001. **SCOPE AND AUTHORITY.** This regulation governs the release of medical records and health information Neb. Rev. Stat. §§ 81-663 to 81-675 which are contained in the registries that record certain medical conditions occurring in this state, as prescribed by law. These registries include the Birth Defects Registry established in Neb. Rev. Stat. §§ 71-645 to 71-648, the Cancer Registry established in Neb. Rev. Stat. §§ 81-642 to 81-650, the Brain Injury Registry established in Neb. Rev. Stat. §§ 81-653 to 81-661 and the Parkinson’s Disease Registry established in Neb. Rev. Stat. §§ 81-697 to 81-6,110.

002. **DEFINITIONS.** The definitions set in Neb. Rev. Stat. §§ 81-642 to 81-650, 81-653 to 81-675, 81-697 to 81-6,110 and the following definitions apply to this chapter.

   **002.01** **CERTAIN DISEASES OR INJURIES.** Certain diseases or injuries are cancers, birth defects, head and brain injuries and Parkinson’s disease or related movement disorders.

   **002.02** **PERMISSION.** Permission is the written consent or written authorization for contact obtained by the approved researcher from such patient or patient’s family.

003. **CONFIDENTIALITY AND RELEASE OF INFORMATION.** The data released must not be used in a manner to identify the individual and a data processing fee for the request will apply.

   **003.01** **PROHIBITED RE-IDENTIFICATION.** Any de-identified data (other than Class III data) furnished to a researcher may not be intentionally re-identified in any manner. Should a recipient of de-identified information unintentionally or accidentally be able to identify any individual they must not use that information in any way. The recipient must also notify the Department of the means of accidental re-identification in order for the Department to consider additional procedures to safeguard against breaches in confidentiality.

   **003.02** **DATA PROCESSING FEE.** The cost of data retrieved and data processing must be paid by the researchers, private or public entities, or individuals requesting data from a certain disease or injury registry.

004. **APPROVED RESEARCHER.** The Department may approve individuals or entities who submit written application to obtain access to case-specific data or case-specific and patient-identifying data to assist in their research for the prevention, cure and control of certain diseases and injuries. These individuals or entities must show that the applicant is a qualified researcher, that the data requested will be used for bona fide scientific or medical research for prevention,
cure, or control of certain diseases and injuries, and that the applicant will maintain the confidentiality and security of the data obtained. The application must contain the information required by Neb. Rev. Stat. § 81-666 and the following information:

(A) The applicant’s name and address;

(B) The name of the entity, if any, which the applicant represents and its address, and a brief description of the entity; and

(C) The name and address of the principal investigator, if different from the applicant.