

MIDWEST PARKINSON CONGRESS- April 20, 2023

Join us for a one-day symposium focusing on strategies to help you live well with Parkinson disease. The conference features an esteemed line up of industry leading professionals discussing the latest information.

There will also be a resource fair with vendors who provide products and services specifically designed for the Parkinson's community.

Location: Renaissance St. Louis Airport Hotel | 9801 Natural Bridge Road | St. Louis, Missouri 63134

Time: 1:00 PM to 4:30 PM - Doors open at 12:00 PM

Registration is required. Visit our website at www.apdaparkinson.org/mo to register.

Speakers and Topics:



Dr. Gilbert



Dr. Perlmutter

	ROOM 1	ROOM 2
1:00 PM	Rebecca Gilbert, MD, PhD <i>New Treatments</i>	Jamie Archer, MOT, OTR/L <i>Thinking Strategies</i>
2:00 PM	Joel Perlmutter, MD <i>Latest Research</i>	Brigid Fernandez, CELA <i>Planning Ahead</i>
3:00 PM	Tricia Creel, PT, DPT, NCS <i>Balance</i>	Andrea Vaughan, MS, CCC-SLP <i>Speech Strategies</i>

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HELPFUL TIPS FOR LIVING WELL

Amanda Landsbaum MS, OTR/L, APDA-Greater St. Louis Chapter Program Director

Managing Parkinson's medication is a common topic of discussion. It's very important to take your Parkinson's medications on time, every time and not miss a dose. I often hear people say they can remember the morning and evening doses when they are at home, but it's tough to remember their mid-day dose when they are out in the community.

The following strategies may be helpful for those mid-day doses:

- Bring a small pill box or use a keychain pill holder to store a few extra pills
- Carry a water bottle when you are away from home
- Set your phone alarm for your dosage times. Or if you prefer, wear a smart watch with alarm settings. These can be audio or vibration if you prefer a silent alarm.

Making sure you take your mid-day doses will help you stay on a regular schedule and manage

your symptoms better. Talk to others and find out what strategies work for them. Making these small changes in your routine can lead to big improvements.



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An easy way to get started: Call the ADPA office today at 636-778-3378. In under 10 minutes, you can give to the APDA Greater St. Louis Chapter from your IRA.

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Contact Martha Hessler
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Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

Contact Martha Hessler
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Lower Back Pain Study

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Memory Intervention for PD Study

Contact Tasha Doty
tdoty@wustl.edu
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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.

Contact APDA St. Louis for help in locating a Movement Disorders Specialist at 636-778-3377.

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 and 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.



IN-PERSON EXERCISE CLASS SCHEDULE

Contact individual location to register. For more information please call 636.778.3377 or apdastlouis@apdaparkinson.org

MISSOURI CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
Chesterfield ADPA Office	Tuesday	10:00am	Jen Berger	Level 3	Circuit Training
	Tuesday	11:00am	Jen Berger	Level 2	Strength and Cardio
	Wednesday	10:00am	Michelle Valenti	Level 2	Movement Training
	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise
	Thursday	11:00am	Craig Miller	Level 1 & 2	Tai Chi
	NEW Thursday	12:00pm	Jen Berger	Level 3	Parkinson's Boxing
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio
	Friday	10:00am	Craig Miller	Level 1	Tai Chi and Meditation
	Friday	11:15am	Craig Miller	Level 2	Tai Chi
Chesterfield YMCA	Mon/Wed	12:30pm	Michelle Valenti	All Levels	Parkinson's Pedalers
Jefferson Co. YMCA	Mon/Thurs	10:00am	Linda Thompson	All Levels	Exercise for Parkinson's
Kirkwood YMCA	Monday	11:30am	Frank Tucci	Levels 1 & 2	Parkinson's Exercise
Maryland Hts. YMCA	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's
St. Louis City Stephen A Orthwein Ctr.	Thursday	12:00pm	Annie Morrow	Level 1	Interval Training
	Friday	2:00pm	Mike Scheller	Levels 1 & 2	Fit and Fun
St. Peters	Thursday	11:00am	Vicky Frazier	Level 1 & 2	Strength and Cardio
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 2	Parkinson's Exercise
Sunset Hills	Friday	1:00pm	Marina Clements	Level 2	Movement Training
Washington YMCA	Mon/Wed	1:00pm	Lynn/Kindall/Linda	Level 1 & 2	Parkinson's Exercise
ZOOM	Tuesday	9:00am	Jen Berger	Level 1	Seated Exercise
ZOOM	Thursday	2:00pm	Michelle Valenti	Level 1	Seated Exercise

ILLINOIS CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	CLASS
Breese/Clinton Co. YMCA	Tues/Thurs	12:30pm	Jack S.	Exercise for Parkinson's
Champaign YMCA	Monday	1:00pm	Jessica B.	Strength & Balance
	Tuesday	1:00pm	Lindsey R	Functional Chair Fitness
	Wednesday	1:00pm	Jessica B	Seated Yoga
	Thursday	1:00pm	Tesha S.	Functional Chair Fitness
	Friday	1:00pm	Lindsey R.	Standing Functional Fitness
Decatur YMCA	Tues/Thurs	9:00am	Michelle P. & Margie	Pedaling for Parkinson's
Edwardsville YMCA	Tues/Thurs	11:00am	Mary T. Lara C.	Exercise for Parkinson's
Highland Korte Rec Ctr.	M/W/Th	11:00am	Hilary Held	Cycle and Strength
O'Fallon YMCA	Tuesday	12:00pm	Victoria White	Exercise for Parkinson's
	Thursday	12:00pm	Stefanie McLaughlin	Exercise for Parkinson's
Quincy YMCA	Tues/Fri	10:30am	Cathy Schluckebier	Fit to Fight PD Boxing
Springfield First Presb. Church	Tues/Thurs	1:30pm	Eva Fischberg	The Joy of Movement
VIRTUAL	Wednesday	10:30am		

SUPPORT GROUP SCHEDULE

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

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Ballwin	4th Tuesday	2:30pm	Chaplain Carla Schmidt	Meramec Bluffs Care Center
Cape Girardeau	2nd Monday	5:30pm	Jayanti Ray	Cape Girardeau Library
NEW! Chesterfield	3rd Thursday	2:00pm	Michele Dain	Friendship Village Chesterfield
Chesterfield Caregivers	2nd Monday	10:30am	Lynda W. & Jay B.	APDA Office
NEW! Florissant	1st Tuesday	10:00am	Sharon Wells	Garden Villas North
Kirkwood	4th Tuesday	6:30pm	Terri Hosto	VIRTUAL
NEW! Newer Diagnosed	2nd Tuesday	1:00pm		APDA Office
NEW! Olivette	3rd Tuesday	11:00am	Diana Tucker	Private Home Care
Rolla	3rd Tuesday	2:30pm	Julie Riggs	Phelps Health Cancer Inst.
South County	4th Wednesday	10:00am	Melissa Mann	Cedarhurst of Tesson Heights
Ste. Genevieve	2nd Wednesday	10:00am	Teddy R. & Martha R.	Ste. Gen. Community Center
St. Louis Caregivers	3rd Monday	1:00pm	Kathy Schroeder	VIRTUAL
St. Peters	1st Tuesday	1:00pm	Amanda S. & Whitney M.	Spencer Road Library
Washington	2nd Monday	3:00pm	Teresa V. & Chris H.	Washington Public Library
YOPD	Every Thursday	6:00pm	Karen F. & Mike M.	VIRTUAL

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Alton	2nd Wednesday	1:00pm	Dustin Heiser	SSP Main Bldg, The Meeting Rm
Alton, CarePartner	2nd Tuesday	2:00pm	Dustin Heiser	SSP Wellness Center CarePartners Only
Belleville	3rd Monday	1:30pm	Jodi Gardner	SW Illinois College's Programs and Services for Older Persons
	3rd Tuesday	11:00am	Jodi Gardner	Belleville Health and Sport Center Caregivers ONLY
Carbondale	1st Wednesday	1:00pm	Gayla Lockwood	Prairie Living at Chautauqua
Champaign	Every Monday	10:00am	Carol C. & Dave M.	Savoy United Methodist Church
Decatur	3rd Thursday	1:30pm	John Kileen	Westminister Presbyterian Church
Edwardsville	1st Tuesday	2:00pm	Pam P. & Sarah H.	Edwardsville YMCA
Greenville	2nd Tuesday	1:00pm	Robbie Mueth	Bond County Senior Citizens
Highland	4th Tuesday	2:00pm	Kayla Deerhake	St. Joseph Hospital Sullivan Conference Room
Jacksonville	1st Wednesday	1:00pm	Jim & Fran Ringle	VIRTUAL
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library



DRIVING ABILITY





We are all anxious to begin venturing out after two difficult years with COVID. With that in mind, many people are going to be traveling more. In some cases that will involve driving.






Individuals with PD are often able to drive for many years. Your safety and the safety of others on the road, though, has to be taken into consideration.

Driving is a multifactorial task. It requires good mobility, reaction time, depth perception, vision/hearing, and being able to multi-task. There are many visual and spatial inputs that occur simultaneously with driving.

I am asked frequently when Parkinson's may impact driving ability. ***The major predictors of impaired driving in PD include older age, longer duration of disease, slowed movements and cognitive impairment.***

Warning signs that may indicate your driving is impaired include:

-  **Getting lost on familiar routes or forgetting where you're going**
-  **Driving considerably slower than the rest of traffic**
-  **Trouble switching lanes**
-  **Stopping or slowing down when unnecessary**

-  **Drifting in and out lanes**
-  **Forgetting to use traffic signals**
-  **Drowsy/too tired**
-  **Stressed with driving**
-  **Friends/family bring up that they have concerns**

If you have these warning signs. It is time to discuss this with your provider. There are a number of on-the-road assessments available to assess your performance.

From the APDA Iowa Chapter's Live It! Magazine. Written by Lynn K. Struck, MD, Neurologist, Physician Specialty Clinic, UnityPoint Health, Des Moines, Iowa and Medical Director of the APDA Iowa Chapter. Dr. Struck focused her career on advances in treatment of her many patients with Parkinson's disease and ongoing research to find better treatments and, ultimately, a cure.

My doctor says I need to have my driving evaluated. What do I do?

(excerpts in this article are from the Iowa Department of Transportation website and On With Life, a brain injury rehabilitation center in Ankeny, West Des Moines, and Coralville, Iowa.)

For many, driving is a rite of passage that provides freedom and independence to get out and about, keep in contact with family and friends, and enables us to maintain our quality of life. One of the best ways of making sure we are able to keep driving for as long as possible is to keep our driving skills and knowledge up to date. As we age, we

may experience physical or cognitive changes that affect our driving. It's important to recognize these changes and utilize resources and advice on how to adapt if your driving is changing as you get older so you can keep driving safely for as long as possible.

What does a driving evaluation consist of?

Typically, a driving evaluation will consist of at least two parts:

Pre-Driving Clinical Evaluation: This assessment is designed to evaluate the driver's reaction time, processing speed, vision attention, judgement, motor skills required for driving (i.e.: brake reaction and arm function). The assessments of paper and pencil tests and driving simulation.

On Road Evaluation: This assessment is completed once someone passes the pre-driving evaluation. The participant goes on the road with the Driving Evaluator in the evaluation car. During the evaluation, the therapist is assessing the visual, physical and cognitive skills required for driving. The evaluation begins in a parking lot and if appropriate, will proceed to more heavily traveled roads.

How much does it cost?

The comprehensive evaluation is not covered by insurance and is available by private pay only. Costs could run from \$350 - \$450. The fee must be paid in full prior to the evaluation. The evaluating organization can provide more details on cost.

How long does the evaluation take?

The whole evaluation takes approximately 3.5 hours. Half the time is for the pre-evaluation and half for the on-road evaluation. Participants must be able to transfer into and out of the vehicle.

Where do I go?

In Missouri, reach these organizations to assist you with driver evaluations:

Mercy Driver's Assessment & Training Program
636-893-1100
<https://mercy.net/practice/mercy-therapy-services-town-and-country/>

Washington University Occupational Therapy
314-286-1640
<https://otservices.wustl.edu/items/driving-evaluations/>

Driving Rehabilitation Services, LLC
636-220-6334

Independent Drivers, LLC
314-920-583

For Illinois, reach out to:

Memorial Orthopedic and Neurosciences Center, Belleville
618-257-5250
<https://www.ortho-neurocenter.com/occupational-therapy>

Carle Therapy Services, Urbana
217-383-3400
<https://carle.org/services/therapy-services>

Rehabilitation Center, OSF, Peoria
309-692-8670
<https://www.osfhealthcare.org/rehabilitation/>

How to Cope with Changes in Your Driving

Avoid certain driving situations, times and routes

- At Night
- During Rush Hour
- Through high-volume, busy intersections and routes (including congested areas like school drop-off and pick-up times)
- On certain types of roads (like hwy and inter)

Allow more time to get where you need to go, so you can drive safely, at a slightly reduced speed, and not feel rushed.

Learn from you mistakes and near misses, Think about situations you found difficult and what you could have done differently to minimize the likelihood of reoccurrence.

Consider whether it's time to retire from driving. If you travel infrequently, have physical or cognitive changes which are affecting your driving, or travel less than 2,000 miles per year – it is often cheaper and more convenient to use alternative modes of transportation like taxis, bus, or driving services if they are available in your area.

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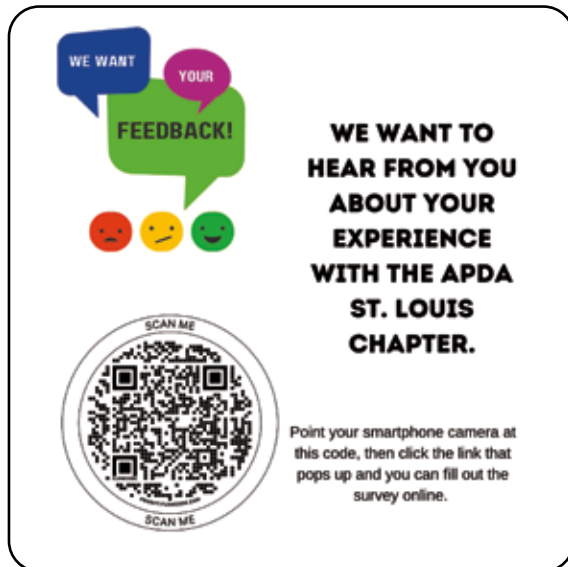
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APDA Greater St. Louis Chapter

16100 Chesterfield Parkway W, Ste. 125 | Chesterfield, MO 63017

Hours: 9:00 a.m. - 4:00 p.m. Tu-F

636.778.3377

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