

Happy  *Thanksgiving*

In A Nutshell
November 2018

Ocrevus and Me

10/30/18 Dear Diary,

After having tried these therapies—betaseron, copaxone, copaxone with novantrone, tysabri, techfidera, ampyra, bee stings, replacement of tooth fillings, etc—I have decided to give this latest medication called Ocrevus a try. As much as I have talked about this with medical people and manufacturing people I still don't know the exact pronunciation of Ocrevus. Some put the accent on the O, some put it on the cre and some on the last syllable. Regardless of how it is pronounced it is the latest and it is quite different from the other therapies. The immune system behaves abnormally in MS. Instead of fighting infections, some B cells and T cells are misdirected to attack myelin. Until recently, scientists have focused on T cells as a primary target in treating MS. Ocrevus was designed to target certain types of B cells. It has proven to delay disability progression of PPMS. The exact way Ocrevus works I not fully known.

But along with my neurologist, Dr Castaldo, it is time to give this a try. The first round is given in two separated sessions, two weeks apart. I had these on 4/5 and 4/19/18. My second infusion was on 10/30/18.

8:17 am Left the house for the infusion center at the Sharon Morse Bldg

8:47 am Arrived at the registration

9:05 am Taken by medical assistant for BP, o2 sats, temps

9:11 am Arrived at treatment room

9:17 am Was stuck for blood draw and to insert port for the infusion

9:30 am Was given Benadryl and Tylenol

9:45 am Normally cortisteroids and antihistamine is given by infusion. But, apparently there has been a shortage of antihistamine solution so I was given pills and the steroids were started by IV. Must wait 60 minutes.

10:32 am Started the Ocrevus

2:15 pm End of Ocrevus and a saline flush is started

3:15 Flush is done, port removed

3:25 pm In car on the way home

Door to door was almost 8 hours. Time at the infusion center was about 7 hours.

11/1 Dear Diary,

I did not sleep well the night of the infusion. Was very tired yesterday but today I feel better and am hopeful, as always, that this treatment will produce positive benefits.

Just For Fun

Ocrevus is infused very slowly. You need to be prepared for a full day at the infusion center. I chose Florida Cancer Specialist which is located in the Sharon Morse Building. My oncologist is part of this practice. I do recommend this infusion center. Bring a good book. I suggest that you bring your own food and beverage. They do provide snacks, coffee, juice, water. You can recline in an easy chair and they will bring you a warm blanket. That was a really nice feature! Dress in loose, casual clothing. I use a wheelchair so going to the bathroom was a challenge when the IV was in place. The bathrooms are plenty big for a wheelchair, or scooter, and the IV pole. The nurses were attentive and very nice.

Let me know if you have been doing Ocrevus and I will write another "In a Nutshell" with updates on my experience as well as yours.