



Parkinson's Perspective

Newsletter of the Colorado Springs Parkinson's Support Group
Colorado Parkinson Foundation, Inc.
www.co-parkinson.org | (719) 884-0103

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The Colorado Springs Parkinson's
Support Group (part of CPF) meets
10AM, the first Saturday of each month
at the Central United Methodist Church,
4373 Galley Rd, Colo Spgs, 80915

(with exceptions to be noted
in this newsletter)

NEW MEETING LOCATION & DATE!

Reminder that our monthly meetings have been moved to Central United Methodist Church and changed to the first Saturday of each month

June Meeting: Saturday, June 3rd – 10:00 am – 1:30 pm

We will be Zooming and recording this meeting

Location: Central United Methodist Church, 4373 Galley Road—just east of Murray Blvd.

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 Central United Methodist Church.



June Program: A New Study on the Effects of a LCHF/Ketogenic Diet on Cognition, Sleep Quality, Fatigue and Quality of Life in Parkinson's Disease

Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP

About the Speaker: Dr. Tidman completed a Bachelor's degree in Occupational Therapy at Colorado State University, a Master's degree from the University of New Mexico, and her Doctorate in Health Science from AT Still University Doctorate in Health Science program in 2011. She is currently working on certification as a Metabolic Health Practitioner with the Society of Metabolic Health Practitioners and certification as a Nutrition Practitioner with the International Nutrition Network.

Dr. Tidman has 40 years of experience as an Occupational Therapist in Pediatrics, Intensive care, and Adult Physical Rehabilitation, emphasizing Neurology and Neurosurgery Rehabilitation. She owned and directed Tidman Therapy Services, a pediatric rehabilitation center, for 22 years, served patients with neurological and neurosurgical disorders in a Neurosurgery Intensive Care Unit for 20 years, and has expertise in all areas of inpatient and outpatient Adult Physical Rehabilitation with specialized expertise in Parkinson's Disease, Stroke and Brain Injury.

In 2019, Dr. Tidman conducted a field research study for the CPF entitled "The effects of a community-based exercise program on mobility, balance, cognition, ADS's and QOL in PD: a community partnership pilot study" which was published in February 2020 in the Journal of Neurodegenerative Disease Management.

During her professional experience, Dr. Tidman has published several professional journal articles, is a contributing chapter author for an Occupational Therapy textbook, and has published the first two books in a series of educational guides for families of patients with neurological conditions. "Families in the ICU: A Survival Guide" was published in 2014, and the sequel book, "Families in the Rehab Center and Beyond" was published in 2017.

Dr. Tidman is an Adjunct Professor for A.T. Still University's Doctorate in Health Science program, Nova Southeastern University's Ph.D. in Occupational Therapy program, and Colorado Christian University's Masters in Healthcare Administration program. In addition to presenting at professional conferences, Dr. Tidman has particular interest in healthcare delivery and reform, patient-centered care, and instruction for doctoral students on professional writing for publication.

The program will be followed by a potluck.

The June Potluck Main Dish – Sandwich Fare!

Picnic lunch items such as sandwiches, veggies and dip, etc. If you would like to sign up to be a provider of the main dish, a side dish or dessert for the May meeting, you can contact Bill Hicks at [redacted] or potluck@co-parkinson.org, no later than Wed. May 31st 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!

The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



BREAKING NEWS: Starting with our June meeting, we will meet at the Fellowship Hall of Central United Methodist Church located at 4373 Galley Road, just east of Murray Blvd. The church is on the south side of Galley Road, between a strip mall to the west and an Ent Federal Credit Union building to the east. The parking lot and the front door are on the south side of the church. Fellowship Hall is the first room on the left when you walk through the front door, making it a much shorter walk than

we've had in recent times. There is a **second big change starting with the June meeting, though: we will have to meet on the FIRST Saturday of each month**, rather than the second, since our new home is already fully booked on the second Saturday. Starting with our June meeting, we will meet in our new home and on a new Saturday: Central United Methodist Church at 10 am on the first Saturday of the month (June 3rd for our next meeting). If you lose this newsletter, remember to check out our website, co-parkinson.org, for these same details.

It never ceases to amaze me that, even after being around people with Parkinson's for 30 years, caregiving for several people with Parkinson's, and teaching Parkinson's caregiving for many years, I always learn something new when we have break-out sessions. During the May caregivers break-out session, I heard about the Frazier Free Water Protocol that is being applied to one of our members who is in rehab at the Center at Centennial (by the way, we've been hearing good reports lately about that rehab center—they've apparently come to understand the needs of people with Parkinson's). I did a little more research on the protocol, and here's what I've learned.

People with swallowing problems (and people with Parkinson's often have them at some point in the disease progression) are likely to aspi-

rate bacteria that can cause pneumonia. In fact, aspiration pneumonia is the leading cause of death in people with Parkinson's. This is not a trivial matter—you need to take it very seriously.

The Frazier Free Water Protocol requires good oral care, first and foremost. Did you know that our mouths are the filthiest openings in our bodies, chock full of nasty bacteria, without good oral care?? With good oral care and the rest of the protocol, a person who aspirates his own saliva will not get aspiration pneumonia while the person who doesn't have good oral care and aspirates his own saliva will!!! That's because the good oral care and the rest of the protocol ensure that your mouth is free of bacteria before normal water is swallowed. Our lungs can safely absorb small amounts of saliva and tap water if our mouths are clean. At the Center at Centennial, our member eats a meal with thickened liquids only, uses a Sonic Care toothbrush and Water Pik after the meal, and waits 30 minutes before swallowing normal (unthickened) water. The 30-minute wait period allows any particles of food still in the mouth to be swallowed through normal tongue and swallowing actions. Our member takes small sips of the water at a time, but he says it is a wonderful treat to be able to drink unthickened water again. Between meals, he can have only water (no coffee or other drinks) so as not to reintroduce bacteria into his mouth.

It sounds pretty straight-forward. BUT DON'T START THIS PROTOCOL until you have been cleared by a speech therapist who is trained in the Frazier Free Water Protocol and who will assess whether you are a good candidate for the protocol. If you are, therapist can train to do it safely.

This month's comedy recommendation is *Some Like It Hot*, starring Marilyn Monroe, Tony Curtis, and Jack Lemmon. A classic comedy, this movie is sure to make you laugh—which is the whole point of watching a good comedy. Enjoy!

Thank You!

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

June Executive Committee Meeting

June 6th 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.

July/August Newsletter Input Deadline: June 16th

Call or e-mail Julie at:

db_mgr@co-parkinson.org



Robert Adams
Donald Ader
Penny Austin
Deloit (Dee) Beatty
Mary Margaret Brummeler
Mark Finger
Carla Holland

Lynette Holland
Mike Koloski
Charles Kovac
Donna Kring
Mark Lekarczyk
Michael McCraley
Rusty Merrill

Suzanne Metzler
Marty Miller
Art Moore
Dave Moross
Ronald Morris
Bill Noe
Jon Nordby

Ronald Null
Patricia Plank
Larry Rush
Jean Saunders
Mary Sauvain
Daniel Skousen
Lauren Sloan

Cindy Stempson
John Sullivan
Celina Terrell
Sherry Whitaker

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

Recipe of the Month: Roasted Vegetable Frittata

Our low carb/good fat ketogenic study that was completed in 2021 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 caregivers who chose to change their diet along with their Parkinsonian). 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. **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.**

Ingredients

1 small zucchini, 1" diced
1 red bell pepper, seeded & 1 1/2" diced
1 yellow bell pepper, seeded & 1 1/2" diced
1 red onion, 1 1/2" diced
1/3 C olive oil
Kosher salt & black pepper
2 tsp minced garlic (2 cloves)
12 extra large eggs
1 C half & half
1/4 C grated parmesan cheese
1 Tbl unsalted butter
1/3 C chopped scallion, white & green parts (3 scallions)
1/2 C grated gruyere cheese



Directions

1. Preheat oven to 425 degrees.
2. Place zucchini, peppers & onion on a sheet pan.
3. Drizzle with olive oil, sprinkle with 1 1/2 tsp salt & 1/2 tsp pepper and toss well.
4. Bake for 15 minutes. Add garlic, toss again & bake for another 15 minutes. Remove from oven & turn oven to 350 degrees.
5. Meanwhile, in a large bowl, whisk together the eggs, half & half, parmesan, 1 tsp salt & 1/2 tsp pepper.
6. In a 10" ovenproof saute pan, melt butter & saute scallions over medium-low heat for 1 minute. Add roasted veggies to pan & toss with scallions. Pour egg mixture over veggies & cook for 2 minutes over medium-low heat without stirring. Transfer the pan to the oven & bake for 20-30 minutes, until puffed & set in the middle.
7. Sprinkle with gruyere & bake for another 3 minutes, until cheese is just melted. Cut into 6-8 wedges & serve hot.



Ask the Doctor!

Dr. Brian Grabert, MD, a Parkinson's Specialist



Dr. Grabert has generously agreed to answer your questions pertaining to Parkinson's Disease each month in our new newsletter column called "Ask the Doctor!"

If you have questions you'd like to submit to Dr. Grabert, send them to our newsletter coordinator, Julie, at db_mgr@co-parkinson.org.

Question 1 A. Is carbidopa/levodopa [CD/LD] prescribed for Essential Tremor?

If the clinician is quite convinced that one has Essential Tremor [ET], the answer is No. Because it is not always easy to classify tremors in an office setting, CD/LD is sometimes prescribed in an attempt to rule out Parkinson's disease. Parkinson's tremor is typically a resting tremor and Essential Tremor is usually a postural tremor with an action component. A substantial portion [> 20%] of Parkinson patients may have both a resting and an action/postural tremor. The proposed definition of ET requires at least a 3-year history of tremor and excludes isolated head and isolated voice tremors. A 3-year history is included to reduce the odds of subsequent development of other neurological signs (e.g., dystonia, Parkinsonism, or ataxia). Even with this safeguard, patients with ET may ultimately develop other signs, at which time they would have a combined tremor syndrome, not 'pure' ET. In other words, ET is a syndrome that may evolve into another tremor syndrome." [from Consensus Statement on the Classification of Tremors. From the Task Force on Tremor of the International Parkinson and Movement Disorder Society :Mov Disord. 2018 January; 33(1): 75-87.]

Question 1 B. Are balance, speech, and gait affected as ET progresses?

Longitudinal studies of individuals with ET, do show development of gait and balance symptoms as well as speech abnormalities in some patients with ET

but not all. If this occurs then the diagnosis as noted above would change to a "Tremor Syndrome". Additional work up would likely be required at this time. A DAT scan may be very helpful when there is a 'diagnostic dilemma'. A normal DAT scan should be present in ET or ET syndromes and dystonic tremor.

Question 2: I take CD/LD every hour or so which is a burden. When recently hospitalized it was impossible to get my CD/LD on this schedule. Is Duopa an option?

This situation is a complex management problem. The requirement for frequent dosing relates to the very short plasma half-life of L-Dopa, which is approximately 90 minutes. When an individual's plasma concentration of L-Dopa falls below a certain level then they experience OFF symptoms of rigidity, immobility or severe bradykinesia, and return of tremor if present. If they take more CD/LD at each dose to keep the plasma concentration higher then severe dyskinesia is likely the result. I assume COMT inhibitors have been tried to extend the half-life of L-Dopa? Extended release CD/LD [Rytary] is often helpful but not always successful. DBS with STN as a target has been the answer for many patients with PD who require frequent dosing. Duopa Pump [a tube inserted in the duodenum and connected to a pump] is a good option for this situation if one is not a DBS candidate. However, it requires a very coordinated team of a Neurologist, Nurse specialist, and Gastroenterologist to manage all aspects of care. I cannot speak to the current availability of such a team in Colorado Springs. It was not available at the time I retired in March 2022.

Question 3. My spouse with Parkinson's [PD] seems depressed all the time. Is this caused by PD? Would an antidepressant help?

Depression is more common in PD than age matched controls and has a prevalence rate of 35-45 % in PD. Depression is not likely due to a reaction to the diagnosis and progression of PD. If this were the case you would expect an association between severity of PD and incidence of depression.

Studies have shown there is no significant association between disease severity and depression. Depression is often present before the onset of PD symptoms. In fact the risk of developing PD is strongest in the first few years after someone is diagnosed with depression. The association between depression and PD likely reflects shared etiologic factors [neurodegeneration] mimicking a causal relationship. Depressed patients with PD are less likely to report feelings of guilt or failure and tend to have higher rates of anxiety. Depression in PD is under-diagnosed and under-treated. Psychotherapy called 'cognitive-behavioral therapy', medications or a combination of both are warranted if depression is debilitating and affecting quality of life. Depression should be screened at all office visits. In my former practice, I used the GDS 15 [Geriatric Depression Scale - 15 questions]. It has excellent psychometric properties, is an excellent screening tool and available in the public domain [copyright free]. Evidence suggests that nortriptyline, venlafaxine, paroxetine, and citalopram may be useful medications in treating depression in PD.

Question 4. My Husband had surgery under general anesthesia a year ago with worsening of PD symptoms post-operatively. He has not returned to pre-operative baseline. What can I do?

Cognitive Decline has definitely been associated with general anesthesia but in my experience and after a brief Pubmed search, irreversible decline in PD motor symptoms has not been reported. In fact, a study in Parkinson's and Related Disorders in July 2021 from the Mayo Clinic compared 431 new cases of Parkinson's disorders with similar number of controls and found no association between general anesthesia and development of a PD related disorder. This would imply that general anesthesia should not create or worsen the motor symptoms of PD. It may be the natural progression of PD? If your husband had Gastrointestinal Surgery, drug absorption could be affected? If it was orthopedic surgery, deconditioning may be present? I don't have a good answer!

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.



Upcoming Michael J. Fox Event in Denver – June 24th –

Parkinson's IQ + You is a series of free in-person events designed to empower patients and care partners to manage the disease, learn about the latest research and connect with local resources.

These events are fully accessible and designed for people at every stage in their journey with Parkinson's.

To ensure a spot, we encourage early registration.

For more information and to register for the Denver event, go to <https://www.michaeljfox.org/parkinsons-iq-you>

Sad News



Charles E. "Gene" Ireland passed away on May 6, 2023. Gene was born and raised in Cincinnati, Ohio, and graduated from the University of Cincinnati with a BA in Radio and Television Engineering in 1963. Gene worked in broadcasting until he started his 20-year US Air Force career as a communications officer. While serving the Air Force he earned his Masters Degree in Business from the University of Utah extension in Germany. After retiring as a Lt. Colonel in 1984 Gene enjoyed his civilian career with several aerospace contractors and finally his own business as a consultant. Gene often said he would "work until it wasn't fun anymore." He retired in 2012 after the onset of Parkinson's disease when he could no longer do the many things he enjoyed.

Gene is survived by his wife, Judy, and two of their three children Kelley Durham and Ronald Ireland, three grandchildren and one great grandchild. Gene will be laid to rest at Pikes Peak National Cemetery with full military honors.

Other Local Support Groups:

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 bbhicks54@gmail.com or [REDACTED] to let her know you are coming.

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].

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 jimdjs22@gmail.com or 719-660-7275.

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.

Other Opportunities:

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

Cognitive-Linguistic Deficits

Aphasia following stroke

Swallowing

- Neuromuscular Electrical

Stimulation Therapy

- Respiratory Muscle Strength

Training

For more information, 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.

PD Exercise Classes:

Caregivers/Care-partners Exercise Class

This exercise class involves strength training and cardio circuits modifiable for any person!

When: Every Friday at 9:30am for 45 mins

Where: Movement Arts Community Studio 525 E. Fountain Blvd (GPS: 150 S. Royer St)

Price: \$20 Drop-in/\$10 a week (\$40 total monthly pay!). Limited space available so please contact Ashley Szekeres, NASM CPT at guardianfitlc@gmail.com or by calling 708-846-0155 before coming.

Rock Steady Boxing – Boxing with Love

New Rock Steady Boxing for folks with Parkinson's Disease at the Boxing with Love Gym

When: Tuesdays @ noon

(please come 15 min early if your first time)

Where: 1710 Briargate Blvd. Suite 100 (Next to Dicks Sporting Goods at the Chapel Hills Mall). For more info contact Karen Bishop PT, DPT at love@rsbaffiliate.com

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!

Colorado Springs Rocksteady Boxing

"Let's kick some PD BUTT!" Tues, Wed, & Thurs: 10am–11:15am & 11:45am–1:00pm
Location: Otis Park. 731 Iowa Ave. For more info, call Bill O'Donnell at 719-243-9422

Max Capacity NeuroFitness

PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training.
Where: 525 E Fountain Blvd. Suite 150. Park on the S. Royer side of the building.
Boxing: T/Th–4 to 5pm & Sat–9 to 10am
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 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.
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

Falcon Exercise Group

Mon and Fri –11:00 – 12:00 noon, Grace Community Church. For more information contact Catherine Reed at [REDACTED]

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 Tues and Thur from 12:30-1:30pm. For more info contact: Karisa Dreyer at (719) 867-4658

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 11:00am 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 and click on "Dance for Parkinson's" under the "Outreach" tab to get the Zoom link. Contact Laura at 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

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.

Where: 5818 N. Nevada Avenue, Suite 325
Phone Number: 719-365-6871

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. Cost: \$10 a class

When: Every Friday at 10:30 am

Where: 525 E Fountain Blvd. MACS–corner of Fountain & Royer

AAN 2023: P2B001 Controls Symptoms with Less Sleepiness

By Marisa Wexler, MS – Parkinson's News Today, 4/28/23

FEWER PARKINSON'S PATIENTS ON PHARMA TWO B THERAPY HAD ORTHOSTATIC HYPOTENSION

The investigational combination therapy P2B001 was similar to Mirapex (pramipexole) at controlling symptoms of Parkinson's disease in a clinical trial. But patients treated with P2B001 were less likely to experience sleepiness and fewer had orthostatic hypotension (a sudden drop in blood pressure on standing) as side effects.

Lawrence Elmer, MD, PhD from the University of Toledo, presented the trial's findings at the American Academy of Neurology (AAN) annual meeting, held this week virtually and in Boston, in a talk titled, "P2B001 (low dose combination of extended-release pramipexole and rasagiline) versus titrated extended-release pramipexole in the management of early Parkinson's disease: Exploratory findings from a randomized, controlled trial."

The study was funded by P2B001's developer Pharma Two B. The company is planning to apply for approval of P2B001 in the U.S. this year, based on the data.

"We believe the data presented at AAN this year continue to support the development of P2B001 as a potential first-line therapy for people with" Parkinson's, Dan Telemann, president of Pharma Two B, said in a company press release.

Parkinson's is marked by low levels of the brain signaling molecule dopamine. P2B001 contains a fixed-dose combination of two medications in extended release form — pramipexole, which mimics dopamine activity in the brain, and rasagiline, which increases dopamine levels by blocking a protein that normally helps recycle it. Extended release means the medicine is formulated so it's released slowly.

Both medications are approved individually to manage Parkinson's symptoms. Pramipexole is marketed by Boehringer Ingelheim as Mirapex; Teva sells rasagiline under the brand name Azilect.

In animal studies by Pharma Two B, the combination of the two medicines showed synergistic effects. "The sum of the parts is much greater than the individual component themselves," Elmer said, noting

P2B001 contains both therapies at doses lower than what's used in the single-medication treatments.

EXERCISE, ESPECIALLY MIND-BODY, EASES MOTOR SYMPTOMS

TESTING P2B001 AGAINST SEPARATE MEDICATIONS, EXTENDED RELEASE MIRAPEX

The company ran a Phase 3 clinical trial (NCT033295508) that enrolled more than 500 people with recently diagnosed Parkinson's who hadn't yet begun treatment. They were divided into four groups and treated for 12 weeks, about three months.

One group received P2B001 and two other groups got pramipexole or rasagiline separately at the same dosage in the combination therapy. The fourth group was treated with the approved extended release formulation of Mirapex. In this group, the dosage was adjusted based on patients' response and tolerability.

Top-line results, reported in late 2021, showed P2B001 was more effective than either of its individual components at controlling symptoms.

At AAN, Elmer presented a comparison between the 157 participants treated with P2B001 and the 77 given Mirapex.

Demographics and clinical characteristics in both groups were similar at the study's start. The average age was in the early 60s, about two-thirds of patients were male, and more than 95% were white. The average time between getting diagnosed with Parkinson's and entering the trial was about half a year.

At the start, the average total score on the Unified Parkinson's Disease Rating Scale (UPDRS) — a global measure of symptom severity in Parkinson's — was about 30 points in both groups. After 12 weeks, the average score decreased by about 8 points in both groups, reflecting less severe symptoms. While there was some variability in response to both medications, about three-quarters of the patients in both groups improved by more than 4 points on the motor UPDRS score.

All in all, both P2B001 and Mirapex showed "comparable efficacy," Elmer said, adding, for clinicians, the take-home message is "if you see a pa-

tient newly diagnosed with Parkinson's disease, this [P2B001] may be an option if indeed it is approved by the FDA."

COMPARING EFFECTS ON SLEEPINESS

Safety data showed that markedly fewer patients on P2B001 than Mirapex had orthostatic hypotension (2.7% vs. 12.2%) or sleepiness (14.7% vs. 31.1%). Over the 12-week study, dopamine-related side effects were significantly less common with P2B001 (44.7% vs. 66.2%), statistical analyses showed.

At a separate poster at AAN, researchers presented detailed analyses of the effect of P2B001 on sleepiness, a common side effect of dopamine agonists like Mirapex in a poster titled, "P2B001 significantly reduced risk of daytime sleepiness: results from a randomized controlled phase 3 trial with active pramipexole arm in early Parkinson's disease (PD)." Daytime sleepiness was assessed with a standard test called the Epworth Sleepiness Scale (ESS). At the start of the study, the average ESS score was about 5.5 points in both groups. After 12 weeks, the average score was about the same with P2B001, but increased to more than 8 points with Mirapex, reflecting more sleepiness.

Most patients (more than 85% in both groups) had ESS scores of 10 or lower at the start of the study, which generally reflects daytime sleepiness that doesn't cause significant daily problems.

Among those starting with low scores, ESS scores increased past 10 in fewer than one in 10 (8.5%) of the patients given P2B001 after 12 weeks of treatment. More than one in three (35.7%) patients on Mirapex experienced new significant sleepiness.

"Patients treated with P2B001 developed significantly less new-onset [excessive daytime sleepiness] and fewer sleepiness-related [side effects]," the researchers said.

"The results of this Phase 3 trial represent positive news for newly diagnosed [Parkinson's] patients, as there has been a clear unmet need for an initial, once-daily treatment that has demonstrable efficacy and safety, requires no titration, and has a lower incidence of excessive daytime sedation compared to" Mirapex, Elmer said.

High-Intensity Boxing Program Seen as Safe, Feasible in Parkinson's

By Marisa Wexler, MS – Parkinson's News Today, 5/9/23

9 OF 10 PATIENTS REPORTED LESS SEVERE SYMPTOMS AFTER TRAINING: STUDY

A high-intensity boxing program can be a safe way for people with Parkinson's disease to exercise both mind and body, according to a new feasibility study.

Nine of the 10 patients in the study reported less severe symptoms after taking part in the program for about four months.

Researchers noted that the study's participants had an average age of 60. While the workouts were high intensity, the boxing was non-contact.

The work "provides a depth of feasibility and safety data, methodological detail and preliminary efficacy for periodized non-contact boxing that is not described elsewhere," David Blacker, a professor at the University of Western Australia and co-author of the study, said in a press release, adding, "It provides a useful basis for fu-

ture studies of boxing training for" Parkinson's.

The study, "[FIGHT-PD: A feasibility study of periodised boxing training for Parkinson disease](#)," was published in PM&R.

3-MONTH BOXING PROGRAM FOUND TO EASE MOTOR, NONMOTOR SYMPTOMS

BENEFITS OF EXERCISE SEEN FIRST-HAND BY ONE RESEARCHER

Physical exercise has a wide range of well-established health benefits. For people with Parkinson's, exercise may help ease motor symptoms, as well as aid in maintaining physical function abilities.

Blacker, who lives with Parkinson's, noted that he's experienced the beneficial effects of exercise firsthand.

"Exercise has significantly helped to reduce my symptoms," Blacker said.

In recent years, boxing has become a popular format for regular exercise

among people with Parkinson's disease. However, there's minimal published research on the safety or feasibility of these sorts of programs.

To learn more, scientists conducted a study called FIGHT-PD — short for Feasibility of Instituting Graduated High Intensity Training in Parkinson's disease.

"There is a dearth of high-quality feasibility, safety and efficacy data on boxing training for [Parkinson's]. FIGHT-PD aimed to examine these features in a periodized boxing training program featuring high intensity physical and cognitive demands," the researchers wrote.

The study enrolled 10 people in the early stages of Parkinson's who were able to safely perform intensive exercise. All of the participants completed a 15-week boxing program, with three hour-long sessions per week. Each session included a warm-up period followed by rounds of non-contact boxing using a training device.

The first five weeks of the program focused on training boxing technique. The next five weeks focused on increased intensity, and the final five weeks focused on tasks that required substantial mental focus in addition to physical activity.

All of the patients stuck with the entire 15-week program. Of a total of 360 training sessions planned for the 10 patients, only 12 sessions — less than 3% — were missed; four absences were due to minor injury.

Scores on the Unified Parkinson's Disease Rating Scale (UPDRS), a measure of symptom severity, showed improvement after the boxing program in all but one of the participants.

Overall, according to the team, these findings suggest that high-intensity boxing programs are safe and doable for people with Parkinson's. The results provide a basis for further research on these types of exercise programs.

Inflammation Elevated in Brains of Newly Diagnosed Patients

By Marisa Wexler, MS – Parkinson's News Today, 3/3/23

STUDY SUGGESTS SUCH INFLAMMATION MAY BE EARLY DRIVER, NOT BYPRODUCT, OF DISEASE

Inflammation in the brain is detectable at the earliest stages of Parkinson's disease and even before treatment is begun, a new study reports.

The findings support the idea that inflammation may be an early driver of Parkinson's itself, rather than merely a byproduct of the disease's neurodegeneration, the researchers noted.

"An association between inflammation and Parkinson's is well known, but a fundamental question remains unanswered: Does inflammation play a role in the onset of Parkinson's, or is it a byproduct of the disease itself?" Talene Yacoubian, MD, PhD, a professor at the University of Alabama at Birmingham (UAB), said in a university press release. "Our findings show that inflammation is present in the early stages of the disease."

The study, "**Brain and Systemic Inflammation in De Novo Parkinson's Disease**," was published in *Movement Disorders*.

PARKINSON'S PATIENTS TUNE INTO MEDRHYTHMS' MUSIC THERAPY

Increased inflammation in the brain is a well-established feature of Parkinson's and many other neurological disorders. However, an important question remains largely unanswered: Does inflammation drive Parkinson's disease, or is it the other way around?

One of the major obstacles in addressing this question, the researchers noted, is that studies assessing brain inflammation in Parkinson's often include people with a wide range of disease severity and duration and who already are on medications that may alter inflammatory status.

In this study, Yacoubian and colleagues at UAB conducted clinical and imaging evaluations of 58 people (33 men and 25 women) who had been diagnosed with Parkinson's less than two years prior and had not yet begun treatment. Their mean age was 66.1 years.

"Enrolling study subjects early in their disease progression was significant. We wanted to see if inflammation was present early on in the disease, before patients had even begun on Parkinson's medications," Yacoubian said.

Compared with 62 age- and sex-matched people without the disease (controls), Parkinson's patients showed significantly worse scores on measures of motor function and cognition. This was generally consistent with the symptoms of the disease.

ANALYZING BLOOD, FLUIDS

To assess inflammatory status, the researchers first analyzed participants' blood samples, as well as samples of the fluid around the brain and spinal cord from a subset of participants.

Results showed that Parkinson's patients had significantly higher levels of certain inflammatory molecules and inflammatory T-cells relative to controls. Pa-

tients also had lower counts of regulatory T-cells (Tregs), a specific group of immune cells with anti-inflammatory activity.

"This decrease in Tregs and increase in non-Tregs suggests a deficient anti-inflammatory response, which may promote chronic inflammation" in Parkinson's, the researchers wrote.

The scientists also assessed inflammation by using positron emission tomography (PET) imaging to detect TSPO, a protein produced by inflammatory brain immune cells called microglia, as well as by other types of inflammatory immune cells.

The scientists were the first in the U.S. to use 18F-DPA-714, a marker used to detect TSPO on PET imaging that was developed in Europe. The marker is injected into a person's bloodstream, and it causes tissue that's dense with TSPO protein to glow on the PET scan.

"Our multimodal study provides further evidence that TSPO signal as measured by 18F-DPA-714 is a marker of inflammation," Yacoubian said.

Data showed increased TSPO levels in most brain regions among Parkinson's patients relative to controls, such as in the thalamus, a region that helps relay signals through different parts of the brain.

"We found elevations in TSPO binding in untreated subjects at early stages of Parkinson's, indicating the presence of inflammation. Our data clearly demonstrate that increased TSPO binding is present in Parkinson's independent of treatment effects," Yacoubian said.

Additional analyses in Parkinson's patients showed that higher TSPO levels in the thalamus and other brain regions were associated significantly with scores on cognitive tests and with blood levels of some inflammatory molecules.

This is consistent with other research suggesting an association between damage to the thalamus and cognitive problems in Parkinson's, the researchers noted.

"This study supports the conclusion that central inflammation is observed early in the disease process in [Parkinson's], is independent of treatment for [Parkinson's], and is correlated with cognitive features and peripheral markers of inflammation," the scientists wrote.

FOLLOW-UP CONTINUES

The team is continuing to follow and analyze this early-disease group of patients.

"Follow-up of these study subjects will be critical to determine the significance of early inflammatory changes and to observe whether certain inflammatory changes predict clinical progression," Yacoubian said.

"We will continue to collect biospecimens annually to determine whether the inflammatory measures change over time in Parkinson's disease. Future studies will need to examine the potential causal relationship between inflammation and neurodegeneration," Yacoubian added.

Community Exercise May Help to Ease Parkinson's Motor Symptoms

Margarida Maia, PhD – Parkinson's News Today, 1/23/23

slowness of movement, and difficulties with balance, all of which can increase the risk of falling.

Various treatments for Parkinson's aim to ease disease symptoms and maintain quality of life, and can include non-pharmacological treatments such as physiotherapy.

"At present, rehabilitation is mainly performed with equipment or professional therapists, which improves the condition of patients but also increases the economic burden of patients," the researchers wrote.

"Community-based exercise ... does not require a professional physical therapist, expensive equipment, or a particular location and is suitable for long-term recovery from illness, with easy access and low cost," they added.

To get a clearer view of the potential benefits of community-based exercise, scientists in China searched six databases for published studies reporting results of trials comparing the effects of community-based exercise with usual care of Parkinson's motor symptoms.

Community-based exercise was considered any form of exercise not guided by a physiotherapist or not

requiring special equipment. Patients given usual care — that not including any exercise therapy — were considered a control group for comparisons.

A total of 22 studies, involving 809 people with Parkinson's, were included in the meta-analysis. Community-based exercise included dance in five studies, tai chi in five, QiGong in four, tango in three, yoga in two, Nordic walking in two, and home-based exercise in one.

Tai chi originated as a Chinese martial art but, similar to QiGong, now largely is a low-impact exercise program involving postures and breathing techniques. Nordic walking uses poles to work the upper body as well as the legs.

TWICE-WEEKLY EXERCISE MOST EFFECTIVE AT EASING MOTOR SYMPTOMS

Most studies were conducted in North America and Asia (nine each), while four took place in Europe and one in Oceania.

Most programs ran for 12 weeks (about three months), but duration ranged from one month to one year. The sessions typically were held two to three times a week, and each session lasted one hour in all but two studies.

(Continued on the bottom of the next page...)

PROGRAMS EVALUATED IN META-ANALYSIS INCLUDE DANCE, TAI CHI, AND NORDIC WALKING

Taking part in a community-based exercise program appears to help relieve the motor symptoms of Parkinson's disease, a review study suggests.

Researchers also observed that older people and those engaging in these programs for longer periods may get the most benefit.

The review study, "[Effects and parameters of community-based exercise on motor symptoms in Parkinson's disease: a meta-analysis](#)," was published in *BMC Neurology*.

EXPERT VOICES: EFFECTIVE, SAFE EXERCISE FOR PEOPLE WITH PARKINSON'S DISEASE

REVIEW STUDY INTO POTENTIAL BENEFITS OF COMMUNITY EXERCISE WITH PARKINSON'S

Parkinson's is marked by the degeneration and death of nerve cells that make dopamine, a chemical that sends signals to neurons that control how the body moves.

Their loss brings about a range of motor symptoms, such as involuntary shaking (tremor), stiffness and

Former Parkinson's Caregivers Could Help Those Now in That Role

By Marisa Wexler, MS – Parkinson's News Today, 10/24/22

Former caregivers could serve as a helpful resource in supporting current caregivers of people with Parkinson's disease, a study reported. The intent is to "provide guidance for developing peer-to-peer support programs, incorporating former carers," its researchers wrote. The study, "Using former carers' expertise in peer support for carers of people with Parkinson's Disease," was published in *npj Parkinson's Disease*.

50 PARKINSON'S GENES FOUND WITH NEW MULTIDISCIPLINARY APPROACH

As Parkinson's disease progresses and a person becomes less able to perform day-to-day tasks independently, it's common for loved ones, particularly spouses or children, to step into the role of informal caregiver to help the patient. This role can be immensely stressful, and prior research has shown that many informal Parkinson's caregivers end up feeling isolated and under strain as they navigate its challenges.

This research has shown a clear need to deliver better support for people caring for Parkinson's patients — but there is little consensus on how best to give this support.

'MISSED OPPORTUNITY' IN PARKINSON'S CAREGIVER SUPPORT SYSTEM

In the study, a quartet of scientists in the Netherlands highlight what they see as a "missed opportunity" when it comes to delivering support to caregivers.

"During the care process, informal carers of persons with [Parkinson's] gain unique knowledge from their own practical experiences in dealing with the challenges of [Parkinson's] care. Yet, this relevant and unique knowledge often remains unused, and in fact disappears entirely once the loved one with [Parkinson's] has passed away," the researchers wrote.

They suggested that former Parkinson's caregivers could act as peers and mentors for current caregivers, sharing their acquired knowledge and expertise. In addition to helping support current caregivers, those once in that role could find it rewarding to share their experiences and feel part of a community.

To assess how this support network setup might be received, the researchers conducted a survey of 141 current caregivers and 15 former caregivers. Most of the respondents were women; most current caregivers were partners of someone with Parkinson's, while the former caregivers were about evenly split between partners and children of someone with Parkinson's.

A near majority of current caregivers (45%) were offering support both during the day and night; help was needed only during day hours for 28% of this group. A majority of the former caregivers (60%) had helped to care for a person with Parkinson's for more than 10 years.

Although most caregivers had sources of support — ranging from healthcare professionals to friends, family, and neighbors — many expressed a desire for more support in navigating difficult issues, such as finding a balance between caring for themselves and their partner, dealing with how the disease alters the dynamics of a relationship, and recognizing and managing specific Parkinson's symptoms.

"It is not about the support, but about being seen and heard. The focus is on my partner — I often have to take action in order to be heard as well in a conversation," one caregiver wrote.

"It is a search for the right information and tools. So, often I have the feeling that I need to re-invent the wheel by myself," said another.

Slightly more than half (50.4%) of current caregivers said they would be interested in having a former caregiver share their experiences and knowledge.

"I want to talk freely with someone who knows my situation. I would hope for some advice, for understanding, for a restful arm around me, for someone to tell me that I cannot do more than my best," one caregiver said.

Among those not expressing an interest, many stated they were not currently in a position where they felt they needed much additional support.

Nearly all former caregivers said they would be interested in sharing their experiences with current caregivers. The two exceptions both had been recently bereaved, and said they felt it was too soon for them to have such discussions.

"I believe that I have valuable experience to provide carers as well as the person they care for the opportunity to make choices that they otherwise would avoid and which they might regret in a later stage," one former caregiver said.

For former carers, most (92%) said their main motivation for offering peer support was that current informal carers could benefit from shared experiences. This was followed by a desire to use their knowledge and skills to support current caregivers (69%) and their experiences of a lack of support when they were providing informal care themselves (30%).

When asked about the potential design for a program connecting former and current caregivers, most respondents in both groups expressed interest in social connections, ranging from getting coffee or going for a walk to an organized support group meeting or lecture. Both groups also highlighted the importance of having other things in common to form these connections.

Study findings, the researchers concluded, "indicate the potential of former informal carers as peers to enhance support for informal carers who are currently taking care of a loved one with [Parkinson's], by sharing their own experiences and knowledge."

(Community Exercise May Help to Ease Parkinson's Motor Symptoms...continued from the bottom of the previous page)

The effects of community-based exercise on Parkinson's motor symptoms were determined mainly through changes in the Unified Parkinson's Disease Rating Scale (UPDRS)-Part 3.

Pooled data revealed that community-based exercise resulted in a mean decrease of 7.91 points in the UPDRS-Part 3 relative to controls, indicating a relief of motor symptoms. Exercising twice a week was most effective, the researchers noted.

In a Timed Up and Go test, which measures balance and the risk of falling, patients who engaged in community-based exercise shortened the time they took to stand up from a chair, walk three meters (about 10 feet), and then come back to the chair by a mean of 2.32 seconds.

Those undergoing such exercise were able to walk a mean of 55.84 meters longer than controls in a six-minute walk test. They also scored a mean of 4.33 points more in the Berg Balance Scale, indicating better balance.

Community-based exercise also associated with a mean decrease of 7.28 points in total UPDRS scores, indicating less severe disease.

While data varied widely across studies, "this meta-analysis suggests that community-based exercise may benefit motor function," the researchers wrote.

A patient's age and the program's duration were seen to influence the effects of community-based exercise on UPDRS-Part 3 scores. That is, older people and those engaging in such a program for longer periods experienced greater reductions in motor symptoms.

"This meta-analysis suggests that community-based exercise may benefit motor function in patients with [Parkinson's disease]," the researchers wrote, adding that it "provides strong evidence for patients to choose more rehabilitation pathways."

"Future studies should consider the influence of age, duration of treatment, and weekly frequency," the team concluded.



**Help 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 at [REDACTED].

Important Info on Getting Help after a Fall!

Did you know that if your loved one has a fall and you are unable to get him or her up, you can make a non-emergency call to the Colorado Springs Fire Department's "Lift Assist" at (719) 444-7000 to get help?

Two firefighters will come, minus sirens and lights.

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

PARKINSON'S PERSPECTIVE

JUNE 2023

Coming Events

See inside for more information

June 3rd - Reg Mtg at at Central United Methodist Church — 10 am

Program: A New Study on the Effects of a LCHF/Ketogenic Diet on Cognition, Sleep Quality, Fatigue and Quality of Life in Parkinson's Disease; **Speaker:** Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP

July 1st - Reg Mtg at Central United Methodist Church — 10 am

Program: Scam Prevention; **Speaker:** Officer Scott Mathis, Colorado Springs Police Department

August 5th - Program: Picnic at John Venezia Park!!!! — 11 am

September 2nd - Reg Mtg at Central United Methodist Church — 10 am

Program: Deep Brain Stimulation; **Speakers:** Dr. David VanSickle and Dr. Abhijeet Gummadavelli

October 7th - Reg Mtg at Central United Methodist Church — 10 am; **Program:** TBD

November 4th - Reg Mtg at Central United Methodist Church — 10 am; **Program:** TBD

More useful websites:

<https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpcf.org; 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; www.parkinsonheartland.org;
<https://www.pdself.org>; https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org;