

FIRST REGULAR SESSION

# HOUSE BILL NO. 1254

## 94TH GENERAL ASSEMBLY

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INTRODUCED BY REPRESENTATIVES HARRIS (110) (Sponsor), MEADOWS, KUESSNER, FALLERT,  
McGHEE, SANDER, SCHIEFFER, ONDER AND FUNDERBURK (Co-sponsors).

Read 1st time March 29, 2007 and copies ordered printed.

D. ADAM CRUMBLISS, Chief Clerk

2643L.01I

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### AN ACT

To amend chapter 191, RSMo, by adding thereto one new section relating to the prenatally diagnosed condition awareness act.

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*Be it enacted by the General Assembly of the state of Missouri, as follows:*

Section A. Chapter 191, RSMo, is amended by adding thereto one new section, to be  
2 known as section 191.385, to read as follows:

3       **191.385. 1. This section shall be known and may be cited as the "Prenatally**  
4 **Diagnosed Condition Awareness Act".**

5       **2. As used in this section, the following terms shall mean:**

6       **(1) "Down syndrome", a chromosomal disorder caused by an error in cell division**  
7 **that results in the presence of an extra whole or partial copy of chromosome 21;**

8       **(2) "Health care provider", any person or entity required by state or federal law**  
9 **or regulation to be licensed, registered, or certified to provide health care services, and who**  
10 **is so licensed, registered, or certified;**

11       **(3) "Prenatally diagnosed condition", any fetal health condition identified by**  
12 **prenatal genetic testing or prenatal screening procedures;**

13       **(4) "Prenatal test", diagnostic or screening tests offered to pregnant women seeking**  
14 **routine prenatal care that are administered on a required or recommended basis by a**  
**health care provider based on medical history, family background, ethnic background,**  
**previous test results, or other risk factors.**

EXPLANATION — Matter enclosed in bold-faced brackets [thus] in the above bill is not enacted and is intended to be omitted from the law. Matter in **bold-face** type in the above bill is proposed language.

15           **3. The director of the department of health and senior services may authorize and**  
16 **oversee certain activities, including the awarding of grants, contracts, or cooperative**  
17 **agreements, to:**

18           **(1) Collect, synthesize, and disseminate current scientific information relating to**  
19 **Down syndrome or other prenatally diagnosed conditions; and**

20           **(2) Coordinate the provision of and access to new or existing support services for**  
21 **patients receiving a positive test diagnosis for Down syndrome or other prenatally**  
22 **diagnosed conditions, including:**

23           **(a) The establishment of a resource telephone hotline and Internet web site**  
24 **accessible to patients receiving a positive test result;**

25           **(b) The establishment of a clearinghouse of scientific information, clinical course,**  
26 **life expectancy, development potential, and quality of life relating to Down syndrome or**  
27 **other prenatally diagnosed conditions;**

28           **(c) The establishment of statewide and local peer-support programs;**

29           **(d) The establishment of a state registry, or network of local registries, of families**  
30 **willing to adopt newborns with Down syndrome or other prenatally diagnosed conditions,**  
31 **and links to adoption agencies willing to place babies with Down syndrome or other**  
32 **prenatally diagnosed conditions, with families willing to adopt; and**

33           **(e) The establishment of awareness and education programs for health care**  
34 **providers who provide the results of prenatal tests for Down syndrome or other prenatally**  
35 **diagnosed conditions to patients.**

36           **4. The director shall provide assistance to local health departments to integrate the**  
37 **results of prenatal testing into a state vital statistics and birth defects surveillance program.**  
38 **The director shall ensure that activities carried out under this subsection are sufficient to**  
39 **extract population-level data relating to state rates and results of prenatal testing.**

40           **5. Upon receipt of a positive test result from a prenatal test for Down syndrome or**  
41 **other prenatally diagnosed conditions performed on a patient, the health care provider**  
42 **shall provide the patient with the following:**

43           **(1) Up-to-date scientific written information concerning the life expectancy, clinical**  
44 **course, and intellectual and functional development, and treatment options for a fetus**  
45 **diagnosed with or child born with Down syndrome or other prenatally diagnosed**  
46 **conditions;**

47           **(2) Referral to supportive services providers, including information hotlines**  
48 **specific to Down syndrome or other prenatally diagnosed conditions, resource centers or**  
49 **clearinghouses, and other education and support programs described in subdivision (2) of**  
50 **subsection 3 of this section.**

51           **6. (1) Notwithstanding the provisions of subsections 4 and 5 of this section, nothing**  
52 **in this section shall be construed to permit or require the collection, maintenance, or**  
53 **transmission without the health care provider obtaining the prior written consent of the**  
54 **patient of:**

55           **(a) Health information or data that identify a patient, or with respect to which**  
56 **there is a reasonable basis to believe the information could be used to identify the patient,**  
57 **including the patient's name, address, health care provider, or hospital; and**

58           **(b) Data that are not related to the epidemiology of the condition being tested for.**

59           **(2) Not later than one hundred eighty days after the effective date of this section,**  
60 **the director shall establish by rule guidelines concerning the implementation of subdivision**  
61 **(1) of this subsection.**

62           **7. Not later than two years after the effective date of this section and every two**  
63 **years thereafter, the director shall submit a report to the general assembly concerning the**  
64 **implementation of the guidelines described in subdivision (2) of subsection 6 of this section.**  
65 **Not later than one year after the effective date of this section, the director shall submit a**  
66 **report to the general assembly concerning the effectiveness of current health care and**  
67 **family support programs serving as resources for the families of children with disabilities.**

68           **8. The department of health and senior services may promulgate rules to implement**  
69 **the provisions of this section. Any rule or portion of a rule, as that term is defined in**  
70 **section 536.010, RSMo, that is created under the authority delegated in this section shall**  
71 **become effective only if it complies with and is subject to all of the provisions of chapter**  
72 **536, RSMo, and, if applicable, section 536.028, RSMo. This section and chapter 536,**  
73 **RSMo, are nonseverable and if any of the powers vested with the general assembly**  
74 **pursuant to chapter 536, RSMo, to review, to delay the effective date, or to disapprove and**  
75 **annul a rule are subsequently held unconstitutional, then the grant of rulemaking**  
76 **authority and any rule proposed or adopted after August 28, 2007, shall be invalid and**  
77 **void.**

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