



Loving Life...

Our son Hayes is now 2 years old and as we sit reading excerpts we wrote during his first week of life, tears fill our eyes for we had a rough start. The 20 week ultrasound indicated that our baby had two abnormalities that may have resolved or been indicative of something like Trisomy 21. We decided to forgo further testing and hoped for the best. Hayes was born on his due date and a healthy and hefty 8 lbs 12oz or so we thought. Shortly after his birth the doctor said he had physical attributes that might mean Down syndrome and would do the genetic tests. Because we were somewhat prepared for this news, we were not heartbroken, just happy to have a healthy baby. Things changed quickly from there. Several hours later decreased oxygen levels and a heart murmur were detected and the drama began. Hayes and Julie were life-flighted to Salt Lake City about 20 hours after his birth for heart surgery. Although the mother is not usually allowed to accompany the flight so soon after giving birth, the maternity nurses rallied for her benefit and she was allowed to go with Hayes. We are forever grateful to them.

After surgery and almost a month in intensive care we finally brought our baby home with a feeding tube, oxygen, and several medications to administer. Everyone wore masks around the house and his 2 year old brother was only allowed to gaze at him from outside the room. As Hayes progressed and tubes were gradually withdrawn we celebrated nursing, babbling and rolling. Initially the Down syndrome diagnosis seemed somewhat insignificant; we just wanted him to live. But as the medical concerns lessened, we gathered books and scoured the internet learning as much as we could about DS. We began therapy. Then at about 6 months of age Hayes began regressing developmentally. He was treated for infantile spasms, a rare seizure disorder, but again pulled through.

All this seems ages ago as we look at our delightful little boy. His smile lights up a room, he gives great hugs, and loves to listen to music and dance. He has figured out the CD player and will push the buttons until he finds his favorite songs. He cruises around the house crashing into things with his walker-wagon, yelling when he gets stuck. He sits and plays four or five drums at once like a rocker. He will read books endlessly. He takes his sign language seriously and gets so excited when we know what he is saying. He loves his older brother and wants to do everything he is doing.

Just like any child, Hayes amazes us almost daily with what he tries and what he accomplishes. He doesn't know he has Down syndrome and it doesn't matter to him or to us because he is too busy being a kid, loving life and bringing us and the world around him joy.



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