CellR4 2013; 1(2): E390

WHEN "NO OPTION" IS NOT AN ACCEPTABLE OPTION

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Keywords: Stem cells, Cell therapy, Multiple sclerosis, Regulatory, FDA.

Here in the midst of a typical, hot, Austin, Texas summer afternoon, I'm reflecting back on my Multiple Sclerosis (MS) journey, and what brought me to this treatment crossroads. I realize there are literally thousands of "MS'ers" with stories just as compelling and dramatic as mine. Bottom line, I am not unique! Many patients run out of options with FDA approved treatments about five to ten years after their diagnoses. We then turn to our MS patient community to find out what to do next.

Recent editorials and commentaries highlighted elements of heated debate on current regulations limiting the translation and verification of cellular therapies[1,2] and I am pleased to see that CellR4 could represent a platform for better communication and understanding in the field, including also the voice and perspective of patients.

Over the past few years, I have had a growing suspicion that something in the Multiple Sclerosis community was not quite right. More specifically, something just doesn't addup. I keep asking myself, why are so many MS patients seeking overseas, alternative treatments? MS patients in particular seem to be at the top of the list of "disease communities," seeking treatment abroad. There has to be more to this than meets the eye. The claims the drug companies, the FDA and many scientists are making, are in direct opposition to what MS patients are actually experiencing. I hope to dispel the idea that the majority of MS patients are being targeted for marketing by foreign stem cell clinics. In reality, patients share their successes and failures in regard to adult stem cell treatments and clinics. We then make informed decisions in becoming medical tourists. The successes we are seeing and hearing from other patients far exceed any those derived from any FDA approved treatment available to us in the United States to date. You could then form a hypothesis about other "disease communities," like ALS, Alzheimer's, Parkinson's COPD, etc, seeking overseas treatment for exactly the same reasons. There is a giant breakdown in our current regulatory system, and the huge popularity of medical tourism is a direct reflection of this gaping black hole in domestic treatment options.

I was diagnosed with Multiple Sclerosis in September of 2004. When faced with a medical crisis of an unexpected nature, your whole world gets turned upside down. So what did I do? I turned to advocacy work with the Lone Star Chapter of the MS Society in Austin,Texas, and became a grassroots activist for Texans living with chronic illness. I spent three sessions doing grassroots advocacy work, and got three priority bills passed in one session at the Texas State Capital. While there, I met quite a few MS patients who had become medical tourists to receive adult stem cell therapy. At the time I had injected an FDA approved maintenance drug for five years. Not long after, my body began to reject the MS drug I was on, and I had to abruptly stop it. It was then that I made the decision that I would get adult stem cell therapy one day.

Fast forward a few years, to October 5th, 2012. I was set to begin my first adult stem cell treatment in Houston, Texas. My dear friend, who also has MS, had just finished her adult stem cell therapy with my same doctor, that past August. We drove down together to Houston early that morning. Little did we know that my treatment would begin and end all on the sameday! I was scheduled to receive 600 million cells, divided into three treatments. The first treatment went off without a hitch. On the drive back home, we re-

ceived a phone call that the FDA had shut the IRB study down. Talk about an emotional roller coaster! I had just been overjoyed to start my treatment, and then became very confused and angry, as to why the FDA would pursue this course of action. Over the following weeks, I expected a phone call to say that everything was fixed, and I would be able to continue my treatment, but that never happened. Now I face the fact that I may have to leave the country, like many of my friends have done, to finish my treatment.

Since then, a small group of patients have banded together to speak out about being denied treatment with our own cells, in our own country. We feel this to be a medical procedure; done between one informed and consenting patient and our fully capable physician. At http://www.patientsforstemcells.org we give a history of the timeline of FDA control of the cells inside your body. We show the safety and efficacy of being treated with your own stem cells compared to riskier procedures or dangerous, FDA approved medications. We also vet media sources that present biased reporting on autologous stem cells. This is the "Cliff Notes" to the last nine years of my life. We at Patients For Stem Cells find ourselves in a unique position to have pretty big voices in this stem cell debate. We hope to approach each discussion, with integrity, honesty, intelligence, compassion and with our own personal experiences. Hopefully we can help to press for change within the medical and bureaucratic communities, filling in the gaps with an informed and well connected patient community.

MS patients, along with many other orphan diseases, are often left with no treatment options. We have put our faith in FDA approved treatment only do be left confused and wanting. We hope to seek answers and partnerships with those of you in the scientific community who have been doing this a lot longer than we have. We at Patients For Stem Cells appreciate the effort brought forth by ICMS (International Cellular Medicine Society), to have more open and honest debate regarding autologous stem cells therapy and FDA or other agency regulations. Everyone around us seems to be well versed in identifying all the wrongs and concerns of an unregulated stem cell treatment, but offers little in the way of solutions. We are hoping to draw on this fact and ask the scientific community to help "no option," chronically ill patients, find legal solutions. We've got too much living yet to do!

References

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