

Parkinson's Post

to educate, inspire and empower individuals affected by Parkinson Disease

Welcome to the May/June 2018 edition of Parkinson's Post!

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The Spring season at Nebraska Medicine/ UNMC has been filled with adventure! We were Silver Sponsors for the Inaugural Parkinson's Moving Day OMAHA – A Walk for Parkinson's on Saturday, April 28 at Stinson Park in Aksarben Village. It was such a privilege for the Movement Disorder Team to have the opportunity to visit with so many members of our Parkinson's Community! The morning was fun-filled with entertainment, activities, food, exercise demonstrations, and of course walking! There are more details regarding Moving Day and photos of this awesome event later in the newsletter. We are looking so forward to Parkinson's Moving Day OMAHA April 27, 2019 and hope you will ALL join us!

The FIRST Parkinson Disease Support Group at Nebraska Medicine/UNMC was held on April 20th at the Fred & Pamela Buffett Cancer

Center; this meeting was an organizational meeting and had 6 members in attendance. Our second meeting was held May 18th and we quadrupled our attendance to 24 – Dr. Bhatti, 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 presented a very informative review of Parkinson Disease Research. We are looking forward to our next meeting June 15 when Nebraska Medicine Physical Therapy and Occupational Therapy will be our guests! Additional information regarding our support group is under UPCOMING EVENTS later in the newsletter. Anyone is welcome at this support group – we are encouraging RSVP's as we are quickly outgrowing our space and enough refreshments and materials/handouts available for everyone.

The May/June 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.



Inside this issue

- Exercise is Medicine
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Exercise is Medicine

Jennifer McKune, PT
Physical Therapist | Nebraska Medicine

Exercise is important for everyone. For an individual with Parkinson's disease, it is vital! Exercise is a key element to maintaining balance, functional mobility, and daily activities.

Exercise may have a neuroprotective effect, as well as improve neuroplasticity. In the brain, dopamine, which plays a role in starting movement, functions as a neurotransmitter. A neurotransmitter is a chemical released by nerve cells to send signals to other nerve cells. Exercise improves dopamine efficiency by modifying areas of the brain where dopamine signals are received. Exercise protects nerve cells that are at risk for damage, degeneration, or cell death. Another benefit is improvement in neuroplasticity—the brain's ability to discover new nerve cell connections. In other words, exercise helps the body and brain find new ways to move.

Any level of physical activity is beneficial; however, studies show that increasing physical activity to at least 2.5 hours/week can slow decline in quality of life. Exercise improves strength, gait, balance, tremor, flexibility, grip strength, motor coordination, and endurance. It is important to include a combination of aerobic exercise to improve fitness, walking to practice gait, and resistance training to strengthen your muscles. There are many forms of exercise



First Parkinson's Disease Support Group at Nebraska Medicine/UNMC

you may find to participate in: biking, running, Tai Chi, Yoga, Pilates, dance, weight training, non-contact boxing, group classes for Parkinson's disease, or physical therapy to learn a focused program specific to your needs. It is beneficial to perform random practice with activities. This may include changing the speed of movement, the direction, or varying the activity. Increase the intensity of your exercise for as long as you can and as often as you can.

Choosing to exercise gives you an active role in the management of your symptoms associated with Parkinson's disease. In

addition to the already mentioned benefits, exercise can positively affect mood and self-confidence, bone health, cognitive function, sleep, digestion and constipation, fatigue, rigidity and stiffness, and fine motor skills. The best way to see benefit from exercise is to exercise on a consistent basis. It is important to make exercise part of your regular routine. Sometimes it is helpful to make yourself an "appointment" for exercise. Put it on your calendar and make it something you commit to, just like you would a doctor's appointment. When taking your medications, remember that exercise is medicine!

Upcoming 2018 Events

Nebraska Medicine/UNMC Parkinson Disease Support Group Every Third Friday | 2pm

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

Speakers:

June 15
Nebraska Medicine Physical
Therapy and Occupational
Therapy

July 20
Dr. John Bertoni

August 17
Nebraska Medicine Nutrition
and Speech Therapy

September 21
Dr. Deigo Torres

October 19
Dr. Mara Seier

November 16
Dr. Magnuson

December 21
Holiday Party

After entering the front of the Fred & Pamela Buffett Cancer Center, take the elevators to 9th 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: parkinson.network@nebraskamed.com

UNMC's Mind Brain Health Registry:

A growing research resource for Parkinson's disease

David E. Warren, PhD

Assistant Professor | Department of Neurological Sciences | University of Nebraska Medical Center

Understanding how Parkinson's disease (PD) changes the brain, thought processes, and behavior through research is a key part of developing better treatments for PD. The PD community clearly understands this principle, but it isn't always clear how to contribute to research efforts. Meanwhile, researchers studying PD often face the other side of this challenge: how best to reach out to the PD community to share new research opportunities? Put another way, many people with PD — as well as their friends and family members — are interested in participating in research studying PD; many researchers who study PD are interested in recruiting people from nearby communities for their studies.

How best to match up these two groups?

UNMC's Mind Brain Health Registry (MBHR) provides a way for scientists studying PD and other disorders to contact community members who are interested in research opportunities. The Registry — sponsored by Dr. Matthew Rizzo, MD and administered by Dr. David E. Warren, PhD (both of UNMC's Department of Neurological Sciences) — collects information including demographic and health status when individuals are inducted, and that information is updated once per year afterward. The health and demographic information is stored in a secure database, and UNMC researchers can apply for access to the database in order to

receive contact information for people whose information matches the recruitment needs of new studies. Researchers can then reach out to interested individuals to share new research opportunities.

The Registry database already includes information from more than 400 community members and continues to grow rapidly. Greater enrollment from the PD community in the Registry will further expand the possibilities for research studying PD at UNMC. Registry enrollment is voluntary, there is no cost to enroll, and there is no commitment to participate in any research beyond the Registry itself.

For more information about the Mind Brain Health Registry, please visit www.unmc.edu/mbhl, email mbhl@unmc.edu, or call 402-559-6870.

Nutrition Tips

Jenna Paseka, MS, RD, LMNT

Nutrition Therapist | Department of Neurological Sciences | Nebraska Medicine

Not only does the month of May bring flowers, sunshine and warmer weather, it is also the time of year that fresh produce is available at local farmer's markets, grocery stores and roadside stands. Checking out the local produce available in your area will allow you to enjoy the best flavor and often save some money!

Here are types of produce in season throughout the year:

- **SPRING**

artichokes, asparagus, avocados, greens/lettuce, kohlrabi, herbs, peas, rhubarb, radishes, strawberries, turnips

- **SUMMER**

apples, apricots, avocados, beets, bell peppers, blackberries, blueberries, broccoli, cabbage, cantaloupe, carrots, cherries, cucumbers, eggplant, green beans, herbs, mangos, onions, peaches, peas, plums, potatoes, sweet corn, raspberries, strawberries, tomatoes

- **FALL**

apples, beets, Brussels sprouts, cabbage, carrots, cranberries, garlic, grapes, green beans, gourds, herbs, onions, peas, potatoes, pumpkins, squash, sweet corn, sweet potatoes, tomatoes, watermelon, zucchini

Buying locally allows you to get produce that was picked within the last day or two, typically at peak ripeness. Not only will the produce taste better, but also will provide optimal nutritional value. You may also find some unique items that you would not find in a large grocery store. Purchasing local produce will also support the local economy and family farms. Another added bonus is enjoying beautiful weather, getting some exercise in, and socializing with friends, family and community members! To find a farmer's market near you, go to <https://www.nebraska.gov/apps-ag-farmers-market/> for Nebraska listings or <https://www.idalsdata.org/fmnp/index.cfm?fuseaction=main.formFarmersMarketDirectory> for Iowa listings.



**Produce list adapted from <http://ourbesttoyou.nebraska.gov/consumers.html>*

Parkinson's Moving Day OMAHA: A Walk for Parkinson's

Jane Ann Gorsky

Executive Director | Parkinson's Foundation

Nebraska's first-ever Parkinson's Foundation Moving Day took place April 28 at Simpson Park, drawing more than 480 people with Parkinson's and their families and volunteers who raised \$65,332 to beat Parkinson's!

Moving Day would not be possible without its national sponsors: Abbvie, Adamas, Impax, Lundbeck, Medtronic, Right at Home, Sunovion and local sponsors: Life care Center of Elkhorn, Nebraska Medicine, Remington Heights Retirement, Tenaska, Union Pacific and US WorldMeds. Resource Pavilion vendors included: CHI Health at Home, ClearCaptions, Hillcrest Health Services, Home Care Assistance of Omaha, Home Nursing with a Heart, Parkinson's Nebraska, Rolling Hills Ranch Retirement and Way to Stay Homecare.

Funds raised through Moving Day Omaha will go towards better serving the Nebraska

Parkinson's disease (PD) community year-round by providing expert PD care through free resources, such as Parkinson.org, Aware in Care hospitalization kits, education books and the Parkinson's Foundation free Helpline at 1-800-4PD-INFO (473-4636), which has answered more than 230 calls from Nebraskans addressing PD questions, medical referrals and providing support.

Funds raised also help the Foundation continue cutting-edge research, like the Parkinson's Outcomes Project — the largest clinical study of Parkinson's in the world that drive expert care resources and programming.

Moving Day Omaha gives the Nebraska community the chance to raise Parkinson's awareness and move others to take action. Next year's Moving Day Omaha will take place at Simpson Park on April 27, 2019.



Give It "Heck" – H. Don Osborne TEAM



Give It "Heck" – H. Don Osborne TEAM

Top Moving Day Omaha fundraising teams and individuals:

Team	Amount	Team Captain
1. Give it "Heck" – H. Don Osborne	\$3,540	Connie King Osborne
2. Barada Brigade	\$3,430	Jennifer Barada
3. Nebraska Medicine/UNMC	\$2,875	Julie Pavelka
4. Walking for Ron	\$2,757	Cassie Krontz
5. Paul's Rangers	\$2,710	Debbie Kelly
6. Dopadestrians	\$1,810	Beth Broderick
7. Keep Moving On	\$1,540	Julie Black
8. Life Care Center of Elkhorn Fighting Parkinson's	\$1,515	Michelle Strecker
9. Union Pacific	\$1,335	Brian Salmon
10. Walk Don't Park	\$1,015	Dave Arneson
Individual	Amount	Team
1. Jennifer Barada	\$2,750	Barada Brigade
2. Cassie Krontz	\$1,472	Walking for Ron
3. Debbie Kelly	\$1,330	Paul's Rangers
4. Judy Upson	\$1,215	Walking for Ron
5. Brian Salmon	\$1,100	Union Pacific
6. Connie King Osborne	\$935	Give it "Heck" – H. Don Osborne
7. Megan Kelly	\$890	Paul's Rangers
8. Kris Shady	\$865	Dopadestrians
9. Shelley Fulton	\$785	Individual Walker
10. Rob Hills	\$725	Hill's Hopefuls



Barada Brigade TEAM



Parkinson's Moving Day OMAHA Planning Committee



Osborne TEAM



Union Pacific TEAM



Paul's Rangers TEAM



Walking For Ron TEAM



Walk Don't Park TEAM



Beginning of Parkinson's Moving Day OMAHA



Nebraska Medicine



Family



Dr. Torres with Volunteers



Cognitive Compensatory Strategies

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

As promised in the last newsletter, below is a table that outlines some of the cognitive compensatory strategies patients and their caregivers can use to help compensate for cognitive weaknesses or impairments that might develop in Parkinson's disease (PD). This is not an exhaustive list, and consultation with a neuropsychologist can provide more insight into implementing the most effective strategies given the patient's individual patterns of cognitive strengths and weaknesses.

Legend: • Defines the domain or skill » Shows an example

Cognitive Domains & Compensatory Strategies		
Cognitive Domain	Definition & Example Functions	Cognitive Compensatory Strategies
Processing Speed	<ul style="list-style-type: none"> Thinking speed and response time. <ul style="list-style-type: none"> » How quickly you "connect the dots." 	For patients: <ul style="list-style-type: none"> Establish social cues that signal others to slow down. Pace yourself and allow sufficient extra time when completing tasks or going somewhere to avoid feeling rushed. Go over new information multiple times, so you may pick up things you didn't catch the first time. For caregivers: <ul style="list-style-type: none"> Slow down in conversation to ensure everyone is following along.
Working Memory	<ul style="list-style-type: none"> Manipulating information in your mind in order to accomplish a goal or solve a problem. <ul style="list-style-type: none"> » Calculating a tip. » Planning your day. 	For patients: <ul style="list-style-type: none"> Use conversation techniques such as talking to one person at a time and ensuring eye contact. Write down information to give yourself a visual reference. For caregivers: <ul style="list-style-type: none"> Provide verbal cues when important information is shared. <ul style="list-style-type: none"> » "This is important... we have an appointment this afternoon."
Cognitive Flexibility	<ul style="list-style-type: none"> Moving quickly from one idea to the next and then back. Shifting between ideas or tasks. <ul style="list-style-type: none"> » Talking on the phone while cooking. » Thinking of many solutions to one problem. 	For caregivers: <ul style="list-style-type: none"> Starting, stopping, or maintaining a task may be difficult for patients with cognitive change related to PD. Don't assume the person is lazy, tired, or uninterested. Encourage and assist when possible. Cues, signals, or "heads-up" reminders that denote and end of or shifts in tasks may be helpful in alerting the person that the task demands are changing.
Visuospatial Abilities	<ul style="list-style-type: none"> Perceiving relationships of objects in space. <ul style="list-style-type: none"> » Perceiving the depth of the stairs. » Judging the distance to the curb. Driving is a complex visual task, and specific recommendations require a full work-up or consultation with your providers. 	<ul style="list-style-type: none"> Place brightly colored tape on the corners of rugs, tables, or step edges to provide cues and navigate safely. Reduce visual clutter to reduce confusion or overwhelm with the visual environment. <ul style="list-style-type: none"> » This means cleaning countertops, walk-ways, and living spaces. Establish visual scanning strategies <ul style="list-style-type: none"> » Start at the top of the cabinet and work left-to-right all the way to the bottom. Ensure adequate lighting.
Learning	<ul style="list-style-type: none"> Studying or practicing new information. Not just related to school! New learning also includes learning things from conversations, media, etc. 	<ul style="list-style-type: none"> Minimize distractors in the environment. <ul style="list-style-type: none"> » Turn off the TV when talking with others. Focus on one task at a time. <ul style="list-style-type: none"> » Pay bills, then watch a YouTube video – not at the same time. Repeat or rehearse information. <ul style="list-style-type: none"> » "It's nice to meet you (repeat new acquaintance's name here)!" Ask questions to ensure understanding. <ul style="list-style-type: none"> » "If I'm understanding correctly... (summarize what they said)." Takes notes, and review them regularly. <ul style="list-style-type: none"> » Take notes during a doctor's appointment, and review them with a family member.
Memory	<ul style="list-style-type: none"> Recalling information at a later time. "Memory" actually includes a huge amount of information, from what you had for breakfast this morning to your favorite animal when you were 5 years old. 	For patients: <ul style="list-style-type: none"> Use a memory notebook, daily planner, post-it notes, to-do lists, a calendar, or alarm reminders. <ul style="list-style-type: none"> » Set an alarm on your phone to prompt when it's time to take your medications. » Using a calendar or memory notebook will take some practice. Keep at it in order to learn this new skill to help your memory. Place it in a spot where you'll see it daily. Change your environment to help keep a consistent routine and places for small items. <ul style="list-style-type: none"> » Place a basket by the door for your keys. » Create a habit to put your purse in the same spot every time you get home. Label drawers, cabinet, dressers. For caregivers: <ul style="list-style-type: none"> Provide prompts or choices when the person is struggling to recall information.
General Strategies	<ul style="list-style-type: none"> Make use of preserved skills to compensate for impaired ones. This will be individually-based, and a neuropsychologist can guide you in this process. Caregivers, help direct the person toward tasks that best fit their abilities. If the task is too simple it may fail to capture their attention; if too complex, they may feel overwhelmed or frustrated. Keep a high-level of daily structure or routine. By keeping the same schedule, less mental energy is dedicated to dealing with changes, and more can be used in service of the task at hand. Schedules and routines can reduce confusion and frustration. 	

Can Uric acid save us from Parkinson 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

In this article, we will continue where we left off in the last newsletter in terms of research and neuroprotection in Parkinson's Disease. This article may be read separately but is a continuation of the theme of neuroprotection research in Parkinson's Disease.

Gout, the *unwalkable disease*, was first identified by Egyptians nearly 2,600 years BC, but the most famous reference is to the description by Hippocrates in the Fifth Century B.C. whose aphorism for Gout still hold true. Over the years, it has been referred to as the *disease of kings* because of its association with rich foods and alcohol consumption. The word gout comes from the Latin word 'gutta' and refers to the belief at that time that it results from a drop or flow into a joint of one of the four humours, causing pain and inflammation.

The disabling gouty arthritis of the British statesman William Pitt the elder, may have been a major factor in Britain's loss of the American colonies as it resulted in his absence from parliament during acts when levies and taxes were passed on British colonies and later on the tea imports. The birth of America and the American Constitution have also been affected by gout as Benjamin Franklin, Thomas Jefferson and a French nobleman Vergennes were all severely affected by gout, and who can forget the famous gout attack of John Hancock that delayed the ratification of the Constitution by Massachusetts.

Crystals of uric acid in the joints causing gout were seen as far back as 1679 but were only described to be made of uric acid by 1776. It's amazing that semi-quantitative method of measurement of uric acid in the serum or urine, the thread test, was the first-ever clinical chemical test to be designed in 1859.

But what is even more remarkable is that humans and primates (apes and monkeys) lost the ability of processing uric acid into something more soluble over the last 50 million years during the evolution as they gradually had changes in their genes and slowly lose the ability to process the uric acid into something more soluble, such as Allantoin. It's still a curiosity why we lost the

ability to process the uric acid into something that is less damaging and why we ended up with more uric acid in our system. One proposed hypothesis is that the ability to not process uric acid was somehow linked with increased ability to make fat from sugar. **But what I want to tell you today is that uric acid could have saved us from having more Parkinson's Disease, and let me tell you how.**

Uric acid is the final product during metabolism of the building blocks of genes, or DNA. The uric acid, a simple molecule, has been linked with benefits on protecting against hypertension and potentially even being an antioxidant. What we have observed in large-population studies looking at the risk of Parkinson's Disease is that the higher the uric acid levels in the blood the less likelihood that person belongs to a group with Parkinson's Disease. So, prospective epidemiological studies have shown that the higher rate of uric acid in the blood is associated with a reduced risk of getting Parkinson's Disease. The higher the level, the lower the risk. This has been confirmed through many large population studies including *health professional follow-up study*, *Honolulu Heart Program* and the *Rotterdam study*. It has also been shown that the diet that increases uric acid, the same linked with gout, is also linked with lower risk of Parkinson's Disease.

This observation that among healthy individuals a high uric acid level predicts a reduced risk of Parkinson's Disease have led to the hypothesis that among patients with the Parkinson's Disease a high uric acid will predict a slower rate of progression of Parkinson's Disease and will continue to provide the same protective benefits. To test this hypothesis, over the last 10 years a group of researchers have been looking at using high uric acid levels in various animal models of Parkinson's Disease and then led to forming the concept of the current study, **Sure PD3 (Study of URate Elevation in Parkinson's Disease)** to slow the progression of Parkinson's Disease. In this study, we will be taking Parkinson's Disease patients who have a low serum uric acid level, within



the normal range, which are likely half to two-thirds of PD population and we will give them a supplement called Inosine to be converted into uric acid resulting in elevation of serum uric acid level. We be following the uric acid levels so that we bring them up to high normal range without overshooting the maximum level expected from a normal person, and then we will follow them over the two years while keeping the uric acid levels elevated to see if that results in delayed or slower progression of Parkinson's Disease. This will be measured based on the rate of increase of their Unified Parkinson's Disease Rating Scale (UPDRS). We will compare between two groups with only one getting the supplement. However, bringing up the uric acid level is not without risks. Even when the uric acid level is within normal range it can cause uric acid stones in the kidney and attack of gout. However, there is a risk that the uric acid level could overshoot because of the supplement without frequent testing, and thus the Inosine supplement dose is frequently adjusted in the study.

We have currently enrolled all of the required patients (270) that were needed for the study and we will now be following them for the next two years to look at the outcome or benefits that we are expecting because of a high uric acid level. Currently, it is not established that taking uric acid levels would actually be beneficial and is only a presumption at this time. While the risks are real and the side effects such as kidney stones have been observed in the ongoing trials. Therefore, it is not clinically recommended to check your uric acid levels or to take supplements to increase levels because of the associated risks, which are definitive; and an unknown benefit, which may not be there.

Neurological Sciences
988440 Nebraska Medical Center
Omaha, NE 68198-8440

unmc.edu

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

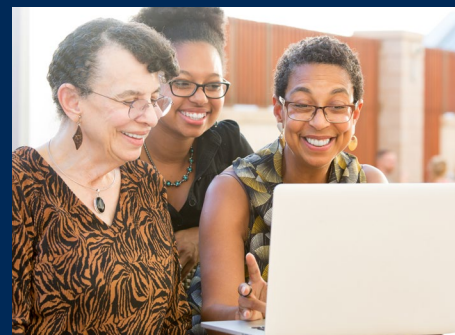
www.parkinsonalliance.org

The Parkinson's Disease Foundation

www.pdf.org

The Parkinson's Resource Organization

www.parkinsonsresource.org



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neurologicalsciences/
patient-care/programs/
movement-disorders](http://www.unmc.edu/neurologicalsciences/patient-care/programs/movement-disorders)

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