

I am 36 years old and was diagnosed with PKU when I was 14 days old. At the time my parents were told that I could be taken off the diet at age 18 and that I might not be able to have children as it would be unsafe for them. As I grew older and knowledge in the field grew, we were told that in order to stay healthy and keep my same quality of life I was experiencing, the medical community now recommended the special low protein diet for life. My parents (particularly my mother) spent long hours throughout my childhood on the phone with various insurance companies trying to get coverage for the PKU formula and special low protein food that I needed. She spent thousands and thousands of dollars out of pocket to cover these expenses when insurance companies continued giving her denials or postponing reimbursement. I am lucky that my parents were able to make so much sacrifice for me growing up because I was able to lead a normal happy life other than eating this strict diet. I went on to graduate college with honors and I still remember my mom prepping me for how to “battle” the insurance companies for coverage of the formula and special foods before I went on to my own insurance plans. I am so thankful that she gave me the crash course she did in navigating the paperwork and tedious work it takes to get coverage of these medically necessary food items (still to this day!)

Growing up I was always very nervous about the prospect of ever starting my own family. I had heard so many stories of how difficult it would be to maintain the strict blood phe level required to have a healthy pregnancy and baby. Four years ago I decided to go for it and worked closely with my doctors and dietitians at Johns Hopkins to stick to an even stricter diet regimen that was required to have the family I so badly wanted. I now have 2 perfectly healthy baby girls (they will be 1 and 3 next month). This would NOT have been possible without access to the low protein formula and specially modified low protein food items! My formula intake was actually increased for both pregnancies and I relied on that low protein food to keep me full and satisfied but still within the strict phenylalanine limits.

I am from Maryland and my husband is from New York – we have lived in both states over the past 15 years. It was a learning curve to try and navigate the various insurance laws and coverage requirements in each state. My husband works in DC and we have considered relocating to Virginia, however it is a daunting task to think about relearning the ropes in another state and risking the coverage that I am receiving here in Maryland. My health and well being shouldn't be dictated by what state I live in. Why should a woman in Maryland have access to insurance coverage that will allow her to have a healthy life and pregnancy while a woman in another state without coverage suffers and has a potentially less successful pregnancy outcome?