

PKU: Grant – A Family’s Story



Our child, Grant, was born with Phenylketonuria (PKU). This was definitely a surprise to us, as he was our third child. We had never heard of this condition before. Shortly after arriving home from St. Joseph’s Hospital, we received a call telling us a test that was done shortly after birth revealed that our son may have a metabolic condition. We really thought the test to be wrong. Our pediatrician did another heel stick blood draw. We were soon told that our child for sure had classic PKU, and we would be given an appointment to meet a specialist.

We soon realized that this test had saved our son. Even though our baby looked so healthy, he would need special treatment. A baby with PKU, left untreated, will suffer severe brain damage by three months old. Through a strict diet that includes precisely measured, medically prescribed food and formula he can live a normal life. He must avoid many of the foods we enjoy such as all dairy, eggs, meats, breads, pasta, nuts and rice. This must be maintained for life to avoid brain damage and to ensure proper development of bones, muscles, skin, brain tissue, etc.

Grant is now 10 years old, and our family, including his brother Chandler and sister Elizabeth, help him to stay on his diet and drink his special formula. We are so grateful to have the chance to help our son by finding out about his condition through the newborn screening test, allowing us to begin Grant’s special diet from birth, before any brain damage could occur.

My name is Grant Hall and I am 10 years old and have PKU. It is a metabolic disorder where I cannot process one of the things in protein called Phenylalanine (Phe) that other people can. So I have to use math to figure out how much “Phe” I can eat. I have learned to measure out all my foods that I eat. I have learned what foods I can and cannot eat. I can’t eat most foods. Many of my foods come from special companies. Every day I must weigh out all the food I eat and record it. I can only have a small amount of protein each day. When people ask me what is that? I tell them it is special food. Every few weeks I have to take a blood test because I need to check a level to see how much “Phe” is in my system. It is not that bad - I am used to it.



Grant Hall (age 10)

The Hall Family – Elizabeth, Ann, Grant, Brian and Chandler