

# NAVIGATING YOUR CAREER WITH HCU

## A Personal Experience Story

by Danae' Bartke

Ever since I was a little girl I dreamed of being a teacher. I'd line up my dolls and stuffed animals and reteach them what I had been learning in preschool and school. My great-grandma, grandma, my mom, and my aunt were all teachers, so to me it always seemed like a no brainer – I was going to be a teacher.

Although it wasn't necessary, when I attended our local community college, I declared my major as Early Childhood Special Education. When it came time to transfer to a four-year university, I chose a school close to home (30 minutes away), so I could continue the job I had as a nanny. When I met with their admissions office, the advisor convinced me there were no jobs in Early Childhood Special Education, and I really should switch my major over to Elementary Education. So out of practicality I did. Throughout my college experience, I always worked full time as a nanny. For the majority of the time it was for the same family. I split my days up; Monday and Wednesday were my classes and then Tuesday, Thursday, Friday I worked 12-hour days. I had an additional job on the weekends getting groceries and cooking meals for the week for another family. I loved being busy with school and work, and I figured the experience as a nanny was a good choice for my resume.

I graduated college in December 2007 and decided I'd use that time to buckle down and start subbing and applying for teaching jobs for the following school year. The Spring came and went with no job offers and very few sub jobs. It was discouraging, but I was not about to give up. I thought I'd go a different route and started looking at daycare centers that offered preschool and kindergarten. In June 2008 I started working at a daycare center teaching preschool, it seemed like the perfect fit. I loved the enthusiasm and excitement the kids had for learning and loved watching them blossom in their academics and social skills. However, in September 2009, I had a blood clot due to Homocystinuria and the time in the hospital gave me time to think about my life. At the time of my blood clot, I was working splits, so I'd open and close and have an extended lunch. Long days made me exhausted and gave me little time to make sure I had time for healthy lunches that worked for HCU. It didn't allow me time to exercise, and because my regular prep time (their nap time) had been removed, I ended up planning at night. I knew I couldn't keep myself going at that pace and needed to take better care of myself and hopefully find a job too that had health insurance. So, I made the hard decision to quit my job and really pursue teaching, or subbing – something that would get me into the classroom.

This time around I was very busy with substitute teacher jobs. I was able to work full time and got to know many teachers and administrators in many schools. I learned a lot about teaching from subbing and used the time to hone my skills in the classroom. In 2010 I was offered a full-time job as a paraprofessional. It wasn't my dream job, but it got me in the door at a school and many of their para's eventually became teachers. With the encouragement of my aunt (who was a teacher), in 2011 I went

back to school while still working as a para to get an endorsement in English as a Second Language (ESL). In 2012 I completed my ESL endorsement and was offered a part time ESL position in the school I worked as a para. The other part of my day they kept me on as a para – I finally felt I was moving in the right direction. When the 2013-2014 year came to a close though, our district decided to restructure and move their ESL students to one school and my position was eliminated. They offered me a position as a full-time para, but I decided I needed to move on. Being a para I functioned in many ways as a teacher, but without the benefits – I had no planning time, no health benefits and the pay was alright at best.

At the same time that I started originally working as a substitute teacher, I started getting involved in the PKU Organization of Illinois (PKU IL ). Initially it started at just attending their low protein cooking classes, then their social events, then their educational workshops (it was more than just information on PKU). In 2013 I joined the PKU IL board as their Newsletter Coordinator. I was in charge of coordinating with various people in the community to find patient stories, diet advice columns, low protein recipes, events, and more. Despite having never done anything like this, I was told it was easy and I'd do great. Well, the first PKU Press I sent to the printing company was laughable at best. The printer emailed me back asking – is this really what you want to print? They offered to “fix it”. All the content was there, but not in the format they were used to. Embarrassed for myself, I replied I'd be glad to accept the help, but was determined to do better next time. So, I quickly threw myself into learning how to format newsletters and doing better graphic design for event flyers. It turned out that I loved it. Growing up I had 10 years of private art lessons, and this gave me a great creative outlet. I continued in this role until the end of 2015.

In January 2016, I was elected the PKU IL President. I was determined to clean things up for the organization, both figuratively and literally. The first thing I did was clean up the storage unit they had – we pitched over 80 gallons worth of outdated material and garbage. We organized the remainder so we didn't end up rebuying things we already had for future events. I also went through and restructured how events were done. Initially, each event was running start to finish by 1 person – it didn't make sense since all 11 board members were volunteers. I was determined to have everyone pull their weight! I created a Chair, a list of positions and jobs for each event. I created the rule that everyone needed to participate in so many events, that way it wasn't so stressful for the chair person. As the president, I also functioned as the National PKU Alliance Rep for Illinois and organized our annual meeting. I officially rolled off the PKU IL board in December 2017 after my term was up.

In July 2014 I did something I told myself I'd never do, I went to work for my mom. My mom runs a violin shop that my dad started in 1981. My mom had always asked me to work in the shop, and I always said I never would. This time though, her offer sounded good, but I told myself it would be temporary until I figured out my next move. At her shop, I was initially hired as a secretary. Quickly I added book keeper, inventory manager, route coordinator and office manager to my titles. My love for organization was key in these roles, but even with my obsession of organization, it was not meant to be. Working in a family business presents a lot of its own issues ,and I will leave it at that.

While working in my mom's shop and running PKU IL, I started another adventure. In 2015, Margie McGlynn (now HCU Network America's President and co-founder) reached out to me about possibly starting a non-profit with her for the Homocystinuria community. I was apprehensive because my plate

was so full between my job and PKU IL, but I also knew that this was finally my opportunity to do something for the Homocystinuria community – something I very badly wanted to do. In February 2016 in Prague, Czech Republic, I attended the first Homocystinuria Patient-Expert Meeting hosted by HCU Network Australia and European Network and Registry for Homocystinurias and Methylation Defects (E-HOD). At the end of this meeting, they had a session on starting other HCU organizations since there were families from the US, UK, Brazil and other European countries. It was pretty much at that moment when I made the decision to be 100% in.

“People are always blaming their circumstances for what they are. I don’t believe in circumstances. The people who get on in this world are the people who get up and look for the circumstance they want, and if they can’t find them, make them”

– George Bernard Shaw

After coming back from Prague, Margie started the necessary paperwork to get HCU Network America established. At record speed, by June 2016 HCU Network America was incorporated. Then just as fast as HCU Network America was incorporated, in October 2016 HCU Network America received their 501c3 status from the IRS. The first few months were extremely exciting (it still is almost 4 years later). In March 2017, I was hired part time to continue building upon HCU Network America’s mission on a daily basis. This truly is my dream job, and I feel honored to have it.

If someone would have told 10-year-old me (the year I was diagnosed), or even 20-year-old me I would one day co-found a non-profit for HCU, and it would become my full-time job I would have laughed. If someone told me at 16 I would one day work for my mom, I also would have said no way on earth. The point being life takes you to unexpected places and your path to the place you settle down isn’t always a straight line. The steps outlined in the previous part of the article (evaluate your skills, interest and abilities, know yourself, engage in trial and error) were all part of my process to get where I am now. Was it easy? No way! Was it worth it? Definitely! With determination and creativity you can find a job that makes you feel fulfilled too.

### **Meet Patient Parent Advisory Committee Member – Ruth Kelly!**



Ruth is a wife to Dan and mother to four children. They live in Cincinnati. Ruth & Dan's third child, Josie, has HCU. She was diagnosed while in kindergarten. While initially shocked, Ruth diligently read every medical article she could on HCU and listened to every available lecture. Ruth & Dan manage their daughter's diagnosis by tracking every gram of protein and her medication on a spreadsheet every day. Through the metabolic clinic in the genetics division of Cincinnati Children's Hospital, Ruth was referred to HCU Network America. By serving and supporting HCU Network America, Ruth hopes to help other parents navigate the many aspects of the diagnosis of their child. She also supports efforts for more accurate newborn screening. In addition, Ruth is an adoption attorney and advocates for foster children and adoption in general.