A Personal Inspiration 2009

We first heard the name Prader-Willi Syndrome 6 days after the birth of our daughter Kloe on May 28th 2003. The formal diagnosis by deletion would be confirmed 2 days later but wasn't necessary for us to accept because the signs and symptoms of our new baby were textbook typical for an infant with PWS. Initially we didn't realize that having this diagnosis would be much better than many other possibilities. This is because the information of an older child and adult along with the delivery of what to expect by doctors was very devastating news. Later we would find the clinical portrayal of the syndrome could have a more positive outcome when various treatments were applied. With the lack of medical support and research about PWS at the time, this wouldn't be an easy journey. We were faced with more questions than answers; would Kloe achieve higher education, have a career, raise a family of her own; would our marriage be strong enough to persevere through the challenges of raising a child with exceptional needs; who would advocate for Kloe when were gone???????

We began our journey by being very guarded about Kloe's diagnosis around extended family and friends. This was partly a grieving process and mostly us not wanting people to treat Kloe differently. We didn't want stigma to impede her potential socially, academically, mentally or physically. In time, we overcame our anguish with determination to provide the best opportunities for Kloe to grow into her beautiful being and have a very meaningful and rewarding life. This meant we had to let our guards down and inform and educate our family, friends, doctors, teachers, caregivers, the community and ourselves. We also knew that we wanted parents new to a PWS diagnosis to have a new day and get a head start on treatments as soon as possible for their child. We had seen ourselves the difference it had made when comparing our child to the expectations of the syndrome. We knew that growth hormone, physio, occupational, speech and language therapies all played a very important role in this difference.

Kloe inspired us to become part of this new day. The strength and determination she has to conquer everyday of her life gives us encouragement to get involved and keep pushing to bring new information and hope forward. Kloe and Prader-Willi Syndrome have brought meaningful people to our lives that we think of as real friends - people who have taught us, people who have learned from us and people who empathize and support us every step of the way to keep moving forward to make a difference. The Foundation For Prader-Willi Research Canada is made up of some of these people who continue to drive us forward with hope. We did "Choose To Believe" that Kloe would have a successful future and happy life. After all, this is what any parent wishes for their child.

Danielle and Kirk Livingston