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Transplant frees scleroderma patient from excruciating pain and gives him back his hope for the future

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In the summer of 2014, Dan Muscat's fingertips started to tingle. It felt like tiny shards of glass were piercing under his fingernails. Over the next weeks and months the pain crept into his hands.

His family doctor thought it might be arthritis and prescribed a steroid to get things under control. "Within days, the disease sped up," says Muscat. "It went from the top of my head to my toes. My ankles and my feet were so inflamed I couldn't walk 20 feet."

Muscat, who owns a jewelry business in St. Thomas, Ontario, was referred to a rheumatologist who immediately recognized what was happening to him: "Dan had rapidly progressive early onset diffuse scleroderma," says Dr. Janet Pope of St. Joseph's Health Care in London. Scleroderma is a rare autoimmune disease that involves hardening of the skin and connective tissues due to an overproduction of collagen. Diffuse scleroderma affects not only the skin and muscle but also the digestive tract and internal organs, ultimately leading to death.

By late 2015, Muscat was growing desperate. He had heard that Dr. Richard Burt at Northwestern University in Chicago was offering a treatment using a patient's own bone marrow stem cells to rebuild their immune system and shut down scleroderma. Muscat reached out to the Canadian Stem Cell Foundation for guidance.

Because the American treatment is similar to the combination chemotherapy/ bone marrow stem cell transplant treatment that The Ottawa Hospital's Dr. Harold Atkins has used successfully against extreme forms of multiple sclerosis (MS, which is also an autoimmune disorder), the Foundation suggested Muscat reach out to him. Earlier this year Dr. Atkins agreed to take Muscat on as his first scleroderma patient.

"He fit the profile of the kind of patient best treated with these kinds of stem cell transplants" says Dr. Atkins, who is also an associate professor at the University of Ottawa.

Muscat began the therapy in June and spent much of last summer undergoing the treatment designed to destroy the diseased immune system and rebuild it with his own purified stem cells, ideally to produce a new, scleroderma-free one.

He made it through chemo with few noticeable side-effects beyond losing his hair and tolerating a couple of infections. He is now back in St. Thomas, working part-time at the store. His range of motion with his arms and legs is much improved and he can get around on foot again.

Grateful for the excellent care provided by The Ottawa Hospital's bone marrow transplant team, Muscat is unswerving in his belief that he can beat this disease. "I feel physically and mentally better. I just don't feel that I'm being attacked."

In Ottawa, Dr. Atkins urges caution. "It's going to take months and months to know if this is a real improvement. The changes with scleroderma don't happen overnight. This is not a curative treatment; it doesn't make scleroderma go away and never come back. It's something that helps a population of scleroderma patients: some patients improve, some not. There are patients that progress or relapse again."

Muscat is positive about the future: "I still have the remnants of the disease, but I can jump in and out of my truck again and I can walk a couple of kilometres with no problems. I feel very optimistic, like I've been given a second chance."

This is an excerpt from an <u>article</u> by Joe Sornberger, Director of Communications Programs at the Canadian Stem Cell Foundation.

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