

Live it!

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
IOWA CHAPTER

A Resource for Iowans with
Parkinson's Disease and those
who care for them.



COGNITIVE FITNESS

HOW TO
IMPROVE YOUR
COGNITION

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Scan the QR code at left to go directly to www.apdaparkinson.org/iowa



Live it! is also available online! Visit www.apdaparkinson.org/iowa for an electronic copy.



Also, follow us on Facebook (www.facebook.com/iowaAPDA)

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Reader Submissions

Live it! magazine is intended to be a voice for the Parkinson's disease community. We encourage and are pleased to consider your words, an article, art, and photo submissions for future issues from our readers – anything that shows how you Live It! Please send your submission requests to Iowa Parkinson's Disease Association, 2951 86th St. Suite 125, Urbandale, IA 50322, with *Live It!* on the attention line, or email them to apdaiowa@apdaparkinson.org. Please note: The decision to include reader submissions is at the discretion of the editorial staff. The editorial staff reserves the right to edit or otherwise alter any material submitted. If you would like submission material returned to you, please include a stamped, self-addressed envelope.

Disclaimer

All material related to Parkinson's disease contained in this magazine is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the editorial staff, the medical director, The Iowa Chapter of APDA, or the APDA.

Upcoming Events

PD Moves

Des Moines Ballroom Dance Class Mondays at 6:30 p.m., September 9 – November 11

Des Moines Ballroom, 1925 High Street, Des Moines, Iowa 50309. Register on our website: apdaparkinson.org/iowa or call: (515) 782-4386.

Brain Fitness for PD

Tuesdays at 2 p.m., October 1 – November 19

Connect Therapy, 9325 Bishop Dr, Suite 110, West Des Moines, IA 50266. Register on our website: apdaparkinson.org/iowa or call: (515) 782-4386.

Burlington Conference

Living Well with PD, Friday, October 4, check-in 12:15 p.m., Conference 1-4:30 p.m.

Southeast Iowa Regional Medical Center, Wellness Plaza, 1221 S. Gear Ave, West Burlington, IA 52655. Register on our website: apdaparkinson.org/iowa or call: (515) 782-4386.

Parkinsons Education Program (PEP)

Comprehensive Rehab for PD

Wednesday, October 9, 1:30-3:45 p.m.

University of Iowa Recreation Services, Iowa City, Rachel Rose, MOT, OTR/L, Kelsey Paul-Charlson, MS, SLP, CDP. Register on our website: apdaparkinson.org/iowa or call: (515) 782-4386.

Northwest Iowa Conference

Thursday October 24, Registration 10 a.m., Conference 10:30-3:30 p.m.

St Joseph's Catholic Church, 1305 Okoboji Avenue, Milford, IA 51351.

Partner Parkinson's Education

Coralville On With Life Parkinson's Conference, Wednesday, November 6, 9 a.m.-12 p.m.

Grand Living at Bridgewater, 3 Russell Slade Blvd, Coralville, IA 52241, (319) 259-6224.

Partner Parkinson's Education

Ankeny On With Life Parkinson's Conference, Thursday, November 7, 9 a.m.-12 p.m.

On With Life - 717 SW Ankeny Road, Ankeny, IA 50023
Space is limited. Registration required, opens in October, (515) 289-9600.

CONNECTING THROUGH ART

In partnership with the Des Moines Art Center and Spirit Art Move Studio.

Register for one or many sessions on our website: apdaparkinson.org/iowa or call: (515) 782-4386

Creative Activity

For people with PD.

Tuesdays 1:30-3 p.m.

September 3, October 1, November 5, December 3

Spirit Art Move Studio, 939 Office Park Road, West Des Moines, IA 50265

Gallery Experience

For people with PD and care partners.

Tuesdays 1:30 – 3 p.m.,

September 17, October 15, November 19, December 17

Des Moines Art Center, 4700 Grand Ave., Des Moines, IA 50309

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Parkinsons and Me

By Anne Scherer

Editor's Note: APDA volunteer Anne Scherer has interviewed many people with Parkinson's for *LiveIT!* magazine. Earlier this year Anne was also diagnosed with PD. Following is her interview with herself.

I was asked many moons ago to interview persons diagnosed with Parkinson's or their surviving care partners. Then, I was to write an article sharing the information gleaned from the interview. I loved doing it as it combined two loves of mine, writing and getting to know people.

So, for this magazine volume, I am once again writing about a person diagnosed with the big "P," but, how uncanny, that the interview is with me.

For about two years, I had noticed a tremor that affected my left and dominant hand. Occasionally, I had a trembling lower jaw as well. My balance was iffy at times too. After a period of time I saw a doctor about it who was very confident some of my other medications were the cause. My next diagnosis was essential tremor along with the suggested use of a cane. At the end of 2023, it was suggested that I see a neurologist. That happened at the end of January of this year. She reviewed my medical history thoroughly. Apparently, I had taken a stomach medicine for more than 15 years to treat my IBS. It is now known that this medicine destroys dopamine in the brain. She wanted me to have a DScan on January 27, but not to stress because she was quite confident, I had this damage due to medicine previously used which, though not reparable, was also not going to progress. I would take meds and relieve the symptoms. It was with this attitude that I had my testing done. The next day, January 28, the doctor's nurse called and said, "The doctor wants to know if you want to start your Parkinsons medication before your appointment with her."

Have you ever watched a football game where the winning coach gets an ice-cold bucket of water thrown on him? That is how I felt. I was blindsided. I was kicked in the gut. I was scared! I was blanketed in "NOW WHAT?"



Anne Scherer

I retreated into myself to deal with feelings I just didn't know what they were. Things I was immediately sure of:

1. I am not sure I believe it.
2. I believe it.
3. I am not telling anyone until I can deal with it.
4. I can't handle this alone.
5. I just finished being a caregiver for my Alzheimer's stricken husband. I have 10 years experience so I'm ready.
6. I'm lost and live alone and have no idea what's ahead.
7. Don't get advice yet.
8. Don't compare war stories with other PD persons.
9. Everyone's journey is their own.
10. Until you're ready do not do research!!!

And so it began. I wanted to run but not only is there no escaping, but I can't run worth a plug nickel.

I guess it was two days before I shared the diagnosis with my sons. One lives here and one in Connecticut. They, too, were blind sided and gave the appropriate responses that summed up to, "We'll be there for you." I tried not to dwell on being my husband's caregiver and what it entailed. I only got sad knowing that they wouldn't be able to "be" there for me in all the ways I may need.

It was then, three days past my news, that I googled and used the APDA website to find out what I had and what I may face. I remember my first two words: incurable and certain progression. Progression is the “P” word to me since the years of watching my husband progress into a hellacious place. I thought well, my husband's meds delayed the progression. Parkinson’s meds do not.

**WHY DID I DO THIS? WHO NEEDS THIS INFORMATION?
IT'S GOING TO HAPPEN, SO JUST HAPPEN!**

Computer off. Ignorance is bliss. I’ll watch inane TV. I’ll try to sleep. I’ll eat ice cream. By the time I saw the neurologist three weeks later, I had an outer countenance of strength. My son went to the appointment with me because I was sure I would hear progression and nothing else. I knew there would be sugar coating and you’ll be okay phrases showered upon me to ease me into my new reality. People saying the earth was flat were more right than I was about her approach. I was ready to ask if she was sure when out came the DScan and the explanation of how sure she was. No cure. Definite progression. Meds to abate symptoms and usually need to be increased. I’m sure there was more. I was only physically present at this point.

I came home with a book from her office. That night I finally talked to someone who understood me more than anyone. I chatted with my husband. “I’m afraid, baby boy. I’m afraid to become a drooling, demented person who cannot take care of myself. I am afraid of hallucinations and being alone, I’m afraid to become a burden.” Clear as can be, I had the thought to get up and read the doctor’s book. As always, he had the answer.

So, yes, there is progression. Also, there is no cure but there is a “but.” I never got past the bad news to get to the hope and the work I could do to help myself. I realized I got my diagnosis on a Friday and went into a spiral of doom. But I was no different that I was Thursday. I just had a name for my issues. So, welcome to the back of the book where the answers always dwell.

The progression is different for everyone and can take many years to

become debilitating, if at all. You don’t sit and wait for it, you work at keeping it at bay. EXERCISE is the key. The kinds are innumerable and readily available. Socializing keeps you out and about and not in a world of gloom and doom. Brain exercises like puzzles and word games and trivia are fun and another form of exercise. Singing, dancing, hobbies are all recommended. So, in a nutshell, I get that I should keep on keeping on. Live as I have lived using the safety measures I need. Realize I may be limited but not out of the picture.

New attitude.

Healthy attitude.

Hopeful attitude.

That’s the key. And the knowledge that I will not be perfect. I will have bad days. I will be scared when my tremor seems worse. I will need to take the day and regroup. I still have some ice cream. But I will strive to be upbeat. I will strive to remain hopeful. I will learn that needing and asking for help is a strength and not a weakness.

As I join this community of fighters, I will use you to learn from and lean on as we face tomorrow together.



Cognitive Fitness

How to Improve Your Cognition

By Cassandra Serrata, MS CCC-SLP,
Speech Language Pathologist and owner of Connect Therapy



It's estimated that 20-50% of people with PD experience mild cognitive impairment (MCI). MCI can include problems with memory, language and problem solving. MCI is the stage between typical age-related cognitive changes and the more severe cognitive decline of dementia. As people age, it's common to be forgetful and occasionally lose the keys or forget a person's name or a word. But this does not impact a person's ability to function and perform daily activities. A person with MCI will demonstrate cognitive changes that do impact daily functioning and tasks, such as missing appointments or social events, losing your place in a conversation or forgetting the names of friends and family. Symptoms of MCI can stay the same or worsen over time.

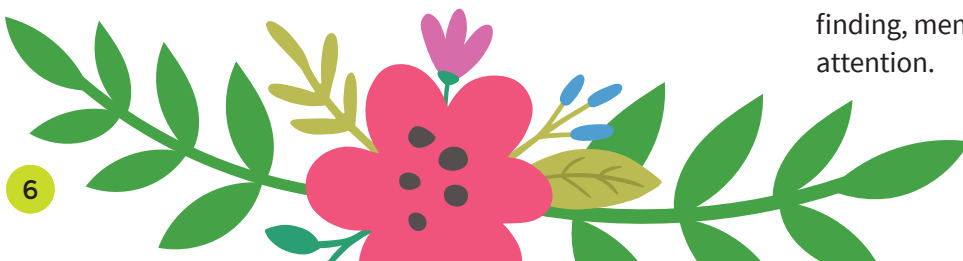
Cognition refers to all forms of knowing and awareness, meaning our ability to process information and apply it. The areas of cognition include:

- **Attention:** Attention is the ability to focus despite distractions. People with PD often find it difficult to concentrate, especially when distractors are present or if you are attempting to do two or more things at the same time.
- **Language:** People with PD often describe language difficulties as trouble with word finding, or expressing that the word they want is "on the tip of their tongue."
- **Memory:** Memory includes immediate, short term and long term memory. Changes in memory for people with PD can impact daily activities, such as remembering someone's name, where you put the keys or difficulty learning steps to complete a task.

- **Executive functions:** Simply put, these are the set of skills people use to get things done. Executive functions include working memory, inhibitory control and cognitive flexibility to switch between tasks or think about something in more than one way. People with PD often explain executive function difficulties with following a recipe or balancing a checkbook.
- **Visuospatial skills:** These are the skills that allow us to understand and use visual information. PD can cause visuospatial impairments such as difficulty with visual perception including judging distances, facial recognition and difficulty maintaining visual attention.

Cognitive changes in PD happen because of protein accumulation in regions of the brain that are responsible for these cognitive processes. Cognitive changes in PD can range from mild to severe and can change over time as PD progresses. PD isn't the only thing that impacts cognition and it's important to know other factors that can contribute to cognitive impairment. Medical illnesses, seizures, strokes, traumatic brain injury and mental health disorders can impair cognitive functions.

If you or a loved one is experiencing mild cognitive decline (MCI), seeking medical advice is recommended. Diagnosing MCI can be done by a primary care provider, neurologist, occupational therapist or speech language pathologist. Once diagnosed, intervention can be helpful to maintain independence and train cognitive strategies. An occupational therapist can assist with complex activities of daily living, such as medication management, cooking, driving, etc. A speech language pathologist assists with cognitive-communication, including word finding, memory strategies, executive functions and attention.



In recent years, there has been more research done in our brain's ability to build new neural networks and improve, or at least maintain, cognitive abilities as we age. Researchers have determined a set of principles that help to optimize brain health and function and have coined the term Cognitive Fitness.

Cognitive Fitness is a state of optimized ability to learn, remember, reason, plan and adapt. The more cognitively fit you are, the better you are at making decisions, solving problems and dealing with stress and change. Cognitive fitness can be helpful for all of us, not just those who are experience MCI. Focusing on brain and cognitive health helps to improve independence and quality of life. Here are the key principles to maintain an engaged brain:

Cognitive Stimulation

Complete any form of mental stimulation that you enjoy on a daily basis. If you enjoy jigsaw puzzles and crosswords, keep doing them! But if you're looking for more ideas, here are some other cognitive exercises you might like to try: learn something new (new language, new boardgame, new hobby), card games, word games, listen to a podcast, read an article or book, sudoku and more. Any activity that makes you think is a mental exercise.



Optimize Sleep

Maintain a healthy sleep routine for brain health. Adults should aim to get 7-9 hours of sleep per night. Create routines that optimize sleep, such as avoiding screens before bed and stick to a routine where you wake up and go to bed at the same time every day. Good sleep improves your physical and mental health. Sleep disturbances are common in PD. Talk with your doctor about medications and sleep treatments.



Nutrition

Your diet impacts your brain health. Aim for a diet containing abundant fruits, vegetables, legumes, nuts and whole grains. Limit the amount of animal products, instead opt for plant-based protein such as beans, nuts, chia seeds, legumes and quinoa.



Navigate Stress

Finding healthy ways to manage stress is important for your cognitive health. Ideas of stress management include: deep breathing, going for a walk, meditation, calling a friend or relative, yoga and therapy.



Exercise

Physical activity strengthens brain health. Adults with PD should aim for 150 minutes of exercise per week. This includes aerobic activity, strength training, balance and flexibility. Find the type of exercise you enjoy, so you'll stick with it.



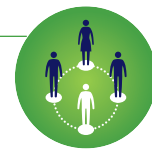
Check-ups

Managing your medical health is a vital part of brain health. Staying up to date with all medical providers, managing chronic disease and taking your medications as prescribed are important ways to help take care of your brain.



Talk

Socialization improves brain health by stimulating the brain and challenging your thinking. Social interactions can lead to new neural connections and helps to boost mood. Consider combining a few principles and taking an exercise class which can help with exercise, socialization and cognitive stimulation all at once!



Cognitive Fitness Class

If you have PD and would like to learn more about cognitive fitness, Connect Therapy offers a free 8-week course through the APDA Iowa Chapter.

In this class, you will learn more about cognitive fitness, gain tangible strategies for improving cognition and engage in mental exercises, all while socializing with others.

This class is offered in person, care partners are encouraged to attend. The class will be held on Tuesdays at 2 p.m., running October 1 through November 19, 2024, at Connect Therapy, 9325 Bishop Dr, Suite 110, West Des Moines, IA 50266.

Register at apdaparkinson.org/iowa or call: (515) 782-4386.

Traveling with PD

By Sydney Marshman, OTD, OTR/L, BCG

Whether you are a routine snowbird or traveling for an adventure, flying can be quite the task for someone with PD. Check out these tips below on ways to make your flying experience easier.

Booking Your Flight

Several flight search engines offer filter options to optimize your travel. Two filters that may be helpful as you're planning:

- **Arrival and Departure Times**

Filter out flights during off times, such as early mornings or late into the evening. Avoiding off times may help you have an easier time getting through the airport.

- **Layover Length**

Avoid rushing through the airport to make a connecting flight OR sitting too long in the airport. Filter flights with layovers that allow you enough time to find the restroom, get to the next gate, and maybe eat something too.

Once you've selected the ideal flight, move carefully from screen to screen. Eventually, you will be provided an option to enter "passenger assistance." This is where you can indicate for wheelchair assistance through security, or gate to gate transportation during a connection.

If you plan to rent a car during your trip, consider if the rental car agency is onsite or offsite. An onsite rental car agency allows for pickups at the airport and does not require an additional transfer. While this is not available at all airports, it can be helpful to know in advance. An offsite car rental agency will require a transfer from the airport to the rental agency. This is typically done by bus, and depending on the airport may be one bus to a centralized off-site area of individual rental care agency busses. To check if your agency is on site, simply search for the company's address online. This will show whether it is listed at the airport or at another location.

Packing

There are three types of luggage used while traveling. Depending on the airline, you may need to pay for different types of luggage.



- **Personal Item** - A backpack, purse, or other small bag that fits under the seat in front of you.
- **Carry On** - Generally a medium sized suitcase or duffel bag that is stored in the overhead bins on the plane.
- **Checked Bag** - This is a larger suitcase, or other item that will be stored in the cargo area of the plane.

It may be worthwhile to check your luggage to your final destination. This allows for easier movement through the airport with both hands free to navigate moving walkways and escalators.

All medications should be stored in your personal item, as this will never be separated from you. While carry on items are often stored in the overhead bin, there is a chance carry on luggage is gate checked or checked to your final destination if there is not ample overhead space. This particularly happens when traveling from a smaller airport to a connecting flight at a larger airport. Carrying your medications in your personal item can prevent any delays in medication schedule. It should also be noted your medication list should be readily available when you travel, whether it is available in print or digitally on a smart device.

Choosing the bags you travel with is just as important as how you pack them. Personal items should be easy to carry. Ideally, a personal item such as a purse or backpack is not heavy. A heavy backpack or over the shoulder bag could negatively affect your balance. Another important consideration is ease of access, a front wearing cross body bag can provide easy access to your ID, phone, and a place to store your boarding pass.

Luggage comes in all shapes, sizes, and wheel types. Luggage with 4 caster wheels can be easier to push and manage through a busy airport, in comparison with its two wheel counterpart. If you do plan to push luggage through an airport, consider a personal item with a luggage strap. This allows it to easily slide over the handle of your luggage and prevents it from falling off.

Medical equipment such as walkers and wheelchairs can be gate checked at no charge. It's important to consider that any checked equipment has the potential to be damaged. Purchasing a cover for equipment can help protect it in the process. It may be necessary to find creative covers such as a golf club case for a device like a U step walker.



At the airport

You'll need your ID and boarding pass handy throughout your time at the airport. A simple lanyard ID carrying case can help keep these items readily available for checking bags, security, and boarding the plane. If you don't plan to check a bag, you may consider using your smart phone to check in and access your boarding pass. This generally requires downloading the airline's app, with check in available 24 hours in advance. After checking in, your boarding pass is loaded onto your phone and scannable at the gate when boarding the plane. Another great feature of airline apps on your smart phone is they often have airport maps and can help identify time between gates and accessible routes.

Passing through security can be a daunting task for anyone, particularly as you are feeling rushed to move through the line. TSA provides Passenger Support Services which can help individuals move through security. This is separate from wheelchair assistance provided by each airline. While this service does not exempt you from screening, it can be helpful to move through security with additional assistance. Passenger Support Services need to be scheduled 72 hours in advance and can be done so on by completing the TSA Cares form or calling TSA Cares at (855) 787-2227.

Other considerations may be purchasing slip on shoes that are easy to put on and take off, like Sketchers or Kiziks. Another option is investigating if you qualify for TSA Pre-Check. In advance of your trip, you would schedule an appointment at a TSA Pre-Check office with approved documents. The cost is \$95 and may be reimbursable if you have a travel credit card. If you are TSA Pre-Check it is often a shorter line at airport security and you do not need to remove your shoes. Keep in mind if you are traveling with another, you would both need to be approved to move through the Pre-Check line.

Don't Forget Your Gym Bag

Traveling is a significant test to your physical fitness and endurance. Just like you would carefully plan an itinerary, consider preparing your body for this adventure! If you have upcoming travel via plane or car here are some functional exercise options.

- Sit to stand
- Side steps
- Hip flex
- Core
- Fine motor coordination

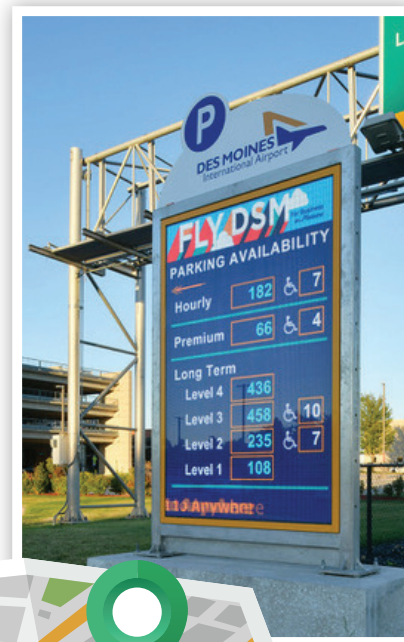
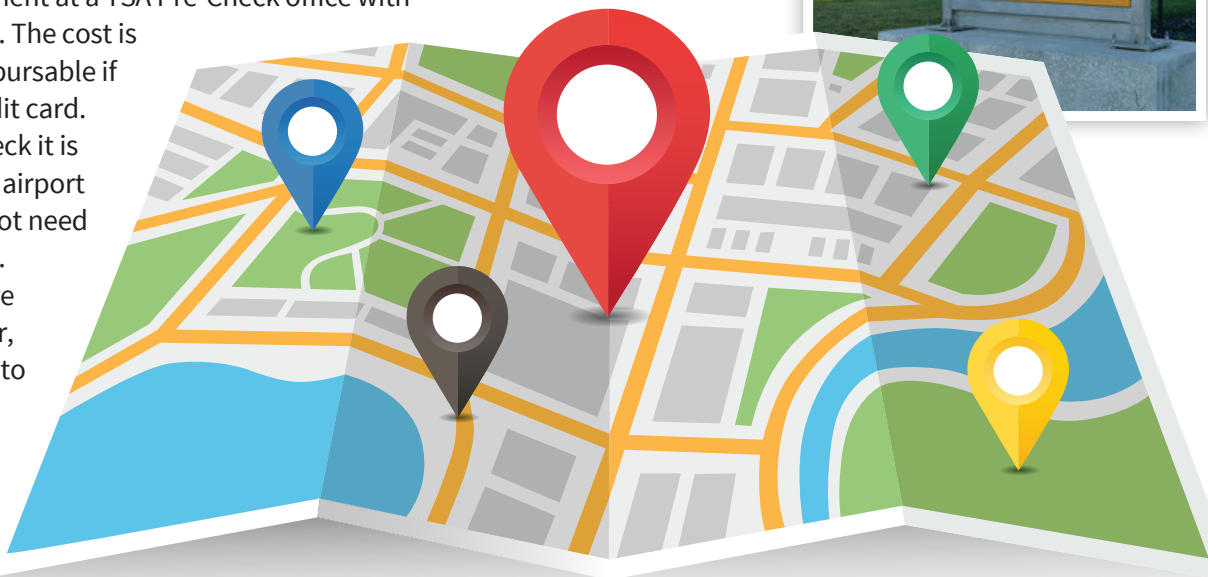


Photo courtesy of Des Moines International Airport



FREE EXERCISE CLASSES

Ankeny

Edencrest Siena Hills

455 SW Ankeny Rd. Ankeny

Movement Training Level 1 • Wednesdays, 10 a.m.

Bettendorf

Palmer Hills Senior Living

2617 Maplecrest Rd, Bettendorf

Movement Training Level 2 • Saturdays, 9 a.m.

Creston

Salem Lutheran Church

602 W Townline St

Movement Training • Mondays, 1:30 p.m.

Des Moines

Des Moines Ballroom

1925 High Street, Des Moines

PD Moves Dance Class, Level 1 • Mondays, 6:30 p.m.,
September 9 – November 11

Des Moines

Northside Senior Center

3010 6th Ave., Des Moines

Movement Training Level 1 • Wednesdays, 9:15 a.m.

Indianola

Indianola Senior Center

2204 W 2nd Ave., Indianola

Movement Training Level 2 • Thursdays, 12 p.m.

Iowa City

Iowa City Senior Center

410 E Washington St., Iowa City

Movement Training Level 2 • Wednesdays, 10 a.m.

Waukee

Independence Village

1605 SE Holiday Crest Cir., Waukee

Movement Training Level 2 • Mondays, 11 a.m.

Funding for the classes is provided by the APDA Iowa so they are free to people with Parkinsons. Contact the APDA Iowa at (515) 782-4386 for more information. Registration is required. To register, visit: apdaparkinson.org/iowa and click on the exercise button.

SPARX 3 – An Exercise Research Study for People Recently Diagnosed with Parkinson’s Disease

Have you been diagnosed with Parkinson’s disease within the past 3 years?

SPARX3 is a research study to learn more about the effects of aerobic exercise on people with Parkinson’s disease who have not yet started medication for their PD.

It will compare the effects of moderate intensity treadmill exercise to high intensity treadmill exercise on the signs and symptoms of Parkinson’s disease.

To participate you must:

- Be between 40 to 80 years old
- Have been diagnosed with Parkinson’s no more than three years ago
- Not currently taking any PD medication or expect to start taking PD medications within the next six months

- Be able and willing to do moderate to high intensity exercise on a treadmill 4x/week for 18 months and participate in study visits for 24 months
- Be able to travel to Iowa State University periodically for study related visits

CONTACT US If you or someone you know would like further information regarding this research study, please contact the study coordinator: Caelia Marshall at cmarshal@iastate.edu, (515) 294-5476 or Dr. Elizabeth Stegemöller, Site Primary Investigator at esteg@iastate.edu This study is funded by The National Institute of Neurological Disorders and Stroke.



Virtual PRESS - Save the Date

Tuesdays, January 28 – March 18, 2025 • 10-11:30 a.m.

Join the PRESS Program (Parkinson's Roadmap for Education and Support Services) if you've been diagnosed with Parkinson's within the last five years.

This 8-week program offers a supportive group setting where you can share and learn about managing PD. Topics covered include daily living tips, building your healthcare team, and dealing with physical symptoms. The program is free and is open to care partners. These are not drop in sessions, participants are encouraged to attend all 8 sessions.

Quote from a participant: *"The program is designed as an informative but informal program that covers eight different topics that pertain and are relative to those of us with Parkinson's disease. Each one of the sessions is hosted by a person who understands the disease and works with those that have the disease. The guest speaker at each session is a specialist in their field, is knowledgeable and understanding of the concerns and challenges each of us face. I strongly encourage everyone to take advantage of this program, it's a zoom meeting that you can do right from the comfort of your own home. It is time well spent!"*

→ Registration will be available in December on our website: apdaparkinson.org/iowa or call: (515) 782-4386.



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Music Listening Study – Volunteers Needed

A new study identifying biomarkers of music listening and how they are related to movement is now starting at Iowa State University (ISU). To participate, you must be between 18-30 if you are a young adult or between 50-85 if you are an older adult or have Parkinson's disease (PD), do not have any other neurological or musculoskeletal disorder, and you are on stable medications for the last 30 days.

Participants will complete a series of movement tasks of the fingers, hand, arm, and foot, a sit to stand task, and a short walking task. You will also be asked to sit quietly with a sensor placed on the back of the hand and upper arm and an EEG headband on the forehead for about three minutes. You will do these tasks in the rounds, once while listening to no sound, once while listening to your preferred music, and once while listening to white noise.

This study requires one visit to the Alternative Medicine and Music for PD lab on the ISU campus and may take approximately two hours. Further screening for eligibility will occur during the first study visit.

If you would like more information, please contact the AMMPD Lab at (515) 294-5476.



Connect with us.

We are here to help.

- Stop in our new office space:
APDA Iowa
2951 86th St., Suite 125
Urbandale, IA 50322
Tuesday - Friday, 9-4
- Sign up for our Newsletter, **News You Can Use**
- Attend an event
- Registration available on our website:
apdaparkinson.org/iowa
- Questions please call (515) 207-6296

American Parkinson Disease Association
Iowa Chapter
PO Box 643
Ankeny, Iowa 50021

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Des Moines, IA
Permit No. 1340

Sign Up Now



2024

September 21, 2024
Walker Johnston Park -
Giovannetti Shelter

