**O.C. woman traveling to Moscow to undergo stem cell treatment for rare condition**

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Janell Carlson will land Thursday in Moscow, prepared to wire $43,500 to the National Pirogov Medical Surgical Center.

Her head newly shaved, the former EMT from Huntington Beach will walk with a black cane and wait for a driver to whisk her and her best friend away to the clinic.

Carlson, 41, does not have cancer, but at the center, she’ll undergo chemotherapy for four days, and a medical team will insert a catheter in her neck to extract some 200 million blood-forming stem cells that will be treatedthen re-injected in an attempt to reboot her immune system, which is attacking her nerves.

In the U.S., similar types of adult stem cell transplants are common treatments for blood cancers and are performed at major hospitals. But it’s considered radical and highly experimental for the condition Carlson has coped with for four years, a chronic neurological disorder she hopes tostop in its tracks.



Janell Carlson receives immunoglobulin, whose effectiveness she sees ebbing. She's opted to seek a $43,500 stem cell treatment in Russia.

Carlson will be the fifth patient with chronic inflammatory demyelinating polyneuropathy, or CIDP, to undergo a stem cell transplant at the surgical center in Moscow. There’s a clinical trial underway in Chicago, but Carlson is convinced that if she waits to grapple with her insurance company over coverage, her condition will deteriorate.

If left untreated, the disorder can cause the progressive loss of arm and leg strength and sensation. It could eventually paralyze all of her limbs.

“It’s imminent. I need this,” she said. “My deterioration the past six months has been amazing. I was not walking with a cane. They’re already talking about putting me on a respirator.”

In her search for relief, she’s gamblingwith tens of thousands of dollars – given to her by her father who tapped into his retirement savings. There is no proven stem cell treatment for CIDP and myriad other diseases for which stem cell therapies are marketed across the Internet, which is where Carlson learned about it.

There are serious risks, predominately infection. Carlson is also prone to major blood clots, which could complicate her return home. Her visa is good for three months (the stem cell transplant without complications takes one month), and she won’t be allowed to fly with a blood cot.

Last year, a[Brisbane mother with a rare neurological disorder died of a heart attack](http://www.brisbanetimes.com.au/queensland/brisbane-mum-dies-undergoing-stem-cell-therapy-in-russia-20140727-zxfuz.html) while undergoing the same procedure by the same doctor in the same facility.

But Carlson said she fears death less than the life she envisions if her condition continues to worsen. She lives alone, and as her parents age, she wonders who would care for her.

It’s that fear that has driven her to the other side of the world, and she’s not alone. Sleek websites and online testimonials are luring patients who are frustrated by the limited effectiveness of standard treatments and drugs to clinics in Russia, China and Latin America, where they pay for stem cell transplants not approved in the U.S.

“Rarely a day goes by when we don’t get a phone call or email from a patient or family member of someone with a horrible disease asking what stem cell therapies are available and if they should consider going abroad for a therapy,” said Kevin McCormack of theCalifornia Institute for Regenerative Medicine, a state agency that is awarding $3 billion to scientists to speed up development of stem cell treatments in the U.S.

“I can understand the fear they have, the desire to try something, anything. That’s what these clinics offer, a sense of hope – even when it’s unproven and expensive,” he said.

**Balancing hope and doubt**

At first, Carlson was skeptical about the legitimacy of the procedure. She questioned whether the patients she communicates with on Facebook and Internet message boards are real.She’s envisioned arriving in Russia only to have it all be a sham.

She became convinced after watching a “Sixty Minutes Australia” episode featuring the physician who will perform her stem cell transplant, Dr. Denis Fedorenko. In the segment, which was advertised as “the most inspirational story of the year” and titled, “Russian Roulette,” a 35-year-old woman is documented bouncing back from a slow decline into multiple sclerosis after undergoing an adult stem cell transplant.

MS Australia issued this statement after the episode aired: “Internationally, there are hundreds of people with MS who have undergone this type of procedure and whilst it is true that several have seen immediate benefit, it is also true that there are people who have undergone the treatment and received no benefit at all and continue to deteriorate.”

It’s not just overseas treatments that are of concern. There are sketchy claims in the U.S., too.

In November, 2012, two men were convicted of fraud in Nevada for selling ineffective stem cell treatments. One of the men, Alfred Sapse, who claimed to be a retired foreign physician but who was never licensed to practice medicine in the U.S., used websites and press releases to market a “proprietary” procedure that could cure multiple sclerosis and cerebral palsy, according to the Food and Drug Administration, which investigated the case.

“More of these clinics are opening up in the U.S., offering these kinds of therapies and the FDA is struggling to deal with it,” McCormack said.

That the FDA pursued criminal charges and put the two Nevada men out of practice, highlights the importance of the agency’s regulatory role, the editors of the journal Nature wrote in February 2013.

“The FDA is valuable; it’s extremely skeptical,” said Dr. Steven Cramer, a stroke neurologist and clinical director of the Sue and Bill Gross Stem Cell Research Center at UC Irvine. “If a procedure is done outside the U.S, there’s a good chance it won’t be up to FDA standards. There are articles describing all sorts of tumors and horrible things that happened to people who went to Russia.”

But there are critics who say the FDA is standing in the way of progress by creating rules for large clinical trials that are so “expensive that many researchers and biotechnology companies cannot afford to conduct them.”

“The longer it takes to develop a workable and affordable system in nations such as the United States, the more patients will travel for treatment to countries where there are even more unknowns,” the editors of Nature wrote.

There’s no way to know how many people are going abroad for stem cell transplants or if warnings issued over the past five years about the dangers of doing so are persuading desperate people not to pursue the chance for a miracle cure.

“There’s no way of tracking it. The clinics aren’t registered or licensed in most cases,” said McCormack. “And if we do know something about the clinic, they don’t publish scientific evidence … they don’t track the outcomes afterward.”

None of the physicians interviewed for this story knew of Fedorenko or were familiar with his work.

In the U.S., it’s estimated that 5,000 to 10,000 people are living with CIDP, which,for unknown reasons, is caused by the immune system gone haywire, attacking insulation that wraps around nerves. It launches an assault that damages, if not destroys, critical electrical impulses that stimulate muscle contraction and transmit sensory information, leading to numbness, tingling and pain, a loss of reflexes and weakness.

“In this country, the diagnosis and treatment of CIDP are very substandard. There’s not a single gold-standard test,” said Johns Hopkins Hospital’s Dr. Lyle Ostrow, who specializes in the disorder. “When a patient is truly not responding or is progressively getting worse, we are most commonly concerned that we made a wrong diagnosis and something else is going wrong. Those are the times when we do nerve biopsies or do labs to look for cancers.”

He said there’s no “clear rationale” why stem cells would offer a cure.

**Confident in her decision**

For 3 1/2 years, Carlson has been injected regularly with healthy antibodies from donated blood. In high doses, intravenous immunoglobulin, or IVIG,is the only drug that has FDA, Canadian and European approval for treatment of CIDP.

It works for her, Carlson said, but “not as well as it should. I have to get it more often now.” She began with monthly treatments and is now up to every other week, for three consecutive days.

Carlson’s doctor, Fountain Valley-based neurologist Mindy Bixby, declined to be interviewed for this story. Bixbyand Carlson spoke last week to again go over her diagnosis, which has been reaffirmed by a handful of other neurologists over the past four years, Carlson said.

In an airy mobile home in Huntington Beach shared with a boxer and a striped cat, Carlson said her decision to go overseas has divided her family.

But she expresses no doubts in her decision.

“I’m full of expectations that God is going to meet me there. I love science, but my faith is everything. He created me. Who created science? God did. I know the reality of what can happen to me. I’ve written my will. I’ve researched how to get a body back from Russia,” she said.

“I know the reality of chemo. In the worst case scenario, I know where I’m going and I’m going to be a heck of a lot happier there.”

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