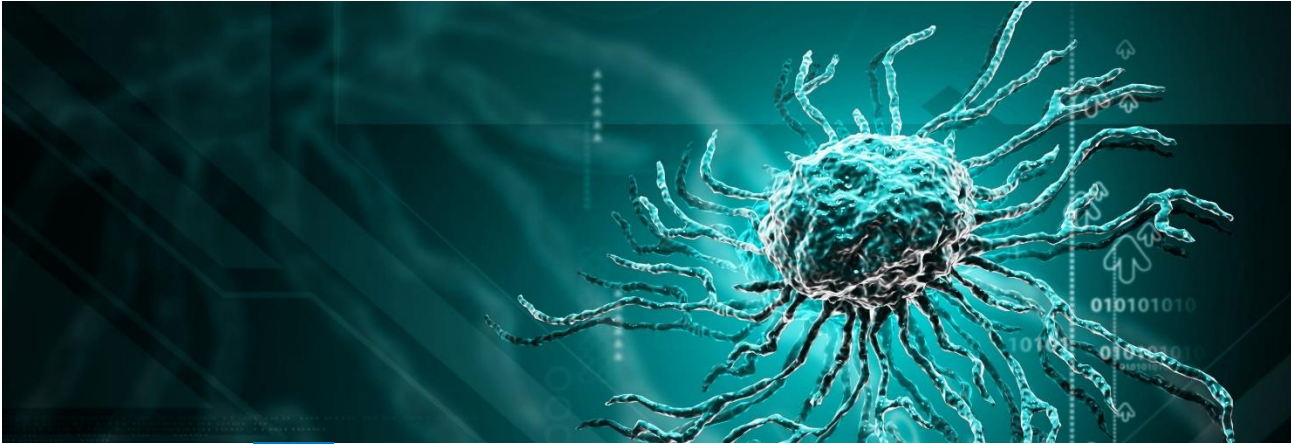


Individual with PPMS Shares His Experience of Undergoing Stem Cell Therapy



[February 2, 2016](#)  by [admin](#) In [News](#).

Geoff Flynn, 42, was diagnosed with multiple sclerosis (MS) two and a half years ago. As unsettling as that diagnosis was, more troubling — both then and now — were the five long years of struggle it took for him to get a proper evaluation as to the cause of his neurological symptoms.

“The first thing I noticed was that, when I was sitting, if I tilted my head up I felt like I was going to pass out. Slowly over time walking got more difficult, fatigue increased, and my bladder got more impatient. I realized fairly early on that my symptoms matched many that come along with MS,” Flynn, of Alberta, Canada, said to [Multiple Sclerosis News Today](#).



Geoff Flynn with nurses in Israel during his stem cell therapy.

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His doctors dismissed his concerns for a long time, focusing on cardiac and circulatory problems as the likely cause. So Flynn began to research his symptoms on his own, and ultimately asked his doctor to perform an MRI (magnetic resonance imaging) scan, an established method of confirming the lesions that typify MS. The MRI revealed lesions on the brain, and his physician finally came to diagnose what, for Flynn, was obvious: he had MS.

Not satisfied with the care he received at a nearby MS clinic, particularly because it offered no treatment due to the progressive nature of his MS, Flynn continued researching his disease and options. He said that he eventually “stumbled upon a [website by George Goss](#) which is packed with information,” and increasingly looked at stem cell therapy as a promising route. “And finally a paper from the annals of hematology solidified my decision to pursue HSCT [hematopoietic stem cell transplantation],” he said.

The paper [described a single-center study conducted in Russia](#) by researchers at the Pirogov National Medical Surgical Center. The clinical trial included 43 individuals with relapsing-remitting MS ([RRMS](#)), and 56 with progressive MS, who underwent high-dose immunosuppressive therapy and autologous HSCT. Because Flynn had primary progressive MS ([PPMS](#)), the study was of particular interest. Some researchers and clinicians doubt that PPMS is suitable for stem cell treatment, but all but one of the people in this trial reported disease improvement or stabilization six months after chemotherapy and transplant. Even more important, the gains were long term. Eight years after undergoing the therapy, only 16.7 percent of study participants reported MS progression.

Flynn was convinced by these results that chemotherapy coupled with stem cell treatment would help him. “The next step was figuring where to have it done,” he said. “I discovered that only two clinics will treat PPMS. One in Russia, and one in Israel. Israel said they could get me in 2016, for Russia the wait was till 2018.” His decision was made.

Flynn was able to schedule the procedure in Israel for October 2015. The next hurdle was covering the cost, he said, which in Russia was about \$40,000 U.S. dollars, but in Israel would be as high as \$126,000. Flynn raised money via an [online fundraiser](#), and his parents covered the rest of his charges. “The online fundraiser was a big help and I was quite touched by the generosity of others, both family, friends and people I’ve never met,” he said.

Doctors began the procedure on Oct. 7 at the [International Center for Cell Therapy & Cancer Immunotherapy](#) in Tel Aviv, Israel.

Treatment started with Flynn taking several medications: trimethoprim/sulfamethoxazole, omeprazole, acyclovir and allopurinol. On the second day, a doctor inserted a picc line into a vein near his elbow to deliver chemotherapy.

The medication [alemtuzumab](#), a humanized monoclonal antibody, began on Oct. 10, followed by a second and larger dose through the picc line the following day. Alemtuzumab is given prior to the bone marrow aspiration to remove overactive T-cells as a preparatory step to the stem cell transplantation, so that those cells are not among the harvested [stem cells](#). Doctors performed the bone marrow aspiration on Oct. 12, and began chemotherapy.

Fludarabine and cyclophosphamide were the drugs for this phase, two powerful anti-cancer medications typically used to treat leukemia. That day was followed by a second day of chemotherapy, and then, at last, the

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final treatment. “On the 14th I got my stem cells back. After that it’s just wait and don’t do anything till your immune system shows it’s on the mend,” he said.

Flynn and his parents, who had accompanied him to Israel, stayed at a hotel in the same building as the clinic. Doctors monitored his progress through blood tests, and he continued to take medication to stimulate the bone marrow and to prevent infections. On Nov. 3, less than a month after the procedure’s start, he returned home.

Due to his immunocompromised state, Flynn said that he avoided people due to the risk of infections. A hematologist monitored his blood count until it returned to safe levels.

The stem cell therapy helped, largely by stopping progression, he said, but it couldn’t return what had been lost to years without treatment. Some symptoms have improved, others have remained the same. “What I noticed immediately was my fatigue is gone. Also the chronic pain in my eyes and feet had disappeared. Aside from that, nothing. My walking and balance are still poor, and my bladder still very temperamental and insistent,” he said.

“My own theory is that the benefits I see in pain and fatigue are because the disease is no longer active, but there’s no change to the damage done — so my walking, balance, etc., are still lacking.”

Flynn left his job as a seismic data processor in September 2015 and remains on disability due to fatigue. But he at least is back at the gym, working his body as best he can. That’s something he feels would have been impossible before the stem cell therapy.

Healthcare needs to change, he said, and healthcare professionals need to listen to patients’ symptoms more openly so that proper diagnosis and treatment begin sooner. “Basically, I think I have been failed by the healthcare system at every turn,” he concluded. “This procedure, if done as close to the start as possible, could prevent disability.”