



Disability  
Rights  
Oregon

TO: House Committee On Behavioral Health and Health Care  
FROM: Disability Rights Oregon  
DATE: February 23, 2025  
RE: SB 3192

Chair Nosse, Vice-Chairs Javadi and Nelson,

My name is Ben Gurewitz, I am a Public Policy Advocate at Disability Rights Oregon (DRO). DRO is the State's Protection and Advocacy System which is charged with protecting, advocating and enforcing the rights of people with disabilities. We are writing in proud support of HB 3192.

Oregon's Northwest Regional Bloodspot Screening Program screen's infants for certain rare conditions, and which provides families the critical information to make informed decisions make informed decision about the necessary care and avoid years of difficult and unnecessary diagnostic journey's and avoid negative health outcomes.

Approximately one in 250 babies born annually in Oregon are diagnosed with a treatable condition to Oregon's NBS Program. Without newborn screening, treatable conditions present at birth may go undiagnosed for years or even decades, resulting in missed opportunities to access life-changing care.

Early detection through this program can mean the difference between a healthy life and severe, lifelong disabilities—or even death. However, as medical advancements expand the number of conditions that can be identified and treated, the program requires increased funding to keep pace with the latest screening technologies, improve testing turnaround times, and ensure equitable access to screening for all newborns, regardless of geographic or socioeconomic barriers. Without adequate funding, Oregon risks delays in diagnosis and treatment, which can lead to devastating health outcomes for infants and increased long-term healthcare costs. Investing in this program is an investment in the health and future of Oregon's children, ensuring that every newborn has the best possible start in life.

Currently Oregon's NBS program lacks the resources to review new conditions and clear its current backlog of treatable rare conditions. HB 3192 will provide 4,000,00 to Oregon's Newborn screening program to purchase test supplies and hire personnel to begin screening newborns for these rare conditions. No family should have to experience the fear, isolation and anxiety of dealing with endocrine, hemoglobin, cystic fibrosis and metabolic conditions when we have the treatments to slow, pause or even prevent symptoms.

### **About Disability Rights Oregon**

511 SW 10th Avenue, Suite 200 / Portland, OR 97205

Voice: 503-243-2081 or 1-800-452-1694 / Fax: 503-243-1738 / [www.droregon.org](http://www.droregon.org)

Disability Rights Oregon is the Protection and Advocacy System for Oregon

Since 1977 Disability Rights Oregon has been the State's Protection and Advocacy System.<sup>1</sup> We are authorized by Congress to protect, advocate, and enforce the rights of people with disabilities under the U.S. Constitution and Federal and State laws, investigate abuse and neglect of people with disabilities, and "pursue administrative, legal, and other appropriate remedies".<sup>2</sup> We are also mandated to "educate policymakers" on matters related to people with disabilities.<sup>3</sup>

**If you have any questions regarding DRO's position on this legislation, please call Ben Gurewitz 971-806-7908 or email him at [bgurewitz@droregon.org](mailto:bgurewitz@droregon.org)**

---

<sup>1</sup> See ORS 192.517.

<sup>2</sup> See 42 U.S.C. § 15041 et seq; 42 U.S.C. § 10801 et seq.

<sup>3</sup> See 42 U.S. Code § 15043(a)(2)(L).