



99TH GENERAL ASSEMBLY

State of Illinois

2015 and 2016

HB3158

by Rep. Robyn Gabel

SYNOPSIS AS INTRODUCED:

New Act

Creates the Down Syndrome Information and Awareness Act. Requires the Department of Public Health to make available up-to-date, evidence-based written information about Down syndrome. Sets forth a list of the type of information the Department must offer. Provides that the Department shall make this information available to persons who render prenatal care, postnatal care, or genetic counseling to parents who receive a prenatal or postnatal diagnosis of Down syndrome. Requires a health care provider who renders prenatal or postnatal care, or genetic counselor who renders genetic counseling to, upon receipt of a positive test result from a test for Down syndrome, provide an expectant or new parent with the information provided by the Department.

LRB099 06581 JLK 26654 b

FISCAL NOTE ACT
MAY APPLY

A BILL FOR

1 AN ACT concerning health.

2 **Be it enacted by the People of the State of Illinois,**
3 **represented in the General Assembly:**

4 Section 1. Short title. This Act may be known as the Down
5 Syndrome Information and Awareness Act.

6 Section 5. Definitions. As used in this Act:

7 "Clearinghouse" means a central institution or agency for
8 the collection, maintenance, and distribution of materials
9 related to Down syndrome.

10 "Down syndrome" means a chromosomal condition caused by an
11 error in cell division that results in the presence of an extra
12 whole or partial copy of chromosome 21.

13 "First call program" means a volunteer group of individuals
14 who make themselves available to parents of children newly
15 diagnosed with Down syndrome.

16 "Health care provider" means any physician, hospital
17 facility, or other person that is licensed or otherwise
18 authorized to deliver health care services.

19 Section 10. Down syndrome information. The Department
20 shall make available up-to-date, evidence-based written
21 information about Down syndrome that has been reviewed by
22 medical experts and State and national Down syndrome

1 organizations, including physical, developmental, educational
2 and psychosocial outcomes, life expectancy, clinical course,
3 intellectual and functional development, and treatment
4 options. The written information shall include contact
5 information regarding first call programs and clearinghouses,
6 national, State and local Down syndrome organizations, and
7 other educational and support programs. The Department shall
8 make this information available to persons who render prenatal
9 care, postnatal care, or genetic counseling to parents who
10 receive a prenatal or postnatal diagnosis of Down syndrome. The
11 Department shall also make this information available to any
12 person who has received a positive test result from a test for
13 Down syndrome. The information provided under this Section
14 shall be culturally and linguistically appropriate for a woman
15 receiving a positive prenatal diagnosis of Down syndrome and
16 for the family of a child receiving a postnatal diagnosis of
17 Down syndrome.

18 Section 15. Distribution of information to parents. A
19 health care provider who renders prenatal or postnatal care, or
20 genetic counselor who renders genetic counseling shall, upon
21 receipt of a positive test result from a test for Down
22 syndrome, provide the expectant or new parent with the
23 information provided by the Department under Section 10 of this
24 Act.