



AMERICAN
PARKINSON DISEASE
ASSOCIATION

GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

March/April 2022

MIDWEST PARKINSON CONGRESS In Person on April 7th, 2022

We can't wait to see you in person at this one-day conference focusing on living well with Parkinson's disease. The conference features an esteemed panel of industry leading professionals discussing the latest information, as well as a Resource Fair, all to help you live your best life.

Location: Logan University Purser Center - 1851 Schoettler Rd, Chesterfield, MO 63017

Time: 9:00 AM to 2:30 PM

Registration is required. Visit our website to register. COVID safety precautions will be taken and we ask that everyone who attends please wear a mask

Speakers and Topics:



Stein Keynote Speaker
Tim Hague Sr.

*Live Your Best
A Life Experience Living
with Parkinson*

Dr. Joel Perlmutter – *The latest in PD research*

Dr. Joyce Balls-Berry – *Disparities in PD Healthcare*

Dr. Robert Cunningham – *Assistive Technology for PD*

Dr. Peggy Barco & Gabrielle Blenden, MS, OTR/L – *Driving Retirement*

Dr. Mwiza Ushe – *Deep Brain Stimulation: What Do I Need to Know*

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PARKINSON'S EFFECTS ON VISION

People with Parkinson's disease (PD) may have a variety of complaints related to their vision such as trouble reading, double vision and dry eyes. While these issues don't affect every person with PD, it is important to know what the different issues are and that there are a variety of ways to treat them.

How Parkinson's Affects Your Eyes

Eye Movement Problems

There are 3 fundamental types of eye movements.

- **Pursuit eye movements** allow the eyes to travel together to follow a moving target in the horizontal or vertical direction.
- **Saccadic eye movements** are the rapid eye movements that allow the eyes to quickly jump to a new target. They are important when reading as the eyes need to jump from the end of one line and to the beginning of the next.
- **Vergence eye movements** are used when the target is coming towards or away from a person. When the target comes towards a person for example, the eyes have to move slightly together, or converge, to keep vision of the target clear.

In PD, the saccades tend to be slow, which means reading can be difficult if the eyes are unable to find the correct place on the next line. If a person has Levodopa-Induced Dyskinesias, the saccades can become fast and erratic which can also be problematic.

Another common eye movement issue for people with PD is difficulty with vergence eye movements. In PD, the eyes are often not able to come together sufficiently as a target draws near. This is called convergence insufficiency, which can cause double vision, especially when focusing on near tasks. This problem can also affect a person's ability to read.

Eye Movement Solutions

If a person with PD is having visual complaints, the first thing to consider is whether a simple refractive error is contributing to the problem. This is a

common cause of vision issues for many people with and without PD, and as we age it is normal for a lens prescription to need adjustment. A refractive error can be picked up by an ophthalmologist or optometrist. In order to diagnose an eye movement problem however, different types of evaluations need to be done that may not be performed at a routine visit with an ophthalmologist. Therefore, if you are having visual problems and a trip to the ophthalmologist with a new lens prescription does not solve the problem, ask for a referral to a neuro-ophthalmologist.

Neuro-ophthalmologists attempt to bridge the gap between ophthalmology and neurology by diagnosing and treating the vision manifestations of neurological disease. A neuro-ophthalmologist is either an ophthalmologist or a neurologist who has additional post-residency training in neuro-ophthalmology.

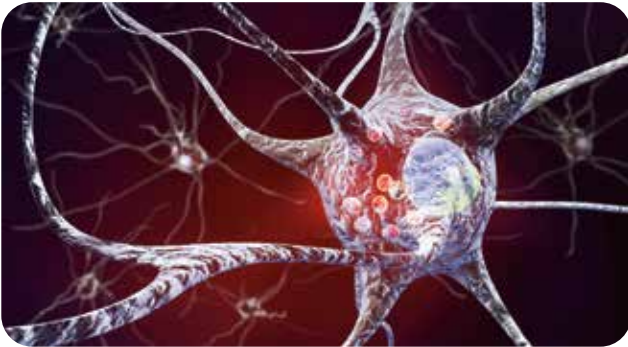
If an eye movement abnormality is found, you may be prescribed two pairs of glasses, one for distance and the other for close activities and reading. This often works better than bifocals. If you are found to have convergence insufficiency, you may be prescribed glasses with prisms. A neuro-ophthalmologist may in turn refer you to an ophthalmologist or optometrist with special training in fitting prisms. Often these are pediatric ophthalmologists or optometrists since convergence insufficiency is common in children.



- continued on page 7

CURRENT RESEARCH

Please visit our website for more information on each of these studies



Cognitive Stimulation Therapy Group -

Contact Zainab Ali zainab.ali@wustl.edu
or YeaJi Kim k.yeaji@wustl.edu

Improvisational Movement Study -

Contact Julie Chen c.julie@wustl.edu
or Alex Tan a.m.tan@wustl.edu

Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3 -

Contact Martha Hessler mjhessler@wustl.edu
or 314-286-1478

Lower Back Pain Study -

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Walking and Music Study -

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Walking Study -

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Sleep Study -

Contact Mengesha Teshome teshomem@wustl.edu
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Memory Intervention for PD Study -

Contact Tasha Doty tdoty@wustl.edu
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Cognitive Stimulation Therapy at Home Study -

Contact Tasha Doty tdoty@wustl.edu
or 314-362-7160



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(continued from page 3)

Prisms help to bend light to the proper focal point on the retina when the eyes are not able to achieve this on their own.

In terms of complementary and alternative therapies, art therapy has been seen to alleviate some of the vision effects associated with Parkinson's disease.

Abnormalities of Blinking

The blink reflex, which occurs normally at about 16 to 18 times per minute, may decrease in PD, sometimes substantially. Less commonly, the flipside may occur, with excessive blinking known as blepharospasm. Occasionally, there is apraxia of eyelid opening, which is an inability to open the eyes voluntarily.

People with PD who have blepharospasm may benefit from injections of botulinum toxin in the muscle surrounding the eye. This treatment, performed by a movement disorders specialist, ophthalmologist or neuro-ophthalmologist, is usually repeated every three to four months and can be very effective. Those who experience apraxia of eyelid opening can also sometimes benefit from botulinum toxin injections. In addition, lid crutches can be used to help keep the eyes open.

External Eye Disease

Decreased blinking can cause dry eyes. In addition, as a result of the dysfunction of the

autonomic nervous system, blepharitis, or irritation of the eyelids can occur.

Blepharitis can be managed with warm, moist compresses, lid scrubs, and at times, medicated ointments. Dry eyes can be treated with artificial tear substitutes in an eyedrop or an ointment form. These treatments can go a long way toward making the eyes look and feel better, and increase vision.

Sensory Deficits

Dopamine neurons in the retina can be lost in PD. The dysfunction of these neurons can lead to a loss of contrast sensitivity for some people making it more difficult to distinguish between items that are of similar color intensity. There can also be color vision deficits, usually along the blue-yellow axis making it harder to distinguish certain colors from others. Visual disturbances, such as visual hallucinations can also occur. Although it is difficult to treat the sensory deficits which at times can affect people with PD, sometimes certain lens tints can be helpful.

Finally, in addition to everything already discussed, a person with PD can still get the garden variety ophthalmologic diseases, just like everyone else. Diseases such as glaucoma, cataracts and macular degeneration must also be properly diagnosed and managed. With proper attention to each problem, as well as routine eye care, people with PD can protect and improve their vision.

LOVE MAKES US STRONG



Caroline Hayes, a senior at Rosati Kain high school, loves spending time with her grandparents, Larry and Judith Hayes. “I just love my grandpa so much and I’ve learned a lot from my grandparents,” says Caroline. Caroline and her sister have a special bond with Larry and Judith, and they spend at least one weekend with their grandparents every month.

Larry was diagnosed with Parkinson disease (PD) in 2007 and has kept a positive attitude despite the challenges presented by the disease. “He is always looking on the bright side and doesn’t dwell on things. He’s so funny and one of the smartest people I’ve met.

Caroline is a member of the Cross-Country team at Rosati Kain and this year she decided to run a marathon to honor her grandfather and raise funds for American Parkinson Disease Association-Greater St. Louis Chapter. Caroline successfully ran in the

Frostbite series held on January 22 in Forest Park—running 13.1 miles in 2 hours and 30 minutes and raising more than \$800 for APDA.

“My favorite memory of my grandfather was when I was about ten at my grandparent’s house. We were watching Frozen and my grandfather was watching so closely. He thought it was the best movie. He was on the edge of his seat and his mouth was open.” Caroline’s love for her grandparents is very apparent. “I facetime my grandma at least once a day. I always tell my grandpa what I’m studying, and they like to tell me what it was like when they were in school.”

And that love goes both ways. Judith and Larry are so proud of Caroline for running the marathon. “Our granddaughters come over about twice a month for the weekend. We have fun, we laugh, and they help with us little chores. We really look forward to it,” explains Judith.

Caroline’s giving heart doesn’t stop at running marathons. She plans to go to college and study Occupational Therapy so she can work with underserved communities in nursing homes. “I’ll probably work with Parkinson’s patients, just like my grandfather,” says Caroline.

APDA Greater St. Louis Chapter thanks Caroline for her incredible generosity and allowing us to help honor her grandfather.

IRA DESIGNATIONS

If you are 70½ years old and older, you can give any amount (up to a maximum of \$100,000) per year from your IRA directly to a qualified charity such as the APDA without having to pay income taxes on the money. Gifts of any value \$100,000 or less are eligible for this benefit and you can feel good knowing that you are making a difference at APDA. This popular gift option is commonly called the IRA charitable rollover, but you may also see it referred to as a qualified charitable distribution, or QCD for short. Since the gift doesn’t count as income, it can reduce your annual income level. This may help lower your Medicare premiums and decrease the amount of Social Security that is subject to tax.

An Easy Way to Get Started - Call the ADPA office today at 636-778-3377.

In under 10 minutes, you can give to APDA Greater St. Louis Chapter from your IRA.



SPOTLIGHT | Meet the Exercise Instructors



Jennifer Berger

Jen received her Bachelor's degree from Bradley University in Peoria, IL and began her career in retail management after school where she worked for Famous Barr and Lancome Cosmetics, until she "retired" from retail to

be a stay-at-home mom to her children, Samantha, Addie and Charlie.

After her first child, Samantha (17), was born, she became increasingly interested in fitness and exercise and decided to tie being a mom and her passion for fitness together. In 2005 Jen became a certified Group Fitness Instructor through The Aerobics and Fitness Association of America and taught a Stroller Bootcamp for several years.

As her love for teaching exercise grew, she decided to take her education in fitness to a higher level and became a certified Personal Trainer through The American Council of Exercise in 2008. She continued to grow both her personal training business and her family with her husband, Rob. She gained more

clients in her personal training business and two more children, Addie (15) and Charlie (12).

In 2015, her dad, Dave was diagnosed with Parkinson's Disease.

In 2016, when looking to do her "every-other-year" Personal Training Recertification, a postcard landed in her mail for a specialized class in Community Exercise for People with Parkinson's Disease. With her dad's recent diagnosis, her love for him and passion for fitness, she felt it was meant to be.

Soon after completing the class, she began teaching fitness classes at The American Parkinson's Disease Association (APDA). She also began volunteering at Rock Steady Boxing (RSB) in Chesterfield. Jen is currently teach several classes through the APDA and volunteer/teach boxing through RSB.

"To say that my job is rewarding would be an understatement. I consider myself more than blessed to be able to work with such an amazing group of people; people determined to fight back against Parkinson's Disease every day. What they teach me is more than I will ever be able to teach them!"



Michelle Valenti

After graduating from Southern Illinois University with a Bachelors of Science in Biology, Michelle started her career with Monsanto Company. There she worked for ten years as a

biochemist and study director, researching chemical and pharmaceutical metabolism.

She took a hiatus from work to raise her 2 daughters until 15 years ago when she decided to become a certified personal trainer. Her love for physical fitness has taken her into other areas such as group exercise and nutrition as well as specializing in training people

with ailments such as stroke recovery, Alzheimer's and Parkinson's disease.

She has taught Parkinson's classes for three years at the Chesterfield YMCA and the APDA Greater St. Louis Chapter facility. Besides raising her family, Michelle says, "There has been nothing more rewarding in my life than working with this special group of people."

On a more personal note, Michelle is an Oregonian from birth and developed a love for nature and hiking outdoors. She wants to continue traveling to see different parts of this beautiful world in the years to come. Five years ago, she remarried and added four more children to her family tree. She hopes to pass on my love for optimal physical health and well-being to her six children and future grandchildren as well.

EXPLORING ASSISTING LIVING FACILITIES

Written with the assistance of Lea Ann Coates, Residency Counselor, Bethesda Hawthorne Place and Charless Village.

Exploring Assisted Living Facilities can be a unsettling task and is often done in an emergency situation. It is important to investigate facilities while you are still feeling good so you are not making a rushed decision.



What Is Assisted Living?

Assisted living is typically for individuals who may need some assistance with moderate levels of care unlike a nursing home which requires a higher level of care. Assisted living facilities range in size from as few as 25 residents to 120 or more. Typically, a few “levels of care” are offered, with residents paying more for higher levels of care.

Assisted living residents usually live in their own apartments or rooms and share common areas. They have access to many services, including up to three meals a day; assistance with personal care; help with medications; housekeeping, and laundry; 24-hour supervision, security, and on-site staff; and social and recreational activities.

When Should I Start Looking Into Assisted Living Communities?

When your needs become less predictable and more situations arise in which you/your loved one is having trouble with everyday tasks and regiments.

Where Do I Start?

A lot of factors will go into your decision on whether to move into a facility. First and foremost, think about **what is important to you**. What kind of food do you like? What activities do you want to continue? Do you have any hobbies that are important to you? Do you want to be in a certain area of the community in which you live? Do you have pets? Make a list of the most important factors.

The second step will be to **conduct research into facilities in your area**. Use your list of the most important factors when researching. The internet is a great place to gather information. You can call the facilities that interest you and ask questions and you can also ask friends who live in these communities.



You can do the research on your own or you can elect to work with a professional referral service, such as **A Place For Mom** or **SeniorAdvisor.com**, at no cost to you. *A note of caution is that some of these services tend to work with the communities who pay them a finder's fee.*

Next, **visit and tour** your top 3 choices based on your research.

What to Look For?

Typically, Assisted Living Facilities are not covered by insurance, so **cost** is an important factor. Some facilities are part of **continuum of care** where you could easily move into skilled nursing if that is ever needed.

Upon your visit, take a look at **physical layout and amenities**. For people with mobility issues, it may be important for your room to be located close to the dining room. You will want to look at the safety and security features, such as, is there 24/7 on-site staffing, do they have hand rails and grab bars, and do they have emergency call systems. You may want to know if they offer

housekeeping, laundry and maintenance and if there are extra fees for these services. Do they have a fitness center, art studio, hair salon/barber?

Check out the **activities calendar**. Look for physical activities, intellectual stimulation, and socialization, these are especially important for people with PD.

You will also want to observe **staff** while they are interacting with residents. Is this how you would like to be treated? Key for people with Parkinson's is ensuring the staff has a true understanding of the timing of medications which is important for controlling symptoms. Ask about the staff to patient ratio. Also, does your **primary care physician** still provide care or is there an in-house physician you can use.

Finally, in these times, you'll want to know their COVID policies.

Ultimately, you want to be safe, happy and well-cared for over the rest of your life.



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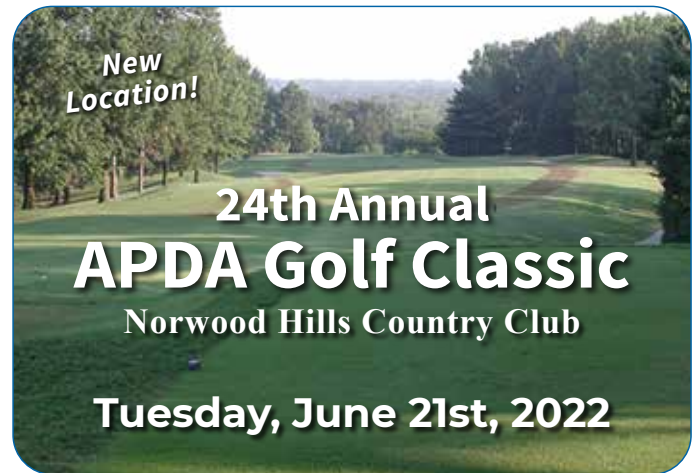
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