Welcome to the July/August 2018 edition of Parkinson’s Post! Summer has been very busy for our Movement Disorder Team – we have attended and presented at multiple PD Support Groups including Adams, NE; Norfolk, NE; and North Platte, NE. In addition, our Nebraska Medicine/UNMC PD Support Group has continued to grow – in fact, we have outgrown our original meeting room and will continue our monthly meetings in a larger room to accommodate our future meetings. In June, we were fortunate to have Nebraska Medicine Physical Therapist (Jennifer McKune, PT) and Occupational Therapist (Narmean Pedawi, OTR,L) presented on specifics of exercise and provided strategies that are beneficial to prevent falls and improve safety. In July, Dr. Bertoni, Professor, Director of Parkinson’s Disease Department of Neurological Sciences University of Nebraska Medical Center, and Co-Director Nebraska Medicine Comprehensive Parkinson Disease Clinic, provided a very informative presentation/question and answer session entitled “Overview of Parkinson’s Disease Management.”

We are looking forward to our next meeting August 17th when Nebraska Medicine Nutrition Therapy and Speech 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 to ensure enough materials/handouts and refreshments available for everyone.

The July/August 2018 edition of Parkinson’s Post 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.
Loss of Appetite – What Can Help?

Jenna Paseka, MS, RD, LMNT  
Nutrition Therapist | Neurological Sciences Department | Nebraska Medicine

People with Parkinson’s disease may experience a loss of appetite at various times throughout the stages of PD. A loss of appetite may lead to inadequate intake and nutrient deficiencies. Unintentional weight loss can also occur. Lacking proper nutrition may then impact other areas of life including having poor energy levels, muscle wasting, difficulties with walking and balance and a weakened immune system.

Appetite can be affected if experiencing changes in your sense of taste and smell, nausea from medications, constipation, swallowing issues or depression, all of which are common in PD.

Try these tips if you notice your appetite declining:

1. Eat smaller, more frequent meals. Shift your routine to having breakfast, a mid-morning snack, lunch, a mid-afternoon snack, dinner and an evening snack before bedtime instead of eating three large meals. Set an alarm to remind yourself to eat.

2. Choose energy-dense foods. Things like nuts, peanut butter, dried fruit, cheese, butter, oils, mayonnaise, salad dressings, heavy cream, and avocados can add more calories to your meals without adding a lot of volume.

3. Use spices, seasonings and condiments to make food taste more appealing.

4. Drink the majority of your fluids between meals. Avoid filling up on liquids during meals and snacks.

5. Be active. Exercise can actually stimulate appetite. Just be sure to eat an extra snack on the days you are exercising.

6. Talk to your doctor about any underlying digestive or health issues. Seek treatment for nausea, constipation, difficulty swallowing or depression.

Rock Steady Boxing – Fighting Back Against Parkinson Disease!

Cheri Prince, DPT, DOR  
Physical Therapist | Director of Rehabilitation Services | Life Care Center of Elkhorn

“Think Big, Move Strong, Never Quit”!! One of my favorite “Bring It In” Chants that we use at Rock Steady Boxing (RSB) Omaha at Life Care Center of Elkhorn. We “bring it in” to a huddle as a group of boxers, volunteers, coaches and corner men at the end of every class and chant something loud and uplifting. It promotes camaraderie, loud voices and power and that’s what RSB is all about.

Rock Steady Boxing for Parkinson’s enables persons with Parkinson Disease to fight back against their disease through non-contact boxing inspired fitness classes that provide encouragement through a “tough love” approach inspiring maximum effort, speed, strength, balance and flexibility. Most recent studies about exercise and Parkinson Disease indicate that “forced use” exercise or exercise that is intense and makes you work harder than you might on your own is the most beneficial for PwPD and exercise right now is the only treatment that actually may be “neuro-protective,” working to slow the progression of your disease.

RSB began in 2006 in Indianapolis and now they have over 500 affiliates around the world. We became an affiliate in December of 2015 and started holding classes in February 2016.

We have two RSB coaches and utilize volunteers to provide assistance and encouragement. While each workout is different, all parallel a boxers training program. We condition for optimal agility, speed, muscular endurance, accuracy, hand-eye coordination, footwork and overall strength. Each workout includes a warm-up, a “get to know you” time to work on voicing and socialization, a circuit based or station approach to strengthening, agility, balance and core strengthening utilizing boxing techniques and boxing equipment. This is followed by a cool down and of course a Bring It in Huddle.

The workouts can be adapted to meet your needs and stage of PD and a brief assessment will be completed at the time of the first class. Classes are offered on Mondays and Wednesdays from 4 – 5 p.m. at Life Care Center of Elkhorn and we will be adding additional classes in September. No reservation is required and the first class is always free.

For more information contact Cheri Prince at 402-779-3521.
Relationship between Parkinson Disease and Melanoma

Julie Pavelka, MS, APRN-NP
Memory and Movement Disorders | Department of Neurological Sciences | Nebraska Medicine

Research demonstrates that people with Parkinson Disease (PD) have an increased risk of developing melanoma (type of skin cancer that develops from melanocytes), and melanoma patients have a higher risk of developing PD. The relationship between Melanoma and PD occurs both ways – specifically PD patients are 4 times more likely to develop melanoma, and melanoma patients have a 4 times risk of developing PD. However, despite these statistics, it’s essential to know that many PD patients will NOT develop melanoma and many melanoma patients will NOT develop PD.

The exact relationship between PD and melanoma is still a mystery; researchers have suggested many reasons for this association, including social-environmental factors, immune system irregularities, and genetics. PD and melanoma are each independently associated with family history – a person’s risk of melanoma increases if someone in their family has also experienced melanoma, and a person’s risk of PD increases (slightly) if they have a family history of PD. In addition, a family history of one of these conditions (PD or melanoma) may also impact your likelihood of being diagnosed with the other; research demonstrates that people with a family history of melanoma (in a first degree relative) have twice the risk for developing PD.

Both PD and melanoma are associated with melanin (the pigment that colors your hair, skin, and eyes). PD occurs because of the death of dopamine-producing cells (which are high in melanin), while melanoma results from the overproduction of melanin-producing cells. Although these changes are different (PD results from the loss of cells, while melanoma results from the overproduction of cells), both conditions result from melanin-related abnormalities which leads some researchers to believe that the same genetic abnormality affects both PD and melanoma patients.

PD patients should have routine screenings (every 12 months) by their Primary Care Provider or Dermatologist. Individuals affected with PD should also take appropriate steps to minimize their risk of developing melanoma. Primary prevention focuses on reducing and limiting exposure to UV radiation. This includes UV from sunlight and artificial sources, such as tanning beds. Following and combining the guidelines below will greatly reduce your risk of developing melanoma.

Follow these tips:

- Use a sunscreen that provides broad spectrum protection from both UVA and UVB rays and has a sun protection factor (SPF) of at least 30.
- Generously apply sunscreen to all exposed skin year round and including cloudy days.
- Use approximately one ounce of sunscreen and apply it approximately 15 minutes before sun exposure - then reapply every two hours and after swimming or sweating.
- Sunscreen is just one component of sun safety – remember, just because you’re wearing sunscreen, doesn’t mean you can spend unlimited time in the sun.
- Wear protective clothing (wear a long sleeved shirt, pants, a wide-brimmed hat and sunglasses when possible).
- Remember that the sun’s rays are the strongest between 10am and 4pm (seek shade when possible).
- Use extra caution near reflective environments – water, snow and sand reflect and magnify the damaging rays of the sun, increasing your chance of sunburn.
- Do not burn – severe sunburns, especially during childhood, increase your risk of developing melanoma and other skin cancer. Just one blistering sunburn can double your chances of developing melanoma later in life.
- Avoid intentional tanning and indoor tanning beds – current research indicates there is no way to get a tan through ultraviolet exposure without increasing the risk for skin cancer.
- Get plenty of Vitamin D – replace vitamin D safely through a healthy diet that includes vitamin supplements if recommended by your doctor – don’t seek the sun.
- Be aware of your medications - certain prescription medications and over-the-counter drugs can increase your skin’s sensitivity to sunlight.

Melanoma is a common form of skin cancer and appears to be linked with Parkinson’s disease.
RAD-PD: Registry for the Advancement of DBS for 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

RAD-PD is a collaborative Quality Improvement Research Project, a form of health services effectiveness research that intends to generate a huge amount of information from patients receiving deep brain stimulation surgery for Parkinson’s disease in a systematic goal driven process across multiple institutes. Collection of such a large data set will provide insights into treatment patterns and related outcomes.

What we know about the use of Deep Brain simulation surgery comes from a handful of trials. Designing a trial is important to prove the effectiveness of a treatment. But the same time it is very limited in its scope. Only a few dozen or a few hundred patients are enrolled in a trial at best. If you take all the patients in various randomized deep brain stimulation surgery trials so far together you will hardly reach a number of 1000 patients probably much less than that.

However nearly 150,000 patients have received deep brain stimulation surgery since the approval of this therapy which means that a huge amount of information available in a real clinical care setting has been lost. It’s lost for various reason. it’s lost because not all places collect the information in a searchable manner and not collect the same type of information. And there is no standardized or central way of collecting and sorting such the information.

These days we are realize the importance of practice base research, where information collected during routine clinical care is considered valuable research information. We’re always learning from our patients no matter what we are doing and sometimes the lessons learned in real clinical care are far more useful and appropriate than what we learn from a research setting. Which brings me to this quality improvement project. I think it’s a huge deal. We intend to collect a far larger amount of data from a really big number of patients much bigger than any of the largest DBS trials.

This project is being done in collaboration with Michael J. Fox Foundation which is the primary source of funding and has been organized by a group of researchers called Parkinson’s Study Group. The top notch researchers in the field of Parkinson’s disease are members of this elite research group. The trial intends to involve 10 universities in the first year and then add another 10 universities in its second year. University of Nebraska Medical Center was one of the 40 applicants to be selected as the first tier for this prestigious and highly important trial and we were successful in winning a position in the top 10. The project launch is expected later in summer 2018.

We intend to achieve the following three goals with RAD-PD. 1) Identifying the best practices surrounding DBS therapy. Who are the right patients? What are the factors we need to consider before, during and after surgery? What is the best management? 2) We intend to identify the adverse events and factors that determine those adverse events with the DBS therapy including surgical and post-operative complications, long term device therapy, hospitalizations and even death. 3) Health economics and disparities. We want to understand the economics of healthcare delivery in DBS therapy and what disparities exist among various groups of population. We also want to look at differences and similarities in motor and non-motor outcomes. Treatment costs and quality of life improvement with this therapy.

I have talked to my patients whenever selecting the DBS surgery about the side effects and I tell them about the risk of bleeding in the brain that could lead to death. But we have no way of finding out who among the surgical candidates will be at risk for any particular side effect. Hopefully with this data being collected we will be able to answer that important question.

The data will be collected in coordination with a central data collection site or repository that will coordinate with all the sites to store data in a central location. The data will be accessible by all investigators immediately but in the near future we intend to make the data available to all researchers in Parkinson’s disease. We don’t want data to be locked away as a treasure.

We expect to have a large number of the patient population in this study. Our estimates are that by the end of first year we’ll have more than 150 patients in this registry. By the end of second year, the number will go up to 450 or higher and by the end of the third year we expect to enroll nearly 790 patients into this registry. These are estimates of course and the numbers could be higher or lower than this. But in this five year long project we expect to have more than a thousand number of patients enrolled with providing very useful information in a coordinated manner.

What kind of data will we gather? We will gather all kinds of data, Demographics and social outcomes both patient and physician reported, Parkinson’s disease history, medical and surgical interventions, operative procedures and post op complications, effects on motor function and non-motor symptoms, effect on quality of care, cost of surgeries, and healthcare economics.

The data is being collected as part of the routine ongoing clinical care of the patients. Patients are not being offered DBS for the study specifically but as part of their routine clinical care. A lot of what we are gathering has already been collected at multiple sites in different forms and shapes. The main change that we would be collecting a more uniform data and importantly collecting this data in a uniform fashion in a central secure location where the data can be accessible for all to start seeing trends which are hard to see at smaller scale.

I’m really excited about the study and I’m sure we will learn many useful lessons from this study over the next two to three years. Stay tuned for the results.
Caregiving Strategies – Setting Goals and Seeking Solutions

Julie Pavelka, MS, APRN-NP
Memory and Movement Disorders | Department of Neurological Sciences | Nebraska Medicine

In previous issues of Parkinson’s Post, we have discussed strategies and tools for caregivers to utilize when providing care for individuals with PD including effects of caregiving on the health and well-being of the caregiver and reducing personal stressors. This newsletter will focus on setting goals and seeking solutions for caregivers.

Setting goals or deciding what you would like to accomplish in the next three to six months (keep time frame of goal short and attainable) is an important tool for taking care of yourself. Goals are generally too big to work on all at once – our success for reaching a goal is more realistic when we break it down into smaller action steps. Examples of goals may include:

• Engage in activities that will make you feel healthier
• Take a break from caregiving (seek family, friends, or in-home companion to come into your environment and care for your loved one)
• Obtain assistance with caregiving tasks like bathing and preparing meals

After you have set your goals, proceed with identifying your action steps. For example, if your goal is to “feel healthier,” your possible action steps could be:

1. Make an appointment for a physical check up
2. Take a half hour break once during the week
3. Walk three times a week for 10 minutes

Seeking solutions to difficult situations is one of the most important tools in caregiving. Once you’ve identified a problem, taking action to solve it can change the situation and also change your attitude to a more positive one.

Steps for Seeking Solutions:

1. Identify the problem – look at the situation with an open mind – the real problem may not be the first thing that comes to your mind. For example, you may think the problem is that you are tired all of the time, however, the more basic difficulty is your belief that “nobody can care for my loved one as well as I can.” With this example, the problem is actually “thinking that you have to do everything yourself.”

2. List possible solutions – try a different perspective. For example, “even though someone else provides help to my loved one in a different way than I do, it can be just as good.”

3. From your list of solutions to your problem, select ONE solution and proceed with it.

4. After you have completed the solution, it’s essential to evaluate the results and determine how well your solution worked.

5. Try a second solution or fine tune the first solution if it didn’t work.

6. UTILIZE RESOURCES – discuss with family, friends, your health care providers.

7. Concentrate on keeping an open mind, not feeling defeated and stuck, while continuing to identify and experiment with other solutions.

“If ever there is tomorrow when we’re not together... There is something you must always remember. You are braver than you believe, stronger than you seem, and smarter than you think. But the most important things is, even if we’re apart... I’ll always be with you.” — Christopher Robin in Winnie the Pooh

Upcoming 2018 Events

OMAHA
(Caregivers Support Group)
Third Monday every month
10 a.m.
Hillcrest Health Services
The Grand Lodge
Hillcrest Country Estates
6021 Grand Lodge Avenue
Papillion, NE

For any questions or concerns, please contact Dr. Anna Fisher, Facilitator at 402-682-4272

Nebraska Medicine/UNMC Parkinson Disease Support Group
Every Third Friday | 2 p.m.
Fred & Pamela Buffett Cancer Center, 505 S. 45th St, Omaha, NE

Speakers:

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, walk to the left of the registration desk and you will be directed to the appropriate meeting room which is on the MAIN FLOOR (Conference Room 0.12.103). Available parking will be in GREEN PARKING, across the street from the Fred & Pamela Buffett Cancer Center – there also is a circle driveway in front of the 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
EXCITING NEWS!!!

Parkinson Disease Specific Home Exercise Classes have Arrived!

Georgie Kuhl, PWR!Moves Certified Instructor, Dance for PD instructor, Dance Teacher, and Group Fitness Instructor.

Those of you who would love to participate in a group exercise class from the ease and comfort of your own home-your time is NOW!! We are very excited to announce the roll out of PD TELE-FITNESS classes.

What is a TELE-FITNESS class? It’s a technology driven format (internet access required) that allows participants to INTERACT with each other LIVE in the moment, via a mobile device. You can SEE and TALK to everyone who is participating in the class. Do you have a last minute change in your schedule? No problem! You can access the class at your convenience via the tele-fitness class library located on the web!

Not computer savvy? We will set up a time to personally walk you thru the set-up. We assist you in downloading an app to your mobile device (app is free). We provide you with a code that allows access to the live class. Yes, it really is that SIMPLE!

PD TELE-FITNESS classes are offered with the support of Daryl Kucera, founder and owner of MS (Multiple Sclerosis) Forward Gym located at 13530 Discovery Drive, Omaha. Daryl was diagnosed with MS in 2001. He opened MSforward in 2010. He can personally attest to the need for physical exercise to combat the potentially damaging effects of the disease. Daryl has been using tele-fitness classes to reach people with MS across the United States who want and need group exercise classes but are unable due to common challenges. These include lack of transportation, weather extremes “too cold” “too hot”, low energy level “too much effort to get dressed and drive to class and then work out”, or health issues that result in being homebound. Any of these challenges sound familiar? We recognize many of the same needs and challenges exist among MS and PD folks. Daryl has offered an opportunity to collaborate with his team and expand tele-fitness classes to the PD community-“Why not work together to deliver the best options possible?”

"Music and Movement" will be the first tele-fitness class offered. Moving to the beat of music helps each of us move with more fluidity, larger range of motion, increased effort, and it’s more FUN! This class combines two internationally recognized PD movement programs into one sixty minute work out. The two programs are Dance for PD and PWR!Moves. Following is a very brief overview of each.

Dance for PD uses some of the basic concepts of dance-rhythm, movement, artistry, creativity and connecting movements, to assist the body in handling some of the challenges of PD-i.e. stiffness, tremors, shuffling, small movements, imbalance and depression, to name a few.

PWR! (Parkinson Wellness Recovery) Moves is a research-based, neuroplasticity-principled way to move. There are four foundational movements targeted for everyday mobility - getting up and down, weight shifting, reaching and twisting, and transition steps.

Georgie Kuhl is the "Music and Movement" tele-class instructor. Georgie currently teaches PD specific exercise classes in the Omaha/Bellevue area. She is a PWR!Moves Certified Instructor, Dance for PD instructor, Dance Teacher, and Group Fitness Instructor.

There is a free pilot class July 26. Class begins Thursday August 2, 3 – 4 p.m. This is a weekly class. Pre-registration is required.

For more information, registration, cost details, or questions, contact Georgie Kuhl at 402-502-2407 | mspdstrong@gmail.com
The group you know (& love!) from UNMC’s Annual Skate-a-Thon for Parkinson’s is busy at work to bring the local Parkinson’s community together for another unforgettable event (this time though—you can leave your snow boots at home!). Parkinson’s Nebraska is a small and locally based 501c3 organization that is dedicated to connecting Nebraskans who are along the journey of Parkinson’s disease with important resources like information, educational programs, specialized exercise classes and support. Parkinson’s Nebraska is pleased to present the Walk & Run the Park for Parkinson’s—featuring the 1st Annual “Shake-a-Leg 5K!” This family-friendly event will take over Elmwood Park in Omaha on Sunday, September 30 from 9 – 11:30 a.m..

Walk & Run the Park for Parkinson’s will bring the community together by offering something for everyone: a 1 mile loop through Elmwood Park is a great work out (or a leisurely stroll) for walkers, activities for the kids with plenty of space to run around, entertaining performances featuring groups from the LOCAL Parkinson’s Community, awesome t-shirts, and a delightful picnic brunch sponsored by Anderson Convenience Market. After the success of last year’s Walk, Parkinson’s Nebraska has decided to add a 5K run to the event to engage Omaha’s active running community. Locally owned Peak Performance is lending its expertise to offer runners of all ages and abilities a professionally timed 5K *(3.1 miles)* course through scenic Elmwood Park!

Speaking of bringing people together — Nothing brings the family together around the TV like NBC’s American Ninja Warrior. For the Parkinson’s community, 2017 and 2018 contestant Jimmy Choi was an instant fan favorite. His pure athleticism and indomitable spirit inspires others living with Parkinson’s to find the courage to push past their own perceived limits. Parkinson’s Nebraska is excited to announce that American Ninja Warrior Jimmy Choi is showing up in spirit for the Walk & Run the Park for Parkinson’s by leading the pack of “Virtual Runners.” Follow Jimmy Choi on social media to see him in action and to learn more about his journey.

Facebook: https://www.facebook.com/jcfoxninja/
Instagram: https://www.instagram.com/jcfoxninja/

Katrina Wulf, Parkinson’s Nebraska’s Administrator and Event Director shares her hopes for the event, “We want to make sure that Walk and Run the Park is a fun day for community to come together to relax and enjoy themselves. We would love for this event to become a tradition that families look forward to each year.”

Online registration is open! Go to: https://runsignup.com/Race/NE/Omaha/WalkandRuntheParkforParkinsonsNE before September 13th to reserve your t-shirt and to take advantage of the Early Bird Registration pricing.

Can’t make it to the event? Be there in spirit! Join American Ninja Warrior Jimmy Choi by registering as a “Virtual Participant.” Virtual Participants registered before September 26th will be sent an official Shake-a-Leg 5K Race Bib. Virtual Participants are encouraged to Walk or Run on their own and to share pictures of the journey via social media.

Bringing people together is what Parkinson’s Nebraska does best. Parkinson’s Nebraska has recently helped to get a group of people with a lot in common together in the same room. “Movin’ On” is an Omaha-based support group specifically for people who have been diagnosed with Parkinson’s (of all ages) and for those living with Young Onset Parkinson’s. “Movin’ On” offers a safe environment for people who are newly diagnosed to be welcomed to the community by others who can relate to the overwhelming feelings that can accompany diagnosis—because they have been in the same shoes. The group also offers a comradery for members who are living with the unique challenges of Young Onset Parkinson’s Disease. The group meets monthly and members stay in touch between meetings to support and encourage one another. “Movin’ On” founder, Katie Domayer, says that the group is good for the spirit and helps member’s combat feelings of loneliness and isolation. “We are all in the same boat and try to make sure everyone is staying positive. We have adopted the saying, ‘Make this your best day ever!’.” For more information about “Movin’ On”, please contact the group’s designated “Welcome Wagon”, Katie Domayer: domayer65@gmail.com, 402 551-0602

Parkinson’s Nebraska is HERE to help. Visit www.parkinsonsnebraska.org to get connected with local resources, and to subscribe to the monthly newsletter to stay up to date with community events. For more information on Parkinson’s Nebraska’s services, please contact Katrina Wulf: info@parkinsonsnebraska.org, 402 715-4707
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

To download a copy of the Parkinson’s Post newsletter, please visit:

www.unmc.edu/neurologicalsciences/patient-care/programs/movement-disorders