

## "This is the first time I have publicly shared my story" - Jacqueline Bell

When I was four years old, my life changed forever. On November 30, 1963, I was in a terrible head-on collision and fell into a coma. **Two and half weeks later, I woke up in a hospital, with my right-side paralyzed and unable to speak.**

My father's legs were crushed; causing fractures that left him in casts for several months and kept him in life-long chronic pain. My mother was severely cut and bruised but was largely physically spared from our accident. However, the wounds weighed on her emotionally for the rest of her life.

After three weeks in the hospital, I began showing movement in my right-shoulder and was sent home to be with my family on Christmas Eve. While I regained my speech, my right-side began twisting inwards. **My right-ankle twisted so much that I had to walk on the outside of my foot. I walked like this until I was seven, when I could no longer walk and was forced into a wheelchair.**



*Me at 14, just before my first thalamotomy surgery (predecessor to Deep Brain Stimulation), which I underwent three times because the results would always wear off.*



*Me and my mom. I had just turned 12 in this photo, and you can notice, I'm holding my right arm in an attempt conceal it.*

With no formal diagnosis, I underwent numerous surgeries at 10 different hospitals. Initially, each surgery was successful. I would spend weeks at home seemingly getting better. However, like clockwork, my right-side would twist again and I was back in a wheelchair. I would then spend weeks in the hospital undergoing tests, treatments, and surgeries. **This cycle went on for years: two weeks at home, two weeks at the hospital.** Doctors were puzzled by my symptoms, and it wasn't until I was 12, when I first heard the word dystonia. Eventually, I was diagnosed with secondary dystonia caused by trauma.

**Because of my disability, society tried to limit me.** In high school, I couldn't take classes on the second floor because I couldn't walk up the stairs; there was no elevator and no consideration for people with disabilities. Even if I excelled in a subject, if it was upstairs, I couldn't attend.

During high school, I decided my dystonia wasn't going to hold me back. No longer would I allow people to put me down or get in my way. Regardless of how long it took me to do things, I had the conviction to lead an independent life.

## **My life blossomed, despite my dystonia**

In 1978, I met my husband, John. He had been in a car accident the year prior resulting in a brain injury that left him largely unable to speak. Although we struggled to communicate, we bonded over our similar life experiences and shared interests.



*Me with one of my greatest supporters: John Bell*

With John's encouragement, I attended college. I still used a wheelchair occasionally and struggled with commuting to school, but I persevered and eventually became a Developmental Service Worker. **For me, my education and my career were proof that I could achieve anything.**

In 1985, John and I got married and by 1990, we were raising two wonderful boys. It was a monumental task for two people with disabilities to raise children, but we managed. 36 years later, John and I are still married and over the last three years have welcomed two amazing grandsons to our family.

More than a decade ago, I was introduced to DMRF Canada, and I joined the Toronto-area support group. Our close-knit group has bonded over our experiences and shared struggles, and **for the first time in my life, I was welcomed to a community of people just like me.** Without the peer-support network I discovered through DMRF Canada, my life would be far emptier.

As the only foundation in Canada dedicated to the dystonia community, I know what a crucial role they play in finding better treatments and a cure for dystonia. Continued updates on DMRF-funded research findings renews my hope for a cure for this devastating disorder.

My car accident still plagues me 57 years later. I have never regained the use of my right-arm and hand, and some days I still need my wheelchair. I have undergone over 40 operations, and I take regular medication and require several treatments a year to help control the pain and muscle spasms.

**Yet, I am grateful for my life.** My wonderful family and support system including my brilliant doctors, nurses, and therapists, has fueled me to achieve my goals, despite the challenges that dystonia has brought. The community that I've found through DMRF Canada has provided me with purpose and has inspired my passion for disability awareness and advocacy.

**I am proud of my story and honored to be able to share it, but it is just one of tens of thousands.**

*Jacqueline Bell*

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*This is me today. No longer trying to conceal my right-arm in photos. All my life, I have refused to give up, and I am proud of the life that I've fought for.*