'Miracle' sickle cell cure limits ability to have children: What are the options?

When Celenise Mahmood first learned about two new gene therapies that could cure sickle cell disease, she felt a wave of relief.

Her 9-year-old son, Navid, has the inherited blood disorder. By age 5, he'd had over 30 life-saving blood transfusions. He has also lost hearing in his left ear. Though he's too young to get the treatments now — eligible patients must be 12 or older — Celenise began to imagine a brighter future for him.

But then she learned about a significant drawback: Patients who undergo the therapies must take a toxic drug that can leave them infertile. Unless they're able to freeze their reproductive cells, a costly proposition, they're forced to choose between freedom from a painful lifelong condition and having children someday.

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Now, under a new plan from the Biden administration, many people with the blood disorder would no longer face that difficult decision.

The main goal of the plan, which was announced <u>in January</u>, is to help states pay for gene therapies, which have steep prices that can strain limited state budgets. But it also requires drugmakers to pay for <u>fertility</u> preservation services for people on Medicaid who get their treatments.

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A Vertex spokeswoman said it's "working with urgency" to provide fertility services for government-insured patients that get its treatment, "with the goal of providing equal support for all patients regardless of insurance."

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