

Sept. 21, 2009

recently i was saddened to learn that another family listed on the "living with trisomy 13" website's prenatal page had lost their precious baby girl a few days ago. just a couple of months earlier, we were one of five families listed on the page. now, we are the only family on there. it is a lonely place to be. the picture there of the three of us smiling happily belies the sorrowful journey we are now walking a few months after that picture was taken. being the only family on there really puts things into perspective for us. it is now our turn.



Sept. 17, 2009

everything went well today at the appointment. jonathan's heart sounded good and we were able to get a recording of it! he's been pretty active lately so i've been praying he's on the move to get into the head-down position. ... i guess one good thing about having too little amniotic fluid is that i can really feel jonathan's movements, both inside my belly and from the outside with my hand. i can tell exactly where his head is at all times and i can usually feel his arms, hands, and body when he's moving around. he also gets the hiccups quite frequently now, and my entire belly shakes along with them. this is one thing i found quite annoying when i was pregnant with kate, where now i desperately soak up every movement jonathan makes.



Sept. 14, 2009

"Therefore, if anyone is in Christ, he is a new creation; the old has gone, the new has come!" ~2 Corinthians 5:17

i am so hopeful to see that this concept, albeit on a much smaller scale, is what God is doing in jonathan's life. yes, jonathan can still be healed. we pray for that. i would do just about anything if it would mean that jonathan would be

born healthy and "normal." but i truly believe that God is showing me that jonathan's life might mean so much more in his death. knowing how many people jonathan's life is touching even now, i can't believe anything other than this would be true.



Aug. 20, 2009

this past week, greg and i made a majority of the funeral arrangements for our baby boy. ... there was one moment, as we sat in a very cold room surrounded by displays of urns and coffins, that as the funeral director casually described how they would pick up our son from the hospital and bring him back there, i almost lost my composure. ... i also had a heightened awareness of jonathan's little jabs and kicks while we were there. i did feel a little guilty about planning a funeral for a baby who is very much alive. i know it must be done, but it was like he was reminding me the whole time, "but mommy, i'm still right here with you!" i wish i could tell him that everything we are doing for him is because we love him. ... there is no doubt our little guy is growing. i don't blame all the weight gain on him, but he DOES like chocolate, something i couldn't eat at all while i was pregnant with kate.



Aug. 2, 2009

so many of you have loved us and encouraged us daily with cards, emails, and blog comments. i thank God for you everyday. we have heard many times now how strong and even surprising our faith has been during this trial.



July 30, 2009

i received sad news this week from a family who had previously contacted me through the "living with trisomy 13" website: the T13 baby they were expecting (and due with a week before

jonathan is due) has already been born @ 23 weeks. it has been a very sad wake-up call for me. ... last night for the first time, jonathan snuggled up to the very top of my belly so that i could actually feel his little body. he seems to fit entirely into my hand. it was a very sweet time for me to love on him.



July 15, 2009

I confess, the first couple of days after hearing the diagnosis were so devastating to greg and me, that we both immediately expressed our desire to each other and to only a couple other people that we wanted to miscarry naturally as soon as possible, and we asked for prayer for that very thing. we thought at that time, from deep in our sorrow, that it would be the most merciful thing God could do for us and our baby. i was only 17 weeks along. it would allow us to avoid many potentially heartbreaking issues the further i progressed. it seemed like that would be the easiest and best solution.



July 9, 2009

there is nothing like housework, cooking, and chasing a toddler around to snap you right back to normalcy. and i never thought i would be so thankful for the first two (i'm always thankful for my toddler!)

yesterday i was quite the picture: barefoot, pregnant, not a bit of makeup on, and standing in the kitchen mixing a huge batch of chocolate muffins while spaghetti was simmering and the embroidery machine humming. once i noticed myself, i couldn't help but be amused. my, my, how things have changed over the past 2 years. but i know i'm right where i'm supposed to be!



July 7, 2009

that first week, it was very hard for me to sleep. i saw the numbers 3:30 on my alarm clock almost every night. my brain was going full speed ahead while my body was completely worn out.

those nights were the hardest.

it was during one of those nights that i went over boy names in my head. greg and i knew we needed a name with significant meaning because this was going to be a very special baby. ...

but as i lay there, a name literally popped in my head from nowhere: "what about Jonathan?" i liked the name a lot, but it wasn't necessarily a name i would have picked out originally. i thought about jonathan of the Bible: he was a young man of courage, strength, and determination who looked to and relied on God. i decided to look the meaning of the name up on the internet first thing in the morning.

so imagine my pleasant surprise when i found that the name means "Gift from God." i can't help but believe that this name was meant to be.



July 6, 2009

it's a boy! i'm in shock. i really thought i was having a girl. and then our doctor sees something on the ultrasound that caused her to refer us to a high-risk specialist, just to make sure there was nothing else going on. our hearts became heavy, but we were still hopeful that our son was going to be OK.

by wednesday morning, our hopes for a normal, healthy baby were dashed ... the diagnosis is Full Trisomy 13, an extremely rare chromosome disorder which is not compatible with life outside of the womb. ... some days it doesn't seem real. both greg and i have said many times that we're ready to wake up from this bad dream. ... but when i feel the baby kick or move and it snaps me right back to reality. he is here. he is with me. i still have to take care of him the best i

can and love him like he was
perfect. he has no other
mommy but me.