

Representative Susan McLain
House District 29



HB2987 Hearing Testimony on 3/30/21

Chair Prusak, Vice Chairs Hayden and Salinas, and members of the committee, thank you for your time. For the record my name is Susan McLain and I represent House District 29 in Western Washington County.

I was the Chief Sponsor of HB2563 in 2019 that created the Northwest Regional Newborn Bloodspot Advisory Board. Our goal was to ensure that Krabbe and other diseases were tested for at birth. After the creation of the board and progress in adding Krabbe in other states, and despite major advances in treatment, Oregon has not added it. Tragically, our state's delay in adding Krabbe to our newborn screening panel has resulted in yet another Oregon child being diagnosed with the disease too late for disease altering treatment.

Additionally, the advisory board is not applying standards consistently when deciding what diseases to add. In particular, the board uses the federal Recommended Uniform Screening Panel, or RUSP system to help determine which diseases to test for some of the time, but not always.

Krabbe is a truly horrific disease and it must be tested for early in order to have any hope of a treatment. The good news is that there have been rapid advancements in the treatment of Krabbe and other rare genetic diseases, but the treatment requires intervention within a few months of birth. To ensure families get access to these life saving treatments, we must test our newborns for Krabbe and other genetic diseases at birth.

Bill 2987 not only makes medical sense, but it makes financial sense as well. It is far cheaper to test a newborn for Krabbe than it is for the state to have to help pay for a lifetime of intense medical care. The state testing lab already has the necessary machinery to test for Krabbe, and adding it to the newborn screening panel would cost an estimated .10 to .30 cents since there is already a lab tech running the machine. The cost would only be the chemical to drop on the bloodspot and an extra push of a button.

Eight states do this right now and Oregon must be the 9th.