



AMERICAN PARKINSON DISEASE ASSOCIATION

MISSOURI CHAPTER NEWSLETTER

Nov/Dec 2023
Jan 2024

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ESSENCE OF MUSIC IN PARKINSON'S DISEASE

Dr. Elizabeth Stegemoller, PhD, MT-BC, Interview - By Cookie Cranston

Music has the power to change worlds. And in the world of Dr. Elizabeth Stegemoller, PhD, the musicality of sound, tempo and rhythm not only enrich her career as a musician and certified music therapist, but also contributes to and guides her research.

Dr. Stegemoller has spent the last 18 years combining neuroscience and music to understand Parkinson's disease and help people with PD keep their voices strong. She is an Associate Professor at Iowa State University in the Department of Kinesiology, and Director of the Graduate Interdepartmental Neuroscience Program. Her credentials include a PhD in Neuroscience, a Bachelor of Science in Biology and a Bachelor of Arts in Music Therapy. Whether through research or outreach groups, the APDA has long been supportive of her work, and she likewise feels that her association with APDA has been a great match.

Music can be relaxing and ease stress levels, allow individuals to explore and experience various emotions, reduce anxiety and depression, impact mood, strengthen communication and build social skills while improving speech and language skills—all of which are key to improving PD health outcomes.

Dr. Stegemoller is currently researching the effects of music, singing and group singing on Parkinson's symptoms with impressive results. "When we sing, it's like we're doing little mini exercises for the same muscles you use to swallow, breathe and cough to make them stronger and work together," Stegemoller



ESSENCE OF MUSIC (continued)

explains. And by significantly improving respiratory and swallow control, singing may be protective against aspiration pneumonia, as was discovered in a previous groundbreaking study conducted by Dr. Stegemoller and her team of research colleagues.

Music therapy may also be an effective nonpharmacological treatment for improving motor and non-motor symptoms of PD by naturally increasing dopamine levels. Dr. Stegemoller has been particularly touched by intriguing results from a study that found both a reduction of tremor and improved gait in people with PD after only one hour of singing. The harmony of rhythm, beat, lyrics and movement combine to produce a symphony of results as singing is known to be a dopamine agonist. At the same time, singing has been shown to improve posture, movement, mindfulness, breath, voice strength, swallow function and facial expression.

Also among the findings is the importance and significance of individual feelings of well-being and joy for those participating in group activities, music therapy and research trials. Recognizing small joys in our daily lives can positively impact changes and challenges that occur, especially when facing a difficult journey such as Parkinson's or other chronic diseases.

Not only does music positively supports and impacts neuroplasticity and the brain's ability to form new

Music and singing can and does change worlds for those with Parkinson's disease.

synaptic connections, music also supports important connections among social, emotional, cognitive and physical aspects. It taps both motion and emotion, and Dr. Stegemoller advocates heavily for singing as a super exercise that proves to be a great tool for those wanting to live their best life—sing, sing, sing with confidence,' chirps the cheerful, resounding advice of Dr. Stegemoller! "We know music is a powerful tool for health and healing. These research projects get us a little closer to understanding why."

Dr. Stegemoller and her peer research teams' findings are very much in tune with the treatment of PD symptoms. The research has actively taken the world stage by storm in Movement Disorder centers around the globe. Music and singing prove to not only bring considerable symptom relief, but also bring essential elements of joy and hope for those on the PD journey—a powerful opus that contributes substantively to basic needs and quality of life. Music and singing can and do change worlds for those with Parkinson's disease.

Cookie Cranston,

Writer, author. Volunteer: Lewy Body, Alzheimer & Parkinson Associations; Writing and living her best life in Central Iowa



CURRENT RESEARCH



Please visit our website for more information

Protein and Imaging Biomarkers (PIB) Study

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

Protein Aggregation and Neurotransmitter Deficits (PAND) Study

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

Precision-Mapping Study

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

Movement, Speech, and Thinking Study

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

Lower Back Pain Study

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

Improving Diversity in Parkinson's Research and Care Study

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

Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3

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

Memory Intervention for PD Study

Contact Tasha Doty
tdoty@wustl.edu
or 785-865-8943



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NEW DOCS IN TOWN



Dr. Daniel Di Luca, MD, MSc - Dr. Di Luca is an Assistant Professor of Neurology at Washington University in St. Louis. He completed his Neurology residency at the University of Miami, where he served as a chief resident. He subsequently completed a Clinical and Research Movement Disorders fellowship at the University of Toronto under the supervision of Prof. Anthony Lang, followed by a master's in Clinical Epidemiology and Health Care Research from the Institute of Health Policy, Management and Evaluation (IHPME) at the University of Toronto.

He has extensively studied movement disorders and published in high-impact journals. His main research interests include neuromodulation, epidemiology, and novel therapies for motor and non-motor symptoms in Parkinson's disease and other movement disorders, including multiple system atrophy.



Dr. Robert Huermann, MD/PhD - Dr. Huermann grew up in St. Louis and did his undergraduate degree at Washington University, prior to spending some time in Chicago for his MD/PhD at Northwestern. He was thrilled to return home for his Neurology residency and Movement Disorders fellowship training, and is now truly honored to be staying as faculty. Patients with Parkinson disease are what drew Dr. Huermann to Movement Disorders -- specifically how individualized each visit is, working together with patients to find the treatment plan that works best for them.

Outside of the clinic, Dr. Huermann is interested in why Parkinson's causes chronic pain for some people. His research tests how dopamine affects pain signals as they move through the brain. Hopefully his studies will lead to better treatments for the uncontrolled pain many Parkinson's patients experience and other types of chronic pain as well.

Otherwise, Dr. Huermann is a sucker for all things soccer (go City!). He spends his time helping his wonderful wife wrangle their 3 kids between school, soccer games, piano lessons, and the occasional trip to the Emergency Room (never a dull moment!).



MIDWEST PARKINSON CONFERENCE
(formerly Congress)

SAVE THE DATE
Thursday, April 11, 2024

Location:
Holiday Inn - St. Louis SW
10709 Watson Road
St. Louis, MO 63127

Details and Registration Info will follow.

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.

EXERCISE IS THE BEST GIFT YOU CAN GIVE YOURSELF: THESE CLASSES CAN BE ACCESSED ANYWHERE

Zoom

Tuesday 9:00am - Seated Exercise | Level 1

Thursday 2:00pm - Seated Exercise | Level 1

Zoom classes are live every week. To attend a Zoom Class, you must register online or call 636-778-3377. You will receive the Zoom link to join virtually.

YouTube

Seated Exercise | Level 1

Tai Chi | Level 1 & 2

Movement Training | Level 2

Strength and Cardio | Level 1 & 2

Yoga | Level 1 & 2

Parkinson's Boxing | Level 3

Building Your Abilities | Short Video for All Levels

YouTube classes are not live and can be watched at any time. New classes are added each week.

How to join classes on YouTube:

STEP 1: From your web browser, enter the following website: www.apdaparkinson.org/mo

STEP 2: Click the box that says EXERCISE CLASSES.

STEP 3: In the yellow box that says EXERCISE AT HOME, click GO TO YouTube.

STEP 4: Select the class or classes you would like to take by hovering your mouse over the blue box with the class description and double click. The video should load, and you are able to start, stop and pause as needed.

EXERCISE CLASS SCHEDULE

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

MISSOURI CLASS SCHEDULE

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
Friday 11:00am - Tai Chi and Meditation

Chesterfield YMCA

Mon/Wed 12:30pm - Parkinson's Pedalers | Level 2

Jefferson County YMCA

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

Kirkwood YMCA

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

Maryland Heights YMCA

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

St. Louis County YMCA

Tues/Thurs 3:30pm - Exercise for Parkinson's | Levels 1 & 2
(NOTE: Classes will move to 9:30am starting Jan. 8, 2024)

St. Louis City - Stephen A. Orthwein Center

Thursday 12:00pm - Interval Training | Level 2

St. Peters - BJC

Thursday 11:00am - Strength and Cardio | Levels 1 & 2

Ste. Genevieve Co. Community Center

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

Sunset Hills - Friendship Village

Thursday 1:00pm - Movement Training | Level 2
(NOTE: Schedule varies, please call ahead to confirm)

Washington YMCA

Mon/Wed/Fri 1:00pm - Exercise for Parkinson's | Levels 1 & 2

Virtual via Zoom

Tuesday 9:00am - Seated Exercise | Level 1
Thursday 2:00pm - Seated Exercise | Level 1

ILLINOIS CLASS SCHEDULE

Breese/Clinton Co. YMCA

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

Champaign YMCA

Monday 1:00pm - Strength and Balance
Tuesday 1:00pm - Functional Chair Fitness
Wednesday 1:00pm - Seated Yoga
Thursday 1:00pm - Parkinson's Fitness
Friday 1:00pm - Functional Chair Fitness

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 - Grant Conservatory of Music & Dance

**New Location*

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 2:30pm

Chesterfield - APDA Office
2nd Monday 10:30am - Caregivers ONLY
2nd 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 (*NOTE: New time*)

NEW - Kirkwood - SPEAKeasy Therapies & Fitness
2nd Wednesday 6:00pm (*begins 12-13-23*)
Young Onset ONLY

Olivette - Private Home Care Co - 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. Genevieve - Community Center
2nd Wednesday 10:00am

***NEW - St. Charles - Kisker Road Library**
2nd Tuesday 10:00am (begins 1-2-24) - Caregivers ONLY

St. Peters - Spencer Road Library
1st Tuesday 1:00pm

Washington - Public Library
2nd Monday 3:00pm

VIRTUAL
4th Tuesday 6:30pm - All welcome
3rd Monday 1:00pm - Caregivers ONLY
Every Thursday 6:00pm - Young onset 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 and 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

Champaign - Savoy United Methodist Church
Every Monday 10:00am

Decatur - Westminster Presbyterian Church
3rd Thursday 1:30pm

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 Tuesday 2:00pm

Quincy - Quincy Public Library
2nd Saturday 10:00am

***NEW - Quincy Senior Center**
4th Thursday 1:00pm - small group discussion

Virtual via Zoom - Jacksonville
1st Wednesday 1:00pm

MANAGING PD IN THE HOSPITAL: STRATEGIES FOR SUCCESS

By Nicole Hill

Hospital stays throw a wrench into our routines. It's a mess for anyone, but for folks with Parkinson's disease (PD) it can be especially challenging and potentially risky.

PD isn't foreign to healthcare workers, but the level of knowledge varies greatly. They also won't be experts on your unique experience with the disease so it's important to communicate your needs during your stay. Here are some tips to help you get ready for your time in the hospital.

Care partners and working with hospital staff

A care partner is crucial for emotional and physical support during a hospital stay. They can be a spouse, partner, adult child, family member, or friend you can rely on. While it's always good to advocate for yourself, don't discount the toll a hospital stay can take.

Educating the staff about the most relevant aspects of PD and how they impact you is helpful. It's valuable for the staff to know certain details of your daily routine, like when you typically feel your best, what foods help with nausea or constipation, how they can best assist with mobility, and information about your medication schedule.

The reality is, many hospitalizations are not planned and can't be prepared for as much as we would like. Identifying who will act as your advocate (care partner) and discussing these tips with them prior to an emergency can be of great help.

Medications

Medications are a big deal and your care team might not fully realize how important your meds are and the impact they have on your symptoms. Make sure you emphasize with them the need to stick to your medication schedule.

Tips for handling your medications in the hospital:

- Organize your medication list and ensure it is complete and accurate.

- Bring your medications with you in their original bottles, not in a pill box.
- Timing can be a challenge due to pharmacy schedules, so educate the nurses about the importance of sticking to your medication schedule as closely as possible.
- Be aware that specific brands and dosages may not be readily available in the hospital pharmacy. If substitutes are suggested, inform the provider that it is usually not appropriate for PD patients unless absolutely necessary.
- Inquire about the option of taking your own medications during your hospital stay.
- If new medications are prescribed, ask about potential interactions with your PD medications and inquire about side effects, especially those related to movement or cognition.
- If the person with PD is not awake enough to swallow medications, then the care partner should consult the person's neurologist to discuss options.

Mobility

You can't talk about mobility without talking about falls. The risk of falling increases when you're in the hospital. It doesn't matter why you're there, changes in medications, hospital equipment, and lack of sleep can all make mobility issues worse. There are ways to prevent falls and keep yourself safe:

- Follow the hospital's policies for fall risks. The staff knows what they're doing, so listen to their advice.
- Don't hesitate to use your call light when you need help. That's what it is there for!
- Be aware of any side effects that new medications may have, especially if they can cause dizziness or drowsiness.
- Be honest with your care team about your current level of activity. They need to know so they can provide the right support.



- Consider consultation with PT and/or OT. If it's not ordered, don't be shy—ask for it! Doctors often make decisions based on PT and OT recommendations.

Mobility and Bedsores:

- Avoiding bedsores is crucial when confined to a bed or wheelchair.
- Turn every two hours to prevent bedsores; ask for assistance if needed.
- Nurses should assess skin integrity and provide padding for bony areas.
- Ask about using silicone dressings, gel pads, or heel protectors to prevent bedsores.

Mobility and Hospital-Acquired Pneumonia:

- Reduced mobility increases the risk of fluid accumulation in the lungs.
- Take deep breaths multiple times an hour to prevent pneumonia.
- Try a breathing exercise to open up airways: Inhale deeply, hold, take an extra puff in, and then exhale.

Other issues

Other common situations you might encounter:

Pain control: Clearly communicate your preferred methods of pain management, whether it's medication, alternative therapies, or a combination of both.

Surgery: Medications are typically halted right before a procedure. Most meds can be taken with a sip of water, even when a patient is on NPO status (nothing by mouth). Ask about resuming regular meds as soon as it's safe.

Dysphagia and aspiration risk: If you have difficulty swallowing (dysphagia), your risk of developing pneumonia increases. Inform your doctor if you're on a modified diet (e.g., soft foods, thickened liquids.)

Deep brain stimulator (DBS): If you have a DBS device, let the doctor and care team know, as they may not be familiar with it. Have the manufacturer's card on hand so staff can contact them for information if needed. DBS may impact the type of imaging you can undergo.

Duopa therapy: Similar to DBS, inform your care team about your Duopa therapy and be prepared to educate them about it. Have the manufacturer's information available for reference.

Discharge

Ideally, a social worker, case worker, or discharge planner should have been in contact with you during your stay, assessing your home situation, coordinating with the care team, and planning for a successful discharge. If you haven't seen such a person by the second day of your stay, ask a staff member about it.

Support groups can also be incredibly helpful. Seek advice from those who have gone through similar experiences. They might have valuable insights about additional community resources. Or perhaps you just need a couple of meals brought in and a listening ear. Sometimes this can make a world of difference.

Navigating a hospital stay can be done. It takes preparation, communication, and advocacy. Do your best to be proactive, assert your needs, and reach out for support. If you can approach the process with a positive mindset, you make your pathway much easier.

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2022-2023 APDA RESEARCH

by the numbers

\$2.35 million

19

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The amount awarded in 2022-2023 to support cutting-edge PD research. This represents a 25% increase from the prior year.

Researchers received APDA funding including four Post-Doctoral fellowships, 13 research grants, one Diversity in PD grant and one George C. Cotzias Memorial Fellowship.

APDA funded Centers for Advanced Research, which support various programs like research trainees, clinical fellowships, and early-stage discovery programs.

THREE RESEARCHERS FROM THE MIDWEST REGION RECEIVE APDA GRANTS

Post-Doctoral Fellowship Awarded

Post-Doctoral Fellowships are awarded to support post-doctoral scientists who recently completed their PhD work and whose research holds promise to provide new insights into the pathophysiology, etiology, and treatment of PD. This year's awardees include:

- **Abdulmunaim Eid, MD** from Washington University in St. Louis, St. Louis, MO for his study in the neurobiological basis of Parkinson's disease clinical subtypes

Research Grants

Research Grants are awarded to investigators performing innovative PD research at major academic institutions across the United States. This year's awardees include:

- **Enrico Opri, PhD** from the University of Michigan, Ann Arbor, MI for his study in stimulation induced evoked potentials for guided intra and post-operative functional mapping
- **Nikhil Panicker, PhD** from Cleveland Clinic, Cleveland, OH for his study in using iPSC models to interrogate Inflammasome-mediated pathogenesis in Parkinson's disease

OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

Thanks for Showing Up

amneal
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