



AMERICAN PARKINSON DISEASE ASSOCIATION

ILLINOIS CHAPTER

Jan/Feb/March
2025
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LET'S TALK ABOUT **BRAIN DONATION**



One of the most fundamental ways for scientists to learn about Parkinson's disease (PD) as well as other brain disorders, is by studying the brain tissue of people with these diseases.

There is never too much of this extremely valuable material for research studies. While there are major strides in developing cellular and animal models to study the disease, novel findings from these model systems need to be verified and access to human brain material with PD is critical. **Lack of brain samples is a roadblock for research by the scientific community.**

Below is an interview between Dr. Rebecca Gilbert, APDA Chief Mission Officer and Dr. Dennis Dickson, Professor of Pathology and Laboratory Medicine, at Mayo Clinic, Jacksonville to discuss brain donation.

Dr. Dickson is the Director of the Brain Bank for Neurodegenerative Disorders and the Director of the APDA Center for Advanced Research, also at Mayo Clinic, Jacksonville. Dr. Dickson is also a long-standing and valued member of APDA's Scientific Advisory Board. By studying brain tissue in a variety of neurologic diseases, Dr. Dickson has made fundamental discoveries regarding the abnormal accumulation of various proteins and their ability to cause neurodegenerative diseases.

1. Why are post-mortem brains so important for your work? Can you describe some of the experiments that you do that require brain tissue?

Evaluation of the brain provides a definitive pathologic diagnosis that provides closure to the family as they learn what affected their loved one. While clinical diagnosis has greatly improved over the years, it is still not perfect. Clinical syndromes are driven by damage to particular brain regions, but we do not yet have ways to see and evaluate this damage in a living brain. It is not until the actual brain is examined that we can truly confirm the diagnosis. For example, in PD the dopamine producing neurons in the midbrain are particularly vulnerable, and the

THOUGHTS ON BRAIN DONATIONS (continued)

degenerating neurons accumulate α -synuclein protein in inclusion bodies known as Lewy bodies. Midbrain dopamine neurons can be damaged by other processes and these other disorders can clinically resemble PD.

A brain donation is also valuable in providing tissue samples that can be used in a wide range of investigative studies, including structural, chemical, biochemical, immunologic, genetic and molecular biologic studies. These studies can complement and validate research that has been done in animals and cells. Additionally, DNA isolated from the brains of PD patients can be used in genetic investigations of genes that increase or decrease the risk of PD.

2. When a brain arrives at your brain bank, what happens to it? How is it processed?

The brain donation is performed by a skilled pathologic assistant, pathologist or medical examiner, who removes the entire brain in such a way as to not interfere with funeral arrangements, including viewing of the deceased. It is important to note that the procedure is not disfiguring.

The fresh brain is most often divided into right and left halves, with one half frozen for research and the other placed in preservatives (formalin) for diagnostic evaluation. It is important to note that the preserved (or “fixed”) tissue can also be used for research. The fixed brain is weighed, photographed and dissected. The dissection involves taking samples from all parts of the brain. The small tissue blocks are embedded in paraffin wax. It is from these wax-embedded tissue samples that very thin slices are taken and mounted on glass microscope slides. The tissue-mounted slides are put through a variety of tests that reveal normal and abnormal changes when viewed under the microscope.

3. How many brains do you receive at the brain bank in a year?

The brain bank in Jacksonville receives about 200 brains each year, from all 50 states including Alaska and Hawaii, as well as from Canada. Given that the brain bank takes in and distributes tissue, it is important for there to be a consistent stream of donated brains, and we encourage people to consider this meaningful gift.

4. Does the family of the person who donates the brain get any information about the brain once it is donated?

Absolutely. When the diagnostic report is finished, a copy is sent to the family with a cover letter summarizing the findings in lay person language. We are also able to provide answers to follow-up questions that the report may generate via email, phone or fax.

5. What steps can a person take to arrange for their brain to be donated for Parkinson’s research?

It is important to note that for research purposes, **arrangements for brain donation need to be made before death**, so that the time from death to removal of the brain is as short as possible. As soon as death occurs, there are changes that occur in the brain tissue that make it much less valuable for research.

So how can arrangements be initiated during life? There are a variety of places that can assist with and facilitate brain donation. For example, at the Mayo Clinic brain bank, a coordinator assists with collecting information about the patient and then later helps with the logistics of the brain harvest and shipment, when that occurs. There are also not-for-profit organizations such as Brain Support Network and Brain Donor Project that help coordinate the logistics of the brain. Both of these organizations will guide you step-by-step to get you set up for donation.

It is vital to communicate with your loved ones about your decision to donate your brain and the logistics that you have pre-arranged so that they can help make the donation a reality.

6. What happens after death if a brain donation has been arranged?

If you have registered with a brain bank during life (with one of the organizations listed in question 5) your family members will be given a 24-hour phone number to call upon death to initiate the brain donation process. Transportation will be arranged and a pathologist will be contacted. Then the family will receive the body back to continue with funeral arrangements.

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Tips and Tricks for Parkinson's

Driving



Plan your trips: Choose familiar routes, beat rush hour, stay home in bad weather, and prioritize driving in the daylight if vision is affected.



Easy Entry and Exit: Utilize a swivel seat cushion, leg lifter and/or car cane to assist with getting in and out of the car. Add a thicker steering wheel cover with grips for a more secure grasp



Passenger Support: Have a friend or family accompany you while you drive long distances



Sitting down while getting ready to go out will conserve energy and support balance.



GETTING TAX BENEFITS WHILE DONATING TO YOUR FAVORITE ORGANIZATION



By Anne Haudrich, CFP® - Senior Advisor at Moneta



Happy New Years! Have you ever considered there may be a more tax-efficient way to donate to the APDA other than paying with a credit card or sending in a check? Donating cash from your bank account makes you eligible for the charitable deduction on your tax return (assuming you itemize your deductions), but did you know depending on your age and financial situation, there may be other options to consider? If you're looking to make a significant impact to the APDA with your gift, consider donating appreciated securities or utilizing a Qualified Charitable Distribution (QCD).

A Qualified Charitable Distribution is a donation to a 501(c)(3) charitable organization made directly from your Traditional Individual Retirement Account (IRA) – it cannot be paid to you first. If you are at least 70.5 years old, you can direct any amount up to \$110,000 to a charitable organization from your IRA without paying taxes on the distribution. Because your charitable contribution is a tax-free distribution from your IRA, you do not take the charitable deduction on your tax return. This technique is especially effective for those who are subject to a Required Minimum Distribution (RMD) and for those who typically elect the standard deduction on their federal tax return. Please consult your tax and/or financial advisor to see if this technique would be beneficial, and remember, you cannot make a QCD from employer-sponsored IRAs, like SIMPLEs or SEPs.

If you are not eligible for a QCD, donating appreciated securities from a taxable account (non-retirement, like a brokerage account) may be another option for you. Appreciated securities (Exchange Traded Funds (ETFs), stocks, or mutual funds, to name a few) that have increased in value which you have held for longer than one year can be donated to the APDA “in-kind.”

The benefit of using shares of appreciated securities is that you can transfer the unrealized gain out of your account and over to the APDA where they are able to sell and are not subject to the capital gains tax. This is especially effective if you are someone who typically sells some of your investments to fulfill your charitable intentions – consider instead donating the shares rather than selling to potentially avoid a realized capital gain that may be taxable. Again, consult your tax advisor as to whether this technique will be beneficial to you, as there are some other factors to consider like how much of your gift can be deducted based on your Adjusted Gross Income (AGI).

While for most, charitable giving isn't just about the tax benefit, if you intend to support the APDA and can do so in a more tax-efficient manner, I see that as a win-win. Wishing everyone a wonderful holiday season surrounded by your loved ones.

Disclosures:

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PD & PIZZA

Monthly social group for individuals with Parkinson's Disease.

1ST TUESDAY EVERY MONTH 2025

6:00 - 7:30 PM

TRAVERSO'S ITALIAN RESTAURANT

2523 PLAINFIELD-NAPERVILLE RD. NAPERVILLE, IL

Upcoming Programs

**February
15, 2025**

Let's Get Physical
-An APDA Parkinson's Education Program

Rockford, IL

**April
2025**

A-Round PD
-A Round Table Discussion
More information coming soon!

Aurora, IL

**March
18, 2025**

Speaking of... Memory & Cognition while living with PD
-An APDA Parkinson's Education Program

Bolingbrook, IL

**May
2025**

A-Round PD
-A Round Table Discussion
More information coming soon!

South Cook, IL

**May
15, 2025**

Most Requested Topics: Balance, Sleep, and Caring for Someone with Parkinson's-An APDA Parkinson's Education Program

Glenview, IL

Scan me



Keep an eye on our website for more information!

2024 PARKINSON'S CONFERENCE

Understanding Each Piece of the Puzzle

On November 19, APDA Illinois Chapter held a Parkinson Conference at the NIU Grand Ballroom Naperville Conference Center. We were thrilled to have. Rebecca Gilbert, MD, Chief Mission Officer for APDA and a movement disorders neurologist talk about Hacks, Tricks and Tweaks. As always, she provided the latest information to help us live our best lives.

“I truly enjoyed the APDA conference today- I’ve been to other (non-PD) conferences where I don’t feel that I really gained anything, but today was completely different. All of the speakers were very engaging and the panel was really valuable, so I certainly think it made a great impact!” – conference attendee.

Several key takeaways from the conference include:

- During the panel discussion, we learned that it takes connections to absorb all the information and options surrounding PD. Keep connected!
- Clinical trials are so important for the future of PD. Learn about your options!
- It’s never too early to ask for help and continue to learn and engage! Make sure you are signed up for the Friday e-news!

Thank you to all the speakers, sponsors, exhibitors, and most of all everyone who attended the conference. You all made it a great and helpful event.

We’ve already started the planning for next year’s conference, October 2025.



From the left, Dr. Mahesh Padmadaban, Dr. Tao Xie, Dr. Daniel Corcos, Dr. Nicole Reidy, Dr. Rebecca Gilbert



Panelists: Audrey Southard and Austin Pohlman



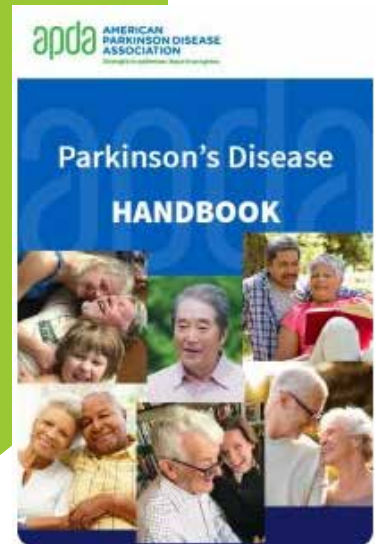
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HAVE YOU RECEIVED YOUR WELCOME PACKET?

You'll get a packet of critical information about Parkinson's disease and information and resources. For people Newly Diagnose or further along on your journey. This packet has something for everyone.



To get your Welcome Packet, email apdail@apdaparkinson.org, call (708) 329-9527, or visit our website at www.apdaparkinson.org/il.



Optimism Walk
SAVE!
THE DATE!

June 21st
Naperville Riverwalk

can't wait to see you there!

2025



New & improved!

APDA SYMPTOM TRACKER

An easier way to track your symptoms and manage your care.

Includes in-app Spanish language option
Download the free APDA Symptom Tracker mobile app today.



IMPROVING YOUR COGNITIVE FITNESS: MORE THAN PUZZLES

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**
- **Language**
- **Memory**
- **Executive functions**
- **Visuospatial skills**

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.

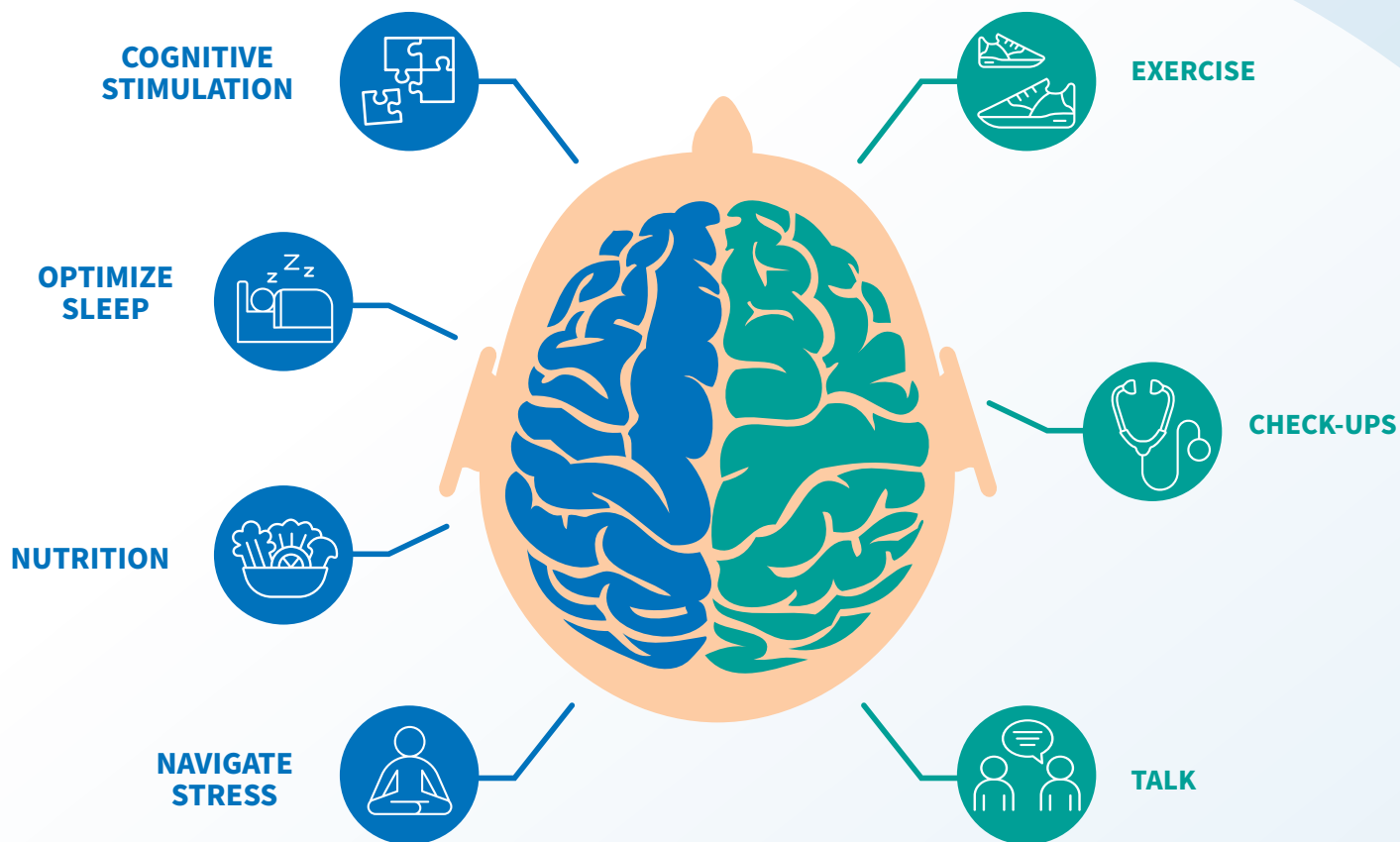
In recent years, there has been more research done in our brain's ability to build new neural networks and improve, or at least maintain, cognitive abilities as we age. Researchers have determined a set of principles that help to optimize brain health and function and have coined the term Cognitive Fitness.

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!



WHAT DOES A MOVEMENT SPECIALIST DO?

People are eager to learn about the differences between the PD care received from a general neurologist versus a Movement Disorders Specialist. What distinguishes one from the other? While there are many similarities between the two, there are some distinct differences that I will explain.

Let me begin by stating unequivocally that there are many superb general neurologists in the United States who treat PD patients with exemplary care. Many of you reading this are taken care of by such neurologists. Just because a neurologist has not undergone specialized movement disorders training, does not mean that they are not able to offer excellent PD care. Having said that however, those who do undergo extra movement disorders training and focus their practice on taking care of PD patients may have additional perspectives, especially in challenging clinical situations. If you are not satisfied with your current PD care, consider getting a second opinion from a Movement Disorders Specialist if one practices in your area.

What is a Movement Disorders Specialist?

A Movement Disorders Specialist undergoes the same training as a general neurologist — both complete a one-year internship in Internal Medicine after finishing medical school, followed by a three-year residency in neurology. A general neurologist stops training at that point and enters practice, whereas a Movement Disorders Specialist continues to complete a movement disorders fellowship, which is an extra 1-2 years of training focused on PD and related disorders. This additional time allows for:

- **Additional experience in prescribing PD-specific medications** – There are currently 23 medications approved for use in PD, including 7 medications containing levodopa, and 6 variations of dopamine agonists. These medications can be used in combination, and dosages and timing of all these medications can make a difference in clinical outcomes. It therefore takes skill and practice to use these medications most effectively.
- **Extra proficiency at managing medication side effects** – Many of the medications used for PD have side effects that need to be managed and a movement disorders fellowship allows for more training in managing these.

- **Added skill at non-motor symptom management.** Movement disorders fellowship allows for more comfort in managing non-motor symptoms such as depression, psychosis, constipation, and low blood pressure, including prescribing medications for these conditions.
- **Additional experience in botulinum toxin injections,** both for drooling as well as for limb dystonia that can accompany PD.
- **Training in deep brain stimulation (DBS) management** – Movement disorders training includes learning how to program the multiple DBS systems currently in use in the US. Trainees learn how to perform both the initial programming after insertion of the system as well as the ongoing adjustments of the system in response to disease evolution. Depending on the fellowship, a movement disorders fellow may also learn how to operate the neurophysiologic equipment in the operating room during insertion of DBS, which allows for precise placement of the system in the brain.
- **Training in clinical trial methodology,** as well as recruitment for and conducting of PD clinical trials

Those who complete a movement disorders fellowship will then typically focus their practice on PD and related disorders. Therefore, they will continue to learn the intricacies of all the areas mentioned above, as each patient provides a new opportunity to learn.

In addition, by limiting their practice to PD and related disorders, it is more likely that a Movement Disorders Specialist will:

- **Keep up on new developments in the field including newly approved medications.** Movement disorders physicians will typically use these medications more frequently and be more familiar with their benefits and limitations.
- **Work alongside other health care professionals who have specialized knowledge of PD.** These health care professionals may include nurses, social workers, physical therapists, occupational therapists, and speech and language pathologists. These various professionals can then collaborate as a team to deliver the best results.

- **Have access to clinical trials.** A Movement Disorders Specialist may be directly involved in conducting clinical trials and be able to refer patients to clinical trials at his/her own facility, or may have knowledge of the available clinical trials in the area and be able to refer patients that are eligible to the appropriate trials at other institutions.
- **Have access to other Movement Disorders Specialists to discuss cases and share videos of complicated cases and clinical situations.** They will also typically attend medical conferences about PD with other movement disorders specialists. These interactions provide new ideas and perspectives to allow for delivery of optimal care.

All in all, seeing a Movement Disorders Specialist may offer you additional avenues to improve your PD-related care.



Used with permission from Dr. Rebecca Gilbert's blog.

REBECCA GILBERT
APDA Vice President & Chief Scientific Officer

Dr. Gilbert received her MD degree at Weill Medical College of Cornell University in New York and her PhD in Cell Biology and Genetics at the Weill Graduate School of Medical Sciences. She then pursued Neurology Residency training as well as Movement Disorders Fellowship training at Columbia Presbyterian Medical Center. Prior to coming to APDA, she was an Associate Professor of Neurology at NYU Langone Medical Center. In this role, she saw movement disorder patients, initiated and directed the NYU Movement Disorders Fellowship, participated in clinical trials and other research initiatives for PD and lectured widely on the disease.



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