

Feb 15 - 21, 2011

Written by NickyBear's Momma

Monday, 21 February 2011 20:55 - Last Updated Tuesday, 22 February 2011 01:24



Christian (our oldest) loves holidays - so every holiday is big! We always do decorative holiday cupcakes and his valentines box for school. I was able to attend his schools party and it was honestly refreshing to be in a normal enviroment with Christian. It's the first time I have been able to go to his school this year. I met his teacher and most the Moms that know me asked the same question, "How is everything?" It's hard to sum up everything to anyone that hasn't been with us throughout this journey. It's hard for me to convey in words how different everything is now.

We had an extra set of labs drawn on Thursday this week and thankfully we did since Nicholas has been fighting off a viral cold on top of getting chemo. His ANC was 810 a huge drop since Monday and a slight drop in platelets at 111. So no change in plans and he stays on course with the rest of this chemo. We were hoping his counts would be higher to travel, but they just aren't. He is also still congested, so please pray that is gone asap because they will delay his scan if he is too congested. He is a natural drummer for sure. He loves beating them on everything! Its great because we know that he is not weak on either side by the way he does it in perfect rhythm. His hair is growing in fast now and even in the spots where he was radiated it is growing in thicker and fast now. All the signs of what he has gone through are slowly being hidden - one less reminder to stare at once his hair completely covers his scar.



Over the weekend Bayside hosted their annual Ice Fishing Derby. The proceeds went to St Jude in honor of baby Nicholas' goal we are trying to meet. I am very grateful to everyone who donated and worked on this event. Thank you, Shannon told me that they rased \$1,056.00. I saw a few people I grew up with, Norm G. and Matt B. among other faces it was good to get

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hugs from people that really care about our little guy and some people that did not realize that Nicholas was my son that was going through this. I can't thank everyone enough for coming out for this event. It was hard to get through talking on stage. Thank you Shan for all your hard work.



Also this week we got another donation from one of my husbands friends whom has been so supportive through this whole journey and always checking in on us, Kim Calabrese. Thank you for the card .. and check for St Jude your support that is truly from your heart and for the donation. This will also be hand delivered to the hospital when we get there.

We leave tomorrow for St. Jude - I ask you all to please pray extra hard for our boy this week. His MRI is Thursday and as you all know that is the only test that really matters. We know that with certainty that this is in God's Hands and in His control. As parent, it's still very scary to sit and await results so please pray that God gives us peace while we await the results. We ask God to give us NED, clean and stable results. most of you ask how long will these tests keep happening for Nicholas every 3 months for 5 years and then every 6 months for another 5 and then 1 a year after 10 years I say that because this is far from over and we need you to keep lifting our boy up and praying please.



Last week Jill the moderator for the largest group of parents that had a child diagnosed with the same cancer Nicholas "HAD" asked me to take over the group. She is ready to move on with her life after 13 years of running it and her son is now turning 21 and she knows I am always here for other families and willing to help. The group is called ependyparents. It was there where I was given my son's protocol. I will always have such gratitude for this group because it was there when I needed support and guidances from other families to help us find the right treatment for Nicholas. I kept this fortune cookie paper with me since St Jude I loved what it said not everything has to be big sometimes small efforts go a long way... helping the families and the children is so important ... I hope my son changes just a little part of your heart ... I hope he inspires you ... he inspires me every day.

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Dear Lord..... I pray with my whole heart that you keep Nicholas cancer free and that you never allow cancer to ever harm him again. Please God watch over us this week and always ...