HCS HB 2658 -- SICKLE CELL AWARENESS WEEK

SPONSOR: Dogan

COMMITTEE ACTION: Voted "Do Pass with HCS" by the Standing Committee on Health and Mental Health Policy by a vote of 12 to 0.

The following is a summary of the House Committee Substitute for HB 2658.

This bill designates the third full week of September of each year as "Sickle Cell Awareness Week".

This bill also requires the Advisory Council on Rare Diseases and Personalized Medicine to conduct at least one review annually, at which time the Council shall dedicate time to:

(1) Discuss and evaluate whether the available covered medications, treatments, and services are adequate to meet the needs of MO HealthNet beneficiaries with a diagnosis of sickle cell disease;

(2) Review information on treatments for sickle cell disease in late-stage studies that show promise in peer-reviewed medical literature; and

(3) Review the importance of provider education on the disproportionate impact of sickle cell disease on specific minority populations.

After each such review, staff members of the MO HealthNet Division, within the Department of Social Services, under the guidance of the Council, may develop their own report on the issues addressed in the review to be made available to the public or may solicit expert testimony or input on such issues, which may be compiled and posted on the website of the MO HealthNet Division.

This bill is similar to HB 2653 and HB 2559 (2022).

The following is a summary of the public testimony from the committee hearing. The testimony was based on the introduced version of the bill.

PROPONENTS: Supporters say that victims of sickle cell disease often face discrimination and receive substandard medical treatment due to a lack of education and understanding surrounding the disease. This bill is an important step in raising awareness within the state of the disease, resulting in greater preparedness and awareness in both the medical community, family members, and support networks of those with the disease.

Testifying for the bill were Representative Dogan; Betty Schrandt; Ellen Sheridan; Shawna Mazeitis; William J Schrandt; Missouri Biotechnology Association; MOBIO; Arnie C. Ac Dienoff; Jemela Williams; Kevin Wake, Uriel Owens Sickle Cell Disease Association; Rosemary Britts, Sickle Cell Association; and the Missouri State Conference of the National Association of the Advancement of Colored People.

OPPONENTS: There was no opposition voiced to the committee.

Written testimony has been submitted for this bill. The full written testimony can be found under Testimony on the bill page on the House website.