# MS patients going abroad to find help from stem-cell therapies

Promising stem-cell therapies remain hard to obtain in U.S.

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Photo: Brett Coomer, Chronicle

Linda Jayaram, shown with her husband, David Barish, says she is feeling the best she has in decades after traveling to Israel for stem-cell therapy to treat her multiple sclerosis.

Linda Jayaram battled multiple sclerosis for four decades, her condition worsening all the while, before she made the 2009 decision that she says changed her life.

In Israel with her husband, Houston furniture magnate **David Barish**, Jayaram arranged a meeting with a university doctor conducting experimental therapy she'd



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recently read reversed the effects of MS in a patient. The therapy, not available in the United States, involved adult stem cells.

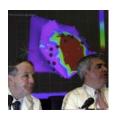
"I was ecstatic about the possibility," Jayaram says. "I thought, this is something I can easily do, this is something that could work. It's certainly worth a try."

Two years later, feeling the best she has in decades, able to get around without her Segway, Jayaram pronounces the experiment a resounding success.

She is one of an increasing number of Americans traveling abroad, often at great cost and to the dismay of their U.S. doctors, for what might be the best hope for MS patients in ages: treatments that use adult stem cells in efforts to reboot the immune system or repair the damage inflicted by the disease. The treatment is offered in Europe and Asia and south of the U.S. border, sometimes in university-affiliated research, sometimes in unregulated, hole-in-the-wall clinics.

The treatment's availability is extremely limited in the U.S. because there's little scientific proof it works.

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early years of the AIDS epidemic, between desperate patients frustrated that therapeutic progress comes too slow and a medical establishment that insists there be ample evidence a therapy is safe and effective before



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Complicating matters is that MS is an unpredictable disease with symptoms that may come and go and periods of naturally occurring remission that can be confused with treatment responses. Doctors say patients must be followed for years before concluding a treatment worked.

## Showing benefit is key

"There is a lot of hope stem-cell therapies can be an important tool in battle against MS," said Dr. Timothy Coetzee, chief research officer of the National MS Society. "But at the end of the day, the key is that they show benefit — that they reduce disease progression, relapses, lesions in the brain. That is what it'll take for stem-cell treatment to become available in the U.S."

An estimated 400,000 Americans suffer from MS, a degenerative disease of the nervous system for which there is no cure. The cause of the disease is not known, but sufferers' immune systems eat away at the protective sheath that covers the nerves, interfering with the communication between the brain and the body, resulting in symptoms such as fatigue, loss of balance and muscle coordination, tingling or numbness, problems with speech and bladder and bowel difficulties.

Neurologists say they now have an array of drugs to effectively manage the condition if it's diagnosed early. But once it progresses to more advanced stages, many patients complain they don't get much help from the approved drugs and look for alternatives.

One stem-cell therapy modeled on a kind of cancer treatment is being investigated in the United States. It involves giving patients chemotherapy to destroy their immune system, then injecting them with their own

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immune stem cells, obtained from their blood before the chemo. The idea is that the new cells will "reset" the patient's immune system so it no longer attacks the nerve covering.

#### 'Most exciting advance'

In a Northwestern University study published two years ago, the treatment reversed the neurological dysfunction of 17 of 21 early-stage MS patients. Its principal investigator, Dr. Richard Burt, calls the therapy the "most exciting advance in MS in 25 years" and says that if his ongoing late-phase trial produces similar results, that should constitute the necessary proof it works.

Among the advocates is **Craig Garrison**, who received the therapy in 2001 as part of a **Baylor College of Medicine-Methodist Hospital** trial. The trial is still tracking patients but not taking new ones.

"I'm nine years out and doing great," says Garrison, a Lake Jackson retiree who's had the condition since 1982. "Before the therapy, I used two canes and was on a trajectory to end up in a wheelchair. Now I'm about to throw the canes away."

Still, the therapy is mostly only available in other countries, ineffective in later-stage patients and too risky for some. The body is nearly helpless against infection during the weeks before the immune system reboots.

In the therapy Jayaram received in Israel, Dr. Dimitrios Karussis of Hadassah Hebrew University Hospital in Jerusalem does not give chemotherapy. He instead injects into the blood and spinal canal primitive stem cells taken from the patient's bone marrow that have greater plasticity than other adult stem cells. The hope is that they migrate to the site of MS patients' nerve damage and reduce inflammation and promote healing. The research is in its infancy - Karussis in 2010 published a study showing the therapy is safe - and it's still unclear how often therapy is needed. Jayaram is currently in Israel hoping to learn she can receive a fourth infusion. She reported the most dramatic improvement after the second infusion.

The renowned **Cleveland Clinic** recently began a Phase 1 study into the therapy, the first in the United States.

## Lack of oversight

U.S. doctors who treat MS patients express concern about treatment offered outside academic centers, the clinics in Mexico and Costa Rica and China that use donor umbilical cord and placental cells and tout them as safe, effective and ready for routine use.

Although some patients report improved health from such clinics - Houston artist **Cecilia Johnson** is making a documentary film about one Mexican clinic, so grateful is she for the life she credits it with giving her back - U.S. MS experts worry that such offshore clinics operate without oversight and don't monitor patients to track improvements and declines.

"With the variable options out there, the concern is that patients could go to the wrong places," says Dr. Jerry Wolinsky, director of the MS Research Group at the University of Texas Health Science Center in Houston. "For patients who find the existing drug treatment inadequate, we can direct them to places doing credible research."

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