First, let me come clean about my motivations. I am a spinal cord injury physician scientist and I work daily both to push back the frontiers of spinal cord injury medicine and to care for my patients in the best, safest and most efficacious way I can.

I believe in the potential of stem cells and other therapies that seem to work so well in the lab on rats and mice and actually study adult progenitor cells myself as a potential therapy.

I also believe that desperation, fear, anxiety, greed, the search for fame, the search for the cure and other human emotions and motivations cloud the minds of some spinal cord injury patients, researchers and physicians battling this terrible insult to a “normal” life and lead to unsafe, unethical and unsound methods of fighting back.

I have patients who won’t forgive themselves if they don’t try every possible treatment under the sun and who spend all their time on the internet and on the e-stim bike neglecting their education, their employment and their love lives. I also have patients who go back to the lives they had before spinal cord injury and neglect their health and the possibility of a better future. I can’t tell any of these patients where to find peace, I can only encourage those focused only on the future to also accept living today and I can only encourage those living only for today to better prepare for a different future. That all said, I swore at my medical school graduation to “do no harm” and I think one way to do that is to arm patients with information.

This article is to serve as a cautionary tale to those who wish to pursue the “cure” in the form of going overseas to get “stem cell transplants”.

My story is about Bob (not his real name). Bob was an outgoing, athletic guy who let nothing stand in his way and who was in control of his destiny until he suffered a cervical spinal cord injury. After his injury, Bob had sensation all the way down to his bottom and had movement and some strength in his biceps and triceps but not in any lower muscles.

He had surgery and went through rehab but couldn’t accept that there wasn’t something more to do. He searched high and low for an alternative and found the program in Portugal that was transplanting olfactory epithelium into the damaged spinal cord. Now that idea had come from some very good animal data that showed olfactory ensheathing glia grown in cell culture and transplanted into spinal cord injured rats had helped their locomotor function.

The human program, however, was not part of a scientific study, did not have FDA approval, had no published reports about their clinical successes or failures, did not have U.S. scientists or physicians carrying out the work and had combined that therapy with lots of other rehabilitative strategies to give sort of a “everything in the kitchen sink” kind
of approach. The procedure cost $40,000 but Bob had heard of one girl who had undergone the procedure and was reportedly better afterwards.

Bob came to see me for the first time after he had been to the program and had gotten the procedure. He was out the $40,000, had lost sensation below the level of his injury and had lost use of his triceps muscle on one side. He had come to me to see if he could participate in our clinical trials where we are studying robotic body weight supported treadmill training. I had to tell him that his participation in the Portugal program had disqualified him from our studies; he was too different from the average spinal cord patient we were studying to be included with them.

Of course Bob is disappointed, frustrated, and a bit regretful about his course of actions but that doesn’t make his situation worthy of any less empathy on my part, I just have to figure out what I can do for him given that I have less to offer him in terms of more careful, scientifically well-grounded studies for improving recovery after spinal cord injury.

Unfortunately, it’s not Bob’s story that is on the internet, nor does one find the stories of the hundreds of patients that have been to China, Russia, Latin America, some European centers or elsewhere for their embryonic stem cell transplants and who have gotten no benefit or have gotten worse, suffered meningitis or died.

There are a few stories of wonderful recoveries but recovery sometimes occurs on its own, with time, and I often wonder if more recovery might have been seen had the patient not gotten “treated” in one of these overseas programs. I also wonder if it makes sense that someone who spends their life savings on one of these programs and afterwards has some new tingling somewhere would attribute it to their investment to feel like they got something for their money.

These thoughts lead me to some observations and considerations for patients thinking of pursuing these kinds of programs.

First off, set aside the story that gave you perhaps unrealistic hope. The fact that someone wins the lottery doesn’t mean millions didn’t lose with their chosen numbers. Find out what is being done, what has been published about it, how it has been received by other researchers, care providers and patients (the CareCure website is a good example of a large enough internet site to get multiple views and some expert opinions), what is the track record of success and failure, and what is the long term effect.

While someone has to be the first 50 patients to get a new treatment, I would want to be number 51 with public evidence that 49 are significantly better off than before. There is at least one Russian physician who tells his patients he is allowed to only work in military hospitals and that his methods are secret for that reason.

Don’t buy into this tempting secrecy, if what is being done works, you will be able to find lots of patients who are doing more than minimally better and lots of people will
know about it. Penicillin is not a secret because nobody is afraid to share the evidence of its efficacy.

Second, legitimate scientific studies pay you to participate not the other way around. This also means you might be put in the non-treatment group so we can really learn if the treatment is better than no treatment. This frustrates patients but ensures the study will learn something that could benefit all patients now and in the future. When you pay for “treatment” you have to wonder about the motivation of the care providers.

While there are most probably those trying to help and who just need to cover their costs, there are those running to the bank with money earned for what they know is smoke and mirrors. Someone may tell you they will transplant stem cells but how can you really know? Studies in this country approved by the FDA at least have the benefit of oversight, multiple committees reviewing the activity for patient protection and safety, and there is public reckoning. Trust is a difficult thing, so many spinal cord injured patients have been asked to give it to so many so often but it can be a casualty of desperation and too easily given to snake oil salesmen.

Lastly, consider the possible downsides. Many of my patients offer themselves up for study and experimental treatment with the comment, “Doc, you can’t make me worse than I am”. Not true. Like Bob, there is getting functionally worse. There is being put in perpetual pain. There is being disqualified from future studies or treatments. It is hard to know what is around the corner but it would be a shame that an ineffective treatment today, sought after out of desperation, might preclude a genuine treatment in the future.

Most of my spinal cord injured patients are not particularly patient and I know bone loss, muscle loss, contractures, skin breakdown, de-conditioning, chronic pain, the inconvenience of bowel and bladder dysfunction and other consequences of spinal cord injury weigh heavily on them. Nevertheless, we continue to improve on how we can maintain health until safe studies or treatments are found.

So, is all lost? Not by a long shot. Spinal cord injury research and treatment has never had it so good. The number of talented minds, research dollars and patients enrolling in safe, ethical research studies is higher than ever before.

Christopher Reeve used to say that money was time; that more dollars spent on investigation would lead to treatments sooner. Just think if everyone’s $40,000 got invested in legitimate research here rather than paid to a dubious overseas program. We continue to learn more and more about neural plasticity and neural repair and we continue to strive to move discoveries from the bench top to the bed side.

In the last few years we have had the first multi-center, FDA approved studies in locomotor therapy and cell transplantation here in the US. More is in the pipeline and more is under development. We will have failed clinic trials, that is for sure, but we will also have clinical successes. The “cure” will not be one intervention nor will it come quickly or easily. We as a community of patients, physicians and researchers have to hold
our desperation, fear, anger, and greed in check and ensure that the field of spinal cord injury medicine is advanced effectively, as quickly as possible, but above all, as safely as possible, doing no harm. Bob agrees.