

Chris

Connecticut | Phenylketonuria (PKU) | Annual costs: \$600

In 2017 I started working at my current employer. In January 2018 I filled out the paperwork with Cambrooke Therapeutics to have them bill my insurance for my food and formula. While my food was covered by my insurance, my formula was not covered over the age of 12. I fought tooth and nail with my employer (as did my clinic) but ultimately was unsuccessful in getting formula coverage. I stopped taking the formula because it's \$2000/month out of pocket and I couldn't afford that. Even with the proposed assistance from Cambrooke (lowering to ~\$400/month) it was still too expensive to buy. Later that year I visited my clinic, where I found that my vitamin levels were critically low because I didn't have access to the formula. I essentially went the whole year without any kind of formula or protein supplement. This year (2019) my employer added the formula to my coverage regardless of age and I'm happy to say that I've been back on the formula since February 2019 and feeling much better. Regardless though, there should be no circumstances in which any insurance plan, whether through an employer, your state, or privately purchased, does not cover protein modified formula. PKU is a lifetime disease, you don't magically get cured when you turn 13. My insurance should've never put me in the situation I was in last year.

Chris depends on medical nutrition to stay healthy. Chris and thousands of others across the country are depending on you to co-sponsor the Medical Nutrition Equity Act. Please contact the offices of Sen. Casey, Rep. McGovern or Rep. Herrera Beutler.