

STATE OF HAWAII
DEPARTMENT OF HEALTH
FAMILY HEALTH SERVICES DIVISION
NOTICE OF PUBLIC HEARING

Pursuant to sections 91-3 and 92-41, Hawaii Revised Statutes (HRS), the Hawaii State Department of Health (DOH), Family Health Services Division will receive written comments and hold a public hearing to receive testimony on the proposed amendments to Hawaii Administrative Rules (HAR), Chapter 11-143, Testing of Newborn Infants for Metabolic and Other Diseases.

The subjects and purposes of the proposed amendments are:

Section 11-143-3. Definitions: Mucopolysaccharidosis Type I (MPS I), Pompe, Spinal muscular atrophy (SMA), and X-linked adrenoleukodystrophy (X-ALD) are added to the Hawaii screening panel of diseases.

Section 11-143-4.5. Fees and special fund. The cost of each kit will be increased from \$99.00 to \$155.00.

Public hearings on the proposed amendments of Chapter 11-143, HAR will be held at the following location on April 30, 2024, at 10:00 a.m. as follows:

In Person: Wilcox Building, 741 Sunset Avenue, Honolulu, HI 96816

Virtually/Zoom Meeting for All Islands (All interested persons statewide):

Topic: Public Hearing: Hawaii Newborn Metabolic Screening Program Updates

Time: April 30, 2024, 10:00 AM Hawaii

Join Zoom Meeting

<https://zoom.us/j/95710720854>

Meeting ID: 957 1072 0854

One tap mobile

+12532050468, 95710720854# US

+12532158782, 95710720854# US (Tacoma)

Oral/Written Testimony: All interested persons may submit testimony orally or in writing to the presiding hearings officer at the public hearing. Written testimony will also be accepted until 4:30 p.m. on April 29, 2024, at: Children with Special Health Needs Branch (HAR 11-143) 741 Sunset Avenue, Honolulu, Hawaii, 96816.

Copies of the proposed rules are available for review at the Children with Special Health Needs Branch at the address above during the hours of 8:00 a.m. to 4:00 p.m., Monday through Friday (not including State Holidays). The proposed rules are also available at:

<http://health.hawaii.gov/opppd/administrative-rules/>.

A copy of the proposed rules will be mailed or emailed to any interested person who requests a copy. For a mailed copy, call (808) 733-9069 (Oahu) for information and send to the Children with Special Health Needs Branch at the address above a written request with the name/address of the requestor. For emailed copies please send request to dana.mulcahy@doh.hawaii.gov.

Persons requiring special assistance or services (e.g., sign language interpreter, large print, etc.) should call the Newborn Metabolic Screening Program at (808) 733-9069 (Oahu) by April 16, 2024, to secure and assure accommodation, although all reasonable attempts will be made to support access to the hearing.

DOH will make the final decision on the proposed amendments after considering all presented testimonies from the hearing and will send notice of the final decision taken with respect to the proposed HAR.

(MN: Mar. 16, 2024)