AN ACT to renumber and amend 253.12 (1) (b); to amend 69.03 (12), 69.20 (2)
(a) (intro.), 69.20 (3) (b) 3., 69.20 (3) (c), 69.20 (3) (d), 253.12 (1) (a) (intro.),
253.12 (1) (a) 1., 253.12 (2) (a) (intro.), 253.12 (2) (am), 253.12 (2) (b), 253.12 (2)
(e), 253.12 (3) (a) 1. (intro.), 253.12 (3) (a) 1. c., 253.12 (3) (c), 253.12 (4) (a),
253.12 (5) (a) 1., 253.12 (5) (a) 2. and 253.12 (5) (a) 4.; to repeal and recreate
253.12 (2) (d); and to create 69.20 (2) (a) 3., 253.12 (1) (e), 253.12 (1) (f), 253.12
(1) (g), 253.12 (2) (a) 3., 253.12 (2) (a) 4., 253.12 (5) (c) and 253.12 (5m) of the
statutes; relating to: the birth defect prevention and surveillance system.

Analysis by the Legislative Reference Bureau
Under the birth defect prevention and surveillance system (system) in current
law, pediatric specialty clinics and physicians are required to report to the
Department of Health and Family Services (DHFS) any birth defects of infants or
children who are diagnosed or treated in the clinics or by the physicians. A “birth
defect” is defined as a structural deformation, disruption, or dysplasia or a genetic,
inherited, or biochemical disease that occurs prior to or at birth and that requires
medical or surgical intervention or interferes with normal growth and development.
An “infant or child” is defined as a human being from birth to the age of two years.
DHFS may not require a pediatric specialty clinic or physician to report the name
of a reported infant or child if the parent or guardian of the infant or child refuses in writing to consent to the release of the name or address of the infant or child.

Also under current law, information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only or that involves the birth of a child to an unmarried mother may be disclosed only in certain instances. One instance is disclosure of this information, under an interstate cooperation agreement, from the vital record of the resident of another state or a resident of this state born in another state, for use by the state registrar in compiling statistics. Another instance is disclosure of statistical or medical information for use in the conduct of official duties of a federal agency, a Wisconsin governmental agency, or the agency of a county, city, town, or village. In addition, hospitals and funeral directors must provide and the state registrar must accept reports of certain fetal deaths. Before destroying these reports, the state registrar may record the reports’ information for use in medical research and use the information to compile statistics.

Lastly, under current law, DHFS must establish and maintain an up-to-date registry that documents the diagnosis in this state of any infant or child who has a birth defect. Among the information that DHFS is required to include in the registry is information that will facilitate the development of primary preventive strategies to decrease the occurrence of birth defects without increasing abortions.

This bill changes the process by which the parent or guardian of a stillborn human, infant, or child may decide not to consent to the release of the human’s, infant’s, or child’s identifying information, to require that a physician or physician’s designee first inform the parent or guardian of the intent of the system and to require signature of the parent or guardian on a DHFS form. Further, the bill specifies a process by which, using the DHFS form, the parent or guardian of a stillborn human, infant, or child may effect withdrawal of consent to the release of identifying information about the stillborn human, infant, or child, and requires that, if consent to the release is withdrawn, DHFS remove the information from the system. DHFS must prescribe and distribute to pediatric specialty clinics and local health departments the form for these purposes by July 1, 2009.

The bill requires the division of DHFS that deals with vital statistics to report to the system information that is contained in a vital record and is designated as being collected for statistical and medical use or statistical use only, including this type of information that is available under an interstate cooperation agreement, if this disclosure is agreed to by the other state. In addition, the bill requires the entity that contracts with the Department of Administration for collecting, analyzing, and disseminating health care information of hospitals and ambulatory surgery centers to report to the system concerning birth defects as recorded in public use data files of hospitals and ambulatory surgery centers.

The bill authorizes DHFS to contract with an entity to perform the development of primary preventive strategies to decrease the occurrence of birth defects as information to be included in the birth defect registry.

The bill also permits the state registrar to record information from reports of certain fetal deaths for use in research conducted under the system.
Lastly, the bill includes stillborn humans, as defined in the bill, under the requirements of the system, expands the definition of “birth defect” to include structural malformations, and makes other minor changes.

For further information see the state and local fiscal estimate, which will be printed as an appendix to this bill.

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The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:

**SECTION 1.** 69.03 (12) of the statutes is amended to read:

69.03 (12) Accept fetal death reports under s. 69.18 (1) (e). The state registrar may record the information on the reports for use in medical research, including research conducted under s. 253.12 (5) (b), and may use the information to compile statistics. After recording the information on a fetal death report, the state registrar shall destroy the report.

**SECTION 2.** 69.20 (2) (a) (intro.) of the statutes is amended to read:

69.20 (2) (a) (intro.) Except as provided under sub. (3), information in the part of a certificate of birth or divorce or annulment or a marriage document that is designated on the form as being collected for statistical or medical and statistical use only and information in the part of a death certificate that is designated on the form as being collected as statistical-use-only information under s. 69.18 (1m) (c) may not be disclosed to any person except the following:

**SECTION 3.** 69.20 (2) (a) 3. of the statutes is created to read:

69.20 (2) (a) 3. As provided under sub. (3).

**SECTION 4.** 69.20 (3) (b) 3. of the statutes is amended to read:

69.20 (3) (b) 3. The information is from the vital record of a registrant who is a resident of another state or who was born in another state and is transmitted to the office responsible for keeping the vital statistics in such state under an interstate
cooperation agreement which requires that the information be used for statistical 
and administrative purposes only and which provides for the retention and 
disposition of such copies. If under such an agreement the state registrar receives 
information from an office responsible for keeping the vital statistics in another 
state, the state registrar may not use the information for any purpose except for the 
compilation of statistics and, if agreed to by the other state, in meeting requirements 
for reporting under s. 253.12 (2) (a) 3.

SECTION 5. 69.20 (3) (c) of the statutes is amended to read:

69.20 (3) (c) Notwithstanding sub. (2), a. A local registrar may disclose 
information on a birth certificate or issue a copy of the certificate to a local health 
department, as defined in s. 250.01 (4), for health or demographic research or a public 
health program if the local health department pays the copying costs and if the birth 
of the registrant occurred within the boundaries of the political subdivision served 
by the local health department or the registrant is a resident of the political 
subdivision. The local health department may not disclose any information from any 
copy which it receives under this paragraph to any person and shall destroy the copy 
no later than one year after receipt.

SECTION 6. 69.20 (3) (d) of the statutes is amended to read:

69.20 (3) (d) Subject to par. (f), the state or a local registrar may disclose 
information from the vital record of a specified registrant, except information under 
sub. (2) (a), to a federal agency, to any agency of the government of this state, or to 
any agency of a county, city, town, or village if the agency requests the information 
for use in the conduct of its official duties, except that the state registrar may disclose 
information under sub. (2) (a) only in order to meet requirements for reporting under 
s. 253.12 (2) (a) 3.
SECTION 7. 253.12 (1) (a) (intro.) of the statutes is amended to read:

253.12 (1) (a) (intro.) “Birth defect” means any of the following conditions affecting a stillborn human or an infant or child that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development:

SECTION 8. 253.12 (1) (a) 1. of the statutes is amended to read:

253.12 (1) (a) 1. A structural malformation, deformation, disruption, or dysplasia.

SECTION 9. 253.12 (1) (b) of the statutes is renumbered 253.12 (1) (cm) and amended to read:

253.12 (1) (cm) “Pediatric specialty clinic” means a clinic that is located in a hospital or is a freestanding clinic, the primary purpose of which is to provide pediatric specialty diagnostic, counseling and medical management services to persons with birth defects by a physician subspecialist.

SECTION 10. 253.12 (1) (e) of the statutes is created to read:

253.12 (1) (e) “Research” means a systematic study through scientific inquiry for the purpose of expanding a field of knowledge, including environmental or epidemiological research or special studies.

SECTION 11. 253.12 (1) (f) of the statutes is created to read:

253.12 (1) (f) “Stillbirth” means a birth for which a fetal death report is required under s. 69.18 (1) (e) 1.

SECTION 12. 253.12 (1) (g) of the statutes is created to read:

253.12 (1) (g) “Stillborn human” means a human whose birth resulted in stillbirth.

SECTION 13. 253.12 (2) (a) (intro.) of the statutes is amended to read:
253.12 (2) (a) (intro.) Except as provided in par. (b), all of the following shall report in the manner prescribed by the department under sub. (3) (a) 3. a birth defect in a stillborn human or an infant or child:

SECTION 14. 253.12 (2) (a) 3. of the statutes is created to read:

253.12 (2) (a) 3. The division of the department that deals with vital statistics, with respect to the information received under s. 69.20 (3) (b) 3. or available under s. 69.20 (3) (d).

SECTION 15. 253.12 (2) (a) 4. of the statutes is created to read:

253.12 (2) (a) 4. The entity under contract under s. 153.05 (2m) (a), with respect to public use data files under s. 153.46 (1) (b).

SECTION 16. 253.12 (2) (am) of the statutes is amended to read:

253.12 (2) (am) Any hospital in which a birth defect is diagnosed in a stillborn human or an infant or child or treatment is provided to the infant or child may report the birth defect in the manner prescribed by the department under sub. (3) (a) 3.

SECTION 17. 253.12 (2) (b) of the statutes is amended to read:

253.12 (2) (b) No person specified under par. (a) need report under par. (a) if that person knows that another person specified under par. (a) or (am) has already reported to the department the required information with respect to the same birth defect of the same stillborn human or infant or child.

SECTION 18. 253.12 (2) (d) of the statutes is repealed and recreated to read:

253.12 (2) (d) If the parent or guardian of a stillborn human or an infant or child for whom a report is made under par. (a) decides, after having been informed by a physician or a physician’s designee of the intent of the system under this section, not to consent to the release of identifying information concerning the stillborn human or infant or child and signs the form specified in sub. (5) (c), the department may not
require a person specified under par. (a) 1., 2., or 3. to report information identifying
the stillborn human or infant or child.

SECTION 19. 253.12 (2) (e) of the statutes is amended to read:

253.12 (2) (e) If the address of an infant or child or the place of delivery of a
stillborn human for whom a report is made under par. (a) is included in the report,
the department shall encode the address to refer to the same geographical location.

SECTION 20. 253.12 (3) (a) 1. (intro.) of the statutes is amended to read:

253.12 (3) (a) 1. (intro.) Establish and maintain an up-to-date registry that
documents the diagnosis in this state of any stillborn human or infant or child who
has a birth defect, regardless of the residence of the infant or child or place of delivery
of the stillborn human. The department shall include in the registry information
that will facilitate all of the following:

SECTION 21. 253.12 (3) (a) 1. c. of the statutes is amended to read:

253.12 (3) (a) 1. c. Development of primary preventive strategies to decrease
the occurrence of birth defects without increasing abortions. The department may
contract with an entity to perform the development required under this subd. 1. c.

SECTION 22. 253.12 (3) (c) of the statutes is amended to read:

253.12 (3) (c) The department shall, not more than 10 years from the date of
receipt of a report under sub. (2), delete from any file of the department the name of
a stillborn human or an infant or child that is contained in the report.

SECTION 23. 253.12 (4) (a) of the statutes is amended to read:

253.12 (4) (a) Make recommendations to the department regarding the
establishment of a registry that documents the diagnosis in the state of a stillborn
human or an infant or child who has a birth defect, as required under sub. (3) (a) 1.
and regarding the rules that the department is required to promulgate under sub.
(3) (a) 2. and 3. on the birth defects to be reported under sub. (2) and on the general content and format of the report under sub. (2) and procedures for submitting the report. The council shall also make recommendations regarding the content of a report that, because of the application of sub. (2) (d), does not contain the name of the subject of the report.

**SECTION 24.** 253.12 (5) (a) 1. of the statutes is amended to read:

253.12 (5) (a) 1. The parent or guardian of a stillborn human or an infant or child for whom a report is made under sub. (2).

**SECTION 25.** 253.12 (5) (a) 2. of the statutes is amended to read:

253.12 (5) (a) 2. A local health officer, a local birth-to-3 coordinator or an agency under contract with the department to administer the children with special health care needs program, upon receipt of a written request and informed written consent from the parent or guardian of the infant or child under the requirements of subs. (2) (d) and (5m). The local health officer may disclose information received under this subdivision only to the extent necessary to render and coordinate services and follow-up care for the infant or child or to conduct a health, demographic or epidemiological investigation. The local health officer shall destroy all information received under this subdivision within one year after receiving it.

**SECTION 26.** 253.12 (5) (a) 4. of the statutes is amended to read:

253.12 (5) (a) 4. A representative of a federal or state agency upon written request and to the extent that the information is necessary to perform a legally authorized function of that agency, including investigation of causes, mortality, methods of prevention and early intervention, treatment or care of birth defects, associated diseases or disabilities. The information may not include the name or address of an infant or child or the place of delivery of a stillborn human with a
condition reported under sub. (2). The department shall notify the parent or guardian of a stillborn human or an infant or child about whom information is released under this subdivision, of the release. The representative of the federal or state agency may disclose information received under this paragraph only as necessary to perform the legally authorized function of that agency for which the information was requested.

SECTION 27. 253.12 (5) (c) of the statutes is created to read:

253.12 (5) (c) By July 1, 2009, the department shall prescribe and distribute, and periodically distribute thereafter, to pediatric specialty clinics and local health departments copies of a form to be used by the parent or guardian of a stillborn human or an infant or child for whom a report is made under sub. (2) (a) in indicating any of the following:

1. Refusal under sub. (2) (d) by the parent or guardian to consent to the release of identifying information concerning the stillborn human or infant or child.

2. The decision under sub. (5m) by the parent or guardian to remove from the system any identifying information entered for the stillborn human or infant or child.

SECTION 28. 253.12 (5m) of the statutes is created to read:

253.12 (5m) REMOVAL OF IDENTIFYING INFORMATION. If the parent or guardian of a stillborn human or an infant or child for whom a report is made under sub. (2) (a) decides to withdraw consent to the release of identifying information concerning the stillborn human or infant or child, the parent or guardian may request from the local health department or the stillborn human’s or infant’s or child’s physician the form specified in sub. (5) (c). If the parent or guardian decides, after having been informed by the stillborn human’s or infant’s or child’s physician or physician’s
designee of the information contained in the system under this section, and signs the
form, the local health department, physician, or physician’s designee shall forward
the form to the division of the department that deals with public health. On receipt
of the signed form, the department shall remove from the system under this section
any information identifying the stillborn human or infant or child.

(END)