MedicalXpress

Stem cell therapy combats a one-in-a-million immune disorder for 4-year-old boy

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If it weren't for the wheeled IV stand that squeaks behind him as he moves, Jovon Moss might seem like any other 4-year-old boy.

Wearing a tot-sized costume modeled after the comic book character, The Flash, he races through the Sylvester Comprehensive Cancer Center clinic so quickly that nurses have to make sure he doesn't trip on the tube administering his twice-monthly immunoglobulin drip. He regularly swipes his mother's iPhone to watch YouTube videos during his treatment, yet is so eager to share his Scooby Doo gummy treats that his toothy smile disappears if someone says no thanks.

Just six months ago, Jovon hovered near death, diagnosed with a rare immune disorder that had bounced him in and out of the hospital since his third birthday. His symptoms had ballooned from flu-like coughs and tiredness into seizures and a tumor blocking half his airway. Doctors at UHealth would find Jovon had cancer - stage 2 lymphoma - connected to X-linked lymphoproliferative syndrome, a literally one-in-a-million genetic disorder that made him vulnerable to certain infections.

"That's the reason he got all of this," said Gary Kleiner, Jovon's physician and a pediatric immunologist at Sylvester.

Now, thanks to chemotherapy and a new stem cell treatment, Jovon is on the mend, his mother Brittany Fluellen said.

Jovon's year-long journey started last September, when his mother first

noticed he was coughing and feeling tired. She took him to the hospital, where doctors said it was likely he just had a virus.

But the virus didn't go away. It got worse.

His mother took him back to a hospital a week later, and he was hospitalized in the ICU with Epstein-Barr virus, commonly known as mono. He spent weeks in a coma and began suffering seizures. Fluellen remembered the first time she woke up to see Jovon's tiny 3-year-old body shaking in the hospital bed. She ran into the hallway, screaming for help.

"Then, he couldn't breathe. He was intubated twice," she said.

Jovon eventually recovered enough that he was discharged in November after three weeks of rehab, though he didn't seem that much better to his mom. His urine was still a murky brown, and he seemed lethargic, she noticed.

What she didn't know then was that Jovon's genetic disorder - yet undetected - meant his body's immune system couldn't correctly respond to the Epstein-Barr virus that would otherwise remain latent. Jovon kept losing weight. He developed pneumonia. Usually brimming with energy, the toddler began sleeping constantly.

"He was just staring off into space; he wouldn't focus his eyes on anything," she said.

Jovon re-entered the hospital to treat his pneumonia in January, but it wasn't until the end of March, when his symptoms worsened considerably, that he was admitted to Jackson Memorial Hospital for a possible immune disorder. By then, the boy's weight had plummeted to 20 pounds, Fluellen said. He couldn't walk, eat or talk. She feared she

might lose her only son before he got to kindergarten.

The doctors at other hospitals had done some immune tests, but Jovon's visit in the spring of 2017, which showed he had the mono virus in his blood again, finally gave Fluellen's fear a name: X-linked lymphoproliferative disease, or XLP. His lymph nodes were so enlarged Fluellen noticed the swelling, and doctors found he had a tumor in his neck so large it was blocking half of his air pipe.

Jovon and his family had an appointment at the Sylvester Comprehensive Cancer Center scheduled that May. Jovon's dire condition bumped them up the list.

At Sylvester's pediatric clinic, named Alex's Place, Jovon was quickly put on a four-month chemotherapy regimen to treat the tumor. Kleiner successfully requested permission from the FDA to try a new stem cell treatment on Jovon, intended to replenish his supply of T cells, which help fight infection. By the time his main chemotherapy had ended in August, Fluellen said, her son had started to gain weight again and return to his normal, rambunctious self.

Jovon's renewing health was clear this week, when just in time for Halloween, he was zooming around the floor during his immunoglobulin therapy in his appropriately speedy Flash costume. Nurses trailed behind him so his IV stand, tethered to the port still implanted in his left chest, wouldn't get tangled in his own legs as he scrambled around.

He had to remain hooked up to the immunoglobulin drip for just over three hours, so nurses distracted him by handing him a tiny pumpkin to paint and decorate with Elmer's Glue and foam stars.

The next step in his treatment, Kleiner said, is a bone marrow transplant, which doctors hope to complete in the next month. The infusion acts as

"a bridge to transplant," he added.

After that, Fluellen hopes, Jovon will recover enough that the regular hospital visits will eventually become a thing of the past.

She said she looks forward to when Jovon won't have to wear hospital bracelets on each wrist, like the ones that poked out under the red cuffs of his superhero costume as he bounced from the desk where he was painting his pumpkin to his mother's side.

"I still cry seeing him now," Fluellen said, as she bounced him on her lap. "We'll be glad when it's over soon."