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Treatment offers hope to Princeton woman fighting rare neurological disease



PHOTO COURTESY OF TERRY POLHEMUS

Rarely without a smile, even in the toughest moments, Jaime Russell-Polhemus mugs for the camera as her stem cells were removed at Northwestern University Hospital in Chicago in mid July. Jaime is undergoing a stem cell transplant in a promising new treatment for people suffering from autoimmune disorders. Jaime has a rare, life-threatening disease called Stiff Person Syndrome.

Leslie Renken
Journal Star reporter

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PRINCETON — Jaime Russell-Polhemus' body is trying to kill her.

The 46-year-old Princeton resident is a former police officer who worked for Peoria Heights, School District 150 and the Peoria Park District. She has an autoimmune disease, a condition where the immune system goes haywire and attacks the body's own tissues. Symptom severity varies among the different autoimmune diseases — for Jaime, who was diagnosed with Stiff Person Syndrome (SPS) in 2013, the symptoms are progressive and deadly.

SPS is a neurological disease. It's extremely rare — only one person in a million gets it. For that reason, it took a long time for Jaime to get a proper diagnosis. Symptoms began about five years ago.

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“They think that something triggers it — something in the environment, surgery or a virus,” Jaime explained.

After diagnosis, Jaime was put on high doses of some very strong medicines, and her symptoms slowly eased. Attempts to taper down the doses were unsuccessful, however, and Jaime’s doctors became concerned. The medicines themselves are destructive — the cure could also prove fatal.

The outlook was grim until early this year, when Jaime and her husband, Terry Polhemus, read about a trial at Northwestern University showing promise for people suffering from a variety of autoimmune disorders. The key component in the treatment is stem cells, which could potentially “reprogram” Jaime’s malfunctioning immune system.

Writing her will

Late in 2010, Jaime was busy raising her three boys and running a part-time house cleaning business when she started experiencing stiffness, pain in her back and fatigue. At first, Jaime thought she was just getting older, but then the tachycardia, low blood pressure and tremors started. The symptoms, and the fact that they would come and go, stumped her doctors.

Over the next two years, Jaime got progressively sicker, and new symptoms kept appearing. A thyroid imbalance caused Jaime to lose 20 pounds in two weeks. Her fingers and toes periodically turned blue, and she began suffering from painful muscle spasms.

“She would have these spasms in muscles you don’t really have control over,” said Terry. In 2013, he made a video of the muscle spasms in his wife’s back moving to the rhythm of music.

“Turn the radio on and the muscle spasmed, turn it off and it stopped,” said Terry.

It wasn’t just music that sparked painful spasms. All types of sounds (even quiet ones), a gentle touch or emotional stress could prompt an excruciating episode.

“Inflammation in the brain and spinal cord can make muscles contract at weird times,” explained Terry. It can make them react to noise, vibration, and other stimuli.”

By this time, doctors knew Jaime was suffering from some type of autoimmune disorder, but they didn’t know what kind and had no idea how to treat it. Treatments for various diagnoses all failed, and Jaime continued to get worse. She spent a lot of time confined to her bedroom, trying to avoid the stimuli that prompted the spasms — not only were they painful, they were affecting her ability to breathe.

“We were writing her will. We thought she was going to die,” said Terry.

Jaime was seeing a number of specialists, including a pulmonologist who was helping with the breathing issues. At one point, he suggested she go to Mayo Clinic.

“He said ‘If you get to the right doctor at Mayo, they may be able to figure out what’s going on with you,’ ” said Jaime.

In September of 2013, Jaime met with Dr. Sean Pittock, a specialist in autoimmune neurology at Mayo.

“Dr. Pittock diagnosed me that day after doing a neuro exam and reviewing my symptoms,” said Jaime. “He asked if I could stay so they could start treatment.”

Stiff Person Syndrome affects people in different ways. Typically, the stiffness and spasms occur in the lower body, affecting the abdomen and legs. For Jaime, the spasms affect the upper body, causing worrisome diaphragm and laryngeal spasms.

Treatment — a cocktail of very powerful drugs — slowly began easing symptoms. By December 2014, Jaime felt good enough to go shopping for a pair of boots to wear in the snow while playing with her sons. But Jaime’s doctors were worried — every time they tried to reduce her medicines, the symptoms came back. The drugs she was taking weren’t meant to be administered in high doses long-term. Treatment was unsustainable. Dr. Pittock was also concerned about the laryngeal spasms — he feared a sudden attack could lead to suffocation.

This past March, Jaime read about research being done by [Dr. Richard Burt, chief of the Division of Medicine-Immunotherapy and Autoimmune Diseases at Northwestern University’s Feinberg School of Medicine](#). Burt is studying the effect of stem cell transplantation on autoimmune diseases. Burt and his team harvest the patient’s own stem cells and re-insert them after the patient’s diseased immune system is ablated with chemo. In some cases, the immune system was “rebooting” — free of the “bad programming” affecting the other cells in the immune system, the stem cells rebuild a healthier immune system.

When Jaime asked her doctor at Mayo about the trial, he was encouraging.

“He said, ‘I met Dr. Burt. He is a pioneer and the best at what he does,’ ” said Jaime. Pittock believed there was a good chance Burt’s treatment could put Jaime into remission.

Hope and more worry

On Tuesday afternoon, Jaime was alone in her hospital room in Chicago suffering through the ravages of chemo.

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“Terry was going to come up today, but I told him not to,” she said. “It’s such a long drive, and I just don’t feel good enough. I don’t want to be a burden.”

At that point, Jaime was more than halfway through the six-week long stem cell transplant procedure. On Thursday, with her immune system greatly diminished, doctors inserted her own stem cells back into her body.

Burt’s work is bringing hope to people with incurable autoimmune disorders. He performed the first hematopoietic stem cell transplant on a patient with multiple sclerosis in 1996. Study results published early this year in The Journal of the American Medical Association stated that half of the patients in the M.S. study showed marked improvement two years after the transplant. Burt also is studying the effect of stem cell transplants on other types of autoimmune diseases. SPS is one of the rarest. Jaime says she is only the third SPS patient to have the treatment at Northwestern. She’s been communicating with the other two.

“One of the girls stopped by four days ago, and she looks really good,” said Jaime. “Her muscles have all loosened up, and she’s feeling good — each day is a little better.”

While the treatment has given the Polhemus family hope, it has also created a new worry — the family’s health insurance has refused to pay for it. A career law enforcement officer who worked for the Peoria County Sheriff’s Department until 2000, Terry is currently a patrol sergeant for the city of Princeton.

The news has added another crushing burden to the struggling family. The cost of treatment — estimated at \$300,000 to \$350,000 — is more than they can afford. They’ve launched several fundraisers, including an online gofundme campaign, and a benefit dinner Aug. 8 in Princeton.

In spite of the financial concern, when it came time to decide whether or not to do the treatment, the decision was easy — Jaime’s prognosis was so bad. Sitting on the sofa close to his wife at the family’s Princeton home one day late in June, Terry expressed both frustration and a measure of peace with the situation.

“We’ll figure something out,” he said.



LESLIE RENKEN/JOURNAL STAR

Jaime and Terry Polhemus pause for a portrait with their sons Jonathan, 12, Jaydan, 11, and Terran, 9, at the family’s Princeton home in June.

Fundraiser for Jaime

- ▶ **What:** Jammin’ 4 Jaime! — a benefit dinner for Jaime Russell-Polhemus.
- ▶ **When:** Starts at 4:30 p.m., Aug. 8. Live music begins at 7:30.
- ▶ **Where:** Right Downtown Banquet & Event Center (under Fitzgerald’s), 432 S. Main St., Princeton.
- ▶ **Tickets:** \$15 for adults, \$7 for children 4-10, free for children 3 and younger. Available at Fitzgerald’s and Guys & Gals in Princeton, or by calling (815) 409-1126. The menu includes LaGondola spaghetti, salad, bread, Rip’s chicken

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and desert by Mark Allen's. There will also be a cash bar and a silent auction. Live music by Rodeo Drive & Double Dave's Trio.

► **Information:** Visit <http://hope4sps.com> and www.facebook.com/hope4sps.

► **Donations:** To donate, online visit www.gofundme.com/jaime-polhemus.

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