



Spokane's Fight Against Multiple Sclerosis

by Blythe Thimsen

DARIN JUSTUS LOOKS LIKE ANY OTHER YOUNG, ON-THE-GO GUY AS HE STRIDES PURPOSEFULLY into Starbucks and orders a tall white chocolate mocha at the counter. He, like many other people in line, is trying to balance a busy schedule, take care of his work and family, and is ready to get a jumpstart of caffeine. Unlike others in line though, Justus has the added burden of thinking about Multiple Sclerosis.

Justus was diagnosed in March 2002, at the age of 33, after he and his wife took a trip to Fairmont Hot Springs. Half an hour after getting out of one of the famed hot spring-fed tubs, his body was numb from the waist down. "It was a really strange feeling," says Justus, who thought it was due to running across the cold snow in bare feet and jumping immediately into the hot water. He assumed it would go away, which it did – two weeks later.

With the numbness gone in his lower body, the left side of his face then went numb while he was on a business trip in Oregon. When he got home he and his wife went to the hospital where they ran numerous tests, including an MRI. The doctors initially guessed his MRI would reveal that he either had a brain tumor or Multiple Sclerosis. When the results of his MRI came back they indicated there were lesions on Justus' brain. He had Multiple Sclerosis (MS).

Multiple Sclerosis is a disease that, according to estimates, is diagnosed in 10,000 people each year in our country. For reasons which have not been completely determined, the Northwest and Spokane specifically have an exceptionally high rate of occurrence. Because of that, chances are you know someone who has the disease themselves or who has a friend or family member with it.

An autoimmune disease which affects the central nervous system, MS attacks the fatty tissue called myelin surrounding your nerve fibers. The myelin helps nerves conduct electrical impulses from the brain. When the ability to conduct these impulses is interrupted, a variety of MS symptoms can occur.



Symptoms vary from person to person; however, common symptoms include extreme fatigue, vision problems, loss of balance, difficulty walking, slurred speech, tremors, loss of muscle control and bladder problems.

There are four types of MS, each of which take a different toll on the patient:

Relapsing/ Remitting – This type is defined by clear flare-ups (sometimes called relapses or attacks). Patients experience episodes of acute worsening neurologic function followed by partial or complete recovery periods. This is the most common form of MS.

Primary Progressive – A slow yet continual worsening of the disease is experienced from the onset and there are no distinct relapses or remissions. The rate of dete-

rioration may be slow and there may be occasional temporary improvements. This form is rare.

Secondary Progressive – Patients experience relapsing-remitting MS for a period of time and then they begin steadily worsening.

Progressive Relapsing – Patients experience a steadily worsening form of the disease from the onset, but they also have clear acute relapses with or without recovery.

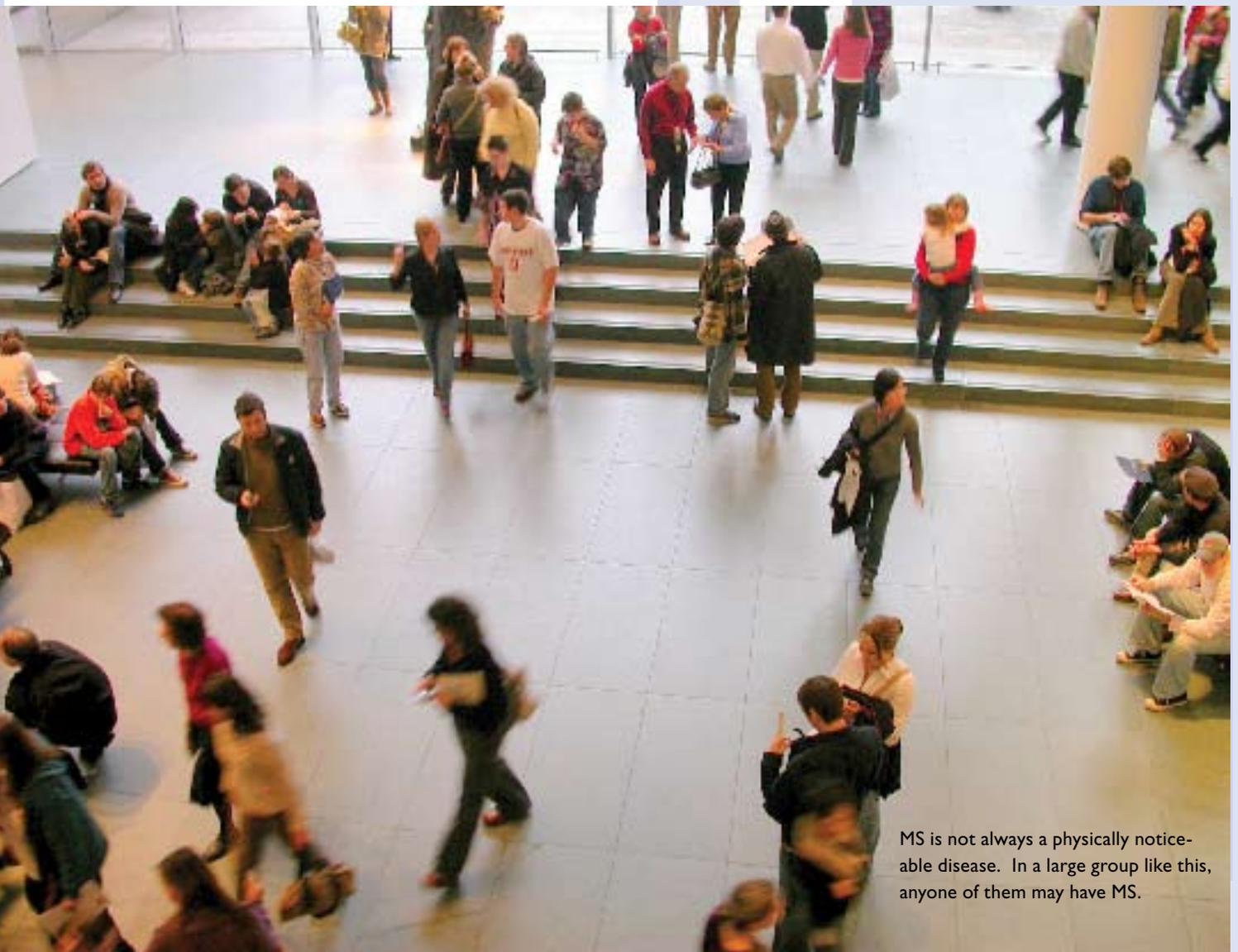
Doctors and researchers have yet to determine the exact cause of MS, although there are several theories. It is generally believed MS is caused by the body's abnormal response to the immune system. Some ideas of the cause for that range from genetics to viruses to something in the envi-

ronment that a patient was exposed to as a child.

As confusing as the cause of the disease is, diagnosing it can be even trickier. "It is a hard diagnosis to make in some people. Sometimes it takes several visits over several months, or several years," says Dr. Roy Kanter, one of two neurologists in Spokane who works exclusively in the field of MS. "It is like piecing together a puzzle with pieces missing."

The reason it is so difficult to diagnose the disease is because there is no official test for MS – although an MRI is generally considered the most useful tool – and it cannot be diagnosed until there have been at least two "anatomically separate demyelinating events" thirty days apart.

"There are the symptoms of MS and



MS is not always a physically noticeable disease. In a large group like this, anyone of them may have MS.

the pathology of MS,” explains Dr. Steven Pugh, a neurologist at Rockwood Clinic, and the second of Spokane’s two MS-exclusive doctors. “Symptoms include things like loss of vision, difficulty balancing, dizziness and fatigue, while pathology of the disease is what we see in the MRI. If you don’t know what the pathology of the disease is, you will never be able to treat it.”

“MS is probably not one disease. It is probably several diseases that are pathologically different but clinically the same,” says Pugh.

Although many neurologists in the area treat MS patients as part of their practice, Kanter and Pugh are the only two who work exclusively in the MS field of neurology. Each often works in partnership with a patient’s primary neurologist to provide care. Both Kanter and Pugh have dedicated themselves to working exclusively with MS patients in our community, and to treating them for their MS symptoms only. That means if an MS patient has another medical condition they would see their regular doctor, while they work with Kanter and Pugh specifically for their MS needs. “I want to be able to focus on needs related to MS,” says Kanter. “I can do that most effectively if I don’t have to deal with other medical issues.”

Dr. Kanter was a general neurologist for 18 years in Cheyenne, Wyoming, where he began to see an increasingly larger amount of MS patients in his work. He was personally familiar with the disease due to his own mother’s diagnosis. “That’s fueled some of my interest in working with MS,” he says. His skill and reputation as one of the best led to him being recruited to come to Spokane to head the MS Center at Holy Family Hospital three years ago. “It is nice to be able to focus my efforts on one area,” he says of working strictly with MS.

“Although other places talk about having MS clinics, I know Holy Family Hospital felt it was part of their mission to take care of folks who have MS,” says Kanter of the services provided at the MS Center of Holy Family Hospital. The center has drawn patients from North Idaho, Northwestern Oregon, Missoula, Butte and even Alaska.

Holy Family’s MS Center, which opened in 1999, is the only center of its kind in this part of the country. Within the center, and available to patients are the services of an on-site neurologist, physical therapist, occupational therapist, psychologist, a

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It was an "unmet need" at Rockwood Clinic that brought Dr. Pugh to Spokane from the University of Washington. "I found some of these patients were my favorite," he says of the MS patients he treated. "They were young patients with whom you can develop long term relationships." This is because MS patients are typically diagnosed at a young age (between 20 and 50 years old) and doctors follow them over the course of years, during which time they learn about their families, experience significant milestones and become connected. Although many specialists see their patients on a limited basis for a short time, the relationship between an MS doctor and their patients is similar to that of a family physician.

"We are a neurology department within a center," says Pugh, explaining how MS care works at Rockwood. With MRIs available on-site and close connection of specialists all available within the building, it is a center unto itself.

Although they work for different organizations, neither Kanter nor Pugh see themselves as competitors; instead, they are working toward the common goal of helping patients. "Our goal is to be able to go downtown [into a restaurant] and sit at the bar and have people come up to us and thank us for curing them," say Pugh of what he and Kanter would like their job to be. Until that day comes, and as patients need to be treated, they are perhaps the best hope for local MS patients.

The good news for patients is that in addition to excellent local care, an incredible amount of progress has been made in understanding and treating MS. "Absolutely! Absolutely," says Kanter with a steady gaze and conviction in his eyes when asked if good progress is being made. "Twelve years ago we had no preventative therapies [to slow relapses or growth of the disease], now we have six FDA approved medications. A lot of progress has been made toward treating particular symptoms. They are making progress."

Kanter sees great changes in the area of research and the available drugs. "If we never learn anything new from MS.... the research going on with MS is so dramatic, ten years from now, no one will be on the

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medication they are on now.”

Much of that research is done through clinical trials, which have their pros and cons. Kanter realizes there are a variety of medical studies which involve MS patients, and several of his patients are eager to get involved. “There are certain of those therapies that sound good on the surface,” but you need to dig deeper, he says. “We work through with each individual patient to see what their needs are.”

MS clinical trials are conducted throughout the country, including some that are local. A good way to learn about clinical trials is to visit the National MS Society website (www.nationalmssociety.com). An upcoming clinical trial in which Rockwood Clinic will be involved is looking at using an oral treatment for MS. Most MS medications now are delivered through an injection, so if it proves successful it would be another leap of progress within the field. Although clinical trials are often enticing to patients, they are not for everyone. “Not everyone is a candidate,” says Pugh of clinical trials. He stresses it is important to find a trial that is right for you and your symptoms.

The same goes for the different treatment options available; it is essential to patiently work to find the one that is right for each person. “You can’t identify who will do well for a long period of time when you first meet them,” says Pugh. In this day and age of instant gratification, it is important to have patience when trying a treatment, as it can take several months to see how your body will respond.

One treatment option that has gained recent attention is called Tysabri®. “It is a designer antibody that is designed to go after one particular receptor,” explains Kanter. “It is a very effective drug.” There are risks, however; it carries with it a one in one-thousand risk of developing a potentially fatal viral disease called progressive multifocal leukoencephalopathy (PMO). They key, says Kanter is to figure out which patient’s it makes sense to treat with this, based on their individual situation. Because each case of MS is so different, that advice rings true for any treatment approach.

Justus takes a medication called Copaxone®, which is a pre-filled needle with a daily injection. It is time consuming and requires a commitment for Justus to take the drugs. Every night around the same time, his injection, which must be refrig-

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erated, has to be prepared and sit at room temperature for close to half an hour before he can take it. He must rotate the location on his body where the injection is made.

Since taking his medication and seeing a doctor on a regular basis, Justus has not had another attack; however, it is never far from his mind. "That is the fear of the unknown," he says. "It comes and goes with MS."

Regardless of the treatment path you take, doctors agree early treatment is best with preventative therapies. The earlier you start treatment the more effective it can be.

"I see a difference between those who can tolerate FDA drugs and those who can't," says Pugh. He stresses that is not a very scientific observation, but rather a personal observation that those who can handle the drugs and take them do better than people who abstain from the medications all together. Of course, there is no accounting for why someone is not taking a drug – perhaps it had a bad effect on them, they don't want to take it, or it is too expensive; the reasons are numerous.

"It is an insurance policy," say Pugh. You may still get sick with the medications, but it is a preventative device. He compares it to getting into a car accident while wearing a seat belt. You will still get hurt, but the seat belt helps prevent further injury; similarly, you may still suffer symptoms of MS while on the medication, but you are likely to not suffer as many or to such an extreme.

The truth is, with the right care the impact of MS can be minimized. "Although there is not a cure yet, for most people it is a controllable disease," says Kanter. "Most people can live an active fulfilled life." It is a belief Pugh echoes. "The majority of patients do well over a long period of time," he says. "They live productive lives. They may experience disabilities at a time but it is not a death sentence."

"I love working with folks who have MS," says Kanter. "People initially are depressed; they feel like a ton of bricks fell on them, like their life is going nowhere. It is neat watching people work through the progress, get their life back on track and be productive with their family and their jobs."

Four years after being diagnosed with the disease, Justus is doing well, although the road was bumpy for a while. The night of his diagnosis, as he digested the news

of MS, he sat up searching on-line for information. "For some reason, it just hit me," he says of the impact of the diagnosis. The next day he didn't feel well. "I walked downstairs to my wife and I got really dizzy," he says. For the next 10-12 days, Justus was plagued with extreme dizziness, to the point that when he was lying down he couldn't open his eyes and focus on someone above him because it made him dizzy. Along with the dizziness were extreme headaches, and a complete loss in appetite, which led to weakness.

"It was really scary," he says of this time in his life. Sitting at home, lying in pain and dizziness, Justus' thoughts turned to his wife and three children, who at the time were ten, six and two. "I was thinking, 'What is going to happen to them?'" he says. "You start thinking 'is this the end?'"

Once put on a regime of medications, the extreme dizziness he had experienced cleared up and gradually his symptoms disappeared. When or if another attack would hit was unknown though. That was four years ago and Justus has not had another attack or any more symptoms since.

While MS should not take over your life, Pugh warns not to ignore symptoms that do come up, though. He has seen many patients who had been living with symptoms for months or years but just brushed it to the side, either figuring it would go away, or fearful of receiving a frightening diagnosis.

According to Justus, the best way to face the disease is head on with a positive attitude.

"The biggest struggle for me is my thought process," he says. "We are all human. I think 'why me', but I don't want to go there. Regardless of how bad off it is, its one of those things where you have to find good in it, find the diamond in the rough. In every challenging time in life, in my opinion there is a purpose and good will come of it."

"I don't want to come across as insensitive to others that have more intense physical struggles with MS than I do," he says. "My heart really breaks for those who are wheelchair bound. I struggle with those thoughts of that happening to me. Bottom line is the fact that it is not easy living with this diagnosis on a daily basis. Just the fact that I have this diagnosis is just not fun to even ponder; however, I would rather be proactive in this battle because I really do

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feel we can win this war.”

Justus says the diagnosis has made him think about things, such as, “how’s my health, am I eating right?” He has changed his diet and watches his intake of proteins and trans-fats in order to keep his overall health in check.

Another relative within Justus’ family was diagnosed with the disease roughly six to eight months after he was, which leads to the yet unanswered question, is MS genetic? If it is, does that mean Justus’ children will have an increased chance of getting it? “It’s a concern,” he says. “You don’t want that to happen. I can live with it because it is me, but the thought of them even thinking they could have it...I don’t want to even think about it!”

One of the reasons he wouldn’t want them to face it is the emotional toll it can take on you. Justus is aware of this and works to maintain a positive attitude. “The onslaught when you are first diagnosed, that was really hard to swallow. I think your attitude really affects it. You have to look at yourself and say I can either sit in a corner and be a victim, or say, okay, here is the hand I have been dealt, I can beat this!”

“I am going to beat MS, MS is not going to beat me,” he says. “It won the first battle, but not the war!” **■**

MS FACTS

- 400,000 Americans are diagnosed with MS
- 200 people are diagnosed per week in the US with MS
- 2.5 million people have it, world-wide
- Most people who develop MS get it between the ages of 20 to 50
- It is two to three times more common in men than women
- It is more prevalent in people with northern European ancestry, and it increases in occurrence the farther away you get from the equator
- Common triggers of relapses or attacks include emotional and physical stress as well as colds or the flu

Source: Wikipedia.org

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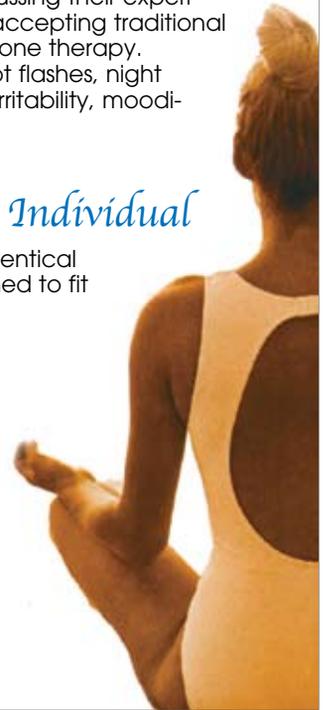
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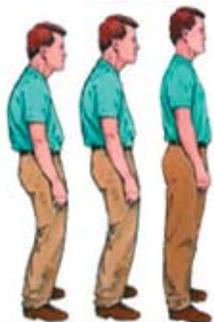
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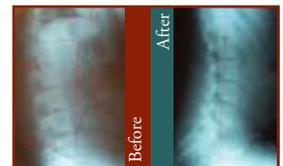
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