

DATE: August 1, 2022

TO: Hearing attendees and commenters: Oregon Administrative Rules chapter 333, division 24 – "Update fees and exemption language for newborn bloodspot screening collection kits"

FROM: Brittany Hall, Hearing Officer  
Public Health Division

cc: John Fontana, PhD, (HCLD) ABB  
Laboratory Director  
Oregon State Public Health Laboratory  
Public Health Division

Patrice K. Held, PhD, FACMG  
Manager, Northwest Regional Newborn Bloodspot Screening Program  
Oregon State Public Health Laboratory  
Public Health Division

SUBJECT: Presiding Hearing Officer's Report on Rulemaking Hearing and Public Comment Period

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### Hearing Officer Report

**Date of Hearing:** June 16, 2022, via Microsoft Teams

**Purpose of Hearing:** To receive testimony regarding the Oregon Health Authority (Authority), Public Health Division, Oregon State Public Health Laboratory's (OSPHL) Northwest Regional Newborn Bloodspot Screening Program's (NWRNBS Program) proposed permanent amendments to administrative rules in chapter 333, division 24 pertaining to newborn screening. The proposed rule changes to OAR 333-024-1100 seeks to increase fees for newborn bloodspot screening.

**Hearing Officer:** Brittany Hall

**Testimony Received:** Two individuals provided oral testimony at the hearing. Their comments are briefly summarized as follows:

Silke Akerson, CPM, MPH, Executive Director, Oregon Midwifery Council

Ms. Akerson spoke on behalf of the Oregon Midwifery Council, which represents midwives who attend home births and birth center births in Oregon. She began by saying that they are huge supporters of newborn screening and the newborn screening program and appreciate the increased costs that the program is facing. She stated that they are deeply concerned about the proposed fee increase, which would more than double the cost of newborn screening in Oregon and have huge impacts on families, midwives, and small businesses. She opined that if the fee increase is implemented, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses.

Ms. Akerson stated that the proposed fee increase will disproportionately impact approximately 1,800 families per year who plan to have a home birth or birth center birth in Oregon and the midwives who serve them. Newborn screening kits for most of this population are paid for by the families themselves or by the midwives' small businesses. She provided an example of how the cost of newborn screening kits would go from \$480 a month to \$1050 a month for a small home birth practice attending 6 births a month if the fee increase were implemented as proposed. Home birth midwives are unable to bill insurance for supply costs, including newborn screening, so the midwives would have to decide whether to provide newborn screening at a steep financial loss or to require families to pay for the newborn screening kit themselves with the worry that passing on the increase cost would cause some families to forgo the screening entirely.

Ms. Akerson recognized that the program has a fee waiver for the screening kit for uninsured, low-income families, but the waiver will address only a small portion of the families affected by this. She also recognized that the Oregon Health Authority will ensure that the Oregon Health Plan (OHP) will reimburse midwives for the full increased cost of the newborn screening kits for families planning a home birth or birth center birth that are covered by OHP, but this will only apply to 21.2% of these births.

Ms. Akerson referred to a model like one used in Washington state where newborn screening kits are provided to healthcare providers without charge and the program directly bills private insurers and Medicaid for the cost of the test. She also referred to a model used in New York and other states where newborn bloodspot screening is free to all families and funded by the state. She encouraged the program and members of the Oregon Legislature to look at these and other approaches to meet the increasing costs of the program.

Ms. Akerson also submitted written comments similar to her oral testimony that are attached to this report as Exhibit 1.

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

The Oregon Newborn Bloodspot Screening (NBS) Program does not currently have the data systems or contracts in place to support billing private insurance or Medicaid for NBS services. However, the Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. Oregon Health Authority will ensure that midwives are represented on that subcommittee. It is probable that this potential solution will be explored with the subcommittee.

Megan Coppock, Andaluz Waterbirth Center

Ms. Coppock introduced herself as a licensed certified professional midwife. She agreed with all that Ms. Akerson stated in her oral testimony and provided experience in her career as a home birth practitioner and a birth center provider to reiterate the points made by Ms. Akerson. In both experiences the midwives had to buy a good amount of the newborn screens at the current cost, hoping that they can recoup the fee from clients. Only about 20% of the time do they get the fee recouped, and midwives have yet to find a way to add that fee without having the burden on themselves.

She stated that they work with a specific population who, more often than families who use hospitals, are inclined to consider and often decline screenings and the fee is part of the decision-making for a lot of families. She opined that seeing the fee double will mean an increase in families declining the screening. She further opined that the screening is helpful, as is being able to have information that the screening provides in order to provide families with intervention as soon as possible, and it would be a detriment to see families decline this due to an increase in fees.

Ms. Coppock closed by saying that she hopes that Oregon can consider a model similar to Washington where the burden of trying to recoup the financial piece would no longer be on the midwives or have to be passed on to the families.

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

In addition, Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

The Oregon Newborn Bloodspot Screening (NBS) Program does not currently have the data systems or contracts in place to support billing private insurance or Medicaid for NBS services. However, the Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. It is probable that this potential solution will be explored with the subcommittee.

**Other Comments:** Fifteen individuals or organizations submitted additional written comments to the Division within the period allotted for public comment, which closed on June 30, 2022 at 5:00 PM PDT. These comments are briefly summarized as follows:

Hannah Payseno, CPM, LDM

Ms. Payseno is a licensed midwife in Oregon serving as a provider for pregnant women and their families. She wrote that "I and my clients are deeply concerned about the proposed fee increase, which would more than double the cost of newborn screening in Oregon and have huge impacts on families, midwives, and small businesses." She opined that "if the fee increase is implemented as planned, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses." She further wrote that "as a home birth midwife I am unable to bill insurance for supply costs, including newborn screening" and expressed her concern that the increased cost of the newborn screening kit will either cost her more annually if she continues to provide the screenings at no charge to clients, or that some families will forgo the screening entirely if she passed the cost of the newborn screening kit to them.

Ms. Payseno wrote to "encourage the [Northwest Regional Bloodspot Screening] program and the members of the Oregon legislature to look at other approaches to meet the costs of the program." She suggested "a model like Washington state where newborn screening kits are provided to healthcare providers without charge and the program directly bills private insurers and Medicaid for the cost of the tests."

Ms. Payseno's written comments are attached to this report as "Exhibit 2".

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

In addition, Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

The Oregon Newborn Bloodspot Screening (NBS) Program does not currently have the data systems or contracts in place to support billing private insurance or Medicaid for NBS services. However, the Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. It is probable that this potential solution will be explored with the subcommittee.

Hannah Swan, CPM, LDM

Ms. Swan is a licensed midwife practice in rural Oregon, serving a community that is often paying cash for services out of pocket. She wrote "I have major concern that by increasing the fee for metabolic screening over double will increase the amount of families decide [*sic*] to not get the testing, just based on that price increase.

Ms. Swan's written comments are attached to this report as "Exhibit 3".

**Agency response:** The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

In addition, Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

Hayley Hirt, RN, CNM

Ms. Hirt opined that "this increase is a huge burden for community midwives who often pay for this test out of pocket (because insurances don't reimburse) or pass the cost on to the family." She wrote "if this were to go into effect, midwives may ask parents to have this test done at a pediatric office within the first 48 hours of life, a huge barrier for new parents just trying to survive the first couple of days with a newborn."

Ms. Hirt's written comments are attached to this report as "Exhibit 4".

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

In addition, Oregon Administrative Rule (OAR) 333-024-1020 specifies the persons responsible for ensuring that first specimens are collected and submitted. If a healthcare provider is considering process changes, the program suggests they review this rule.

Lydia Douglas

Ms. Douglas is a Licensed Direct Entry Midwife in Oregon. She wrote that she "usually provide[s] the NBS kits to my families as part of their midwifery care, but with the price increase, I will have to have families buy the kits themselves." She further wrote that she is "concerned that families will begin opting out of this important screening due to cost" and opined that "this is going to cost babies their lives."

Ms. Douglas's written comments are attached to this report as "Exhibit 5".

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

In addition, Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

Mariah Wharton, DNP

Ms. Wharton wrote to express concern regarding the proposed price increase for newborn screening tests in Oregon, opining that "this more than double price increase will have a HUGE impact on families, midwives, and small businesses." She further opined that "the price increase will directly decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses." She wrote that "this could have lifelong ramifications for newborns who may suffer from undiagnosed and untreated disorders."

Ms. Wharton wrote that "this proposed fee increase will disproportionately impact the approximately 1,800 families per year who plan to have a home birth or birth center birth in Oregon and the midwives who serve them" as the "newborn screening kits for most of this population are paid for by the families themselves or by the midwives' small

businesses." She opined that "midwives are already living in fear of the major impact this fee increase would have on our businesses and the families we serve."

Ms. Wharton requested that the fee increase be reconsidered because "the Oregon families, midwives, and small businesses most affected by this proposed change cannot bear a cost increase that more than doubles the expense of this important and life-saving screening. The proposed fee increase will discourage families who pay directly for this testing from providing it for their babies."

Ms. Wharton's written comments are attached to this report as "Exhibit 6".

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

Melissa Gordon-Magnus, CPM, LDM, LM, Nest Midwifery

Ms. Gordon-Magnus has been a practicing midwife in Oregon since 2006 and wrote that she "deeply believe[s] in state advised Newborn Screening" and has had experience in catching carrier traits and occasionally a disorder valuable to families in her care through this screening program. Like other commenters, she wrote to request reconsideration of the fee increase, stating that she is "deeply concerned about the proposed fee increase, which would more than double the cost of newborn screening in Oregon and have huge impacts on families, midwives, and small businesses." She opined that "if the fee increase is implemented as planned, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses." Also like other commenters, she wrote to "encourage the [Northwest Regional Newborn Bloodspot Screening] program and the members of the Oregon legislature to look at other approaches to meet the costs of the program," citing the model that Washington state uses that is described in Ms. Payseno's comments above and attached in Exhibit 2. Ms. Gordon-Magnus also referenced a model used in New York and other states "where newborn screening is free to all families and funded by the state."

Ms. Gordon-Magnus's written comments are attached to this report as "Exhibit 7".

**Agency response:** Thank you for your support and acknowledgement of the importance of newborn bloodspot screening and your insights into the billing challenges faced by midwives.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

The Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. The Oregon NBS Program anticipates that looking at other states' funding models and their potential applicability to Oregon will be explored with the subcommittee.

Lynette Pettibone, MSM, LM, LDM, CPM, The Bridge Birth and Family Services

Ms. Pettibone wrote that she is not opposed to the fee increase as it is important testing and costs have increased, but noted that "it is an unusually significant jump – over 100%."

Ms. Pettibone wrote to "propose OHA also implement a program for community providers (mostly midwives) to receive screens FREE OF CHARGE and submit insurance billing information along with the specimen. OHA/Newborn screening lab would then bill insurance companies on behalf of the families for which the screen is provided." She noted that this procedure was implemented in Washington state several years ago and, being licensed in Washington as well as Oregon, she offered her assistance in connecting OHA with Washington Health Care Association (WHCA) staff who worked to implement that program.

Ms. Pettibone's written comments are attached to this report as "Exhibit 8".

**Agency response:** The Oregon Newborn Bloodspot Screening (NBS) Program does not currently have the data systems or contracts in place to support billing private insurance or Medicaid for NBS services. However, the Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. It is probable that this potential solution will be explored with the subcommittee.

Cheryl Hanna, MD, Oregon Pediatric Society

Dr. Hanna provided written comments on behalf of the Oregon Pediatric Society (OPS). She wrote that she is a retired pediatric endocrinologist with 35 years of experience working with the Newborn Screening Program and is also an original member of the Northwest Regional Screening Program (NWRNBS) Advisory Board that was created by the legislature in 2019.

Dr. Hanna opined that "newborn screening is one of the major public health successes of the 20<sup>th</sup> century" and stated that "the Oregon Pediatric Society supports that proposed rule changes to increase the fees for newborn bloodspot screening kits."

In addition to the increase in fees for the newborn bloodspot screening kits, Dr. Hanna noted that "the proposed rule change also permits the program to authorize a fee exemption in lieu of a refund or kit replacement." She further wrote that "OPS endorses these rulemaking changes" and noted that "the additional fee revenue will be used to modernize services in alignment with national and local recommendations and cover an anticipated budget shortfall for the program." Dr. Hanna opined that the proposed fee exemption, rather than the current reimbursement process, "should improve the likelihood that no infant in Oregon will miss the opportunity to have a newborn screen.

Dr. Hanna's written comments are attached to his report as "Exhibit 9".

**Agency response:** The Oregon Newborn Bloodspot Screening Program thanks Dr. Hanna and the Oregon Pediatric Society for their input on and support for this rule change.

Patricia Edmonds

Ms. Edmonds opined that "for so many families who do not have insurance or inadequate compensation these costs are prohibitive!"

Ms. Edmonds's written comments are attached to this report as "Exhibit 10".

**Agency response:** The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

Sarah Dinger, CPM, LDM

Ms. Dinger is a licensed community midwife in Portland and wrote "to request that the bloodspot screening program bill insurance directly, as this would simplify the process for us with both Medicaid and private insurance clients." She opined that "this would be a huge improvement in this process."

Ms. Dinger's written comments are attached to this report as "Exhibit 11".

**Agency response:** The Oregon Newborn Bloodspot Screening (NBS) Program does not currently have the data systems or contracts in place to support billing private insurance or Medicaid for NBS services. However, the Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. It is probable that this potential solution will be explored with the subcommittee.

Shannon Klein, MBA, BSN, RN, Manager of the Family Birth Center, Columbia Memorial Hospital

Ms. Klein requested that the Oregon State Public Health Laboratory (OSPHL) elaborate on the proposed courier and shipping services described in the Notice of Proposed Rulemaking. Following a response from the OSPHL, which can be read in Ms. Klein's written comments attached to this report as "Exhibit 12," Ms. Klein wrote "we already pay to have a courier when FedEx won't work and with the rising cost of the screening cards, it will hit small hospitals particularly hard."

**Agency response:** The Oregon Newborn Bloodspot Screening Program is currently piloting two timeliness projects which are providing specimen transport services with providers or facilities for whom data shows support would benefit timeliness of screening. Funding for this project is through a grant and the Oregon legislature, separate from core program funding. One intended enhancement to the newborn bloodspot screening program from the fee change is to leverage the lessons learned from these pilot projects to expand these services to most or all providers collecting first screen specimens in Oregon.

Terri Bates-Knippert, RN, BSN, BAE, Manager, Patient Care Service (Obstetrics), ATRMC Family Birth Center

Ms. Bates-Knippert wrote on behalf of the Asante Family Birth Center at Three Rivers Medical Center to oppose the fee increase for the newborn bloodspot screening kits. She opined that "the fee increase is to cover enhancements that have not proven to be effective or beneficial" and noted that "historically, our rural entity (ATRMC) does not have transport issues nor do we have a large population that declines the newborn screening; therefore, the enhancements do not support added value for such a cost

increase." Ms. Bates-Knippert further wrote to "propose that the suggested enhancements take effect after the state provides hospitals with quantitative data to support a positive impact." She further opined that "currently, the burden for hospitals with this cost increase who may not actually see benefits does not seem equitable."

Ms. Bates-Knippert requested that an opt-in/opt-out action be considered for various areas that serve populations who do not meet criteria.

Ms. Bates-Knippert's written comments are attached to this report as "Exhibit 13".

**Agency response:** The Newborn Bloodspot Screening Program values the input of our healthcare partners in rural settings. The enhancements planned have been utilized in other states and found to benefit both rural and urban settings. Many enhancements to education and follow-up services will support all providers and infants in Oregon. Infants are just as likely to be diagnosed with a condition identified through newborn bloodspot screening regardless of whether the birth occurs in a rural or urban area.

Tracee Goodell, CCMA, Evergreen Family Medicine

Ms. Goodell wrote to express concern that occasionally parents lose the newborn screening kits. She opined that "if there is a charge to replace them, we will have a lot of parents opt out of this testing."

Ms. Goodell's written comments are attached to this report as "Exhibit 14".

**Agency response:** The proposed rule change does not affect whether a fee is charged for a lost newborn bloodspot screening kit. The Oregon Newborn Bloodspot Screening Program currently charges a fee for the purchase of a single newborn bloodspot screening collection kit to be used when the second part of the original kit is misplaced or lost.

Orna Karlin, BSN, RN

Ms. Karlin opined that "a price increase in these kits will disproportionately affect home birth and birth center families/practices, who already face steep challenges in providing a safe alternative to hospital birth." She requested that the price increase be reconsidered or that an easily accessible fee waiver be built in for private pay families.

Ms. Karlin's written comments are attached to this report as "Exhibit 15".

**Agency response:** Thank you for your comment, acknowledgement of the importance of newborn bloodspot screening, and your insights into the challenges for healthcare providers.

The Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. Oregon Health Authority will ensure that midwives and other affected parties are represented on that subcommittee.

The Oregon Newborn Bloodspot Screening (NBS) Program offers a fee waiver for families who do not have insurance and have a qualifying income for the waiver. Information about this waiver is on our website. As a result of feedback during this rulemaking, the Oregon NBS program will begin permitting a fee waiver be submitted with a kit order form, rather than requiring payment for the kit and providing reimbursement. In addition, the Oregon NBS Program will be making information about the fee waiver more visible on our website based on feedback provided by our partners during this rulemaking.

Catherine Akerson Bailey, CPM, LDM

Ms. Akerson Bailey wrote on behalf of her midwifery practice, Unfurling Birth and Midwifery Services. She stated that she has been a licensed midwife in Oregon since 2014 and the NWRNBS Program is important to her and the clients she serves. She expressed concern that "this huge fee increase, which more than doubles the current cost, will prevent some people from choosing the screening," and wrote that she "fear[s] for the safety and well-being and long-term risk to these newborns this fee increase will have."

Ms. Akerson Bailey wrote that in her practice she pays for the newborn screening out of pocket and is sometimes reimbursed by insurance or families. She noted that "the Oregon Health Plan (OHP) is supposed to reimburse me for these tests but they have not yet finished the billing pathway to allow this." She stated that if OHP is able to fix this issue, she will be able to bill OHP for screening tests for her OHP clients, but clients on private insurance who have to pay out of pocket for a portion of their care may choose to not do the screening if the fee increases so drastically. She opined that "I would not be able to afford to cover these newborn screening tests for my clients at the increased cost and would like to continue to be able to for people on private insurance who can't prioritize the cost."

Ms. Akerson Bailey further wrote that "I am aware that the NWRNBS Program has a fee waiver for the screening kit for the uninsured, low-income families but almost all of my clients in Oregon are either on Medicaid or on private insurance and unable to afford any extra fees."

Ms. Akerson Bailey's written comments are attached to this report as "Exhibit 16."

**Agency response:** Thank you for your comment, acknowledgement of the importance of newborn bloodspot screening, and your insights into the billing challenges faced by midwives.

The Oregon Health Plan has implemented a change to reimburse the full cost of newborn bloodspot screening kits for community birth providers and freestanding birth centers separate from the supply bundle reimbursement which increases reimbursement to midwives. They released a [provider bulletin](#) on this topic in June [linked].

The Northwest Regional Newborn Bloodspot Screening Advisory Board, which advises the Oregon NBS Program, has formed a subcommittee on long-term program funding to explore the best ways to fund the NBS program long-term. Oregon Health Authority will ensure that midwives are represented on that subcommittee.

In addition, Oregon Administrative Rule (OAR) 333-024-1030 states that a facility or individual responsible for collecting newborn bloodspot screening specimens must do so for every infant born in Oregon. An exemption for newborn bloodspot screening may be permitted if the parent(s) adhere to a religion opposed to such testing (ORS 433.285; OAR 333-024-1050). This is the only reason exemption is currently permitted.

June 21, 2022

RE: Proposed rule change to OAR 333-024-1100

To Whom it May Concern,

I am writing on behalf of the Oregon Midwifery Council to provide public comment on the proposed rule change and fee increase in the Northwest Regional Newborn Bloodspot Screening Program (NWRNBS Program). The Oregon Midwifery Council is the professional organization for midwives who attend home births and birth center births in Oregon. We are deeply concerned about the proposed fee increase, which would more than double the cost of newborn screening in Oregon and have huge impacts on families, midwives, and small businesses. If the fee increase is implemented as planned, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses.

This proposed fee increase will disproportionately impact the approximately 1,800 families per year who plan to have a home birth or birth center birth in Oregon and the midwives who serve them. Newborn screening kits for most of this population are paid for by the families themselves or by the midwives' small businesses. This fee increase may not have much impact on large businesses like hospitals and insurance companies but midwives are already living in fear of the major impact this fee increase would have on our businesses and the families we serve. As an example, a small home birth practice with just 2 employees attending 6 births a month would go from paying \$480 a month to \$1,050 a month for newborn screening kits. Because home birth midwives are unable to bill insurance for supply costs, including newborn screening, midwives would have to decide whether to provide newborn screening at a steep financial loss or to require families to pay for the newborn screening kit themselves with the worry that passing on the increased cost would cause some families to forgo the screening entirely.

We are aware that the NWRNBS Program has a fee waiver for the screening kit for uninsured, low-income families but that will address only a small portion of the families affected by this. We are also aware that the NWRNBS Program has worked with the Oregon Health Authority to ensure that OHP will reimburse midwives for the full increased cost of newborn screening kits for families planning a home birth or birth center birth. This is very helpful for the 21.2% of these births that are covered by OHP but will not address the concern for the large majority of these births that are not.

We understand that the costs of newborn screening are increasing and that the NWRNBS Program needs to increase revenue to cover these costs. We encourage the program and the members of the Oregon legislature to look at other approaches to meet the costs of the program. The NWRNBS Program could switch to a model like Washington state where newborn screening kits are provided to healthcare providers without charge and the program directly bills private insurers and Medicaid for the cost of the tests. Alternately Oregon could move to a model where newborn bloodspot screening is free to all families and funded by the state as is done in New York and other states.

Newborn screening is meant to be universal screening, reaching every newborn in Oregon. This proposed cost increase would compromise the goal of universal screening. The Oregon families, midwives, and small businesses most-affected by this proposed change cannot bear a cost increase that more than doubles the expense of this important and life-saving screening. This proposed fee increase will discourage families who pay directly for this testing from providing it for their babies. Please reconsider this fee increase.

Thank you for your consideration,

Silke Akerson, MPH, CPM, LDM

Oregon Midwifery Council

**From:** [Hannah Payseno](#)  
**To:** [Public Health Rules](#)  
**Subject:** RE:Proposed rule change to OAR 333-024-1100  
**Date:** Thursday, June 23, 2022 12:36:20 PM

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To Whom it May Concern,

I am writing to provide public comment on the proposed rule change and fee increase in the Northwest Regional Newborn Bloodspot Screening Program (NWRNBS Program). I am a licensed midwife in Oregon serving as a provider for pregnant women and their families. I and my clients are deeply concerned about the proposed fee increase, which would more than double the cost of newborn Screening in Oregon and have huge impacts on families, midwives, and small businesses. If the Fee increase is implemented as planned, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses.

This proposed fee increase will cost me anywhere from \$1000-\$2000 more annually as I currently provide the screenings no charge for my clients. As a home birth midwife I am unable to bill insurance for supply costs, including newborn screening, i would have to decide whether to provide newborn screening at a steep financial loss or to require families to pay for the newborn screening kit themselves with the worry that passing on the increased cost would cause some families to forgo the screening entirely.

I am aware that the NWRNBS Program has a fee waiver for the screening kit for uninsured, low-income families but that will address only a small portion of the families affected by this. We are also aware that the NWRNBS Program has worked with the Oregon Health Authority to

ensure that OHP will reimburse midwives for the full increased cost of newborn screening kits

for families planning a home birth or birth center birth. This is very helpful for the 21.2% of these births that are covered by OHP but will not address the concern for the large majority of these births that are not.

We understand that the costs of newborn screening are increasing and that the NWRNBS Program needs to increase revenue to cover these costs. We encourage the program and the members of the Oregon legislature to look at other approaches to meet the costs of the program.

The NWRNBS Program could switch to a model like Washington state where newborn screening kits are provided to healthcare providers without charge and the program directly bills private insurers and Medicaid for the cost of the tests.

Thank you for your consideration.

Sincerely,

Hannah Payseno, CPM, LDM

## EXHIBIT 3

**From:** [Hannah Swan](#)  
**To:** [Public Health Rules](#)  
**Subject:** Newborn Screening Increase  
**Date:** Thursday, June 9, 2022 5:27:05 PM

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Dear Oregon Health Authority,

I would like to make comment on the fee increase for the blood spot newborn screening kits. I am a licensed midwife practice in rural Oregon, serving a community that is often paying cash for my services out of pocket. I have major concern that by increasing the fee for metabolic screening over double will increase the amount of families decide to not get the testing, just based on that price increase. I am an advocate for the blood spot screening to be done and I think it can give invaluable information when it comes to babies' health. I want to see this continue and have fear that less families will opt out of getting their children tested when they hear the price of \$175.

Thank you for taking public comment into consideration, I appreciate the effort each of you put into keeping our families safe.

Sincerely,  
Hannah Swan CPM, LDM

**From:** [Hayley Hirt](#)  
**To:** [Public Health Rules](#)  
**Subject:** Increase in charge for newborn metabolic screening  
**Date:** Wednesday, June 22, 2022 10:20:30 AM

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Hello,

I am writing to provide my comments and perspective on the increase in cost of the newborn metabolic screenings. This increase is a huge burden for community midwives who often pay for this test out of pocket (because insurances don't reimburse) or pass the cost on to the family. If this were to go into effect, midwives may ask parents to have this test done at a pediatric office within the first 48 hours of life, a huge barrier for new parents just trying to survive the first couple of days with a newborn. This test saves lives and should have FEWER barriers to access not more.

Thanks

-Hayley Hirt, RN, CNM

## EXHIBIT 5

**From:** [Lydia Douglas](#)  
**To:** [Public Health Rules](#)  
**Subject:** Newborn Screen Fee Increase  
**Date:** Monday, June 27, 2022 9:10:37 AM

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My name is Lydia Douglas. I am a Licensed Direct Entry Midwife in Oregon. I usually provide the NBS kits to my families as part of their midwifery care, but with the price increase, I will have to have families buy the kits themselves.

I primarily serve low income families, and I am concerned that families will begin opting out of this important screening due to cost, and quite frankly, that is not okay. This is going to cost babies their lives.

**From:** [Mariah Wharton](#)  
**To:** [Public Health Rules](#)  
**Subject:** Newborn Screening Cost Increase Restricts Care - Please Reconsider  
**Date:** Tuesday, June 28, 2022 12:06:56 PM

You don't often get email from wharton.mariah@gmail.com. [Learn why this is important](#)

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To whom it may concern,

This letter is to express my deep concern regarding the proposed price increase for newborn screening tests in Oregon. This more than double price increase will have a HUGE impact on families, midwives, and small businesses. The price increase will directly decrease access to newborn bloodspot screening in Oregon and create a financial strain for families and small businesses. For those that chose to opt-out of the newborn screening due to financial strain, this could have lifelong ramifications for newborns who may suffer from undiagnosed and untreated disorders.

This proposed fee increase will disproportionately impact the approximately 1,800 families per year who plan to have a home birth or birth center birth in Oregon and the midwives who serve them. Newborn screening kits for most of this population are paid for by the families themselves or by the midwives' small businesses. This fee increase may not have much impact on large businesses like hospitals and insurance companies but midwives are already living in fear of the major impact this fee increase would have on our businesses and the families we serve.

Newborn screening is meant to be universal screening, reaching every newborn in Oregon. This proposed cost increase would compromise the goal of universal screening. The Oregon families, midwives, and small businesses most affected by this proposed change cannot bear a cost increase that more than doubles the expense of this important and life-saving screening. This proposed fee increase will discourage families who pay directly for this testing from providing it for their babies. Please reconsider this fee increase.

Sincerely,

Mariah Wharton, DNP  
Nurse-Midwife

**From:** [Melissa Gordon-Magnus](#)  
**To:** [Public Health Rules](#)  
**Subject:** Proposed Fee Increase for Newborn Screening  
**Date:** Tuesday, June 21, 2022 11:04:08 AM

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RE: Proposed rule change to OAR 333-024-1100

To Whom it May Concern,

I am writing on behalf of Oregon families in midwifery care, to provide public comment on the proposed rule change and fee increase in the Northwest Regional Newborn Bloodspot Screening Program (NWRNBS Program). I have been a practicing midwife in OR since 2006 and deeply believe in state advised Newborn Screening and have participated in catching carrier traits and occasionally a disorder valuable to families in my care, through this screening program. I am deeply concerned about the proposed fee increase, which would more than double the cost of newborn screening in Oregon and have huge impacts on families, midwives, and small businesses. If the fee increase is implemented as planned, it will decrease access to newborn bloodspot screening in Oregon and create financial strain for families and small businesses. There needs to be more support, and less barrier, to this screening process for families.

Because home birth midwives are unable to bill insurance for supply costs, including newborn screening, midwives would have to decide whether to provide newborn screening at a steep financial loss or to require families to pay for the newborn screening kit themselves with the worry that passing on the increased cost would cause some families to forgo the screening entirely. We understand that the costs of newborn screening are increasing and that the NWRNBS Program needs to increase revenue to cover these costs. We encourage the program and the members of the Oregon legislature to look at other approaches to meet the costs of the program. The NWRNBS Program could switch to a model like Washington state where newborn screening kits are provided to healthcare providers without charge and the program directly bills private insurers and Medicaid for the cost of the tests. As a licensed midwife in WA as well, I deeply appreciate their program for our WA families. Alternately Oregon could move to a model where newborn bloodspot screening is free to all families and funded by the state as is done in New York and other states. Newborn screening is meant to be universal screening, reaching every newborn in Oregon. This proposed cost increase would compromise the goal of universal screening. The Oregon families, midwives, and small businesses most-affected by this proposed change cannot bear a cost increase that more than doubles the expense of this important and life-saving screening. This proposed fee increase will discourage families who pay directly for this testing from providing it for their babies.

Please reconsider this fee increase.

Thank you for your consideration,

Melissa Gordon-Magnus, CPM/LDM/LM

Nest Midwifery

333 NE Russell St. #204

Portland OR, 97212

**From:** [Lynette Pettibone](#)  
**To:** [Public Health Rules](#)  
**Subject:** Public comment regarding Cost increase for newborn screening kits  
**Date:** Thursday, June 30, 2022 10:30:32 AM

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I'd like to officially comment. I am not opposed to the fee increase, although it is an unusually significant jump - over 100%. I do think this is important testing and I realize costs across the board have skyrocketed.

In conjunction with this increase, I would like to propose OHA also implement a program for community providers (mostly midwives) to receive screens FREE OF CHARGE and submit insurance billing information along with the specimen. OHA/Newborn screening lab would then bill insurance companies on behalf of the families for which the screen is performed. This procedure was implemented in Washington state several years ago. The state was initially resistant ("we're not in the business of billing insurance") but with a little effort it was worked out. It has made collecting screens easier and much more affordable for families and community providers. (Midwives in particular, can't afford to absorb \$175 PER client to pay for this and insurance reimbursement is not in alignment.)

I am also licensed in Washington state and am a leader in the midwifery community there, I would be happy to assist OHA in connecting with WHCA folks who worked to implement that program. Feel free to reach out.

Lynette Pettibone, MSM, LM, LDM, CPM  
The Bridge Birth and Family Services  
206-552-0061



# Oregon Pediatric Society

A Chapter of the American Academy of Pediatrics. Incorporated in Oregon

June 21, 2022

TO: Oregon Health Authority, Public Health Division  
Brittany Hall, Administrative Rules Coordinator  
publichealth.rules@dhsosha.state.or.us

FROM: Cheryl Hanna, MD - hannac@ohsu.edu  
Representing the Oregon Pediatric Society

SUBJECT: Support for NWRNBS rule changes to OAR 333-024-1100

For the record, I am Dr. Cheryl Hanna, writing on behalf of the Oregon Pediatric Society (OPS). I am a retired pediatric endocrinologist with 35 years of experience working with the Newborn Screening Program. I am also an original member of the Northwest Regional Screening Program (NWRNBS) Advisory Board that was created by the legislature in 2019. OPS is the state chapter of the American Academy of Pediatrics, and our members are committed to improving the health and well-being of all Oregon children. Newborn screening is one of the major public health successes of the 20<sup>th</sup> century. The Oregon Pediatric Society supports the proposed rule changes to increase the fees for newborn bloodspot screening kits.

Newborn screening involves collecting a small sample of blood on filter paper from all infants born in Oregon on the first day of life. The sample is used to screen for medical conditions that are not detectable on physical examination and that require immediate treatment to prevent death or disability.

The US Secretary of Health and Human Services provides guidance to state newborn screening programs about which conditions should be included in screening through the Recommended Uniform Screening Panel (RUSP). This guidance is by evidence-based (scientific) recommendations by the Advisory Committee on Heritable Disorders in Newborns and Children. This advisory board is composed of national experts, including physicians from academic medical centers specializing in pediatrics, genetics, and child development, as well as from the Centers of Disease Control and Prevention, National Institutes of Health, and the Federal Drug Administration. The individuals on the advisory board have access to published and unpublished data on the nominated condition to aid in their decision making. The committee meets regularly to consider new conditions to recommend to the RUSP as expertise in treatment of rare conditions expands and even new treatments become possible. With this guidance two conditions



# Oregon Pediatric Society

A Chapter of the American Academy of Pediatrics. Incorporated in Oregon

were added to the NWRNBS panel this year: spinal muscular atrophy (SMA) and X-linked adrenoleukodystrophy (X-ALD).

The NWRNBS Program is proposing rule changes to change the fees for newborn bloodspot screening kits effective August 1, 2022.

- A one-specimen kit from \$59 to \$100.
- Two-specimen kit and three-specimen kits from \$80 to \$175.

The proposed rule change also permits the program to authorize a fee exemption in lieu of a refund or kit replacement.

OPS endorses these rulemaking changes because the additional fee revenue will be used to modernize services in alignment with national and local recommendations and cover an anticipated budget shortfall for the program. Enhancements will include adding new conditions to the screening panel based on federal recommendations, providing educational outreach to clinicians serving historically underserved communities, broadening translation services in parent education materials, improving follow-up services for increasingly complex medical conditions, and providing courier and shipping services to improve newborn bloodspot screening timeliness.

Recognizing that a fee increase could be difficult for some families whose insurance does not cover their infant's birthing process, the lab is also streamlining the process for waiving the fee. The lab is proposing a fee exemption rather than the current process which involves buying the screening kit and then the family being reimbursed. This should improve the likelihood that no infant in Oregon will miss the opportunity to have a newborn screen.

**From:** [Humphrey King Sarah](#)  
**To:** [Patricia Edmonds](#)  
**Subject:** RE: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#  
**Date:** Friday, June 3, 2022 6:14:08 PM  
**Attachments:** [image001.jpg](#)

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Hi Patricia,

Please forward your comment to the Public Health Division Rules coordinator. We are not able to accept official comment at the program level during rulemaking. The email address for this is [publichealth.rules@dhsosha.state.or.us](mailto:publichealth.rules@dhsosha.state.or.us).

All the best,

--Sarah

---

**From:** Patricia Edmonds <[patricia.edmonds@pcc.edu](mailto:patricia.edmonds@pcc.edu)>  
**Sent:** Friday, June 3, 2022 6:11 PM  
**To:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)>  
**Subject:** Re: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

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For so many families who do not have insurance or inadequate compensation these costs are prohibitive! You keep adding on more tests, increasing the costs of screens.

On Fri, Jun 3, 2022 at 11:03 AM Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)> wrote:

To All NWRNBS Clients,

The Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program is proposing rule changes to change the fees for newborn bloodspot screening kits effective August 1, 2022. The proposed rule change also permits the program to authorize a fee exemption in lieu of a refund or kit replacement. Please share this information with your colleagues who may need the notice.

The fee revenue will be used to modernize services in alignment with national and local recommendations and cover an anticipated budget shortfall. Enhancements will include adding new conditions to the screening panel based on federal recommendations, providing educational outreach to clinicians serving historically underserved communities, broadening translation services in parent education materials, improving follow-up services for

increasingly complex medical conditions, and providing courier and shipping services to improve newborn bloodspot screening timeliness.

The proposed rule changes edit the fee for:

- A one-specimen kit from \$59 to \$100.
- Two-specimen kit and three-specimen kits from \$80 to \$175.

A public hearing will be held on June 16, 2022 at 10:00am to receive oral testimony. Written comments may be submitted until 5:00pm on June 30, 2022. Complete details can be found at [www.bitly.com/nbs-news](http://www.bitly.com/nbs-news). Contact information is provided within the documents posted on this page.

This information is being shared with multiple distribution lists. Please accept our advance apologies for any duplication of messaging.

All the very best,  
Sarah and the NWRNBS Team

**Sarah M. Humphrey King (she/her/hers)**  
Client Services Coordinator; Acting Business Engagement & Policy Analyst  
Oregon State Public Health Laboratory  
Public Health Division  
[sarah.m.humphrey@dhsosha.state.or.us](mailto:sarah.m.humphrey@dhsosha.state.or.us)  
Main: 503-693-4100 | Cell: 971-217-3522 | Fax: 503-693-5602



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**From:** [Sarah Dinger](#)  
**To:** [Public Health Rules](#)  
**Subject:** Re: public comment for proposed fee increase for newborn bloodspot screening  
**Date:** Thursday, June 16, 2022 10:54:02 AM

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Just after sending this I received an email stating that OHP reimbursement has increased to cover the full cost of the kit, and will increase if costs increase, so please disregard that portion of my previous email. However, I still would like to request that the bloodspot screening program bill insurance directly, as this would simplify this process for us with both Medicaid and private insurance clients.

On Thu, Jun 16, 2022 at 10:45 AM Sarah Dinger <[dinger.sarah@gmail.com](mailto:dinger.sarah@gmail.com)> wrote:

I'm writing to offer input on the proposed increase in the fee for the newborn screening kits. I am a licensed community midwife (CPM, LDM) in Portland.

My practice provides care for many clients who are on Medicaid. The cost of the newborn screen is a burden to our practice, as Medicaid reimbursement for this service is significantly less than the cost of the kit. This means we are paying the difference in cost for all of our Medicaid clients as we can't bill our clients for the difference, and, as you can imagine, the global fee that is paid by OHP is also significantly lower than our usual fee. This means that the newborn screening fee contributes to making it less sustainable to accept Medicaid reimbursement for the clients who can often most benefit from our care.

I understand that the cost of newborn screening will increase over time, and my request is that, **rather than having community midwives purchase the test kits, the newborn bloodspot screening program bill insurance directly for these tests.** This is how we manage things like lab work and ultrasounds; we provide insurance information when we send a referral, and that provider bills directly. My understanding is that this is happening in other states. This would be a huge improvement in this process.

Thank you,

Sarah Dinger, CPM, LDM

**From:** [Klein, Shannon M](#)  
**To:** [Humphrey King Sarah](#)  
**Cc:** [Public Health Rules](#); [Held Patrice Karyn](#)  
**Subject:** RE: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#  
**Date:** Tuesday, June 14, 2022 8:37:08 AM  
**Attachments:** [image001.jpg](#)  
[image002.png](#)  
[image003.png](#)  
[image004.png](#)

Some people who received this message don't often get email from [sklein@columbiamemorial.org](mailto:sklein@columbiamemorial.org).  
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Thank you Sarah for getting back to me on this issue. We already pay to have a courier when FedEx won't work and with the rising cost of the screening cards, it will hit small hospitals particularly hard.

**Shannon M. Klein, MBA, BSN, RN** | Manager of the Family Birth Center

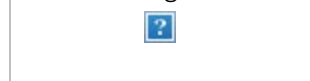
Columbia Memorial Hospital | 2111 Exchange St | Astoria | OR | 97103

Phone: 503.325.4321 Ext: 61201 | Email: [sklein@columbiamemorial.org](mailto:sklein@columbiamemorial.org)



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**From:** Humphrey King Sarah <SARAH.M.HUMPHREY@dhsosha.state.or.us>  
**Sent:** Tuesday, June 14, 2022 7:36 AM  
**To:** Klein, Shannon M <sklein@columbiamemorial.org>  
**Cc:** Public Health Rules <PublicHealth.Rules@dhsosha.state.or.us>; Held Patrice Karyn <Patrice.K.Held@dhsosha.state.or.us>  
**Subject:** RE: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

**EXTERNAL EMAIL: If unknown sender, do not click links/attachments. If you receive a suspicious email, contact IT.**

Good Morning Shannon,

I apologize for the delay in my response. Starting in July, OSPHL is initiating a pilot project to offer courier services to relatively higher volume hospitals with longer specimen transit times. The pilot project will run through June 2023. This project is being funded by state general fund allocated for public health modernization. We know that approx. 35 states offer specimen transport services to facilities in their jurisdictions.

We anticipate we will need two things before we implement the courier service more broadly or statewide: 1) An analysis of the pilot project which shows improvement in transit times for participating locations; and 2) The fee change needs to be ratified by the legislature.

I will certainly record your interest in this service and will be in contact when we are able to expand this work.

Please let us know if you have additional questions.

--Sarah

**Sarah M. Humphrey King (she/her/hers)**

Client Services Coordinator; Acting Business Engagement & Policy Analyst

Oregon State Public Health Laboratory

Public Health Division

[sarah.m.humphrey@dhsosha.state.or.us](mailto:sarah.m.humphrey@dhsosha.state.or.us)

Main: 503-693-4100 | Cell: 971-217-3522 | Fax: 503-693-5602



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**From:** Klein, Shannon M <[sklein@columbiamemorial.org](mailto:sklein@columbiamemorial.org)>

**Sent:** Friday, June 3, 2022 11:49 AM

**To:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)>

**Subject:** RE: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

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Can you elaborate on the proposed courier and shipping services? We currently pay an employee to be the courier when we cannot use Fed Ex in meeting the required deadlines for getting the cards to the lab.

Thank you

**Shannon M. Klein, MBA, BSN, RN** | Manager of the Family Birth Center

Columbia Memorial Hospital | 2111 Exchange St | Astoria | OR | 97103

Phone: 503.325.4321 Ext: 61201 | Email: [sklein@columbiamemorial.org](mailto:sklein@columbiamemorial.org)



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**From:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsola.state.or.us](mailto:SARAH.M.HUMPHREY@dhsola.state.or.us)>

**Sent:** Friday, June 3, 2022 11:06 AM

**To:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsola.state.or.us](mailto:SARAH.M.HUMPHREY@dhsola.state.or.us)>

**Subject:** For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

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To All NWRNBS Clients,

The Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program is proposing rule changes to change the fees for newborn bloodspot screening kits effective August 1, 2022. The proposed rule change also permits the program to authorize a fee exemption in lieu of a refund or kit replacement. Please share this information with your colleagues who may need the notice.

The fee revenue will be used to modernize services in alignment with national and local recommendations and cover an anticipated budget shortfall. Enhancements will include adding new conditions to the screening panel based on federal recommendations, providing educational outreach to clinicians serving historically underserved communities, broadening translation services in parent education materials, improving follow-up services for increasingly complex medical conditions, and providing courier and shipping services to improve newborn bloodspot screening timeliness.

The proposed rule changes edit the fee for:

- A one-specimen kit from \$59 to \$100.
- Two-specimen kit and three-specimen kits from \$80 to \$175.

A public hearing will be held on June 16, 2022 at 10:00am to receive oral testimony. Written comments may be submitted until 5:00pm on June 30, 2022. Complete details can be found at [www.bitly.com/nbs-news](http://www.bitly.com/nbs-news). Contact information is provided within the documents posted on

this page.

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All the very best,  
Sarah and the NWRNBS Team

**Sarah M. Humphrey King (she/her/hers)**  
Client Services Coordinator; Acting Business Engagement & Policy Analyst  
Oregon State Public Health Laboratory  
Public Health Division  
[sarah.m.humphrey@dhsosha.state.or.us](mailto:sarah.m.humphrey@dhsosha.state.or.us)  
Main: 503-693-4100 | Cell: 971-217-3522 | Fax: 503-693-5602



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**From:** [Etienne Sara](#) on behalf of [NW Regional NBS](#)  
**To:** [Public Health Rules](#)  
**Cc:** [Humphrey King Sarah](#); [Held Patrice Karyn](#)  
**Subject:** FW: Proposal objection ATRMC  
**Date:** Wednesday, June 22, 2022 7:10:40 AM

---

Forwarding an email received in the Newborn Screening inbox.

***Sara Etienne***

Newborn Screening Follow Up Coordinator  
Oregon State Public Health Laboratory

[sara.etienne@dhsosha.state.or.us](mailto:sara.etienne@dhsosha.state.or.us)

503-693-4173

NBS Office 503-693-4174  
Fax 503-693-5601

---

**From:** Batesknippert, Terri <Terri.Batesknippert2@asante.org>  
**Sent:** Wednesday, June 22, 2022 6:20 AM  
**To:** NW Regional NBS <NWRegional.NBS@odhsosha.oregon.gov>  
**Subject:** Proposal objection ATRMC

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The Asante Family Birth Center at Three Rivers Medical Center opposes the proposed fee increase for the newborn bloodspot screening kits. Such a proposal would be more than a 200% increase for which our facilities have not budgeted, resulting in a significant negative financial impact. I suspect most hospitals in the area feel the same. The fee increase is to cover enhancements that have not proven to be effective or beneficial. Historically, our rural entity (ATRCM) does not have transport issues nor do we have a large population that declines the newborn screening; therefore, the enhancements do not support added value for such a cost increase. We would like to propose that the suggested enhancements take effect after the state provides hospitals with quantitative data to support a positive impact. With quantitative data or research demonstrating a positive impact and improved outcomes, we may support reevaluating this proposal. Currently, the burden for hospitals with this cost increase who may not actually see benefits does not seem equitable. Additionally, here in Josephine County in Southern Oregon over 75% of the population is on OHP; thus, it seems like the cost increase will be paid out by the state which seems like an unnecessary and inefficient cycle. Three Rivers Medical Center would like to offer a solution for your consideration as follows: provide an opt-in/opt-out action for various areas that serve populations who do not meet criteria.

Thank you kindly for considering and for your time.

With Gratitude,  
Terri Bates-Knippert, RN, BSN, BAE  
Manager Patient Care Service (Obstetrics)  
ATRC Family Birth Center  
O. 541-472-7222 | C. 970-531-7370

**From:** [Humphrey King Sarah](#)  
**To:** [Tracee Goodell](#)  
**Cc:** [Public Health Rules](#)  
**Subject:** RE: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#  
**Date:** Tuesday, June 7, 2022 7:41:46 AM  
**Attachments:** [image001.jpg](#)

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Hi Tracee,

Thank you for sharing your feedback. I have cc'd our Public Health Division Rules Coordinator for your comments to be part of our official rulemaking records.

--Sarah

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**From:** Tracee Goodell <[tgoodell@efmpc.com](mailto:tgoodell@efmpc.com)>  
**Sent:** Tuesday, June 7, 2022 7:37 AM  
**To:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)>  
**Subject:** Re: For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

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Hello Sarah,

Something to consider - alot of Oregon children are on State insurance. Most of these families cannot afford this cost. Not often, but sometimes parents lose these.

I fear if there is a charge to replace them, we will have alot of parents opt out of this testing. Just a thought.

**Tracee Goodell CCMA**  
**Evergreen Family Medicine**  
**541-677-7200**  
**Fax 541-229-3309**

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**From:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)>

**Sent:** Friday, June 3, 2022 11:06 AM

**To:** Humphrey King Sarah <[SARAH.M.HUMPHREY@dhsosha.state.or.us](mailto:SARAH.M.HUMPHREY@dhsosha.state.or.us)>

**Subject:** For Review: NBS Fee Change Notice of Proposed Rulemaking #u#

To All NWRNBS Clients,

The Northwest Regional Newborn Bloodspot Screening (NWRNBS) Program is proposing rule changes to change the fees for newborn bloodspot screening kits effective August 1, 2022. The proposed rule change also permits the program to authorize a fee exemption in lieu of a refund or kit replacement. Please share this information with your colleagues who may need the notice.

The fee revenue will be used to modernize services in alignment with national and local recommendations and cover an anticipated budget shortfall. Enhancements will include adding new conditions to the screening panel based on federal recommendations, providing educational outreach to clinicians serving historically underserved communities, broadening translation services in parent education materials, improving follow-up services for increasingly complex medical conditions, and providing courier and shipping services to improve newborn bloodspot screening timeliness.

The proposed rule changes edit the fee for:

- A one-specimen kit from \$59 to \$100.
- Two-specimen kit and three-specimen kits from \$80 to \$175.

A public hearing will be held on June 16, 2022 at 10:00am to receive oral testimony. Written comments may be submitted until 5:00pm on June 30, 2022. Complete details can be found at [www.bitly.com/nbs-news](http://www.bitly.com/nbs-news). Contact information is provided within the documents posted on this page.

This information is being shared with multiple distribution lists. Please accept our advance apologies for any duplication of messaging.

All the very best,

Sarah and the NWRNBS Team

**Sarah M. Humphrey King (she/her/hers)**

Client Services Coordinator; Acting Business Engagement & Policy Analyst

Oregon State Public Health Laboratory

Public Health Division

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**From:** [Orna Karlin](#)  
**To:** [Public Health Rules](#)  
**Subject:** Newborn Screening Kit Price Increase  
**Date:** Thursday, June 30, 2022 11:46:24 AM

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To whom it may concern,

I am writing to provide public comment on the newborn screening kit price increase, and ask that you please reconsider.

As a postpartum nurse at an Oregon hospital, I see the many ways that the price of healthcare services are hidden from patients until the bill shows up months later. In the hospital, newborn screening is not offered as an added option to their postpartum care- which in reality only impacts the small number of private pay clients.

But in out of hospital birthing situations, where insurance is less likely to cover care, private pay is much more common. A price increase in these kits will disproportionately affect home birth and birth center families/practices, who already face steep challenges in providing a safe alternative to hospital birth.

Please, do not (unintentionally) be a part of driving out-of-hospital birth out of our communities. Every day at work I see the harms our hospital policies have on families, and I strongly believe we need an alternative available.

Please reconsider this price increase, or build in an (easily accessible) fee waiver for private pay families.

Thank you for taking the time to read this,

Orna Karlin BSN, RN

**From:** [Catherine Bailey](#)  
**To:** [Public Health Rules](#)  
**Subject:** Public Comment about Newborn Screening Test rule change/cost change  
**Date:** Thursday, June 30, 2022 11:45:37 AM

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Dear NWRNBS Team,

My name is Catherine Akerson Bailey and I am writing on behalf of my midwifery practice, Unfurling Birth and Midwifery Services in Portland, OR to provide public comment on the proposed rule change and fee increase in the Northwest Regional Newborn Bloodspot Screening Program (NWRNBS Program). I have been a licensed midwife in Oregon since 2014 and the NWRNBS program is very important to me and the clients I serve. It is important to me to encourage my clients to choose to do the newborn screening tests for their newborns and I am concerned that this huge fee increase, which more than doubles the current cost, will prevent some people from choosing the screening. I fear for the safety and well-being and long-term risk to these newborns this fee increase will have.

In my practice I pay for the newborn screening tests out of pocket and then am sometimes reimbursed by insurance or families. Theoretically the Oregon Health Plan is supposed to reimburse me for these tests but they have not yet finished the billing pathway to allow this. Assuming they are able to fix this issue, I will be able to bill OHP for these tests for my OHP clients, but all of my clients who are on private insurance and struggling to pay their insurance premiums and pay me out of pocket for at least a portion of their care (because we bill as out-of-network providers) through private insurance companies, might choose to not do this screening if the fee increases so drastically. I already noticed a change in the numbers of my clients willing to cover this fee the last time the fee increased many years ago now, and it was a much smaller increase. I would not be able to afford to cover these newborn screening tests for my clients at the increased cost and would like to continue to be able to for people on private insurance who can't prioritize the cost.

Wouldn't it be great if every baby had access to this program without worry about the cost for families? Wouldn't it be great if every baby had access to this program without worry to midwives about their livelihood or income decreasing? How about the state funding the program like happens in New York and other states so the cost doesn't fall to families?

I am aware that the NWRNBS Program has a fee waiver for the screening kit for uninsured, low-income families but almost all of my clients in Oregon are either on Medicaid or on private insurance and unable to afford any extra fees.

Thank you for your consideration,

Catherine Akerson Bailey, CPM, LDM