

PKU: Cadence - A Father's Perspective



Cadence was born on a Sunday in 2007. At two weeks we were called in to see a specialist. They informed us that Cadence's newborn screening had come back abnormal. She was diagnosed with a metabolic disorder we had never heard of: Phenylketonuria, commonly referred to as PKU. They explained what PKU was and how we would have to treat it. I remember being washed with sadness for my newborn child.

There was a tremendous amount of trepidation in the days that followed. Cadence was given a strict diet to limit the amount of Phenylalanine she took in. We researched all we could about PKU which only added to our fear initially. Eventually we learned that PKU was not something that had to adversely affect Cadence.

Initially, Cadence had to have blood drawn weekly to monitor her level of Phenylalanine. She also had to see a geneticist and dietary nutritionist regularly. We monitored her diet and kept her levels in the safe range. Currently, Cadence gets her blood drawn once monthly and has visits once a quarter.

As time gradually passed and Cadence aged, we adjusted to her needs. As a family, we had to learn which foods she could eat and which foods she could not. Every member of the family is educated and well informed about PKU. She has an older sister named Lillian and a younger brother named Theodore. Cadence is the only one with PKU, but her sister and brother are very involved and help with her diet.

Treatment for PKU requires supervision of everything she eats. Her food is weighed to determine how much Phenylalanine is present. Cadence is allowed to have 600mg of Phenylalanine a day which is very liberal for a child her age with PKU. She has a prescribed formula she must drink daily as well as a healthy diet void of meats, dairy, or any food high in Phenylalanine.

Today Cadence is a precocious and beautiful child. She is excited by learning and is eager to start school in the fall. She asks many, many questions about the world around her. She enjoys playing dress-up and playing sports with her siblings. She wears her heart on her sleeve and strongly voices her opinions. She is a very happy child and smiles constantly.

