MARCH 2024

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)

Next Meeting: Saturday, March 2nd – 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.

Topic: Exercise is Medicine – What's the Prescription?

Speaker: Danielle Mulligan

Exercise is for everyone – not just people with Parkinson's Disease. Danielle will define the undeniable benefits of exercise based on respected research studies; will introduce the exercise prescription based on the American Physical Therapy Association and the Parkinson's Foundation; dive into each component of this exercise prescription; explain how to implement these exercises into your lives today and discuss the barriers to exercise.

The meeting will be followed by a potluck

The March Potluck – Something Green!
i.e. salads, casseroles, etc.

If you would like to sign up to be a provider of the main dish or to bring a side dish/dessert for the meeting, you can contact Bill Hicks at [redacted] or potluck@co-parkinson.org, no later than Wednesday, January 31st and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

21st ANNUAL CAREGIVER PAMPERING DAY!!

Save the Date

Saturday, April 6th, 2024

Pikes Peak Area Council of Governments
Communities Working Together

The 21st Annual Caregiver Pampering Day will be held on Saturday, April 6th at the Westside Community Center located at 1628 West Bijou Street in Colorado Springs.

The event is open to people caring for a family member or non-relative who is 60 years of age or older. Caregivers who attend will be able to choose 3 different pampering activities from 7 different options. Respite care in the home will be available for caregivers who need someone to be with their care receiver while they attend the event.

Registration opens March 1st and will close on March 25th.

The event this year is limited to the first 80 caregivers who register. Registration will be available online at www.ppacg.org/pamperingday, via email at kmathews@ppacg.org or by phone at (719) 886-7526.

Please contact Kent Mathews at (719) 471-2096 for questions or more information.

Send in your questions!

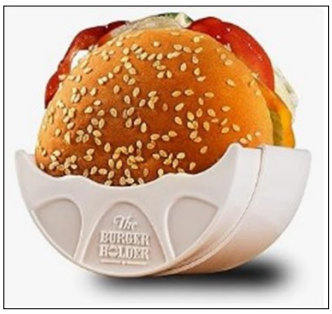
Dr. Grabert has generously agreed to answer your questions pertaining to Parkinson's Disease each month in our newsletter column called "Ask the Doctor!" If you have questions you'd like to submit to Dr. Grabert, send them in an email to Julie, our newsletter coordinator, db_mgr@co-parkinson.org.

The President's Corner

| Jill Reid - Acting President, CPF & CSPSG

I need to mention members-at-large again. Until recently, our newsletters have listed a lot of people who volunteered to be members-at-large representing the membership at all our functions and at our executive committee meetings. However, very few of them have actually attended the executive committee meetings, and we've missed their inputs sorely. The same small group of people for a long time have been the active participants who have kept our support group going; but we need new ideas, new thoughts, and the renewed energy that comes from a larger pool of people helping out. It isn't a time-consuming job — attend the monthly general meetings, which many of you are doing already, and attend the monthly executive committee meetings the following Tuesday (the executive committee meetings usually last less than an hour). If you have valued the benefits this support group has given you, please consider volunteering to become a member-at-large. Let any of the following active volunteers know that you are willing to do so: Janet Adams, Dave Moross, Julie Pfarrer, Mary Sauvain, Bill Hicks, Annette Garcia, Carole Henrichsen, Patricia Beatty, and, of course, myself.

I've recently made the happy discovery of the Burger Holder pictured here. A two-piece light-weight tool priced at $9.95 on Amazon, it makes eating a hamburger a piece of cake☺. One of our members, Joe Facer, told me that the Burger Holder enabled his wife to eat hamburgers again, without his having to cut them into small pieces for her. She easily fed herself! The other item pictured to the right, a portable car door assist handle, makes getting out of a car much easier; using it may even enable you to get out of a car completely unassisted. And you can take it with you to use in whatever car you're riding in. It sells for just under $9 on Amazon.



Enjoy this month's comedy recommendation, Houseboat, starring Cary Grant and Sophia Loren. These two make a great comedic team, expertly playing off each other to make us laugh.

Understand the Differences in Carbidopa/Levodopa Formulations for PD

By Ami Patel, PharmD, BCPS – Pharmacy Times, 2/1/2024

Understanding differences in the various levodopa formulations and assisting with medication therapy management is a crucial role for pharmacists.

Parkinson disease (PD) is the second most common neurodegenerative disease after Alzheimer disease.[1] Approximately 1 million people in the US are diagnosed with PD and this number is expected to rise to 1.2 million by 2030, per the Parkinson's Foundation Parkinson's Prevalence Project.[1]

Carbidopa/levodopa is considered the gold standard for the management of PD motor symptoms. A retrospective cohort study spanning 5 years in 11,280 patients revealed that carbidopa/levodopa was the most prescribed first-line treatment in 70% of the population.[2] Since its approval in 1970, multiple formulations have become available. This has expanded options for patients, but also complicated pharmacologic management for patients, caregivers, and their providers. Understanding differences in the various levodopa formulations and assisting with medication therapy management is a crucial role for pharmacists.

Carbidopa/Levodopa Immediate Release and Orally Disintegrating Tablets

Carbidopa/levodopa immediate release (IR) tablets are commonly the first levodopa formulation prescribed to patients with PD. The IR formulation has a peak onset of 30 minutes to 1 hour with a half-life of 1.5 to 2 hours.[3] There is also an orally disintegrating tablet (ODT) formulation for patients with difficulty swallowing pills.[4] The ODT has a peak onset of 30 minutes and does not require water for administration. However, as PD progresses, the window of levodopa's effectiveness is significantly reduced, resulting in more "off" time and subsequent requirement of increased doses and/or frequency.[5] Dyskinesia and motor "on/off" fluctuations develop in about 50% of PD patients within 5 years of treatment.

For those new to therapy, pharmacists should counsel patients to space doses evenly throughout waking hours. Spacing doses throughout the awake hours helps to optimize observed benefits during activities of daily living. Additionally, patients should be advised to avoid taking doses with high fat, high caloric meals because this can delay gastrointestinal absorption up to 2 hours.[3,4]

Carbidopa/Levodopa Controlled Release Tablets

Carbidopa/levodopa controlled release (CR) tablets provide a sustained release formulation. It has a bioavailability of 70% to 75% relative to that of IR formulations, with a time to peak of 1.5 to 2 hours.[5,7] Because the time to reach maximal concentration is delayed, some patients may concomitantly take an IR formulation with the first morning dose. The CR tablets utilize a polymeric based drug delivery system that is designed to release carbidopa/levodopa over 4 to 6 hours allowing for 3 times-per-day dosing. However, CR is less systemically bioavailable than IR formulations and may require higher daily doses in some patients to achieve the same level of symptomatic relief. As such, levodopa doses > 800 mg may be divided every 4 to 8 hours during the waking hours. In clinical trials, the CR formulation provided the same therapeutic benefit as the IR formulation; however, with less frequent dosing when compared to IR. Pharmacists should advise patients not to crush, chew, or cut the CR formulation as this may result in carbidopa/levodopa being released too fast.

Carbidopa/Levodopa Extended-Release Capsules

Carbidopa/levodopa extended release (ER) formulations have a bioavailability of 70% relative to that of IR formulations with an initial peak at 1 hour.[8] The ER formulation allows for an extended duration of action due to

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Sad News

Tina Facer passed away in January. She was born in Teaneck, NJ, placed in an orphanage and adopted with another child who became her brother. She lived in upstate NY as a child and moved with her family to Houston in her teens. She had a special talent for languages and spoke four.

After a field trip to San Francisco, she fell in love with the city and moved there with her 2nd husband. While raising her 2 children as a single mother, she ran a daycare out of her home and completed her college education with a Masters in Communications Disorders from San Francisco State University. She met Joseph, they married and she had a third child.

Tina worked at various school districts, put up a shingle as freelance speech therapist, managed an independent company that supplied speech therapists on a contract basis to various entities and worked at Burt Center in the afternoons as time permitted. Her caseload in the SF School District consisted mostly of children who were autistic, schizophrenic, had cerebral palsy, or were profoundly handicapped. Tina was adopted into an abusive home and at one time told Joe "I couldn't save my little brother so I work with my little broken kids."

An aspiring writer, she left behind some unpublished stories and novels.

Tina was an iron lady, sweet, intelligent, with a heart as big as all outdoors and three times the size of the package she came in.

FDA Sets Date in 2024 for Decision on SPN-830 Apomorphine Pump

By Steve Bryson, PhD – Parkinson's News Today, 11/3/2023

Agency agrees to review Supernus' device for approval for Parkinson's

The U.S. Food and Drug Administration (FDA) has accepted Supernus Pharmaceuticals' new application seeking approval of its apomorphine infusion pump — known as SPN-830 — to treat motor fluctuations in people with Parkinson's disease.

A decision on the company's request, resubmitted last month in the form of a new drug application (NDA), is expected by April 5, 2024.

"We are pleased with the FDA's acceptance of our NDA resubmission for SPN-830 and look forward to continuing to work with them during their review," Jack Khattar, Supernus' president and CEO, said in a company press release.

In submitting the new application, Supernus had stated that all previous concerns raised by the FDA — on manufacturing and other non-efficacy issues — had been addressed.

AAN 2023: Apomorphine infusion pump SPN-830 reduces 'off' time

Apomorphine pump may be more convenient for patients

Parkinson's disease is caused by the dysfunction and death of cells in the brain that make the signaling molecule dopamine. The resulting dopamine deficiency leads to the onset of Parkinson's symptoms, affecting both motor and nonmotor skills.

Levodopa and derivatives are the standard Parkinson's treatment and provide patients with the materials to make dopamine. However, the long-term use of these medications is associated with so-called off periods, when therapeutic effects wear off and symptoms re-emerge between scheduled doses.

Supernus' approved therapy Apokyn (apomorphine hydrochloride injection) is a subcutaneous or under-the-skin injection of apomorphine, a small molecule that mimics the action of dopamine in the brain, and is intended to reduce off periods on demand.

SPN-830 is a subcutaneous formulation of apomorphine that is delivered continuously through an infusion pump. Such administration has the potential to be less invasive, with fewer injection sites, and more convenient than Apokyn.

> *SPN-830 is an important product candidate which, if approved by the FDA, represents a novel and less invasive treatment option for [Parkinson's] patients.*

According to Khattar, "SPN-830 is an important product candidate which, if approved by the FDA, represents a novel and less invasive treatment option for [Parkinson's] patients."

Supernus acquired the rights to Apokyn and the SPN-830 pump from US WorldMeds in 2020 and, a few months later, asked the FDA to approve the device for Parkinson's. However, the agency said the application was missing certain data needed to complete the review.

Following a meeting with the FDA to clarify the requirements for refiling, the company resubmitted its application at the end of 2021.

However, the agency last year again requested additional information — with a focus on the therapy's labeling, performance, risk analysis, and manufacturing. On manufacturing, the COVID-19 pandemic had prevented the completion of required facility inspections.

Importantly, no new clinical safety and efficacy data were requested.

Supernus' regulatory application was based mostly on results from two Phase 3 clinical trials: TOLEDO (NCT02006121) in Europe and INFUS-ON (NCT02339064) in the U.S.

TOLEDO involved 107 Parkinson's patients who had at least three hours of daily off time while on an optimized dopamine-replacing therapy. Three months of treatment with SPN-830 was found to be superior to a placebo continuous infusion at reducing off time, with benefits sustained through the trial's 1-year extension phase.

In INFUS-ON, all 99 Parkinson's patients in the trial received the experimental therapy for about a year. After about three months on SPN-830, patients' daily off time was seen to decrease by about three hours from an average of six hours per day.

The therapy was generally well-tolerated, with the most common side effects including nodules or redness at the infusion site, nausea, dyskinesia or involuntary movements, and sleepiness.

LENDING LOCKER INVENTORY

If you would like to borrow any of the equipment listed here, please contact: Mary Sauvain at (719) 331-3424.

Back brace	1
Bed cane	7
Bed pan	1
Bed rails	1
Bed risers (set)	1
Bedding lifters	2
Bedside toilets	5
Canes	8
Chair/sofa cane	2
Crutches (set)	2
Double floor exercise pedals	1
Freestanding toilet rails	1
Hospital bed	4
Hospital bed food trays	2
Hoyer Lift	1
Lazercue for freezing help	1
Lift chairs	2
Lift-ware tremor compensating utensils	1 set
Monthly med carousel with reminder alerts	1
Pick-up assist	6
Shower seats/benches	7
Sock helper	2
Stand-up assist	1
Standup Walker	1
Squatty potty	2
Swivel seat	1
Toilet arm assist	1
Toilet rail	1
Toilet seats	3
Transfer pole	2
Transport chairs	11
Tub rail	2
U-step	3
Walkers with wheels & seat	9
Waterproof mattress protector (Twin)	1
Wheelchairs	8

Items in our LENDING LOCKER that are free for the taking:

Contact Julie Pfarrer at db_mgr@co-parkinson.org if interested in any of these items

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: 2 sets of sheets 1 mattress pad	
Hospital gown	1
Hospital slippers – XL & XXL	2
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
Thick-it	1
Transfer pads – can handle a person up to 300 lbs	4
Attend advanced briefs, maximum protection–large –24 count	3 pkgs
Cardinal health guards for men - extra heavy absorbency -14 count	2 pkgs
Depend men's guards – 52 count – 1 unopened and 3 opened with a few missing	8 pkgs
Fitright guards for men – 52 count	1
Generic briefs, L/XL – 18 count	4 pkgs
Prevail daily male guards – one size fits all – maximum absorbency-14 count	2 pkgs
Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size – maximum absorbency-16 count	2 pkgs
Women's Always Discreet s/m/ p/m maximum protection underwear – 42 count	2 pkgs
Women's Always Anti-Bunch extra long panty liners. Extra protection – 92 count	1 pkg

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

April Newsletter Input Deadline: March 14th

Call or e-mail Julie at: [redacted]
db_mgr@co-parkinson.org

CSPSG Executive Committee Meeting

March 5th at 10 am at a place to be determined

Contact Jill 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 the address. Leave your email address so Jill can contact you if anything changes.

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 db_mgr@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. Gregory Ales, DO – Neurologist at CS Neurological Associates; (719) 473-3272

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

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

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

Denver

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

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

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

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

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

Dr. Brooke Heffernan, MD – Movement Disorders Fellow at UCHealth, Anschutz Medical Campus, (720)848-2080

Potluck Favorites—Shakin' & Bakin' Cookbook Now Available!

The updated cookbooks are here!

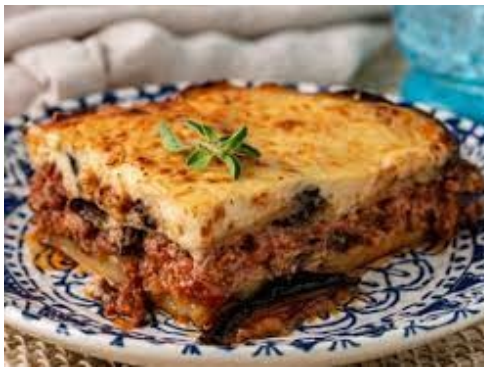
The price is a donation or free if you can't afford to donate. You can order them from Julie Pfarrer at db_mgr@co-parkinson.org. The cookbooks are bound so that new recipes can be added in the future. So continue to send in your favorite recipes – old or new family recipes, newly discovered favorite 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: MOUSSAKA (Greek Meat & Eggplant Lasagna)

Our low carb/good fat ketogenic study that was completed in 2021 showed incredible results. Not only was there remarkable improvement in the symptoms of Parkinson's but also with overall health in general (including the health of caregivers who chose to change their diet along with their Parkinsonian). Since it seems clear that everyone's health would improve exponentially if we all changed our diet to eat this way and since we have potlucks, we thought we would feature an easy low carb/good fat recipe or two in the newsletter each month to promote healthy eating.

If you have a favorite low carb/good fat recipe you'd like to share, please send it to Julie at: db_mgr@co-parkinson.org.



Main Ingredients:
- 1 ½ lb eggplant, cut in ¼" slices
- Kosher salt & pepper
- Olive oil
- 1 lb ground beef or ½ lb ground lamb & ½ lb ground beef
- 1 large yellow onion
- 5 cloves garlic, sliced
- 2 Tbl tomato paste
- 1 C red wine
- 2 fresh bay leaves
- 1 cinnamon stick
- Small batch of fresh oregano
- 1 28-oz can crushed tomatoes

Directions:
- preheat oven to 400°
- season eggplant slices on both sides with salt & pepper & drizzle with olive oil
- grill slices, flipping once, until tender & lightly golden brown on both sides, 5 to 7 minutes
- transfer slices to plate & set aside
- in a 6 qt Dutch oven, add 3 Tbl of olive oil along with the ground meat & season with salt & pepper
- cook, stirring to break up the meat until well browned, about 5 minutes
- add onions & garlic and cook until soft, about 5 minutes
- add tomato paste & cook until rust colored, another minute
- add wine & cook, stirring occasionally, until almost completely evaporated, about 5 minutes
- tie the bay leaves, oregano & cinnamon stick together
- add crushed tomatoes and spice bunch to pot
- simmer until thickened, about 30 minutes
- remove from heat & discard spice bundle

White Sauce Ingredients:
- 2 Tbl butter
- 2 C heavy cream
- 6 egg yolks
- ¼ tsp nutmeg
- ¼ tsp fine sea salt
- ¼ tsp pepper
- ½ C grated parmesan cheese

Directions:
- over low heat, melt butter & whisk in cream, yolks, nutmeg, salt, pepper and half the parmesan.
- cook while whisking until thickened, about 10 minutes.
- place eggplant slices on bottom of 'braiser' pan & cover with meat sauce.
- pour white sauce all over top in even layer, sprinkle with remaining cheese & nutmeg.
- bake for 45 minutes.

John Baker
Karen Baker
Marci Braithwaite
Donna Deis (Rickett)
Terry Fabian
John Farley
Stephanie Graczyk
Judy Horton
Mary Lekarczyk
Keith Mitchell
Jay Norman
Marti Purdy
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.

Other Local Support Groups:

Parkinson's Caregivers Support Group

All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings. We meet the 3rd Thursday of each month from 10:00 to 12:00 at the Central United Methodist Church, 4373 Galley Rd, Colo Spgs, 80915. Contact Brenda Hicks at [redacted] or [redacted] to let her know you are coming.

Ladies w/ Parkinson's Support Group

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

If you're interested please notify Julie Pfarrer at db_mgr@co-parkinson.org or [redacted].

Essential Tremor Support Group

Meeting Location: ENT Conference Room - Pikes Peak Library District.; Colo Spgs Library 21c, 1175 Chapel Hills Drive. For meeting dates/times or for questions, contact Jim Sanchez at jimdjs22@gmail.com or [redacted].

Tri-Lakes Parkinson's Support Group

Meets the 3rd Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. For more info contact Syble Krafft at [redacted] or Barry Hanenburg bhanenbu@hotmail.com.

Other Opportunities:

Adult Speech Therapy at Home: Outpatient speech therapy services conducted in the comfort of the patient's home. Personalized speech therapy for restoration of function due to illness or injury.

Treating:

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

Cognitive-Linguistic Deficits
Aphasia following stroke

Swallowing
- Neuromuscular Electrical Stimulation Therapy
- Respiratory Muscle Strength Training

For more information, contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or by phone at (719) 338-8165.

Parkinson's Sing-a-Long Group: 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/text Heather at719-345-2887 or email heatherjohnson@squaremusic.co.

PD Exercise Classes:

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

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

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

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

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

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

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

Falcon Exercise Group

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

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

Tired of Parkinson's beating you up?

THEN FIGHT BACK WITH P.A.R.K.!
Parkinson's **A**ctive **R**esistance **K**arate

If you want to slow the advance of PD you need to stay active. Exercise is the only proven way to slow or halt progression of this disease, and that means cardio, strength, neuroplasticity, and flexibility training. PARK helps with all four, by unleashing these ancient fighting arts to battle PD: **Karate, Kempo, Taekwon Do, King Fu** (Balance, Range of Motion, Cardio); **Arnis/ Kali (Filipino Stick Fighting)** (Hand-Eye Coordination, Range of Motion); **Judo, Jiujitsu, and Aikido (grappling defenses)** (Flexibility, Strength, Balance).

Tues @ 7pm, Woodmen Hills East Rec Center, 9205 Meridian Ranch Blvd

Sat @ 8am, Palmer Park in the grass west of baseball fields

To sign up, call (719) 357-5739 or email parksenseichris@gmail.com
(cost free/space limited)

What Is Parkinson's Masking? A Guide

By Kim Taylor – Healthgrades.com, 1/17/2024

What causes Parkinson's masking?

Parkinson's disease causes a loss of nerve cells in the brain area involved in movement. This leads to muscle stiffness in many body areas, including the face.

When the facial muscles become stiff or take longer to move, it may be more difficult for a person to move their face to express emotions, according to the Parkinson's Foundation. Over time, a person's face may appear more mask-like or inexpressive.

Learn more about the early signs of Parkinson's disease.

What are the features of Parkinson's masking?

Parkinson's masking can cause a person's face to look blank, inexpressive, or serious. It's usually not asymmetric, meaning it affects the muscles on both sides of the face.

A person may be unable to smile, narrow or widen their eyes, or raise their eyebrows as they did in the past. Facial expressions can be important in communication, meaning masking may make recognizing emotional cues in a person with Parkinson's disease more difficult.

It's important to note that Parkinson's disease only affects the ability to communicate with facial expressions, not a person's ability to feel emotions.

Can Parkinson's masking be treated?

Some general treatments for Parkinson's disease may help improve the function of facial muscles and reduce masking.

For example, a small 2020 study showed that people with masking may benefit from levodopa, which doctors often prescribe to manage Parkinson's disease.

Drug manufacturers usually combine levodopa with carbidopa to make the medication Sinemet, designed to promote dopamine production in the brain and relieve Parkinson's disease motor symptoms.

The Parkinson's Foundation also notes that speech-language pathologists can recommend facial exercises to help with masking.

Learn more about the stages of Parkinson's disease treatment.

How can people with Parkinson's masking adjust how they communicate?

If you have facial masking, it may help to explain to the people around you how Parkinson's disease affects your muscles. Once they understand why expressing your feelings through facial expressions is difficult, they may be more understanding and won't continue asking questions like, "What's wrong?"

It may also be helpful to verbally express your feelings to people you're around the most, including family members or caregivers.

Learn more about tips for living with Parkinson's disease.

How can caregivers and families adjust how they communicate with people who have Parkinson's masking?

It may be difficult for caregivers and family members to tell how someone with Parkinson's disease feels. Instead of always asking them what's wrong, it may help to ask how they feel about a particular event or situation.

Once a person with Parkinson's masking knows that you find it difficult to understand their emotions, they may begin to express themselves through words without you asking them questions.

Facial masking can be stigmatizing for people with Parkinson's disease, as others may assume they're indifferent or depressed. It's important to respectfully and openly communicate to avoid causing distress or embarrassment.

Other frequently asked questions

Nancy Hammond, MD, reviewed the answers to these common questions about Parkinson's masking.

Does masking mean Parkinson's disease is getting worse?

A small 2021 study shared that masking may link to more noticeable motor symptoms, such as a freezing gait. This could show that masking may develop as the disease progresses, affecting more of the body's muscles.

Does Parkinson's masking ever go away?

Parkinson's disease is a progressive condition, meaning symptoms don't get better as time goes on. However, treatments like medications and facial exercises may relieve masking.

Summary

Facial masking can occur in people with Parkinson's disease when the condition affects the facial muscles, making them stiffer and more difficult to move. This may cause a person's face to look indifferent or detached, not reflecting the actual emotions a person feels.

Facial masking may make communication more difficult, but treatments like levodopa or facial exercises may relieve it. If you have facial masking, ask your doctor about treatments that may benefit you.

... continued from page 2 | Understand the Differences in Carbidopa/Levodopa Formulations for PD

its unique formulation of time release beads. Each capsule consists of one-third of IR carbidopa/levodopa beads, which allows it to start working immediately, while the other two-thirds consists of ER carbidopa/levodopa beads, which, when coupled with the IR beads, allows it to maintain serum levels for up to 5 hours. In addition to IR/ER beads, each capsule also contains an excipient containing tartaric acid. This is intended to provide an acidic environment to enhance levodopa absorption.6Because of its duration of action, ER formulations can be initiated at 3 times a day and titrated to a maximum of 5 times a day.[8]

ER formulations are not interchangeable with other carbidopa/levodopa formulations due to variations in dosages and pharmacokinetics. The prescribing information should be consulted when converting to the ER product. For patients who have difficulty swallowing, the capsule may be opened, and the contents of both halves sprinkled into applesauce and consumed immediately.

Carbidopa/Levodopa Continuous Enteral Solution

Enteral carbidopa/levodopa bypasses the stomach to allow for continuous administration over 16 hours directly into the small intestine.[9] It is administered via a specialty pump into the jejunum through a percutaneous endoscopic gastrostomy (PEG-J). For temporary administration prior to PEG-J tube placement, treatment may be initiated via a naso-jejunal tube. Continuous infusion provides steady pharmacokinetics, increased efficacy, and fewer oral doses throughout the day. Prior to initiating enteral therapy, all carbidopa/levodopa forms should be converted to the IR formulation to facilitate conversion. Conversely, if a patient receiving enteral carbidopa/levodopa is admitted to the hospital and does not have access to it for inpatient use, a neurologist should be consulted to temporarily switch to an IR formulation. Communication with the outpatient neurologist prior to discharge is also warranted to facilitate transition of care.

Levodopa Inhalation Powder

Levodopa inhalation powder provides on-demand inhaled levodopa that starts to work as early as 10 minutes after taking.[10] It is intended to reduce the duration of "off" periods in advanced disease. Because it is a rescue therapy, it should not be used as primary therapy. Levodopa powder for inhalation is supplied in capsules that are inhaled with a product-specific inhaler. Each dose is comprised of 2 capsules, with each capsule loaded into the device and inhaled individually. However, since the inhalation route is intended for "off" periods, patients with severe symptoms may have trouble setting up the inhaler. As such, caregivers should also be instructed on proper use of the inhaler device.

Pharmacist's Role

Errors related to incorrect levodopa formulations are amongst the top errors observed in patients with PD admitted to the hospital.[11] With the variety of formulations, each with their own unique pharmacokinetic properties, appropriate selection is vital. Other safety concerns include delays in medication reconciliation and administration. Pharmacists should ensure timely reconciliation along with documentation of the patient's dosing schedule to avoid standardized administration times and omission errors. ISMP recommends setting a goal of obtaining a medication history within 2 hours of admission.

In patients that are alert and oriented, discussion with the medical team regarding self-administration may be an option to minimize delays. Although this is not routinely suggested, it may be a solution when frequent (every <4 hours) doses are needed.

Additionally, delays in obtaining nonformulary medications should be minimized. Consultation with the patient's neurologist may be of benefit if a specific formulation cannot be provided while hospitalized. Ensuring abrupt discontinuation of PD medications is essential to avoid significant adverse events.

Spinal Device Helps Man with Parkinson's Walk without Freezing

By Marisa Wexler, MS – Parkinson's News Today, 11/13/2023

The implanted device delivers electrical stimulation to nerve cells in the spine

An implanted device that delivers electrical stimulation to nerve cells in the spine helped reduce gait freezing in a man with Parkinson's disease, improving his ability to walk. Gait freezing occurs when a person stops walking without meaning to, which can lead to falls.

The device's development was described in *Nature Medicine*, in "A spinal cord neuroprosthesis for locomotor deficits due to Parkinson's disease."

"I would fall five to six times per day. I would often stay home as well, and was forced to stop working three years ago. For example, walking into a store was impossible before, because of the freezing of gait that would happen in those environments. And now it doesn't happen anymore," Marc Gauthier said in Nature.

Most people with Parkinson's, especially those in the disease's more advanced stages, will have problems walking, difficulty with balance, or gait freezing.

Medications and deep brain stimulation (DBS), a surgical intervention where a device is implanted to deliver electrical stimulation to specific brain regions, may help improve walking for some Parkinson's patients, but many continue to have problems despite available therapies.

Freezing of gait more likely to occur with long-term levodopa use

Unfreezing gait in Parkinson's

Scientists here developed a device to help normalize walking by targeting the nerve cells in the lower spine directly responsible for controlling leg movements.

"Our specialty is in our understanding of how to stimulate the spinal cord in order to be very precise in the way we adjust leg movement. The novelty of this study is to leverage this understanding and technology in Parkinson's," said Grégoire Courtine, PhD, a neuroscientist at the Swiss Federal Institute of Technology in Lausanne (EPFL) and co-author of the study.

The scientists first worked to understand how the activity of nerves in the spinal cord of monkeys with Parkinson's-like disease differs from healthy monkeys while walking. Then, they developed a device to deliver electrical stimulation that would help normalize electrical activity.

In order to sync the device's stimulations with the monkey's movements, the researchers used a sensor implanted into their motor cortex, the part of the brain chiefly responsible for controlling movement.

The system let monkeys with Parkinson's-like disease walk essentially normally and the effects improved when they were given DBS, suggesting the two approaches may work together.

The researchers then adapted the technology to treat Gauthier, who received an implant in his lower back over the spinal cord. To coordinate electrical signals delivered by the implant, the researchers used motion sensors he could wear, which could determine the needed electrical stimulation by tracking his movements. These sensors couldn't be used in the monkeys because they wouldn't tolerate wearing them, the researchers said.

The device led to notable improvements in Gauthier's walking ability. A computer-based analysis of his gait with it suggested he was walking in a way similar to a person without Parkinson's.

"There are no therapies to address the severe gait problems that occur at a later stage of Parkinson's, so it's impressive to see him walking," said Jocelyne Bloch, a neurosurgeon at the EPFL and a lead author of the study.

Before getting the device, Gauthier "exhibited frequent freezing-of-gait episodes," said the researchers, who noted with the device these episodes "nearly vanished."

Gauthier has been using the device daily for nearly two years and is able to walk more than "several kilometers without any additional assistance," wrote the researchers, who are running a clinical trial called STIMO-PARK (NCT04956770) that's collecting data on Gauthier and another participant's use of the device. The trial is expected to run through early 2026.

A pair of researchers at the University of California, San Francisco, writing in an editorial that was published alongside the study, said further research is needed to test the technique in more patients, but noted early data was promising. "It will be exciting to see how this approach translates to a larger group of patients with freezing-of-gait in the setting of advanced" Parkinson's, they said.

Walking Tall App Goes to Bat for People with Parkinson's Disease

By Andrea Lobo – Parkinson's News Today, 8/10/23

People with Parkinson's disease can learn how to re-train their gait and improve their walking ability with the help of a new app that's available for free on both the iOS and Android stores.

Walking Tall lets users define their own training time and rhythm, and delivers a rhythmic beat for three different walking speeds.

Developed by biomedical engineer Matthew A. Brodie, PhD, from the UNSW Sydney University, Australia, the app was developed by employing key suggestions from people with Parkinson's disease.

"This app can give people confidence and also a sense of achievement that they can be empowered and do something for themselves to help their own condition," Brodie, who has since set up the company Walking Tall Health, said in a university news release. "My goal in terms of my research is to have an impact now, not an impact in 10 years' time. And I believe this app can help people with Parkinson's [disease] all around the world right now."

A feature of Parkinson's disease is the dysfunction and death of dopaminergic neurons (nerve cells) that release the signaling molecule dopamine. This causes motor symptoms, such as tremors, slowness of movement, and muscle rigidity.

Wearable cyborgs improve walking for Parkinson's patients: Study

Taking the thinking out of walking

People with the disease often have balance and gait difficulties associated with decreased coordination and affected step length. Gait dysfunction can negatively impact patients' quality of life and independence, and about 70% experience falls.

"Those who live with Parkinson's [disease] have to think about every single step they take. We asked them how much mental effort it takes for them to walk, and often they would say 100%," Brodie said.

The researchers developed the app following a clinical trial (NCT04613141) of 62 people with Parkinson's disease, which was funded by the Shake It Up Australia Foundation and the Michael J Fox Foundation for Parkinson's Research.

In it, half the participants used a version of the app to help train their gait, while the other half followed a walking program called Otago Exercise Program (OEP). This program, based on strength, balance, and walking exercises performed three times a week at home, reduces falls by 35-40% for frail older adults.

After 13 weeks, an analysis of patients' self-reported feedback showed those using Walking Tall were exercising for 150 minutes (2.5 hours) a week, on average, compared with 60 minutes with OEP.

Based on the trial's positive feedback, the researchers developed it further, adding specific training sessions, split into five different walks and rest periods, with users guided to walk at slow, normal, and fast speeds by delivering a rhythmic metronomic beat.

"With the metronome beat of the app the aim is to replace the need to think about walking and help with the timing of their steps," Brodie said. "The feedback we got from the trials is that the people who used the app really liked the simple metronome beat via their phone that helped to [stabilize] their gait."

The app also includes instructions such as "walk tall," "shoulders back," and encourages users to "focus on big steps."

"We're training [patients] in gait adaptability. Sometimes they also need to [visualize] a walking style because often people with [Parkinson's disease] suffer from hypokinesia where their movements are not actually as big as they feel they are," Brodie said. "So we are encouraging them to take exaggerated steps, which will actually be more like regular steps."

A Tyree Institute of Health Engineering (Tyree IHealthE) Catalyst Grant also contributed to the app's development after the initial clinical trials. "Walking Tall Health addresses a significant unmet need experienced by people with [Parkinson's disease]," said Ian Goon, head of Strategy and Innovation at Tyree IHealthE.

Walking Tall Health's chief science officer Martin Ostrowski has Parkinson's disease. "I think an app like this empowers people living with Parkinson's to have some control over helping themselves and [realizing] they can still have a long and productive life," he said, adding it "gives me that beat that means I am able to walk without using all of that mental effort."

Colorado Parkinson Foundation, Inc.
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Colorado Springs, CO 80920

Coming Events

See inside for more information

March 2nd - Reg Mtg at Central United Methodist Church – 10 am
Program: Exercise is Medicine — What's the Prescription?
Speaker: Danielle Mulligan, PT, MSPT

April 6th - Reg Mtg at Central United Methodist Church – 10 am; **Program:** The Benefits of Dance for Parkinson's; **Speakers:** Laura Treglia & Robin Izer, Ormao Dance Company

May 4th - Reg Mtg at Central United Methodist Church – 10 am
Program: Break-Out Sessions – Caregivers & Parkinsonians separate into different rooms to talk

June 1st - Reg Mtg at Central United Methodist Church – 10 am; **Program:** TBD

July 6th - Reg Mtg at Central United Methodist Church – 10 am; **Program:** TBD

August 3rd - Annual Picnic at the Barn pavilion at John Venezia Park!!!

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