

PARKINSON'S PERSPECTIVE

Published by the Wisconsin Chapter APDA in collaboration with the APDA Information & Referral Center at St. Mary's Hospital, Madison

UPCOMING EVENTS

PD 101

Wednesday, November 17
5:30-7:30 p.m.

St. Mary's Hospital
Bay 6

Please RSVP by November
12 to 608-229-7628

Wine Tasting

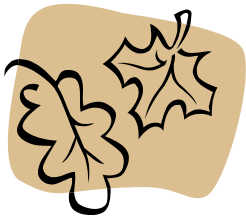
February 12, 2011

Blackhawk Country Club
More information to come

Walk-a-Thon

Spring 2011

More information to come



NOVEMBER IS NATIONAL FAMILY CAREGIVERS MONTH

The chapter recognizes the important role of the caregiver and is committed to easing the stress of Parkinson's caregivers by promoting caregiver connections and trying to lessen the isolation that can occur. National Family Caregivers Month is organized by the National Family Caregivers Association every November to "thank, support, educate, and empower family caregivers."

The chapter considers all Parkinson's caregivers "family" and takes this opportunity to recognize these important people. We are spouses, partners, children, parents, siblings, other family members, and friends. Our roles may differ, but we share the goal of providing the best care we can for someone who is living with Parkinson's disease. And, we should not forget one other very important role we have—caring for each other.

We join the National Family Caregivers Association in proclaiming these **Caring Every Day** messages:

Believe in yourself.

Protect your health.

Reach out for help.

Speak up for your rights.

EMPOWERED CAREGIVING FORUM

Wednesday, November 10, 2010 • 8:30 a.m. - 2:00 p.m. • Covenant Presbyterian Church, Madison

Knowledge is power. Learn and discuss the essentials of caregiving with the experts. This annual event is hosted by the Dane County Caregiver Alliance in conjunction with National Family Caregiver Month. The cost is \$10 per person and is open to all Dane County family caregivers. For more information or to register, please contact Claire Culbertson at 608/261-5679. All attendees must register by November 3.

From the President

Michelle Ciucci



Each time I do a literature search for my research projects on Parkinson's disease (PD), I am overwhelmed by the sheer volume of work being generated. This means that voices of people living with PD have been heard, the scientists and clinicians are making progress, and the funding agencies believe this is a worthy cause. This is very encouraging! However, as with any significant scientific progress, it is complicated and slow. Sometimes a "breakthrough" will happen in the lab that looks promising, but sadly it doesn't directly translate into a benefit during clinical trials. Conversely, sometimes the progress has an immediate and direct positive impact.

I can't tell you how many times I have been asked, "When are they going to find a cure?" That's what we all want, and we want it now! So, how do we balance hope of discovering a cure with the reality that we just don't know when this is going to happen?

Lessons I have learned from the trials and tribulations of life guide me to change the things that I can and learn how to manage the things that I can't. What is under our immediate control, what can we change? Well, for one, we can steer our thoughts toward the positive. We also can change what we do—form healthy eating habits, exercise, sleep, relax, cultivate friendships, and enjoy life. Unfortunately, for those with PD, almost all of these tools are more difficult to utilize. But, no matter what we are hoping to change, improve, or manage, none of us do it alone.

That is where the Wisconsin Chapter of the APDA can help. We are here to offer you education, support, fun activities, and even exercise classes. We are committed to providing support to you and your families as well as raising money to help find a cure and make life better for those living with PD. Please become a volunteer and get involved with us! Together, we can make a positive impact TODAY!

MEMBERSHIP RENEWAL

Chapter members, please send in your membership renewal form if you haven't done so yet. If you aren't a member and would like to join, you can do so online at www.wichapterapda.org or contact Jessica at 608/229-7628.

"Success is not final,
Failure is not fatal,
It is the courage to continue that counts."
Winston Churchill

 FIND US ON FACEBOOK

From the Information & Referral Center

Jessica Olejniczak



Ah, Fall, when the temperatures are cooler, and the leaves paint the landscape with beautiful colors. It's a welcome relief after the extreme heat and humidity we had this summer. People can get out of the house and be more active since it isn't as warm.

With Fall, come some changes. First of all, I would like to welcome Teresa Mangin, M.D., the new movement disorders specialist at Dean Clinic in Madison. Dr. Mangin, who comes to us from Portland, Oregon, where she did her residency, is filling the vacancy left by Dr. Efrain Perez, who is practicing in Waukesha.

Another change is coming in February, and it will be a big one for some people. I will be taking a few months off for maternity leave. We are working out how the office will be covered and will have that in place by the time I start my leave. The chapter will still be very active during this time, since the second annual wine tasting will take place in February and the annual walk-a-thon in April. Please keep your eyes open for more information about these two events.

As mentioned above, please stay active, even when the weather starts to turn colder. Research shows that people with PD who are more active do better. Have a great Fall and enjoy the nice weather.

Helpful Hint

Get a better grip on jars by wearing a rubber glove or using a jar- or bottle-opening device found in a kitchen supply store (some can be mounted under the counter for easy access).

This hint comes from a caregiver in the Fox Valley area.

If you have a helpful hint to share, contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

If you received this newsletter via mail and would like it electronically, please contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

Wisconsin Chapter Part of Community Health Charities

The Wisconsin Chapter of the American Parkinson Disease Association is proud to be a member of Community Health Charities. Community Health Charities is a federation of America's premier health organizations that have joined together to raise charitable contributions in the workplace. Please keep us in mind as a place to donate to when you receive your annual workplace campaign information this Fall.



LEWY BODY DEMENTIA: A WEEK TO REMEMBER

The Lewy Body Dementia Association is committed to increasing awareness about LBD 365 days a year. This year, October 10-16 will truly be **A Week To Remember** as LBD families are **Standing Strong with LBDA** to raise LBD awareness and support throughout the country. (<http://www.lbda.org/go/awareness>)

LBD is a hateful disease to live with, for the person suffering with the condition and their family. Diagnosis can be difficult, and few people and medical professionals know much about it or even that it exists. For more information about LBD, contact the Lewy Body Dementia Association, Inc.: 404-935-6444; P.O. Box 451429, Atlanta, GA 32245; Caregivers' Helpline, 1-800-539-9767; or www.lbda.org.

If you are interested in a Madison-area support group, please contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.



A WEEK TO REMEMBER

OCTOBER 10-16, 2010
Standing Strong with LBDA

DEMENTIA WITH LEWY BODIES

What Is Dementia with Lewy Bodies?

Dementia with Lewy bodies (DLB) is possibly the second most common cause of dementia after Alzheimer's disease (AD) and generally under recognized. Lewy bodies are abnormal proteins that accumulate in different parts of the brain in patients with DLB and are thought to be responsible for disease progression. Little is known about risk factors. Male gender and old age are two possible risk factors. Although rare, inherited cases of DLB can occur.

Clinical features and diagnostic criteria

The diagnosis of DLB is primarily based upon a patient's symptoms rather than specialized laboratory or imaging tests. In order to make the diagnosis, certain features are essential, and others are supportive.

Essential features of dementia Dementia is defined as progressive decline in brain functions sufficient to affect daily activities. The onset of dementia is gradual. As opposed to AD, memory impairment may not be an early and prominent deficit in DLB. Patients with DLB tend to have more difficulty with attention, planning, and navigating.

Fluctuating attention Attention and alertness may vary over minutes, hours, or days. This is the most persistent feature of the disease although very difficult to measure.

Recurrent visual hallucinations (VH)

Patients may see things, such as little animals and people, when they don't really exist. VH are typically non-threatening, and patients recall the details of the hallucinations. VH occur early in the course of the illness in up to 80% of patients and often are the symptom that first alerts the clinician to a DLB diagnosis.

Parkinson-like symptoms 25-50% of patients will have such symptoms as resting tremor, limb stiffness, or slowness of movements at the time of diagnosis. Patients with Parkinson's disease also may develop dementia but usually many years after the onset of the movement disorder.

Supportive Features

REM sleep behavior disorder (RBD) RBD is a sleep disorder that can commonly occur with dementia with Lewy bodies. RBD is associated with vivid and often disturbing dreams coupled with complicated movements, like kicking or jumping. RBD may cause injury to patients and their bed partners and may result in significant caregiver stress. This condition is treatable and should be reported to prevent possible injuries.

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Severe side effects from antipsychotic medications Physicians may treat hallucinations with antipsychotic medications, but patients with DLB can worsen with these therapies.

Abnormal brain imaging PET and SPECT imaging are being tested in research.

Other Complications

Repeated falls and unexplained loss of consciousness can occur that may be associated with sweating and severe changes in blood pressure. Additionally, urinary incontinence can occur.

Treatment and Planning

Medications called cholinesterase inhibitors, originally developed for Alzheimer's disease, are considered standard treatment for the dementia symptoms in DLB. In practice, it is shown that people with DLB may be more responsive to these medications than those with AD. Hallucinations are difficult to treat, although careful use of antipsychotics may improve hallucinations. Treatment of RBD with medications has shown improvement of nighttime movements, fluctuating attention, and quality of life. Unfortunately, the tremor, stiffness, and slowness are less

responsive to medications used to treat Parkinson's disease. Physical and occupational therapy may improve certain aspects of quality of life, such as reducing falls.

DLB is a serious disorder of the nervous system that does not yet have a cure. Because the condition does shorten life expectancy, advanced directives and living wills are an important part of the planning process.

Helpful Websites

<http://www.lbda.org/index.cfm>

<http://alzonline.phhp.ufl.edu/en/reading/lewybody.php>

<http://www.helpguide.org/elder/lewybodydisease.htm>

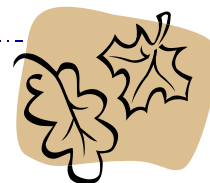
<http://www.ninds.nih.gov/disorders/dementiawithlewybodies/dementiawithlewybodies.htm>

Lead author: Mahmud Ali, M.D., MPH; Research Fellow, Madison VA Geriatric Research, Education and Clinical Center (GRECC)

Co-author: Steven Barczi, M.D., Director of Education & Evaluation, Madison VA GRECC; Associate Professor of Medicine, Division of Geriatrics, University of Wisconsin School of Medicine and Public Health

Mary Gets Her Wish!

On September 26, the wonderful, generous family and friends of Mary Hoffman came together for the third annual *Mary's Wish Golf Outing* at Door Creek Golf Course in Cottage Grove. With over 140 participants and standing room only, over \$8,000 was raised for the Wisconsin Chapter APDA. *Mary's Wish* has donated almost \$20,000 to the chapter in Mary's honor over the past three years to help find a cure and to support people with Parkinson's and their families. Thank you!



APDA Support Groups

The following support groups are sponsored by the Wisconsin Chapter of the American Parkinson Disease Association. For information on other support groups in the state, please contact Jessica at 608/229-7628 or visit www.wichapterapda.org.

Endeavor

Short Circuiting Support Group
Contact: Renee Bloss at 608/566-3379

Fitchburg

Fitchburg Senior Center
5510 Lacy Road
2nd Friday at 9:30 a.m.
Contact: Mary Hoffman at 608/249-9109

Madison

Parkinson's Disease Caregiver Support Group
(caregivers only)

East Madison/Monona Coalition
4142 Monona Drive
1st Tuesday at 4:00 p.m.
Contact: Jessica at 608/229-7628

Young Onset PD Support Group
St. Mary's Hospital
700 South Park Street
Conference Center
1st Thursday at 6:00 p.m.
Contact: Jessica at 608/229-7628

Asbury United Methodist Church
6101 University Avenue
3rd Thursday at 6:00 p.m.
No meeting in December
Contact: Jessica at 608/229-7628

Resource Book

The *Wisconsin Parkinson's Disease Resource Book* has been updated. Printed copies are available from Jessica at 608/229-7628 or parkinson_assn@ssmhc.com. The resource book also is available at the Wisconsin Chapter APDA website, www.wichapterapda.org.

Portage

Bethlehem Lutheran Church
W8267 Highway 33
3rd Thursday at 2:00 p.m.
Contact: Elayne Hanson at 608/742-2410

Sun Prairie

Colonial Club Senior Center
301 Blankenheim Lane
Therapy Room
4th Monday at 1:00 p.m.
Contact: Jessica Olejniczak at 608/229-7628

Waunakee

Village Center of Waunakee
Senior Center Stage
333 South Madison Street
4th Tuesday at 2:00 p.m.
Contact: Dee Henning at 608/849-8834

GoodSearch & GoodShop

Search the web with Yahoo-powered GoodSearch.com, and they'll donate a penny to the chapter. Shop at over 600 GoodShop.com merchants, and a percentage of each purchase will go to the chapter.

You can make GoodSearch or GoodShop your home page or add it to our toolbar. Just type in *American Parkinson Disease Association—Wisconsin Chapter* to begin your search.

Questions? Contact Jessica at parkinson_assn@ssmhc.com or 608/229-7628.

“A Day in the Life of Mary Hoffman”

Excerpt from Mary Hoffman's speech at the 9/26/2010 Mary's Wish Golf Outing

P is for Promise...I live each day knowing there is promise in every tomorrow.

A is for Answers...Sometimes there are answers to hard questions...sometimes not...that's when you must have faith.

R is for Relationship...I am grateful for all the people I have met who share my journey.

K is for Knowledge...There are so many really smart people who work every day to find a cure.

I is for Inspiration...I try to inspire people each day to live life to the fullest and enjoy every minute.

N is for Normal...Every day, I adjust to living a new normal...life has changed.

S is for Steadfast...You are here for me today, and I know you will always be here for me.

O is for Optimism...My glass is never half empty; it is always half full.

N is for New...I live in a new home, have a new granddaughter, and have a new schedule due to my early retirement.

D is for Determined...I refuse to give up or give in to this disease.

I is for Interruption...PD is not a death sentence; it is an interruption of the way life was supposed to be.

S is for Support...On the tough days, I am going to need you, and you will need each other.

E is for Extra...I do need extra time, extra space, and extra patience from you when movement is difficult.

A is for Active...An active mind and an active body will help me to be healthy for a longer period of time.

S is for September 2011 and the third annual Mary's Wish Golf Outing!

E is for Extraordinary...The people who give my life meaning...my mom and dad, my mother-in-law, my brothers and sisters and their families, my husband, my beautiful daughters, my sweet little Maci, and all of you who made today an unforgettable experience for me...I thank you!

Parkinsonism

Teresa Mangin, M.D.

The term *parkinsonism* refers to a cluster of four cardinal symptoms: slowness of movement (also called *akinesia* or *bradykinesia*), tremor (typically a rest tremor), muscle stiffness, and poor balance. Although all patients with Parkinson's disease (PD) have parkinsonism, not all patients with parkinsonism have Parkinson's disease. A number of other conditions can produce these symptoms and need to be taken into consideration by your neurologist when making a diagnosis. Many of the questions your doctor asks and the tests he or she orders are intended to rule out mimics of Parkinson's disease, which may require a

different treatment approach or progress at a different rate. These mimics include other primary neurologic diseases that are associated with “red flags” or symptoms that differentiate them from typical PD. These disorders cause *atypical parkinsonism* and are sometimes called *Parkinson-plus syndromes*. Parkinsonism can also be secondary to a medication side effect, certain types of toxins, vascular disease of the brain, trauma, encephalitis, or normal pressure hydrocephalus. What follows is an overview of alternate causes of parkinsonism.

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Primary Causes of Atypical Parkinsonism

Multiple system atrophy (MSA) is a rare degenerative neurologic disorder that causes symmetric parkinsonism along with signs of dysfunction in other parts of the nervous system. MSA typically begins between ages 55 and 60 and does not run in families. In addition to parkinsonism, patients have problems with coordination and/or regulation of blood pressure, temperature, respiration and urologic function. These features are clues to the diagnosis. Medications used to treat PD are not very effective for the parkinsonism of MSA but should still be tried in case some benefit can be achieved. The other features of MSA are also treated symptomatically, with medications to boost blood pressure and reduce incontinence and CPAP machines to help regulate breathing at night. MSA progresses more quickly than regular PD, with falls occurring relatively early in the course. In patients who present with symmetric parkinsonism but no other features to suggest MSA, it may take time to evaluate the rate of progression and response to treatment before the diagnosis can be made.

If early falls and balance problems are present, another important diagnostic consideration is **progressive supranuclear palsy (PSP)**. Similar to MSA, this rare disease can cause symmetric parkinsonism, usually without tremor, that progresses more quickly and is less responsive to treatment than typical PD. The most distinctive feature of PSP is the eye movement disorder, characterized by drastically reduced blinking, trouble opening the eyes, and difficulty moving the eyes up and down voluntarily. Patients with PSP are very prone to falls, often falling backwards. Despite this, patients often seem reckless in their walking, which may be a sign of the cognitive problems that accompany PSP. Patients may develop behavior changes/impulsivity and difficulty performing complex tasks. Speech and swallowing changes are also common in this disorder. As with MSA, treatment should be tried but is not very effective. There is anecdotal evidence

supporting the use of amantadine to decrease falls. Patients with PSP also progress more rapidly than PD patients and need to be monitored closely due to the risk of falls and choking. There are several trials underway looking for a medication that could slow progression of PSP.

Unlike PSP and MSA, which cause relatively symmetric symptoms, **corticobasal degeneration (CBD)** causes asymmetric rigidity and slowness of movement initially affecting one limb, usually an arm. A jerky tremor can occur, which can make it particularly difficult to distinguish from PD early on. Patients may describe the affected limb as “dead” or “useless” or feel that the limb has a mind of its own. This is known as the “alien limb phenomenon.” Over time, the hand may become clenched in an uncomfortable position, which can be relieved with botulinum toxin injections into the affected muscles. Patients with CBD develop difficulty using even the good hand appropriately and may also have sensory deficits. Speech and language problems and other cognitive changes are prominent features of this disorder. There is no cure for CBD, and, similar to MSA and PSP, treatment is aimed at the individual symptoms and preventing complications.

When hallucinations or problems with thinking and memory are present early in the course of parkinsonism, particularly if these symptoms are present without being on medication for PD, the diagnosis of **dementia with Lewy bodies (DLB)** needs to be considered. This disease is a challenge to manage, because there is such a delicate balance between motor and cognitive symptoms: medications used to treat the motor symptoms (levodopa or other PD meds) tend to worsen hallucinations, and medications aimed at controlling hallucinations can drastically worsen movement. DLB is characterized by fluctuating levels of alertness, attention, and cognition. Hallucinations tend to be of a visual type, usually of people or animals, and are worse in the evening. Short-term memory tends to be better preserved

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than in Alzheimer's disease. Patients with DLB can benefit from medications such as donepezil and rivastigmine, which work to promote the brain chemical acetylcholine.

Secondary Causes of Parkinsonism

Drug-induced parkinsonism is most often caused by medications that block the brain chemical dopamine, which is necessary for regulating movement and many other brain functions. In Parkinson's disease, the cells that make dopamine in the brain die off too quickly, resulting in a dopamine shortage. In drug-induced parkinsonism, the brain is able to produce dopamine, but it is prevented from doing its job by the medications. Drugs that have this effect are anti-psychotics, used to treat psychiatric conditions such as schizophrenia, bipolar disorder, and severe depression, and anti-emetics like metoclopramide (Reglan), which are used to prevent nausea or improve digestion. Valproate, which is used for epilepsy or to prevent migraines, can also cause parkinsonism as can certain cardiac medications. If a patient has parkinsonism and is currently taking one of these medications, the medication should be tapered off gradually. Your neurologist can work with your other physicians to find an alternate medication that is less likely to cause these side effects. It can take several months for the effects of these drugs to wear off, so patience and close monitoring are important.

When your physician orders an MRI or CT scan of the brain, it is in part to exclude the possibility of **vascular parkinsonism**. In this condition, hardening of the arteries occurs in the brain and causes poor blood flow to the areas that control walking and movement. This will have the appearance of strokes on a brain scan, even though patients may not have a history of a discrete event that was recognized as a stroke. Vascular parkinsonism is also referred to as "lower-body parkinsonism" due to its tendency to cause prominent gait difficulties early in its course. This helps to distinguish it from typical PD.

Vascular parkinsonism may respond partially to treatment with levodopa, which should be used in conjunction with physical therapy. It also is important to prevent further vascular damage by treating high blood pressure, high cholesterol, and diabetes and by taking aspirin or clopidogrel (Plavix) to prevent blood clotting.

Normal pressure hydrocephalus

Normal pressure hydrocephalus (NPH) is another PD mimic that causes prominent problems with walking and can be seen on a brain scan. This condition does not produce tremor or muscle rigidity, but the gait disorder of NPH can sometimes be confused with Parkinson's disease. An MRI or CT will demonstrate dilation of the fluid-filled areas in the brain. A lumbar puncture is typically performed next. This allows the gait to be tested after removal of some of the fluid that surrounds the brain and spinal cord. If gait improves after this test, the patient is referred to a neurosurgeon for placement of a shunt to allow continuous drainage of the excess fluid. In addition to a gait disorder, NPH can cause incontinence and problems with thinking and memory. The gait symptoms are the main indication for treatment, however, as the other symptoms do not reliably improve with shunting.

Because PD is still a clinical diagnosis, meaning we do not have a test that can prove or disprove someone has it, we rely on clinical signs and symptoms, response to treatment, and how patients do over time to determine the most accurate diagnosis. It is always a good idea to discuss any unusual symptoms you have noticed or concerns you have with your doctor. The following websites are good resources for learning more about these and other movement disorders:

www.wemove.org

www.curepsp.org

www.pspeur.org

www.movementdisorders.org

TRIBUTES

The Wisconsin Chapter received gifts in memory and in honor of the following individuals from June through September 2010. The chapter gratefully accepts these gifts to support programs and activities, including this newsletter. We apologize for any errors or if we missed anyone.

IN MEMORY

Don Hermann

Orvil and Arlis Roetman

Michael Jackson

Madison Homebrewers & Tasters Guild

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Wendy and David Maas

Joseph Upright

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IN HONOR

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Farm & Fleet of Watertown

Cheryl Rykken

Marie Wilhelm

Eldred and Elaine Wilhelm

OTHER CONTRIBUTIONS

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Courage is not the towering oak that sees storms come and go; it is the fragile blossom that opens in the snow.

Alice Mackenzie Swain

GLOBAL QUILT

The Wisconsin Chapter APDA is proud to have participated in the collaborative effort that brought the Parkinson's Quilt to the 2nd World Parkinson Congress in Glasgow, Scotland. Check out the Facebook page at <http://www.facebook.com/ParkinsonsQuilt> (you don't have to be a member to view the quilt photos). The chapter panels are on Block 23.

FAMILY COOKBOOK

Ruth Keller is an avid recipe and cookbook collector as well as a fantastic cook . . . and several years ago, she was diagnosed with Parkinson's disease. As a tribute to Ruth, family and friends used those collections to put together a cookbook featuring over a thousand of their favorite recipes. The cookbook is available for a \$25 donation, and all proceeds will be donated to APDA.

A limited number of cookbooks is being printed. For more information, please contact Kris Dahmen at 608-523-4340 or ruthsrecipes@hotmail.com.

**Thank you to the sponsors of
our wine-tasting event**



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**St. Mary's
HOSPITAL**

Wisconsin Chapter APDA
P.O. Box 7513
Madison, WI 53707
608/229-7628
chapter@wchapterapda.org
www.wchapterapda.org

*Chapter meetings are held
the second Wednesday of the
month at 5:30 p.m. in Bistro B
at St. Mary's Hospital.*

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APDA Information & Referral Center

St. Mary's Hospital
700 South Park Street
Madison, WI 53715
608/229-7628
parkinson_assn@ssmhc.com

Efrain Perez, M.D.
Medical Advisor
Jessica Olejniczak
Coordinator

Newsletter Co-Editors

Jessica Olejniczak
Pamela Crapp

PARKINSON'S PERSPECTIVE

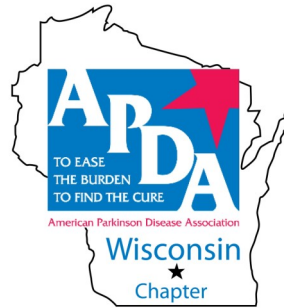
This newsletter is published three times a year for Parkinson's patients, their families, and caregivers by the APDA Information & Referral Center and the Wisconsin Chapter of the APDA.

If you no longer wish to receive the newsletter, please contact Jessica at 608/229-7628 or parkinson_assn@ssmhc.com.

The newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. Newsletter content is the sole responsibility of the editors.

INSIDE

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