A Personal Inspiration 2015

Our journey began on September 27, 2013 with the birth of our first child, a beautiful girl we named Darwin Eleanor. Being first-time parents we knew we were unprepared but we had no idea how true this statement would hold. Darwin was a planned c-section and we expected a routine birth. There were no indications that there was anything for concern; in fact the pregnancy was text-book. All this changed immediately though. Darwin's birth was a silent affair. We told ourselves "just because she doesn't cry it doesn't mean there is something wrong." But as the delivery room went from 8 to 9 to 12 to 18 healthcare professionals we knew this was not the journey we had prepared for.

Outwardly Darwin looked like any other newborn but the silence that accompanied her was deafening. Soon it was apparent that she was as limp as a rag doll and could not suckle, earning her the title "failure to thrive" – such a foreign term for two people expecting their typical baby.

With this the watching, waiting and testing began. We were lucky that Darwin was a big baby – 8 pounds 8 ounces, with no immediate medical concerns – so we were able to avoid the NICU experience that so many other families must endure. After 4 days we were sent home with a week of daily appointments scheduled. Test after test followed and week after week passed, then we received a call from the pediatrician asking us to come in the following day. Friday, October 27, 2013 – Darwin's 1-month birthday – was the day we first heard the words Prader-Willi Syndrome uttered. We were devastated.

I don't remember leaving the pediatrician's office. In fact I don't remember much of the week that followed. I cried non-stop, I couldn't eat. I felt so alone in my new-found reality. It soon became concerningly apparent to those around us that I needed help. After repeated, unanswered calls to suicide prevention lines, Mark called 911 and I was taken in for observation. No one knew what to do. No one knew what to say, I even made the on-staff social worker cry. I was sent home with drugs to help me sleep. After another 2 days of darkness I voluntarily admitted myself to 9C, the Mount Sinai psychiatric ward – Darwin's diagnosis had broken me.

Through this time Mark was amazing and I can honestly say that I wouldn't be here without him. He attended to Darwin and arranged a bevy of family and friends to take shifts to help in her care. He went to all of her appointments, visited with me on the ward multiple times a day and made contact with Foundation for Prader-Willi Research Canada (FPWR Canada). He was in survival mode and doing what he could to save his new family.

Mark found that knowledge was power so he began educating himself on PWS and fed this information to me during our visits. He began reaching out to the PWS community and we soon found that we really weren't alone in this. There was a caring, organized and driven group of parents and caregivers advocating for their children – our children – raising funds for research and symptom mitigation. This support and the knowledge that we didn't have to sit idly by waiting for the future to unfold helped us to move forward and put the darkest time of our lives behind us.

We have become active in the PWS community and with FPWR Canada. We found that what we needed most after our diagnosis was someone to talk to who understood what Darwin's diagnosis meant for our future as a family - someone to help us sort through the new vocabulary of medical terms and appointments and specialists that are now a part of our lives. We felt like this is what could have helped to mitigate some of the initial difficulties that we encountered, and decided that we wanted to help other newly diagnosed families as they begin their unforeseen journey. To date we have reached out and been first contact for three local families, creating friendships and building a support system that will help us all. Mark has joined the Growth Hormone Access Committee as a way to channel his energies and has also spoken at a number of events to raise awareness for PWS over the past year. We attended the 2014 FPWR Convention and took part in 2 One Small Step Walks (contributing over $15,000 to research thanks to the combined efforts of our family and friends).

With your support, FPWR Canada is not only helping our daughter Darwin and all those living with Prader-Willi Syndrome, it is also helping families by providing a sense of control over their future – a life-line in coming to terms with a difficult and frightening diagnosis.

Sincerely,

Jennifer, Mark & Darwin Joseph