

127th MAINE LEGISLATURE

FIRST REGULAR SESSION-2015

Legislative Document

No. 1134

S.P. 403

In Senate, March 31, 2015

An Act To Require the Department of Health and Human Services To Distribute Information Regarding Down Syndrome to Providers of Prenatal and Postnatal Care and to Genetic Counselors

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

forth & Puit

HEATHER J.R. PRIEST Secretary of the Senate

Presented by Senator VOLK of Cumberland. Cosponsored by Representative LAJOIE of Lewiston and Senators: BRAKEY of Androscoggin, CUSHING of Penobscot, EDGECOMB of Aroostook, LIBBY of Androscoggin, MASON of Androscoggin, PATRICK of Oxford, Representatives: CRAFTS of Lisbon, TIMBERLAKE of Turner.

- 1 Be it enacted by the People of the State of Maine as follows:
- 2 Sec. 1. 22 MRSA §1642 is enacted to read:

3 §1642. Down syndrome

4 <u>The department shall establish, maintain and operate an information service for</u> 5 <u>Down syndrome. For the purposes of this section, "Down syndrome" means a</u> 6 <u>chromosomal condition caused by an error in cell division that results in the presence of</u> 7 <u>an extra whole or partial copy of chromosome 21.</u>

8 **1. Expectant or new parent; others.** A hospital, physician, health care provider or 9 certified nurse midwife who renders prenatal care or postnatal care or a genetic counselor 10 who renders prenatal or postnatal genetic counseling shall, upon receipt of a positive test 11 result from a prenatal or postnatal test for Down syndrome, provide the expectant or new 12 parent with information provided by the department under subsection 2. The department 13 shall also make such information available to any other person who has received a 14 positive test result from a prenatal or postnatal test for Down syndrome.

15 2. Information provided. The department shall make available to a person who
16 renders prenatal care, postnatal care or genetic counseling to expectant or new parents
17 who receive a prenatal or postnatal diagnosis of Down syndrome the following:

18A. Up-to-date evidence-based written information about Down syndrome that19includes physical, developmental, educational and psychosocial outcomes, life20expectancy, clinical course and intellectual and functional development and treatment21options. The information must have been reviewed by medical experts and national22Down syndrome organizations; and

B. Contact information regarding support programs and services, including
information hotlines specific to Down syndrome, resource centers and
clearinghouses, national, statewide and local Down syndrome organizations and other
educational and support programs.

Accessibility of information. Information provided under this section must be
culturally and linguistically appropriate for a person receiving a positive prenatal
diagnosis and for the family of a child receiving a postnatal diagnosis of Down syndrome.

30 SUMMARY
31 This bill requires that hospitals, physicians and other health professionals provide
32 information about Down syndrome to expectant or new parents who have received a
33 prenatal or postnatal diagnosis of Down syndrome. The Department of Health and
34 Human Services is directed to distribute appropriate information to health care providers
35 for distribution.