

The "life sentence" of MS; Disease has more victims in the Northwest than elsewhere

By: Linda Thomas, Journal Newspapers

04/03/2007

[✉ Email to a friend](#) [🗨 Post a Comment](#) [🖨 Printer-friendly](#) [🖼 View photo gallery](#)



Photo Gallery

An annual walk to raise money for MS research begins Saturday morning, April 15th at Husky Stadium. The goal this year is to raise \$1.8 million.

[Top of Page](#)

Ballard resident Trevis Gleason always thought he was kind of clumsy. He'd trip for no reason or drop things. No worries. It happens to all of us.

One evening he walked barefoot in his home and heard his left foot make a strange slapping sound on the hardwood floor. That was odd.

The next morning he woke up and the left side of his face felt like dough. Reluctantly, he went to the doctor. He was worried he might be having a stroke. That wasn't the diagnosis.

Lyn Laielli, who lives in Magnolia, had problems walking when she was in her early 20s. Sometimes the simplest thing, such as lifting one leg up onto a step, threw off her balance.

Often she got a tingling sensation up and down her spine—a pins and needles poking feeling.

After a series of tests, her doctor came back with a two-word diagnosis. It was a disease she didn't know anything about.

Both Laielli and Gleason have multiple sclerosis. The chronic disorder affects their central nervous systems and has changed both their lives in different ways.

"MS isn't a death sentence, it's a life sentence," said Gleason. "You have to figure out how you're going to live out that sentence."

More MS in Northwest than anywhere else

According to the National Multiple Sclerosis Society, each week about 200 people—generally between the ages of 20 and 40—are diagnosed with the disease. They estimate 50,000 people in Washington State are affected by it.

There is no cure, and until 1993 there weren't even any medications to treat MS.

One disturbing tendency with the disease has caught some residents' attention through billboards in the area that state: The Northwest has a higher incidence of MS than most anywhere on earth.

Dr. James Bowen, a neurologist at Evergreen Health Care's MS Center in Kirkland, is one of the area's leading researchers on the disease. He cautions that the higher incidence of MS isn't limited to the Northwest.

"Northern tier states and southern Canada have equally high rates. Worldwide we see the high prevalence of MS in northern and central Europe also," he explained. "The converse is true in the southern hemisphere, where South Africa and southern parts of Australia have high rates of the disease."

Why?

Dr. Bowen said there is no satisfactory explanation of this phenomenon. Certain variables have been researched such as the climate, humidity, and hours of daily sunshine.

"Causes of MS still elude us," said Dr. Bowen. "We do know that susceptibility to MS is determined by a complex interaction between genetics, the environment, as well as a person's resistance to viruses."

Living with MS

Gleason, 40, is originally from Michigan. He's been around the world several times, first as a Coast Guard navigator and then as a corporate executive chef for a German manufacturing company.

Other than feeling exhausted most of the time, life was good for Gleason.

"In a lot of ways I was 'the man,'" he said. "I was heading toward the peak of my career. Being a chef wasn't just what I did, it was who I was."

Was. Six months after being diagnosed with MS, Gleason was unable to work. He went on a disability leave and took on a new full time job-dealing with insurance companies and trying to manage his disease.

Gleason has an "aggressive and progressive" form of MS.

"Every day starts with an inventory when I wake up of what I can move, what I can feel, what I can't feel. I sort of go through the day in my head trying to figure out what I can get done given how I feel," he said.

MS is different for each person. Some people have episodes of numbness and tingling in their arms and legs. Others have a loss of balance, slurred speech, stiffness, difficulty thinking, or extreme fatigue.

The symptoms can be mild for years, which made it easy for Laielli to hide the fact that she had MS from co-workers.

Laielli had a rather normal life after she was diagnosed with MS 20 years ago. She got married and even spent a year hiking around Australia.

"When I was diagnosed they told me I had a neurological condition and I could end up in a wheel chair," Laielli said. "I wasn't scared though because I felt fine and I still had my 'I can take on the world' attitude."

The world became a little harder to take on about four years ago when the quality of her work in the graphic design field started slipping. It became difficult for her to concentrate and move.

"I remember one day at work when my manager said, 'Hey Lyn, come over and take a look at this,' and I couldn't get up. My leg had cramped up and I couldn't move," she said.

Laielli, a self-described "stoic Navy brat," received a lot of support from her co-workers after she finally told them she had MS. Even so, she was unable to keep working.

Only one out of three MS patients stay in the workforce, according to Dr. Theodore Brown, whose expertise at Evergreen Health Care's MS Center is in physical medicine and rehabilitation.

"I would like to see this disease lose its stigma," Dr. Brown said. "Although it's not curable, it's definitely treatable. There's a good prognosis with MS and it's getting better all the time because of advances in medicine."

Since the first MS drug treatment became available in 1993, the Food and Drug Administration has approved six new treatments. In another five years, Brown expects there will be four more.

MS research is one of the "fastest moving areas of medical research," according to Dr. Brown. He is optimistic MS will be cured during his lifetime.

"Optimistic" is also a word that describes the attitudes of both Laielli and Gleason.

Laielli now works as a volunteer/educator/activist with the Greater Washington Chapter of the MS society.

"If I were to cave in to MS, I'd curl up in a ball in the corner and I wouldn't be a very fun person to be around," she said.

Gleason is an advocate for those with MS. Among other things he runs a "poker night" support group for men the first Tuesday of every month at the Seattle MS office (192 Nickerson Street, Suite 100.) They don't play poker, incidentally. Gleason said it's easier for some men to leave work by saying, "It's my poker night," instead of telling others they're going to a support group.

"This is not what I planned for my life," Gleason admitted, "but I'd say my life now has a purpose and direction that I didn't have before."

Make a difference

More than 8,000 walkers are expected to participate in this year's MS Walk, in an attempt to raise \$1.8 million dollars. The walk takes place in several Western Washington communities Saturday, April 14. Seattle's walk begins at Husky Stadium, Sunday, April 15. For more information, visit www.whyhere.org.