

TRAVIS NELSON
STATE REPRESENTATIVE
HOUSE DISTRICT 44
NORTH/NORTHEAST PORTLAND



HOUSE OF REPRESENTATIVES

Testimony in Support for House Bill 2741

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

For the record, my name is Travis Nelson, and I am the State Representative for House District 44 - North and Northeast Portland. I am here today to speak in strong support of HB 2741. I come today as healthcare provider and advocate for public health. I truly believe it has the power to change lives, prevent suffering and ensure that no parent or guardian has to navigate a devastating diagnosis of their child alone.

HB 2741 did not come out of nowhere. It has a history rooted in efforts to improve care for vulnerable communities. In the 2023 session, I introduced HB 2927, a bill focused on sickle cell disease. That bill would have established a statewide steering committee through the Oregon Health Authority (OHA) to improve resources for sickle cell patients. Though, it ultimately stalled in the Ways and Means Committee due to its fiscal impact, the work did not stop there.

I continued to work alongside Pastor Marcia Taylor, the director and founder of the Sickle Cell Anemia Foundation of Oregon and connected her with OHA. Our conversation about how our state could do better for sickle cell patients lead to a realization that both parties share a common goal about how our state could do better to provide better support, resources, and pathways to care for infants diagnosed through newborn blood spot screenings. Ultimately, what came to light was merging with an LC that OHA was already working on and thus came about HB 2741.

Here is the truth, many parents regardless of their child's specific diagnosis continue to lack the support system they need to navigate the healthcare system and their child's diagnosis. Please, just take a moment to imagine, being a parent and you have just been told that your newborn has a lifelong medical condition. This is a period of profound fear, confusion, and uncertainty. And while Oregon has excellent doctors and medical professionals, the reality is, that even one misstep in this process—one missed referral, one moment of miscommunication—can have lifelong consequences.

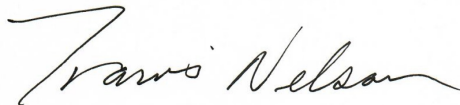
These consequences are closer to home than you may realize. A staffer in my office has a close friend who experienced this firsthand. Their child was diagnosed with a serious but manageable condition as a newborn. They were referred to a specialist, who did not recognize the severity of the diagnosis. The parents trusted the medical advice given and followed the prescribed protocol. It wasn't until six years later, and after exhaustive research and conversations with other parents through online support groups, that they realized their child had been on the wrong treatment plan. But by then, the damage had already been done. Their child suffered medical and developmental consequences that could have been prevented if they had been connected with the right resources from the start. This should never had happened, but it did.

HB 2741 is a safeguard. It creates a Newborn Bloodspot Screening Program to ensure that when a child is diagnosed through newborn screening, support doesn't end with the test results. Each year, 40,000 babies are screened for 45 conditions, with nearly 100 infants receiving life-saving treatment. This bill directs OHA to expand education, follow-up care, and long-term support for families. We learned from the Sickle Cell Foundation of Oregon that many parents are unaware of their support, resources, and community. To address this, we proposed a simple yet critical addition to the original OHA policy: ensuring parents receive additional notifications about organizations that provide resources and advocacy for their child's medical condition. No child should suffer because their parents were left to navigate a complex and overwhelming system alone.

I also have good news. This is not a costly overhaul. OHA already collects resources for outside organizations and support. This bill simply ensures that those efforts don't end once the diagnosis is made. If there is a fiscal at all, it would be for the administrative task of sending out the information for these families to be connected with real support, and guarantees that parents have a place to turn, providing a true lifeline when they need it most.

I urge you to support HB 2741, not just as policymakers, but as people who understand the weight of a parent's love, the fear and confusion that comes with a diagnosis, and the responsibility we all share in ensuring that every newborn child in Oregon gets the best possible start in life, no matter their diagnosis.

Thank you,

A handwritten signature in black ink that reads "Travis Nelson". The signature is written in a cursive, flowing style.

State Representative Travis Nelson
House District 44, North/NE Portland