifts, presented her with our package to "the Magic Kingdom" and arranged everything for us! We were chauffeured to Logan Airport in a gorgeous, long, beautiful limo driven by "Ed" who was so sweet and funny! We were greeted at Logan Airport by another MAWF angel who assisted us with getting to our flight, along with a Pluto Dog for Johanna!! Greeted again at Orlando Airport by a GKTW angel, who had a colorful welcome sign made just for Johanna - and who gave us keys to our own car for the whole week!

GKTW is an adorable village for children with life-threatening illnesses and their families to stay; the village itself is simply wonderful! The best description is that it's a life-sized Candy Land game! There are pretty cobblestone streets, a Gingerbread House where all the meals are served, a gorgeous carousel, a mini golf course, a fishing pond, 2 pools - one which we were right next to, an cool arcade, a movie theater complete with popcorn, an enchanted Castle of Miracles where Johanna's own gold star hangs on the ceiling with thousands of others visitors forever, an Avenue of Angels, all you can eat ice cream parlor (Michael's favorite place!), pizza deliveries to your door, treat carts driving around, talking garbage cans, a giant snoring tree, and geckos here, there and everywhere!

Johanna was truly in heaven! The Mayor and Mayor-ess of the Village are rabbits: Mayor Clayton and Ms. Merry - Ms. Merry came one night to give a special tuck-in to Johanna - so cute! The cottages are perfect, spacious, immaculate, colorful and cheery - each day there are gifts at the door! I'll cry if I keep going on about GKTW - please check out their website: www.gktw.com - you just will not believe what an incredible place it is!

Johanna was truly treated like a princess the entire trip! Her magic button from GKTW enabled her to be escorted to the front of every line to every ride at Disney! She was personally greeted by Mary Poppins and Bert on the merry-go-round and then whisked off for a private ride with them - it really brought the 7-year-old out in me, too! She was "beautified" in the princess castle and dressed as Aurora - just made us cry with joy! We were given free passes to Mickey's Very Merry Christmas Party - which was just unbelievable! We were granted free tickets to see Cirque Du Soleil's La Nouba, best seats in the house - words cannot describe this! She had a long, private talk with Santa. She and Michael swam with their own dolphin: Diego, and swam and snorkled with stingrays at Discovery Cove - a once in a lifetime thing - simply incredible! Johanna's caricature was done at Animal Kingdom - then she was chosen to be part of the Festival of the Lion King Show! She rode on every rollercoaster she could, multiple times! The faster, the better - no fear at all!! We have millions of photos and the best memories to keep forever! Honestly, it's very difficult to put into words the extreme kindness bestowed on us by these two fantastic organizations, and Disney World as well!!

Johanna turned 8 in December, has a new kitty: Baxter aka: Baxie (ragdoll breed) - he's a little devil, sheds tons, but we love him to pieces!!

Thanksgiving and Christmas were truly special and blessed this year as you can imagine - Santa took a close-up photo of himself on Johanna's camera!!

We toasted the New Year in up at Felsengarten and kissed 2007 goodbye, or should I say, bah-bye! Whew! Glad that's over!

The school year has flown by! She's about to complete the 2nd grade - a beautiful and fun year at school during which she made her First Penance on 1/12/08 and First Communion on 5/4/08 - I cried going up for communion with her, tried not to, but it really was quite special to me...She has learned to write cursive so beautifully - I treasure every piece of paper she writes on! She's into gymnastics, taekwondo, soccer and tennis - is veerrryyyy active! She sings to Hannah Montana, dances, colors/draws with extreme detail and vivid colors, loves patterns, searches for interesting bugs, toads or frogs, flies kites, can't resist a playground, never wants to sleep, still loves Spongebob, just got into Nancy Drew books, loves to laugh & giggle, wants to grow her hair to her knees for locks-of-love, is never wrong (at-a-girl!), has Cronin-freckles popping out everywhere, mimics her Dada's crazy ways, skips and jumps just because, prays sincerely, won't let me get rid of any toy she ever received, loves fiercely, is extremely sensitive, cares for every living thing, has a heart as big as the universe, will never tan, collects rocks and other things of nature, might have my thighs, will never be dull, and is growing into a beautiful young girl!!!! As I mentioned earlier, Johanna has put her battle with cancer behind her, and with her victory, she's off to discover the world!

We know how incredibly lucky we are, but also feel the tremendous guilt associated with surviving when others do not. Our lives are changed forever; our perspective made clearer. Our eyes are now opened to a world that we once knew so little about. We MUST do all we can to research and forever stop childhood cancers...So, here we ask that each of you please go to the following website and sign this petition - it's only a moment of your time, but is worth so very much to each child suffering from dreadful cancers...This petition has been started by the father of a 14-year old boy who lost his battle with Burkitt's Lymphoma:

<http://www.thepetitionsite.com/1/CureChildhoodCancer>

As always, thank you to all - Carol, Michael and Johanna-Brave...