Welcome to the Spring 2020 edition of Parkinson’s Post!

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Despite being one month into “Spring 2020,” it’s finally “feeling” like Spring with some warmer weather, green grass and trees, and flowers blooming! However, this year has been far from our “normal Spring” or anything else for that matter. During this unprecedented time of the COVID-19 pandemic, it has forced many of us to change our comfortable “normal” routine into a new “normal.” As Parkinson’s disease (PD) patients, family, and caregivers, you are already accustomed to taking one day at a time, acclimating to managing whatever comes your way, figuring out strategies to solve the current problem, adapting to your life with PD, and navigating a new “normal.” You are used to challenges that many others do not understand, and you strive to continuously make your life the best it can be. You are all constantly training for “unknowns” and this is just one more hurdle for you to overcome. As a Parkinson’s Community, we will be stronger, more cohesive, and resilient!

April is Parkinson’s Awareness Month and due to the circumstances, the PD community activities have changed to virtual events. Also encouraging us to a new “normal” and to become more computer savvy so we can participate! At the end of this newsletter, please review all available opportunities for Virtual Events included in the Upcoming Events section. I encourage each of you to continue to educate anyone you encounter about PD! We will continue to navigate this journey together as PD is just a bump in our road - we will not allow it to define us!

We will restart our Nebraska Medicine/UNMC PD Support Group beginning May 15 and it will continue virtually via ZOOM only. Our PD Support Group has a new link for ZOOM as we now require registration. If you will be accessing – please utilize the following registration link:

https://unmc.zoom.us/meeting/register/uZElfu6srjwuovUY26qT6nk3BKrZlUg

We recently created a Facebook page and group - both are titled “Nebraska Parkinson’s Community.” I encourage each of you to “Like” our page and “Join” our group.

Stay updated with all COVID-19 recommendations as they change frequently, and it is essential that you are knowledgeable and complaint with the guidelines. Please utilize reliable internet sites including our link at Nebraska Medicine nebraskamed.com/patients/covid19 and the Centers for Disease Control and Prevention (CDC) cdc.gov.

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Anxiety Management

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Given what is going on in the world with the COVID-19 pandemic, we are constantly flooded with information about health, sickness, and death. It is easy to feel overwhelmed by this situation and to also feel like one has lost control.

According to the American Psychological Association (APA), there is a fine line between stress and anxiety.

- Both stress and anxiety share the same emotional and physical symptoms, such as feelings of nervousness or tension, increased blood pressure, sweating, thinking difficulties, and loss of sleep.
- Stress is typically caused by an external trigger, such as a deadline at work or fight with a loved one, and subsides once the situation has been resolved.
- Anxiety is internal and relates to one’s specific reaction to stress. It is characterized by persistent and excessive worry or dread that will not go away even in the absence of a stressor.

Research shows that up to 40 percent of patients with Parkinson’s disease (PD) have some degree of anxiety (Dissanayaka et al., 2010). In addition to life stress, individuals with PD may experience anxiety as part of the disease process due to chemical changes in the brain. Anxiety can fluctuate throughout the day coinciding with dopamine levels and is experienced most acutely during OFF periods (American Parkinson Disease Association, 2019). If the latter is occurring, make sure to speak to your Movement Disorder specialist about this.

Given the current COVID-19 pandemic, many people are reporting increased stress and anxiety. Layering this on top of a chronic medical condition, such as PD, can increase stress and anxiety beyond normal levels. Increased stress and anxiety can also worsen PD symptoms, so learning to manage stress and anxiety is particularly important during this very tense time.
Behavioral Management of Anxiety

While the strategies below are not a magic bullet, regular and consistent practice of stress and anxiety management strategies can help you to feel more in control and thereby reduce symptoms.

- Set limits appropriately and say no to requests that would create excessive stress in your life.
- Do not rely on alcohol or drugs for stress relief.
- Establish daily routines
  - Go to bed and wake up at around the same time each day
  - Schedule times to have meals
  - Develop an exercise regimen (under the guidance of your physician)
- Stay connected to family and friends (online or via the phone)
  - Schedule time in your day to connect with others
- Take a break from the non-stop news coverage on COVID-19 and:
  - Enjoy a good book
  - Watch a fun TV show or movie
  - Listen to music
  - Get outside and enjoy nature – of course at the appropriate social distance
  - Walk and / or play with your pets
  - Discover a new hobby
  - Cook a new and different meal
  - Clean and organize your house, car, garage, etc.
- Focus on what you can change and have control over:
  - Stop and breathe
  - Figure out what is bothering you
  - Focus on something less anxiety provoking.
- Practice Grounding:
  - Name 5 things you can see
  - Name 4 things you can touch
  - Name 3 things you can hear
  - Name 2 things you can smell
  - Name 1 thing you like or enjoy
- Get on YouTube on your computer, phone, or tablet and search for videos on:
  - Diaphragmatic breathing
  - Progressive muscle relaxation
  - Guided imagery
  - Meditation
- Download and explore apps that focus on guided breathing and challenging automatic negative thoughts:
  - Self-Help for Anxiety Management (SAM)
  - Sanvello
  - Calm

If your anxiety becomes problematic and is interfering with your ability to function in daily life, it is worth talking to your Movement Disorder specialist and/or a mental health professional, such as a psychologist or psychiatrist, to address your symptoms.
Carbidopa-levodopa intestinal gel (DUOPA) Therapy for PD

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In this article, I will start by explaining some of the challenges faced by Parkinson’s disease (PD) patients with moderate to advanced PD. Next, I will explain how an intestinal delivery of the medication can help ameliorate these problems. I will describe the procedure, the expected benefits, and the complications of the procedure.

The cornerstone for PD medications for most patients is carbidopa-levodopa. When the medication is working, most of the motor symptoms, including the tremor, stiffness and slowness improve. This beneficial time is called the ON time. When the medication stops working, the symptoms return, and that period is called the ‘OFF’ time.

It is important to talk a little bit about the absorption of levodopa. After the oral tablets are ingested, the pills stay in the stomach for some time, until the stomach empties and pushes them to the small intestine. The pills cannot be absorbed while they are in the stomach. Unfortunately, the stomach motility is slow in many patients of PD. The result is that the pills keep on staying inside the stomach for long periods where they cannot be absorbed. To the patient, it seems as if they did not take the pills at all. This is the basis for the so-called dose failures.

Early in the disease, the ON times are long and the Off periods are short, meaning that a twice a day or thrice a day dosing of carbidopa-levodopa is sufficient to keep the patient in an ON state during most of the waking time. As the disease progresses, the ON periods become progressively short. Moreover, the response to each dose also becomes inconsistent. Sometimes the dose works prominently and effectively but other times it does not. These inconsistent and sub-optimal responses along with the aforementioned dose failures are called motor fluctuations.

The other complication of advanced disease is that, the same dose that used to provide benefit and would be tolerated easily, now produces involuntary ‘wiggly’ movements called dyskinesia. A mild dyskinesia is usually not bothersome to the patient but a moderate to severe dyskinesia can be very troublesome and can be harmful to the patient, as it can actually cause falls and injuries.

The goal of PD therapy is to keep the patient either ON without dyskinesia, or ON with non-troublesome dyskinesia (the middle two states, shown in Figure 1). The logical way to achieve this is by taking the medications more frequently, because of the early wearing off, and by keeping each of the doses smaller, to avoid dyskinesia. Another option is to use ‘booster’ medications that prolong or increase the effect of the carbidopa-levodopa. Many patients can be satisfactorily managed by using these strategies, but others require doses so frequent and dose so small that a continuous administration is required. The carbidopa-levodopa intestinal gel (DUOPA) does just that. It delivers the drug (levodopa) by giving small boluses every minute, so that the patient gets a continuous supply without peaks and troughs.

It requires a stomach tube to be placed by a gastroenterologist. An upper GI endoscopy is performed to identify the exact spot on the abdomen right over the stomach. A small hole is made, and a gastrostomy tube is inserted. The inner end of the tube is advanced through the stomach and into the small intestine (jejunum), the part where the levodopa is absorbed. Once the tube is in place, it is secured, and the person is discharged home the same day.

Initiation of the DUOPA therapy is usually performed a few days later in the clinic. How many doses that need to be programmed into the pump depends upon how much the patient was taking before. Similar to the oral medications, too little a dose does not produce enough benefits and too much of a dose causes dyskinesia. Once an appropriate dose is found and programmed into the pump, the patient is discharged home.

The medication (carbidopa-levodopa intestinal gel) is dispensed in cassettes that have to be stored in a refrigerator. Every morning, the patient or their caregivers hook up the pump and load a new cassette containing the drug. Then, they press the ‘Morning Dose’ button. This delivers the prescribed amount to the patient and they usually notice a kick-in in 10-15 minutes. Then, for the rest of the day, usually for 16 hours, they receive a ‘Continuous Dose’ that delivers small doses every minute. An adequately programmed pump gives the patient enough benefit to stay ‘On’ during the day and does not produce dyskinesia.

As most of the patients with PD say, they have ‘good days’ and ‘bad days’ with regards to their PD. If, the DUOPA patient is having a ‘bad day’ and feels like some extra medication can help, they have the option to use an ‘Extra dose’ by pressing a button on the machine. However, there is a time lock (which is usually two hours) before they can use another extra dose. This has been built into the pump, so that the person does not keep on hitting the extra dose button.

Figure 1: States in which a PD patient can be, with regards to medications. The medication dose is increasing from left to right. Patients usually prefer to be in the middle two states.
more often. If they feel that they need the extra dose all the time, then the rate of the continuous dose probably needs to be increased. This will lower the need for the extra doses.

Managing the pump is fairly straightforward for the patient and their caregivers. In the beginning, the patients usually find it cumbersome to carry the weight of the pump, but there are many good options of various vests and corsets designed to make this as comfortable as possible. Most patients get used to this. After a days’ dose is completed and right after they unhook the pump, they need to flush the stomach tube with water, so that the remaining medication inside the tubing dose not clog it up. Whatever medication is left in the cassette at the end of the day needs to be discarded and a new cassette is used the next day.

Most of the complications are related to the procedure of placing the stomach tube itself. There is a risk of infection as with most procedures. Some people feel bloating and diarrhea, but this is usually transient. Once the wound has healed, most patients tolerate having a stomach tube well. It is important to remember that the whole process is reversible. Meaning that if for whatever reason, it is decided to terminate the DUOPA therapy, the tube can be pulled out and the wound is stitched with no residual side effects.

A few words about the comparison of DUOPA with other advanced therapies in PD. Deep brain stimulation (DBS) is also a very effective therapy for PD. Scenarios in which DUOPA may be preferred over DBS are when the patient cannot or does not want to get brain surgery, and in cases with dementia. DUOPA is still safe in such patients. It should be emphasized that the symptoms that do not respond to oral levodopa will not respond to the intestinal levodopa, because it is after all, the same medication. But since the effects of stomach motility are bypassed and the medication is delivered right where it is absorbed, the benefit is more consistent and reliable.

In conclusion, when motor fluctuations and/or dyskinesia start interfering with the quality of life in PD, it is time to consider the advanced treatment options. DUOPA is a powerful and effective option for moderate to advanced PD.

Distanced but not Disrupted!

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This is an unprecedented time for everyone!

We are all figuring out a new way of living under physical distancing guidelines. For many, this means no longer attending support groups or going to exercise classes at the local fitness center. Others may no longer be going to in-person therapy appointments. Staying home feels isolating and can lead to lack of motivation for normal activities, including exercise. Engaging in a personal exercise program at home is vital to your well-being, not just to manage symptoms related to Parkinson’s disease, but to ensure a healthy mind, body and spirit.

Many resources are available for exercise at home. Some clinics, including Nebraska Medicine, have telehealth services available to maintain continuity of care. There are online options for participating in exercise classes as well. Two good websites for a variety of online exercise ideas and videos include:

1. apdaparkinson.org/article/online-exercise-classes-and-resources
2. parkinsonsnebraska.org/online-exercises

If you have recently been to physical or occupational therapy or participated in PWR! (Parkinson’s Wellness Recovery) or LSVT BIG, continue to do your home exercises! A Homework Helper video is available for purchase through LSVT Global (www.lsvtglobal.com) or Amazon to help guide you through the LSVT BIG maximum daily exercises. Many PWR! Moves are available on YouTube. Perhaps you have attended a Rock Steady Boxing or Delay the Disease Exercise class, connect with fellow gym-goers through a Zoom call and do exercises together! Yoga is another great exercise option. Yoga provides physical and emotional benefits while practicing posture positions, breathing, and meditation. Having body-mind connection and staying present in the moment is so important and can increase feelings of well-being. If you are able to safely exercise outdoors, go for a walk or bike ride. As the weather gets warmer, begin doing yard work, mow the grass, plant flowers, or do gardening. Breathe in the fresh air and get some sunshine! Keep moving! Keep exercising!

Remember that physical distancing does not have to mean social isolation. We are fortunate to live in a time where technology can keep us connected. Prevent disruption of your exercise routine by utilizing online options for exercise classes. Connect with friends and family through phone calls or text, set-up a zoom call or do a FaceTime visit, schedule an exercise session with a friend or create an exercise challenge and check-in with each other on your progress. Be safe, stay healthy, maintain your distance but do not become disrupted or discouraged!
Speech Therapy and Home Practice during the Pandemic

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Staying motivated with your speech therapy goals while practicing social distancing and spending more time at home can be a challenge. However, there are ways to use this to your advantage to continue progressing towards your goals. The simple modification of activities in your daily routine is a great place to start.

In addition to home programs, your speech language pathologist (SLP) might also provide telemedicine services. This means that speech therapy evaluation and treatment may be available through your home computer. Through easy to use video conferencing applications such as Webex or Zoom, you can meet with your SLP as opposed to coming into the clinic and risking additional exposure during this pandemic. Research has shown that this type of therapy can be just as effective as face-to-face therapy. In her recent article, Elizabeth Grillo (2019) noted, “no difference in [Lee Silverman Voice Treatment LSVT-LOUD] treatment outcomes across in person and telepractice methods” for patients with Parkinson disease. Similar findings were discovered across patients with a variety of other voice disorders as well. Additionally, LSVT-LOUD has a computer software program called the LSVT Companion which is available for purchase. This software guides you through your daily practice, provides visual feedback, and tracks your progress. For more information, please visit https://www.lsvtglobal.com/store/IdaHomeLSVT?filter=LSVT+Client+Edition

Before diving in, it is important to consult with your SLP to establish a home program. Daily home practice is crucial for both maintenance and progress. Additionally, home practice allows you to work in your natural environment but also may present additional challenges not encountered in face-to-face sessions with your SLP. The environment in the clinic with your SLP is set up to be conducive to success. It is quiet with little background noise, few distractions, and you have an SLP providing suggestions to guide you towards more consistent successful speech productions. On the contrary, your home environment may be full of distractions such as the television or your family members bustling about the house. However, practicing in this environment can be used to your advantage as this is most likely the environment in which you speak the most often, being both beneficial and functional.

Get creative with your home practice and try to incorporate natural activities that occur in your daily routine, in a natural environment, and with primary communication partners. Most communication can be used as practice if you are focusing on your goals and monitoring your progress. Several suggestions for practice activities are listed below. Alter them to fit your needs and discuss them with your SLP to set specific goals (a targeted loudness level, for example).

Track Your Progress

When getting creative about your home practice, it is important to consider a variety of factors, regardless of the activity. Firstly, it is important to track your progress to assess efficacy. I recommend recording your practice sessions with a cellular telephone app, such as “Voice Memos” (https://apps.apple.com/us/app/voice-memos/id1069512134). Doing this allows you to listen to your speech and track progress, assess successes and areas that could have used more attention, and improve self-awareness of your voice and speech production. If you have already completed the LSVT-LOUD program, consider downloading a sound level meter app, such as “Decibel: dB sound level meter” (https://apps.apple.com/us/app/decibel-db-sound-level-meter/id1227650795), on your phone to monitor loudness while completing your exercises or any other practice activities. This
gives you additional feedback for when you are meeting your target loudness, which was previously established with your SLP. Measure 50cm distance from your mouth to the microphone, to ensure consistent loudness measurements.

Additionally, involve your primary communication partner (spouse, friend, or other family member) whenever possible. This will provide additional feedback from a listener who knows you and your voice well. This also provides functional practice in a more natural communication environment. To go a step further, write tick marks on a piece of paper for each time your conversation partner asks you to repeat yourself. Set a goal for your next conversation with how many requests are made for repetition, and decrease this number over time. For example, your first conversation you might have been asked to repeat yourself 10 times. Make your goal for the next conversation eight times, and when you meet that goal, decrease the number again.

Reading Aloud

Use your daily reading as an opportunity to practice. Reading aloud is less difficult than conversational speech, because it doesn’t require you to simultaneously formulate your message. Try reading news articles, e-mails, books, recipes, or anything you read as part of your daily routine.

Social Distancing & LSVT-LOUD

These activities, allow you to simultaneously practice increasing your loudness while implementing social distancing. Encourage an increase in volume by sitting farther from your conversation partner. Being a farther distance way, naturally encourages an increase in loudness to ensure your conversation partner can hear you. This is a strategy I frequently use in face-to-face sessions. Additionally, practice using your loud voice while speaking on the telephone or video chatting with your friends and family. Speaking on the phone or computer on speaker, encourages louder volume to ensure that we are heard.

Adding Background Noise

Practice in the presence of background noise to increase difficulty and encourage natural increase in loudness. For example, speaking while sitting on your porch or during a walk outside. The outdoors naturally has higher levels of background noise, requiring you to speak louder to be heard. Or perhaps try playing music in the background while you enjoy meals and conversation at home with your family.

Conclusion

A few simple modifications can incorporate speech therapy practice into your daily routine. Practice in your natural environment with your primary communication partner, and track your progress to monitor improvements. Don’t forget to include your SLP in your home practice and progress towards your goals. Speech language pathology services are also available via telemedicine and current research is showing promising support for this therapy delivery method. These services are currently being offered at the Munroe-Meyer Institute at UNMC.

Please contact 402.559.6460 for more information.

Skate-a-Thon raises record $34,000 for Parkinson’s Research

This year’s 13th annual Skate-a-Thon for Parkinson’s disease January 24 – 25 at UNMC raised a record $34,000 for research.

In addition to the 525 skaters who skated over the 24-hour period, five individuals skated all 24 hours. The Nebraska Warriors hockey club had a representative on the ice all 24 hours, as well.

Proceeds from the event will go toward clinical and basic science Parkinson’s research at UNMC and Parkinson’s Nebraska. To date, $244,000 has been raised.

The Skate-a-thon was the idea of an Omaha couple, Ted and Colleen Wuebben, who hosted their own skate-a-thon for three years by flooding their back yard. To grow the event, it was moved to the UNMC Ice Rink in 2011.

Colleen Wuebben was diagnosed with Parkinson’s in 2005 at age 52. She died in 2013 at age 60. The Wuebben family, which includes five children, has kept Colleen Wuebben’s memory alive by continuing to hold the skate-a-thon every year. Parkinson’s Nebraska was founded by Colleen Wuebben when she was diagnosed in 2005.

Team Cary was the top fundraising team at this year’s Skate-a-Thon.

“Thanks to the community for making this a winter tradition,” said Jenny Knutson, the daughter of Ted and Colleen Wuebbens.

“The encouraging words of physicians give us the belief that we won’t have to host this event much longer. We hope a cure is on the horizon.”

References


PDWELL: A Parkinson’s Therapy, Wellness and Resource Center — ONLINE IS OPEN!

Cheri Prince, DPT
Director | PDWell

We know most of the exercise, support group and education offerings for the Parkinson’s community are closed right now but PDWELL Online is OPEN!

As the corona virus closed everything, PDWELL felt it was important to keep the Parkinson’s community connected and MOVING! We had already applied for and received a grant from Parkinson’s Nebraska to start pursuing some online educational programming, but as we saw everything happening we knew we had to act quickly!

So, with Parkinson’s Nebraska’s blessing, we used the equipment and got to work! The result... PDWELL is now offering online programming to help support you during this time! We are offering a daily support group (Monday - Friday) that consists of a variety of education, information, sharing, some movement and ALWAYS positivity. We were even blessed with a “Ask the Experts” session with Julie Pavelka and Dr. Torres!

We follow the support group each day by a Parkinson’s specific exercise class. We are offering boxing, flexibility/yoga, voicing, PWR! Moves and Dance for PD in addition to Live It Up! – a combination voicing and movement class. We are also offering a weekly educational series, a LOUD Crowd (voicing and cognition class), a caregiver forum and young onset support group (PD Connections).

We will likely be adding other educational and exercise options in the weeks ahead. We don’t know how long other gyms and facilities will be closed but we know that PDWELL will be online for you as long as needed! Those that have participated have shared positive feedback and are grateful to have a way to connect and exercise. Here is a quote from a participant:

Paul and I are extremely grateful that when the Parkinson’s exercises classes in Omaha halted due to COVID-19, PDWell almost immediately offered online exercise classes via zoom. I’ve noticed that Paul is excited to join the daily support group and gladly attends all exercise class offerings. More importantly, he is improving his balance and has not fallen even once this week. This was becoming a daily occurrence. I’m terrified to think about the decline of mobility there would have been without this opportunity. We are both so thankful for Cheri, Georgie, and Amy for everything they are doing to keep the Parkinson’s community connected and moving!

For those of you not yet familiar with PDWELL, let me take this opportunity to tell you a little about us:

PDWELL was born out of a desire to meet the needs of the PD community in the Omaha metro area: The three pillars of PDWELL are Exercise (Skilled therapy and community exercise classes), Education (pt, caregiver, and professional) and Community (fostering a sense of community among the members).

PDWELL will provide PD specific skilled therapy (PT, OT, SLP) and PD specific exercise classes under 1 roof with staff that are specially trained and invested in the Parkinson’s community here, as well as to provide a space and resources for quality PD education for Persons with PD (PwPD) and their caregivers. We also want to be the place for professionals from all over the state to obtain quality PD-specific advanced training in PD therapy assessment, treatment and community based exercise. PDWELL will provide a continuum of care from community to wellness to skilled therapy. A place to come from diagnosis on to meet the unique needs of the PD PT and caregiver.

While we can’t be together in person right now, we can connect online and for that, I am grateful! Soon, we will be able to meet again and I am looking forward to connecting with each one of you in person in whatever capacity you need PDWELL.

Stay safe and healthy and “see” you on Zoom soon!

To Register or to see additional descriptions of each class, go to pdwell.com and select the calendar tab. All of our online offerings are listed in green. Click on the events you would like to attend and follow the prompts to register. We would love for you to join us!

Please feel free to reach out to cheprince@ensignservices.net or at 531.444.8945 with any questions you may have!
Mindful Eating
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How often do we sit down and enjoy eating? Actually take in the aromas, flavors, and textures of what we just dished up on our plate?

Most often we eat when it’s time for our usual meals and don’t think twice about what we just had. “Mindful eating” is a strategy you can use to appreciate your food more and develop a healthy eating habit. Mindfulness refers to the practice of being aware and in the moment.

Often our minds are in ten different places – thinking about what you have to do later in the day, an upcoming doctor’s appointment, calling a family member back – the list goes on! Mindfulness encourages you to put aside those preoccupations and bring yourself back to now. Studies suggest that mindful eating can improve eating habits and may even aid in weight loss.

Mindful eating includes the following concepts. Try some of these throughout the day.

• Listen to your body and stop when you are full.
• Pay attention to other cues to tell that you are hungry (stomach growling, low energy). Ask yourself if you are hungry.
• Eat with others at set times and places. Sit down at the table, turn the TV off and keep your phone in another room.
• Eat foods that are nutritiously healthy.
• Chew your food more. Take time to enjoy the flavors and textures in your mouth before you swallow. Try putting down your utensils after each bite.
• Think about where your food comes from. Be thankful for the farmers, factory workers, the earth and the chefs who might have made that meal possible.

The opposite is what we call “mindless eating.” These may be things you find yourself doing. Try to do these less often.

• Eating past the point of feeling full.
• Eating when you experience different emotions (sad, bored, stressed, and lonely).
• Eating at random times and places.
• Having foods that are emotionally comforting.
• Eating while multitasking on other things.

Purposefully focusing your attention on the present can help you truly enjoy the foods you eat every day!
New Research is attempting to treat disabling symptoms of Parkinson Disease

Danish Bhatti, MD
Assistant Professor
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gLIDe Study: A Study to Assess the Safety and Effectiveness of Pridopidine Compared to Placebo in the Treatment of Levodopa-Induced Dyskinesia in Patients with Parkinson’s Disease (ClinicalTrials.gov Identifier: NCT03922711)

The University of Nebraska Medical Center (UNMC) Department of Neurological Sciences is always looking to bring clinical trials with new drug development to our patients with Parkinson’s disease. We feel this is important because it not only provides much needed help in development of new drugs for patients with this disabling disease, but it also offers an opportunity to participate in potential options for disabling symptoms of Parkinson’s disease (PD), where nothing exists right now.

What is the title of this study?
The study is called gLIDe and is intended to look for improvement of levodopa induced dyskinesia or LID in patients with PD. This is a multi-center study involving more than 30 different institutions recruiting patients to test potential new drug. This is a Phase 3 study which means that this is the last phase in drug development before it becomes commercially available after FDA approval.

What is levodopa induced dyskinesia?
In PD, we get good benefits by medications with the replacement of dopamine in the brain early on; regardless of how much dopamine is replace in the brain patient are able to handle it very well. However, with progression of PD, the capacity to handle the amount of dopamine goes down and as they are given higher dose of dopaminergic medications to improve their symptoms, they tend to overshoot with the dopamine state which results in excessive involuntary cont. pg. 11
movements in their neck, shoulders, and body overall. This happens when the medication absorbs and peaks in the blood, which is usually approximately 45 to 60 minutes after taking the medication. It lasts a couple of hours for most patients and then gradually improves as the medication starts wearing off and the amount of dopamine or level of dopamine goes down.

However, it can happen in many other patterns and in severe cases it can be continuously present throughout the day. Although sometimes we are able to spread out the drug with less amount of medication at a time given in frequent intervals. It is not always possible to get rid of the symptom because the only way to get enough benefit is to take enough medication and get dyskinesia.

These dyskinesia can be very bothersome to the patient and result in loss of weight, due to constant movement, tiredness and fatigue, muscle weakness even damage the muscle resulting in loss of muscle mass. A characteristic feature of dyskinesia is that they get worse the more you try to do something and they get better if you relax and calm down, which reduces the physical activity the patient tries to do. Necessary actions like eating and talking brings out dyskinesia to a point that they interfere. The involuntary movements of the arms or legs could be so strong that they make eating, drinking and even walking impossible. And sometimes the patient is so restless that even conversation is difficult given that the speech is already soft in Parkinson’s.

How does the drug being studied work?
The glide test is testing a new drug called Pridopidine. It is a highly selective Sigma-1 Receptor (S1R) agonist. The S1R regulates key cellular processes relevant to neurodegenerative diseases, such as calcium homeostasis, restoring mitochondrial health and neurotrophic factor release. S1R is implicated in cellular differentiation, neuroprotection, and cognitive function of the brain. This drug was previously tested for other forms of dyskinesia, such as in Huntington’s disease and has been used in Parkinson’s patients in Phase 1 and Phase 2 studies. Currently there is only one FDA approved medication for levodopa-induced dyskinesia and that is amantadine ER.

What is the design of the study and what will it require to participate?
We are actively recruiting patients for this study. This trial is a placebo controlled trial, which means that half of the patients will get the real drug and the other will get an inert substance which doesn’t have any activity or action, so that we can differentiate between improvement that is related to hop, motivation and close care by their physicians). All those things can improve patient symptoms regardless of the medications benefit. We don’t want to falsely assume that the medication is working when the benefits are just related to those factors.

The study involves taking that medication regularly for a period of 4 to 6 months and following with frequent assessments by the doctor to see if the drug is working, if it’s safe and if it’s helping. Both the physician and the patient does not know if they’re taking the actual drug or an inert substance or placebo. All patients are examined and treated the same assuming that they are on the drug when we look for any benefit or side effects and document all of that to be analyzed later.

Are there any risks involved in participating in this trial?
Yes, there are some associated risks. Just as there are with any medications, even the medications that have been approved and on the market have known risks. The side effects go away when the medication is stopped. This is also true for the drug in this study that there are some known side effects that have been seen in trials or use with other patients. But there is always a possibility of getting a side effect which is new and has never been seen before because the drug is still new to us and is still under study. However, just like your clinical care, if you notice any side effects that are concerning, then the drug will be stopped regardless of whether you’re on placebo or the actual drug, and you will be monitored for symptoms improvement. Then, if you have any need for management or clinical care then you will get you clinical care, just like for any other reasons by going to your regular doctors or in the hospital.

Then there are some additional burdens of the study. You will have to give your valuable time to come in, make some trips to the hospital and take an additional medication. But more importantly, it will be good for care of future patients with PD and help in finding out a new solution to a very bothersome problem, which doesn’t have many solutions right now.

How can I find out more about the study and figure out if I am a potential participant in this study?
To participate in this trial, you have to have PD and you have to have these problems that we called dyskinesias, where taking the medication causes restlessness or excessive movement. This way, we can see if those symptoms can be treated with this new medication. If you believe you have something like that, you can reach out to us on the following contacts. You can also find out more details about the study on UNMC’s research webpage.

There, you can discover other PD trials at UNMC. You can also go on to the webpage to get more information on the study. We’re partnering with many different organizations to get the word out, to spread information and enhance our recruitment of the patients, including our collaboration with Michael J. Fox Foundation trial finder.

For the first time, we’re partnering with an organization called 23andMe. This entity offers free genetic testing to find out your ancestry. It also helps screen patients who are carriers of the mutations that may put them at higher risk of genetic conditions. An example would be PD. They have a database of many patients that have reached out to them to have tested genetic testing done for themselves, and have disclosed that they have PD. We will also be sending letters to the neurologists in the region, and we’ll reach out to the primary care physicians who see a lot of Parkinson’s patients. We’ll also be reaching out to the PD Support Groups and through this newsletter, we’re reaching out to you.

Please help spread the word so that the patients can get right treatment and right patients can participate in this trial.
### Reliable Parkinson Resources

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

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<tr>
<th>Organization</th>
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<tr>
<td>American Parkinson Disease Association</td>
<td><a href="http://www.apdaparkinson.org">www.apdaparkinson.org</a></td>
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<td>Davis Phinney Foundation for Parkinson's</td>
<td><a href="http://www.davisphinneyfoundation.org">www.davisphinneyfoundation.org</a></td>
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<td>International Parkinson and Movement Disorders Society (WE MOVE)</td>
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<td>Michael J. Fox Foundation for Parkinson's Research</td>
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To obtain access to our Nebraska Medicine/UNMC Parkinson Disease Patient, Family, and Caregiver Symposium (October 2019) PowerPoint presentations and video playlist on YouTube (scroll to the bottom): [unmc.edu/neurologicalsciences/patient-care/programs/movement-disorders](http://unmc.edu/neurologicalsciences/patient-care/programs/movement-disorders)

To download a copy of ALL Parkinson's Post newsletters, please visit: [www.unmc.edu/neurologicalsciences/news/newsletters](http://www.unmc.edu/neurologicalsciences/news/newsletters)