

MS and HSCT in Russia

By Robert Humbarger

On January 9, 2018, I went with my son, David, to Moscow, Russia, for him to receive Haemopoietic Stem-Cell Transplantation (HSCT) treatment for his multiple sclerosis. We returned on February 8, 2018. I want to let others know about this treatment which is not available in the United States.

Multiple sclerosis is an insidious disease, the cause of which is unknown. There are approximately 400,000 cases in the United States and 2,5 million worldwide. The disease is a result of the leucocytes (white blood cells) attacking the myelin sheath of the nerve cells in the brain and spinal column. The myelin is the insulation on the nerve cells and destruction of the myelin prevents the cell from conveying sensory and motor signals to and from the brain. The damage to the myelin is called a sclerosis, and when a person has several of them, he or she has multiple sclerosis.

David's case is typical, although no two cases are the same. About 12 years ago, he discovered he had numbness in the fingers of one hand. Thereafter, he had a severe bout of vertigo. Doctors diagnosed him with MS and he was started on the usual drug treatment to try to slow down, but not cure, the disease. He was prescribed several drugs, which had some effect but did not stop the progression of the disease. The most successful drug was Tysabri, but fatal side effects in certain patients with risk factors were discovered and he had to stop that drug.

Three years ago I learned from a friend that his sister was going to Russia for HSCT treatment for her MS. She had been told by her neurologist that her disease was progressing quickly and that within 3 months, she would be confined to a bed or wheelchair. She discovered HSCT treatment based on her own research. Although her doctor and family opposed her going, she raised the money and went to Russia. Two years later, I asked my friend how she was doing and learned that she had been cured and has had no further progression whatsoever.

I arranged to meet with her, along with my wife and son. We were amazed at her success. Although the treatment cannot restore nerves that have been destroyed, she has recovered some use and no longer has the debilitating fatigue often associated with MS.

HSCT treatment for MS has been performed throughout the world for at least 20 years. We know that he can cure (Yes, cure) MS. In the United States, it is performed only as part of a study in three locations, including Chicago. My son was rejected by Chicago, because he had been diagnosed with MS more than 10 years before (his was 10 years and 8 months) and because he had taken more than two MS drugs. I learned that most US citizens go to either Russia, Mexico, or the Philippines for the treatment. Canada only treats its own citizens, as do most European countries. Dr. Fedorenko, who runs the clinic in Moscow, has performed about 25% of all of the treatments in the world, and his results are generally considered to be the best anywhere. He treats about 16 patients at a time and each treatment takes about 30 days.

After family discussions, David elected to go to Russia. There is a 2-year waiting list, and David applied in August, 2017. However, Dr. Fedorenko (Dr. F) gives priority to patients

for whom he believes he can have the greatest effect on the quality of their life. David sent a personal letter with his medical records explaining that he has a one year old and a five year old, and that he wants to be able to help them learn to ride a bicycle, etc. Within two weeks, David received a reply asking when he would like to come in 2018. He said as soon as possible and was scheduled in the first group of patients in 2018.

The hospital requires that patients stop taking all MS drugs for three months before treatment, which David did. After arriving in Moscow, he was admitted to the hospital for five days of extensive physical to determine if he was physically able to withstand the treatment. During the testing, Dr. F discovered an active brain lesion that the doctors in the US had not detected, perhaps because the hospital there uses a more powerful MRI machine than is available in this country. After David was found to be well, treatment started.

The course of treatment is as follows:

1. Three days of steroid and shots to stimulate the growth of stem cells. The stem cells are “undifferentiated”, which means they can develop into any body cell that is needed.
2. After a day of rest, one to three days of harvesting stem cells through a catheter into the jugular (neck) vein, using a machine similar to dialysis. Dr. F said that in Mexico, they extract 1 million stem cells, in Europe the standard is 1.5 million, but that he insists upon 2 million. The process takes 5 hours each day, until 2 million have been obtained. The stem cells are then cleaned to remove any of the leucocytes that are causing the MS, and then flash frozen with preservatives.
3. After a day of rest, four days of intense chemotherapy commences. This kills the nucleus of the leucocytes, rendering them incapable of dividing to reproduce. Since they have a life cycle of seven days, the leucocytes have all died after seven days.
4. After another day of rest, the harvested stem cells, are thawed and transplanted back into the patient. On that day, Dr. F holds a party for each patient with all of the other patients attending, gives a short talk about this being the patient’s new “birthday”, and that each is now free of MS. He then ceremonially assists the patient in pouring the liquid nitrogen that had stored the stem cells onto the floor to celebrate. He also gives each patient an Iris pin, symbolizing hope for their new life.
5. By this time, the leucocytes have crashed to near zero and the stem cells are just starting to develop into new leucocytes, which do not have the habit of attacking myelin. The patient then goes into isolation until blood tests show the new leucocyte count is up to a sufficient level.
6. After coming out of isolation and another day of rest, the patient receives an infusion of Rituximab, a drug that kills B cells which may also be associated with MS.
7. After a couple days of rest and satisfactory blood tests, the patient is released to go home.

This treatment cures MS. Neurologists nevertheless generally oppose the treatment, often “firing” patients who go abroad to receive it. They will never suggest it to a patient. I want to get the word out to those who have MS. My son was never even nauseous during

the treatment and never had any discomfort whatsoever. His chief complaint was the food in the hospital, but he soon adapted to that and ate everything he was given.

Regarding cost, the treatment in Russia costs \$50,000.00 USD. It is not covered by insurance. It is actually much cheaper than anywhere else and the treatment and care is absolutely wonderful. Dr. F is an amazing person, as are all of his staff. It is also interesting that many patients return to him for followup. An MRI on his 3.0 Tesla machine costs \$500 to \$600, compared to an estimated \$6,000 to \$7,000 in the US, on only a 1.5 Tesla machine. Dr. F does not refer to his patients as patients, but rather as friends. He will review subsequent MRIs or medical information without charge. He gives his "friends" his personal email address and cellphone number when they leave after treatment.

I suggest the following resources for anyone interested in learning more:

YouTube video of Dr. F and his assistant (a former MS patient) being interviewed in the Pirogov Hospital: <https://www.youtube.com/watch?v=EusZyYUXjKY>

Article from Multiple Sclerosis News Today from June 10, 2016 issue:
<https://multiplesclerosisnewstoday.com/blog/2016/06/10/stem-cell-transplants-stop-ms-long-term-clinical-trial/>

Article listing the facilities around the world where HSCT is provided and the requirements of each: <http://hsctstopsms.com/hsct-facilities-worldwide/>

Facebook group: <https://www.facebook.com/groups/404629779644453/>

Also, Google HSCT and MS for numerous other articles.

I would be happy to provide more information and meet with anyone considering treatment. With MS, the sooner treatment is received, the better. My email address is RLHUMBARGER@GMAIL.COM.