

**REPORT TO THE TWENTY-NINTH LEGISLATURE
STATE OF HAWAI'I
2017**

**PURSUANT TO SECTION 321-291, HAWAI'I REVISED STATUTES
REQUIRING THE DEPARTMENT OF HEALTH TO GIVE AN
ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND**

**PREPARED BY:
STATE OF HAWAI'I
DEPARTMENT OF HEALTH
FAMILY HEALTH SERVICES DIVISION
DECEMBER 2016**

EXECUTIVE SUMMARY

The Hawai'i Newborn Metabolic Screening Program (NBMSPP) is administered by Children with Special Health Needs Branch, Family Health Services Division, Hawai'i State Department of Health. NBMSPP has statewide responsibilities for assuring that all infants born in the State of Hawai'i are tested for phenylketonuria (PKU), congenital hypothyroidism, and other diseases which if left untreated could cause intellectual disabilities, developmental disorders, severe health problems, and even death. This program tracks and follows up on infants to assure satisfactory testing and to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment.

The 1996 legislature established a Newborn Metabolic Screening Special Fund (NBMSPPF) which is used for operating expenses. The Hawai'i Administrative Rules (HAR), Chapter 11-143, last revised and adopted on January 22, 2009, pertains to NBMSPP. The newborn screening fee effective January 22, 2009 is \$55.00 per specimen kit. The HAR is currently being revised to increase the fee from \$55.00 to \$99.00 due to the increase in laboratory fees as the testing now includes DNA based technology, providing additional courier services to improve timeliness of specimen delivery, and program expenses. The monies are deposited in the NBMSPPF which pays for the following expenses:

- Centralized laboratory testing for thirty-three (33) disorders. The Oregon State Public Health Laboratory was selected to be Hawai'i's newborn screening testing laboratory awarded the contract through the procurement process. None of the laboratories in Hawai'i have the equipment or resources to do newborn screening testing.
- Repeat testing for initial specimens collected at less than twenty-four (24) hours of age.
- Confirmatory testing up to the point of diagnosis if specimens are sent to the designated testing laboratory.
- Specimen collection and handling.
- Overnight mailing costs of the initial specimens to the testing laboratory. Courier services must include tracking and overnight delivery capabilities to ensure that newborn screening specimens are not delayed, misplaced or lost. Timely screening tests performed on the newborn screening blood specimens are essential for early medical detection of thirty-three (33) disorders that can cause intellectual disability, growth retardation, severe illness, and even death if not treated early in the newborn period.
- Newborn Metabolic Screening Program staff salaries and fringe benefits.
- Hawai'i Community Genetics for contracted Metabolic Clinic and Hemoglobinopathy

Clinic follow-up services.

- Contracted alpha thalassemia DNA testing for alpha thalassemia follow-up.
- Screening and diagnostic costs for the uninsured indigent.
- Tracking and follow-up, and the administration of the statewide newborn screening system.
- Continuing education and educational materials.
- Quality assurance.
- Equipment.
- Indirect costs.
- Administrative overhead and other operating expenses.

The attached financial report for FY 2016 (July 1, 2015 to June 30, 2016), required by HRS §321-291, identifies all fund balances, transfers, and expenditures made from the NBMSSF and the purposes for each expenditure.

**Report on Non-General Fund Information
For Submittal to the 2017 Legislature**

Department: HEALTH

Date: November 4, 2016
Prepared by: William L. Aakhus
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Name of Fund: Newborn Metabolic Screening Special Fund
Legal Authority: Section 321-291, H.R.S.
Fund Type (MOF): B
Approp. Acct. No.: S 302 H

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.

Current Program Activities:

The Newborn Metabolic Screening Program (NBMSPP) has statewide responsibilities for assuring that infants born in the State of Hawai'i are satisfactorily tested for thirty-three (33) disorders which can cause intellectual disability and even death, if not detected and treated early in the newborn period. NBMSPP tracks and follows-up on infants to assure that the infants with the specified diseases are detected and provided with appropriate and timely treatment. Other activities are assessment, quality assurance, continuing education, and standard setting.

	FY 2016
Beginning Cash Balance	1,049,158
Beginning Encumbrances	107,019
Revenues	844,581
Internal Transfers	
Expenditures	1,292,661
Transfers (List Each Transfer by JV# and Date)	
Net Total Transfers	
Amount Derived from Bond Proceeds	
Ending Cash Balance	601,079

PURPOSES FOR EXPENDITURES FOR FY 2016

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (4 FTE authorized) – includes salaries, overtime, differential, and fringe benefits.	438,035.10
B.	Subsistence allowance, intra-state and out-of-state employee travel	582.00
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	675,126.00
B.	Air freight charges to deliver specimens to the testing laboratory	31,896.60
C.	Stationery and office supplies	2,084.23
D.	Training and educational materials and other supplies	715.00
E.	Queen’s Genetics Laboratory	25,000.00
F.	Thalassemia Clinic	10,000.00
G.	Laboratory services for the uninsured	4,263.95
H.	Repair and maintenance of office equipment	754.45
I.	Central Service Assessment and Administrative Fees	41,879.00
J.	Other miscellaneous current expenditures	62,325.00
	TOTAL	\$1,292,661.33