



SEPTEMBER

2021

# Parkinson's Perspective

Newsletter of the Colorado Springs Parkinson's Support Group  
Colorado Parkinson Foundation, Inc.

www.co-parkinson.org | (719) 884-0103

## Acting President:

Jill Reid [redacted]  
president@co-parkinson.org  
**President Emeritus:** Ric Pfarrer  
**Vice President:** Jill Reid  
**Secretary:** Linda Christian  
**Treasurer:** Julie Pfarrer

## Members at Large:

Janet Adams, Beth Clarke,  
Gene Clarke, Jack Dashosh,  
Pat Dashosh, John Farley,  
Carole Henrichsen,  
Paul Mackendrick,  
Dave Moross, Mary Sauvain,  
Rich Sauvain

**Facilitator:** Patrick Holland

## Committee Chairmen

**Programs:** Jill Reid  
**Educational Outreach:** Jill Reid  
**Membership:** Carole Henrichsen  
**Chaplain:** Rusty Merrill  
**Parkinson's Awareness Day:**  
Vacant

**Photographer:** Vacant

## Lending Locker Coordinator:

Rich Sauvain (719) 337-7911  
**Main Dish Coordinator:** Stephen  
Rudawsky [redacted] or  
potluck@co-parkinson.org

**Picnic:** Carole Henrichsen  
and Janet Adams

**Media Relations:** Mary Sauvain

**Medical Advisor:** Curt Freed, MD

## New Member Table Chairmen:

Pat Dashosh  
**Sunshine (Cards):** Sharon Carlson  
[redacted]

**T-Shirt Chairman:** Vacant

**Webmaster:** Julie Pfarrer

**Newsletter Editor:** K. Schleiker  
**Address/Email/Database Updates  
and Newsletter Coordinator:**

Contact Julie Pfarrer at  
db\_mgr@co-parkinson.org or  
call [redacted]

The Colorado Springs  
Parkinson's Support Group  
(part of CPF) meets the second  
Saturday of each month at 10AM  
(with exceptions to be noted  
in this newsletter).

## NEW MEETING LOCATION!!!

First United Methodist Church in downtown Colorado Springs has agreed to let our support group meet in their Fellowship Hall starting in September at our regular dates and times. This move will get us back to a larger and more centrally located venue. Being so far north was difficult for some of you and if we return to pre-COVID numbers, we would be too large for Academy Christian Church to accommodate us. Because First Presbyterian Church is still understaffed because of COVID layoffs they don't know when they'll be able to open up the Weber Street Center for weekend use again.

Parking at First Methodist is on the north end of the building - a smaller parking lot with handicapped spots next to the building and a larger one across St. Vrain Avenue. Enter the door facing the parking lots, continue to the end of the main hallway and turn right. Elevators are on the right and stairs are at the end of that hallway. After exiting the elevators jog a bit to the right and go straight down the hallway in front of you. If you take the stairs follow the hallway at the bottom of the stairs and take the first right. Part way down that hallway you'll see a sign that points to Fellowship Hall on the left. We will try to have people and signs in strategic places so you don't get lost. Give yourself a little extra time because it's a longer walk than getting to the meeting room at 1<sup>st</sup> Pres or Academy Christian.

**Next Meeting: Saturday, September 11th — 10:00 am - 1:30 pm Meeting**

Location: First United Methodist Church, 420 N. Nevada Ave – downtown just south of St Vrain  
9:45 am, Sept 11<sup>th</sup> – Come in a few minutes early to check in, greet other members and ask questions.

*First time visitors:* Be sure to sign in, get a name tag and proceed to the visitors' table for some special attention and information.

**Knowledge is power and enables us all the live well with Parkinson's,  
so plan to attend the meeting at Academy Christian Church or join us on Zoom.**

The program will be followed by a potluck lunch.



## September Program: Urinary Tract Issues with Parkinson's Speaker: Danielle Spivey Mulligan, PT, MSPT

Danielle is a Certified Vestibular Therapist holding a Master of Science degree in Physical Therapy from Regis University in Denver, Colorado, in 1999. Her research topic was on the reliability of the sensory organization on balance, which started her in the direction of vestibular rehabilitation. She passed the vestibular competency exam with Susan Herdman PT, PhD at Emory University in March of 2004. She established the Balance Center at Orthopedic Rehabilitation Associates in Colorado Springs to focus her attention to providing compassionate one on one care to individuals with balance and mobility impairments from vestibular dysfunction and neurological diseases. In addition to her work at Orthopedic Rehabilitation Associates, she instructs other physical therapists in the specialty of vestibular rehabilitation. In January of 2012, Danielle added another certification called LSVT BIG for the treatment of people with Parkinson's disease. She is seeing amazing gains with this additional treatment approach. She prides herself by seeing each patient as an individual and helping them reach their fullest potential by providing Physical Therapy founded in science while having the compassion to see them as a whole person, not just a patient with a diagnosis.

## The September Potluck – Casseroles

If you would like to be a provider of the main dish or a side dish, you can sign up through our website or you can contact Stephen Rudawsky at [redacted] or potluck@co-parkinson.org, no later than Wed. September 8<sup>th</sup> and tell him what you would like to bring. If you'd like to go through the website, go to the "Events" page of the website and find the meeting you're volunteering for and select "Event Details". That will take you to the main sign-up page. In addition to the meeting information, you will see how many chefs and the number of servings per batch are needed. Click on "Sign Up" in the box and then select "Submit and Sign Up" which will take you to a page where you will select how many of the number of chefs you are signing up for. For example, if the # of servings requested is 10 but you're making 20 servings then the quantity you would select should be 2...the equivalent of 2 chefs. There is also a place for any comments you may have there. You must then provide your name & email address. When finished, select "Sign Up Now" and you will receive a confirmation email and your information will be sent to our potluck coordinator, Stephen. This capability should help make Stephen's job considerably easier. To return to the website, close the sign-up tab at the top of the screen.

Remember that bringing food for the potluck is voluntary.  
**We look forward to seeing you there!**

## The President's Corner - ATTITUDES ARE INFECTIOUS | Jill Reid - Acting President, CPF & CSPSG



One day, Dad bought a bunch of bales of hay (around 16, if memory serves). After Dad loaded the hay into the bed of our pick-up truck, the old gentleman he bought the hay from insisted on tying down the load, a job Dad never trusted anyone but himself do. But he didn't want to hurt the old man's feelings. With a hope and a prayer, Dad let him tie the load down and then headed home.

A few miles down the road, Dad noticed that there were two or three cars behind him. As Dad and the line of cars were negotiating a series of tight S-curves, he happened to look at the driver of the car coming toward him. Her eyes were as big as saucers and he immediately knew the worst: the load of hay had come untied and was spilling bales into her lane. In the chaos that followed, her car ended up on top of one of the bales as did the lead car behind Dad's truck. The other

following cars scattered to avoid hitting the lead car. Bales, intact and broken, blocked both lanes. Dad screeched to a halt and endured the disgusted scowls of all the drivers, with the exception of one lady, the one whose car was on top of the bale, who was

literally hopping mad and screaming at Dad. Until, that is, he giggled and then started

laughing his head off. Little by little, the drivers started smiling and then laughing hilariously. They all got out and cheerfully lifted the two cars off the bales and helped Dad reload the intact bales into the truck bed. Dad's positive attitude about the event infected each of them, and they all went home laughing instead of fuming.

My brother-in-law, Ric Pfarrer, who was diagnosed with Parkinson's in 2003, made similar choices after his diagnosis. He chose to find funny ways to talk about his symptoms so as to put other people at ease. He'd say, "I make a great martini—shaken, not stirred." Or "On camping trips, I always

get to make the Jiffy Pop popcorn." Or "A big advantage of my tremors is that I can spread grass seed by hand perfectly." What a great way to face his own challenges and make those around him glad to be with him!

I'm sure that Dad wasn't born with an innate positive attitude. It was something he chose to cultivate, and he did so throughout his life. His intentional cultivation of a positive outlook enabled him to lead a joyful life in spite of being rejected at age 7 by his mother, who couldn't be bothered with raising him; in spite of spending his developmental years in a series of foster homes; and in spite of tremendous setbacks to his career brought about by an ambitious person who had to get Dad out of the way in order to succeed himself. Both Dad and Ric could've chosen to see the worst of their tough experiences - but that wouldn't that have helped either of them. And besides, where's the fun in having half-empty glasses? Their glasses were always at least half full and fully blessed!

### Thank You Lil & Bob Ray!!

For many years, because their daughter, Carl Holland, has Parkinson's and is a member of our group, Lil and Bob Ray faithfully decorated our meeting tables with table cloths and beautiful homemade centerpieces. Their work added "a touch of class" that we never had before, to our monthly meetings. Their volunteer work for us continued even through a protracted period of time that Carla lived out of state and could not attend our meetings. The next time you see them be sure to thank them for their years of dedicated service to us.

For health reasons the Rays can no longer provide this service for us. We are looking for volunteers to take their place. Since the Rays are donating all the center pieces they made, you would only have to pick which centerpieces to use each month, lay out the table cloths, place the centerpieces on the tables and pack it all up at the end of the meeting – creativity optional! If interested contact Julie at [db\\_mgr@co-parkinson.org](mailto:db_mgr@co-parkinson.org) or 719-495-1853.

## Turmeric Oil May Offer New Ways of Treating Parkinson's

By Kumamoto University via EurekAlert

Turmeric oil may be beneficial in treating Parkinson's disease, according to researchers from Kumamoto University in Japan.

Their findings support the known properties of aromatic turmerone (arturmerone), a compound found in turmeric essential oil, which reduces inflammatory responses caused by cells associated with Parkinson's -related neurodegeneration.

Using midbrain slice cultures – laboratory cellular models that mimic brain activity – the team analyzed the effects of a natural form of aromatic turmerone and eight structurally similar derivatives. They tested the

derivatives' anti-inflammatory effects, as well as their ability to protect dopamine-producing neurons.

Those with the strongest anti-inflammatory effects were found to prevent the loss of dopamine-producing neurons. Among these were aromatic turmerone and its derivatives, suggesting their role as a "potential candidate for treating Parkinson's disease".

In a press release, lead author Takahiro Seki said: "Our study elucidated a new mechanism by which ar-turmerone and its derivatives directly protect dopamine-producing neurons."0

## Fruit compound may have potential to prevent and treat Parkinson's disease

By John Hopkins University School of Medicine

Johns Hopkins Medicine researchers say they have added to evidence that the compound farnesol, found naturally in herbs, and berries and other fruits, prevents and reverses brain damage linked to Parkinson's disease in mouse studies.

The compound, used in flavorings and perfume-making, can prevent the loss of neurons that produce dopamine in the brains of mice by deactivating PARIS, a key protein involved in the disease's progression. Loss of such neurons affects movement and cognition, leading to hallmark symptoms of Parkinson's disease such as tremors, muscle rigidity, confusion and dementia. Farnesol's ability to deactivate PARIS, say the researchers, could guide development of new Parkinson's disease interventions that specifically target this protein.

"Our experiments showed that farnesol both significantly prevented the loss of dopamine neurons and reversed behavioral deficits in mice, indicating its promise as a potential drug treatment to prevent Parkinson's disease," says Ted Dawson, M.D., Ph.D., director of the Johns Hopkins Institute for Cell Engineering and professor of neurology at the Johns Hopkins University School of Medicine.

Results of the new study, published July 28, 2021, in Science Translational Medicine, detail how the researchers identified farnesol's potential by screening a large library of drugs to find those that inhibited PARIS.

In the brains of people with Parkinson's disease, a buildup of PARIS slows down the manufacture of the protective protein PGC-1 alpha. The protein shields

brain cells from damaging reactive oxygen molecules that accumulate in the brain. Without PGC-1 alpha, dopamine neurons die off, leading to the cognitive and physical changes associated with Parkinson's disease.

To study whether farnesol could protect brains from the effects of PARIS accumulation, the researchers fed mice either a farnesol-supplemented diet or a regular mouse diet for one week. Then, the researchers administered pre-formed fibrils of the protein alpha-synuclein, which is associated with the effect of Parkinson's disease in the brain.

The researchers found that the mice fed a farnesol-supplemented diet had twice as many healthy dopamine neurons than mice not fed the farnesol-enriched diet. The farnesol-fed mice also had approximately 55% more of the protective protein PGC-1 alpha in their brains than the untreated mice.

In chemical experiments, the researchers confirmed that farnesol binds to PARIS, changing the protein's shape so that it can no longer interfere with PGC-1 alpha production.

While farnesol is naturally produced, synthetic versions are used in commerce, and the amounts people get through diet is unclear. The researchers caution that safe doses of farnesol for humans have not yet been determined, and that only carefully controlled clinical trials can do so.

Though more research is needed, Dawson and his team hope farnesol can someday be used to create treatments that prevent or reverse brain damage caused by Parkinson's disease.

LENDING LOCKER INVENTORY								
3 wheeled walker	1	Crutches	2	Lift Ware – tremor compensating fork & spoon	1	Suction cup hand rail	1	
<b>Note:</b> a stair chair lift system has been donated to us. It's a seat on a rail that takes you up & down a staircase. This one is for a 14 step or less straight staircase (no turns).	Arm assist for wheelchairs	1	Exercise bike	1	Lumbar traction belt	1	Suction cup hand rail	4
	Arm splint	1	Exercise pedals for 2	1	Pickup assist	5	Tub rail	1
	Bed Cane	2	Hospital beds	2	Raised toilet seats	4	Transport chairs	4
	Bedpan	1	Ice man - therapeutic for knee replacement surgery	1	Shower benches/chairs	9	U-Step	1
	Bedside toilet	5			Stair Chair Lift System	1	Voice amplifier	2
If you would like to borrow any of the equipment listed here, please contact Rich Sauvain at [REDACTED]	Black back brace	1	Knee splint	1	Stand-up walker	1	Walkers with wheels/ seat	9
	Canes	1	Lift chairs	2	Suction cup hand rail	1	Wheelchairs	4



**Other Local Support Groups: Due to Coronavirus concerns, check ahead to see if canceled**

**Ladies w/ Parkinson's Support Group**

The leader of this support group, Carla, is stepping down. The group meets once a month to do various fun activities such as lunch, crafting, baking, etc. If you are a fun-idea person and would like to make sure that this group that has been so valuable to its members continues, please consider volunteering to lead the group. If you're interested please notify Julie Pfarrer at db\_mgr@co-parkinson.org or [redacted]

**Parkinson's Caregivers Support Group**

Due to a scheduling conflict, the new Caregivers Support Group will be starting up again in October rather than September. The new leader, Brenda Hicks, has made arrangements for the group to meet the 3<sup>rd</sup> Thursday of each month from 10:00 to 12:00 at New Life Church Midtown – 3958 N. Academy Blvd., Suite 103, Academy & Austin Bluffs. All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings. For questions contact Brenda Hicks at [redacted]

**Tri-Lakes Parkinson's Support Group**

Meets the 3<sup>rd</sup> Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3<sup>rd</sup> Street, Monument. For more information contact Barry Hanenburg at [redacted] or Syble Krafft at [redacted]

**Essential Tremor Support Group**

The essential Tremor Support Group is moving from Monument to Colorado Springs starting October 16<sup>th</sup>. The meetings will be in the ENT conference room at Pikes Peak Library District – Colorado Springs Library 21c, 1175 Chapel Hills Drive. For questions contact Jim Sanchez at [redacted]

**Other Opportunities: Due to Coronavirus concerns, check ahead to see if canceled**

**LSVT BIG & LOUD at Home**

At Home Healthcare offers the LSVT BIG & LOUD therapy program for individuals with Parkinson's Disease in the comfort of their homes. Their therapists are LSVT certified and can accommodate patients' home schedules. Medicare covers out patient therapy at 80% and home health therapy at 100%. If you have questions about this service or would like a referral coordinated through your primary care provider please call their office at: (719) 227-8624.

**Creativity Lab**

**On sabbatical for the time being.**

With concerns for the health and safety of our participants, we at The Unsteady Hand have suspended all in person programming. We hope to resume around the first of the year.

www.TheUnsteadyHand.org  
Re-Imaging Parkinson's - Mo

**Adult Speech Therapy at Home**

Outpatient speech therapy services conducted in the comfort of the patient's home. Personalized speech therapy for restoration of function due to illness or injury.

Treating:

*Parkinson's: Voice & Swallowing*  
- SPEAK OUT!  
- LSVT, an evidenced based voice treatment program designed for Parkinson's patients

*Swallowing*  
- Neuromuscular Electrical Stimulation Therapy  
- Respiratory Muscle Strength Training  
*Aphasia following stroke*  
*Cognitive-Linguistic Deficits*

For more info, contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or by phone at (719) 338-8165.



Your birthday isn't listed?  
Fill out the membership form and check BD listed "YES".

Mike Ballo  
Teri Ballo  
Jackie Casey  
Gloria Chism  
Larry Christian  
Ray Coddington  
Janet Conover  
Gerald Costanzo  
Nancy Crosier

John Fletcher  
Karen Fletcher  
Carole Henrichsen  
Patrick Holland  
Alan Knight  
Maralyn Legleiter  
David Lydon  
Paul Metzler  
Alison Meyer

Corinne Nelson  
Marge Parrott  
Ric Pfarrer  
Carol Rushing  
Gary Shrewsbury  
Dennis Smith  
Judith Stauffer  
Onda Waller  
Alan Whitaker

**September Executive Committee Meeting**

September 14<sup>th</sup> at 12:00 at a place to be determined.  
(you will be notified by email)

Contact Linda at secretary@co-parkinson.org if you haven't been to an Executive Meeting so we will know that you're coming. Leave your email address so Linda can contact you if anything changes.

**October Newsletter Input Deadline: September 17th**

Call or e-mail Julie at:

db\_mgr@co-parkinson.org.

**Thank You!**

Thanks to **ALL** who brought food and to those that helped setup & cleanup at the last meeting!



**2021 Summer Picnic**

**PD Exercise Classes: Due to Coronavirus concerns, check ahead to see if canceled**

**Dance for Parkinson's**

Moving with joy, creativity, and community to support people living with Parkinson's.

All are welcome and care partners are encouraged to move with us!

Classes meet in person every Friday at 11:00 am at Ormao Dance Company, 10 S. Spruce Street \$5/class. Free for care partners.

You can also join us for this class online. Visit our website [www.ormaodance.org](http://www.ormaodance.org) and click on "Dance for Parkinson's" under the "Outreach" tab to get the Zoom link.

Questions: Contact Laura at [laura.hymers@gmail.com](mailto:laura.hymers@gmail.com) or 719-640-8478.

**Max Capacity NeuroFitness**

is offering PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training.

**NEW LOCATION:** 525 E. Fountain Blvd. Suite 150. Park on the S. Royer side of the building.

Boxing: Tues/Thur – 4:00 to 5:00pm and Sat – 9:00am to 10:00am

PWR Boot Camp: Mon/Wed – 3:30pm to 4:30pm

**Boxing is free of charge, Boot Camp packages available!** Contact Emily Moncheski at (719) 213-3996 or [emily@maxcapacitypt.com](mailto:emily@maxcapacitypt.com) for info.

**YMCA PD Exercise Classes**

We utilize exercise as medicine to increase quality of life so that you can get better and stay better.

**NOTE: All classes have been suspended except the following:**

Tri-Lakes YMCA: PWR!Moves Tuesday & Thursdays, 1:30-2:30 PM

Briargate YMCA: PWR!Moves Monday, Wednesday & Friday, 1:30-2:30 PM

**For more information contact Jamie Clayton at [jclayton@ppymca.org](mailto:jclayton@ppymca.org)**

**NeuroRehab Project at ORA Water and Movement Classes**

**Note:** We were told that these classes have been discontinued, check ahead to see if canceled.

**Improve your mobility in the water:**

We offer warm water (92 degrees) pool classes for people with movement disorders. Mondays and Wednesdays from 1:30-2:30. \$10.

**Parkinson's Wellness Recovery Exercise Class:**

Power Moderate level. Fri at 1:30. \$10

**Parkinson's Wellness Recovery Exercise Class:**

Power Advanced level. Wed at 1:30. \$10.

Danielle Spivey, PT and Rachel Johnson, SLP have created these opportunities to augment skilled Physical and Speech Therapy.

Location: Pikes Peak Athletics, 602 Elkton Drive in Rockrimmon. Please call us at (719) 559-0680 for information and to get signed up.

**UCCS Center for Active Living - at the Lane Center**

Power Moves group exercise and Balance & Agility classes.

For more information call (719) 255-8004 or email [CAL@uccs.edu](mailto:CAL@uccs.edu).

**PWR!Moves Class**

Skyline Wellness & Aquatics Center is partnering with the YMCA to help the PWR! Moves class be more available to everyone. We are reaching out to help individuals who may be located on the south side of town and need a closer location to their home. We are located within

Brookdale Skyline at 2365 Patriot Heights near Bear Creek Dog Park. Our classes are held every Tuesday and Thursday from 12:30-1:30 pm.

If you have any questions, please contact the Fitness Coordinator Karisa Dreyer at (719) 867-4658

**PWP: Parkinson's With Poles**

Come join Emily Moncheski and Eileen O'Reilly for a great exercise workout at Monument Valley Park.

Every Friday, 9 am at the north parking entrance of Fontanero and Culebra streets. Poles are provided. Everyone is welcome.

**NIA Class**

Moving to Heal – the art of feeling better; slower movements with joy and purpose. NIA works with balance, breath, cognitive mind/body function, mobility and stability. You can go at your own pace. Stop if you want, sit down and dance while sitting in a chair for a while. All while dancing to music from all genres; Jane, the instructor, often asks what we need that day and works her routine around what can help. She has done a wonderful job making the routines fit our Parkinson's needs.

When: Every Friday at 10:30

Location: 525 East Fountain Blvd.

MACS–corner of Fountain & Royer

Cost: \$10.00 a class.

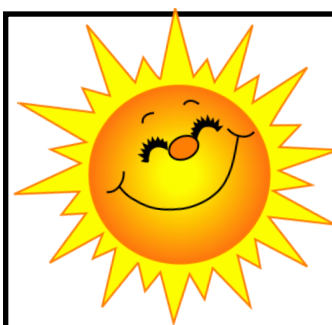
**Falcon Exercise Group**

Mon and Fri –11:00 – 12:00 noon, Grace Community Church.

For more information contact Catherine Reed at [REDACTED].

**Coronavirus and Parkinson's Disease**

For information on coronavirus and Parkinson's Disease go to: [www.parkinson.org/CoronaVirus](http://www.parkinson.org/CoronaVirus).



**Help us spread some sunshine to our members!**

If you know of a Parkinsonian or PD caregiver that is having a tough time (illness, surgery) or one of our members has passed away, please let our Sunshine Chairman, Sharon Carlson know.

Sharon can be reached by calling [REDACTED]

## Experts Share Views on Managing Patient's Sleep Problems

By Michael J. Fox Foundation via Parkinson's News Today

Between symptoms of Parkinson's and the side-effects of modern life, quality sleep can be hard to maintain. Still, with many factors come opportunities to experiment.

Sleep disturbances common to Parkinson's include insomnia, restless leg syndrome, sleep apnea, and excessive daytime sleepiness. REM sleep behavior disorder (RBH), where individuals physically act out their dreams, is particularly common, affecting as many as 90% of Parkinson's patients over the course of their disease, the experts said.

These and other non-motor symptoms, such as constipation and loss of smell, can manifest long before motor symptoms become apparent. Sleep can also be indirectly affected by other aspects of Parkinson's such as anxiety, frequent urination, physical discomfort, and treatment side effects.

Factors that aren't directly related to Parkinson's – such as the use of alcohol or caffeine, exercise late in the day, looking at bright screens (i.e., computers and TVs) late at night, or a bedroom's temperature (cooler is better) – can affect sleep, too. Managing these issues is also important with Parkinson's-related sleep disturbances.

"All of these things together form what we neurologist or sleep physicians call 'sleep hygiene,' and it's really an important part of managing any sleep problem that a person with Parkinson's will experience," said Michele Hu, PhD, a professor of clinical neuroscience and consultant neurologist at Oxford University.

"Good sleep hygiene is key" for managing sleep problems in Parkinson's, added Maria Cristina Ospina, MD, a movement disorder neurologist and assistant professor of clinical neurology at the University of Arizona.

### Sleep Hygiene

Hu and Ospina both stressed the importance of avoiding blue-light screens at night, not consuming caffeine or alcohol late in the day, and not taking long daytime naps as ways to help manage sleep problems.

They also noted the importance of getting the right balance of medications and other therapies.

"Always talk to your doctor about your medications and how well they're working," Ospina said. "Sometimes you many need a dose of levodopa [a dopamine-replacement therapy] in the middle of the night to keep you sleeping through the night."

Ospina added that exercise early in the afternoon can help with sleep at night – however, exercising too late in the day can make sleeping at night difficult. It's also important to have a balance of different types of exercise (e.g., aerobic exercise and resistance training).

"Just like you have a well-balanced diet, you want a well-balanced exercise program," Ospina said.

Complementary and alternative therapies may also aid people with Parkinson's in getting better sleep. For example, light therapy can help "reset the clock" for patients, according to Ospina. In general, things that help manage physical discomfort in Parkinson's can also help with sleep.

"Anything that helps you with the rigidity of Parkinson's disease, like massage, tai chi, yoga, acupuncture, helps relax the body so that it can fall asleep," Ospina said.

These activities can also relax the brain to aid in sleep, she added, also noting that meditation and mindfulness can be helpful to help the brain calm down.

Hu recommended an app, called Sleepio, that delivers cognitive behavioral therapy aimed at reducing insomnia. She said the app was "a similar approach to mindfulness" that can help people get back to sleep at night.

### Cannabis, Melatonin, and Clonazepam

Cannabis use as a potential sleep aid has attracted interest in recent years as it has become more widely legalized in the U.S. according to Ospina, cannabidiol (CBD), a compound found in cannabis, has helped some Parkinson's patients with sleep and pain.

However, Opsina noted that conclusive data are lacking on CBD as a sleep aid, and more research needs to be done. Additionally, there aren't widely accepted guidelines for CBD use, and regulations on CBD vary among U.S. states. As such, there is a lack of uniformity for CBD as a Parkinson's treatment.

"So everybody has to sort of try it and see what works for them," Ospina said.

She shared stories of some individuals who would "only eat the head" of a CBD gummy, saying that was enough for them. She also said that a patient could ingest too much CBD – especially considering that its possible interactions with other medications aren't well understood. As such, patients need to be careful, start at low doses, and communicate with their healthcare providers, the experts agreed.

Hu said she had recently reviewed a study that "showed some promising benefits" for the use of CBD as a Parkinson's sleep aid – however, due to confidentiality agreements, she was unable to share details.

"I think we need more studies of this nature to really tease out what works," Hu said.

Notably, CBD is no psychoactive – that is, it doesn't induce a "high." The main psychoactive compound in cannabis is tetrahydrocannabinol (THC); Ospina recommended that people with Parkinson's try to avoid THC.

"In Parkinson's patients, you usually want to stay away from the THC because you're already on psychoactive medications," Ospina said, noting that levodopa and dopamine agonists can cause hallucinations.

## Parkinson's Drug May Ease Dementia-linked Psychosis

By New England School of Medicine via UPI

A drug that eases hallucinations in people with Parkinson's disease may be able to do the same for those with dementia, a new clinical trial finds.

The medication, called Nuplazid, or pimavanserin, is already approved in the United States for treating hallucinations and delusions related to Parkinson's.

The new study, published this week in the *New England Journal of Medicine*, suggests that drug may help dementia patients plagued by those same symptoms.

Researchers found that over 18 weeks, patients given Nuplazid were 65% less likely to see a resurgence of their hallucinations and delusions, compared to those on a placebo.

The trial had been planned to run longer, but was stopped early when it became clear the drug was effective.

Experts said the findings offer hope of a new treatment for some of the more troubling symptoms of dementia. But longer-term studies are still needed.

"I don't want people to think this is a miracle drug. It isn't," lead researcher Dr. Pierre Tariot, director of Banner Alzheimer's Institutes in Phoenix.

But, he added, the findings suggest Nuplazid could help many patients with dementia-related psychosis – possibly without all the risks of current medications.

Alzheimer's disease and other forms of dementia are commonly seen as memory disorders, but they affect the whole brain.

And it's the psychiatric and behavioral symptoms – including delusions, hallucinations, agitation and aggression – that can be the most difficult for patients and caregivers.

It's common, for example, for patients to believe that people are constantly trying to steal their possessions, said Dr. Joseph Friedman, an associate professor of psychiatry and neuroscience at Icahn School of

Medicine at Mount Sinai in New York City.

It's a false belief, but one that can be very distressing, Friedman said.

Hallucinations, meanwhile, may involve seeing or hearing people who are not there. Friedman said that in some cases – if a person is seeing a long-dead loved one, for example – the hallucination may not be a negative experience.

In other cases, the imagined encounters can be frightening or trigger dangerous behaviors.

Right now, no medications are officially approved for managing dementia-related hallucinations and delusions. But doctors commonly prescribe antipsychotic medications – the types used for schizophrenia and bipolar disorder.

A big problem, Friedman said, is the drugs' side effects: Movement problems, sedation, dizziness and falls are among them.

"And chronic exposure to antipsychotics can actually worsen the cognitive decline," Friedman said.

In that context, he said, the new findings may offer families "hope that there's a possible alternative treatment out there."

Friedman wrote an editorial published with the study, which was funded by Nuplazid's maker, Acadia Pharmaceuticals.

The trial was conducted in separate stages. First, Tariot's team screened nearly 800 dementia patients who were having hallucinations and delusions.

All patients and their caregivers were given counseling on how to deal with those symptoms without medication, which is what medical guidelines recommend.

Caregivers might, for example, offer reassurance or use distractions – like music or going for a walk – when hallucinations or delusions arise.

After five weeks, 351 study patients were still having symptoms and enter an "open-label" trial: All were given Nuplazid for 12 weeks. Of those patients, 62% had a lasting response to the medication and moved on to the final trial phase.

At that point, about half were randomly assigned to stay with Nuplazid for another 26 weeks, while the others were switched to a placebo.

After 18 weeks, a clear difference emerged: 28% of placebo patients were suffering hallucinations or delusions again, compared with 13% of Nuplazid patients.

As for side effects, the most common were headache, constipation and urinary tract infection.

Three patients showed a heart rhythm irregularity called a long QT interval – a known side effect of the drug. The labeling advises people with certain conditions that affect heart rhythm not to take the medication.

Friedman said longer-term data is still needed, and it's unclear whether Nuplazid works better for certain forms of dementia than others.

The majority of study patients had Alzheimer's, but about one-third had dementia due to Parkinson's, vascular disease or a buildup of abnormal structures called Lewy bodies in the brain.

Tariot agreed that larger, longer trials are needed.

Given the current options for managing these symptoms, he said, "if we have something else we could use, that would be terrific."

There have, however, been no head-to-head comparisons of Nuplazid and standard antipsychotics, to gauge how much safer or more effective it might be, Tariot noted.

Nuplazid is much more expensive. When it came to market in 2016, it was reportedly at a cost of \$24,000 a year.

## Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

Parkinson's Perspective

SEPTEMBER 2021

# Coming Events

See Inside for Details, Phone Numbers, and for More Information

**September 14<sup>th</sup> – Reg Mtg** at First United Methodist Church – 10 am

**Program:** Urinary Tract Issues with Parkinson's – **Speaker:** Danielle Spivey Mulligan, PT, MSPT

**October 9<sup>th</sup> – Reg Mtg** at First United Methodist Church – 10 am

**Program:** Your questions answered by a Parkinson's expert – **Speaker:** Dr. Brian Grabert, MD

**November 13<sup>th</sup> – Reg Mtg** at First United Methodist Church – 10 am

**Program:** The Alexander Method & Parkinson's – **Speaker:** Travis Chastain, Neuro-Muscular Rehabilitation & Movement Specialist

**December 11<sup>th</sup> – Christmas Party** with Entertainment by the Song Spinners!!!

- 
- ◆ Tri-Lakes PD Support Group meets the 3rd Sat of each month – Contact Barry Hanenburg at bhanenbu@hotmail.com.
  - ◆ NeuroRehab Project at ORA – Call Danielle for PWR!MOVES or Rachel for Speech Therapy & Swallowing at 719-265-6601.
  - ◆ YMCA- Parkinson's Wellness Recovery Exercise – call (719) 329-7295 or email wellness@ppymca.org.
  - ◆ Colorado Springs Senior Center: Exercise, Yoga, and TaiChi for older adults - (719) 955-3400 or <http://www.ppymca.org/colorado-springs-senior-center/about-us>.
  - ◆ UCCS Center for Active Living – at the Lane Center - Power Moves group exercise classes. Also: Balance & Agility Class for information: Call 719-255-8004 or email CAL@uccs.edu.
  - ◆ Max Capacity NeuroFitness – Contact Emily at (719) 213-3996 or visit maxcapacitypt.com
  - ◆ The Resource Exchange – the single-entry point for Medicaid long-term care – must be eligible for Medicaid and for Social Security disability.

*More useful websites:* <https://parkinsonsnewstoday.com>; [www.parkinsonrockies.org](http://www.parkinsonrockies.org); [www.parkinson.org](http://www.parkinson.org); [www.nwfp.org](http://www.nwfp.org); [michaeljfoxfoundation.org](http://michaeljfoxfoundation.org); [www.parkinsonheartland.org](http://www.parkinsonheartland.org); <https://www.pdself.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>; [www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons](http://www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons); <http://caremap.parkinson.org>; [https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo\\_C](https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C); <https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers>; [pmdalliance.org](http://pmdalliance.org)