

Ohio Rehabilitation Services Commission



NEWSNET

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Promoting employment of Ohioans with disabilities

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October celebration, p 4**
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Taming Tourette's tics

**FREED SETS EXAMPLE
FOR PEOPLE WHO SHARE
HIS SYNDROME**

Journey toward acceptance ends with job at Coleman

Story and photos by Trudy Sharp,
RSC public information officer

With the frenetic delivery of comic Robin Williams and a catchphrase of, "It's all good," at 38, Nelson Freed of Canton is an energetic and upbeat person to be around. Conversation is often peppered with specific dates and minute details of occurrences, and occasionally sprinkled with words not typically used in polite settings. It is hard to imagine him as the shy, quiet adolescent he was before a diagnosis of Tourette Syndrome.

The physical tics began when he was 15, Freed recalled. "I was an only child. My mother had me when she was 44 and a half. She fell on the ice, then found out she was pregnant, not just getting fat. Anyway, I was born May 23, 1969, same day as Drew Carey, who's hosting the *Price is Right*. I don't quite agree with that, but that's another story. I was very shy in school – never talked to my peers – just answered yes or no. Boy, that's changed, hasn't it? Now, I'd be the class clown."

Freed remembers a very traumatic tenth grade year. "Kids used to make fun of me: 'you're jerking, you're jerking.' This was when Tourette's was unknown in 1985." Two years later, while at camp, someone suggested that the explanation for his symptoms was Tourette Syndrome. "I said, 'Turd's syndrome?' – what I thought he called it," Freed said with a laugh. "Anyway, my mom said that she read about it in Ann Landers."

A trip to a doctor in Canton confirmed it. "August 11 was my 20th anniversary of being diagnosed. They put me on Haldol. I almost didn't make it through Kent that first semester," Freed remembered of his 18th year. "I just dropped myself out." However, with determination and family encouragement, Freed did complete a degree in public relations at Kent State University's Stark County campus.

Tourette Syndrome is a biologically based, neuropsychiatric disorder characterized by involuntary movements and sounds called tics. Every person with the diagnosis is unique in how it may manifest. The motor movements can range from subtle – an eye blink or nose twitch – to severe convulsions that can cause injury or make it difficult to function.

Verbal tics might include hoots, barks or grunts, or echolalia – a propensity to repeat words or echo sounds in the environment. In a minority of cases, verbal tics are expressed as coprolalia – involuntary cursing or use of inappropriate words. This rare symptom has been sensationalized by the media, according to advocates.

The condition most often appears between the ages of two and 16, and is more common among males. Tics can start small and escalate as a child ages. It's also common for youngsters to outgrow the syndrome before adulthood. Symptoms of attention deficit hyperactivity disorder (ADHD) and/or obsessive compulsive disorder (OCD) are commonly associated with Tourette Syndrome. Current medical treatments are not equally effective in all cases and the side effects of medications to suppress tics may be intolerable.

In Freed's case, the symptoms that started with head jerking, escalated. "It seemed to get worse as I grew older," he said. "I even have neck herniations and sensory loss on my right side from my breast bone down to my hip." He also developed vocal tics such as whoops, spitting and using curse words. Many years of trial and error with various medications brought him to a point where the tics are less severe, less frequent and easier for him to suppress.

However, even with more control

over his Tourette's, Freed has found that employers are less than accepting of his involuntary outbursts. He wrote about his recent experiences for the Tourette Syndrome Association of Ohio Web site at www.tsaohio.org: "It was May Day 2002, and I was in a dead-end telemarketing job in Canton, where I loved the co-workers, but not the job exactly. I had the old coprolalia and was taken into the office and let go that day.

"Having a bachelor's degree in public relations from Kent State University and not knowing what to do, I headed to a lawyer's office. My goodness, this had to be discrimination!"

Eventually, Freed was connected to the Ohio Rehabilitation Services Commission's Bureau of Vocational Rehabilitation. At RSC's Canton office, he began working with Counselor Jennifer Wells. Now, successfully employed for more than two years with Coleman Data Solutions, Freed said, it wasn't an easy journey for him or Wells.

Freed had eight years of experience in telemarketing. Ironically, his tics are not evident when he talks on the phone. However, he felt that the stress of that type of job exacerbated his issues. He just didn't feel that he could do telemarketing anymore.

Even if Freed was able to get past the interview for a new job with Wells' help, sometimes the job lasted only a day. "This particular client faced horrible discrimination," Wells said. "His



After years of searching for a good job fit, Canton-resident Nelson Freed (center) is a data entry specialist at Coleman Data Solutions in Akron, where tics related to Tourette Syndrome are taken in stride by his employer and colleagues. RSC Counselor Jennifer Wells (left) and Coleman Human Resource Specialist Phillip Jackson (right) are part of Freed's job success.

verbal tics were related to whatever situation he was in. On the first job, he was learning people's names and was the only male in the office. He would have a verbal tic with one girl's name, saying her name over and over again. It freaked her out.

"He's been asked to leave other agencies where he went for help because people saw him behaving strangely," Wells continued.

"A year on welfare and food stamps ticked by, with car payments and other debts running behind, and me getting by on loans from Catholic Charities and the like," Freed recalled.

A local job placement agency that RSC partners with suggested that Freed take an on-line course in medical transcription. His detail orientation and writing ability would be compatible skills for this type of career. "I passed the course, took a job and was let go the first day, as they were uncomfortable with my tics," Freed said.

Next, Wells and Freed considered a job in transcription in a home-based environment, where his tics wouldn't impact other employees. "He began working from home for a company in Southern Ohio," said Wells. "He had to listen to audio tapes and then transcribe what he heard. It could be a meeting or a Congressional hearing."

Freed found the job very tedious. A job placement agency found him another medical transcription job in Dover/New Philadelphia in early 2004. "I drove down and the woman kept me for one day," said Freed. "She said that the other two workers were intimidated by the swearing and the tics."

In a meeting of professionals hoping to help Freed, someone mentioned Coleman Data Solutions (formerly known as SAGE Computers), a company located between Canton and Akron that makes a point of hiring people with disabilities. It would involve data entry, a slightly different skill set, but Freed and Wells were willing to give it a try.

"I wasn't really sure because I didn't have experience in data entry, but I said, 'I'll come test,'" Freed reported. "I was on welfare and I have elderly parents. I had car payments that I was running behind on. I was getting frustrated, although I was always a positive person." He passed the test and got through a tough interview, that Wells recalls: "I attended with him. The HR guy at Coleman is an African-American. All through the interview

Nelson was having a horrible verbal tic that included a racial slur."

Phillip Jackson, the aforementioned human resources specialist at Coleman, didn't let the tics get in the way of hiring Freed. However, he was concerned about how other employees might react, so he suggested a home-based position with Coleman as soon as the necessary equipment could be set up. This took longer than expected, so in December 2004, Freed took another telemarketing job to make ends meet. "I just said, 'I'll hold my horses.'" Then, trouble on the telemarketing job put him close to getting fired again.

Just in the nick of time, Beverly Moore, director of Human Resources at Coleman, decided that Coleman could accommodate Freed's tics on-site, instead of waiting for a home-based position. "Phil and I talked about putting him in a separate room or cubicle, or providing some type of sound barrier," said Wells.

"Initially, when we started off, we used the training room," said Jackson of the solution. Since then, Freed has been moved to an office space just off the main floor.

As one of the largest data management companies in Ohio, Coleman provides document scanning, entry, archiving and processing to customers in banking, government, marketing, health care and other disciplines. It is an enterprise of Coleman Professional Services, a nationally recognized non-profit provider of behavioral health and rehabilitation programs in Northeast Ohio. Its corporate philosophy is to offer a workplace where people with and without disabilities work in unison.

Freed's co-workers at Coleman have welcomed him, and he is grateful that the home-based situation didn't come to pass, because his colleagues have become a second family. "They can distinguish between what is a tic and what's not a tic, now," Freed said. For example, they've learned to distinguish an involuntary spit or curse, from a whoop of excitement when he listens to the radio broadcasts of Cleveland Indians games. His employer is happy with his performance and officially awarded him for his attendance. "Two and a half years later, every single day, I'm ready for work. Everybody knows there's Nelson, saying 'It's all good.'"

See Page 6 for more about the Tourette Syndrome Association of Ohio.

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RSC Contributors: Chris Estep, James Gears, Elizabeth Sammons, Marilyn Sydow and Lucille Walls

Staff: Louise Czatt, David Lauridson, Steve Ostrander, Kelly Rammell and Valerie Snaveley

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