

Welcome back to the Kids Crusaders corner. This year has been off to a wild and crazy start. Depending on where you live, if you are anything like me, you are probably already contemplating 1001 ways to (humanely) terminate the groundhog for seeing his shadow. Another 6 weeks of winter. I am SO over it. Nick and I donned our new Kids Crusaders t-shirts (in protest of all of the snow we are buried in) and immediately felt warmer.

(We now resume you to your regularly scheduled program...)

In the past 22 years, I have spent a lot of my time finding creative ways to incorporate Nick's world of walkers, wheelchairs, and endless physical barriers into a "typical" kid's world of playgrounds, friendships, and fun. I will admit proudly that I was not always graceful; however I was almost always successful.

If my other 2 kids could do something than I was on a personal mission to make sure that Nick could too somehow. Horseback riding was a huge success that we started at age 5 and continued until almost age 10. Nick gained great upper body strength from this and I cannot say enough positive things about therapeutic riding programs other than, if you haven't done it, please try it.

Swimming was one of Nick's very first activities, which he still loves to do to this day. As a baby he was easy to hold in our arms and walk around the pool with. As he got older, we got creative with pool noodles trying to make some sort of device that would give him independence in the water. Many a boat capsized with him still aboard, but we kept trying. Now Nick swims independently with just a life jacket and water wings for his arms. A local chapter of the YMCA opened its newest facility a few years back less than a mile from our house. So off we went, geared up and ready for some fun. The YMCA pools are staffed with a lot of lifeguards. Young lifeguards. Eager to save people lifeguards. We watched the looks of horror/panic as we wheeled Nick as close to the edge of the pool as possible and just launched him in. It took a lot of convincing that he was FINE. He had enough flotation devices on him to raise the sunken Titanic. Needless to say, years later, the lifeguards have finally stopped choking on their whistles while running down the length of the pool like some bad episode of Baywatch to jump in and SAVE Nick, while his very bad parents just stand by and watch.

Bowling was a breeze. In the modern day of bumper bowling and bowling ball ramps that position nicely in front of a wheelchair, Nick was always able to enjoy that. He would use his foot to kick the ball down the ramp, repeatedly getting strikes while I somehow managed to still find that teeny tiny spot that would get me a gutter ball. I think bowling was never really a big hit because it lacked the drama that usually follows our adventures.

Sledding is a whole different story. That was adventure. First let me preface this by saying I never enjoyed sledding, even as a kid. The ride down was fun but then the walk up just never really seemed worth it. But, he wanted sledding so sledding we went. Once. Never again. We used a 2 person plastic toboggan sled and my husband and I agreed to take turns riding with Nick down the hill. Nick would lie in our lap between our legs and loved the ride down. The hike back up was insane. It required not only pulling your own body weight up that dreaded hill but also pulling Nicks weight behind you as he laid in the sled bundled up in a snowsuit. I, being the superior parent, would ride to the bottom of the hill and endure the long walk back to the top. My husband however, tried to cheat the system. He would go halfway down the hill, put his feet out to stop the sled and then walk halfway back up the hill. Of course this angered me because it wasn't fair for Nick to not enjoy the "full" ride to the bottom. So after my second haul UP the hill, I watched as my husband once again rode halfway down and stopped the sled. This time, his foot was on a patch of ice and he fell. And I watched as the black sled took on a life of its own with Nick still in it and no adult behind him. Smooth move Ace. I watched as the sled made it to the bottom of the hill and managed to fly up one of the jump hills, sending Nick in one direction and the sled in another. My husband sauntered slowly down the hill in his direction as I borrowed a sled from another parent and flew down to his pile of snowsuit which was now surrounded by non-sauntering fathers. He was face down in the snow and I could hear him laughing hysterically, which to an untrained ear, sounds like very painful screaming at times.

I rolled him over and pulled as much snow out of his snowsuit as possible and plunked his body back into the black plastic sled to begin our journey to the top of the hill (of course we would pass the still sauntering father figure). The other fathers were begging me not to move him. They were shouting at me that he had a potential neck injury and yes they had already called an ambulance. WHAT???

WHY?? I yelled back at this group of very concerned people. One father yelled back at me “He can’t walk!!” “Don’t move him”. I stopped for a brief moment not really knowing what to say other than “He never COULD. Do you see the wheelchair at the TOP of the hill? That’s his!!!” Looking back now, I guess I should have thanked them for their concern, but at the time I was so focused on the still sauntering father. Sledding was over. The ambulance people were very nice.

And while this list could go on forever, my all-time, far out crazy adventure would have to be the year I enrolled Nick in the Sabah ice skating program. Their mission “is to challenge individuals with special needs and volunteer partners to experience the success, pride, freedom and joy of therapeutic ice-skating while achieving personal growth.” Sounded good to me. My sauntering husband however said “are you crazy? You are going to put razor blades on this kid that can’t walk and expect him to actually ice-skate?” Absolutely. Their web site said so. Period.

So off we went. We put the (very sharp) ice skates on him as he sat in his wheelchair. I put on a pair of skates (first time in over 20 years) and met our personal volunteer partner, who happened to be a rather husky hockey player. Together we lifted Nick out of his wheelchair and got him to the edge of the ice. Our volunteer asked me how well I could skate and my reply was “I grew up on the ice”, which was basically true. However, at the age of 8 or 9 ice-skating was easy and you are much closer to the ground when you fall than when you are an adult. Lessons are always learned the hard way for me. We stepped onto the ice, one on each side of Nick supporting him, and wham. I fell first, total wipe out. Bringing Nick down on top of me with his VERY SHARP ice skates and Hockey man on top of Nick. I think I heard him mumble something along the lines of “oh joy, this should be fun”. We eventually got better (I learned how to hang onto the wall and Nick at the same time) and then graduated to a special sling seat walker device that allowed Nick’s feet to be on the ice and Hockey man free to race him around the rink at ridiculous rates of speed (perhaps the freedom from the falling down mom) and the pure joy on Nick’s face. One season was enough. It was worth the blood and the Band-Aids to see Nick smile. No regrets.

I think the point that I’m trying to make is that it is not easy to adapt everything, but it is not impossible. I am glad I wasn’t afraid to try and I am grateful for people that supported my efforts. Would it have been easier to have

just stayed within the safety and comfort zone of our home? Absolutely, but I wouldn't trade these memories for the world. As long as I am given a new day, I will continue to seek out new adventures for Nick to fully enjoy this beautiful world that we live in.

“All children with special needs just need a little help, a little hope, and someone who believes in them.” (A Very Special Needs Resource)

Until next month, live each day with laughter and love. And always remember, you are not alone on your journey!

Julie

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