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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

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

Sec. 1. 22 MRSA §1642 is enacted to read:

§ 1642. Down syndrome

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

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

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

A. Up-to-date evidence-based written information about Down syndrome that includes physical, developmental, educational and psychosocial outcomes, life expectancy, clinical course and intellectual and functional development and treatment options. The information must have been reviewed by medical experts and national Down 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.

3. 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.

SUMMARY

This bill requires that hospitals, physicians and other health professionals provide information about Down syndrome to expectant or new parents who have received a prenatal or postnatal diagnosis of

SP0403, LD 1134, item 1, 127th Maine State Legislature
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Down syndrome. The Department of Health and Human Services is directed to distribute appropriate information to health care providers for distribution.