



Running for a Reason

By Gary Williams

It's been almost 5 months since I made a decision that would affect not only my life, but the life and family of a little girl. That little girl belongs to some very dear friends of mine who have become even closer friends since her birth.

Julia (pictured on next page) came into the world on July 12 and since that day has been fighting a battle against a genetic disorder that many will never hear about until they are personally touched by it. The disease is called Prader-Willi Syndrome (PWS).

Prader-Willi Syndrome is an organic brain disorder which is generally caused by a deletion in Chromosome 15. The current incidence of PWS is 1 in 12,000 births. PWS is a complex genetic disorder that includes short stature, mental retardation or learning disabilities, incomplete sexual development, characteristic behaviour

problems, low muscle tone, and an involuntary urge to eat constantly, which, coupled with a reduced need for calories, leads to obesity.

At first it was devastating news for me, and I couldn't even imagine how my friends felt. When Julia was born doctors knew there was a problem but couldn't confirm anything for weeks, it took that long to get the results of the genetic tests back. During that time I didn't know what Julia was dealing with and my mind started thinking the worst. So did the minds of my friends. It went from Julia being in a wheel-chair for the rest of her life to many other devastating disorders. It was a troubling and uncertain time.

Finally I found out that it was Prader-Willi Syndrome. I had no clue what Prader-Willi Syndrome was. My friends explained to me that basically the biggest problem, besides the slow development



and learning difficulties, is that Julia would have a strong urge to eat constantly without feeling full. This would lead to obesity problems, and of course with obesity comes many other health issues.

I could see the pain in the eyes of my friends. I didn't know what to do. How do you comfort someone when you yourself feel like this is basically the worst thing that could have happened?

It took a couple of months until I really started to understand what exactly PWS was. It helped seeing Julia. She is a beautiful little girl that, besides being a little less responsive than normal, looks like a very typical baby.

Even though I was beginning to feel more comfortable around Julia and understood the syndrome much better, I was still struggling with how I could show my friends that I supported them



and their daughter. I wanted them to know that I would do whatever I could to help Julia along the way throughout her life.

It was then I started thinking about the challenges she will face when she begins to grow up, such as obesity. Oddly enough at that same time I was struggling with my own weight issues. I had steadily been packing on the pounds and found myself at a very unhealthy weight. And I couldn't exactly help Julia with maintaining her weight if I myself was overweight.

November had quickly rolled around and I knew that the holidays would only add to my own "weight woes" so I had to do something. And then I had my revelation that has now changed my life. I figured the only way I was going to stick to the challenge of losing some weight was giving myself a tough, but obtainable, goal to keep me going. And it just so happened that my goal had a two pronged result, helping me and Julia. What I

decided to do is to run the half marathon (21 kms) at the annual Mississauga Marathon. In addition, I decided to raise funds and awareness in support of PWS.

Well, I'm proud to say that since that day I haven't looked back. I'm down 8 pant sizes and 45 pounds, I've recruited six more runners to help me collect funds for PWS and I feel great. I haven't been this fit since early high school. I've had to clean out my closet as nothing fits any more. I'm running 16 kms on a regular basis now working my way up to 21 kms – all this and I have never ever been a runner.

The best part, besides the weight loss, is being able to look at my friends and know that I am doing something for them, for Julia. If I can provide them with the slightest ounce of hope and optimism then I've accomplished what I set out to do. I want them to realize that anything is possible.



So thanks Julia! Without even knowing it you've provided me with a life changing experience. One that has re-energized me and (I hope) has inspired others to get fit.

For more information about Prader-Willi Syndrome go to www.opwsa.com