Brenda Lewis Battles Hereditary Disease, and Stigma

Brenda Lewis is a fighter. She’s had a nasty note put on her car because somebody didn’t think she should park in the accessible parking spot. She’s been let go from two jobs because her employer didn’t like the way she walked. She’s had friends leave her when times got tough. But she fought back. Quitting is far from her consciousness. She says that people give her looks when she’s out and about, but she goes about her business anyway.

After progressively having difficulty walking, Brenda sought medical treatment. At first doctors thought she had MS. Tests eventually revealed Hereditary Spastic Paraplegia (HSP), which leads to progressive weakness in the legs. Only about 24,000 people in the US and Canada have it. The devastating news was made worse by the fact that her son, Coleman, had a 50 percent chance of contracting HSP.

Now age 43, Brenda was diagnosed 12 years ago. At the time she was working as a dental hygienist, which she dearly loved. Her first three bosses were very understanding of her condition and treated her well. The next one, a young doctor, was not so kind. Brenda said he told someone: “She walks like she’s drunk.” She got fired from that job. Her next dental employer also let her go. She chose to continue in dentistry. She had several interviews, but was unemployed for five months.

A friend told her she should be a paraprofessional. She left dentistry after 20 years, and started with Moorhead schools in September 2016. When cold weather hit, she found it very painful to be outside for recess. She asked for an accommodation, but the school continued on page 2
demanded exact temperature ranges from Brenda’s doctor. The doctor could not provide that, as every person is different.

Brenda then asked for part-time work, which was refused. Over the summer, a series of emails did not resolve the issue. She called a family friend, Tom Thompson, who works at Freedom Resource Center. He told her the employer has a responsibility to provide reasonable accommodations. After cc’ing Tiffany Hovelson, of Freedom’s Moorhead office, on one email, Brenda got her accommodation. She is now working half time at Dorothy Dodds Elementary School. And loves it.

“The kids ask me about my cane,” Brenda said. “I tell them it’s my magic stick.” So while helping with their school work, Brenda is also teaching them about acceptance--valuable lessons for later in life.

Brenda is heavily involved with the Spastic Paraplegia Foundation. Shortly after being diagnosed, she attended the annual convention in St. Louis. Upon returning home, she went out and raised $5,000. Money goes toward research and greater public awareness.

Part of Brenda’s journey toward adapting to her disability was to get out in public and enjoy life. Having gone through a divorce, she was reluctant to think about the world of dating and relationships. She thought no one would be attracted to her because of her disability. Then she met Steve at a street dance in Sabin. They hit it off wonderfully. When she confessed to him that she had this hereditary condition he said he didn’t care. They later married and now have a five-year-old son, Jackson.

“There are days when I feel comfortable with who I am. And then there are days when I hate the world,” Brenda said. But overall, life is going pretty well. She has a great family, a job she loves, and a purpose in life. “I want to make a difference and advocate for people with disabilities. We are people too and we deserve respect,” she said.

From Where I Sit

On October 5 we held our fifth annual Art of Freedom event at Dakota Medical Foundation in Fargo. It was a big success. We had around 80 artists sign up, which was significantly more than any other year. The music, food, and silent auction were all great. People enjoyed themselves and spent a lot of time looking at the art, visiting, and listening to the great music by Steven and Sarah Dunkel.

I was struck by the feeling of teamwork. That word gets thrown around a lot, but it really was powerful. I saw our board step up and do more than ever to make this a great event. They contributed to silent auction items, helped set up and clean up, and were at the front door greeting people. They were excellent ambassadors for our organization.

Our staff were tremendous as well. I may be wrong, but I didn’t see any lack of effort from anyone. They all pitched in and did what needed to be done wherever that was. Some of our staff live an hour or more from Fargo. They stayed until the very end and made sure the facility was put back in its original condition and everything was taken care of. It’s fun to see everyone working together. Many times organizations falter because there is not that teamwork. I am very fortunate to have such great coworkers.

On Friday, I spent some time talking with my coworkers about the event. To me, it was amazing to hear some of the back stories of the people who entered art pieces. These people have made huge strides in their independence, self-confidence, and adaptations to their situation. A couple of months ago we featured the story about Cindy Johnson from Fergus Falls. She displayed the most amazing paintings. I was very impressed, and voted for one as my choice for best entry in the show.

Another person from Fergus Falls, Jeff Williams, entered two fantastic drawings. He did not even want to put them in the show, but Tanya Stoll, who works in our Fergus Falls office, talked him into it. His ship drawing ended up winning first place. I even put a couple of items in the show. One that I almost left at home got the most complements. It’s amazing how much something small like that can help boost your mood and self-confidence.

The essence of why we do this event is so that people with disabilities have a chance to do something they didn’t think they could. That feeling of accomplishment, along with learning a lifelong hobby, is important to having more enjoyment out of life. I have found through my various struggles over the last few years that trying new things and taking risks is worth it.

Jamestown
Cooking is a SNAP – Culinary Nutrition Education Program
Time ~ 1:30 to 3:30 pm the first 3 Thursdays in Oct. and Nov.
Stutsman County Extension Office
502 10th Avenue SE ~ Jamestown, Call Beth to register at 701-252-4693

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Be Aware of Mental Health by Tanya Stoll

Our brains are powerful. They’re delicate and intricate networks of information that define who we are and how we behave, not to mention the total command they have of our bodies. Because our brains are so delicate there are a lot of ways things can become imbalanced. And because of that, some of us will experience mental illness. Just like any other medical condition, there are internal and external factors that contribute to experiencing symptoms. Mental Health Awareness Month is about taking the time to educate ourselves and others about not being mentally ill, but to be mentally healthy!

Mental health has become a hot topic as if it is something scary and should be feared – let me tell you, this is not the case. The likelihood that you or a close family member will experience it at some point is 1 in 5. Some people will find the symptoms debilitating, but most manage the symptoms well enough to work, raise families, and have meaningful relationships.

Mental health is managing stress, keeping our brain and body healthy, and having support systems in place. Everyone manages differently and each one of our realities and resources are different. Education is huge in fighting stigma around mental health because we fear the unknown.

Learn what you can do to stay mentally healthy or to help a friend at www.NAMI.org. The National Alliance on Mental Illness is working to change the stigma, educate, and advocate on behalf of those who are working toward mental health. In the meantime; if you have concerns about a friend, simply ask them how you can help.

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What’s Wrong With This Picture?

This is an example of a protruding object. An object that is between 27 and 80 inches above the floor that extends more than 4 inches from the wall must have a Cane Detectable Device (CDD). A CDD is a permanently mounted item no more than 27 inches above the floor that a person using a cane will detect before they run into the object. Free standing objects on posts may extend no more than 12 inches. The sign has been removed since the picture was taken. The railing on the right also needs a cane detectable device.