JOSH GREEN, M.D.
GOVERNOR OF HAWAIʻI
KE KIAʻĀINA O KA MOKUʻĀINA ʻO HAWAIʻI

KENNETH S. FINK, M.D., M.P.H., M.G.A.
DIRECTOR OF HEALTH
KA LUNA HOʻOKELE

STATE OF HAWAI'I
DEPARTMENT OF HEALTH
KA ʻOIHANA OLAKINO
P. O. BOX 3378
HONOLULU, HI 96801-3378

In reply, please refer to:
File:

December 29, 2025

The Honorable Ronald D. Kouchi,
President and Members of the Senate
Thirty-third State Legislature
State Capitol, Room 409
Honolulu, Hawaii 96813

The Honorable Nadine K. Nakamura,
Speaker
and Members of the House of
Representatives
Thirty-third State Legislature
State Capitol, Room 431
Honolulu, Hawaii 96813

Dear President Kouchi, Speaker Nakamura, and Members of the Legislature:

For your information and consideration, I am transmitting a copy of the Annual Report of the Newborn Metabolic Screening Special Fund to the Legislature, pursuant to Chapter 321, Section 291, Hawaii Revised Statutes.

In accordance with Section 93-16, Hawaii Revised Statutes, I am also informing you that the report may be viewed electronically at:

https://health.hawaii.gov/opppd/department-of-health-reports-to-2026-legislature/

Sincerely,

Kenneth S. Fink, M.D., M.P.H., M.G.A.
Director of Health

Enclosures

c: Legislative Reference Bureau
Hawaii State Library System (2)
Hamilton Library

REPORT TO THE THIRTY-THIRD LEGISLATURE

STATE OF HAWAIʻI

2026

PURSUANT TO SECTION 321-291
HAWAIʻI REVISED STATUTES

REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN ANNUAL REPORT FOR THE NEWBORN METABOLIC SCREENING SPECIAL FUND

PREPARED BY:

STATE OF HAWAIʻI
DEPARTMENT OF HEALTH
HEALTH RESOURCES ADMINISTRATION
FAMILY HEALTH SERVICES DIVISION
CHILDREN WITH SPECIAL HEALTH NEEDS BRANCH

DECEMBER 2025

ANNUAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND
FISCAL YEAR 2025

PROGRAM MEASURE REPORT

Introduction

The Newborn Metabolic Screening Program (NBMSP) is administered by the Children with Special Health Needs Branch (CSHNB), Family Health Services Division (FHSD), Hawai‘i State Department of Health (DOH). NBMSP has statewide responsibilities for assuring that all infants born in Hawai‘i are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases that, if left untreated, could cause intellectual disabilities, developmental disorders, severe health problems, and even death. Currently, the program screens for 37 disorders. The program tracks and completes follow-up on infants to ensure satisfactory testing and that infants with the specified diseases are detected and provided with appropriate and timely treatment and care. Newborn screening (NBS) has existed since 1963 and is a mandated public health activity in all 50 states. Parents in Hawai‘i can opt out of screening only as a religious exemption.

The 1996 legislature established a Newborn Metabolic Screening user fee and a Newborn Metabolic Screening Special Fund (NMSSF), which is used for operating expenses. The Hawai‘i Administrative Rules (HAR), Chapter 11-143, revised and adopted on May 27, 2017, pertains to NBMSP. Effective April 11, 2024, the newborn screening was increased to $155.00 per specimen kit. The fee covers staffing for the program; initial test; repeat testing (if necessary); testing for indigent families; overnight courier services; laboratory services; follow-up diagnostic tests as determined by the program; clinical genetic services; educational materials and activities; and quality assurance and improvement activities. Fees also cover expenses for implementation of new disorders to the NBS panel.

1. Statement of Objectives

The NBMSP provides screening and follow-up services for newborns in the State of Hawai‘i with the following objectives:

a. Screen 99% of newborns (95% is the national goal).
b. All newborns with out-of-range results will receive immediate follow-up to include repeat NBS, additional diagnostic testing, and referrals to specialists as needed.
c. Suitable specimen collection – complete saturation of blood spot, proper drying technique, non-layered blood spot.
d. Timeliness of newborn screening activities: collection time, transport time, reporting time, follow-up time.
e. Provide education to parents and families about the importance of NBS.
f. Provide education/training to healthcare providers/facility staff on all aspects of NBS, including best techniques for obtaining newborn blood spots.
g. Provide physicians with information of each disorder with the necessary next steps and recommended laboratory tests to rule out/diagnose newborns.

2. Measures Quantifying the Target Population to be Served for the Next Six Fiscal Years

Target Population	FY 2026	FY 2027	FY 2028	FY 2029	FY 2030	FY 2031
All newborns in the State of Hawai'i will get screened at a rate of 99%.	99%	99%	99%	99%	99%	99%

3. Measures Assessing the Effectiveness in Attaining the Objectives

a. Each birthing facility is reviewed monthly for the measures outlined in number 1 above. Feedback will be provided to facilities with actions for performance improvement.

b. All out-of-range results will receive timely follow-up care with linkage to specialists as needed.

c. Meet all national quality indicators to include acceptable collection/transport; complete essential data fields; timeliness of NBS activities; tracking data for babies with out-of-range results; number of newborns with confirmed diagnosis by a medical professional; and number of missed cases.

4. Level of Effectiveness Planned for the Next Six Fiscal Years

Measure of Effectiveness	FY 2026	FY 2027	FY 2028	FY 2029	FY 2030	FY 2031
1. Errors of specimen collection cards to less than 5%.	8%	7%	7%	6%	6%	5%
2. Specimens arriving to laboratory within 24 hours after collection.	92%	93%	94%	95%	95%	95%
3. Out-of-range results for critical disorders reported within 5 days of specimen collection.	99%	99%	99%	99%	99%	99%

5. Brief Description of Activities

Activities paid by the NMSSF:

- Centralized laboratory testing for 37 primary and secondary disorders. None of the laboratories in Hawai'i have the equipment, resources, expertise, or interest to complete NBS testing, and they have all expressed to the program that they will not make the investment to do NBS. The Washington State Department of Health Laboratory (WSDHL) is the contracted NBS testing laboratory for the Hawai'i program.
- Repeat testing for initial specimens collected at less than 24 hours of age because the laboratory testing is not as accurate before 24 hours of age per national standards.

- Confirmatory testing up to the point of diagnosis, and when necessary, if specimens are sent to the designated testing laboratory.
- Specimen collection and handling.
- Overnight mailing costs of the initial and repeat specimens to the testing laboratory. Courier services must include tracking and overnight delivery capabilities to ensure that NBS specimens are not delayed, misplaced, or lost. Services include additional costs for Saturday pick-up when available. Timely screening tests performed on the NBS blood specimens are essential for early detection of disorders that can cause intellectual disability, growth retardation, severe illness, and even death if not treated early in the newborn period.
- NBMSP staff salaries and fringe benefits.
- Hawai‘i Community Genetics in Hawai‘i Pacific Health for contracted Metabolic Clinic and Hemoglobinopathy Clinic follow-up services.
- Contracts with clinical specialists as needed for the disorders on the panel.
- Contract for alpha thalassemia DNA testing for alpha thalassemia follow-up.
- Screening and diagnostic costs for the uninsured indigent.
- Tracking, follow-up, and the administration of the statewide NBS system.
- Continuing education and educational materials for program/hospital staff and families.
- Quality assurance to monitor performance and identify issues to improve performance of the program activities.
- Supplies for the program.
- Indirect costs.
- Administrative overhead and other operating expenses.

The WSDHL maintains a proactive approach to achieving better accuracy in screening outcomes by reviewing the Hawai‘i NBS data and revising laboratory result cutoffs to minimize false positive NBS results. Through this effort, they were successful in identifying trends and patterns to determine more precise cutoffs for out-of-range results.

During this next fiscal year, NBMSP will have one additional activity that will require the use of NMSSF funds:

- NBMSP utilizes an application developed by Natus through an existing contract with Washington Public Laboratory. This system is updating its software to a web-based application, specifically the Neometrics iCN Data Management System. This update is expected to be completed in 2026 and will allow Hawai‘i to have direct access to data elements. Currently, the Hawai‘i staff have to request data to be pulled by Washington State staff to conduct queries. This update will enable more autonomy with respect to data management for the NBMSP related to samples collected from Hawai‘i that are processed at the Washington Public Laboratory.

6. Program Size Indicators

The percentage of eligible newborns receiving newborn metabolic screening:

In Fiscal Year 2025, 14,824 infants were born in the State of Hawai‘i. There were 34 fetal deaths. There were 14,668 infants screened, or 99.2% of all infants born. Of these, 1,965 screens were presumptive positive, with one or more results out of the reference range and requiring further follow-up or a repeat test. There were 34 infants confirmed as having a critical disorder requiring medical treatment and management. Key findings

identified in demographic analyses of the critical cases showed 30 cases in Oʻahu County; 3 cases in Maui County; and 1 case in Hawaiʻi County.

7. Program Size Planned for Each of the Next Six Fiscal Years

Program Size	FY 2026	FY 2027	FY 2028	FY 2029	FY 2030	FY 2031
Registered Nurse V	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE
Registered Nurse IV	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE
Human Services Professional	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE
Human Services Professional	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE
Office Assistant III	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE
Office Assistant III	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE	1.0 FTE

COST ELEMENT REPORT

1. Budget Details by Cost Element

Description	Amount
Payroll	$ 621,499.20
Out-of-State Travel	$ 4,220.90
Stationery and Office Supplies	$ 0.00
Other Supplies	$ 345.63
Subscription	$ 5,093.42
Air Freight	$ 49,554.26
Printing	$ 4,660.73
R & M Office Furniture and Equipment	$ 500.46
Laboratory	$ 1,499.54
Other Non-State Employee Services on a Fee Basis	$ 770,791.81
Other Miscellaneous Current Expenses	$ 117,946.39
M & E – Other Machinery and Equipment	$ 0.00
TOTAL	**$ 1,576,112.34**

2. Fund Name and Account Code for Each Item or Account Code

Name of Fund: Newborn Metabolic Screening Special Fund
Acct. No.: S 302 H

REPORTING OF NON-GENERAL FUND INFORMATION

1. Name of Fund: Newborn Metabolic Screening Special Fund
Legal Authority: Section 321-291, H.R.S.

2. Intended Purpose

This fund is to be used for payment of its lawful operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

3. Current Program Activities

The NBMSP has statewide responsibilities for assuring that infants born in the State of Hawai‘i are satisfactorily tested for disorders that can cause intellectual disability and even death if not detected and treated early in the newborn period. NBMSP tracks and follows up on infants to ensure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities include assessment, quality assurance, continuing education, standards setting, and activities to add new disorders to the newborn screening panel.

4-11. Requested Fund Information

	FY 2025
Beginning Cash Balance	$ 470,518
Beginning Encumbrances	$ 0.00
Revenues	$ 2,372,819.93
Internal Transfers	$ 1,490,744.82
Expenditures	$ (1,577,318.12)
Transfers (List each transfer by JV# and date)	N/A
Net Total Transfers	$ 0.00
Amount Derived from Bond Proceeds	$ 0.00
Ending Cash Balance[1]	**$ 2,756,764.63**

[1] Ending cash balance before encumbrances

EXPENDITURES IN FY 2025

I. Newborn Metabolic Screening Program Personnel Costs

A.	Payroll (5 FTE authorized) – includes salaries, overtime, differential, and fringe benefits	$ 621,499.20	
B.	Subsistence allowance, intrastate and out-of-state employee travel	$ 4,220.90	
	SUBTOTAL		**$ 625,720.10**

II. Implementation of Newborn Screening System Utilizing a Centralized Laboratory, All Other Expenditures

A.	Kapi'olani Medical Specialists $10,000.00 (2025)	$ 10,000.00	
B	Diagnostic Laboratory Services	$ 549.66	
C.	GeneDx 0.00 (2024); $950.00 (2025)	$ 950.00	
D.	Michael Maeda $3,500.00 (2024)	$ 3,500.00	
E.	Washington State Dept of Health Lab $428,838.77 (2024); $337,503.04 (2025)	$ 766,341.81	
F.	Other supplies & subscriptions	$ 5,439.05	
G.	Air freight, postage & other printing	$ 49,554.26	
H.	Office & other equipment, R&M	$ 500.46	
I.	Laboratory services for the uninsured	$ 1,499.54	
J.	Other miscellaneous current expenditures[2]	$ 117,946.39	
	SUBTOTAL		**$ 956,281.17**
	TOTAL EXPENDITURES		**$ 1,582,001.27**

[2] Includes Special Fund Assessment Fees