

Blood Donors Quietly Revolutionizing Sickle Cell Treatment

(NAPS)—For Jimi Olaghere, sickle cell disease once meant a life of limitations, sudden pain episodes and frequent hospitalizations. Today, thanks to groundbreaking gene therapy and blood donors, he is reaching new heights.

"I don't think I would have had the opportunity to have a gene-editing transplant without blood donations," said Olaghere.

Complications of Sickle Cell Disease

Prior to gene therapy, Olaghere's life was consumed by severe health complications caused by sickle cell disease—the most common genetic blood disease in the U.S. He experienced acute chest syndrome, pneumonia, avascular necrosis, lung damage, and more. Once, he suffered cardiac arrest due to not receiving a preventative blood transfusion before a minor surgery.

"Sickle cell was like a dream killer for me," said Olaghere. "I like to equate it to a succession of time bombs in terms of what it feels like living with sickle cell and having all these complications."

Newfound Hope

In 2019, hope appeared when Olaghere discovered a news article detailing how gene therapy could be used to boost fetal hemoglobin production in patients with sickle cell disease, potentially reducing symptoms.

Inspired to have a better quality of life, Olaghere signed up to participate in a CRISPR gene-editing clinical trial under the care of Dr. Haydar Frangoul at Sarah Cannon Research Institute.

"When we went with Dr. Frangoul's team, it was like when Dorothy goes into Oz and all of a sudden everything turns from black and white to color," said Amanda Olaghere, Jimi Olaghere's wife. "To finally have somebody listening to us and hearing us...it was a relief to know that while we were fighting our fight in the dark, somebody else was doing good work behind the scenes."

For a year, Olaghere underwent the gene therapy process. Before treatment, he had bi-weekly red blood cell exchanges—a non-surgical procedure that replaces abnormal red blood cells with healthy ones from blood donors to keep him well throughout the trial. During the first phase, in which his blood stem cells were collected and sent to a lab for genetic editing, he had whole blood transfusions after each collection. Post chemotherapy, patients may need platelet donations to increase their platelet levels before getting the edited stem cells.



Jimi Olaghere and his wife, Amanda, are grateful for blood donors who helped save his life and enabled him to complete gene therapy to treat his sickle cell disease.

"I received about 20 to 30 units of blood in total," said Jimi Olaghere, who has had over 200 blood transfusions throughout the course of his life.

Since he completed gene therapy, Jimi Olaghere's life has transformed. He no longer experiences sickle cell pain crises requiring transfusions. His energy has skyrocketed, allowing him to manage work and family life in ways he never imagined.

He and his wife now have three children and have transitioned from a life of "Netflix and chill" to one filled with swim lessons, travel, and constant activity. Recently, Jimi Olaghere hiked a 14,000-foot mountain in Colorado, preparing to climb Mount Kilimanjaro to raise awareness for sickle cell disease.

"It kind of feels like I'm living my dream, but at the same time I'm still able to go after things I've always dreamed of that I haven't been able to attain because of my disease," he explained.

"What I would say to the blood donors who helped Jimi through this process is 'we could not be here without you," said Amanda Olaghere. "Our story is your story."

What You Can Do

Blood and platelet donations are vital for people with sickle disease getting gene therapies and stem cell transplants as well as those in need of regular blood transfusions to alleviate pain and help manage their disease.

A patient undergoing gene therapy for sickle cell disease may need as many as 50 units of blood and up to 25 units of platelets.

To schedule a blood donation appointment, visit RedCrossBlood.org/ OurBlood or call 1-800-RED-CROSS (1-800-733-2767).