

Where I am and How I got Here

By Paul Botarri

My name is Paul, and I'm 22 years old. The course of my life was set at a very tender age. As a matter of fact, you could say that the course was set before I was born. I was born with a condition called Duchenne Muscular Dystrophy. Girls are rarely born with this condition, which is said to effect about one in every 3,600 male babies. I'll abbreviate the condition to DMD for the purpose of this memoir. I don't want to confuse the reader by using the abbreviation MD, which is more commonly used when referring to Medical Doctors.

According to my Mother, I was diagnosed with DMD before I was a year old. She noticed that something wasn't right, because I wasn't reaching milestones on time. I was a few months old and not moving around the way my older sister had, or the way other babies my age were. In case you aren't familiar with Muscular Dystrophy, it's a condition that affects the muscles, just as the name implies. DMD worsens more quickly during childhood than some other types of Muscular Dystrophy. In some cases DMD is inherited, but it sometimes occurs in people without a known family history of the condition. I'm one of those people, with no family history.

With DMD, symptoms usually appear before the age of six, if they haven't already appeared during infancy. Although my parents were aware of the problem, I wasn't really aware until I was about six years old. It was then that I realized that I couldn't run as fast as the other kids. Between the ages of seven and eight, the muscles in my legs weakened dramatically. At eight years of age, I had surgery to lengthen my ankle tendons, so that I could continue to walk. Shortly thereafter, I began using a walker. I also began using a wheelchair to help me with getting around more easily. By age nine, I was confined to using a wheelchair all the time. At ten years old, I got my first power chair. To this day, I'm in a power chair, which enables me to get around and change my position. I'm completely reliant on the chair to experience any level of independent movement.

DMD also resulted in me developing spinal scoliosis. Ultimately, I had to have, or should I say endure, a spinal fusion procedure. I had this surgery at the age of twelve. Besides the pain involved in recovery from the surgery, there was a lot of emotional pain too. I spent a lot longer in rehabilitation than I had ever anticipated. Even though I have a wonderful family, who have always been there for me, the post op period was more than any twelve year old should have to deal with. There was pain, fear and a lot of anger. All I really wanted was to go home as soon as they said I was going to, and that wasn't the way it went at all.

I'll take this opportunity to mention more about the wonderful family that I've been blessed with. My parents are both devoted to me, and have always been there like "Rocks of Gibraltar". They are wonderful to me in every possible way. They've helped and encouraged me through the most difficult times, and continue to do everything possible to normalize my life. Their love and guidance is beyond measure, and I'm so very, very fortunate to have them as my parents, companions, caretakers and friends. And then there's my sister Laura. Even though Laura and I

fought like cats and dogs when we were kids, my sister is a terrific person. I couldn't wish for a better sibling, even though I've never admitted that to her. Each member of my family has a terrific sense of humor. I'm really grateful for that too. We've spent more hours than I could possibly count, laughing at one another's crazy jokes and sarcastic jibes. The humor has helped me through lots of disappointments and over many hurdles.

Even with a severe disability, I enjoy the day to day life with my parents and my three cats, Zoe, Beanie and Margo. In the past, we had cats named David and Maddie, and have cat-sat for my sister Laura's cats, Eddie and Clark. The cats are a great source of comfort and amusement. I also love going on vacation with my family. We have a nice place on Long Island that's near the beach, and its great being able to go out there on weekends during the summer. Then, there are the family cruises that my parents arrange for us annually. These are most often to the Caribbean cruises. Given that airplane travel is extraordinarily difficult for someone like me, the cruises are a perfect alternative.

I guess I should mention that I'm a big movie fan, as well as a foodie. I go to the movies with my parents as often as I can, although more often with my Dad. My Dad and I really enjoy action films, that my Mom is happy to pass on. Going out to restaurants is another activity that I wouldn't want to do without. My parents and I usually go out to restaurants in Westchester, but also dine out in Manhattan and elsewhere. My parents have an equipped vehicle that enables them to transport me wherever I need to go. Even though I particularly like "Italian" cuisine, like my Mom makes, I like to experience other flavors from around the world as well. Besides my favorite Italian dishes, I can get pretty enthusiastic about Japanese, Thai, Mexican or Middle Eastern foods. Like most people my age, I can also enjoy a good burger with fries. The bottom line; if you put a plate of Chicken Parm in front of me I'm one happy guy, but I'm open to other options.

In my spare time, I pursue a variety of interests. They include playing video games. Games with action, adventure and racing are my favorites. When not going out to the movies, I watch action movies on TV and on my laptop. Playing pinball on a full-size, adapted machine that my "pinball wizard" Dad bought for me, is a blast. I'm also a "sneaker head". Sneaker collecting is a hobby of mine, and my parents totally indulge me in my pursuit of nice sneakers. I have more than 100 pairs of Air Jordans. Some of them, of course, go back quite a few years. I wear all of them, and make every effort to make sure that the sneakers go with the rest of my clothes, including my extensive collection of baseball caps. I'm very conscious about style and like to wear nice clothing. My Dad is a major influence in my interest in dressing in the latest fashions, although everyone in the family likes looking good.

I think you've got the picture. Even though I can barely move, I'm not unlike your average guy. In fact, I attended my local public schools until the 10th grade. During 9th and 10th grades, issues arose, involving the physical layout of the high school that I was attending. The buildings hadn't been sufficiently upgraded to accommodate students in wheelchairs. The only available elevator was broken most of the time. Well, I'm exaggerating, but it certainly seemed that way. I was late for classes too often, and sometimes missed classes entirely. I also started feeling that the

faculty just didn't understand my special needs, especially when they complained about my lateness or absence from a class that I physically couldn't get to. Eventually, my parents and I decided that I should switch to a school that could really meet the needs of students like me. That just made sense.

I transferred to the Henry Viscardi School in Manhasset Hills on Long Island. It was a long trip from Westchester, but well worth it. At first I wondered if I had made the right decision. The change was tough. Just fitting in was one issue, and missing my friends was another. In retrospect, I realize that big changes are difficult for everyone. In my case it was definitely worth the difficult transition and the daily trip, to have everything physically accessible to me. The teachers were more understanding of my special needs, and both the teachers and the curriculum seemed to be of a higher caliber than what I had experienced in my neighborhood school. In fact, I chose to stay at Viscardi for an extra year to attend the RAMP Vocational Program. RAMP being an acronym for "reaching all my potential". Being part of that program, gave me greater confidence in myself, and I'm reaping the rewards of that increased confidence to this day.

Subsequently, my school advisors, parents and I considered a college program for me. I'm pleased to say that I have no intellectual deficits. It was decided that my intellectual abilities were more than adequate to excel at college level studies. The one thing that we were all concerned about, were the physical demands. They would be considerable, even if I had the assistance of a personal aide. Ultimately, my parents and I decided to defer applying to college, and we began investigating other vocational opportunities. Once I had received my New York State Regents diploma, I was no longer eligible for the RAMP Program. I had no choice, but to leave the Henry Viscardi School. I was really upset about leaving, but it was time to move "upward and onward". Where to go instead of college? That was the question.

Everything that you've read up to this point, was a lead up to telling you about where I am today. After HVS, I became a program participant in the Vocational Services Program at Cerebral Palsy of Westchester in Rye Brook, NY. While it took me a few months to adjust, I feel like I found a home. I've been here for three years, and can honestly say that I've found my niche.... at least for now. The staff, to a person, are wonderful. They're attentive, caring, pleasant and completely understanding of my physical situation. Everyone involved in the Program realizes that I have abilities, and always seem to be looking for ways to keep me intellectually and socially stimulated. I really appreciate that.

One of the activities that I'm deeply involved in, is the WAVE Radio broadcast. It's produced and broadcast on location, and can be heard over the internet. I'm the food critic, which should be no surprise, considering my food interests and experiences. I review restaurants on the show, and I also give recipes for dishes that I enjoy and that I think others might enjoy too. In addition to serving as the food critic, I edit each broadcast before it's uploaded for airing. We want to put out the best quality of show possible, and that requires a significant amount of editing. Aside from me, there's a cast of real characters on air. I say this affectionately, because they're a fun group of people, who include those who report news, sports, new music and review video games.

We sometimes interview people, on air, and there's one woman who writes and recites her own poetry. We all had a lot to learn at the beginning, and continue to learn more with each show. Recently, a volunteer from the Rye Arts Center has been coming over to conduct an audio workshop with us. I fully enjoy the time spent on this activity and with these guys. It's a unique experience and I am always looking forward to the next show.

I'm also a DJ. I assist the CPW music specialist by DJ-ing on different occasions and at various locations around the building. He's a great guy, and gives me enough freedom and responsibility to keep me interested. From playlists that I've created for my own pleasure, I select and play songs that I think people will enjoy. The music is played through my laptop, which gets connected to a large speaker. Through a sophisticated program that I have in my computer, I'm even able to go totally hip hop, by adding a lot of the scratching sounds that are popular with many of the people here. I get a lot of compliments on my musical choices and I find DJ work to be a lot of fun as well as satisfying.

Recently, the Vocational Services Program opened a "Market Place" that sells food and small gift items. The purpose of the Market, is for training people to work in retail establishments. Because of my physical limitations, I began assisting by providing eyes and ears to the establishment. In other words, volunteering as the security guard. I determined, pretty quickly, that it wasn't a job that interested me in the least. I told the staff that I didn't want to be involved in that aspect of the training program. They understood my feelings about it, and put their heads together to find another role for me. To my surprise, and delight, I was offered the opportunity to be one of the Market Place "buyers". I go shopping with staff at a restaurant supply store, and make recommendations on what we should stock. The restaurant supply store is cavernous, and is geared towards those who purchase in bulk quantities. The prices are substantially lower than those you would expect to find at local stores, and even lower than places like Sam's or Costco. The selection of products is enormous, and includes foods and condiments that you won't typically find in supermarkets. Additionally, it offers sale items and equipment that are only used in restaurants. I really enjoy the time spent there. It's really interesting, and it gives me the opportunity to make recommendations and decisions, as well as getting out into the community.

There's always something going on at CPW. We have discussion groups geared towards analytical thinking and broadening our knowledge of ourselves as well as the world around us. We occasionally have parties or special events, and people are also given a certain amount of freedom to pursue individual projects that interest them. Before I end this part of my memoir, I want to mention a unique opportunity that all of us, in Vocational Services, had in 2013.

We had the good fortune for CPW to have contracted with a very passionate and talented musician by the name of Billy Ayres. He specializes in working with people who have disabilities, and he came to share his passion for music with us. Most specifically, he helped us to put on a musical variety show. I basically came up with the premise for the show. It was a musical performance "dinner and show" experience that we called "Whatever Happens in Vegas". We all worked on the script, and with Billy's talent, enthusiasm and commitment, we came up with a winner. I was really proud of my contribution and felt that coming up with the basic premise

for the show was about all I was going to be able to do. As it happened, I really got interested in being more involved and possibly playing an instrument, as implausible as that might seem. Billy spurred me on by suggesting that I play the harmonica, and hooked me up with one that was attached to something that went around my neck. A set-up designed for people in blues bands who play both guitar and harmonica, it worked for me. It was such a great idea, and something that I probably would never have tried if I hadn't been involved with the show. The entire experience was great fun, and gave me much more confidence in myself. I've recently learned that Billy Ayres will be returning again this year. I have to admit that I'm really looking forward to it. I can't wait to get my creative juices flowing again.

So here I am. I'm participating in a lot of great activities, in spite of having a severe disability. Thanks to my parents and other special people, I can see possibilities for myself. Yes, I have my down periods, but everyone does. Especially anyone who might find themselves in my position. I don't let my disability hold me back from enjoying life, and taking advantage of whatever opportunities are presented to me. I'm still young, and smart enough to realize that I've barely touched the surface of life experiences. I look forward to every day as an adventure, filled with opportunities. I see every day as an opportunity to succeed in those things that I put my mind to.