

Welcome to this month's edition of Kids Crusaders. It is so hard to believe that August is coming to a close. I'd like to open this month's article by saying that in the beginning of 2014 when I was asked to write for the monthly newsletter for DIG, I was honored. This would be an outlet where I could share my experiences of raising a child with special needs and to let other families know that they are never alone on their journeys. Everyone at DIG has become like family to me and though geographical locations may divide us, every month our hearts once again unite us. A very special thanks to Debbie Dietz for tackling the task of pulling all of the articles together and making this newsletter come to life. (An added thanks for letting me keep my articles personal and real, sometimes raw with emotion and sometimes filled with fun and adventure; for never getting upset with my procrastination!)

So on with August and the topic "exercise and the quality of life." At first when I asked Debbie what the topic was going to be for August, I have to admit I felt stumped. I could feel a major writers block coming on. In the world of parenting a child with special needs (who happens to be an adult now, still living at home with us), "exercise and quality of life" didn't feel like they naturally belonged in the same sentence. Every day is exercise when you are parenting; those of use with special needs children sometimes have a different curve ball that gets thrown in. I am a strong advocate for giving my son Nick the best quality of life that I possibly can. Exercise, outside of caring for Nick, should be equally important so that I will always be healthy and strong enough to continue doing the things that we enjoy doing together.

One of Nick's favorite activities is swimming. In the water he is free. Free to move around and to enjoy the sensory stimulation of the water and the relaxation it brings to his overworked and exhausted muscles. Throughout the years, we have tried many different floatation devices and have even gotten creative making some of our own out of pool noodles. Not everything worked perfectly, but we always tried. For the past 8 years, we have found that the best thing for Nick to use in the water is a heavy duty life jacket (used for water skiing) and inflatable arm wings. With those as a combination he has full independence in the water.

A local branch of the YMCA opened less than 2 miles from our house in October 2006. We were happy to have a place so close to home that would enable us to let Nick swim year round. It was a brand new state of the art facility and we were asked for input for any suggestions that we could make to allow the facility to be as accessible as possible for anyone. The staff has always been amazing and understanding when it comes to the difficulty we have with transferring Nick in and out of the water. The facility does have motorized lift chairs into both of their swimming pools and their hot tub as well. These lifts don't work well with Nick, or should I say, Nick does not work well with these lifts (is more the case).

We have developed a routine when we take Nick swimming that works. It may not look graceful, but for us, it works. We start out in the family dressing room where the process of getting Nick geared up begins. We usually have him wear his bathing suit from home to facility to eliminate one step in our struggles. It is a 2 person, minimum, task to take Nick swimming. The life jacket that he wears is extremely bulky and difficult to get on him while he is in his wheelchair. Once that is secure, we alternate with blowing up his arm "wings". For ANY parent that has had to endure the painful process of

blowing up the chambers in these arm wings you can appreciate the undying love we have to continue this ritual. Usually, on a good day, we can have him ready to enter the pool area in around 30 minutes.

On this one particular day, our struggles in the locker room were real. One of the arm “wings” kept losing air, or one of the uh-hum, parents did...the jury is still out on that one. However, I was determined that Nick was still going to swim since I had been promising him all week that we would go. I was suited up and ready to get in the water with him. When we had passed the windows looking over the pool on our way in, I was happy to see the adult pool was almost empty. We had left much later than we usually would have to swim, but the idea of having a lot of the pool almost all to ourselves was nice.

My husband assisted in taking Nick from the locker room and into the pool area, remaining in his street clothes. He had decided not to swim with us that night, but rather was going to watch from outside the pool area until I needed his help in getting Nick back out. Just as we approached the edge of the pool with Nick in his wheelchair, one of the lifeguards on duty informed me that Nick wouldn't be able to swim (clearly my struggle in the locker room and my already sweaty face went unnoticed to her) because the “open swim” time was over. Already exhausted, I glanced up at the clock and looked at the still almost empty pool. It was 7:25pm. The facility was open until 10:00 pm. Nick was beginning to get wiggly in his wheelchair, wanting badly to swim. I asked her why he couldn't swim if there was nobody in the pool. Her response was that there was a water aerobics class that was scheduled to begin in 5 minutes.

Having done a water aerobics class in the past, and some quick thinking on my part I asked the lifeguard if the class was open to members or if it was a fee class. She said it was open to members. Problem solved. I told her that Nick and I were getting in the water because we were going to participate in the class since we were both “members”. My husband laughed and said I was crazy. Ahh, perhaps he was right about the crazy part, but take note...it got Nick into the water!

Within minutes the pool was filled with a lot of people (to my surprise). Most of them older (I am trying to be easy with the “elderly” word as I just passed another year closer to polka dotted bathing suits with ruffles and matching swim caps) and all very friendly. A quick visual of the people taking the class (sizing up anyone that would potentially have any “issues” with Nick participating) and I was ready (or as ready as I could have ever been) for a new adventure.

The music started and I positioned myself strategically closer to the deep end with Nick to keep our splashing to a minimal (impossible). I could see my husband out in the lobby through the wall of windows, talking to some people and not watching us. While we marched in place I found a position that would allow me to hold onto Nick and somewhat actively participate in the class. (Refer to pictures of Nicks swim gear for the full visual of how difficult this was) I wrapped my left arm around Nick's body, which included his life vest and half inflated arm wings. Holding onto the life jacket straps in the front, I was able to march in place with everyone else. Easy. Nick was in the water, we had music, I had one arm free to follow the instructor...it was all good. It was all good until the marching in place turned into jumping in place. Nick found this activity to be extremely fun. I, on the other hand, still exhausted from the locker room pre-pool, inflating wing failure prep, was finding this activity to be beyond exhausting.

Not only did I have the water resistance of my own body weight jumping in and out of the water (one handed), I also had Nick's weight (which is exponentially heavier than his usual weight of 140 pounds thanks to his water soaked swim gear). The jumping combined with the music was a lot of fun for Nick as I noticed he had increased his "splashing" in the water and he was laughing hysterically. Another glance around the other participants showed a lot of genuine smiles that Nick was having such a great time (I think I was looking for perhaps some looks of empathy as my struggle was real, very real.) In the midst of Nick's splashing and my concerted efforts to keep up my jumping pace with the rest of the class, I felt a tapping on my right shoulder. I glanced over and saw an older gentleman who was behind me. I assumed that Nick's splashing was bothering him so I managed to yell "sorry" over my shoulder and simply (not really, remember I said I was struggling) relocated Nick (still splashing and laughing) further away from this guy. More jumping and more splashing and another tap on my right shoulder. Another quick glance and I see it is the same guy. So, I yelled "sorry" over my shoulder again and moved to yet another spot as far away from him as I could without getting in the way of others. As physically exhausted as I was, I refused to quit jumping as long as Nick was laughing and having so much fun. My left arm was pretty much numb by that point, but it didn't matter to me.

What's the old saying? "Third time is a charm?" So, despite my second relocation with Nick in the water, I felt a third (and now final in my mind) tap on my right shoulder. Needing an excuse to stop jumping because I was truly exhausted, I stopped and spun around to face him. I had to tell Nick to be quiet because it was so hard to hear anything in the pool and I anchored his still jumping arms with my left hand to silence the splashing.

My body's natural "fight or flight" response had obviously already kicked in seeing as how I had "flighted" to 2 separate locations to avoid having this man splashed by Nick. Now, I felt the fight in me brewing. I simply wanted Nick to have fun. In my mind, you are in the water which means you are already wet, so why are you about to say anything to me about my son splashing water on you? In my quiet "fight" mode (which had taken a brutal beating in the locker room before any of this had taken place) I scrambled to find just the right "special needs speech" to hit this guy with. In the seconds that passed (which felt like hours) I looked at this man and all I could muster up was "look, I'm sorry. He wanted to swim and they wouldn't let him because this class was taking place, so I decided to do the class with him....." He was trying to interrupt my apology to him (which was really a much needed break from all the jumping for me). I continued with "I moved out of your way twice so that you wouldn't get splashed. I am sorry. He's excited to be doing the class and it is in the water and water does splash." Again, he stood there, speechless as I rambled on and on. His eyes never left contact with mine except for when I finally stopped talking long enough for him to say something, anything.

He quietly said "I don't mind the splashing. I am glad he is having fun. I was simply trying to tell you (as he hesitated), umm "wardrobe malfunction". My puzzled expression gave him no other choice but to break our eye gaze and glance quickly down before looking back at me again. My mind could not even begin to process what he might have been referencing and it sure was not prepared for what it was about to see when I finally had the courage to also glance "down". And there she was. My right "tit" (and yes I called it a TIT because no self-respecting breast would have ever done this to me) was floating on top of the water without a care in the world. There was no bathing suit in sight, at least not on the

right side of my body. The force of jumping up and down while holding Nick is what probably unleashed the beast. While I am extremely quick to come to Nick's defense in the special needs arena, I found myself at an utter loss for words or action when my own "special need" felt the need to break free. So, what did I do? I did what any "I am so exhausted and don't really have any fight left in me" woman would do at that moment. I looked back down at my floating TIT (which truly for a few moments felt like an out of body experience), managed to utter a quick "thank you" to my shoulder tapping savior and turned my back so that I could spare him from having to look any longer than he already had. A quick duck under the water to retrieve my suit and the escaped convict was jailed once again. (I can only thank the universe that this memorable moment was not caught on camera.)

I was now done "exercising" and my "quality of life" had taken a quick turn for the worse as I frantically waved to the wall of windows trying to capture my husband's attention. When I finally did, it took him forever (it seemed) before he got anywhere remotely close to assisting us out of the water. In the time spent waiting for him, what was racing through my mind you ask? Well, I will tell you. My immediate thoughts went to how this man gently said "wardrobe malfunction" when what he probably wanted to say was "your TIT slapping against the surface of the water for the past 10 minutes has been splashing me more than your son has and I find it rather distracting". But instead he chose to be a gentleman and say "wardrobe malfunction." (Who said chivalry is dead?) The poor man is probably still at some bar trying to drink away the visual. There is not enough alcohol in the world.

Nick still loves to swim. I personally, carefully choose my bathing suits and the times that I will show my face publicly at the YMCA. In the lifetime I have spent learning how to tactfully deal with people regarding my son's disability, I was surprised that I was unable to make a quicker recovery during my own personal time of vulnerability. I choose to laugh instead of cry because honestly, I don't make this stuff up. This is truly my life and I have to find humor in it. My fight for equal rights for my son and breaking down barriers will never end. Perhaps that "wardrobe malfunction" was my body's way of saying the bathing suit was a barrier and that's why she made her great escape. (Cue music.... "Born Free").....

As for exercising, I am making a genuine effort to make the time I need to get myself into better physical shape. It's a work in progress. And yes, parenting a child with special needs is an exercise category all in its own. As for quality of life...I can't wait for the next adventure and the opportunity to share it with all of you.

Until next month...laugh, live and love. And know that you are never alone on your journey.

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"The quality of your life will be determined by the quality of your contribution. When you work to improve the lives of others, your life improves automatically." (Kurek Ashley)

