

## Support Testimony HB 2741

Chair Nosse, Vice-Chairs Nelson and Javadi, and Members of the House Committee on Behavioral Health and Health Care,

My name is Pastor Marcia Taylor, CEO and Executive Director of The Sickle Cell Anemia Foundation of Oregon & PNW, known as SCAFO, a direct service agency. I founded SCAFO in 1985 to honor of my daughter, Ramona, who passed away at 36 due to a lack of SC education they pulled her oxygen and allowed her to walk to the restroom instead of giving her a bedpan and she transitioned. Because of SCAFO, Oregon began testing for sickle cell hemoglobinopathies which is a part of Oregon's history.

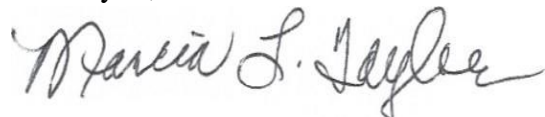
My commitment is to avert families from being prematurely forced to say goodbye to their loved one due to a similar situation. SCAFO provides programs specifically designed and dedicated to accommodating the needs of those faced with sickle cell challenges which include educational webinars to the community and clinicians and free diagnostic community testing and follow-up.

I am here today in support of House Bill 2741 to improve follow-up care and resources for families with infants newly diagnosed with Sickle Cell Disease, or Trait and other medical conditions included in the newborn bloodspot screening. These parents and caregivers need support, education, advocacy and to be connected with organizations like Sickle Cell Anemia Foundation of Oregon for needs assessment and follow-up

Our organization strives to identify people with Sickle Cell Disease and Trait, but we cannot find everyone on our own. If the Oregon Health Authority informs families about our organization, those families might not turn to the internet which contains misinformation. Families connected with SCAFO find the resources they need, a community who share their experiences, long term follow-up to ensure they are provided the proper care as they grow, updated sickle cell information and medical opportunities.

I urge you to support House Bill 2741 so future generations have access to accurate treatments, education and families have resources in their time of need.

Thank you,

A handwritten signature in cursive script that reads "Marcia L. Taylor". The signature is written in dark ink and is positioned above the typed name and title.

Pastor Marcia L. Taylor, MA, CEO  
Executive Director/Founder,  
Sickle Cell Anemia Foundation of Oregon