

It Was The Worst Possible News

Instead of the happy words and smiles you might expect on your birthday, I was greeted by concerned looks from the doctor, anxious whispers from the nurses and the heartbreaking sound of my mother crying. At least that's how I imagine the scene when I was born, in a Northern Ontario mining town, more than 40 years ago. The truth is, I came into this world different – I have spina bifida. Here's my story.

Soon after I was born, it became apparent that I needed more specialized care than could be provided in Sudbury – the doctors told my parents that I wouldn't even be able to sit up. Just two weeks into my life I was headed to Toronto for surgery at Toronto's Hospital for Sick Children – "Sick Kids" to us veterans. My parents packed up the car and we headed south.

Worried about their son and unfamiliar with the roads, Mom and Dad were halfway to London before they realized we were lost. The story goes that a kind police officer found us on the side of the road and offered to lead us to the hospital; his siren and lights cutting a path through the snow and confusion.

The next day I had surgery to close the lesion on my back. My parents were introduced to a true giant – Dr. E. Bruce Hendrick. The father of pediatric neurosurgery saved my life and gave me hope for a future. Although in and out of hospitals many times, my parents fought to give me every opportunity to make the most of my life.

Apparently, opportunity begins at school. So I was told. But, just getting there proved to be the biggest challenge. Buses were not accessible and neither were many schools. I was sad to be separated from my childhood friends when I had to go to another school in grade six because it was wheelchair accessible. I finally got into the classroom, but my frustration didn't end there. I had to endure being told that I was lazy and not "applying myself" when I knew in my heart that I was trying. I know now that the bad marks had "almost" everything to do with my spina bifida.



Steve (right) and wife, Joanne (left).

Somehow, through it all, I knew just how important school would be. You see I came from a blue-collar family. My Dad and later my Step-Father worked at very demanding jobs to support the family. My path would have to be different. Being paralyzed from the waist down because of spina bifida meant that I would have to use my brain to make a living.

At Laurentian University, in Sudbury, I studied Economics. It was there that I finally learned to appreciate the value of education and I started having fun! During this time, I worked for the university newspaper as a photographer. Photography got me through university. I graduated with shiny new skills, and brimming with excitement for what was to come.

I moved to Toronto to work for a bank. It didn't take very long for me to discover that I was not meant for a career in financial services. I spent the next two years looking for more suitable work. What an emotional roller coaster! I had to dig deep to find the motivation to send a flurry of resumes, only to get no positive responses and end up feeling useless.

I Never Felt Crippled Until I Couldn't Support Myself

I'll bet you're wondering how I got through that dark time in my life. I met Joanne, now my wife, who stuck with me and wouldn't let me give up.

Her unwavering support and encouragement were the greatest gift I could ever receive; I cannot imagine life without her. I was welcomed into a new family of friends. One worked for an organization that as it turns out, was of great help to my parents as I was growing up.

The Spina Bifida and Hydrocephalus Association of Ontario (SB&H) was a lifeline supporting my parents and providing much-needed information during those difficult early years. Over 40 years ago, SB&H was there for my family in every way.

My life has come full-circle. I am the Programs & Services Coordinator at the Association. For almost 20 years, I have been part of the dedicated team that helps individuals struggling with the challenges of spina bifida and/or hydrocephalus. I've seen young people with these conditions gain confidence and find their way in the world. The self-confidence I have developed working for SB&H has made me feel like I could achieve my dream of being a professional photographer and artist. I get to spend some time making a difference with my camera as well as supporting others to get the most out of their lives – it doesn't get much better than that. However, I have also seen too many families shattered by the loss of a loved one from some complication stemming from spina bifida or hydrocephalus.

My story is still being written and so is the history of the Spina Bifida and Hydrocephalus Association of Ontario. I encourage you to be a part of the future of this brilliant organization. SB&H is a beacon of light that grows brighter each time you give generously. You make it possible for us to continue our work and find new ways to support individuals and families. We receive no government or United Way funding.

Thank you for your contributions to SB&H. People like me have benefited greatly from your past donations. I urge you to renew your support of SB&H with your gift of \$40, \$60, \$80, \$100 or whatever you can afford at this time. Consider joining our 'Monthly Giving Club'. Giving through the Club is easy and convenient for you and it provides the Association with stable, predictable funds for our critical work.

Your thoughtful gift today will ensure that SB&H will be there when it matters most. Your donation will enable us to continue delivering direct support, guidance, information and referrals to parents and adults with spina bifida and/or hydrocephalus in Ontario. It's caring friends like you who make it possible. However you choose to give, your gift will touch countless lives.



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