

Doctors Reviews - Jan 16, 2013

Written by NickyBear's Momma

Wednesday, 16 January 2013 19:42 - Last Updated Wednesday, 16 January 2013 20:38

I know how overwhelming this has been for some of you for us - it stopped our world. Tonight we waited for St Jude and our entire team to sit in a room for Brain Tumor Board meeting and review Nickys case. The Oncologist, Radiologist and the Nuerosurgeons all met to discuss our little man. I need to thank everyone for your texts, private messages, your emails to encourage us and your love and support we are blessed!!!! Sorry that we can not respond to all the amazing messages you sent us!

Monday night I left St Jude DEVASTATED ... that's an understatement truly, I came home and contacted doctors and emailed them and I just couldn't wait for them - I needed to do something for my baby. I sat with a fully charged phone for an hour waiting for the St Jude screen to light my phone up. It was our doctor that said that everyone agrees that the surgery is needed on the spine - FINE bring it on!!!! So we are again packing in a few days to go for a 4-5 possibly 6 day stay in Memphis.

She then said there were mixed views with doctors believing that the two issues could be connected. Our radiologist in Jacksonville said - it would be such a rare situation that these two oddities are happening at the same time without being somehow connected. Through him I learned that our Jude radiologist also leaned that way. With that being said Neurosurgery was not convinced that they were connected. Our doctor said this surgery is going to have everyones eyes on it, it will be interesting to see how this plays out and if in fact the area of concern clears up and resolves itself because in radiation it can and does, we have seen it ourselves. While everyone agrees there is no solid answer physiologically as to why these two areas at the same time had issues ... lets see what this surgery does.

With that being said THANK YOU JESUS OUR LORD AND SAVIOR I asked are they still considering that this is a possible secondary cancer or anything growing.... her answer was no, they are just radial changes - it would only be concerning if it kept changing when it could resolve itself as most of the post radiation things eventually do. DO YOU HAVE ANY CLUE WHAT THAT FELT LIKE ????? I have been reaching out to families with tumors in that locations for questions, signs, what to look for Nicky has not one symptom.

A test of faith NO DOUBT and still nervous about the surgery - of course praying this surgery relsoves both issues is a huge possibility and a relief that I can not being to explain. I am GRATEFUL FOR GODS MERCY Prayerful that this surgery could be the key to resolving this inflammation - even if it is gradual. I have the right surgeon and I know GOD guides his hands Please keep praying ... because this wasn't a big bandaid on this situation

any brain surgery is a big deal and healing and pain management is a task I am ready for - anything for my NickyBear. We are planned to go to Jude either Jan 23 or 24th for meetings with them and then Surgery is 7:30am Jan 25, 2013.

While no I don't want him to need at surgery - he needs it and I know God like he always has will show his mercy and have HIS HANDS ON IT. Because that is what he doesn't even in the scary storms He is ALWAYS with us. My husband reminded me of that while I wrote to Beaumont Hospital for records to be released to Boston Mass - regardless of anything - Dr. Yock will be meeting again on Wednesday next week with her Brain tumor board and reviewing Nicky's case. You might wonder why I would still do this and work my butt off to get them everything I want the best - this is my baby this doctor see the most proton radiation children in the world and I want her voice on this and she will now be our second team working with St Jude, she will review his scans and be another sound voice. Our Doctor did speak with Dr. Yock today about us and well they all know that this MOMMA doesn't stop when it comes to her Bear I was already working away at records and getting the best this world has to review him. The rest we must leave in GODS HANDS.

I wrote this last night on facebook :::::

Its not about trying harder---- some of this only happens through prayer---- We are powerless to anything except prayer and that is the MOST we can do - we can not confront evil on our own, we are not that good, but prayer- engages is with the power of heaven - I believe, but help my unbelief - stand with us in prayer for our son our beautiful Nicky - thank you Pastor [Jamie-Kim Kjos](#) for these words I just watched from this Sunday we missed but were able to watch upon returning with our hearts in knots - please when we are weak intercede in prayer for us believe he is healed because we are going to do our best to believe ! Satan you will not touch our child! He is from the Kingdom and God will not let him be harmed - if I travel with evil - I will not leave without CHRIST - prayer moves the hand of God - this is the book of Mark

While I leave this entry ---- We never got to share the news we got an hour before the results we were told in May that Nicky had lost his hearing completely in his left ear, so for 6 plus months we thought that his hearing was gone and his right was weak ... he proved that God again is **ABLE** he can hear from both ears and his hearing is not as strong on the left but that he qualified for hearing aids on both ears - we were amazed that what we thought was gone forever -

God has restored I need to say that Mays result was a flat line no response at all on the left you should have seen our faces when we knew he could hear

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THANK YOU LORD

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While we still have mountains to climb and still need to pray for this area and surgery, please help us move mountains in prayer prayer is an amazing thing and the only weapon we have and I am so blessed to have an amazing husband that has been here every single minute with me, praying and supporting me being that crazy mom reaching doctors and wanting something to hold on to.

Please pray this surgery is quick, successful and healing is swift I can not ever being to thank you all for your continued prayers PLEASE KEEP THAT PRAYER CHAIN UP long weeks and healing ahead and a scan 8 weeks from now so we will have more answers and prayerfully - we look forward to hearing NED again - which by the way this scan was NED (no evidence of disease) with a spin of stress and questions.....

We love you for loving our son I will update after the next review from Boston next Wednesday before surgery next Friday so we will keep you updated as much as we can.