

DAVID Y. IGE
GOVERNOR OF HAWAII



VIRGINIA PRESSLER, M.D.
DIRECTOR OF HEALTH

DEPT. COMM. NO. 119

STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. BOX 3378
HONOLULU, HI 96801-3378

In reply, please refer to:

December 15, 2017

The Honorable Ronald D. Kouchi,
President and Members of the Senate
Twenty-Ninth State Legislature
State Capitol, Room 409
Honolulu, Hawaii 96813

The Honorable Scott K. Saiki, Speaker
and Members of the House of
Representatives
Twenty-Ninth State Legislature
State Capitol, Room 431
Honolulu, Hawaii 96813

Dear President Kouchi, Speaker Saiki, and Members of the Legislature:

For your information and consideration, I am transmitting a copy of the Annual Financial Report for the Newborn Metabolic Screening Special Fund pursuant to §321-291, Hawaii Revised Statutes.

In accordance with Section 93-16, HRS, I am also informing you that the report may be viewed electronically at:

<http://health.hawaii.gov/opppd/department-of-health-reports-to-2018-legislature/>

Sincerely,

A handwritten signature in cursive script that reads "Virginia Pressler".

VIRGINIA PRESSLER

Director of Health

Enc.

c: Senate
House
Legislative Reference Bureau
SOH Library System (7 copies)
University of Hawaii

**REPORT TO THE TWENTY-NINTH LEGISLATURE
STATE OF HAWAII
2018**

**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 2017**

**ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND
FISCAL YEAR 2017**

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 to assure that infants with the specified diseases are detected and provided with appropriate and timely treatment.

In Fiscal Year 2017, 17,810 infants were screened. Of these, 967 screens were presumptive positive, with one or more results out of the reference range and requiring further follow-up or a repeat test. Twenty-six infants were confirmed as having a disorder requiring medical follow-up.

The 1996 legislature established a Newborn Metabolic Screening Special Fund (NBMSPPF) which is used for operating expenses. The Hawaii Administrative Rules (HAR), Chapter 11-143, revised and adopted on May 27, 2017, pertains to NBMSPP. The newborn screening fee effective May 27, 2017 was increased from \$55.00 to \$99.00 per specimen kit. This increase in fees was necessary because of the increase in cost of DNA based technology for testing, 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 Hawaii's newborn screening testing laboratory awarded the contract through the procurement 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 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.
- 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 2017 (July 1, 2016 to June 30, 2017), 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: December 1, 2017
Prepared by: William L. Aakhus
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 (NBMSp) 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. 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.

	FY 2017
Beginning Cash Balance	601,079
Beginning Encumbrances	3,498
Revenues	1,030,871
Internal Transfers	
Expenditures	703,936
Transfers (List Each Transfer by JV# and Date)	
Net Total Transfers	
Amount Derived from Bond Proceeds	
Ending Cash Balance	928,014

PURPOSES FOR EXPENDITURES FOR FY 2017

I.	Newborn Metabolic Screening Program Personnel Costs	
A.	Payroll (4 FTE authorized) – includes salaries, overtime, differential, and fringe benefits.	352,974.58
B.	Subsistence allowance, intra-state and out-of-state employee travel	193.48
II.	Implementation of newborn screening system utilizing a centralized laboratory	
A.	Oregon State Public Health Laboratory	182,073.16
B.	Kapiolani Medical Specialists	50,000.00
C.	Air freight charges to deliver specimens to the testing laboratory	37,437.97
D.	Stationery and office supplies	749.89
E.	Advertising and Court Reporter	1,680.23
F.	Laboratory services for the uninsured	15,364.11
G.	Repair and maintenance of office equipment	456.11
H.	Central Service Assessment and Administrative Fees	3,927.00
I.	Other miscellaneous current expenditures	59,079.61
	TOTAL	<u>\$703,936.14</u>