

MAINE STATE LEGISLATURE

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No. 1616

H.P. 1144

House of Representatives, December 23, 2009

An Act To Enhance Newborn Blood Spot Screening To Conform to Federal Newborn Screening Standards

Submitted by the Department of Health and Human Services pursuant to Joint Rule 204.
Received by the Clerk of the House on December 21, 2009. Referred to the Committee on
Health and Human Services pursuant to Joint Rule 308.2 and ordered printed pursuant to Joint
Rule 401.

Millicent M. MacFarland
MILLICENT M. MacFARLAND
Clerk

Presented by Representative JONES of Mount Vernon.

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

2 **Sec. 1. 22 MRSA §42, sub-§5**, as amended by PL 2007, c. 508, §1, is further
3 amended to read:

4 **5. Confidentiality of records containing certain medical information.**
5 Department records that contain personally identifying medical information that are
6 created or obtained in connection with the department's public health activities or
7 programs are confidential. These records include, but are not limited to, information on
8 genetic, communicable, occupational or environmental disease entities, and information
9 gathered from public health nurse activities, or any program for which the department
10 collects personally identifying medical information.

11 The department's confidential records may not be open to public inspection, are not
12 public records for purposes of Title 1, chapter 13, subchapter 1 and may not be examined
13 in any judicial, executive, legislative or other proceeding as to the existence or content of
14 any individual's records obtained by the department.

15 Exceptions to this subsection include release of medical and epidemiologic information in
16 such a manner that an individual can not be identified; disclosures that are necessary to
17 carry out the provisions of chapter 250; disclosures made upon written authorization by
18 the subject of the record, except as otherwise provided in this section; and disclosures that
19 are specifically provided for by statute or by departmental rule. The department may
20 participate in a regional or national tracking system as provided in ~~section~~ sections 1533
21 and 8824 ~~or both~~.

22 Nothing in this subsection precludes the department, during the data collection phase of
23 an epidemiologic investigation, from refusing to allow the inspection or copying of any
24 record or survey instrument, including any redacted record or survey instrument,
25 containing information pertaining to an identifiable individual that has been collected in
26 the course of that investigation. The department's refusal is not reviewable.

27 **Sec. 2. 22 MRSA §1532**, as amended by PL 2007, c. 450, Pt. A, §7, is further
28 amended to read:

29 **§1532. Detection of serious conditions**

30 The department shall require hospitals, ~~maternity homes~~ birthing centers and other
31 ~~maternity birthing~~ services to test newborn infants, or to cause them to be tested, by
32 means of blood spot screening for the presence of treatable congenital, genetic or
33 metabolic abnormalities conditions that may be expected to result in subsequent cognitive
34 disabilities, serious illness or death. The department shall adopt rules to define this
35 requirement and the approved testing methods, materials, procedure and testing
36 sequences. Reports and records of those making these tests may be required to be
37 submitted to the department in accordance with departmental rules. The department may,
38 on request, offer consultation, training and evaluation services to those testing facilities.
39 The department shall adopt rules according to which it shall in a timely fashion refer
40 newborn infants with confirmed treatable congenital, genetic or metabolic abnormalities
41 conditions to the Child Development Services System as defined in Title 20-A, section
42 7001, subsection 1-A. The department shall also adopt rules according to which it shall

1 in a timely fashion refer a newborn infant to the Child Development Services System if at
2 least 6 months have passed since an initial positive test result of a treatable congenital,
3 genetic or metabolic abnormality condition without the specific nature of the ~~metabolic~~
4 abnormality's condition having been confirmed. The department and the Department of
5 Education shall execute an interagency agreement to facilitate all referrals in this section.
6 In accordance with the interagency agreement, the Department of Education shall offer a
7 single point of contact for the Department of Health and Human Services to use in
8 making referrals. Also in accordance with the interagency agreement, the Child
9 Development Services System may make direct contact with the families who are
10 referred. The referrals may take place electronically. For purposes of quality assurance
11 and improvement, the Child Development Services System shall supply to the department
12 aggregate data at least annually on the number of children referred to the Child
13 Development Services System under this section who are found eligible for early
14 intervention services and on the number of children found not eligible for early
15 intervention services. In addition, the department shall supply data at least annually to
16 the Child Development Services System on how many children in the ~~metabolic~~
17 abnormality detection newborn blood spot screening program as established by rule of the
18 department under section 1533, subsection 2, paragraph G were screened and how many
19 were found to have a ~~metabolic~~ disorder. The requirement in this section that a newborn
20 infant be tested for the presence of treatable congenital, genetic or metabolic
21 abnormalities conditions that may be expected to result in subsequent cognitive disability
22 does not apply to a child if the parents of that child object on the grounds that the test
23 conflicts with their religious tenets and practices.

24 **Sec. 3. 22 MRSA §1533, sub-§2**, as enacted by PL 1983, c. 848, §2, is amended
25 to read:

26 **2. Responsibility for the program.** The commissioner shall designate personnel
27 within the ~~Division~~ department's division of ~~Maternal and Child Health~~ family health to:

28 A. Coordinate matters pertaining to detection, prevention and treatment of genetic
29 conditions and metabolic disorders;

30 A-1. Establish, maintain and operate a tracking system to assess and coordinate
31 treatment related to congenital, genetic and metabolic disorders;

32 A-2. Evaluate the effectiveness of screening, counseling and health care services in
33 reducing the morbidity and mortality caused by heritable disorders in newborns and
34 children;

35 A-3. Collect, analyze and make available to families data on certain heritable
36 disorders;

37 A-4. Ensure access to treatment and other services that will improve clinical and
38 developmental outcomes. To accomplish this, the department is authorized to share
39 data with other states' public health newborn blood spot screening programs;

40 B. Cooperate with and stimulate public and private not-for-profit associations,
41 agencies, corporations, institutions or other entities involved in developing and
42 implementing eligible programs and activities designed to provide services for
43 genetic conditions and metabolic disorders;

- 1 C. Administer any funds ~~which~~ that are appropriated for the services and expenses
2 of a genetic screening, counseling and education program;
- 3 D. Enter into agreements and contracts for the delivery of genetic services;
- 4 E. Establish, promote and maintain a public information program on genetic
5 conditions and metabolic disorders and the availability of counseling and treatment
6 services;
- 7 F. Publish, from time to time, the results of any relevant research, investigation or
8 survey conducted on genetic conditions and metabolic disorders and, from time to
9 time, collate those publications for distribution to scientific organizations and
10 qualified scientists and physicians; and
- 11 G. ~~Promulgate regulations~~ Adopt rules necessary to carry out the purposes of this
12 section chapter.

13 **SUMMARY**

14 This bill amends the newborn screening program law to describe conditions for
15 which screening is available and reliable and for which treatment improves outcomes.
16 The bill also allows the program to align with national and regional efforts in screening,
17 treatment and evaluation consistent with the federal Newborn Screening Saves Lives Act
18 of 2007. The department's genetics program is responsible to coordinate matters
19 pertaining to detection, prevention and treatment of genetic conditions and metabolic
20 disorders. The collection and sharing of data with other states involved in the same
21 newborn blood spot screening programs will allow the department to assess the
22 comprehensive newborn screening system's strengths and weaknesses and will promote
23 quality assurance, quality improvement and ongoing evaluation of the effectiveness of the
24 newborn blood spot screening program as established by rule of the Department of Health
25 and Human Services.