

Sampling of PKU Stories

Binghamton, NY: Jennifer Ruland, 5 month old daughter McKenna

Jennifer's insurance is through her employer. When she became pregnant last year, she elected to take the most expensive and comprehensive HMO available. She says, "I never thought for one minute that something like PKU would not be covered" when they discovered her daughter had PKU.

She writes, "McKenna's formula is not covered by my insurance plan. It is important for her formula and low protein foods to be covered by insurance because without the coverage, we won't be able to afford to buy all of the wonderful low pro foods available to her and she will be stuck with a very boring diet consisting of the few foods available to us at the local grocery store, which I'm afraid isn't very much.

New York State does have a law requiring coverage for enteral formulas, however, my insurance plan is "self-insured" and that is the reason they are stating for not covering the formula because it is classified as "over the counter". Since McKenna has been born, I have spent countless hours on the phone with the insurance company, my employer, her doctors and our State Assemblyman trying to get coverage for her formula. This is time after work that I should be using to play with and nurture my daughter, but instead it is a never ending battle of people telling me that it's not a necessity."

She concludes, "I think the health care industry just needs to realize that PKU is serious and the diet is not optional. McKenna is a real person with real needs and I don't want her to be just another statistic or number to the people that decide whether or not her formula and food will be paid for."

Murfreesboro, TN: Alesha, Adult and mom with PKU

Alesha's story is one of the most heart breaking. Women with PKU have special challenges because if they can't access the medical foods and formula while pregnant, their baby will not develop properly and will likely be born with severe physical birth defects. But, if the mother has access to medical care and an adequate supply of the medical foods and formula, she can have a healthy baby. Alesha writes, "My entire life I have struggled with getting my food and formula covered by insurance, still to this day I can not afford the food so I have to live with the effects of my untreated PKU. I can't afford a \$12 box of pasta or thousands of dollars for formula, so instead I go untreated and have trouble with education, health, employment, and relationships...my quality of life in general. I need the food and formula to live but insurance companies don't want to pay for it. It broke my heart when I found out I was pregnant and my insurance still wouldn't cover the special foods I needed while I was pregnant. It was a constant battle to get them to just cover the formula, and after the pregnancy they didn't want to cover it anymore – the insurance industry put the life and welfare of my baby on the line. I want a better quality of life for me and for my daughter." An untreated adult with PKU is challenged with low IQ, cognitive difficulties, and often seizures, severe depression, and pareses.

Decatur, GA: JoAnne Hunt, 6 year-old son Lucas

JoAnne's story is a compelling representation of the daily worries of a family with PKU. The formula is almost \$20 per day and the family is concerned what the costs of formula and low-protein foods will be as Lucas requires more intake as a growing teen. The family is also worried about the struggling economy and what could happen if they lose their job and health insurance and being denied because of Lucas' pre-existing condition. The Hunt family also worries how Lucas' formula will be obtained once he no longer qualifies for coverage under his parents' plan. They fear he will have no choice but to go off diet as an adult because of the insurance coverage and financial struggles currently experienced by adults with PKU, and as a result will experience the medical issues related with being an untreated adult: depression, impulse control disorder, phobias, epilepsy, tremors, and pareses.

JoAnne further states in her story, "We live in a wonderful country, and as a mother all I ask is for my son to be able to grow up like any other healthy American boy and realize his full potential. To do this he needs access to affordable, lifetime insurance coverage to cover his PKU treatment without penalty for pre-existing medical conditions, age, or income caps."

Austin, TX: Annaliese Martinec, adult with PKU

Annaliese Martinec is a 26 year old female with PKU. Annaliese has a new job and a new health insurance plan that requires her to pre-pay the \$400 for her formula shipment and then spend countless hours and months battling with her insurance company for reimbursement. She is a college graduate, but her current entry level job does not pay a high enough wage for her to pay for her formula outright without knowing if and when she will be reimbursed and still afford basic rent and living expenses. Annaliese says "I don't need the food and formula handed to me on a silver platter, but I would like a little help with the most basic foods, and to pay a normal copay for my formula."

New York: Brenda, 9 year old daughter Molly

Brenda (last name omitted for privacy of daughter) from NY writes, "In order to get the nutrition that Molly's body needs to grow, she must consume a synthetic phenylalanine-free protein drink throughout the day. This formula is not a nutritional supplement; it provides her with almost 80% of her nutritional needs. While New York State requires that the formula is covered, my husband's company is under an ERISA (self-funded) plan, and federal mandate does not require coverage. We pay over \$8000 a year in formula and another \$2000 for special lo protein foods out of pocket. Knowing how important the diet is to our daughter's neurological integrity, there is no choice but to find a way to pay for it."

Brenda further states, "The loopholes must be closed. Aside from the devastation of my child not reaching her potential, it does not make fiscal sense. Not having the formula would end up costing a lot more to the insurance company and to the federal government because instead of becoming a tax paying citizen, she would be someone on disability"

Missouri: Jaci Engel, 11 month old daughter Julianna

Jaci states that she is puzzled that although there is a federal mandate for states to require newborn screening, and that the treatment for a positive diagnosis of PKU is "diet-for-life", the state of Missouri only requires insurance to provide the nutritionally required formula for metabolic disorders until the age of 6. Jaci further states that Julianna's formula costs her family \$544 for formula and \$80 for the low-protein food products (her daughter is only 11 months old and will require greater intake as she grows). In addition, the family has experienced financial strain due to the PKU doctor visits which are considered by insurance as "out of Network" which doubles their deductible and lowers the coverage by 20%, which seems unreasonable since the family has no choice of another Dr. The closest one already being 3 hours away, Jaci also loses a day's wages for the 4 clinic visit required per year for Julianna's care.

Honolulu, Hawaii: Kelsey Medrano, 14 month old son Diego

Kelsey believes that compliance to the PKU diet is exacerbated by the prohibitive cost of both formula and food. Access and affordability of the required formula and foods, even with insurance assistance, have been an enormous economic burden for the Medrano family. Kelsey states, "In our son's short 14 months, we have been flipped around between 4 pharmaceutical companies. During one such transition my son was left without formula for almost 3 weeks. Even though the formula was on the island, the insurance company would not release it." This is a potentially dangerous situation for PKU infants as not having formula for even short periods of time can result in young children suffering permanent and severe neurological damage. The formula was not released until the family agreed to a higher cost, which amounted to Diego being denied care. Kelsey further adds that "every time I call insurance I have to speak with a new individual who is not familiar with our son's case or situation and we start over completely. PKU adds a ton of stress to the lives of parents as it is, shouldn't insurance lighten that burden rather complicate it?"

Houston, Texas: Judy 16 year old son Zachary

"Since the time Zachary was born, my employer has provided insurance coverage for his formula. The state of Texas passed a law requiring that insurance companies cover special formulas for inherited diseases but as I am covered by a self-funded plan there was obviously no guarantee. When Zack was born, I worked for a small privately owned company which was bought out approximately 8 or 9 years ago. My greatest fear when our company was bought was that my coverage would change. Fortunately they seemed to understand the importance of the coverage and life went on as usual. Last year, Zachary started to have more difficulty taking his formula, so we started exploring different options. After trying several alternatives, the best option seemed to be ½ medical pills and ½ formula. I approached my insurance company about coverage for the pills and that's when the red flag went up. I'm guessing that someone who has the job of deciding what is and what is not covered under our plan saw the cost of Zack's formula and sent the letter that I had always dreaded. They told me that not only would they not cover the pills, but as of December 2009 they would no longer provide coverage for his formula at all. As you can imagine, I went into full blown panic mode. The letter came around October

of 2008 and I fought with them up until the end of the year when they told me to put it to rest and we would address it again in October (2009).

I am a single mother who receives little, if any, assistance from Zack's father so you can imagine how upset I am with this situation. I am currently purchasing all the formula that I can to get us through this year but not quite sure what I'll do next year. I currently pay \$286 per case (6 cans) for Phenex-2. Once I purchase the formula I submit my receipt to insurance and wait, oftentimes up to a month, for 80% reimbursement. A case of formula lasts approximately 10 days. As you can see, even with the insurance coverage it's a financial strain to manage."

Phoenix, AZ: Margaret Delaney, 18 month old son Connor

Margaret writes, "I am currently on my third appeal with Aetna insurance to cover my son's medical formula. Our policy is through my husband's employer and is a self-insured plan. Aetna is denying the formula stating that it is not a covered benefit unless Connor is fed through a feeding tube. "

Today, Margaret received word that due to state budget cuts in Arizona, she will also no longer receive any assistance from the state health department in providing life-saving formula for her son.

Pennsylvania: Steve D.

Steve's story illustrates him losing his insurance through his parent's plan once he graduated from college. A COBRA plan cost him \$400 and did not cover his \$1600 per month cost of PKU coolers which provide 80% of his nutrition. Steve managed to barely get by on some free samples and help from non-profits and his parents in paying out-of-pocket for his medical food. Steve now has a job with insurance that covers his PKU coolers, but fears changing jobs and the likelihood of battles with obtaining coverage with a new insurance company.

Kentucky: Don

Don (last name withheld for privacy) from KY is an adult with PKU who is currently without health insurance to cover PKU foods and formula due to his "pre-existing condition". Don writes that he currently receives his formula through the state and has given up obtaining insurance because of the complicated process and repeated denials. Don writes "I would just settle for anything that would make insurance accept PKU patients. I am getting sick and tired of being told "pre-existing" condition. I don't have health care now, but I would purchase at a fair price if I could. I have since learned to not even try. I will be denied as soon as I apply. Any idea of direction you plan to take in regards to adults (with PKU) would be appreciated."

Atlanta, GA: Kristen Vanags, 2 year old son Joseph

When Kristen's son was diagnosed with PKU at birth, they never considered that their insurance plan would not cover his treatment. Kristen writes, "Our policy was comprehensive and we had selected it carefully. Scott discovered a few days later that medical food was not in the category of prescription drugs. PKU was not captured in the fine print. His company was self-insured, so our insurance

commissioner would not be able to help. We appealed, but it was met with a very strong letter of denial. Thankfully, on the last possible day, Scott was able to switch plans on account of “our life event” and luckily one of the other options had PKU coverage. It was an absolute relief, at least for now.”

Kristen is thankful for the modified low-protein foods that offer substitutes for standard grocery items. She included the cost of some of these products that are essential in maintaining diet compliance: low-protein pizza crusts - 3 shells for \$10, pasta – 1box/bag \$12, MixQuick (similar to Bisquick) – 6lbs \$35, pretzels – 8oz bag \$7, mushroom burgers – 4 for \$14, birthday cake mix – 1 cake/12 cupcake mix \$6.50, Tweeks (imitation chicken nuggets) – 1 box \$17. She concludes, “The thought that many children are not able to afford these PKU products is heartbreaking. Diet compliance without them is nearly impossible.”

She ends her story by saying, “As a mother to a beautiful child with PKU, I will be forever grateful for Joseph’s opportunity to lead a full, happy and healthy life. To continue on a path of wellness, Joseph will have to religiously drink his medical food (Phenex-2 approx. \$800 per month) as he does today. He will have to continue to fill his plate with fruits, vegetables and a large amount of modified low-protein food products. I worry there will be a day when our family’s medical insurance does not cover his medical food, and the cost of modified low-protein foods exceeds our ability to purchase them. “

Alpine, Utah: Rachel LaComb, 3 children with PKU

Rachel wrote that as a mother of three children with PKU, she is affected daily in multiple ways: “emotionally, physically, and economically.” Rachel further wrote, “ We spend so much time making things that they can eat, that is difficult when we have to spend time working with insurance companies to pay for the expense of keeping my children healthy and growing. I don’t understand when insurance companies can just decide that the formula AND food that keeps these individuals growing with no negative side affects is not important enough for them to cover. This formula and food is their ONLY way to a normal and happy life.” She asks “ It is such an easy treatment, why do they not want to pay for it?”