

Testimony in Support of HB 2940-1

Chair Nosse, Vice-Chair Nelson, Vice-Chair Javadi and Members of the Committee,

My name is Pastor Marcia Taylor, I am the CEO and Executive Director of The Sickle Cell Anemia Foundation of Oregon and Pacific Northwest, known as SCAFO, a direct service agency in 1985 after years as a support group. SCAFO is my legacy to the sickle cell community in honor of my late daughter, Ramona Taylor, who passed away at 36 due to a lack of SC prematurely. My commitment is to prevent families being forced to say goodbye prematurely to their loved ones, which is a lifetime of pain.

Because of my persistence, the SCAFO board and Dr. Richard Cohen, Oregon began testing newborns for sickle cell hemoglobinopathies. SCAFO provides programs specifically designed and dedicated to accommodating the needs of those faced with sickle cell challenges including education, counseling, free diagnostic community testing and patient follow-up.

Sickle cell disease (SCD) is an inherited blood disorder. It affects over 100,000 Americans of various nationalities, of which over 200 reside in Oregon, causing patients to suffer unpredictable episodes of debilitating acute pain and over time, evolves into daily chronic pain. SCD patients are on pain medication most of their life resulting in high medication tolerance. There is a difference between tolerance and addiction. SCD causes organ failure various disabilities and even early death. Sickle cell clients are often triaged within 15-30 minutes but left to sit in cold waiting areas exposed to germs and viruses detrimental to them for several hours, without blood draws to determine infection and other causes, no pain medication, oxygen, hydration, or blood products which could save lives.

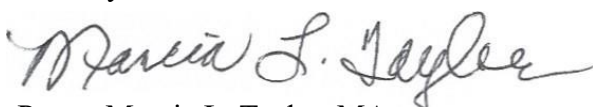
Situations differ and vary in the same person from time to time. Many doctors in Oregon have never treated sickle cell patients and are unfamiliar with sickle disease as we do not have the volume of patients as in California and other states. This is particularly true in rural areas. Patients are reluctant to go to the ed because they are often made to feel like drug seekers and disrespected as physicians do not want anything to happen on their watch, lack understanding and SCD education.

The Sickle Cell Anemia Foundation of Oregon does assist patients with sickle cell disease with protocols written by their physicians, but we often have clients who are transient without a doctor yet and patients who do not carry their protocols with them. I would like to see a basic sickle cell protocol in every emergency department in the state of Oregon to save lives called CODE RED.

HB 2940-1 is an important step towards better emergency department protocols. Implementing a real-time alert system that identifies patients with sickle cell disease and connects staff to a hematologist immediately is a lifeline that could save lives and prevent emergency department staff from "guessing" how to care for someone with a disease that can manifest pain in many ways they may not understand.

I SEEK YOUR SUPPORT TO HELP IMPROVE THE QUALITY OF LIFE AND TO HELP SAVE SICKLE CELL LIVES!

Thank you,



Pastor Marcia L. Taylor, MA
Executive Director and Founder,
Sickle Cell Anemia Foundation of Oregon and Pacific Northwest