



GreeleyTribune



Clinical trial involving stem cells gives Greeley man chance for normal life

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Caleb Jackson sits with his dog, Blue Eyes, on Tuesday at their home in west Greeley. Jackson has slowly been recovering after he became the 60th person in the world to receive a chemotherapy and bone marrow transplant as part of a clinical trial. He received the transplant after being diagnosed with chronic inflammatory demyelinating polyneuropathy, an autoimmune disease that causes the immune system to attack its own nerves.

Joshua Polson/jpolson@greeleytribune.com | The Greeley Tribune

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DR. RICHARD BURT'S CLINICAL TRIALS

A clinical trial for patients with severe autoimmune diseases is still recruiting candidates for treatment.

Dr. Richard Burt and his team at the Division of Immunotherapy and Autoimmune Diseases at Northwestern University are the only ones in the world treating patients with chemotherapy and an injection of their own stem cells that have been modified by Dr. Burt and his team.

Caleb Jackson had two goals for 2014: Get chemotherapy and buy a home.

“People don’t usually beg insurance companies, ‘Give me chemo,’ ” said Jackson, 24. “But I did.”

A Greeley resident and recent graduate of the University of Northern Colorado, Jackson is the 60th person in the world to receive chemotherapy and a bone marrow transplant as part of a clinical trial after being diagnosed with chronic inflammatory demyelinating polyneuropathy at age 22. CIDP is an autoimmune disease that causes Jackson’s immune system to attack his own nerves.

He can list the dates associated with his journey to chemo off the top of his head.

“I think it’s a new future for treating these diseases,” Burt said. “It’s showing results no other treatment has.”

Burt and his team have treated patients from all 50 states, and many from other countries, as well, and will publish a paper on its treatment of patients with Multiple Sclerosis this month.

“I think it’ll be a game-changer for MS,” Burt said. “It takes a lot of time and a lot of persistence, but it is changing the world.”

The team is currently recruiting patients with the following autoimmune disorders:

Autoimmune bullous skin disorders

Autoimmune-Related Retinopathy and Optic Neuropathy

Chronic Inflammatory Demylinating Polyneuropathy

Chrohn’s Disease

Devic’s Disease

Idiopathic Inflammatory Myopathy diseases

Leukocyte Adhesion Deficiency Type I

Morphea

Multiple Sclerosis

Myasthenia Gravis

Primary Biliary Cirrhosis

His leg began to drag on Sept. 14, 2012.

He couldn’t pick up a 10-pound bowling ball on Sept. 26, 2012.

He couldn’t unscrew the cap on his toothpaste or turn the key in his car on Oct. 1, 2012.

He was diagnosed on Oct. 29, 2012.

There’s no cure for CIDP, which is diagnosed in an estimated one in 1 million patients every year. When he received the diagnosis, doctors told him he’d eventually be completely paralyzed.

“THAT’S WHY I LOOKED INTO SOMETHING DIFFERENT BECAUSE THAT WAS NOT AN OPTION,” JACKSON SAID FROM HIS KITCHEN, WITH HIS 3-YEAR-OLD DOG, BLUE EYES, LAPPING AT HIS HAND. “WHEN LIFE GIVES YOU LEMONS LIKE THAT, I THINK YOU HAVE TO PUSH THEM AWAY.”

AT FIRST, THE DIAGNOSIS WAS A RELIEF. JACKSON’S BODY WAS WITHERING AWAY, AND HE HAD NO REASON FOR IT. THE STANDARD TREATMENTS FOR HIS DISEASE WORKED, AS WELL: HE BEGAN RECEIVING IMMUNOGLOBULIN INJECTIONS IN NOVEMBER 2012, ESSENTIALLY GETTING THE ANTIBODIES OF OTHER PEOPLE’S BLOOD.

But a relapse in the first quarter of 2013 left him in even worse shape, in both body and mind. The injections stopped working, and Jackson was plunged back into a pit of anxiety.

“I was depressed,” Jackson said. “I didn’t have any focus to do anything. I couldn’t do schoolwork. I couldn’t focus on anything at all.”

Resigned to his fate, he started watching YouTube videos of people with CIDP with a dark curiosity of what his life would be like in the coming decades. Rather than add to his depression, he found a flash of hope. There was a comment on one of the videos, something about a clinical trial for people with autoimmune disorders being conducted at a university. The trial had a chance to effectively cure his illness, using a treatment normally reserved for those in leukemia.

Pulmonary Fibrosis

Rheumatoid Arthritis

Sarcoidosis

Scleroderma

Systemic Lupus Erythematosus

Systemic Necrotizing Vasculitis

Type I Diabetes

Umbilical cord blood stem cell injection for Critical Limb Ischemia

To learn more about the trials, go to [Dr. Burt's website](#). To learn about how to get in contact with Dr. Burt and his team of doctors, go to [this federal website](#) and search for his trial.

“When you first read it, it’s too good to be true,” Jackson said. “This is a chronic disorder. It’s there, and it’s not going away. But when you eliminate the immune system, you decide who is boss.”

It turns out Dr. Richard Burt at the Northwestern University Feinberg School of Medicine in Chicago noticed about 30 years ago that leukemia patients’ immune systems would lose all memories of their ability to fight diseases after the patients received chemotherapy and bone marrow transplants, including diseases for which they had been vaccinated as children.

Burt said it made sense, then, that such procedures would effectively reset the immune systems of people with autoimmune disorders, including CIDP.

“We knew this would work,” Burt said, “but we knew we would have to modify the procedure for autoimmune diseases.”

After more than 10 years of testing the procedures on animals with autoimmune disorders, and after getting the go-ahead from the Food and Drug Administration and other agencies, Burt began a clinical trial in 2005. The trial’s conclusion is expected in December of this year, and the results are scheduled to appear in December 2016.

Because traditional treatment failed Jackson, participation in Burt’s trial represented his only chance to live a normal life. He reached out to Burt and was told he was a good candidate for the trial, especially because he had a definitive diagnosis of CIDP.

Jackson applied and was accepted. Everything seemed to be falling into place.

“Then began the insurance battles,” he said.

‘YOU HAVE TO FIGHT AND FIGHT AND FIGHT’

Jackson applied to both of his medical insurance companies in May 2013 to determine if they would cover the chemotherapy and bone marrow transplant. Right away, he was discouraged.

Under the Affordable Care Act passed by Congress in 2010, insurance companies are required to pay for procedures that are part of a clinical trial if the patient has cancer or any disease considered life-threatening. Because CIDP isn’t on that list, Jackson’s insurance wasn’t required to cover the bone marrow transplant he was requesting.

“It’s hard to get insurance to pay for something when it has the words ‘clinical trial’ attached to it,” Jackson said. “Plus, insurance doesn’t typically classify CIDP as a life-threatening condition, even though it threatens

everything about your life. You know, being bed-ridden? That to me is your life right there.”

Both of the companies that insure Jackson refused to cover the procedure.

From the companies’ standpoint, the trial represented a \$200,000 experimental treatment with no guarantee of success.

But to Jackson, and even to Burt, the trial is a bargain for the insurance companies. The globulin injections Jackson was receiving cost \$36,000 apiece, and he was receiving them every three weeks. Jackson’s insurance company was therefore paying more than \$600,000 per year for the injection treatments, which had stopped working for Jackson anyway.

In contrast, the clinical trial would constitute a one-time payment, at a third of the cost, without any need for future treatments. At least that was the idea.

“It’s an incredible win-win,” said Burt.

And yet, Burt said many of the patients who apply for the trial face the same battle with their insurance companies. Sure enough, Jackson appealed the decisions, and was told no again by both companies.

“Then you have the right to talk to a committee of medical doctors that don’t work for the insurance company, and they can make a final ruling,” Jackson said.

He argued his case in front of the panel, his hands and voice quivering as he explained to the doctors the opportunity for a normal life.

He went to work afterward. Later that day, he received a call from the panel informing him his secondary insurance would cover the procedure.

“I typically don’t answer my cell phone at work, but that day I answered it because I needed to know the answer,” Jackson said. “I had a huge smile all day.”

It took 18 months from the time Jackson applied to the time he was informed he would be covered, but he said never doubted he would succeed in the end.

“You have to fight and fight and fight,” he said. “I was really confident that I just had to get to the point where people could make a real, common-headed decision, and that they would make the right decision. It just takes time to get there.”

‘A LIFETIME OF FREEDOM’

With a green light from his insurance company, Jackson trekked to Chicago to begin chemotherapy. His stay in the hospital began in December. Once he began the treatment, he was forced into isolation for 17 days while his blood cell count returned to normal levels.

The days passed slowly for Jackson as he watched the cloudy Chicago winter cast a pall on the skyline outside his window. He had to put on a mask and gloves just to leave his room. Doctors allowed him only a few slow circles around half of the hospital floor.

His mother stayed with a friend and made sure to visit Jackson every day. She had to spend a good five minutes scrubbing her hands and arms with soap every time she wanted to enter her son's room, let alone hold his hand. His sister and brother visited as well.

He would occasionally read Facebook and Twitter messages of solidarity from friends and family, but the nausea that accompanies chemo drugs left him thankful visitors were few and far between.

"There's also this thing called chemo brain," he said. "It's just a fog. You can't really focus on anything at all."

The fog is still dissipating; Jackson said his appetite is slowly returning and he feels better every day. He began physical therapy Wednesday, where he learned of the path he'll need to take to gain his strength back.

He's read some blog posts from others who have taken part in the clinical trial, and he agrees with them that while he's glad he decided to go through with it, he wouldn't want to do it again.

"If I can achieve a lifetime without getting treatment every three weeks and without the idea that I'm going to be bed-ridden some day, if I can live the rest of my life with that confidence and that quality of life, it's definitely worth doing it once," Jackson said. "You'll undergo six weeks of heck for a lifetime of freedom."

His last injection of immunoglobulin was Dec. 1, and he said he passed the three-week benchmark without needing another injection. He plans to return to work Jan. 19, about a month after being released from the hospital.

For now, Jackson is happy doting around his house with Blue Eyes and Sadie Mae, a 10-year-old Labrador Retriever, at his heels.

"Right now I'm in relaxing mode," he said. "Readjusting out of the hospital is kind of a weird transition."

He'll return to Chicago in about six months so doctors can evaluate whether his nerves are regenerating. There will be a second check-up in about a year.

If everything looks good and his strength begins to return — as he expects it will — Jackson said he looks forward to living life again.

"I want to hike more," he said. "I've never done a 14er. I just want to get out and live more."

As for the goals he set for 2014, Jackson accomplished the most important one.

"I got the chemo," he said, "so this year I'll buy a house."