

MS grabs ahold and doesn't let go

How? Why? What? Where? Much remains unknown about this disease

By Dave Schafer

Pinned up against a light in the darkened room was an X-ray of what the doctor had said was her brain.

It didn't look like a brain to Anita Sowell. It looked like a bunch of white spots.

The spots were scars where her body's defenses had attacked the myelin in her central nervous system, damaging the fatty substance that protects the nerve fibers.

"We see that you have multiple sclerosis," Dr. Michael Newmark had said.

No one in her family knew anything about MS, except that it had ended comedian Richard Pryor's career, leaving him almost immobile.

Her husband wouldn't want to deal with an immobile wife. He hadn't asked for this. Neither had she.

Sowell had gone to the doctor because she'd felt faint on the way to work one day, and the

next day her vision had blurred temporarily. But those were minor. This was serious, a lifetime of dependence on others.

This is a dream, she thought. I'll wake up and none of this will be real.

The buzz of Newmark's voice stopped and the lights turned on, snapping Sowell out of her trance.

This is treatable, Newmark told her. MS is unpredictable, and

See **MS** on page 9.

MS continued from page 1.

we don't know what's going to happen. But there are medicines you can inject that can freeze the progression. This doesn't mean you have to change your life.

"I'm totally scared of needles," she said. She needed to act like a grown up. *No crying.*

A nurse entered the room carrying a red box. She sat it down on the counter and opened it. Inside was a syringe, a vial of medicine, wipes and bandages.

It hit Sowell then. She was awake. This was real. The tears broke free.

When they stopped, Sowell seized her future by taking those injections and refusing to yield to the disease.

Different person, different symptoms

It took Tamara Jennings 10 years to accept the disease fate had dealt her.

"I'd always been so healthy," she said. "I thought, no way. I don't have MS."

She thought that even as the tingling that had begun in her legs spread to the rest of her body and became so persistent that now she doesn't even notice it until she stops to notice it. It feels like when her foot falls asleep, but not as severe.

That she experienced different symptoms than Sowell isn't surprising. Each MS sufferer experiences different symptoms that may change over time.

The tingling, combined with pain radiating down her neck, sent Jennings to a specialist. Her X-ray had one dark blob on the cervical spine.

Although she took her medicine, the disease progressed. Her legs grew weaker. Occasionally, they would stop responding, and she couldn't get them moving again.

She learned to walk along the wall in case her legs wobbled and threatened to give out. She used the walls to get to a bench or planter to sit down. The walls give her the support many MS patients get from walkers or canes.

After changing the bed sheets, doing a few loads of laundry, and vacuuming her two-story house, she was as exhausted as if she'd just finished a high-intensity workout.

She still exercises but doesn't take long walks. At the store, she rides a buggy. As a 911 PSAP supervisor, she sits.

Over the past two years, the weakening in her legs has become more frequent.

"I've seen people tied to wheelchairs or walkers," she said. "So that's concerning. I still have a brain that's active and ready to go."

She hopes the disease will go away

some day. "But I don't know," she admits. "I might be like this the rest of my life."

There's no cure yet. But for many patients, the symptoms plateau.

"We'd like it to plateau when the patient is doing very well and is functional," Newmark said.

MS 101

Newmark, interim chief of neurology at St. Luke's and a neurologist with Kelsey-Seybold Clinic, sees a lot of MS patients. Most of are doing well, he said.

Even without medicine, MS patients can do well, but injections increase the odds, Newmark said. So does maintaining good health, a balanced diet and exercise.

In MS, the brain shows lesions separated in time and space. The disease affects more women, tends to affect better-educated people, and has higher rates among middle-class people. While it can strike at any age, it's more common from 20 to 40, Newmark said.

About 85 percent of sufferers are diagnosed with relapsing-remitting MS, which includes clearly defined attacks of worsening neurologic functions followed by periods of partial or complete recovery. (See Four courses of multiple sclerosis box, page 11.)

The farther from the equator, the higher the incident rates. It's not infectious but might be inherited in 1 to 3 percent of babies, Newmark said. Most MS sufferers have a normal life expectancy.

No one knows what causes MS, an autoimmune disease thought to be caused by environmental factors. The prevailing belief is that Sowell, Jennings and the 400,000 other Americans with the disease were exposed to some virus early in life that their bodies didn't handle well. Ten, 20, 30 years later, it reared up and caused the body to attack its nerve fibers.

More people are being diagnosed with MS. Whether more people are getting it, or whether the increased numbers are the result of better detection, is unknown, Newmark said.

"It can be very frightening because it is unpredictable," Newmark said.

It used to be, Newmark said, that a third of the people who contracted MS would be severely affected, possibly to the point of disability or blindness. A third would be moderately affected, and a third not much affected.

But newer medicines have changed those percentages, he said.

"Now, more are doing well, and a much

Symptoms of multiple sclerosis

The disruption of nerve signals produces the primary symptoms, which vary depending on where the damage occurred.

Below are some common symptoms.

- Numb limbs.
- Stiffness.
- Slurred speech.
- Tremors.
- Coordination problems.
- Weakness or unsteadiness.
- Dimming or darkening of vision in one eye that can last for weeks before it returns to nearly normal.

smaller percentage are doing poorly," he said. "Hopefully, in 10-20 years, the ratio will be better, or the disease cured."

Friday is date night

In her cubicle at 611 Walker, where she's a human resources specialist for Municipal Courts Administration, Sowell's mood is growing darker. Her legs and thighs hurt, like someone is hammering them with a sharp edge. She wants to disappear.

Instead, she massages them to take the edge off. When her co-worker, overhearing her discomfort, insists, she takes a Tylenol.

But it's not the leg pain that is souring her mood. It's Friday afternoon, and each passing moment brings her closer to her weekly injection.

Each Friday after work for 10 years, she's taken the injection. She still hates needles. But she knows the importance of taking her medicine if she wants to stay independent.

Jennings, too, hates taking her medicine. "But it's there. You've got to take it," she said.

"I think in five or six years, the injections will be considered barbaric," said Newmark. Oral treatments are in the works, but testing takes years.

Except for the anxious Fridays and the pains in the legs and thighs that can last as long as a week, she has no effects from the MS. She still walks the stairs and drives.

When the pain starts, she finds something to do to keep her busy. She refuses to dwell on it or ask, "Why me?"

See **MS** on page 11.

MS continued from page 9.

When she goes for a walk with her family, and they ask her if she can make it, she replies, "Don't do that to me. I can do it, so don't try to limit me."

"I encourage people to go on with their career plans, family plans, and the vast majority of times, things have turned out well," Newmark said.

Usually, after 10 years with no new or worsening symptoms, as is the case

for Sowell, what a patient has won't get worse, Newmark said.

For several years, Sowell went to MS get-togethers and seminars. Listening to other sufferers, many worse than she, made her thankful and determined to do what she had to do to not get to that stage.

At 6 p.m., Sowell, in a raging foul mood, takes a syringe out of her home refrigerator. The nurse told her to stab the needle into her thigh. Sowell can't do that, though.

The medicine is supposed to sit out for half an hour. At 7:15, she picks it up and rests the point of the needle on her thigh. Anxious moments later she pokes it, creepingly, into the side of her thigh, and depresses the plunger.

The drug makes her drowsy, so she goes to bed. Five hours later, she wakes up, her mood light and her outlook sunny. Ahead are days filled with possibilities and happiness.

Until the next bout of leg pain, at least.

Four courses of multiple sclerosis

1

Relapsing-remitting MS

People experience clearly defined attacks of worsening neurologic function. These attacks are followed by partial or complete recovery periods. About 85 percent of people are initially diagnosed with relapsing-remitting MS.

2

Primary-progressive MS

People experience slowly worsening neurologic function from the beginning with no distinct relapses or remissions. About 10 percent of people are diagnosed with primary-progressive MS.

3

Secondary-progressive MS

Following an initial period of relapsing-remitting MS, about 50 percent of people develop a secondary-progressive course in which the disease worsens more steadily.

4

Progressive-relapsing MS

About 5 percent of MS sufferers experience steadily worsening disease from the beginning, but with clear attacks of worsening neurologic function along the way.