

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.





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