

## **LOUISIANA REVISED STATUTES TITLE 40, PART VII, SECTIONS 31.41–31.48**

### **Part VII. Louisiana Birth Defects Surveillance System**

#### **§31.41. Legislative intent**

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.

Acts 2001, No. 194, § 1.

#### **§31.42. Definitions**

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.

Acts 2001, No. 194, § 1.

#### **§31.43. Louisiana Birth Defects Surveillance System**

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.

Acts 2001, No. 194, § 1.

#### **§31.44. Confidentiality**

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.

Acts 2001, No. 194, § 1.

#### **§31.45. Report**

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.

Acts 2001, No. 194, § 1.

#### **§31.46. Advisory board**

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.

Acts 2001, No. 194, § 1.

#### **§31.47. Cooperation by other state entities**

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.

Acts 2001, No. 194, § 1.

#### **§31.48. Rules and regulations**

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

Acts 2001, No. 194, § 1.