

AMENDMENTS TO LB 152

1 Amendments to Final Reading copy)

2 1. Insert the following new sections:

3 "Sec. 3. Section 81-664, Reissue Revised Statutes of  
4 Nebraska, as amended by section 34, Legislative Bill 209,  
5 Ninety-seventh Legislature, First Session, 2001, is amended to  
6 read:

7 81-664. For purposes of sections 81-663 to 81-675:

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

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

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

21 (4) Department means the Department of Health and Human  
22 Services Regulation and Licensure;

23 (5) Medical record and health information registry means  
24 the system of reporting certain medical conditions occurring in

1 this state, as prescribed by law, which are reported and recorded  
2 in order to achieve the goals of prevention, cure, and control  
3 through research and education, and includes the birth defects  
4 registry established in section 71-646, the cancer registry  
5 established in sections 81-642 to 81-650, ~~and~~ the brain injury  
6 registry established in sections 81-653 to 81-661, and the  
7 Parkinson's Disease Registry established in the Parkinson's Disease  
8 Registry Act;

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

12 (7) Research means study specific to the diseases or  
13 injuries for which access to data is requested and which is  
14 dedicated to the prevention, cure, or control of the diseases or  
15 injuries.

16 Sec. 4. Section 81-672, Reissue Revised Statutes of  
17 Nebraska, is amended to read:

18 81-672. Any person who receives or releases information  
19 in the form and manner prescribed by sections 81-663 to 81-675 and  
20 the rules and regulations adopted and promulgated pursuant to such  
21 sections shall not be civilly or criminally liable for such receipt  
22 or release unless the receipt or release is done with actual  
23 malice, fraudulent intent, or bad faith. In an action brought  
24 against a person for wrongful receipt or release of medical record  
25 and health information registry information, the party bringing the  
26 action shall plead specifically the allegation that the immunity  
27 provided in this section does not apply because the person

1 receiving or releasing the information did so with actual malice,  
2 fraudulent intent, or bad faith.

3           Sec. 5. Sections 5 to 19 of this act shall be known and  
4 may be cited as the Parkinson's Disease Registry Act.

5           Sec. 6. The purpose of the Parkinson's Disease Registry  
6 is to provide a central data bank of accurate, historical and  
7 current information for research purposes. The Parkinson's Disease  
8 Registry Act will provide for screening and collecting patient and  
9 family data that may be useful in detecting the incidence of and  
10 possible risk factors concerning Parkinson's disease and related  
11 movement disorders. The act will also aid in planning for health  
12 care requirements and education needs.

13           Sec. 7. For purposes of the Parkinson's Disease Registry  
14 Act:

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

20           (2) Department means the Department of Health and Human  
21 Services Regulation and Licensure;

22           (3) Parkinson's disease means a chronic, progressive  
23 disorder in which there is a lack of the chemical dopamine in the  
24 brain as a direct result of the destruction of the  
25 dopamine-producing cells in the portion of the brain called the  
26 substantia nigra. Clinical features of the disease include tremor  
27 at rest, slow movements, rigidity, and unsteady or shuffling gait

1 and may be indicated by improvement after using medications used  
2 for Parkinson's disease; and

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

6 Sec. 8. The department shall establish and maintain the  
7 Parkinson's Disease Registry. The registry shall consist of a  
8 compilation of the reports of cases of Parkinson's disease and  
9 related movement disorders occurring among residents of this state  
10 which are with the department. The registry shall include  
11 information the department deems necessary and appropriate for the  
12 statistical identification and planning for treatment and education  
13 of health care providers and persons diagnosed with Parkinson's  
14 disease and related movement disorders.

15 Sec. 9. The department shall:

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

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

23 (3) Receive and record the data obtained from reports  
24 filed under sections 10 and 11 of this act;

25 (4) Compile and publish a statistical report annually or  
26 at reasonable intervals containing information obtained from  
27 patient data to provide accessible information useful to medical

1 personnel, approved researchers, and the public; and

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

4 Sec. 10. (1) If a resident of this state is diagnosed  
5 with Parkinson's disease or a related movement disorder within this  
6 state in the office of a physician licensed under the Uniform  
7 Licensing Law, the physician shall file a report of the diagnosis  
8 and pertinent information with the department within sixty days  
9 after the diagnosis.

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

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

18 (a) Name;

19 (b) Social security number;

20 (c) Date of birth;

21 (d) Gender;

22 (e) Address at time of diagnosis;

23 (f) Current address;

24 (g) Date of diagnosis;

25 (h) Physician;

26 (i) Identification of reporting source; and

27 (j) Any additional information the department

1 demonstrates is reasonable to implement the Parkinson's Disease  
2 Registry Act.

3           Sec. 11. The pharmacist in charge of each pharmacy  
4 located within the state or doing business in the state shall file  
5 a semiannual report with the department listing persons to whom the  
6 pharmacist has dispensed drugs on the list of drugs required to be  
7 reported under this section for Parkinson's disease. The report  
8 shall include the name, address, and social security number of the  
9 person for whom the drugs were prescribed and the name and address  
10 of the prescribing physician. The department shall issue a list of  
11 drugs used for the treatment of Parkinson's disease to be reported  
12 under this section, shall review and revise the list annually, and  
13 shall distribute the list to each pharmacy located within the state  
14 or doing business in the state.

15           Sec. 12. All data and information developed or collected  
16 pursuant to the Parkinson's Disease Registry Act and the receipt  
17 and release of data from the Parkinson's Disease Registry is  
18 subject to and shall comply with sections 81-663 to 81-675. For  
19 purposes of the Parkinson's Disease Registry, data may be released  
20 as Class I data, Class II data, Class III data, or Class IV data as  
21 classified in section 81-667.

22           Sec. 13. Nothing in the Parkinson's Disease Registry Act  
23 shall be deemed to compel any individual to submit to any medical  
24 examination or supervision by the department, any of its authorized  
25 representatives, or an approved researcher. No person who seeks  
26 information or obtains data pursuant to the act shall contact a  
27 patient or such patient's family without first obtaining the

1 permission of a physician actively involved in the care of such  
2 patient.

3           Sec. 14. Nothing in the Parkinson's Disease Registry Act  
4 requires a physician or pharmacist to deny medical treatment or  
5 services to an individual who refuses to provide the information  
6 necessary to make complete reports required under section 10 or 11  
7 of this act.

8           Sec. 15. (1) Any physician or pharmacist required to  
9 make reports under section 10 or 11 of this act is immune from  
10 liability, civil, criminal, or otherwise, for filing an incomplete  
11 report as a result of the failure of an individual to provide the  
12 information necessary to make such report.

13           (2) Any physician or pharmacist who fails to file reports  
14 as required under section 10 or 11 of this act shall be guilty of a  
15 Class V misdemeanor for each offense.

16           Sec. 16. The initial reports required under section 11  
17 of this act shall be made within thirty days after January 1 of the  
18 year following issuance by the department of the list of drugs to  
19 be reported under section 11 of this act.

20           Sec. 17. (1) On and after the effective date of this  
21 act, for purposes of the Parkinson's Disease Registry Act:

22           (a) Any rules, regulations, and orders of the Department  
23 of Health and Human Services Regulation and Licensure adopted  
24 pursuant to the former Parkinson's Disease Registry Act, as such  
25 act existed prior to February 14, 2001, and in effect on February  
26 13, 2001, shall be revived and continue in effect until revised,  
27 amended, repealed, or nullified pursuant to law;

1           (b) Any contracts entered into by the department prior to  
2 February 14, 2001, and in effect on February 13, 2001, in  
3 connection with the duties and functions of the former act are  
4 recognized and may be revived upon the agreement of all contract  
5 parties. If revived, the department shall succeed to all rights  
6 and obligations under such contracts;

7           (c) Any cash funds, custodial funds, gifts, trusts,  
8 grants, and appropriations of funds which were available for use by  
9 the department for purposes of the former act shall continue to be  
10 available for use by the department if such funds continue to  
11 exist; and

12           (d) Any documents created, information compiled, or  
13 property used by the department under the former act shall continue  
14 to be available to and may be used by the department.

15           (2) For purposes of this section, former act means the  
16 Parkinson's Disease Registry Act, as such act existed prior to  
17 February 14, 2001, which act was outright repealed in LB 209,  
18 Ninety-seventh Legislature, First Session, 2001.

19           Sec. 19. The Parkinson's Disease Registry Act terminates  
20 on June 30, 2003, or if no requests are received for two years from  
21 approved researchers to obtain access to data contained in the  
22 Parkinson's Disease Registry, the act terminates two years after  
23 the date of the last request, whichever occurs sooner, unless  
24 reenacted or reestablished by the Legislature."

25           2. On page 1, line 1, after "amend" insert "section  
26 81-672, Reissue Revised Statutes of Nebraska,"; in line 2 after  
27 "2000" insert ", and section 81-664, Reissue Revised Statutes of

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1 Nebraska, as amended by section 34, Legislative Bill 209,  
2 Ninety-seventh Legislature, First Session, 2001"; and in lines 3  
3 and 4 strike "eliminate a termination date" and insert "change  
4 registry information provisions; to adopt the Parkinson's Disease  
5 Registry Act; to provide penalties; to provide for and eliminate  
6 termination dates; to harmonize provisions".

7           3. On page 4, line 9, after "Original" insert "section  
8 81-672, Reissue Revised Statutes of Nebraska,"; and in line 10  
9 after the last comma insert "and section 81-664, Reissue Revised  
10 Statutes of Nebraska, as amended by section 34, Legislative Bill  
11 209, Ninety-seventh Legislature, First Session, 2001,".

12           4. Renumber the remaining sections accordingly.