



Ryan's Journal Entry 8/26/08:

Dylan's 2nd Birthday, how time flies by. Two years since we welcomed her into this world and yet it is still so fresh in my head the first time I heard her cry, our first look at her, holding her for the very first time so vivid in my mind. I go back to that day a lot because there had been so much uncertainty and the moment I saw her things, though still very hard seemed to in an instant feel so right. She was meant to be ours and we were meant to be hers. As I looked at her today in her pretty brown dress with pink, blue, and green hearts all over it, it was hard to imagine a time I was ever sad about her having Down Syndrome. Today she is a very independent 2 year old and I wouldn't have it any other way. Today on her birthday I wish of course the obvious health but also that she grows up feeling like a "normal kid" I want her to have play dates (which she does) friends, (that too she has) hobbies, sleep over's, silly sayings, laugh a lot and DREAM as big as she wants. I want what all parents want a happy child that goes far in life and I know she will. As I watched her today in her pretty birthday hat blowing out her candles I was so thrilled thinking how far we all have come and realizing that the sky is the limit for her. She is the one thing we never knew we needed and now the one thing we can't live without. We welcome each day with her as a gift and although sometimes our patience is tested to the limits I wouldn't trade her for anything. As our favorite book God Gave Us You says "god had given her little her to mama and papa and they wouldn't trade her for anything in the whole world because god gave us you mama had said, god gave us you!"

Our Trip to Holland

By Ryan Robinson

Where to begin? That is a good question. I'll start with August 8th 2006 a day that forever changed my life. I went in for an ultrasound because I had been having contractions and my doctor wanted to make sure everything looked ok because I was just 33 weeks. The tech starts the ultrasound and in my mind I'm thinking this is taking awhile, she finishes up and says she is going to have the radiologist come in because she has some concerns with the measurement of the baby's arms and leg bones. In that moment time stopped. Something was wrong with my baby. She leaves the room and it is just me and my husband and he says "I'm sure it's nothing everything is fine." I knew however it wasn't and when the radiologist came in he confirmed it he used terms like the gestational age and the measurements don't match, she is littler then she should be, and her head appears to be large. Then the words came "I think she has dwarfism." Acondroplasia Dwarfism. He said he was going to call my doctor.

My husband and I were in the car and on our way to Billings by 1:00 to see the perinatologist. The car ride over I went from periods of sobbing to periods of extreme numbness and anger. We arrived in Billings and the doctor came in and did some more examining with the ultrasound and finished up and said. "I am fairly certain your little girl has Acondroplasia dwarfism." What this means is that her head will be large for her body and that her arms and legs will be short but she will have normal intelligence. There was more but that is the gist of it. Then came the question do you want to do an amnio or wait until the baby is born to get the answer. All I could think was there was no way I was going to make my baby get poked and prodded if I could do it instead so we proceeded with amnio. After he was done he said the words that forever ring in my head we will also do the FISH test (test for trisomys) since we have the sample, adding that he wasn't too concerned about it because he really felt the acondroplasia studies is what was needed. They said they would have the FISH study back in a few days but the other would take longer probably 2 weeks. We asked that they call us with results no matter what they were we wanted to know right away.

We found out during this time they hadn't gotten enough cells for the rapid FISH study so it wouldn't be back for another week or so but then again he hadn't really seemed to concerned about that test. Looking back it seems it was an omen because it turns out the FISH results were the only ones we needed.

My husband came home on Aug. 23rd and I was surprised to see him he said the perinatologist's office had called and told him they needed to talk to us both and would be calling. They did and I remember her saying I have some results, Are you sure you want me to tell you on the phone and we both said yes. She then totally shocked me she said "she has down syndrome." I don't remember the rest of that conversation I just remember saying NO! NO! How could this be we weren't prepared for this down syndrome hadn't even been discussed. That day I

broke I couldn't take anymore, my husband called my sister to come over because he couldn't get me to go to the clinic and all I was doing was crying hysterically and saying NO! He didn't know what to do. Two days later my water broke, 35 weeks and this baby had decided she too had had enough.

Looking back it is a blessing the way Dylan Dana arrived it only took a husband driving way to fast to the hospital because my water broke at home, an ambulance ride to the airport, a life flight to Missoula, another ambulance ride to the hospital, and then a STAT c-section upon arriving. All this to have my husband and I say those 3 little words "cry baby cry" and she did, the best sound I have ever heard in my life our first child's cry. For the first time in weeks looking at my newborn briefly in the warmer and my husband in the silly OR hat I somehow knew things were going to be ok.

Dylan was whisked off to the nursery and Jarrod went with her we had also found out the day before she needed surgery because she had duodenal atresia. She had that surgery at 1 day of life that moment in itself I could write a story about. She pulled through with flying colors and has been proving to us ever since how strong she is. Would I have asked that my child be born with DS no, today would I take it away if I could NO! She is who she is all because of my now favorite number 21. It's amazing what 1 extra chromosome can do. She is now a 3.5 year old busy toddler and I wonder where did the time go, my best advice to you as a new parent is enjoy your baby, hold them, love them, rock them but above all enjoy them this is time you can't get back, believe I know. Everyone's stories may be different, my hope is that within them all you may find pieces that you relate too and above all take comfort in knowing we have walked in the shoes you are about to and we are all still standing, and you will too.

Ryan, Jarrod and Dylan
Belgrade, MT