

Happy New Year, and welcome to the Kids Crusaders corner of the Disability Independence Group, otherwise known as DIG.

I am honored to be a part of such an amazing organization and will be writing for Kids Crusaders from the perspective on being the parent of a child with special needs. This will be a place where people can come together, ask questions, share stories, find information and support.

About me. First and foremost, I am a mom. I am a mom to 3 amazing kids. My oldest son, Nick, was born on April 17, 1991. I was 23 years old and just starting out on what I thought would be like any other journey my friends had started on. However, there were complications, and my journey was about to take on a path all of its very own. The neonatologist's words still resonate through my head. "Congratulations. You have a beautiful baby boy. However, he is very sick and we are not sure what is wrong with him. We are not certain that he will survive."

It was the moment where I first experienced how sheer joy and excruciating pain could share the space in a single heartbeat. It was a moment where the course of my life would be forever changed.

For the first 10 days, we watched helplessly as my son fought to survive. But survive he did. After 25 days in the neonatal intensive care unit, we were finally able to bring our son home. We brought him home with a feeding tube in his stomach since he was unable to swallow, an apnea monitor to alert us to episodes where he would stop breathing, a portable suction machine to suction out his excessive secretions, and last but not least, no owner's manual.

I was determined that despite any odds that had been stacked against him, my son would survive, even if it was on love alone. And survive he did. We were "officially" given his diagnosis when he was 10 months old. His diagnosis of "developmentally delayed" changed to Cerebral Palsy.

And so our journey began, a plethora of specialists and therapists and medical terms and isolation. It was during those early years that I felt very isolated and alone. My friends could not relate, for they all had "normal" babies. I could not relate because I had nothing to relate it to. I was young and scared and needing to

do something, anything to help me gain some control over a situation where I obviously had none.

I enrolled myself into a nursing program in hopes that knowledge would become power. Please note it was never my “dream” to become a nurse. I became a nurse simply to better understand my son’s “condition”. While it has helped tremendously throughout the years, knowledge is not always your best friend.

We are approaching 23 years that we have been navigating our way through the “special needs” world. It has been 23 years of a lot of things - anger, resentment, guilt, blame, confusion, depression, sadness, and exhaustion...just to name a few. Flip the coin (which I can honestly say I was not able to do for many years) and find sheer joy, happiness, excitement, people (yes people) that we would have never met had we traveled down the “traditional” journey, insight, humor (very important for survival), and unconditional love unlike anything you’ve ever experienced.

While I am a Registered Nurse, I am not here to diagnose or give “medical” advice. I am here to share with you some of my insight. I am here to share stories and information on the ups and downs, ins and outs of being the parent to a child with special needs. I am not an expert. I have fallen many times, but have always stood back up.

The most important insight that I will share is that you are never alone. If you are just starting out on your own special journey, try to remember that no matter how frightened you are, you are not alone. Networking will be your very best friend. It will remove the barriers of isolation and give you the strength that you need to stand back up when you fall.

For those of you that have been traveling down your own unique journeys, please reach out and share your stories. If there are any topics you would like to see covered here at Kids Crusaders, we will do our best to cover them.

Once again, welcome to the Kids Crusaders corner. Here we are dedicated to breaking down the barriers of isolation, sharing good times and bad, happy and sad. Here we are all “family”.

“A special needs family is a circle of strength and love. Every crisis faced together, makes the circle stronger.” (A Very Special Needs Resource)

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