

WE NEED YOUR SUPPORT!

Now that you know about the Nebraska Parkinson's Disease Registry, we hope that you will recognize its importance and submit your data to us.

For more information about the Nebraska Parkinson's Disease Registry, contact:

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Nebraska Parkinson's Disease Registry



PARKINSON'S DISEASE IN NEBRASKA

Approximately 700 Nebraskans are diagnosed with Parkinson's disease (PD) each year. To date the Nebraska Parkinson's Disease Registry contains nearly 14,000 patients who have been diagnosed with the disease since we began collecting data in 1997. Research has shown that farming communities and rural areas of the Midwest have a higher rate of Parkinson's disease due to exposure to pesticides. One study using our data linked the disease to manganese and iron.

Summary Statistics for Cases of Confirmed Parkinson's Disease

Avg Age at Diagnosis	73.71 years
Avg Longevity	7.09 years
Male	7346 (52.95%)
Female	6528 (47.05%)
Deceased	9785 (70.53%)
Living	4089 (29.47%)
Nebraska Resident	13354 (96.25%)
Other Resident	520 (3.75%)

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

* Began collecting data in 1997

HISTORY OF THE REGISTRY

The Nebraska Legislature passed a law in 1996 (Neb. Rev. Stat. 81-697 to 81-6,110) that mandated the nation's first statewide

Parkinson's disease registry. This law was a result of a grassroots effort by patients and researchers seeking knowledge of and ultimately a cure for this debilitating disease. To date it is the only statewide population-based Parkinson's Disease Registry in the nation. The Parkinson's Disease Registry Advisory Committee represents consumers, researchers, and medical and pharmaceutical professionals. It meets annually to review the list of reportable drugs and other registry issues.

WHO REPORTS TO THE REGISTRY?

Physicians are required by statute to report new cases of Parkinson's to the Registry within sixty days of diagnosing the patient. All pharmacies licensed in Nebraska are required to report basic patient information to the Registry when they dispense medications from a reportable list of drugs decided on by the Registry's advisory committee. The department then contacts the prescribing physician to confirm a diagnosis of PD and request additional information such as date of diagnosis and patient address at the time of diagnosis. Patients may self-report.

WHY IS THE REGISTRY IMPORTANT?

Over 600 Nebraskans with PD die each year. The population is aging and the likelihood of Parkinson's increases as we age. Issues include increased risk of falls and fractures and other co-morbidities that challenge effective treatment. We need to understand the growing impact of PD disease on society and the healthcare system and develop prevention and control strategies.

For statistics regarding PD in Nebraska, please visit our website www.dhhs.ne.gov/parkinsons