

Nebraska Parkinson's Disease Registry

Diagnosis Report

November 8, 2013



Information Confirmed (Y/N) by Diagnosticians

Total Patients Diagnosed with Parkinson's Disease*	13,083
Total Patients Reported by Diagnostician	11,912
Total Patients Diagnosed on Death Certificate Only	1,171
Total Ruled Out / Not Parkinson's Disease	<u>9,415</u>
Total Records Confirmed (Y/N) by Diagnosticians	22,498

Information not Confirmed by Diagnosticians

Outstanding (Awaiting Physician Reply)	775
Other **	<u>4,204</u>
Total Records Not Confirmed by Diagnosticians	4,979

* The registry began collecting data January 1, 1997

** Unable to follow-up with physician

Cases of Confirmed Parkinson's Disease by Diagnosis Year Pre 1997 — 2013

Year	Total
Pre 1997	3481
1997	775
1998	790
1999	592
2000	533
2001	610
2002	538
2003	533
2004	406
2005	427
2006	612
2007	731
2008	836
2009	514
2010	536
2011	421
2012	478
2013	270
Total	13,083

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

For questions regarding this report, please contact Jill Krause at (402) 471-8582 or by email: jill.krause@nebraska.gov.

Visit the registry website (www.dhhs.ne.gov/parkinsons) for information regarding its history, reporting procedures, legal requirements, aggregate patient data, and data request forms.

Source of First Report, 2000 — 2013

Year of Report	Patient	Pharmacy	Physician	Total
2000	2	753	407	1162
2001	1	456	225	682
2002	0	638	268	906
2003	0	648	194	842
2004	0	893	98	991
2005	31	114	0	145
2006	27	1565	137	1729
2007	3	1996	135	2134
2008	2	2528	66	2596
2009	1	2024	162	2187
2010	3	1868	123	1994
2011	0	2135	23	2158
2012	1	1988	40	2029
2013	0	1953	48	2001
Total	71 (0.3%)	19559 (90.8%)	1926 (8.9%)	21556

*Parkinson's data as of 10/24/2013

*Date of report was not accurately recorded until 1/1/2000

Reports of Parkinson's Disease Received and/or Confirmed by Physicians

2000-2013

Year of Report	Never	Yes	Total
2000	42 (4%)	1120 (96%)	1162
2001	33 (5%)	649 (95%)	682
2002	48 (5%)	858 (95%)	906
2003	50 (6%)	792 (94%)	842
2004	104 (11%)	887 (89%)	991
2005	10 (7%)	135 (93%)	145
2006	267 (15%)	1462 (85%)	1729
2007	401 (19%)	1733 (81%)	2134
2008	632 (24%)	1964 (76%)	2596
2009	542 (25%)	1645 (75%)	2187
2010	432 (22%)	1562 (78%)	1994
2011	789 (37%)	1369 (63%)	2158
2012	785 (39%)	1244 (61%)	2029
2013	880 (44%)	1121 (56%)	2001
Total	5015 (23%)	16541 (77%)	21556

*Parkinson's data as of 10/24/2013

*Date of report was not accurately recorded until 1/1/2000

*Includes cases where physician was unable to be contacted

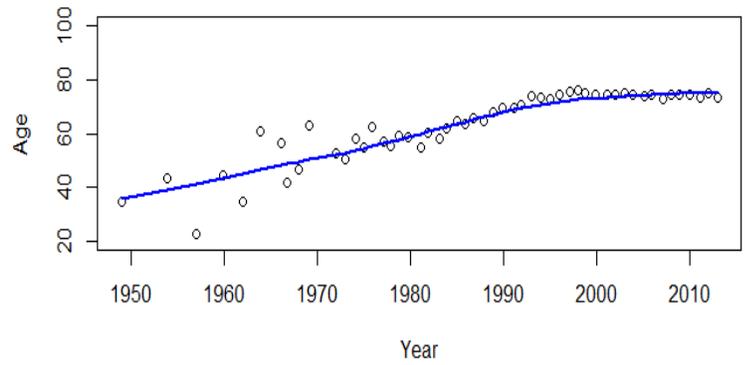
Summary Statistics for Cases of Confirmed Parkinson's Disease

	Mean (SD) , Median / N (%)
Age at Diagnosis	73.72 (10.67), 75.34
Longevity	7.23 (5.49), 6.12
Male	6893 (52.69%)
Female	6190 (47.31%)
Deceased	9545 (72.96%)
Living	3538 (27.04%)
Nebraska Resident	12551 (95.93%)
Other Resident	522 (3.99%)

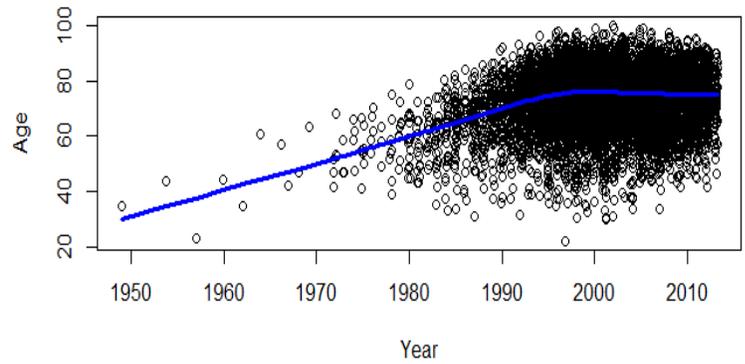
*High Age at Diagnosis and Low Longevity is due to missing data

*Began collecting data in 1997

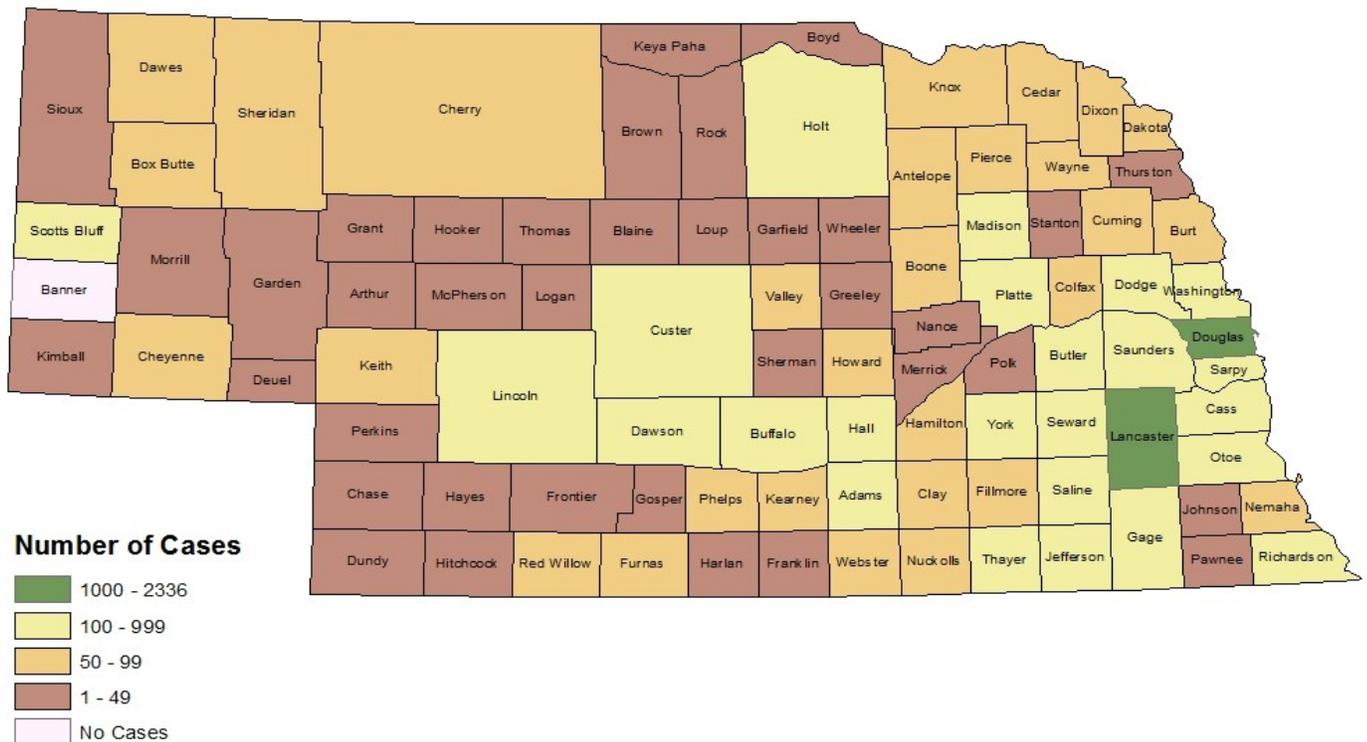
Average Age at Diagnosis by Year for Confirmed cases of Parkinson's Disease



Age at Diagnosis by Year for Confirmed cases of Parkinson's Disease

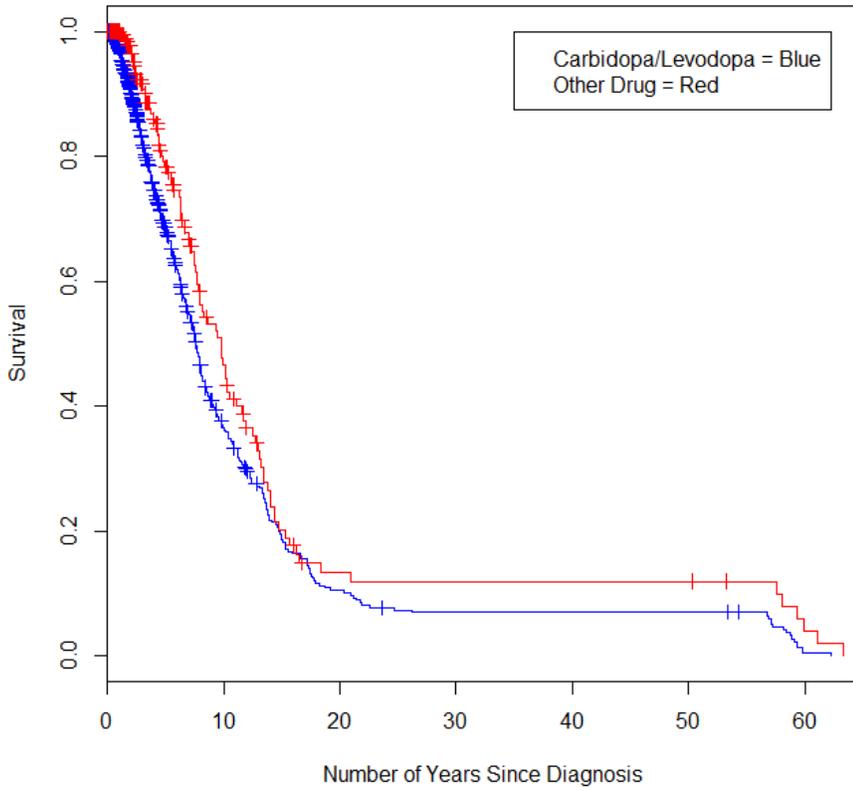


Number of Confirmed Cases of Parkinson's Disease, by County, Nebraska 1997 - 2013



Future Research Projects

Survival for Carbidopa/Levodopa vs. Other Drugs for Confirmed Parkinson's Disease Cases



Treatment Studies

We fit a proportional hazards model adjusting for Age at diagnosis and found a p-value of 0.887 which indicates no significant difference between the two drug groups (Carbidopa/Levodopa vs. other) in terms of survival. This plot is based off of a total of 852 cases of Confirmed Parkinson's Disease. These results are based on a limited dataset since medications are not required to be reported to the registry.

Results for Confirmed Parkinson's Registry Data & Hospital Discharge Data Linkage

Based on Patient Diagnosis Date and Date of Hospital Admission, 2005—2011

	Inpatient	Outpatient	Inpatient and Outpatient
Number of Patients	188	835	920
Mean Length of Stay (days)	4.3	3.1	
Mean Total Charge	\$17,708	\$818	
Number with PD and Cancer	23 (12.2%)	146 (17.5%)	157 (17.1%)
Cancer before PD			58 (36.9%)
Cancer after PD			99 (63.1%)

*Individuals with Parkinson's Disease listed as primary diagnosis of hospitalization

*Linkage rates for Parkinson's Disease Registry to Hospital Discharge Data via Master Race Index are 69.7 % for inpatient and 82.2% for outpatient.