A Personal Inspiration 2015

March 9, 2011, after a very typical, worry free pregnancy, our son Daniel was born. Our second child, after our daughter (who caused us much stress during pregnancy with multiple ultrasounds and doctor's appointments - but, in the end, was born perfectly healthy).

After a very quick, intervention free delivery, Daniel spent the night next to me in the maternity ward. He wasn't terribly alert and didn't seem interested in eating. He barely moved, did not cry, and was excessively sleepy.

After 24 hours Daniel was moved to the NICU where he spent 10 days, until his diagnosis of Prader-Willi Syndrome (PWS) came in. We were discharged on March 19 and sent home, Daniel with an NG tube for feeding, a letter stating his diagnosis, and really nothing more to help us on our journey.

Here we were, home, settling in, and researching any and everything we could find about PWS. We spent the first month of Daniel's little life grieving for the little boy we thought we were going to have, all the things we thought we were going to do with him, the loss of the life we had expected. Then, one day, we sort of 'woke up'. The lightbulbs came on and we realized, this did not happen to us, this diagnosis happened to Daniel, and it did not change the amazing person he was born to be. It was now our job, as his parents, to make sure he had all the tools and resources necessary to become that amazing person! And so, our journey truly began. Our new attitude was not one of "woe is me" it was one of "we CAN and WILL help our son".

We immediately reached out to other PWS families in our area, and quickly developed lasting friendships with our new circle of friends.

We attended our first One Small Step walk when Daniel was just 5 months old and have attended every Calgary, and Edmonton walk since. We've attended PWS conferences, and even hosted a Pub Night fundraiser 2 years ago in Calgary, just months before the birth of our third child!

We know that FPWR is funding the best possible research in the world and what better way to help our son than to support the best possibility the PWS community has for a cure!

Daniel turned 4 this year. Although the insatiable hunger hasn't surfaced yet, he has certainly faced more than his fair share of challenges. Scoliosis being the biggest obstacle on his journey thus far. Daniel underwent the initial surgery to put rods in his back in April. The second procedure will happen sometime in the fall of 2015. Thankfully this has not stopped him from blossoming into an energetic and inspirational preschooler.

With the help of many professionals, Daniel has met his infant and toddler developmental milestones, albeit late. He still struggles with speech delays, and fine and gross motor delays, and continues his endless therapy and doctor appointments, but he lets none of these things slow him down!

We have encouraged Daniel to know no limits and challenge himself, and his determination to love life has no bounds. He surprises us every day with his triumphs and resilience, to be the best he can be!

Having a child with PWS has changed our family, it has made us stronger, it has made us more patient, it has made us better overall. Daniel has taught us that he may have Prader-Willi Syndrome, but Prader-Willi Syndrome will never have him! It is only a tiny part of who he is, and who he is, is amazing!