Winter 2019 Parkinson's Post!

Welcome to the Winter 2019 edition of Parkinson’s Post and first edition of 2019! Parkinson’s Post will be published four times (March, June, September, December) in 2019 to coincide with the seasons!

The Movement Disorder Team has been planning our upcoming symposium, Parkinson’s Disease in 2019: A Conference for Patients, Family, and Caregivers that is Monday, October 14, 2019 from 8 a.m. to 3:30 p.m. at the Embassy Suites and Conference Center, La Vista, Neb. The Symposium offers an excellent opportunity for all individuals affected by Parkinson’s to network with Parkinson Disease Experts; vendors representing treatments, products, and services specific to Parkinson Disease; and others who understand the daily struggles, battles, and triumphs that patients, families, and caregivers endure daily. The curriculum includes sessions presented by our Movement Disorder Team including our Physicians, Therapy Department (Physical, Occupational, and Speech) and Nutritionist. Our Keynote Speaker for our Symposium is Brian Grant who was an NBA idol, known for tenacious rebounding and a fearless attitude on the court. During his 12-year career, he played for five teams and became a strong contributor to his surrounding communities.

Today, Brian continues to inspire as a speaker, philanthropist, and a patient who insists on thriving with Parkinson’s disease. His mission is to help people become their best, even when it seems impossible. Brian started his career at Xavier University where he was Player of the Year twice for the Midwestern Collegiate Conference. He was drafted in the first round, eighth overall, in the 1994 NBA draft by the

cont. pg. 2
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This article is the first of a three part series to highlight the main macronutrients in our diets. The foods and some beverages we eat and drink consist of carbohydrates, fat and protein. Each macronutrient plays an important role in supplying energy for our bodies.

Carbohydrates make up the largest portion of calories in most diets and are our main energy source. The Dietary Reference Intakes and 2015-2020 Dietary Guidelines recommendations are to consume between 45-65% of calories from carbohydrates.

Carbohydrates supply energy to the brain, cells, tissues and organs.

Carbohydrates are broken down into two different types – simple and complex carbohydrates. Simple carbohydrates include sugars found naturally in foods and sugars added to foods. Simple carbohydrates are found naturally in fruits and milk, and also added into foods such as fruit canned in syrup, baked goods, candy, soda and sweetened yogurts. Complex carbohydrates are starches and take longer for the body to digest. These are typically higher in fiber and can help keep blood sugar levels steady. Whole grains such as barley, brown rice, buckwheat, bulgur, millet, oatmeal, popcorn, quinoa, whole wheat crackers, whole wheat flour and whole wheat pasta are complex carbohydrates. Other complex carbohydrates include vegetables, beans, lentils and sweet potatoes.

People with Parkinson’s disease can benefit from carbohydrate intake. Carbohydrates can help alleviate some of the side effects from medications like carbidopa-levodopa. Taking the medication with a carbohydrate such as fruit, crackers or toast can help manage the side effects while still allowing the medication to be effective.

As a general rule of thumb, choose less processed carbohydrate sources to maximize the fuel you can provide your body. Reading nutrition facts labels can also help guide your choices. Look for foods with a higher fiber content and ingredients that use the term “whole,” such as “whole wheat flour” as the first ingredient in bread. Avoid foods that have “sugar” as one of the first three ingredients.

Registration for the symposium will begin August 1 and will be completed on-line – registration process details will be in the next Parkinson’s Post published in June. There also are Sponsorship, Vendor, and Donor opportunities for the symposium available – contact Julie Pavelka for further details at parkinson.network@nebraskamed.com.
Impulse control disorders (ICDs) occur in 14-60% of Parkinson’s disease (PD) patients and are characterized by impulsive and compulsive behaviors. Impulsive behaviors refer to actions that a person cannot resist doing, with the behaviors providing an immediate feeling of pleasure or reward. Compulsive behaviors consist of an intense urge to carry out an action repetitively and in a very particular manner. The failure to resist engaging in these behaviors rises to the level of a disorder when it causes distress, impairs functional abilities, and / or reduces quality of life. ICDs can be time-consuming and often go unrecognized, only becoming obvious once they have wreaked havoc on the lives of patients and their families.

Examples of ICDs include gambling, excessive spending, sexual behaviors (e.g., hypersexuality, paraphilias), and binge eating, as well as less severe behaviors such as punding (i.e., stereotyped, repetitive, purposeless behaviors), hobbyism, aimless wandering, and hoarding. For some people, ICDs may be mild and / or just a minor annoyance (e.g., increased focus on eating sweets with a 10 lb. weight gain). For others, the impact is more severe (e.g., compulsive gambling to the point of bankruptcy). It is possible to have more than one ICD concurrently. Hypersexuality and gambling are more common in men and excessive spending and binge-eating behaviors are more common in women.

ICDs are related to the dopamine replacement therapy used to treat the motor symptoms of PD, particularly with dopamine agonists. Because individuals with PD have long-term exposure to dopamine replacement therapies, it is thought that some individuals develop hypersensitivity, which may cause a person to “overreact” to the medications. One common overreaction is dyskinesia, while another example of how the body overreacts to dopamine medication is ICDs.

Not every PD patient undergoing dopamine replacement therapy will develop ICDs. There appears to be specific clinical factors that may increase risk. These include younger age of PD onset, male gender, prior history of depression or substance abuse, family history of pathological gambling, novelty seeking personality, REM sleep behavior disorder, and higher rate of dyskinesia.

ICDs often start when dopaminergic medications are increased or when a second dopaminergic drug is added. Because of this, it is important for the treatment team to continue monitoring and screening for ICDs at follow-up visits, especially after dose changes. It is also important for caregivers and loved ones to communicate these ICD symptoms to the treatment team if the PD patient does not want to reveal that these behaviors are problematic.

If ICDs are suspected, working with your Movement Disorders specialist to lower dopaminergic medications is the first step. This can be challenging, as these medications are needed to treat the motor symptoms of PD. Stopping medications all together is not advised, though stopping or reducing the dose of the suspected medication that is causing the ICD symptoms often helps. If ICDs are occurring in you or a loved one, speak with your Movement Disorders specialist before making any medication changes yourself.

Behavioral management of symptoms is also important, as it can help to reduce the consequences of such behaviors. Taking away credit and bank cards, limiting bank account access, restricting internet access, and 12-step gambling programs are examples of behavioral techniques that may be helpful in minimizing ICDs. A referral for cognitive-behavioral therapy is another option to help reverse unwanted thoughts and behavioral patterns once dopaminergic medications have been reduced.
Home Modifications to Reduce Falls and Live Safely at Home with Parkinson’s Disease

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Falls are the leading cause of injury in people who are age 65 and older. One in four elderly individuals has at least one fall per year. Most falls are caused by a combination of risk factors. The more risk factors a person has, the greater their chances of falling. People with Parkinson’s disease are at increased risk for falls due to weakness, trouble with balance or walking, along with visual problems. Many falls can be prevented by simple modifications in the home.

General Principles
1. Remove clutter from floor and walkways.
2. Increase lighting especially in darkened areas.
3. Install grab bars where necessary.
4. Keep a phone near you or in your pocket in case you do fall.
5. Keep moving and exercising.

Bedroom and Living Area
» Arrange furniture so there is plenty of space between pieces. Remove furniture that is not necessary.
» Remove trip hazards such as throw rugs and cords. If you must use extension cords, they should be secured with tape.
» Try to buy chairs with armrests, straight backs and firm seats. This makes getting up and sitting down easier.
» Install sturdy handrails in the bedroom, living room, kitchen, bathroom, and in stairways where there is nothing to hold on to.
» Increase lighting in various parts of the house, including the bathroom and bedroom.

Bathroom
» Use an elevated toilet seat and/or grab bars that are securely fastened to the wall to make it easier to get off of the toilet.
DON’T use towel racks or bathroom tissue holders to help you stand because they may not be adequately fastened to the wall.
» Put grab bars inside and outside your bathtub or shower.
» A bathtub bench can be useful so you don’t have to sit in a tub or stand for long periods of time in the shower.
» Get rid of small bathroom mats that may cause you to trip.
» Clean up water and spills immediately to avoid slipping.

HOW CAN YOU REDUCE YOUR RISK OF FALLING?

EXERCISE
Find a program that challenges your balance, strength, and flexibility. Join a local fitness facility that you enjoy and meets your needs. Stay physically active!

REGULARLY REVIEW YOUR MEDICATIONS
Consult your doctor or pharmacist to make sure side effects of your medications aren’t increasing your risk of falling. Take medications only as prescribed.

CHECK YOUR VISION ANNUALLY
Your eyes are a big component of balance and keeping you on your feet. Get your vision checked annually and make sure to update your eyeglasses.

KEEP YOUR HOME SAFE
Remove tripping hazards, increase lighting throughout your home, and install grab bars in key areas.

WEAR QUALITY SHOES
Find shoes that fit your feet properly and have a non-slip sole. Avoid shoes with a tall heel. Slipping shoes can cause falls and lead to injury.

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Occupational Therapy for Parkinson’s disease and Driving

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Parkinson’s disease (PD) is a progressive neurodegenerative disease that affects movement and cognitive functions. These functions affected could potentially lead to impaired driving performance. Parkinson’s disease symptoms vary from mild to severe. Primary symptoms of Parkinson’s disease can interfere with driving. The most obvious symptoms include: tremor, rigidity, bradykinesia and postural instability. While less obvious symptoms include subtle visual deficits. Cognitive symptoms include impairments with thinking, language and problem-solving. Some people with PD may realize the severity of their symptoms and safety risks with driving and voluntarily limit or stop driving. But others may be unable to recognize their driving skills are significantly impaired and insist on driving despite the safety risk to themselves and others.

Parkinson’s disease symptoms vary from patient to patient and can worsen over time. Although there are medications that can reduce symptoms, some medications may have side effects such as dizziness or drowsiness. Understanding how these symptoms and side effects can affect driving is important. Episodes of tremor in the arm, hand, legs or trunk can affect the ability to control a steering wheel or operate other car controls like the gas and brake pedals. Rigidity can cause jerky motions while steering or limit flexibility for checking for blind spots. Bradykinesia or slow movement can affect your reaction time with braking in hazardous or emergency situations and in rush hour traffic. Postural instability can result in poor or stooped posture which can reduce your awareness to the environment or your surroundings and when checking blind spots.

Occupational therapy can work on treating the severity of these symptoms or slow the progression of symptoms to allow for that independence and freedom people take pride in, especially with driving. However, your doctor may recommend an occupational therapist (OT) who is a driving rehabilitation specialist to assess your driving performance skill using knowledge to recognize changes associated with your medical conditions and tailors evaluation and intervention plans to each individual. The OT will assess driving skills including but are not limited to: observation of blind spot, use of signals, braking/accelerating, lane positioning, spacing between vehicles and merging skills. An occupational therapist driving specialist will also assess your driving performance in terms of safety and detect any problems that could lead to accidents with an on the road test. Some driving behaviors an OT will also assess include but are not limited to: coordination, judging distance and space, ability to handle multiple tasks, any memory deficits, confusion or irritability and decreased information processing and making decision. All these skills are essential to ensure the safety of you as a driver and for the safety of others who you share the road with.

Some people with Parkinson’s disease may be able to continue to drive, but not indefinitely. Others may be given strict guidelines like driving only on familiar roads, driving only during daylight hours and in good weather. If the results of your driving evaluation indicate the need to stop driving, your OT can help you and your loved ones understand why it is important to do so. In addition, they can help identify transportation alternatives in your community. Your OT may suggest driving adaptations for those who present with minimal errors during testing. Discussions with your doctor and your state’s department of motor vehicles could be beneficial in easing the transition out of driving.
Greetings to all readers. This is the third of my contributions to this newsletter. Please go back to the articles in the previous newsletters if this is your first time reading this newsletter, as they may provide information and helpful hints that will not be included in today’s article. The symptoms addressed in this article will be movement problems of tremor, dystonia, and gait. Always discuss these problems with your neurologist, as adjustment of medications (or brain stimulation in some cases) may be needed. But you as the caregiver can also be of great assistance in assisting with these problems on an everyday basis.

1. Tremors and incoordination. These may interfere with activities of daily living. Have your PD person use big sweeping motions of hands and arms before attempting a task such as eating, writing, or buttoning. That sometimes helps reduce the tremors temporarily so they can complete the task. Even the person with less troublesome tremors will find it helpful before starting small motor tasks. My husband, although his tremors were minor, could no longer write his name legibly without the big motions first. Then it was quite legible and similar to his normal handwriting.

For assistance with eating, specially designed spoons and forks are available. My husband did not need these for eating, but he did need assistance with cutting meat because he no longer could hold the knife correctly and perform the appropriate motions needed to complete the task.

Participate in a LSVT BIG or similar program to help maintain coordination and effective large and small movements.

2. Dystonia. Dystonia is involuntary contraction of muscles of a part of the body, such as toes, so that there is twitching or spasm or twisting of a toe or limb. This was one of the first symptoms of PD that my husband had. In the beginning there were occasional hours at night when the twitching was bothersome, but in the last few months of his life, both his big toes were so “active”, as he called it, that he had difficulty sleeping. Dystonia can increase because of too little OR too much medication. It is often difficult to find the right balance. And illness or the stress of being hospitalized can exacerbate the problem. Work with your neurologist when this is worsening. Occasionally injections in the nerves of affected muscles may reduce the symptoms for a time.

3. Gait. People with PD do not recognize that their gait of leaning forward and taking small steps is abnormal, but cuing by a partner or caregiver can help normalize it. Remind to swing arms and stand taller and take big steps. Attend a BIG style program. Every day have your person cross the room several times in a certain number of big steps. All these will help keep the gait more normal. When my husband and I took walks, I sometimes had to cue (remind) him every few minutes but it definitely helped him to maintain a more normal gait and to prevent falling. He and I had talked about the need for cuing and agreed with necessity for cuing. I remember the first time I ever suggested he take big steps, when we were out at the mall several years after his diagnosis. He straightened up immediately and took off with normal strides, although to him they seemed like giant strides. I think he surprised himself as much as me. We laughed all the way down the hall.

Late in the PD progression, you may even need to cue individual movements, if the person is “stuck” in place. I will talk about this in a later newsletter.

Over and over we must remember that PD is not just a matter of the motor difficulties but of the brain figuring out the steps to do something, as it is no longer automatic. Medication, cuing, exercise, and various therapies all must be part of maintaining the PD person’s quality of life. And caregivers are in the middle of it all. We make a difference!

Best wishes to all caregivers.
Nebraska State Registry for PD

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Nebraska was the first state and still one of the only three states in U.S. which have a state mandated registry for Parkinson’s disease (PD).

This registry was established 20 years ago with work and efforts by the faculty of public health and movement disorders neurologist in Nebraska. This has accumulated a large amount of data over the last years of patients with PD through various sources. This included mandatory reporting by the physicians who have diagnosed patients and capturing data from various pharmacies across the state looking at prescribed medications typically used for PD and also other avenues such as patient self-reporting. Although a minimal amount of data set or information is collected for each patient. This data has been comprehensively maintained and updated annually over the last 20 years or so.

Even though data has been captured with minimal information is still highly useful and recently used to publish to very interesting articles. One of the study that we recently completed in collaboration with the College of Public Health at the University of Nebraska Medical Center (UNMC) and the Movement Disorders division at the department of neurological sciences. It looked at the most common comorbid conditions among PD patients seen between 2004 and 2012 in clinic and hospital. We looked for health problems are more common in patients with PD. This was done by linking the Nebraska Parkinson’s disease registry data along with another large database of hospital discharge information. We identified for comparison nearly 4,000 Parkinson’s patients who were hospitalized and compared them with nearly 19,000 non Parkinson’s patients who were discharged. Similarly, we identified 5,000 Parkinson’s patients and 26,000 non-Parkinson’s patients from the databases in outpatient setting to compare with each other during the eight years of review. We tried to match the two patient populations to be as comparable as possible by matching them with age at initial hospital admission or outpatient visit, gender distribution, county of residence using a random sampling method etc.

What we found out was that Parkinson’s patients who are hospitalized have more often dementia, mood disorders such as depression and anxiety, gastrointestinal disorders and urinary tract infection. We also noted that in outpatient PD had a higher risk of comorbidities of spondylosis or spine damage, genital urinary disorder, gastrointestinal disorder and dementia. This highlights that certain conditions are more prevalent in PD and certain diseases are much less frequent in Parkinson’s patients, most notable was the cardiovascular diseases or heart problems. One other study that was previously published compared the database of pesticide and insecticide purchase per county with the incidence and prevalence of Parkinson’s disease in that county from the state registry and found certain counties showed a clear higher risk of Parkinson’s disease who were also higher purchasers of pesticide and insecticide. We will be working on developing other such research ideas of comparing the Parkinson’s disease registry database with other large databases in Nebraska to find commonalities and patterns that are useful. Similar comparisons can be done with the state register of Parkinson’s disease whether such large registries such as Well water database of Nebraska, the distribution of minerals, the occupation distribution and so on and so forth. And in the future, as we enhance and improve the registry database with a much larger collection of information then a far more useful and detailed research projects will be possible using the state registry of Parkinson’s disease.

This registry is currently being updated to enhance the amount of data collection taking advantage of the resources available in electronic medical records so that a much more comprehensive amount of data is available on each patient added to the registry thus making it a far more powerful tool for providing research in Parkinson’s disease and making it much more effective. We are actively involved in this process to identify the appropriate data elements to be captured through electronic medical record to be added to this registry for good studies in the future.
The Mind & Brain Health Labs

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The Mind & Brain Health Labs (MBHL) is a multidisciplinary group of researchers who have expertise in medicine, cognitive science, human factors, driving research, public policy, computer science, statistics, biomechanics, and engineering. We use a broad range of tools to investigate and improve real-world mind and brain health, safety, quality of life, and mobility in individuals with diseases.

Our goal is to advance the use of personal vehicles and technologies to detect, monitor, and predict real-world safety in at-risk individuals. We believe that by improving understanding of driver safety in a range of medical populations, we can develop tools and technologies that can support and improve safety in individuals with diseases, including early detection of disease and potential cognitive decline. Our ultimate goal is to preserve mobility and quality of life for individuals with disease.

To date, we have run over 300 individuals who have a range of diseases and collected over 600,000 miles of real-world driver behavior data (Figure 1) that is linked with demographic, health, cognitive, and real-world physiologic and activity data from our drivers. Analyses of these data show promise to aid in the development of safety interventions, patient and caregiver education, policy, fair and accurate guidelines for clinicians, and the development of supportive in-vehicle technologies for at-risk drivers.

A particular interest in our research is developing techniques, methods, and technologies to improve mobility and quality of life in individual’s with Parkinson’s Disease. To accomplish this goal, we are conducting a novel, pilot study investigating how the effects of Parkinson’s Disease impact driving behavior and quality of life. Individuals with Parkinson’s are at-risk of driving cessation, which may lead to inactivity and social isolation. By determining how health, medication, and cognitive abilities link to safety critical driving behavior we are working to develop models to predict safety from vehicle and wearable sensor data (like Fitbits) so that we can develop interventions to improve driver safety and mobility in Parkinson’s.

A major goal of our lab is not just to conduct research that improves real-world outcomes in medical populations, but is also to support clinical translational research in the department and broader institution. In support of this goal, we have developed a growing registry with 500 individuals currently enrolled, with and without diseases, who are interested in participating in clinical translational research at UNMC. Our research depends on the collaboration of the community. We are grateful to all of our research participants for their commitment to helping participating in research that is working to improve mind and brain health, safety, and quality of life.

We’re excited to continue our research this year in projects. To read more about our research, please visit us at http://www.unmc.edu/mbhl/. If you are interested in working with our lab or participating in our research, please contact us at 402.559.6870 or mbhl@unmc.edu.

Figure 1. We have collected driving data on individuals with a range of functional abilities that spans the United States.
UNMC Skate-a-thon for Parkinson’s brings in more than $20,000
More than 500 skaters participate in 24-hour event

In spite of a wide range of weather that included temperatures of near zero wind chills and four hours of snow, more than 500 skaters turned out for 9th annual UNMC Skate-a-thon for Parkinson’s, as the 24-hour skating event concluded at 2 p.m. this afternoon at the University of Nebraska Medical Center Ice Rink.

This marked the fifth consecutive year the event has topped 500 skaters. 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 once again top the $20,000 mark. She said online proceeds, pledges for skaters, and corporate sponsorships are yet to be processed.

With this year’s total, the UNMC Skate-a-thon for Parkinson’s has now netted more than $210,000 in proceeds during its nine years at the UNMC Ice Rink.

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 snow arrived around 2:15 a.m. on Saturday and lasted for about four hours, Knutson said. The skaters who had committed to skating all 24 hours continued throughout the snow. They helped broom the snow off the ice along with members of an adult hockey team known as Menace to Sobriety.

“It was just crazy,” said Knutson. “The snow was beautiful at first, then it got rather annoying. It just kept coming. It was grueling for all the skaters.”

Five skaters – Chris Rush, Oscar Knutson, Ryan Cary, Tyler Cary and Jenny Knutson – skated all 24 hours. This marked the fifth consecutive year that Rush has skated all 24 hours and the second straight year for Oscar Knutson and Ryan Cary. In skating all 24 hours, it is estimated that each of the marathon skaters logged nearly 70 miles.

The leading fundraising team was LTi Technology Solutions (headed by Ryan Cary). The team raised more than $4,200 in donations.

The Creighton Prep High School hockey team, the Omaha Junior Lancers and several adult hockey club teams participated in this year’s skate-a-thon.

A huge throng of skaters was on the ice for the closing hour on Saturday as temperatures crept into the 30s to provide skaters with some relief from the roller coaster weather experienced over the 24 hours.

UNMC physicians – John Bertoni, M.D., Ph.D., and Howard Gendelman, M.D. – spoke at the opening ceremonies, while Diego Torres-Russotto, M.D., participated in the closing ceremonies. Longtime UNMC faculty member, Jeff Baldwin, Pharm.D., who just retired this month after a 45-year career in the UNMC College of Pharmacy, was recognized at the opening ceremonies. He has been battling Parkinson’s disease since 2013.

Damian Montez, co-host of the weekday morning show on KGOR-FM (99.9), was the emcee for the opening ceremonies. He was joined by his partner, Shari Stone, for the closing ceremonies on Saturday afternoon. Montez and Shari are on the air from 5:30 to 10 a.m. Montez is a member of the Parkinson’s Nebraska board.

Sponsors this year included: Anderson Convenience Market; Project Advocates; Masimore, Magnuson, & Associates, PC; Acadia Pharmaceuticals; Heritage Communities; LTi Technology Solutions; and Lundbeck Pharmaceutical Company.
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

Parkinson’s Action Network
www.parkinsonaction.org

Parkinson’s Foundation
www.parkinson.org

Parkinson’s Foundation Heartland Chapter
www.parkinson.org/heartland

Parkinson’s Nebraska
www.parkinsonsnbraska.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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