

**HFS**Illinois Department of  
Healthcare and Family Services

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## Illinois announces participation in federal Cell & Gene Therapy Access Model for Sickle Cell Disease treatment

Following Sickle Cell Disease Awareness Month, the initial focus of the model will increase access to gene therapy treatments for people living with Sickle Cell Disease

**FOR IMMEDIATE RELEASE:**  
**Oct. 1, 2025**

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Illinois has been selected to participate in a federal model that will increase access to potentially transformative treatments for people living with rare and severe diseases, advancing the work already underway in the state's Medicaid program. The Illinois Department of Healthcare and Family Services (HFS) was accepted into the federal Cell and Gene Therapy (CGT) Access Model, a multi-year agreement among states and drug manufacturers to increase Medicaid beneficiaries' access to treatments. Illinois is expected to be awarded up to \$9.55 million in federal dollars over the course of 10.5 years to support Illinois' implementation of the model, including screenings, referrals and wraparound support services, with the ultimate goal of directly resolving documented barriers to care. 84% of the total model administrative operating costs are federally funded, and the remaining 16% of costs will be funded by the state – up to approximately \$1.8 million.

“In Illinois, we're focused on supporting access to healthcare for the people of our state,” **said Governor JB Pritzker**. “As Illinois continues its efforts to make healthcare systems more equitable and affordable through state initiatives, our participation in this model will further support that mission. With access to more services and cutting-edge gene therapy treatments, people living with Sickle Cell Disease in Illinois will have better access to potentially life-changing care.”

“Participation in the federal CGT Access Model will be a key part of ensuring Illinois Medicaid customers can access these groundbreaking treatments,” **said HFS Director**

**Elizabeth M. Whitehorn.** “We are proud to have also received a grant award to be able to better serve our customers who are eligible for these transformative treatments by supporting them through this journey.”

Illinois is one of 33 states that will be participating in the model, along with the District of Columbia and Puerto Rico. This work will focus on increasing Medicaid beneficiaries’ access to emerging and innovative treatments, thereby improving health outcomes, and reducing health care costs to state Medicaid programs. While cell and gene therapies are showing incredible promise for halting disease progression and correcting underlying disease causes, they also come at a high cost. This model marks the first time the federal government has negotiated an outcomes-based agreement with manufacturers on behalf of state Medicaid agencies, with the goal of mitigating cost barriers to access. Additionally, participation will further the Pritzker Administration’s efforts to promote health equity for all Illinoisans, as Sickle Cell Disease is a genetic blood disorder that most commonly impacts Black people and other minority populations.

Many patients battling rare diseases face significant challenges to accessing available care, including specialized provider access and other logistical and financial barriers. Participation in this model is part of HFS’ strategy to begin addressing those challenges for Illinois residents more directly. Care will be provided in partnership with hospital systems both in Illinois and neighboring states. States participating in the model must ensure that participants have access to at least one gene therapy provider either in-state or out of state.

The initial focus of the model is on access to gene therapy treatments for people living with Sickle Cell Disease, and the participation announcement follows Sickle Cell Disease Awareness Month in September. Two manufacturers are taking part, Vertex Pharmaceuticals and Genetix Biotherapeutics. As part of the federal model, both manufacturers will pay for patient fertility preservation services. Through Medicaid and federal grant funding, participants will also have access to other wraparound and support services while undergoing treatment, including travel expenses for care.

The funding will also support state implementation, as well as additional patient support services and research funding, through a partnership with a community-based organization – the Sickle Cell Disease Association of Illinois (SCDAI). The funding will go toward expanded patient support work through SCDAI. The model also provides a framework that Illinois can build on long term to prioritize access to advanced therapies

and improved outcomes using outcome-based agreements, while managing financial strain on state budgets.

“At the Sickle Cell Disease Association of Illinois (SCDAI), we believe that every advancement in care must be met with equal dedication to equity, access, and community support,” **said Sickle Cell Disease Association of Illinois Executive Director TaLana Hughes.** “This groundbreaking model is more than just a pathway to gene therapy—it’s a promise to uplift individuals and families living with sickle cell disease by removing barriers and surrounding them with the wraparound services they deserve. SCDAI is honored to stand at the heart of this effort, ensuring that hope, healing, and opportunity reach every corner of our community. Together, we are not only changing treatments—we are changing lives.”

Illinois’ participation is also an advancement of the work of the Advisory Council on Financing and Access to Sickle Cell Disease Treatment and other High-Cost Drugs and Treatment, which was established via [executive order](#) signed by Gov. Pritzker in 2024. The advisory council submitted its recommendations [report](#) to the Governor and the General Assembly earlier this year, which included 23 recommendations for financing and increasing equitable access for these types of treatments in Illinois. One of the Council’s recommendations was to evaluate the federal CGT Access Model to determine whether participation would provide cost and access benefits.

Additional information about the CGT Access Model can be found on the federal Centers for Medicare & Medicaid Services [website](#).

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