

**2022**  
*December & January*  
**2023**

# 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:** Vacant

**Treasurer:** Julie Pfarrer

## Members at Large:

Janet Adams, Beth Clarke,  
Gene Clarke, John Farley,  
Carole Henrichsen, Steve Locke,  
Paul Mackendrick, Dave Moross,  
Mary Sauvain, Rich Sauvain

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**Educational Outreach:** Jill Reid

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**Chaplain:** Rusty Merrill

**Parkinson's Awareness Day:**

Vacant

**Photographer:** Vacant

**Lending Locker Coordinator:**

Rich Sauvain [REDACTED]

**Main Dish Coordinator:**

Bill Hicks [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:**

Vacant

**Sunshine (Cards):** Sharon Carlson

[REDACTED]

**T-Shirt Chairman:** Vacant

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webmaster@co-parkinson.org

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**and Newsletter Coordinator:**

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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).

**December Meeting: Sat, December 10th – 10:00 am – 1:30 pm**

*We will NOT be Zooming or recording this meeting*

**January Meeting: Sat, January 14th – 10:00 am – 1:30 pm**

*We will be Zooming and recording this meeting*

**Location:** First United Methodist Church, 420 N Nevada Ave, downtown just south of St. Vrain.

9:30am – Come early for a group sing-along with music therapist, Heather Johnson.

See more about Heather's business under **'Other Opportunities'** later in this newsletter.

9:45am – Everyone else come 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 to live well, so plan to attend the meetings at First United Methodist Church.

## December Meeting: Annual Christmas Party

*The "Song Spinners" Show Choir will be entertaining us!*



also...

and...

### The Annual Christmas Outlandish Apparel Contest!

You are invited to participate in an ugly Christmas apparel contest during this meeting.

*The most outlandish sweater, tie, hat or combination thereof as judged by your applause. Ties will be broken by a new member to our group.*

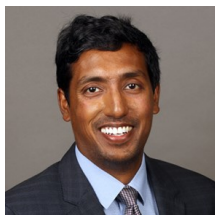
*Winner will receive a prize!*

### A Gift Exchange!

We will also have a gift exchange for those who wish to participate, with a \$10 limit.

*Give a gift – get a gift.*

**Come Join Us!**



## January Program: Deep Brain Stimulation

**Speaker: Dr. Amit Ayer, MD - Neurosurgeon**

Amit Ayer, MD, is passionate about patient-focused, technologically advanced care to provide individuals and their families with a variety of options to process with care best suiting their needs. He believes strongly in the importance of continued research and leading-edge therapies to provide the best possible options for patients and their loved ones.

Dr. Ayer received his undergraduate degree in Immunology at Queen's University in Kingston, Ontario, Canada. He earned his medical degree at Wake Forest School of Medicine in Winston-Salem, North Carolina, and completed his residency program at Northwestern Memorial Hospital Chicago, Illinois, in Neurosurgery. During his residency, he trained in skull base surgery and neuro-oncology in Italy at Agostino Gemelli University Hospital (2019). He then completed a fellowship in Epilepsy and Functional Neurosurgery at Stanford Healthcare in Stanford, California. Additionally, Dr. Ayer holds a Master of Business Administration from Kellogg School of Management in Evanston, Illinois.

Special Interests include: deep brain stimulation, movement disorders, epilepsy monitoring & treatment, spine disorders, brain tumors, neurosurgical trauma, minimally invasive neurostimulation, spinal cord stimulation, microvascular decompression, brain tumor surgery, spine surgery, spasticity surgery.

**See page 2 for both December's and January's Potluck Menus and Information!**

## The President's Corner

| Jill Reid - Acting President, CPF & CSPSG

**Wow!** The holidays are here already! I'm thinking that the quick passage of time this year is an indication that we have very busy lives. So I think it's appropriate that we slow down and take time to enjoy fully our Christmas party on December 10th.

**But** don't slow down getting to the party. Normally, we have the luxury of starting our meetings late to give late-comers time to check in and get settled. For the December meeting, we'll need to start right at 10 am (but if you're late, come on in!). And **BRING CHILDREN** - Santa will be with us and will enjoy having us adults, of course, but will be even jollier if he gets to have children sit on his lap.

Here's our party plan:

- Free photos with Santa (10 am to 11 am)
- Announcements
- Ugly Apparel contest (winner gets a prize!)
- Gift Exchange
- Christmas Show by the show choir, *The Song Spinners* (11 am to ???)
- Pot luck lunch (ham will be provided) after the Christmas show finishes

For those who wish to participate in the gift exchange, don't spend more than \$10. If you are a man, bring a wrapped gift for a man and mark it "Male"; if you are a woman, bring a wrapped gift for a woman and mark it "Female." Children can also participate and should bring a

gift for a male or female child, marked either "Male Child" or "Female Child."

The main thing is to enjoy the fun and each other.

Now here's something new. In January, we'll start an on-going fundraising campaign for the Colorado Parkinson Foundation (CPF), our parent 501c3 charity. It's a very easy fundraiser. You'll simply go each month to a specific restaurant on a specific day, show the coupon or flyer that we will provide you, and buy lunch or dinner! The restaurant will donate to CPF an agreed-upon percentage of your total ticket. In our newsletters and during the monthly meetings, we will announce the participating restaurants and the dates they will honor our coupons/flyers. Feel free to give the coupons/flyers to as many people as possible so we'll maximize the fundraising.

Lastly, in keeping with my campaign to get you to laugh as much as possible, I'm going to recommend funny movies for you to watch each month. For December, in honor of Christmas, I highly recommend *The Santa Clause* and *The Santa Clause 2*, both starring Tim Allen. For January, in honor of football season, you should watch *The Game Plan*, starring Dwayne "The Rock" Johnson.

Merry Christmas and Happy New Year!



## December Potluck – Christmas Ham! & January Potluck – Chili and Cornbread

CPF will be providing the main dish of ham for December's lunch. If you would like to sign up to be one of the providers of the main dish in January or to bring a side dish or dessert for either meeting, you can contact Bill Hicks at [REDACTED] or [potluck@co-parkinson.org](mailto:potluck@co-parkinson.org), no later than Wed. December 7th for the December meeting and Wed. January 11th for the January meeting and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

**We look forward to seeing you there**

## Recipe of the Month: Keto Spinach Salad with Warm Bacon Dressing & Keto-candied Pecans

Our low carb/good fat ketogenic study that was completed this past year showed incredible results. Not only was there remarkable improvement in the symptoms of Parkinson's but also with overall health in general (including the health of the caregivers who chose to change their diet along with their Parkinsonians). Since it seems clear that everyone's health would improve exponentially if we all changed our diet to eat this way and since we have potlucks, we thought we would feature an easy low carb/good fat recipe or two in the newsletter each month to promote healthy eating at our potlucks.

**If you have a favorite low carb/good fat recipe you'd like to share, please send it to Julie at:**  
**[db\\_mgr@co-parkinson.org](mailto:db_mgr@co-parkinson.org)**

The Salad	
4 slices (3 oz) bacon, cut into 1/2" pieces	1/4 tsp freshly ground pepper
1 Tbl cider vinegar	1 shallot, finely minced
2 tsp sugar substitute (Swerve or erythritol)	3 oz (4 C) baby spinach
1 tsp Dijon mustard	2 oz blue cheese, crumbled
1/2 tsp sea salt	1/2 Keto candied nut, recipe below



Line a small plate with a few layers of paper towels, set aside.

Place bacon in a large nonstick skillet over medium heat, and cook, stirring occasionally, until the bacon is crisp, 8 to 10 minutes.

While the bacon cooks, start the dressing: in a medium bowl, whisk together the vinegar, sweetener, mustard, salt and pepper. Set aside.

Using a slotted spoon, transfer the cooked bacon to the paper towel-lined plate. Return the skillet to the burner over low heat. Add the shallots to the bacon fat in the skillet and cook, stirring frequently, until softened, 1 to 2 minutes. Do not brown.

Add the vinegar mixture to the skillet with softened shallots and whisk to combine. Add the spinach to the skillet and toss to coat evenly. Taste and adjust the seasoning with salt and pepper, if necessary. Divide the salad between 2 plates or bowls; evenly divide the cooked bacon, blue cheese and candied nuts among them. Serve immediately.

The Pecans	
2 Tbl butter	1/4 tsp sea salt
2 Tbl brown sugar substitute (Swerve)	1/4 tsp cayenne pepper
1/4 tsp cinnamon	1 1/2 C (6 oz) whole Pecan nuts
1/4 tsp cumin	

Preheat oven to 325 degrees. Line a baking sheet with parchment paper and set aside

Melt butter in medium sauce pan. Take off heat. Add sugar, cinnamon, cumin, salt and cayenne. Stir until well combined and sugar has pretty much dissolved.

Add nuts to mixture in saucepan and mix gently until nuts coated.

Pour out into prepared pan. Spread out, no overlapping.

Bake until coating has caramelized and set and reached a golden brown, 10 to 15 minutes. Check after 8 minutes, as the nuts can

burn quickly. If there is still butter that's runny, they are not done yet. Check often.

Take nuts out of oven and let them cool completely in the pan. The nuts will harden up as they cool.

Break apart any clusters and serve.

October 8, 2022, Program Review

| by Heather Johnson

## PARKINSON'S DISEASE: A Look Back at Thirty-Seven Years of Treating Parkinson's Disease

Dr. Brian Grabert, MD

Glossary – must-know terms to converse with your neurologist

- On = when your medication is working
- Off = when your medication is not working
- Stage of Parkinson's – ask before you leave your appointment
- Axial Symptoms = midline (speech, gait, facial expression, swallowing, freezing)
- Autonomic nervous system – need to know what is regulated by this system and therefore what can be symptoms
- Dopaminergic = ingredient in the brain

PD is a systemic disorder – involves almost every system and sense

Dichotomy of Symptoms

- Motor symptoms – tremor, rigidity, bradykinesia—these should not be the only focus of treatment \*
- Non-motor symptoms – often the most disabling of PD

Never stop learning about your Parkinson's! Knowledge is very powerful – verify research by using peer reviewed studies – PubMed.com is the most reliable.

### QUESTIONS AND ANSWERS

Is there any medication better than carbidopa/levodopa (carb/levo)? There is no PD medication more potent nor more appropriate for initial treatment than immediate-release of carbidopa/levodopa (or Rytary if affordable). A 14-year randomized study found that starting on an agonist instead of or with carb/levo has no long-term benefit.

Can you get addicted to CD/LD? Yes – but it is rare. Found in 4% in PD cases. Called dopamine dysregulation syndrome and is more common in individuals with other types of addictions.

What are the pros and cons of rasagiline? As a primary drug, it's not that powerful; depression is a side effect of PD, and rasagiline is contra-indicated with Serotonin Reuptake Inhibitor anti-depression medications. Called Serotonin Syndrome, it is potentially life threatening; symptoms include restlessness/ agitation, confusion, anxiety, hyperreflexia, hypertonus/rigidity, hallucinations, fever, chills, tachycardia.

What types of hallucinations are part of Parkinson's and are they caused by PD or by PD medications? They are caused by either or both and include:

1. Delusions, which are false, fixed beliefs, that are held despite evidence to the contrary
2. Well-structured visual hallucinations
3. Hallucinations in other senses

\*Only FDA-approved drug for PD psychosis is Prevegin.

Is Orthostatic Hypotension caused by PD? Or the medication?

- Yes to both – Orthostatic BP's should be measured at EVERY visit
- Very common in later stages of PD; a "primary" autonomic failure, it can be serious and lead to serious injury or death and increased risk of dementia
- Caused by drop in BP by 20 points (30 points if hypertensive)

sive)

Would testosterone treatment help PD? Evidence from RCT's does not support treatment for low testosterone; testosterone treatment ultimately does not increase strength

How long does Deep Brain Stimulation (DBS) last? To some degree "indefinitely." It may become less effective over time but there are always positive effects.

Recommendations:

1. Offer DBS to patients who have had a diagnosis less than 4 years if they have fluctuations
2. Do not offer DBS to patients who have had a diagnosis less than 4 years and do not have fluctuations
3. Offer DBS to advanced PD patients not controlled with medications – at least a 33% improvement

What is freezing? Freezing of Gait – sensation that your feet feel stuck to the floor, \*\*\*[get a CAT scan!] [???

- Ask does freeze happen in On or Off state?
- Can occur when starting to walk, turning, in tight spaces, or during stressful situations
- Numerous ways to override – "cognitive overrides" – find what works for you, can use a laser, talk to your feet, "step" over something
- May not respond to CD/LD or to any other PD medications
- DBS may help with freezing

What are the effects of exercise on PD? Exercise releases various physiological benefits in the brain naturally

- Reduces risk and may slow down PD
- Increased longevity with PD
- Cognitive scores are better
- Larger brain volumes associated with exercise

What if idiopathic PD diagnosis is incorrect?

- Time is one of the best indicators
- Was your trial of carb/levo adequate? It may take up to 600mg to be certain.
- Are there levels of uncertainty\*? Then get a DAT scan

\*Levels of uncertainty

1. Only 1 in 3 cardinal features of PD
2. Tremor or rigidity without bradykinesia
3. Lack of disease progression over time
4. Lack of asymmetry
5. Poor or questionable response to L-dopa
6. Early falling or dementia in the first year? May be something else

Do any dietary supplements help with PD?

- Vit E – alone no effectiveness
- Omega 3 Fatty Acids 1000mg + Vit E – improvement in rating scales
- Vit D3 – low levels associated with higher risk of PD
- Creatine – no effect on disease progression
- Vit C – increased intake reduces risk of PD
- Cannabis – meta-analysis showed no benefit – may benefit other areas



**Other Local Support Groups:***Due to Coronavirus concerns, check ahead to see if canceled***Parkinson's Caregivers Support Group**

All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings.

We meet the 3rd Thursday of each month from 10:00 to 12:00 at 6310 Gemstone Way, Colo Spgs, 80918.

Contact Brenda Hicks at [REDACTED] or [REDACTED] to let her know you are coming.

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

Meets the 3rd Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. For more information contact Barry Hanenburg at bhanenbu@hotmail.com or Syble Krafft at 719-488-2669.

**Essential Tremor Support Group**

Meeting Location:  
ENT Conference Room  
Pikes Peak Library District.  
Colorado Springs Library 21c,  
1175 Chapel Hills Drive.

For meeting dates/times or for questions, contact Jim Sanchez at jimds22@gmail.com or 719-660-7275.

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

If you are a fun-idea person, please consider volunteering to lead this valuable group.

If you're interested please notify Julie Pfarrer at db\_mgr@co-parkinson.org or [REDACTED].

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

**Parkinson's Sing-a-Long Group**

No music experience necessary!

Join board certified music therapist, Heather Johnson, every Monday at 1 pm as we participate in group singing focused on improving breath control, strengthening of the throat muscles, and improving voice control, volume, and quality!

Parkinson's Sing-a-Long is held at Square Music Co located at 2332 Vickers Drive in Colorado Springs.

An online participation option is available as well.

Square Music Co also offers individual music therapy to work towards motor movement goals along with the voice qualities listed above.

For more information or to sign up, please email heather@squaremusic.co or call/text 719-345-2887.

**Thank You!**

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

**December & January Executive Committee Meetings**

Dec 13th and Jan 17th at 11:00 a.m. at a place to be determined (you will be notified by email)

Contact Jill at president@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 Jill can contact you if anything changes.

**February Newsletter Input Deadline: Jan 20th**

Call or e-mail Julie at: (719)495-1853

db\_mgr@co-parkinson.org.

**HAPPY Birthday**

**DECEMBER BIRTHDAYS:**

Robin Alvord  
Christine Bishop  
Jerry Corns  
Amy Coyle

Pat Dashosh  
Nicole de Naray  
George Guerrero  
Carol Hamill  
Bruce Hughes  
Michelle Kahley  
Jean Koch

Connie Kremer  
Helene Lemire  
Steve Locke  
Clayton McCoy  
Bill Page  
Gregg Pinchuk  
James Rochon

Ted Rudawsky  
Sue Seery  
Janie Shore  
Sukey Skousen  
Marge Sullivan  
Charles Winkler  
Kristin Woestehoff

**JANUARY BIRTHDAYS:**

Lisa Benhammou-Osur  
Ron Bowman  
Doris Briggs  
Bill Byars  
Linda Byars

Linda Christian  
Claudia Christiansen  
Vince Cologne  
Christa Donley  
Hannah Duncan  
Elinor Edwards  
Marv Essing

Sue Geist  
Bill Hicks  
Patricia Kayser  
Bill Koch  
Lynn Kozeliski  
Bob Meredith  
Randy Meyer

Ronald Nickelson  
Mary Ellen Palmer  
Carol Prest  
Tom Prest  
Stanley Rapaport  
Jill Reid  
Mary Roney

Kathi Rudawsky  
Rich Sauvain  
Lonny Seery  
Larry Suhr

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

**A CPF Charitable Giving Opportunity!**

Another reminder about an easy and painless way for you to help CPF. An ongoing charitable giving opportunity each time you order merchandise from Amazon. It's called **Amazon Smile**. Colorado Parkinson Foundation (which includes CSPSG and all its other support groups) is listed with Amazon Smile as a charity that you can generate donations for. Rather than starting your Amazon shopping by pulling up **Amazon.com**, type in **SMILE.AMAZON.COM** instead.

The first time you do that you will have to designate Colorado Parkinson Foundation, Inc. as the recipient of charitable donations based on your purchases. From then on 0.5% of the eligible purchase prices you place through Amazon Smile will automatically generate donations from Amazon to CPF—at no cost to you!

**PD Exercise Classes: 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.ormaadance.org](http://www.ormaadance.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

**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)

**YMCA PD Exercise Classes**

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

Tri-Lakes YMCA: PWR!Moves  
Tuesday & Thursday, 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)

**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!

**One-on-One Physical Therapy for people with Parkinson's Disease and all movement disorders**

Provided by Danielle (Spivey) Mulligan, PT, MSPT who is a Physical Therapist, Certified Vestibular Therapist, LSVT and PWR for Parkinson's  
Location: 5818 N. Nevada Avenue, Suite 325  
Phone Number: 719-365-6871

**PWR!Moves Class**

Skyline Wellness & Aquatics Center has partnered 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.

LOCATION: 2365 Patriot Heights  
(located within Brookdale Skyline, 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

**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 E 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]

**Max Capacity NeuroFitness**

PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training.  
LOCATION: 525 E Fountain Blvd. Suite 150.  
Park on the S. Royer side of the building.  
Boxing: T/Th – 4:00 to 5:00pm  
and Sat – 9:00am to 10:00am  
PWR Boot Camp: M/W – 3:30pm to 4:30pm  
Boxing is free of charge, Boot Camp packages available! Contact Emily Moncheski at (719) 213-3996 or email [emily@maxcapacitypt.com](mailto:emily@maxcapacitypt.com) for info

**Colorado Springs Rocksteady Boxing**

**New!** "Let's kick some PD BUTT!!!"  
Tuesday, Wednesday and Thursday  
10 am – 11:15 am & 11:45 am – 1:00 pm  
Location: Otis Park  
731 Iowa Avenue  
(Free for the month of December)  
For more information, contact Bill O'Donnell at 719-243-9422

**LENDING LOCKER INVENTORY**

If you would like to borrow any of the equipment listed here, please contact:  
Rich Sauvain at 719-337-7911.

**Note:** A stair chair lift system has been donated to us. It's a seat on a rail that takes you up and down a staircase. This one is for a 14 step or less straight staircase with no turns.

3-wheeled walker	1
Back brace	1
Bed cane	3
Bed pan	1
Bed rails	1
Bed risers	1 set
Bedside toilets	6
Canes	7
Crutches	2 sets
Double exercise pedals	1
Exercise bike	1
Lift chairs	2
Lift-ware tremor compensating utensils	1 set
Pick-up assist	6
Shower benches	10
Sock helper	2
Stair chair rail system	1
Swivel seat	1
Toilet arm assist	1
Toilet seats	3
Transport chairs	3
Tub rail	2
U-step	3
Walkers with wheels & seat	12
Wheelchairs	6

**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].

**Coronavirus and Parkinson's Disease**

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

## Phase 1/2 Trial Supports Ketamine for Levodopa-induced Dyskinesia

By Andrea Lobo, PhD – Parkinson's New Today, 9/20/22

Low-dose ketamine safe, well-tolerated — and reduces dyskinesia for 3 months

New trial data suggest that low-dose ketamine — which does not induce anesthesia — may be a potential treatment for levodopa-induced dyskinesia, or involuntary movements, in Parkinson's disease.

"Ketamine was safe [and] well-tolerated with 100% of patients treated with ketamine demonstrating reduction in dyskinesias," PharmaTher Holdings, the Canadian-based company developing the therapy candidate, said in a press release announcing the results of a Phase 1/2 clinical trial.

According to PharmaTher, which specializes in ketamine pharmaceuticals, plans are in the works for further clinical trials.

"Data from the Phase 1/2 study of ketamine [demonstrates] ketamine's safety and tolerability with clinically meaningful efficacy that supports further investigation in a proposed Phase 3 clinical study as a potential new treatment for levodopa-induced dyskinesia in Parkinson's disease patients," said Fabio Chianelli, CEO of PharmaTher.

A presentation of the trial's results, titled "Subanesthetic infusion of ketamine produces long-term reduction in levodopa-induced dyskinesia," was displayed at the Movement Disorder Society (MDS) International Congress of Parkinson's Disease and Movement Disorders, held in Madrid, Spain, Sept. 15–18.

Levodopa, a standard Parkinson's therapy, is a precursor molecule that is converted to dopamine in the brain. It is well-known for controlling Parkinson's disease symptoms such as rigidity and slowness of movement.

However, prolonged use of levodopa may result in spontaneous involuntary movements — a condition called dyskinesia.

PharmaTher recently received a U.S. Notice

of Allowance on its patent application for ketamine as a potential treatment for Parkinson's disease and other motor disorders.

Ketamine (sold as Ketarx) is approved by the U.S. Food and Drug Administration (FDA) as an anesthetic and pain reliever.

### Investigating Ketamine for Parkinson's dyskinesia

In Parkinson's disease, the results of a previous Phase 2 trial (NCT04912115) indicated that low-dose ketamine — which, unlike higher doses, does not induce anesthesia — reduced dyskinesia in patients with the neurodegenerative disorder.

Now, results from the Phase 1/2 clinical trial confirmed that ketamine is safe and well-tolerated. The medication also was found to promote a reduction of dyskinesia in treated patients for at least three months.

The trial was an open-label study to test the safety, tolerability, and pharmacokinetics — i.e., the process of absorption, distribution, metabolism, and excretion of a compound — of low-dose ketamine as a treatment for dyskinesia induced by levodopa. The study also aimed to find the effective dose to use in patients.

A total of 10 people with moderate to advanced Parkinson's were enrolled in the study. The participants received two ketamine intravenous (into-the-vein) infusions within one week. The dose used was 0.30 mg/kg/hour, for five hours per infusion. Nine patients completed the infusion schedule.

Results showed that the maximum tolerated ketamine infusion rate was 0.20-0.30 mg/kg/hr. These doses were not associated with discomfort due to hypertension, also called high blood pressure, or dissociation. Dissociation is a common side effect of ketamine in which patients enter a mental state where they are less aware of their surroundings and start to feel disconnected from the body.

Dyskinesia decreased 51% during ketamine administration, 49% at three weeks after treatment, and 41% at three months. This effect was measured by the Unified Dyskinesia Rating Scale (UDysRS), a scale developed to evaluate involuntary movements.

Ketamine also had effects on Parkinson's symptoms as assessed by the Unified Parkinson's Disease Rating Scale (UPDRS). The UPDRS is the most widely applied rating scale to assess Parkinson's severity and progression.

During ketamine infusion, UPDRS was reduced by 27%. The reduction at three weeks was 28%, and at three months after treatment it was 5%.

No adverse events after the treatment were reported.

"Our results provide further support for the repurposing of sub-anesthetic ketamine for individuals with [levodopa-induced dyskinesia]," the researchers wrote.

Based on these data, PharmaTher is planning a Phase 3 clinical trial to allow Ketarx approval by the FDA for Parkinson's treatment under the 505(b)(2) regulatory pathway. This procedure is a new compound application based partially on previous studies, and offers a faster route for approval compared with traditional regulatory pathways.

"We are now focused on obtaining an agreement with the FDA to pursue approval under 505(b)(2) regulatory pathway with a potential Phase 3 clinical study for ketamine in the treatment of levodopa-induced dyskinesia in patients with Parkinson's disease," Chianelli said.

Ketamine also is believed to have a positive impact in pain relief and to offer additional benefits in easing depression, another frequent symptom in Parkinson's patients.

## Potluck Favorites - Shakin' & Bakin' Cookbook!!!

Another reminder about a new CSPSG endeavor to add new recipes to the original cookbook the support group created years ago. Sherry Whitaker has volunteered to lead this effort to add your favorite recipes – old or new family recipes, newly discovered favorite recipes, etc.

We only want recipes that you have actually tried and liked – not ones that you think should be good but haven't tried or tasted. They don't have to be gluten-free or Keto. We will, however, indicate which ones fit those categories. We will also add a conversion table that will tell you how to convert ordinary recipes into gluten-free or Keto recipes if you would like to know how to do that.

*All favorite recipes are welcome*

*Send them to Sherry at [project@co-parkinson.org](mailto:project@co-parkinson.org).*



## The Power of the Voice: "Think of Singing as an Exercise"

By Sarah McGrath – Parkinson's Life, 8/25/22

**US-based professor Elizabeth Stegemöller shares how she became "hooked" on helping others through music therapy – and how singing may help people with Parkinson's to manage their symptoms**

**Please tell us a bit about yourself and your career in music therapy.**

I am an associate professor in the Department of Kinesiology and director of the Graduate Neuroscience Program at Iowa State University, US. I'm also a music therapist. I've always loved music – I've been part of a band and a choir, and I've played the piano for years. I didn't like to perform, so helping people through music seemed perfect.

However, it wasn't long after starting music therapy that I realized there wasn't much understanding about how music worked. I saw many amazing things during my undergraduate course in neuroscience, and that's when I knew I wanted to research how music therapy influences the brain.

During my PhD, I began working in a lab that conducted research on Parkinson's. At the same time, I was working with music therapy groups at a Parkinson's clinic, and I was hooked. I have been working with people with the condition ever since, trying to understand how music helps their symptoms.

**How can music therapy support people with Parkinson's?**

Parkinson's affects how a person controls their muscle activity – which is why people with the condition are encouraged to exercise. This symptom can impact one's ability to breathe and swallow. People with Parkinson's may experience that some thinner liquids and foods can seep through into the lungs when swallowing, because the timing and force of the muscles that control swallowing are impaired. This is further intensified by the reduced ability to cough and clear the lungs.

Singing exercises the muscles that control breathing and uses the same muscles involved in swallowing. So, participating in singing is like exercise for these smaller muscle groups that are sometimes forgotten but are really important for a person's health.

Here at Iowa State University, we are running our third funded study on the link between singing and Parkinson's symptoms. This one explores the effects of singing on stress, inflammation, swallowing, and voice and respiratory control. By conducting a 16-week group therapeutic singing program, we hope to learn more about the underlying physiology of why symptoms may improve from exercising the voice.

**What has been most rewarding about your work?**

The most rewarding part is being able to help others. I also enjoy receiving feedback from participants who have taken part in my studies. They can tell me exactly how singing affects them, and then I can develop a research study based upon their experiences.

There is also something about singing with a group of people that builds community. I was afraid after COVID - 19 that my singing group wouldn't continue to grow – but thankfully, it has.

**What would you say to someone with Parkinson's who is nervous to start singing?**

Think of singing as an exercise. You would not start exercising with the goal of running a marathon – but rather because it is good for you. There are no expectations to be the next opera star. Just sing!

## How Not to Lose Sleep Over Parkinson's Disease

By European Parkinson's Disease Association, Nov. 25, 2021

*Did you know that 90% of people with Parkinson's suffer sleep disturbance? We hear from an advanced nurse practitioner, a physiotherapist and a person with Parkinson's about why good sleep hygiene matters*

"Have you ever been fishing and caught a fish – an it's landed, flipping around, on the bank?" asks Matt Eagles. He is describing his typical night in bed with Parkinson's disease. "I can be very, very still, then start flapping. My wife leans over and puts her hand on my leg or my tummy and, usually it stops. During that time I'm semiconscious, but it's not a good quality of sleep."

Throughout his 46 years of having Parkinson's, Matt has tried many ways of getting to sleep. Like 90% of people living with the condition, he suffers from sleep disturbance brought on mainly by troubles with movement when lying in bed – although he admits things are not as bad as they once were. His limbs can go from being highly active, to completely rigid. "Trying to move your legs in the middle of the night can be like you've got somebody else's legs, or you're stuck in treacle, frozen in your bed," he says.

Years of trial and error have taught him what makes a difference. He is now a firm advocate of good sleep hygiene which, these days, involves going to bed between 22:30 to 23:00 every night, and waking up at 7:30. He aims to get at least seven hours of sleep a night.

**What is sleep hygiene?**

To ensure we get a good night's sleep, the human body has an internal alarm clock that regulates our sleep-wake cycle. Keeping to a regular night-time routine, creating an ideal sleeping environment and getting into healthy habits during the day can all help you develop good sleep hygiene.

Brian Magennis, an advanced nurse practitioner in Parkinson's disease and movement disorders, thinks sleep hygiene is vital to improving your sleep. "It's one of the most important things I consider when assessing the sleep problems of a person who has Parkinson's. There are other things like insomnia, urinary issues, movement problems and mind disturbances – but sleep hygiene is an obvious first step," he says.

"If you get this right, you'll be on your way to improving the quality and quantity of your sleep. If you still have problems, you need to talk to your doctor or neurologist, who can help adjust your medication as getting the timing and dosage of this right is essential, too."

**How to get a good night's sleep**

General habits like having regular mealtimes and going to bed at the same time every night, keeping alcohol and caffeine to a minimum and ensuring your bedroom is cooler during the night have all been shown to improve the quality and quantity of your sleep. Sleeping in total darkness and making sure you have the

right bedding can also be important as Matt testifies. "We have black-out curtains in the bedroom which really help," he says. "And a good mattress is essential. I have a memory foam mattress which is very comfy. The only issue for me is that it mimics my body shape and sometimes it means when I want to turn over, I have to climb out of the dip I've just created for myself!"

One thing that's not a healthy habit is exposure to blue spectrum light before bedtime. Computer monitors, smartphones, tablet screens and televisions all produce light in the blue spectrum, which tricks the brain into believing it's daytime, thereby reducing the production of melatonin – a hormone that helps you sleep.

Getting your nutrition right is also key to a good night's sleep. It's important not to eat too late and to ensure you don't have too many high-protein food, or carbohydrates, which can sometime interfere with the absorption of Parkinson's medications or be associated with poor sleep quality.

A good dose of exercise can also aid sleep quality. Physiotherapist Josefa Domingos helps people with Parkinson's to improve their functional wellbeing. She says: "During the day it's important to get proper aerobic exercise when you have Parkinson's – not only because it potentially helps delay progression of the disease, but also because it's been shown to improve sleep and relieve a variety of motor and non-motor symptoms." Stretching and slow mobility exercises before bed can also help in reducing rigidity and some discomfort during the night too, according to people with Parkinson's.

For Matt, improving his sleep hygiene has helped to boost his energy and cope better with the condition. "Parkinson's is exhausting," he says. "If you wake up and you're tired, apathy can kick in and you really don't feel like doing anything. I think sleep is so important to Parkinson's."

**7 ways to improve your sleep**

1. *Keep to a regular routine*, including a regular pattern of meals, exercise and going to bed and getting up – it will help your body clock get into the habit of sleeping.
2. *Get your nutrition right* – regular mealtimes & a well-balanced Mediterranean-type diet has been shown to have therapeutic effects on sleep.
3. *Stay hydrated during the day*, depending on your body type and needs, and avoid caffeine and alcohol which are stimulants.
4. *Exercise on a regular basis* – how much you should do depends on your personal fitness and circumstance.
5. *Sleep in a cool, dark room* – but take care to have some kind of lighting should you need to get up in the night.
6. *Upgrade your sleeping accessories* – pillows, mattresses, sheets can all make the difference between a comfortable & uncomfortable night.
7. *Avoid electronics* at least 1 hour before bed. Computer monitors, smartphones, tablet screens and televisions all produce blue spectrum light, which mimics daylight.

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**PARKINSON'S PERSPECTIVE**

**December 2022  
& January 2023**

# Coming Events

See inside for more information

**December 10<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Christmas Party!!!!

**January 14<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Deep Brain Stimulation;  
**Speaker:** Dr. Amit Ayer MD - Neurosurgeon

**February 11<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Breakout Sessions  
Moderators: Steve Locke – Parkinsonians; Jill Reid & Julie Pfarrer – Caregivers

**March 11<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Parkinson's 101;  
**Speaker:** Jill Reid, Educational Outreach

**More useful websites:**

<https://parkinsonsnewstoday.com>; [www.parkinsonrockies.org](http://www.parkinsonrockies.org); [www.parkinson.org](http://www.parkinson.org); [www.nwpf.org](http://www.nwpf.org); [michaeljfoxfoundation.org](http://michaeljfoxfoundation.org);  
<http://caremap.parkinson.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); [www.parkinsonheartland.org](http://www.parkinsonheartland.org);  
<https://www.pdself.org>; [https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo\\_C](https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C); [pmdalliance.org](http://pmdalliance.org);