

**REPORT TO THE TWENTY-FIFTH LEGISLATURE
STATE OF HAWAII
2010**

**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
OCTOBER 2009**

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 that are added to the screening panel. 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 objectives are to prevent mental and growth retardation, severe health problems, and even death, resulting from disorders detectable through newborn metabolic screening.

In 1996, legislation was passed, H.R.S. §321-291, which established a newborn metabolic screening special fund which is used for operating expenditures, including, but not limited to, laboratory testing, follow-up testing, educational materials, continuing education, quality assurance, equipment, and indirect costs.

The Hawai'i Administrative Rules, Chapter 11-143, revised and adopted on January 22, 2009, reflect the following changes:

- Expansion of the newborn metabolic screening testing battery to include tests for:
 - Phenylketonuria (PKU)
 - Congenital Hypothyroidism
 - Galactosemia
 - Hemoglobinopathies
 - Congenital Adrenal Hyperplasia (CAH)
 - Maple Syrup Urine Disease (MSUD)
 - Biotinidase Deficiency
 - Amino Acid Disorders
 - Fatty Acid Oxidation Disorders
 - Organic Acid Disorders
 - Urea Cycle Disorders

- Cystic Fibrosis
- Newborn screening fee increased from \$47.00 to \$55.00 per specimen collection kit beginning January 22, 2009. The fees are deposited in the newborn metabolic screening special fund, which pays for the following expenses:
 - Centralized laboratory testing for the thirty-two (32) disorders. The Oregon State Public Health Laboratory was selected to be Hawai‘i’s newborn screening testing laboratory after they were awarded the contract through a Request for Proposal 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 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 not be delayed, misplaced or lost. Timely screening tests performed on the newborn screening blood specimens are essential for early medical detection of thirty-two (32) disorders that can cause mental and 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
 - Educational materials
 - Quality assurance
 - Equipment

- Indirect costs
- Administrative overhead

The attached financial report for FY 2009 (July 1, 2008 to June 30, 2009), required by H.R.S. §321-291, identifies all fund balances, transfers, and expenditures made from the newborn metabolic screening special fund and the purposes for each expenditure.

**Report on Non-General Fund Information
for Submittal to the 2010 Legislature**

Department: HEALTH

Date: October 1, 2009

Prepared by: Paul Takishita

Phone: 733-9062

Name of Fund: Newborn Metabolic Screening Special Fund
 Legal Authority: Section 321-291, HRS
 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 (NBMSp) has statewide responsibilities for assuring that infants born in the State of Hawai'i are satisfactorily tested for 32 disorders which can cause mental retardation and even death, if not detected and treated early in the newborn period. NBMSp 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.

Financial Data		
	FY 2009	FY 2010
Beginning Cash Balance	945,850.20	899,736.37
Beginning Encumbrances	266,364.70	225,572.62
Revenues	1,027,186.73	
Internal Transfers	0.00	
Expenditures	1,016,100.60	
Transfers (List Each Transfer by JV# and Date) JM4291, 2/25/09	57,199.93	
Net Total Transfers	57,199.93	
Amount Derived from Bond Proceeds		
Ending Cash Balance	899,736.37	
Amount Required for Bond Covenants as of 7/1/03		
Amount held in Certificates of Deposit, Escrow Accounts, or Other Investments as of 7/1/03		

PURPOSES FOR EXPENDITURES FOR FY 2009

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE – includes salaries, overtime, differential, & fringe benefits for an RN V, Medical Technologist IV, & Office Assistant III)	\$259,530.63
B.	Car Mileage	603.50
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	578,608.00
B.	FedEx services to deliver specimens to the testing laboratory	41,655.77
C.	Fax machine maintenance	382.49
D.	Maintenance and repair of the NBMSP printer	157.07
E.	New computer for NBMSP	1,486.70
F.	Tyvek envelopes for mailing NBS specimens to the Oregon Lab	1,761.24
G.	Legal Ads for Public Hearing Notice on HAR 11-143	1,536.30
H.	Hawai'i Community Genetics Contract	100,000.00
I.	Desiccant packets and barrier bags	293.20
J.	Stationary and office supplies	1,324.78
K.	Laboratory services for the uninsured	1,452.00
L.	Queen's Genetics Laboratory	12,000.00
M.	Thalassemia Clinic	12,500.00
N.	Interest on late payments	626.14

III. Continuing Education, Training, and Meetings

A. 2008 Newborn Screening and Genetic Testing Symposium, San Antonio, Texas, 11/1-7/08	2,019.84
B. Registration fee for the ASCLS/CLMA Annual Meeting	145.00
C. Subscription fee for PKU News	18.00
TOTAL	<u>\$1,016,100.60</u>

JV #JM4291 Assessments for central services and administrative expenses for FY 2008 \$57,199.93

BEGINNING ENCUMBRANCES FY 2010

Mileage	35.00
Oregon State Public Health Laboratory	106,014.00
Thalassemia Clinic Contract	25,000.00
Queen's Genetics Laboratory	33,000.00
University Children's Laboratory	300.00
Diagnostic Laboratory Services	3,444.62
Clinical Laboratories of Hawai'i	279.00
Assessments for central services and administrative expenses for FY 2009	<u>57,500.00</u>
TOTAL	<u>\$225,572.62</u>