

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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Jill Reid (XXX) XXX-XXXX

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Programs: Jill Reid

Educational Outreach: Jill Reid **Membership:** Carole Henrichsen

Chaplain: Rusty Merrill
Parkinson's Awareness Day:
Vacant

Photographer: Annette Garcia Lending Locker Coordinator: Mary Sauvain (XXX) XXX-XXXX

Main Dish Coordinator:
Bill Hicks (XXX) XXX-XXXX or potluck@co-parkinson.org

Picnic: Carole Henrichsen and Janet Adams

Media Relations: Mary Sauvain

Medical Advisor: Dr. Brian Grabert, MD

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MJ Thompson (XXX) XXX-XXXX

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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)

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

We will NOT be Zooming or 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.

May Program:

Topic: Break-out Sessions

Moderators: Parkinsonians: Kathleen Foster and for the caregivers: Jill Reid & Julie

Pfarrer

The Parkinsonians get together in one room and the caregivers in another to discuss their questions and concerns about their PD journey.

A Potluck will follow the monthly program

May Potluck: SALADS!

If you would like to sign up to be one of the providers of a main dish or to bring a side dish/dessert, you can contact Bill Hicks at (XXX) XXX-XXXX or potluck@co-parkinson.org, no later than Wednesday April 30th 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!

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.

Question #1: If someone is on Rytary, is it okay to add a 25/100 sinemet (carb/levo) tablet (or a half of one) on occasion when the person with Parkinson's feels like he needs a little more carb/levo to hold him over until the next Rytary dose? In other words, can you mix the two?

Answer: There is no reason you cannot combine "immediate release" Carbidopa/Levodopa 25/100 [CD/LD or Sinemet] with Rytary. It is helpful to recall that Rytary is 1/3 immediate release CD/LD and 2/3's delayed released CD/LD. If this is a constant requirement, then one may want to try the next larger dose strength of Rytary. Rytary comes in 4 dosing strengths: 95 mg of L-Dopa; 145 mg of L-Dopa; 195 mg of L-Dopa; 245 mg of L-Dopa.

Question #2: Does melatonin interfere with any of the Parkinson's medications?

Answer: Melatonin should not interfere with PD medications. There is good evidence to support the use of Melatonin for helping sleep quality and REM Sleep Behavior disorder. Because it is an anti-oxidant it may have some theoretical neuro-protective qualities. There are few contraindications for the use of melatonin.

The President's Corner

Jill Reid-Acting President, CPF & CSPSG



You caregivers have been on my mind a lot lately. I actually worry more about you than about our folks who have Parkinson's. Caregiving is an honor, but I know it comes with a lot of stress and very little opportunities to relieve it. I wonder what more, if anything, the support group and our 501c3 umbrella organization, the Colorado Parkinson Foundation, can do for you. We offer reimbursement for occasional respite care. Our caregivers' support group continues to meet the

third Thursday of each month at Central United Methodist Church between 10 am and noon. We have caregiver breakout sessions once a quarter during our monthly meetings. You have each other at every monthly meeting, even when we have guest speakers instead of breakout sessions. But I know that it's not enough. Please tell me and anyone else wearing a green name tag at our meetings any ideas you may have of real, practical ways we can help you.

As I wrote last month, the brother of a friend of mine is an engineer who is a close friend of a man with Parkinson's. Jon is always on the lookout for things that can make his friend's life easier. Recently, he found AnkhGear, a company which created a revolutionary magnetic zipper that combines convenience with cutting edge design. The bottom of the zipper has two magnets that come together so you don't have to aim the locking mechanisms together. All you have to do is marry up the magnets, pull up on the zipper tab, and voila! you are zipped up. You can check out the zipper at ankhgear.com, and I'll bring the samples that Jon sent me to the May meeting.

This month's comedy is Out to Sea, starring Jack Lemmon and Walter Matthau. I shouldn't have to work very hard to convince you that this one is funny since the Lemmon/Matthau pairing is always entertaining and highly humorous. In search of lonely ladies with big bank accounts, Matthau cons Lemmon into joining him on an all-expenses-paid luxury cruise — with them signed on as dance hosts! You can readily imagine that it doesn't take long before they find themselves in proverbial rough water!

Care Partner and Helpline Information

L______

The Parkinson Foundation has four resources for caregivers, including a manned Helpline that is available by phone or computer. These resources are especially important for caregivers experiencing burnout, depression, and/or isolation.

- 1. **Care Partners:** This is a good blog post and directs people to their online learning lab with additional training:
 - https://www.parkinson.org/blog/care/address-prevent-burnout
- 2. Full overview of Care Partners resources:

https://www.parkinson.org/resources-support/carepartners

3. Care Partner Conversations:

https://youtu.be/fiQOukEIKWg?feature=shared

4. **Helpline:** https://www.parkinson.org/resources-support/helpline or call the Parkinson's Foundation Helpline 1-800-4PD-INFO (1-800-473-4636) for answers to your Parkinson's disease (PD) questions. Staffed by nurses, social workers and health educators, the Parkinson's Foundation Helpline is here to support you in ANY possible way.

The Parkinson's Foundation Helpline is open Monday through Friday from 7 a.m. to 5 p.m. MT. We can assist you in either English or Spanish. You can also email us with a question at any time: Helpline@Parkinson.org or interact with us and the Parkinson's community at large on PD Conversations.

What are my options when I dial 1-800-4PD-INFO?

Press 1 or stay on the line to speak to a Helpline specialist in English. Press 2 to speak with Donor Services.

Press 3 to speak with a Helpline specialist in Spanish.

LENDING LOCKER INVENTORY

If you would like to borrow any equipment listed here, please contact: Mary Sauvain at (XXX) XXX-XXXX.

AccVoice TV speaker w/ hearing aid technology

Air mattress
Back brace

Bedding lifters

Bed pan

Bed canes

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
Hover Lift

Lazercue for freezing help

Lift chairs

Lift-ware tremor compensating utensils

Monthly med carousel with reminder alerts

reminder alerts
Pick-up assists

Punching bag - freestanding

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

ITEMS THAT ARE FREE FOR THE TAKING:

Contact Julie Pfarrer if interested in these items at info@co-parkinson.org

1

4

1

1

8

1

2

4

2

1

1

2

8

1

4

3

pkqs

2

pkgs

8

pkgs

1

4

pkgs

2

pkgs

2

pkgs

2

pkgs

pkg

7-day/7 compartments per day pill dispenser

7-day medium-size pill dispenser

Aluminum walker tennis balls
Aluminum walker tray

Bedside toilet commode liners: 3 big boxes with 6 smaller boxes in each

 Bibs
 8

 Blood Pressure Monitor
 1

 Disposable bed pads
 7

Gate belt

Easy sip hydrate bottle

Hospital bed bedding: 3 sets of sheets

1 mattress pad

2 washable bed pads (new)

Hospital gown
Hospital slippers–XL&XXL
In-bed knee lift

Male portable urinals, new in individual packages – 32 oz capacity

Plastic handicap plate

Plastic handicap bowl

Pill crusher, storage, & drink cup combination

Rehab squeeze balls
Reusable bed pads

Waterproof twin mattress protector

Weighted utensils 6
Seat cushion 1
Thick-it 1

Transfer pads – can handle a person up to 300 lbs

Attend advanced briefs,

maximum protection–lg–24 ct

Cardinal health guards for men - extra heavy absorben-

cy -14ct

Depend men's guards-52ct 1 unopened and 3 opened

with a few missing

Fitright guards for men–52ct

Generic briefs, L/XL – 18ct

Prevail daily male guards – one size fits all – maximum absorbency-14ct

Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size maximum absorbency-16ct

Women's Always Discreet s/ m/ p/m maximum protection underwear – 42ct

Women's Always Anti-Bunch extra long panty liners. Extra protection – 92ct

Program Review: April 5, 2025

By Jill Reid

Solutions to Pay for the High Cost of Long-Term Care Presented by Kim Searles

According to guest speaker, Kim Searles, Director of Education for Beneficent, Beneficent specializes in serving the middle class by preserving assets for families while securing funding for long-term care options (assisted living, memory care, nursing homes, and non-medical services (in-home care and adult day care)). [By the way, the numbers quoted in her presentation change annually and are good only in 2025.]

Beneficent's mission is to help the middle class family whose spouse has a chronic illness or disability since his assets tend to disqualify him for long-term-care programs other than long-term-care insurance. Such middle class families can find themselves in the situation of having to run out of money and spend down their assets before they qualify for long-term-care government programs. Fortunately, middle class families have three viable long-term-care options available to them: private pay, long-term-care insurance, and two long-term-care programs that Beneficent is licensed to offer. Beneficent can help with all three options and avoid the need to spend down assets. They can ensure that seniors and disabled adults can access the care required without the burden of financial distress, care which can improve healthcare outcomes and lower rehab and hospital admissions.

In addition, the long-term-care programs that Kim talked about can help caregivers. Caregiving is an honor, but it comes with stress. Caregivers are often overworked, and some give up their careers to support their loved ones. These programs can pay a caregiver or care facility if that assistance is needed.

Pre-planning is an important step for applicants to take as early as possible. Beneficent offers free, no-obligation pre-planning appointments, which include helping fill out long-term-care program applications. Applicants are welcome to handle carrying out the free plan themselves or hire Beneficent to carry out the plan for them. Estimated fees for Beneficent to do all the work will be provided during the pre-planning appointment.

There are two government long-term-care programs for which middle class families can qualify: Long-term Care Medicaid (this is NOT low-income Medicaid) and VA Aid and Attendance Private Pay (which provides tax-free funds).

VA Aid and Attendance is a monthly monetary benefit paid to veterans, dependent spouses, and surviving spouses who need home or facility care. The benefit is tax-free and does not need to be paid back. For the veteran, dependent spouse, or surviving spouse to qualify for VA Aid and Attendance, the veteran must have served at least 90 days of active duty, one day of which was during wartime. The applicant must have no more than \$159,240 in assets (NOT including one car and a home) and be totally disabled (needing help with at least two Activities of Daily Living). Beneficent does not charge veterans for getting them into this program.

Since Beneficent is staffed by Certified Medicaid Planners, it is a great resource for overcoming access limits and getting people qualified for Long-term Care Medicaid with the least amount of erosion of personal assets. An applicant must be at least 65 and blind or disabled (in need of help with two Activities of Daily Living). There is a monthly income cap; but if the applicant's income exceeds that amount and he can't afford private-pay care, he can put his income in an Income Trust. One car and one home are exempt from asset calculations. An applicant can give assets away within the last 5 years and still get care paid for. The spouse's income is of no consideration to qualify. An applicant can qualify even if he doesn't qualify for long-term-care insurance.

The Department of Health and Human Services says that 70% of applicants that apply for long-term care on their own are denied benefits due to inaccurate information and incomplete filing. Beneficent, on the other hand, has a 100% success rate, even if the applicant is over-qualified.

Here are some quick myth-busting facts about Long-term Care Medicaid in Colorado:

- It covers the cost of assisted living, memory care, nursing homes, and non-medical services (in-home care and adult day care).
- Applicants do NOT have to sell their homes in order to qualify.
- 3. With proper planning, Colorado estate recovery against a home can be avoided.
- 4. Assets can be given away in the 5-year look-back period. The state will assess a penalty of time before benefits will begin based on how much was given during that period.
- 5. The income of the spouse who does not need care is of no consideration to qualify. The spouse's income does not affect the one needing care.
- 6. Medicaid Long Term Care is for middle class individuals as well as low-income people.
- 7. Clients can qualify for Long-term Care programs if they can't qualify for long-term-care insurance.

An application for long-term-care programs cannot be turned in until the applicant needs help with two Activities of Daily Living.

Case studies:

Mr. Johnson is in a rehab center and must be discharged next week.

They have a home, car, 401K and they have anywhere between \$2,020 - 200,000 in cash. **Solution:** Mr. Johnson's assets can all be given to his spouse without any penalty. She can have the assets assigned to her, and Mr. Johnson will then qualify for Long-term Care Medicaid.

Betty was residing in a non-Medicaid Certified Assisted Living Facility.

She declared a vehicle, a life insurance policy, and cash.

- Prior to application, Betty sold her property receiving \$193,000 in cash
- · Betty's vehicle is exempt
- Betty's life insurance policy had a face value of \$25,000 and a cash value of \$2,000 which she transferred to a family member
- Betty gave a cash gift of \$170,000 to a family member
- The penalty assessed by the State was 20 months (based on cash gift and life insurance transfer)
- A spend down fund account was created for \$35,000 increasing her monthly income for 20 months

Outcome: Betty will continue to live in her current Assisted Living Facility during the penalty and has the money from the spend-down account to pay for this care.

Beneficent can be reached by phone at 719.645.8350

or by email at info@doinggoodforothers.com.

Their website is www.doinggoodforothers.com.

Thank you____for 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! **June Newsletter Input** Deadline: May 16th

Call or e-mail Julie with your input for the newsletter at: (XXX) XXX-XXXX

info@co-parkinson.org

- Ken Harder

Judy Ireland

Don Jaeger

- Donald Joiner

- Becky Helmsing - Ross Huddleson

May CSPSG Executive Committee Meeting

May 6th @ 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.



- Janet Adams
- Owen Briggs
- Pat Bush
- Deborah Carnes
- Patrick Carrigan
- John Fly
- Joan Foutz
- Carol Gugat
- Kurt Hansen
- Sue Coen
- Donna Malmgren - Phil McDonald
 - Carol Morris
 - Jaros Murphy
 - Lu Ann Nickelson

- Caitlin O'Reilly
- Eileen O'Reilly
- Katrina Rochon
- Randy Rogers
- Meredith Sage
- Henry Schulz
- Sonya Shannon
- Hope Winkler
- Valerie Wollen

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

Potluck Favorites — Shakin' & Bakin' Cookbook



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.

Recipe of the Month: Pistachio Herb Salad

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.

Ingredients:

2 C chopped romaine lettuce

½ C cubed avocado

½ C chopped tomato

1/4 C finely chopped red onion

2 Tbl olive oil

2 T red wine vinegar

1/4 tsp salt

1 tsp minced fresh thyme or 1/4 tsp dried

1 tsp minced basil or 1/4 tsp dried

1/4 tsp dill

1/8 tsp pepper

1/4 C pistachios

Directions:

- In a small bowl, combine romaine, avocado, tomato and onion.
- In a jar with a tight-fitting lid, combine the oil, vinegar and seasonings.
- Drizzle over salad and toss to coat.
- Sprinkle with pistachios.
- Serve immediately.

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 (XXX) XXX-XXXX.

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

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 (XXX) XXX-XXXX.

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 or (XXX) XXX-XXXX.

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 (XXX) XXX-XXXX.

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 Syble Krafft or Barry Hanenburg.

Other Opportunities:

Trazer — Brought to you by the YMCA of the Pikes Peak Region:

Designed for injury recovery, injury prevention, and enhancing performance, Trazer aligns perfectly at the point where biology, technology, and data intersect to track, measure, and improve physical and cognitive function regardless of age or capability.

A multi-purpose technology with wide-ranging applications spanning healthcare, senior care, sports, wellness, orthotics and prosthetics, Trazer helps every body move better.

> For more information or to schedule, stop by the YMCA front desk.

Adult Speech Therapy:

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

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.

PD Exercise Classes:

Falcon Exercise Group

Mon & Fri: 11:00 - noon. Grace Community Church. For more info contact Catherine Reed at (XXX) XXX-XXXX.

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

SAD NEWS!

The support group has recently lost 3 of our Parkinson's members. They are Sherry Whitaker who passed away in November of Lewy Body Disease, Jerry Nelson who passed away on March 27th and Deborah Herrman who passed away on March 28th. Deborah Herrman was a longtime member of our support group and the mother of our beloved newsletter editor, Kristy Schleiker. We will greatly miss all of them. We have not received any information about memorial services for Sherry.



Jerry Nelson passed away on March 27, 2025 at the age of 84. He grew up in Fullerton, North Dakota and graduated from Fullerton High School followed by the University of North Dakota. Jerry was a lifelong employee of Bridgestone/ Firestone. After spending the early part of his career moving around the country, he decided to return to Colorado permanently and purchased the downtown Colorado Springs franchise. Jerry and his second wife, Joy, lived in Manitou and

enjoyed biking and hiking the trails in the surrounding area.

Jerry enjoyed spending time with his son Mike, daughter-in-law Danielle, and their children after they moved back to Colorado Springs in 2005. Mike's family has particularly fond memories of Jerry taking them to Denver Bronco football games and boating at Lake Pueblo during summertime.

In addition to being a caring father, grandfather, husband, brother, and son, Jerry was a deeply loved member of the Manitou and Colorado Springs communities. He spent most weekends at First Presbyterian Church in downtown Colorado Springs, where he volunteered and mentored others while cultivating many friendships. Jerry was compassionate and selfless, always looking for ways to help others. His thoughtful, witty, wise, and generous character was apparent in everything he did. Jerry was diagnosed with Parkinson's disease in 2021. He will be greatly missed.

Jerry was preceded in death by his wife, Joy and is survived by his son, daughter-in-law and his three grandchildren, as well as Joy's daughter. There will be a Celebration of Life on Friday, May 9th at 1:00pm held at First Presbyterian Church 219 E Bijou St, Colorado Springs, CO 80903.



Deborah Herrman passed away on March 28, 2025, at the age of 72. She was born and lived the majority of her life in Colorado Springs. Debbie was a woman of immense creativity and passion. She excelled at jewelry making, flower arranging, painting, scrapbooking, and countless other crafts. Throughout her career, Debbie worked at numerous military installations, where she ran multiple craft shops at various bases. She also served with Morale, Welfare, and Recre-

ation on Fort Carson, working at the Information, Tickets, and Recreation (ITR) office and the Bowling Alley. Debbie loved working with and supporting the military Soldiers and their families. She retired from Federal Service on Ft Carson in 2003.

Debbie was diagnosed with early-onset Parkinson's Disease in 1996 and later with Dementia in 2023. Despite these obstacles, she maintained her spirit and love for her family.

Debbie was a devoted wife, mother, grandmother, and greatgrandmother and is survived by her loving husband of 44 years, Leon Herrman, five children, nine grandchildren and two greatgrandchildren. She will be greatly missed by all who knew & loved her.

A rosary and mass service will be held at 10:30am, Friday, May 30, 2025 at St. Dominic's Church, located at 5354 S US Highway 85/87, Security, CO 80911. Interment will follow at the Pikes Peak National Cemetery. A Celebration of life will follow at 2:00pm, with a reception at the American Legion Post #38, in Security, CO. All friends & family are welcome to attend. In lieu of flowers, the family kindly requests that you consider making a donation to the Colorado Parkinson Foundation and the Colorado Springs Parkinson's Support Group. This local support group was an invaluable resource for Debbie and her family for nearly 30 years. Donations can be made at: https://co-parkinson.org.

Chinese Scientists Make Breakthrough in Blocking Parkinson's Progression

By UNB News - 2/23/25

Chinese researchers have identified a new therapeutic target for Parkinson's disease, a neurodegenerative disorder with high disability and mortality rates, and have successfully discovered a promising small-molecule drug.

A research team from Huashan Hospital, affiliated with Fudan University in Shanghai, achieved this breakthrough, which could enable early intervention in Parkinson's disease and offer hope for slowing its progression. The findings were published on Friday (Beijing time) in the renowned academic journal Science.

Parkinson's disease, the second most common neurodegenerative disorder after Alzheimer's, affects around 3 million people in China—roughly half of the global total. Patients often first experience a diminished sense of smell and sleep disturbances before developing more severe movement-related symptoms. As the disease advances, the effectiveness of existing medications decreases, significantly impacting patients' quality of life.

While current drugs and surgical treatments mainly alleviate symptoms without halting disease progression, further research into its underlying mechanisms and targeted therapies remains essential, scientists say.

Following five years of dedicated research, the team identified FAM171A2 as a crucial risk gene for neurodegeneration. Leveraging artificial intelligence, they screened over 7,000 approved compounds and identified bemcentinib, an anti-cancer agent currently in clinical trials, as a promising candidate.

According to the researchers, the small-molecule drug effectively prevents the interaction between FAM171A2 and the pathogenic protein associated with Parkinson's.

Team leader Yu Jintai stated that, based on an international patent, future efforts will focus on pre-clinical research and the development of small-molecule drugs, antibodies, and gene therapies for Parkinson's disease, with the goal of advancing clinical trials and innovative treatments.

The elderly, particularly those over 60, are more susceptible to Parkinson's. As China's

population continues to age, this medical breakthrough has generated optimism among academics, medical professionals, and patients, with expectations that it will lead to practical applications soon.

"The experimental results have allowed us to precisely understand the pathophysiological mechanisms of Parkinson's disease, bringing us closer to overcoming a challenge long considered insurmountable," said Wang Jian, director of the neurology department at Huashan Hospital, a national medical center for neurological diseases.

A Science journal reviewer described the discovery as a "holy grail" in Parkinson's research, emphasizing its potential to prevent the spread of pathological changes and, ultimately, the disease itself.

As neurological diseases like Parkinson's and Alzheimer's pose growing global public health and social challenges, Chinese experts are urging increased efforts in brain science research. They highlight the need for improved diagnostic tools, early intervention strategies, and novel treatments to enhance patients' quality of life.

LCIG, DBS Show Quality of Life Gains, Symptom Easing: Real-World Study

By Patricia Inacio, PhD - Parkinson's News Today, 7/21/23

infused directly into the intestines, and subthalamic deep tinuous infusion, 19 with LCIG, and 34 with STN-DBS. brain stimulation (DBS), but not with a continuous subcutaneous apomorphine infusion, according to a real-world, single center study.

Apomorphine also didn't show any major changes in pa- ration and higher nonmotor scores. tients' nonmotor or motor symptoms. Those given Duopa showed significant motor symptoms gains, however, and patients who received STN-DBS saw improvements in both.

Because patients had different characteristics at the start of assessing and offering device-assisted treatment options," three device-assisted therapies for Parkinson's disease," the apomorphine group. which was published in npj Parkinson's Disease.

A feature of Parkinson's disease is the progressive loss of the brain's dopaminergic neurons, or nerve cells, that produce the neurotransmitter dopamine — a chemical messenger essential for muscle control.

Standard treatment includes levodopa and its derivatives, which provide cells more material to make dopamine. However, with prolonged treatment patients can develop off episodes when symptoms aren't adequately controlled between doses. Involuntary, jerky movements, or dyskinesia, can also

'Clueless' Gene May Lead to New Parkinson's Treatments: Fly Model

sodes

help ease off episodes and dyskinesia.

Among these are apomorphine (sold as Apokyn, among others) that mimics dopamine's activity in the brain. Injected subcutaneously (under the skin) with a pen, it's approved in the as a continuous infusion during the day.

Duopa, a levodopa/carbidopa intestinal gel (LCIG), has been shown to efficiently treat motor fluctuations. It's administered with a portable pump into the duodenum or upper jejunum by a permanent tube that's been surgically inserted.

Deep brain stimulation (DBS) is a nondestructive surgical approach that involves placing a device inside the brain to deliver electrical impulses to stimulate specific brain areas.

Despite the number of studies that have tested each strategy's effectiveness, few have compared the three with respect to patient outcomes, leading researchers in Australia to compare nonmotor and motor fluctuations, and quality of life, with each strategy at six and 12 months in a real-world observational study.

A total of 66 patients (46 men, 20 women; median age at start of treatment, 62) followed at the Neurology Department,

Parkinson's disease patients' quality of life significantly im- Westmead Hospital, Australia between 2014-2019 were anaproved with Duopa, a formulation of levodopa and carbidopa lyzed. Among them, 13 were treated with apomorphine con-

> At the start of the study, the patients in the STN-DBS group showed significantly less severe cognitive, nonmotor, and motor scores, while the LCIG group had a longer disease du-

The median total levodopa equivalent daily dose (LEDD; a sum of all Parkinson's medications taken) significantly increased in the LCIG group after six (median, 2,014.5 mg) and 12 months (median, 2,038 mg) over the beginning of the the study, such as symptom severity, however, "treatment study (median, 1,358 mg). In contrast, those receiving STNcenters should be aware of this potential confounder when DBS saw a significant reduction in LEDD, decreasing from 1,125.7 mg at baseline to 475 mg after six months and 462.5 researchers wrote in "A single centre prospective study of mg after 12 months. No changes were observed in LEDD in

> Initially, all the apomorphine and LCIG patients began with a 16-hour infusion rate. Only one patient in the apomorphine group switched to a 24-hour infusion after 12 months. In the LCIG group, after six months, four patients transitioned to 24 hours. Changing to a 24-hour infusion was prompted by freezing of gait, a sudden and temporary inability to begin or continue walking.

> During the 12 months of follow-up, the STN-DBS group had fewer clinical visits (median, 8). The apomorphine group had a median of 10 clinical visits and the LCIG group had 15.

Quality of life gains with LCIG, STN-DBS

Quality of life, as assessed using the Parkinson's disease questionnaire (PDQ-39), significantly improved at both six Comparing device-assisted strategies for treating off epi- and 12 months in the LCIG and STN-DBS groups. No improvements were seen in the apomorphine group.

Several device-assisted strategies have been developed to Only STN-DBS patients saw an ease in nonmotor symptoms at both six and 12 months, as shown by a decrease in Unified Parkinson's Disease Rating Scale (UPDRS) part I scores, from a median score of 13 to 10.5 after six months, and 8.5 after 12 months.

U.S. for managing off episodes. It can also be administered Patients in both the STN-DBS and LCIG group saw significant gains in motor parameters, but none were seen in the apomorphine group. The gains were in UPDRS-IV scores, which assesses treatment-related complications, and the Unified Dyskinesia Rating Scale (UDysRS), which measures dyskinesia.

> The LCIG group saw a reduction in freezing of gait, which was measured using the New Freezing of Gait Questionnaire (FOG-Q). These improvements were observed up to 12 months.

> At the six-month mark, there were no changes in caregiver burden for any group. However, at 12 months, only the STN-DBS group showed a reduced caregiver burden, as measured using in the Zarit Burden Interview and Caregiver Strain

> Side effects occurred in 59% of patients, but none were deemed severe or resulted in hospitalization or death.

Colorado Parkinson Foundation, Inc.

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PARKINSON'S PERSPECTIVE

MAY 2025

Coming Events

See inside for more information

May 3: Reg Mtg at Central United Methodist Church —10 am

Program: Break-Out Sessions

Moderators: Kathleen Foster - Parkinsonians; Jill Reid & Julie

Pfarrer - Caregivers

June 7th: Reg Mtg at Central United Methodist Church —10 am Program: How to Prevent / Reverse Parkinson's through nutrition

Speaker: Dr. Bruce Fife, C.N., N.D.

July 5th: Reg Mtg at Central United Methodist Church —10 am

Program: Break-Out Sessions

(Caregivers & Parkinsonians separate into different rooms to talk)

August 2: Save the Date — Annual Picnic at the Park!!
Location & Time: Barn Pavilion at John Venezia Park — 11 am

September 6: Reg Mtg at Central United Methodist Church —10 am **Program:** Mobile Physical Therapy Services for people with PD

Speaker: Ryan Mueller, PT, DPT, NCS

October 4: Reg Mtg at Central United Methodist Church —10 am

Program: TBD; Speaker: TBD

November 1: Reg Mtg at Central United Methodist Church —10 am

Program: Break-out Sessions

(Caregivers & Parkinsonians separate into different rooms to talk)

December 6: Save the Date — Annual Christmas Party!!

Location & Time: 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=PLkPlhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org; https://www.michaelifox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers