

SESSION OF 2023

**SUPPLEMENTAL NOTE ON HOUSE BILL NO. 2338**

As Amended by Senate Committee on Public  
Health and Welfare

**Brief\***

HB 2338, as amended, would designate Sickle Cell Disease Awareness Week as the third full week of September and encourage Kansans to observe the week to raise awareness of sickle cell disease and efforts to improve treatment options for patients.

The bill would state sickle cell disease is a genetic disease in which a person's body produces abnormally shaped red blood cells that resemble a crescent and do not last as long as normal, round red blood cells, leading to anemia.

**Background**

The bill was introduced by the House Committee on Health and Human Services at the request of Representative Clifford on behalf of Vertex Pharmaceuticals.

***House Committee on Health and Human Services***

In the House Committee on Health and Human Services hearing on February 20, 2023, **proponent** testimony was provided by a representative of the Uriel E. Owens Sickle Cell Disease Association of the Midwest who described the disease and how this bill would assist those who have this disease. A representative of the Kansas Department of Health

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\*Supplemental notes are prepared by the Legislative Research Department and do not express legislative intent. The supplemental note and fiscal note for this bill may be accessed on the Internet at <http://www.kslegislature.org>

and Environment (KDHE), Bureau of Family Health, provided written-only proponent testimony.

No other testimony was provided.

***Senate Committee on Public Health and Welfare***

In the Senate Committee hearing on March 14, 2023, **proponent** testimony was heard from a representative of the Uriel E. Owens Sickle Cell Disease Association of the Midwest who testified that this bill would provide awareness of the disease to the public and trait carriers.

Written-only proponent testimony was received from a representative of KDHE.

No other testimony was provided.

The Senate Committee amended the bill to:

- Remove the requirement for an annual review of the topic by the advisory council established by the Secretary of Health and Environment (Secretary) to advise KDHE on newborn screening guidelines;
- Remove the requirement the advisory council, during one regularly scheduled meeting each calendar year, devote time to:
  - Discuss and evaluate the adequacy of available covered medications, treatments, and services to meet the needs of those individuals with a sickle cell disease diagnosis;
  - Review treatment information on late-stage studies from peer-reviewed medical literature; and
  - Review the importance of health care provider education on the disproportionate impact of

sickle cell disease on specific minority populations; and

- Remove the authorization for KDHE, under the guidance of any appropriate advisory council as directed by the Secretary, to develop a publicly available report from the advisory council meetings and activities; and
- Remove the authorization for KDHE to request expert testimony or input in the development of the report and any report and solicited testimony or input to be compiled and published on KDHE's website.

### **Fiscal Information**

According to the fiscal note prepared by the Division of the Budget on the bill, as introduced, KDHE indicates any costs associated with the activities outlined in the bill would be absorbed within existing program functions and resources.

Any fiscal effect associated with enactment of the bill is not reflected in *The FY 2024 Governor's Budget Report*.

Sickle Cell Disease; anemia; Sickle Cell Awareness Week; Kansas Department of Health and Environment