

December 19 - 25, 2010

Written by NickyBear's Momma

Saturday, 25 December 2010 22:40 - Last Updated Tuesday, 28 December 2010 04:37



Merry Christmas, and Happy Birthday to our Lord, Jesus Christ! I will skip around in the week on this post. This week Nicholas has done really well on his oral chemo and his ANC is 900 so it has dropped since we left St. Jude when it was 1300 to start chemo. Next weeks labs are a good indicator if we will be stuck not able to leave at all or not. We are praying they do not drop too low. We are now set up with Beaumont (the hospital) with Beaumont Home Care. Since he is on chemo and it is so crucial to keep him from getting sick during the next 5 1/2 months, nurses come out weekly to do labs on him and vitals and they fax them to St Jude. Then monthly we go to our pediatric office for a full work up, we also go to the hospital for his monthly Pentamidine IV infusion.



On a different note, boy is he so happy to be home and he just loves his big brothers attention! For there being such a big age difference between the two of them, Christian being 9 and Baby Nicholas being 15 months now - Christian is an amazing big brother and is so careful with him and makes him laugh so much. It is just a joy. This week I have been so grateful to be home with my family. I think of all the families I know at St. Jude and across the country in treatment centers battling this horrible fight so far away ... my heart is with you all.

On Christmas Eve I got a call from a family I love and they told me that they were scanned and that the doctors say that their son doesn't have much time Lord, you know who I am talking about surround that family please and give them direction with their choices. A new child I had just started following, when I woke up Christmas morning, I woke up to a letter that broke my heart. A 6 year old after a year of fighting a brain tumor had died in the early hours of the

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morning.

I am attaching her letter because I want people to understand that this fight doesn't stop after treatment, its years of praying for clear scans that are stable..... I ask that you please say a special prayer for a few friends, first our Nickybear, Kendal, Mason, Ryken, Lyssie, Jake, Avery, Megan, Jonathan's family and most of all The Ballew Family, which is why my boys are in plaid. The shirt Nicholas is wearing was Baby Wades and boy how he is missedhe's changed me forever, the ornament to the left was sent by his Momma to me - it's Nicholas' 2nd one since I save one every year for my boys ...



From Jonathan's Momma::::

Saturday, December 25, 2010 9:33 AM, CST

At about 12:10 am this morning John went to be with Jesus.

I was so sad to see all the presents under the tree this morning.

When my other two woke up, they looked at there stockings and said there's John's can we take it to him?

How horrible to have to tell your children on Christmas morning that their brother is gone.

We told them that the Christmas Angels came in the middle of the night and took John's spirit to Heaven to be with Jesus. They went to his room and his bed was empty. How terrible for them.

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They came out and opened their presents, they had fun with their things. I imagine that they would have more fun if they hadn't had the bad news from us before hand.

Even though John was not healed, he is with Jesus, he has a new body and is able to do all the things that he has not been to do over the past year or so.

I held him in my arms when he was taking his last breaths, I loved him so much. My husband and mother were here also and talked to him, gave him hugs and said their good byes.

The last couple hours of his life were spent hearing the Christmas story and watching "The Search for Santa Paws" John loves the Buddies movies so much and this was the new one.

He struggled to breath much of the day yesterday but thank God he never looked like he was in pain. He was and is such a precious child and we will miss him so much.

John truly was our joy. His story is so full of pain and misunderstanding. He is with someone now though, who has always loved him and understood him. Jesus please hold my baby today and care for him, because there is no one in the universe that cares for my son the way you do!