LEGISLATIVE BILL 496

Approved by the Governor April 12, 1996

Introduced by Health and Human Services Committee: Wesely, 26, Chairperson;
Day, 19; Dierks, 40; Jensen, 20; Matzke, 47; Schimek, 27;
Beutler, 28; Schrock, 38; Fisher, 35

AN ACT relating to public health and welfare; to amend section 81-664, Reissue Revised Statutes of Nebraska; to adopt the Parkinson's Disease Registry Act; to provide a termination date; to harmonize provisions; and to repeal the original section.

Be it enacted by the people of the State of Nebraska,

Section 1. Sections 1 to 16 of this act shall be known and may be cited as the Parkinson's Disease Registry Act.

Sec. 2. It is the intent of the Legislature to require the establishment and maintenance of a Parkinson's Disease Registry for the State of Nebraska. The purpose of the registry is to provide a central data bank of accurate, historical and current information for research purposes. The Parkinson's Disease Registry Act will provide for screening and collecting patient and family data that may be useful in detecting the incidence of and possible risk factors concerning Parkinson's disease and related movement disorders. The act will also aid in planning for health care requirements and education needs.

Sec. 3. For purposes of the Parkinson's Disease Registry Act:

(1) Aggregate data means data contained in the Parkinson's Disease Registry which is compiled in a statistical format and which does not include patient-identifying data;

(2) Approved researcher means an individual or entity who is approved by the department in accordance with section 81-666 to obtain access to data contained in the Parkinson's Disease Registry to assist in scientific or medical research for the prevention, cure, or control of Parkinson's disease;

(3) Case-specific data means data contained in the Parkinson's Disease Registry concerning a specific individual other than patient-identifying data;

(4) Department means the Department of Health;

(5) Parkinson's disease means a chronic, progressive disorder in which there is a lack of the chemical dopamine in the brain as a direct result of the destruction of the dopamine-producing cells in the portion of the brain called the substantia nigra. Clinical features of the disease include tremor at rest, slow movements, rigidity, and unsteady or shuffling gait and may be indicated by improvement after using medications used for Parkinson's disease;

(6) Patient-identifying data means the patient's name, address, record number, symbol, or other identifying particular assigned to or related to an individual; and

(7) Related movement disorder means a disorder that resembles Parkinson's disease in some way, such as another kind of tremor.

Sec. 4. The department shall establish and maintain the Parkinson's Disease Registry. The registry shall consist of a compilation of cases of Parkinson's disease and related movement disorders occurring among residents of this state reported and recorded to achieve the goals of statistical identification for research, planning for health care requirements, and education of health care providers and persons with Parkinson's disease and related movement disorders and shall include information the department deems necessary and appropriate for the statistical identification and planning for treatment and education of health care providers and persons diagnosed with Parkinson's disease and related movement disorders.

Sec. 5. The department shall:

(1) Adopt and promulgate rules and regulations, including a uniform system of classification of Parkinson's disease which is consistent with medically and clinically accepted standards and definitions for use in reporting by medical personnel treating the disease;

(2) Execute any contracts that the department deems necessary to carry out the Parkinson's Disease Registry Act;

(3) Receive and record the data obtained from an individual reporting under subsection (2) of section 6 of this act and medical records reported under sections 6 and 7 of this act;

(4) Compile and publish a statistical report annually or at reasonable intervals containing information obtained from patient data to

provide accessible information useful to medical personnel, researchers, and the public; and

(5) Comply with all necessary requirements to obtain funds or grants.

Sec. 6. (1) If a resident of this state is diagnosed with Parkinson's disease or a related movement disorder within this state in the office of a physician licensed under the Uniform Licensing Law, the physician shall report the diagnosis and pertinent information to the department within sixty days after the diagnosis.

(2) An individual resident of this state who has been diagnosed with Parkinson's disease or a related movement disorder by a licensed physician may file a report with the department providing relevant information. The department shall provide for validation of individual reports.

(3) A report under this section shall contain the following information about the person diagnosed with Parkinson's disease or a related movement disorder:

(a) Name;

(b) Social security number;

(c) Date of birth;

(d) Gender;

(e) Address at time of diagnosis;

(f) Current address;

(g) Date of diagnosis;

(h) Physician;

(i) Identification of reporting source; and

(j) Any additional information the department demonstrates is reasonable to implement the Parkinson's Disease Registry Act.

Sec. 7. The pharmacist in charge of each pharmacy located within the state or doing business in the state shall file a semiannual report with the department listing persons to whom the pharmacist has dispensed drugs on the list of drugs required to be reported under this section for Parkinson's disease. The report shall include the name, address, and social security number of the person for whom the drugs were prescribed and the name and address of the prescribing physician. The department shall issue a list of drugs used for the treatment of Parkinson's disease to be reported under this section, shall review and revise the list annually, and shall distribute the list to each pharmacy located within the state or doing business in the state.

Sec. 8. All data and information developed or collected pursuant to the Parkinson's Disease Registry Act and the release of data from the Parkinson's Disease Registry shall be subject to and comply with sections 81-663 to 81-675. For purposes of the Parkinson's Disease Registry, data may be released either as Class I data or Class II data or as Class III data or Class IV data as classified in section 81-667.

Sec. 9. Any physician, pharmacist, or medical professional participating in good faith in the reporting of information required under the Parkinson's Disease Registry Act is immune from liability, civil, criminal, or otherwise, that might result from divulging such information. Neither the department nor any of its officials or employees shall be liable civilly or criminally for the release of information contained in the Parkinson's Disease Registry or for the conduct or activities of any individual or entity permitted access to data of the Parkinson's Disease Registry if done pursuant to sections 81-663 to 81-675.

Sec. 10. Nothing in sections 81-663 to 81-675 shall be deemed to compel any individual to submit to any medical examination or supervision by the department, any of its authorized representatives, or an approved researcher. No person who seeks information or obtains data pursuant to such sections shall contact a patient or such patient's family without first obtaining the permission of a physician actively involved in the care of such patient.

Sec. 11. Nothing in the Parkinson's Disease Registry Act requires a physician or pharmacist to deny medical treatment or services to an individual who refuses to provide the information necessary to make the reports required under section 6 or 7 of this act.

Sec. 12. Any physician or pharmacist required to make reports under section 6 or 7 of this act is immune from liability, civil, criminal, or otherwise, for filing an incomplete report as a result of the failure of an individual to provide the information necessary to make such report.

Sec. 13. The initial reports required under section 7 of this act shall be made within thirty days after January 1 of the year following issuance by the department of the list of drugs to be reported under section 7 of this act.

Sec. 14. Any private or public entity, individual, or approved researcher who wrongfully discloses confidential data obtained from the medical record and health information registries or uses such information with the intent to deceive shall be guilty of a Class IV misdemeanor for each offense.

Sec. 15. Any person or entity which fails to make reports in good faith as provided by the Parkinson's Disease Registry Act shall be guilty of a Class V misdemeanor for each offense.

Sec. 16. The Parkinson's Disease Registry Act terminates on June 30, 2015, or if after January 1, 2002, no requests are received for two years from approved researchers to obtain access to data contained in the Parkinson's Disease Registry, the act terminates two years after the date of the last request, whichever occurs sooner, unless reenacted or reestablished by the Legislature.

Sec. 17. Section 81-664, Reissue Revised Statutes of Nebraska, is amended to read:

81-664. For purposes of sections 81-663 to 81-675:

(1) Aggregate data ~~shall mean~~ means data contained in the medical record and health information registries maintained by the department which is compiled in a statistical format and which does not include patient-identifying data;

(2) Approved researcher ~~shall mean~~ means an individual or entity which is approved by the department pursuant to section 81-666 to obtain access to data contained in the medical record and health information registries maintained by the department to assist in the scientific or medical research for the prevention, cure, or control of a disease or injury process;

(3) Case-specific data ~~shall mean~~ means data contained in the medical record and health information registries concerning a specific individual other than patient-identifying data;

(4) Department ~~shall mean~~ means the Department of Health;

(5) Medical record and health information registry ~~shall mean~~ means the system of reporting certain medical conditions occurring in this state, as prescribed by law, which are reported and recorded in order to achieve the goals of prevention, cure, and control through research and education, and ~~shall include~~ includes the birth defects registry established in section 71-646, the cancer registry established in sections 81-642 to 81-650, ~~and~~ the brain injury registry established in sections 81-653 to 81-661, and the Parkinson's Disease Registry established in section 4 of this act;

(6) Patient-identifying data ~~shall mean~~ means the patient's name, address, record number, symbol, or other identifying particular assigned to or related to an individual patient; and

(7) Research ~~shall mean~~ means study specific to the diseases or injuries for which access to data is requested and which is dedicated to the prevention, cure, or control of the diseases or injuries.

Sec. 18. Original section 81-664, Reissue Revised Statutes of Nebraska, is repealed.