

Not our typical update - far more concerning and I just truly am scared.

There is any area in the pons/ the brain stem area and it has radial changes and is abnormal. This was not there last scan from what my doctor said.

They have never seen it before 2 yrs out from proton and they are all concerned (3 doctors looked at it already). What this means is that while he shows no sign of relapse - it is not ruled out what they are looking at is not a secondary cancer induced from radiation. Our doctor even brought up that it is like DIPG, though she has the DIPG tumor Doctor look at it and he doesn't believe that is it that but agreed this was abnormal. For those of you that do not know the term DIPG it is a type of tumor whether cancer or not that grows in the brain stem and is lethal and there is no treatment to cure it. Children diagnosed with that disease have a 0% survival rate. For her to even compare this abnormality to such severity when my doctor knows I am so educated in brain tumors was really concerning - because I understood everything she said. She is 100% this is abnormality is radiation induced.

I am numb..... I am praying to God is it nothing at all but terrified, She will be consulting with Boston and speaking with Dr Yock and MD Anderson as well since they have not seen this before. As if that wasn't hard enough to hear she said its reassuring that he is behaving normal and looks great, then followed that comment with if he has swallow breathing, you notice him snoring or becoming limp or one sided weakness this is signs that cause for immediate attention to us (those signs are the signs of any type of brain stem glioma and are all lethal diagnoses because they are non operable, thus treatment only holds it at bay for so long. I am sorry if my last post was all over the place I had 5 minutes to write it and was surely not expecting this news at all.

We just got home to process this and jumped on a flight immediately. The second issue is that the inflammation has grown from two spots to one larger one that does require surgery so we will be back in Memphis for this in the next week or two - **THIS IS NOT CANCER AND NOT RELATED TO THE ISSUE ABOVE.** Again I can't wrap my head around any of it so please just pray for us and pray to God that this spot is going to be nothing concerning.

All I can ask of you is that this new concern be prayed over and over because I want my son to LIVE so I beg you to understand that this is scary and real and we are going to be on our

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hands and knees praying over this we truly ask you to do the same for him. Thank you for all your texts and voicemails and facebook posts My heart is torn tonight and my mind is racing I will write more when I hear more from the doctors.

NO MATTER WHAT GODS HAND ARE ON THIS !