Alaska

Newborn Genetic Testing & Surveillance System

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<td>AK</td>
<td>STATUTE: A.S., Title 18, Article 02, Chapter 18.15, Sec. 18.15.200 and Sections 18.15.355 – 18.15.395</td>
<td>18.15.200. Screening for phenylketonuria. (a) A physician who attends a newborn child shall cause this child to be tested for phenylketonuria (PKU). If the mother is delivered in the absence of a physician, the nurse who first visits the child shall cause this test to be performed. (b) The department shall adopt regulations regarding the method used and the time or times of testing as accepted medical practice indicates. (c) The necessary laboratory tests and the test materials, reporting…</td>
<td>18.15.200. Screening for phenylketonuria …(f) A licensed physician or licensed nurse attending a newborn or infant who violates this section is guilty of a misdemeanor and, upon conviction, is punishable by a fine of not more than $500. However, a person attending a newborn or infant whose request for appropriate specimens from the newborn or infant is denied by the parent or guardian is not guilty of a</td>
<td>Sec. 18.15.355. Prevention and control of conditions of public health importance. (a) The department may use the powers and provisions set out in AS 18.15.355 - 18.15.395 to prevent, control, or ameliorate conditions of public health importance or accomplish other essential public health services and functions. (b) In performing its duties under AS 18.15.355 - 18.15.395, the department may (1) establish standards (A) for the prevention, control, or amelioration of conditions of public health importance; (B) to accomplish other essential public health services and functions; and (2) adopt regulations to implement and interpret AS 18.15.355 - 18.15.395.</td>
<td>NO</td>
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forms, and mailing cartons shall be provided by the department. (d) All tests considered positive by the screening method shall be reported by the screening laboratory to the physician and to the department. The department shall provide services for the performance of a quantitative blood phenylalanine test or its equivalent for diagnostic purposes. A confirmed diagnosis of phenylketonuria shall be reported to the physician and to the department. The department shall provide services for treatment and clinical follow-up of any diagnosed case. (e) When presumptive positive screening tests have been reported to the department, it shall

misdemeanor. The fact that a child has not been subjected to the test because a request for appropriate specimens has been denied by the parents or guardian shall be reported to the department. [emphasis added]

Sec. 18.15.360. Data collection. (a) The department is authorized to collect, analyze, and maintain databases of information related to (1) risk factors identified for conditions of public health importance; (2) morbidity and mortality rates for conditions of public health importance; (3) community indicators relevant to conditions of public health importance; and (4) longitudinal data on traumatic or acquired brain injury from the registry established under AS 47.80.500 (c)(1); and (5) any other data needed to accomplish or further the mission or goals of public health or provide essential public health services and functions. (b) … The department is authorized to obtain information from federal, state, and local governmental agencies, Alaska Native organizations, health care providers, pre-hospital emergency medical services, or other private and public
provide, on request, either the true blood phenylalanine test or subsidize the performance of this test at an approved laboratory…

**Sec. 18.15.210. Testing for certain other heritable diseases.** The department shall administer and provide services for testing for other heritable diseases that lead to mental retardation and physical disabilities as screening programs accepted by current medical practice and as developed.

**7 AAC 27.570. Annual review and report.** The department will appoint a committee to annually review the results of the newborn child metabolic disorder screening program, consider a copy of the card with complete information provided. The information on the front of the card must be completed by the medical facility or service and the card sent to the designated laboratory. "[emphasis added]"

From, **"State of Alaska FY 2005 Governor’s Operating Budget,“** Department of Health and Social Services Medical Assistance Administration Component Budget Summary, 12/15/03: **“Newborn Metabolic Screening Program (NBMS).”** NBMS tests all Alaska newborns for congenital metabolic disorders as well as endocrine organizations operating in the state. The department may also use information available from other governmental and private sources, reports of hospital discharge data, information included in death certificates, other vital statistics, environmental data, and public information. The department may request information from and inspect health care records maintained by health care providers that identify individuals or characteristics of individuals with reportable diseases or other conditions of public health importance. …

**Sec. 18.15.375. Epidemiological investigation. (a)** The department may investigate conditions of public health importance in the state through methods of epidemiological investigation. The department may also ascertain the existence of cases of illness or other conditions of public health importance, investigate potential
addition or deletion of tests based on experience in this state and on newly developed tests recommended by the American Academy of Pediatrics, Committee on Genetics, and report to health care providers and the public on these matters.

disorders…Parents are allowed to refuse the test on religious grounds under what it [sic] entitled ‘Informed Dissent’. The back of the form is signed, forwarded to the Oregon Public Health Laboratory, and then on to the NBMS program manager where it is entered into a refusal database. [emphasis added] sources of exposure or infection and ensure that they are subject to proper control measures, and determine the extent of the disease outbreak, epidemic, risk to health and safety, or disaster.

Sec. 18.15.395. Definitions.
…(10) "essential public health services and functions" mean services and functions to (A) monitor health status to identify and solve community health problems; (B) investigate and diagnose health problems and health hazards in the community; (C) inform and educate individuals about and empower them to deal with health issues; (D) mobilize public and private sector collaboration and action to identify and solve health problems; (E) develop policies, plans, and programs that support individual and community health efforts; (F) enforce statutes and regulations of this state that protect health and ensure safety; (G) link individuals to needed health services and facilitate the
provision of health care when otherwise unavailable; \textit{(H)} ensure a competent public health workforce; \textit{(I)} evaluate effectiveness, accessibility, and quality of personal and population-based health services; or \textit{(J)} research for new insights and innovative solutions to health problems; \ldots \text{[emphasis added]}