

FALL 2014

MINNESOTA | Newsletter of the Minnesota
American Parkinson Disease Association

MESSENGER

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AN ESSAY ON THE SHAKING PALSY

“It therefore is necessary, that some conciliatory explanation should be offered for the present publication: in which, it is acknowledged, that mere conjecture takes the place of experiment; and, that analogy is the substitute for anatomical examination, the only sure foundation for pathological knowledge...Some have regarded its characteristic symptoms as distinct and different diseases, and others have given its name to diseases differing essentially from it; The disease is of long duration: to connect, therefore, the symptoms which occur in its later stages with those which mark its commencement, requires a continuance of observation of the same case, or at least a correct history of its symptoms, even for several years.”

– James Parkinson, Member Of The Royal College Of Surgeons
London: 1817



PARKINSON'S DISEASE AND ITS VARIANTS

Anthony Santiago, MD

Our debts to James Parkinson are many; his humility, compassion and wisdom are evident when reading his seminal treatise. History suggests that for at least a century after his publication, the diagnosis of paralysis agitans implied a singular disorder. The emergence of Postencephalitic Parkinsonism (PEP) following the pandemic of encephalitis lethargica (von Economo's disease) early in the 20th Century, and the recognition of vascular ("arteriosclerotic") Parkinsonism shortly thereafter, led to

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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,

Thank you for your excellent response to the spring edition of the *Minnesota Messenger*. Martha Nance, MD, did an outstanding job of addressing the issue of *End of Life Issues in*

Parkinson's Disease, a topic that is not frequently addressed. Julie Eckman RN, Spiritual Director, likewise provided us with additional possibilities in caring for self through her very informative article on *Tending the Spiritual Part of Our Being*.

The responses to these articles were very positive and I appreciate hearing from readers to let me know that I am on track with providing you with useful information.

In this issue you will be hearing about Parkinson's Disease and its Variants. This topic is complex and I am sure you will have questions. Some of the medical terminology may be challenging, but keep in mind that this newsletter is here for a broad audience.

I am grateful to my colleague, Debbie Guyer, Executive Director of the APDA St. Louis Chapter and Michelle Burack, MD, PhD who shared the article on *Apathy – Just Do It!* Dr. Burack does an excellent job discussing how dopamine affects motivation.

On another note, just a reminder that if you have been diagnosed with PD within the past 2 years, I would be happy to send you an excellent book on PD as part of the *Good Start Program*, a video on PD, and of course a complimentary subscription to this Newsletter.

Enjoy the fall and please remember to sign up early for the conference in October!

Warm Regards, Joan

MEDICAL DIRECTOR'S COLUMN



Dr. Okeanis Vaou

Dear Readers,

I have been asked to comment on a recent study on the various classes of medications used for treatment of Parkinson's disease. One of the largest studies ever completed on this subject, compared three different classes of PD drugs and found that levodopa had somewhat better control of motor symptoms of Parkinson's disease than do dopamine agonists and monoamine oxidase type B inhibitors (MAOBI). The study included 1620 PD patients from 2000 to 2009.

Patients in the levodopa group were more likely to develop dyskinesias (involuntary movements) than those in the levodopa-sparing group but there was no difference in motor fluctuations.

Non-motor side-effects such as nausea, hallucinations, leg swelling, and sleep disturbance are more frequent with dopamine agonists than with levodopa and could be more important for patients and their care providers than are motor complications.

It was found that the overall balance of benefits and risks favors levodopa over the other Parkinson's medication with better patient-rated quality of life both in the short and long-term. Levodopa treatment achieved better scores than did dopamine agonists or MAOBIs on the mobility outcome, and a range of other patient-rated outcome measures, including overall quality of life.

In conclusion, the study shows better outcomes with initial therapy with levodopa compared to either dopamine agonists or MAOB inhibitors. However the difference in benefit is small. If levodopa-sparing therapy is preferred, starting with MAOBIs seems to be at least as effective

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as with dopamine agonists. Patients who were started on a dopamine agonist or MAOB inhibitor are more likely to discontinue these drugs due to side effects or add another agent.

With this study, there is sufficient data to support initial therapy with levodopa but starting therapy with any of the other two classes is not incorrect either. The priority is for the physician to work with the patient together as a team and decide which medication fits the patient's needs the best. As the disease progresses, using multiple medication combinations is unavoidable.

Best, Okeanis

PARKINSON'S DISEASE AND ITS VARIANTS *cont. from page 1*

the general acceptance that at least secondary forms may exist. Notwithstanding, a cursory review of the literature of the last nearly 200 years demonstrates that it was commonly held that patients with primary Parkinsonism (not secondary to an acquired insult but rather due to a degenerative brain disease) were believed to have a unitary disorder that had a distinct neuropathology, and that it was not until fairly recently – the 1960s – that Atypical Parkinsonian Disorders were discovered.

But, as early as 50 years after Dr. Parkinson described patients with tremor, postural changes and gait impairment as the clinical hallmarks of the disease that would come to bear his name, Dr. Jean-Martin Charcot returned repeatedly to those early case descriptions, and comparing them with his patient base numbering in the thousands while he worked at the Hopital de la Salpetriere in Paris, more clearly defined the features of the disorder: differentiating a “tremor at rest” from one associated with Multiple Sclerosis (MS) or tremor most pronounced while maintaining limb

posture or performing a task; emphasizing the specific change in limb tone seen in Parkinsonism as rigidity and not the spasticity seen after a Stroke or in MS; focusing on the primary feature of bradykinesia or slowness instead of weakness as the cause for the patient's lack of movement– hence his admonition to abandon the original designation of paralysis agitans in favor of the eponym Parkinson's Disease (PD); and a sophisticated and detailed description of the stance and gait of typical patients (flexed), distinct in appearance from the extended and upright posture of others - variants or *forme frustes* – cases that shared some of the cardinal features described above but dissimilar enough to warrant his term Atypical Parkinson's Disease.

As the pathologic substrate of PD had yet to be discovered, his differentiation of patients' diagnoses was purely clinical– yet it is now evident that Dr. Charcot and his colleagues were describing cases of Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD). Additional entries clearly demonstrate Parkinsonian patients with distinct clinical features - the absence of rest tremor, symmetrical features of the limbs at onset, extended postures of the neck and trunk, early loss of balance, facial bradykinesia and contracted forehead muscles (PSP); patients with profound progressive atypical tremor (myoclonus) with associated extremity contractures and apraxia, cortical sensory deficits (CBD).

As medicine “evolved” from the 19th to the 20th Century– there was a movement from the bedside to the bench – and the definition of a disease required a pathological correlate rather than simply a clinical description. Eventually, PD became defined by its pathologic hallmark, the Lewy Body – initially described by FH Lewy (and later named for him by his colleague, Tretkioff who refined the work) while a researcher in Alzheimer's lab in 1912. Lewy reported finding

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proteinacious intraneuronal cytoplasmic inclusion bodies in the brainstem of individuals with PD; many advocated changing the name of the disease to “Lewy Body Disease”, reflecting the bias of the time towards anatomic pathology rather than clinical phenomenology, but both have stood the test of time.

However, future reports of patients presenting with both Parkinsonism and dementia together early in the course of their disease, led to the description of the first clinically and pathologically distinct “atypical” Parkinsonian syndrome – Dementia with Lewy Bodies (DLB) – associated with a pattern of Lewy Body distribution distinct from PD and differing appearing Lewy Bodies relative to their respective locations in the brain. Ultimately, additional neurodegenerative syndromes – Multiple System Atrophy (MSA), Progressive Supranuclear Palsy (PSP) and Corticobasal Degeneration (CBD) – soon appeared (again) in the literature, with rich clinical descriptions accompanied by distinct pathological underpinnings. If that were not enough to demonstrate that primary Parkinsonism has many variants, finally, more recent discoveries of multiple genetic variants of PD, some without Lewy Bodies, have been well-described – further challenging whether even PD is a single entity.

To patients and their loved ones, the issue is not merely academic. As all of us embrace the value of the bench, it is at the bedside that we meet, physician and patient, to confront our common enemy. Whereas all Parkinsonian syndromes are clinically defined by bradykinesia associated with rigidity and/or rest tremor, the atypical Parkinsonian disorders are characterized by a rapidly evolving Parkinsonism with poor or transient response to dopaminergic supplementation; are associated with one or more distinct clinical feature(s) uncommonly seen in PD – early postural instability and falls, early autonomic failure (early and severe urinary or bowel dysfunction, orthostatic hypotension)

vertical supranuclear gaze palsy (often initially experienced as double vision), weakness/spasticity, ataxia, apraxia, early cognitive impairment, present visual hallucinations even before the introduction of PD treatment medications; and as a group of disorders, they carry a more ominous prognosis, with a shorter survival time, more severe complications and clinical features frequently refractory to either medication or surgical interventions.

Diagnosis of these atypical Parkinsonian disorders can be challenging, especially early in their presentation, as their clinical features initially overlap considerably with those seen in typical PD, and the atypical features described above may not emerge for more than 2-4 years after symptom onset. But, early postural instability and falls, Parkinsonism not responsive to dopaminergic medications and the presence of spontaneous visual hallucinations prior to introducing treatment medications are important suggestive features that must not be overlooked.

There is no definitive diagnostic biomarker or imaging test for the diagnosis of PD. It is a clinical determination that is both inclusionary and exclusionary in form and substance. It requires an extensive neurological history and exam, and particular ancillary studies (brain imaging, analysis of blood, urine and/or spinal fluid) as the history and exam warrants. The United Kingdom Parkinson’s Disease Society Brain Bank clinical diagnostic criteria delineate a 3-step process for the diagnosis of PD in the clinical setting. As referenced above, the first step is the diagnosis of a Parkinsonian syndrome based on the presence of bradykinesia and at least 1 of 3 other signs: muscular rigidity, rest tremor, and postural instability not caused by primary visual, vestibular (balance problems), cerebellar (coordination of movement), or proprioceptive dysfunction (loss of ability to sense position of body). The second step defines exclusion criteria for PD, including prior conditions, such as repeated strokes, repeated head injury, and

encephalitis (brain infection/inflammation); exam signs such as oculogyric crises (sustained rotation of eyeballs), ataxia, early severe autonomic involvement, and/or the presence of abnormal reflexes that reflect injury to portions of the brain or spinal cord more commonly seen in other neurologic disorders. The third step outlines what is the anticipated response to commonly prescribed treatments and a common clinical evolution that reflects PD rather than one associated with other atypical Parkinsonian disorders. As approximately 30% of patients with PD do not have tremor, the absence of rest tremor is not exclusionary per se; also, symptoms in PD are asymmetrical in almost 80% of presenting patients and early symmetrical presentation may suggest an alternative atypical syndrome; finally, as previously emphasized, postural instability and falls typically occur in later stages of PD and their early presence is cause for concern.

Thus, clinically defining the particular Parkinsonian Syndrome at onset can be challenging, especially when the signs and symptoms seem indistinct. But, undaunted, we should recall the wisdom of Dr. Parkinson, and recognize that to reach an accurate diagnosis “requires a continuance of observation of the same case, or at least a correct history of its symptoms, even for several years”.

Anthony J. Santiago, MD is Associate Professor and Vice Chair of Neurology, Director of the Neurology Residency Program, Section Chief of the Divisions of Movement Disorders and Ataxia, and Director of the Movement Disorders Fellowship Program at the University of Minnesota. Previously, he was Associate Professor of Neurology at the Muhammad Ali Parkinson Research Center of Barrow Neurological Institute (MAPRC/BNI), where he served as the National Parkinson Foundation Center Director, Director of the Movement Disorders Fellowship Program and the Director of Clinical and Translational Research in Neurodegenerative Disorders.

NAVIGATING THE PATH FOR ASSISTIVE DEVICES

Beth Millage, DPT

Courage Kenny Rehabilitation Institute, Mercy Hospital Outpatient Therapy



Some people with Parkinson's Disease benefit greatly from use of an assistive device to improve walking stability, decrease freezing episodes, and to reduce pain from orthopedic issues by reducing weight-bearing. People often

report feeling more confident, especially in the community and busy public settings, if they have a device to hold for balance. There are now a variety of devices available, and it is beneficial to utilize a Physical Therapist to determine the most appropriate device to meet your needs as well as provide some training in the correct use. I will briefly outline a few of the ones that we commonly use in our clinic:

Walkers are known to be very stable as they provide four points of contact. There are pick up types, front rolling, and four-wheeled walkers with brakes and a seat. A specialty walker, the Ustep, is also available with a reverse braking mechanism for those who struggle with control of speed in walking, but this requires additional documentation to support and more training. Each one requires various levels of control and need to be selected carefully.

Canes provide minimal support and are easy to transport. There are single-point, wide-based quad canes, narrow-based quad canes, and tripod canes. Canes also come with a variety of handles to accommodate those with arthritis or need for various hand grips for comfort.

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Hiking poles/trekking poles/walking sticks are often lightweight and can be used on one or both sides of the body. Because they are taller, they allow people to stand more upright and may assist with lengthening strides by achieving more arm swing. Nordic walking has become quite popular in the area, and there is research to support its use to improve walking and balance in PD.

With any device selected, patients often ask, “Will my insurance cover this?” The quick answer is that most insurances do cover devices to help with walking with a physician’s order that includes name of the device, why it is needed, and length of time needed (usually lifetime). It is also helpful if there is medical documentation from the therapist or physician about how the device improved walking, decreased falls, or otherwise has improved mobility. Be aware that you may have a co-pay or percentage that you may have to pay out of pocket depending on your coverage. Also know that most companies will only pay for an assistive device every 5 years, and this includes wheelchairs. As a Therapist, I often encourage people to self-pay for lower cost items, like a single end cane, if they anticipate that they may later need a wheelchair or specialty walker to best utilize their insurance resources.

Assistive devices can be purchased in a variety of places (medical equipment vendors, specialty clinics, drug stores, warehouse stores, online stores) but quality can vary. Again, it can be helpful to talk with a Physical Therapist for guidance in this area.

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.

APATHY – JUST DO IT!

*Michelle Burack, MD. PhD
Assistant Professor, Department of Neurology,
University of Rochester Medical Center*



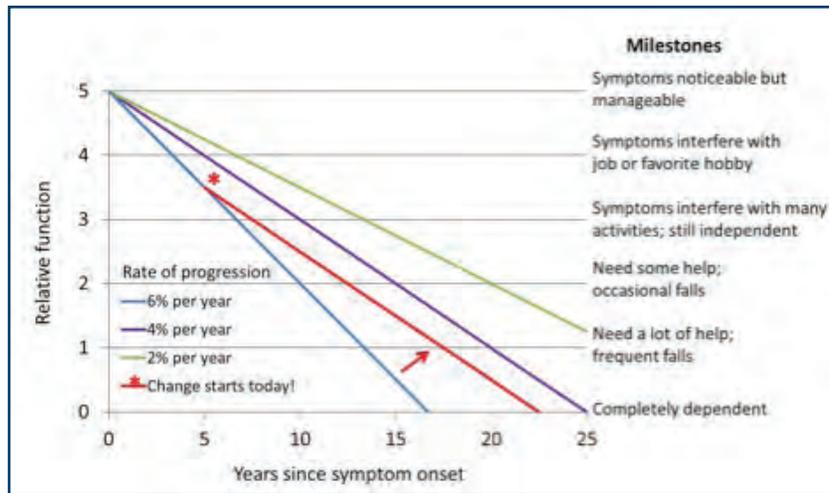
Our local support group chapter’s annual symposium was held in April, and I had the opportunity to hear John Baumann, a motivational speaker who “just happens to have Parkinson disease.”

His action-oriented, positive perspective, and quirky sense of humor were the highlight of the day. A video of one of his presentations can be found on the internet at <http://theinspiringesquire.com>.

The transformation John described—the improvement in well-being that came about once he changed his lifestyle –is something that I have observed in my clinical practice many times, but has been hard to “prescribe” effectively for everyone. For some people, just knowing that it is possible to change the future is enough to energize and motivate action. For others, it’s not so easy. No matter how it’s phrased—“Commit,” “Just Do It,” “Mind Over Matter,” “Whatever it Takes”—it can feel like trying to pull yourself up by your bootstraps.

Fortunately, the rules of gravity do not apply here! Daily choices and mental attitude can have a significant long-term impact on the evolution of the disease. YOU DO have the power to change what happens. No matter what milestone you may have heard about that seems like an inevitable part of your future, it is possible to push those milestones farther into the future through the choices you make today. Researchers are hunting and searching for medication that can change the course of the disease, but you already have access to powerful interventions that can bend the curve.

Everyone's PD progresses differently; some progress more slowly, others more rapidly. There are many different tools that researchers use to measure progression for clinical trials, and different tools show different rates of



change per year. It doesn't necessarily progress in smooth linear fashion. So this graph is a rough sketch I created simply to illustrate the following point: *No matter which curve you find yourself on today, you can bend that curve and change the future.*

The fundamental principle is “use it or lose it”—physical activity and social engagement are key to keeping brain cells alive, and can even stimulate brain cells to form new connections. Inactivity leads to faster decline not only in the brain, but also erodes mobility, flexibility, and strength through changes in the muscles and joints.

Some common barriers that can make it feel like a struggle against the boot straps:

1. Apathy and depression are common symptoms of PD.

We know that PD can affect the mood circuits in the brain—“it’s not just a movement disorder.” Sometimes the mood changes are easily recognized as depression, with loss of motivation and interest accompanied by feelings of hopelessness, worthlessness, or sadness. Other times, there can be loss of motivation without the sad hopeless feelings—i.e., apathy without depression.

In studies that looked at mood and motivation symptoms in people with PD, 40% had apathy with depression, 20% had apathy without depression, 15% had depression without apathy,

and 25% had neither. Many antidepressants are known to be effective for treatment of depression in PD. In contrast, we don't really know what treatments are most effective for apathy that is not associated with

depression, and well-designed research studies will be essential to determine what interventions can help.

Take-home point: If you are experiencing apathy, talk to your provider about whether depression might be at the root of it. Depression is treatable!

2. Dopamine is important for movement, but it is also important for motivation.

In the movement circuits, dopamine helps the brain decide when to move and when not to move. Without dopamine, the brain decides “don't move” too often, leading to problems with coordinated movements like walking, talking, swallowing, writing, etc.—causing smaller movements, slower movements, fewer movements, and difficulty starting movements.

Dopamine also helps the brain decide at a higher level whether actions are a good idea or a bad idea. In some areas of the brain, dopamine serves as a “reward hormone,” helping the brain remember actions that led to something good. Opportunities for similar actions in the future are remembered as a “good idea” that can hopefully lead to similar rewards. (Drugs of abuse like cocaine hijack this reward system, leading to addiction.)

In PD, the dopamine neurons in the movement circuit are usually affected earlier and more severely than dopamine neurons in the “reward”

system, resulting in greater changes in movement than in motivation and decision making.

However, the dopamine in the reward circuits can also become involved with PD. Using a special type of brain scan, researchers measured dopamine in the brain's reward centers in people with PD, and found that individuals with apathy symptoms had lower dopamine release in the reward centers compared to individuals without apathy symptoms. Other studies have found that on average, individuals with apathy take lower doses of PD medication than individuals without apathy. Apathy can also sometimes emerge when medications are lowered after deep brain stimulation surgery. This all suggests that apathy might respond to increased dopamine-replacement medication. However, too much PD medication in the reward circuits can lead to altered decision making and risky behavior in some individuals. It is important to work closely with your provider to make sure your dose of medication is optimally balanced to maximize symptom control while minimizing side effects.

Take-home point: If you lack energy and motivation to push back against PD, talk to your provider about whether your PD medication dose is adequate.

3. Logistics can sometimes seem complicated.

Compared to swallowing a pill, exercise takes investment of significant time and energy. Some types of exercise require transportation to access the equipment or facilities needed to do it. Thinking about these logistics can become so overwhelming that a miracle pill seems easier. But every day that goes by is a lost opportunity to bend that curve. Don't wait. Just like retirement savings, you lose the cumulative benefit of "compound interest" if you don't start early. You don't have to go from zero to 60 in a day. Start simple. How do you eat an elephant? (One bite at a time.)

If your daily activity is zero minutes, start with 5 minutes. If it is 5 minutes, celebrate! and then make it 10. Slow and steady wins the race, but only if you take that first step off the starting line. You can do it!

If you're already exercising an hour a day, Bravo! You can still benefit from trying to push the intensity a little harder. Beyond the personal anecdotes like John Baumann's, there is scientific evidence that forced exercise, i.e., pushing a little bit beyond what you think you can do leads to global improvements in PD.

Take-home points:

- Start today. Every day adds up to a difference down the road.
- Start small, and build up gradually.
- Choose something that you will actually do on a regular basis. It doesn't have to be fancy. A simple home exercise program that you do every day is going to pay off much more than an elaborate exercise routine you only get around to doing once a month.
- Pushing yourself just a little harder may create new pathways in the brain to slow down the disease.
- Find a friend to exercise with.

Dr. Burack is a movement disorders fellowship trained physician from Rochester, NY and St. Louis, MO. With her permission and editor, Debbie Guyer's permission, this article is reprinted from the St. Louis APDA LINK newsletter .

FINDING THE "RIGHT" PHYSICAL THERAPIST

Beth Millage, DPT, Courage Kenny Rehabilitation Institute at Mercy Hospital

You likely wouldn't see a Cardiologist for a sore on your foot, and you wouldn't likely see a Dermatologist for a stomach issue. Point being, in our busy world and complex medical system, we need to get to the right kinds of specialists to take care of our needs and best utilize our resources. It is very important that people with Parkinson's Disease and other related movement disorders be seen by a Movement Disorders Specialist or a Neurologist who has specialized or has interest in the complexities of this disease for their medical care and medication management. It also is very important to be referred to a Physical Therapist who is a specialist in working with people with PD.

In Physical Therapy school, students are only provided with a very small amount of information about PD and may not always work with people with PD during their clinical affiliations. When Physical Therapists graduate from school, many work in a clinic where their specialties and interest areas are developed. Physical Therapists who have undergone additional training and have additional experience working with people with PD can provide a wealth of knowledge to the person with PD as well as their families and caregivers. Sessions one-on-one with a PT will address PD symptoms that are affecting mobility and can teach the person with PD how to complete home activities that can further improve their daily lives. I strongly encourage you to do all that you can to improve your

Parkinson's symptoms by working with a PT to help you feel better and stay at a higher level of mobility. PT can work to reduce muscle stiffness and pain, improve your balance, improve walking mechanics, improve activity tolerance and energy level, and may improve posture.

When looking for a PT that has had continuing education in some of the latest research-based approaches for amplitude-based training and working to slow disease progression, you can look up clinicians in your area using <http://lsvtglobal.com> to look for PTs who have completed certification in the LSVT BIG approach or <http://pwr4life.org> for PTs who have completed PWR! (Parkinson's Wellness Recovery) Clinician training. Research is showing us that exercise needs to be done intensively and regularly to receive the maximal benefit. You can also contact the Courage Kenny Central Scheduling line at 612-262-7979 to set up an initial evaluation for Physical Therapy (most insurances will require you to have a Physician's Order for PT for this service to be covered) and request to work with a PT in your area that specializes in working with people that have Parkinson's Disease.

Once you have found a Physical Therapist that meets your needs, stay in touch and return to PT as needed for "tune ups"! Since PD is a progressive disease at varying rates for everyone, sometimes people need to return to PT for short durations to update their exercise program, address new issues, or look at medical equipment that may assist with walking and daily activities. Your Physical Therapist can be a valuable member of your care team, and he/she can be a great resource.

SAVE THE DATE

AMERICAN PARKINSON DISEASE ASSOCIATION FALL CONFERENCE

Saturday, October 18, 2014

Black Bear Crossings, Pavilion Place Meeting Center
1360 North Lexington Parkway, St. Paul, MN 55103
Phone: 651-488-4920

Conference Agenda

- 9:30 a.m. Registration and Vendor Displays
- 10:20 Welcome and Announcements
Joan Brandl, APDA Coordinator
- 10:30 Improving Mood and Motivation with PD
Michael Schmitz, PsyD
- 11:30 Lunch and Exhibits
- 12:15 p.m. Visual and Auditory disturbances in PD
Okeanis Vaou, MD
- 12:45 What's New in PD Diagnosis and Treatment?
Okeanis Vaou, MD
- 1:15 Evaluation and Adjournment

Cost

There is no charge for lunch and the program but registration is mandatory to reserve lunch and seating. Donations are appreciated. Please make checks out to the AMERICAN PARKINSON'S DISEASE ASSOCIATION MN CHAPTER.

Speakers



Okeanis Vaou, MD,
Noran Clinic,
Minneapolis.



Michael Schmitz,
PsyD

The program will be held on the third floor of the Historic Como Lakeside Pavilion. An elevator is available.

Black Bear Crossings is located centrally, between Minneapolis and St. Paul. **Parking is free.**

Questions? Call Joan at **651-241-8297.**



CONFERENCE REGISTRATION *(Please register by October 9, 2014)*

Please fill out the following form and mail to: **American Parkinson's Disease Information and Referral Center, Attn: Joan Brandl, United Hospital MR 63201, 333 N. Smith Ave., St. Paul, MN 55102** or call Joan Brandl at 651-241-8297.

Name(s) _____

Address _____

City _____ State _____ ZIP _____

Phone _____ # of people attending _____

REMEMBERING SUPPORT GROUP PIONEERS



(Left to right) Lucille Lieder and Louise LaBone

A pioneer in establishing the Wadena area APDA support group, Lucille Leider passed away this year. She and her twin sister, Louise, (who passed in 2009) both had Parkinson's disease. They contacted our center in the mid 1990's and organized a support group that continues to this day. They set a positive "can do" attitude in the group and felt strongly about the educational component of the group so members learned all they could about managing the disease. They both used their teaching background in organizing and directing the group. (Their husbands were always there too, connecting with the care partners who came).

Lucille and Louise had both been elementary school teachers for over 40 years, beginning their careers in a one room schoolhouse. The sisters both married and the two couples did many things together through the years and eventually came to live in adjoining rooms at the Heritage Care Center in Park Rapids.



*Kathy Kehrberg,
former APDA
Coordinator*

Kathy Kehrberg, the center coordinator who worked with them, visited them after they retired from the group. They were always glad to hear that the group was continuing on. The current group leader, Beverly Richard still has a few members who have been coming over these past 12 years.

It is this kind of on-going community involvement that helps new members from surrounding towns and farms feel truly supported. APDA Minnesota is grateful to Lucille's family who made a memorial contribution to the Chapter in her honor.

SUPPORT GROUP MEMBERS VISIT THE STATE CAPITOL



(Left to right, back row) Art Miller, Mike Gevelin, Dennis Patraw, Robert Hardman, Kathryn Gilbertson; (Left to right, front row) Erin McGee, Kay Gevelin, Joan Brandl, Jean Patraw, Susan Hardman, Nan Carpenter.

On March 28, 2014 volunteers from the Bethesda Capistrant Support Group visited the State Capitol to accept the proclamation from Governor Mark Dayton specifying that April was Parkinson's disease awareness month. Many thanks to the people who gave up their time to increase awareness of the need to "Ease the Burden and Find the Cure" for Parkinson's.

PARTY FOR PARKINSON'S FUND RAISER

Congratulations to the APDA Board of Directors for hosting another wonderful fund raiser to benefit the programs and services in MN as well as raise awareness of PD, and support needed research to "Ease the Burden and Find a Cure". The fund raising event provided dinner, dancing and a great silent auction for over 150 people at the Town and Country Club in St. Paul, MN. The Board would like to thank all of the people who attended, all of the individuals that donated time, expertise and silent auction items, The

WHITESIDEWALLS who provided the wonderful music and silent auction items, and especially our Corporate Sponsors including the Capistrant Family Foundation, Allina Health, and the Noran Neurological Clinic.

The Board of Directors are planning for further programs in MN to assist individuals and care partners with living well with PD. They include emergency grants, educational event support, transportation scholarships and more. Please contact Joan Brandl for further information.



From left to right: 1) The WHITESIDEWALLS Rock'n Roll Revue; 2) Patricia Skalski, Kathleen Lynch, Kathleen Kehrberg; 3) APDA MN Chapter Board of Directors; 4) Kathryn Gilbertson, Amy Kieffer, Jacqueline Capistrant, Dr. Laura Li, Dr. Terry Capistrant; 5) Jacqueline and Dr. Terry Capistrant, and Linda Kelley and Stuart Bauman; 6) Joan Brandl and Dr. Okeanis Vaou; 7) Sabrina Anderson, Brandi Lunneborg, Todd Lunneborg, Ara Lunneborg, Becky Skillings, Ian Lunneborg, Steve Skillings

PARKINSON'S DISEASE COMMUNITY SUPPORT GROUPS

For questions or for help in starting a support group, please call the APDA Information & Referral Center at 651-241-8297 or toll free 888-302-7762. Before attending your first meeting, please contact the support group facilitator. For information about the APDA Center, visit www.allinahealth.org/APDA.

Location	Site in the Community	Day of Week	Time	Facilitator/Contact	Contact Phone
Albert Lea	Senior Ctr.	4th Tuesday	9:30 AM	Anne Troska	507-874-3367
Aurora	White Community Hospital Cafeteria	2nd Thursday	6:00 PM	Barb Hammer	218-229-2493
Baxter	Excelsior Place	1st Thursday	1:30 – 2:30 PM	Jennifer Gillette	218-828-4770
Bemidji	WoodsEdge/WindSong Apts	3rd Tuesday	1:30-3:00 PM	Chuck and Ann Austad	218-444-9992
Big Lake (Under age of 60)	Saron Lutheran Church	2nd Tuesday	6:30 PM	Camille Johnson	763-350-7401
Bloomington	Friendship Village	1st Monday	10:45-11:45 AM	Chaplain Janell Weum	952-646-9027
Burnsville	Prince of Peach Church	2nd Thursday	6:00 PM	Leu Killion	952-898-9320
Burnsville	Regents of Burnsville	1st Wednesday	1:00-2:00 PM	Amber Stein	952-898-8728
Carlton	Interfaith Care Center	3rd Monday	2-3:30 PM	Kathy Waseen	218-389-6025
Coon Rapids	Coon Rapids Civic Ctr	2nd Thursday	2:00-3:30 PM	Glen Barcus	763-561-2494
Coon Rapids (Caregivers)	Mercy Hospital	4th Thursday	3:30-5:00 PM	Erin Vesey	763-236-8910
Duluth	Primrose Retirement Community	3rd Monday	10:30 AM-Noon	Doug & Avis Lindberg	218-729-9749
Eden Prairie	Victory Lutheran Church/Prairie Adult Care, INC	2nd Wednesday	1:30-3:00 PM	Kathleen Evanson Natalie Olive	952-949-3126 952-221-3228
Forest Lake	Birchwood Arbors Asst Living	1st Thursday	1:00-3:00 p.m.	Joyce Heimer	651-466-1025
Grand Rapids	Public Library	2nd Wednesday	1 PM	Sandy Layman Kristi Bogelgesang	218-328-5378 218-326-2766
Hastings	Senior Ctr.	3rd Wednesday	2:00-3:30 PM	Laurie Thrush	651-480-7689
Mankato	1st Congregation UCC Church	3rd Tuesday	2:00-3:00 PM	Irene Pfeffer	507-304-7026
Maple Grove	Maple Grove Medical Center	2nd Tuesday	1:00-3:00 PM	Sara Dooley Susan Metcalf	763-898-1532 763-898-1533
Maplewood (Caregivers only)	Gladstone Senior Ctr.	2nd and 4th Monday	9:30 -11:00 AM	Lorna Breiter	651-770-8172
Marshall	Sr. Adult Ctr	1st Wednesday	3:00-5:00 PM	Terry Hennen	507-929-5624
Minneapolis	Veterans Adm Med Ctr	3rd Thursday	1:00-2:30 PM	Ann St. Jacque	612-467-1380
Minnetonka (YOPD/Women)	Byerly's Comm. Room	3rd Tuesday	7:00 PM	Ruth Lotzer	952-888-1734
New Ulm	Oak Hills	2nd Monday	1:30-2:30 PM	Michelle Buerkle	507-794-3594
New Prague	Community Library	TBD	1-2:30 PM	Betty Tupy	952-758-3924
Prior Lake	McKenna Crossing	2nd Wednesday	6:00-7:00 PM	Mary Hagebusch	952-230-3303
Red Wing	Red Wing Area Senior Center	4th Thursday	2:00 PM	Patricia Kerman Patrice O'Reilly	651-327-2255
Richfield/Bloomington	Main St. Village	Last Monday	1:30- 3:30 PM	Bev Hampton	952-888-2376
Rochester	Realife Cooperative	3rd Thursday	1:30-3:00 PM	Dorey Johnson Marita Olson	507-281-1843 507-286-9277
St. Cloud	St. Cloud Public Library	3rd Monday	1:00-2:30 PM	Pamela Tritz-Okia	320-217-5100
St. Paul	Fairview Rehab Services 2200 Univ. Ave. W	1st Friday	1:00-3:00 PM	Sue Metcalf Becky Horton	612-273-3868
St. Paul-Bethesda	Bethesda Hospital	3rd Thursday	10:00-12:00 N	Kathryn Gilbertson	651-325-2150
St. Paul-Bethesda (Young PD)	Bethesda Hospital 1st Floor Board Room	3rd Wednesday	6:00-8:00 PM	Tanya Rand	651-232-2202
St. Paul-Como	Black Bear Crossings	3rd Friday	1:00 PM	Sue Knight Nancy Andrews	651-653-1045 651-698-4158
Springfield	Springfield Community Center	4th Wednesday	2:00-3:00 PM	Shari Koll	507-723-6120 507-227-0386 (c)
Stillwater	Boutwell's Landing Community Room	3rd Wednesday	10:00-11:30 AM	Aimee Stanton	651-351-2364
Virginia	Evelyth Health Park Services	3rd Wednesday	2:00-3:00 PM	Bonnie Saumer Mary Maki	218-638-2692 218-741-8069
Wadena	United Methodist Church	2nd Tuesday	12:15-1:15 PM	Beverly Richard	218-837-6323
Wilmar	Bethesda Pleasantview	2nd Wednesday	10 AM-Noon	Bunne Frost-Johnson	320-220-2512
Windom	Windom Hospital	2nd Tuesday	2:00-3:00 PM	Karen Denzer	507-831-0687

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.

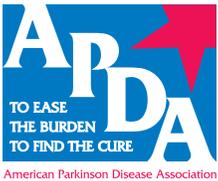
DONATE NOW!

Donate at <http://apdaparkinson.donordrive.com/event/2014MNPark>. 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

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ALLINA HEALTH
SYSTEM



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.