

Regular Session, 2014

HOUSE BILL NO. 1058

BY REPRESENTATIVE HARRISON

HEALTH/DHH: Requires the Dept. of Health and Hospitals to provide information concerning Down syndrome to healthcare providers and on its website

1 AN ACT

2 To enact Part LXXV of Chapter 5 of Title 40 of the Louisiana Revised Statutes of 1950, to  
3 be comprised of R.S. 40:1300.381 through 1300.382, relative to public information  
4 concerning Down syndrome; to provide for definitions; to require the Department  
5 of Health and Hospitals to disseminate information regarding Down syndrome to  
6 healthcare providers and to publish such information electronically; and to provide  
7 for related matters.

8 Be it enacted by the Legislature of Louisiana:

9 Section 1. Part LXXV of Chapter 5 of Title 40 of the Louisiana Revised Statutes of  
10 1950, comprised of R.S. 40:1300.381 through 1300.382, is hereby enacted to read as  
11 follows:

12 PART LXXV. PUBLIC INFORMATION CONCERNING DOWN SYNDROME

13 §1300.381. Definitions

14 As used in this Part, the following terms have the meaning ascribed in this

15 Section:

16 (1) "Department" means the Department of Health and Hospitals.

17 (2) "Down syndrome" means a chromosomal condition caused by the  
18 presence of an extra whole or partial copy of chromosome 21.

1           (3) "Healthcare facility" means a facility, including but not limited to a  
2           hospital, or an office where a healthcare provider furnishes care to patients for health  
3           needs or medical conditions.

4           (4)(a) "Healthcare provider" means a person who is licensed, certified, or  
5           otherwise authorized by the laws of this state to provide health care or medical  
6           treatment in the ordinary course of business or practice of a profession.

7           (b) "Healthcare provider" includes a genetic counselor.

8           (5) "Hospital" means a facility that is duly licensed as a hospital in  
9           accordance with the provisions of the Hospital Licensing Law, R.S. 40:2100 et seq.  
10          §1300.382. Public information concerning Down syndrome

11          A. The department shall identify current, evidence-based, written  
12          information concerning Down syndrome that meets all of the following criteria:

13           (1) Has been reviewed by medical experts and national and local Down  
14           syndrome organizations.

15           (2) Is designed for use by an expectant parent who receives a prenatal test  
16           result for Down syndrome or a parent of a child who receives a diagnosis of Down  
17           syndrome.

18           (3) Does not engage in discrimination based on disability or genetic variation  
19           by explicitly or implicitly presenting pregnancy termination as a neutral or  
20           acceptable option when a prenatal test indicates a probability or diagnosis that the  
21           unborn child has Down syndrome or any other health condition.

22           (4) Is culturally and linguistically appropriate for potential recipients of the  
23           information and includes all of the following:

24           (a) Information addressing physical, developmental, educational, and  
25           psychosocial outcomes, life expectancy, clinical course, and intellectual and  
26           functional development and treatment options for individuals with Down syndrome.

27           (b) Contact information for national and local Down syndrome education  
28           and support programs and services, including information hotlines, resource centers,  
29           and clearinghouses.

1           B. With respect to public information concerning Down syndrome, the  
2           department shall do all of the following:

3           (1) Provide the information identified pursuant to Subsection A of this  
4           Section to healthcare facilities and healthcare providers that furnish prenatal care,  
5           postnatal care, or genetic counseling to expectant parents who receive a prenatal test  
6           result for Down syndrome and parents of a child diagnosed with Down syndrome.

7           (2) Make available the information identified pursuant to Subsection A of  
8           this Section on its Internet website.

9           C.(1) Upon receipt of a positive test result from a test for Down syndrome,  
10          a healthcare facility or healthcare provider shall provide to the expectant parent or  
11          the parent of the child diagnosed with Down syndrome the written information  
12          provided or made available by the department pursuant to Subsection B of this  
13          Section.

14          (2) All information provided pursuant to the provisions of this Section shall  
15          be culturally and linguistically appropriate for the recipient of the information, and  
16          shall not engage in discrimination based on disability or genetic variation by  
17          explicitly or implicitly presenting pregnancy termination as a neutral or acceptable  
18          option when a prenatal test indicates a probability or diagnosis that the unborn child  
19          has Down syndrome or any other health condition.

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#### DIGEST

The digest printed below was prepared by House Legislative Services. It constitutes no part of the legislative instrument. The keyword, one-liner, abstract, and digest do not constitute part of the law or proof or indicia of legislative intent. [R.S. 1:13(B) and 24:177(E)]

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Harrison

HB No. 1058

**Abstract:** Requires the Department of Health and Hospitals to provide information concerning Down syndrome to healthcare providers and on its website.

Proposed law provides relative to public information concerning Down syndrome, a chromosomal condition caused by the presence of an extra whole or partial copy of chromosome 21.

Proposed law requires the Department of Health and Hospitals (DHH) to identify current, evidence-based, written information concerning Down syndrome that meets all of the following criteria:

- (1) Has been reviewed by medical experts and national and local Down syndrome organizations.
- (2) Is designed for use by an expectant parent who receives a prenatal test result for Down syndrome or a parent of a child who receives a diagnosis of Down syndrome.
- (3) Does not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.
- (4) Is culturally and linguistically appropriate for potential recipients of the information and includes all of the following:
  - (a) Information addressing physical, developmental, educational, and psychosocial outcomes, life expectancy, clinical course, and intellectual and functional development and treatment options for individuals with Down syndrome.
  - (b) Contact information for national and local Down syndrome education and support programs and services, including information hotlines, resource centers, and clearinghouses.

Proposed law requires DHH to do all of the following:

- (1) Provide the information identified pursuant to proposed law to healthcare facilities and healthcare providers that furnish prenatal care, postnatal care, or genetic counseling to expectant parents who receive a prenatal test result for Down syndrome and parents of a child diagnosed with Down syndrome.
- (2) Make available the information identified pursuant to proposed law on its website.

Proposed law provides that upon receipt of a positive test result from a test for Down syndrome, a healthcare facility or healthcare provider shall provide to the expectant parent or the parent of the child diagnosed with Down syndrome the written information provided or made available by DHH pursuant to proposed law.

Proposed law stipulates that all information provided pursuant thereto shall be culturally and linguistically appropriate for recipients, and that such information not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.

(Adds R.S. 40:1300.381-1300.382)

#### Summary of Amendments Adopted by House

Committee Amendments Proposed by House Committee on Health and Welfare to the original bill.

1. Deleted reference to an error in cell division as a cause of Down syndrome.
2. Among criteria for information on Down syndrome that DHH is required to identify for publication, added a requirement that such information not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option

when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.

3. Added a requirement that information provided pursuant to proposed law not engage in discrimination based on disability or genetic variation by explicitly or implicitly presenting pregnancy termination as a neutral or acceptable option when a prenatal test indicates a probability or diagnosis that the unborn child has Down syndrome or any other health condition.