



AMERICAN PARKINSON DISEASE ASSOCIATION

ILLINOIS CHAPTER

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LIVING IN A SMART HOME

By Sydney Marshman OTD, OTR/L, Program Consultant, Iowa APDA Chapter

It's essential to ensure that your home is a comfortable and safe space. This article focuses on simple, yet impactful indoor modifications tailored to support individuals living with Parkinson's disease (PD). By emphasizing changes that enhance safety and ease of movement, these adjustments aim to create a smart home environment that fosters independence. Symptoms like tremors, stiffness, and balance issues, can increase the risk of falls and make daily tasks challenging. Implementing slight modifications within the home can significantly enhance safety and ease of living with PD.

Flooring and Lighting

Installing non-slip flooring throughout the house, especially in high-risk areas like bathrooms and kitchens, can reduce the chances of slipping. Bright and evenly distributed lighting helps improve visibility, aiding movement and preventing accidental falls. It's important to consider lighting during both day and nighttime, ensuring pathways during midnight bathroom trips are well lit. Night lights now come in various shapes and styles, offering features like rechargeable batteries, removability, and motion sensors.

Furniture Selection & Arrangement

As the winter months have you cozied up in your favorite chair, you might start noticing it's asking for a bit more TLC – perhaps a fluff-up or a brand-new replacement! Furniture selection is equally important as furniture arrangement. Furniture should not only be comfortable, but also stationary, firm and an appropriate height to easily sit to stand from. Chairs with armrests are typically preferred as armrests can assist with moving from sitting to standing. Furniture should be arranged to create clear pathways. This means removing unnecessary obstacles and reducing the number of sharp corners on coffee tables and large pieces. This process minimizes the risk of tripping and accidental injury. We'll talk about technology a bit later, but consider cord management and how to remove cords from walkways.



LIVING IN A SMART HOME (continued)

Bathroom Modifications

I think we're familiar with standard bathroom recommendations to reduce fall risk – tall toilets, grab bars, a shower seat for additional support. There are many other solutions that may improve bathroom safety and independence. Non-slip strips and non-slip paint that adheres to the shower floor reduces the need to fuss with a nonslip shower mat. A bendable, long handled shower brush might help with hard to reach places. A security or transfer pole can be easily installed in places that may not accommodate a traditional grab bar.



Kitchen Adjustments

The kitchen often functions as the heart of our home particularly during the holiday season and winter months. It's a great time to consider where your most often used appliances and utensils are stored – are they in easy to reach locations? Utilizing pull-out shelves and lazy susans in cabinets reduces the need to reach or bend extensively which in turn improves fall risk. It's common to have rugs throughout the kitchen, consider removing or securing rugs with rug tape to reduce the likelihood of tripping.

Home Technology

Integration of smart home devices such as smart speakers, voice-activated lights, thermostats, or security systems reduces the need for manual

adjustments and can enhance daily routines. Smart home technology can also be synonymous within fall detection systems, helping individuals and their caregivers in the event of a fall. Smart home technology can be a simple “plug and play” set up, or extensive with multiple connected speakers and pieces of technology. Common uses for smart speaker systems may be asking questions such as date and weather, video conferencing with family, or turning lights on/off.

Home Maintenance

Last, but not least, is the importance of regular home maintenance. As we spend more time indoors, you may notice the need for simple fixes in your home. Winter is a great time to tighten handrails on stairs, replacing batteries in smoke detectors, and update lightbulbs to long lasting LED options. These small and at times mundane tasks ensure we can sustain a safe home environment.

Incorporating these modifications promotes a more accessible and safer living space for individuals with PD. However, it's essential to assess the specific needs and abilities of the person with Parkinson's regularly to make further adjustments as required. Consulting with healthcare professionals or occupational therapists can provide personalized recommendations for home modifications tailored to individual needs. Improving your home environment not only reduces the risk of accidents but also promotes independence and a higher quality of life.





Illinois Optimism Walk 2024!

Saturday, June 22, 2024

Check-In 9:00 am, Walk Starts: 10:00 am

Naperville Riverwalk - Grand Pavilion

For event details and to register, scan the QR code or go to our website: apdaparkinson.org/IL



*"This will be my 10th Optimism Walk. It's a great time to connect with the PD community."
- Ed Hatteberg - Naperville, IL*

*"I can't think of a better way to show I love this community and hate Parkinson's disease at the same time."
- Jeremiah Nast - Lisle, IL*

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ADVOCATING FOR YOUR LOVED ONE

The intricacies of long-term care can be overwhelming, especially if it is your first time navigating this system. When you have someone you love living in a long-term care community, advocating for your loved one becomes an important job.

Advocating on an Individual Scale

Advocating for your loved one doesn't have to be formal all of the time. For many, the most effective and easiest way to advocate is to visit. When you visit, check on your loved one, and help them to get what they need, when they need it.

Unfortunately, not everyone can visit in person regularly. For these individuals, reaching out and advocating via phone is the best option. Sometimes, it isn't as easy as calling, reaching the right staff member, and coming up with a solution to the problem. Instead, families find barriers like difficulty getting a hold of anyone or problems working with the long-term care community. There are ways to improve your communication with long-term care communities to get better results when you advocate for your loved one.

► TIPS FOR COMMUNICATING WITH LONG-TERM CARE COMMUNITIES

- 1. Establish a point of contact:** The staff are providing direct patient care and aren't always able to field multiple phone calls. Work with the facility to understand who you should call with concerns. You may need to establish two contact points, one for general needs and one for nursing concerns.
- 2. Establish expectations for returned calls:** If you call your point of contact and leave a message, you might be tempted to call back and reach out to someone else. If this is not an emergency, wait for a callback, but ensure that you are waiting for a reasonable timeframe. Establish this timeframe beforehand. If the long-term care community says you can expect a callback within 24 hours, and no one returns your call in that timeframe, you can reach out to them again or ask to speak with someone higher up in the chain of command.
- 3. Take notes:** As you talk about your concerns, more issues will come up. It is easy to get sidetracked. Take notes so you have something to refer back to during phone calls, meetings, and check-ins.
- 4. Establish specific resolutions to issues:** When discussing concerns, you and the community will work together to determine a resolution. Establish a specific and tangible resolution that you can check on the progress and hold the long-term care community accountable.
- 5. Follow Up:** Once you have reached a resolution, follow up. Check-in with your loved one and the long-term care community. Find out if they have done what they said they were going to do. If not, find out why.
- 6. Contact your ombudsman:** We are here to help. If you feel like you aren't making progress, call us. If you aren't sure whether your loved one's rights are being upheld, whether you are being ignored, or whether you need additional assistance, we are here. Our confidential and free program provides you with the education and support you need to advocate for your loved one.

Advocating for Your Loved One and Others on a Larger Scale

There may come a time that you realize that the issues you face are systemic problems. This is when advocating for your loved one can look even bigger. Now more than ever, families want to help. They want to know what they can do to advocate, not just for their loved ones but for all residents in long-term care. Fortunately, there are things you can do to help this vulnerable population.

► WAYS TO HELP

- 1. Tell your story:** When residents and their loved ones agree to share their stories, we are better prepared to advocate for real systemic change.
- 2. Find resources:** Consumer Voice also has resources for families, including ideas to stay connected and ways that families can advocate.
- 3. Watch webinars:** VOYCE hosts monthly webinars that you can watch live or later in our Library. Check out our upcoming Community Education sessions.
- 4. Look into organizations that are advocating:** Consumer Voice, Center for Medicare Advocacy, Long-Term Care Community Coalition, and Justice in Aging are some of the organizations advocating for long-term care residents on a national scale.
- 5. Reach out to your representative:** Discuss your concerns with your representative and let them know what their constituents would like to see for residents.
- 6. Receive updates:** VOYCE has a policy and advocacy program dedicated to engaging in individual and systematic advocacy. You can sign up to receive advocacy updates.

Families and concerned individuals want to help their loved ones in long-term care. Your dedication and passion improve your loved one's quality of life in long-term care.

Shared from www.voycestl.org

If you would like to speak to a Home Care Ombudsman, you can call the Illinois Department on Aging Senior Helpline at 1-800-252-8966 or 711 (TRS). Please press 4, "other services", and ask for a Home Care Ombudsman or email us at Aging.HCOProgram@illinois.gov

<https://ilaging.illinois.gov/programs/lcombudsman/the-home-care-ombudsman-program.html>



Join us

Thursday, March 14, 2024 | 10:00am - 12:00pm

for an In-Person Parkinson's Education Program
at the Advocate Good Samaritan Health and Wellness Center
3551 Highland Ave., Downers Grove, IL 60515

PD PROGRESSION & LOWERING FRUSTRATION

As Parkinson's disease progresses into later stages, frustrations can run high. PD can affect mental health, mobility, swallowing, speech and other aspects of everyday life. This program will provide an overview of Parkinson's disease progression and strategies to manage the advancement at each level.



Speaker Spotlight:

Dr. Natalie Witek, MD

Dr. Witek earned her medical degree at Boston University, completed her residency in neurology at the University of California (San Francisco) School of Medicine and her fellowship at Rush University Medical Center. She is board certified in neurology and is affiliated with Advocate Christ Medical Center, Good Samaritan Hospital and Lutheran General Hospital.

Registration is required.

www.apdaparkinson.org/il or call 708.329.9527

Point your smartphone
camera at this QR code and
click the link to register



AMERICAN
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Volunteers
needed

To join this group of fun people, contact Melanie Adams
at madams@apdaparkinson.org or call 708.522.4772

SUPPORT GROUPS

A support group is a collection of participants who meet on a regular basis, facilitated by a support group leader, to discuss issues of mutual concern – in this case, PD. Support groups play a vital role in the lives of many people with Parkinson's disease (PD)

Here is a list of support groups offered by the APDA Illinois Chapter.

Please check out our [website](http://www.apdaparkinson.org/il) for more information on these groups – www.apdaparkinson.org/il.

Alton - Senior Services Plus, Main Building

2nd Tuesday 2:00 pm - Care Partners ONLY
2nd Wednesday 1:00 pm
Call 636.778.3377

Aurora - Waterford Place Cancer Resource Ctr.

1st Tuesday 10:30 am - People living with PD ONLY
3rd Tuesday 10:30 am - Care Partners ONLY

Belleville - SWIC Programs and Services for Older Persons

3rd Monday 1:30 pm
3rd Tuesday 11:00 am - Care Partners ONLY
Call 636.778.3377

Carbondale - Prairie Living at Chautauqua

1st Wednesday 1:00 pm
Call 636.778.3377

Carlinville - Carlinville Area Hospital

4th Tuesday 11:00 am
Call 636.778.3377

Champaign - Savoy United Methodist Church

Every Monday 10:00 am
Call 708.329.9527

Decatur - Westminster Church

3rd Thursday 1:30 pm
Call 708.329.9527

Edwardsville - YMCA Niebur Center

1st Tuesday 2:00 pm
Call 636.778.3377

Glen Ellyn (DuPage Area) - Movement Revolution

3rd Mondays 7:00 pm
Call 708.329.9527

Glenview - Endeavor Health

2nd Tuesdays 11:00 am
Call 708.329.9527

Greenville - Bond County Senior Citizens

2nd Tuesday 1:00 pm
Call 636.778.3377

Highland - St. Joseph Hospital

4th Tuesday 2:00 pm
Call 636.778.3377

Jacksonville - Virtual

1st Wednesdays 1:00 pm
Call 636.778.3377

Maywood - Loyola Outpatient Center

1st Mondays 2:00 pm
Call 708.329.9527

Normal/Bloomington - The Activity and Rec. Ctr.

3rd Tuesdays 1:00 pm
Call 708.329.9527

North Utica - Utica Fire Station

1st Mondays 1:30 pm
Call 708.329.9527

Northbrook - Brandel Care Center

2nd and 4th Wednesdays 2:00 pm
Call 708.329.9527

Northfield - North Shore Senior Center

1st and 3rd Wednesdays 1:00 pm
Call 708.329.9527

Quincy - Quincy Library

2nd Saturday 10:00am
Call 636.778.3377

We are proud to partner with the APDA Information and Referral Center at the University of Chicago Parkinson and Movement Disorder Clinic for these support groups.

Contact: Nicole Reidy 1-773-834-1688 or nicole.reidy@uchospitals.edu for more info.

Virtual - Parkinson Disease support group

4th Tuesdays 11:00 am

Virtual - Education and Enrichment Group

1st and 3rd Mondays 12:00 pm

Virtual - African Americans Living with PD

2nd Tuesdays 10:00 am

Virtual - Acknowledging Purpose During Adversity

Thursdays, February 29 – April 4 10:00

COGNITIVE DECLINE IN PARKINSON'S DISEASE - IS THERE ANYTHING WE CAN DO ABOUT IT?

Dr. Gilbert's blog post for March 5, 2019

For many people, one of the most concerning non-motor features of Parkinson's disease (PD) is cognitive decline. Attention, working memory, executive function, memory, language and visual reasoning are the cognitive skills most frequently affected in PD.

Cognitive changes can be an underlying part of PD, caused by abnormal accumulation of the protein alpha-synuclein into Lewy bodies in the thinking areas of the brain. When this occurs, there are strategies ranging from cognitive therapy to medications to help support cognitive function.

On the vast array of treatable medical problems that can worsen cognitive function. The following factors are crucial to identify, because if they are treated, cognitive function may improve.

Hearing Loss & Cognitive Decline

Abundant research exists that supports the claim that hearing loss impacts cognitive function. One Johns Hopkins research study reviewed thousands of medical claims and demonstrated an association between hearing loss and an increased 10-year risk of dementia, falls, depression and heart attack. Research also suggests that improving hearing with hearing aids can improve cognitive function. One study showed that memory decline slowed in patients who started wearing hearing aids, highlighting the importance of detecting and treating hearing loss early.

Other Possible Contributors to Cognitive Decline in Parkinson's

Hearing is not the only modifiable contributor to cognitive decline. Consider reviewing this list with your doctor to make sure that you do not need to be evaluated for any of these conditions:

- **Medication effects**

Certain medications given for urinary frequency, migraine, seizures, anxiety, and other conditions, can interfere with cognitive function or make your thinking feel sluggish. Even some medications given for PD can contribute to this problem, so be sure to review your medication list frequently with your neurologist and speak up if you're noticing changes in your cognitive abilities. If a medication is identified that can worsen cognitive function, it can be changed.

- **Intercurrent infection**

If cognitive difficulty (or hallucinations) seem to start or worsen quickly, it is important to check for a urinary tract infection or pneumonia. If an infection is identified, it can be treated with antibiotics.

- **Depression**

It is well established that depression can mimic cognitive decline. When someone is depressed, he/she tends to withdraw socially and not exert themselves cognitively. When this occurs, the condition is referred to as pseudo-dementia, and with proper treatment of the depression, cognitive function can be restored.

- **Abnormal thyroid function**

Cognitive difficulties can result from too little thyroid hormone which can be easily checked with a blood test and corrected with a prescription of synthetic thyroid hormone.

- **Abnormal Vitamin B12 levels**

Cognitive difficulties can also result from low levels of Vitamin B12. This can also be easily checked with a blood test and corrected by taking supplemental Vitamin B12.



- **Orthostatic hypotension**

Periodic drops in blood pressure may occur as a non-motor symptom in PD. During periods of low blood pressure, cognitive function may decline because of decreased blood flow to the thinking parts of the brain.

- **Dehydration**

Dehydration can exacerbate low blood pressure and can contribute to changes in alertness.

- **Vascular brain health**

Poor circulation of blood to the brain, often due to narrowed or damaged arteries from high blood pressure, high cholesterol and diabetes, can cause strokes. Strokes can be apparent and result in a sudden neurologic deficit such as the inability to move one side, or to speak. Strokes can also be silent and not cause any noticeable neurologic deficit, if they affect areas of the brain that are not involved in particular functions. However, an accumulation of both these types of strokes can contribute to cognitive decline.

- **Poor sleep and sleep apnea**

Poor sleep from Parkinson's disease typically leads to daytime fatigue which can make cognitive tasks more difficult. Sleep apnea, which often is suspected due to persistent, loud snoring, is one cause of poor sleep which has an increased incidence in people with PD. In the general population, this condition is often associated with obesity, with fat deposits in the upper airway resulting in obstruction of normal breathing at night. In PD however, the condition may

be due to a combination of factors including rigidity, hypokinesia and postural abnormalities of the trunk muscles as well as autonomic dysfunction. Another contributor to the disordered breathing of PD may be abnormal signaling from sleep and respiratory centers in the brain. Regardless of the cause, in this condition, there are frequent awakenings during the night, due to intermittent starts and stops of breathing and resultant episodes of drops in blood oxygen levels. If sleep apnea is detected, it can be treated with an array of breathing devices which can supports breathing at night.

- **Head trauma**

As you may be aware, past head trauma likely contributes to a small increased risk of PD. When cognitive changes occur, they may be related to a more acute head trauma. A fall which results in hitting the head, for example, may cause bleeding in various areas in and around the brain. Usually, it will be clear that a trip to the emergency room is necessary because of changes in consciousness. Sometimes, however, the injury may seem mild even though it caused internal bleeding. For example, bleeding in the subdural space around the brain could be slow and subtle and result in cognitive changes that develop over weeks to months. Therefore, it is generally recommended that after even minor head injury if there is headache, vomiting, short-term memory loss, seizure or visible trauma above the collar bone, a computed tomography (CT) of the head is performed.

APDA'S IMPACTFUL RESEARCH IN PARKINSON'S DISEASE

APDA proudly invests in the most promising clinicians and scientific projects focused on the discovery of the cause(s) and finding the cure(s) for Parkinson's disease (PD). APDA is committed to scientific research and has been a funding partner in many major PD scientific breakthroughs, investing nearly \$60 million in research since 1961. We are very proud of the impact our research funds have made in the past, and we're excited to give you some updates on the impact we're having today, and also explain how we measure that impact.

Many APDA-funded researchers have utilized the funding they received to develop the pilot data they need to then successfully secure multimillion-dollar grants through the National Institutes of Health and other funding partners. One of our researchers told us how APDA's seed funding made all the difference in securing a grant from the NIH, not once, but twice!

How APDA Research Funding Works

Every year, our esteemed Scientific Advisory Board meets in the spring to carefully select the scientists who will receive APDA research funding. It's a very specific and thorough process.

APDA's Newly Funded 2024 Research Awardees

Our current group of grantees is working on exciting projects which you can read about on our website. Our grantees are required to send us six-month and 12-month progress reports to keep us up to date on their projects. This is an important part of the process and helps us evaluate and measure our impact.

Tracking the Impact of APDA-Funded Research

There are various methods APDA uses to understand the impact of our grant money:

- The number of papers published in medical literature that acknowledge APDA funding.
- The quality of the journals in which the APDA-funded papers are published.
- The number of times the individual APDA-funded papers were cited. Since 2020, APDA-funded work has collectively been cited more than 4,000 times!

Academic Journals and ADPA-Funded Research

In 2023, 28 APDA-funded research articles were published in academic journals, investigating various aspects of PD, including understanding how dopamine neurons are generated, the use of augmented reality as a treatment for freezing of gait, and the development of a novel PD-specific drug screening tool. Even though these papers have only been published within the past year, they have already been cited in 72 other research articles.

It is important to note that research may take more than one year to reach its conclusion. Therefore, some papers published in 2023 were funded by APDA one or more years ago.

APDA-Funded Research Papers

To give you some examples, below we highlight several research papers published in 2023 that APDA has proudly funded.

How two different types of dopamine neurons are generated.

In April 2023, Dr. Umemori published a paper in the very prestigious journal *Cell* which highlights findings from his APDA-funded work. There are two distinct dopamine neuron populations in the midbrain, those in the substantia nigra that regulate motor behaviors and those in the ventral tegmental area that regulate motivation. The dopamine neurons in the substantia nigra degenerate in Parkinson's disease while the dopamine neurons in the ventral tegmental area do not show nearly as much damage. Dr. Umemori's project sought to understand how these two dopamine populations developed and why only one was targeted in PD. In this work, Dr. Umemori discovered that two different nerve growth factors were responsible for the development of the two types of dopamine neurons. He also identified two molecules that acted downstream of these two different nerve growth factors, Smad1 and Smad2. Mice missing Smad1 showed motor deficits, and mice missing Smad2 showed a lack of motivation. The next steps could involve manipulating one of these specific pathways to treat diseases such as PD which demonstrate abnormal dopamine signaling.

Developing an innovative PD-specific drug screening tool.

In June 2023, Dr. Gabsang Lee published a paper that described a novel drug screening system called OASIS (Opto-genetic Assisted Alpha-Synuclein Aggregation Induction System) in which alpha-synuclein production and aggregation within the dopaminergic neurons is regulated by shining blue light on the cells. The system was used to screen potential drugs that can interfere with the aggregation of alpha-synuclein, thought to be the primary driver of the pathology of PD. Of the long list of potential compounds, BAG956 was identified as having the most potential at reducing aggregation. They then further tested the molecule in various cell and animal systems. BAG956 not only reduced alpha-synuclein aggregation, but also reduced nerve cell death in dopaminergic cells. In a mouse model of PD, the introduction of BAG956 improved many tests of motor and behavior function.

Can augmented reality be used as a treatment for freezing of gait?

In June 2023, Dr. James Liao published an article that analyzed the available data on the use of augmented reality (a technology in which a computer-generated image is superimposed on top of a user's actual view of the world) for the treatment of freezing of gait (FOG). The article also highlighted his own work, supported by APDA, which includes a clinical trial studying the use of augmented reality for FOG.

The presence of Lewy body pathology in the thinking parts of the brain is not enough to cause dementia in Parkinson's disease

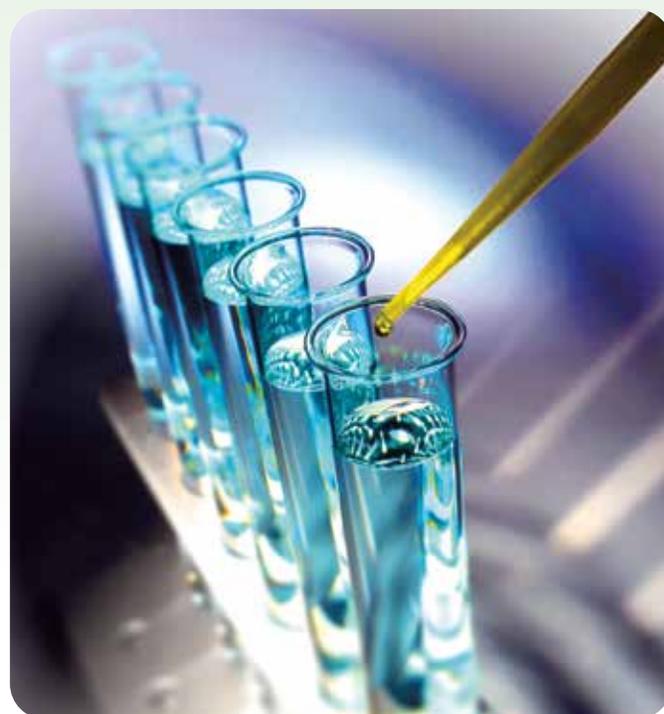
APDA funds eight Centers for Advanced Research at major medical centers around the country. These APDA Centers support large research programs which include research trainees, fellowship programs, early-stage discovery programs, and later-stage clinical translation. A recent study published in January 2023 from the APDA Center for Advanced Research at Washington University investigated the relationship between neuropathology and dementia and showed, predictably, that the vast majority (94%) of individuals with PD and dementia had Lewy bodies, or abnormal

accumulations of the protein alpha-synuclein in the neocortex, the part of the brain involved in higher-level thinking. However, 68% of the individuals with PD but without dementia also had neocortical Lewy bodies! This surprising discovery indicates that other factors besides neocortical Lewy bodies contribute to the development of dementia.

The effects of deep brain stimulation on walking in PD

The Dr. George C. Cotzias Memorial Fellowship is APDA's most prestigious award, given over a three-year period to a physician-scientist with the goal of fostering a career in research, teaching, and patient care of PD and related disorders. A recent Cotzias awardee, Dr. Aasef Shaikh published a paper in July 2023 that analyzed improvements in the gait patterns of those receiving deep brain stimulation of the subthalamic nucleus.

We continue to be very mindful of the impact of our funding and make every effort to maximize the effect of our research dollars to advance our understanding of PD.



Strength in optimism. Hope in progress.

PO Box 814
River Grove, Illinois 60171

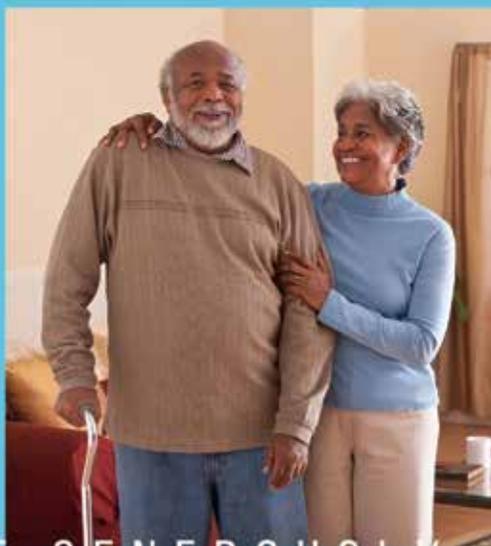
MONTHLY GIVING

"We felt isolated in the PD diagnosis and now we have this incredible connected community."

APDA Missouri participant

By giving a monthly donation to the APDA Missouri Chapter, you will help provide consistent, high quality programs for people with Parkinson's disease and their care partners and family members.

A donation of \$25 a month or more, will help people move from diagnosis to hope.



GIVE NOW, GIVE GENEROUSLY.

APDA Illinois Chapter

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