

LEGISLATIVE BILL 891

Approved by the Governor April 07, 2016

Introduced by Brasch, 16; Baker, 30; Bloomfield, 17; Coash, 27; Cook, 13; Craighead, 6; Crawford, 45; Davis, 43; Ebke, 32; Fox, 7; Friesen, 34; Garrett, 3; Gloor, 35; Groene, 42; Haar, 21; Hansen, 26; Harr, 8; Hilkemann, 4; Howard, 9; Hughes, 44; Johnson, 23; Kintner, 2; Kolowski, 31; Kolterman, 24; Krist, 10; Kuehn, 38; Larson, 40; Lindstrom, 18; McCollister, 20; Mello, 5; Morfeld, 46; Murante, 49; Pansing Brooks, 28; Riepe, 12; Scheer, 19; Schilz, 47; Schnoor, 15; Schumacher, 22; Seiler, 33; Smith, 14; Stinner, 48; Sullivan, 41; Watermeier, 1; Williams, 36.

A BILL FOR AN ACT relating to public health and welfare; to adopt the Down Syndrome Diagnosis Information and Support Act.
Be it enacted by the people of the State of Nebraska,

Section 1. Sections 1 to 4 of this act shall be known and may be cited as the Down Syndrome Diagnosis Information and Support Act.

Sec. 2. For purposes of the Down Syndrome Diagnosis Information and Support Act:

(1) Department means the Division of Public Health of the Department of Health and Human Services;

(2) Down syndrome means a chromosomal condition caused by cell division that results in the presence of an extra whole or partial copy of chromosome 21;

(3) Down syndrome organization means any national, state, or local nonprofit organization primarily involved in providing advocacy, support, and education to individuals with Down syndrome and their parents;

(4) Health care practitioner means any person who is credentialed under the Uniform Credentialing Act to provide health or medical care in the ordinary course of business or practice of a profession, including a genetic counselor; and

(5) Parents means (a) expectant parents of a child who receive a test result from a prenatal screening or diagnostic test that indicates a high likelihood or the definite presence of Down syndrome, (b) parents of a child postnatally diagnosed with Down syndrome, and (c) a legal guardian of a child diagnosed with Down syndrome.

Sec. 3. A health care practitioner who provides prenatal or postnatal care, who administers or requests administration of a prenatal or postnatal screening or diagnostic test that detects Down syndrome, and who receives a test result from such test that indicates a high likelihood or the definite presence of Down syndrome shall deliver to the parents the information support sheet provided by the department under section 4 of this act.

Sec. 4. (1) The department shall make the following information available:

(a) Up-to-date information about Down syndrome that has been reviewed by medical experts and Down syndrome organizations. The information shall be provided in a written format and shall include the following:

(i) A clinical course description, including possible physical, developmental, educational, and psychosocial outcomes;

(ii) Treatment and therapy options; and

(iii) Life expectancy; and

(b) Contact information for Down syndrome organizations that are nonprofit and that provide information and support services for parents, including first-call programs and information hotlines specific to Down syndrome, resource centers or clearinghouses, and other education and support programs for Down syndrome.

(2) The department shall post the information required in subsection (1) of this section on its web site and shall include an information support sheet to be delivered by health care practitioners to parents as prescribed in section 3 of this act.

(3) The department shall ensure that the information required in subsection (1) of this section is culturally and linguistically appropriate for parents.

(4) A Down syndrome organization may request that the department include the organization's informational material and contact information on the web site. The department may add the information to the web site upon request.