

Regular Session, 2001

ACT No. 194

SENATE BILL NO. 229

BY SENATORS SCHEDLER AND HINES AND REPRESENTATIVES
DURAND, KATZ, MCDONALD, SCHWEGMANN,
STRAIN AND WELCH

AN ACT

To enact Part VII of Chapter 1 of Title 40 of the Louisiana Revised Statutes of 1950, to be comprised of R.S. 40:31.41 through 31.48, and to repeal R.S. 40:31.2, relative to health care; to provide for legislative intent; to provide for definitions; to create the Louisiana Birth Defects Surveillance System; to provide for confidentiality of data in the surveillance system; to provide for annual reporting; to create an advisory board and provide for its duties, membership, terms, vacancies, and officers; to provide for cooperation by other state entities; to provide for promulgation of rules and regulations; to repeal certain provisions of law relative to reporting of congenital anomalies; and to provide for related matters.

Be it enacted by the Legislature of Louisiana:

Section 1. Part VII of Chapter 1 of Title 40 of the Louisiana Revised Statutes of 1950, comprised of R.S. 40:31.41 through 31.48, is hereby enacted to read as follows:

PART VII. LOUISIANA BIRTH DEFECTS SURVEILLANCE SYSTEM

Part VII is all new law.

§31.41. Legislative intent

R.S. 40:31.41 is all new law.

It is the intent of the legislature to establish a system to collect, analyze, and disseminate data regarding birth defects in the state and to

provide information to families of children born with birth defects regarding services available in their community and the development of appropriate prevention programs.

§31.42. Definitions

R.S. 40:31.42 is all new law.

As used in this Part, the following definitions shall apply unless the content clearly states otherwise:

(1) "Advisory board" means the advisory board of the birth defects surveillance system.

(2) "Birth defect" means an abnormality of structure, function, or metabolism that develops during prenatal, perinatal, or early postnatal life that is diagnosed before a child reaches three years of age.

(3) "Department" means the Department of Health and Hospitals.

(4) "Office" means the office of public health within the Department of Health and Hospitals.

(5) "Reporting source" means any physician, nurse, allied health professional, hospital, laboratory, and any other facility or agent which directly or indirectly provides medical services or other health care to a child affected by a birth defect.

(6) "Secretary" means the secretary of the Department of Health and Hospitals.

(7) "Surveillance system" means the process that is used to collect data about children with birth defects.

§31.43. Louisiana Birth Defects Surveillance System

R.S. 40:31.43 is all new law.

A. The department shall establish a birth defects surveillance

system within the office of public health to collect, analyze, interpret, and disseminate data relative to birth defects in Louisiana.

B. In establishing the surveillance system, the department shall require reporting sources to report information on birth defects to the office. However, reporting sources shall not collect or report information on birth defects of a child to the office whenever there is a written objection by the parent or legal guardian that collecting and reporting such information would conflict with their religious tenets or practices.

C. The system has the authority to collaborate with other interstate and interagency efforts as they relate to the surveillance system.

§31.44. Confidentiality

R.S. 40:31.44 is all new law.

Notwithstanding any other provision of the law to the contrary, individual identifying data in the surveillance system shall be confidential and shall not be subject to discovery. Such data shall not be released unless express written informed consent of a parent or legal guardian has been obtained. Data gathered by the office shall be used only for the purposes set forth in this Part.

§31.45. Report

R.S. 40:31.45 is all new law.

The department shall produce an annual report on the results obtained through the surveillance system to be submitted to the advisory board, the secretary, and the House and Senate committees on health and welfare.

§31.46. Advisory board

R.S. 40:31.46 is all new law.

A. The secretary shall establish an advisory board to make recommendations on the implementation and continuing operation of the surveillance system.

B. The secretary shall appoint nine members, each of whom shall have an expressed interest in a birth defects surveillance system, and shall be appointed in the following manner:

(1) One pediatrician from a list of names submitted by the Louisiana State Medical Society.

(2) One board certified clinical geneticist from a list of names submitted by Ochsner Clinic.

(3) One board certified clinical geneticist from a list of names submitted by Tulane University Medical Center.

(4) One board certified clinical geneticist from a list of names submitted by Louisiana State University Health Sciences Center-New Orleans.

(5) One board certified clinical geneticist from a list of names submitted by Louisiana State University Health Sciences Center-Shreveport.

(6) One maternal/fetal medicine physician from a list of names submitted by the March of Dimes.

(7) One parent representative from a list of names compiled from various parent groups or by individual application.

(8) One consumer representative from a list of names compiled from various consumer groups or by individual application.

(9) One epidemiologist employed by or contracted to the department.

C. Each member shall serve at the pleasure of the secretary.

D. Vacancies shall be filled in the manner of the original appointment.

E. The members of the advisory board shall serve on a voluntary basis and shall receive no compensation for their services.

F. The members of the advisory board shall elect from their membership a chairman and a vice-chairman.

§31.47. Cooperation by other state entities

R.S. 40:31.47 is all new law.

All departments, commissions, boards, agencies, officers, and institutions of the state and all subdivisions thereof shall cooperate with the office in carrying out the purposes of this Part.

§ 31.48. Rules and regulations

R.S. 40:31.48 is all new law.

The department shall promulgate rules and regulations in accordance with the Administrative Procedure Act to implement the provisions of this Part.

Section 2. R. S. 40:31.2 is hereby repealed.

PRESIDENT OF THE SENATE

SPEAKER OF THE HOUSE OF REPRESENTATIVES

GOVERNOR OF THE STATE OF LOUISIANA

APPROVED: _____