

Date: March 1, 2023  
To: House Committee on Behavioral Health and Health Care  
From: Stephanie Phillips Bridges, Policy Analyst for the Urban League of Portland  
Re: Support for Sickle Cell Disease Committee, HB 2927

Chair Nosse, Vice-Chairs Goodwin and Nelson, and Members of the Committee:

My name is Stephanie Phillips Bridges, and I am a Policy Analyst with the Urban League of Portland and I respectfully submit this testimony in support of House Bill 2927. The Urban League of Portland is one of Oregon's oldest civil rights and social service organizations, empowering African Americans and others to achieve equality in education, employment, health, economic security, and quality of life across Oregon and SW Washington.

"The Centers for Disease Control and Prevention estimates that sickle cell disease affects 90,000-100,000 people in the United States, mainly Black people. The disease, a red blood cell disorder, causes a constant shortage of red blood cells, cells that can get stuck in small blood vessels and block the flow of blood and oxygen to organs in the body. These blockages cause repeated episodes of severe pain, organ damage, serious infections, or even stroke, and occurs among about 1 of every 500 Black births."<sup>1</sup> Researchers from the Centers for Disease Control and Prevention conducted a study on deaths related to sickle cell disease that, "used death certificate information from the National Vital Statistics System to calculate the number of sickle cell-related deaths from 1979 through 2017, and reported there were 25,665 recorded deaths among Black people in the United States (2020). Researchers found that persons with sickle cell disease may live longer: from 1979 to 2017, the median age at death increased from 28 years to 43 years. Over that same period, sickle cell disease-related death rates among Black children younger than 5 years of age declined by 158%. From 2015–2017, sickle cell disease-related deaths were most often related to chronic heart conditions such as high blood pressure (27%). Sickle cell disease-related deaths were more likely to be caused by infection, stroke, heart disease, liver disease, kidney disease, and lung disease."<sup>2</sup>

"The goals of treating sickle cell disease are to relieve pain and prevent infections, eye damage, and strokes which can lead to longer life spans. To date, the only cure for sickle cell disease is a bone marrow or stem cell transplant."<sup>3</sup> In a study "Lifetime Medical Costs Attributable to Sickle Cell Disease Among Nonelderly Individuals with Commercial Insurance" published in *Blood Advances* (2022), "researchers found that privately insured individuals with sickle cell disease spend approximately \$1.7 million on disease-related medical expenses over their lifetime. These findings highlight the enormous economic burden affecting individuals living with sickle cell disease and raise questions about how medical advancements, like gene therapy, may one day factor into the cost of care. Study author Kate Johnson, PhD, of the Comparative Health Outcomes, Policy & Economics Institute, Department of Pharmacy, University of Washington, explained "our findings suggest that the lifetime

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<sup>1</sup> Centers for Disease Control and Prevention, Sickle Cell Diseases (SCD) website, 2022. Centers for Disease Control and Prevention, What You Should Know About Sickle Cell Disease, 2022.

<sup>2</sup> Centers For Disease Control and Prevention, Study of Sickle Cell Disease-related Death in The United States Suggests Average Age at Death Is Increasing, 2020.

<sup>3</sup> Centers for Disease Control and Prevention, Sickle Cell Diseases (SCD) website, 2022. Centers for Disease Control and Prevention, What You Should Know About Sickle Cell Disease, 2022.

out-of-pocket cost of medical care is about \$44,000 for people with sickle cell disease, for this population, the annual out of pocket cost burden could be five to 10% of their annual income.”<sup>4</sup> Sickle cell disease is an expensive disease to maintain, with some medical care services being essential to quality and longevity of life. Research, treatment, resources, and awareness for sickle cell disease lacks in the United States.

“The Centers for Disease Control and Prevention and participating states began sickle cell disease surveillance (monitoring) in 2010. Sickle cell disease surveillance involves collecting information on diagnoses, treatment, and healthcare access for people with sickle cell disease in the United States. The Centers for Disease Control and Prevention and participating states developed many educational materials based on this information. The Centers for Disease Control and Prevention coordinated these efforts as part of the 2 projects: Registry and Surveillance System for Hemoglobinopathies and Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies. The states that participate in these 2 projects under the Centers for Disease Control and Prevention are California, Florida, Georgia, Michigan, Mississippi, New York, North Carolina, and Pennsylvania.”<sup>5</sup> Oregon is not participating in these lifesaving projects that support people with sickle cell disease, this is crucial to Black people. Oregon does screen for sickle cell disease in newborn screenings and has the Sickle Cell Anemia Foundation of Oregon, formerly the Portland Sickle Cell Anemia Foundation, which was established in 1981 by Pastor Marcia L. Taylor, but does not do enough research, surveillance, education, or awareness for sickle cell disease.

HB 2927 can start to address the lack of efforts for sickle cell disease. Under HB 2927 a statewide Steering Committee on sickle cell disease will be established, and they will create a statewide network of stakeholders, provide education services, identify funding sources, and make recommendations. This will help with spreading awareness and education for sickle cell disease. HB 2927 requires the Oregon Health Authority to provide social support and other services for individuals with sickle cell disease and establish a system to provide information to individuals or parents/guardians of individuals who have sickle cell trait. As well as conducting an annual review of treatment plans and services provided for individuals with sickle cell disease eligible for medical assistance under the Oregon Health Plan. With sickle cell disease treatments and health maintenance being expensive, identifying funding will be essential to supporting people where insurance falls short. Additionally, HB 2927 requires health benefit plans to cover fertility preservation for individuals with sickle cell disease. This is important for family planning and options. HB 2927 also requires the committee to study ways to provide outreach and improve access to and coordination of health care, social support, and other services for individuals with sickle cell disease. This will result in unified and prioritized efforts statewide to research sickle cell disease. If we do nothing, the necessary efforts to support those with and at risk of sickle cell disease will go unaddressed.

Additionally, we ask that the State of Oregon participate in the Centers for Disease Control and Prevention 2 projects: Registry and Surveillance System for Hemoglobinopathies and Public Health Research, Epidemiology,

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<sup>4</sup> Blood Advances, Lifetime Medical Costs Attributable to Sickle Cell Disease Among Nonelderly Individuals with Commercial Insurance, 2021.

<sup>5</sup> Centers for Disease Control and Prevention, Sickle Cell Diseases (SCD) website, 2022. Centers for Disease Control and Prevention, What You Should Know About Sickle Cell Disease, 2022.



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and Surveillance for Hemoglobinopathies. Collectively we all can address the health crisis and disparity that sickle cell disease imposes on Black Americans who experience this disease at a higher rate. Please pass HB 2927 to protect Black Oregonians who suffer from sickle cell disease or are at higher risk of sickle cell disease when they start a family.

Respectfully,

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