

Mixed News Again

Written by Nicholas' Mom

Friday, 30 August 2013 09:43 - Last Updated Friday, 30 August 2013 13:45

Once again our results are just confusing and give no true answers at all. While no one thinks that Nicky has relapsed, St Jude said that the radial change has gotten worse in the brainstem calling it edema / radial damage - in his ventricles and spine have cleared up completely, so the shunt did fix the CSF issues. Our news really is no different than it was in June except its slightly changed more and they did a spectroscopy and the cellular activity was normal so it gave us no more information - it's frustrating not knowing what this change is they and they can not do a biopsy in this location - again our team does not believe we are dealing with ependymoma, we just have to watch and wait and hope whatever it is resolves itself and heals itself - scanning in 4 months because I'm sick of rushing every 2 months down there with a child who shows no symptoms and they have no plan at all the only thing that was brought up was HBOT - because they do believe its radial damage - so I'm my opinion it's just mixed concerning results with no solid answers.... I have had people ask me how are we doing are we are stressed? Yes, but we are living life no differently and we will keep praying ever harder for these changes to resolve. I do miss those simple scan results....

In the mean time, Boston has us slotted for a full view By Dr. Yock and we are hopeful that she will be able to give us more information than just telling us to sit back and wait....

God has a plan though and we will focus on how great Nicky is doing - because we is doing really well. This photo below was last night, TENT TIME with Christian they love making tents. We are now focusing on our bambino's that will be here soon and pray for a safe and healthy delivery....

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Ready for the night, this little Nilly is ready to go to bed. He is playing with a new friend at the moment.