



What a week! First I will say it has been personally challenging with an MRI a few weeks away. I haven't posted because I have just been overwhelmed by so many other children's battles. Today I woke up and got a text at 10am from Charise (Baby Mason's Momma) that told me that Baby Mason went to be with Jesus at 9:30am this morning, Feb 1, 2011. My phone immediately was flooded with texts from other moms that all knew Mason to let me know. Charise, Baby Mason's Momma is such a spirit filled woman with such grace and yet in the last few days through our texts, she was weak and watching her child's little body be taken over by cancer became intolerable. That was clear when she said pray for mercy and that she just wanted him to be at peace, and I did just that yesterday. He was 8 months old and diagnosed a birth, this is Charise and Michael's only child and I ask you to pray for them and in the days to come.

Another family was scanned yesterday, they do not have a page but the little boy's name is John B. and his Momma Ari and I met right before we left for radiation. 2 weeks ago they got bad news there were 2 new tumors right before they were suppose to leave to go to radiation. They were heartbroken, and I was for them also, it brought back flashbacks of Baby Wade. They went home for 2 weeks and came back to get scanned again and decide their course of action. The new scan showed not 2, but 5 tumors in such a short period that the doctors told them they could do surgery, but that we will progress and won't make it through treatment. They have decided to do nothing, take their 2 year old home and leave it in God's Hands. Please pray for the Barone family ...



Nicholas woke up from his nap and I rocked him and just held him in my arms for about 40 minutes while he slept today... I cried for all the mothers I know who can't rock their babies - I cried for all the children I know including my son whom is still in the fight of their life against cancer. I spoke to my dad and he told me I need to pull back from all of this, my reply was, "How when these are people I love?" The one thing I learned is that the bond we share is like another family, how could I possibly distance myself from my family .... as much pain as it brings me to love these families and these children, they have all brought so much into my life personally and I am so grateful for each of them. So many special moments that are in my heart, I remember the week Nicole (Baby Wade's Momma) took Baby Wade home after they were told there was nothing more they could do. I remember the following day Charise receiving news that Baby Mason's tumors had progressed and he was rushed to the hospital

across the street. I remember for a week I couldn't think straight and I text Charise crying... I was hurting so much over everyone else I couldn't focus on my son finishing his final round of chemo. Charise, despite her situation, while they told her that they basically could do no more for her then 4 month old son .... she stopped and called me and prayed with me the most powerful prayer I witnessed during my whole stay at St. Jude with another parent, she prayed for me, my son and our children. I learned so much from her in those days that followed, she dropped off a book to me and she encouraged me to stay faithful to God even after all she was going through she still took the time to comfort me. In my heart, in those St Jude days ... you have no idea how many times we as parents would comfort each other. I remember crying on the porch with my cell in my hands and Jennifer (Ryan's Momma) looking at me and said, "you need a hug?" I just shook my head and she grabbed me .... she didn't realize how bad I needed that hug ... I could tell you so many stories of every family I met there and love ... but this is why I can not turn my back, not even for a moment.

As for Nicholas, his ANC this week was 1650, hgb (red blood) 12.3 and platelets 185 so everything looks great. He's eating better and is just a joy to be around. He seems to like drinking milk from a straw now which is great but we have to hold the cup to him and he won't drink it out of sippy cups with straws, only cups that spill. He loves any playtime his big brother will have with him and he is into everything. We have our monthly doctors appointment this week as well as the hospital for his pentadamine infusion and bloodwork.

We ask you to pray for a few other children whom have all relapsed this week , Ehhren, Iveen, and Austin, they are all children diagnosed with the same type of brain tumor Nicholas had. We also met a new family sitting in the PICU in Buffalo New York .... their pathology is not confirmed but please pray for Anna Rose .... she's 11 months old and their parents only child.... please pray right now ...

I want you all to know that we ourselves are a PARTNER IN HOPE for St Jude, we would never ask of others, what we are not willing to do ourselves..... that means we donate monthly to St. Jude .... we ask with our hearts exposed to join the fight so that children are afforded the chance at life. To the right of this page is Nicholas' donation page - but feel free to become a monthly partner to fight this cause - not out of guilt, but because you truly know you CAN make a difference, this research will one day assure that no child will suffer like this ... HELP US CHANGE THIS.

Tonight when I rocked my son these words came to mind ...I love him so so much ..... he's changed everything about me ... and that I am so grateful for ....

Aerosmith ....

I could stay awake just to hear you breathing  
Watch you smile while you are sleeping  
Far away and dreaming  
I could spend my life in this sweet surrender  
I could stay lost in this moment forever  
Well, every moment spent with you  
Is a moment I treasure

I don't wanna close my eyes  
I don't wanna fall asleep  
'Cause I'd miss you, babe  
And I don't wanna miss a thing  
'Cause even when I dream of you  
The sweetest dream will never do  
I'd still miss you, babe  
And I don't wanna miss a thing

Lying close to you  
Feeling your heart beating  
And I'm wondering what you're dreaming  
Wondering if it's me you're seeing  
Then I kiss your eyes and thank God we're together  
And I just wanna stay with you  
In this moment forever, forever and ever

I don't wanna close my eyes  
I don't wanna fall asleep  
'Cause I'd miss you, babe  
And I don't wanna miss a thing  
'Cause even when I dream of you  
The sweetest dream will never do  
I'd still miss you, babe  
And I don't wanna miss a thing

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Written by NickyBear's Momma

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I don't wanna miss one smile  
I don't wanna miss one kiss  
Well, I just wanna be with you  
Right here with you, just like this  
I just wanna hold you close  
Feel your heart so close to mine  
And stay here in this moment  
For all the rest of time

Don't wanna close my eyes  
Don't wanna fall asleep  
'Cause I'd miss you, babe  
And I don't wanna miss a thing  
'Cause even when I dream of you  
The sweetest dream will never do  
'Cause I'd still miss you, babe  
And I don't wanna miss a thing

I don't wanna close my eyes  
I don't wanna fall asleep  
'Cause I'd miss you, babe  
And I don't wanna miss a thing  
'Cause even when I dream of you  
The sweetest dream will never do  
I'd still miss you, babe  
And I don't wanna miss a thing

Don't wanna close my eyes  
Don't wanna fall asleep, yeah  
I don't wanna miss a thing

Dear Lord,

I ask you from my heart to watch over all the families that have lost their children, give them

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strength to keep going and not allow cancer to steal anymore of their lives. I ask that you guide all of us fighting these diseases with strength and faith. Please God .... give us CURES ... please ....

