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CLINICAL TRIALS IN PARKINSON'S DISEASE:

Who, What, Where & Why

By Jen Gillick, APDA Northwest Program Director

If you live near the St. Louis metro area, you don't have to travel far to participate in Parkinson's disease (PD) research. Several research centers are conducting exciting, leading-edge research and offer different ways in which you can get involved. Here's all the information you need to get started!



Why should I participate in a clinical trial?

Improving the treatment of Parkinson's depends on conducting clinical trials to collect information about PD patients and test potential new medications and procedures. Current treatment methods for PD are only available because of volunteer participants in clinical trials. Your participation will allow you to have firsthand experience with developing new medical treatments that may benefit others.

Who is eligible to participate in a clinical trial?

There are varying qualifications for any given trial. Some require participants to be of a certain age or stage of PD, while others require you to be experiencing specific symptoms of the disease. As all studies vary in qualification, you will have to refer to the trial coordinator to participate. Some trials ask that you complete a survey, while others have you contact the trial coordinator directly.

What types of clinical trials can I join?

There are many types of clinical trials, mainly divided into two large categories, with both types taking place at research institutions in the area.

Observational Clinical Trials

In this type of trial, a new treatment is not tested. Instead, the trial carefully observes a particular aspect of the disease to learn more about it. These trials may require donating blood or other specimens, including spinal

CLINICAL TRIALS IN PARKINSON'S DISEASE:

Who, What, Where & Why (continued)

fluid, urine, or stool. Gene testing, imaging, neuropsychological testing, and questionnaires may all be components of an observational trial.

Interventional Clinical Trials In this type of trial, a new treatment is tested to see if it either improves a particular symptom of PD or is neuroprotective and acts to slow down the course of PD. The intervention can be an exercise or therapy regimen, cognitive therapy, medication, surgery, or any other procedure. People without PD can often participate as well (e.g., family members), especially in observational trials, which typically collect the same information from both a PD population and a non-PD population to compare the results.

Where can I get involved in clinical trials?

Whether through national or regional organizations, many clinical trials are available for people with PD. Below is a list of trial opportunities and contact information to get you started. Your neurologist can also be a great source of information regarding research projects near you.

National websites:

clinicaltrials.gov

Hosted by the National Institutes of Health (NIH), this directory lists all clinical trials, past and present, for all conditions and can be searched for trials that specifically address PD.

clinicaltrials.gov

This National clinical trial guide allows you to search by zip code to find a study near you. Specific study and contact information are included.

michaeljfox.org/trial-finder

A resource run by the Michael J. Fox Foundation. Both people with PD and clinical trials can register on the site, and the Trial Finder matches willing participants and trials.

APDA as a resource;

apdaparkinson.org/research/clinical-trials

Visit the APDA Missouri Chapter website research page for details on the below studies.

<https://www.apdaparkinson.org/community/mo-resources-support-2/research/>

- **Washington University** - St. Louis, Missouri
As of this printing, seven different clinical trials are recruiting participants with Parkinson's and control groups.
- **St. Louis University**- St. Louis, Missouri
As of this printing, one clinical trial is recruiting participants with Parkinson's.



Questions to ask the trial coordinators

- *What have previous studies shown about the safety and effectiveness of the new treatment?*
- *What are the most common adverse effects seen with the use of this treatment?*
- *How will the treatment team monitor me for adverse effects?*
- *Is there anything in my medical history that puts me at higher-than-average risk in this trial?*
- *What will I need to do during the trial, and how long will the trial last?*
- *Will I have to travel to a different medical center for participation in the trial? Are those costs covered?*
- *What are the chances that I will receive a placebo in this trial?*
- *Who should I contact if my condition worsens during the trial?*
- *Will I be able to continue the new medication (or begin it, if I received a placebo) after the trial is over?*

CURRENT RESEARCH

Please visit our website for more information



How Your Life Has Been Impacted Since Living at Home After Leaving the Hospital

Please contact Laura Butka
lbutkka@wustl.edu to find out more

Music Based Walking Program

Classes in August and September
Please contact Sydney Baudendistel
bsidney@wustl.edu or 314-273-6206

How Deep Brain Stimulation Changes the Function of the Brain's Cortex

Please contact Kaeli-Skye Spight
DeepBrainStimulation@wustl.edu

Please include in your email if you are with or without PD and your age.

Studies of Neuroinflammation in Parkinson's Disease

Please contact Brooke Watkins
nil-PDinflammation@email.wustl.edu or 314-747-3083

Protein and Imaging Biomarkers (PIB) Study

Please contact Kayleigh Oberndorfer
nil-pdpibstudy@email.wustl.edu or 314-362-0420

Protein Aggregation and Neurotransmitter Deficits (PAND) Study

Please contact Emma Carr
nil-PANDstudy@email.wustl.edu or 314-362-7586

Precision-Mapping Study

Please contact Emma Carr
nilprecisionmapping@email.wustl.edu or 314-362-7586

Movement, Speech, and Thinking Study

Please contact Jason Longhurst
jason.longhurst@health.slu.edu or 314-977-8533

Lower Back Pain Study

Please contact Martha Hessler
mjhessler@wustl.edu or 314-286-1478

Improving Diversity in Parkinson's Research and Care Study

Please contact Dominique Woodhouse
woodhouse@wustl.edu or 618-401-2328

Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

Please contact Kevin Holley
kevin.h@wustl.edu or 314-286-1641



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FREEZING OF GAIT IN PARKINSON'S DISEASE

What is Freezing of Gait?

By: Beth Crowner, Neurological Clinical Specialist at Washington University Physical Therapy

Freezing of gait is an abnormal gait pattern that can accompany Parkinson's disease (PD) in which there are sudden, short and temporary episodes of an inability to move the feet forward despite the intention to walk. In a sense, you're stuck. This results in the characteristic appearance of the feet making quick stepping movements in place. However, while the feet remain in place, the torso still has forward momentum which makes falls unfortunately common in the context of freezing of gait. For some, these episodes can simply be frustrating, annoying and perhaps embarrassing; for others freezing of gait can become incredibly disabling and lead to injury.

Freezing of gait episodes tend to occur least often when walking on an unobstructed, straight path. Any deviation from that can induce freezing – for example, when you first try to start walking, when you go to make a turn, or try to navigate around obstacles or through narrow spaces – any of these can cause you to get “stuck.”

The particular triggers for one person may be different than for another. An episode is typically very brief, often lasting only 1-2 seconds, although they can last longer. Freezing of gait can be affected by anxiety, so if a person feels rushed (e.g. under a time constraint to board an elevator before the doors close), freezing may be particularly prominent.

Treating freezing of gait for people with Parkinson's

Freezing of gait episodes often occur when a person is under-medicated and can improve with increased amounts of their PD meds, usually carbidopa/levodopa. However, the brain abnormalities that lead to freezing of gait are very complex, so giving more dopaminergic medication is only part of the solution. In fact, some people have what is referred to as ON freezing. This means that freezing of gait episodes occur even when other PD symptoms are well treated with their medication regimen.



Cueing, or the introduction of an external sensory stimulus to facilitate movement, has been identified as a way to “break” a freezing episode. Terry Ellis, PhD, PT, NCS, Director of the APDA National Rehabilitation Resource Center at Boston University, and Tami DeAngelis, PT, GCS, compiled this list of cues that can be used to get out of a freezing episode:

TEN TIPS TO PUT THE FREEZE ON FREEZING!

- Try another movement – raise an arm, touch your head, point to the ceiling, then re-start
- Change direction: if you can’t move forward, try stepping sideways first, and then go forward
- Carry a laser pointer in your pocket; when you freeze – shine the laser in front of your foot and step on the light – this visual cue can help you re-start.
- Visualize an object on the ground in front of you and try to step over it.
- Wear a metronome on your belt or carry a small one in your pocket – turn it on and the external beat can help you re-start.
- Try humming a song and time your re-start with the beat of the music
- Count “1-2-3-go” and then step forward
- Shift your weight from side to side to help initiate taking a step
- March in place a few times and then step forward
- Don’t fight the freeze by trying harder to step forward – shift your attention from moving the legs to moving the arms – then resume walking forward

While these methods can be helpful to get out of a freeze that is already underway, physical therapy techniques that incorporate these types of cueing strategies are utilized to reduce freezing of gait overall. Rhythmic auditory cueing is one such technique which utilizes rhythm and music to improve gait in PD and other neurologic diseases.

Tips and takeaways

Freezing of gait is a complex PD gait disorder in which people get “stuck” in place and temporarily have a hard time moving their feet forward.

For some people, freezing of gait can become a major source of disability.

There are options for treating freezing of gait, including adjusting your PD medications, using tools like sensory cueing, and using a walking aid.

If freezing of gait is an issue for you or a loved one, be sure to speak to your neurologist and physical therapist about it. They can help you learn how to get “unstuck” and better manage freezing of gait episodes.



EXERCISE CLASS SCHEDULE

For more information please refer to www.apdaparkinson.org/mo or call 636.778.3377

MISSOURI CLASS SCHEDULE

Carondelet YMCA

Tues/Thurs 11:00am - Exercise for Parkinson's

Chesterfield APDA Office

Tuesday 10:00am - Circuit Training | Level 3

Tuesday 11:00am - Strength and Cardio | Level 2

Tuesday 12:00pm - Dancing through the Decades

Wednesday 10:00am - Movement Training | Level 2

Wednesday 11:00am - Seated Exercise | Level 1

Thursday 11:00am - Tai Chi for Parkinson's

Thursday 12:00pm - Parkinson's Boxing | Level 3

Thursday 1:00pm - Strength and Cardio | Level 2

***NEW** | Thurs 2:00pm - Seated Exercise | Level 1

Friday 11:00am - Tai Chi and Meditation

Chesterfield YMCA

Mon/Wed 12:15pm - Parkinson's Pedalers | Level 2

Crestwood - Sports Medicine & Training Ctr.

Tuesday 9:00am - Exercise for Parkinson's | Level 2

Eureka - The Timbers Recreation Center

Tues/Thurs 1:00pm - Exercise for Parkinson's

Jefferson County YMCA

Mon/Thurs 10:00am - Exercise for Parkinson's

Kirkwood YMCA

Monday 11:45am - Parkinson's Pedalers | Levels 2

Maryland Heights YMCA

Tues/Thurs 11:30am - Exercise for Parkinson's | Level 2

South County YMCA

Tues/Thurs 3:00pm - Exercise for Parkinson's

St. Louis City - Stephen A. Orthwein Center

Thursday 12:00pm - Interval Training | Level 2

St. Peters - BJC

Thursday 10:00am - Strength and Cardio | Level 2

Thursday 11:00am - Seated Exercise | Level 1

Ste. Genevieve Co. Community Center

Wednesday 11:00am - Exercise for Parkinson's | Level 2

Sunset Hills - Friendship Village

Thursday 1:00pm ****Starting July 11, 2024**

Warrenton - SSM Day Institute

1st and 3rd Tuesdays 3:30pm - Exercise for Parkinson's | Levels 1 and 2

Washington YMCA

Mon/Wed 1:00pm - Exercise for Parkinson's

Friday 11:30am - Exercise for Parkinson's

Virtual via Zoom

Tuesday 9:00am - Seated Exercise | Level 1

Thursday 2:00pm - Seated Exercise | Level 1

ILLINOIS CLASS SCHEDULE

***NEW** | East Belleville YMCA

Tues/Thurs 11:00am - Exercise for Parkinson's

***NEW** | Downtown Belleville YMCA

Mon/Wed 11:00am - Exercise for Parkinson's

Breese/Clinton Co. YMCA

Tues/Thurs 12:30pm - Exercise for Parkinson's

Carlinville Area Hospital

Tuesday 10:00am - Exercise for Parkinson's

Decatur YMCA

Mon/Wed/Fri 11:00am - Parkinson's Pedalers

Tues/Thurs 9:00am - Parkinson's on the Move

Edwardsville YMCA

Tues/Thurs 11:00am - Exercise for Parkinson's

Highland - Korte Recreation Center

Mon/Wed/Thurs 11:00am - Cycle and Strength

O'Fallon YMCA

Tues/Thurs 12:00pm - Exercise for Parkinson's

Quincy YMCA

Tues/Fri 10:30am - Fit to Fight PD Boxing

Springfield - First Christian Church

Tues/Thurs 1:30pm - The Joy of Movement

Virtual via Zoom

Wednesday 10:30am - The Joy of Movement

Exercise Level Descriptions:

Level 1: Participants exercise seated or standing with support. Movements are done at a pace and intensity that are appropriate for each participant.

Level 2: Participants must be able to walk and stand up from a chair without assistance. Most exercises are done standing.

Level 3: Higher intensity, faster paced classes where participants perform multiple step exercises and may get on/off the floor.

SUPPORT GROUP SCHEDULE

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

MISSOURI SUPPORT GROUPS

Ballwin - Meramec Bluffs Care Center
4th Tuesday 2:00pm

Cape Girardeau - Cape Girardeau Library
2nd Monday 5:30pm

Chesterfield - APDA Office
2nd Monday 10:30am - Caregivers ONLY
2nd Tuesday 1:00pm - Early in diagnoses
***NEW** | 4th Tuesday 1:00pm - Newly diagnosed

Chesterfield - Friendship Village, Trillium Rm.
3rd Thursday 2:00pm

Florissant - Garden Villas North
1st Tuesday 10:00am

Kansas City - Johnson County Rehab Hospital
2nd Wednesday 4:00pm

Kirkwood - First Presbyterian Church
2nd Monday 1:30pm

Olivette - Private Home Care Company - Hybrid
3rd Tuesday 11:00am

Rolla - Phelps Health Cancer Institute, Conf. Rm. B
3rd Tuesday 2:30pm

South County - Cedarhurst of Tesson Heights
4th Wednesday 10:00am

St. Charles - Kisker Road Library
2nd Tuesday 10:00am - Caregivers ONLY

Ste. Genevieve - Community Center
2nd Wednesday 10:00am

St. Peters - Breeze Park Independent Living
1st Tuesday 1:00pm

Washington - Public Library
2nd Monday 3:00pm

Virtual via Zoom
4th Tuesday 6:30pm - All welcome
3rd Monday 1:00pm - Caregivers ONLY
Every Thursday 6:00pm - Young onset ONLY
***NEW** | 3rd Friday 2:00pm - We Care: South Asian families
***NEW** | 2nd Wednesday 9:00am - Adult Children ONLY

ILLINOIS SUPPORT GROUPS

Alton - SSP Main Bldg., The Meeting Room
2nd Wednesday 1:00pm

Alton - SSP Wellness Center
2nd Tuesday 2:00pm - Caregivers ONLY

**Belleville - Southwestern Illinois College's
Programs & Services for Older Persons**
3rd Monday 1:30pm

Carbondale - Prairie Living at Chautauqua
1st Wednesday 1:00pm

**Carlinville - Carlinville Area Hospital,
MOB Comm Rm.**
4th Tuesday 11:00am

Edwardsville - YMCA Niebur Center
1st Tuesday 2:00pm

Greenville - Bond County Senior Citizens
2nd Tuesday 1:00pm

Highland - St. Joseph Hospital, Sullivan Conf. Rm.
4th Wednesday 2:00pm

Quincy
2nd Saturday 10:00am | Public Library
4th Thursday 1:00pm - small group discussion |
Senior Center

Tips and Tricks for Parkinson's

Cooking Edition

- ✓ Use a gripping mat to stabilize bowls and cutting boards for safer food preparation. Grippers can also be used to open up jars and lids.
- ✓ Rearrange cabinets to place frequently used items within easy reach, between knee and shoulder level.
- ✓ Choose pre-cut or prepped foods from the store to save time and energy when cooking.
- ✓ Use a rolling cart or basket to transport heavy items around the kitchen.
- ✓ Invest in a slow cooker/instant pot to make meals easier.



Running on Empty

Save the date for a special event featuring Guy Deacon, who is living with Parkinson Disease and traveled throughout Africa raising awareness for PD. He wrote a book about his adventures, and there will be a documentary coming out too!

Friday, August 16, 7:00 pm
Clark Family Branch of the
St. Louis County Library
1640 S. Lindbergh Blvd.
St. Louis, MO 63131



TREMBLE CLEFS SINGING & VOICE EXERCISES

St. John United Church of Christ (Fellowship Hall)
405 S 5th St. | St. Charles, MO 63301
Every Friday 1:00 to 2:30 pm.



(NOTE: Tremble Clefs will be on a short break over the Summer and will start again on August 16, 2024)

HOW ALPHA-SYNUCLEIN AFFECTS BRAIN CELL COMMUNICATION: APDA Funded Research Published

In a recently published study, Dr. Gary Ho, a recipient of APDA's most prestigious George C. Cotzias grant, studied the role of alpha-synuclein in the formation and recycling of synaptic vesicles, the system that allows nerves to talk to each other.

Abnormally aggregated alpha-synuclein is a main component of the Lewy body which is the pathologic hallmark of Parkinson's disease (PD). However, alpha-synuclein is normally present in the brain and deciphering its various and complex roles is a key research strategy to understanding what goes wrong in PD.

One possible function of alpha-synuclein is in the regulation of synaptic vesicles, the cell's transport containers that move signaling chemicals from one neuron to the next. This process allows for nerves to communicate across the synapse, the space that exists between neurons.

To investigate this potential key function, Dr. Ho used a system that he developed for measuring the recycling and release of signaling chemicals from synaptic vesicles. He started with iPSCs, induced pluripotent stem cells, from several sources, including those that were derived from a skin biopsy of a person with PD who harbored a genetic mutation that caused too much alpha-synuclein to be produced. Dr. Ho then differentiated the iPSCs into cortical nerve cells.

Dr. Ho utilized these nerve cells in his novel system to see if they were able to recycle synaptic vesicles and release signaling chemicals as efficiently as nerve cells without the overabundance of alpha-synuclein. He showed that too much alpha-synuclein reduced synaptic vesicle cycling, impacting the interaction

between nerves. This impaired communication could be a core feature of PD pathology and finding ways to normalize this could play a role in treatment of PD.

APDA is thrilled to be funding Dr. Ho's work.

Dr. Ho said "I am tremendously grateful for the support of APDA, which made this work possible. Our findings shed light on how alpha-synuclein, a critical protein in PD, directly affects how brain cells communicate. This is an important step in understanding how different PD symptoms arise at a cellular level, in particular cognitive dysfunction. In supporting this and other research, the APDA is contributing meaningfully to our collective efforts in finding new treatments to slow the progression of PD."



Gary Ho, MD, PhD
Brigham and Women's Hospital
Harvard Medical School, Boston, MA

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