



ANNUAL REPORT - 2023

Newborn Screening Program

Reporting Requirements

(1) The department shall report to the board annually the following information concerning tests conducted under WAC [246-650-020](#):

- (a) The costs of tests as charged by the department;
- (b) The results of each category of tests, by county of birth and racial or ethnic group, as reported on the newborn screening specimen/information form; and
- (c) Follow-up procedures and the results of such follow-up procedures.

(2) The department shall compile an annual report for the public that includes:

- (a) The compliance rate of each hospital in meeting the deadlines established under RCW [70.83.020](#) for newborn screenings; and
- (b) The performance rate of each individual hospital.
- (3) The reports must be made available in a format that does not disclose the identifying information related to any infant, parent or guardian, or health care provider.
- (4) The report must be posted in an accessible location on the department of health's website.

Program Updates

- Screening Costs
 - Fee charged for each infant through the facility that collected the initial specimen
 - The charge was increased from **\$119.30** to **\$135.10** on 7/1/23
 - Cystic Fibrosis DNA testing expanded
 - New real-time PCR instruments with higher testing capacity
 - Courier implementation (ongoing)
 - Next-day delivery for newborn specimens from any birth setting

Program Updates

- Cases by County
 - King – 82
 - Pierce – 29
 - Snohomish – 18
 - Spokane – 17
 - Clark – 10
- Douglas – 1 (out of only 6 births in the county!)

Program Updates

- Cases by Race & Ethnicity (N = 217)
- 34.5% of babies were non-white
- 55.6% of cases were non-white
- Most common condition in all races was congenital hypothyroidism, except in black babies (hemoglobin disorders)

Program Updates

- Follow-up of Confirmed Cases
 - 205/206 were seen by specialists
 - 1 baby died (unrelated to their NBS condition)
- Median Age at Treatment
 - Amino acid disorders – 7d
 - Hemoglobin disorders – 10.5d
 - Cystic fibrosis – 15d
 - Organic acid disorders – 124.5d

Program Updates

- New Conditions
 - OTCD deficiency
 - GAMT deficiency
 - ARG1 deficiency
- Candidate Conditions
 - cCMV infection – 2025 review
 - MPS-II – 2025 review
 - BCKDK deficiency – likely 2025 review

Program Updates

- Regional Newborn Screening Program
 - Washington State
 - Hawaii (2018)
 - Idaho (2021)
- Organizational Changes – New Positions
 - NBS deputy director
 - Method development chemist
 - NBS quality improvement specialist
 - NBS health information exchange epidemiologist

Public Report

- Report will be available as a Power BI dashboard on the Newborn Screening Program website
- Includes compliance metrics, transit performance, and specimen quality indicators

