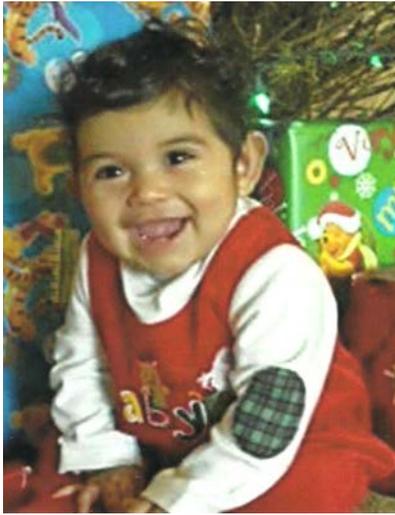


CAH: Alexis – A Family’s Story



“Medicine time,” I shout as 3-year-old Alexis plays around the house with his 4-year-old sister. Alexis comes running to me, looks up, smiling and says, “ready, Mommy.”

Alexis Batres was born on April 29, 2010, and was soon after diagnosed with Salt Wasting Congenital Adrenal Hyperplasia (CAH), which is the most severe form of CAH. When Alexis was born, he appeared physically to be a normal baby. He was much darker than we expected for him to be and had excess hair on his thighs, forearms, and back. However, coming from a dark-skinned Mexican family, we didn’t give his skin color much attention. My husband and I were so excited to take our child home, but I noticed that nurses would talk amongst each other about Alexis’s blood sugar being too low. We had everything packed and ready to go home when they checked Alexis sugar a second time, and he was low again. His

discharge from the hospital was put off until the sugar test came back normal. By midday the nurses did a third sugar test, and thank goodness it came back normal. That was the only thing we needed to take home who we thought was our “healthy baby.”

The first day Alexis was home, he slept for most of the day. I breast-fed him for the first five days, but he wouldn’t suck anything. I gave up the breast-feeding and started bottle-feeding. Alexis would eat only half of his formula and would never cry of hunger.

On Mother’s Day 2010 we had a family gathering, and family members would make comments about how a good baby Alexis was, and how dark we was. My husband and I disregarded the skin color comments. By this time Alexis was 11 days old, and without our knowing he was slipping away from our hands.

The following Tuesday is a day I will never forget. Alexis’s pediatrician called me to ask about his health, and I immediately sensed something was wrong. However, I responded to the doctor that Alexis was fine and he had just slept a little too much, but that that was expected from newborns. The doctor continued, explaining that the newborn screening tests had come back positive, and it was possible that Alexis had a very rare illness. As the doctor spoke further, the world seemed like it was falling apart on me; I was devastated and overwhelmed. The doctor told me to take Alexis a second time for the newborn screening test, because it was possible that the first test could have been a false positive. Unfortunately, the second newborn screening test also came back positive for Congenital Adrenal Hyperplasia, and I received a second call from the doctor. This time the doctor’s call was to instruct me to take Alexis immediately to the Neonatal Intensive Care Unit (NICU), and that it was very important for me to drop everything and to not waste a single minute.

Alexis is a true miracle. He was already 15 days old when he got to the NICU, and if we would have waited much longer it was for sure he would have died. Alexis is now 3-years-old and stable. Despite his young age, Alexis has learned that taking his medications three times a day is an important routine to maintain a healthy lifestyle. He does catch airborne illnesses easily, but as he gets older his immune system should grow stronger. He gets labs done every two to three months to make sure that his

medication dosage is adequate for his development. Bone age exams are also an important part of his continual care plan. We have learned to be proactive in giving Alexis his Solu-Cortef, an emergency shot, when necessary.

As a family, we were fortunate to meet endocrinologist Dr. Moinuddin H. Mokhashi, who took over as Alexis' specialist and pediatrician. It is very important that both parents and the endocrinologist work together as a team, because the well-being of the child depends on it. I have faith in God that one day there will be an adrenal gland transplant that will change the lives of all affected children with Congenital Adrenal Hyperplasia. However, in the meantime, as a parent one should seek appropriate, attentive and high quality care for his/her affected son or daughter.

