

## I Wasn't Really Expected to Live

Montreal, December 1970. My mother went through 44 hours of labour and when I arrived the room fell silent, even I was silent. The doctor didn't slap my behind so my mother knew something wasn't right. The nurse whisked me away. Little did my parents know that I, their first born, would change their lives forever, in so many ways.

Spina bifida (myelomeningocele) was the diagnosis. My parents had never heard of any such thing much less pronounce it. I remained in the hospital for about 2 weeks. My parents were devastated and didn't know what to do. We were a family with very little means and no education. Nonetheless there I was and even though doctors said that my life expectancy was weak, time would reveal the truth.

My first surgery was at six months. My mother couldn't bear seeing me in so much pain and she became deeply affected with depression and despair. To this day, I don't know how she kept a level head and made the decisions she did. Although I was a bright, happy baby and child, it was torture for my mother. My father couldn't bear it and didn't have the courage and will my mother had. After my sister was born my parents divorced although my father was always a part of our lives. My mother was the one who carried us and I commend her for that.

I started to walk at 12 months old, which baffled the medical profession. By then I had already defied the odds of being alive. The second surgery came when I was 2 years old. At twelve, further surgery rerouted the muscle in my right thigh to create an anal sphincter that gave me the control of retention. I can't explain how that changed my life. A few years later, another surgery at sixteen enabled me to be free from diapers and those horrid socially devastating incontinence issues.

School brought a great influence to who I am today. I just couldn't wait to learn new things and make friends. Little did I know how difficult it would be. My world turned into a complete disappointment.



*Katty's life with spina bifida has not been easy, but she faces the challenges and welcomes the good times with the same passion.*

My social life was always a mess; school was horrible. I loved to learn but the problem was the students, most of the teachers and an administration that wanted nothing to do with me. Back then, kids with disabilities didn't belong in regular schools, my mother spent every day at school to provide the support I needed. Socially, I was a complete outcast, ostracized by the other children. At school I was alone. People didn't understand. Awareness and social acceptance were not the social norm. My heart broke over and over again having to deal with the constant social neglect. I had no friends. I was bullied every single day.

In elementary school I joined track and field. I loved running and I wanted to win the gold. I never won the gold, of course. The back of my legs are partially paralyzed, I have clubbed feet, my left leg is missing some parts, and it is 2 cm shorter than the right. Let's just say that I wasn't seen as a threat to the competition. I was determined not to come in last if I couldn't come in first. And, no matter how many races I ran, I never came in last. I was unstoppable.

I'll always remember the time I ran when I was 14 years old. I was coming into my final turn and there was one girl behind me. You can't imagine how much I tried pushing my body; there was no way I was coming in last. I couldn't do it, so about 40m from the finish line my mother and sister each grabbed a hold of an arm, my feet lifted from the ground and they carried me across the finish line. I didn't finish last that day. That day reminds me that no matter what I set out to do, there will always be someone there to carry my spirit. I'm never alone and I've always been blessed with people that have helped me across that finish line. In return, I do the same for others.

Eleven years ago, I was blessed with the most amazing miracle of all, my daughter Sabrina. I was told that having children would either be impossible or detrimental to my health. The pregnancy went very well and my daughter was born healthy, however I can't have any more children because I wish to continue walking. Being a mother is the best thing I've ever done. I wake up every day grateful to see my beautiful girl.

Last year, Sabrina asked me if having a disability bothered me. "Yes", I told her. But I accept that it is what it is and even though it's challenging and sometimes frustrates me, I'm fine with it. Besides, I wouldn't be the person I am today without it.

I now teach grade 5 at Princess Anne French Immersion in London. I am so happy and excited to go to work every day. It's not really work for me, it's too much fun. I get to work with amazing people and the students are just incredible. I can't put into words how unbelievably happy I am to have found my passion and live it every day.

I'm forever grateful to my mother for loving me, for making the right decisions, for encouraging me, for never letting others tell her what couldn't be, for being there for me every step of the way and especially for believing in me. It wasn't always easy but thanks to the wonderful support from the Spina Bifida Association, it made it easier.

I'm grateful to be here, to live my life and to make it count. It is difficult sometimes, as pain and sorrow must be endured. Yes, I know the meaning of discrimination and injustice that comes with life. Yes, I've been disappointed. I also know that it all comes together and at the end of the day it will all be right. I know when to trust my instinct and go for what I want; sometimes I get it and sometimes I move on. Nonetheless I gain great personal growth. There are no mistakes, just life lessons that are there to enrich my life. I don't know what the future holds. Will it be good? I hope so. Will it test my spirit? Probably. Will it work out? Of course it will. I intend to live to be 100 and who knows, with my determination there's a really good chance.

Katty has a tremendous passion for life but it has not been easy. With the support of others, she has crossed many hurdles. Hydrocephalus Canada, formerly The Spina Bifida and Hydrocephalus Association of Ontario, was there for her as well. We provided information about Folic Acid, ergonomics in the workplace and provided referrals regarding disability support. We also connected her to another adult with spina bifida so they could share experiences and coping strategies. In 2001, she won one of our scholarship awards that helped her achieve her post-secondary education goals.

## Hydrocephalus Canada

We are the voice of  
Canadians living with hydrocephalus and spina bifida.

Every day we strive to empower those impacted by both conditions to experience the best life possible.

We do this by establishing environments that protect, support and enhance the lives of those living with, or at risk of developing, these conditions.



Bridging, Advocacy, Research & Innovation  
With Awareness, Education & Support

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