

AMENDMENT TO COMMITTEE AMENDMENT

HOUSE OF REPRESENTATIVES

State of Oklahoma

SPEAKER:

CHAIR:

I move to amend amendment SB1645 FULLPCS1

			Of the printed Bill
Page	<u>5</u>	Section	<u>2</u>
		Lines	<u>4-1/2</u>
			Of the Engrossed Bill

By adding a new Section 2 to read as follows and by renumbering subsequent sections:

(please see attached document)

AMEND TITLE TO CONFORM TO AMENDMENTS

Amendment submitted by: Ryan Kiesel

Adopted: _____

Reading Clerk

1 "SECTION 2. NEW LAW A new section of law to be codified
2 in the Oklahoma Statutes as Section 1-548.1 of Title 63, unless
3 there is created a duplication in numbering, reads as follows:

4 This act shall be known and may be cited as the "Prenatally and
5 Postnatally Diagnosed Conditions Awareness Act".

6 SECTION 3. NEW LAW A new section of law to be codified
7 in the Oklahoma Statutes as Section 1-548.2 of Title 63, unless
8 there is created a duplication in numbering, reads as follows:

9 As used in the Prenatally and Postnatally Diagnosed Conditions
10 Awareness Act:

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

14 2. "Health care provider" means any person or entity required
15 by state or federal law or regulation to be licensed, registered, or
16 certified to provide health care services, and who is so licensed,
17 registered, or certified;

18 3. "Postnatally diagnosed condition" means any fetal health
19 condition identified by postnatal genetic testing or postnatal
20 screening procedures during the twelve-month period beginning at
21 birth;

22 4. "Postnatal test" means diagnostic or screening tests offered
23 with respect to an individual from birth to one (1) year of age that
24 is administered on a required or recommended basis by a health care

1 provider based on medical history, family background, ethnic
2 background, previous test results, symptoms the child is presenting,
3 or other risk factors;

4 5. "Prenatally diagnosed condition" means any fetal health
5 condition identified by prenatal genetic testing or prenatal
6 screening procedures; and

7 6. "Prenatal test" means diagnostic or screening tests offered
8 to pregnant women seeking routine prenatal care that are
9 administered on a required or recommended basis by a health care
10 provider based on medical history, family background, ethnic
11 background, previous test results, or other risk factors.

12 SECTION 4. NEW LAW A new section of law to be codified
13 in the Oklahoma Statutes as Section 1-548.3 of Title 63, unless
14 there is created a duplication in numbering, reads as follows:

15 It is the purpose of the Prenatally and Postnatally Diagnosed
16 Conditions Awareness Act to:

17 1. Increase patient referrals to providers of key support
18 services for patients who have received a positive test diagnosis
19 for Down syndrome, or other prenatally or postnatally diagnosed
20 conditions, as well as to provide up-to-date, comprehensive
21 information about life expectancy, development potential, and
22 quality of life for a child born with Down syndrome or other
23 prenatally or postnatally diagnosed condition;

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1 2. Strengthen existing networks of support through a State
2 Department of Health patient and provider outreach program;

3 3. Improve available data by incorporating information directly
4 revealed by prenatal or postnatal testing into existing state-based
5 surveillance programs for birth defects and prenatally or
6 postnatally diagnosed conditions; and

7 4. Ensure that patients receive up-to-date, scientific
8 information about the accuracy of the test.

9 SECTION 5. NEW LAW A new section of law to be codified
10 in the Oklahoma Statutes as Section 1-548.4 of Title 63, unless
11 there is created a duplication in numbering, reads as follows:

12 The Commissioner of Health may authorize and oversee certain
13 activities, including the awarding of grants, contracts, or
14 cooperative agreements to:

15 1. Collect, synthesize, and disseminate current scientific
16 information relating to Down syndrome or other prenatally or
17 postnatally diagnosed conditions; and

18 2. Coordinate the provision of, and access to, new or existing
19 supportive services for patients receiving a positive test diagnosis
20 for Down Syndrome or other prenatally or postnatally diagnosed
21 conditions including, but not limited to:

22 a. a resource telephone hotline and internet website
23 accessible to patients receiving a positive test
24 result,

- 1 b. an outreach system for new and expecting parents to
2 provide them with up-to-date information on the
3 clinical course, life expectancy, development
4 potential, quality of life, and available resources
5 and services for children with Down syndrome or other
6 prenatally and postnatally diagnosed conditions,
- 7 c. the expansion and further development of statewide and
8 local peer-support programs, so that such programs can
9 more effectively serve parents of newly diagnosed
10 children,
- 11 d. a statewide registry or network of local registries of
12 families willing to adopt newborns with Down syndrome
13 or other prenatally or postnatally diagnosed
14 conditions, and links to adoption agencies willing to
15 place babies with Down syndrome or other prenatally or
16 postnatally diagnosed conditions, with families
17 willing to adopt, and
- 18 e. awareness and education programs for health care
19 providers who provide the results of prenatal or
20 postnatal tests for Down syndrome or other prenatally
21 or postnatally diagnosed conditions to patients
22 consistent with the purposes of this section.
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1 SECTION 6. NEW LAW A new section of law to be codified
2 in the Oklahoma Statutes as Section 1-548.5 of Title 63, unless
3 there is created a duplication in numbering, reads as follows:

4 A. Prior to the reporting of the results of a prenatal or
5 postnatal test under this section, the patient involved shall be
6 provided with a disclosure statement, a form to be developed by the
7 State Department of Health, that describes the manner in which the
8 results of the tests shall be used. These results may not be
9 reported unless the patient consents to the reporting after receipt
10 of the disclosure statement.

11 B. Nothing in this section shall be construed to permit or
12 require the collection, maintenance, or transmission, without the
13 health care provider obtaining the prior, written consent of the
14 patient, of:

15 1. Health information or data that identifies a patient, or
16 there is a reasonable basis to believe the information could be used
17 to identify the patient, including the name, address, health care
18 provider, or hospital; and

19 2. Data not related to the epidemiology of the condition for
20 which testing is being performed.

21 C. Upon receipt of a positive test result from a prenatal or
22 postnatal test for Down syndrome or other prenataally or postnatally
23 diagnosed conditions performed on a patient, the health care
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1 provider involved, or a designee, shall provide the patient with the
2 following:

3 1. Up-to-date, scientific, written information concerning the
4 life expectancy, clinical course, and intellectual and functional
5 development and treatment options for a fetus diagnosed with or
6 child born with Down syndrome or other prenatally or postnatally
7 diagnosed conditions; and

8 2. Referral to supportive services providers, including
9 information hotlines specific to Down syndrome or other prenatally
10 or postnatally diagnosed conditions, resource centers, or
11 clearinghouses, and other education and support programs as provided
12 for in the Prenatally and Postnatally Diagnosed Conditions Awareness
13 Act.

14 D. The State Board of Health shall promulgate rules in
15 accordance with the provisions of the Prenatally and Postnatally
16 Diagnosed Conditions Awareness Act.”

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