



AMERICAN PARKINSON DISEASE ASSOCIATION

ILLINOIS CHAPTER

Oct/Nov/Dec
2024
Highlights

2-3

Wow! What a Great Walk!

4-5

Tips for Getting In & Out of Car
Better Brain Health & Balance

7-8

Taking Exercise to Heart
Sparx3 Clinical Trial

8-9

Getting Ready Tips
Balance Exercises

10-11

PD and the Microbiome

2024 ILLINOIS PARKINSON'S CONFERENCE

Understanding Each Piece of the PD Puzzle



Conference Schedule:

8:00-9:00

Registration/Visit Resource Fair

9:00-9:15

Welcome - Melanie Adams, APDA

9:15-10:15

Dr. Rebecca Gilbert - Hacks, Tricks, Tweaks

10:15-11:15

Dr. Padmanaban and Dr. Xie - Research Updates

11:15-11:45

Break & Snacks/Visit Resource Fair

11:45-12:45

Panel Discussion

- Mental Wellbeing & Self Care - Nicole Reidy
- DBS: What You Need to Know - Dr. Tao Xie
- Is it Aging or PD - Dr. Rebecca Gilbert
- Living with PD and Communicating with Your Care Partner
- Exercise - Austin Pohlman

Evaluation and Conclusion by 1:00pm

**Join us
Tuesday,
November 19th**

NIU Grand Ballroom
Naperville Conference
Center

1120 E. Diehl Rd.
Naperville, IL 60563



SCAN TO REGISTER 
or visit apdaparkinson.org/il



WOW! WHAT A GREAT WALK!

June 22 was a great day in Illinois.

It was the day hundreds of people gathered at the Naperville Riverwalk Grand Pavilion and walked for our Parkinson's community. Over \$64,000 was raised which will fund programs and services in the 2024-2025 Fiscal Year. Last fiscal year we added four Parkinson Education Programs held around the community.

This fiscal year we are:

- Adding a conference being held on November 19 at the NIU Naperville Conference Center;
- Holding another four Parkinson Education Programs; and
- Producing three issues of this newsletter for people with Parkinson's in Illinois and their care partners

Melanie Adams, Executive Director of the APDA Illinois Chapter, says, "I was blown away by all the people who came out to support the PD community. We had a blast all day, starting with doing the warm-up exercises to Survivor's "Eye of the Tiger".

Thank you to everyone who made this day possible!



Executive Director Melanie Adams and Dr. Tao Xie warming up for the Walk.





apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
ILLINOIS CHAPTER

**APDA STAFF AND
BOARD OF DIRECTORS**

STAFF

Melanie Adams, Executive Director
Mary Wesley, Program Coordinator
Laura Rossmann, Regional Director of Marketing and Communications
Alix Huffman, Regional Office Coordinator

BOARD OF DIRECTORS

Jessica Kirby-Aranda, President	William Bucklew	Dan Glisovic
Ed Hatteberg	Alex Houston	Claudia Ong
Austin Pohlman	Jim Sullivan	Jennifer Vince

APDA Illinois Chapter | P.O. Box 814 | River Grove, Illinois 60171



TIPS FOR GETTING IN AND OUT OF A CAR

By Amanda Landsbaum, MS, OTR/L

Getting in and out of the car can become challenging because it is an awkward space with limited supports. Here are a few tips that can assist in making it safer and easier:

- Think “Sit first, then legs”. It’s better to stand at the side of the seat (with the back of your legs touching the side of the car/seat) and then sit.
- Once you are seated, you can lift one leg at a time into the car, and rotate your body to face the front of the car.
- When getting out of the car, you would reverse this process and rotate in the seat to face the side of the car while lifting one leg out at a time. Then move to the edge of the seat and then stand up.
- The following items can help with this process:



This “Handybar” can be placed in the door jam to create a handle for getting in and out



A Swivel seat or large plastic bag covering the seat can make turning in the seat easier



A seatbelt extender can be used to make it easier to buckle the seatbelt

If you use a mobility device, there will be extra considerations and the best thing to do is work with a physical or occupational therapist to practice a safe technique that is tailored for you.

BETTER BRAIN HEALTH AND BALANCE

By Dr. Beth Templin, PT, DPT, GCS



We know that exercise is one of the best ways to improve and maintain your physical fitness with a Parkinson's diagnosis. Just as important is maintaining good brain health. When you take a deeper look into brain health, there are several recommendations including: participating in regular physical activity, getting a good night sleep, engaging in mentally stimulating activities, eating a brain healthy diet, managing your health, and staying socially engaged.

Today we're going to focus on two of these recommendations, physical activity and mentally stimulating activities. We know that exercise increases blood flow to the brain, helping to bring in nutrients and carry away wastes, promoting healthy brain tissue. **Physical activity** also stimulates the production of Brain-Derived Neurotrophic Factor (BDNF), which helps support the growth and survival of new brain cells.

Mentally stimulating activities can range from playing brain games to learning new hobbies. By challenging your brain and continuing to learn new information, you strengthen your brain, making it easier to think faster, focus and remember more. When you overlap these two activities and perform cognitive challenges while exercising, you amplify the benefits of both for your brain health.

The combination of moving and thinking at the same time requires more concentration and is known as **dual tasking**. Typically, when you dual task, one or both of the activities suffer, meaning they are not performed as effectively. People living with PD often demonstrate larger gaps in performance compared to adults living without PD. This can affect activities like walking and lead to increased fall risk or loss of independence.

The good news is research shows dual tasking can be improved in people living with PD with practice.

There is an app called **Lock Yourself** that you can install on smart phones or tablets that can help you perform these activities



at the same time. This specific app works on reactive stepping or stepping in different directions randomly. Performing reactive step training has been shown to be an important part of balance training and reducing fall risk.

Inside the app are several different dual tasking options from which to choose. We recommend starting with the **Simple Colours**, which is the easiest level. This activity will start by having you imagine standing in the "middle" of 4 colors. The app will call out a color and the objective is to step on that color with one foot, while the other stays in place. In between each color, you will want to return both feet to the center. The activity will



have you stepping in 4 different directions: forward, backward, left and right. You can set the speed of how fast the colors will be called out. I'd recommend starting with 40-50 steps per minute.

The second level is the **Simple Clock**. In this level you will imagine yourself standing in the middle of a clock face. The 12 in front of you, the 6 behind you, the 3 to your right and the 9 to your left and so on for a full clock face. Again, start at a slow speed of 40-50 SPM until you feel confident stepping in all 12 directions.

When you're ready for a bigger challenge, you can move onto **Brain Games**. These challenges add another layer of thinking into the mix. For example, months of the year will call out a month like March. You need to figure out that March is the third month of the year and then step towards the 3 on the clock.

We love this app because it can be customized to many different levels of speed of movement, direction of movement and complexity of thinking. It also requires no special equipment or much space to successfully complete the workouts. When you're just starting out 2 minutes may feel exhausting, but as your body gets used to and better at dual tasking, you may be able to increase to 5 minutes/session. Plus, you get the added benefit of working on your balance recovery strategies, which will decrease your fall risk.

APDA recommends checking with a healthcare professional before starting any new exercises.

TAKING EXERCISE TO HEART:

The Importance of Aerobic Activity

By Gammon M. Earhart, PT, PhD, FAPTA

Are you looking for ways to increase your fitness, facilitate better movement function, boost your mood, and enhance your thinking abilities? What if I told you there is one thing you can do that will give you all these benefits and more? The one thing that can convey all these benefits (and more) is aerobic exercise.

Aerobic exercise is the fancy term for doing activities that get your heart pumping faster. It doesn't matter so much what form of exercise you do, just that you do something, do it at a high enough intensity, and do it regularly. **Here's some more detail to help guide you:**

- **Do something.** There are lots of different forms of aerobic exercise, including brisk walking, cycling, dancing, swimming, jogging and rowing. It doesn't matter which one(s) you do, they are all good, so do what you enjoy!
- **Do it at the right intensity.** You have to work hard enough to challenge yourself if you want to see gains. This means exercising at a moderate to vigorous intensity. Moderate intensity activity gets your heart rate up to 50-70% of your maximum heart rate, while vigorous intensity is in the range of 70-85% of your maximum heart rate. You can estimate your maximum heart rate by taking 220 minus your age. Or, you can use a simpler method and just pay attention to how hard you feel like you are working and rate your effort level. You can do this using a 1 to 10 scale where 1 is hardly any exertion and 10 feels almost impossible to keep going. On this scale, scores of 4 to 6 indicate moderate activity where you are breathing heavily and can carry on a short conversation. Scores of 7-8 indicate vigorous activity where you are short of breath and can speak just a sentence at a time.
- **Do it regularly.** Current guidelines recommend accumulating 150 minutes per week of moderate to vigorous intensity exercise. You could do that by exercising 30 minutes a day five days per week. If 30 minutes of exercise is not doable or does not fit into your schedule, doing as little as five minutes of exercise at a time can be beneficial. The key is to accumulate minutes throughout the week to reach the 150-minute goal.

Research shows that people with PD who exercise regularly for at least 150 minutes per week have better mobility and physical function, less disease progression, more stable thinking ability and higher quality of life compared to those who do not exercise regularly. In addition, aerobic exercise can reduce risk for obesity, heart disease, high blood pressure, high cholesterol, diabetes, stroke and some types of cancer. Aerobic exercise can also ease depression and anxiety, promote relaxation and even enhance self-esteem. And weight-bearing forms of aerobic exercise like walking can also reduce risk of osteoporosis.

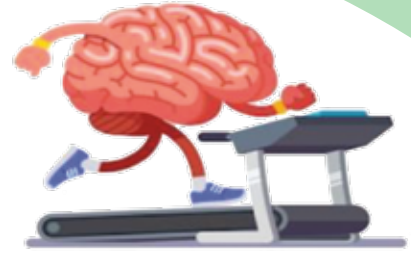
Getting Started:

Before beginning any exercise program, consult a health care provider such as a physical therapist. A physical therapist can evaluate your current fitness level and prescribe an exercise program tailored for your needs and interests.

If you are looking for a physical therapist to help you get started, ask your doctor, or contact the **APDA Illinois Chapter office at 708-329-9527 or apdail@apdaparkinson.org** to get a list of locations which have a neurologic physical therapist on staff.

If you are interested in participating in research studies focused on exercise, please contact Camryn Butze at Northwestern University Department of Neurology, **312-503-6824 or camryn.butze@northwestern.edu**.





Study Title: Study in Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

We are seeking volunteers to participate in a clinical research trial to learn more about the effects of aerobic exercise on people with Parkinson's disease.

You may be eligible to participate if you:

- Have been diagnosed with Parkinson's disease within the last 3 years and are not yet taking medication for your PD symptoms
- You do not plan to start medication for PD within the next 6 months
- Are willing to take part in a regular treadmill exercise program 4x/week for 18 months and participate in study visits periodically for 24 months
- Are 40-80 years old
- Are not already participating in a structured exercise program

Principal Investigator: Cynthia Poon, PhD
Department: Neurology

If interested, please contact Camryn Butze at camryn.butze@northwestern.edu | 312-503-6824

Participants will be recruited under study number: STU00211903

Tips and Tricks for Parkinson's

Getting Ready to Go Out

- ✓ Brushing Teeth - try an electric toothbrush to avoid movement troubles. It may also help to use your non-tremor hand
- ✓ Drying Hair - a hands-free hair dryer can be mounted to the vanity or wall for an easier experience.
- ✓ Steady your hand - prop your elbows on the counter or sink to reduce tremors and fatigue.
- ✓ Sitting down while getting ready to go out to conserve energy and support balance.
- ✓ Shaving - Invest in an electric razor for an easier and safer shave.
- ✓ Makeup - Tap your lipstick, mascara, etc. rather than trying to swipe. Sitting down or propping your elbows can help here too.
- ✓ Plan ahead - break down grooming tasks into smaller, more manageable steps.



DONOR-ADVISED FUNDS

A donor-advised fund (DAF) is a charitable giving program that allows you to combine the most favorable tax benefits with the flexibility to support your favorite causes.

- You can contribute cash, securities or other assets to a donor-advised fund. Typically you are eligible to take an immediate tax deduction and then the funds are invested for potential tax-free growth. You can then recommend grants to any qualified public charity, such as APDA.
- You can make a one-time gift or set your DAF account to make automatic recurring grants in the amount and frequency of your choice. It's easy to do. Just log into your account on your charitable sponsor's website and select "recurring" option. It's a great way to make your charitable giving more convenient.

If you have any questions about making a tax-deductible gift to the American Parkinson Disease Association through a DAF, please contact **Melanie Adams at 708.522.4772 or at madams@apdaparkinson.org.**

This information does not constitute legal or financial advice. Because everyone's situation is different, you should seek the advice of your own attorney, tax advisor and/or financial planner.

BALANCE AND STRENGTH EXERCISES FOR FALL PREVENTION

1 Chair Sit to Stand

Sit in a sturdy, stable chair with arms. From a standing position, reach back to the armrests to use as a guide and extra support and slowly sit down in the chair. Be sure to use the leg muscles and not drop down into the chair. Then, use both legs and arms (pushing down on armrests) together to stand up. Then, pause for a moment. *Repeat.*

2 Heel Toe Stand

Stand between two sturdy chairs of the same height and hold on for support. Slowly move one foot alongside the other until it's directly in front and in line with the other foot. Stand and balance in that position.

3 Heel Toe Walk (more challenging)

Stand next to a countertop and hold on with one hand. It's best to use a cane or another person to provide support on the other side. Walk along a straight line, placing the heel in front of the toe.

4 Balance On One Leg

Stand in front of a counter or between two sturdy chairs of the same height. Hold on to the supportive surface and bend the knee to raise one foot and balance on one leg. Then do the same on the other leg. *Aim to balance for 10 – 15 seconds on each leg.*

5 Standing Side Leg Lift

Stand up straight behind a chair, holding the back with both hands. Slowly lift your right leg straight out to the side about 6 inches off the floor. Hold. Return to starting position. *Repeat 10 times on each side.*

6 Back Leg Raises

Stand behind a chair. Slowly lift your right leg straight back – don't bend your knees or point your toes. Hold that position for one second, then gently bring your leg back down. *Repeat 10 times on each leg.*

7 Rock the Boat

Stand with your feet apart, so that the space between them is the same width as your hips. Make sure both feet are pressed into the ground firmly. Stand straight, with your head level. Then, transfer your weight to your right foot and slowly lift your left leg off the ground. Hold that position for as long as possible (but no more than 30 seconds). Slowly put your foot back onto the ground, then transfer your weight to that foot. Slowly lift your opposite leg. *Start by doing this exercise five times per side, then work your way up to more repetitions.*

8 Heel Raises

Stand up straight behind a chair, holding the back with both hands. Position your feet hip-width apart. Lift up on your toes. Hold. Lower your heels to the floor. *Repeat 10 times.*

9 Standing Hamstring Curls

Stand up straight behind a chair, holding the back with both hands. Extend your right leg behind you with your toes touching the floor. Bend your right knee and try to bring the heel to your right buttock. Hold. Slowly lower your foot to the floor. *Repeat 10 times on each leg.*

10 Wall Pushups

Stand an arm's length in front of a bare wall. Lean forward slightly and put your palms flat on the wall at the height and width of your shoulders. Keep your feet planted as you slowly bring your body towards the wall. Gently push yourself back so that your arms are straight. *Do 10 of these at a time.*



PD and the MICROBIOME

From Dr. Rebecca Gilbert's blog, *A Closer Look*

What is the microbiome?

The human gut harbors trillions of micro-organisms referred to collectively as the microbiome. Current understanding is that the microbiome provides a number of benefits to the human including help with digestion of food, help with warding off harmful microorganisms, aid in the absorption of particular nutrients, and creation of needed vitamins. These functions can influence the nervous system of the gut, called the enteric nervous system (ENS). In addition, the gut microbiome releases byproducts and metabolites that have effects on nerves. The microbiome varies from person to person and is influenced by many factors including diet, environment, and genetics. Although no two microbiomes are identical, people with certain diseases may share similarities in their microbiomes.

How is the microbiome and gut bacteria different in people with PD?

Based on numerous studies comparing the microbiome from the gut of people with PD with the microbiome from the gut of people without PD, there appear to be some differences. The studies are not consistent in their findings, but there are similarities across studies.

Parkinson's gut bacteria differences

- An increase in certain families of bacteria such as Lactobacillaceae and Verrucomicrobiaceae
- A decrease in the family Prevotellaceae.

How are gut bacteria and the brain connected?

In a previous blog, we discussed how the ENS is directly connected to the brain through the vagus nerve which travels between the two. We highlighted a theory that suggests that Lewy bodies (an abnormal accumulation of alpha-synuclein), the pathologic hallmark of PD, develop first in the ENS and then can migrate to the brain via the vagus nerve. The brain and the gut also communicate via the bloodstream

as well, through alterations in inflammatory signals, neurotoxins and neuroprotective factors. One of the elements that contributes to both these communication channels between the gut and the brain is the gut microbiome.

The microbiome and Parkinson's Disease

Can an altered microbiome contribute to a diagnosis of PD?

Research studies in animals have shown that an altered microbiome might contribute to PD pathology. For example, one study showed that in a mouse model of PD that overexpressed alpha-synuclein, there was more alpha-synuclein accumulation (also known as Lewy bodies, the pathologic hallmark of PD) in the brain of the mice with an intact microbiome as compared to the same mice who were raised in a germ-free environment with no bacteria in their gut. This supports the theory that abnormal alpha-synuclein accumulation in the brain is enhanced by a particular microbiome in the gut.

Other studies showed that transplantation of fecal material from PD mice to normal mice, thereby introducing a "PD microbiome" into mice without PD pathology their brain, led to impairment of motor function and a decline in brain dopamine. These studies also support the theory that a particular microbiome might be integral in causing PD pathology in the brain.

How might an altered microbiome contribute to PD pathology?

These studies beg the question – how might the gut microbiome contribute to PD pathology in the brain? Several different theories have been proposed:

- Short chain fatty acids (SCFAs) are one of the main products of the microbiome. Research has shown that SCFAs can enter the brain and exert neuroprotective effects via increase of nerve growth factors. A number of research studies have shown that there are less SCFAs in fecal samples from

people with PD as compared to healthy controls and this could contribute to a lack of neuroprotection that then fuels PD.

- A “PD microbiome” may release pro-inflammatory molecules such as TNF-alpha and interferon-gamma which can enter the brain. These pro-inflammatory molecules may contribute to PD pathology.
- A “PD microbiome” may increase the ability of molecules to permeate the intestinal wall. This may allow neurotoxins to enter the gut.

Can altering the microbiome improve Parkinson’s symptoms?

With the awareness that the microbiome may play a role in PD, came the idea that altering the microbiome may help with PD symptoms. While there is still a lot of research to be done, there have been some small, but promising findings so far.

Probiotics, or particular strains of bacteria that are ingested in order to alter the gut microbiome, have been studied to help PD symptoms. A number of small studies suggest that probiotics may improve constipation in people with PD, which is a common problem for many people with the disease.

As mentioned above, treatment of *Helicobacter pylori* and SIBO typically requires **antibiotics**, which are drugs designed to kill particular bacteria. Antibiotics can be helpful, but are only considered if a particular gut organism is being targeted. Otherwise, antibiotics can kill both “good” and “bad” bacteria, and potentially be detrimental to the overall health of the gut microbiome.

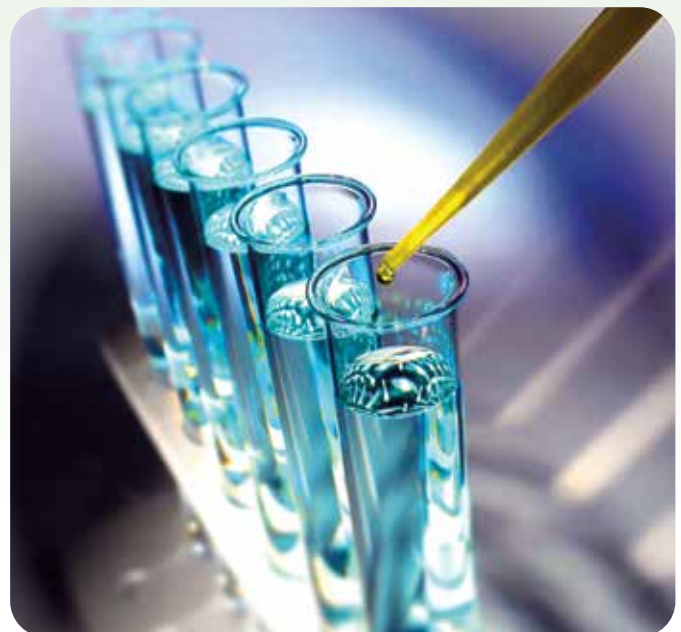
Another idea that has been considered is **fecal transplantation**, a technique in which fecal matter from a healthy person is delivered to the gut of a person with PD, with the goal of restoring a less “PD-like” microbiome. Only case reports and very small studies have been reported so far in the literature, but this may be an area worth exploring. There are a few additional studies underway which you can read about here:

- [Study of the Fecal Microbiome in Patients with Parkinson’s Disease](#)
- [Fecal Microbiota Transplantation for Parkinson’s Disease](#)
- [Fecal Microbiota Transplantation as a Potential Treatment for Parkinson’s Disease](#)

We await the results of this research to assess whether fecal transplantation will prove to be useful for patients with PD.

Tips and Takeaways

- The gut microbiome refers to the trillions of microorganisms that live in the human gut.
- Research has shown that there are differences in the microbiome between someone with PD and healthy controls.
- A number of theories are being tested to understand whether and how the microbiome differences can contribute to the development and symptoms of PD.
- Probiotics and fecal transplantation can alter the microbiome in people with PD and are under investigation as possible treatment options.



Strength in optimism. Hope in progress.

PO Box 814
River Grove, Illinois 60171

Thank you to our Sponsors

Gold



Silver



Bronze



APDA Illinois Chapter

PO Box 814 | River Grove, Illinois 60171
708-329-9527

email: apdail@apdaparkinson.org | website: apdaparkinson.org/il