

Niles woman fights for insurance coverage of MS treatment

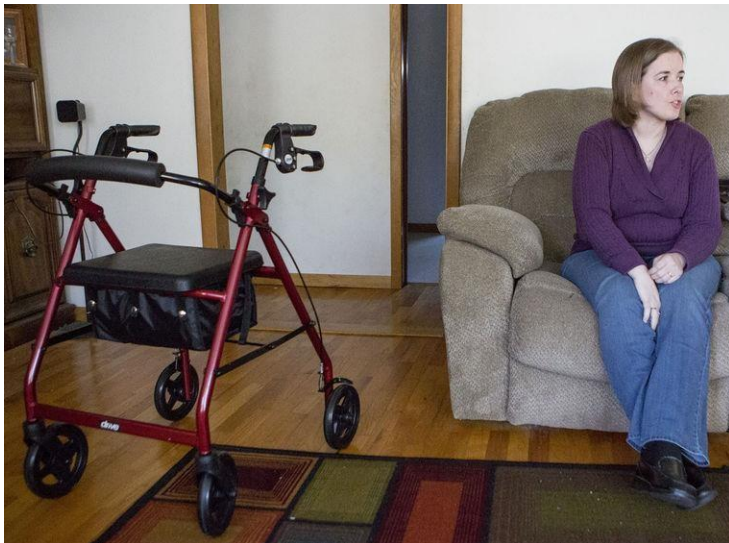
But doctor says process that involves patient's own stem cells is proven

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NILES — Janet Elms first noticed she could see only partially out of her left eye.

An eye doctor called it optic neuritis, and it eventually went away.

A little more than a year later, it happened again, but this time in her other eye.

A different eye doctor quickly suspected multiple sclerosis and referred her to a neurologist, whose tests were inconclusive. Two months

later, her left leg stopped working, forcing her to drag it as she walked. That's when she was diagnosed with relapsing/remitting MS.

That was nearly 20 years ago. Since then Elms, now 45, has battled the degenerative neurological condition with various approved medications, yet it has steadily grown worse.

She has difficulty walking, sometimes needing a cane or walker of sorts. She has no balance or depth perception, so she often trips, if she is not careful. Sometimes she experiences numbness, and her muscles often seize up.

"In the last five years, it just seems things are progressing more and more," she says. "I know I will end up in a wheelchair."

Unless, she believes, she is approved for a therapy that she first read on Facebook last year, one that for many people has stopped the progression of their autoimmune conditions and even reversed many of the symptoms.

Hematopoietic stem cell transplantation, or HSCT, has been performed for nearly 30 years with promising results. Essentially, a patient's own stem cells are retrieved from the bloodstream; chemotherapy drugs are administered, wiping out the patient's immune system; and the stem cells are replaced, resetting the immune system.

Elms' health insurance carrier, Blue Cross Blue Shield of Michigan, has twice denied her request for approval for the treatment, which costs about \$140,000.

'Nothing experimental about it'

Helen Stojic with Blue Cross responded to an inquiry to say she can't comment specifically on Elms' case. But generally, she says, "We don't cover this procedure for MS on a routine basis because it is under study for its effectiveness by researchers in clinical trials and is considered experimental. Researchers are investigating as to whether it is needlessly risky when safer alternatives are available and may be just as effective."

But Dr. Richard Burt, who leads the Division of Immunotherapy and Autoimmune Diseases at Northwestern Memorial Hospital, says the treatment is far from experimental at this point.

Burt has been refining this treatment since he was a fellow at Johns Hopkins nearly 30 years ago, he says. "The concept, the design, the results, there's nothing experimental about it."

A research paper, with Burt as the lead author, was published in the Journal of the American Medical Association in January. It describes the effectiveness of the treatment on MS patients whose disease was still in the relapsing-remitting stage and even some whose MS had progressed into what's known as the secondary-progressive phase.

Elms is now in the secondary-progressive phase, so she says Burt told her she's not eligible to be considered part of the ongoing clinical study. But she would still likely benefit from treatment if they act before the MS progresses much further.

Although killing off a person's immune system is risky, nobody has died from the protocol.

"We know how to do it," Burt says. "The five-year incidence of relapse is only about 10 percent."

In fact, the doctor says, "some people 10 years later have never had evidence again of MS." Conducting randomized trials, which the Northwestern team is undertaking now, is difficult.



Ethically, Burt points out, how do you ask patients to undergo a placebo-type treatment or none at all when you know the real process works?

I heard from several people on an HSCT Facebook page who sent emails telling me how much better their lives are since they underwent the treatment.

One of those was Elkhart native Keith Ludwig, who now lives in St. Petersburg, Fla. The University of Notre Dame grad was diagnosed with MS in 2011, at 48.

He was treated by Dr. Burt in late 2013.

"My MS has been halted," he writes, and he says his physical symptoms, such as numbness in his little fingers, are improving, too. "I am convinced that if I had not had HSCT treatment, I would be in a wheelchair by now and on disability retirement."

His insurance company, Blue Cross Blue Shield Federal Employee Plan, covered his procedure.

A 'stunning' treatment

Because of the cost of the approved MS drugs, which can run thousands of dollars a month alone, Burt says, most insurance companies recognize the cost-effectiveness of HSCT.

"This procedure pays for itself within about 18 months, so it's a cost savings," he says. "When you're dealing with a chronic disease, you can't look at it in the short term."

Yet one of the larger insurance companies seems to do that, either refusing to cover it or to do so only after a long fight. He hesitates a moment when asked whether that insurer is Blue Cross Blue Shield.

Yes, he acknowledges. That's the company.

"For some reason, there's something going on there I just don't understand," the doctor says, despite his efforts to educate the company.

The Northwestern team has nothing to gain financially — no license and no drug royalties, for instance — "this is just to help humanity. It would be great to make it available to other people."

"What we do reverses disability," Burt says. It has worked for other autoimmune conditions, too, such as lupus, scleroderma, Crohn's and rheumatoid arthritis. "That's the stunning thing about what we do. ... It's phenomenal for me to take people nobody can help and do this."

Patients from Ukraine, Turkey and Norway have traveled to Chicago for the treatment just this summer.

God's timing

Elms knows the first several months after the treatment, she'd have to be very careful, because of her depleted immune system. Her family — husband Brett, 14-year-old daughter Brianna and 11-year-old son Ty — even know they'd have to keep the house cleaner, she chuckles.

Members of her church, Summit Church in Niles, and her co-workers at United Federal Credit Union have been supportive. She's appealed now to the Michigan Department of Insurance and Financial Services, her last hope for coverage.

Otherwise, she's heard the procedure can be done more cheaply in some other countries, such as Mexico. Her sister is a missionary in Mexico and could help her recover, if it came to that.

She still holds out hope she can receive the treatment closer to home, before it's too late to help her.

"But I'm seeing more and more every day that I need to rest in the knowledge that God is in control," she wrote on her website, "and his timing is perfect!" Virginia Black: 574-235-6321 yblack@sbtinfo.com

To learn more

Visit the Northwestern team's website, www.stemcell-immunotherapy.com.
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