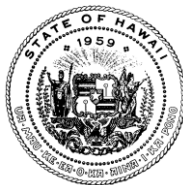


DAVID Y. IGE
GOVERNOR OF HAWAII



BRUCE S. ANDERSON, Ph.D.
DIRECTOR OF HEALTH
DEPT. COMM. NO. 324

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

In reply, please refer to:

December 26, 2019

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

The Honorable Scott K. Saiki, Speaker
and Members of the House of
Representatives
Thirtieth 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 Report on Newborn Metabolic Screening to §321-291 of the Hawaii Revised Statutes (HRS).

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

<https://health.hawaii.gov/opppd/department-of-health-reports-to-2020-legislature/>

Sincerely,

A handwritten signature in black ink that reads "Bruce S. Anderson".

Bruce S. Anderson, Ph.D.
Director of Health

Enclosures

**REPORT TO THE THIRTIETH LEGISLATURE
STATE OF HAWAII
2020**

**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
NOVEMBER 2019**

**ANNUAL FINANCIAL REPORT FOR THE
NEWBORN METABOLIC SCREENING SPECIAL FUND
FISCAL YEAR 2019**

The Hawaii Newborn Metabolic Screening Program (NBMSPP) is administered by the 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. The 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 2019, 16,718 infants were screened. Of these, 1,122 screens were presumptive positive, with one or more results out of the reference range and requiring further follow-up or a repeat test. Fifty-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) primary and secondary disorders. None of the laboratories in Hawaii have the equipment or resources to do newborn screening testing. The Oregon State Public Health Laboratory was Hawaii's contracted newborn screening testing laboratory for fiscal year 2019 (selected through the State's procurement process).
- Repeat testing for initial specimens collected at less than twenty-four (24) hours of age because the laboratory testing is not as accurate before 24 hours of age per national standards.
- 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 detection of 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.

Starting October 7, 2019, the contracted newborn screening laboratory was changed from the Oregon State Public Health Laboratory (OSPHL) to the Washington State Department of Health Laboratory (WSDHL). Although most laboratories in the country have moved to having staff run newborn screening tests on the weekend, OSPHL has not been able to move to weekend hours for the past several years. OSPHL has also had difficulty retaining and hiring staff which delays the laboratory testing and reporting. The WSDHL has staff working on weekends and holidays and a much larger workforce in the laboratory and follow-up programs. This change will ensure that Hawaii newborns get more timely newborn screening and follow-up especially when a long weekend occurs. More information about this laboratory change will be in the fiscal year 2020 legislative report.

The attached financial report for FY 2018 (July 1, 2018 to June 30, 2019), 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 2020 Legislature

Department: HEALTH

Date: October 15, 2019

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 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 2019</u>
Beginning Cash Balance	\$ 1,790,108.85
Beginning Encumbrances	\$ 311,308.60
Revenues	\$ 1,691,741.00
Internal Transfers	N/A
Expenditures	\$ (1,365,926.00)
Transfers (List each transfer by JV# and date)	N/A
Net Total Transfers	\$ 0.00
Amount Derived from Bond Proceeds	\$ 0.00
Ending Cash Balance ¹	<u>\$ 2,115,923.85</u>

¹ Ending cash balance before encumbrances

Purposes for Expenditures in FY 2019

I. Newborn Metabolic Screening Program

Personnel Costs

A. Payroll (4 FTE authorized) – includes salaries, overtime, differential, and fringe benefits	\$ 526,367.02	
B. Subsistence allowance, intra-state and out-of-state employee travel	\$ 130.16	<u>\$526,497.18</u>

II. Implementation of Newborn Screening System Utilizing a Centralized Laboratory

A. Oregon State Public Health Laboratory	\$ 584,402.12	
B. Kapiolani Medical Specialists	\$ 50,000.00	
C. Air freight charges to deliver specimens to the testing laboratory	\$ 37,496.02	
D. Stationery and office supplies	\$ 0.00	
E. Advertising and court reporter	\$ 0.00	
F. Repair and maintenance of office equipment	\$ 366.63	
G. Laboratory services for the uninsured	\$ 17,902.21	
H. Other miscellaneous current expenditures ²	\$ 149,261.84	<u>\$ 839,428.82</u>

\$ 1,365,926.00

² Includes Special Fund Assessment Fees