Submitter: Charles Smith

On Behalf Of:

Committee: House Committee On Behavioral Health and Health Care

Measure: HB2927

In my 40 plus years of working with families and children in the community I have found that sickle cell disease is one of the few conditions that have a major impact on every dimension of a persons life; and every aspect of a person's world has a major impact on their disease status and progression- things like housing quality, economic opportunities, transportation, health care quality, access to the outdoors, and food access. Sickle cell disease affects our physical health, our social interactions, our spiritual well-being, our mental health, and our intellectual development. Severe and unpredictable pain is extremely stressful and interrupts the flow of having a normal daily life routine.

Imagine if you experience so much unpredictable pain that you can't maintain a job, you can't get out of the house to connect with friends and family or walk in the park, and you can't take care of your basic needs like buying and preparing food, maintaining your home or helping your children with their daily routines. Imagine if the people around you can't “see” the source of your pain and can't believe how much this stress is affecting you physically, mentally, and spiritually. Now imagine that you have to deal with a healthcare system and larger world that has been so accustomed to devaluing you and your circumstances that it hardly recognizes the biased and harmful ways that you are treated, even by well-meaning individuals. The power of these social determinants of health are often not fully appreciated, to our detriment.

We need a comprehensive approach to meet the medical and social needs of people throughout the state whose lives are compromised by the most common genetic blood disorder; a condition that receives inadequate attention and care to support the individuals living with sickle cell disease and their families. Unfortunately, not approaching the people affected by sickle cell disease in a comprehensive way leads to poor quality of life and early death. Less than half of the people with sickle cell disease receive basic screening and needed treatment medications.

I want to close with two short stories to highlight the urgency and the hope that envelops our present circumstances. I had the honor of sitting in the hospital with a young father in his early 30s as he dealt with painful life and death decisions and limited options. He and his wife and child lived in rural Oregon. Not having access to specialized local health care and community supports, and not having the financial resources to move to the Portland metro area left him with no practical options for being with his family and receiving lifesaving care. He returned to his wife and child and passed away days later. Another family who I had known in the community contacted the Sickle Cell Anemia Foundation of Oregon with concerns about their

young child who has a milder form of sickle cell disease. She was starting to have pain and swelling that resembled sickle cell crises. The parents were able to spend time with Pastor Taylor and I, understand more about the many faces of sickle cell disease, receive the emotional support that they needed, and figure out next steps to advocate for the high-quality specialized care that their child deserves.

Living. . . Living with sickle cell disease does not have to be a constant struggle with quality of life and death hanging in the balance. Comprehensive and focused attention, education and awareness, and a commitment to attend to the whole family and the world in which they live can improve the lives of people throughout the state of Oregon. The Sickle Cell Anemia Foundation of Oregon and community partners like the Coalition of Black Men, the Urban League of Portland, the Black Food Sovereignty Coalition and others encourage your support