

SESSION OF 2023

SUPPLEMENTAL NOTE ON HOUSE BILL NO. 2338

As Recommended by House Committee on
Health and Human Services

Brief*

HB 2338 would designate Sickle Cell Disease Awareness Week as the third full week of September and would require an annual review of the topic by an advisory council established by the Secretary of Health and Environment (Secretary) to advise the Department of Health and Environment on newborn screening guidelines.

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.

The bill would require the advisory council, during one regularly scheduled meeting each calendar year, 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.

*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>

The bill would authorize the Kansas Department of Health and Environment (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. The bill would authorize 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.

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 KDHE Bureau of Family Health provided written-only proponent testimony.

No other testimony was provided.

Fiscal Information

According to the fiscal note on the bill prepared by the Division of the Budget, 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