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PARKINSON DISEASE  
ASSOCIATION

GREATER ST. LOUIS CHAPTER

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JULY 2020



— VIRTUAL —

# Midwest Parkinson Congress

Thursday, August 13 and Friday, August 14, 2020

10:00 AM – 1:00 PM

**THURSDAY SPEAKER SCHEDULE**

- 10:10 AM **Joel Perlmutter, MD** *What's New in Research*
- 11:05 AM **Aasef Shaikh, MD** *Parkinson's Disease: A Balancing Act*
- 12:00 PM **Rebecca Gilbert, MD** *Sleep and Fatigue*

**FRIDAY SPEAKER SCHEDULE**

- 10:10 AM **Jennifer Goldman, MD** *Cognitive and Other Non-Motor Behaviors and How to Cope with Their Manifestations*
- 11:05 AM **Tao Xie, MD** *DBS in PD: Optimal Patient Selection, Limitations and New Developments*
- 12:00 PM **Rebecca Gilbert, MD** *Medical Marijuana and Parkinson Disease*

There is no cost for this event, but registration is required. For more information or to RSVP visit our website at [www.apdaparkinson.org/greaterstlouis](http://www.apdaparkinson.org/greaterstlouis) or call **636.778.3377** or **630.933.4392**

**RSVP TODAY to reserve your spot!**





## SLEEP PROBLEMS AND PARKINSON'S DISEASE



### Questions About Sleep?

**Johanna Hartlein, APRN**  
Washington University School of Medicine  
Department of Neurology,  
Movement Disorders Section

### Answers Your Most Pressing Questions!

**Q: What are some common types of sleep problems in Parkinson Disease (PD)?**

PD can cause several different kinds of sleep problems including REM sleep behavior disorder (thrashing, kicking, screaming, falling out of bed while sleeping called RBD), Periodic Limb Movements of Sleep (PLMS), vivid dreaming, insomnia (either not being able to get to sleep at night or trouble staying asleep all night), Restless Legs Syndrome, excessive daytime sleepiness, and/or nighttime confusion or hallucinations. Many people with

PD also have sleep apnea or urinary frequency/urgency/incontinence which can interrupt sleep and wreak havoc on them (and their bed partner). If you have trouble sleeping or staying awake, please discuss it with your doctor as there may be treatment options available.

**Q: What are some non-medicine recommendations for getting a better night sleep?**

Sleep hygiene is important for all of us. That means several things:

1. Use your bed only for sleep and sex, not for eating, playing on your phone, watching TV or reading.
2. Try to go to bed and arise from bed at the same time each day. This teaches your brain that bed/night means sleep and out of bed/day means awake.
3. Limit napping to no more than an hour or two per day and not napping within 4 hours of bedtime. This also means to try not to doze off



in the chair in the evening while watching TV.

4. No caffeine after about 1pm.
5. No exercise within 4 hours of bedtime.
6. Try a sleep mantra like counting sheep or count backwards or even a phrase like “It’s ok” (inhale), “Peace” (exhale). Try to clear your mind and push out unwanted thoughts.
7. Limit ambient lighting (except for nightlights to get to the restroom).
8. If you awaken and have trouble getting back to sleep, try to get up and sit in a chair for 15 minutes then try going back into bed.
9. If nighttime urination is a problem, limit fluids within 3 hours of bedtime—but make up for those lost fluids during the rest of the day.
10. If you think you/your loved one may have restless legs, sleep apnea or hallucinations, this should be discussed with a doctor.
11. If daytime sleepiness is an issue, it may be okay to have 1-2 cups of coffee at breakfast and lunch or ½ to 1 200 mg caffeine pill for daytime wakefulness, assuming that you have no heart issues that would prevent this.

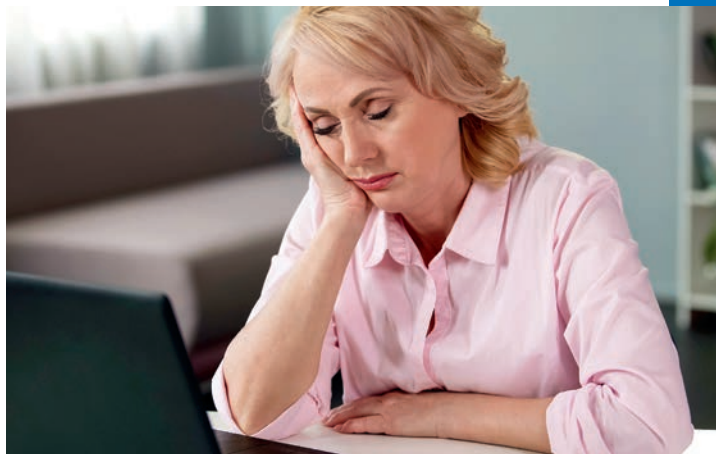
**Q: Are natural supplements or over the counter sleep medications recommended?**

We usually ask patients to avoid over the counter sleeping meds as most contain diphenhydramine (the active ingredient in Benadryl) and this can worsen mental foginess, balance and can cause hallucinations. We do recommend melatonin, usually 1-5 mg taken 2 hours before bedtime but if you have RBD, higher doses are frequently used. Other supplements may not be as helpful. There are prescription medicines that may help with sleep and these can be discussed with your doctor.

**Q: Does my PD medication timing impact my sleep?**

It depends. Some people find that overall, medicines like levodopa or ropinirole or pramipexole cause them to feel sleepy any time they take it, whether day or night. Amantadine, on the other hand, if taken too close to bed can cause insomnia. Some people find that their motor symptoms would be intensely uncomfortable if they did not take a bedtime

or middle of the night dose of PD meds. Other people find that they do not require bedtime doses at all. Occasionally, patients may feel PD meds cause insomnia. There is no question that PD meds at bedtime can worsen RBD and vivid dreams. So, it is overall a mixed bag and I would suggest discussing your specific PD meds sleep issue with your neurologist.



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## Donor Spotlight: Lindsey Carlie and Nancy Rapp



Lindsey Carlie and her mother, Nancy Rapp, have been loyal supporters of APDA-Greater St. Louis Chapter since 2011. Their gifts through the James and Alison Bates Foundation, a family foundation established by Lindsey's great uncle, help to support programs, services, and research throughout Missouri and Illinois. Lindsey was only 24 years old when her entire life changed. In February 2007, her father unexpectedly passed away. And that August, her mom, Nancy, was diagnosed

with Parkinson disease (PD). That year was a blur for Lindsey. She didn't know much about PD and didn't realize how much it would end up affecting her life in the long run. Nancy was immediately proactive in securing the best care and learning as much as she could about her disease. Nancy learned about the APDA-Greater St. Louis Chapter through her school PTO connections and got involved within a year of her diagnosis. She joined a support group and was attending a variety of activities including Tai Chi.

Lindsey credits APDA for how well her mom has been able to manage her PD. "I think for a long time, and even to this day, the knowledge my mom gained from APDA has kept the Parkinson's at bay. She has had a very slow progression of PD. Mom really benefited from support group. She didn't know anyone else with PD, so that really helped to have others going through the same thing"

APDA helped with finding the right support for Nancy on her Parkinson's journey. "Without the APDA resources, I don't know that she would have received the care that she has been receiving," Lindsey shares. "APDA helped her be proactive about her disease. It gave her the knowledge of the importance of movement and medication management, which still helps her to this day. She knows the disease really well and how it affects her and that comes from her involvement with APDA."

As for Lindsey, APDA has been helpful in understanding what it means to have a loved one with PD and with knowing what resources are available. She wants to continue supporting the programs and services APDA provides to help others impacted by this disease and to help future generations. "PD has impacted my family in a very close way. Not only has it affected me through my mother's diagnosis, but my great uncle had it as well. Through our family foundation, I am really trying to make sure I am honoring my great uncle and mother with our support of APDA-Greater St. Louis Chapter. We want to make sure we are supporting APDA not only for the programs and services they provide, but also for the research they support. We want to make sure this disease doesn't carry on."

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