

A Personal Inspiration 2014

In August of 2011, our daughter Brooke was born. She is our third child, and while having a baby is never routine, we thought we at least sort of knew what to expect. After delivery, Brooke was not showing signs of thriving. She was barely moving, she was not crying, she was sleeping even more than a normal new-born, and most importantly, she didn't have the ability to suckle so she couldn't feed on her own. This led to her being dependent on a feeding tube, and a stay in the hospital of just over two weeks.



That is not much compared to what many other PWS families endure, but to us, without any notion of the cause or what the future held, it felt like a lifetime. While the doctors performed all kinds of scans and tests to try to determine what the problem might be with Brooke, all we could do was wait, hope, and pray for the best.

We were extremely happy when Brooke got strong enough to feed on her own and was discharged, but we still didn't know what to expect going forward. We went to a ton of doctors appointments hoping for a diagnosis, but Brooke continued to stump everyone. In the meanwhile, though, she started to hit little mile-stones that were very important to her development. Finishing whole bottles of milk. Making a little bit of a cry. And best of all – smiling – which showed us that there was a little person trying to surface, inside her weak-muscled little body.

Just after our first Christmas with Brooke who was then 5 months old, we got a very special gift, of sorts. A gift of knowing. After the third round of genetic tests, the geneticist told us that Brooke had something called Prader-Willi Syndrome, or PWS for short. And thus began our PWS journey. On the day we received the diagnosis we cried, we panicked, we went through the whole range of emotions that you get when you receive any life-altering news. But we also made the firm decision that we would not succumb to hope-lessness. We would be strong for Brooke. We would fight, and never give up. There and then we adopted the motto "Keep Moving Forward". We started making plans to live by this motto in our PWS journey. We created a Facebook page to not only create awareness about PWS, but also to share Brooke's successes and hardships with others. We joined organizations and special parent groups. We started attending PWS conferences, and became committee members for the Canadian National FPWR Conference and Toronto Gala as well. We've networked with other PWS families and worked at spreading awareness in our community, and this year we will be hosting our third annual One SMALL Step walkathon to raise funds for the Foundation for Prader-Willi Research. We know that FPWR is funding the best possible research in the world, and what better way to keep moving forward than support the best chance the PWS community has for a cure!

Brooke will turn 3 this year. She has blossomed into an amazing, friendly, energetic and inspirational preschooler. With the help of many professionals, Brooke has met most of her infant and toddler developmental milestones,

even if they've come a bit late. She still struggles with speech delays, and continues her endless therapy and doctor appointments for endocrinology, neurology, orthopedics, and sleep clinics. She gets a GH needle every night, which she endures like a champ, and during playtime she pretends to give shots to her dolls too.

We have encouraged Brooke to know no limits and continuously challenge herself, and her determination to love life has no bounds. She never gets tired from learning and keeping up with her siblings. Although she is still young, she has developed a definitive love and interest in things like music and dancing, colouring, puzzles, and animals. She surprises us everyday with her triumphs and strong will to be the best she can be! She inspires us to realize our blessings and therefore we have become a stronger family unit and a driving force advocating for our daughter. Like all parents, we want the best for our children and to give them the best quality of life they deserve. This is our driver to Keep Moving Forward.

Sincerely,

Jack and Belinda Jones

