

Written by Carolynn Siewicki (Mom)

Jennifer Siewicki

28 years old

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Diagnosed with CHARGE Syndrome which along with a multitude of problems the character of a person with this syndrome is often described as one with determination and strong character which describes Jennifer. Another diagnosis is Pulmonary Hypertension – high pressures in the pulmonary artery which means Jennifer runs out of breath easily. She uses a 24-hour sub-acute infusion pump which delivers an amazing drug, Remodulin, to help her get through her days. Even with all Jennifer's challenges she sees herself as a regular person with all the hopes and dreams as anyone else. She just has to work harder to make it happen.

2004

Getting her diploma from Stevenson High School, in Livonia, MI. was HUGE! Lots of hard work on Jennifer's end as well as ours. Even then, The Arc of NW Wayne County, Redford, Michigan was always there to advocate on Jennifer's behalf at her IEP's at school.

When Sylvan Learning Center, where Jennifer was tutored during high school, heard of Jennifer's graduation, they offered her a part-time job. She worked there for four years during which time she used job placement services to help her obtain an additional job without success. Jennifer kept busy in the community with activities which included volunteering with the Livonia Jaycees, the Michigan Humane Society, Make-A-Wish Foundation of Michigan, Project Linus (making blankets for the local children's hospital). She joined Michigan Adaptive Sports and learned to down-hill ski beginning from sitting in a chair to now standing. She also learned to water ski and kayak. She joined a Program to Educate All Cyclists to learn to ride a two-wheeler bike and enjoys Family Rides with the group on Thursday evenings. She became a member of the Detroit Puppeteers Guild and attends their events even out-of-state. Jennifer loves puppeteering and learned much about her idol, Jim Henson. She took private ice skating lessons and even though her lips would turn blue because she would run out of breath and didn't have the best balance so it was a lot harder to skate she took lessons every week for several years.

With her love for animals Jennifer still enjoys horseback riding. Her therapeutic riding facility closed so we went to a local regular riding stable for a few years but was refused riding lessons the fourth year stating they didn't think she could handle the riding. I know, it didn't make any sense to me either and I did file a formal complaint with the State but did move on to private lessons from an OT instructor for another few years until they closed. Now, Jennifer rides with the 4-H Therapeutic Riding Club and is happy once again.

2005 and 2006

Knowing Jennifer had a passion for TV and Film (Jennifer is always passionate about the things she loves) I went to the Office of Disability at Madonna University, in Livonia, MI and asked about Jennifer attending their Media Production class. After Madonna consulted with the class instructor, Jennifer was signed up to audit the class. I think her dad and I were more nervous

than she was. We would watch her from the parking lot through the glass structure, walk up the steps to the second floor to the class. My heart raced but slowed down a little bit each week she went. Here was my special ed student with huge medical issues to deal with and with a cognitive impairment but she finished the class out and did a great job. So much so that she signed up for the next class of Video Editing and did an equally great job. This college experience was the “stepping stone” to what was to come in Jennifer’s school career.

Next adventure was drivers training. Jennifer decided she was ready to learn to drive. She passed the written test at the Secretary of State and received her permit. She took driver’s training but after much frustration decided to give it a rest for a while.

2007

Jennifer enrolled in an 8-week Television Production Certification Training Program at Community Media Network in Troy Michigan, paid for by Friends of Community Living Services. We drove her across town during rush hour every week for 2 months to make her dream come a little closer.

Jennifer enrolled in a 3-day George Michael’s Actor’s Workshop in a nearby community. (Keeping her dream alive).

Jennifer enrolled at Schoolcraft College, Livonia, MI and took an on-line creative writing class and an on-line veterinary assistant class.

Won the Georgie Rudin Award for self determination from The Arc of Northwest Wayne County, Redford, MI. It was so refreshing to have Jennifer recognized for her accomplishments in spite of her challenges. (Jennifer does not like the word disabled. She prefers calling it challenges.)

2008

The Winter of 2008 was probably the most important turning point in Jennifer’s transition to adult life. She applied, interviewed for and was accepted into a new O.P.T.I.O.N.S. Program at Oakland University in Rochester Hills, MI. This was a 3-year program designed for people with disabilities to attend a University and to get the full experience of campus life. The director of the program saw in Jennifer what we saw. A person full of life, hard working, dedicated and with big dreams. We will always be grateful she was given this amazing opportunity in her life. Because she wasn’t going for a degree and the classes were considered as audited, she was not eligible for any student loans or grants for the tuition. We were committed to the idea of college and felt this was a chance in a life-time for our high-spirited daughter with big dreams. This opportunity also meant that Jennifer would have her own apartment during the school year for the next three years. To look at our 4’9” daughter people were skeptical about this endeavor but WE KNEW she could do it with assistance. We tried to get Jennifer a room-mate but the apt. we chose, that was most suited for her and in the Rochester area for the bus, was 8 miles from school. A little further than the other students wanted to travel. Jennifer’s Personal Agent, Ann Mansour, from Community Living Services of Oakland County was phenomenal at helping us adjust to the new living arrangements and life at school. She even recommended the best staff to help Jennifer travel back and forth to Livonia on weekends, shopping, helping her with homework, and helping her clean her apartment. The Arc was with me every step of the way to

help us make this happen. I called them all the time. But, the best was when they helped me get a budget to help with staffing and transportation. The Arc ALWAYS came to any meeting I requested. They were always there for Jennifer and in turn her family.

It wasn't easy setting up Jennifer's new life at college. I was not getting any support from my local Department of Mental Health agency. They actually gave me the most grief about her attending college. It wasn't until I was able to get my Oakland County Personal Agent, Ann- again with the help and advice from the Arc- to help get things turned around.

That summer before school Jennifer and I made many trips to Rochester Hills to get things ready for her. We looked and looked for the right apartment complex that could accommodate her electric scooter. We went to the bus yard and personally measured the bus opening to make sure the scooter would fit between the door opening. I spent the first week with Jennifer and accompanied her for the bus ride to school to make sure there were no glitches. We made many trips to the campus checking out her classrooms and the best route to take. The most important thing for Jennifer to know was that if she got lost all she had to do was to ask any student for directions. That is what any other student would do.

Jennifer would take a bus to school every day and would maneuver around campus in an electric scooter. By the third year of school she knew all the short-cuts around campus and was a very confident student. Always having lunch with other students that were around. A very happy young woman.

Jennifer's major was Communication. She took 3-4 classes every semester.

She took everything from the History of Rock and Roll to Anthropology. She was referred to as a "model" student. She not only did all of her homework but attended her classes faithfully. She joined many clubs from a Sorority to trying to join a Paranormal Club but didn't have transportation to the locations. (Jennifer doesn't drive). She had her own radio show at WXOU, the campus radio station. She volunteered to help the students at the OU Cares Film Camp. It's a 2-week camp during the summer at Oakland University with Joey Travolta and crew from Hollywood, CA. The students of the camp are autistic and learned how to put on a film production. Jennifer loved it so much she still signs up to volunteer each summer taking a cab from Livonia, or friends or family driving.

When Jennifer was starting out in college, we heard about a couple of programs we thought would be useful for Jennifer. Dragon Speaks-you speak and it types what you speak and Kurzeweil, Jennifer's favorite, a program that can read what is printed. That one was a godsend as she had lots of books to get through for school. After some research, emails, and phone calls, we contacted the Ladies of the Lions and they generously donated the programs to Jennifer. We were very grateful.

## 2011

Jennifer received her certificate of completion from OU. What a wonderful three years this had been. A lot of work for a lot of people but worth every moment of it. Many times people do not give people with challenges a chance and say "they can't" while we taught Jennifer to say "I can try".

## 2012

Jennifer has been looking for work in the TV/Film/Radio industry as well as typical, local jobs since graduation without success. We've tried what seems like everything. Jennifer has

emailed, and mailed some of her works (she writes stories and parodies) to people she looks up to as Steven Spielberg and Carrol Spinney. Jennifer would love to work on the documentary about Carrol Spinney. You can watch some of her work on You Tube- Horrorfan 436. She has even put in an application to Sesame Street just last week. Jennifer volunteers once a week at Friends of MI Animal Rescue, a no kill animal shelter, in Belleville, Michigan.

Jennifer has big dreams and I know some day her dreams will come true but the journey to that dream is a bumpy road. All it will take is one person to give her a break. Everyone deserves a break. Jennifer says “no one takes me seriously” when applying for a job. She is very talented, creative, dependable, hard working and would be an asset to any employer given the chance. Did I mention she is a riot? If she doesn’t bring you joy after several minutes of meeting with her I’d be very surprised.

Other hopes and dreams of Jennifer are typical of most young people. Have a career, get her own place (preferably a condo), a husband, and more pets. Of course I am always calling my local Arc to help facilitate these dreams. The Arc has attended and facilitated every yearly Person Center Plan Jennifer has had through-out the years. It gives us peace of mind knowing an organization is there to be “on our side”. The Department of Mental Health is suppose to do things in the best interest of their client but don’t forget they are going to try and hold onto monies from the State the best they can.

Another resource I’d recommend is going to every ‘After I’m Gone’ Series the Arc presents. Knowledge is power and we as parents will not be around for our child forever. We need to make them as independent as they can be and have safeguards set-up for them when we are gone.

We are currently writing a book about Jennifer’s achievements in her life to give hope to families. How she has overcome huge challenges and never gives up. Her dad always said even as an infant **she** never gave up so how could **we** give up on her?

We always lived by the words-

*High Goals, High Expectations, High Achievements.*