

# SPECIAL EDITION TOPIC: BACK TO CARE, A PATIENT EXPERIENCE

## Back to Care - a Patient Experience, by Danae' Bartke

It's not that I ever made the intentional decision to go "off diet", it's just that I never really was on diet to begin with. There were times where I was closer to being on diet though, than others, but it still was a far cry from how the diet really should be done. Why you may ask was this the case, well let's start from the beginning.

### Diagnosis/ Middle School

In 1995, at the age of 10, I was diagnosed with homocystinuria, shortly after my younger brother was diagnosed. We were trialed on B6, then the addition of betaine, but it was finally decided we needed to follow the low protein diet and formula. We were told to aim for 15 grams of protein from food and to take our formula, which at the time was Hominex-2. We weren't really given much advice or education beyond that. We struggled for a very long time with the diet – in middle school my diet was pretty much sugary cereal, Cheeto's, Budding products (a company that sells very thinly sliced meats so they are 1 g per slice) and pop (Midwest term for soda) – I could fill up and not go over my protein. It was easy to turn to prepackaged foods because the protein content was listed – vegetables and fruit didn't come with labels, so they were this mystery of unknown protein content. Formula on the other hand was a much larger battle – it tasted awful no matter what we did to it. We mixed it with pudding, apple sauce, Jell-O, smoothies – you name it, we tried it, and I was not having it. In middle school though my aunts cornered me and told me that if I didn't take my formula they were going to either force my mom to get me a feeding tube or call Child Protective Services. The thought of a feeding tube or being removed from my family scared me into compliance with my formula.

### College/Working

The years went by and having finished my associate degree, it was time to transfer to a 4-year university. As college progressed, my class load became heavier, and I worked more to offset the cost of the classes. I would work 3-12-hour days during the week, cram my classes and assignments into the other 2 days, then work another 16 hours on the weekends. With little spare time, I found myself eating out quite often. When I was with friends between classes, if they offered me food, I would take a bite of a sandwich (with meat) or eat a slice of pizza with cheese. I was so busy that I wasn't thinking of the consequences. By the time I graduated college I was eating regular cheese, bread, pasta and because Hominex doesn't travel well, I was taking it less regularly. Most days I was lucky to finish half. My last semester of college I ended up having emergency gallbladder surgery. I no longer could take my Hominex because of the large caloric load. Our clinic was able to get HCU Express 15 covered – it really turned out to be a blessing because it was a lot more convenient; it was a much smaller volume and came pre-mixed in individual servings. With the switch, I was able to get in two of the three required servings per day.

In December 2007 I graduated college, but my crazy schedule did not stop. I was motivated to find a teaching job, so I applied in multiple districts as a substitute teacher. Subbing didn't pay very well, so I also had a job in the evenings and on weekends. Similar to my time in college, I was working so much

it left little free time. When the new school year started up and I hadn't found a teaching job, I decided to find something that was more consistent and accepted a job teaching preschool in a daycare facility. The hours were consistent, the pay was better, but it would still require me to drive a long way and I'd still need to work on the weekend. Not too long after starting the hours changed. I found myself having to leave home at 5:30 a.m. to get there by 7 a.m. My workday would not end until 6:15 p.m. It made for very long days and I knew something had to change. After a year of working at that location, I accepted a job transfer to a center closer to my home. It was a small pay cut, but I also got back 2.5 hours a day of free time that I had previously spent driving. At this point, I had fallen so deep into my bad food habits, it never even crossed my mind to use that time to reevaluate what I was eating and cook healthier meals.

### **Blood clot**

In September 2009, I started having pain in my hand and arm. I went to a clinic and the first doctor told me it was a hang nail. I knew it wasn't a hang nail, but wasn't sure what it was, so I just dismissed it and went on with life. A week later my hand turned blue, then white and very cold – I knew that it wasn't normal so back to the doctor I went. This doctor agreed it wasn't a hang nail, but wasn't sure what was wrong, so he referred me to a hand specialist. The hand specialist immediately recognized it was a blood clot and referred me to pulmonology. I called to make the appointment with pulmonology and they said they couldn't see me for two weeks. It was at that point I finally called my genetic counselor. I told her what was going on and she was flabbergasted and told me to find a ride and come to the hospital that evening. She told me they would have a specialist there to meet me that had expertise in homocystinuria and could address this.

I went to the hospital and met the specialist in the ER. I spent a week in the hospital. I wasn't allowed to do much of anything. If I wanted to eat, I had to have someone feed me. If I had an itch, someone had to scratch my itch for me – they were so afraid any movement would dislodge the clot and cause it to be fatal. After surgery to remove and break up the clot, I had to spend a couple more days there to ensure the left-over pieces didn't cause issues. While in the hospital bed recovering, I realized how lucky I was and that I needed to change my lifestyle.

### **Back to Care**

After the blood clot, I had to be monitored closely by Hematology. I felt like I was always at the lab. They did little though, other than prescribe blood thinners, to address the real heart of the issue – my diet.

Two weeks after being released, I received an invitation to a cooking class hosted by the PKU Organization of Illinois. In one cooking class I learned more about the low protein diet, than I had acquired in the 14 years I had been diagnosed! It felt like there finally was some real education and advice that I had lacked for so long. I quickly started to change my diet. Between the hospital and cooking class, I had already stopped taking bites of things like a burger or sandwich and stopped eating regular cheese. After the cooking class, I quickly made the switch from regular breads and pasta to the low protein versions.

I continued going to events put on by the PKU Organization of Illinois, and at one of their meetings I met Malathy, owner of Taste Connections. I even traveled to Michigan and Iowa to attend her cooking classes. I finally felt like I had options that were not just low protein, but also tasty! I later found Cook for Love and that opened my options even further! I don't think I've ever made a recipe from Brenda

Winarski, founder of Cook for Love, that wasn't anything but delicious! I loved cooking before, but now I could cook for myself knowing these recipes were not only delicious, but low in protein.

Throughout the diet transformation, I still struggled with my formula consumption. It just never tasted good and was always clumpy. Then in 2011, I met my now husband. His passion for fitness rubbed off on me, and I started working out, but struggled with weightlifting and extreme muscle fatigue. It would take over a week to recover from a work out -even after working out regularly for a few months. He had always been great about helping me with the food part of HCU but hadn't really taken much of an interest in the formula portion. It wasn't until he put two and two together that he realized my body wasn't getting enough energy to recover because I wasn't drinking enough formula. He's the one who actually got me to start taking my full dose of formula. Once I started taking the full dose, muscle recovery wasn't really an issue anymore. I was able to quickly lose weight and build muscle.

It's been almost 12 years since my blood clot, and I haven't had any events since. I still struggle with motivation to take my formula but have learned subtle cues that my body needs it - such as brain fog, headaches, fatigue - something that was just a constant part of my life before. I get in food ruts, but then I realize it's time to look at vegetarian/vegan recipes and start trying to adapt them. When I first started my journey back to diet my levels were over 150. The more I cleaned up my diet and the more adherent I was with my formula and betaine the better my levels became. My total homocysteine now is typically 17-20. Being consistent with the diet provides me the best health outcomes and allows me the opportunity to be present for my husband and 2 year old daughter. I'm thankful that I had a second chance and was provided the guidance and education to make my way back to diet.



Pictured, Danae's husband Matt, their daughter Dana, and Danae'