

Empowered by *Hope*

It is our hope that this publication will encourage you to see past the diagnosis and see your child through your eyes, and not a definition of PWS. Each child with PWS will be affected in different ways by this syndrome. We are on the cusp of many breakthroughs for treatments, and the future is very optimistic.

These are just some of the stories* that you will likely hear and read, from some

of the wonderful families that will embrace and support you through your journey. One of the biggest gifts from PWS is the community: the fact that you are NOT alone in this. We have a community that celebrates every victory and applauds even the smallest successes!

This community and PWSA | USA will always be here for you.

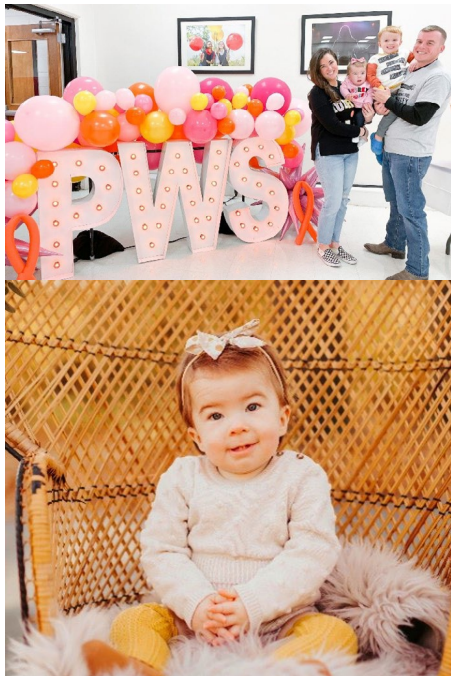




Like everyone, we felt lost after receiving Lily's diagnosis. Our genetics counselor from the NICU did some research for us (she warned us to stay away from Google) and recommended we start by submitting a 'New Diagnosis Form' on the PWSA | USA site. A parent advocate called my husband soon after and let us know that we were not alone in this. She also advised us to do two things as soon as possible: find a PWS specialist and start growth hormone. That conversation is what led us to visit Dr. Jennifer Miller in Florida. Thanks to PWSA | USA, we had our first meeting with Dr. Miller when Lily was just six months old and started her growth hormone soon after.

We learned early on not to spend a second thinking "why us?" While we dealt with Lily's diagnosis in our own ways, we know that that question has no good answer. It's also the wrong question to ask since it assumes something is wrong, and there is nothing wrong with Lily. We're all born a little different, she more than others, but she's feisty, and silly, and so cute, and exactly what this world needs. So, for us, it took very little time to adjust to this new life, but it helped us immensely to never think "why us" and to focus on how amazing Lily and Layla truly are.

- Huma Onorato, Mom to Lily



When we first received Audrey's diagnosis, we were devastated. Our extended families were devastated. I hated telling people the name of the syndrome because I knew they would Google it and see the misleading Wikipedia page, after doing the exact same thing myself. The Social Worker from the hospital said she did a quick search and found a support group for Prader-Willi syndrome, so I filled out the new parent form and read. I read everything there was to read on the website, over and over again to get a grasp on what this diagnosis could mean for our family. Emphasis on could, because PWS has such a wide range and affects every person a little bit differently. It was then that other moms reached out and I felt comfortable to reach out to other moms with a child of the same age. It is because of this group I have connected with another mom and whenever we have a bad, scary, or unnerving thought about anything we pick up the phone. It is nice to not feel judged for your thoughts and have someone who completely gets it as a safe place to land after having those types of thoughts.

Just know the beginning is scary and the unknown is frustrating but once you can get past the initial shock of a diagnosis, you will realize you still have a beautiful, loved child who is yours. PWS will change you, challenge you, and honestly give a whole new meaning to your world. PWS is scary, but with such a strong community, you never feel alone.

- Michelle Spring, Mom to Audrey



Shealynn's journey with PWS started at birth on New Year's Eve. Right after she was born as the clock struck midnight, we received the news. Shealynn had to be transferred to a different hospital and admitted to the NICU. We had no answers, just that she wasn't doing well and not feeding. Against everyone's advice, I decided the next day to sign out of the hospital I was to be by her side. It was days and nights in the NICU with no answers. After two months, we received the life-changing news: Shealynn Grace Williams has Prader-Willi syndrome.

My first question was, what is Prader-Willi syndrome? We then were told probably all the negatives possible, and until Shealynn bottle feeds her full bottle for a full week, she couldn't go home. My husband Gregg and I cried, and I ran out of the meeting room feeling alone, lost, and with nowhere to turn. At least that's what I thought. That night, I did all my research and requested PWSA | USA on Facebook. They immediately reached out and sent me information to better understand PWS and the healthcare that would be needed. The next day, I called a meeting with the NICU director, nurses, social worker, and genetics team and gave them the PWSA | USA information and booklets. That very day, we scheduled the Gtube surgery, and a week later came home. PWSA | USA also assigned me a mommy mentor, Noelle. She came to the NICU to visit, and she was just amazing and so helpful. It was exactly what I needed during such a hard time. Someone who was there and would understand all the feelings and help answer questions that come with a diagnosis like PWS. I still turn to her with questions three years later. Without the help of PWSA | USA, none of this would have been possible. We would've been in the NICU believing we were the only people in the world going through this. I can't thank PWSA | USA enough for all the help, support, and impact they've had in our lives.

Shealynn is now a three-year-old toddler who is growing and thriving. She tends to surprise me with her witty ways, just an overall amazing personality and little person filled with so much love to give.

- Sujeiri Colon, Mom to Shealynn