

# SARAH'S STORY:

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## How did you come to work at Nutricia?

February 12th marks my 23rd anniversary as a metabolic field sales rep. I joined Nutricia in December of 2012 when Nutricia acquired Applied Nutrition. At the start of my career, I was the first sales rep Applied Nutrition hired and only the sixth employee, including the husband-and-wife owners. My life experience combined with being an active member of the metabolic community introduced me to owners and resulted in them creating a role for me at the suggestion of a mutual acquaintance.

In the early days, I worked hand and hand with the owners to plan which metabolic clinics, conferences and events to visit. Over the years, I think I've visited nearly every metabolic clinic in the US and Canada. **During those years I was also able to provide a lot of feedback and input into product development and design which I really enjoyed.** My favorite project was as the primary developer of a small product line of low protein baking mixes called Maddy's.

I was happy when the acquisition of Applied Nutrition by Nutricia was announced in December of 2012 as I knew they offered high quality products and qualified people that worked in the field of metabolics. **Whenever things get challenging, I always remind myself how fortunate I am to work in an area that means so much to me personally.** It is a rare gift for anyone to be able to work in something that means so much to them, it is even rarer for someone with a rare disorder, such as PKU, to be able to do so.

## What is your experience living with PKU, your challenges and what gives you strength?

I was born in 1970 at a hospital just outside of Washington, DC. At 16 days old I was diagnosed with Classical PKU. The knowledge we have today about PKU is light years from where things were in 1970. My mom has told me that she wasn't sure if I was going to live or die when my parents first brought me for admission to Johns Hopkins. While that statement sounds funny now, even today, parents can be devastated when hearing their child has PKU. My parents didn't have the assurance that everything was going to be okay as even the medical professionals weren't completely sure what the future would hold.

In the early days of PKU management in the US, the standard of care was to remove diet at the age of 5 because prevailing medicine at the time thought brains were fully formed and developed by that age. Johns Hopkins Hospital was one of 15 participating sites in a longitudinal study starting at the time to examine the effects of diet continuation. The study ultimately resulted in the recommendation of "diet for life". I was lucky to be one of the 211 people enrolled in the study, but looking back it felt like we were guinea pigs. There is no doubt I benefited from being "under the microscope" but, to paraphrase the movie Gattaca: "When a flaw is looked at for so long, after a while the flaw is all that is seen".

**It is fair to say, I was the kid who hated PKU and hated having it. There wasn't a single person I knew who was like me and I felt utterly alone.** I went off diet at around the age of 10 by gradually not drinking my formula and "cheating". I don't advocate the path but I was able to complete college with honors (Political Science) and grad school (Policy Science) off diet. Like anyone, I have strengths and weaknesses. One could argue, my weaknesses are what have made me strong. **I returned to diet in early 1997 and went from being the kid who was dumping formula down the drain to working for a formula company.** Needless to say, my parents found it rather funny given my hatred of formula as a child.

Balancing the "extra" that goes along with a rare diagnosis can be a lot of times. I'm so fortunate that personally and professionally, I've been able to meet probably thousands of people with PKU and their families as well as clinicians and experts managing PKU from various parts of the world. **Some of my closest friends are PKU and their support along with the support of my parents is what gets me through.** I'd also be remiss if I didn't mention the best and most understanding co-workers that anyone could ask for!

## What is your dream for the future of PKU?

**2024 celebrates the 90th anniversary of the discovery by a scientist in Norway and a persistent mom of two mentally underdeveloped children. Please stop for a minute and think about what that really means.**

In the span of a lifetime, PKU has gone from discovery to timely identification in the neonate period and management to the point of completely mitigating the neurotoxic affects that previously meant profound developmental delay, to at least two people with PKU working at Danone Nutricia. The Danone motto of "Bringing health through food to as many people as possible" carries a little more of a special meaning when it comes to working at Nutricia and rare inborn errors of metabolism.

As far as we've come in the management of PKU, there is room for improvement. In the US, depending on which state you live in and which insurance you have, coverage of medical foods can be very difficult. In other parts of the world the reality is even harder. Developing countries have varying degrees of screening, access to medical foods and treatment is not a given. **It is humbling to know that if I had been born somewhere else, I might not have been screened or diagnosed, much less have access to the tools necessary to achieve full self-actualization.** While there will always be harsh realities of the world, screening and management of PKU and other rare inborn errors of metabolism (IEM) shouldn't be one of those.

**Far more than a dream and hope for the future, it is an obligation to provide the same level of care for people with an IEM no matter where they are born!**