A Personal Inspiration 2013

On November 5th 2010, our little princess Giulianna was born. She was perfect: Pink, cute, and calm – very calm … too calm… When we took her home, we realized something was wrong. We were force feeding her, with a syringe because she couldn't breastfeed or suck on a bottle. She would not gain enough weight and was constantly sleeping. Finally, we consulted. The doctor was not sure and ordered tests. And our adventure began. I cringed the first time they put a needle in her arm, but little did I know this was the first of many. She stayed in the hospital for 3 weeks. It was getting close to Christmas so they allowed us to go home as long as we used the NG tube to feed her. We enjoyed the holidays and really believed there was nothing wrong and she would be just fine.

On January 31st 2011, we went in for what we thought was a routine check-up. That is when we got the diagnosis of Prader-Willi Syndrome. The picture of my beautiful princess melted away and was replaced by the large list of symptoms that we were informed she would likely have to endure. This could not be. This doesn't happen to us. We were healthy. I think I cried all the tears in my heart that week. Like many, I of course turned to the internet. I read the horrific experiences and the news reports on people with PWS. I found out about Prader-Willi Syndrome Association (USA) and called them to try and get some information – weeping as I was talking to the person at the end of the line. Then I came across the fpwr.ca website and read to stop here, as most of the information on the internet is obsolete. After watching a YouTube video of Tanya and Keegan with Dante, I was relieved when Keegan said "if only I knew then what I know now".

My Giulianna has had more invasive tests in her 2 years of life than any typical person will have in a lifetime. She is, however, so strong and resilient. Since the PWS diagnosis she has indeed been afflicted with some of the symptoms such as strabismus, scoliosis, developmental delays, speech delay and the beginning of her high interest in food. She is seen at least twice a week by some specialist or therapist and accepts to take a needle of GH every night. She wears glasses and a back brace and she will show them to you by pointing them out as she is proud she can endure wearing them. She loves puppies, stuffed toys and jewellery that sparkles, especially bracelets. She is so social, even when I am sad and feel overwhelmed, she just needs to crawl into the room and give me a huge hug and life is perfect again.

We attended the Toronto Gala and Conference in April 2011 – Giulianna was five months old and had just started to drink her bottle with no tube. Like other PWS families, we felt scared and helpless. Yet talking with Tanya and Keegan helped us immensely as we later felt encouraged to do more. And more we did, as we too hosted a walk in August of that same year. But we didn't stop there! Three months later on Giulianna's 1st birthday, we hosted the 1st Montreal Gala. In 2012, we helped a then newly diagnosed family to start hosting their own walk as well in our city, and we later hosted the 2nd Montreal Gala. However we stepped it up by having the first Medical Conference in Montreal that same week-end. In our short 2 years of fundraising involvement we have raised over $40,000 for Prader-Willi research. We have also created a pamphlet for newly diagnosed families in the province of Quebec, and an electronic package that identifies nutritional guides, educational information on PWS, plus necessary steps involved on how to incorporate growth hormone (GH) into their child's care regime, along with information on how to potentially seek GH financial assistance if required. In addition to being active members of the Quebec association, we are also part of a North American committee working on creating a "First Steps" information package (digital form) for newly diagnosed families in North America. Sometimes we might think we cannot do much. But for us, doing nothing is worse. We love Giulianna, to the moon and back – and if that's what it takes, that's how far we will go. Our hope is to find treatments to help control the various PWS symptoms and help people who have PWS lead a life that is full and independent.

One day, we will say, it was all worth it.

Sincerely,

Carole, Marco & Christopher Del Cane