

**REPORT TO THE THIRTIETH LEGISLATURE
STATE OF HAWAII
2019**

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

**PREPARED BY:
STATE OF HAWAII
DEPARTMENT OF HEALTH
FAMILY HEALTH SERVICES DIVISION
DECEMBER 2018**

**ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND
FISCAL YEAR 2018**

The Hawaii Newborn Metabolic Screening Program (NBMSPP) is administered by Children with Special Health Needs Branch, Family Health Services Division, Hawaii State Department of Health. NBMSPP has statewide responsibilities for assuring that all infants born in the State of Hawaii 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 that infants with the specified diseases are detected and provided with appropriate and timely treatment.

In Fiscal Year 2018, 17,127 infants were screened. Of these, 1,071 screens were presumptive positive, with one or more results out of the reference range and requiring further follow-up or a repeat test. Forty-one infants were confirmed as having a disorder requiring medical treatment and management.

The 1996 legislature established a Newborn Metabolic Screening Special Fund (NBMSPP) which is used for operating expenses. The Hawaii Administrative Rules (HAR), Chapter 11-143, revised and adopted on May 27, 2017, pertains to NBMSPP. Effective May 27, 2017, the newborn screening fee was increased from \$55.00 to \$99.00 per specimen kit. This was the first fee increase in five years. The additional fees are necessary to cover the cost of adding new disorders requiring the use of DNA based technology for testing, additional courier services to improve timeliness of specimen delivery, and program expenses.

The monies are deposited in the NBMSPP which pays for the following expenses:

- Centralized laboratory testing for thirty-three (33) disorders. None of the laboratories in Hawaii have the equipment or resources to do newborn screening testing. The Oregon State Public Health Laboratory is Hawaii's contracted newborn screening testing laboratory (selected through the State's procurement process).
- 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. Services include additional costs for Saturday pick-up when available. 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.
- Hawaii 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 2018 (July 1, 2017 to June 30, 2018), 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 2018 Legislature

Department: HEALTH

Date: October 26, 2018

Prepared by: Paul M. Uchima

Phone: 733-9062

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 Hawaii 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.

	<u>FY 2018</u>
Beginning Cash Balance	\$928,014.18
Beginning Encumbrances	\$0.00
Revenues	\$1,808,339.89
Internal Transfers	\$0.00
Expenditures	-\$881,047.83
Transfers (List each transfer by JV# and date)	
None	
Net Total Transfers	\$0.00
Amount Derived from Bond Proceeds	\$0.00
Ending Cash Balance	<u>\$1,855,306.24</u>

Purposes for Expenditures in FY 2018

I. Newborn Metabolic Screening Program Personnel Costs	FY 2018	
A. Payroll (4 FTE authorized) – includes salaries, overtime, differential, and fringe benefits	\$418,243.02	
B. Subsistence allowance, intra-state and out-of-state employee travel	\$286.51	<u>\$418,529.53</u>
II. Implementation of Newborn Screening System Utilizing a Centralized Laboratory		
A. Oregon State Public Health Laboratory	\$229,677.00	
B. Kapiolani Medical Specialists	\$70,000.00	
C. Air freight charges to deliver specimens to the testing laboratory	\$35,252.90	
D. Stationery and office supplies	\$195.51	
E. Advertising and court reporter	0	
F. Laboratory services for the uninsured	\$17,679.73	
G. Repair and maintenance of office equipment	\$725.60	
H. Central service assessment and administrative fees	0	
I. Other miscellaneous current expenditures ¹	\$98,987.56	<u>\$462,518.30</u>
		<u>\$881,047.83</u>

¹ Includes ASO Special Fund Assessment fee.