

THE GENERAL ASSEMBLY OF PENNSYLVANIA

HOUSE BILL

No. 2111 Session of 2014

INTRODUCED BY MARSHALL, MAHER, TURZAI, MUSTIO, READSHAW, P. COSTA, MATZIE, D. COSTA, KAUFFMAN, SONNEY, KILLION, B. BOYLE, MILLARD, TALLMAN, KINSEY, MARSICO, GODSHALL, SWANGER, COHEN, D. MILLER, BIZZARRO, V. BROWN, M. K. KELLER, BARRAR, CALTAGIRONE, KAVULICH, WHITE, THOMAS, DENLINGER, YOUNGBLOOD, GINGRICH, ROCK, FARRY, MCNEILL, COX, DiGIROLAMO, STERN, R. MILLER, GROVE, VEREB, BROOKS, HICKERNELL, GIBBONS, MOUL, C. HARRIS, OBERLANDER, MURT, GALLOWAY, WATSON, DeLUCA, MENTZER, BROWNLEE, REESE, EVERETT AND DELOZIER, MARCH 19, 2014

AS REPORTED FROM COMMITTEE ON HEALTH, HOUSE OF REPRESENTATIVES, AS AMENDED, APRIL 9, 2014

AN ACT

1 Requiring certain health care practitioners to disseminate
2 information relating to Down syndrome; and imposing duties on
3 the Department of Health.

4 The General Assembly of the Commonwealth of Pennsylvania
5 hereby enacts as follows:

6 Section 1. Short title.

7 This act shall be known and may be cited as the Down Syndrome
8 Prenatal AND POSTNATAL Education Act. <--

9 Section 2. Definitions.

10 The following words and phrases when used in this act shall
11 have the meanings given to them in this section unless the
12 context clearly indicates otherwise:

13 "Department." The Department of Health of the Commonwealth.

14 "DOWN SYNDROME." A CHROMOSOMAL CONDITION CAUSED BY AN ERROR <--

1 IN CELL DIVISION THAT RESULTS IN THE PRESENCE OF AN EXTRA OR  
2 PARTIAL COPY OF CHROMOSOME 21.

3 "Health care practitioner." ~~A health care practitioner that~~ <--  
4 ~~provides prenatal or postnatal care or genetic counseling to~~  
5 ~~expectant or new parents.~~ A PERSON WHO IS LICENSED, CERTIFIED OR <--  
6 OTHERWISE AUTHORIZED BY LAW OR REGULATION TO PROVIDE OR RENDER  
7 HEALTH CARE SERVICES OR GENETIC COUNSELING TO EXPECTANT OR NEW  
8 PARENTS.

9 Section 3. Dissemination of information on Down syndrome.

10 (a) Requirement.--A health care practitioner that  
11 administers, or causes to be administered, a test for Down  
12 syndrome to an expectant or new parent shall, upon receiving a  
13 test result that is positive for Down syndrome, provide the  
14 expectant or new parent with educational information made  
15 available by the department under section 4.

16 (b) Compliance.--Delivery of information prepared by the  
17 department in accordance with section 4 at the time genetic  
18 results or diagnostic conclusions are provided shall constitute  
19 compliance with this section.

20 Section 4. Informational publications by department.

21 (a) General rule.--The department shall make the following  
22 available to health care practitioners ON THE DEPARTMENT'S <--  
23 PUBLICLY ACCESSIBLE INTERNET WEBSITE:

24 (1) Up-to-date, evidence-based, ~~printed~~ information <--  
25 about Down syndrome that has been reviewed by medical experts  
26 and national Down syndrome organizations. The information  
27 provided shall include the following:

28 (i) Physical, developmental, educational and  
29 psychosocial outcomes.

30 (ii) Life expectancy.

1 (iii) Clinical course.  
2 (iv) Intellectual and functional development.  
3 (v) Treatment options.  
4 (VI) ANY OTHER INFORMATION THE DEPARTMENT DEEMS <--  
5 NECESSARY.

6 (2) Contact information regarding First Call programs  
7 and support services, including the following:

8 (i) Information hotlines specific to Down syndrome.

9 (ii) Relevant resource centers or clearinghouses.

10 (iii) National and local Down syndrome  
11 organizations, such as:

12 ~~(A) The Jerome Lejeune Foundation USA. <--~~

13 ~~(B) (A) Parent to Parent of Pennsylvania. <--~~

14 ~~(C) (B) Pennsylvania Early Intervention. <--~~

15 ~~(D) (C) Other relevant education and support <--~~  
16 programs.

17 ~~(b) Additional dissemination. The department shall post the <--~~  
18 ~~information under subsection (a) on its publicly accessible~~  
19 ~~Internet website.~~

20 ~~(c) (B) Form.--The information provided under this section <--~~  
21 ~~shall be culturally and linguistically appropriate for the~~  
22 ~~intended recipients of the information. THE INFORMATION PROVIDED <--~~

23 IN ACCORDANCE WITH THIS ACT SHALL CONFORM TO THE APPLICABLE  
24 STANDARD OR STANDARDS PROVIDED IN THE ENHANCED NATIONAL  
25 STANDARDS FOR CULTURALLY AND LINGUISTICALLY APPROPRIATE SERVICES  
26 IN HEALTH AND HEALTH CARE AS ADOPTED BY THE UNITED STATES  
27 DEPARTMENT OF HEALTH AND HUMAN SERVICES AND PUBLISHED IN THE  
28 FEDERAL REGISTER ON SEPTEMBER 24, 2013.

29 Section 5. Effective date.

30 This act shall take effect in 60 days.