

Nebraska Parkinson's Disease Registry for Public Health Applications

Jill Krause

Parkinson's Disease Registry Coordinator

2017 UNMC Parkinson's Update Conference

October 21, 2017

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

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

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

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

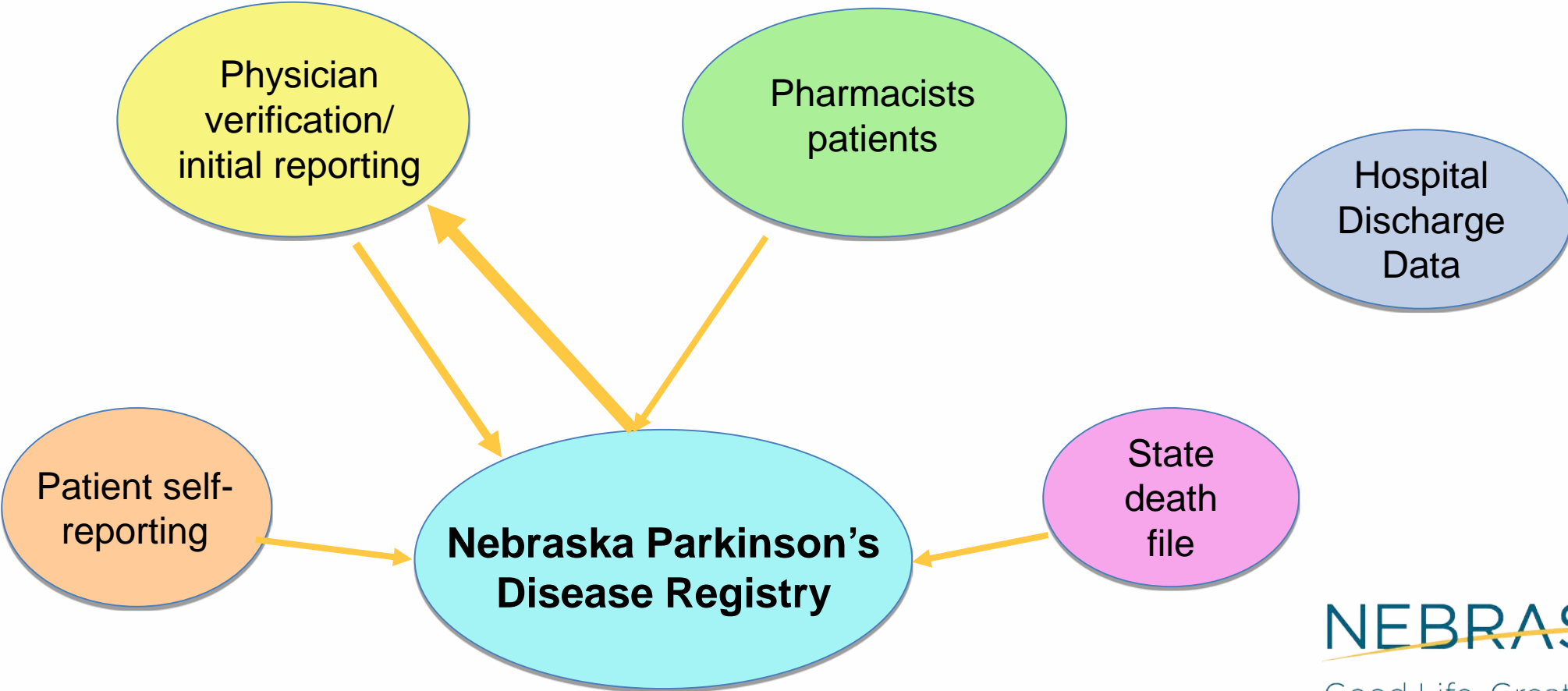
NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

Data Flow Chart



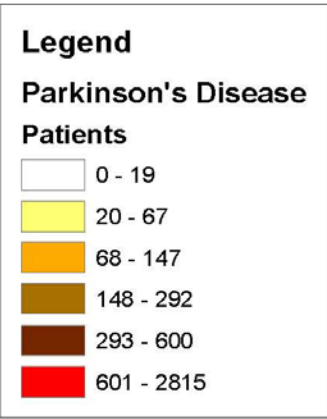
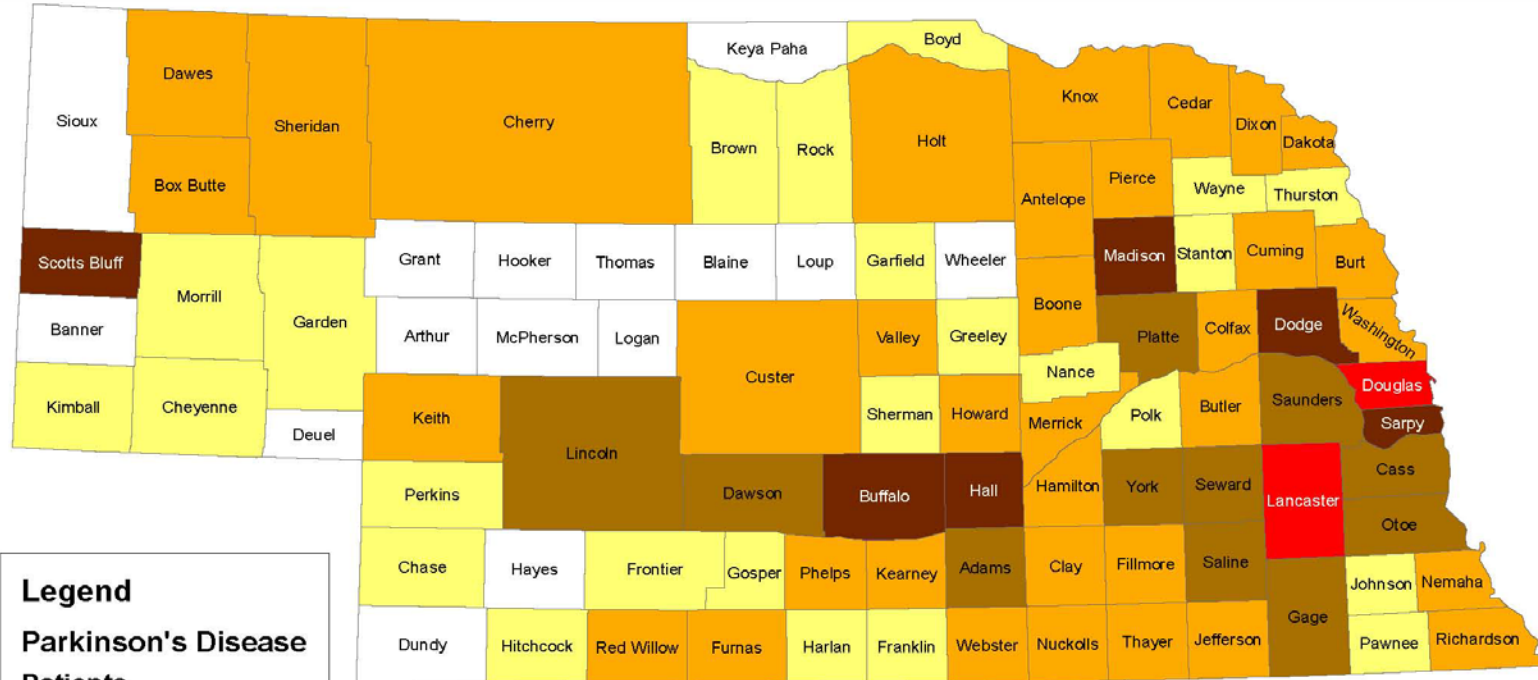
NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

Patients per County Map Pre-1997 - 2016



Nebraska 15,053
 Out-of-State 574
 Total Cases 15,627

The registry began collecting data in 1997.
 Diagnosis of PD based on physician office confirmation or death certificate.
 Registry was terminated from Oct. 2004 - Feb. 2006 due to lack of funding.

NEBRASKA
 Good Life. Great Mission.
 DEPT. OF HEALTH AND HUMAN SERVICES

Nebraska Parkinson's Disease Registry Diagnosis Year Report Pre-1997 - 2016 (Confirmed by Diagnostician)

>

YEAR	TOTAL	
Pre-1997*	3,359	
1997	746	Non-NE Residents 574
1998	761	TOTAL PATIENTS 15,627
1999	569	
2000	518	
2001	593	
2002	524	
2003	525	
2004**	399	
2005**	416	
2006	606	
2007	675	
2008	795	
2009	525	
2010	596	
2011	497	
2012	616	
2013	625	
2014	651	
2015	541	
2016	<u>516</u>	
TOTAL NE RESIDENTS	15,053	

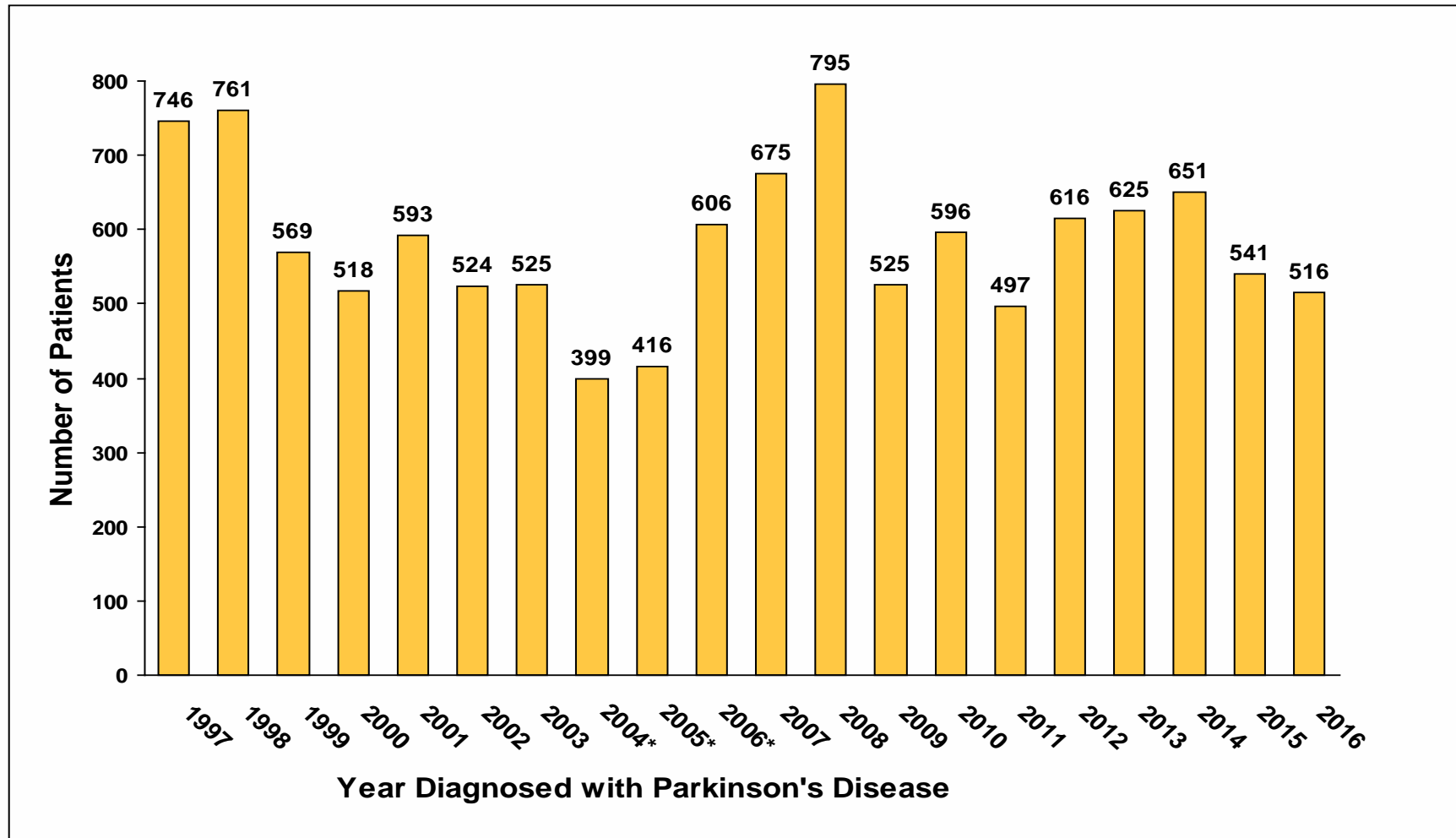
NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

Nebraska Parkinson's Disease Registry Diagnosis Year 1997-2016



Diagnosis of PD based on physician office confirmation or death certificate

Data collection is on-going, therefore yearly totals are not final.

*Decrease in cases reported due to registry downtime caused by lack of program funding.

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

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**

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

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

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.

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

NEBRASKA

Good Life. Great Mission.

DEPT. OF HEALTH AND HUMAN SERVICES

Helping People Live Better Lives.