

FALL 2015

MINNESOTA | Newsletter of the Minnesota
American Parkinson Disease Association

MESSENGER

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DIFFERENTIATING PARKINSON'S DISEASE DEMENTIA, LEWY BODY DISEASE AND ALZHEIMER'S DISEASE

Okeanis Vaou, MD



Parkinson's disease (PD) is the second most common progressive neurodegenerative illness after Alzheimer's disease (AD). Cognitive impairment and dementia are common features in PD and characterized by a wide range of cognitive deficits distinct from those seen in AD. For a person to be considered to have dementia, he or she must have 2 or more impaired mental functions. These functions may include loss of memory, language skills, visual perception and the

ability to focus and pay attention. Also, the loss of brain function must be severe enough that a person cannot do normal, everyday tasks. Dementia is a term that is used to indicate loss of intellectual abilities. It does not speak to the cause of the loss of these abilities. It applies to many conditions that meet the criteria discussed.

Dementia in PD is seen in 30-50% of the patients, typically around 10 years after onset of motor symptoms. Old age and long duration of the disease, worse motor disability and depression increases the risk of dementia. There is also evidence to suggest that postural instability and gait disorder are more predictive of dementia than the tremor predominant form of PD.

The most common complaint in patients with PD dementia (PDD) is difficulty with memory and difficulty learning new material. Language disorders are rarely present. PDD is characterized by impairment in

(cont. on page 3)



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COORDINATOR'S COLUMN: A FOND FAREWELL



Joan Brandl

Dear Readers,

With mixed emotions I am announcing my retirement effective October 23rd, 2015 as APDA Program Manager and Coordinator for Minnesota. I have greatly

enjoyed my time with APDA and working for Allina. However, it is time for me to move on to the next chapter of my life. I hope to be able to spend more time with my grandchildren, play more tennis, enjoy our condo in Florida, help my adult son who has a disability and of course travel. In time I will find new opportunities to volunteer and continue to help others which has been my life long purpose.

I have enjoyed working with a wonderful Board of Directors, fantastic support group facilitators and have had the privilege and honor to meet many people with Parkinson's disease and their carepartners. I have learned a great deal in carrying out my responsibilities and will always be grateful for this opportunity. I hope that in some small way, I have helped to "Ease the Burden" for you and your family, by providing resources, direction, advocacy or education for you.

Allina Health has been a great community partner with APDA and has very generously supported the work that I do by providing an office, mailings, assisting with the creative design and mailings of the newsletter and so much more.

Thank you to my colleagues who have supported APDA with assisting at educational

conferences and symposiums. I have had the honor of meeting many of the neurologists, neurosurgeons, therapists psychologists and social workers in our area who have generously given of their time to present at programs and conferences that I have organized. I am also very grateful for the vendor support from the pharmaceutical industry and medical industry for conferences and symposiums throughout the past 4½ years.

Although, my replacement has not yet been hired, I am sure someone will be in the upcoming months. In the meantime, if you have questions, please first of all contact your provider. If you are needing resources or support, please call the National Office at 1-800-223-2732. Brochures and booklets can be downloaded at apdaparkinson.org.

Thank you too, for the many individuals and groups that have supported the Optimism Walk. I hope that you had a wonderful time and perhaps I will see you at the Walk next year.

Until then, I wish you all the best and am hopeful that soon, we can all say that we have been part of the solution of "finding a cure for Parkinson's Disease." Blessings to each and everyone of you.

Wishing you all the very best,

Joan

MEDICAL DIRECTOR'S COLUMN



Dr. Okeanis Vaou

Dear Readers,

According to the American Parkinson's Disease Association, more than 1 million people in the United States have Parkinson's

disease, and 50,000 to 60,000 new cases are diagnosed each year. Those numbers prove that supporting the Parkinson's disease community is even more important than ever.

Unfortunately I have recently become aware of patients with PD that were approached and treated very unfavorably due to their symptoms, even within health care institutions. Dyskinesia, slurred speech and unsteady gait may lead people to believe that a patient with Parkinson's disease is intoxicated. Sadly these are symptoms of PD. Tremor is thought to be the main symptom in PD. Even though that may be true, multiple other symptoms, accompany this disease. We need to raise awareness for PD and educate people and caretakers about the different symptoms a patient with PD may have.

Lets all help to make this disorder known to the public by participating in our growing community of PD through support groups, non-profit organizations and speaking up and educating family and friends.

If you missed the walk, you can still donate by going to joining the <http://apdaparkinson.donordrive.com/event/2015/Walk/>.

Thank you for your help in contributing to research for a cure for Parkinson's disease as well as supporting programs and services in our Minnesota Parkinson's communities.

Best, Okeanis

DIFFERENTIATING PARKINSON'S DISEASE (cont.)

executive functions, visuospatial skills, free recall memory. This should not be confused with bradyphrenia, a common syndrome characterized by forgetfulness, slowness of thought and mental processing, apathy and depression and altered personality. Behavioral symptoms such as depression, hallucinations, delusions, apathy and anxiety are commonly seen in patients with PDD.

At least 10% of the general elderly population will develop Alzheimer's disease (AD). There is little doubt that some signs of parkinsonism can occur late in AD. Dementia in AD is characterized by memory impairment, language difficulties or problems with executive functioning. AD may co-exist with PDD. AD may be familial in 15-25% of the cases and tends to present at an earlier age.

Lewy body dementia is a disorder where patients present with intellectual decline as an initial presenting feature. Parkinsonian symptoms soon follow and can therefore be frequently misdiagnosed as PD. The clinical features of Lewy Body Dementia consist of progressive cognitive decline with deficits on attention, memory and visuospatial functioning. The patient's cognitive function fluctuates significantly in time even from one day to the next. Recurrent visual hallucinations are present along with symptoms similar to PD such as slow movements, stiff muscles and tremors. Dream re-enactment is frequently seen but is not specific to the disease. Presence of Lewy bodies, abnormal aggregates of protein in the brain nerve cells were initially thought to be the pathological hallmark of the disease but we now know that these bodies can also be seen in PD.

Another type of dementia, frontotemporal dementia is characterized by a gradual change in personality change, language dysfunction,

and social behavior, with neglect of personal care, disinhibition, impulsivity, depression, loss of insight and a reduction in speech and is often associated with parkinsonian symptoms. It affects patients between 35-75 years of age. In 30%-50% of the patients, a family history of dementia is present.

Overt and acute cognitive worsening may be worsened by intercurrent illness or drug therapy such as sedating medication. They may cause confusion or even psychosis. Such treatable conditions should be considered and carefully evaluated before assuming that changes to the cognitive problems are due to progressive pathology or PD or coincidental illness such as AD.

Sorting out the various signs and symptoms of these syndromes can be a challenging and time consuming endeavor. The assessment begins with the patient and family history, a physical exam, neurological evaluation, serological tests, brain scans. Cognitive and neuropsychological tests may be helpful to assess memory and other mental functioning abilities. Laboratory tests may help to rule out other conditions.

Some types of dementias are secondary, caused by depression or B12 deficiencies and can be treated. Certain medications may be helpful in managing symptoms and behavioral problems associated with the disorder but not all types of dementias can be treated. Aside from medical management, physical and mental exercise, a healthy lifestyle has been proven to provide significant benefit to cognitive dysfunction.

Patients with cognitive decline and dementia need a multidisciplinary approach with a large support system for the patient as well as the caregiver.

Dr. Vaou is a board certified neurologist and is a Movement Disorders and Sleep Specialist. She practices at The Noran Neurological Clinic in Minneapolis.

ACTIVITY TRACKERS – SO MUCH MORE THAN JUST A Pedometer!

By Beth Millage, DPT NCS, Courage Kenny Rehabilitation Institute-Mercy Hospital Outpatient Therapy



I'll admit that I thought that activity trackers were just a fad to attract gadget-savvy people, however, I recently found a good deal on one and jumped on the bandwagon. I have been very pleased with it and thought I could

share with my patients, co-workers, and readers of this newsletter what I have learned through personal experience and research.

For me, my job requires a great deal of physical activity and movement throughout the day as I assist those in their rehabilitation. I have found that as work and family life require more of my time, I have not been as good about working on my personal fitness. Having an activity tracker has helped me get back on track with setting some goals and improving this. I love that I don't have to remember to reset it daily, and I just wear it all the time so that I don't forget to use it.

There are many activity trackers out there, and I am not here to recommend one over the other. Instead, I would like to give you some guidelines to select the right one for you. Many companies out there provide various levels of devices in a variety of price ranges. Some examples include Garmin's vivofit, FitBit (Charge, Flex), Jawbone, Omron, Adidas Fit Smart, and many more.

(continued next page)

Here are some things to consider when you are shopping and comparing various devices:

- Do you have a Smartphone? Many of these trackers are designed to work with apps on a smartphone to graph your progress although some will download data to a personal computer as well.
- Do you want your data to download wirelessly or use a cord? To see all of the information that is being tracked, some devices need to plug-in with a cord while others use Bluetooth/wireless transmission.
- Will your tracker require charging or a change of battery? This varies greatly with each type—consider cost of battery replacement or the need to remember to charge a device as needed.
- Will your device get wet? There are many models that are water-resistant to certain depths so it does not need to be taken off during bathing, chores, or water activities.
- Will you need a larger screen? If you have vision challenges, you may want to consider the screen size and if it is backlit or not.
- Do you want a clock? If you are going to wear this in addition to your favorite watch, skip the clock. Otherwise you may choose to wear this instead of a watch.
- How much are you willing to spend? Think of this as part of your plan for fitness and consider how much you can dedicate to this device. Some start with a basic and less expensive model to see how they can utilize and then may upgrade later.
- How does the device go on your body? Some clip onto a waistband, others are a wrist or ankle strap. Be sure you are able to put it on yourself to maximize its use. Some manufacturers recommend wearing the device on your non-dominant side to avoid counting your movements as steps as you go about your day.

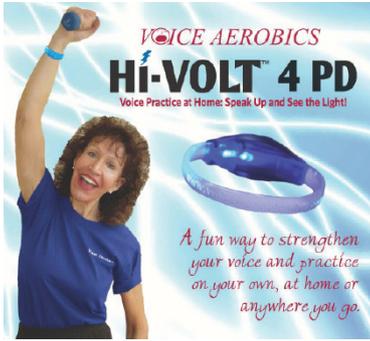
- What activities do you do for fitness? Activity trackers typically do not track things like cycling, swimming, and weight lifting, but some of the apps do allow you to input this information via website or smartphone.
- What information would you like to know? Activity trackers can simply count steps or some models can give information about sleep cycles, track mood or symptoms (you have to input this information manually however), estimate calories burned, graph progress, monitor heart rate (may need to wear chest strap for this), and automatically set more progressive goals for steps per day. This information can be useful for fitness but also to assist your neurologist with information regarding your PD symptoms.

Whether you choose an activity tracker or a simple pedometer, the recommendation is for adults to try to achieve 10,000 steps a day for health. This is almost 5 miles! However, this is spread throughout the entire day. For those with limited mobility, it may be difficult to achieve this but personal goals can be set to try to increase average steps by 10% each week. If you need an assistive device or help to walk, you can still utilize a device to track your activity level and work on goal-setting. Walking and standing provide many benefits to our bodies, so it is important to work on this daily. If you have concerns about your fitness or mobility, consider seeing a Physical Therapist to talk about a program that would work for you.

Beth Millage is an Outpatient Physical Therapist who specializes in Parkinson's Disease Rehabilitation at Courage Kenny Rehabilitation Institute, located in the lower level of Mercy Hospital. Call 763- 236-8910 for questions or to find out more about Physical Therapy and PD

BEST KEPT SECRETS – DID YOU KNOW...

Hi-VOLT™ 4 PD is an audio CD of guided voice practice



Developed by speech-language pathologist, Mary Spremulli, MA, CCC-SLP, Hi-VOLT™ for PD is an audio CD containing 27 minutes of voice practice. The CD contains words, phrases, and sentences, all designed to help users access breath support and feel the effort it takes to achieve or maintain adequate voice loudness.

The accompanying Hi-VOLT™ voice-on-light is a voice-activated bracelet. It has been calibrated so that when the user speaks loud enough to activate the light, they will be loud enough for others to hear them. “In therapy with my own patients,” Spremulli says, “I give only one cue: speak loud enough to activate the light.” The bracelet can be worn like a watch or placed in front of the user. Just like a speedometer on your car provides feedback, the Hi-VOLT™ voice-on-light provides feedback, helping users stay loud enough for everyday conversation.

(The battery life on the Voice-on-Light is 30 continuous hours of static and active engagement in the ‘ON’ position. Based on one hour/day of use, the bracelet should provide 30 days of use before needing to be replaced. Many people have expressed a desire to use the device throughout the day, so, the manufacturer is currently investigating options for a longer lasting or easily replaceable battery.)

Portable Digital Voice Amplifier



A portable voice amplifier can be a great tool for those instances when it feels harder to use your voice. Mobility devices, like canes and walkers, help you move more safely and independently, so, why not have a voice amplifier available as a “vocality” tool? Amplifiers

are used routinely by teachers and public speakers as a way of reducing vocal strain. A person with a weak voice from Parkinson’s or related diagnosis might enjoy using an amplifier for social gatherings or other settings where you just want your voice to be heard. This amplifier is dispensed with a headset microphone and long lasting rechargeable battery. You may obtain further information about these new devices/tools at their website: www.voiceaerobicsdvd.com

There are other helpful amplifiers and loudness monitors. Check with your speech and language pathologist for options available to you. Amazon.com also carries a variety of models.

Vibrating Watch for Medication Reminders



Vibra-Lite wrist watches have large, easy to read displays, and easy, user-friendly prompts assist in settings. Unique to this medication reminder is that you may select vibration, audible or both as options. There are multiple daily alarm settings, with a countdown timer with auto

repeat option and option of alert reminders before zero. www.vibralite.com/

Liftware Spoon



Liftware is a stabilizing handle and a selection of utensil attachments that include a soup spoon, everyday spoon, and fork designed to help people with hand tremor eat more easily. It works best for those with

mild to moderate tremor. This adaptive device automatically stabilizes so the attached utensil shakes 70% less than your hand. It enables you to worry less about spilling and focus more on enjoying your meal. Liftware automatically turns on the moment both parts are connected, and temporarily “goes to sleep” when not in use.

Liftware comes with its storage pouch so you can bring it with you where you go. A full battery charge can last you through several meals, so you don't always have to worry about bringing the charger along.

New Prescription Medication Co-Pay Program

The Patient Access Network Foundation recently established a co-pay program for individuals with Parkinson's. Co-pay programs provide direct financial assistance to qualified patients, assisting them with prescription drug co-payments their insurance requires relative to their diagnosis.

To qualify:

- Patients must have either Medicare or a commercial insurance, and
- Not have income in excess of 500% above the federal poverty line.

Co-pays for all drugs prescribed for the treatment of Parkinson Disease are eligible with a maximum yearly reimbursement of \$16,500.

Patients, their clinicians or their pharmacy can register for the program at the Patient Access Network Foundation by phone at 866-316-7263 or through the PAN Web site www.PANfoundation.org by answering a few questions. Individuals will know immediately if they are eligible for this new co-pay program.

Pill Pack – Pharmacy Simplified



People with Parkinson disease often have a large number of medications to manage. Sorting medications can be difficult and time consuming. PillPack, a new kind of pharmacy,

simplifies the process of managing medications.

- Medications come organized in individual packs organized by date and time
- Your PillPack is delivered to your door every 2 weeks
- The service comes with proactive refill management. Pharmacists manage your refills, so you'll never run out.
- Pharmacists are available 24 hours a day to answer your questions via phone or email.
- Packs can include prescribed and over-the-counter medications and multivitamins

There is no charge for PillPack beyond your standard 30-day co-pays. Pill pack accepts most major insurance plans, including forms of Medicare Part D. There are no shipping, handling, or extra fees associated with switching to PillPack.

To learn more about PillPack or to enroll, visit the website at www.pillpack.com or call, 1-855-745-5725.

Reprinted with permission from the St. Louis Parkinson APDA Chapter per Debbie Guyer, Executive Director.

2015 OPTIMISM WALK SPONSORS

The American Parkinson Disease Association Information and Referral Center and Chapter would like to recognize and thank the sponsors of our 2015 Optimism Walk who so generously donated funds or silent auction items for the success of the Walk. Please take a moment to review these sponsors and community partners and thank them for their support. APDA is committed to “Easing the Burden and Finding a Cure” for Parkinson’s disease. Donations will be used to support the vital programs and services of the MN Information and Referral Center as well as the research approved by the APDA Scientific Committee.

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PARKINSON MN APDA OPTIMISM WALK 2015



Young volunteers



Family volunteers



Silent auction volunteers



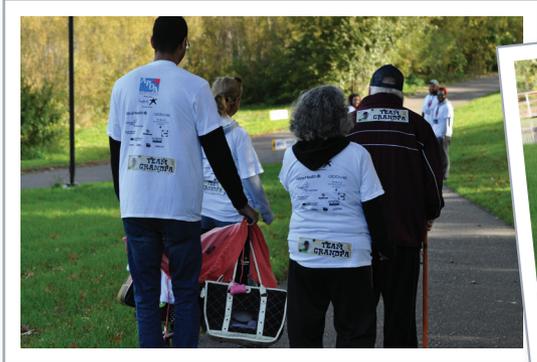
Face painting



Clear skies in October



Governor Al Quie



Family Walkers



Visitors from Greece



Theresa's Walkers



Support group Walkers



MN Chapter Board of Directors

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.

Unity Hospital, Lower level, Classroom C or Boardroom BIG & LOUD Fridley, MN 55432

Classes meet the first and third Tuesday of

each month, 9-10 a.m. BIG (physical therapy); 10-11 a.m. LOUD (speech therapy).

For more information or to register at this location call 763-236-3000.

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 Ellen 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 Ellen 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 Ellen 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 Ellen 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 Ellen 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.



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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 call the National Office at 1-800-223-2732.

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.