Public Health Division

Oregon State Public Health Laboratory

Northwest Regional Newborn Bloodspot Screening

OREGON HEALTH AUTHORITY

Oregon Newborn Bloodspot Screening Program

2024 Annual Report

OREGON HEALTH AUTHORITY OSPHL

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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 death or disability. According to the CDC, NBS is one of the great public health achievements of the first part of the 21st century. Within the first day of life, a provider collects a small blood sample from the newborn's heel and sends it to a newborn bloodspot screening laboratory for testing. Once testing is complete, the results are shared with providers, who consult with parents. If a baby screens positive for a condition, necessary diagnostic testing is conducted, and life-saving treatments are initiated as needed.

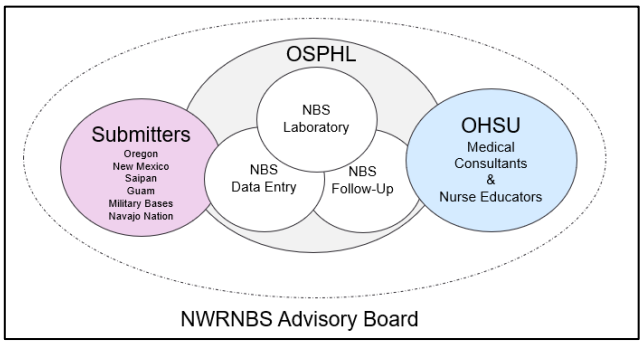


Figure 1: component parts of Oregon's NBS program

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 45 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.[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 2024 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.

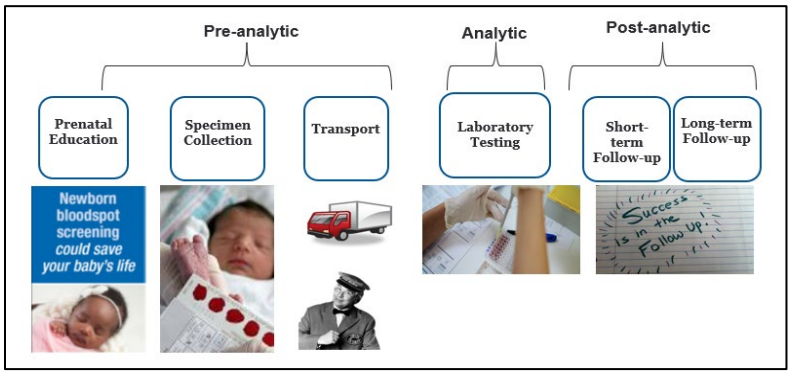


Figure 2: Phases of newborn bloodspot screening program

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 45 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 confirmatory 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.

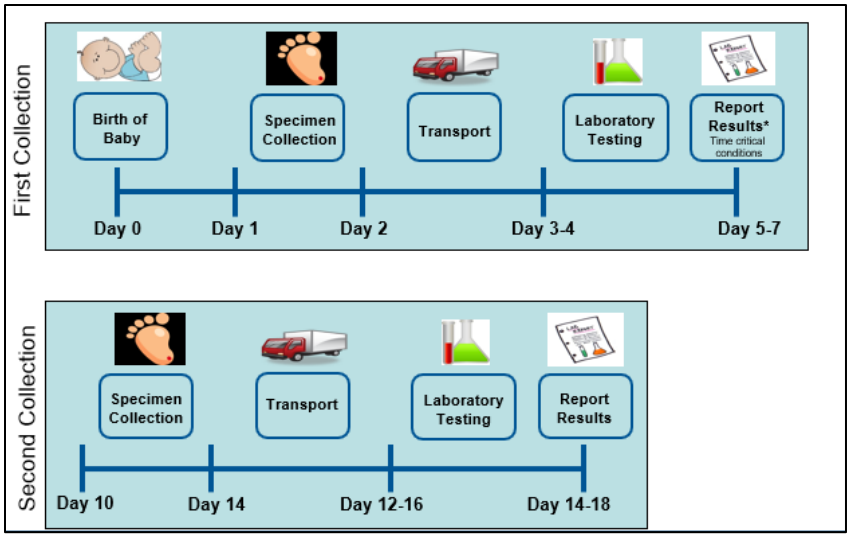


Figure 3: Timeline for screening

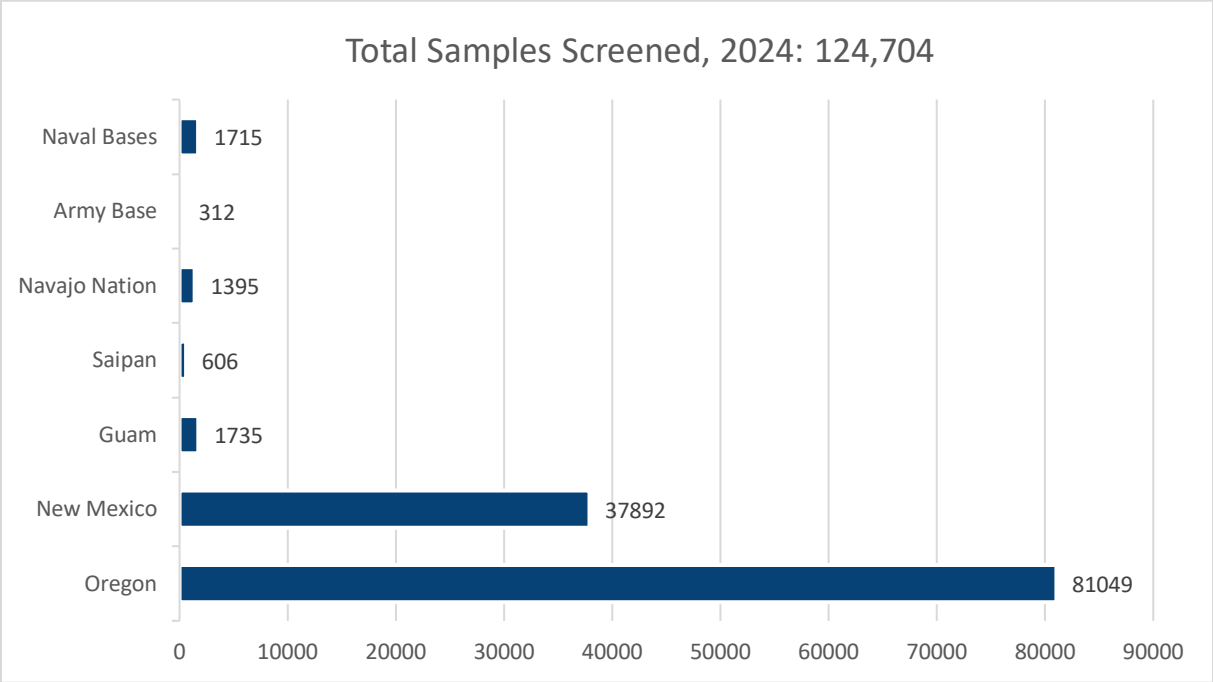
To meet these goals, the timeline in Figure 3 was proposed, and metrics assessing each step of the process are monitored closely.

All babies also receive a second screen at 10 to 14 days of life to identify milder forms of the disease and to prevent against 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, number of unsatisfactory specimens collected, number of specimens missing key data elements on the card, and transit times, among other metrics.

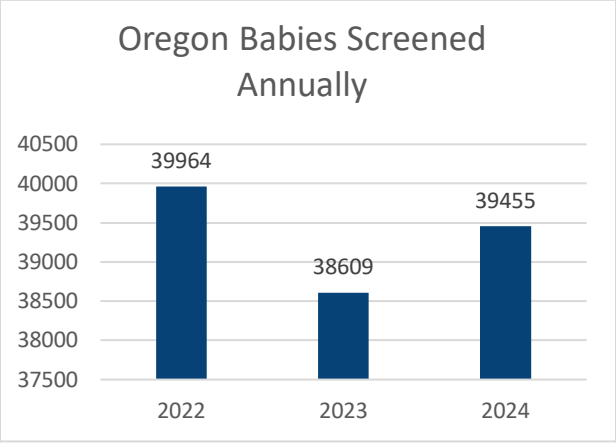
Submitters by location

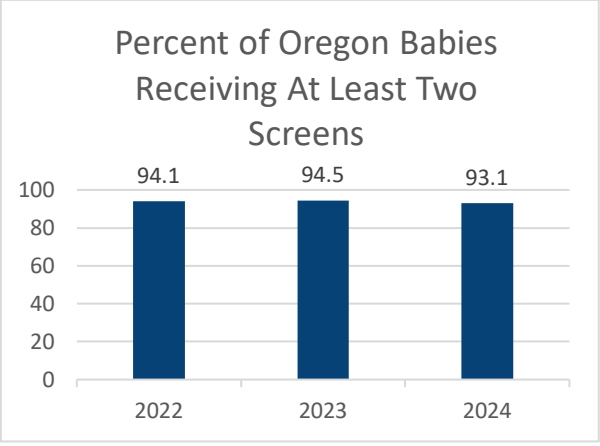


In 2024, NWRNBS program tested 124,704 samples. The majority (65%) were from babies born in Oregon, with an additional 30% coming from New Mexico. The remaining submissions were divided between Guam, Saipan, Navajo nation, and U.S. military bases.

Oregon babies screened, and percent receiving two screens 2022-2024

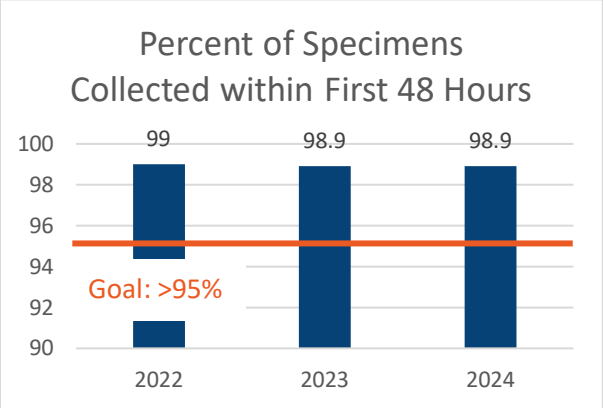
On average, over 39,000 babies from Oregon are screened each year.





In Oregon, it is mandated that every baby receives two screens. Greater than 90% of Oregon babies received two screens.

Oregon babies with timely specimen collection, 2022-2024



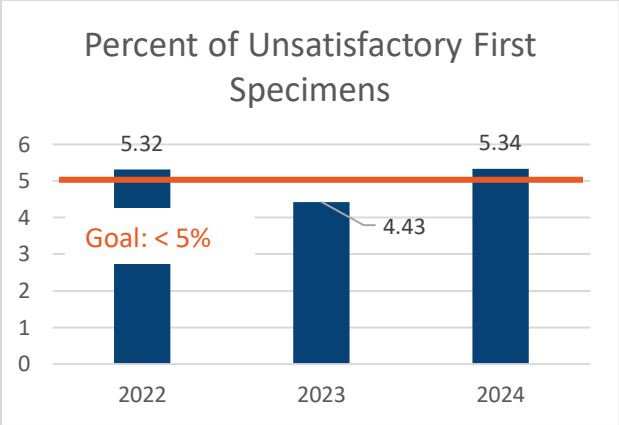
To meet timeliness goals for results reporting, the first screen should be collected within the first 48 hours of the baby's life, ideally between 24 and 48 hours.

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

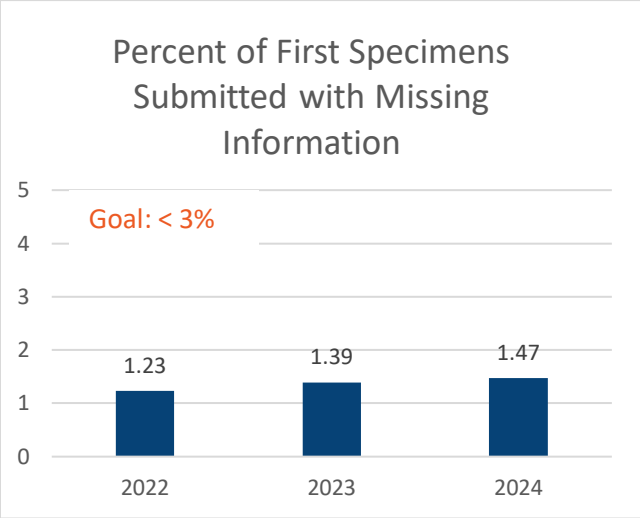
Oregon first specimens with an unsatisfactory collection

Adequate specimen collection is critical for obtaining accurate results. In 2024, 5.3% of specimens were deemed unsatisfactory. The goal is to have less than 5%.

Additional educational tools and support for submitters introduced in 2024 may help to reduce the percentage of unsatisfactory specimens. See 2024 Projects and Accomplishments for more detail.



Oregon specimens with missing essential information on card

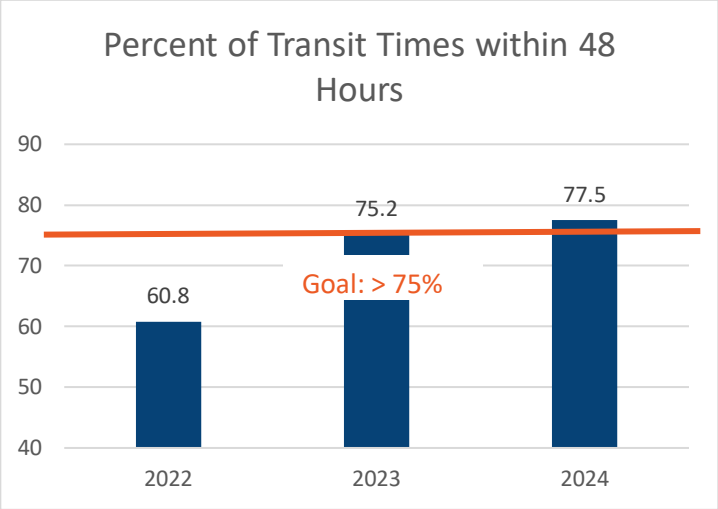


Each newborn bloodspot screening specimen must contain essential information for proper interpretation of test results. The following items are considered critical for testing and reporting:

- 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 2024, the percentage was less than 2, although it has been trending slightly upward in the last three years.

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 2022, approximately 60% of specimens were received within 48 hours of collection. After implementation of a courier for rural and frontier hospitals and providing community birth providers with overnight mailers, the average jumped up to 75% in 2023 and 77% in 2024, exceeding the goal of 75%. These initiatives represent a significant investment from the laboratory and hospitals of both financial and staffing resources to support timely transport.

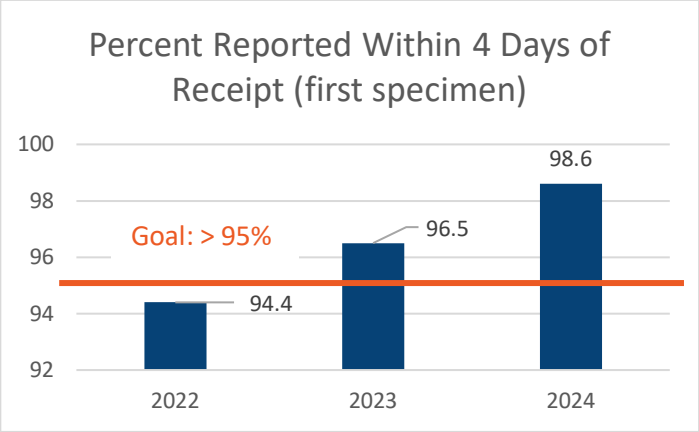
Specific improvements include:

- Including Mercy Medical Center-Roseburg and McKenzie-Willamette Medical Center-Springfield in the state-supported courier service.
- Adding a Saturday delivery for Salem Health.
- OHSU courier delivering specimens in the morning rather than the afternoon and adding a Saturday delivery.
- Adding a Saturday delivery for Providence birth facilities.
- Implementing a courier service at Adventist Health Tillamook.

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.

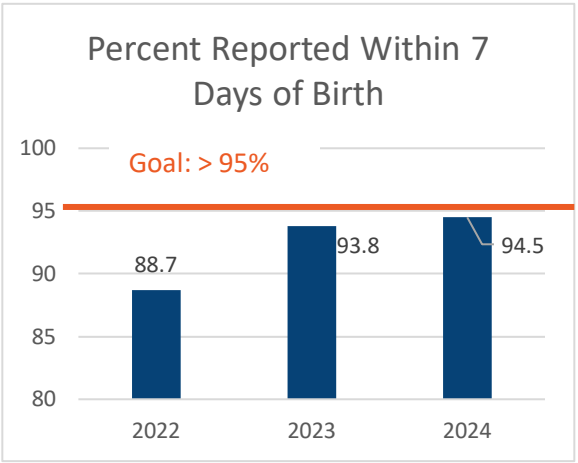
Oregon time from receipt to report



The laboratory turnaround time, or time from receipt of samples to results reporting, has been steadily improving since 2022. For the last two 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, but the program is still falling slightly short of its goal. Factors impacting this metric include timing of collection, transport, and testing. There is room for improvement in timely transport through expansion of courier services, and reduction of the testing time through optimization and efficiencies of laboratory processes.

Post Analytical Statistics

The following tables provide a summary of the screening results 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.

For each condition, the total number of screened positive babies is provided. The table further categorizes the screened positive babies into those requiring a repeat screen or a referral. Repeat indicates a report where the baby is at mildly increased risk of disease. Referral indicates high risk for a given condition; in these cases, the infant is referred to medical specialists and the providers are notified as quickly as possible. The total number of confirmed true cases is also provided.

2023 Screening results

Disorder	Positive Results				True Cases
Amino Acid Conditions					
PKU	Total Positive			11	4
	Repeat	8	Referral	3	
MSUD	Total Positive			32	0
	Repeat	30	Referral	2	
Citrullinemia/ASA	Total Positive			45	1
	Repeat	41	Referral	4	
Tyrosinemia Type I or II	Total Positive			45	0
	Repeat	39	Referral	6	
Arginase Deficiency	Total Positive			0	0
	Repeat	0	Referral	0	
Homocystinuria	Total Positive			28	1
	Repeat	26	Referral	2	(MATI/III deficiency)
Organic Acidemias					
3-MCC	Total Positive			30	5
	Repeat	21	Referral	9	
GAI	Total Positive			16	0
	Repeat	9	Referral	7	
IVA	Total Positive			15	3
	Repeat	9	Referral	6	
PA/MMA	Total Positive			252	2
	Repeat	237	Referral	15	
Malonic Acidemia	Total Positive			4	0
	Repeat	4	Referral	0	

Fatty Acid Oxidation Defects					
MCAD Deficiency	Total Positive			23	5
	Repeat	18	Referral	5	
VLCAD Deficiency	Total Positive			23	4
	Repeat	6	Referral	8	
SCAD Deficiency	Total Positive			25	1
	Repeat	23	Referral	2	(IBD NM case)
CPTI	Total Positive			3	0
	Repeat	2	Referral	1	
CPTII	Total Positive			4	0
	Repeat	2	Referral	2	
CUD	Total Positive			57	1
	Repeat	52	Referral	5	
LCHAD Deficiency	Total Positive			4	0
	Repeat	0	Referral	4	
GAII	Total Positive			1	1
	Repeat	1	Referral	0	
Other disorders					
XALD	Total Positive			225	6
	Repeat	207	Referral	18	
Biotinidase Deficiency	Total Positive			98	3
	Repeat	71	Referral	7	
Galactosemia	Total Positive			22	3
	Repeat	0	Referral	6	
	Optional testing			16	
SCID	Total Positive			164	2
	Repeat	148	Referral	16	
SMA	Total Positive			4	4
	Repeat	0	Referral	4	
Congenital Adrenal Hyperplasia	Total Positive			103	4
	Repeat	56	Referral	5	
	Serum			42	
Primary Congenital Hypothyroidism	Total positive			432	40
Cystic Fibrosis	Total Positive			1789	13
	Repeat	1657	Referral	32	
Sickle Cell	Total Positive			271	
	Sickle cell disease	5	Sickle cell trait	264	
	Hemoglobin H disease			2	

2023 Screening results: MPS1, Pompe, Fabry, and Gaucher

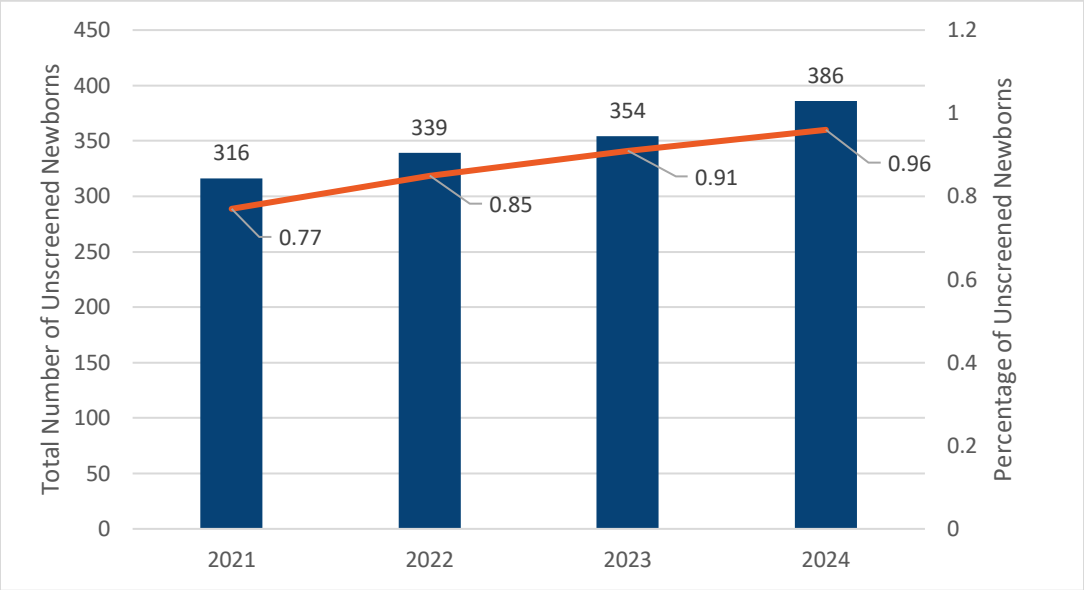
		Number of Cases Second-Tier Molecular Assessment
MPS1 (IDUA)	No mutations identified	0
	Pseudo deficiency	2
	One variant identified	3
	Two variants identified	2
	Total screened positive	**7**
		Number of Cases Second-Tier Molecular Assessment
Pompe (GAA)	No variants identified	2
	Pseudo deficiency	54
	One variant identified	7
	Two variants identified	4
	Total screened positive	**67**
		Number of Cases Second-Tier Molecular Assessment
Fabry (GLA)	No variants identified	136
	One variant identified	10 total *9 with late onset/inconclusive variants (5 of 9 with A143T variant)* *1 case with a likely pathogenic variant*
	Total screened positive	**146**
		Number of Cases Second-Tier Molecular Assessment
Gaucher (GBA)	No variants identified	0
	One variant identified	0
	Two variants identified	0
	Total screened positive	**0**

Vital Records Matching: Unscreened Babies

In 2021, the newborn screening program initiated vital records matching to track and determine how many babies born in Oregon received screening by linking the newborn screening record to the birth record. Birth records contain additional information that helps to query reasons why a baby might not receive screening. Three factors were evaluated: place of birth, provider of record, and source of payment.

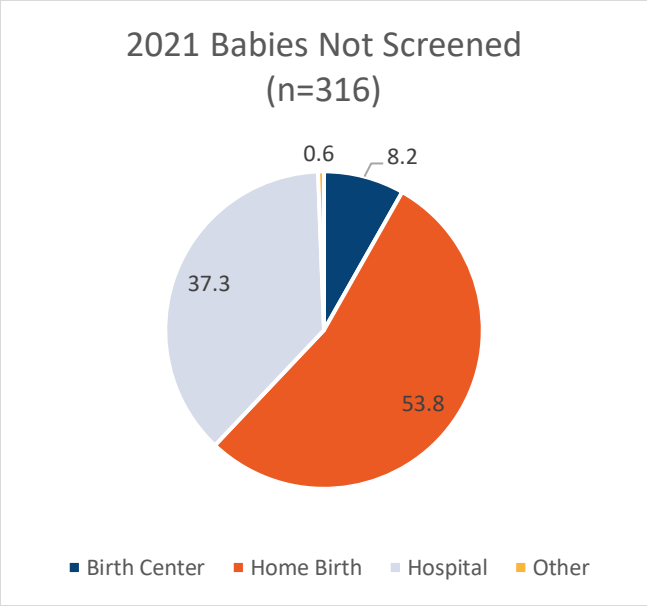
Four year trend – Oregon unscreened babies

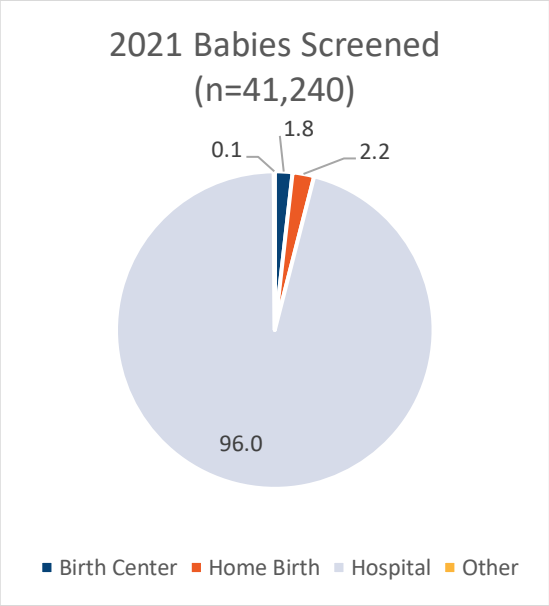
In 2021, there were 316 babies born in Oregon that did not have a record of screening (0.77%). Over the past four years, the number of unscreened babies has increased steadily to almost 1% in 2024.



Place of birth for Oregon unscreened babies, 2021

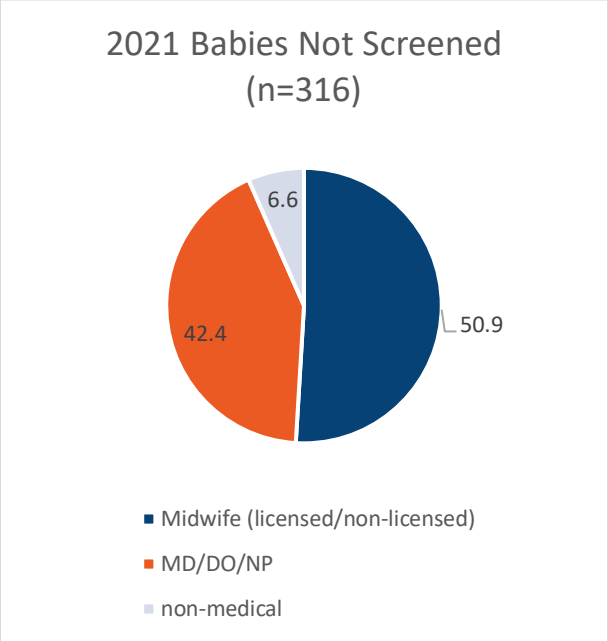
The majority of unscreened babies are born in a home birth setting (54%) as compared to 96% of screened babies born in the hospital setting. This finding has remained unchanged since 2021.

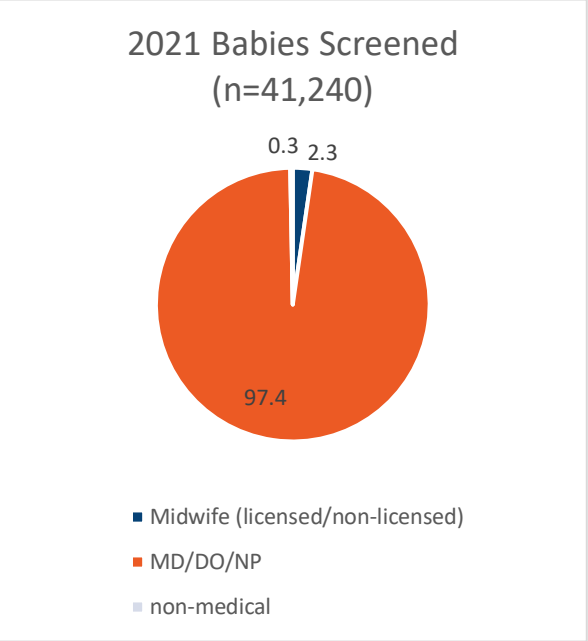




Birth provider for Oregon unscreened babies, 2021

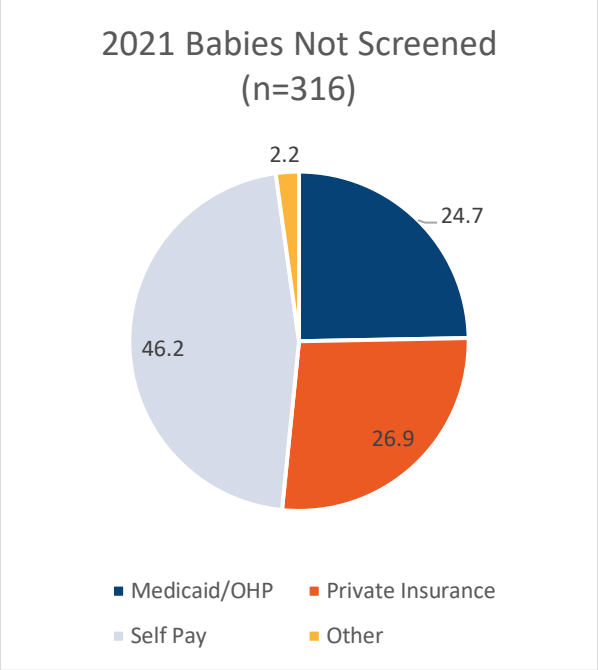
Similarly, midwives delivered about 51% of unscreened babies, medical providers averaged around 42%, and non-medical providers about 7%.

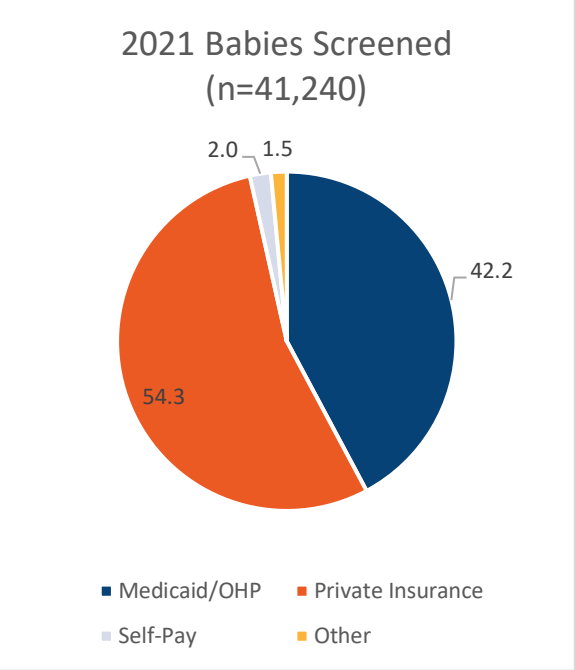




Method of payment for the birth, Oregon unscreened babies, 2021

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 50%. In comparison, less than 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 birth of their baby. As of December 31, 2024, 139 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.

2024 Projects and Accomplishments

In 2024, the NWRNBS program undertook multiple quality improvement projects focused on trainings, 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:

- 41 PCP clinics
- 16 birth facilities
- 3 community birth providers

In New Mexico:

- 2 trainings for all submitters

For military bases and Navajo nation:

- 5 trainings at 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 2024, the NWRNBS program completed 24 site visits at 20 different 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, a NBS process questionnaire, and a tour of the facility.

Of the 20 facilities visited,

- 3 facilities had zero unsatisfactory specimens at 3 months after the visit.
- 67% saw a decrease in unsatisfactory specimens at 3 months after the site visit.
- 85% saw a decrease in unsatisfactory specimens at 3 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 collection training video
- Specimen collection card training video
- Specimen collection card poster

All resources are available on the program website:

www.healthoregon.org/nbs

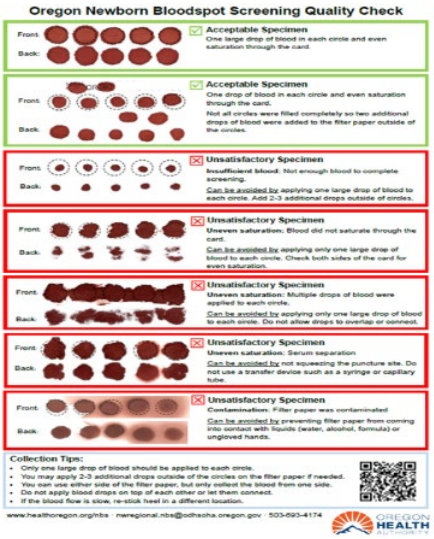


Figure 4: Quality check poster provided to submitters

Updated NICU specimen collection guidelines

The NBS program updated its specimen collection guidelines to match best practices established by the Clinical & Laboratory Standards Institute:

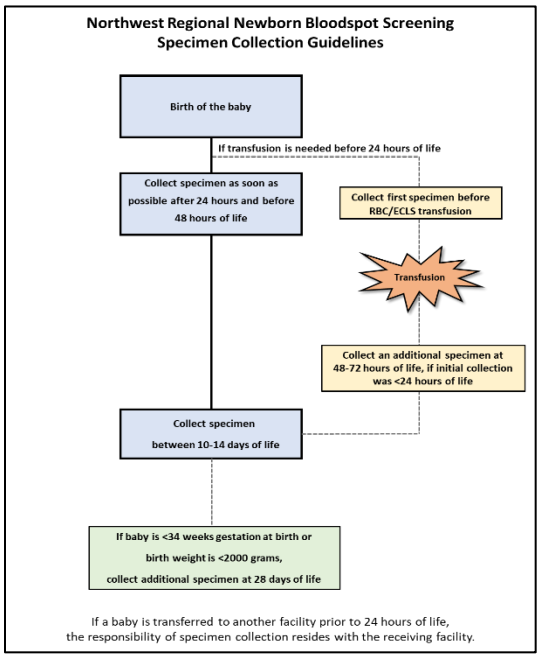


Figure 5: NWRNBS specimen collection guidelines

Updated guidelines include:

- Collect initial specimen between 24-48 hours of life, and a second specimen at 10-14 days of life.
- An additional specimen collection at 28 days of life is recommended ONLY for babies who are <34 weeks gestation at birth or have a birth weight of <2000 grams.
- Specimen collection should occur before an RBC transfusion. If collected prior to 24 hours, collect an additional specimen at 48-72 hours.
- If a baby is transferred to another facility prior to 24 hours of life, the responsibility of the specimen collection between 24-48 hours of life resides with the receiving facility.

Redesigned QA report for first screen submitters

The submitter quality assurance report redesign was completed in January 2024. In the new design (figure 6), the state's goals are clearly defined for each area, and data is now color-coded to indicate whether the goal is being met.

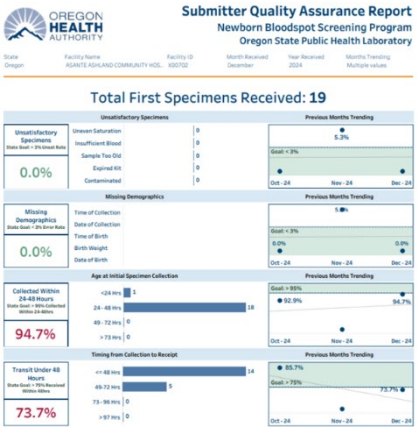


Figure 6: sample quality assurance report

Paperless reporting

On July 1, 2024, the NBS program initiated paperless reporting of newborn bloodspot screening results. Paper copies of the baby's normal newborn bloodspot screening report are no longer mailed to facilities, and providers can access the report using a web portal (SRV). Positive or inconclusive results are faxed directly to provider facilities to ensure providers are aware of any results requiring immediate action.

This implementation of paperless reporting has resulted in:

- 3.5 hours of staff time saved per day.
- Huge reduction in paper, envelope, and postage usage (both fiscal and environmental benefits).
- Providers can access patient results sooner.

Redesigned NBS specimen collection card

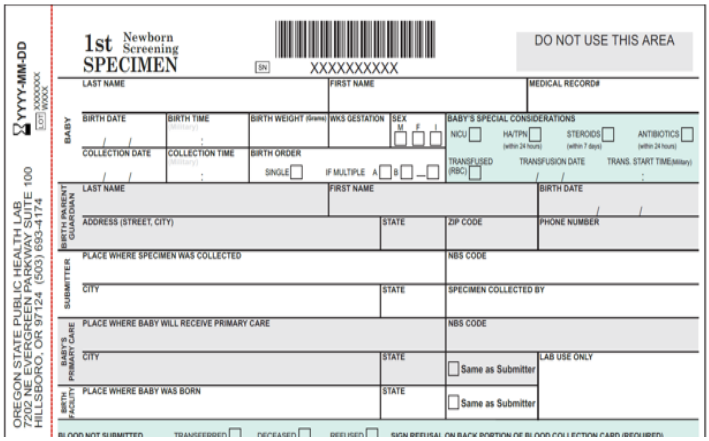


Figure 7: sample specimen card

In 2024, the program completed a redesign of the NBS specimen collection cards. The new cards will be 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.

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 at least through 2025, with the goal of implementing one single integrated and efficient LIMS with embedded analytical tools.

Legislative actions

In November of 2024, the rules that govern the NBS program were updated (OAR 333-024-1000 through 333-024-1100).

The following changes were made:

- Practitioners' manual was removed from rule.
- Updates were made to the collection guidelines for premature and Low Birth Weight newborns.
- Updates were made to the screening methodologies used within the laboratory.
- Language was added to ensure the reporting of confirmatory test results to the program for screened positive cases.
- Language was added to ensure the reporting of false negative cases (missed cases) to the program.
- Retention of residual specimens change from 18 months to 12 months.
- Language was added to address the inability of families to pay for newborn bloodspot screening.

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 Advisory board approved Infantile Krabbe Disease in 2024, and the NWRNBS advisory board plans to review this condition in 2025.

2025 Goals and Priorities

Jan/Feb/Mar

- Implement new screening algorithm for Congenital Hypothyroidism to help reduce the number of false positive screens.
- Begin distribution of the new specimen collection card.
- Review of Infantile Krabbe Disease by the NWRNBS advisory board.
- Validation of SeqStudio instrument for cystic fibrosis screening.
- Creation of a newborn screening video for education and outreach to the general public.

Apr/May/Jun

- Validate NeoLSD assay for Infantile Krabbe disease, with evaluation of incubation times (18 hours and 40 hours).
- Begin validation of GAMT deficiency.
- Updates to the Practitioner's Manual.
- Updates to the cutoff for succinylacetone to reduce false positives for tyrosinemia type I.
- Updates to the biotinidase procedure to reduce false positives.

Jul/Aug/Sep

- Validate Sebia for hemoglobinopathy screening.

Oct/Nov/Dec

- Implement screening for Infantile Krabbe screening.
- Implement screening for GAMT deficiency.

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 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 *(in process).*

Funding Model

- ☐ Explore additional funding models for the program.
- ☐ Consider invoicing for screening services rather than pre-pay model.

Laboratory

- ☑ Redesign NBS collection card and data elements.
- ☑ Modify the congenital hypothyroidism screening algorithm.
- ☐ Improve and expand the state contracted courier service *(in process).*
- ☐ 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 *(in process).*
- ☐ Consider revamping the OR NBS website.

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 *(in process).*
- ☐ 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. army and naval bases. The program provides screening for 45 conditions and reports results within 5-7 days of life.

In 2024, it screened almost 125,000 specimens, including providing 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 opportunity to further reduce the number of unsatisfactory specimen collections, but the additional provider education and tool kits implemented in 2024 may impact this number in 2025.

All metrics tracked in the analytical phase have been improving for the past three years. Oregon NBS has exceeded its goals for time from receipt of first specimen to reporting of results in 2023 and 2024. It is nearing its goal for overall time from birth to results reporting, but still has room for growth in this area.

In 2023, 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, but is still under 1%. 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 2024 included:

- Collection trainings and site visits for hospitals, clinics, and community birth providers.
- Updated resources for submitters.
- Changes to specimen collection guidelines.
- Redesigned QA report form and specimen collection cards.
- Implementation of paperless reporting.
- Selection of a new LIMS vendor.

In 2025, NWRNBS plans to:

- Add new conditions to testing panel.
- Continue to improve vital records matching.
- Improve efficiency through quality improvement projects.
- Update the Practitioners' Manual.
- Continue work on improvement and implementation of new LIMS.

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 children 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!