

Carl Jones' "Merry Christmas", will not be seen this Christmas. He will be back next year at this time. In its place, we gladly bring you "The New Birth"! A one-time event chronicling the "Journey of Carl and his family and friends", as he looks for a key to a new life.

A lot has taken place prior to the beginning of this story; like the Star Wars saga, it will be expanded upon at a later time. Characters will be developed and others introduced.

This story begins with Carl having left work on July 31, 2014, to begin his 60 day Short Term Disability (STD), because he had been stricken with the autoimmune disease, multiple sclerosis. After 50 years of vibrant life, and a very full one at that, Carl's body decided to start attacking itself. My nerve sheathing are being eaten away; electrical shorts are starting to happen all over the place; mostly in the brain stem and in the upper spinal area. These areas cause a problem with motor functions.

This, of course, is pretty close to the time where Carl and his wife, Wilma C Patterson Jones, (whom he calls Wilma C.) have been working toward their whole life. The time of retirement, visiting friends and family, as well as, friends and family visiting them and, of course, looking for the perfect home to accommodate them as well. They always have room for visitors! Life is a funny thing; it tests you and it is up to you to rise to the occasion.

Carl begins doing what he has been told – taking physical therapy and the MS medication, that is said to have a record of somewhat slowing the progress of this debilitating disease. It seems the harder he works, the worse he gets. He finds the type of MS he has, Primary Progressive Multiple Sclerosis (PPMS), is only present in 15% of the MS population. There is no known medication for it, yet, they say take the other medication - "You might as well take something".

In the meantime, Carl has now become very physically challenged. His legs simply don't listen; though, they still work a little. Every step has to be 'thought' and his balance isn't worth a plug nickel! His family has gone all out to help him stay mobile and somewhat independent. They purchased a scooter that folds to stick in his trunk, so he can still go to the local store. They have also gone out of their mind and bought him a golf cart, so he can get up the hill to their pool to exercise and just have fun with everyone else.

I don't know how long it might take, but this was a true, life altering journey. My intent in the future, is to elaborate, enhance and develop all the characters in this saga and make them known. I did not go through this alone; there was a group of six patients and our perspective Care Givers. Not to mention a plethora of medical personnel and other workers. One patient in my "mini-group" was a Scot, whom I haven't decided who to call yet, but without his candid talks, the journey would have been different. Thank you Sir!



Please understand, all of these things are fantastic, very much appreciated, and known to be given out of an abundance of love. He would knock out the first person to belittle them or his acceptance of them. He means that; nonetheless, he is still in the same boat.

Since Carl has so much time on his hands, he begins to look into his disease. The causes, the possible ways to retard it. He comes across something different; his sister-in-law, Gloria, tells him about a trial in Chicago that is doing some work in this field call **Hematopoietic Stem Cell Transplantation (HSCT)**. He reads further about it and finds it is an

experimental procedure where your own stem cells are gathered and you are then given chemotherapy, in a low dose, to kill off most of your immune system, which is the part responsible for the bad behavior. Your stem cells, having been reconstituted and refrigerated, are re-injected and basically you are rebooted.

Now, there is no guarantee your lost mobility will be restored, but, the MS will be gone. No more pills; no more degenerative bouts where you don't come back!! This was enough to make a person, as adventurous as Carl, say Hmm! He calls this office in Chicago, Northwestern University, and talks with the coordinator. It is explained, this is a trial and only for those with Relapsing Remitting Multiple Sclerosis (RRMS). PPMS patients are just not a large enough population (15%) to be included. Well, Carl being Carl and one of those 15%, was not about to accept such a flimsy reason for being excluded from something that could be "Life Altering"! All the time, one needs to remember - this COULD be just another of those scams and you could lose your money. It is not cheap!!!

Carl begins to look into it with real fervor and zeal. He comes across a Face Book forum called "Hematopoietic Stem Cell Transplant - MS & Autoimmune Diseases". It is a "Closed forum, so he asks for admittance and it is granted. This forum is like looking behind the curtain and seeing how the world of autoimmune disease really works. It is a forum of personnel who either have been touched personally or a loved one has been touched with the disease.

In conversing with some of the people in this forum, he finds some who say they have actually had the procedure and they are all the better for it. Carl then asks if they are all RRMS and they say "Oh Chicago eh?" They explain, Dr. Burt at Chicago, is the true father of HSCT process, but is limited to RRMS during this trial phase. Carl was informed by the forum members, that there are a number of locations that actually address PPMS patients; one of which, is just being accepted by the masses and is now accepting international patients, called Clinica Ruiz in Puebla, Mexico. Dr. Ruiz has a list of acclamations and international awards as long as your arm! Yes, I checked that out as well, to include the **Mayo Clinic Alumni Association Distinguished Alumni Award!** They let Carl know, Clinica Ruiz has a growing waiting list so he may want to look into it soon.

The problem as they couched it, simply stated it is out of country and therefore not covered by insurance. Not to be deterred, Carl calls their coordinator and gets the low down. Danielle Smith, the Clinica Ruiz coordinator, tells him the medical info needed, immediately, to see if he even qualifies. If all is good, she will get back to him letting him know the next step. All the while, Carl is still looking into the process and now, heavily into Clinica Ruiz! Danielle gets back; all looks good and the doctors will accept him. Now, of course, the real worry starts. He has to explain what he would like to do to Wilma C. She is more receptive than he thought she would be. Of course, she is not totally on board, because she has never heard of such a thing. She knew Carl had looked into the process thoroughly and would only ask if it were something he really wanted to pursue.

Carl and Wilma C. talked with Danielle together on Skype to find out more of the particulars. Next they were slotted for the procedure. Boom! Well, it was boom! But, due to an unfortunate happenstance for someone else, they were offered, and accepted an earlier date, 23 November 2015. They are rushed but get it all together and make the flight, landing eventually in Puebla, Mexico late on Sunday 22 November.

Carl and Wilma C are picked up by a driver/attendant, named Chris (he has a sign saying Mr. Jones)!

Christmas 2015 by Carl Jones



He speaks Spanish and English and knows his way around. Chris gathers their luggage and takes them to their apartment. Just as Carl and Wilma C are beginning to believe "this may not be a scam we just paid all our money, 30 days in advance as far as we knew, to Harry or Harriett around the corner!" There is a knock on the door. They open the door; it is Danielle Smith, the coordinator.



She is there, to simply make sure, they have what they need for the moment and to let them know what the morning will be like. No need to worry about transportation, as everywhere they need to go medically has already been coordinated. A schedule will be given to them in the morning. First thing in the morning, there is a meet and greet

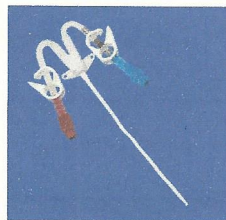
Christmas 2015 by Carl Jones

which includes the doctors, nurses, facility staff and other patients we will be interfacing with for the next month or so.



As promised, all things were taken care of. The medical records were checked. X-rays and bloodwork were taken to ensure Carl could actually tolerate the procedure. All the doctors were met and questions asked and answered by all three parties, as Wilma C was by Carl's side the whole time.

The stem cells were overproduced or mobilized using a drug called filgrastim. Over the next few days, filgrastim is taken to make the stem cells proliferate and jump out of the usual bone marrow home location into the bloodstream where they were to be gathered and separated by a process called apheresis. **A Mahurkar Catheter** was surgically implanted just under the collarbone for stem cell collection and re-introduction, as well as, the chemo treatments. I don't want to get too heavy about the catheter; however, I do feel a short explanation will help.

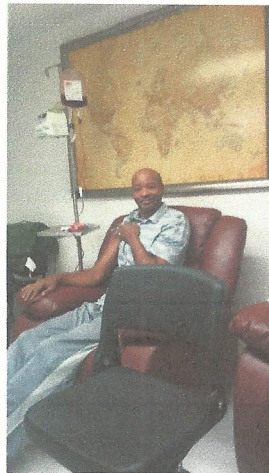


Mahurkar Catheter

The Mahurkar catheter has two valves. Once initiated, it pulls the blood from you and sends it through the Apheresis machine, in this case, where the stem cells are “harvested.” This is possible, because the stem cells are a particular size and weight as compared to the other bodies in the blood, and that is what the Apheresis machine is looking for. This was performed. A certain number of stem cells needed to be collected per KG of weight per individual. In Carl’s case, he needed approximately 100,000,000 stem cells per KG. He created 195,000,000 - Mission Accomplished! The stem cells were refrigerated for later re-infusion.

Carl went through a two day series of chemo therapy treatments, which he said wasn’t bad. The process was long, and tedious, but not arduous. He was connected to an IV for 6 hours each session. This was needed to start killing off the remaining autoimmune cells. He sat there and listened to an audiobook while Wilma C did office work.

After the final chemo treatment, there is a chillin’ out period of approximately 24hrs to allow the chemotherapy to sink in real good. The chemo then becomes somewhat inert. Though the chemotherapy has acted on the intended cells, it is no longer active to affect the newly infused ones. Now comes the moment of truth, referred to by Carl as “**The Rebirth**”. The harvested stem cells are reinfused via IV, to start heading back to their normal bone marrow home. At this point, the procedure was basically over and Carl had been Reborn!



The following is referred to as your Hematopoietic Stem Cell Birthday (HSCB)

As of approximately 7pm CST on 5 December 2015, Carl Jones was Reborn!

It is like, after graduation, you switch your tassel over to the other side!!

In attendance was Doctor Jose Manuel Priesca of Clinica Ruiz and my Wilma C, the Love of my life, and without whom, everyone knows I am incomplete anyway so...

The medical process is basically over. Now comes the monitoring; waiting for you to get to a good place with your autoimmune system. Carl and Wilma C. are now at the mercy of a new round of Filgrastim to assist in the replenishment of the immune system.

So, the medical personnel come to the apartment each morning to administer a filgrastim injection and take blood samples every 48 hours. They check the stem cells, and make sure y white blood cell count is rebounding. When the white blood cell count has rebounded to about 4,000, which takes about a week, he will be ready for the final parting gift. The parting gift is an IV full of Rituximab (Rituxan).

Christmas 2015 by Carl Jones

Time and Carl's determination, will have a lot to do with what happens as far as recovery. The neurological damage already sustained will also be a factor in Carl's recovery. The point is, the symptoms are not going to get any worse. The Multiple Sclerosis is gone! This is not the end of the Journey. They are just about to take a different fork in the road!!

I thank you for taking the time out to check out this new Journey of the Jones' and hope you were able to find it a bit interesting.

I don't know how long it might take, but this was a true, life altering journey. My intent in the future, is to elaborate, enhance and develop all the characters in this saga and make them known. I did not go through this alone; there was a group of six patients and our perspective Care Givers. Not to mention a plethora of medical personnel and other workers. One patient in my "mini-group" was a Scot, whom I haven't decided who to call yet, but without his candid talks, the journey would have been different. Thank you Sir!

Love You All!

See you next year.