

Foreign Stem Cell Treatments: How to Avoid Being Scammed

By

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On April 18, 2010 CBS's 60 Minutes program aired a half-hour segment on a stem cell treatment for amyotrophic lateral sclerosis (ALS), multiple sclerosis, and Parkinson's disease promoted by Lawrence Stowe, Ph.D. at Stowe Bio Therapy (La Mesa, California) and administered by Frank Morales, M.D. in a Monterrey, Mexico hospital. During the course of this investigative piece Stowe was captured on video claiming a "permanent fix" for ALS during the course of a hidden video recorded conversation with ALS sufferers Michael Martin and Steven Watters ([Quote from "21st Century Snake Oil" on CBS's 60 Minute website](#)).

From the segment (Links to the entire CBS expose in two parts follow this article):

"Is there a stem cell fix for ALS?" (CBS 60 Minute correspondent Scott) Pelley asked Professor Sean Morrison, the director of the University of Michigan Center for Stem Cell Biology.

"No," Professor Morrison replied.

Of course, Dr. Morrison is absolutely correct. There is absolutely no stem cell cure for ALS. Who would believe otherwise, you may ask? To claim a cure for ALS or any other progressive disease requires the claimant have some pretty heavy duty proof; that is, hard evidence that stands up to scrutiny when submitted to experts in the field. Those who make such curative claims in the absence of having such evidence generally turn out to be scam artists ("con men"), pathological liars, delusional or sociopaths.

But no ALS patient would ever buy into such claims, right?! They are too outrageous to be believed. Sadly, desperation can undermine cautionary skepticism. It can even lend a person to believe not just the improbable, but the fantastic. This is exactly what unscrupulous souls count on when selling the suffering on a useless or bogus treatment.

Is there some way the vulnerable can make it far less likely they will be victimized? There is. Here is one very basic "rule of thumb" that can make "being had" less likely:

Extraordinary claims that are not backed up by extraordinary proof should without exception be disbelieved

If someone claims they have cured ALS, Multiple Sclerosis, Muscular Dystrophy, Alzheimer's, Parkinson's or such using stem cells he or she should be able to produce

solid evidence in the form of well designed and executed clinical studies published in a mainstream peer reviewed medical or scientific journal.

But what about stem cell treatments that are not purported to cure a serious disease or medical condition, but rather are regarded as having the potential to effect relief or bring about some degree of clinical improvement?

Many experts and critics would argue that such experimental intervention, in which a given stem cell treatment has not yet been proved safe and effective, should not be done outside of formal, government approved or sanctioned clinical trials. And yes, when done correctly, [randomized controlled clinical studies](#) are the best way to generate reliable scientific evidence concerning a treatment's intended or expected effects (albeit [anecdotal evidence and observational studies are regarded by some researchers as a more reliable means of discovery and explanation](#). More on anecdotal evidence follows below). Unfortunately, studies involving people with terminal or intractable medical conditions cannot accommodate all who qualify for them and want to participate. And, of course, many will be beyond rescue or dead by the time sufficient evidence of a given stem cell treatment's efficacy for their condition exists to win it FDA approval.

This brings us full circle to the question of suffering people undergoing experimental stem cell treatments abroad, most of which are administered at private clinics and institutions that by-and-large appear to lack the wherewithal to conduct prospective randomized placebo-controlled clinical studies. Given the fact many are dying or only a have a narrow biological window of opportunity to achieve relief or remediation of their condition, are they foolish or reckless to do so? To, in essence, become paying participants in what amounts to an [uncontrolled experiment](#) (or in some instances an [open-label study](#)).

Apparently scores of people do not think so. Untold numbers, in fact, have expressed opinions in print and on the Internet that can be characterized as supportive of those faced with few or no mainstream approved treatment options undergoing experimental stem cell procedures abroad (A link to one of some of the more popular cyber-forums follows below). Some physicians who routinely deal with terminally ill patients and who actually oppose such treatments readily appreciate why they do so. One, neurologist Dr. Jang-Ho Cha at Massachusetts General Hospital, spoke to this very thing in a (June 13, 2008) article in the Boston Globe titled "[More Patients Seek Experimental Stem Cell Therapy](#)" by Globe Correspondent Neil Munshi:

"I can't completely blame people because I think it's reasonable and normal to feel very frustrated at the pace of advancement," he said. "I really believe [stem cell therapy] is going to be very powerful one day, but there are a lot of people out there who feel like they don't have time to wait."

For those suffering souls who conclude experimental stem cell intervention outside the mainstream a worthy calculated gamble, the most pressing task becomes one of sorting the wheat from the chaff (scams) and then zeroing in on a particular treatment which offers genuine promise in terms of conferring relief or clinical benefit. In most cases this hinges on the weakest kind of scientific evidence for effectiveness: Anecdotal (Case histories or testimonials).

Just exactly what place in science do testimonials hold? In an article titled "[Science vs. Alternativism](#)" posted on Quackwatch, writer Gregory L. Smith, MD states that:

*"Testimonials can be great places to start looking for answers, but they should not be considered the end of the journey. Many scientific discoveries start with an observation that leads to a hypothesis that eventually can be tested with a randomized controlled trial (Emphasis mine). However, people who use testimonials probably have little better to offer. After all, it is possible to get a testimonial from someone for nearly anything. In the 19th century, quack doctors sold medicines that were radioactive or gave patients bits of radioactive metal to wear near their skin. Many patients gave enthusiastic testimonials. They may have sincerely *felt* they were better, but experience showed that it wasn't doing them any favors—it ultimately made them much worse."*

Of course, for people saddled with a terminal illness and very little time in which to act, a treatment supported only by testimonials or case histories is all they have to go on. It is sometimes the "end of the journey" for people nearing the end of theirs.

This is not to say all anecdotes are equal. Some reflect greater rigor in terms of trying to eliminate things the patient has done prior to their treatment or afterwards that might account for the improvements or benefits attributed to said treatment.

Steven Novella, MD, an academic clinical neurologist at Yale University School of Medicine, ably captures this in an article he penned titled "[The Role of Anecdotes in Science-Based Medicine](#)":

"But should anecdotes play any role in medical evidence? Yes, but a very minor and clearly defined one. Anecdotes, with all their weaknesses, are real life experience. It is possible that a treatment does in fact work and personal experience may be the first indication that there is a meaningful biological effect in play. But here are two limiting factors in how anecdotes should be incorporated into medical evidence:

The first is that anecdotes should be documented as carefully as possible. This is a common practice in scientific medicine, where anecdotes are called case reports (when reported individually) or a case series (when a few related anecdotes are reported). Case reports are anecdotal because they are retrospective and not controlled. But it can be helpful to relay a case where all the relevant information is carefully documented - the timeline of events, all treatments that were given, test results, exam findings, etc. This at least locks this information into place and prevents further distortion by memory. It also attempts to document as many confounding variables as possible."

However, what if only one patient with a particular medical condition or disease was treated by clinic x using stem cell treatment y and reported reaping substantial clinical benefits? A few? Three to five? And if three had good responses, how many had none or poor ones? (The clinic or institution should be able to provide this information. If not, a red flag should go up). Also, what turns up on blogs and websites in the way of patient postings concerning their impressions and experiences of the stem cell clinic or institution in question? (If sensible, negative patient accounts abound, additional red flags should go up).

Some would no doubt argue that a single spectacular turnaround that is attributable to the treatment (and little or nothing else) is compelling enough to warrant a terminally ill patient's pursuing having it done. In some instances, perhaps so. And, yes, while great responses in three treated people may suggest the treatment has great merit, if thirty others had no or poor responses or those who did well were doing other things at the time of their treatment that could better account for their improvements, the treatment is not worth pursuing (Unless, of course, the three that got fabulous results had a particular form of the disease – a genetic variant – in common. In such a case people afflicted with this variant would naturally want to take a closer look).

There are, of course, other issues and caveats that need to be taken into consideration by everyone looking into doing some kind of stem cell therapy. Some are discussed in this 2009 article of mine (Updated slightly during March 2010): [For Those Considering Doing Stem Cell Therapy Abroad](#). Others are ably covered in various articles that follow below.

In conclusion, if it sounds like evaluating stem cell providers and their treatment offerings require a great deal of critical digging, reading, sorting and analyzing, it does. It does – and it should – because anything less increases one's vulnerability to being mistaken or misled; even scammed.

Praemonitus praemunitus (To be forewarned is to be forearmed)

References & Resources

[60 Minute's expose "21st Century Snake Oil" Part 1](#)

[60 Minute's expose "21st Century Snake Oil" Part 2](#)

[Stem Cell Pioneers \(Stem cell discussion cyber-forum\)](#)

[International Cellular Medicine Society](#)

[International Society for Stem Cell Research \(ISSCR\)](#)

[“Anecdotal Evidence”: Why Narratives Matter to Medical Practice”](#) by Rafael Campo

[Dr. Carl Sagan's "Baloney Detection Kit"](#)

[Private Foreign Stem Cell Clinics: Most Are Not Doing Hard Science Yet -- Though Some Are Working On It](#)

[ALSUntangled Update 3: Investigating stem cell transplants at the Hospital San Jose Tecnologico de Monterrey \(Mexico\)](#) - We applaud the openness of this clinic in publishing its preliminary results. However, at the present time, there are insufficient safety or efficacy data to support stem cell transplants at the Hospital San Jose Tecnologico de Monterrey as a treatment option for ALS. Also, more rigorous studies are needed to clarify safety and efficacy concerns.

[Cellular Transplants in China: Observational Study from the Largest Human Experiment in Chronic Spinal Cord Injury](#) - Based on the observations in this series of 7 subjects, the safety and efficacy of Dr Huang's implantations procedure are unclear. Patients have encountered serious medical complications and no lasting increase in sensorimotor function or functional ability.

[Medical Tourism Ethics: China Offers Unproven Medical Treatments](#) - Noting the lack of evidence, three Western doctors, undertook their own limited study. It involved seven patients with spinal cord injuries who chose to get fetal brain tissue injections at one hospital in China. The study reported "no clinically useful improvements" — even though most patients believed they were better. Five developed complications such as meningitis.

["Why we need observational studies to evaluate the effectiveness of health care"](#)

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