

# NEBRASKA HEALTH AND HUMAN SERVICES SYSTEM



## NEBRASKA PARKINSON'S DISEASE REGISTRY ANNUAL REPORT 1999

As a result of 1996 legislation, Nebraska became the first and only state to create a Parkinson's disease registry. A registry provides information about the incidence of the disease in the populace. The law requires that physicians and pharmacists report newly diagnosed patients or persons taking a select number of drugs to the Regulation and Licensure Department within the Nebraska Health and Human Services System (HHSS). Individuals may also self-report to the registry. HHSS appreciates the many pharmacies and physicians who have faithfully reported over the past two years.

This report documents the current status of data collection efforts and uses of data maintained in the registry. However, before discussing the requirements for reporting and facts about the registry, a little background information is provided.

### *What is Parkinson's Disease?*

Parkinson's disease (PD or simply Parkinson's) is a chronic neurological condition that is a motor system disorder. Parkinson's is a slowly progressive disease that affects a small area of nerve cells in a portion of the brain that controls muscle movements. In a normal brain, some nerve cells produce the chemical dopamine, which transmits signals within the brain to produce smooth movement of muscles. In Parkinson's patients, 80 percent or more of these dopamine-producing cells are damaged, dead or otherwise degenerated. This causes the nerve cells to fire randomly, leaving patients unable to control their movements. Symptoms usually show up in one or more of four ways: 1) resting tremor on one or both sides of the body, 2) generalized slowness of movement (bradykinesia), 3) stiffness of limbs (rigidity) and 4) gait or balance problems (postural dysfunction). Persons with Parkinson's may not experience all of these symptoms, but any combination of these classic signs may be used to diagnose the condition.

Parkinson's disease is not a fatal illness in itself, although it forces a person to adapt to the loss of mobility and other symptoms. While the cause of Parkinson's disease remains a mystery, it is not contagious and does not appear to be an inherited condition. Environmental factors may be one cause, but additional research is needed to establish such a conclusion. There is no known prevention or cure for the disease. Also, there is no definitive lab test or brain scan to verify the clinical diagnosis of Parkinson's. Primary care physicians can generally diagnose the condition based on symptoms, but board-certified neurologists who specialize in movement disorders are the most qualified to clinically diagnose Parkinson's.

An estimated 1.5 million Americans are affected with Parkinson's. As many as 50,000 Americans are newly diagnosed with Parkinson's each year. Although 15 percent of patients are diagnosed before age 50 and persons in their 20s sometimes get the disease, Parkinson's is generally associated with senior citizens. One percent of the population over 60 is affected by Parkinson's disease. Slightly more men than women are diagnosed with Parkinson's, but the chances appear to be rather close. Parkinson's disease is not a rare disease as more people suffer from it than from multiple sclerosis, muscular dystrophy, and amyotrophic lateral sclerosis (ALS, known as Lou Gherig's disease) and myasthenia gravis combined. Michael J. Fox, Muhammad Ali, Janet Reno and the late Charles Schultz are just a few notable people who have been diagnosed with Parkinson's.

### *Treatment*

Persons with Parkinson's disease are generally treated with medications, but certain surgical interventions are performed or investigated. The primary drug used to treat (and diagnose) Parkinson's was levodopa, but the side effects and limitations have led to newer medications that generally supplement, or in some cases, substitute for levodopa. The Nebraska Parkinson's Disease Registry collects data regarding the use of six drugs which, when prescribed, are most often used for Parkinson's: carbidopa/levodopa, entacapone, pramipexole, ropinirole, selegiline and tolcapone.

## ***Requirements in the Law Creating the Registry***

Physicians and pharmacists are required to report, and individuals may self-report, the occurrence of Parkinson's Disease. Section 81-689 of the statute states that "any physician, pharmacist, or medical professional participating in good faith in the reporting of information required under the Parkinson's Disease Registry Act is immune from liability, civil, criminal, or otherwise, that might result from divulging such information."

HHSS requires pharmacists to report all new prescriptions for carbidopa/levodopa, entacapone, pramipexole, ropinirole, selegiline or tolcapone. For each drug dispensed they are to report the patient's name, address, social security number, and the name and address of the prescribing physician. The Section of Data Management then contacts the prescribing physician to verify that the drug was prescribed for Parkinson's, and to collect additional information.

Required information from physicians includes the patient's name, Social Security number, date of birth, gender, address at the time of diagnosis, current address, date of diagnosis and physician name. Physicians are also required to report newly diagnosed cases within sixty days of diagnosis of Parkinson's.

The Parkinson's Disease Registry Advisory Committee meets each December to review the 'Reportable List of Drugs' and determine which prescriptions are to be included to keep reporting to a minimum and to meet the needs of identifying new cases of Parkinson's disease. It also makes decisions regarding general policies of the Registry. Only new Parkinson's cases diagnosed since January 1, 1997 are required to be reported, but the registry also includes data on persons who had a diagnosis of Parkinson's prior to that time. Current data are reported in the table that follows. Members of the Advisory Committee represent consumers, researchers, and medical and pharmaceutical professionals.

The Registry is a database that can be utilized to achieve the goals of statistical identification for research detecting the incidence of and possible risk factors concerning Parkinson's, planning for health care requirements, education of health care providers and hopefully a cure for the disease. The law which created the Parkinson's Disease Registry specifies that patient-identifiable information may be released to approved researchers. A major research project is already in progress.

## ***The Parkinson's Disease Registry Advisory Committee***

John Bertoni, M.D., Ph.D. – Parkinson's Specialist/Neurologist, Creighton University School of Medicine

Lewiston Birkmann, M.D. – Private Practice Neurologist

Lorraine Edwards, M.D. - Private Practice Neurologist

John Goldner, M.D. – Private Practice Neurologist

Allison MD Jorgensen, PharmD, RP – Assistant Executive Director, Nebraska Pharmacists Association

Daniel Strickland, Ph.D. – Researcher, University of Nebraska Medical Center

Carolyn Eberly – Formerly of the Nebraska Parkinson's Action Information Network

Thomas Safranek, M.D. – Epidemiologist, Nebraska Health and Human Services

Stephen Frederick, M.A. – Administrator, Data Management, Nebraska Health and Human Services

Jill Krause – Staff Assistant, Nebraska Health and Human Services

## ***Additional Information***

For additional information regarding Parkinson's, the following websites are available:

nol.org/home/SOS/hhs/t174-17.pdf – the Rules & Regulations for the Parkinson's Registry

\*parkinson.org – National Parkinson Foundation, Inc.

\*apdaparkinson.com – American Parkinson Disease Association

\* These website addresses are provided for informational purposes only and are not under the control of the Nebraska Health and Human Services System.

For information regarding Nebraska's Parkinson's Disease Registry, contact Stephen Frederick, Administrator, Data Management Section, at (402)471-0147 or by e-mail at [steve.frederick@hss.state.ne.us](mailto:steve.frederick@hss.state.ne.us). For forms to report individuals to the Nebraska Parkinson's Disease Registry, contact Jill Krause at (402)471-8582 or by e-mail at [jill.krause@hss.state.ne.us](mailto:jill.krause@hss.state.ne.us).

**NEBRASKA PARKINSON'S DISEASE STATISTICS**  
**(As of December 31, 1999)**

Total Patient Records 6147

Total Records Confirmed by Physician 5436

INFORMATION CONFIRMED BY PHYSICIANS

	<u>Since 1/1/97</u>	<u>Total</u>
Patients Diagnosed with Parkinson's Disease	1221	4426
Males	633	2234
Females	588	2179
Unknown	0	13

Total Patients Diagnosed As Not Having Parkinson's Disease 1044

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