

Our oldest daughter Stephanie was born with PKU. The costs for her food and supplies is very costly! We as parents do what we can do for our children. My husband works long hours and has very few days off to even spend time with our children. I have to be a stay at home mom to our four children simply just to stay within the guidelines of the state to keep the help our daughter does get at this time. We have another daughter who is two, Ella. She was born with another type of hereditary disease. Hereditary Spherocytosis, a blood disease where her spleen kills off the majority of her blood cells. The only cure for this is to remove her spleen. With that being said, no spleen equals no immune system. Even with her spleen right now she gets sick from common everyday germs monthly. I homeschool our children because simply the school does not do well with watching Stephanie's diet making her phe levels go through the roof. Also now that Ella has been diagnosed too, her immune system would definitely fail in the public school system! We don't look at any of our children as a burden, but simply blessings! God gave us these children not punish us but to make sure that they would get what they needed in life. Stephanie and Ella have a brother Steven Jr. and Ella's twin sister Ellie who are also very supportive of their sister's conditions!