

SPRING 2015

MINNESOTA | *Newsletter of the Minnesota
American Parkinson Disease Association*

MESSENGER

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Joan Brandl, RN
APDA I & R Coordinator
Newsletter Editor
Phone: (651) 241-8297 (metro)
or 888-302-7762 (toll free)
Fax: (651) 241-6505
Email: joan.brandl@allina.com
National APDA Web Site:
www.apdaparkinson.org
APDA Young Parkinson
Website:
www.youngparkinsons.org

ADVANCES IN TREATMENT OF PARKINSON'S DISEASE

Eleanor Orehek, MD



I am thrilled to have the opportunity to write an article for you all. Parkinson disease is a specific interest of mine for a number of reasons, one of which is the amazing patients and patient families that I have the privilege to see and treat. So far during my treatment of PD patients, I have found that while there's no cure or clear way to slow down the disease yet, there are still a lot of ways to make my patients' lives better. This is an exciting time to be involved in

treating patients with PD. Recently, there have been both advances in symptomatic treatments as well as possible disease modifying treatments, which I plan to touch on in this article.

Whenever the topic of PD treatments comes up, I always mention first the importance of exercise for all people with PD. There is no consensus yet as to what type of exercise or amount of exercise that should be done. We do know from the literature that a variety of exercises have been shown to improve quality of life and may also have an effect on disease progression. The key part of this recommendation is to do some form of regular exercise and start an exercise program as soon as you are diagnosed with PD. I recommend you find an activity or a few different activities that you like and can do safely, which will then keep you motivated to continue them on a regular basis. If you don't enjoy the exercise, it will be much harder for you to maintain the exercise program.

(cont. on page 4)



The American Parkinson Disease Association, Inc.
135 Parkinson Avenue
Staten Island, NY 10305
800-223-2732

Minnesota American Parkinson Disease Association
Information and Referral Center
333 N. Smith Ave., MR 63201, St. Paul, MN 55102
651-241-8297 or 1-888-302-7762
www.allinahealth.org/APDA

COORDINATOR'S COLUMN



Joan Brandl

Dear Readers,

The journey of PD begins in many different ways. When diagnosis occurs, some people are shocked and seek out a 2nd, 3rd or even 4th opinion. Others may feel overwhelmed and don't know where to turn. Everyone's reaction and acceptance vary. How then do you get the support that you uniquely need during this period? Certainly family and friends may be helpful, but they too, may be confused, and overwhelmed with many questions.

Your doctor or health care provider is key to your finding the answers that you seek, but what can you do in the interim? Most health care providers would suggest that you take a number of important steps during this process.

1. Stay physically active. Make sure that you have an exercise program that you can commit to and that you can do five or six times per week.
2. Stay socially active. Do not retreat or hide. PD is nothing to be ashamed of and people with Parkinson's can live long, productive lives filled with optimism and joy.
3. Contact the APDA Information and Referral (I&R) Coordinator for resources. Learn as much as you can about the disease. My office has a large supply of brochures, books and videos to borrow.
4. Fill out a "Good Start" application form. If you have been diagnosed with PD in the last 2 years, you may be eligible to receive one of 2 excellent books generously donated by the Capistrant Parkinson's Family Foundation.

5. Use the telephone help line of the I&R Center. I have worked as a registered nurse with three different neurologists that specialized in the treatment of PD. I am available to help problem solve, and formulate questions with you for your doctor, as well as refer you to therapists, psychologists and more.
6. Sign up for educational programs sponsored by APDA.
7. Consider signing up for a support group. If you feel reluctant at this time, I would be happy (with signed permissions) to put you in touch with a person who has PD and is at your stage.
8. Become an advocate. You can become a PD advocate whenever you become involved in activities intended to improve the lives of people living with PD.
9. Sign up for clinical trials. Your doctor can direct you to potential trials, or you can call study coordinators for information about what is being offered in the area.

Beyond that, it is always important to eat right, get a good night's sleep, and consider alternative approaches which may include yoga, tai chi and meditation. Consult with your health care provider or an integrative medicine physician before beginning any course of therapy.

Warmest regards, Joan

MEDICAL DIRECTOR'S COLUMN



Dr. Okeanis Vaou

Dear Readers,

Clinical, pathologic and epidemiological evidence now supports that motor symptoms in Parkinson's Disease (PD) are the tip of the iceberg, with non-motor manifestations (NMS) preceding the diagnosis of PD. These early features include decrease in sense of smell, rapid eye movement (REM) sleep behavior disorders (SBD), constipation, depression, anxiety, apathy and have been proposed as possible biomarkers of PD. A recent multi-center study of 109 patients with PD showed that smell loss, REM behavior disorder symptoms, constipation, and mood disorders were the most common NMS reported. The most bothersome symptoms preceding motor symptoms were apathy, EDS (erectile dysfunction), sleep problems, and constipation.

Symptoms such as RBD (acting out of dreams), constipation, abdominal discomfort with eating, erectile dysfunction occurred more than 10 years before motor symptoms appeared whereas neuropsychiatric symptoms, such inability to experience pleasure and lack of positive emotional responses, apathy, memory complaints, and inattention were seen close to the time of onset of motor symptoms.

This study supports that otherwise healthy subjects reporting certain non-motor symptoms (smell loss, taste loss, constipation, dream-enacting behavior, frequent nightmares, and chest pain) in isolation or combination (especially smell loss, constipation, and dream-enacting behavior) might be at increased risk of

developing PD. This study proves the importance and need of more investigation in this field in order to be able to reach an even earlier diagnosis of PD and the importance and need of more investigation in order to be able to use these symptoms as biomarkers to reach an even earlier diagnosis of PD. This is urgently needed to differentiate between neurodegenerative disorders, screen novel therapeutics, and predict eventual clinical PD before the onset of symptoms. Furthermore, introduction of new treatments and interventions for PD will depend on improved diagnosis, preferably at early, premotor stages at which a larger population of dopaminergic cells remains.

Best, Okeanis



2015
Parkinson
Walk

**Register and donate
at**

**[http://apdaparkinson.
donordrive.com/
event/2015MNWalk/](http://apdaparkinson.donordrive.com/event/2015MNWalk/)**

ADVANCES IN TREATMENT OF PARKINSON'S DISEASE (cont.)

The development of new drugs for PD has been somewhat limited. Sinemet (carbidopa/levodopa) was approved in the 1970s and is still the gold standard of therapy for PD patients. The exciting news is that just recently there were two new medications approved for levodopa treatment of Parkinson Disease. As you probably know, carbidopa/levodopa is used for treating symptoms only and does not have an effect on disease progression. The first medication is Rytary by Impax Pharmaceuticals and is similar to Sinemet in that it is carbidopa/levodopa but is somewhat different in how it is absorbed and released into the body. It has a combination of both immediate and extended release beads of carbidopa/levodopa which has shown to help decrease “off” times for patients. In the ADVANCE-PD study, it improved “off” time by 37% compared to 17% on the current immediate release carbidopa/levodopa that is used. The medication also increased “on” time without the bothersome abnormal movements that can come as a side effect of levodopa, called dyskinesias, by 1.8 hours. This medication could be used in both early and late stages of PD. Although it is extended release, it is still supposed to be taken at least three times daily. Duopa, made by AbbVie Pharmaceuticals, is the other medication that was just FDA approved for patients with advanced PD. Duopa is also carbidopa/levodopa, but in a gel form and is administered via a pump delivery system directly into the small intestine for maintaining a more stable level of levodopa in the brain. In the trials, this medication showed an increase in “on” time by 1.9 hours without bothersome dyskinesias.

A newer focus of drug development is on a nondopaminergic pathway. The nerve cells involved in PD have receptors for dopamine and another nerve signaling chemical called adenosine. Research has shown that blocking adenosine A2A receptor can help with the

motor symptoms of PD. These medications are called adenosine A2A antagonists and are caffeine derivatives. Of note, caffeine also blocks this receptor and may be why it has shown mild benefits in PD. There have been several medications in this class that have come through testing but have yet to be approved. One medication, called istradefylline, is approved for use in Japan but not yet in the US. Istradefylline has shown to have some improvement in the ON/OFF fluctuations that are seen with dopaminergic therapy. This drug is currently in a phase III trial in the US through the drug company Kiowa. One of the study sites is the University of Minnesota and contact information is at the end of this article.

As of now, there are no medications on the market that are intended to or able to slow down the progression of the disease, which is what we all hope will be achieved in the near future. One major difficulty in developing these treatments is that studying the effect on disease progression in controlled trials is difficult because there is not a good way to measure the effect a particular treatment has on the disease process itself. A biomarker is a measurable marker in the body that indicates the presence of a particular disease. As of now, there are no clear biomarkers for PD. In an effort to identify potential biomarkers, the Michael J. Fox Foundation funded a study in 2012 called bioFIND, that involves collecting blood and spinal fluid from people with PD and people without PD as controls to develop a database and hopefully identify potential biomarkers that could be used both in the research and clinical setting.

There have been some observational studies of people with early PD that noted that higher uric acid levels in the blood were associated with a slower rate of progression over 2 years compared to patients with lower levels. Uric acid has antioxidant properties and has been shown in animal models to have protective effects against loss of dopamine neurons. This knowledge led

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to the Safety of Urate Elevation in PD (SURE-PD) study to evaluate whether inosine, which is used by the body to make uric acid, could be used to safely increase uric acid levels in PD patients with the eventual goal to see if it has an effect on disease progression. The SURE-PD results, showing that inosine was safe and well tolerated, was published in JAMA neurology a year ago. The next step is a phase III study to show efficacy.

Another route for potential disease modification is the use of calcium channel blockade. Prior studies that compared PD and non-PD patients who were also taking different types of blood pressure medications showed that patients on a group of medications called “calcium channel blockers” were 30% less likely to develop PD than patients not taking this class of medication. Isradipine is a medication in this class that has been studied in animals and showed a potential for slowing progression of disease. One of the potential mechanisms for cell loss in PD and other neurodegenerative disease is poor regulation of calcium within the cells. The nerve cells in the brain that seem to be vulnerable and are lost in PD are structured so that they end up with higher amounts of calcium within the cell. This concept is somewhat complex, but these nerve cells have a specific type of calcium channel which allows entry of calcium into the cell. In theory, the protective effect of calcium channel blockers is from decreasing the calcium burden in the cell by blocking the entry channels and thus reducing the toxic effects to the cell. There is also evidence that isradipine may promote waste disposal within the cell, which is potentially protective because build up of waste, particularly the protein alpha synuclein, is thought to contribute to cell loss. The advantage of this class of medications is that they are already FDA approved and shown to be safe for patients for treatment of high blood pressure. It was also shown to be safe and well tolerated in patients with PD. Isradipine is already in phase III testing, which is the last phase in the process to try to

show the medication is safe and effective. Contact information for this study is listed at the end of this article.

A major area of PD research is targeting the protein involved in PD called alpha synuclein. This protein forms clumps called lewy bodies in the nerve cells of patients with PD. The formation of these lewy bodies is involved in the loss of these cells. Nerve cells in the brains of PD patients have 2-3 times the normal amount of alpha synuclein. Different approaches are being looked at to try to help these cells deal with this abnormal amount of alpha synuclein. One possible therapy is a vaccine that will cause the immune system to produce antibodies against alpha synuclein to help the cell break down the abnormal protein clumps and prevent brain cell loss. The challenge here, similar to the challenge of having no biomarkers for PD, is that there is currently no good way to measure levels of alpha synuclein in the brains of PD patients and so there is no way of evaluating whether the therapy is effective at decreasing alpha synuclein.

Gene therapy is still a promising area of research, as several trials for PD have shown safety and tolerability of treatments. However none have been able to show significant amount of effectiveness to this point. Gene therapy uses a virus to deliver genetic material to a certain area of the body or brain to increase production of a protein that may be lacking in that disease. In PD, as the disease progresses, the brain not only loses cells that produce dopamine, but also an enzyme that turns levodopa into dopamine which can then be used by the brain. This decrease in the enzyme (called aromatic L-amino acid decarboxylase, or AADC) is another reason why patients require larger doses of levodopa as the disease progresses and the brain gets less efficient at using the medication over time. One recent study tested a drug to increase the production of this enzyme. The drug Prosavin was developed by Genzyme; it is surgically placed into a specific

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ADVANCES IN TREATMENT OF PARKINSON'S DISEASE (cont.)

area of the brain that utilizes AADC. Again, the drug was shown to be safe, but did not have significant efficacy. Genzyme, with the help of Michael J. Fox Foundation funding, will be conducting another phase I trial to test different drug delivery methods and dose ranges.

The last area of treatment research to mention is deep brain stimulation (DBS). It is being utilized by an increasing number of patients with PD and other diseases as well. However, it is estimated that only a small number of patients with PD who would benefit from DBS are receiving this treatment. Currently, Medtronic has the only DBS therapy available that is FDA approved. Boston Scientific is in the process of obtaining FDA approval for their DBS system and the University of Minnesota is also a site for this research.

From a nutrition and supplements standpoint, what we eat and the quality of the foods we eat is emerging as a hot topic for everyone's health. Evidence is emerging that nutrition may play an important role in PD. As of now, there are no clear cut recommendation about what foods to eat or not to eat for patients with PD. The best advice I would give you at this point is to eat a diet that has benefits for brain health in general, is rich in antioxidants (for example, colorful fruits and vegetables), as well as natural sources of omega-3s/DHA, with fish being the best source.

The last point I would like to make is that research requires participation, so I urge all of you to consider getting involved in research.

Doctor Eleanor Orehek, a Minnesota native, earned her undergraduate degree in neuroscience at Colorado College. She obtained her medical degree at the University of Minnesota Medical School. Doctor Orehek was a chief resident at Boston University Medical Center, Boston, MA, where she completed

her neurology residency. Then, returning to her roots, she completed a movement disorders fellowship at the University of Minnesota. Doctor Orehek is board certified in neurology and fellowship trained in movement disorders. Her special interests include Parkinson's disease, deep brain stimulation, dystonia, ataxia, and Huntington's disease.

RESEARCH STUDY INFORMATION

bioFIND

University of Minnesota, Minneapolis, MN

Contact: Christa Raszkowski, 612-624-6778 or rask001@umn.edu

Principal Investigator: Paul Tuite, MD

Isradipine study

Struthers Parkinson's Center, Golden Valley, MN

Contact: Kathryn Duderstadt, 952-993-5903 or kathryn.duderstadt@parknicollet.com

Principal Investigator: Sotirios Parashos, MD, PhD

University of Minnesota, Minneapolis, MN

Contact: Susan Rolandelli, 612-624-7745 or cnru@umn.edu

Principal Investigator: Paul Tuite, MD

Istradefillyne study

A 12-week randomized study to evaluate oral istradefylline in subjects with moderate to severe Parkinson's disease.

University of Minnesota, Minneapolis, MN

Contact: sfinder@umn.edu

Boston Scientific DBS trial

University of Minnesota, Minneapolis, MN

Contact: sfinder@umn.edu

Principal Investigator: Jerrold Vitek, MD, PhD

BEATING CAREGIVER GUILT

Terri Hosto, MSW, LCSW



“Guilt is the gift that keeps on giving.” This quote is credited to the American satirist Erma Bombeck. With wit and humor she chronicled the trials and tribulations of family life in books and syndicated newspaper columns. In her

writings, she was able to make light of difficult family situations and laugh about them with her readers. Funny how certain emotions, like guilt, are universally shared, yet rarely talked about. Perhaps this is why guilt is a favorite topic of psychologists and other mental health experts, although family caregivers arguably are the *real experts* on the topic of guilt!

Studies of family caregivers have shown strong associations between guilt and depression. Physical signs of guilt may include tension in one’s voice, unexplained pangs of pain, pressure on one’s shoulders, or a heavy feeling in the chest. Fatigue, difficulty concentrating, lack of pleasure, sleep disturbances and appetite changes—all of which are signs of depression—often accompany feelings of guilt. When left unmanaged, guilt and depression can become debilitating and negatively affect the health and well-being of the caregiver.

If you are a caregiver for a loved one, then you probably have experienced recurrent feelings of guilt along your caregiving journey. Guilt is an emotional state that arises when your thoughts and behaviors are not consistent with your values and beliefs. For example, family caregivers often feel guilty because they think that they should be doing *more* to help the person for whom they are caring, or feel that they could do a *better* job. This type of guilt arises when you feel that you haven’t

measured up to your own expectations—even though you probably wouldn’t hold anyone else to the same impossible high standard!

Admittedly, you have probably made mistakes that you wish you could undo ... perhaps you failed to do things you feel you “*shoulda*” done ... or maybe there were situations that you think you “*coulda*” handled differently ... or possibly you wish you “*woulda*” not said some unpleasant things that you did. When you hold onto “*shoulds, coulds and woulds,*” guilt can spill over and cause you to emotionally beat yourself for supposed wrongs.

The truth is that as a caregiver, you likely are a nurturing and selfless individual. You think of others first, before ever considering your own needs. You do all that you can to meet the needs, wants and desires of the person you are providing care for. This self-sacrificing quality, however, may trigger guilt feelings inside of you. Guilt can seep in if you believe that you aren’t satisfactorily devoting time to others in your life and fulfilling responsibilities you have to extended family, friends, work, or the community. You also may feel guilty when you take time for your own needs and even find it difficult to relax because you constantly worry about your loved one. Too many demands on your time, energy and personal resources can foster feelings of helplessness and caregiver guilt, which can lead to burnout.

The caregiving experience evokes an array of emotions—many of which are undeniably negative. Getting angry and losing patience with the person you are caring for. Feeling resentful at having to put your own needs, wants and desires second. Feeling helpless when you think of the seemingly endless caregiving tasks ahead of you. Worrying about the future. Feeling overcome by a general sense of inadequacy when you realize that despite your best efforts, your loved one continues to decline. Recurrent thoughts like these can dominate a caregiver’s mind and exacerbate feelings of guilt.

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BEATING CAREGIVER GUILT (cont.)

Guilt can thwart communication and erode relationships between you, the person you are caring for and significant others in your support system. For instance, you may communicate to others that you are managing everything that comes your way, when in reality you are feeling overwhelmed and need help! You are the person everyone else relies on, not only to do the tasks of caregiving, but also to keep them informed. Yet you won't ask for help. Caregivers without assistance tend to experience the highest rates of burnout.

How do you get off this merry-go-round of guilt and avoid caregiver burnout? First, it is important to get in touch with your thoughts and feelings about your caregiving situation. Do not be ashamed if you find that you harbor some negative emotions. Instead, share them with someone who will listen without judging you. You may find it helpful to speak with a professionally trained counselor. Also consider seeking out other caregivers who are dealing with similar circumstances, perhaps by joining a caregiver support group. Support groups can offer enormous relief by providing an outlet for you to safely vent your feelings and frustrations. Most importantly, understand that your negative feelings and guilt won't go away if you simply ignore them. Working through them can be very cathartic and healing.

Secondly, allow yourself to be less than perfect and learn from mistakes made. You know you want the very best for your loved one; but like everyone else, you have limitations and shortcomings. Accept that there will be times and situations where you fail to meet your own self-imposed standard of care. There will be ups and downs along the caregiving journey. When you get that gnawing feeling that you've let yourself and others down, it's time for you to review and adjust your expectations. Learn to let go and tolerate things that might not get done perfectly.

Also learn to appreciate and value your work as a caregiver. Make a list of what you do *for your loved one*, such as prepare meals, run errands, pay bills, assist with personal care, accompany to medical appointments, plan activities that your loved one enjoys, etc. Be sure to include all the positive qualities you bring to the caregiver role, such as being dependable, attentive, careful, knowledgeable, committed, etc. When you look at your list, you'll likely see that the things you do to care for your loved one far outweigh any omissions and failures. This new awareness may help you draw strength and encouragement from your hard work and caregiving efforts. Find positive affirmations of your worthiness to replace negative thoughts and feelings.

Next, make a list of what you do to care *for yourself*. You'll likely find a shortfall on your side of the ledger. How do you balance meeting your own needs with the needs of your loved one? Even though there may not seem to be enough hours in a day to devote time to self-care, it is essential that you take time to look after yourself. This requires establishing limits on your time and energy. If you are physically and/or mentally stressed, then you can't expect to be at your best for your loved one who depends on you. Instead, the care you give may reflect the tension and weariness you are feeling rather than compassion and comfort. Learn to prioritize your daily tasks to more realistically match your available time and energy. Divide your day into the things you *must do* and the things you *would like to do*. Be sure to include time for your own self-care—even if it is not proportional to the amount or hours of care given to your loved one.

Self-care involves maintaining a healthy lifestyle (through proper nutrition, regular exercise, adequate rest), participating in activities you find meaningful and personally enjoy, staying connected to family and friends, and having some time away from caregiving. Taking breaks from the demands

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and duties of caregiving is vital to your well-being. This is called “respite,” and a variety of programs are available to provide short periods of relief from caregiving, including in-home companion services and facility-based activity programs. Periods of respite can help restore your physical energy as well as provide mental relief from the worries and concerns of caregiving. Even when you can’t get away physically, there are various ways you can take a mental break, such as absorbing yourself in a good book, immersing yourself in your favorite music, using deep breathing exercises and relaxation, or taking a long hot bath. Taking steps like these can help reduce the stress and guilt of caregiving and ensure your well-being. When you reach a healthy balance, you become a more capable and effective caregiver and your loved one is all the more better for it.

Terri Hosto is a licensed clinical social worker and instructor at Washington University School of Medicine (WUSM) in St. Louis. In addition to her social work credentials, she has additional training and specialization in the field of gerontology.

UNIVERSITY OF MINNESOTA PARKINSON’S RESEARCH

The Department of Neurology at the University of MN is offering a number of research opportunities for people with Parkinson’s disease. Below is a brief description of the studies.

BIOFIND STUDY

Biofind is a 2 year observational study focused on generating biomarkers related to Parkinson’s disease (PD) with a goal of 240 enrolled participants at 8 Universities in the US including the University of Minnesota. This project is wrapping up with collection of blood, spinal fluid, urine and saliva samples from those with PD and healthy controls. No additional research participants are needed at this time. Meanwhile

studies are underway at several institutions evaluating the bio specimens including a self-funded project at the University of Minnesota to look at the effects PD medications have on blood antioxidants and if antioxidants can be reliably measured in the spinal fluid. For more information on the study please refer to the MJ Fox Foundation website <https://www.michaeljfox.org/page.html?biofind-clinical-study>.

MINNESOTA PARKINSON REGISTRY

This will be an option in the coming months whereby people with Parkinson’s who have been referred by their neurologist will fill out a questionnaire and provide specimens (toe nail clippings for heavy metals, urine for pesticides and saliva for gene profile of detoxifying genes). The goal of this project is to better understand the genetic and environmental factors in PD. Additional background on this study is at the following website:

<http://inquiry.research.umn.edu/2015/01/14/building-a-framework-for-parkinsons-research/>

CLINICAL DRUG TRIAL

A clinical trial funded by Parkinson UK is being conducted to evaluate the effects that oral doses of the antioxidant n-acetylcysteine have on brain and blood antioxidant levels. Individuals in this study undergo brain imaging using a research MRI machine at the beginning and the end of the study to evaluate for changes in brain chemistry. The goal is to develop a medication that may help boost antioxidant levels and thereby slow the progression of PD.

<https://clinicaltrials.gov/ct2/show/NCT02212678>

https://www.parkinsons.org.uk/sites/default/files/towards_an_anti-oxidant_treatment_for_parkinsons_-_research_project_summary_pdf_176kb.pdf

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FREEZING OF GAIT STUDY

This study is for people with Parkinson's disease who have a syndrome called "freezing of gait". Freezing of gait is a term often used to describe the sudden stoppage of walking or problems with the initiation of walking. The purpose of this study is to examine if the ability to initiate walking can be improved by altering the activity of brain regions that contribute to movement planning, preparation and initiation. Brain activity will be modulated using a technique called transcranial direct current stimulation. This method uses a low intensity current that is applied to the surface of the scalp overlying the brain region of interest. The effects last for about one hour. During this time we will measure changes in the capacity to generate forward stepping.

For more information please contact:

Jackie Vachon, M.S.

*Department of Neurology, University of Minnesota
(612) 626-8052 | jmvachon@umn.edu*

IN THE NEWS

EXCITING PARKINSON'S DISEASE TREATMENT NEWS

New York, NY, January 12, 2015 – The American Parkinson Disease Association is pleased to share with the Parkinson's community the arrival of two new medications in the treatment arsenal to address Parkinson's symptoms. Both of these therapies offer a better way to deliver carbidopa/levodopa medication.

RYTARY™, (pronounced rye-TAR-ee) approved by the Food and Drug Administration on January 8 is an extended release formulation of carbidopa/levodopa and is manufactured by Impax Pharmaceuticals. RYTARY™ is designed to address one of the most significant unmet needs for patients living with Parkinson's disease, which is

to reduce the amount of time during the day when their symptoms are not adequately controlled. This is a significant treatment option for the 1 million patients living with Parkinson's.

Patients who take carbidopa/levodopa may find over time that the drug becomes less effective and may experience a worsening of symptoms as the drug ceases to work successfully. As Rytary™ is developed to release more slowly over time it will maintain the levodopa levels and will provide greater treatment stability.

This treatment will help those in the middle stages of Parkinson Disease who have problems with wearing off of their medication.

RYTARY™ contains immediate release and extended-release beads, with a specific amount of carbidopa and levodopa in a 1:4 ratio, and provides both initial and extended levodopa plasma concentrations after a single dose. RYTARY™ may be swallowed whole or, for patients who have trouble swallowing, the capsule may be opened and the beads sprinkled on applesauce and consumed immediately. It will be available for commercial distribution in February 2015.

DUOPA™ approved January 12 by the U.S. Food and Drug Administration (carbidopa and levodopa developed by AbbVie) is an enteral suspension for the treatment of motor fluctuations for people with advanced Parkinson's disease. DUOPA™ is administered using a small, portable infusion pump that delivers carbidopa and levodopa directly into the small intestine for 16 continuous hours via a procedurally-placed tube.

Duopa™ is the first and only treatment providing 16 continuous hours of carbidopa and levodopa for motor fluctuations in advanced Parkinson Disease. In a clinical trial, patients treated with Duopa™ experienced significantly greater improvement in symptom control than patients treated with oral carbidopa-levodopa immediate release tablets.

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Duopa™ is for those patients with advanced Parkinson Disease wearing off or dyskinesia who cannot manage symptoms with regular tablets and other oral medications.

In Parkinson disease patients, the spontaneous emptying of the stomach becomes delayed and unpredictable, which can affect the timing of when orally administered medicines leave the stomach and are absorbed in the small intestine. DUOPA™ provides patients with the same active ingredients as orally-administered carbidopa and levodopa immediate release, but is delivered in a suspension that goes directly into the small intestine via a tube placed by a percutaneous endoscopic gastrostomy procedure with jejunal extension (PEG-J). This type of administration is intended to bypass the stomach.

Dr. David G. Standaert, Chairman of Scientific & Advisory Board of the American Parkinson Disease Association says, “These are two very exciting new treatments which offer new opportunities to patients at different stages of their disease and help to better control their symptoms.”

American Parkinson Disease Association recommends discussing these therapies with your neurologist before making any changes to your treatment plan.

HANDICAPPED ACCESSIBLE TAXICABS

The *Star Tribune* reported on March 1, 2015 that ramp-equipped taxicabs will be coming to Minneapolis. City officials have arranged these services with five different cab companies including Airport Taxi, Yellow Taxi, Green and White Taxi, Minneapolis Taxi and La Mexican Taxicab.

This is great news for the thousands of people in our city who no longer drive. See the article in the *Star Tribune* for more information.

THE PATIENT ACCESS NETWORK FOUNDATION FINANCIAL ASSISTANCE PROGRAM

The Patient Access Network Foundation (PANF) is proud to announce the launch of its newest financial assistance program for patients being treated for Parkinson’s disease. The new fund will be one of nearly 60 disease-specific funds offered by the PANF, spanning programs for cancer, chronic illnesses and rare diseases.

PANF’s new Parkinson’s disease fund will help eligible individuals and their families by paying for the out-of-pocket costs of critical medications; thereby reducing financial barriers to treatment and hopefully improving the quality of life for many people living with Parkinson’s.

Patients who qualify for PANF’s Parkinson’s disease fund are eligible to receive up to \$16,500 per year to cover costs associated with their medications. To qualify, applicants need to have insurance that covers the medication for which they seek assistance, they need to reside and receive treatment in the United States, and they need to have a household income less than or equal to 500 percent of the Federal Poverty Level.

For applications and eligibility questions, call 866-316-PANF (7263). To learn more, visit panfoundation.org/parkinsons-disease

APDA SPRING PARKINSON'S CONFERENCE APPLE VALLEY, MN

Saturday, May 9, 2015

GrandStay® Hotel and Conference Center
7083 153rd Street West, Apple Valley, MN 55124

Conference Agenda

- 9 a.m. REGISTRATION AND EXHIBITS
- 9:30 **Welcome and Opening Remarks**
Joan Brandl, RN, Program Manager
American Parkinson Disease Association
MN Information and Referral Center
- 9:40 **Lewy Body Disease and Dementia**
J. Eric Ahlskog, PHD, MD
Mayo Clinic, Rochester, MN
- 10:40 **Driving and Parkinson's Disease**
Kathy Woods Rakowczyk, OTR/L CDRS, LDI
Courage Kenny Rehabilitation Institute Driver
Assessment and Training Services
- 11:30 LUNCH AND EXHIBITS
- 12:15 **Planning for the Journey: When, How and Where to Find Help**
Tanya Rand, MSW, LICSW, Clinical Social Worker
Capistrant Parkinson and Movement Disorder
Clinic and
Kelly Freeburg, BSW, LSW, Clinical Social Work
Intern, Bethesda Hospital Outpatient Services

Cost: Free registration and lunch but must register by May 4th to secure your place.

Speakers



Eric Ahlskog, PhD,
MD, Mayo Clinic,
Rochester



Kathy Woods
Rakowczyk OTR/L
CDRS, LDI,
Courage Kenny
Rehabilitation
Institute



Tanya Rand, MSW,
LICSW, Capistrant
Parkinson and
Movement
Disorder Clinic



Kelly Freeburg,
BSW, LSW,
Bethesda Hospital
Outpatient
Services



CONFERENCE REGISTRATION *(Please register by May 4, 2015)*

Mail registration to the following address: Joan Brandl, RN, APDA Program Manager, Information and Referral Center, United Hospital MS 63201, 333 N. Smith Ave., St. Paul, MN 55102

Questions? Call Joan at 651-241-8297 or 1-888-302-7762

Name(s) _____

Phone _____ # of people attending _____

SAVE THE DATE: 2015 PARKINSON WALK AND CELEBRATION SATURDAY, OCT. 10 | 9 A.M. REGISTRATION | 10 A.M. WALK

Roseville Central Park | 2540 Lexington Ave. N. | Roseville, MN 55113

Start creating your walk team – register and raise funds for Parkinson’s disease

Please join us as we spread awareness of Parkinson’s and raise funds to support APDA’s efforts through our dual mission to **Ease the Burden** through patient services and **Find the Cure** through research approved by our prestigious Scientific Advisory Board. There will be:

- Prizes
- Refreshments
- A chance to honor or remember your loved one
- Art contests for children
- Cake Walk
- And more!
- Exhibits and giveaways
- A fabulous silent auction

The Walk is a 1.1 mile route around beautiful Lake Bennett. The route is wheelchair accessible and walking is optional. Create or join a team and begin collecting pledges. For ease of registration, go on line and register as an individual, a team captain, or team member.

Walkers who have raised a minimum of \$25.00 and are present on the day of the Walk, will receive a t-shirt while supplies last.



DONATE NOW: ON LINE AT <http://apdaparkinson.donordrive.com/event/2015MNWalk/> OR USE THIS FORM FOR PLEDGES

___ I cannot participate, but am enclosing my donation of _____
 ___ I would like this contribution to be in Memory or Honor (please circle one) of: _____
 ___ Donations listed below sponsor a walker or team (Name of Walker or Team) _____

Name	Address	City	State	Zip	Amount	Paid

Walker’s Name _____ Fundraising Goal _____

Address _____ City _____ State _____ Zip _____

Email _____ Telephone (_____) _____

Waiver: I understand that I am voluntarily participating in this event at my own risk and my own request. I hereby waive all claims against the American Parkinson Disease Association (APDA), sponsors, staff, event personnel or volunteers for any injuries or damages that I might suffer at this event. I grant full permission for the organizer to use my name, video, photographs of me in the legitimate accounts and promotions with this event.

Please make check out to **MN Chapter of the American Parkinson Disease Association** and mail to:
 United Hospital
 333 N. Smith Ave., MR 63201
 St. Paul, MN 55102

Questions: Call Joan Brandl at 651-241-8297 or e-mail joan.brandl@allina.com

COMMUNITY CLASSES ALLINA HOSPITALS

ATTN: LSVT Big and Loud Graduates!

Courage Kenny Rehabilitation Institute (CKRI), part of Allina Health, is offering community exercise and speech classes for people with Parkinson's Disease. The group setting is led by therapists certified in the LSVT technique. A great way for participants to review exercises, renew enthusiasm for completing home exercises, interact with others who have completed LSVT, and have some fun!

Classes offerings at the following locations and day/times:

United Hospital Campus, Exercare Fitness Center, (BIG) and Outpatient Rehab (LOUD) St. Paul, MN 55102

Classes meet the 1st and 3rd Thursday of each month, 10-11 a.m. (BIG – physical therapy)

Classes meet the 1st Thursday each month, 11 a.m.-12 p.m. (LOUD – speech therapy)

For more information or to register at this location call 651-241-8290.

Abbott Northwestern Hospital, Coyne Conference Room (LOUD) and Physical Therapy gym (BIG), Minneapolis, MN 55407

Classes meet the first Tuesday of each month, 3-4 p.m. (LOUD – speech therapy); 4-5 p.m. (BIG – physical therapy)

For more information or to register at this location call 612-863-1924.

Mercy Hospital, lower level, classroom C (BIG & LOUD), Coon Rapids, MN 55433

Classes meet the 1st and 3rd Wednesday of each month, 10-11 a.m. (BIG – physical therapy); 11-noon (LOUD – speech therapy)

For more information or to register at this location call 763-236-8910.

CKRI–St. Croix, Fitness Center, (BIG & LOUD), Stillwater, MN 55082

Classes meet on Friday, 10-11 a.m.

Cost is \$55 for a 10-week session

For more information or to register at this location call 651-241-3336.

CKRI–St. Croix, Pool Exercise Class (for people with PD and/or other neurological disorders), Stillwater, MN 55082

Classes meet Tuesday & Thursday, 10-11 a.m.

Cost is \$105 for a 10-week session

For more information or to register for pool exercise at this location call 651-241-3346.

PARKINSON'S DISEASE/ MOVEMENT DISORDERS FITNESS EXERCISE CLASSES, CAPISTRANT CENTER AT BETHESDA HOSPITAL

Fitness Exercise Classes for Parkinson's Disease/Movement Disorder

4 classes designed to provide fitness opportunities for participants across the continuum of their disease. This unique exercise program emphasizes 4 key components; cardiovascular, stretching, strengthening and balance.

The class schedule varies by class level; **Fitness 1, Fitness 2, Fitness 3, Fitness 4.**

Classes follow a circuit and highlight Parkinson's specific exercises from the PWR! fitness training model.

Prior to starting an exercise class, every new participant will meet with a physical therapist for a free assessment to determine appropriate class. New participants please call 651-326-2150 to schedule a free fitness assessment.

Bethesda Hospital B Level Gym

Class day and time vary per class

\$5 per class. Scholarships available.

Call Erin for information at 651-232-2166.

Nordic Walking

Nordic walking makes walking a new fitness experience. Using poles while walking has all of the benefits of walking plus it engages the muscles of the upper back, shoulders, arms and torso. The swinging arm motion of walking with poles is important for the balance and coordination of people with Parkinson's.

\$5 participation fee. Caregiver/care partner walk for free

Call Erin for dates and more information at 651-232-2166

On-going Tai Chi Class for Parkinson's and Wellness

Tai Chi is a chinese exercise of slow circular movements that help promote energy flow and a sense of well-being. This Tai Chi can be done standing or sitting in a chair.

New members begin 1st Monday each month 9:30 a.m. orientation / 10-11 a.m. class

Bethesda Hospital, 7th Floor Conference Rm

\$5 per class. No charge for caregiver/care partner.

Registration required. Call Erin at 651-232-2166.

Clay Class with Northern Clay Center Artist

Try something new and creative in a fun, supportive, and relaxed atmosphere. This class allows participants to work on fine motor skills and hand strength. Patients and caregiver/carepartners welcome. No charge.

Bethesda Hospital Therapeutic Recreation Department 2nd Floor

For dates and information call Erin at 651-232-2166.

Dancing with Parkinson's

This class is modeled after the Dance for PD program from the Mark Morris Dance Company in Brooklyn, NY. Come alone or with a caregiver/partner. Enjoy live music & move to feel energized. This class is an interactive experience for all.

Jewish Community Center
1375 St. Paul Ave., St. Paul, MN 55116

Please bring photo ID for each person.

Thursdays 10-11 a.m.

\$5 per class. No charge for caregiver/carepartner

Registration required. Call Erin at 651-232-2166.

DULUTH CLASSES

Parkinson's Dance Studio

Fridays 1-2:15 p.m.

Class is based on the Dance for Parkinson Disease Program of the Mark Morris Dance Group.

Class begins in chairs; later dances can be done standing or seated. People with Parkinson's and their family, caretakers and friends are welcome.

Unitarian Universalist Congregation,
835 W. College St., Duluth

Suggested donation: \$3.00 per person or \$5 per pair

For more information call Jessica at 218-727-8286.

ROCHESTER CLASSES

Power Classes

Classes are held 2 times per week at ExercisABILITIES, INC., a physical therapy and medical fitness clinic.

For more information contact Melanie Brennan, PT DPT, at 507-261-4474

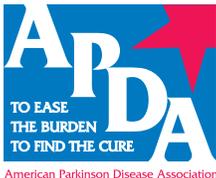
HELP US CONTINUE THIS VITAL SERVICE IN MINNESOTA.

DONATE NOW!

Donate at <http://apdaparkinson.donordrive.com/event/2015MNWalk/>. For more information about our services in Minnesota, please contact Joan Brandl, RN at 651-241-8297 or via email at Joan.Brandl@allina.com.



**American Parkinson Disease Association
Information and Referral Center of Minnesota**
United Hospital
John Nasseff Medical Building (MR 63201)
333 N Smith Avenue
St. Paul, MN 55102



SUPPORT APDA MINNESOTA! JOIN APDA MINNESOTA: A CAMPAIGN TO EASE THE BURDEN HERE AT HOME

APDA Minnesota's mission is to be a partner in easing the burden of our families and neighbors afflicted with Parkinson's disease.

By providing helpful resources such as our Information & Referral Center, support groups, a well-stocked library, special events and programs, educational symposium and seminars, we work with patients and their families to maintain the highest standard lifestyle possible for as long as possible. And, we do this without charge or membership fees.

We need your help, however, and ask that you make a donation to allow APDA Minnesota to continue these services and resources for free. No amount is too small and will have a positive impact on the many families in Minnesota burdened with a progressive degenerating neurological disease. If you cannot give at this time, please think of those in your life who would like to contribute on your behalf and share this request with them.

If you have an address change or want your name taken off our subscriber list, please give us a call toll free at 888-302-7762 or in the Twin Cities area 651-241-8297. Also, feel free to call with any questions or comments.

DISCLAIMER: The material presented in this issue is solely for the information of the reader. It is not intended for treatment purposes, but rather as a basis for discussion with the patient's physician.