Human Services Committee
JOINT FAVORABLE REPORT

Bill No.: SB-1473
Title: AN ACT REQUIRING MEDICAID COVERAGE FOR FDA-APPROVED GENE THERAPIES TO TREAT SICKLE CELL DISEASE.
Vote Date: 3/14/2025
Vote Action: Joint Favorable
PH Date: 3/11/2025
File No.: 384

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SPONSORS OF BILL:

Human Services Committee

CO-SPONSORS OF BILL:

Rep. Sarah Keitt, 134th Dist.
Sen. Saud Anwar, 3rd Dist.
Sen. Patricia Billie Miller, 27th Dist.
Sen. Joan V. Hartley, 15th Dist.

REASONS FOR BILL:

This bill aims to expand Medicaid coverage for gene therapies needed to treat sickle cell disease. Therapies of this nature are costly and are not always affordable and accessible to patients diagnosed with Sickle Cell Disease. This bill will help improve both the cost-effectiveness and affordability to Medicaid recipients who need treatment for Sickle Cell Disease.

RESPONSE FROM ADMINISTRATION/AGENCY:

Connecticut Department of Social Services (DSS), Andrea Barton Reeves, Commissioner **:** does not oppose the bill but does not deem it necessary. The Medicaid program is required to cover FDA-approved treatments from pharmaceutical manufacturers, which includes gene therapies for Sickle Cell Disease. Additionally, the Department of Social Services applied for the Cell and Gene Therapy Access Model. Through this, the state can participate in federally negotiated prices for two FDA-approved gene therapies for Sickle Cell Disease. For these reasons, the bill is not completely necessary but also is not opposed.

Commission on Women, Children, Seniors, Equity and Opportunity (CWCSEO), Michael Werner, Lead Aging Policy Analyst: expresses their full support of this bill. Werner states that this bill is crucial to improving accessibility, all while acknowledging how Sickle Cell Disease disproportionately affects African Americans. The two FDA-approved treatments that have been introduced include Casgevy and Lyfgenia. Both treatments are durable and offer curative benefits that can help patients live long, healthy lives. Currently, there is an existing model called "Cell and Gene Therapy Access Model," which enables states to enter outcome-based agreements with therapy manufacturers. This would result in payments being linked to the various patient health outcomes. This bill would allow for Connecticut to both manage costs while improving patient access. Sickle Cell Disease treatments remain both unaffordable and inaccessible, which exacerbates existing health disparities. As a result, the CWCSEO expresses their full support for the bill.

NATURE AND SOURCES OF SUPPORT:

Connecticut Children's Medical Center, Donna Boruchov, MD, Pediatric Hematologist Oncologist**:** supports the bill given the nature of the population with whom she works. Gene therapy used for Sickle Cell Disease is an incredibly valuable tool to help diagnosed individuals live a healthy life. The disease is serious and devastating in nature, and there are now curative treatments out there that are exciting to be able to access. Treatment cost is exponentially high, and the cost to the healthcare system for ongoing and prolonged treatment is quite significant. It is stated, if the state were to support gene therapy being covered by Medicaid it would ultimately lead to significant savings for the state in the long-run by reducing repeated hospitalizations and continuing treatments.

Connecticut Rare Disease Advisory Council (RDAC), Lesley Bennett, Co-Chair**:** the Connecticut Rare Disease Advisory Council, expresses full support for the bill. Bennett encourages the Department of Social Services to apply for the Cell and Gene Therapy Access Model as soon as possible. She states how there are many innovative therapies that can target the underlying cause of the disease while also stopping the disease from progressing. These therapies could also lead to a cure. However, the astronomical cost of the therapy makes it difficult for both insurers and state programs to pay for these innovative, life-changing treatments. The Cell and Gene Therapy Access Model will allow CMS to negotiate with manufacturers for a payment system that is based on outcome-based agreements. Through negotiating lower prices and connecting Medicaid payments to patient outcomes, access to these therapies will be improved. Thereby, the RDAC expresses their full support for the bill.

Connecticut Rare Disease Advisory Council (RDAC), Mary Caruso, Member: fully supports the bill. She states that Sickle Cell Disease is a debilitating, life-threatening condition that disproportionately affects marginalized communities. Access and affordability remain significant barriers for patients with Sickle Cell Disease. She believes the bill will help reduce suffering and improve quality of life, all while improving cost-effectiveness regarding

emergency interventions. She urges the committee to support the bill to promote equitable access to life-saving treatments.

NATURE AND SOURCES OF OPPOSITION:

None expressed.

Reported by: Ayesha Middya **Date: April 3, 2025**