AMERICAN
PARKINSON DISEASE
ASSOCIATION
GREATER ST. LOUIS CHAPTER
Strength in optimism. Hope in progress.

JULY/AUGUST 2021

UNDERSTANDING THE LEVODOPA SIDE EFFECT

If you have Parkinson's disease, there is a good chance that you've been, or will be taking medication containing levodopa. Levodopa is administered in combination with the drug carbidopa (Sinemet® and its generic versions). This drug combination is considered standard treatment for Parkinson's disease symptoms such as tremor, muscle stiffness, and slowness of movement. A side effect of long-term use of levodopa is dyskinesia.

What is dyskinesia?

The features of dyskinesia include rapid, involuntary, and uncontrollable movements other than the tremors typical of Parkinson's. Dyskinesia can present as body swaying, writhing, twisting, squirming, arm flailing, fidgeting, or head bobbing. Dyskinesia initially appears on the side of the body most affected by Parkinson's. Although it can be localized to one part of the body such as the legs and arms, it can also spread to the torso, head, and neck. In rare circumstances, dyskinesia can also affect speech and respiratory and eye muscles.

What causes dyskinesia?

Dyskinesia is a side effect of levodopa use. The underlying cause of dyskinesia is complex and is not completely known. Normal brain function depends on a complex network of cells that communicates and functions via an array of different brain chemicals. One of these chemicals is dopamine. In Parkinson's, there is a loss of brain cells called dopaminergic neurons that make dopamine; therefore, the level of dopamine in the brain starts to decrease. The purpose of taking levodopa is to temporarily restore the dopamine that is lost. However, since levodopa is intermittently taken over the course of a day, the level of dopamine will rise and fall. These dopamine level fluctuations, in combination with the loss of dopaminergic neurons, are thought to cause dyskinesia. Dyskinesia can occur when the level of levodopa in the body is at a maximum, referred to as peak dose dyskinesia, or when the levels of levodopa are rising or falling, referred to as diphasic dyskinesia.

If levodopa causes dyskinesia, then why should I take it?

At present, treatment with levodopa is the most effective way to relieve tremor, stiffness, and slow movement associated with Parkinson's.

[continued on next page]

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In the early stage of Parkinson's, levodopa may not be necessary and there are other medications available to treat this stage of the disease. However, as the disease progresses and symptoms begin to interfere with daily living, your doctor will prescribe levodopa.

- It typically doesn't develop immediately. It's important to note that there is usually a time lag of roughly 4 to 10 years from the start of treatment with levodopa to when dyskinesia emerges, and its severity will vary among different individuals.
- Younger people are at a greater risk – People who get Parkinson's in their later years (70 years and older) may not show signs of dyskinesia or may have only mild symptoms within their lifetime. Being diagnosed with Parkinson's at a younger age (less than 60) is associated with a greater chance of developing dyskinesia.
- As with every aspect of Parkinson's, there is variability in dyskinesias. Some (even among patients who develop PD earlier in life) do not develop dyskinesias at all. For those who do get them, not all experience them the same. Dyskinesia in its milder form may not be bothersome, and the mobility afforded by taking levodopa may be preferable to the immobility associated with not taking levodopa. People with Parkinson's must weigh the benefits from using levodopa versus the impact of dyskinesia on their quality of life.

Are there ways to manage dyskinesia?

Once dyskinesia has started it is difficult to treat. However, there are several ways to delay it from starting or reduce it once it has begun.

Supplemental or alternative treatment options.

- If you have Parkinson's with mild symptoms but do not yet have dysknesia, your doctor may prefer to begin your treatment with drugs known as dopamine receptor agonists instead of levodopa. However, at some point these drugs will typically cease to be sufficiently effective and levodopa will be needed.
- Once dyskinesia has started and begins to interfere with daily life, your doctor may lower the dosage and adjust the time at which carbidopa-levodopa is taken, prescribe an extended-release formulation of this drug combination (Rytary®), or recommend continuous intestinal infusion of carbidopa-levodopa (Duopa™). These treatment strategies may help reduce fluctuations in dopamine that contribute to dyskinesia.
- Extended-release formulation Gocovri™ maintains a high level of amantadine in the body throughout the day and has shown good results in reducing dyskinesia. In addition, the extended-release formulation taken orally – once at bedtime – may be more advantageous to some people than the multiple daily doses of immediate-release amantadine. Additionally, Gocovri was recently approved to treat PD patients experiencing "off" episodes. The approval of a second indication for GOCOVRI is a major milestone for patients with Parkinson's who experience motor complications in their daily lives. GOCOVRI is now the first and only medication approved to treat both OFF and dyskinesia motor complications in Parkinson's disease.
- Deep brain stimulation is a surgical method that can be used for severe symptoms of dyskinesia. It has been shown to be remarkably effective in carefully selected patients. There are very specific criteria for this procedure to be effective and is only done when other methods have not worked. Are there coping strategies for living with dyskinesia? There are several ways to manage dyskinesia and Parkinson's in general by incorporating some basic routines into your lifestyle.

Things you can do on your own.

- Keep a diary that logs the time and frequency of dyskinesia, which will help your doctor assess if your medications are working and help you schedule daily activities when mobility is better.
- Physical activity, including mild aerobic exercise such as walking, dancing, and swimming, will help keep the body strong and prevent muscle weakening.
- Stress can make dyskinesia symptoms worse, so find ways to reduce stress (breathing exercises, massage, yoga, etc) and try to keep a positive attitude.
- Poor sleep at night is associated with dyskinesia. Aim for good sleep quality and try to experiment with different positions in bed that will help you relax and sleep better.

Make a Gift Tax-Free with an IRA

Make a difference today and save on taxes. It's possible when you support APDA Greater St. Louis Chapter through your IRA.

A Special Opportunity for Those 70½ Years Old and Older

You can give any amount (up to a maximum of $100,000) per year from your IRA directly to a qualified charity such as APDA Greater St. Louis Chapter without having to pay income taxes on the money. Gifts of any value $100,000 or less are eligible for this benefit and you can feel good knowing that you are making a difference at APDA. This popular gift option is commonly called the IRA charitable rollover, but you may also see it referred to as a qualified charitable distribution, or QCD for short.

Why Consider This Gift?

Your gift will be put to use today, allowing you to see the difference your donation is making.

Beginning in the year you turn 72, you can use your gift to satisfy all or part of your required minimum distribution (RMD).

You pay no income taxes on the gift. The transfer generates neither taxable income nor a tax deduction, so you benefit even if you do not itemize your deductions.

Since the gift doesn't count as income, it can reduce your annual income level. This may help lower your Medicare premiums and decrease the amount of Social Security that is subject to tax.

An Easy Way to Get Started

Ready to give directly from your IRA? Donors 70½ or older who have a traditional IRA can call the office at 636-778-3377 to make your smartest gift yet and save on your taxes. In under 10 minutes, you can give to APDA Greater St. Louis Chapter from your IRA.

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When Joel Perlmutter started college, he didn't have any plans of going to medical school. He wanted to be a biochemist.

Now Joel Perlmutter, MD, is the Elliot H. Stein Family Chair in Neurology, Professor of Radiology, Neuroscience and Physical Therapy, and is the Medical Director of the APDA-Greater St. Louis Chapter—quite a change of plans from his original career goals.

Throughout his time in his undergraduate program, Dr. Perlmutter was always interested in brain chemistry. However, after deciding to apply to medical school, Dr. Perlmutter landed in neurology by happenstance. In his third year of medical school, Dr. Perlmutter was scheduled to do a rotation with one of the best mentors who happened to be a liver specialist. However, that mentor ended up moving away, leaving Dr. Perlmutter scrambling to find a last-minute rotation. Neurology wasn't even a required rotation in his medical program at the time, but that is what he decided to do. When Dr. Perlmutter started his neurology rotation, that is when it all clicked for him.

From there, Dr. Perlmutter studied clinical Movement Disorders under David Marsden in England, then started a fellowship with Marc Raichle using PET scanning to study the neurochemistry of dopamine in the brain, and finally stayed at Washington University School of Medicine in St. Louis, Missouri where his interest in trying to measure dopamine and the conditions associated with that (including Parkinson's disease) led him to start the Movement Disorders Clinic.

“I really like taking care of people and interacting with patients. And I really like making discoveries and doing research and training people. I want to provide the best care possible right now, but I want to make it better tomorrow. That's what drives me. It won't be enough until the disease is eradicated,” Dr. Perlmutter shares.

Dr. Perlmutter and his team work every day to find a cure for Parkinson's disease. Currently, one of the projects they are working on is a drug called carboxyfullerene which may reverse the damage in the brain. This is a drug that was developed at Washington University School of Medicine by Dr. Laura Dugan. While the results so far have been promising, nothing has been able to measure how carboxyfullerene hits its target in the brain. “We need some way to measure if it hits the target to let us know if it missed or hit the target. Target engagement helps to make sure what you think is happening is actually happening.” Currently Dr. Perlmutter is in the midst of a study to determine if new PET measures will be able to meet this goal.

Most research is typically funded by the National Institutes of Health (NIH). However, before a project can be funded by NIH, Dr. Perlmutter and his team must collect and present preliminary data, which is expensive. “Donors make a big difference in collecting that preliminary data. They also help provide the new tools and equipment that make the research possible. Every dollar helps. Five dollars or five million dollars—every single dollar makes a difference.”

Donors to APDA – Greater St. Louis Chapter help provide that critical support for Dr. Perlmutter's research. “Not only your financial support but volunteers willing to participate in our studies. Both of these components permit us to move forward. Thank you for all of your help.”

PREPARING FOR YOUR NEUROLOGY APPOINTMENT:

HELPING YOUR NEUROLOGIST TO HELP YOU!

An appointment with your neurologist will be most productive if you are prepared to share your information and concerns. Here is a checklist to help you get organized.

Get ready!

☐ If this is your first appointment, ask the neurologist's office **what types of information you should bring.** These may include office notes from other doctors, MRI or CT images of your brain, and lab reports.

☐ **Medication list:** Document all prescription medications (including non-Parkinson's drugs), over-the-counter medications, vitamins, and supplements; dosages, when medications are taken; and when you first start taking each. Are there any medications that you were on in the past that were discontinued? Have you experienced any side effects?

☐ **List of Parkinson's symptoms you are experiencing:** Which are new? Which are most troublesome?

- Movement symptoms (walking, getting out of chair, moving in bed, etc.)
- Fluctuations in your symptoms (typically correlated with medication cycle, eating, sleeping, and exercise)
- Dyskinesias (involuntary movements caused by Parkinson's medications)
- Non-movement symptoms (swallowing, speech, nausea, constipation, urinary frequency and/or urgency, drooling, excessive sweating, dizziness upon standing, swollen ankles, sleep disorders, restless legs, and more.
- Changes in mental status (depression, anxiety, cognition, ability to make plans, hallucinations, compulsive or excessive behaviors such as shopping, gambling, or sex)

☐ **List three items that you most want to discuss with the neurologist.** (There may not be time to address everything during your appointment, so it is important to prioritize your needs.)

Go!

☐ **Arrive early** to allow time for parking, using the restroom, getting to the appropriate reception desk, checking in, and filling out paperwork.

☐ **Bring along water, a snack, and any medications you might need** in case your appointment is delayed.

☐ **Ask a family member or friend to accompany you** to take notes, and remind you of anything important that has not been discussed.

At your neurology appointment:

You did your homework, so you are prepared when your neurologist asks about your symptoms and medications!

☐ **Special requests:** Ask early in the appointment about prescription refills, disability forms, handicapped parking permits, etc. Often a nurse or secretary is available to work on these during your appointment.

☐ **Address those three major concerns on your list of priorities.**

☐ **Ask for a referral to a physical therapist** for help with balance, gait, strength, pain, and flexibility issues.

☐ **Ask for a referral to an occupational therapist** for help with handwriting, home modifications, driver evaluations, computer modifications, and adaptations to make dressing, grooming, cooking, and eating easier.

☐ **Ask for a referral to a speech language pathologist** for help with speech and communication problems (including vocal volume, clarity of speech, and increasing facial expressivity) and swallowing.

☐ **Ask for recommendations** regarding exercise and nutrition.

☐ **Ask about participation in clinical research trials.**

☐ **Ask the best way to get in touch with the neurologist** in between appointments: contact with nurse or secretary, by phone or email?

For more information about Parkinson's disease, contact the APDA Greater St. Louis Chapter at 636.778.3377 or visit our website at www.apdaparkinson.org/ greaterstlouis/

THE SURPRISING BENEFITS OF SINGING

Linda McNair MT-BC

If you have ever struggled to be heard or understood and are living with Parkinson's, you are not alone.

It has been estimated that somewhere between 80-90% of those who live with Parkinson's will develop some type of voice impairment over the course of their disease.[6,7] The voice may become monopitch (the loss of its characteristic "color"), exhibit a reduced voice volume level and intensity, or become harsher and breathier. Individuals may develop an abnormal speaking rate and rhythm, which may result in short rushes of speech. Vocal jitter may develop and become more pronounced as the disease progresses.[1] The same laryngeal, facial, and respiratory muscle coordination used for speech may also affect one's ability to swallow. The sum of these vocal impairments can have a significant impact on a person's ability to communicate. This may lead to social isolation and depression and ultimately, affect one's quality of life. So, is it all bad news? Is there anything that can be done to stave off the vocal problems or is it just an inevitable part of the disease?

BENEFITS OF SINGING

The good news is there is definitely reason to be optimistic. Research is demonstrating that group singing can have significant benefits in improving areas of vocal quality as well as having the added advantage of decreasing symptoms of depression while also lowering stress and anxiety levels. Singing has the potential to promote a greater quality of life.[5,7]

In a recent international study done using a therapeutic group singing program called "Sing to Beat Parkinson's," participants from the UK, South Korea, and Australia demonstrated significant benefits in several key areas. Throughout the 6-month study, participants met for weekly sessions and were led through an hour long guided session of breathing exercises, vocal warm-ups, simple warm-up songs and rounds, and 30 minutes of preferred song singing. The study results found improvements in reducing stigma ("stigma" defined in the study as feeling inadequate and/or embarrassed due to PD symptoms), decreasing stress, promoting an improved quality of life, and enhanced mental well-being.[2]

A study begun in 2016 and conducted over the course of 12 months examined the effects of a therapeutic singing program called "ParkinSong" on communication outcomes in PD. In the study, participants chose one of three study groups: a ParkinSong group meeting weekly, a ParkinSong group meeting once monthly , or another non-singing support group (which was used as the control group). The results of the research showed a significant increase in voice intensity and speech intelligibility for both of the singing groups, but were most dramatic with the weekly ParkinSong groups. Improvements were also evident in voice related quality of life measures.[4]

TREMBLE CLEFS

And finally, a study completed in 2016 was conducted using the Tremble Clefs of Greater St. Louis at Salem United Methodist. In this study, Sarah Risso (Master's student in the Occupational Therapy program at Washington University), used the group as she researched "The Effects of Tremble Clefs Group Singing Therapy on Persons with Parkinson's Disease." Sarah examined the physical vocal aspects of group singing as well as voice related quality of life. She worked with the Tremble Clefs group over the course of 12 months with data being collected every 3 months. The quantitative and qualitative data she collected as part of her research demonstrated that the members felt a strong sense of community and social support as a result of singing with the Tremble Clefs. As a result of the research she did, Sarah concluded that: "Tremble Clefs has the potential to have a substantial impact on persons with PD." [3]

SO WHY TREMBLE CLEFS?

While it may be argued that any singing done may improve the Parkinson's voice, therapeutic singing groups specifically designed for those living with Parkinson's have the distinct advantage of targeting the specific vocal issues associated with the disease (i.e., breath support and vocal volume). (6) Under the guidance of a board –certified Music Therapist, rehearsals and song choices can be designed to address specific non-musical goals and objectives. Additionally, the fact that everyone in the Tremble Clefs understands the symptoms that go along with PD makes it a much less intimidating experience for the singers.[3]

While we eagerly await the chance to sing in person, we encourage those who are interested in singing to take advantage of the videos under the "Tremble Clefs" link on the APDA website - www.apdaparkinson.org/community/st-louis/resources-support-stl/voice-singing/.

References

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5 Tamplin, J. "Singing May Provide People with Parkinson's Disease a Medley of Benefits" Mind, Mood & Memory, vol.15, no.1, Jan. 2019, p.2. Gale Academic OneFile. Accessed 17 May 2021.

6 Stegemöller, E., " Parkinson's Disease Patients' Singing Improves Voice and Swallow Impairment." Today's Geriatric Medicine Vol. 11, no. 1, Jan./Feb. 2018, pp. 18 -21.

7 Young-Mason, Jeanine. "Singing for the Joy of It, Singing for Hope, Singing to Heal: Music and Song Improves Lives of Persons with Parkinson's Disease." Clinical Nurse Specialist CNS, vol. 26, no. 6, Nov. 2012, pp. 343–344. EBSCOhost, doi:10.1097/NUR.0b013e31826e3d92.

LIVE STREAM EXERCISE CLASS SCHEDULE

Please visit: bit.ly/APDAYouTube for exercise classes.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
MONDAY	10:00am	Strength & Cardio	Level 2	Marina Clements
MONDAY	1:00pm	Interval Training	Level 2	Jen Berger
TUESDAY	1:00pm	Seated Exercise	Level 1	Michelle Valenti
TUESDAY	posted weekly	Yoga & Meditation	All Levels	Ulrikke Malik
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Valenti
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:15am	Tai Chi	Level 2	Craig Miller

ZOOM EXERCISE CLASS SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
TUESDAY	9:00am	Seated Exercise	Level 1	Jen Berger
TUESDAY	10:00am	Strength & Cardio	Level 2	Jen Berger
THURSDAY	10:00am	Strength & Cardio	Level 2	Vicki Frazier
THURSDAY	11:00am	Seated Exercise	Level 1	Vicki Frazier
FRIDAY	10:00am	Strength & Cardio	Level 2	Michelle Valenti
FRIDAY	11:00am	Seated Exercise	Level 1	Michelle Valenti

SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org.

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER	RETURN TO IN-PERSON
Ballwin	Fourth Tuesday	2:30pm	Chaplain Carla Schmidt	July 27th 1 Meamec Bluffs Dr. Veterans Room
Chesterfield	First & Third Tuesday	11:00am	Carrie Burgraff	TBA
Chesterfield Caregivers	Second Monday	11:00am	Lynda Wiens & Jay Bender	TBA
Carthage	Last Tuesday	2:00pm	Tericia Mixon	July 27th Fair Acres Family YMCA
Kirkwood	Fourth Tuesday	6:30pm	Terri Hosto	TBA
South County	Fourth Wednesday	10:30am	Caitlin Jones	TBA
St. Peters	First Tuesday	1:00pm	Jodi Peterson	TBA
St. Louis Caregivers	Third Monday	1:00pm	Kathy Schroeder	Virtual
Washington	Second Monday	6:00pm	Carol Weber	July 12th Washington Public Library
YOPD	Every Wednesday	6:00pm	Karen Frank & Mike Mylenbusch	Virtual

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER	RETURN TO IN-PERSON
Carbondale	First Wednesday	1:00pm	Gala Lockwood	August 4th Prairie Living at Chauauqua
Edwardsville	First Tuesday	2:00pm	Pam Pinegar	July 6th Drost Park
Highland	Fourth Tuesday	2:00pm	Kayla Deerhake	August 24th HSHS St. Joeseph's Hospital
Quincy	Saturdays	10:00am	Dave & Terri May	July 10th Quincy Public Library

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UPDATE YOUR INFO WITH US!

Are you new to APDA? Have you moved recently, updated your email address or phone number? Do you want to receive weekly emails or receive this newsletter electronically? Let us know!

To update your contact information, call **636.778.3377** or email **apdastlouis@apdaparkinson.org**

1415 Elbridge Payne Road, Suite 150
Chesterfield, Missouri 63017
Address Service Requested

OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

Help Us Beat Parkinson's Disease — One Step at a Time!

Join us for the 5th Annual APDA Optimism Walk on Saturday, October 9, at Logan University.

The Optimism Walk is a short, non-competitive walk with family-friendly activities that is part of a nationwide movement to mobilize and inspire people to step up and put an end to Parkinson's disease.

Each year, the Greater St. Louis Chapter serves more than 12,000 people impacted by Parkinson's disease through support groups, exercise classes, wellness programming, educational events, and more. Your support of the Optimism Walk helps ensure these programs and services are there for people when they need them the most.

Sign up today at www.apdaparkinson.org/greaterstlouis or call 636.778.3377. If you are unable to join us in person, create a virtual team by asking friends, family and neighbors to join your fundraising efforts.

Lace up your sneakers and step up to help us put an end to Parkinson's disease!

OPTIMISM SOCIETY

In the fall of 2020, the APDA Greater St. Louis Chapter established the Optimism Society to honor those who provide annual support of $1,000 or more. Optimism Society members are a vital component of the Greater St. Louis Chapter, and each year we extend our gratitude to those who support us with a special Optimism Society celebration.

To join the Optimism Society, contact Director of Development, Melissa Skrivan at mskrivan@apdaparkinson.org or 636-778-3377.

APDA Community Resource Center

1415 Elbridge Payne Rd, Ste 150 | Chesterfield, MO 63017
Hours: 8:00 a.m. - 4:00 p.m. M-F
636.778.3377
www.apdaparkinson.org/greaterstlouis

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