

By Senator Wasserman Schultz

34-394A-03

1 A bill to be entitled
2 An act relating to birth defects; creating s.
3 381.00323, F.S.; requiring the Department of
4 Health to maintain and expand the Florida Birth
5 Defects Registry; providing confidentiality of
6 certain information held by the department;
7 providing legislative intent regarding funding;
8 providing requirements for a program of pilot
9 projects for an active birth defects reporting
10 and prevention system; requiring a summary of
11 outcomes; providing an effective date.
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13 WHEREAS, birth defects are the leading cause of infant
14 mortality and contribute substantially to illness and
15 long-term disability and continue to be a major cause of death
16 through age 14 years, and
17 WHEREAS, birth defects are a major cause of morbidity,
18 mortality, and disability in the state, and
19 WHEREAS, the handicapping and fatal conditions
20 resulting from birth defects represent problems of significant
21 health importance, about which little is known, but which
22 frequently require expensive medical care, and
23 WHEREAS, these conditions influence the overall quality
24 of life of affected individuals and their families and
25 increase the need for social services and special educational
26 programs, and
27 WHEREAS, birth defects surveillance systems are vital
28 for monitoring and detecting trends in birth defects,
29 providing the basis for studies of the causes of birth
30 defects, and planning and evaluating the effects of prevention
31 activities, and

1 WHEREAS, working with maternal and child health
2 programs, birth defects surveillance systems can help improve
3 prevention and intervention services, and

4 WHEREAS, an enhanced birth defects reporting system
5 will provide information that is timely and accurate and will
6 result in appropriate referral for services and development of
7 effective prevention programs, and

8 WHEREAS, the Legislature intends with this legislation
9 to codify, enhance, and expand the Florida Birth Defects
10 Registry, an existing birth defects surveillance program
11 presently operating within the Department of Health under Rule
12 64D-3.027, Florida Administrative Code, NOW, THEREFORE,

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14 Be It Enacted by the Legislature of the State of Florida:

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16 Section 1. Section 381.00323, Florida Statutes, is
17 created to read:

18 381.00323 Statewide birth defects reporting and
19 prevention system.--The department shall maintain the Florida
20 Birth Defects Registry, with information collected in
21 accordance with s. 381.0031, to support activities and studies
22 directed toward the prevention of birth defects and the
23 reduction of morbidity, mortality, and disability resulting
24 from birth defects. The birth defects reporting and prevention
25 program shall operate statewide, and the department may use
26 information collected by the Florida Birth Defects Registry to
27 notify affected individuals and their families about available
28 services and programs. All information and records held by the
29 department or its authorized representatives relating to birth
30 defects remains confidential and exempt from s. 119.07(1), as
31 provided in s. 381.0031. The current passive, population-based

1 birth defects registry shall continue until over 50 percent of
2 the state's population is served by an active surveillance
3 system. It is the intent of the Legislature that adequate
4 resources be allocated annually for the current system to
5 continue operating within the department under Rule 64D-3.027,
6 Florida Administrative Code, and that funding be provided for
7 a program of pilot projects, leading to a statewide active
8 reporting and prevention system over a 10-year period. Initial
9 active birth defects reporting and prevention system pilot
10 projects shall be established in Hillsborough, Duval, and
11 Broward Counties, beginning in fiscal year 2003-2004, shall be
12 designed to support epidemiological research in accordance
13 with s. 381.0032 and Rule 64D-3.027, Florida Administrative
14 Code, and shall facilitate collaborative partnerships among
15 state agencies, advocacy organizations, health care providers,
16 hospitals, laboratories, and other organizations working to
17 identify and prevent birth defects. The active birth defects
18 reporting and prevention system shall:
19 (a) Identify and describe birth defects.
20 (b) Detect trends and clusters of birth defects.
21 (c) Quantify morbidity, mortality, and disability
22 related to birth defects.
23 (d) Stimulate epidemiological research regarding birth
24 defects.
25 (e) Identify risk factors for birth defects.
26 (f) Facilitate intervention in and prevention of birth
27 defects, including secondary conditions.
28 (g) Facilitate access to support services and
29 treatment for birth defects.
30 (h) Inform and educate health care professionals about
31 birth defects.

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(i) Inform and educate the public about birth defects.

Section 2. This act shall take effect July 1, 2003.

SENATE SUMMARY

Requires the Department of Health or a contractual designee to maintain and expand the Florida Birth Defects Registry. Provides for confidentiality of certain information held by the department. Provides legislative intent regarding continued and expanded funding. Provides requirements for a program of pilot projects for an active birth defects reporting and prevention system.