

**August 24, 2012**

Written by NickyBear's Momma

Friday, 24 August 2012 20:52 - Last Updated Friday, 24 August 2012 21:09

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Working out the scheduling kinks of this pending surgery. I was beyond upset last week with my primary telling me that they wanted to schedule the surgery Sept 26th meaning admission Sept 25th. I told her I wanted to be home for Nicky's Birthday and the CURE SEARCH Walk and wow to line this up right after was an overload of stress. More importantly, she told us the scan didn't need to be done before this surgery. I went into my Raging Mommy Mode - that means DO NOT MESS WITH ME!!! I called neurosurgery and told them we are not scheduling surgery until his disease has been evaluated first!

Isn't that that logical choice to make sure that this issue is in fact needing surgical invention still and that this is the only issue that we are dealing with before performing a brain surgery???? I was red hot and emailed my doctors and told them there is no way we are having surgery without an MRI first. Apparently the neurosurgeon nurse and my doctor spoke and she told my doctor about the lengthy message I left her because my primary called today and Nicky's MRI was moved to Sept 28th 8:45am because of course I wouldn't allow him to have a later slot either. I have become pretty demanding, but that's what a great mom has to do right? He will be admitted to Le Bonheur Sept 30 and the surgery is scheduled Oct 1, after all was scheduled, I had my own mini meltdown and cried and prayed in the shower for 20 minutes asking God for healing and strength to endure whatever we must.

Keep me strong Lord .... so how should you pray? - pray that God removes that inflammation and that they wont need to do any surgery ..... I am praying that over him daily, placing my hands down his spine and head and I need you all to also - I wont accept it unless I have to! My Heavenly Father please show mercy and grace to my little man PLEASE! Pray that MRI is clear and disease free! Pray harder because we need it please. Pray God restores his body without anything needed surgically. We know our Lord is capable, so please keep praying that this will resolve itself.

The following day, the above post we written last on Monday while I awaited the neurosurgeon calling me to answer 2 1/2 months of questions that had no answers from my doctors. I want to share a short video of our neurosurgeon so you can see why we will only allow his hands to be entrusted with Nicky's ( possible hopefully not surgery)

So let me list my questions so it is answered for you also:

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1. ( THIS WAS MY LAST QUESTION, BUT I BELIEVE IT SHOULD BE POSTED FIRST!!!)  
Can this still change and not show up on the next scan ... he said "YES, I would have requested a scan been done prior to any surgical invention... " This answer is most important when we pray - yes it can change, yes its possible and so PRAY it will just be gone - In Jesus' Name ....
2. Could this surgery leave him with deficits?, the answer was" It is not near the cranial nerves so no its fairly easy but can be complicated due to how he healed and how he was closed up and what was used and scar tissue."
3. Does this procedure always work? His answer, Most hospitals have a 50-60% rate at working to correct the issue - he personally has the record of 70% and a little more - however if he feels that he can not just fix the issue he places a small line from the 4th ventricle to the spine. I in return asked if this changes with growth and he replied that it does not that it remains in tact and working, he explained that long ago that use to place a spine shunt but that they do not work so this is the only fix that long term doesn't need a second surgery.
4. What is the recovery? The recovery is 3-4 days and normally never after this do you go to the ICU they just want to assure the patient is stable enough to go home.
5. Surgery time .... that's up in the air they don't know because they don't know what type of scar tissue and radiation tissue scarring is there that may pose any challenge - but not long.
6. The incision, about 1-3 1/2 inches straight in the back of the head - ( NO HAIR CUTS FOR NICKY TO COVER THAT UP .... : )
7. Pain management, first night might be tough but after that nothing Motrin cant handle....  
sighhhhhh

So after all that .... I remain so hopeful that my son can still be relieved by faith and PRAYER!  
Dr. Boop our neurosurgeon also said this is an elective surgery that may not be needed yet but eventually will if the scans show change, reason so is that this inflammation in the spine over years can hallow out the spine and cause major deficits so early intervention is suggested among the best pediatric neurosurgeons. Gotta love Boop!

My side notes - the surgeon was shocked my doctors did not think that evaluating for disease first was the way to go ..... I just can't imagine what my Dr. was thinking when this is our first 4 month scan for his brain. Nonetheless - bringing out the claws worked, THIS TIME!