

Welcome back to Kids Crusaders. As we head into the middle of March, I'm beginning to wonder if upstate New York has only 2 seasons now. Winter and winter, ugh. The sun did manage to make an appearance today though so maybe there's a small chance.

Last month I wrote about some of the crazy activities that I had managed (or bravely attempted) to adapt for Nick to try while he was growing up. Most were successful, some were almost even graceful. But through the years, there was always an element of Nick's life that remained a locked door for me. And that was his inner trust that he had.

I look at trust as something we learn growing up. Something that we take for granted, until that trust is broken. But there was still always something about Nick's trust that remained a deep mystery, one that I needed to somehow tap into.

Nick requires total care. Since he was born he has been fed, held, diapered, bathed, loved, comforted...this list goes on and on. And of course, these are things that any parent would (hopefully) do for their child, disability or not.

But as Nick got older and bigger, tasks such as showering him were no longer "cute baby moments". Shower days consist of a 6 ft tall, 140 pound young man that happens to have the wing span of a Boeing 747 and can take lamps out from across a room. Add in the naked factor, strapped into a shower chair

made out of PVC piping and extremely slippery mesh seating systems and even I start to question my own trust. How can I trust that “slippery when wet” won’t go sailing across the room when I take my hands off of him for one split second?

Transferring him out of the shower chair and safely onto the floor (which is not one of our more graceful acts, by the way) requires some sense of “trust”?

With Nick I never got the feeling that it was the “trust” that we know. This is something more of a “knowledge” to him. If I had to guess, which I am, perhaps it’s the lack of fear from knowing that the people that love him will just somehow always make it ok? So despite every effort I made, I could not fully understand this part of my son’s world.

So, with some encouragement from a crazy friend, I agreed to go skydiving. Factor in my fear of heights and follow me. This had nothing to do with overcoming any fear of heights. As a matter of fact, participating in this activity probably elevated that fear to a whole new level. However, it also unlocked the door to Nick’s world of “trust, or knowledge or whatever it is” even if only for a few minutes.

Your first jump consists of ground and aerial training. This basically teaches you everything on the ground that you need to know while exiting an aircraft at a tremendous rate of speed in order to maintain some sense of calm so as to not kill

yourself and the person crazy enough to strap himself to your back. (Insert breath). During ground training you get to meet and talk to the person that will be jumping with you. I was pleasantly surprised that my jump buddy was not only incredibly easy on the eyes (I mean, honestly...if I'm going to die jumping out of an airplane the bonus had to be at least it was with a hot guy strapped to my back) but equally and more importantly a genuinely nice guy. He asked why I wanted to skydive (as he kept a jump log) and I'm sure he was expecting the typical answers of "want the adrenaline rush", "it's on my bucket list". "to overcome my fear of heights", etc. Much to his surprise, I sat down with him in the grass and shared my feelings about Nick. About how I needed to understand this part of his life, to experience that total "knowledge or trust" in another human being without giving it any thought, even if it was only for a few moments. His reaction? Tears. Great. So I said, "I should have just told you I'm afraid of heights. Now you don't want to jump with me." He shook his head and hugged me and said "I have never wanted to do a jump more than this one."

And with that, the insanity began. Ground training, muscle memory, squeezing into a jump suit that should have had a sign hanging off my buttocks that said "wide load", climbing into the twin otter jump plane (have to say that was the worst part of

the whole experience...climbing up that ladder), and getting ready to experience a whole new dimension.

With Joe strapped to my back and all of our gear ready, the plane took off. I had promised myself that in order to have any remote chance of experiencing what I was really hoping for, I needed to check my fear at the door of the aircraft, which I did. The ride up was peaceful and beautiful. There were other jumpers (maybe 14 total) and Joe made sure that we were the last ones to jump. This gave us more time in the exit door to just take everything in. And at 13,500 ft. above the ground, with Joe right behind me, I jumped.

So many people have asked me what it was like. And the only word that comes to mind is surreal. It was very windy and cold. It was very loud but yet quiet. There was no fear. Just an inner "feeling" that everything was ok; a window into my son's world. And for a few moments, I felt like I was embracing the universe.

I often watch my son when he's sleeping. (I know, creepy mom thing.) His muscles rest, his hands open up, he doesn't fight against the daily gravity of life. It's peaceful. And I wonder when he dreams if he feels like he's embracing the universe.

I'm beyond grateful for that experience. But as I sit here writing this I can't help but think how lucky I am that Nick IS my universe and I get to embrace him each and every day.

“Special needs parents want to inspire others. We want someone to look at us and say because I know your child, I didn’t give up.” (A Very Special Needs Resource).

Don’t ever give up. You are never alone. Live each day and when the opportunity presents, don’t be afraid to embrace the universe.