# Welcoming Vinny

By Alicia Pedroza, Grand Junction Area Parent Guide

In the summer of 2010, my husband Paul and I found out we were going to parents.

We were both excited and scared. What was parenthood going to look like? We decided to have homebirth for many different reasons. I wasn't really worried about having a baby at home. I knew if something happened, we lived three minutes from the hospital.

I was 37 weeks when Vincent (now Vinny) was born. His birth was beautiful and he was healthy. Then on day six of his life, we went to the emergency room because he he seemed lethargic and his temperature was low. I won't get into details, but our midwife, who had been checking on him, neglected to take his jaundice seriously. Now I take any opportunity to educate families on the dangers of untreated JAUNDICE.

Vinny was admitted to Gunnison hospital and then airlifted to St. Mary’s in Grand Junction. He received two double volume blood transfusions. It was the scariest moment of my life! My newborn baby was plugged into all these machines and we were told DAMAGE had been done. I thought in the beginning:  "Damage? He is healthy - what do you mean?" His bilirubin numbers were off the charts and caused damage to his brain. The doctors told us we will not know until he gets older to what extent he may be affected.
While at the hospital, we were also told that he had failed his newborn hearing screening. The midwife had not mentioned anything about the hearing screening available for all newborns. The staff thought we should wait to follow up with a more complete hearing test because he had been through a lot of trauma.

We were excited when we finally learned that we could take him home. We left the hospital knowing he had sustained brain damage, had failed his newborn screening test and had developed seizures. Obviously, that was way too much to take in as new parents but we looked
forward to getting him home.

But He Hears the Dog, Doesn’t He?
When he was nine months old, (in May, when it is easier to travel through the mountains) we went to have his ABR. I read everything I could about the test. Like most parents,

we thought for sure Vinny could hear. He would startle when the dogs barked

and heard loud noises. He'd also been given the diagnosis of cerebral palsy.

Surely, he wouldn't have another diagnosis!

The ABR and OAE were done, and we learned these new words: auditory neuropathy. At the time, the local audiologist didn't give us much information. We were referred to Children's Hospital for more testing. I left the appointment with hope that maybe the equipment was faulty so the audiologist couldn't get an accurate test. I held on to that HOPE until we made the long trip to Denver, at Children’s Hospital Colorado, and had another ABR. That audiologist gave us more information about Auditory Neuropathy Synchrony Disorder (ANSD) along with a packet of information. She told us how auditory neuropathy was very complex, and that every child looks differently. I don't know how much of that I heard.

It was a lot to take in.
Then, the grieving process hit in earnest. I was sad, mad, blaming myself, blaming

everyone else, with moments of occasional calm. I was sometimes depressed. Our CoHear connected with us right away, and we realized we weren't alone. (We joked that she met us in the driveway as we got home from Denver.) We immediately began receiving services

from the Colorado Home Intervention Program (CHIP) with a weekly visit

from a facilitator to our house.

Vinny had many other appointments: OT, PT and Early Intervention Services in the home. It seemed so unfair that our son's time was taken up with all these things. He was one BUSY baby! We had trips to Children's every three months -- that's a four-hour drive
each way for one appointment. We wouldn't learn much from those early appointments because he had motor control issues that made testing difficult.

I researched more about ANSD and the more I read the less I knew! I attended conferences, met with deaf and hard of hearing adults, took sign language classes…pretty much tried to understand what would work best for Vinny.

Vinny’s World at Three
Now, at three years old, his speech is delayed but coming along.
He has good "hearing" days and days that are not so good. He can say

"I love you mommy" which made my YEAR. Vinny is aided although

they aren't set high because he has mild ANSD. He is also trialing an augmentative

communication device because of his motor issues. We started off with ASL

but he seemed to stop using sign in favor of his voice. We are still

trying to understand the degree of his ANSD and so are his professionals.

He receives speech therapy in preschool and privately, and we continue to “fire”

his auditory pathways with music and lots of talking and narrating our day.

This journey is just beginning and we don't mind the ride. We as a family continue

to learn from Vinny. It’s exciting to see him teaching others as well. We celebrate every milestone. I look forward to meeting other families around Grand Junction and from all over Colorado and learning from your children, too.