

SECOND REGULAR SESSION  
HOUSE COMMITTEE SUBSTITUTE FOR  
**HOUSE BILL NO. 2658**  
**101ST GENERAL ASSEMBLY**

5339H.02C

DANA RADEMAN MILLER, Chief Clerk

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**AN ACT**

To amend chapters 9 and 208, RSMo, by adding thereto two new sections relating to sickle cell disease.

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*Be it enacted by the General Assembly of the state of Missouri, as follows:*

Section A. Chapters 9 and 208, RSMo, are amended by adding thereto two new sections, to be known as sections 9.236 and 208.184, to read as follows:

**9.236. The third full week in September of each year shall be known and designated as "Sickle Cell Awareness Week". Sickle cell disease is a genetic disease in which a person's body produces abnormally shaped red blood cells that resemble a crescent and that do not last as long as normal round red blood cells, which leads to anemia. It is recommended to the people of the state that the week be appropriately observed through activities that will increase awareness of sickle cell disease and efforts to improve treatment options for patients.**

**208.184. 1. During at least one regularly scheduled meeting each calendar year, the advisory council on rare diseases and personalized medicine established in section 208.183 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.**

EXPLANATION — Matter enclosed in bold-faced brackets **[thus]** in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

11           **2. After each annual review of the issues described under subsection 1 of this**  
12 **section, staff members of the MO HealthNet division, under the guidance of the advisory**  
13 **council on rare diseases and personalized medicine, may develop their own report on the**  
14 **issues described under subsection 1 of this section to be made available to the public or**  
15 **may solicit expert testimony or input on such issues, which may be compiled and posted**  
16 **on the website of the MO HealthNet division.**

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