



## 2019-21 Biennium Budget Decision Package

**Agency:** 303 - Department of Health  
**Decision Package Code-Title:** 2H - Address Newborn Screening Shortfall  
**Budget Session:** 2019-21 Regular  
**Budget Level:** Policy Level  
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### Agency Recommendation Summary

During the 2017 legislative session, the legislature authorized increasing the newborn screening fee by \$8.10 per infant to screen for X-linked adrenoleukodystrophy (X-ALD), a deadly genetic disorder that affects about 1 in 17,000 babies. However, current budget forecasts project a shortfall by the end of the 2019-21 biennium. The Department of Health (DOH) requests an additional fee increase of \$1.90 to fully support screening for X-ALD.

### Fiscal Summary

*Dollars in Thousands*

Operating Expenditures	FY 2020	FY 2021	FY 2022	FY 2023
Fund 001 - 7	\$166	\$166	\$166	\$166
<b>Total Expenditures</b>	<b>\$166</b>	<b>\$166</b>	<b>\$166</b>	<b>\$166</b>
<b>Biennial Totals</b>		<b>\$332</b>		<b>\$332</b>
Object of Expenditure	FY 2020	FY 2021	FY 2022	FY 2023
Obj. E	\$166	\$166	\$166	\$166
Revenue	FY 2020	FY 2021	FY 2022	FY 2023
001 - 0597	\$165	\$165	\$165	\$165
<b>Total</b>	<b>\$165</b>	<b>\$165</b>	<b>\$165</b>	<b>\$165</b>
<b>Biennial Totals</b>		<b>\$330</b>		<b>\$330</b>

### Package Description

Approximately 87,000 babies are born in Washington State each year. The Newborn Screening Laboratory

tests blood samples from each of these babies for heritable conditions. This provides an opportunity for medical intervention prior to the babies becoming sick, thereby preventing permanent disability and death. The Newborn Screening Program significantly contributes to the Department of Health's mission to protect and improve the health of people in Washington State.

The Department of Health (DOH) requests a fee increase to support screening for X-linked adrenoleukodystrophy (X-ALD), a condition added to the mandatory newborn screening panel March 1, 2018. X-ALD is a deadly genetic disorder that affects about 1 in 17,000 babies. During the first five months of screening, DOH has helped diagnose three babies with X-ALD. X-ALD newborn screening saves lives.

During the 2017 legislative session, DOH requested \$10 per infant to screen for X-ALD. The legislature authorized increasing the newborn screening fee by \$8.10 per infant. The current budget forecast has a shortfall by the end of the current biennium. Testing for X-ALD for all newborns is not sustainable at the original funding level authorized by the legislature.

## Assumptions and Calculations

### **Expansion or alteration of a current program or service:**

During the 2015-17 biennium, the total expenses of the Newborn Screening – General Fund – Local account (MI 16101716) was \$12,307,206. Total revenue during this period was \$13,280,975.

Through FM 11 of the 2017-19 biennium, the total expenses of the Newborn Screening – General Fund - Local account is \$6,282,836. Total revenue during this period was is \$7,051,268.

### **Detailed assumptions and calculations:**

Revenue:

This proposal will increase the newborn screening fee by \$1.90.

Using the past year as an estimate, the anticipated number of infants screened is expected to be approximately 87,000 babies born. The estimated revenue for 2019-2020 and thereafter = 87,000 x \$1.90 = \$165,300 per year. This revenue estimate is ongoing but will fluctuate each year based on the number of births.

Expenditures:

The Newborn Screening Laboratory started screening for X-linked adrenoleukodystrophy (X-ALD) in March 2018. This increase will pay for reagents and consumables to perform the testing on about 175,000 specimens per year or about 560 per day.

**Workforce Assumptions:**

See attached FNCal.

**Strategic and Performance Outcomes**

**Strategic framework:**

Early identification and treatment of affected infants supports Goal 2, Objective 1 of the Agency's Strategic Plan to give all babies a planned, healthy start in life. Early identification and treatment of X-linked adrenoleukodystrophy prevents death and disability of affected newborns.

This proposal would add additional fee based revenue and expenses to ALD Screening Proviso fund. Additional revenue will be \$1.90 per baby born in WA state. Additional expenses for the cost of screening are for testing supplies.

**Performance outcomes:**

For a relatively small investment in screening costs, DOH anticipates that babies with X-linked adrenoleukodystrophy (X-ALD) will be saved from death and permanent disability. X-ALD is a deadly genetic condition that affects 1:17,000 births. Early diagnosis of X-ALD is the key to saving lives by providing an opportunity to intervene prior to symptoms.

**Other Collateral Connections**

**Intergovernmental:**

The WA State Board of Health conducted a public vote in January 2016 and recommended adding X-linked adrenoleukodystrophy (X-ALD) to the mandatory screening panel. Prior to this meeting, the ad hoc Newborn Screening Advisory Committee held a public meeting and conducted a closed ballot vote, ultimately recommending adding X-ALD to the mandatory screening panel. The Health Care Authority pays for approximately half of the births in Washington State through the Medicaid program and had representation on the advisory committee during the formal review of this condition.

**Stakeholder response:**

WA State Hospital Association – Unknown; closed ballot voting

Biochemical geneticists – Unknown; closed ballot voting

WA State Nurses Association - Unknown; closed ballot voting

March of Dimes Foundation - Unknown; closed ballot voting

Save Babies Through Screening Foundation - Unknown; closed ballot voting

Insurance companies - Unknown; closed ballot voting

Bioethicists – Unknown; closed ballot voting

Community members - Unknown; closed ballot voting

**Legal or administrative mandates:**

N/A

**Changes from current law:**

N/A

**State workforce impacts:**

N/A

**State facilities impacts:**

N/A

**Puget Sound recovery:**

N/A

## Agency Questions

**Did you include cost models and backup assumptions?**

No answer was provided.

## Reference Documents

- FNCal ALD shortfall 7-12-18.xlsx

## IT Addendum

**Does this Decision Package include funding for any IT-related costs, including hardware, software, (including cloud-based services), contracts or IT staff?**

No