

‘There is no sound I don’t like’ — In gene editing breakthrough, Lilly’s 30-day gene therapy restores hearing of 11-year old boy, with more deafness treatments on the way

Aissam Dam, an 11-year-old boy, grew up in a world of profound silence. He was born deaf and had never heard anything. While living in a poor community in Morocco, he expressed himself with a sign language he invented and had no schooling.

Last year, after moving to Spain, his family took him to a hearing specialist, who made a surprising suggestion: Aissam might be eligible for a clinical trial using gene therapy.

On Oct. 4, Aissam was treated at the Children’s Hospital of Philadelphia, becoming the first person to get gene therapy in the United States for congenital deafness.

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The treatment was a success, introducing a child who had known nothing of sound to a new world.

“There’s no sound I don’t like,” Aissam said, with the help of interpreters during an interview [recently]. “They’re all good.”

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The goal of the gene therapy is to replace the mutated otoferlin gene in patients’ ears with a functional gene.

Although it will take years for doctors to sign up many more patients — and younger ones — to further test the therapy, researchers said that success for patients like Aissam could lead to gene therapies that target other forms of congenital deafness.

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