

May 22, 2012

Written by NickyBear's Momma

Tuesday, 22 May 2012 14:38 - Last Updated Wednesday, 23 May 2012 13:04

Last night I looked down at my phone around 12:40am and noticed the pending date of May 22, 2012 had arrived. I tried not to replay too much of the hours that led up to sitting in the OR at 4am. I foolishly decided to pull up the photo from after surgery thinking it wouldn't be so bad and I could handle it. Wow was I wrong! My heart immediately went into that place, that moment, the desperation of helplessness of watching my baby suffer and the months that followed watching this viberant baby lose his ability to swallow and placed on a feeding tube was so painful. Watching him lose his hair and having to shave my 8 month olds head to seeing his eye brows and eyelashes all fall out through chemo... I could go on and on but the photo brings me to tears and in the same exact time it brings me such a gratitude for Our Lord and our Savior Jesus Christ I am humbled by the out pouring of love and friendships that have carried us through the last 2 years. Yes today Marks 2 years since we were told he had a tumor and May 24, 2010 it was removed by God's guiding hands through our surgeon. For these moments I am so grateful for the "GIFT" of my boy, my family ... my husband. Sometimes we have to look back no matter how painful it is in order to see how far you've come and what a complete blessing it is that we have our son.



So while today marks our 2 yr mark, it oddly falls on the National Brain Tumor Awareness Day, so please wear Gray today - or tomorrow or any day this month since the entire month is GRAY for MAY, if you are on facebook please change your profile photo for the rest of the month to any of the facebook images at <http://www.project467.org> . We will be arriving at St Jude next Tuesday with a line up of tests. As you know the most important test is Wednesday, May 30th and we hope to be able to share the results as soon as we get them. We have learned the hard way Wednesday's are long waits for results since our doctor is in meetings that day every week. We stopped trying to move the schedule because the just seem to do it following our last scan so we have no choice in it. So I urge you to pray that Nicky remains cancer free and that he is NED (no evidence of disease) I also ask you to pray for Ryan D. who scans the day after us at Jude and David P. also scanning that day in PA.

So I wanted to share with you what a year after treatment and 2 yrs after diagnoses looks like. Our silly little man is a feisty 2 1/2 year old that wants everything his way. Can you blame him?

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While we celebrate life I will share a moment with you from last night ... a casual dinner at California Pizza Kitchen (it felt normal) like we were a normal family - no one can tell what we have lived through and well its better that way. We left and Nicky went running into the mall, laughing and silly and he eyed a Yo-Gabba Gabba toy on the wall in a store he got Christian to hand them to him and he tried bolting out of the store lol I looked at the woman behind the counter and said he's a 2 1/2 year old thief!!! We managed to only have to buy one to keep moving. Yet he was in the best mood running and playing and I know Nick and I were smiling just as big to watch him be normal with his big brother. He then bolted to the escalators and we took two rides while people sitting in the court watched how often to to see parents willing to just ride the escalators because their 2 1/2 year old is laughing and having a blast? Pretty rare to the people observing us, totally unaware how much we appreciate these moments we are given ... taking nothing for granted. I know for the people watching, our faces said it all they even laughed that we allowed him to take the lead and all along we were laughing with him and his silliness. We are so grateful for moments like these small treasures indeed.

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So I will leave you with this thought we have come a long way - but this journey doesn't end and we need our friends and family to keep praying and lifting up little Nicky Bear as often as you can that God continues to keep him cancer free. Anxiety is a battle, so pray that we have peace with sitting through all these tests. We just want to come home and enjoy all the normal moments God allows us to have. In the same breath I ask you to pray for a little boy, he is 9 and he has been struggling to hold on his name is Ryan Kennedy and we know that in Gods time, God will welcome him with open arms to complete healing. He lives in Clarkston, MI and we met at the CURE SEARCH WALK last year. Ryan has been battling the same diagnoses as our Nicky for 5 years and this little boy has endured 7 relapses in that time frame ... pray for his family and pray for him in whatever way God lead your heart to pray for him he has suffered so much and his Momma prays for comfort for him in his final days. His family can be found here <http://www.carepages.com/carepages/RyanKennedy52402/> Watching Ryan's Momma handle her son's situation with just love and grace is truly humbling and it carries the heavy weight of the devastation of this disease and how vicious it can be.

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think you've had a gift for ages. And I hope we can raise some money for CURE for every