MARCH 2025

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

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)

March Meeting: Saturday, March 1st – 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.

March Program:

Topic: Scam Prevention

Speaker: Scott Mathis, Colorado Springs Police Department

Scams are largely targeted to us, the older generation. Many scammers are very clever and have convincing approaches to get us to hand over money or our financial information. Older people lose millions of dollars to scammers each year. How do we know when a scammer is making a move on us? Come to the March meeting and find out. An officer from the Colorado Springs Police Department's Scam Prevention section will teach us how to protect ourselves from these vicious and hard-core criminals.

In keeping with the subject of this month's program, the following is a scam story that happened to one of our members recently on February 6th:

Scammed, But Rescued: How to Short-circuit a Scam

by Ann Grant Martin, 2025

Male voice with a noticeable accent -- "***This is your credit card Fraud Department calling.***" I was on FaceTime, but the caller's face was not. The word "*FRAUD*" in an official-looking bronze rectangle appeared on my phone screen. The voice continued, "*There has been suspicious activity in your credit card account. Someone has attempted to make wire transfers of $18,000.00 and $4000.00 to an overseas party.*" It asked more questions, I dutifully answered: "*Are you traveling?" "Do you know _____?" "Did you authorize this amount to be transferred?"*

His indistinct elocution, a poor phone connection, and my hearing loss combined to make understanding difficult. As he gathered more information from me, I became concerned about my credit card account -- so logged in on my laptop. Everything looked fine to me, but the man described my situation as being very serious and in the interest of protecting my money, he connected me to his 'supervisor'.

A second male voice, with a southern accent and grammar that wasn't always correct, lapsed into informal slang after prolonged questioning. He suggested that since the credit card company had flagged my account, the real problem was in my bank account. He transferred my call to a third 'fraud detection officer' who asked increasingly worrisome questions. Could there be a problem with bills paid directly from my bank account?

(Continued on page 2…)

February Potluck:
Green or Irish Dishes in honor of St. Patrick's Day

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 [redacted] or potluck@co-parkinson.org, no later than Wednesday February 26th 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

I attended last month's Caregivers Support Group meeting to touch base with the folks who have been attending and to encourage them to continue to meet even though there is no official leader any longer (they don't really need an official leader). Only three women came, but we shared a lot of good information and learned a good bit from each other. It's an important resource, and I'm hopeful that it will continue to thrive and provide the support that our caregivers so desperately need.

One of the women at that meeting asked me where to find clothing for people who have lost dexterity and find it difficult to cope with everyday things like buttons. Years ago, we had a presentation on that very subject. There is such a line of clothing. The company is Janska, and the presenter, who has another job now, told me the other day that you can order them online and even through Amazon and eBay.

Check out the Trazer information on page under "Other Opportunities" in this newsletter. Elizabeth Rowen took advantage of this "test" offered at the YMCA. She said it was difficult, but difficult in a good way. It let her know where her physical and cognitive weaknesses are so that she can concentrate on them and overcome them. She was so impressed with Trazer that she is planning to be tested periodically. To take advantage of it, you may have to be a member of the Y, but check with them to find out for sure. The cost of each test is $35.

I recently came upon a resource that has a lot to offer. Even though we are in the midst of getting a book on Parkinson's and families published ourselves (our research team, Julie Pfarrer, and I), I don't want to steer you away from other resources that may be helpful to you, too. As always, we may not agree with everything in this resource (we haven't read it all yet); if you find something that contradicts what you've heard from the support group, you may want to let us know so we can help you decide if we've been wrong and they are right. After a cursory look, I found two things that they advocate that I don't agree with: (1) having a Living Will or other final wishes document (from our own experience and the experience of others, we strongly oppose that kind of document and recommend instead a Medical Durable Power of Attorney containing your final wishes; it is much safer for you and keeps life-and-death decisions in the hands of people who know and love you and out of the hands of random hospital doctors) and (2) the Mediterranean diet, which is high in whole grains (therefore, high in carbohydrates) and low in beef; they don't offer research to back up the claim of efficacy for people with Parkinson's (unlike our own scientific research that has shown that diets high in good fats (coconut, olive, avocado oils and animal fat) and the ketogenic diet (one high in good fats and low in carbohydrates along with moderate amounts of protein including beef) DO IN FACT help reduce the symptoms of Parkinson's). But in the same cursory look, I learned some valuable things. I'm looking forward to learning more from it.

This resource, called Every Victory Counts, is from the Davis Phinney Foundation. According to their website, the Every Victory Counts® manual was first published in 2010 and broke new ground as the only resource of its kind at that time, devoted solely to the principle of proactive self-care and a holistic approach to managing Parkinson's. In subsequent editions, it has gained international recognition as a superb and comprehensive resource for changing the way people live with Parkinson's. Now in its sixth edition, the manual is the cornerstone of their new Every Victory Counts suite of resources, a robust collection of printed and digital manuals (including a new Every Victory Counts Manual for Care Partners) that embrace the Davis Phinney Foundation's philosophy of taking action to improve your quality of life with Parkinson's. Go to everyvictorycounts.org, and filling out the order form. To ask questions or get help placing your order, you can call (855) 744-6639.

☺ This month's recommended comedy, Merrily We Live, is about a dizzy but charitable society matron (played by Billie Burke) who has a habit of hiring ex-cons and hobos as servants. Her household is as much a loony-bin as happy home. You'll laugh at the shenanigans of Billie and the others (Constance Bennett, Brian Aherne, and Alan Mowbray).

(...continued from the cover: Scammed, But Rescued: How to Short-circuit a Scam | Ann Grant Martin)

Oh, dear… I logged into my bank account. Again everything looked fine but this third voice (which sounded like the second) kept insisting that someone had tried to withdraw the 18 and 4 thousand dollars. He wanted to make sure that I wouldn't be charged.

I began to wonder if the caller was indeed a scammer. I asked some questions. To prove that he was legit, he hung up and called me back so that his number ID came up "frauddepartment247@icloud-.com". He would not give me his direct number, only the extension number. He kept insisting that it was important to quickly take care of this attempt of an unauthorized withdrawal. I had been on the phone for an hour, and felt anxious and weary.

Then he announced that he was employed by my credit union's fraud prevention department. He was working on a huge fraud case where 43 accounts were compromised by one particular bank teller. "They" were working with the FBI trying to catch him. Some people had already lost thousands of dollars. Fortunately, my money was safe for the moment, but my account and routing numbers had to be changed right away. He urged me to personally go to my bank branch and withdraw $20,000 in $100 dollar bills. He told me to say that I needed this money for "personal use." He said to go around to the drive up window and deposit it into a new account that had been set up for me since my old account was going to be closed.

Can you believe I actually agreed to put on my shoes and drive to my bank and make this transaction? He was on the phone with me as I prepared to leave. He warned me the situation with the embezzler was possibly dangerous (subtle inference of violence) but not to worry since there were many cameras on the lobby area of the bank. I felt uneasy and asked my partner to go with me. She immediately began asking questions of the scammer on speaker phone.

In the bank lobby, the teller immediately was suspicious and called her manager. It was really unusual for someone like me to ask for a withdrawal of $20,000 in $100 bills. They asked if I'd been pressured, coerced, or threatened. I said no. The bank manager noticed I was on the phone with someone and asked to speak to him. When the manager's face and badge appeared on the phone, the scammer immediately hung up. There has been no further contact.

The manager invited my partner and me into her office for a private conversation. **Yes, indeed I had been scammed and came very close to putting my $20,000 right into the scammer's bank account** instead of the promised new personal account. Fortunately, I hadn't given my Social Security number, bank account number, or credit card number. However, I had given him information about my balances and charges. I'll need to keep a close watch on both my credit and bank accounts.

Am I embarrassed? Of course. But I'm feeling very fortunate there were people watching out for me, the nice old lady. To avoid falling for a scam operation in the future, my bank supervisor shared that Credit Card companies do not make video calls. Fraud departments do not involve the victim. She advised to not answer any calls that aren't local or you don't know… let them go to voice mail. AND… if someone contacts you with news about fraudulent actions in your bank/credit card company/mobile device, etc., hang up and verify their validity by directly calling the main number of the institution they pretended to represent. If I had first called my credit card company the scam would have been immediately short-circuited.

Today was a big learning day with an ending for which I feel very grateful. Fortunately, this was also a NeuroPong day and I got to play with the robot ball pitcher, Dave, and then a hilarious doubles game. Thank you, Larry and Scott, for your kind coaching and Jill, Julie and others for picking up balls. You guys ROCK!!!

THE END

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].

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: How does altitude affect a person with Parkinson's Disease?

Answer: There is no good research that I know of to answer this question. Any effect of altitude would likely relate to the relative decrease in oxygen at 6,000 feet. There's about 33% less oxygen available at 6,000 feet compared with sea level. If someone had a respiratory condition or sleep apnea, then their PD may worsen at altitude. Increased oxygen availability when one goes to sea level may help L-Dopa absorption but this is conjecture. Better functioning for a PD patient at sea level may also be an epiphenomenon, such as getting more exercise at sea level which is dopaminergic.

Note: *When I took my mother, who had Parkinson's, back east to visit relatives she became dyskinetic (over-medicated) for the first time ever. I had to cut back on her carb/levo dosage to get rid of the dyskinesia. When we came home, I had to increase the dosage again. This continued to happen every time she went down to a lower altitude. So those experiences showed us that carb/levo seems to work better at lower altitudes – Julie Pfarrer*

Researchers to Advance Imaging of Parkinson's Diseases

By Penn Today, December 20, 2024

A Penn-led collaboration of radiology, computational chemistry, and neurology experts will identify and test new tracers for PET scans to help diagnose and monitor diseases.

A Penn Medicine-led consortium of radiology and chemistry researchers across the United States will advance imaging of diseases like Parkinson's by testing radiotracers they identified that illuminate α-synuclein (αSyn) or 4R tau proteins on positron emission tomography (PET) scans. Armed with a five-year, $30 million grant from the National Institutes of Neurological Disease and Stroke, researchers hope that improved imaging will expand the number of neurological disorders that can be diagnosed with PET scans, track their progression over time, and more accurately measure a patient's response to treatments.

PET imaging uses a radioactive drug (tracer) that binds to certain proteins or sugars, to show areas of the body that have higher levels of chemical activity, indicating disease. It was just over a decade ago that researchers first identified a radiotracer that could be used to detect the presence of amyloid protein plaques in the brain, which are among the markers for Alzheimer's disease. As new amyloid-clearing Alzheimer's drugs have come to market, such as lecanemab, this radiotracer has become integral for diagnosing Alzheimer's disease and tracking the progress of the drug.

Now, Robert Mach, the Britton Chance Professor of Radiology, will lead a collaboration with experts around the country to pursue similar tracers for Parkinson's and several other diseases that are characterized as "proteinopathies," which occur when certain proteins "misfold," and aggregate on the brain. Called the Center Without Walls, the project connects radiology, chemistry, and neurology experts from The University of California-San Francisco, the University of Pittsburgh, Washington University-St. Louis, and Yale University to develop two different radiotracers: one that will bind to a protein in the brain known as αSyn for the imaging of Parkinson's and multiple system atrophy, and the other that will bind to the protein 4R tau for imaging frontotemporal degeneration and progressive supranuclear palsy.

"Due to the sheer number of possible molecules that could be used, the process of developing new radiotracers has been slow and complicated, like finding a needle in a haystack," says Mach. "The Center Without Walls combines clinical, scientific, imaging, and computational expertise from across institutions to develop a creative solution for this problem and has already resulted in clinical trials for three radiotracers that we identified. We hope that this collaborative model can help develop radiotracers that fundamentally change how we diagnose and treat diseases like Parkinson's."

Read more at Penn Medicine News.

LENDING LOCKER INVENTORY

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

- 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 with 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.

7-day/7 compartments per day pill dispenser	1
7-day medium-size pill dispenser	1
Aluminum walker tennis balls	4
Aluminum walker tray	1
Bedside toilet commode liners: 3 big boxes with 6 smaller boxes in each	
Bibs	8
Blood Pressure Monitor	1
Disposable bed pads	7
Easy sip hydrate bottle	1
Gate belt	8
Hospital bed bedding: 3 sets of sheets 1 mattress pad 2 washable bed pads (new)	
Hospital gown	1
Hospital slippers–XL&XXL	2
In-bed knee lift	1
Male portable urinals, new in individual packages – 32 oz capacity	4
Plastic handicap plate	2
Plastic handicap bowl	1
Pill crusher, storage, & drink cup combination	1
Rehab squeeze balls	2
Reusable bed pads	8
Waterproof twin mattress protector	1
Weighted utensils	6
Seat cushion	1
Thick-it	1
Transfer pads – can handle a person up to 300 lbs	4
Attend advanced briefs, maximum protection–lg–24 ct	3 pkgs
Cardinal health guards for men - extra heavy absorbency -14ct	2 pkgs
Depend men's guards–52ct – 1 unopened and 3 opened with a few missing	8 pkgs
Fitright guards for men–52ct	1
Generic briefs, L/XL – 18ct	4 pkgs
Prevail daily male guards – one size fits all – maximum absorbency-14ct	2 pkgs
Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size – maximum absorbency-16ct	2 pkgs
Women's Always Discreet s/m/p/m maximum protection underwear – 42ct	2 pkgs
Women's Always Anti-Bunch extra long panty liners. Extra protection – 92ct	1 pkg

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!*

April Newsletter Input Deadline: *March 14th*

Call or e-mail Julie with your input for the newsletter at:

[redacted]

info@co-parkinson.org

March CSPSG Executive Committee Meeting

March 4th @ 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.

- John Baker
- Karen Baker
- Dave Blackwell
- Beth Blakney
- Marci Braithwaite
- Donna Deis (Rickett)
- John Farley
- Gerrie Fooks
- Stephanie Graczyk
- Judy Horton
- Mary Lekarczyk
- Keith Mitchell
- Jay Norman
- Marti Purdy
- Elizabeth Rowan
- Ken Rowe
- Shelley Runkle
- David Smith
- Francel Smith
- Patrick Smith
- Karl Stengel
- Marny Weckwerth
- Keith Woestehoff

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 Julie Pfarrer at info@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: SAUTEED WILD MUSHROOMS

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 lbs wild mushrooms *(cremini, shitake, porcini, Portobello)*
- ½ C olive oil
- 1 C chopped shallots (4)
- 4 Tbl unsalted butter
- 2 tsp kosher salt
- ½ tsp black pepper
- 2 Tbl chopped garlic
- 1 C chopped fresh flat-leafed parsley

Directions:

- Brush caps of each mushroom with clean sponge to remove dirt.
- Remove and discard stems.
- Slice small mushrooms thickly and cut large ones in a large dice.
- Heat olive oil in large (11") Dutch oven or saucepan.
- Add shallots and cook over low heat for 5 minutes or until translucent.
- Add butter, mushrooms, salt and pepper and cook over medium heat for 8 minutes until they are tender and begin to release their juices, stirring often.
- Stir in garlic and cook for 2 more minutes.
- Toss with parsley, sprinkle with salt and serve warm.

Recipe for Relieving Constipation

The following recipe was recommended by one of our member's doctor for constipation. It worked very well for him!! Check with your doctor if you have any concerns before trying this recipe.

1) Pour 1 capful of Miralax into 8 ounces of water and stir until dissolved. Do this once a day every other day or every day, if needed.
2) In addition, pour 1 tablespoon of Bene-fiber into 8 ounces of water and stir until dissolved. Do this once a day every day.

Taking this recipe every day alleviated all of this member's constipation problems and kept him regular.

Here is a homemade remedy that has also helped a lot of people with Parkinson's.

Mix together:

- 1 C applesauce
- 1 C prune juice
- 1 C fiber

Take ½ cup, warmed at bedtime.

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 [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 Pfarrer 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 Syble Krafft at [redacted]/Barry Hanenburg [redacted].

Other Opportunities:

*NEW 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.

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.

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

Scientists ID Brain Circuit in Mice that Controls Body's Left, Right Turns

By Marisa Wexler, MS – Parkinson's News Today, 2/16/24

Discovery may ultimately help in improving brain stimulation in Parkinson's

Scientists in Denmark have identified the specific nerve signaling pathway that runs from the brain to the spinal cord in mice to control whether the body makes right or left turns — findings that ultimately may help to treat problems with turning ability in people with Parkinson's disease.

Modulating this neuronal pathway in the mouse model was seen to help normalize turning in the animals, the team showed.

"We have now discovered a new group of neurons in the brainstem which receives information directly from the basal ganglia [in the brain] and control the right-left circuit," Ole Kiehn PhD, co-author of the study and a professor at the University of Copenhagen, said in a press release.

The researchers suggest that this finding may be developed to further improve deep brain stimulation — a surgical procedure to stimulate specific brain regions — to normalize turning ability in Parkinson's patients.

Their study, "Basal ganglia–spinal cord pathway that commands locomotor gait asymmetries in mice," was published in *Nature Neuroscience*.

Exercises for Trunk Rigidity Seen to Help Patients Safely Make Turns

Work IDs neurons in brain that control the right-left circuit

Parkinson's is marked by damage in the brain, particularly in a region called the basal ganglia. This brain region is known to be important for regulating movements, including a person's ability to turn to the left or to the right. Problems turning, such as needing to take many small steps to turn, are a common symptom of Parkinson's especially in the disease's later stages.

When a person decides to move in a specific direction, signals flow from nerves in the brain down through the spinal cord and out to muscles in the body, ultimately causing the muscles to move. Turning to the right or left is a complex process that requires simultaneously coordinating movements — all autonomic, or unconsciously done — on both sides of the body.

Jared Cregg, PhD, a study co-author and also a University of Copenhagen professor, noted that some of the autonomic processes done in turning involve regulating the length of a person's steps.

"When walking, you will shorten the step length of the right leg before making a right-hand turn and the left leg before making a left-hand turn," Cregg said.

Although it's previously been established that the basal ganglia helps to coordinate movements during turns, it wasn't clear exactly how signals from this brain region are transmitted out to the body. Now, the researchers used a detailed battery of imaging and functional tests to find out.

The team discovered that, during a turn, nerves in the basal ganglia signal to a specific region at the base of the brain or brainstem called the PnO, for pontine reticular nucleus, oral part. The PnO then signals out to the spinal cord through specialized nerve cells called *Chx10* Gi neurons.

"The newly discovered network of neurons is located in a part of the brainstem known as PnO. They are the ones that receive signals from the basal ganglia and adjust the step length as we make a turn, and which thus determine whether we move to the right or left," Cregg said.

The scientists next conducted a series of tests in a mouse model where turning problems are generated by damaging one side of the basal ganglia. As a result, the mice will increasingly turn toward the damaged side, while having difficulty turning the other way. The researchers showed that, if they activated cells in the PnO or the downstream *Chx10* Gi neurons, they could normalize turning in these mice.

"These mice had difficulties turning, but by stimulating the PnO neurons we were able to alleviate turning difficulties," Cregg said.

Improved software for deep brain stimulation wins FDA approval

Researchers say discovery may help advance brain stimulation surgery

Though these results are from mouse studies, the scientists suggest that similar principles could be used to help improve turning ability in people with Parkinson's, where the basal ganglia is damaged but nerves in the brainstem and spinal cord usually aren't.

For example, the team suggested the findings could help tailor more precise forms of deep brain stimulation, which is a surgical procedure in which electrodes are implanted in the brain to stimulate specific brain regions.

"Modulation of the PnO [to] *Chx10* Gi pathway could potentially serve as a target for deep brain stimulation aimed at alleviating turning disabilities in Parkinson's disease clinically," the researchers wrote.

Right now, clinicians don't have the ability to stimulate human brain cells as accurately as researchers can in mouse models — in this study, the team used advanced optogenetic techniques — but deep brain stimulation would be a logical starting point should these techniques advance to use in people.

> *Modulation of [this newly discovered] pathway could potentially serve as a target for deep brain stimulation aimed at alleviating turning disabilities in Parkinson's disease clinically.*

In humans, Kiehn noted, "the neurons in the brainstem are a mess."

"Electric stimulation, which is the type of stimulation used in human deep brain sttimulation, cannot distinguish the cells from one another," Kiehn said.

However, he added: "Our knowledge of the brain is constantly growing, and eventually we may be able to start considering focused deep brain stimulation of humans."

Brazilian Dance Boosts Lower Limb Strength Better than Other Exercises

By Lindsey Shapiro, PhD – Parkinson's News Today, 1/5/2024

Clinical trial compared dance to Nordic walking, deep-water exercise

A three-month exercise program focusing on Brazilian dance led to greater gains in lower limb strength among Parkinson's disease patients than Nordic walking or deep-water exercise programs, according to a clinical trial report.

Most measures of motor performance, cognitive function, and quality of life were unaltered by any of the programs, however. Researchers believe longer-term clinical trials are needed to adequately evaluate their potential benefits for Parkinson's patients.

The study, "The effects of Brazilian dance, deep-water exercise and nordic walking, pre- and post-12 weeks, on functional-motor and non-motor symptoms in trained PwPD," was published in the *Archives of Gerontology and Geriatrics*.

As Parkinson's disease progresses, the burden of motor and nonmotor symptoms make daily life activities difficult for patients. While Parkinson's medications help, they often fail to ease all symptoms.

It's been well established that regular physical activity, tailored to a person's needs, is a low-cost and effective way to help ease symptoms, improving mobility, cognition, and life quality for patients.

A wide range of types of exercise have shown to be safe, engaging, and beneficial for Parkinson's patients, including Nordic walking, Brazilian dance, and deep-water exercise.

Study Finds Tai Chi Improves Motor Function in Parkinson's Patients

Comparing three types of exercise

Nordic walking involves walking with poles such as those in cross-country skiing. Thought to promote better brain and muscle activation than regular walking, it's been associated with improved balance and gait for Parkinson's patients. Deep-water exercise, where balance and strength exercises are performed in a pool, and traditional forms of Brazilian dance have also been linked to better mobility and life quality for Parkinson's patients.

Previous studies of these types of exercise have mainly involved sedentary patients, or those who are not routinely physically active, leading scientists here to compare the three regimens among 83 less sedentary Parkinson's patients, ages 50 and older, who were on stable Parkinson's medications and could walk independently, with mild to moderate functional disability.

Participants were randomly assigned to take part in a 12-week (three-month) program of either Nordic walking, deep-water exercise, or Brazilian dance. All the interventions involved one-hour, group-based sessions, taken twice weekly. A battery of tests were performed before and after the 12 weeks to evaluate motor function, including measures of motor symptoms, mobility, endurance, muscle strength, and fear of falling.

For most tests, none of the interventions led to significant or clinically meaningful improvements after 12 weeks, but Brazilian dance was associated with significant improvements in the sit-to-stand (STS) test — a measure of lower limb strength — relative to the other two activities. Patients in that group saw significant gains in STS performance after 12 weeks over their pre-intervention performance, whereas Nordic dance or deep-water exercise participants didn't see any improvements.

The difference could be because the Brazilian dance program involved movements like those in the STS test, whereas the others didn't.

The test involves standing from a sitting position, then sitting back down again and repeating it five times in a row as fast as possible. The movement was part of the beginning and end of each dance class, according to the scientists.

None of the programs were associated with significant changes in measures of cognition or quality of life.

Despite the lack of significant findings, the scientists emphasized that no change in motor or cognitive symptoms, "can be considered a positive result," given that Parkinson's is a progressive disease where function worsens over time. They also said 12 weeks may be too short to see meaningful gains.

"The study findings point to the value of investigating the continuity of these responses over longer periods than that used in this study," they wrote, noting that twice weekly sessions may have been too light of an exercise load. They said further research should explore "the different responses among [Parkinson's] subtypes … to advance understanding and tailor interventions for each subgroup."

DBS for Parkinson's Better than Meds Alone for Quality of Life: Study

By Marisa Wexler, MS – Parkinson's News Today, 2/7/24

Patients found to have more stable long-term life quality with surgery

People with Parkinson's disease who are given deep brain stimulation (DBS) tend to have more stable long-term life quality and motor function than do patients treated with medications only, according to a new study.

Deep brain stimulation, called DBS for short, is a surgical treatment for Parkinson's disease in which an electrode is implanted in the brain to provide gentle electrical stimulation to specific brain regions — typically the subthalamic nucleus, in which case the treatment is referred to as STN-DBS.

STN-DBS is designed to ease Parkinson's motor symptoms, and of course, there also are a number of approved medications that can help reduce the signs and symptoms of the disease. To date, however, little is known about the long-term effects of one treatment versus the other.

"This trial found that patients who received STN-DBS had stable QOL [quality of life] at 5-year follow-up, primarily because of improved mobility," the researchers wrote, adding that this finding "highlights the importance of long-term improvement in outcomes related to activities of daily living."

The study, "Neurostimulation for Advanced Parkinson Disease and Quality of Life at 5 Years — A Nonrandomized, Controlled Trial," was published in *JAMA Network Open*.

Dual-targeted adaptive DBS surgery may work better in Parkinson's

1st study to evaluate DBS vs. medications for Parkinson's patients long term

There have been some previous studies that have compared the effects of STN-DBS against standard-of-care medication (abbreviated MED) in people with Parkinson's — but these generally haven't followed patients longer than about three years.

For a longer-term perspective, a team of scientists across Europe now conducted a clinical trial to compare STN-DBS and MED in more than 100 people with advanced Parkinson's who were followed for five years.

"To our knowledge, this is the first report of 5-year QOL [quality of life] outcomes following STN-DBS for patients with advanced PD [Parkinson's disease] compared with patients receiving only standard-of-care medical treatment," the scientists wrote.

Unlike most clinical trials, in which participants are randomly assigned to different treatment groups, the patients in this study chose whether to undergo STN-DBS or take medications. Given that, at the start of the study, or baseline, the two groups weren't balanced in terms of demographics and clinical factors, as would typically be the case.

To account for this variation, the researchers used a tool called propensity score matching. Put simply, this involves selecting pairs of patients from each group who are similar at baseline. Using this strategy, the researchers identified 25 patients treated with STN-DBS and 25 treated with MED, and these patients were used for the analysis.

> *The main finding of this prospective, quasi-experimental, nonrandomized controlled trial is that QOL [quality of life] outcomes at 5-year follow-up were stable in the … DBS group and worsened in the [medications-only] group.*

To assess quality of life, the trial used a standardized tool called the Parkinson's Disease Questionnaire 8 (PDQ-8). The results showed that, in patients given MED, average PDQ-8 scores were largely stable in the first year, but then gradually worsened over the next four years. Ultimately, after five years, the PDQ-8 scores in the medications-only group were significantly worse than they'd been at baseline, by 49.4%.

In contrast, in the STN-DBS group, PDQ-8 scores improved significantly in the first year after receiving the surgery. Scores then declined somewhat over the following four years — but by the end of the five-year study, the average PDQ-8 score was just a few points worse than it had been at baseline, and the change wasn't statistically significant. That meaning that it's mathematically possible the difference could be due to pure chance.

"The main finding of this prospective, quasi-experimental, nonrandomized controlled trial is that QOL [quality of life] outcomes at 5-year follow-up were stable in the STN-DBS group and worsened in the MED group," the researchers wrote.

DBS helps grandfather, 77, struggling with Parkinson's off times

Serious safety issues were reported, but resolved, for 17 DBS patients

A standard measure of motor function, called the Scales for Outcomes in PD–motor scale (SCOPA-M), worsened significantly after five years in the MED group. But in the STN-DBS group, average SCOPA-M scores were slightly higher after five years than at baseline, though the difference wasn't statistically significant.

The researchers also noted that the average daily equivalent dosage of levodopa — a measure used to express the total amount of levodopa a person takes in a day — increased significantly in the MED group over the five years of the study, whereas it decreased significantly in the STN-DBS group. The medication levodopa is widely considered the gold standard for treating Parkinson's disease.

Over the course of the study, a total of 39 serious safety issues were reported in 17 patients in the STN-DBS group. Of them, 13 were related to the surgery or the device used for DBS. Though all of these safety problems were resolved without further issues, the researchers noted that the safety risks of any invasive operation like DBS "demonstrate the importance of thorough preoperative assessments of risk-benefit ratios."

The researchers concluded that more benefits were seen with DBS for Parkinson's than with the use of medications alone.

"These findings may provide helpful information when counseling patients on the efficacy of STN-DBS for PD and monitoring patients postoperatively in long-term follow-up," the scientists wrote.

Review Study Evaluates Botulinum for Treating Excessive Drooling

By Lindsey Shapiro, PhD – Parkinson's News Today, 10/19/2023

Botulinum was safe, effective when injected into salivary glands to prevent sialorrhea

Botulinum toxin was found to be relatively safe and effective for treating excessive drooling in people with Parkinson's disease, according to a recent systematic review and meta-analysis of previous clinical trials.

While side effects usually were mild, the researchers believe larger and longer studies are needed to establish the safety of this treatment approach.

The study, "The effectiveness and safety of botulinum toxin injections for the treatment of sialorrhea with Parkinson's disease: a systematic review and meta-analysis," was published in *BMC Pharmacology and Toxicology*.

Graphene-based neural platform earns breakthrough device status

In Parkinson's, difficulty controlling the muscles in the face and mouth can cause symptoms of excessive drooling, or sialorrhea. Studies indicate that more than 80% of patients may experience this symptom, according to researchers.

Botulinum is a substance that blocks the release of a chemical called acetylcholine from the nerve cells involved in muscle contractions. It is a potent neurotoxin, but various forms of it are used in small doses for cosmetic and medical purposes.

While its best-known use is a cosmetic one — injections help relax the face muscles and prevent wrinkles — the toxin also can prevent excessive drooling when injected into the salivary glands, and that's why it is used to treat sialorrhea, including in people with Parkinson's.

Brands approved in the U.S. for sialorrhea include Myobloc (rimabotulinumtoxinB) and Xeomin (incobotulinumtoxinA).

Still, the evidence backing the use of the medication for sialorrhea in Parkinson's comes from a number of small studies, each involving a low number of patients.

"Many studies now show that Botulinum toxin has value in treating Parkinson-related saliva, while others suggest that it is less effective," the researchers wrote.

Review included eight smaller studies

In the recent study, researchers conducted a systematic review and pooled analysis of previous placebo-controlled clinical trials in an effort to get a broader sense of botulinum's safety and efficacy for these people.

The eight included studies were conducted in the U.S., Italy and Estonia, cumulatively involving 259 Parkinson's patients. Botulinum type A was evaluated in five studies, whereas type B was tested in three.

Types A and B, with a similar mechanism, are the two forms of the toxin approved for use in humans. The doses of either varied, and most studies evaluated the effects on drooling after one month, using the Drooling Severity Frequency Scale (DSFS).

Analyses indicated a significant reduction in DSFS scores — reflecting a reduction in drooling — with botulinum toxin compared to placebo across evaluable studies, with no significant difference in effect between types A and B.

Overall, "the results provide a new understanding of the effectiveness of [botulinum] injection on sialorrhea with [Parkinson's]," the researchers wrote.

The scientists believe the findings support the use of botulinum for this indication, particularly in light of the fact that physical therapy is time-consuming and other medications, such as acetylcholine blockers, have significant side effects.

Most side effects mild or moderate

A higher rate of side effects was observed with botulinum than placebo, but most side effects were mild or moderate in severity. No serious side effects were considered related to the treatment.

Dry mouth was the most common side effect associated with the treatment, with others including neck pain, diarrhea, and worsened gait. Recovery time from side effects ranged from one to six weeks.

Still, it is important to consider the safety of botulinum, the scientists emphasized, especially considering the short-term nature of the studies. Long-term use of botulinum has been associated with a reduction in salivary gland size, difficulty swallowing, and oral health deteriorations.

"Larger samples and more scientifically designed randomized controlled trials are needed to explore the safety of botulinum toxin as a potential alternative treatment for sialorrhea caused by [Parkinson's]," the researchers wrote.

More work also is needed to understand the best dose, treatment duration, and mode of delivery for botulinum, as well as the mechanisms through which sialorrhea arises in Parkinson's.

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Coming Events

See inside for more information

March 1: Reg Mtg at Central United Methodist Church —10 am
Program: Scam Prevention
Speaker: Scott Mathis, Colorado Springs Police Department

April 5: 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.

May 3: Reg Mtg at Central United Methodist Church —10 am
Program: Break-Out Sessions
(Caregivers & Parkinsonians separate into different rooms to talk)

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

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=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org; https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers