

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson Disease

Spring is Here!

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Welcome to the March/April 2018 edition of Parkinson's Post! April is National Parkinson's Awareness Month which provides a great opportunity for each of us to reflect on Parkinson Disease (PD) and how it affects us individually; this month is also an opportune time to share our journey with others by educating them about PD and continuing our fight to enhance the quality of life of every individual affected by PD!

April is a very exciting time as I will be facilitating our FIRST monthly Parkinson's Disease Support Group at Nebraska Medicine/UNMC Campus on April 20th! The PD Support Group will be held every month on the THIRD Friday at 2 p.m. at the Fred & Pamela Buffett Cancer Center (the PD Support Group will also be available to anyone whom is unable to attend, but has access to a computer); ALL details can be found in "Upcoming Events" at the end of this newsletter. A curriculum will be outlined at the initial meeting and contain the upcoming topics and speakers for the remainder of the year. We will request an RSVP to assure we have adequate room size and seating availability.

In addition, April brings the FIRST Moving Day Omaha event on April 28th! This is a

very exciting event for ALL individuals who are affected by Parkinson's Disease to come together and be cohesive in our efforts to educate, inspire, and empower our PD community! Jane Ann Gorsky, Executive Director, Heartland Chapter, Parkinson's Foundation, has submitted an article in this newsletter outlining information and details regarding the walk! I will be the Friends and Family Team Chair and Volunteer Chair; please contact me with any questions or concerns and I look forward to meeting all of your TEAMS at the walk! ALL details can be found in "Upcoming Events" at the end of this newsletter.

The March/April 2018 edition includes a constellation of articles from Providers who are passionate about caring for individuals with PD. If there are any topics of interest that you would benefit from in future issues of Parkinson's Post, please don't hesitate to send an email with your request. At Nebraska Medicine/UNMC, we are so fortunate to have Experts from many academic and clinical disciplines that are dedicated to the education, research, and treatment of individuals with PD.



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Moving Day Omaha Furthers Local Parkinson's Awareness

Jane Ann Gorsky

Parkinson's Foundation | Executive Director | Heartland Chapter



"When you have Parkinson's Disease (PD) you have the choice to get involved and try to make a difference or let others do the work," Moving Day team captain Scott Rider said. "For me, the best way to do that was to help the Parkinson's Foundation through Moving Day, A Walk for Parkinson's." Because of Scott, and the one million people in the U.S. living with Parkinson's, the Parkinson's Foundation is expanding its Moving Day walk to 39 cities in 2018 and will be hosting

its first-ever Moving Day Omaha on April 28 in Stinson Park in Aksarben Village.

Moving Day Omaha gives the Nebraska community the chance to speak up about Parkinson's and move others to take action. The goal of Moving Day is to celebrate movement. Moving Day Omaha will host such activities as non-contact boxing, yoga and dance classes — all proven through a Parkinson's Foundation study to help manage PD symptoms — and will provide educational resources.

Funds raised through Moving Day Omaha go towards providing expert PD care and funding cutting-edge research, like the largest clinical study of Parkinson's in the world. Funds also help the Foundation

better serve the Nebraska PD community year-round, through free resources, such as Parkinson.org and the toll-free Helpline at 1-800-4PD-INFO, which has answered more than 230 calls from Nebraskans addressing PD questions, medical referrals or just providing support. Additionally, the Foundation has mailed more than 1,300 resources to Nebraskans and 160 Aware in Care hospitalization kits to help people with Parkinson's advocate for their best care.

Join us at Moving Day Omaha. Learn more or register your walk team at MovingDayOmaha.org.

Vision Changes and Parkinson's Disease

Stacy Reichmuth, OTR/L, CSRS

Occupational Therapist | Nebraska Medicine

Symptoms of Parkinson Disease (PD) are often associated with movement impairments of the arms and legs that affect walking, balance, and fine motor coordination. These symptoms ultimately effect activities of daily living, participation in work, and home management tasks. A less known fact is that PD can affect several aspects of vision including blurry vision, double vision, and impaired depth perception.

Eye Movements

Parkinson's may affect a person's ability to move their eyes. The first type of eye movement is called *saccadic eye movements* which are the rapid movements that are important during reading, scanning the grocery store shelf, and crossing the street. In PD, saccades tend to be slow and may show delayed initiation. Some people with PD may require a blink to change their eye position (called Wilson's sign). This makes it hard to fixate changing targets in the environment and makes reading difficult. At times, Levodopa-induced dyskinesia (abnormal voluntary movement) can cause saccades to become faster than normal however inefficient.

Pursuits are the eye movements that stabilize an object on our retina and follow it slowly through space. This skill is important during leisure tasks, eye-hand coordination, and driving. When impaired in PD, this can produce what is called cogwheel (jerky) slow eye movements.

Vergence directs the eye movements to come together to look at objects up close (convergence) or apart at a distance (divergence). This type of eye movement helps give us accurate depth perception. When vergence is impaired, this can result in eyestrain, headaches, and double vision.

External Eye Issues

Another eye health issue may be dry eyes. On average, the normal rate of blinking is 16-18 times per minute. However, with PD, this may decrease to one to two times per minute, which may lead to a foreign body sensation, blurred vision, itching and burning.

Visual Perception

Some people with PD may experience impaired *contrast sensitivity* or the ability to distinguish objects in dim light or with colors that are similar. This may present as difficulty reading fine print. Another type of impairment

might be *spatial orientation or depth perception* issues. This may affect the ability to gauge how far an object is when reaching or stepping. This may create problems during walking or driving.

What can you do?

The first step if you think you or your loved one with Parkinson's is affected by visual changes is to discuss your concerns with your physician that manages your PD symptoms. They can determine if the issues are caused by side effects of the medications you are on or if they are changes caused by the disease. There is an entire team of healthcare professionals that can help to address the issues including the neurologist, optometrist, neuro-optometrist, ophthalmologist, neuro-ophthalmologist, occupational therapist, and physical therapist. It is also important to maintain annual eye exams for general eye health.

Sleeping difficulties and Parkinson's Disease

Mara Seier, MD

Assistant Professor | Department of Neurological Sciences | Nebraska Medicine Movement Disorders Center

People with Parkinson's Disease often have difficulty with sleep. These sleep issues can disrupt quality sleep for not only the person with Parkinson's but also for a spouse or loved one who is sleeping in the same bed. The sleep-wake cycle is affected by the normal aging process and as we age the amount of time spent during sleep at night can change. The sleep requirement may be decreased in older people and often only an average of six and a half hours per night is needed. In addition, older people go to sleep and wake-up earlier than when they were younger.

The sleeping issues facing people with Parkinson's Disease commonly include waking frequently at night with difficulty getting back to sleep, daytime sleepiness with increased need for napping during the day, restless legs, vivid dreams or nightmares, leg movements or jerks, nighttime vocalizations and dream enactment. Dream enactment, also known as rapid eye movement sleep behavior disorder (RBD) is fairly common in Parkinson's Disease and is defined as loss of paralysis that normally occurs during rapid eye movement sleep, allowing the person to "act out" his or her dreams which can be vivid, intense, or even violent. This disorder can even pre-date the typical symptoms of Parkinson's Disease by many years. RBD can be disruptive to the sleep of a bed partner but can also potentially be harmful if movements cause injury to the person with Parkinson's. Lowering the bed, padded rails or padding the floor around the bed can be helpful in reducing risk of injury in RBD. Medications such as melatonin, which can be purchased over the counter, and clonazepam (Klonopin), which can be prescribed by your doctor, can be used to treat this disorder.

Sleep may also be disrupted by frequent nighttime urination, stiffness, cramping or difficulties turning over at night. Wearing off of medications that control Parkinson's symptoms can also disrupt sleep. Unrecognized or untreated depression and anxiety may also cause poor sleep or difficulty getting back to sleep. These above issues should be assessed and treated for prior to starting a sleeping agent as a bladder medication, adjustment of Parkinson's



medications or addition of an antidepressant may correct the sleeping issue.

Proper sleep "hygiene" is also important to practice and includes:

- Avoiding sleeping too much during the day
- Having a regular bedtime and wake-up time every day
- Taking activating medications (like selegiline) earlier in the day
- Decreasing fluids prior to bed to reduce trips to the bathroom
- Avoiding caffeine and alcohol - especially in the evenings. Alcohol can make you sleepy but actually fragments sleep later in the night.
- Making your sleep environment as restful as possible. A quiet room, minimal light, comfortable temperatures, and soothing music promote sleep. A warm bath prior to bed can help you relax. No "screen-time" in bed or just before bed as this can be very activating to your brain.
- Doing regular exercise but exercising immediately before bedtime is stimulating - so exercise should be done earlier in the day.
- If you lie awake for more than 30 minutes, get up and do something relaxing then re-try sleep later when you become tired.

If none of the above reasons seem to be contributing to the problem and sleep disturbance persists, discuss with your doctor about starting a sleep agent. Typically, I recommend starting melatonin. It is a hormone that is secreted in the normal brain when it gets dark and plays a role in regulating sleep. It has no significant short-term side effects and can be purchased over the counter. Start by using 2 mg and work up gradually to 12 mg. If sleep is improved at a certain dose, stop at that level. Your doctor can also prescribe medications for sleep - some include trazodone, mirtazapine or ramelteon. Medications like zolpidem (Ambien) should be used with caution and not long-term.

Cognitive Changes in Parkinson's Disease

Erica Schmidt, Ph.D., Allison Logemann, Psy.D., and Amelia Nelson, Ph.D., ABPP
Department of Neurological Sciences | University of Nebraska Medical Center



Cognitive changes are relatively common in individuals with Parkinson's Disease (PD) and can develop early. In fact, 25-30% of individuals exhibit mild cognitive changes at the time of diagnosis of PD. Like motor symptoms, there can be varying degrees of cognitive impairment.

When cognitive changes exceed what is expected from normal, age-related decline, but the individual is able to compensate and continue to function independently, then the term "mild cognitive impairment" (MCI) is used. When cognitive problems are more

severe, and they result in an inability to take care of oneself or independently complete activities in daily living (e.g., managing finances and medications, driving, etc.), then the term "dementia" is used. When the cognitive changes occur as a result of PD, healthcare professionals use the terms "mild cognitive impairment due to PD" (or "PD-MCI") and "Parkinson's Disease dementia" (or "PDD").

Parkinson's Disease may impact the following cognitive areas:

- Processing speed (e.g., thinking speed and response time may slow down)
- Working memory (e.g., difficulty holding information in mind in order to accomplish a goal/solve a problem)
- Cognitive flexibility (e.g., difficulty shifting rapidly between ideas or tasks)
- Visual-spatial abilities (e.g., difficulty perceiving relationships of objects in space)
- Learning/memory (e.g., difficulty learning new material and/or freely recalling it later)

There may be strategies that individuals with PD and their family/caregivers can use to compensate for cognitive difficulties. For example, for slowed processing speed, family/caregivers should present information slowly and with frequent pauses to allow the message to "sink in." To compensate for difficulty with memory recall, written notes and lists can provide hints/clues to help the individual with PD to retrieve previously learned information.

For individuals with PD who exhibit cognitive changes, a neuropsychological evaluation is often useful. The evaluation involves cognitive testing to 1) assess what changes have occurred, 2) determine what the cause(s) of the changes may be and what diagnosis (e.g., PD-MCI versus PDD) may be most accurate, and 3) assist patients/family in developing compensatory strategies to better cope on a daily basis.

Upcoming 2018 Events

Nebraska Medicine / UNMC Parkinson's Disease Support Group

April 20 | 2 p.m. (every third Friday)

Fred & Pamela Buffett Cancer Center, 505 S. 45th Street, Omaha, NE

After entering the front of the Fred & Pamela Cancer Center, take the elevators to 5th floor, and you will be directed to the appropriate meeting room. Available parking will be in GREEN PARKING, across the street from the Fred & Pamela Cancer Center – there also is a circle driveway in front of Cancer Center that can be utilized for dropping off and picking up.

If you are unable to attend the support group, but would like to watch the meeting from your computer, please utilize the following link to watch the meeting live:

http://www.unmc.edu/livevideo/unmc_live2.html

Please contact Julie Pavelka, Facilitator, with any questions/concerns and RSVP (by April 13): parkinson.network@nebraskamed.com

Parkinson's Moving Day Walk National Parkinson Foundation Heartland Chapter

April 28

9:00 a.m. Registration opens
10:30 a.m. Walk start time

Stinson Park in Aksarben Village
2285 S. 67th Street, Omaha, NE

For more information please visit <https://movingdaywalk.org/event/moving-day-omaha/> or www.parkinson.org/heartland

Or contact: Robyn Tota at 913-341-8828
or rtota@parkinson.org

Neuro-protection trials in Parkinson's Disease

Danish Bhatti, MD

Assistant Professor | Co-Director Comprehensive Parkinson Disease Clinic
Director, International Neurology Program | Associate Director, Movement Disorders Fellowship program
Department of Neurological Sciences | University of Nebraska Medical Center

The biggest efforts in Parkinson's Disease (PD) have been to figure out ways to slow down this condition and then down the road consider ways that will stop or even potentially reverse the progression of Parkinson's Disease. These efforts have been underway for more than 20 years starting as early as 1980s with attempt with vitamin E in high doses (DATATOP Study) along with selegiline a newly discovered agent at that point. Those efforts failed and vitamin E was found to be futile for any detectable improvement in slowing down Parkinson's Disease but a side outcome of that study was finding that selegiline may actually improve the future of PD patients suggesting some form of neuro protection or slowing down of the disease. This was followed by discovery of a newer compound rasagiline which was studied extensively to look for slowing down of the disease and came pretty close to being proven but did not make it completely through.

The idea of neuro protection is basically to prevent ongoing cell loss in part of the brain area of substantia nigra which correlates with loss of dopamine found to be the main cause of motor disability. This idea in itself is limited because now we know very well that the cell loss occurs in many other areas of the brain and dopamine is only part of the reason for complications and there is huge component of nonmotor symptoms that have been ignored in the past. However even in this limited area of Dopamine cell loss, we have not had provable achievement.

Parkinson's Disease comprehensive program at University of Nebraska Medical Center has always had a strong attention and focus at finding ways to prevent slowing of Parkinson's Disease i.e. neuro protection. We are currently involved with Parkinson's Study Group (PSG) in three large multicentre trials which are attempting to solve this problem with three different compounds as neuroprotective agents. These are phase three trials and there is decades of studies and evidence built up to get to study these compounds in phase three trial and there is good promise and a lot of hope from them.

The first of these is STEADY PD 3 or Safety, Tolerability and Efficacy Assessment of high

dose isradipine for early Parkinson's Disease a phase three double-blind placebo controlled study of Isradipine as a disease modifying agent in subjects with early Parkinson's Disease. This study has enrolled more than 300 newly diagnosed Parkinson's Disease patients never treated for PD with any medication and will look at their progression over the next two years.

Isradipine is a calcium channel blocker and like other calcium channel blockers has been used for blood pressure control and regulations in the past. What sets it apart is its ability to penetrate blood-brain barrier and crossover into the brain where it can affect calcium influx into the brain cells. Why would slowing down calcium intake into a brain cells is important? That is because the final common pathway in cell death involves influx of calcium that triggers the mechanisms that finally kill cells and if we can slow or delay that event from occurring we could probably save the cells for somewhat longer and slow down the loss of cells in the brain. The previous phase one and phase two studies with this drug and animal data is very strongly supportive. Use of a blood pressure medication Parkinson's Disease patient seems mostly safe although low blood pressure is unknown implication of Parkinson's Disease and will have to be understood better and watch for if this drug becomes successful. The patient's enrollment has been completed last year and the cohort is now being followed for the two years before the data will be fully analyzed and reported for final outcome. However interim analysis of the data are ongoing both for safety reasons and also for looking at efficacy and sometimes it does occur that a drug become so obviously useful that the study is prematurely stopped and reported however premature stopping of the study is also seen when the drug seems to be completely not useful or futile. Let us keep our fingers crossed.

Over the next few months we will be reviewing the other ongoing neuro-protection trials at University of Nebraska Medical Center before broadening the topic and discussing studies going elsewhere or designed for future for neuro protection.

What are Antioxidants?

Jenna Paseka, MS, RD, LMNT

Nutrition Therapist | Department of Neurological Sciences | Nebraska Medicine

"Antioxidants" are terms you might hear in the news being researched in various health conditions. But why are they important? The cells in our body undergo normal metabolic processes called oxidation that creates toxic by-products known as free radicals. Free radicals can also be triggered from environmental factors such as air pollution, radiation, cigarette smoke and sunlight. These free radicals can attack healthy cells and cause cell damage if not removed. This is where antioxidants come into play – antioxidants hunt down the free radicals to help prevent cellular damage and oxidative stress. Parkinson disease is associated with oxidative stress which can damage nerve cells that produce dopamine.

Antioxidants are found in a variety of foods including fruits, vegetables, nuts, grains and legumes. Here are some common antioxidants:

- Carotenoids (beta-carotene, lycopene and lutein)
 - Carrots, tomatoes, red peppers, squash, sweet potatoes, pumpkin, spinach, broccoli, Brussels sprouts and apricots
- Vitamin E
 - Vegetable oils, wheat germ, whole grains, seeds, nuts and peanut butter
- Vitamin C
 - Oranges, grapefruits, tangerines, kiwi, strawberries, cantaloupe, sweet peppers, tomatoes, broccoli, potatoes and cauliflower

Antioxidants can even be found in coffee, tea, red wine and dark chocolate! Overall, think about eating the rainbow – choose a variety of colors of fruits, vegetables and grains throughout the day. Aim to eat at least two cups of fruit and two and a half cups of vegetables daily to boost your antioxidant intake. Think about grabbing a handful of nuts instead of chips or cookies for a snack. Add some berries to your yogurt or cereal. Or put some spinach on your sandwich. I challenge you to incorporate three new foods high in antioxidants into your diet this month!

Caregiver Strategies – Reducing Personal Stress

Julie Pavelka, MS, APRN-NP

Memory and Movement Disorders | Department of Neurological Sciences | Nebraska Medicine



How we perceive and respond to any event is a significant factor in how we adjust and cope with it. The stress we feel is not only the result of your care giving situation but also the result of your perception of it — whether you see the glass as half-full or half-empty. It is important to remember that you are not alone in your experiences.

Your level of stress is influenced by many factors, including the following:

- Whether your care giving is voluntary. If you feel you had no choice in taking on the responsibilities, the chances are greater that you will experience strain, distress, and resentment.
- Your relationship with the care recipient. Sometimes people care for another with the hope of healing a relationship. If healing does not occur, you may feel regret and discouragement.
- Your coping abilities. How you coped with stress in the past predict how you will cope now. Identify your current coping strengths so that you can build on them.
- Your care giving situation. Some care giving situations are more stressful than others and this can differ from situation to situation.
- Whether or not support is available

“To the world you may be one person; but to one person you may be the world.” — Dr. Suess

Steps to Managing Stress:

- 1. Recognize warning signs early.** These might include irritability, sleep problems, and forgetfulness. Know your own warning signs and act to make changes. Do not wait until you are overwhelmed.
- 2. Identify sources of stress.** Ask yourself “what is causing stress for me?” Sources of stress might be that you have too much to do, family disagreements, feelings of inadequacy, or the inability to say no.
- 3. Identify what you can and cannot change.** Remember we can only change ourselves; we cannot change another person. When you try to change things over which you have no control, you will only increase your sense of frustration.
- 4. Take action.** Taking some action to reduce stress gives us back a sense of control. Stress reducers can be simple activities like walking and other forms of exercise, gardening, meditation, or having coffee with a friend. Identify some stress reducers at work for you.

Skate-A-Thon brings in more than \$20,000

Tom O'Connor

Senior Associate Director | Public Relations | University of Nebraska Medical Center



Thanks to unseasonably nice January weather, more than 600 skaters turned out for the eighth annual UNMC Skate-a-Thon for Parkinson's, as the 24-hour skating event concluded at 2 p.m. Saturday at the UNMC Ice Rink.

This marked the fourth consecutive year the event has topped 500 skaters, and the second straight year it has exceeded the 600 mark.

The event is held in memory of event founder Colleen Wuebben, who was diagnosed with Parkinson's in 2005 at the age of 52 and died in 2013 at the age of 60.

Jenny Knutson, daughter of Ted and Colleen Wuebben and one of the event coordinators, said preliminary estimates are that the event will top the \$20,000 mark. She said online proceeds, pledges for skaters, and corporate sponsorships are yet to be processed.

Over the past eight years, the UNMC Skate-a-Thon for Parkinson's has netted more than \$190,000 in proceeds.

Proceeds go toward clinical and basic science Parkinson's research at UNMC as well as Parkinson's Nebraska, an organization started by the Wuebben family to provide affordable exercise, education and services to improve quality of life for persons with Parkinson's.

"The weather was phenomenal," Knutson said. "It was obvious that everyone had a great time."

Five skaters — Chris Rush, Jim Janicki, Geoff Morris, Oscar Knutson and Ryan Cary — skated all 24 hours. This marked the fifth consecutive year that Rush has skated all 24 hours and the second straight year for Janicki. Gavin Ingram earned honorable mention recognition. In skating all 24 hours, it is estimated that each of the marathon skaters logged nearly 70 miles.

The top two Rock the Clock teams were LeaseTeam, Inc. (headed by Ryan Cary) and the Creighton Prep Hockey Team. Cross Fit Hydro earned honorable mention recognition.

UNMC physicians — John Bertoni, MD, PhD, and Howard Gendelman, MD — spoke at the opening ceremonies, while Danish Bhatti, MD, participated in the closing ceremonies.

Malorie Maddox, co-anchor for the WOWT (Ch. 6) evening newscasts, was the emcee for the opening ceremonies.



Montez, on-air personality from 2 – 7 p.m. weekdays on KISS-FM (96.1), emceed the closing ceremonies. He is a member of the Parkinson's Nebraska board.

Sponsors this year included: Heritage Communities, Abbvie Biopharmaceuticals, Hillcrest Health Services, Anderson Convenience Market, Masimore, Magnuson and Associates, PC, LeaseTeam Omaha, TD Ameritrade, Baer Foundation and Life Care Center of Elkhorn.

Reliable Parkinson Resources

NOTE: This list is not complete, nor is it endorsed by UNMC or Nebraska Medicine

American Parkinson Disease Association

www.apda.org

Davis Phinney Foundation for Parkinson's

www.davisphinneyfoundation.org

International Parkinson and Movement Disorders Society (WE MOVE)

www.movementdisorders.org

Michael J. Fox Foundation for Parkinson's Research

www.michaeljfox.org

Movement Disorder Society

www.movementdisorders.org

National Institute of Neurological Disorders and Stroke

www.ninds.nih.gov

National Parkinson Foundation

www.parkinson.org

Parkinson's Action Network

www.parkinsonaction.org

Parkinson's Foundation Heartland Chapter

www.parkinson.org/heartland

Parkinson's Nebraska

www.parkinsonsnebraska.org

Parkinson's Resource Organization

www.parkinsonsresource.org

The Parkinson Alliance

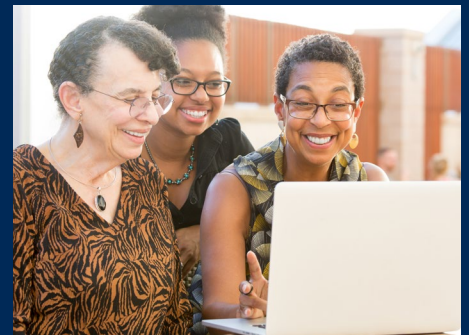
www.parkinsonalliance.org

The Parkinson's Disease Foundation

www.pdf.org

The Parkinson's Resource Organization

www.parkinsonsresource.org



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