



My son was a week old when we got the news that he has PKU. I had no clue what this was and didn't realize just how serious it was until it was explained to me as do most people. For months I was in denial. My son can't eat protein?...How is that possible? How can he live? He's never going to enjoy an ice cream cone on a hot day at the park, or order a burger at a restaurant. I was confused and angry. But with the help of medical foods life has been easier. There are options for him, but the cost is high. I now have 2 grocery bills every month. I can't cut corners when money is tight and sometimes they are very tight. Our Insurance does not cover any medical foods, nor does the state. I bought two boxes of low protein noodles, bread crumbs, and Eggz (an egg alternative) and it was \$60. Medical food coverage would be life changing for us and so many who struggle with this extremely rare metabolic disorder.