



**April 1, 2015**

*by Tim Drake*

## **Legate Linda Stafford recovers from rare brain disease after stem cell treatment . . .**

### **Linda and Jerry Stafford**

Jerry and Linda Stafford first met at a Pittsburgh-area diner. Linda was 18. Jerry was 20. Linda's girlfriend didn't have enough money, so they asked Jerry for 35 cents. In response, he asked for a date. Three months later the couple was married.

Members of Legatus' Las Vegas Chapter, the Staffords have been married 50 years. Jerry, who had been an electrical contractor most of his career, served as president of Republic Energy Services, which provided electrical contracting throughout Nevada and California. He retired last year so that he could concentrate on his wife's health.

### **Health problems**

Linda first noticed the signs of trouble in 2007, when she began experiencing numbness in her left hand.

"While at our Lake Tahoe summer home, she said something wasn't right," recalled Jerry, a member of Legatus' board of governors. "She was an avid golfer with a 12 handicap, and she started whiffing the ball. I wondered how could that be?"

As time progressed, Linda found herself limited physically and cognitively. She began having trouble determining spatial relationships, which led to difficulty driving and staying in the proper lane. That led to an auto accident in 2010. She also began dropping things with her left hand and felt as if it was "floating by itself," a condition known as Alien Hand Syndrome.

A year later, she began having difficulty with her speech. While she could remember what an item was, she would have trouble remembering its name, and was increasingly having difficulty finding the words that she wanted to say. She also began having trouble reading. Two or three times per day, Linda suffered from a tremor behind her right ear that led to spasms in her right shoulder and neck. Overall, she found that the symptoms severely hindered her daily life, rendering her unable to multi-task.

An initial medical work-up found no evidence of either a stroke or a transient ischemic attack (mini-stroke).

During Legatus' 2013 Summit in Scottsdale, Ariz., a health representative suggested that Linda visit a clinic in San Francisco. That May, she was diagnosed with corticobasal degeneration (CBD), a rare, progressive neurodegenerative disease that affects the cerebral cortex and is marked by disorders in movement and cognitive dysfunction.

**Linda hugs her daughter-in-law Jlynn Stafford.**

"We were told they could do nothing; there was no cure," said Jerry. The Staffords were advised to quit their jobs and enjoy what time Linda had left. Patients diagnosed with the disease are typically given five years to live.

## **Adult stem-cell therapy**

Some weeks later, a fellow Legate recommended and set up a conference call with hematologist Dr. Dipnarine Maharaj of the South Florida Bone Marrow/Stem Cell Transplant Institute in Boynton Beach, Fla. After an initial consultation, Maharaj said that he could help Linda.

Maharaj performs stem cell/bone marrow transplants for patients with leukemia and other cancers and blood disorders. He has also pioneered a method for mobilizing patients' own stem cells using protein injections. The protein releases a patient's own stem cells in order to repair the body. Since the treatment doesn't involve killing children in the embryonic stage, Maharaj's therapy is ethical according to Catholic teaching.

"There are plenty of adult stem cells in the body," said Edward Furton, an ethicist with the National Catholic Bioethics Center. "There are no concerns with something like this because it's not dealing with embryonic stem cells."

In 2003, Maharaj developed a process where doctors could allow the stem cells in reserve in the bone marrow to be released in larger numbers. Those cells then find their way to areas of inflammation and reduce it, allowing areas of the brain to function better.

"I was treating a patient for blood cancer who had had a stroke," Maharaj said. "I used a protein to increase the white blood cell count and the patient had a significant recovery."

Because this particular treatment is experimental and not a standard of care recognized by the FDA, it's not covered by insurance. A six-week cycle of treatment costs approximately \$60,000.

## **Successful treatment**

### **Dr. Dipnarine Maharaj**

In June 2013, while attending a Legatus board meeting in Naples, Fla., the Staffords took time to meet with Maharaj for an evaluation. Linda returned two weeks later for her first six-week treatment.

According to Maharaj, Linda experienced significant improvement. Her Unified Parkinson's Disease Rating Scale, a scale used to study the course of Parkinson's and other neurological diseases, improved dramatically. According to Maharaj, Linda's score went from 33 prior to therapy to 12 following therapy.

"She dramatically improved," Jerry agreed. "Everything improved. She got movement back in her left arm."

Jerry noticed some regression at the end of 2013, so they returned for a second treatment the following February and March.

"That treatment gave her significant improvement in the brain," said Jerry. "But after about seven months we began seeing regression again. When we returned, a brain scan showed some inflammation had returned. At that point we decided to go through a third round of treatment."

After her third course of stem cell mobilization therapy, a subsequent SPECT brain scan showed an improvement in hypoperfusion, or blood flow in the brain.

According to the medical report, Linda "now displays increased facial expression, improved speech and memory as well as better gait, balance and control of her left arm/hand. Her spatial understanding has improved with enhanced awareness of her hand when performing tasks such as writing. Her incidence of traumatic fall has decreased significantly. She is sleeping better and all tremors have resolved. Overall there is marked improvement in the patient's ability to perform activities of daily living and in her quality of life."

Jerry says he's overjoyed to see Linda returning to her old self.

"At her worst, she was unable to smile," he explained. "She described herself as 'being in a bubble.' You could look in her eyes and see that something wasn't there. She has completely rebounded from that.

"No one has ever been cured of this. We're very hopeful that her brain will totally heal. Everything has been very positive. Today, she is very healthy physically. I can only attribute that to the work of God. The medical profession will tell you that you can do nothing about some of these diseases, but I want to let people who have who have put some money away know that they can do something."

Linda plans to go through another two weeks of treatment in April and another in August to continue the healing.

"There's no question it's a miracle," said Jerry. "The most important thing is that she has given hope to a lot of people. Corticobasal degeneration doesn't have to be a death sentence."

**TIM DRAKE is Legatus magazine's editorial assistant.**

National Catholic Bioethics Center