

Midwife Bulletin



Washington State
Office of
Newborn Screening

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Welcome

Welcome to the First Edition of our Midwife Newborn Screening (NBS) Bulletin. Midwives play a critical role in ensuring every newborn has the best possible start in life, including timely and accurate newborn screening. We recognize that midwives often work in diverse and resource-limited settings, yet your role is essential in identifying conditions early and guiding families through follow-up.

This bulletin is designed specifically for you. In each edition, we'll share targeted guidance, practical tools and key updates to support your work in NBS. Whether you're collecting samples, educating families, or coordinating care, we hope you find this resource informative and relevant to your everyday practice.

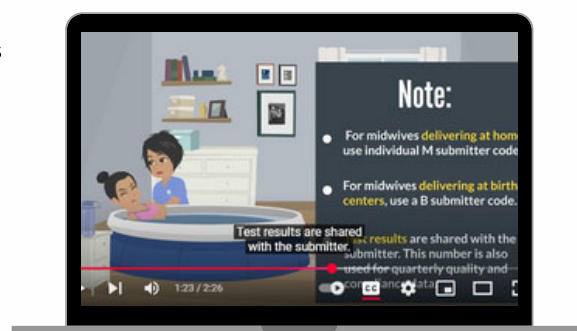
Together, we can ensure every newborn in Washington gets the timely screening they deserve.

NBS Resource Spotlight

Did you know incorrect demographic information on NBS cards can affect result analysis and/or delay follow-up care?

Our program created various new resources to help specimen submitters understand how to correctly complete NBS cards including short, animated videos and instructional handouts.

All demographic videos and card resources are available for viewing at www.doh.wa.gov/nbs-cards.



2024 Newborn Screening Milestones

Reduced transit times State funded over-night courier services for initial specimens premiered February 2024. Since then, we've reduced the average transit time for specimens collected outside hospitals by five hours. See the next page for information on our 2025 courier services.

Updated Screening Cards Updated Washington NBS cards were introduced in Spring 2024 as part of our ongoing efforts to reduce demographic errors and promote greater equity and inclusion in our work.

Education Campaign Our program began an educational campaign in September 2024 to improve specimen quality and reduce demographic errors.

Co-Propel Grant In June 2024, the Center for Public Health Innovation (CPHI), a non-profit organization dedicated to advancing public health, was awarded the Co-Propel Grant to support its collaboration with the Washington Newborn Screening (NBS) Program. The Co-Propel Grant, funded by HRSA, aims to support NBS expansion, develop long-term follow-up infrastructure, and promote the exchange of health information related to NBS orders and results. CPHI is working with the Washington NBS Program on a range of initiatives to enhance NBS services and resources. See the 2025 Forecast below for details on upcoming midwife-focused initiatives.

Positive Cases *More than 200 babies were identified with NBS conditions in 2024! See the table below for data on babies born in Washington State in 2024 who were confirmed as having NBS conditions as of February 2025.*

Newborn Screening Disorder	True Positives
Beta-ketothiolase deficiency (BKT)	1
Biotinidase deficiency (BIO)	1
Congenital adrenal hyperplasia (CAH)	7
Congenital hypothyroidism (CH)	137
Cystic fibrosis (CF)	15
Glycogen storage disorder type II (Pompe)	2
Isovaleric acidemia (IVA)	2
Medium-chain acyl-CoA dehydrogenase deficiency (MCAD)	6
Non-Panel Disorders	4
Phenylketonuria (PKU)	5
Propionic acidemia (PROP)	1
Severe combined immunodeficiency (SCID)	2
Sickle cell diseases and Hemoglobinopathies (HGB)	26
Spinal Muscular Atrophy (SMA)	8
Very-long chain acyl-CoA dehydrogenase deficiency (VLCAD)	1
X-linked adrenoleukodystrophy (X-ALD)	8
Total	226

2025 NBS Forecast



Transition to Qualitative Data We are in the process of updating our mailers to better support our healthcare partners. As part of this update, we are transitioning from reporting quantitative results to qualitative results. Once this change takes place, results will be reported as “normal” or “abnormal.” Reference ranges will no longer be reported. Our goal is to make test results easier to interpret and to streamline the review process for providers.

End of Paper Mailers Our program will cease mailing NBS results for babies with normal findings at the end of 2025. We will continue to mail results with abnormal findings in addition to contacting the care team directly. To ensure access to all results, please sign up for Secure Remote Viewer (SRV) by visiting doh.wa.gov/nbs-srv. A virtual SRV training will be announced in the coming weeks, please visit our website for details.

Education Campaign Education efforts to improve specimen quality and decrease demographic errors will continue in 2025. NBS trainings are available to all specimen collectors. We are also attending various community events to educate the public on newborn screening.

Courier Services Shipping of 2025 NBS mailing supplies for midwives is underway. UPS shipping services are not being offered this year. Each midwife will receive FedEx shipping labels and envelopes. We ask that you use them to ship all newborn screening specimens collected in home settings. Birthing centers and hospitals will continue to receive courier services by General Logistics Systems (GLS).

Focus Groups CPHI is conducting interviews with cystic fibrosis and sickle cell healthcare providers and parents of children within the NBS community. These interviews will be conducted solely by CPHI. Participants have the opportunity to remain anonymous and will receive compensation for their time. Feedback will be used to improve short-term follow-up and aid in the development of long-term follow-up.

Midwife Initiatives

Midwife Website We've created doh.wa.gov/nbs-midwives as a central hub for midwife resources, including this newsletter. Future bulletins and events will be posted there.

Continuing Education Units (CEU's) In collaboration with CPHI, our program has submitted an application to the Midwifery Education and Accreditation Council (MEAC) to offer continuing education units (CEUs). We are excited to announce plans to host the first webinar in July, pending approval from MEAC. An announcement with registration information will be made via our email subscription list and posted on our midwife website once we have received approval.

Screening Supplies We recognize that midwives often face unique challenges, including limited resources and the burden of paying out of pocket for NBS supplies. We are working with CPHI to pilot a program that provides midwives who participate in our education course with NBS supplies such as heel warmers, lancets, and materials that enable the safe transport of specimens collected in home settings without compromising specimen quality.

Please note, initiatives facilitated in partnership with CPHI are funded by federal grant money. These activities are contingent upon the availability of federal funds and may be postponed or cancelled in the event of a reduction or termination of federal funding.