

HCS HB 1745 -- SICKLE CELL STANDING COMMITTEE

SPONSOR: Walton Gray

COMMITTEE ACTION: Voted "Do Pass by Consent" by the Committee on Health Care Policy by a vote of 10 to 0.

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 to address the needs of people with the disease, and develop recommendations for educational services to schools on the traits of the disease and their effects.

The committee will consist of one member who is a licensed physician with experience in the diagnosis and treatment of sickle cell disease and who must serve as chair of the committee, one member who has sickle cell disease or is a family member of someone with sickle cell disease, one member with expertise in sickle cell disease research, one member from a leading sickle cell disease organization, one member with expertise in minority health, and one member from each of the hemoglobinopathy centers which contract with the department.

The committee must meet in at least three urban regions of the state to seek public input and to examine trends in the state sickle cell disease populations and their needs, existing services and resources, needed state policies or responses, and the replacement of the genetic testing and counseling program which has been eliminated due to lack of funding. A report of the findings and any recommendations by the committee must be submitted to the Governor and General Assembly by December 31, 2015. The committee must continue to meet at the request of the chair and at least once each year after that date and submit an annual supplemental report.

PROPONENTS: Supporters say that the bill establishes a subcommittee to study and make recommendations regarding sickle cell disease and the impact it has on urban communities. Sickle cell anemia has no cure and is an inherited disease that is common among minorities and has devastating repercussions.

Testifying for the bill were Representative Walton Gray; Missouri Centers for Independent Living; St. Louis Children's Hospital; and Wayne Lee.

OPPONENTS: There was no opposition voiced to the committee.

OTHERS: Others testifying on the bill say this is a current

subcommittee and the bill merely codifies what exists now. It is beneficial to add the subcommittee into statute because if the subcommittee is not in law it does not have to remain.

Testifying on the bill was the Department of Health and Senior Services.