



128th MAINE LEGISLATURE

FIRST REGULAR SESSION-2017

Legislative Document

No. 265

H.P. 198

House of Representatives, January 31, 2017

An Act Concerning Screening of Newborns for Lysosomal Storage Disorders

Reference to the Committee on Health and Human Services suggested and ordered printed.

A handwritten signature in cursive script that reads "R B. Hunt".

ROBERT B. HUNT
Clerk

Presented by Representative JOHANSEN of Monticello.
Cosponsored by Senator CARPENTER of Aroostook and
Representatives: BRADSTREET of Vassalboro, HARVELL of Farmington, McELWEE of
Caribou, STEWART of Presque Isle, WARD of Dedham.

1 **Be it enacted by the People of the State of Maine as follows:**

2 **Sec. 1. 22 MRSA §1533, sub-§2, ¶D-1** is enacted to read:

3 D-1. Explore options for entering into contracts with other states to test samples
4 collected during screening for lysosomal storage disorders;

5 **Sec. 2. Department of Health and Human Services to amend rules on the**
6 **newborn screening program.** By January 1, 2018, the Department of Health and
7 Human Services shall amend its rules in Chapter 283 relating to testing newborn infants
8 for detection of causes of cognitive disabilities and selected genetic conditions to include
9 screening for the lysosomal storage disorders known as Krabbe, Pompe, Gaucher, Fabry
10 and Niemann-Pick diseases.

11 **SUMMARY**

12 This bill requires the Department of Health and Human Services to amend its rules in
13 Chapter 283 relating to the newborn screening program by January 1, 2018 to add to the
14 program the lysosomal storage disorders known as Krabbe, Pompe, Gaucher, Fabry and
15 Niemann-Pick diseases. It directs the department to explore options to enter into
16 contracts with other states to test samples collected for lysosomal storage disorders.