

# Nebraska Parkinson's Disease Registry for Public Health Applications

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2009 Nebraska Public Health Conference  
April 9, 2009  
Lincoln, NE

# Outline

- Facts About Parkinson's Disease
- History of the Nebraska Parkinson's Disease Registry (NPDR)
- Data Flow Chart
- Basic Statistics
- Applications of the NPDR data
- Challenges/Future plans

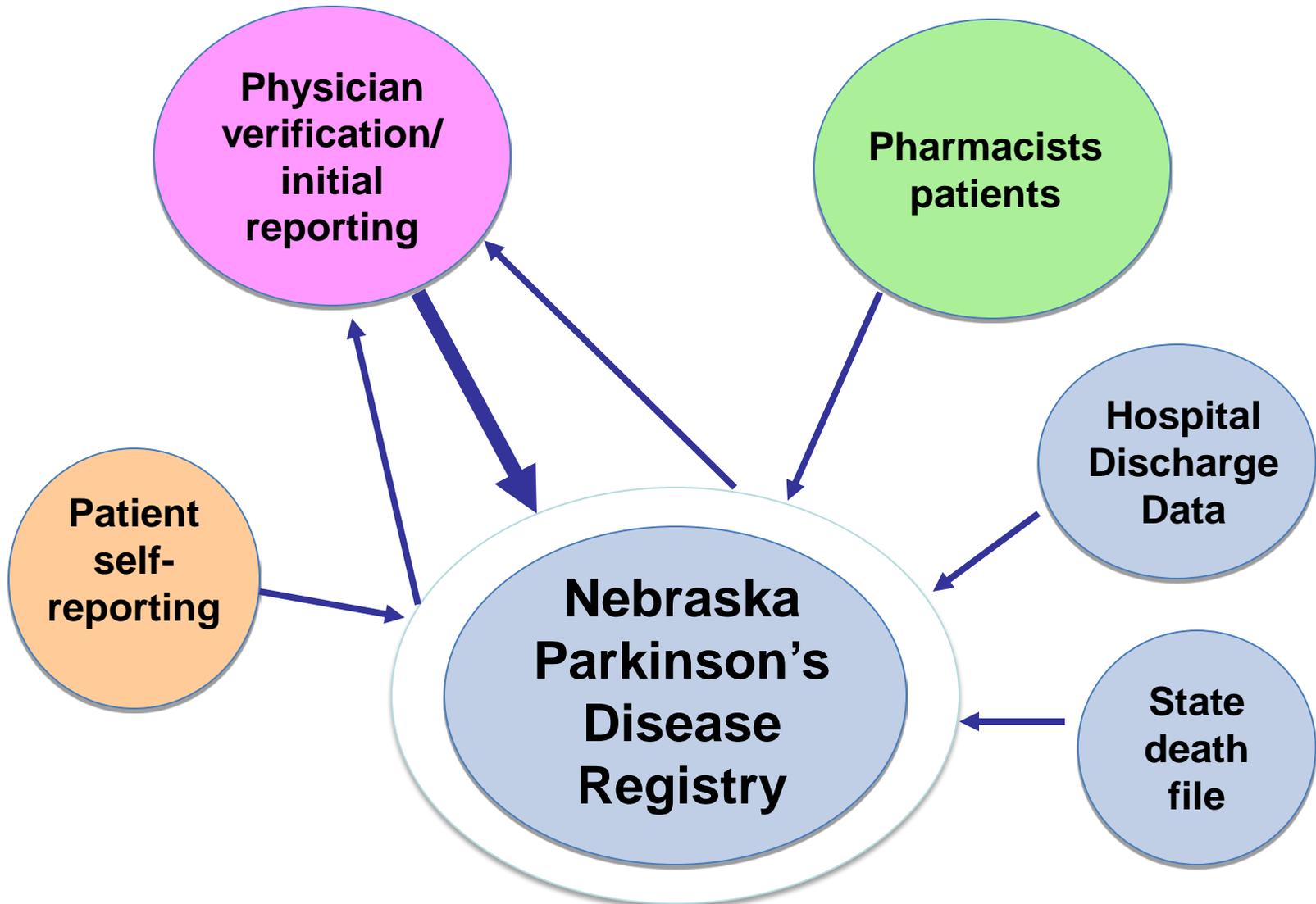
# Facts About Parkinson's Disease

- Parkinson's disease (PD) is a chronic motor system disorder, a degeneration and premature death of dopamine-producing brain cells.
- PD is the second-most common neurodegenerative disease in the US.
- Most common symptoms are tremor, stiffness of limbs and trunk, slowness of movement, and impaired balance and stability.
- Roughly 1.5 million Americans currently have PD and over 60,000 are newly diagnosed each year.
- Usually affects people after age 50.
- 10% of Parkinson's patients are younger than 40.
- No therapy will slow down or cure the disease, only manage symptoms.

# History of the Registry

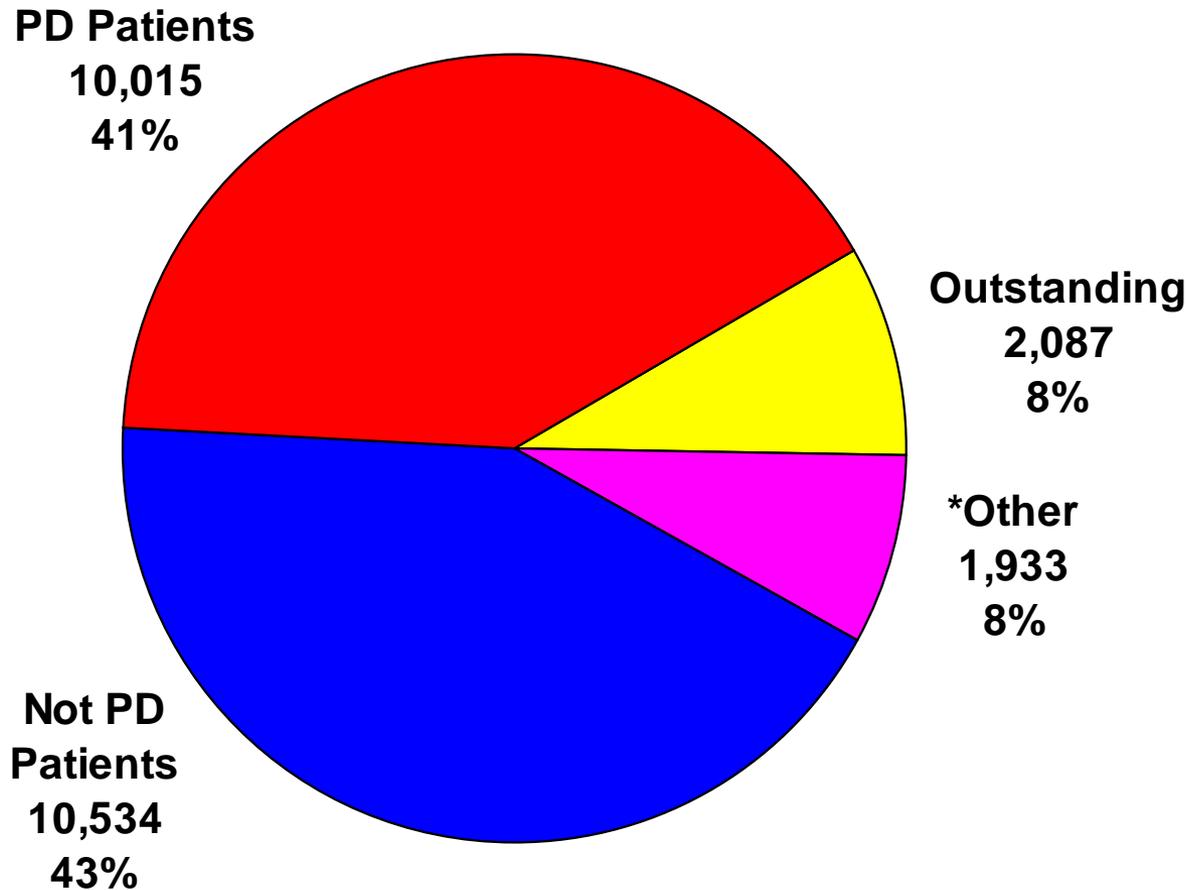
- 1996 - Legislation passed
- Importance of the registry
  - PD is an increasing public health concern as the population is aging
  - Essential for public health professionals and researchers
    - To study the incidence of and possible risk factors concerning Parkinson's
    - To plan for health care requirements, and the education of health care providers
    - Hopefully help find a cure for the disease
- Nebraska is still the only state with fully functional population-based registry.
- 1997 - Data collection began
- October, 2004 – February, 2006 suspended due to lack of funding

# Data Flow Chart



# Basic Statistics 1997-2008

Total Unduplicated Patient Records Received 24,579



\*Unable to follow-up - cannot locate physician, physician does not recognize patient, patient deceased, physician does not treat PD, etc.

# Nebraska Parkinson's Disease Registry Diagnosis Year Report (Confirmed by Diagnostician)

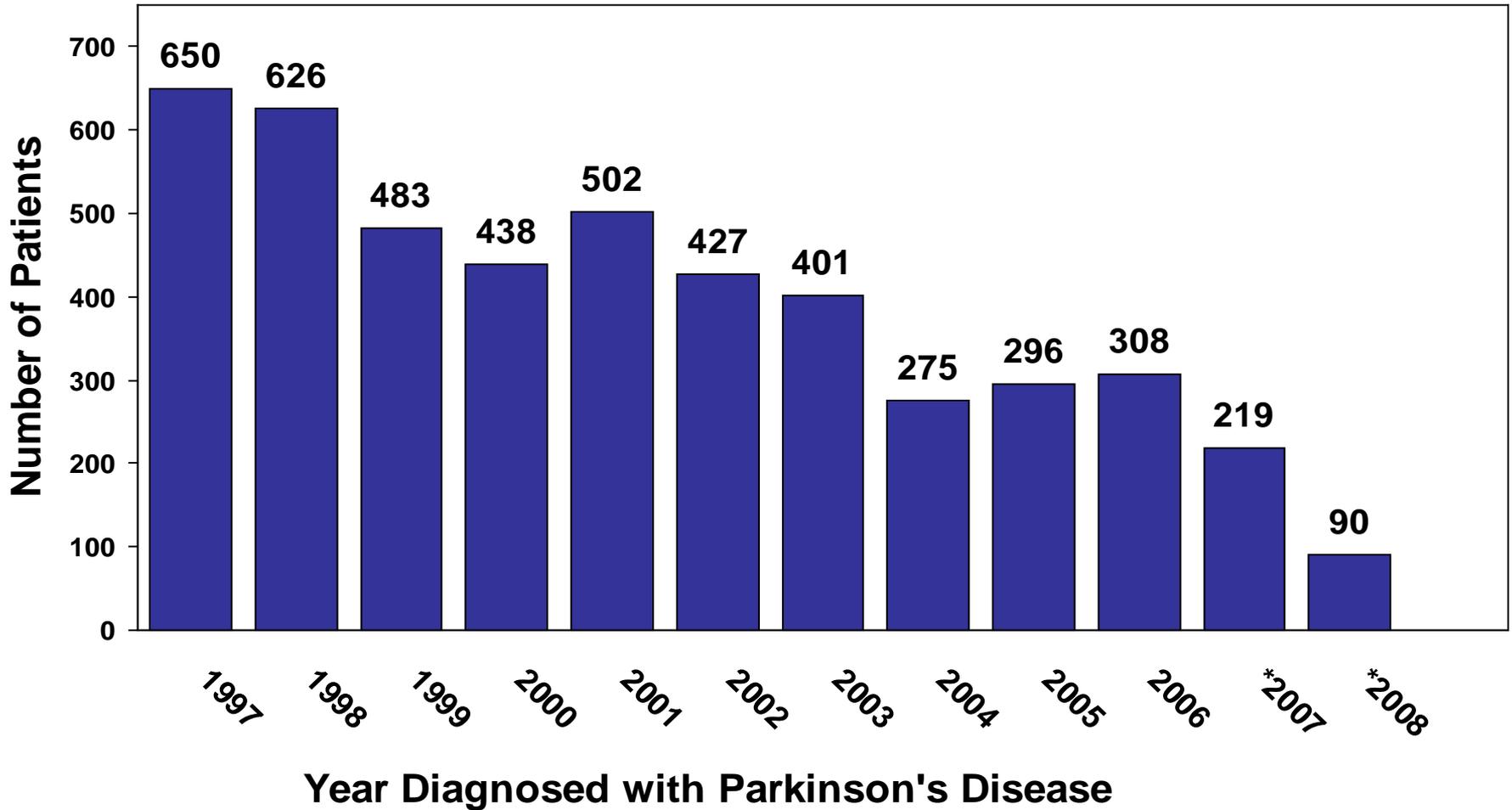
<u>YEAR</u>	<u>PD PATIENTS</u>
Unknown	1,171
DC Only*	662
Pre-1997	3,467
1997	650
1998	626
1999	483
2000	438
2001	502
2002	427
2003	401
2004	275
2005**	296
2006	308
2007	219
2008***	<u>90</u>
<b>TOTAL</b>	<b>10,015</b>

\*Diagnosis of PD reported on death certificate only.

\*\*Registry was suspended October, 2004 - February, 2006.

\*\*\*Not all data entered and verified/lag in reporting.

# Nebraska Parkinson's Disease Registry Diagnosis Year Report



\*Data not all entered and verified

04/06/2009

# Applications of the Data

- Assess status of Parkinson's disease in Nebraska residents
  - Number of new cases each year
  - Social and economic impact of the disease
- Support Researchers
  - Parkinson's prevalence estimation
  - Epidemiology and risk factors
- Public awareness
  - Website
  - Creighton Annual Parkinson's Progress conference
- National MS and Parkinson's Disease Registries Act

<b><u>Challenges</u></b>	<b><u>Future Plans</u></b>
<p>All data manually entered and processed</p> <ul style="list-style-type: none"> <li>– Timely data</li> </ul>	<p>Web-based reporting system</p> <p>Automated reporting from pharmacies and physicians</p> <p>National registry</p>
<p>Obtaining critical patient information such as DOB and SSN</p> <ul style="list-style-type: none"> <li>– Linkage and verification</li> </ul>	<p>Update statute to include more patient information</p>
<p>Physician reporting</p> <ul style="list-style-type: none"> <li>– Awareness of the registry</li> <li>– Lacking specific diagnosis criteria</li> </ul>	<p>Promote the registry</p> <ul style="list-style-type: none"> <li>– More detailed reports/findings</li> <li>– Encourage researchers to use data</li> </ul>
<p>Limited resources – personnel &amp; financial</p>	<p>Continue to explore funding opportunities</p>

# 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
- [Jill.Krause@nebraska.gov](mailto:Jill.Krause@nebraska.gov)

**Thank You  
physicians and pharmacies!!**

**Please spread the word to encourage:  
reporting  
research projects  
funding**