

**Proponent Testimony on HB 2338
Public Health and Welfare Committee
Alyson Dalrymple, Deputy Director for the Bureau of Family Health
KDHE Bureau of Family Health
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Chairwoman Gossage and members of the Committee, thank you for the opportunity to provide written testimony in support of HB 2338. My name is Alyson Dalrymple and I am the Bureau of Family Health Deputy Director, which oversees the Kansas Newborn Screening programs. HB 2338 would designate the third full week of September each year to Sickle Cell Disease awareness and require that the department study and report on topics related to sickle cell disease. The Kansas Newborn Screening Blood Spot program currently screens for 32 heritable conditions, including sickle cell disease and other hemoglobin diseases. In the last 10 years, of all diagnosed hemoglobinopathy cases identified by the Kansas Newborn Screening program, 71% had sickle cell disease. An average of 6 children born in Kansas each year are diagnosed with sickle cell disease. In the last four years, that represents 7% of all children diagnosed with a condition screened for by the program.

The Newborn Screening Program has an active Advisory Council that meets at least twice annually to review program performance and effectiveness and make recommendations for improving the program. The Kansas Advisory Council for Newborn Screening (KACNS) has standing committees for clinical conditions, including hemoglobinopathies, which assist in carrying out the duties of the council. A key indicator for our newborn screening programs is our Lost to Follow-up (LFU) numbers. This measure indicates the number of babies that do not have a conclusion reported in their file, within a given timeframe, when follow-up activities were initiated. An analysis of newborn screening data showed that hemoglobinopathies represent a significant proportion of the LFU population. This highlights the need for intentional program efforts to understand the gaps that exist within the program related to this disorder.

HB 2338 would ensure that the Kansas Newborn Screening Blood Spot program, advisory council and the hemoglobinopathy committee intentionally review the state of sickle cell disease, treatments options, and provider knowledge.

Thank you for this opportunity to provide testimony.

Alyson Dalrymple
Deputy Director for the Bureau of Family Health