

**REPORT TO THE TWENTY-EIGHTH LEGISLATURE  
STATE OF HAWAII  
2016**

**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 2015**

## EXECUTIVE SUMMARY

The Hawaii Newborn Metabolic Screening Program (NBMSp) is administered by Children with Special Health Needs Branch, Family Health Services Division, Hawaii State Department of Health. NBMSp 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 to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment.

In 1996, legislation was passed, Hawaii Revised Statutes (HRS) §321-291, which established a Newborn Metabolic Screening Special Fund (NBMSpSF) which is used for operating expenditures. The Hawaii Administrative Rules, Chapter 11-143, last revised and adopted on January 22, 2009, pertains to NBMSp. The newborn screening fee effective January 22, 2009 is \$55.00 per specimen kit. The monies are deposited in the NBMSpSF which pays for the following expenses:

- Centralized laboratory testing for thirty-three (33) disorders. The Oregon State Public Health Laboratory was selected to be Hawaii's newborn screening testing laboratory through the contract procurement process. None of the laboratories in Hawaii have the equipment, resources, or desire to do newborn screening testing.
- Repeat testing for initial specimens collected at less than 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.
- Kapiolani Medical Center 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, follow-up, and the administration of the statewide newborn screening system.
- Continuing education, training and educational and training materials.
- Quality assurance.
- Equipment.
- Indirect costs.
- Administrative overhead and other operating expenses.

The attached financial report for FY 2015 (July 1, 2014 to June 30, 2015), 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 2016 Legislature**

Department: HEALTH

Date: November 4, 2015

Prepared by: Paul Takishita

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. Beginning in March 2015, newborn screening for Severe Combined Immunodeficiency was the 33<sup>rd</sup> disorder to be added to the Hawaii newborn screening panel. 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 standards setting.

<b>Financial Data</b>		
	FY 2015	FY 2016
Beginning Cash Balance	1,151,680	942,139
Beginning Encumbrances	193,956	107,019
Revenues	1,155,372	
Internal Transfers		
Expenditures	1,257,894	
Transfers (List Each Transfer by JV# and Date)		
Net Total Transfers		
Amount Derived from Bond Proceeds		
Ending Cash Balance	942,139	
Amount Required for Bond Covenants as of 7/1/15		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/15		

**PURPOSES FOR EXPENDITURES FOR FY 2015**

I.	Newborn Metabolic Screening Program Personnel Costs	
	A. Payroll (4 FTE authorized) – includes salaries, overtime, differential, and fringe benefits.	428,052.90
	B. Subsistence Allowance, Intra-State and Out-of-State Employee Travel	2,059.59
II.	Implementation of newborn screening system utilizing a centralized laboratory	
	A. Oregon State Public Health Laboratory	633,941.00
	B. Air freight charges to deliver specimens to the testing laboratory	28,951.44
	C. Stationery and office supplies	2,669.49
	D. Training and educational materials and other supplies	180.00
	E. Queen’s Genetics Laboratory	10,665.54
	F. Thalassemia Clinic	10,000.00
	G. Laboratory services for the uninsured	2,114.38
	H. Repair and maintenance of office equipment	2,340.80
	I. Central Service Assessment and Administrative Fees	83,284.58
	J. Other Miscellaneous Current Expenditures	53,634.25
	<b>TOTAL</b>	1,257,893.94

BEGINNING ENCUMBRANCES FY 2016

Other Non-State Employees Services on a Fee Basis (Contracts)		106,973.00
Other Miscellaneous Current Expenditures		45.90
	<b>TOTAL</b>	107,018.90