

WISCONSIN PARKINSON ASSOCIATION ORGANIZATIONAL INFORMATION

Regional Parkinson Disease Center At Aurora Sinai Medical Center

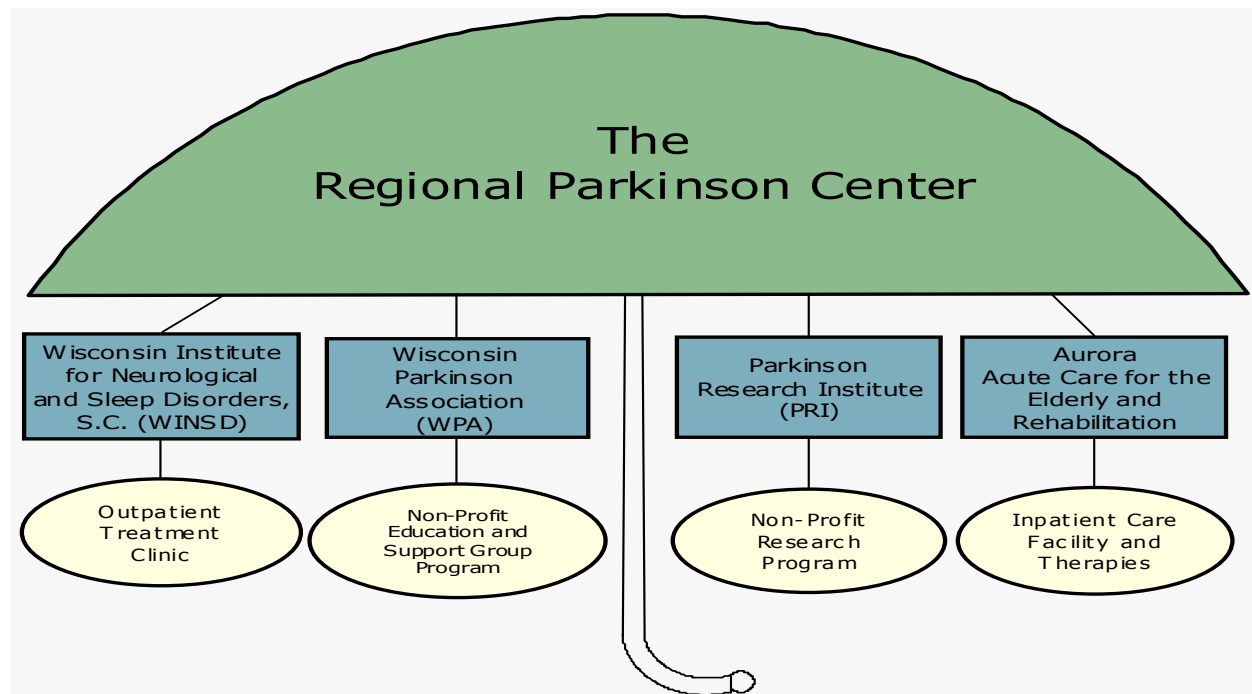
The Regional Parkinson Center is one of the largest centers of its kind in the U.S. and sees more than 150 patients per week. Recognized as a Comprehensive Care Center by the National Parkinson Foundation, the Regional Center is one of the nation's most comprehensive Parkinson's disease programs, featuring diagnosis, education, research, treatment and rehabilitation.

The Parkinson Research Institute - The Parkinson Research Institute was established to uncover the cause(s) of the disease, advance the quality of patient treatment, and identify promising new directions to follow in the quest for the cure. PRI's mission is to gather and analyze data that will build the capacity of national and international research to uncover the cause(s) of Parkinson so we then can find a cure.

Wisconsin Institute for Neurologic and Sleep Disorders, S.C.- More than 20,000 people with Parkinson symptoms have been treated at the Outpatient Center over the past 20 years, and the Center follows the progress of 5,000 patients annually. The Center's standing as a leader in the treatment of Parkinson disease provides an enormous database that can contribute to solving treatment issues, understanding the potential causes of Parkinson's disease and major pharmaceutical studies to better understand the long-term care implications of medications currently used to manage the symptoms of the disease.

The Wisconsin Parkinson Association- the Wisconsin Parkinson Association (WPA) is a non-profit organization affiliated with the National Parkinson Foundation. The mission of the WPA is to increase public awareness and understanding about Parkinson Disease that will lead to greater public support, improved treatment for patients, better assistance for caregivers and families, and increased funding for Parkinson disease research.

Acute Care for the Elderly (ACE) and Rehabilitation Services at Aurora Sinai Medical Center- A 234-bed community-based, not-for-profit hospital serving Milwaukee Wisconsin's diverse urban population. ACE is a nationally know program that focuses on the individuals acute care, recovery, and rehabilitative needs. The nurses and therapists at Aurora Sinai Medical Center have extensive knowledge of Parkinson disease and the needs of its patients.



Organizational Information

Since 1984, The Wisconsin Parkinson Association (WPA), a nonprofit chapter affiliate of the National Parkinson Foundation, provides information and resources about Parkinson disease, to enhance public education and awareness of the disease and to provide support to people with Parkinson's and their families. Its efforts have been primarily achieved through its 60-support groups throughout Wisconsin and its neighboring states.

With more than 6,000 members, the WPA, located within the Wisconsin Regional Parkinson Center at Aurora Sinai Medical Center, is committed to helping its local community.

Based on data from the Regional Parkinson Center, Wisconsin has at least 20,000 patients living with Parkinson disease. Wisconsin has the largest population of Parkinson patients than any other state in the Midwest.

The WPA is the largest and oldest National Parkinson Foundation chapter in the United States. It distributes written materials to its members and to the community at large. It conducts educational training opportunities for health care professionals serving the Parkinson population. One of the WPA's key missions is to raise funds for neurological research. Through its dedication to serve the community and the Parkinson population, the WPA helped launch the Parkinson Research Institute at the Aurora Sinai Medical Center.

Need Statement

As the elderly population increases in the coming years, so, too, will the debilitating effects of neurological disorders. In addition to limiting the quality of life of the men and women diagnosed with these disorders, millions of extended family and loved ones are also affected.

Parkinson disease, an "idiopathic" disease—meaning there is no known cause, is a progressive neurological disorder that results from degeneration of neurons in the region of the brain that controls movement. The National Parkinson Foundation estimates that up to 1.5 million Americans are affected by Parkinson disease, which is a larger number of persons suffering from Multiple Sclerosis and Muscular Dystrophy combined. **The National Institute of Health estimates that as many as 50,000 new cases of Parkinson disease are reported annually—a figure that is expected to increase as our population ages.**

As Parkinson disease progresses, simple tasks become more challenging and can dramatically affect a person's balance and fine motor skills, which could make even the simplest tasks, such as brushing teeth, shaving, and getting dressed, very difficult. Subtle changes in thinking and memory may affect one's judgment and decision-making. These changes may cause loss of motivation, feelings of hopelessness and depression.

One recent survey found that on average, Parkinson patients take 19 pills per day, with a range of 3 to 100 pills daily. This is particularly disturbing given the fact that nearly 60% of these patients report difficulty swallowing.

Parkinson disease truly is one of the most baffling and complex of all neurological disorders because the disease, as well as the treatment, affects individuals in different ways. And, while its cause remains a mystery, extensive and ongoing research is providing new and intriguing findings that will change the lives of those living with the disease. **With more than 150 people being diagnosed with Parkinson's each day, it is imperative that we identify the cause NOW.**

Issues and Responses

1. **INCREASE PUBLIC AWARENESS AND UNDERSTANDING ABOUT PARKINSON DISEASE.**

- There is a great misunderstanding about the disease and its care and treatment. Too many times, people are told that it's just a normal part of aging.
- Too many people think that PD is a chronic disease that leads to physical and mental degeneration and eventually death. People need information about treatment and care options that allow for a normalized quality of life for many years.

2. **EDUCATE HEALTH CARE PROFESSIONS, ESPECIALLY GENERAL PRACTITIONERS AND PRIMARY CARE DOCTORS ABOUT PARKINSON DISEASE.**

- Many people go many years without a correct diagnosis – often frustrated, over or under medicated, and with diminishing health.
- With better understanding of the symptoms for PD and other neurological disorders, pcp's can make referrals to a neurologist or movement disorder specialist for the proper diagnosis and treatment.

3. **EDUCATE PEOPLE WITH PD AND THEIR FAMILIES ABOUT PARKINSON DISEASE AND HOW TO BEST TREAT IT AND LIVE WITH IT.**

- People need to understand the role of nutrition and diet, exercise, counseling, stress reduction and other activities that can help reduce the symptoms of PD and enhance a person's life.
- People with PD need to get treatment from a movement disorder specialist and seek out the latest and best care, including participation in clinical trials.

4. **PROVIDE SUPPORT AND RESOURCES FOR PEOPLE WITH PD, THEIR FAMILIES AND/OR CAREGIVERS.**

- PD is a difficult and life changing illness that effects family and friends. The needs of the person with PD can take a heavy toll on spouses and children. They need a better understanding of the disease, information about the best treatment and care options, knowledge and access to resources and allied health care providers, and support and respite to help deal with the stress and responsibility of dealing with the disease.

5. **PROVIDE SUPPORT FOR RESEARCH AND THE DISCOVERY OF THE CAUSE, CURE AND BETTER TREATMENT FOR PARKINSON DISEASE.**

WPA Programs and Services

A. Information and Referral

WPA can provide basic information about the disease and can provide referrals for help with treatment, care, support groups, assisted living or care facilities and allied health professionals.

B. Resource Library

The WPA offers access to a full resource library that includes literature, books and videos on Parkinson disease.

C. Support Groups

The WPA has organized and developed over 60 support groups of various types throughout the Midwest. These groups meet monthly and are designed for people with the disease and their caregivers. The types of groups include general support, young onset, music, exercise, social, newly diagnosed and others.

D. Public and Medical Education

Through its outreach efforts, the WPA reaches thousands of people each year. These efforts include annual conferences and symposia, workshops and mini-education sessions, Grand Rounds for health care professionals and the creation and dissemination of information through newsletters and the internet.

E. Speakers Bureau

The WPA has compiled a list of speakers on topics of interest to individuals and families faced with Parkinson disease.

F. Public Awareness

The WPA works to educate the public through community-based programs and health fairs. In addition the WPA provides free Parkinson Screenings to help detect the disease in its early stages.

G. Volunteer Program

Individuals, family members and medical professionals all make great volunteers. WPA needs help with facilitating support groups; visiting patients in the hospital; speaking at conferences, workshops or support groups; planning and organizing events and galas; or providing support and guidance for newly diagnosed patients.