10A NCAC 47C .0104 SURVEILLANCE OF BIRTH DEFECTS; CENTRAL REGISTRY

(a) The monitoring program shall operate statewide.

(b) In order for information on a child to be included in the monitoring program's central registry, the following conditions must be met:

(1) The state of birth or the mother's state of residence at the time of birth must have been in North Carolina; and

(2) The child must have a birth defect or other specified perinatal condition that can adversely affect his or her health and development.

(c) The central registry shall include birth defects occurring in a fetal death, miscarriage, or pregnancy termination.

(d) The coding scheme used by the monitoring program to classify birth defects shall be based on a medically recognized system, such as ICD-9-CM or the CDC/BPA system used by the Centers for Disease Control and Prevention in the Metropolitan Atlanta Congenital Defects Program, as described in the report titled "Metropolitan Atlanta Congenital Defects Program Procedure Manual," dated June, 1993.

(e) The program director shall, in consultation with the birth defects advisory committee, develop a list of specific birth defects to be monitored. In developing this list consideration shall be given to the following:

(1) The medical and public health significance of the condition, including potential preventability;

(2) The feasibility of obtaining reasonably complete and reliable diagnostic information on the condition from the data sources available to the monitoring program; and

(3) The consistency with birth defects data collected and reported by the Centers for Disease Control and Prevention and by other state-based birth defects surveillance programs.

(f) The monitoring program may utilize for case ascertainment any data source routinely collected by or available to the State Center for Health Statistics, such as vital records, hospital discharge information, and Health Services Information System files.

(g) The monitoring program may, upon request, review and abstract information on a diagnosed or suspected birth defect from any medical record in a licensed medical facility. When obtaining such information the following conditions shall apply:

(1) The administrator, director, or person in charge of a licensed medical facility shall designate one staff member as the contact person for the monitoring program. That staff member will coordinate scheduled visits by program staff to review disease indices, labor and delivery logs, or other case-finding data sources. That person will also be responsible for arranging visits by program staff for medical records review;

(2) Monitoring program staff and the contact person shall establish a general schedule of case-finding and record review visits. This schedule shall take into account the capabilities of the medical facility in responding to requests, as well as the expected needs and workload of the monitoring program;

(3) Procedures for record management and the use of copiers and other equipment at the medical facility shall be agreed upon with each facility. Monitoring program staff shall abide by these procedures at all times; and

(4) The medical records and other original materials provided by the medical facility shall not be removed from that facility. All information, either on paper or in electronic form, which is removed from the medical facility shall be transported by secure means at all times. Abstracts, printouts, notes, and other information will be carried in locked briefcases.

(h) Physicians and other persons involved in the diagnosis, care, and treatment of birth defects may report information on a diagnosed birth defect to the monitoring program. Physicians and other persons who submit a case report or other information to the monitoring program shall be immune from civil or criminal liability that might otherwise be incurred or imposed for releasing this information based upon invasion of privacy or breach of physician-patient confidentiality.

History Note: *Authority G.S. 130A-131.17;*
Eff. August 1, 2000;
Pursuant to G.S. 150B-21.3A, rule is necessary without substantive public interest Eff. December 20, 2015.