

HCS HB 1387 -- PUBLIC HEALTH (Roeber)

COMMITTEE OF ORIGIN: Standing Committee on Health and Mental Health Policy

This bill establishes within the Department of Health and Senior Services the Sickle Cell Standing Committee as a subcommittee of the Missouri Genetic Advisory Committee to assess the impact of sickle cell disease on urban communities, examine the existing services and resources and develop recommendations for educational services to schools.

The committee chair must be a licensed physician with experience in the diagnosis and treatment of sickle cell disease. The remaining members include someone who has or is a family member of someone who has sickle cell disease, an expert in sickle cell disease research, someone from a leading sickle cell disease organization, an expert in minority health, and someone from each hemoglobinopathy center contracted with the department.

A report of the findings and any recommendations by the committee must be submitted to the Governor and General Assembly by December 31, 2017. The committee must continue to meet at the request of the chair and at least once each year and submit an annual supplemental report.

The bill requires the Department of Health and Senior Services, subject to appropriations, to add severe combined immunodeficiency (SCID), also known as the bubble boy disease to the list of newborn screening requirements.

The bill contains an emergency clause.

This bill is similar to HB 1315 (2015) and HB 86 (2015).