

HB 2927 -3 STAFF MEASURE SUMMARY

House Committee On Behavioral Health and Health Care

Prepared By: Brian Nieubuurt, LPRO Analyst

Sub-Referral To: Joint Committee On Ways and Means

Meeting Dates: 3/1, 3/27

WHAT THE MEASURE DOES:

Establishes Statewide Steering Committee on Sickle Cell Disease (Steering Committee) in Oregon Health Authority (OHA). Specifies Steering Committee membership. Requires Steering Committee to establish statewide network of stakeholders; establish partnerships; educate individuals, health care providers, and the public; identify funding sources, and make recommendations on advancing the care and treatment options for individuals with sickle cell disease. Requires OHA, in consultation with Steering Committee, to provide social support and other services for individuals with sickle cell disease; establish a system to provide information to individuals who have sickle cell trait; maintain a webpage providing a list of resources for health care providers; and conduct an annual review of medications, treatment plans, and services provided for individuals with sickle cell disease who are eligible for the Oregon Health Plan (OHP). Requires Steering Committee, in consultation with OHA, to study ways to improve access to health care, social support, and other services; ways to engage with community-based events or organizations to provide outreach; ways to improve the coordination of health care services; whether the state should establish a sickle cell disease registry; and whether medication, treatments, and services covered by OHP are sufficient to meet needs of individuals with sickle cell disease. Requires study to be submitted to Legislative Assembly by June 30, 2024. Requires health benefit plans to cover fertility preservation for individuals with sickle cell disease.

ISSUES DISCUSSED:

- Prevalence of Sickle Cell Disease
- Sickle Cell Disease symptoms and treatment
- Impacts of lack of knowledge and coordination for those with Sickle Cell Disease
- Impacts of opioid epidemic on provision of appropriate treatment
- Disease and trait testing
- Similar efforts in other states

EFFECT OF AMENDMENT:

-3 Modifies membership of Steering Committee and terms of first appointed members. Modifies issues Steering Committee must study. Modifies report due date to November 30, 2024. Removes requirement that health benefit plans to cover fertility preservation for individuals with sickle cell disease.

FISCAL: Fiscal impact issued

REVENUE: No revenue impact

BACKGROUND:

Sickle cell disease is a group of inherited red blood cell disorders in which abnormal hemoglobin causes the red blood cells to become hard, sticky, and eventually die early. Individuals with sickle cell disease have a constant shortage of red blood cells due to early cell death and also face health complications such as constant pain, along with increased infection and stroke risk due to the hard and sticky nature of the red blood cells. Sickle cell disease is particularly common among those whose ancestors came from sub-Saharan Africa; Spanish-speaking regions in the Western Hemisphere (South America, the Caribbean, and Central America); Saudi Arabia; India; and

HB 2927 -3 STAFF MEASURE SUMMARY

Mediterranean countries such as Turkey, Greece, and Italy. According to the Centers for Disease Control and Prevention (CDC), sickle cell disease affects approximately 100,000 Americans, including one out of every 365 African-American births and one out of every 16,300 Hispanic-American births.

House Bill 2927 would establish a Statewide Steering Committee on Sickle Cell Disease and task the Steering Committee, along with the Oregon Health Authority to study and provide services and supports to individuals who have sickle cell disease.