

## ANALYSIS

### Oregon Health Authority HRSA Newborn Screening

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**Analyst:** Steve Robbins

**Request:** Approve the submission of a federal grant application to the Health Resources and Services Administration in the amount of \$1,725,000 for the State Newborn Screening System Priorities Program.

**Analysis:** As a part of the Oregon Health Authority (OHA), the newborn screening (NBS) program is designed to identify infants affected by specific medical conditions in time to prevent impairment. The testing screens for a specific list of conditions. Infants with these conditions often appear normal at birth, but the medical condition can affect the infant's health and development over time. Although each screening condition is rare, when combined approximately one in 250 infants is affected. Babies that test positive for one of the conditions will have program staff follow up to help them receive appropriate medical care to prevent impairment or death.

Grant funds are to be used to enhance, improve, and expand their NBS, as well as to support implementation of new conditions added to the Recommended Uniform Screening Panel (RUSP). The notice of funding opportunity does not speak specifically to individual conditions on the panel, but is more focused on process improvement.

OHA proposes to utilize these grant funds to support the following initiatives:

- Develop an initial implementation guide that includes the elements needed for the successful and timely addition of new conditions to the Oregon NBS.
- While not required by grant, OHA is choosing to add the screening for mucopolysaccharidosis type II (MPSII) to those conditions screened in the Oregon NBS. Typically, Oregon tries to mirror the RUSP conditions for screening, and MPSII is one of two conditions on the RUSP that is not on Oregon's panel.
- Utilize lessons learned from the process of adding MPSII to improve and complete the implementation guide for use in the future if new conditions are added.

HRSA announced the grant on November 14, 2002, and the application is due February 13, 2023. OHA provided timely notice to the Legislature on January 18, 2023. If awarded, the grant will begin July 1, 2023, and will offer funding of up to \$345,000 per year for five years through June 2028. The grant has no state match or maintenance of effort requirements, and one position will be requested to write the implementation guide and start-up of the screening for MPSII.

If Oregon is awarded the grant, Oregon Revised Statute will need to be modified to include MPSII on the screening panel and modifications will need to be made to statute and rule for how condition reviews are conducted.

**Legislative Fiscal Office Recommendation:** The Legislative Fiscal Office recommends approval.

# Oregon Health Authority Heath

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**Request:** Authorization to apply for a grant of up to \$345,000 per year over five years for the Oregon Health Authority’s Newborn Bloodspot Screening program from the Health Resources and Services Administration.

**Recommendation:** Approve the request.

**Discussion:** The Oregon Health Authority (OHA) requests authorization to apply for a five year, \$345,000 per year Health Resources and Services Administration grant to strengthen Oregon’s Newborn Bloodspot Screening (NBS) program. The NBS program screens each baby born in Oregon twice for over 40 diseases and genetic disorders. OHA would use the funding to develop a comprehensive guide to adding new conditions to the screening panel and use grant funds to purchase equipment needed to add screening for mucopolysaccharidosis type II (MPSII) to the screening panel. MPSII is a rare genetic disorder that affects as many as 1.1 out of every 100,000 live male births, according to the National Institutes for Health. With the advent of an effective medical treatment for MPSII, the federal government recently revised its recommendations to add screening for the disorder and Oregon’s NBS is seeking to follow suit.

If awarded, OHA would use the grant funds to hire a position to work on the implementation guide as well as to purchase the testing equipment, supplies and professional services needed to add MPSII to its screening panel. Below is a table showing how OHA expects to spend the grant over the five years:

	<b>Year 1</b>	<b>Year 2</b>	<b>Year 3</b>	<b>Year 4</b>	<b>Year 5</b>
Personal Services	\$96,153	\$101,672	-	-	-
Contracted Services	\$50,000	\$10,000	\$10,000	\$10,000	\$10,000
Supplies	\$48,017	\$48,944	\$195,907	\$199,825	\$203,822
Equipment	\$69,726	\$72,515	\$75,304	\$78,093	\$80,882
Administration and Other	\$61,520	\$55,647	\$50,787	\$51,998	\$53,224
<b>Total</b>	<b>\$325,416</b>	<b>\$286,851</b>	<b>\$331,998</b>	<b>\$339,916</b>	<b>\$347,928</b>

The implementation guide will create a process to address the full cycle of adding a new disorder to Oregon’s panel, including test and process design, public education, family outreach, and plans for long-term follow-up. Testing for MPSII would be piloted in years 1 and 2 of the grant. OHA would begin screening for MPSII statewide in year 3 of the grant, which accounts for the increase in the cost of supplies during year 3. OHA would also contract with the Oregon Health Sciences University for long-term follow-up for those who screen positive for the condition. After the grant expires, the ongoing costs of screening for MPSII would be paid for out of the fees that support the program.

OHA was notified of the grant on November 17, 2022. Applications are due on February 13, 2023. The grant would run from June 2023 to June 2028. The grant does not have a match

requirement. Funding for the grant is competitive and allocated by region. The federal government expects to make up to three awards per region, and Oregon's region consists of the states of Oregon, Alaska, Idaho, and Washington.



OFFICE OF THE DIRECTOR

Tina Kotek, Governor

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January 18, 2023

Senator Elizabeth Steiner, Co-Chair  
Representative Tawna Sanchez, Co-Chair  
Joint Committee on Ways and Means  
900 Court Street NE  
H-178 State Capitol  
Salem, OR 97301

Dear Co-Chairs:

### **Nature of the Request**

The Oregon Health Authority's Public Health Division requests permission to apply for federal grant funding to enhance the Oregon State Public Health Laboratory (OSPHL) newborn screening (NBS) program. OHA seeks to create an implementation guide for adding new conditions to the NBS panel and then use the guide to initiate screening for mucopolysaccharidosis type II (MPSII). Additionally, OHA will survey families impacted by NBS to understand their unique experience and any challenges or unmet needs. In partnership with communities and providers, the implementation guide will address these challenges, particularly when bringing on a new condition, to ensure that all Oregon newborns have easy and equitable access to care, impacting a child's long-term health or survival.

The federal funding opportunity was announced on November 14, 2022, by the Health Resources and Services Administration (HRSA). The purpose of this grant is to strengthen the NBS systems nation-wide, which aims to improve health outcomes through early screening, diagnosis, and treatment of newborns and children with heritable disorders. The grant due date is February 13, 2023.

### **Agency Action**

Upon notification of funding, the OSPHL NBS program convened a workgroup of individuals, including the NBS program manager, NBS public health nurse, and NBS follow-up coordinators to assess the needs of the program, identify aims for the grant proposal, and survey resources required to apply for funding. OSPHL also solicited input from medical consultants at Oregon Health & Sciences University, who provide necessary follow-up care and treatment for newborns identified through screening.

OHA will be requesting funding to support the following aims:

- OSPHL will develop an implementation guide that includes the six components needed for successful and timely addition of new conditions to the Oregon newborn screening panel.
- OSPHL will survey families, community partners, and providers to understand their experience with the NBS program and any unmet needs or challenges. These responses will be incorporated into the implementation guide, such that when new conditions are implemented, parents and provider needs are addressed.
- OSPHL will screen all newborns for MPSII using the implementation guide as a framework for direction, implementation, timelines, and evaluation.
- OSPHL will review the implementation guide using the implementation of MPSII screening as an example to make appropriate modification such that the guide can be used for future conditions.

### **Action Requested**

To accomplish the aims listed above, funding to cover the cost of the instrumentation and reagents/supplies for MPSII screening for 4 years will be requested in the grant application. The expenditure limits will need to be extended to support purchase of these items.

Additionally, one full-time employee, a program analyst 2, is requested to construct the implementation guide, survey families and providers, and assist with screening for MPSII. OSPHL is requesting that the Committee approve position authority for this employee.

### **Legislation Affected**

The Newborn Bloodspot Screening Program's authority to test all babies in Oregon for congenital disorders is set out in the following statutes: ORS 433.285, 433.290 and 433.295, which were established in 1963. The Newborn Bloodspot Screening Program describes how to carry out the statutory authority in OAR 333-024-1000 to 333-024-1110.

The Northwest Regional Newborn Bloodspot (NWRNBS) advisory board, which was founded in 2019 with HB 2563, provides programmatic guidance and review for the newborn screening program. This includes the review of new conditions to be considered for addition to the screening panel.

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If Oregon is awarded the NBS Propel grant and the aims are carried out as planned, the ORS would need to be updated to include MPSII on the screening panel. Additionally, the HB 2563 would need to be modified for how condition reviews, performed by the advisory board, are conducted.

Sincerely,



James M. Schroeder  
Interim Director

EC: Steven Robbins, Legislative Fiscal Office  
Patrick Heath, Department of Administrative Services  
George Naughton, Department of Administrative Services  
Amanda Beitel, Legislative Fiscal Office