

## Keeping Independence

By Tyler Axness, Communication & Policy Coordinator

Watching Jennifer Bloom march into our Wahpeton office on September 29th, it is hard to believe only months ago I witnessed this same woman barely make it across the hall to discuss the difficulties of Social Security. In fact, I had no idea it was the same woman until Joyce, our staff in Wahpeton, reminded me I had previously met Jennifer.

Shocked at how different Jennifer's appearance had become and how much healthier she looked, I needed to hear her story. So we sat down and had a conversation.

**"On October 8th, 2010, a fall spiraled my life out of control."**

Jen had begun suffering from unexplained pain. "I was struggling with unbelievable pain all over my body," she replied when I asked what she had been dealing with. "On October 8th, 2010, a fall spiraled my life out of control." The fall amplified the pain Jen had been suffering from before. Following her fall, Jen went to the doctor with pain spread across her entire body. With few answers, she was prescribed pain medication. It turns out; the prescription would change her life in an unexpected way. "I began transitioning from working to a person who was doped up all the time," she said. Previously, Jen had worked in the caregiver field. She didn't want to be on the receiving end of that care. "The pain meds kept me in a state where I didn't care about anything."

The pain Jen had been going through was unbearable to the point that she kept returning to the doctor hoping to find relief. Unfortunately, relief came in the form of stronger narcotics. With the inability to move without pain and her exploding medical bills Jen began spiraling into depression. Yet, as Jen will tell you, hope wasn't far off. That hope came in the form of Freedom Resource Center. "I was referred to Joyce at Freedom from a person at Hope Unit. Joyce was going to help me find resources to get through pain management and navigate my way through the Social Security process along with many other systems." With her condition going downhill fast, Jen was facing threats of being forced into a nursing facility by her doctor. "A nursing home would have killed me," she said. "I wasn't going to let someone tell me to give up and die." Jen's personal belief was that going into a nursing home was, "a sign of giving up."

Fighting to stay out of a nursing home, Joyce became Jen's lifeline. "Joyce helped me to begin thinking positively, to stop lying to myself, and don't worry about the judgment of others. Positive thinking helped because

if I focused on how many times things have gone wrong, I'd never leave my house." With the help of Freedom Resource Center, Jen was able to avoid going into a nursing facility.

However, the underlying problem remained heavy use of narcotics. Joyce helped Jen get an appointment for a second opinion. Unfortunately, because of the high dosage of pain killers, Jen went into detoxification before that second opinion. While in detox, "I had Joyce's words in my head, 'don't worry about the judgment of others' and it helped me through." The doctors told her it would take six months to a year until the narcotics are out of her system.



Jennifer Bloom

Since being released from detox, Jen has begun seeing the other doctor with the help of Joyce. Her mobility has improved as well. "I'm able to get up and down the stairs on my own. I want to become more physically active but, of course, I need to start slow." The added mobility has led Jen to work with Vocational Rehabilitation to find employment opportunities in the Wahpeton area. She also intends to begin Freedom Resource Center's class known as *Living Well with a Disability*.

"If I gave up, I would be sitting in a nursing home. I allowed one doctor to keep giving me stronger medication without questioning it. You have to be your own advocate even if it is tough." Jen's story is one of personal perseverance and determination to stay independent. Here at Freedom Resource Center, we strive to help everyone remain as independent as possible and hope to share many more success stories in the years ahead.

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- New office opens in Detroit Lakes

By Nate Aalgaard,  
Executive Director

I've visited with a few former board members lately and they always ask, "What's new at Freedom?" It doesn't take me long to come up with a few things. In particular, we are just opening an office in the Washington Square Mall in Detroit Lakes. We have added three new staff members within the last year, and we stay busy every month working with people with disabilities who come to us with their goals for independence.

One of the most exciting things we have been involved with is the Impact Foundation. Starting in 2009, I had the opportunity to be part of their Nonprofit Leadership program. Another member of our staff, Angie Bosch, was in the Emerging Leaders program. Our board participated in the year-long series of trainings on various aspects of board governance. And now we have the opportunity to be one of the Impact Foundation's twelve Seal of Distinction organizations in the state of North Dakota. We are proud of this honor, and are

## From Where I Sit

using the opportunities it presents to enhance our communications program, as well as get involved in fundraising.

You'll notice a different format for our newsletter. We have gone from an eight page newsletter down to four in hopes that it will be more readable. We plan to put it out monthly, so news will be more current. We also plan to feature one person who we have worked with, who has overcome barriers to independence. We've also added content to our website, and are using other media such as Facebook to be in touch with people who are interested in our work. I encourage you to "like" us!

The Minnesota government shut down last summer was a difficult situation for many nonprofit organizations, as well as state agencies. While Freedom did not close any offices or lay off staff, it was very close to that point. We realized

that we could not put as much faith in government funding as we have in the past. We needed to take control of our financial future. Being involved with the Impact Foundation has helped us develop a plan. You'll notice a pledge envelope in this newsletter.

That is the first part of what we are doing to give people the opportunity to support our mission. I hope you'll give it serious consideration during this holiday season. Look for more information from us throughout the year about the impact that we are having in the lives of people with disabilities.



Nate Aalgaard

## Changes to the Independent

We want to provide you with the latest disability stories, information, and events. In order for us to get that information to you timely, we have decided to change our newsletter. Here are some of the changes you can expect:

- **Frequent editions**
- **Shorter in length**
- **Personal success stories**
- **Helpful hints**
- **Question & Answer**
- **Upcoming events**
- **And more...**

Your feedback is appreciated! Give us your thoughts on the new Independent and what type of information you would like to see in upcoming releases. Know any good "people stories" involving disabilities? We want to feature stories of both the challenges and accomplishments of people in our communities.

Email your ideas to: [freedom@freedomRC.org](mailto:freedom@freedomRC.org)

Tyler Axness  
Communication and  
Policy Coordinator

The past few years have been difficult for many states to fund programs a lot of people rely on to remain healthy, active, and independent. Minnesota is one of them. After the legislature and governor could not agree on how much to fund state programs or how much to collect in tax revenue, the state government shut down after the legislative session came to a close. Weeks passed, eventually leading to a compromise that placed many social programs on the cutting board.

Some of you reading this who are Minnesota residents have probably felt the sting of these cuts one way or the other. However, some of these cuts and changes can go unnoticed until you abruptly find out the hard way. For example, did you know state Medical Assistance will no longer cover general anesthetic for a dentist visit? Medical Assistance in Minnesota will also now cover only one regular dental exam per calendar year. Routine dental work such as fillings are still covered, with Novocain. However, people with private dental insurance are able to get more than one covered exam per year. Is this right and fair?

## Under the Bridge Obstacles to Independence

The only way to get Medical Assistance to cover general anesthetic is if a person has a significant mental or physical disability that requires the numbing application. In other words, the patient must prove that due to their disability they need the general anesthetic. Also, the operation cannot be done in a dentist's office, but at an outpatient hospital or surgical center. We know of a person who would have to come up with \$600 in cash in order to pay for anesthesia. He cannot afford that.

I wonder, is this an indirect way to cut state funding for people who need it? Is the state thinking people will forgo expensive dental work because they will have to deal with added bureaucracy and hassle? Will changes in coverage cause people to simply give up and suffer with painful dental problems?

The potential consequences of this change in policy are very real. People I've talked to said they'd forgo the operation if they cannot find the means to pay for the general anesthetic on their own. This case is an example of why we must be engaged and pay attention to the fine print when it comes to public policy.

# Neurofibromatosis: What Is It?

By Becki Radeck

The following contribution was written by a volunteer from Freedom Resource Center.

Hi, my name is Becki Radeck and I have written an article that I would like to share with you. My hope is to spread some awareness about a genetic disorder called Neurofibromatosis (NF). This is a genetic disorder that causes tumors to grow anywhere outside or inside the body. However, NF is unpredictable and does vary from person to person.

I was diagnosed with NF when I was 4 years old. Tumors have been growing on my body since then, and my condition with the tumors have been getting progressively worse, with the tumors increasing in quantity. Having these tumors have affected my life in a big way. The appearance of them on my face has made me feel somewhat insecure around people. Through the help of Freedom Resource Center, I have begun to overcome my insecurity. I hope sharing my story, along with information about NF will increase awareness while offering support to others who may be affected by this disorder.

There are three types of NF: NF1, NF2 and Schwannomatosis. NF1 is the most common type. A person with NF1 could have what is known as café-au-lait spots on the skin and neurofibromas (tumors) on or just under the skin anywhere on the body. These tumors can also grow anywhere inside the body. NF1 affects about 1 in 3,000 births. It can be very mild to very severe, but can also cause a variety of conditions such as disfigurement, scoliosis, learning disabilities, a

large head, optic gliomas, congenital defects of the bone, and high blood pressure.

NF2 affects about 1 in 25,000 births in the world. People affected by NF2 have multiple tumors on the cranial and spinal nerves and by other lesions of the brain and spinal cord. According to the Children's Tumor Foundation website, tumors affecting both of the auditory nerves are hallmark. Hearing loss beginning in the teens and early twenties is generally the first symptom.

Schwannomatosis is even more rare and not as much is known about this type of NF. It appears to affect around 1 in 40,000 individuals.

Although it seems not many people are affected by NF, it is more common than Cystic Fibrosis, Duchenne Muscular Dystrophy and Huntington's Diseases combined!

If you would like more information about Neurofibromatosis, please visit [www.ctf.org](http://www.ctf.org) (The Children's Tumor Foundation) – which is the source of information for this article.



Becki Radeck

## Information

In an attempt to reduce the cost of mailings please send your email address to [freedom@freedomrc.org](mailto:freedom@freedomrc.org)

If you would like to be removed from our mailing list please call 1-800-450-0459.

Freedom Resource Center and/or its Board of Directors do not necessarily endorse or support any of the views expressed within the personal testimonies contained in this newsletter, unless approval is specifically mentioned.

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Alternate formats available upon request.

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**New  
office opens  
in Detroit Lakes!**

Stop by or give us a call for any disability related issue:

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***“Helping Bridge Your  
Path to Independence”***

According to the United States Census Bureau
<ul style="list-style-type: none"> <li>▪ 19% of Americans had a disability in 2010</li> <li>▪ Of the 54 million people with disabilities, 11 million needed personal assistance with everyday activities</li> <li>▪ 46.2 million Americans live below the official poverty line in 2011</li> <li>▪ The poverty level for a single person under the age of 65 was \$11,344</li> </ul>
Freedom by the Numbers for Fiscal year 2011
<ul style="list-style-type: none"> <li>▪ Direct 1-on-1 services to 574 people, compared to 449 in 2010</li> <li>▪ Responded to 6,406 information and referral requests</li> <li>▪ Provided 609 hours of system advocacy</li> <li>▪ Conducted outreach to 4,164 people</li> <li>▪ Provided community education to 2,743 people</li> <li>▪ There were about 9,500 visits on Freedom’s website</li> </ul>

**HAPPY HOLIDAYS!**

*Warmest thoughts and best wishes for a happy holiday season and healthy, peaceful New Year to you and your family from the staff at Freedom Resource Center.*



*Back Row (L-R): Jim, Tanya, Mark, Raeane, Joyce, Andrea, Rikki, Angie, Diane, Rebecca  
Front Row (L-R): Terry, Jennifer, Tyler, Bobbi, Nate*