

# IIS beyond Immunizations

**Nebraska's Parkinson's Disease Registry and  
NESIIS**



# Agenda

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# Introduction and history

## **Nebraska's Parkinson's Disease Registry. First in the nation.**

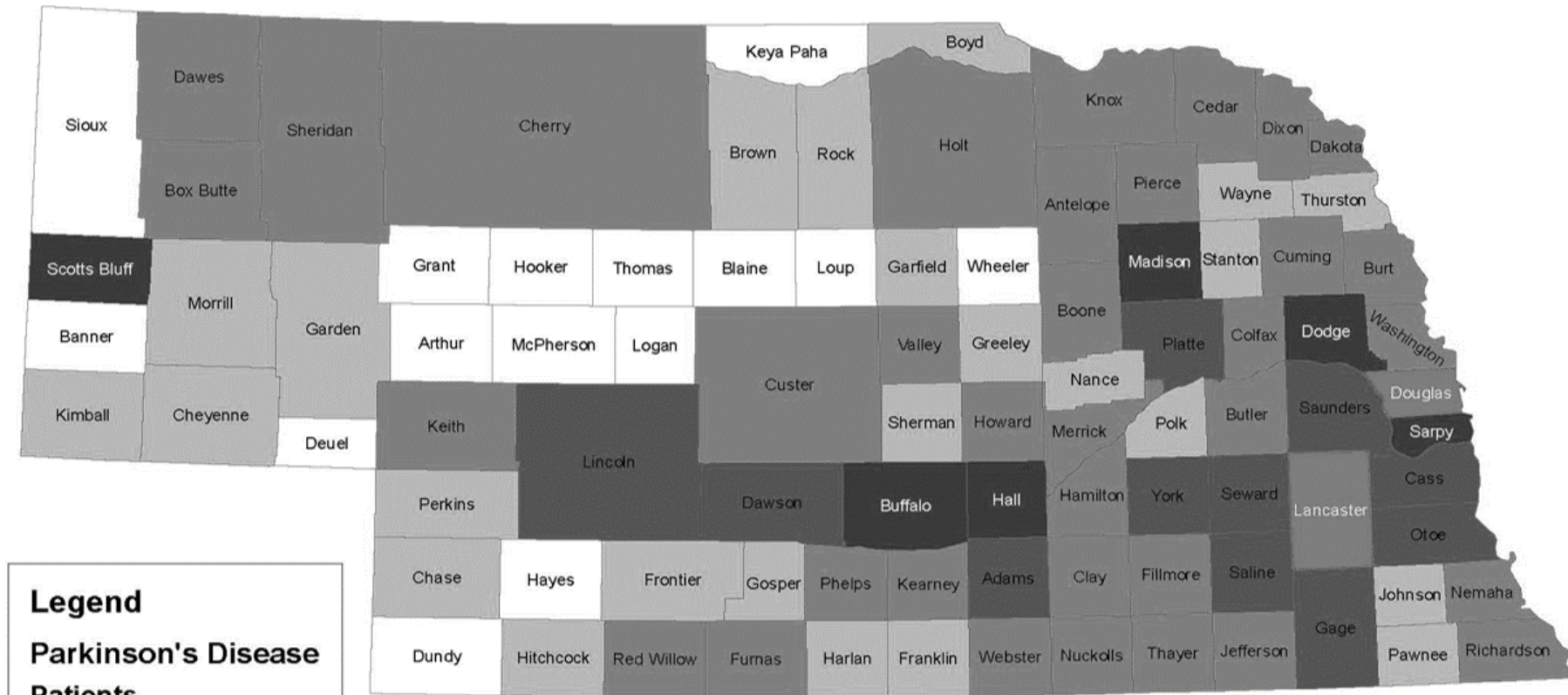
- 1996 - Legislation passed
  - Grass roots effort by PD interest groups and researchers.
  - An increasing public health concern as the population is aging
  - Essential for public health professionals and researchers
    - To study the incidence of and possible risk factors concerning Parkinson's
    - To plan for health care requirements and the education of health care providers

# Introduction and history

## **Nebraska's Parkinson's Disease Registry. First in the nation.**

- 1997 - Data collection began
- Suspended October 2004 due to lack of funding
- Reinstated February 2006 thanks to the American Parkinson Disease Association (APDA) and The Michael J. Fox Foundation for Parkinson's Research (MJFF)
- NE was the first and only fully functional population-based Registry until 2015 when joined by Utah, and shortly to come California.
- We work closely with many stakeholders, such as the University of Nebraska Medical Center and the Michael J. Fox Foundation, to identify the information we need to collect to support their research.

# Introduction and history



## Legend

### Parkinson's Disease Patients

0 - 19
20 - 67
68 - 147
148 - 292
293 - 600
601 - 2815

Nebraska	15,053
Out-of-State	574
<b>Total Cases</b>	<b>15,627</b>

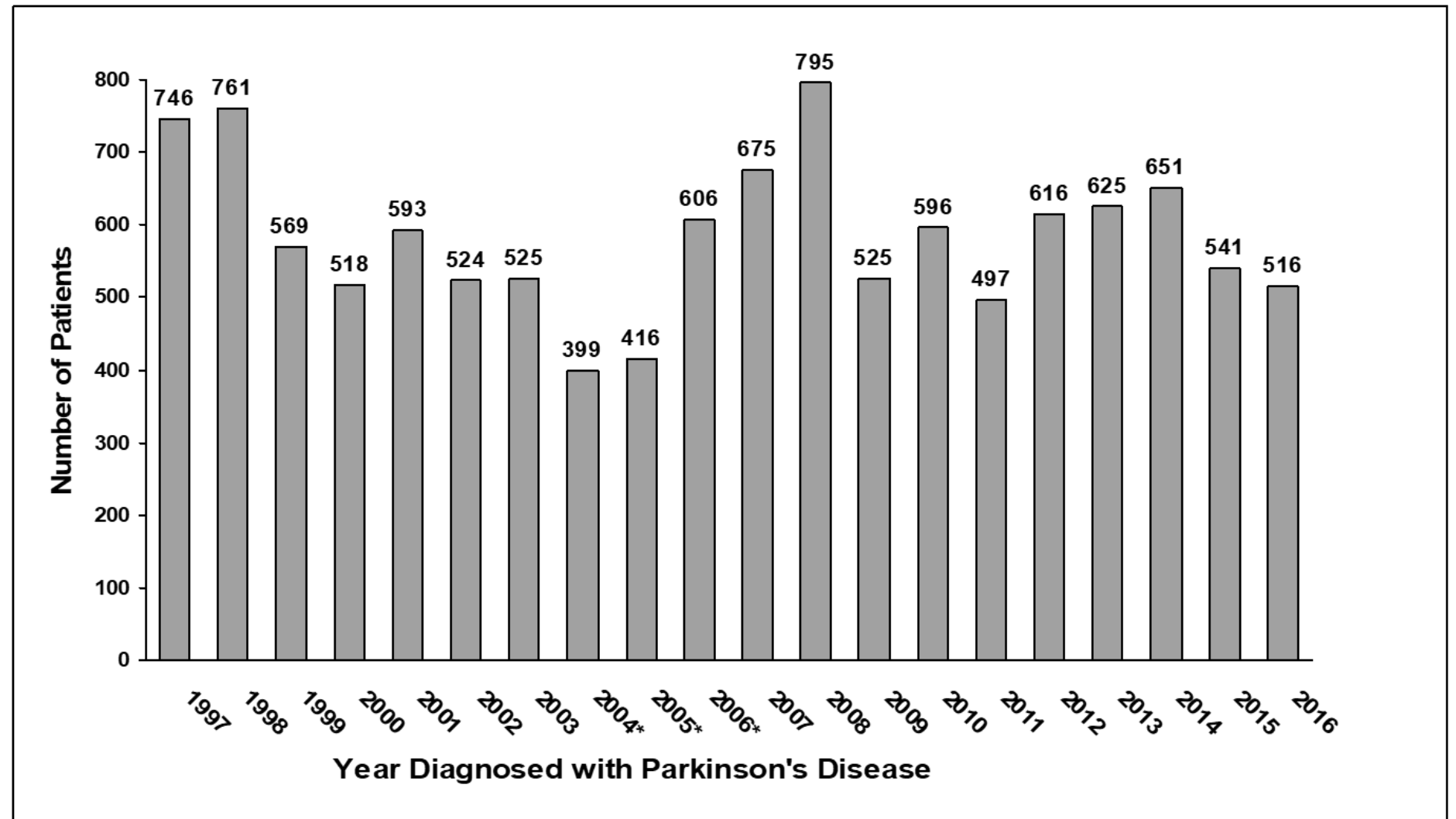
The registry began collecting data in 1997.

Diagnosis of PD based on physician office confirmation or death certificate.

Registry was terminated from Oct. 2004 - Feb. 2006 due to lack of funding.

# Introduction and history

- 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.



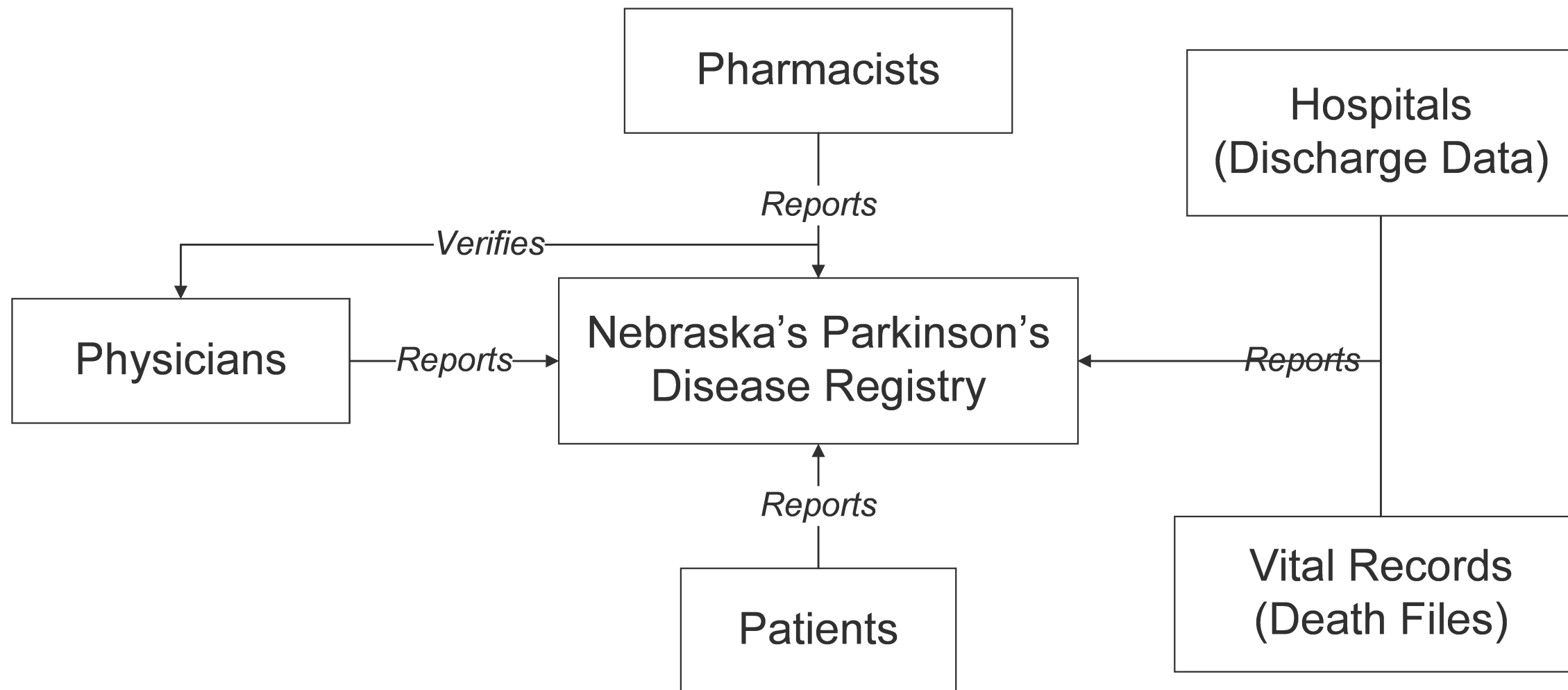
# Introduction and history

## 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



# Introduction and history





# Introduction and history

## Challenges

- Paper!
- Obtaining critical patient information such as date of birth, SSN
- Improve linkages to other data and verification
- Promoting the Parkinson's registry
- Encouraging physician reporting
- Limited resources – personnel & financial

# What we're doing

## Moving forward a step at a time.

- Integration to the Wisconsin Immunization Registry platform
- 90/10 funding
- New team members
- Building the user interface and migration of data
- Vital Death records, HL7, and Webservices
- Additional reporting
- Community awareness
- Automation

# Gains - PD

## Technical

- Web-based UI
- Robust database
- Standards
  - HL7
  - Real-time via SOAP-based web services

# Gains - PD

## Program

- Ability to leverage the over 2 million client records NESIIS contains
- Collection of
  - Contributing factors
  - Co-morbidities
  - Symptoms at onset
  - Full relevant medication history
- End user access
  - Pharmacies
  - Physicians
- Rule in or out

# Gains - NESIIS

## Partnership goes both ways.

- Exposure to a new audience
- Significantly expanded data sources
- Updated look and feel (thank you Maryland!)
- Modern technology
- New IIS-relevant functionality such as address history

# Credits

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# Thank you.

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