## Delaware

### Birth Defects Surveillance System

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<td>DE</td>
<td>STATUTE: Delaware Code, Title 16, Chpt 2, Subchpt I §201 RULE: 6 DE Reg. 1211 (3/1/03 Final)</td>
<td>Subchapter I. Congenital Disabilities Surveillance, Registration and Treatment Program §201. Purpose: The intent of the General Assembly is to …require the establishment and maintenance of a congenital disabilities surveillance system and registry for the State. (1) Surveillance system and registry. -- Responsibility for establishing and maintaining the system and registry is delegated to the Department of Health and Social Services, along with the authority to exercise certain powers to implement the system and registry. To ensure an accurate and continuing source of data concerning congenital disabilities, the General Assembly by this subchapter requires certain health care practitioners and all hospitals and clinical laboratories to make available to the Department of Health and Social Services information contained in the</td>
<td>§ 204. Confidentiality of reports. (a) …Patient-identifying information may be exchanged among authorized agencies as approved by the Department and upon receipt by the Department of satisfactory assurances by those agencies of the preservation of the confidentiality of such information.</td>
<td>§203. Birth Defects Surveillance and Registry Program. (a)(2)a. …Specified information shall be deemed necessary and appropriate to accomplish the purpose of this subchapter and in accordance with the recommendations from the Centers for Disease Control and Prevention, for the following reasons: 1. To identify risk factors for congenital disabilities;</td>
<td>NO</td>
<td>YES</td>
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medical records of patients who have a suspected or confirmed congenital disability diagnosis. All confirmed congenital disabilities shall be classified and coded using the medically recognized system of International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM), as well as the 6-digit modified British Pediatric Association system (BPA/ICD-9), and all subsequent revisions to these publications which are used by the Centers for Disease Control and Prevention. It is intended that the product of these efforts will be a central data bank of accurate, precise and current information regarding all congenital disabilities diagnosed or treated, or both, in this State. (71 Del. Laws, c. 86, § 1; 71 Del. Laws, c. 286, § 3.)

§ 203. (b) The provisions of this subchapter and any rules or regulations issued pursuant to this subchapter shall not apply to any person or private institution that, as an exercise of religious freedom, treats the sick or suffering by spiritual means through prayer alone.

4.0 Confidentiality of Reports. 4.1 No report of a diagnosis or treatment of a birth defect shall be disclosed in such a way as to identify the child who is the subject of the report, or as to identify the child's family. However, 2. To investigate the causes and prevalence of congenital disabilities; 3. To develop preventive strategies to decrease occurrences of congenital disabilities; 4. To analyze incidences, prevalence and trends of congenital disabilities through epidemiological studies; or 5. To investigate the morbidity and mortality rates resulting from congenital disabilities…
§ 202. Definitions. The following words, terms and phrases, when used in this subchapter, shall have the meanings ascribed to them in this section, except where the content clearly indicates a different meaning.  

1) "Department" means the Department of Health and Social Services.  
2) "Congenital disability" means any structural or biochemical abnormality, regardless of cause, diagnosed at any time before or after birth that requires medical or surgical intervention or that interferes with normal growth or development.  
3) "Surveillance" means the process of identifying and investigating congenital disabilities in children under age 5.  
4) "Registry" means a central data bank containing collected, classified, coded and stored data relating to congenital disabilities in children under age 5.  

4.1. Agencies will maintain the confidentiality of any information exchanged for the purpose of delivery of program services, evaluation, early intervention and epidemiological investigation.
§ 203. Birth Defects Surveillance and Registry Program. The Department may adopt, promulgate, amend and repeal any rules and regulations necessary to accomplish the purpose of this subchapter. (1) The establishment and maintenance of an up-to-date registry that shall document every diagnosis or treatment, or both, of any congenital disability in any child under age 5 in this State;

1.0 Purpose…1.2 The purpose of the Birth Defects Registry is to provide information to Public Health officials as to the existence of previously unrecognized health and environmental hazards, help prevent certain birth defects and ultimately decrease the infant mortality rate. …1.4 The Birth Defects Registry will be a component of the Newborn Screening Case Management System, including metabolic and hearing screening. All results of metabolic and hearing screens will become part of the screening record. Tracking and follow-up of incomplete and abnormal cases will be followed by the Division of Public Health Newborn Screening Program.

4.0 Confidentiality of Reports [4.2] Any parent, custodian or guardian of any infant having any birth defect may refuse disclosure to the surveillance system and registry of the infant’s name and identifying information on the grounds that such birth defect identification is contrary to the religious tenets and practices of the infant’s parent, custodian or guardian.]

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