

LEGISLATURE OF NEBRASKA
ONE HUNDRED EIGHTH LEGISLATURE
FIRST SESSION

LEGISLATIVE BILL 680

Introduced by Day, 49.

Read first time January 18, 2023

Committee: Health and Human Services

1 A BILL FOR AN ACT relating to the Parkinson's Disease Registry Act; to
2 amend sections 81-6,101, 81-6,102, 81-6,105, 81-6,106, and 81-6,107,
3 Reissue Revised Statutes of Nebraska, and section 81-6,103, Revised
4 Statutes Cumulative Supplement, 2022; to require reporting of
5 patients with Parkinson's disease or related movement disorders as
6 prescribed; to provide duties for the state-designated health
7 insurance exchange and the Department of Health and Human Services;
8 to harmonize provisions; and to repeal the original sections.
9 Be it enacted by the people of the State of Nebraska,

1 Section 1. Section 81-6,101, Reissue Revised Statutes of Nebraska,
2 is amended to read:

3 81-6,101 The department shall:

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

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

10 (3) Receive and record the data obtained from reports filed under
11 section sections 81-6,102 and 81-6,103; and

12 (4) Comply with all necessary requirements to obtain funds or
13 grants.

14 Sec. 2. Section 81-6,102, Reissue Revised Statutes of Nebraska, is
15 amended to read:

16 81-6,102 (1)(a) Each (1) If a resident of this state is diagnosed
17 with Parkinson's disease or a related movement disorder within this state
18 in the office of a physician licensed under the Uniform Credentialing
19 Act, who has care of, or has diagnosed, Parkinson's disease or a related
20 movement disorder for a non-hospitalized patient not otherwise reported,
21 the physician shall submit file a report of the diagnosis and pertinent
22 information with the department within sixty days after the diagnosis.
23 Physicians may use participation in the state-designated health
24 information exchange to fulfill this requirement.

25 (b) The state-designated health information exchange shall prepare
26 the information required in this report and data from the prescription
27 drug monitoring program regarding persons to whom drugs on the list of
28 drugs required to be reported in section 81-6,103 have been prescribed.
29 The state-designated health information exchange shall share this
30 information with the department as the department deems necessary in the
31 requested format, including at the patient-level and the aggregate-level.

1 (c) In order to ensure compliance with this subsection, the
2 department may inspect, upon reasonable notice, a representative sample
3 of the medical records of patients who have been diagnosed, treated, or
4 admitted for Parkinson's disease.

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

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

13 (a) Name;

14 (b) Social security number;

15 (c) Medical record number ~~Date of birth~~;

16 (d) Race;

17 (e) Ethnicity;

18 (f) Date of birth;

19 (g) ~~(d)~~ Gender;

20 (h) ~~(e)~~ Address at time of diagnosis;

21 (i) ~~(f)~~ Current address;

22 (j) ~~(g)~~ Date of diagnosis;

23 (k) ~~(h)~~ Physician;

24 (l) ~~(i)~~ Identification of reporting source; and

25 (m) ~~(j)~~ Any additional information the department demonstrates is
26 reasonable to implement the Parkinson's Disease Registry Act including,
27 but not limited to: (i) The date of Parkinson's disease symptom onset;
28 (ii) the age at onset of symptoms or diagnosis; (iii) whether the
29 Parkinson's disease diagnosis was confirmed by a neurologist; (iv)
30 whether the symptoms respond to dopaminergic treatment; (v) whether the
31 patient has a first degree relative with Parkinson's disease; and (vi)

1 whether there is a presence of dementia or mild cognitive impairment.

2 Sec. 3. Section 81-6,103, Revised Statutes Cumulative Supplement,
3 2022, is amended to read:

4 81-6,103 ~~(1) The pharmacist in charge of each pharmacy located~~
5 ~~within the state or doing business in the state shall file a semiannual~~
6 ~~report with the department listing persons to whom the pharmacist has~~
7 ~~dispensed drugs on the list of drugs required to be reported under this~~
8 ~~section for Parkinson's disease. The report shall include the name,~~
9 ~~address, and date of birth of the person for whom the drugs were~~
10 ~~prescribed and the name and address of the prescribing physician. The~~
11 ~~department shall issue a list of drugs used for the treatment of~~
12 ~~Parkinson's disease to be reported under this section 81-6,102 and 7~~
13 ~~shall review and revise the list annually, and shall distribute the list~~
14 ~~to each pharmacy located within the state or doing business in the state.~~

15 (2) On or before January 1, 2024, and every year thereafter, the
16 department shall report electronically to the Clerk of the Legislature, a
17 program summary update on the incidents and prevalence of Parkinson's
18 disease in the state which includes: (a) The county of the patient's
19 residence, (b) number of records that were reported into the registry,
20 and (c) demographic information to include the patient's age, gender, and
21 race. Such annual report shall also be published in a downloadable format
22 on the department's website or designated Nebraska Parkinson's Disease
23 Research Registry webpage.

24 (3) On or before January 1, 2024, and every year thereafter, the
25 department shall create and maintain a webpage called Nebraska
26 Parkinson's Disease Research Registry which shall publish the yearly
27 program summary as described in subsection (2) of this section, and any
28 other relevant information related to the registry as deemed necessary by
29 the department.

30 Sec. 4. Section 81-6,105, Reissue Revised Statutes of Nebraska, is
31 amended to read:

1 81-6,105 (1) Nothing in the Parkinson's Disease Registry Act shall
2 be deemed to compel any individual to submit to any medical examination
3 or supervision by the department, any of its authorized representatives,
4 or an approved researcher. No person who seeks information or obtains
5 registry data pursuant to the act shall contact a patient on the registry
6 or such patient's family unless the registry has first obtained the
7 permission of such patient or patient's family. The registry shall
8 coordinate its activities with the person desiring such contact and may
9 authorize the person desiring such contact to perform these contacts
10 under the direction of the registry.

11 (2) Data from the registry, with or without identifiers, shall be
12 made available by the department and the state-designated health
13 information exchange to researchers that have the approval of an
14 institutional review board in accordance with requirements of the Federal
15 Policy for the Protection of Human Subjects (Common Rule), 45 C.F.R. 46,
16 and as applicable, Food and Drug Administration regulations at 21 C.F.R.
17 56 and the HIPAA Privacy Rule, 45 C.F.R. 164, and other relevant federal
18 regulations, state statutes, and policies of the institution where
19 research will be conducted.

20 Sec. 5. Section 81-6,106, Reissue Revised Statutes of Nebraska, is
21 amended to read:

22 81-6,106 Nothing in the Parkinson's Disease Registry Act requires a
23 physician or pharmacist to deny medical treatment or services to an
24 individual who refuses to provide the information necessary to make
25 complete reports required under section 81-6,102 ~~or 81-6,103~~.

26 Sec. 6. Section 81-6,107, Reissue Revised Statutes of Nebraska, is
27 amended to read:

28 81-6,107 Any physician or pharmacist required to make reports under
29 section 81-6,102 ~~or 81-6,103~~ is immune from liability, civil, criminal,
30 or otherwise, for filing an incomplete report as a result of the failure
31 of an individual to provide the information necessary to make such

1 report.

2 Sec. 7. Original sections 81-6,101, 81-6,102, 81-6,105, 81-6,106,
3 and 81-6,107, Reissue Revised Statutes of Nebraska, and section 81-6,103,
4 Revised Statutes Cumulative Supplement, 2022, are repealed.