Still awaiting a reply:

To the Honorable Christopher Van Hollen

Representative District 8 Maryland ( Now Senator Van Hollen)

Good day Sir,

My name is Carl Levon Jones. I reside at XXXXXXXX, Westminster, MD 21157. I have lived here since 2006 and love it. Though I worked in Chantilly, VA and had to commute 90mi each way, it was worth it to have our little home in the country. I say I had to commute and was worth it, because I have since developed an Autoimmune Disease, Multiple Sclerosis (PPMS), which has affected my motor skills and ability to drive long distances.

Just to give you a little background on me, so you don't think I am just a letter writer or some mental case. (Smile)

I am a 12yr veteran of the US Army having served during non-war time 1978-1989. I am a patriot as I have heard are you. I have worked for the Government in the form of a contractor for the past 25yrs. I was employed by Lockheed Martin, BAE, and most recently NJVC. My government agencies were NIMA and NGA respectively in the form of Satellite communications O&amp;S (Operations and Sustainment) maintenance and repair.

As an IT Manager for the aforementioned companies, my area of responsibility was vast. I will not be going into it as it is in the intelligence field. Suffice it to say it is a job I loved and miss immensely. This brings me to the purpose of this letter and the hopes you can bring some of your political pressure to bear. I Know NIH and the FDA are not your jurisdiction. Nonetheless, I don't know where else to turn at this point.

It appears the pharmaceutical companies and their lobbyists, which must be as strong as the NRA (Opinion only of course), seem to have ham strung progress on an autoimmune procedure called Hematopoietic Stem Cell Transplantation (HSCT). This procedure has helped hundreds of personnel who either have a form of MS Called Relapsing Remitting (RRMS) which can be addressed in a trial at Northwestern University in Chicago by Dr. Richard Burt. A world renowned Neurologist. He will also, on a compassionate basis perform the procedure on another type Secondary Progressive (SPMS).

If however, you do not fall into either of the former categories, as myself and millions of others. You cannot be seen by Dr. Burt and are left to the wolves of the Disease Modifying Drugs (DMDs). Or if you can afford it, and Sir this is no easy task for anyone. I will include the link to the different facilities around the world performing the Life Altering procedure. It is a true medical procedure, and people are mortgaging their homes, depleting their savings and whatever else they must do to travel to have this procedure performed. It is not done selfishly. It is not like have an unsightly mole removed or a hair transplant. People are doing this to have some semblance of quality of life with their loved ones. This instead of slowly losing control of their motor skills no matter how they fight it!

Allow me to interject here the different types of MS. There are other autoimmune diseases this procedure will help also, but for the purpose of this writing, let me not stray. There are four recognized categories of Multiple Sclerosis.

Relapsing-Remitting MS

When you have relapsing-remitting MS, the most common form of the disease, you may experience:

- clearly defined relapses or flare-ups that result in episodes of intensive worsening of your neurological function

- partial or complete remissions or recovery periods after the relapses and between attacks when the disease stops progressing

- mild to severe symptoms, and relapses and remissions that last for days or months

Primary-Progressive MS

- This form of MS progresses slowly yet steadily from the time of its onset. Symptoms stay at the same level of intensity without decreasing, and there are no remission periods. In essence, patients with primary-progressive MS experience a fairly continuous worsening of their condition. However, there can be variations in the rate of progression over the course of the disease—as well as the possibility of minor improvements (usually temporary), and occasional plateaus in symptom progression.

Secondary-Progressive MS

Secondary-progressive MS is more of a mixed bag. Initially it may involve a period of relapsing-remitting activity, with symptom flare-ups followed by recovery periods. Yet, the disability of MS doesn't disappear between cycles. Instead, this period of fluctuation is followed by a steady worsening of the condition. People with secondary-progressive MS may experience minor remissions or plateaus in their symptoms, but this is not always the case.

Progressive-Relapsing MS

In this relatively rare form of MS, people experience their condition as steadily worsening, yet also experience clear relapses in the form of acute flare-ups. In some cases, there is no recovery from these flare-ups, although in other cases there is recovery. The difference between progressive-relapsing MS and relapsing-remitting MS is that in the former type, the periods between relapses involve continuing progression of the disease.

MS is no longer considered the death sentence it once was. People live normal length lives after being diagnosed. This is what the pharmaceutical companies are banking on. They have, in a matter of years, come out with a number of drugs touting the ability to reduce the length of exacerbation's, or extend the time between episodes. Also these drugs have leapfrogged the HSCT procedure, which will negate the need of the drugs themselves.

I am a most recent recipient of the HSCT procedure. I had spoken with Dr. Burt during my research and found I am not a candidate in Chicago because I have PPMS. He was very apologetic. But as we say in the country, "That just don't feed the bulldog." This left me few alternatives as far as treatment. As you can see on the following link: http://www.hsctstopsms.com/hsct-facilities-worldwide/

There are a number of facilities as I stated. In most cases you can also see the prices for the procedure and their criteria.

I was able to get into the location in Puebla, Mexico. $49,000.00 and was happy to get it. There is of course no insurance help when you go out-of-country to have a procedure. On top of this, Clinica Ruiz (Mexico) strongly recommends you have booster infusions of a drug called Rituximab 100mg every other month for the first year. This drug is widely used in the US already, just not for MS. Therefore the insurance companies deny payment for it also under the grounds of it being fruit from the poisonous tree.

The real problem, and I will say we are members of the fortunate group because, we had prepared for retirement and were in pretty good financial shape. We could pull from our retirement without penalty for this medical procedure. Also I am on Long Term Disability (LTD) from my job, therefore am receiving 60% of my salary. Back to the problem. There are just so many others who could not have done this in a million years.

That leaves them at the mercy of the Disease Modifying Drug (DMD). I know I keep harping on this sir, but I am trying to drive the point home without you losing interest. Allow me to show you a real quick calculation and I will be finished.

I am using what Tecfidera cost me, not what is in the link.

<strong>$3,000.00 per month x 12 months = $36,000.00 per year. Average life expectancy after diagnosis is 30 years. $36,000.00 x 30 = $1,080,000.00 and that is per patient!</strong> Please see the link for actuals of the DMDs

https://www.google.com.mx/?gfe_rd=cr&amp;ei=ebpmVsC4N6yR8QfflLXQDg#q=tecfidera+cost