Nebraska Parkinson’s Disease Registry for Public Health Applications

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History of the Registry – 20 Year Anniversary

- 1996 - Legislation passed – Grass roots effort by PD interest groups and researchers. The State voted neutral.

Reason for legislation of registry/Importance of the registry
- An increasing public health concern as the population is aging
- Essential for public health professionals and researchers
  - To study the incidence of and possible risk factors concerning Parkinson’s
  - To plan for health care requirements and education of health care providers
- NE was the first and only fully functional population-based Registry until 2015

- 1997 - Data collection began

- Suspended October, 2004 – February, 2006 due to lack of funding
Required Data Elements

Per Nebraska Statute 81-6, 102

From Physicians within 60 days of initial diagnosis:

(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.

Per Nebraska Statute 81-6, 103

From Pharmacies for whom they dispense one or more drugs from the State's 'Reportable List of Drugs':

- Name
- Address
- Social Security number
- Name and address of the prescribing physician

2017 Reportable List of Drugs (brand name or generic):

- Azilect
- Carbidopa/levodopa
- Mirapex
- Neupro
- Requip
- Selegiline
- Stalevo
Data Flow Chart

- Physician verification/initial reporting
- Pharmacists
- Patients
- Hospital Discharge Data
- Patient self-reporting
- Nebraska Parkinson's Disease Registry
- State death file
Nebraska Parkinson's Disease Registry Diagnosis Year Report Pre-1997 - 2016
(Confirmed by Diagnostician)

<table>
<thead>
<tr>
<th>YEAR</th>
<th>TOTAL</th>
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<tbody>
<tr>
<td>Pre-1997*</td>
<td>3,359</td>
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<tr>
<td>1997</td>
<td>746</td>
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<td>2015</td>
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<td>516</td>
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<tr>
<td>TOTAL NE RESIDENTS</td>
<td>15,053</td>
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</tbody>
</table>

Non-NE Residents | 574
TOTAL PATIENTS | 15,627

Nebraska Parkinson’s Disease Registry Diagnosis Year 1997-2016

Diagram showing the number of patients diagnosed with Parkinson’s Disease each year from 1997 to 2016. The data is based on physician office confirmation or death certificate. Data collection is ongoing, therefore yearly totals are not final. A decrease in cases reported due to registry downtime caused by lack of program funding.
Studies Using the Data

- Association between Parkinson’s Disease and Traumatic Brain Injuries – December 2017
- Parkinson’s Disease Patient Comorbidities Compared to All Patients in Hospital Setting – Jan 2017
- Patients and Cancer Risk Registry – Dec 2016
- Parkinson’s Disease and Pesticides Exposure – Journal of Rural Health 2016
- Parkinson’s Disease Patients and Hospital Discharge Data – 2015
- Analysis by Max Theis, Epidemiology Intern – 2007
- Parkinson’s Prevalence Estimated by a State Registry – Movement Disorder Journal 2004
- Studies of Environmental Risk in Parkinson’s Disease by John Bertoni MD and Daniel Strickland PhD – 2003
- Other Studies
Challenges and Future Plans

Challenges
- Obtaining critical patient information such as date of birth, SSN
- Improve linkage and verification
- Promote the Parkinson’s registry
- Encourage physician reporting
- Limited resources – personnel & financial

Future Plans
- Web-based automated reporting, matching, verification
- Update statute to include more patient information
- More detailed reports/findings
- Public awareness
- Continue to explore funding opportunities
Resources and Contact Information

- http://www.dhhs.ne.gov/ced/parkinsons
  - Basic information about Parkinson’s disease
  - History of the registry
  - Statute and Rules and Regulations
  - Reporting forms and file formats
  - Parkinson’s data reports

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