Public Health Division

Oregon State Public Health Laboratory

Northwest Regional Newborn Bloodspot Screening

Oregon Newborn Bloodspot Screening Program

2025 Annual Report

Table of Contents

Northwest Regional Newborn Bloodspot Screening Program

Newborn Bloodspot Screening (NBS) is a coordinated public health system that identifies infants with medical conditions requiring early treatment to prevent disability or death. According to the CDC, NBS is one of the greatest public health achievements of the first part of the 21st century. Within the first days of life, a provider collects a small blood sample from the newborn's heel and sends it to the newborn bloodspot screening laboratory for testing. Once testing is complete, the results are shared with the provider, who consults with the parents. If a baby screens positive for a condition, necessary diagnostic testing is conducted, and life-saving treatments are initiated as needed.

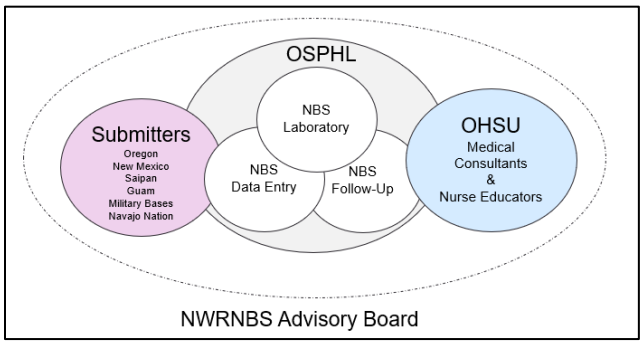


Figure 1: component parts of Oregon's NBS program

Oregon NBS is conducted by the Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program at the Oregon State Public Health Laboratory (OSPHL) ORS 433.285 through ORS 433.295 The program was one of the first in the nation and has been in operation since 1963, expanding from a single test to a panel of 46 disorders. The disorders are individually rare, but each year approximately 1 in 500 infants are identified with a condition on the panel. In Oregon, all infants are required to be screened, except for those whose parents opt out due to religious beliefs or philosophical reasons.[1]

The Oregon program is authorized under ORS 433.295 to collect fees for screening, which is the primary source of funding. Additionally, the program provides screening services to New Mexico, Guam, Saipan, Navajo Nation, and several U.S. military bases. Through newborn bloodspot screening, children who would have been severely affected without early detection are able to lead healthier and more productive lives, thus saving the health care system the costs of more expensive medical care.

In the coming years, the panel of conditions is expected to expand as new screening technologies and effective treatments become available. Each year, 1-2 new conditions are reviewed by the Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program Advisory Board for inclusion on the panel. The NWRNBS program's sustainability and flexibility to respond to these changes, while maintaining a high-quality testing laboratory is imperative. This 2025 annual report summarizes activities within the NWRNBS program and provides data on key performance metrics.

[1] The 2025 legislative session expanded the parental opt out to include both religious and philosophical beliefs.

Phases of Newborn Bloodspot Screening

The screening process begins with prenatal education for expecting families and providers about the benefits of early testing, identification, and treatment.

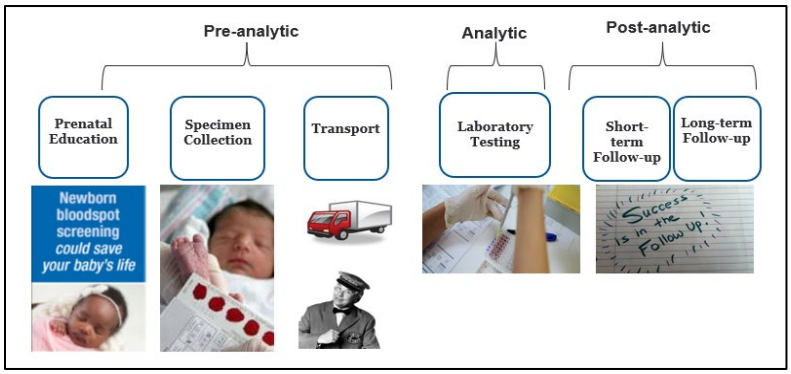


Figure 2: Phases of newborn bloodspot screening program

The first specimen is collected at 24 hours of life by hospitals, birth centers, and community birth providers. The specimen is then transported to OSPHL. The NWRNBS program performs testing for 46 conditions and then reports the results to providers within the first 7 days of life.

Babies who screen positive for a condition receive short-term follow-up care to refer the baby for additional evaluation and diagnostic testing. If the presence of disease is confirmed, the baby then receives long-term follow-up care from medical specialists.

Timeline for screening

Many conditions on the panel are time-critical and require notification by 5 days of life to have optimal outcomes. For other time-sensitive (but not time-critical) conditions, it is recommended that results are reported no later than 7 days of life.

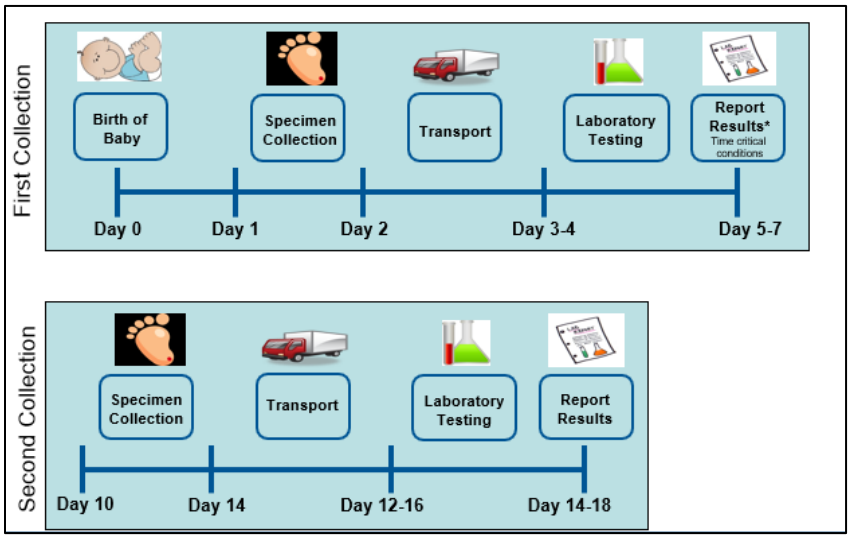


Figure 3: Timeline for screening

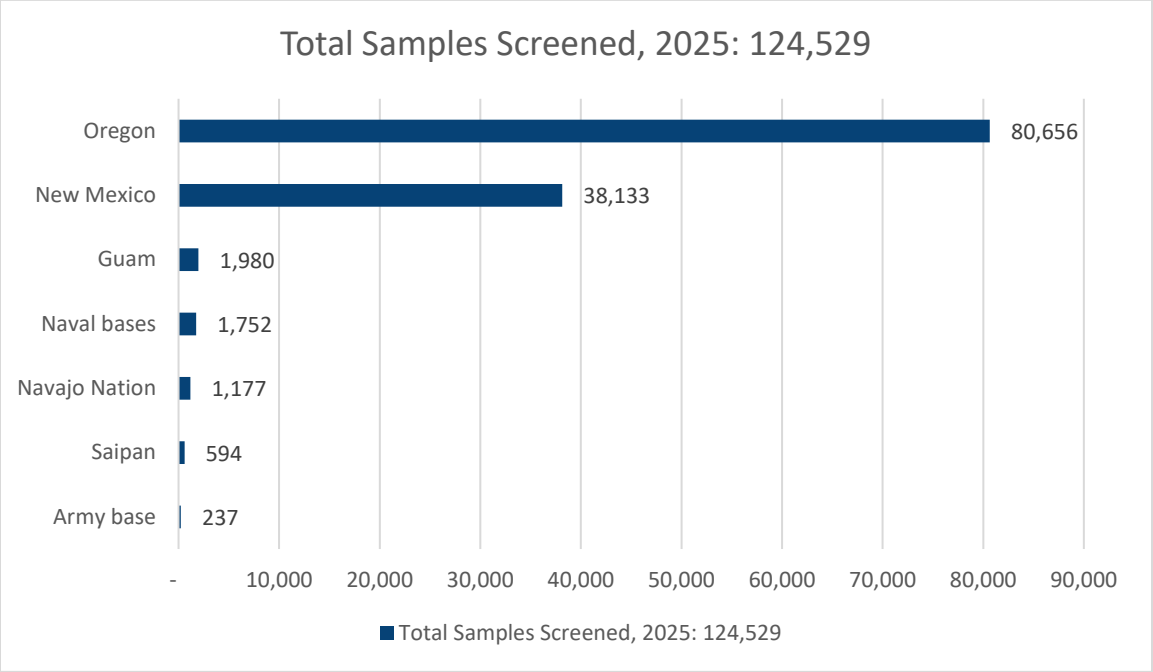
To meet these goals, the timeline in Figure 3 was implemented, and metrics assessing each step of the process are monitored closely.

All babies receive a second screen at 10 to 14 days of life to identify milder forms of the disease and reduce likelihood of missed cases.

Pre-Analytical Statistics

The pre-analytical phase of screening includes specimen collection and transport. The NWRNBS program tracks data on number of specimens submitted, number of babies screened, timeliness metrics for specimen collection and transport, number of unsatisfactory specimens collected and number of specimens missing key data elements on the card.

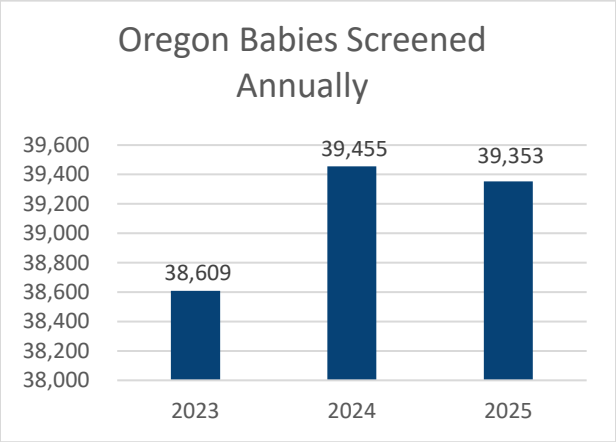
Submitters by location

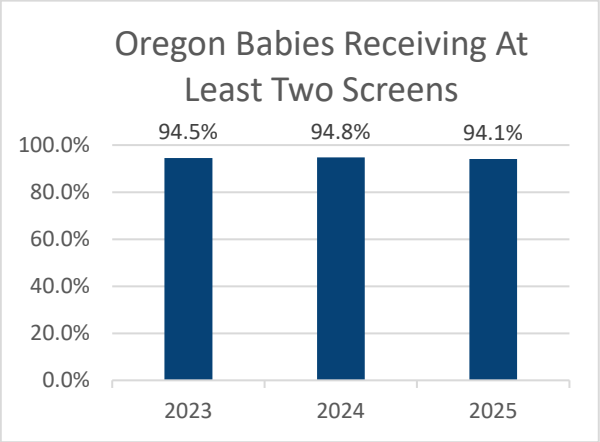


In 2025, NWRNBS program tested 124,529 samples. The majority (64.8%) were from babies born in Oregon, with an additional 30.6% coming from New Mexico. The remaining 4.6% of submissions were divided between Guam, Saipan, Navajo Nation, and U.S. military bases.

Oregon babies screened, and percent receiving two screens

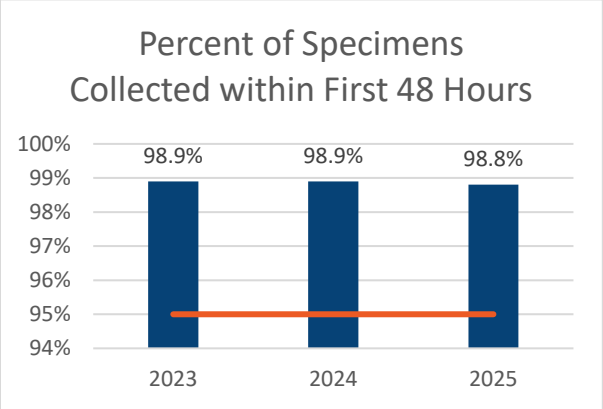
On average, 39,000 babies from Oregon are screened each year.





In Oregon, it is mandated that every baby receives two screens. Greater than 94% of Oregon babies received two screens.

Oregon babies with timely specimen collection



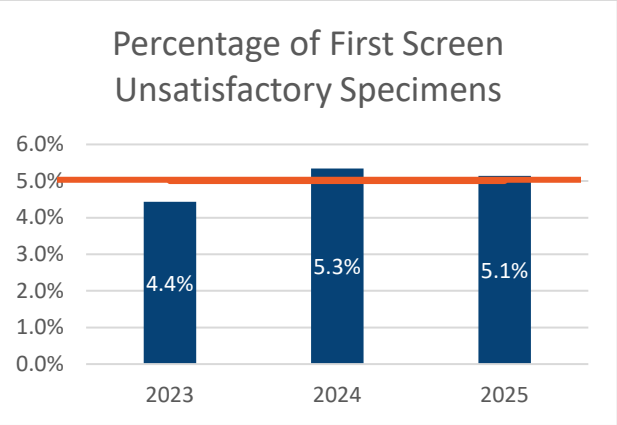
To meet timeliness goals for results reporting, the first screen should be collected within the first 48 hours of the baby's life, ideally between 24 and 48 hours.

Oregon NBS aims to have at least 95% of first screens collected within the first 48 hours of the baby's life. The program has consistently exceeded this goal; in the last three years, it has averaged nearly 99% collection rate within the first 48 hours of life.

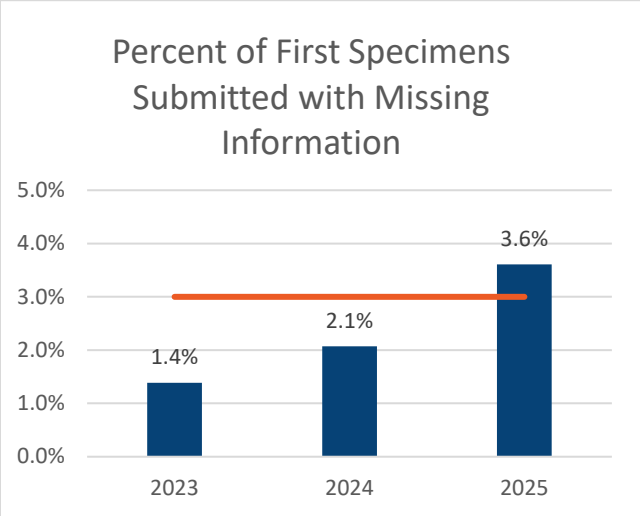
Oregon first specimens with an unsatisfactory collection

Adequate specimen collection is critical for obtaining accurate results. In 2025, 5.1% of specimens were deemed unsatisfactory. The goal is to have less than 5%.

Additional educational tools and support for submitters introduced in 2025 may help to reduce the percentage of unsatisfactory specimens. See 2025 Projects and Accomplishments for more details.



Oregon specimens with missing essential information on card

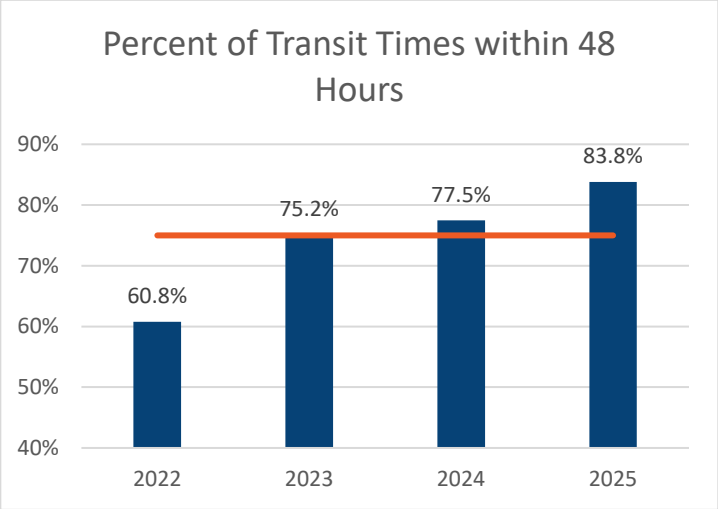


Each newborn bloodspot screening specimen must contain essential information for proper interpretation of test results. The following data points are considered critical for testing and reporting:

- Birth weight
- Birth date
- Birth time
- Specimen collection date
- Specimen collection time

The goal is to have less than 3% of cards submitted with missing or inaccurate information. In 2025, the percentage was 3.6, continuing the upward trend of the last few years. Future quality assurance projects should be constructed to reduce this percentage and increase the number of specimens with complete demographic records.

Oregon time from specimen collection to receipt



The newborn screening program aims to have a transit time of 48 hours or less from specimen collection to receipt at OSPHL. In 2023, approximately 75% of specimens were received within 48 hours of collection following the implementation of a courier for rural and frontier hospitals as well as the provision of overnight mailers to community birth providers. It would rise further to 77% in 2024. In 2025, it would reach nearly 84%. These initiatives represent a significant investment from the laboratory and hospitals of both financial and staffing resources to support timely transport.

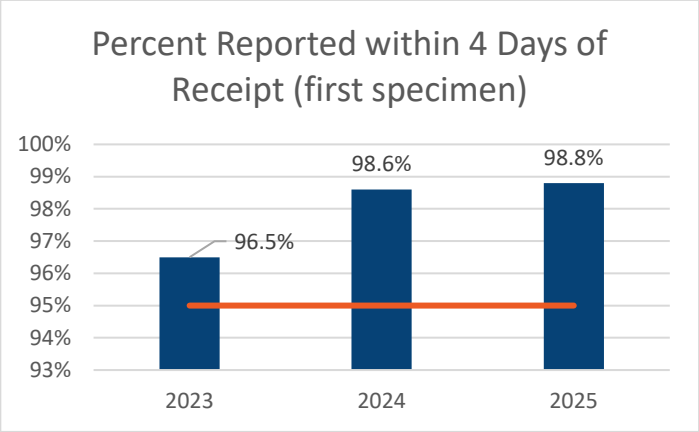
Specific improvements include:

- Legacy Birth Facilities
  - 8/30/25 began delivering specimens on Saturdays.
  - Transit rate improved from 75% to 84%.
- Providence St. Vincent Medical Center
  - 12/6/25 began delivering specimens on Saturdays.
  - Transit rate improved from 77% to 85%.
- OHSU Hillsboro Medical Center
  - 4/1/26 began delivering specimens on Saturdays and specimens arrived in morning more consistently.
  - Transit rate improved from 60% to 86%.

Analytical Statistics

The analytical phase of newborn screening includes all testing activities at the laboratory. Metrics tracked in the analytical phase include time from receipt of specimen to results reporting, and total time from birth to results reporting.

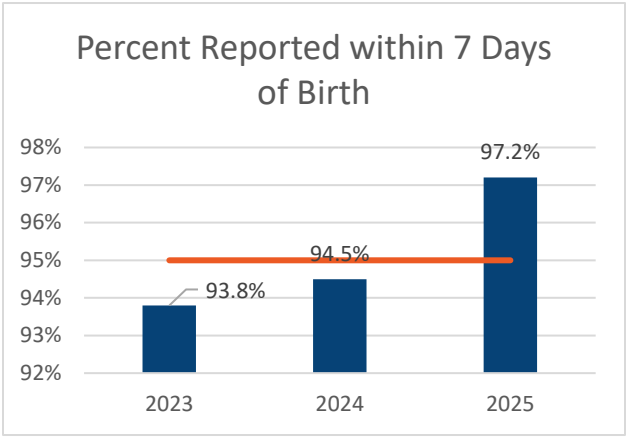
Oregon time from receipt to report



The laboratory turnaround time, or time from receipt of samples to results reporting, has been steadily improving since 2021. For the last 3 years, Oregon has exceeded its goal of reporting results on at least 95% of samples within 4 days.

Oregon time from birth to report

To evaluate the whole system, from birth of the baby to reporting of the first specimen screening results, the time from birth to report is monitored. Oregon aims to have greater than 95% of specimens reported within 7 days of life.



This rate has been trending steadily upwards since 2023. Despite falling slightly short of its goal in previous years, the program surpassed the targeted minimum in 2025. Factors impacting this metric include timing of collection, transport, and testing.

Post Analytical Statistics

The following tables provide a summary of the screening outcomes for all conditions on the screening panel. Because many of these conditions are rare, all submitters (Oregon, New Mexico, Guam, Saipan, military bases, and the Navajo nations) are grouped together.

2024 and 2025 Screening results

Amino Acid Conditions		
Disorder	**2024**	**2025**
Phenylketonuria	3	3 1-benign hyperphe
Maple Syrup Urine Disease	0	0
Citrullinemia/Argininosuccinic Aciduria (ASA)	0	1-ASA
Tyrosinemia Type I or II	0	0
Arginase Deficiency	0	0
Homocystinuria	0	0

Organic Acidemias		
Disorder	**2024**	**2025**
3-Methylcrotonyl-CoA Carboxylase Deficiency (3MCC)	3	1-3MCC 1-Multiple Carboxylase Deficiency
Glutaric Acidemia Type I	2	0
Isovaleric Acidemia (IVA)	0	1-IVA 2-2-methylbutyrylglycinuria
Propionic Acidemia (PA)/Methylmalonic Acidemia (MMA)	1 MMA 2 Cobalamin defect	1 PA
Malonic Acidemia	0	0

Fatty Acid Oxidation Defects		
Disorder	**2024**	**2025**
Medium Chain Acyl-CoA Dehydrogenase (MCAD) Deficiency	6	3
Very Long Chain Acyl-CoA Dehydrogenase (VLCAD) Deficiency	3	1
Short Chain Acyl-CoA Dehydrogenase (SCAD) Deficiency	4	3
Carnitine palmitoyl transferase Type I (CPT1) deficiency	2	2 CPT1 Arctic Variant
Carnitine palmitoyl transferase Type II (CPT2) deficiency	0	0
Carnitine Uptake Deficiency	2	0
Long Chain 3-Hydroxy Acyl-CoA Dehydrogenase (LCHAD) Deficiency	0	0
Glutaric Acidemia Type II	0	0

Other Disorders		
Disorder	**2024**	**2025**
X-linked Adrenoleukodystrophy (XALD)	1 Male XALD 5 Female XALD Carriers	3 Male XALD 1 Female XALD Carrier 1 Zellweger
Biotinidase Deficiency	5 Partial Deficiency	1 Full Deficiency 3 Partial Deficiency
Galactosemia	0	2
Severe Combined Immunodeficiency (SCID)	1 SCID 1 DiGeorge	2
Spinal Muscular Atrophy (SMA)	1	5
Congenital Adrenal Hyperplasia	6	5
Primary Congenital Hypothyroidism	39	53
Cystic Fibrosis	10	8
Sickle Cell	3	2

2024 and 2025 Screening results: MPS1, Pompe, Fabry, and Gaucher

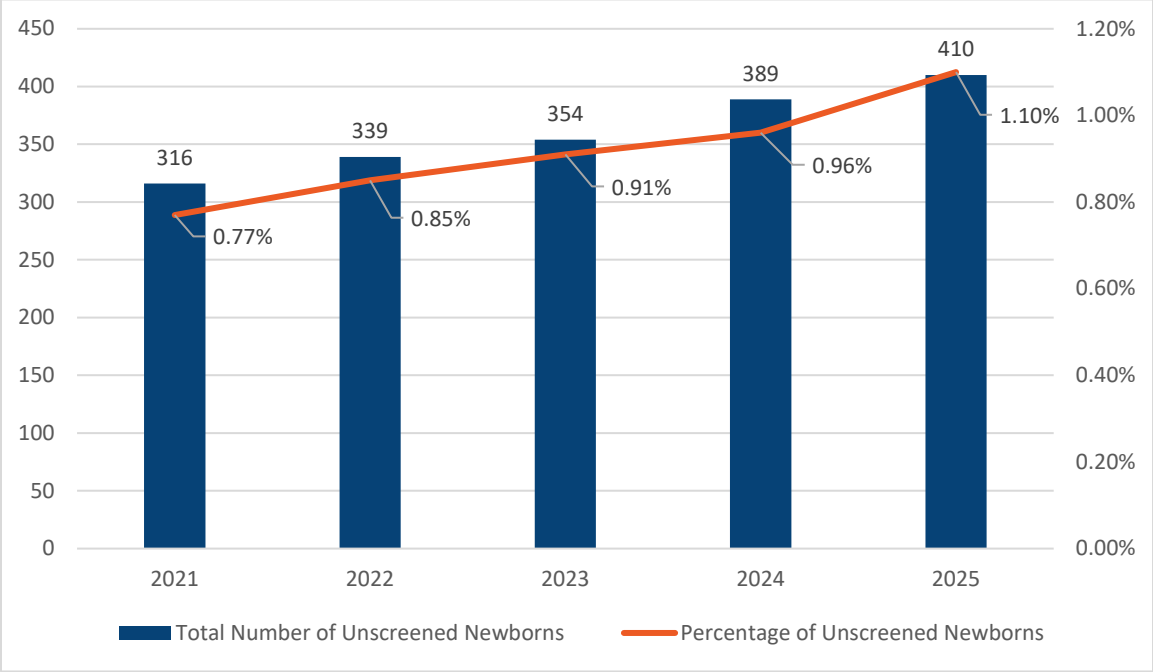
Disorder	2024	2025
MPS1 (IDUA)	3	2
Pompe (GAA)	5-Late Onset Pompe Disease	1- Late Onset Pompe Disease
Fabry (GLA)	15 males	7 males
Gaucher (GBA)	1	1

Vital Records Matching: Unscreened Babies

In 2021, the newborn screening program initiated vital records matching, between the NBS record and the birth record, to track and determine how many babies born in Oregon received screening. Once the screened and unscreened populations were identified, the NBS program used additional information contained within the birth record, to query potential reasons why a baby might not have received screening. Three factors were evaluated: place of birth, provider of record, and source of payment.

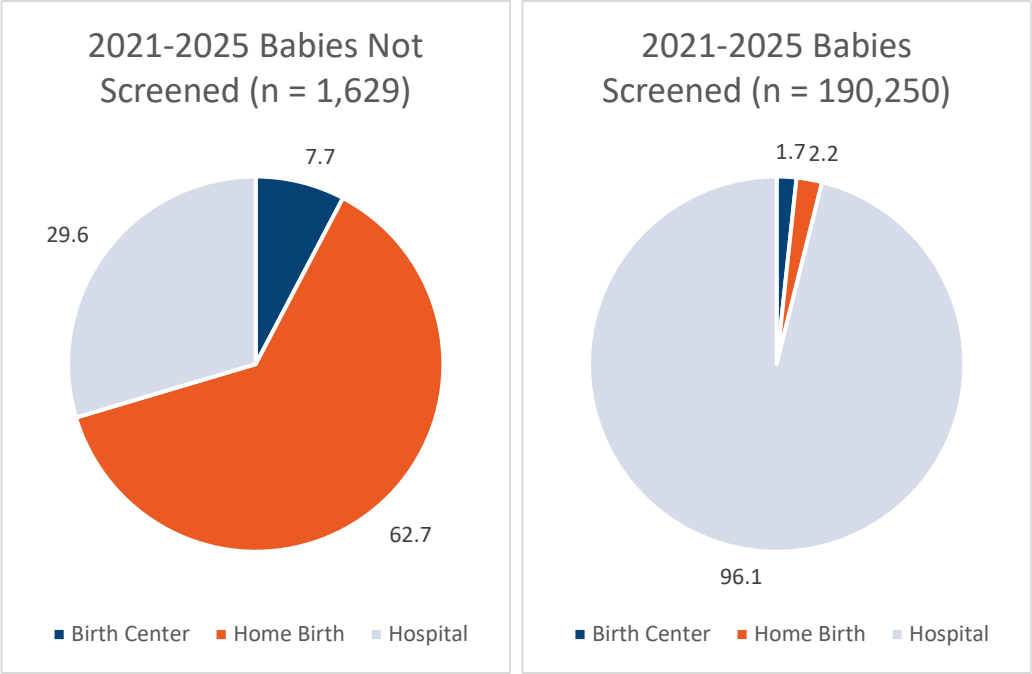
Five year trend – Oregon unscreened babies

In 2021, there were 316 babies born in Oregon that did not have a record of screening (0.77%). Over the past four years, the number of unscreened babies has increased steadily to just over 1% in 2025.



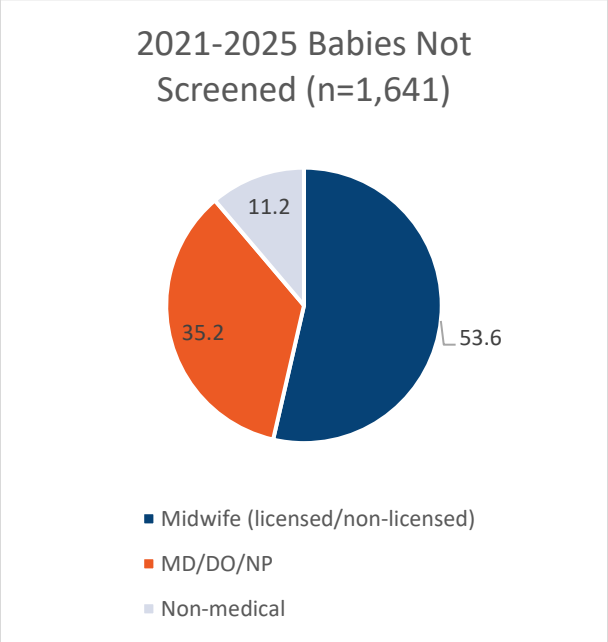
Place of birth for Oregon unscreened babies, 2021-2025

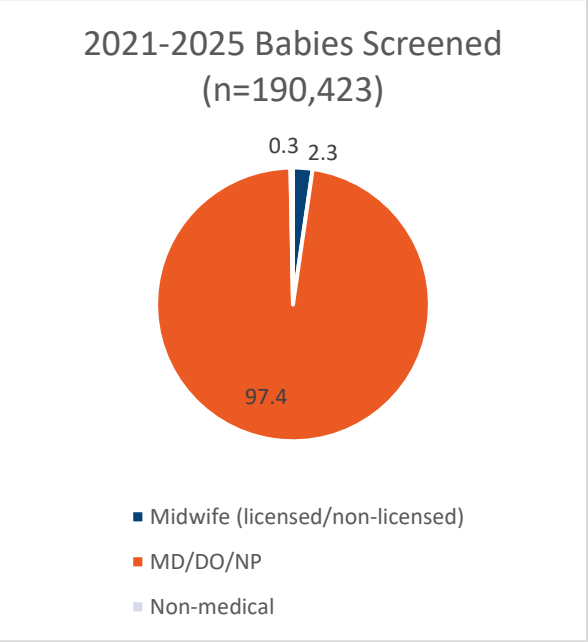
The majority of unscreened babies are born in a home birth setting (62.7%) as compared to 96% of screened babies born in the hospital setting. This finding has remained unchanged since 2021.



Birth provider for Oregon unscreened babies, 2021-2025

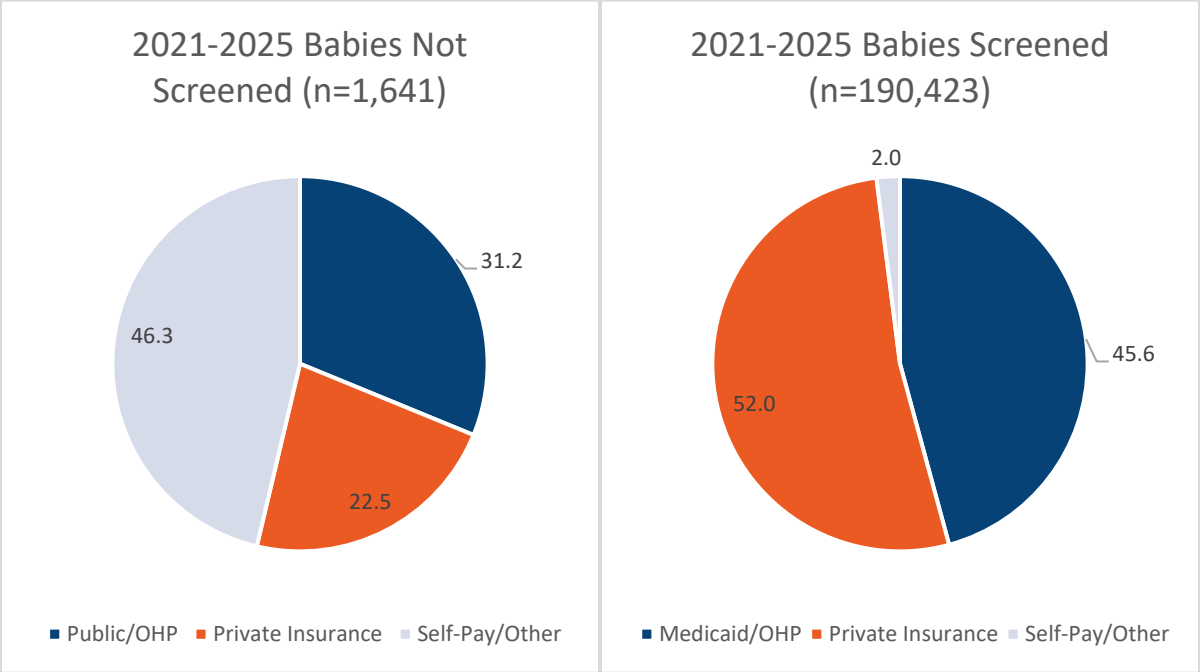
Similarly, midwives delivered about 53.6% of unscreened babies, medical providers averaged around 35%, and non-medical providers about 11%.





Method of payment for the birth, Oregon unscreened babies, 2021-2025

For more than 46% of unscreened babies, the reported payment for the birth was “self-pay”, meaning families paid out of pocket for the birth of their baby. Medicaid/Oregon Health Plan and private insurance comprised most of the other unscreened babies, at a combined total of around 53%. In comparison, only 2% of screened babies paid out of pocket.



During the 2024 legislative session, general funds were allocated for use by families who pay out of pocket for the newborn screen. As of December 31, 2025, 476 subsidized cards have been issued.

The NBS program continues to monitor the number of unscreened babies and evaluate factors that may contribute to a baby not receiving the newborn screen.

2025 Projects and Accomplishments

In 2025, the NWRNBS program undertook multiple quality improvement projects focused on training, site visits, improved provider toolkits, and courier services.

Collection trainings:

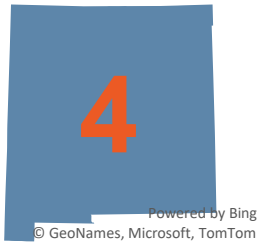
NBS staff provided 67 trainings on best practices for sample collection, using a combination of virtual and on-site training.

In Oregon, training was provided at:

- 29 PCP clinics
- 27 birth facilities
- 3 community birth providers
- 2 university nursing programs
- 2 trainings for all submitters

In New Mexico, training was provided at:

- 1 training for all submitters
- 3 birth facilities



The percentage of unsatisfactory specimens submitted by facilities decreased significantly upon re-evaluation at 3- and 6-months post training.

Birth facility site visits

In 2025, the NWRNBS program completed 12 site visits at birth facilities in Oregon, with the goal of reviewing how each facility operationalizes the NBS program and offering feedback and recommendations as needed.

Each visit included a QA data review with stakeholders, an NBS process questionnaire, and a tour of the facility.

Of the 11 facilities from which data was obtained,

- 2 facilities had zero unsatisfactory specimens at 3 months after the visit.

- 89% saw a decrease in unsatisfactory specimens 3 months after the site visit.
- 4 facilities saw a decrease in unsatisfactory specimens 6 months after the site visit, if NBS collection training was also provided during the visit.

Resources for submitters

The NWRNBS program provides the following resources to assist submitters in the collection of the screening specimens:

- NBS quality check poster (see figure 4)
- Drying rack
- NBS blood collection training video
- Specimen collection card training video
- Specimen collection card poster
- Clinical Skills Assessment (see figure 5)
- NICU specimen collection guidelines
- Pre-analytical quality assurance reports for submitters

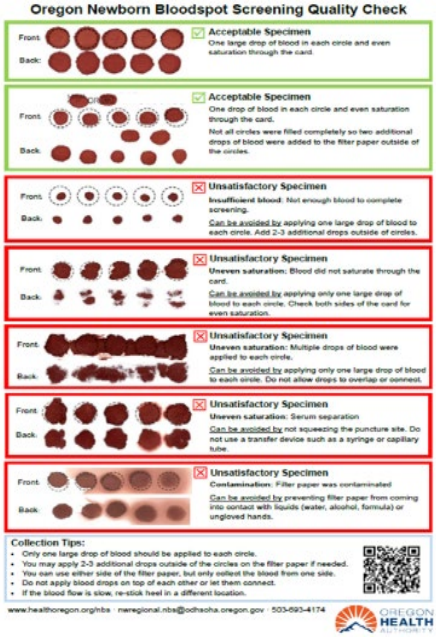
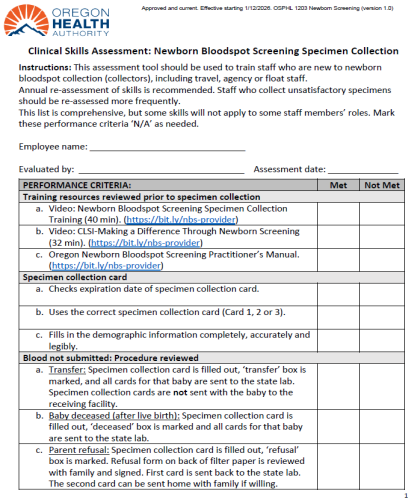


Figure 4: Quality check poster provided to submitters

The Clinical Skills Assessment is a tool that should be used to train staff who are new to newborn bloodspot collection or for those who would like a refresher for maintenance of competency.

All resources are available on the program website:

www.healthoregon.org/nbs



OREGON HEALTH AUTHORITY

Approved and current. Effective starting 1/12/2026. OSPHL 1203 Newborn Screening (version 1.0)

Clinical Skills Assessment: Newborn Bloodspot Screening Specimen Collection

Instructions: This assessment tool should be used to train staff who are new to newborn bloodspot collection (collectors), including travel, agency or float staff.
Annual re-assessment of skills is recommended. Staff who collect unsatisfactory specimens should be re-assessed more frequently.
This list is comprehensive, but some skills will not apply to some staff members' roles. Mark these performance criteria 'N/A' as needed.

Employee name: _____

Evaluated by: _____ Assessment date: _____

PERFORMANCE CRITERIA:	Met	Not Met
Training resources reviewed prior to specimen collection		
a. Video: Newborn Bloodspot Screening Specimen Collection Training (40 min). (https://bit.ly/nbs-provider)		
b. Video: CLSI-Making a Difference Through Newborn Screening (32 min). (https://bit.ly/nbs-provider)		
c. Oregon Newborn Bloodspot Screening Practitioner's Manual. (https://bit.ly/nbs-provider)		
Specimen collection card		
a. Checks expiration date of specimen collection card.		
b. Uses the correct specimen collection card (Card 1, 2 or 3).		
c. Fills in the demographic information completely, accurately and legibly.		
Blood not submitted: Procedure reviewed		
a. Transfer: Specimen collection card is filled out, 'transfer' box is marked, and all cards for that baby are sent to the state lab. Specimen collection cards are **not** sent with the baby to the receiving facility.		
b. Baby deceased (after live birth): Specimen collection card is filled out, 'deceased' box is marked and all cards for that baby are sent to the state lab.		
c. Parent refusal: Specimen collection card is filled out, 'refusal' box is marked. Refusal form on back of filter paper is reviewed with family and signed. First card is sent back to the state lab. The second card can be sent home with family if willing.		

1

Figure 5: Clinical Skills Assessment provided to collector evaluators

Redesigned NBS specimen collection card

In 2024, the program completed a redesign of the NBS specimen collection cards. The new cards were distributed in early 2025.

The new design features:

- Delineation of Place of Birth, Submitter of the NBS Specimen, and Follow-up (PCP) care provider.
- Removal of race and ethnicity fields because of accuracy concerns and limited space to capture all possible responses.
- Inclusion of three options to designate sex (male, female, indeterminate).
- Addition of inclusive language for the birth parent/guardian.
- A "blood not collected" field to link all birth records to screening records. Providers can select the following reasons why blood was not collected: transferred, deceased, refusal. Families can sign the back of cards indicating their choice to refuse screening, even after receiving information on the benefits of screening.

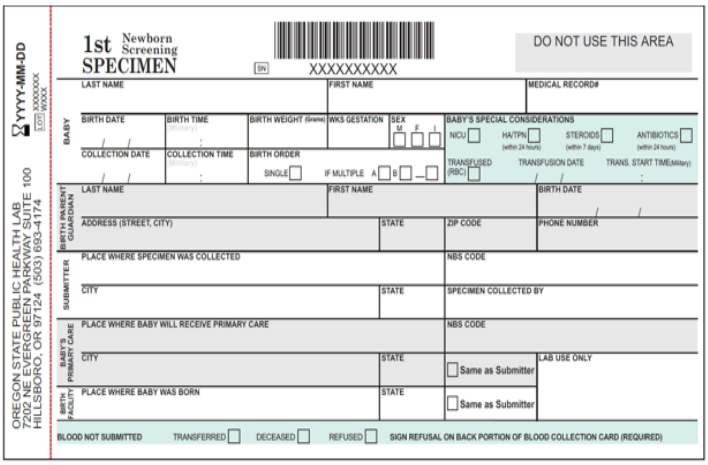


Figure 6: sample specimen card

Creation of a NBS Parent Video

The NBS program filmed a 4-minute video to inform families about the value of screening. The video featured an Oregon family, whose child was identified with MCAD deficiency through screening. The video has footage of the program staff and highlights the testing process.

bit.ly/NBSnewvideoforparents

Scan here to watch a video about how newborn bloodspot screening protects your baby's health.

Laboratory accomplishments

The 2025 laboratory accomplishments included updates to four disease-specific testing algorithms to reduce false positive cases:

- Implemented use of TSH as primary marker for congenital hypothyroidism
- Updated succinylacetone cutoff to improve screening for tyrosinemia type I
- Updated biotinidase procedure to reduce false positives
- Incorporated biochemical second-tier test for Gaucher disease.

The laboratory brought in new instrumentation:

- Replaced 3 genetic screening processors (CH, CAH, GALT, CF)
- Added a SeqStudio for CFTR variant panel analysis

The laboratory also implemented screening for Infantile Krabbe Disease in November of 2025.

New LIMS vendor selected

OSPHL is in the middle of a 5-year project to select and implement a new Laboratory Information Management System (LIMS). Currently, the NBS program is using 2 separate systems; both are outdated and communication between systems is challenging.

In 2024, after a lengthy review process, Lab Vantage was selected as the vendor for a new LIMS system.

Contracting will continue through 2026, with the goal of implementing one single integrated and efficient LIMS with embedded analytical tools by 2028.

Legislative actions

In 2025, HB2741 passed. This allows families to decline screening for any reason and requires the CCO to cover the costs of screening. Information and documentation relating to screening are to be confidential and not subject to disclosure. The NWRNBS program will be responsible for implementing an educational program to include information on medical conditions that are screened on the panel and the overall importance of screening. The NBS program will also conduct a follow-up program to improve the long-term care of individuals with medical conditions, subject to available resources.

Numerous amendments were made to the Oregon Administrative Rules.

OAR 333-024-1000 and OAR 333-024-1050 allow parents or legal guardians to opt out of screening for religious or philosophical grounds. The language of these rules, as well as that of OAR 333-024-1080, was altered to use more inclusive language, broadening the scope to encompass both parents and legal guardians.

OAR 333-024-1040 has been updated to require a specimen collection card to be submitted for all babies born in Oregon. If no blood is collected, a card must still be submitted by hospitals and community birth providers to receive reimbursement for the cost of the card. If screening is refused, the refusal form must be submitted stating that the parents or legal guardians received education about screening.

OAR 333-024-1070 was also adjusted. The specific methods of testing for each listed disorder were removed to allow the laboratory to update methods as needed to ensure the accuracy of results and alignment with best practices. Krabbe Disease was also added to the list of conditions on the Oregon NBS panel.

NWRNBS Advisory board and new conditions

In 2023 the NWRNBS advisory board reviewed and approved the addition of MPSII and GAMT Deficiency to the testing panel. Work continued throughout 2024 and into 2025 to prepare the laboratory for screening of these conditions.

In addition, the HRSA Secretary of Health approved Infantile Krabbe Disease in 2024 for the inclusion on the Recommended Uniform Screening Panel (RUSP), and the NWRNBS advisory board reviewed this condition in March 2025. Krabbe disease screening was implemented on November 1, 2025.

The HRSA Secretary of Health also added Metachromatic Leukodystrophy (MLD) and Duchenne Muscular Dystrophy (DMD) to the RUSP in December 2025. The NWRNBS advisory board will review both conditions in 2026/2027 for possible inclusion on the Oregon NBS panel.

2026 Goals and Priorities

As part of education and outreach, a planned overhaul of the website is underway. Among other things, it will entail the creation of an FAQ section for families on genetic testing and privacy practices surrounding the retention of data and specimens.

For the laboratory, a 2026 priority is the implementation of GAMT screening. The laboratory will also explore options for sequencing of CFTR to enhance screening for cystic fibrosis.

The existing billing system will be redesigned for greater efficiency. OSPHL has contracted with a billing vendor to support NBS and enable it to consider alternative billing models. The program is considering a fee-for-service model, which would address issues with the current pre-pay model, though not without some possible disadvantages. Hospitals, clinics and community birth providers would have broader access to cards and submitters would be able to follow routine billing practices used for other laboratory testing. However, without universal pre-payment, not all balances would be paid in a timely manner.

In 2026, the Oregon NBS program will participate in the BRIDGES-NBS study. BRIDGES-NBS is a three-year research initiative funded by the NIH to assess the feasibility of incorporating whole genome sequencing into existing public health newborn screening programs. Oregon was chosen to be one of seven participating public health programs. The study is not intended to replace the current newborn screening process, rather it will add additional testing for families who have consented to participate. The genomic sequencing will evaluate over 700 conditions in comparison to the 46 currently on the newborn screening panel. All the 777 conditions have actions that can be taken within the first year of life to prevent morbidity and mortality for the baby. https://www.bridgesnbs.org/

Recommendations from NewSTEPs Site Review

The Newborn Screening Technical assistance and Evaluation Program (NewSTEPs) is funded by the Association of Public Health Laboratories (APHL) and the Genetic Services Branch of the US Health Resources and Services Administration. NewSTEPs strengthens existing newborn screening programs by offering technical and educational resources.

In January 2024, a team from NewSTEPs visited the NWRNBS program to complete a comprehensive on-site review of the full system, including the laboratory program, birth facilities, and follow-up program.

Their report praised “leadership that is engaged and open to change; seamless communication between the co-located laboratory and follow-up divisions; a committed Advisory Board; commendable relationships with partners across the NBS system; and forward-thinking approaches.”

The site review report suggested the following changes to the program. Green checked boxes indicate changes that have already been implemented; red boxes are planned or in process.

Organizational Structure:

- ☑ Hire an additional manager to supervise non-laboratory staff.
- ☑ Create a LIMS/Data analyst position.
- ☐ Form partnership with EHDI, CCDH.

Legislation and Policy:

- ☑ Implement new onboard/training for advisory board members.
- ☑ Amendments to statue and rules *(in process).*
- ☐ Post condition review process on website for transparency.
- ☐ Consider the utility of two-screen process.

Ethics

- ☑ Integrate a more robust and timely vital records matching to allow for follow-up on unscreened babies.

Funding Model

- ☐ Explore additional funding models for the program *(in process).*
- ☐ Consider invoicing for screening services rather than pre-pay model *(in process).*

Laboratory

- ☑ Redesign NBS collection card and data elements.
- ☑ Modify the congenital hypothyroidism screening algorithm.
- ☑ Improve and expand the state contracted courier service.
- ☐ Consider staff hours with the goal of not having more than 1 day lapse without testing.
- ☐ Redesign NBS reports and consider adopting CLSI-recommended language (ie screen positive).

Emergency Preparedness

- ☐ Establish a MOU with WA, TX, or other states *(in process).*
- ☐ Develop a COOP procedure.

Follow-up

- ☑ Stabilize staffing.
- ☑ Begin sharing periodic updates on newborns confirmed to have a condition.
- ☑ Initiate quality improvement projects to improve efficiency *(in process).*
- ☑ Modernize follow-up protocols and procedures.

Long-Term Follow-Up

- ☐ Explore implementation of a long-term follow-up program, considering what questions the program wants to answer. Reach out to other states for advice and mentorship.

Education

- ☑ Create on-demand educational materials.
- ☑ Update Oregon Practitioners' Manual.
- ☐ Consider revamping the OR NBS website *(in process).*

Information Systems

- ☑ Hire a LIMS staff dedicated specifically to NBS section of OSPHL.
- ☑ Expand the SRV (web portal for providers to access results).
- ☐ Move towards paperless systems *(in process).*
- ~~☐ Explore ways to improve the LIMS – Natus for follow-up activities *(in process).*~~
- ☑ Improve Quality Assurance reports and their distribution to providers.
- ☐ Work toward implementation of a new, unified LIMS *(in process).*

Summary

The NWRNBS program provides life-saving services to babies in Oregon, New Mexico, Guam, Saipan, Navajo Nation, and several U.S. military bases. The program provides screening for 46 conditions and reports results within 5-7 days of baby's life.

In 2025, the program screened almost 125,000 specimens, including providing at least two screens for about 40,000 babies born in Oregon. The program is meeting or exceeding its goals for timely specimen collection, specimens submitted with complete information, and transit time to the lab. There is an opportunity to reduce the number of unsatisfactory specimen collections, but the additional provider education and tool kits implemented in 2024 and 2025 appears to have positively affected this number. There is also an opportunity to reduce the number of specimens missing essential demographic information at the time of submission. Educational outreach efforts to hospitals, community birth providers, and birthing centers are being considered.

All metrics tracked in the analytical phase have been improving since 2020. Oregon NBS has exceeded its goals for time from receipt of first specimen to reporting of results for the last three consecutive years. Furthermore, as of this year, it has surpassed its goal for overall time between birth and results reporting.

In 2025, the NWRNBS program identified over 130 babies with a condition on the screening panel. The program referred these babies to medical specialists to receive follow-up care and treatment.

The NWRNBS uses vital records matching to help track unscreened babies. The number of unscreened babies has been trending upwards. Most unscreened babies are born in a home birth setting, to parents who are paying out of pocket.

Changes and improvements to the program in 2025 included:

- Collection training and site visits for hospitals, clinics, and community birth providers.
- Updated resources for submitters, including a clinical skills assessment.
- Release of a parent education video showcasing the NBS laboratory and a family positively impacted by NBS.
- Implementation of screening for Krabbe Disease
- Updates to screening algorithms to improve screening metrics (reduce false positives)
- Upgrades to instrumentation required for screening
- Initiation of and ongoing work with the selected LIMS vendor.

2026 NWRNBS program initiatives include:

- Enhancement of education and outreach
    - Redesign of website

    - FAQ for families on genetic testing and privacy, retention of data/specimens
- Updates to testing and algorithms
    - Implementation of GAMT screening
    - Explore options for CFTR sequencing
- Essential changes in program management and operations
    - Redesign of the billing system
    - New LIMS pilot project
- Participation in the nationwide BRIDGES-NBS study

The NWRNBS program provides an essential public health service: screening newborns to identify treatable conditions. In the coming years, the panel of conditions is expected to expand as new screening technologies and effective treatments become available. This will necessitate modernization of the laboratory, expansion of support services for families whose babies are detected through screening, increased public awareness on the benefits of screening, and a continued commitment to quality laboratory services. The sustainability and flexibility of the NWRNBS program to respond to these changes is imperative to be able to best serve our newest citizens.

Newborn bloodspot screening saves lives!