MARCH 2026

COLORADO
PARKINSON FOUNDATION

Parkinson's Perspective

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

Next Meeting: Saturday, March 7th | 10:00 am – 1:30 pm

We will be Zooming AND recording this meeting

Location: Central United Methodist Church, 4373 Galley Rd - 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.

Program: Silver Key
Speaker: Jayme Holligan, Director of Volunteer, Events, & Community Engagement

Jayme also manages the Volunteer Engagement team that includes V.I.P. (Volunteer Impact Program) volunteers.

In 1999, she was a Walt Disney World College Program intern in Orlando. Jayme obtained Disney customer service training that she utilizes within her everyday interactions. She launched her career path working for at advertising agency called Cramer-Krasselt in Orlando, obtained seven years of experience in Human Resources from staffing at ADD STAFF, and ten years of combined leadership and director-level experience from higher education in Admissions and Career Services at Colorado Technical University.

She earned a Bachelor of Science in Journalism from the University of Colorado at Boulder and a Master of Science in Management with a concentration in Project Management from Colorado Technical University. Jayme represents Silver Key in the community through her board involvement over the past twelve years with CommonWorks and four years on the (LPP) Leadership Pikes Peak alumni committee. She is a double star LPP graduate in 2008 and 2016 from this local civic leadership program.

A Potluck will follow the monthly program.

March Potluck – Mexican!

If you would like to sign up to bring a side dish/dessert for the meeting, you can contact Bill Hicks at [redacted] or potluck@co-parkinson.org, no later than Wednesday, March 4th 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

The more I watch my brother-in-law, Ric Pfarrer, since he got on Vyalev and listen to his wife talk about their experience with it, the more I'm becoming convinced that it's the most important advancement in Parkinson's treatment since the invention of levodopa, the dopamine replacement medication that, combined with carbidopa in carblevo, is still the gold standard Parkinson's medication.

You may remember from Sean Kearns' presentation last November that Vyalev is a subcutaneous delivery system for carblevo and that it provides a 24-hour continuous dose of carblevo. I mentioned it during my Parkinson's 101 presentation at the February monthly support group meeting.

You may also remember from my Parkinson's 101 presentation the importance of medication management in living well with Parkinson's. We have been touting good medication management for decades. Good medication management is a key factor, along with exercise and consuming healthy fats, to living well and even slowing the progression of the disease. That's why

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(...continued from the cover: The President's Corner | Jill Reid-Acting President, CPF & CSPSG

having a Parkinson's specialist who understands good medication management is vital for everyone who takes oral carblevo.

While the goal of good medication management is to have one day-long "on" period when the medication is working well accompanied by zero "off" times (when the medication is not working well), it's very difficult, if not impossible, to achieve even one day with zero "off" times after you've been taking oral carblevo for a period of time. The tactics that work best with oral carblevo are to avoid protein within an hour of taking it and to take the next dose of oral carblevo before the previous dose starts to wear off. These tactics work "best," but they never quite achieve the full goal of good medication management: zero "off" times each day. There are always ups and downs to some degree throughout each day.

However, with Vyalev, Ric is not having any "off" times at all. His medication works well 24/7. His sleep has improved tremendously. If he wakes up in the middle of the night to go to the bathroom, he's fully physically functional immediately. He can eat all the protein he wants whenever he wants. He doesn't have to remember to take pills every 3½ hours. He can stop the Vyalev pump to take a shower and never miss a beat. He walks normally and with a full stride again. The pump even reminds him when it's time to put in the once-daily dose so he doesn't have to remember.

His Vyalev has fully vindicated our contention that good medication management is key! In our opinions, Vyalev is the perfect medication management system!

This month's comedy is *Snow Dogs*, starring Cuba Gooding Jr. A dentist, whose very successful business is in Miami, inherits a champion dogsled team in Alaska in an unlikely twist of fate. He goes to Alaska in mid-winter, fully intending to sell off the dogs and return to warm weather as fast as possible. 90% of the movie is laugh-out-loud funny. My husband and I were talking just today about the movie's funniest scene involving a skunk and a Volkswagen Bug. We laugh until we cry whenever we watch that scene. Enjoy!

Program Review: February 7, 2026 | PARKINSON'S 101

By Jill Reid, Educational Outreach

Jill Reid introduced herself as Chairman of the Board of Directors of the Colorado Parkinson Foundation, President of the Colorado Springs Parkinson's Support Group, Program Director for the support group, and Education Outreach Coordinator. She helped take care of her mother, who was diagnosed with Parkinson's disease (PD) in 1993 and who went through all 5 stages of PD before her death. She also correctly diagnosed her mother-in-law with PD before any doctor did, and she helped with her caregiving as well. She has been an officer in the support group since 1995 and has been around probably thousands of people with Parkinson's. She jokingly said that she has a doctorate in Parkinson's from the University of Hard Knocks.

The goals of the presentation are to train the listeners on the do's and don'ts of caregiving for people with Parkinson's disease (PWPs), retrain listeners annually to update their knowledge as the disorder progresses, give information that the listeners can share with others, and give specific things that the listeners can do that will improve the quality of life of PWPs. At the end of the presentation, listeners will know more about Parkinson's disease than most doctors.

There are "new" things in PD: 1) a true diagnostic tool for PD that is available in Colorado Springs; called the DAT scan, it is usually used only when a neurologist has some doubts about whether a patient has PD. The classic ways of diagnosing are still used today most of the time. One of those ways is to try PD medication; if the patient's symptoms improve, he has PD; if they don't, he may still have PD but the medication doesn't work well for him. 2) Duopa. This is a PD medication delivery system similar to an insulin pump. It does require surgery to insert a tube into the intestines and some hospital time to get the dosages right. There are two huge advantages to Duopa: the medication is loaded only once a day AND there are no medication "on's" and "off's" because the PWP is getting a steady stream of PD meds (more on on's and off's later), which means the medication works all the time. Problems with infections can be solved having the tubing changed out every six to twelve months. 3) Sleep Deep Brain Stimulus surgery. Until recent years, DBS surgery was done while the PWP was awake, a grueling 12-hour ordeal in some cases. Now, the surgery can be done in as little as 1 ½ hours while the PWP is asleep. The new version is much more accurate as well, so the results are much better. It treats a variety of PD symptoms: slowness, facial expression, rigidity, tremors, fine and coarse motor skills, flexed elbows and wrists, and stooped posture. It has helped with freezing, to some extent. It initially can replace the need for the medications. Some people have experienced reduced vocalization after the surgery, but this reduction can be overcome by the wonderful voice therapies available for PD. 4) Vyalev. Newly approved and available, this is a subcutaneous medication delivery system, as opposed to delivering though the intestines (see Duopa above). The PWP gets a 24-hour continuous flow of Parkinson's medication directly into the blood stream, completely bypassing the digestive tract and eliminating all interference from proteins (more on protein interference later). There are no "ups" and "downs" as experienced with taking oral medications. 5) Light therapy. I don't have information as to cost or proven efficacy but, since it is a non-invasive therapy, you may be interested. For more information, go to https://www.youtube.com/watch?v=rubtUl_FDt4 and watch the video that features the Australian inventor and a French neurologist. 6) The Free "Aware in Care" hospital kits, once available through the National Parkinson Foundation (1-800-4PD-INFO or www.parkinson.org), has been replaced by a hospital safety guide. The guide contains helpful information for patients and hospital doctors alike, including the need for a PWP to get his medications on time.

There are also helpful technologies available. Voice recognition software helps PWPs whose tremors make it difficult, if not impossible, to use a computer keyboard. Tremor-compensating eating utensils help the PWP use a fork or spoon without throwing food around the dining room. Modern cell phones have movement-compensating camera software enabling PWPs to take beautiful, blur-free photos. Lane Assist cars keep PWP drivers from straying out of their lane and from running up on the rear bumper of the car in front; you don't have to buy a high-end car to get this feature. Lane Assist cars give the PWP and the spouse their freedom back! Theracycles provide forced exercise, which improves motor functions. Check out the report published by the Cleveland Clinic and entitled Forced, Not Voluntary, Exercise Improves Motor Function in Parkinson's Disease Patients, dated July 2009.

Many of the above items are relatively expensive, but there are some great inexpensive tools out there as well. These are button hooks, plate guards, nosey cups and Squatty Potties. Plate guards fit around dinner plates and enable the PWP to push his food onto his fork or spoon. The advantage to a Nosey Cup is it is a much safer way for a PWP to take liquids. A PWP can drink fluids safely from these cups, minimizing the chance of the liquid's going into his lungs and causing aspiration pneumonia. Squatty Potties help overcome constipation safely.

PD is a progressive neurological disorder caused by the loss of dopamine-producing cells in the substantia nigra deep within the brain. The neurotransmitter dopamine allows the smooth, coordinated function of muscles and movement, and its loss adversely impacts movement and other roles of muscles in the body (e.g., intestines, bladders). By the time the first PD symptoms appear, 80% of a PWPs dopamine-producing cells have already died. PD effects every system in the body except the endocrine system that regulates hormones. B6 deficiencies are common but often left untreated. Many PWP experience orthostatic hypotension, which can be caused by PD and/or PD medication; every PWP needs to be check for orthostatic hypotension at every medical appointment. Untreated, orthostatic hypotension can lead to death.

Dr. Brian Grabert (one of the best PD neurologists in Colorado before he retired) likens treating PD to treating diabetes (including self-medicating). Diabetics don't inject insulin on a schedule; they inject insulin when they need it. The same applies to PWPs; they need to give themselves permission to take their PD meds when they need them, not necessarily when a doctor says they should. Pill management is **KEY** to managing PD well and maximizing a patient's quality of life and longevity. More on medication management later. PD is a unique disorder in that it effects each person differently, with different symptoms and different speed of progression. Each person with PD has to figure out for himself how much Parkinson medication to take and how often. A doctor can offer a guideline, but the PWP is the only one who knows whether the guideline needs tweaking.

The primary PD medication is carbidopa-levodopa (carblevo for short or Sinemet until it went generic as few years ago). PWPs need to be treated by a neurologist, PA, or Nurse Practitioner who specializes in Parkinson's. Those who don't specialize in PD don't have enough in-depth knowledge and experience, especially in medication management, to provide good treatment. Good medication management involves intervals between doses as opposed to scheduled pill times. More on intervals later. Providers who specialize in Parkinson's in Colorado Springs include PA Beth Harmon, NP Melinda McClendon, Dr. Bradley Priebe, Dr. Apura Komatineni. Another local neurologist getting good reviews is Dr Andrea Manhart. At UC Anschutz, Dr Michael Korsmo specializes in PD. In reality, PWPs and their family caregivers are their best neurologists.

[In the past, we at this point have shown a video presentation by Dr. Melissa J. Nirenberg, MD, PhD, Associate Professor of Neurology and Neuroscience at Weill Cornell Medical College and Associate Director of the Parkinson's Disease and Movement Disorders Institute at Weill Cornell Medical College presentation to a Partners in Care conference. You can still view this video by clicking on 'Resources' at the top of the main page of our website; select 'Meeting Videos' from the drop-down menu, click on the January 2023 presentation, and fast forward to minute 20:32. Later in 2025, the January 2025 presentation and Dr. Nirenberg's video will be in a separate tab.] A synopsis of this video follows:

PD's most common symptoms are stiffness, lack of facial expression, dystonia, resting tremor, slowness, difficulty with small movements, flexing of the posture (exercise helps), and shuffling. The symptoms are asymmetric and are often mistaken for strokes when the time course is not known: stroke symptoms come on immediately while PD symptoms come on very slowly. There is a tendency for the medical field to fixate on the movement problems of PD, but in fact the non-motor symptoms may be more troublesome. These include sensory (pain and tingling), sleep disorders (REM sleep disorder which can start 20 years before any other symptom shows up, sleepiness, inability to sleep, sleep apnea), cognition (difficulty multi-tasking—PWPs should never try to do two things at once, including conversing and eating simultaneously—and dementia), autonomic symptoms (constipation is almost universal and can start years before other symptoms), hypotension, bladder problems, sexual dysfunction, mood (severe anxiety, panic attacks when meds wear off, apathy, depression; there are meds for all these except apathy), and fatigue. What you see is not all that is going on. The non-motor symptoms are treatable, some without medications (e.g., physical therapy).

Later on in the disorder, not early on, PWPs will look great when they go see their doctors but they aren't great. That's because PD fluctuates with "on's" and "off's." When the medications are working, PWPs look great, even to the extent of not looking like they have PD at all. But when the medications are not working well, they can be severely, severely disabled. So when they are getting ready to go to the doctors, they tend to make sure they've optimized their meds so that they can get out the door. PWPs need to be forthright with their doctors and tell them all the symptoms they experience when their meds are not working well; otherwise, the doctors have no way of knowing because the doctors are only seeing them at their best. The medication (carbidopa-levodopa) works differently from person to person and within a person from year to year so no doctor will know what a PWP needs unless the PWP tells him how the carblevo is working. For a week or two before all periodic appointments with a PD specialist, every PWP should keep a diary of when he takes his meds and how long they last until they start wearing off and take the diary to the appointment so the doctor will know how much carblevo to prescribe.

A myth of PD is that patients should wait until the last dose wears off before taking the next dose because "less is more." There is a fear of the medication. But in fact, if they wait until it wears off, it may not work very well for the rest of the day. They need to take the pill to anticipate the wearing off. The meds don't work very well if they miss a dose or take a dose late; if they crash completely, they will have difficulty getting back "on." Good timers are available on Amazon; they go off every, say, hour and a half all day long. Adherence without a timer is very difficult when a patient has to take his medications every hour.

Abnormal movements are not always from PD but from the medications. When patients have been on the medications for some time, particularly young onset patients, they get these abnormal, flowing movements as a side effect of the medication. These extra movements are called dyskinesia. If they have dyskinesia, they may need less levodopa or a longer interval between doses OR they don't have a happy medium and need to have the dyskinesia in order to be "on." Dyskinesia is usually not disabling unless it adversely effects balance. Many patients aren't aware that they are dyskinetic. These are not tremors and should not be mistaken for the rhythmic shaking that is a classic symptom of PD.

Another major problem is that everyone ascribes every problem that a PWP has to Parkinson's. You always have to apply common sense and consider what else may be the cause of the problem. One example is sudden severe back pain and leg weakness; PD is slow moving and does not cause weakness. The sudden appearance of a problem means that something else is wrong, even if the only symptoms appearing are the sudden worsening of the patient's PD symptoms. PD is NEVER fast. If it's fast, something else is going on, and someone must find the cause. One of the most common culprits is urinary tract infections.

Another myth of PD is that carblevo stops working after five years. There is no truth to this whatsoever. The stuff is good stuff. As PD progresses and symptoms worsen and new ones that don't respond to carblevo appear, it may look like the carblevo has stopped working, but it has not stopped and will not stop working. It has no expiration date, and it improves the quality of life.

Another myth of PD is that it is predictable. The truth is that it is a different disease in each patient, and every patient progresses differently. PD progression is highly variable. But there are many things that you can do to change that course; and that's where physical therapists and occupational therapists can make a tremendous difference.

Walker myths. Most walkers, including rollators with standard brakes and the light-weight aluminum walkers you see in hospitals, are no good for PWPs. Only rollator walkers that have reverse braking systems are safe for PWPs. These walkers require the user to squeeze the brake handles in order for the walker to move; releasing the brake handles applies the brakes. When a PWP is about to fall, it is unlikely he will think to squeeze the brake handles on standard braking systems; however, if he is falling and without thinking lets go of the reverse brake handles, the walker stops. There are two companies that make the reverse-brake walkers specifically for Parkinson's. U-Step is one of the companies, and their walkers can also be weighted properly to prevent backwards and sideways falls. [end of Dr. Nirenberg's presentation]

With Parkinson's, we get a new vocabulary: festination. Festination is the tendency for a PWP to start taking short, fast steps on their toes. Left unstopped, festination can end in a fall. Caregivers can nip a festination episode in the bud by physically stopping the forward motion and getting the PWPs to get off their toes and onto their heels. Then coach the PWP to "walk on your heels."

There are 5 classic stages of PD. Listeners may need to be able to distinguish Stage 1 from the other stages and may also be able to spot someone who has PD and doesn't know it. Pill management becomes critical starting in Stage 2. ***The later stages of PD can be avoided!!! You can slow the progression by exercising and taking 2 ½ tablespoons of healthy fats (coconut oil, MCT oil, olive oil, or avocado***

(Continued on page 6…)

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. They are the monthly on the 3rd Thursday, from 10:00-12:00 at Central United Methodist Church, 4373 Galley Rd, Colo Spgs, 80915.

We're looking for a replacement for Brenda Hicks to head up the Parkinson's Caregivers Support Group.

If you are interested in helping out, call Brenda to find out what the position entails.

You can contact her at [redacted] or [redacted].

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 Donahue at info@co-parkinson.org or [redacted].

Essential Tremor Support Group

Meeting Location: ENT Conf Rm, Pikes Peak Library District; Colo Spgs Library 21c, 1175 Chapel Hills Drive. Contact Jim Sanchez for meeting dates/times at [redacted] or ([redacted].

Tri-Lakes Parkinson's Support Group

Meets the 3rd Saturday of the month at 10am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. Contact Becky Farley at [redacted] *or* [redacted] for more info.

Other Opportunities:

Adult Speech Therapy:

Outpatient speech therapy services.

Personalized speech therapy for restoration of function due to illness or injury.

Treating:
Parkinson's - Voice & Swallowing
- SPEAK OUT!
- LSVT

Contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or call (719) 338-8165 or for more info.

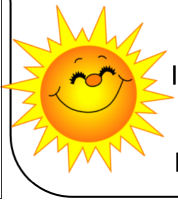
Parkinson's Sing-a-Long Group:

Square Music Co offers individual music therapy services with Heather Johnson, MT-BC! Individual sessions can be held in person in the Colorado Springs area or via telehealth.

Heather has over 5 years of experience working with neuro populations and hosts a Parkinson's singing group before each support group meeting at 9:30 am as well! Music therapy with Parkinson's works towards vocal strength, control, and longevity, increasing fine and gross motor skills, gait training, and other types of therapeutic goals through individualized music experiences.

To learn more or schedule a free consultation, call Heather at (719) 345-2887 or email heatherjohnson@squaremusic.co.

HELP SPREAD SOME SUNSHINE TO OUR MEMBERS!



If you know of a Parkinsonian or PD caregiver that is having a tough time (illness, surgery, etc.) or one of our members has passed away, please let our Sunshine Chairman, MJ Thompson know. She can be reached by calling: [redacted].

PD Exercise Classes:

Falcon Exercise Group

Mon & Fri: 11:00 – noon, Grace Community Church. For more info contact Catherine Reed at [redacted].

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.

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

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.

Neuropong for Parkinson's

Table tennis for Parkinsonians who want to improve both motor and non-motor symptoms and avoid mental decline.

When: Tuesdays & Thursdays
Time: 1:00 - 3:00 p.m.
Location: Downtown YMCA
207 North Nevada Avenue
In the Small Gym

To sign up call the front desk at (719) 473-9622

For more information contact Travis Lerma at (719) 495-5130 or tlerma@ppymca.org.

Neurologicrehab.com

Rock Steady Boxing – Boxing with Love

New Rock Steady Boxing for folks with Parkinson's Disease at the Boxing with Love Gym Tues @ noon (please come 15 min early if your first time) 1710 Briargate Blvd. Ste 100 (Next to Dicks Sporting Goods).
For more info contact Karen Bishop PT, DPT at love@rsbaffilate.com.

Max Capacity NeuroFitness

Free Boxing, PWR Bootcamp and Cardio Circuit for people with Parkinson's. Cognitive Cardio class available for $10/class!

Physical therapist Emily Moncheski at Max Capacity, PLLC, offers individual Parkinson's physical therapy, most insurance accepted
Conveniently downtown
525 E. Fountain Blvd. Suite 150
Contact Emily at emily@maxcapacitypt.com
or call: (719) 213-3996, fax: (719) 284-4624.

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 Tuesday at 11:30 am and every Friday at 11:00 am at Ormao Dance Company, 10 S. Spruce Street.

$5/class | Free for care partners

You can also join us for this class online.

Visit our website www.ormaodance.org 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

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;
Tues & Thurs, 1:00-2:00 PM

Briargate YMCA: PWR!Moves;
Mon, Wed, Fri, 1:30-2:30 PM

YMCA at 1st & Main; PWR!Moves;
Mon & Wed, 1:15-2:15 PM

For more info contact Travis Lerma at tlerma@ppymca.org.

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.

Neuro Logic Rehabilitation and Wellness

One-on-one physical therapy and wellness services for people with Parkinson's Disease and other movement/neuro disorders in the comfort of their home with outpatient mobile services. We come to you, to meet you where you are in your treatment & diagnosis!
Board Certified Clinical Specialist in Neurologic Physical Therapy Certified PWR! (Parkinson's Wellness Recovery) Moves Therapist
For more information, contact Ryan Mueller, PT, DPT, NCS at (719) 306-0009 or ryan@neurologicrehab.com
or visit neurologicrehab.com / Fax: (719) 691-7994

Thank you for helping!

*A big **THANK YOU** to everyone who brought food to share and to those that helped with setup & cleanup at the last meeting!*

April 2026 Newsletter Input Deadline:

March 13th

Call or e-mail Julie with your input for the newsletter at:
[redacted]
info@co-parkinson.org

March 2026 CSPSG Executive Committee Meeting

March 10th @ 09:30am

(Location: Place to be determined)

Contact Jill Reid at: president@co-parkinson.org, if you haven't been to an Executive Meeting so we will know that you're coming and to get you the address. Leave your email address so Jill can contact you if anything changes.

HAPPY MARCH BIRTHDAYS!

- John Baker
- Karen Baker
- Dave Blackwell
- Marci Braithwaite
- Donna Deis (Rickett)
- John Farley
- Stephanie Graczyk
- Judy Horton
- Mary Lekarczyk
- Keith Mitchell
- Christine Morgan
- Jay Norman
- Marti Purdy
- Elizabeth Rowan
- Ken Rowe
- Shelley Runkle
- David Smith
- Francel Smith
- Patrick Smith
- Marny Weckwerth
- Milton Whitaker
- Keith Woestehoff

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

Recipe of the Month:

Our low carb/good fat ketogenic study 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: info@co-parkinson.org.

Creamy Cucumber Salad

Ingredients:

4 hothouse cucumbers, thinly sliced (3-4 lbs)
2 small red onions, thinly sliced in half rounds
Kosher salt
4 C (32 oz) plain whole-milk yogurt
1 shallot, sliced
1 (8 oz) sour cream
2 Tbl champagne vinegar or white wine vinegar
½ C minced fresh dill
1 ½ tsp pepper
1 Tbl thinly sliced fresh mint

Directions:

- Mix the cucumbers, red onions & 1 ½ Tbl of salt in a bowl
- Pour them into a colander & suspend it over a bowl
- Wrap the bowl & colander with plastic wrap & place in refrigerator to drain at least 4 hours or overnight
- Discard liquid that collects in the bowl
- Pour yogurt into a sieve lined with a paper towel & suspend it over another bowl
- Wrap bowl & sieve in a plastic wrap & refrigerate for at least 4 hours or overnight
- Discard liquid
- When cucumbers are ready, roll them up in paper towels & press towels lightly to remove most of the liquid
- Place cucumbers & yogurt in a large bowl with the sour cream, vinegar, dill, 2 tsp salt & the pepper
- Toss well & refrigerate for a few hours to allow flavors to blend
- Sprinkle with ½ tsp salt & ½ tsp pepper & serve chilled

Parkinson's Disease Related Providers:

If you are seeing a provider not listed here that has given you excellent care with any Parkinson's issue, let Julie know at info@co-parkinson.org so that they can be added to this list.

The following providers have been recommended by multiple members:

Colorado Springs

Dr. Bradley Priebe, MD – Neurologist at Peak Neurology, PC; (719) 445-9902

Steven Swank, PharmD, BCACP – Peak Neurology, Clinical Pharmacist Specialist; (719) 445-9902

Dr. Aparna Komatineni, MD – Neurologist at Centura Penrose Hospital and UCHealth;(719) 694-3595

Dr. Andrea Manhart, DO – Neurologist at UCHealth; (719) 365-7300

Dr. Lael Stander, MD – Neurologist at UCHealth; (719) 365-7300 Note: Does well w/PD vision issues

Elizabeth Harmon, PA – UCHealth; (719) 365-7300

Melinda McClenden, NP – UCHealth; (719) 365-7300

Dr. Kevin Scott, MD – Neurologist at UCHealth; (719) 365-7300

Dr. Monica Stanton. MD – Primary Care Physician at UCHealth in Monument; (719) 364-9930

Dr. David Stevens – Neurologist at CS Neurological Associates; (719) 473-3272

Bettner Vision – Neuro-Ophthalmology Vision Therapy; (719) 282-0400

Denver

Dr. Michael Korsmo, MD – Neurologist at UCHealth, Anschutz Medical Campus; (720) 848-2080

Dr. David VanSickle, MD – Neurosurgeon at Neurosurgery One; (720) 638-7500
Note: DBS expert

Erin Van Dok, OD – Neurological Optometrist at UCHealth Sue Anschutz-Rodgers Eye Center; (720) 848-2020

Dr. Victoria Pelak, MD – Neuro-ophthalmology, UCHealth Sue Anschutz-Rodgers Eye Center; (720) 848-2020

Dr. Trevor Hawkins Neurologist at UCHealth Neurosciences Center, Anschutz Medical Campus; (720) 848-2080

Dr. Drew Kern, MD – Neurologist whose focus is DBS at UCHealth, Anschutz Medical Campus: (720) 848-2080

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oil twice daily.

Stage 1: Most newly diagnosed PWPs are in Stage 1 and may or not be prescribed carblevo. Adhering to a hard and fast carblevo schedule is not as important as it is later because PWPs in Stage 1 don’t experience the swings between “on” (when the meds are working well) and “off” (when the current dose stops working well). Still, it’s best to keep as close as possible to a medication schedule that works for them because it makes the Activities of Daily Living (e.g., dressing, brushing teeth) easier.

Stage 1 symptoms appear on only one side of the body. Some or possibly all of the following could appear: greatly reduced eye blinks (8 -12 per minute), tired arm or leg muscle, one arm that doesn’t swing, stiffness, difficulty getting out of a chair, slight stooping, tremors, reduced fine motor skills (e.g., handwriting gets smaller), slightly dragging foot, orthostatic hypotension, anxiety. They can still turn and pivot well, have a normal stride, and rarely, if ever, fall. Why is getting out of a chair a problem? That’s because PWPs place their feet well out in front when they are seated and they don’t move them back when they try to stand up. More on how to counter this problem later.

Stage 2: The symptoms that were seen in Stage 1 will now be on both sides of the body, and they will be worse than before on the original side. In addition, there could be some additional symptoms, such as shorter gait, balance problems with occasional falls, choking, difficulty pivoting, reduced motor skills, cognitive issues. Good medication management is **critical** now. More on good medication management later. ***You can slow the progression and avoid later stages of PD by doing two things: exercising aerobically five times a week and taking 2 ½ tablespoons of coconut oil, MCT oil, olive oil, or avocado oil twice daily*** (work up to this amount very gradually).

Stage 3. ***This stage can be avoided!*** The symptoms from Stage 2 will be worse and there will likely be new ones, such as shuffling, festination, more slowness and stiffness, less stability with more frequent falls, difficulty pivoting without help or coaching, and freezing (more on freezing later). The PWP may need a walker in this stage.

Stage 4. ***This stage can be avoided!*** Stage 3 symptoms will be worse. The PWP will likely not be able to walk with a walker. Pivoting will be extremely difficult if not impossible. He will freeze a lot and probably won’t be able to get out of chairs without help. There will be lots of falls and lots of choking. ***You can slow the progression and avoid later stages of PD by doing two things: exercising aerobically five times a week and taking 2 ½ tablespoons of coconut oil, MCT oil, olive oil, or avocado oil twice daily*** (work up to this amount very gradually).

Stage 5. ***This stage can be avoided!*** PWPs in Stage 5 will be wheel-chair bound and/or bed-ridden. They cannot swallow safely so they will have to take all food, fluids, and medications through feeding tubes.

Medication management. The goal of good medication management is to have one big “on” period that lasts all day, with no “off” periods. To achieve this goal, PWPs should take the next dose of carblevo before the previous one wears off. Time between pills is more important than scheduled times. For example, if a PWP normally takes his first dose at 7 a.m. and his second one at 10 a.m. but he sleeps in one day and takes his first dose at 8 a.m., he should take his next dose at 11 a.m., not at 10 a.m. (Hint: Run quickly from any PD “specialist” who insists that carblevo has to be taken at specific times and find a PD specialist who understands intervals and good medication management!) If PD symptoms appear regularly between doses, the schedule needs to be adjusted; keep a log as recommended in Dr. Nirenberg’s presentation. PWPs can adjust the schedule themselves and inform the PD specialist later for a new prescription but in any case, take the log to the next appointment with the PD specialist. Good medication management gets more critical as PD progresses because the brain produces less and less dopamine. It is most critical in Stage 5, even though use of the limbs is practically non-existent. **Other muscles are critical to survival:** diaphragms and chest walls for breathing and coughing, throat muscles for swallowing saliva safely, intestines, and bladders. Most PWPs die from aspirations pneumonia and bowel blockages resulting from poor pill management. Medication schedule will most likely be dependent on observations by others for a PWP in Stage 5 because he won’t be able to speak for himself.

Self-medicating. No one knows why, but the normal carblevo dose isn’t always sufficient. It’s OK for PWPs to take extra carblevo (say ½ or 1 pill) if needed. Like diabetics with insulin, they can take what they need when they need it. If your provider says anything different, find a different provider!

Protein vs carblevo. Entering the body through the digestive tract, protein and oral carblevo compete for absorption and uptake into the brain, and protein wins out every time. The solution to this problem is to avoid eating protein within one hour of taking oral carblevo OR to take extra oral carblevo if the hour interval can’t be met. Another solution is to avoid all proteins until dinner time since the need to be “on” and mobile is less critical at night. Generally, PWPs don’t need carblevo during sleep because PD symptoms go away. Beware! Protein is in a lot of foods and drinks! Note: **There is no protein/carblevo interaction with Vyalev**, one of the key advantages of this subcutaneous carb/levo delivery system; there is no need to avoid protein with Vyalev.

On the other hand, protein can be a useful tool for those times when a PWP has too much levodopa in his system. Excessive levodopa causes excessive, unwanted movements or talking; these are known as dyskinesia (if you’ve seen Michael J. Fox doing interviews in recent years, you will have seen dyskinesia). A few bites of cheese or some meat, milk, or ice cream will “kill off” excess levodopa and get the dyskinesia under control. If a PWP experiences dyskinesia regularly, he probably needs to cut back on his carblevo dose or extend the time between pills. Unfortunately, some people need to be dyskinetic in order to be “on.”

Carblevo and nausea. Nausea is a fairly common side effect of both oral and subcutaneous levodopa. The levodopa portion of carblevo is the dopamine replacement while the carbidopa portion is an anti-nausea drug. The amount of carbidopa in carblevo is not enough for some people. Carbidopa can be prescribed separately. If separate carbidopa is not available, eating saltines or other non-protein foods before taking carblevo helps.

Constipation. Per Dr. Nirenberg, constipation is almost universal in PD. This is not a trivial matter; bowel blockages are a leading cause of death in PWPs. High-fiber food, good hydration, Miralax (it works well and has no addictive side effects), vigorous aerobic exercise, and Metamucil wafers all help. Our own Greg Ritscher’s book, Rising Above Parkinson’s, has a recipe for a fruit paste that works well for him; see page 183. Another helpful recipe is one capful of Miralax every other day plus up to cone capful plus one tablespoon of Benefiber daily in eight ounces of water.

PD and choking. Choking effects all PWPs sooner or later. The throat muscles react too slowly to direct food or liquid into the esophagus; they end up going down the windpipe and into the lungs instead. This can lead to aspiration pneumonia, the leading cause of death for PWPs. There are several solutions. Tucking the chin against the neck when swallowing directs the food or liquids to the right place. Add thickening to fluids, especially water, the thinnest and therefore the most dangerous of all fluids. Suck on ice cubes to get hydrated; the cold ice triggers the throat muscles to work quickly. Have PWP swallow hard and forcefully --effortful swallowing. If the PWP chokes on pills, have him take the pills with sparkling water. If that doesn't work, grind up pills and put in apple sauce, apple butter, honey, or jam. Be sure NOT to grind an Extended Release or Continuous Release carblevo. In addition, swallowing and voice therapies such as LSVT Loud, physical therapy, occupational therapy, and daily swallowing exercises are of tremendous help.

Cramping. Cramping can happen in the hands and feet. Sometimes the feet turn inwards. These are dystonias that can be treated with Botox injections or prescription cream compounded by the Professional Pharmacy LLC in Colorado Springs (here's the formula: BAC/DIC/GAB/LIDO/PRILO).

Effects of PD on vision. PD can effect vision in a number of ways, including dry eyes, double vision, fatigue, and difficulty reading. Neuro-ophthalmologists and optometrists such as the ones at the UCHealth Eye Center Anschutz in Aurora and Dr. Heather Van Law and Bettner Vision in Colorado Springs can treat the effects of PD on vision. Dr. Stander, a neurologist in Colorado Springs, also treats PD vision problems. Proper diagnosis of the precise vision problems can lead to the restoration of normal vision.

Helpful Hints

Falls. What if a PWP falls or slides out of a seat? You don't have to call 911 for help! If a PWP needs help getting off the floor, call for non-emergent lift assist: in Colorado Springs city limits, call 1-719-444-7000 and in El Paso County outside Colorado Springs city limits, call 1-719-390-5555. This is a free service.

Hospitals. Hospitals are very dangerous places for PWPs. Our website currently lists two safe hospitals in Colorado Springs. Even if a PWP goes to one of those, he MUST have a strong advocate to fight for him while in the hospital's care. Every PWP should name a person or persons you trust your Medical Durable Power of Attorney so that they can protect you if you can't speak for yourself. An MDPOA comes into effect when you can no longer communicate for yourself and has all the same medical rights on your behalf that you have for yourself. Going to a hospital without an MDPOA in place is putting your very life at risk. DO NOT have a Living Will or 5 Wishes documents; both take end-of-life decisions out of your loved one's hands (including your MDPOA) and give them to two doctors in the hospital (you can include the information that would be in a Living Will or 5 Wishes document in your MDPOA—DO NOT have both an MDPOA and either a Living Will or 5 Wishes; the hospital can invoke the Living Will or 5 Wishes document if one exists, thereby rendering the MDPOA invalid). Also be aware that if you're released from a hospital but come back for a second visit for the same (unresolved) issue, the hospital will get penalized and will try to avoid penalties by getting you to sign a form consenting to observation only; DON'T SIGN IT or you'll get billed for the second visit. They may even leave you in the waiting room, even if you're in severe pain, to avoid the penalties of a second visit.

Attitude and activities. Humor is huge for PWPs. Laughter releases dopamine as well as endorphins and boosts mood. Watch funny shows and movies instead of serious ones. PWPs in all stages benefit from activities such as exercise, socialization, and participation in life-long interests. One of our members took up oil painting and found that his tremors completely disappeared while he painted; as an extra plus, his works were beautiful and art-gallery worthy.

PD and exercise. Exercise that involves vigorous movement is VITAL and is the only thing proven in double-blind studies to slow and even reverse the progression of the disease. A former member, Barbara, was a professional ballerina before she was diagnosed with PD. By the time she joined our group, she was in Stage 3 of PD and used a hot pink walker. Many years after she had stopped dancing because of PD, she saw herself in a plate glass window and was shocked at how stiff she looked; so she took up dancing again and went from Stage 3 back to Stage 1! She even donated us her walker that she no longer needed! Movement exercise also increases longevity in PWPs, improves cognitive scores in PWPs, and increases brain volume. Here are some other movement exercises that can slow the progression of PD: walking, hiking, stationary biking, water aerobics, NeuroPong (available in Colorado Springs), moving to music (dancing), rowing, movement exercises in a chair (for safety), boxing, Power Moves (exercise especially designed to PWPs). Be sure to get your heart rate up for 30 minutes 3-5 times a week. Resistance exercises (e.g., weight lifting) improves fine motor skills. Wii Sports is exercise that's fun; it even includes balance exercises and games. The old adage, "Use it or lose it," applies to balance. Stretching and tai chi are also helpful.

Walkers. The company that makes the U-Step walker that Dr. Nirenberg advocates because it has reverse brakes (you have to pull up on the brake handles in order to move the walker; when you release the brake handles, the brakes engage and the walker stops on its own) now offers an upright version of the U-Step. The advantage it offers is that the user is completely upright and not bent over as he would be on all other walkers. Bending over and leaning forward on lower walkers often result in festination (walking on toes while taking small, quick steps), which needs to be avoided at all costs. Here are pictures of both the U-Step walkers specially designed for PWPs.

U-Step Upright walker

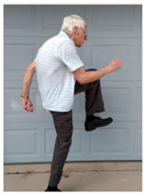
Freezing. Freezing occurs when the feet won't start from a standstill or they stop moving without warning. In both cases, the brain is telling the feet to walk but the message is not getting through. When the feet stop moving without warning, the brain thinks the feet are walking and the rest of the body keeps moving forward, which of course ends in a fall. This often happens in narrow areas like doorways. There is no medication for freezing because it is actually a psychological phenomenon, not a physical one. It can be overcome by changing the PWP's mindset, for example getting the PWP to pick up his knees instead of his feet, to step up like he's climbing stairs, to step over an imaginary log, to follow a flashlight beam on the floor. Marching music helps as well, as do strips of colored tape across narrow areas; the strips of tape and the flashlight beam give the PWP something to aim for. There are also exercises that can help (more on that later). Freezing can also result from fear, which is why going up stairs is easy for PWPs but going down stairs is very difficult. <u>**Never**</u> pull or push a PWP who is freezing—support him and coach him to change his mindset to get him moving. Also, if he is using a walker, make sure he keeps the walker close to his body and not pushed out in front of him.

Exercises that reduce freezing. Bicycling of any sort reduces freezing. Floor-mounted pedals that have no resistance even work because it's the cycling motion that reduces the freezing. If freezing is an issue, do this exercise daily. Below are two other exercises that help:

HELPFUL HINTS:

Exercise that Reduces Freezing

- Stand on right leg
- Lift left foot and raise right arm
- Lower both
- Do 5-10 times
- Repeat with other leg
- Alternate legs 5-10 times



- Stand on left leg
- Put right leg back
- Swing right leg forward
- Touch ground
- Swing right leg back
- Repeat with other leg
- Alternate legs 5-10 times

Touch therapy. Anecdotal evidence about touch therapy (for example, deep tissue massage) has shown that it doesn't raise dopamine levels but can relieve some PD symptoms; improves blood circulation, flexibility, and range of motion; reduces tremors and eases cramping of fingers and toes; and helps PWPs walk better, farther, and more often.

Additional therapies to consider. Treating PD takes a team, so consider adding alternate therapies to your arsenal in addition to medication, PT, OT, LSVT Big and Loud, and exercise. Here are some complementary therapies: massage, vitamins, acupuncture, chiropractic, and the Alexander Technique.

Socialization. Encourage PWPs to socialize. PWPs tend to isolate themselves to avoid the discomforts and embarrassment of being in public with their symptoms showing. PWPs can avoid this discomfort by optimizing their medications and being well-exercised. Studies have shown that a shrinking social network has the same negative impact on health and longevity as taking up a two-pack a day smoking habit. Involve PWPs in as many activities as possible. Cooking meals with the help of Blue Apron or Hello Fresh stimulates the mind and uses fine motor skills. Card games and other board games also exercise the mind and dexterity. Parties and other get-togethers can be non-threatening with a little creativity, like not serving thin liquids and difficult foods and offering finger foods. Sing-alongs with friends provide wonderful vocal exercise; PWPs tend to speak softly and singing is actually excellent therapy to overcome soft voices that no one can hear. The Colorado Springs Senior Center offers excellent programs and activities. Time activities and exercise according to when the PWP is at his best, usually in the afternoons.

Safety. In-home safety is key. Remove trip hazards like throw rugs. Widen narrow openings between pieces of furniture, if possible. Some companies have received grants to add safety features like grab bars and to widen doorways for little or no cost.

Low blood pressure. Hypotension is common amongst PWPs. Taking salt pills is a good solution if there are no other health issues that would make the salt pills dangerous. Eating something salty also helps. There are blood

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pressure-boosting medications if these non-medical interventions aren't sufficient. Florinef is very effective but requires doctor-supervised potassium supplementation.

Creative solutions. Observe what things cause problems and find creative solutions for them. For example, stuff your change into pockets rather than your wallet after purchases. Serve mashed potatoes with peas or corn; this keeps the peas or corn from flying around the room. Drink cooled soups through a straw. Effective solutions to problems take the stress out of the situation, decrease embarrassment, and keep PD medications working (stress kills off carblevo).

Coddling. Don't coddle a PWP. Let him do for himself all that he can. Many PWPs have apathy and will let you do everything if you offer to step in—if you do, you will only accelerate his inability to do things for himself. It's very tempting to step in because it's so much faster but RESIST RESIST RESIST! If necessary, have him start getting ready for appointments and outings two or three hours early so you don't have to step in in order to get out the door on time.

Rushing. Help PWPs avoid rushing at all costs. Rushing is a form of stress and will actually cause the medications to stop working, the symptoms to get worse, and frustration to mount. Rushing brings on the exact opposite of what you're trying to accomplish—it slows him down!

Apathy. There is no medical treatment available. Use inspiration or persuasion. I advocate using brow beating and guilt! I know that sounds terrible, but you caregivers need your PWPs out there doing everything they can to slow the progression of the disease for YOUR sake if not for theirs. So if it's effective, lay on the guilt trips so that you as a caregiver don't burn out! PWPs, if you won't do everything possible to slow the progression of the disease for yourself, do it for your caregivers! Who will take care of you if your caregiver collapses from the stress of caregiving. **Find a goal that will motivate you every day to slow the progression of the disease and stay out of Stages 3, 4, and 5.**

Timing. Exercise and participate in activities when your oral meds are working well. That varies from person to person and from day to day.

Getting out of chairs. Scoot to the edge of the chair. Put both feet as far under you as the chair allows and keep them shoulder-width apart. One foot can be slightly in front of the other. Bend at the hips until your nose is "over your toes." Place both hands on the chair seat or arms. Push with your hands and stand up. Caregivers, you may need to coach your PWP each time he tries to get out of a chair.

Putting on coats without help. Drape your coat over the back of the chair exactly as if you had taken the coat off while seated in that chair. Then, while seated, put your arms in the arms of the coat and raise your arms just enough so the jacket moves onto your shoulders. This works for shirts and sweaters, too.

Getting out of bed. Sleep on the firmest mattress that you can tolerate since getting off a soft mattress is difficult. Bed canes are also useful, as long as they have long straps that reach from one side of the mattress to the other so the cane is strong and secure.

Constipation. In addition to the hints already given, a Squatty Potty is an inexpensive tool to help overcome constipation. It helps straighten the intestines to ease the passage of the BM without straining. Straining can dangerously raise blood pressure.

Support groups. Caregivers, encourage your PWPs to attend our monthly support group meetings, where they will be with other PWPs who completely understand their PD issues. They can learn from others how they have solved PD problems and can be inspired and encouraged to see others who are living well with PD, even decades after diagnosis.

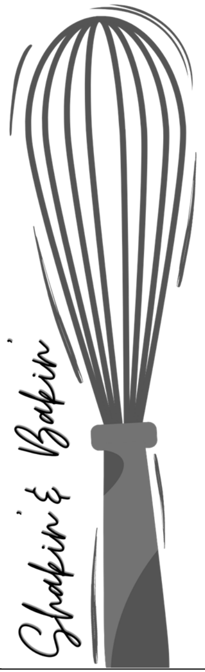
PWPs, encourage your family members and other caregivers to come to our support group meetings—the more they know, the better for everyone!

The Colorado Springs Parkinson's Support Group is an all-volunteer organization striving to improve the quality of life of our members through socializing, sharing knowledge and information, giving each other emotional support, and training professional caregivers. The group provides reimbursement for transportation to our meetings if needed. We meet currently in Fellowship Hall of the Central United Methodist Church (4373 Galley Road) on the first Saturday of each month from 10 am to around noon. Meetings include guest speakers and great potluck lunches. In August, we have a picnic in lieu of a meeting. The support group also provides an extremely informative free monthly newsletter.

See our website, www.co-parkinson.org, for links to other helpful websites and youtube presentations, videos of our most recent presentations, a year's worth of our newsletters, and information about the internationally-known studies that we have sponsored. Dr. Nirenberg's presentation is also on our website; use the following QR code to get to it directly:

One last thought: positive attitudes and humor help everyone!

Potluck Favorites
Shakin' & Bakin' Cookbook



The updated cookbooks are here! The price is a donation or free if you can't afford to donate.

You can order them from Vicki Patterson at project@co-parkinson.org. The cookbooks are bound so that new recipes can be added in the future. So continue to send in 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.

All favorite recipes are welcome.
Send them to project@co-parkinson.org.

Note: *These new cookbooks are bound in a hard-covered 3-ring binder with a spine that identifies the cookbook when on the shelf with other cookbooks rather than the older soft-covered version with 3 single rings and no identifying spine.*

If you would like a hard-covered binder to replace your soft-covered older version, you can get one for $5.

Getting to Know You—Victoria Patterson | Ann Grant Martin

Meet Vicki Patterson, a person who loves to quilt. The wife and care-partner of Mike Patterson who was recently featured in this column, she has looked forward to retirement so she can devote more time to quilting.

Born in South Bend, Indiana, Vicki grew up in Indiana and Michigan. A voracious reader, she remembers a book, Little Britches by Ralph Moody, set in Colorado about 1908. When her family moved to Denver in 1970, she expected it to be just like the book, and was so disappointed that there were no cowboys on horses or stampeding cattle through the center of town. Vicki's education was at Campion Academy, a Seventh Day Adventist High School near Loveland, and then Andrews University, back in Michigan. However, she was so homesick she returned after only one quarter. Then she met Mike and her higher education plans were "totally messed up." From then on, they learned and traveled as a pair.

Looking back after 46 years of marriage, Mike's first job as a paramedic took them to Pagosa Springs, Colorado where they lived for 27 years. Deeply connected to the local community, their two daughters were raised there. The Methodist Church was their spiritual home base. From a musical family, Vicki continued to make music a core value with her family. They sang and performed in the community's musical theater shows. Vicki's most prominent role was as "Marian, the Librarian" in the Music Man musical. She worked in the schools for 16 years as a teacher's aide and when Mike took a job in Farmington, NM, she went back to school to get her teaching degree. As a middle school teacher of language arts and American History, it seemed like she was always grading papers. Referring to her 8th grade students, she says, "it was really a trip …. they were really something!" Her experience confirmed that teachers never have enough time to prepare for their classes and that a few weeks off in the summer is barely enough time to recover from the constant responsibilities and challenges she faced as a teacher. Vicki says, "People who don't teach have no idea of how much time it takes; I'm glad was a teacher, but very thankful that I'm done."

Newcomers to Colorado Springs, Mike and Vicki landed here a year ago last November. Delighted to be nearer to their daughters and families, they have wasted no time in becoming involved in the Colorado Springs PD community. She helps Julie with the Parkinson' Foundation cookbook, "Shakin and Bakin", and really appreciates the help and support from this group. She and Mike love the advantages of a larger town (like having an actual neurologist available), but they are not thrilled by the many vehicles that crowd the roads. "Traffic is the trade-off," she says.

As for being Mike's wife and care-partner, Vicki feels that "when we got married and took the vows, 'In sickness and in health', that promise meant something! There is no question about helping him." She remembers that there are times when both of them feel depressed and worried, like when he was first diagnosed with PD. "You don't have the choice to say, 'I don't want this'. We get each other through those days of one or the other being down." Even though there are challenges, Vicki says that "Mike makes it easy-he's so independent! I feel more like a partner than a care-giver." Vicki knows that "things happen and don't happen and you just roll with it." She would rather put her energy into "what will make things better. When challenges come along, we just deal with them; it doesn't help to spend a lot of time complaining. We try not to stay there." She says, "Mike has always been extremely safety conscious because of his Paramedic training. I don't worry about him; he'll realize when it's not safe to do some things anymore (like driving) even before I do."

Vicki admits that she could take better care of herself. She taught in a school that was three stories and created a stair climbing circuit she followed after the students went home. Their current home has a basement and she walks up and down those stairs extra times a day. Now she is looking forward to attending Silver Sneakers exercise classes and then spending more time quilting. This is the first house they've had where she has a 'sewing room'. Vicki also handles their finances and other paperwork. Having been vegans and vegetarians in the past, they eat some chicken and steak occasionally. She wants to improve their diet and enjoys trying recipes from the Support Group's cookbook.

It is challenging for care-partners to reveal what they are proud of, but Vicki did mention that she was/is a good mom. Her daughters are generous with praise for their mother. She admits to being a good teacher and still has students that she is in contact with. She was the president of the Piecemaker's Quilt Club in Pagosa Springs. She wrote stories about vintage quilts that her friend recreated and patterned. They did four "Stories in Stitches" projects like this that were published in the magazine, Quiltmania. Vicki loves to write short stories.

Vicki still loves to read and currently her most engaging book is an Irish story, The Memory of Music: An Irish Family Saga of War and Redemption. She has borrowed an autographed copy of Jimmy Carter's biography and a stack of other books she looks forward to reading.

Articulate and confident, Vicki speaks of her deep spiritual convictions. She believes that "God loves me unconditionally and that I'm supposed to love everyone else the same way." She often returns to the wisdom of the 'Serenity Prayer' and believes it's really important to accept the things you cannot change and find the courage to change the things you can. In addition, Vicki realizes that a lot of people with PD don't like to be needy and accept help from other people. Even though they realize that just by your presence you care and want to be helpful, they have a hard time saying, 'yes, please help me'. "It is a delicate dance," Vicki says, "You want people to feel good about themselves and what they're doing. At the same time, you don't want to ruin their confidence by holding back your help and letting them fail."

Thank you, Vicki, for sharing your unique journey and wisdom with us.

We each have a story. I'm looking forward to hearing yours.

If you would like to share your story, please contact Ann Grant Martin, [redacted]

Ask the Doctor!

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

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

Untreated Sleep Apnea Raises Parkinson's Risk, but CPAP Helps

By Patricia Inacio, PhD, Parkinson's News Today, December 5, 2025

Analysis of veteran health records shows unmanaged apnea nearly doubles risk

- Untreated obstructive sleep apnea (OSA) nearly doubles Parkinson's disease risk.
- OSA causes brain stress, linked to Parkinson's pathology like alpha-synuclein changes.
- Early CPAP treatment for OSA reduces Parkinson's risk by 30% and improves outcomes.

An analysis of electronic health records from 11.3 million U.S. veterans suggests obstructive sleep apnea nearly doubles the risk of developing Parkinson's disease. But early treatment with continuous positive airway pressure (CPAP), the standard therapy for the condition, may cut that risk by about 30%, the study found, "If you stop breathing and oxygen is not at a normal level, your neurons are probably not functioning at a normal level either," lead author Lee Neilson, MD, assistant professor of neurology at Oregon Health & Science University and a neurologist at the Portland VA Medical Center, said in a university press release. "Add that up night after night, year after year, and it may explain why fixing the problem by using [continuous positive airway pressure] may build in some resilience against neurodegenerative conditions, including Parkinson's."

The findings support the introduction of "early screening and intervention of sleep-disordered breathing as a key strategy in supporting brain health," the researchers wrote.

The study, "Obstructive Sleep Apnea, Positive Airway Pressure, and Implications of Early Treatment in Parkinson Disease," was published in the journal *JAMA Neurology.*

LIFESTYLE CHANGES MAY SLOW NEURODEGENERATION

Parkinson's disease is the world's fastest-growing neurological disorder, driven by an aging population and possibly by lifestyle factors. Although lifestyle changes have been proposed as a way to delay neurodegeneration, evidence specific to Parkinson's disease is limited.

A hallmark of the disease is the accumulation of phosphorylated alpha-synuclein, a modified form of the alpha-synuclein protein that can clump and form insoluble aggregates, leading to the death of nerve cells that produce dopamine, a neurotransmitter needed for coordinating muscle movement.

Obstructive sleep apnea (OSA) is marked by pauses or reductions in breathing during sleep. These events result in intermittent drops in blood oxygen and spikes in carbon dioxide, leading to metabolic, inflammatory, and cardiovascular stress. In the brain, these repeated episodes of low oxygen can cause mitochondrial dysfunction, a process that has been linked with Parkinson's.

People with OSA have been shown to have elevated blood levels of phosphorylated alpha-synuclein and a reduction in dopamine in the striatum, a brain region crucial for motor control.

Despite such biological clues, studies investigating whether OSA increases Parkinson's risk have produced mixed results. Some found no connection, while others — especially those using large electronic health record datasets — suggested an association but were limited by imprecise diagnoses and inadequate control for confounding factors.

No prior research has investigated whether treating OSA with continuous positive airway pressure (CPAP) might reduce the potential increased risk of Parkinson's, the researchers said. CPAP delivers a steady stream of air through a mask worn over the nose or both the nose and mouth, ensuring that the airways remain open and breathing is maintained without interruption.

ANALYZING HEALTH RECORDS

The OHSU researchers analyzed health record datasets from 11.3 million U.S. military veterans (90.1% men, with a mean age of 60.5) who received care through the Department of Veterans Affairs from 1999 through 2022.

About 1.5 million participants (13.7%) had OSA, and 144 ,643 (9.3%) of those had documented CPAP use. Veterans with OSA were generally older and had a higher body mass index (BMI), a measure of body fat.

Over an average follow-up time of 4.9 years, veterans with OSA showed a significantly higher incidence of Parkinson's, corresponding to a 1.92-fold increase in the risk of developing the disease, than those without OSA.

"It's not at all a guarantee that you're going to get Parkinson's, but it significantly increases the chances," said Gregory Scott, MD, PhD, assistant professor of pathology in the OHSU School of Medicine and a pathologist at the Portland VA.

This increased risk remained consistent across multiple analyses, including those that adjusted for BMI and included a one-year delay before counting diagnoses. The effect was especially pronounced in women with OSA, who had a 4.24-fold higher risk.

When OSA severity was assessed using computer-processed clinical notes, researchers found that both mild and severe OSA increased Parkinson's risk, with severe OSA linked to earlier and higher incidence.

The researchers also evaluated whether CPAP use changed the risk of developing Parkinson's. CPAP use within two years of an OSA diagnosis was associated with a significant reduction in Parkinson's incidence. After five years, CPAP users had a 31% reduced risk of developing the disease. This protective effect remained after adjustments for multiple factors, including BMI, blood flow disorders, sleep-related disorders, traumatic brain injury, and medications that affect dopamine signaling.

Further analysis showed that among people who eventually developed Parkinson's, CPAP users did not differ from nonusers in early motor or nonmotor symptoms. However, after diagnosis, early CPAP use was associated with lower rates of falls, fractures, and mortality, suggesting additional long-term benefits.

While people may often resist treatment with CPAP, "the Veterans who use their CPAP love it," Scott said. "They're telling other people about it. They feel better, they're less tired. Perhaps if others know about this reduction in risk of Parkinson's disease, it will further convince people with sleep apnea to give CPAP a try."

FDA Approves Bilateral Ultrasound for Parkinson’s Symptoms

By Andrea Lobo, Parkinson’s News Today, July 11, 2025

The U.S. Food and Drug Administration has approved Exablate Neuro, Insightec’s platform for noninvasive, MRI-guided focused ultrasound therapy, for the bilateral treatment of motor symptoms in patients with advanced Parkinson’s disease who no longer respond to medication.

The therapy targets regions within the pallidothalamic tract, a brain pathway involved in motor control and coordination. Exablate was previously approved for unilateral treatment, or that targeting only one side of the brain, of Parkinson’s motor symptoms.

The approval was supported by positive data from a clinical trial (NCT04728295) conducted across the U.S., Europe and Asia, that tested the effectiveness of Exablate on both sides of the brain. Insightec expects the results from the study to be published later this year.

The company said it plans to launch the bilateral procedure in selected centers during 2025 as it continues efforts to establish reimbursement pathways and provide broader access to the treatment.

“This milestone reflects our commitment to expanding access to safe, effective, and incisionless treatment options for people living with Parkinson’s disease,” Maurice R. Ferré, MD, Insightec’s CEO and chairman, said in a company press release. “With this new indication, we’re advancing care for movement disorders and opening the door to life-changing treatment for those who need it now and in the years ahead.”

FOCUSED ULTRASOUND TARGETS BRAIN PATHWAY

Parkinson’s is caused by the progressive dysfunction and death of dopaminergic neurons, nerve cells in the brain that are responsible for making dopamine, a signaling molecule involved in motor control. This results in the disease’s motor symptoms, including resting tremors, slowness of movement, rigidity, and postural and gait issues.

The mainstay treatment includes levodopa, which contains a molecule called L-DOPA that cells can use to produce dopamine, thus boosting dopamine levels. However, its long-term use is associated with dyskinesia — sudden, uncontrolled movements — and motor fluctuations when symptoms are not fully controlled with the medication.

In such cases, patients may undergo surgical procedures, such as deep brain stimulation to normalize the electrical activity in the brain through small wires implanted in the brain, and ablation, or lesioning surgery, to create small lesions in certain brain areas.

Exablate Neuro uses focused ultrasound, guided by MRI, to destroy targeted areas in the pallidothalamic tract through an intact skull. This pathway connects two brain regions involved in motor control and coordination, the globus pallidus and the thalamus.

The procedure does not require implanted hardware and poses less risk than traditional, surgical interventions.

“The ability of MR-guided focused ultrasound to precisely target both sides of the brain and improve disabling symptoms, without the need for a surgical incision or anesthesia, offers new hope for persons with Parkinson’s disease,” said Arif Dalvi, MD, director of the comprehensive movement disorders program at Palm Beach Neuroscience Institute and investigator in the trial.

Exablate Neuro was previously approved to treat essential tremor, shaking that is usually associated with movement, and tremor-dominant Parkinson’s, by targeting the Vim nucleus of the thalamus, a brain region responsible for causing tremors.

The treatment is available for several movement disorders at centers worldwide, including 84 in the U.S.

ITEMS THAT ARE FREE FOR THE TAKING:

The following items are items that are available but are items that are free for the taking, meaning these items do not need to returned. These are items that we do not need in the Lending Locker or are personal use/ disposable items.

If you see anything that you are interested in, please contact Julie at info@co-parkinson.org and help us free up some space!

Ankle brace (elastic pull on)	1
Back support belt (size XL)	1
Bibs (Adult)	8
Blood Pressure Monitor	1
Catheter supplies (unopened)	1
Diabetes supplies	1
Easy sip hydrate bottle	1
Gate belt	7
Gloves: powder free-vinyl exam LG bx	100
Handicap dinner plates w/ built-in rims	3
Handicap mountable pull handles	1
Hospital gown	1
Hospital slippers–XL&XXL	2
Leg compression machine	2
Liquid thickening packets	1 pkg
Male portable urinals, new in individual pkgs–32oz capacity	2

Reusable bed pads	8
Rims for plates	2
Slipper socks extra-wide (new)	1 pair
Slipper socks XXXL, men size 11+ or women size 12+ (new)	1 pair
Slipper socks L/XL (used but washed)	6 pairs
Slipper socks xtra-wide (used but washed)	5 pairs
Simply Thick easy mix powder (to thicken liquids)	1
Under-pads (disposable) – XL (29”x35”) – maximum absorbency, opened package - Walgreens Brand	1 pkg
Under pads - generic	1 pkg
Under pads (washable)	3
Prevail under pads – 25 count	1 pkg
Washable under-pads – 3 count	1
Wash cloth (disposable, no-rinse, self-sudsing)	1
Weighted utensils	6
Transfer pads – can handle a person up to 300 lbs	4

Briefs (generic), L/XL – 18ct	4 pkgs
Briefs (unisex stretch briefs), L/XL, ultimate absorbency, opened package - Walgreens Brand	1 pkg
Cardinal health guards for men - extra heavy absorbency	2 pkgs 14ct
Depend men’s fresh protection plus underwear. L 35”-43”	84 ct
Depend men’s guards 1 unopened/3 opened few missing	8 pkgs 52 ct
Kroger men’s guards, maximum absorbency, one size fits all (opened)	52 ct
McKesson super briefs with tabs, moderate absorbency, XL	15 ct
McKesson super underwear, moderate absorbency, XL	14 ct
McKesson super underwear, moderate absorbency, XL (opened)	14 ct
McKesson super underwear, moderate absorbency, L (opened)	18 ct
Men’s large (35-43) Depend pull-up underwear – ultimate absorbency	1 pkg 84 ct
Prevail daily male guards – one size fits all – maximum absorbency	2 pkgs 14 ct
Prevail Nu-fit daily briefs w/ fastener tabs–32-44” size–max absorbency-	2 pkgs 16 ct
Tena unisex briefs, L (48”- 59”), super absorbency	2 pks 14 ct
Walgreens deposable under-pads – XL (29”x35”) – maximum absorbency – new items but open package	1 pkg
Walgreens unisex stretch briefs – L/XL fits 40-70” – ultimate absorbency – new items but open package	1 pkg

LENDING LOCKER INVENTORY

If you would like to borrow any equipment listed here, please contact: Mary Sauvain at [redacted].

New & Different Items

* Ramp with rails – 10 foot
* Portable ramp – 10’x4’
* Liberty folding, reclining wheelchair with headrest, tray & cushions

AccVoice TV speaker w/ hearing aid technology
Air mattress
Back brace
Bed canes
Bedding lifters
Bed pan
Bed rails
Bed risers
Bedside toilets
Blood pressure cuff
Canes
Cervical traction machine
Chair-side food tray
Chair/sofa canes
Crutches
Exercise bikes
Exercise floor pedals
Homedic massagers
Hospital beds
Hospital bed food trays
Hoyer Lift
Lazercue for freezing help
Lift chairs
Lift-ware tremor compensating utensils
Monthly med carousel w/alerts
Pick-up assists
Punching bag - freestanding
Ramp (10 foot)
Shower seats/benches
Sock helper
Squatty potty
Standup assist transport lift
Standup Walker
Suction cup hand rail
Swivel seat
Toilet arm assist
Toilet rails
Toilet seats
Transfer poles
Transport chairs
Tub rails
U-step
Walkers with wheels & seats
Waterproof mattress protector (Twin)
Wheelchairs

Colorado Parkinson Foundation, Inc.
1175 Kelly Johnson Blvd., Suite 100
Colorado Springs, CO 80920

PARKINSON'S PERSPECTIVE **MARCH 2026**

Coming Events

See inside for more information

March 7: Reg Mtg at Central United Methodist Church – 10 am
Program: Silver Key Services
Speaker: Jayme Holligan, Director of Volunteer, Events, and Community Engagement

April 4: Reg Mtg at Central United Methodist Church – 10 am
Program: Probate Matters
Speaker: Lynn Vanatta-Perry, Attorney

May 2: Reg Mtg at Central United Methodist Church – 10 am
Program: Breakout Sessions
Moderators: Kathleen Foster – Parkinsonians
Jill Reid & Julie Donahue – Caregivers

June 6: Reg Mtg at Central United Methodist Church – 10 am
Program: Motivation, Learning Tasks, and Behavior Change with PD
Speaker: Ryan Mueller, PT/DPT/NCS

July 4: Reg Mtg at Central United Methodist Church – 10 am
Program: TBD

August 1: Reg Mtg at John Venezia Park–the Barn pavilion – 11 am
Program: Picnic!!

September 5: Reg Mtg at Central United Methodist Church – 10 am
Program: TBD

October 3: Reg Mtg at Central United Methodist Church – 10 am
Program: Scam Prevention
Speaker: Officer Paulette Masias, Colorado Springs Police Department

November 7: Reg Mtg at Central United Methodist Church – 10 am
Program: Breakout Sessions
Moderators: Kathleen Foster – Parkinsonians
Jill Reid & Julie Donahue – Caregivers

December 5: Reg Mtg at Central United Methodist Church – 10 am
Program: Christmas Party!!
Entertainment: The Song Spinners

More useful websites:

https://parkinsonsnewstoday.com; www.parkinsonrockies.org; www.parkinson.org; www.nwpf.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; https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers; laurawayman.com