

LEGISLATURE OF NEBRASKA  
ONE HUNDRED FOURTH LEGISLATURE  
SECOND SESSION

**LEGISLATIVE BILL 891**

FINAL READING

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.

Read first time January 11, 2016

Committee: Health and Human Services

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

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

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

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

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

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

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

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

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

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

31          (a) Up-to-date information about Down syndrome that has been

1 reviewed by medical experts and Down syndrome organizations. The  
2 information shall be provided in a written format and shall include the  
3 following:

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

6 (ii) Treatment and therapy options; and

7 (iii) Life expectancy; and

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

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

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

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