

**REPORT TO THE TWENTY-FOURTH LEGISLATURE
STATE OF HAWAII
2007**

**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
DECEMBER 2006**

EXECUTIVE SUMMARY

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 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 Hawaii Administrative Rules, Chapter 11-143, revised and adopted on November 20, 2003, 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

- Newborn screening fee increased from \$27.00 to \$47.00 per specimen collection kit beginning September 1, 2003. The fees are deposited in the newborn metabolic screening special fund, which pays for the following expenses:
 - Centralized laboratory testing for the thirty-one disorders. The Oregon State Public Health Laboratory was selected to be Hawaii's newborn screening testing laboratory after they were awarded the contract through a Request for Proposal process. None of the laboratories in Hawaii 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-one 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
 - Hawaii Community Genetics for contracted Metabolic Clinic and Hemoglobinopathy Clinic follow-up services
 - 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 2006 (July 1, 2005 to June 30, 2006), required by § 321-291, HRS, 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 2007 Legislature**

Department: HEALTH

Date: 10/20/2006

Prepared by: Roy Sugimoto

Phone: 586-4570

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 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 Hawaii are satisfactorily tested for 31 disorders which can cause mental and growth 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 2006	FY 2007
Beginning Cash Balance	752,678.39	862,778.63
Beginning Encumbrances	202,252.22	215,574.58
Revenues	926,297.67	
Internal Transfers	0.00	
Expenditures	758,619.94	
Transfers (List Each Transfer by JV# and Date)		
JM3151, 01-24-06	57,577.49	
Net Total Transfers	57,577.49	
Amount Derived from Bond Proceeds		
Ending Cash Balance	862,778.63	
Amount Required for Bond Covenants as of 7/1/03		
Amount held in Certificates of Deposit, Escrow		

FY 2006

EXPENDITURES

Object Code	S 05 302 H	S 06 302 H	TOTAL
2000	0.00	156,322.00	156,322.00
2007	0.00	0.00	0.00
2032	0.00	4,092.00	4,092.00
2034	0.00	22,056.78	22,056.78
2036	0.00	31.93	31.93
2037	0.00	9,625.19	9,625.19
2038	0.00	149.76	149.76
2039	0.00	7,148.77	7,148.77
2043	0.00	2,251.00	2,251.00
2044	0.00	10,755.10	10,755.10
2045	0.00	0.00	0.00
2046	0.00	130.69	130.69
2047	0.00	869.18	869.18
Total Payroll	0.00	213,432.40	213,432.40
3040	0.00	0.00	0.00
3210	0.00	0.00	0.00
3410	0.00	1,384.63	1,384.63
3520	0.00	18.00	18.00
3610	2,500.00	31,153.09	33,653.09
3810	0.00	0.00	0.00
3990	0.00	0.00	0.00
4110	100.00	287.88	387.88
4210	0.00	172.00	172.00
4290	0.00	1,620.80	1,620.80
4310	0.00	20.00	20.00
4410	0.00	661.85	661.85
4510	0.00	637.00	637.00
4515	0.00	76.40	76.40
4610	0.00	0.00	0.00
4690	0.00	0.00	0.00
4890	0.00	49.00	49.00
5810	0.00	495.30	495.30
7140	11.75	529.00	540.75
7150	0.00	0.00	0.00
7167	0.00	0.00	0.00
7190	130,000.00	370,118.00	500,118.00
7210	130.00	300.00	430.00
7230	0.00	0.00	0.00
7290	57,577.49	122.97	57,700.46
7300	0.00	305.59	305.59
7790	0.00	4,494.28	4,494.28
Total Others	190,319.24	412,445.79	602,765.03
Grand Total	190,319.24	625,878.19	816,197.43

ENCUMBRANCES

Object Code	S 04 302 H	S 05 302 H	TOTAL
2000	0.00	5,104.00	5,104.00
Total Payroll	0.00	5,104.00	5,104.00
3040	0.00	0.00	0.00
3610	0.00	0.00	0.00
4110	0.00	151.05	151.05
4290	0.00	0.00	0.00
4410	0.00	0.00	0.00
4610	0.00	0.00	0.00
4690	0.00	0.00	0.00
4890	0.00	11.00	11.00
5810	0.00	0.00	0.00
7140	0.00	178.00	178.00
7150	0.00	0.00	0.00
7190	0.00	150,683.00	150,683.00
7210	0.00	100.00	100.00
7290	0.00	59,347.53	59,347.53
Total Others	0.00	210,470.58	210,470.58
Grand Total	0.00	215,574.58	215,574.58

PURPOSES FOR EXPENDITURES FOR FY 2006

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (3 FTE)	\$213,432.40
B.	Car Mileage	387.88
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	450,136.70
B.	FedEx services to deliver specimens to the testing laboratory	33,653.09
C.	Typewriter repair	161.46
D.	Fax machine maintenance	333.84
E.	Tyvek envelopes and office supplies	888.07
F.	Lap top computer	1,662.96
G.	LCD projector	804.79
H.	Rolling carrying case for lap top computer and LCD projector	122.97
I.	Desk top computer	1,694.25
J.	Adjustable work station	332.28
K.	Flash drives	249.98
G.	Laboratory services for the uninsured	545.98
III.	Continuing education	
A.	2005 Newborn Screening and Genetic Testing Symposium, Portland, Oregon, 10/24/05–10/27/05	214.50
B.	New Frontiers in Nutrition Therapy for Inherited Metabolic Disorders, Atlanta, Georgia, 4/27/06-4/29/06	1,499.75

C.	Registration fee for the 2005 ASCLS/CLMA Annual Meeting	130.00
D.	Subscription fee for PKU News	18.00
E.	In-service to nurses, physicians, and laboratory staff at North Hawaii Community Hospital on 10/18/05	202.00
F.	Low protein foods for demonstration, preparation and tasting at Metabolic Parent Support Group	254.96
IV.	Genetic services at Hawaii Community Genetics	50,273.28
V.	Air transportation for endocrinologist services on the Neighbor Islands and Neighbor Island Advisory Committee members	1,620.80
	TOTAL	<u>\$758,619.94</u>

JV #JM3151 Assessments for central services and administrative expenses for FY 05 \$57,577.49

BEGINNING ENCUMBRANCES FY 2007

Personnel	\$5,104.00
Mileage	151.05
Oregon State Public Health Laboratory	125,683.00
Hawaii Community Genetics Hemoglobinopathy Clinic	25,000.00
Other travel	11.00
Laboratory services for the uninsured	178.00
Registration fee for the 2006 ASCLS/CLMA Annual Meeting	100.00
Other miscellaneous current expenditures	2,347.53
Assessments for central services and administrative expenses for FY 2006	57,000.00
TOTAL	<u>\$215,574.58</u>