



**P**ONTIAC — Sean Bennett pointed out medicines that he takes daily for spasticity (inability to control muscles) in his legs and bladder and then gave himself an injection of Copaxone in his abdomen.

He takes Copaxone to reduce the frequency of multiple sclerosis relapses.

Bennett, who was diagnosed with MS last summer, has an aggressive form of the disease. The Pontiac man is 30 years old.

"MS is a long, drawn-out death sentence," said the automotive technician, who kept his cane within reach. "Feeling crippled at 30 is hard."

"But I think this procedure is going to be called a cure," he said.

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The procedure Bennett referenced is hematopoietic stem cell transplantation. HSCT reboots the immune system, which is believed to launch attacks on the brain and spinal cord in people with MS, said the National Multiple Sclerosis Society.

Bennett has been accepted into an HSCT clinical trial with Dr. Richard Burt, chief of the Division of Medicine-Immunotherapy and autoimmune diseases at Northwestern University's Feinberg School of Medicine in Chicago.

"I think it's a godsend," Bennett said of the procedure, conceding that it's still in FDA clinical trials and has no guarantees.

Dr. Herman Dick, of Advocate Medical Group-Neurology in Bloomington, where Bennett is a patient, agrees.

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"I consider this (HSCT) to be a promising treatment program for patients such as Sean who have a severe form of the disease," the neurologist said.

"Our current medicines slow the progression of the disease," Dick continued. "We'd like to see a medicine that would stop the illness right in its tracks and keep it from recurring for years."

Bennett, a Pontiac native, worked as an automotive technician in several communities, including Bloomington.

While healthy overall, Bennett was a smoker and was diagnosed with diabetes about four years ago. He's on medicine for diabetes.

But he felt "healthy as an ox" until December 2014, when he experienced what he thought was a pinched nerve in his back.

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Two months later, he began to experience episodes of dizziness and nausea, then pressure in his right ear.

"I was experiencing interruptions of nerve signals to the muscles, but I didn't know it," he said.

Last June, his legs became spastic, his knees would buckle, he felt weak and fell a couple of times.

"I went to the BroMenn (Advocate BroMenn Medical Center) ER and Dr. (Eric) Jenkie (a neurology resident) said he saw something on my CT scans and wanted to admit me," Bennett recalled.

Two weeks later, Jenkie told Bennett he had MS.

"For a month afterward, I was a depressed mess," Bennett admitted. "Meds may help only temporarily but it'll get worse. I thought my life was over."

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MS is an unpredictable, disabling disease of the central nervous system that disrupts information flow within the brain and between the brain and the rest of the body. Within the central nervous system, the immune system attacks myelin, the substance that surrounds nerve fibers, and the damaged myelin forms scar tissue (sclerosis).

When any part of the myelin or nerve fiber is damaged, nerve impulses traveling to and from the brain and spinal cord are interrupted, producing a variety of symptoms.

"MS is like a cancer of the central nervous system," Bennett explained. "Lesions are growing on my brain and spine."

The cause is unknown, although researchers believe the disease is triggered by environmental factors in a person who is genetically predisposed to respond, according to the MS society.

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Bennett had to quit his job as an auto mechanic and move back into his mother's home in Pontiac but he does work as an attendant at a gas station.

He joined an MS support group and began to do research.

He came across HSCT, in which stem cells are removed from a patient's own blood and stored. Then the patient undergoes chemotherapy to deplete their immune system. The stored stem cells are reintroduced into the body and they migrate to the bone marrow and over time produce new cells, eventually repopulating the body with immune cells.

The goal is that the new immune cells will not attack myelin or other brain tissue, providing the person with a new immune system.

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The approach is being investigated in several countries, including an international clinical trial being led by Burt. The trial is recruiting individuals who haven't responded to other therapies.

"This made sense to me," Bennett said. "It has been in FDA clinical trials for 15 years and has had a 91 percent success rate at stopping the progression of the disease. Existing medicines have only a 50/50 chance of slowing the progression."

Bennett applied for the trial in January when he met several criteria, including trying for six months a drug that didn't help.

By that point, his MS symptoms included spasticity and weakness in his legs and bladder, back pain, erectile dysfunction, incontinence, dizziness, hearing loss in his right ear, occasional vision blurring, cognitive problems including some memory loss and heat and cold intolerance.

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"Without treatment, he would become severely disabled in a few years," Dick said.

Bennett went to Northwestern, underwent tests and learned recently that he was accepted into the FDA clinical trial.

He will return to Northwestern in June, undergo further testing and meet with Burt. Then Bennett will be randomized into the control arm or the transplant arm of the study.

If he's in the control arm, he will be prescribed Tysabri, an FDA-approved drug to treat relapsing forms of MS. Because Bennett has an aggressive form of MS, he believes that Tysabri won't help him. If so, he would be moved to the transplant arm.

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Bennett's stem cells would be harvested and stored, he would receive chemo to kill off his white blood cells ("MS is in the white blood cells," Bennett said) and then his stem cells would be reintroduced to his body four to six weeks later.

"I'd be in seclusion for awhile," Bennett said. "A lot of people (in the clinical trial) begin to see symptom relief two to three weeks later."

"He can hope for some reversal of symptoms but it's uncertain how much or for how long the benefits would last," Dick said.

"I hope for zero disability, having my life back and working again full time at an auto dealership. But I would accept my symptoms not getting any worse," Bennett said.

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"Our thinking has changed on the treatment of MS," Dick said. "Before, we couldn't do much other than to slow the disease down. Now our goal is to stop it."

Bennett hopes that HSCT is approved by the FDA in five years and that sharing his story helps other MS patients.

"There is hope. Don't give up."



Dick

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### How to help

While Sean Bennett's medical insurance provider has agreed to cover the cost of the HSCT procedure and hospitalization, he still will have related expenses, especially when he is undergoing outpatient treatments in Chicago.