



Parkinson's Perspective

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

www.co-parkinson.org | (719) 884-0103

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Educational Outreach: Jill Reid

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Vacant

Photographer: Annette Garcia

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Main Dish Coordinator:

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potluck@co-parkinson.org

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and Janet Adams

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Medical Advisor:

Dr. Brian Grabert, MD

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Norm Tuinstra

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MJ Thompson [redacted]

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call [redacted]

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)

December Meeting: Saturday, December 7th – 10:00 am – 1:30 pm

We will NOT be Zooming OR recording this meeting

January Meeting: Saturday, January 4th – 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.

December Meeting: Annual Christmas Party ... and Annual Christmas

"Festive Apparel" Contest!

You are invited to participate in a festive Christmas apparel contest during the meeting.

The "Song Spinners" Show Choir will be entertaining us!



Winner will receive a prize!

The most festive sweater, tie, hat or combination of thereof as judged by your applause.

Ties will be broken by a new member to our group.

Come have your picture taken with Santa!



January Program: Parkinson's 101

Speaker: Jill Reid-Acting President, CPF & CSPSG



Jill will present the annual Parkinson's 101 program. Designed for People with Parkinson's and their family-member caregivers. Parkinson's 101 provides invaluable information for those new to the disorder as well as for those who already have extensive experience with the disorder. It also includes practical advice on coping with Parkinson's on a day-to-day basis. Since the symptoms of each PWP's Parkinson's change to some degree over the course of a year, we present this briefing annually so that each of you can key in on the information that wasn't relevant to you in the past but is now.

Knowledge is power and enables us all to live well, so plan to attend the January meeting at Central United Methodist Church or join us on Zoom.

Both December and January programs will be followed by potlucks, see page 2 for more information.

DECEMBER POTLUCK: CHRISTMAS!

CPF will be providing the main dish of ham for December's lunch.

JANUARY POTLUCK: CHILI & CORNBREAD!

If you would like to sign up to be one of the providers of the main dish in January or to bring a side dish or dessert for either meeting, you can contact Bill Hicks at [REDACTED] or by email at potluck@co-parkinson.org, no later than Wednesday, December 5th for the December meeting and Wednesday, January 1st for the January meeting and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

WE LOOK FORWARD TO SEEING YOU THERE!

Ask the Doctor!



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

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

Combating Parkinson's with Rock Climbing

The following is the link to a CBS Sunday Morning TV segment on Parkinson's and rock climbing that was aired on Sunday, November 17th, 2024:

<https://www.cbsnews.com/video/combating-parkinsons-with-rock-climbing/>

There is currently no cure for Parkinson's Disease. But some with Parkinson's are finding that an unusual therapy – rock climbing – is helping them improve their balance, mobility, strength and cognition. "60 Minutes" correspondent Lesley Stahl reports.



The President's Corner | Jill Reid-Acting President, CPF & CSPSG



I'm always touting the benefits of the **FREE** NeuroPong sessions at the Downtown Y. I try very hard to keep NeuroPong in front of you in the hopes that all of you with Parkinson's will take advantage of this program that mitigates your Parkinson's symptoms while you have fun. How can you resist?? **Don't forget** - anything you do to mitigate your symptoms will help your wonderful caregivers too, and you need to help them as much as you can so they will always be there for you.

In the spirit of helping your family caregivers, I ask you to encourage them to attend the monthly Parkinson's Caregiver Support Group that meets in Fellowship Hall of Central United Methodist church from 10 am to noon on the third Thursday of each month. They need the moral support and knowledge that only other caregivers can give them. So help yourself (and, as a result, your caregivers) by participating in NeuroPong and other such Parkinson's programs (for example, Ormao's Dance for Parkinson's and YMCA's Parkinson's Exercise Program) and help your family caregivers by insisting they go to the monthly Parkinson's Caregiver Support Group.

Speaking of the Parkinson's Caregiver Support Group, its long-time facilitator, Brenda Hicks, has announced that the November meeting was her last as facilitator. She plans to continue doing all the other things she does for our large support group - attending the monthly Executive Committee Meeting, arriving at 8 am for the large support group meetings to set up the kitchen and pot luck lunches, serving the pot luck lunches, washing serving equipment and table cloths after the meetings, and maintaining the pot luck supplies - and don't forget, cooking a turkey for each November meeting! Whew! Makes you tired just thinking about it all! We so appreciate her willingness to have also facilitated the caregivers group for so long in addition to all the other things she does for us.

The caregivers who have been attending the caregiver support group can attest to how much it has helped. So we don't want to lose this valuable resource. I'm sure it can function without a formal facilitator; but every group like this needs someone who says, "Come join me, and let's help each other."

Please consider stepping into this vital position; ask Brenda what all it entails and then let me know if you're willing.

Please Don't Eat the Daisies



This month's recommended comedy movie is:

Please Don't Eat the Daisies, starring Doris Day, David Niven, Janis Paige, and Spring Byington.

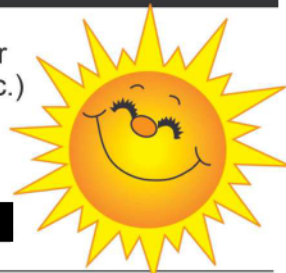


Laugh loudly and laugh often!

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]



LENDING LOCKER INVENTORY

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

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	2
Hospital bed food trays	2
Hoyer Lift	1
Lazercue for freezing help	1
Lift chairs	0
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	1
U-step	1
Walkers with wheels & seat	9
Waterproof mattress protector (Twin)	1
Wheelchairs	8

ITEMS THAT ARE FREE FOR THE TAKING:

Contact Julie Pfarrer if interested in these items at db_mgr@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-Ig-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

U.S. FDA Approves VYALEV™ (foscarnidopa and foslevodopa) for Adults Living with Advanced Parkinson's Disease

By Abbvie News Center, October 17, 2024
(Excerpts from)

- VYALEV™ is the first and only subcutaneous 24-hour continuous infusion of levodopa-based therapy for the treatment of motor fluctuations in advanced Parkinson's disease
- Adults treated with VYALEV reported superior improvement in "on" time without troublesome dyskinesia, compared to oral immediate-release carbidopa/levodopa¹
- VYALEV allows for personalized dosing based on individual needs, morning, day and night

Abbvie (NYSE: ABBV) announced that the U.S. Food and Drug Administration (FDA) has approved VYALEV™ (foscarnidopa and foslevodopa) as the first and only subcutaneous 24-hour infusion of levodopa-based therapy for the treatment of motor fluctuations in adults with advanced Parkinson's disease (PD).

"For too long, the Parkinson's community has had limited treatment options for advanced disease. Due to the progressive nature of the disease, oral medications are eventually no longer as effective at motor symptom control and surgical treatment may be required," said Robert A. Hauser, M.D., MBA, Professor of Neurology and Director of the Parkinson's and Movement Disorder Center at the University of South Florida. "This new, non-surgical regimen provides continuous delivery of levodopa morning, day and night."

The approval was supported by the pivotal Phase 3, 12-week study evaluating the efficacy of continuous subcutaneous infusion of VYALEV in adult patients with advanced PD compared to oral immediate-release carbidopa/levodopa (CD/LD IR), along with a 52-week, open-label study which evaluated the long-term safety and efficacy of VYALEV.

Findings from the pivotal study showed patients receiving VYALEV demonstrated superior improvement in motor fluctuations, with increased "on" time without troublesome dyskinesia and decreased "off" time, compared with oral CD/LD IR. "On" time refers to the periods of time when patients are experiencing optimal motor symptom control while "off" time is when symptoms return.

The majority of adverse reactions (ARs) with VYALEV were non-serious and mild or moderate in severity. The most frequent ARs (greater than or equal to 10 percent and greater than CD/LD IR incidence) were infusion site events, hallucinations, and dyskinesia.

"People living with advanced Parkinson's disease experience daily challenges as a result of uncertainty in managing motor fluctuations, especially as their disease progresses," said Roopal Thakkar, M.D., executive vice president, research & development, and chief scientific officer, AbbVie. "We are proud to bring this innovation to patients who may benefit from motor symptom control through continuous 24-hour administration of VYALEV."

PD is a progressive and chronic movement disorder resulting in tremor, muscle rigidity, slowness of movement and difficulty with balance resulting from the loss of dopamine-producing brain cells.

Timing for a patient's access to VYALEV is dependent on their individual insurance plan. Coverage for Medicare patients is expected in the second half of 2025.

To learn more about this treatment, people should speak with their prescribing healthcare provider.

ABOUT THE PHASE 3 M15-736 STUDY

The Phase 3 randomized, double-blind, double-dummy, active-controlled study compared the efficacy, safety and tolerability of VYALEV to oral CD/LD IR in patients with advanced PD. Participants were provided with a home diary (the PD Diary) to assess their motor state during the day. The primary endpoint of good "on" time (defined as "on" time without dyskinesia plus "on" time with non-troublesome dyskinesia), was collected and averaged over three consecutive days and normalized to a typical 16-hour waking period. Baseline values are defined as the average of normalized good "on" time collected over the three PD Diary days before randomization. Approximately

(Continued on page 6...)

Thank You!

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

February Newsletter Input Deadline: January 10th

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

December & January CSPSG Executive Committee Meetings

December 10th & January 7th @ 09:30am
(Location: Place to be determined)

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

🎉🎉🎉 HAPPY DECEMBER BIRTHDAYS! 🎉🎉🎉

- | | | | |
|--------------------|-------------------|-----------------|----------------------|
| - Robin Alvord | - Carol Hamill | - Clayton McCoy | - John Sloan |
| - Christine Bishop | - Kay Harder | - Bill Page | - Charla Spence |
| - Jerry Corns | - Bruce Hughes | - Gregg Pinchuk | - Marge Sullivan |
| - Amy Coyle | - Michelle Kahley | - James Rochon | - William E. Wallace |
| - Pat Dashosh | - Jean Koch | - Ted Rudawsky | - Charles Winkler |
| - Nicole de Naray | - Connie Kremer | - Sue Seery | - Kristin Woestehoff |
| - John Fooks | - Helene Lemire | - Janie Shore | - Bill Wollen |
| - George Guerrero | - Steve Locke | - Sukey Skousen | |

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

🎉🎉🎉 HAPPY JANUARY BIRTHDAYS! 🎉🎉🎉

- | | | | |
|-----------------------|------------------------|---------------------|--------------------|
| - Andrew Arneson | - Linda Christian | - Patricia Kayser | - Stanley Rapaport |
| - Lisa Benhammou-Osur | - Claudia Christiansen | - Bill Koch | - Jill Reid |
| - Ron Bowman | - Vince Cologne | - Lynn Kozeliski | - Mary Roney |
| - Doris Briggs | - Hannah Duncan | - Bob Meredith | - Kathi Rudawsky |
| - Jerelyn Buhringer | - Elinor Edwards | - Ronald Nickelson | - Lonny Seery |
| - Bill Byars | - Mary Essing | - Mary Ellen Palmer | - Larry Suhr |
| - Linda Byars | - Kathie Fallon | - Richard Parker | - Donna Telatnik |
| | - Bill Hicks | - Carol Prest | |

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 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: CHICKEN IN BLUE

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: db_mgr@co-parkinson.org.

Ingredients:

- | | |
|--|-----------------------------------|
| 2 Tbl olive oil | 4 Tbl dry white wine |
| 1 garlic clove, crushed | 2/3 C heavy cream |
| 1 red bell pepper, seeded & diced | 8 oz Danish blue cheese, crumbled |
| 1 lb boneless chicken, skinned & diced | 2 scallions, finely chopped |
| Salt & pepper | 2 Tbl chopped parsley |
| 8 oz small button mushrooms | |

Directions:

- Heat oil in large skillet and add garlic, red bell pepper and chicken with some seasoning (blue cheese makes it salty).
- Cook, stirring often, for about 20 minutes or until the diced chicken is lightly browned and cooked.
- Add mushrooms and cook for 2 minutes then pour in the wine & bring to a boil.
- Turn heat to lowest setting and allow mixture to stop boiling before pouring in cream and stirring in cheese.
- Stir over low heat until cheese has melted. Do not allow sauce to simmer or it will curdle.
- When cheese melts, taste then pour over pasta substitute (such as zucchini noodles) and sprinkle with scallions and parsley.
- Serve at once and enjoy!

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. 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. It would be nice to fill the position in time for the December caregiver meeting.

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 db_mgr@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/questions at jim-[REDACTED] or [REDACTED]

Tri-Lakes Parkinson's Support Group

Meets the 3rd Saturday of every month at 10am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. Contact Syble Krafft at [REDACTED] or Barry Hanen-burg [REDACTED] for more information.

Other Opportunities:

Adult Speech Therapy:

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

Treating:

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

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 at (719) 345-2887 or email her at 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

Neuroping 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@rsbaffiliate.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

Neurologicrehab.com / Fax: (719) 691-7994

(...continued from page 3: U.S. FDA Approves VYALEV™ (foscarnidopa and foslevodopa) for Adults Living with Advanced Parkinson's Disease)

130 adult participants with advanced PD were enrolled in the study across 80 sites in the U.S. and Australia. Participants were randomized 1:1 to receive either the VYALEV solution as a continuous delivery under the skin (subcutaneous) plus oral placebo capsules for CD/LD or oral capsules containing CD/LD IR plus continuous subcutaneous delivery of placebo solution for VYALEV. The treatment duration was 12 weeks. The increase in "on" time without troublesome dyskinesia at week 12 was 2.72 hours for VYALEV versus 0.97 hours for oral CD/LD IR (p=0.0083). Improvements in "on" time were observed as early as the first week and persisted throughout the 12 weeks. More information on the study can be found on www.clinicaltrials.gov (NCT04380142) and in *The Lancet Neurology* ([https://doi.org/10.1016/S1474-4422\(22\)00400-8](https://doi.org/10.1016/S1474-4422(22)00400-8)).

ABOUT VYALEV™

VYALEV (foscarnidopa and foslevodopa) is a solution of carbidopa and levodopa prodrugs for 24-hour continuous subcutaneous infusion for the treatment of motor fluctuations in adults with advanced PD. VYALEV, also known as PRODUODOPA®, has been approved in 35 countries and over 4,200 patients worldwide have started treatment. AbbVie continues to work with regulatory authorities around the world to bring VYALEV to people living with advanced Parkinson's disease.

[for a complete listing of possible side effects and safety warnings see the original article at Abbvie news, Oct 17th, 2024 at the following link: <https://news.abbvie.com/2024-10-17-U-S-FDA-Approves-VYALEV-TM-foscarnidopa-and-foslevodopa-for-Adults-Living-with-Advanced-Parkinsons-Disease/>]

Fitness, Friendships, and Fun: The Benefits of Boxing with Parkinson's

By Christine Scheer, Parkinson's News Today, July 26, 2024

EXERCISE IS IMPORTANT FOR PEOPLE WITH PARKINSON'S, BUT SO IS CAMARADERIE

When I was diagnosed with Parkinson's in 2015, I didn't know anyone else with the disease. Then I joined Rock Steady Boxing, a program designed specifically for those of us with Parkinson's. I'd found my people!

I had read about the program and its benefits, but thought it was weird. Eventually, though, I decided to give it a try. Rock Steady Boxing was new in our area, and the owner was a retired boxer with Parkinson's. Classes took place at his boxing gym. The other coach was a young fitness instructor who was a powerhouse.

What was the gym like? Think of every boxing gym you've ever seen in the movies: a little dark and a little worn and dingy, located right in the middle of our downtown. It was the real deal. We had to climb 50 steep steps to get into it. Most people were breathless by the time they reached the top.

The gym had a boxing ring that we used during every class, along with hanging heavy bags.

RUMBLE BOXING TEAMS UP WITH MJFF FOR PARKINSON'S AWARENESS MONTH FIGHTING BACK

How do I describe what climbing into the boxing ring feels like? Well, it gives you confidence, and it's a real thrill to punch the focus mitts in the center of a ring. We all cheered one another whenever we did this.

Since I joined, the program has evolved. We've moved to different gyms a few times now, and the program I currently attend has switched to something called Knock Out Parkinson's Disease, which is run by a local physiotherapy clinic. It's the same principle as Rock Steady Boxing, which is that boxing can change those of us with Parkinson's disease for the better. Fighting back gives us hope.

My current classes are a workout! They're 90 minutes long, but the time flies. Going three times a week gives us the most bang for our buck in terms of fitness.

In case you're wondering, the classes are noncontact. The only things we punch are heavy bags and focus mitts.

A typical class involves a 15-minute warmup and a half-hour of exercises, such as core work, agility exercises, footwork, and even vocal exercises. Squats, jumping jacks, and sometimes line dancing are also included. We always focus on having fun but also must push ourselves to benefit from the exercise.

The next 30 minutes focus on the actual boxing. Is anybody angry? Take it out on the bag!

Finally, during the last 15 minutes of the class, we do stretches and cool down. The most challenging part of the workout is often just getting up from the floor!

Why is boxing so good for those of us with Parkinson's disease? Punching the bags improves our coordination and posture, strengthens our core and hand-eye coordination, and builds strength and muscle.

And while we tend to highlight the physical benefits, being around others who share the common goal of doing what we can to fight back against Parkinson's is an absolute joy.

Over the years, I've made wonderful friends, learned so much, and laughed hard, all while keeping Parkinson's at bay to the best of my ability. The camaraderie and support we provide one another in these classes are just as important as the physical benefits of the exercise.

Method Generates Dopaminergic Neurons Lost in Parkinson's Disease

By Andrea Lobo – Parkinson's News Today, 5/2/24

RESEARCHERS USED ANTIBODY TO ACTIVATE RECEPTOR IN PLURIPOTENT STEM CELLS

Researchers in Canada have developed a new method to generate functional dopaminergic neurons, the dopamine-producing nerve cells lost in Parkinson's disease, from human pluripotent stem cells (hPSC).

The scientists used an antibody to selectively activate FZD5, a receptor, in the stem cells, which stimulated a specific molecular signaling pathway involved in generating new neurons from the cells. Human pluripotent stem cells can generate nearly all cell types, including neurons.

The method provides a more precise and controlled activation of this pathway, called Wnt, and may improve the differentiation of stem cells into dopaminergic neurons in the brain regions affected by Parkinson's.

"We used synthetic antibodies that we had previously developed to target the Wnt signaling pathway," Stéphane Angers, principal investigator on the study and director of the Donnelly Centre for Cellular and Molecular Biology at the University of Toronto, said in a press release. "This activation method has not been explored before."

The study, "Exploiting spatiotemporal regulation of FZD5 during neural patterning for efficient ventral midbrain specification," was published in *Development*.

Parkinson's is caused by the dysfunction and death of dopaminergic neurons in the nigrostriatal pathway of the midbrain, a region involved in motor control. Dopamine is a major brain chemical messenger.

Replacing lost dopaminergic neurons may be effective for treating Parkinson's disease. Most studies have relied on an inhibitor of the GSK3 enzyme, whose activity is altered in various diseases, including Parkinson's, to activate the Wnt pathway. This method affects other signaling pathways, and may cause unintended effects and activate off-target cells, however.

The Wnt pathway is a group of signal transduction pathways involved in various cellular processes, including cell growth and development, tissue maintenance, and cell communication. Wnt signaling has been implicated in midbrain dopaminergic

(Continued on the bottom of page 7...)

Noninvasive Deep Brain Stimulation Shows Promise for Parkinson's

Patricia Inacio, PhD, Parkinson's News Today, June 13, 2024

URIS DEVICE WAS TESTED ON 12 WOMEN IN A PILOT CLINICAL TRIAL

Early preliminary data from a pilot study by Stimvia shows a noninvasive neuromodulation device known as URIS eased symptoms among participants in a pilot clinical trial and may serve as an add-on treatment for Parkinson's disease. The device's developer plans to release the complete data in the coming months.

"We are pleased to share preliminary findings indicating promising results. Patients have reported improvements in both the number of Parkinson's disease symptoms and their overall quality of life. Furthermore, we have observed a notable reduction in resting tremor. While the precise data are still under rigorous evaluation, we remain cautiously optimistic about the potential implications of these outcomes," said David Skoloudik, MD, PhD, the study's lead investigator and vice dean for Science and Research at the Medical Faculty of Ostrava University, Czech Republic, in a company press release.

Parkinson's is caused by the loss of nerve cells that produce dopamine, a major brain chemical messenger that helps control movement. Their loss leads to disease symptoms, including tremor and slowed movements.

Deep brain stimulation (DBS) has been used to treat Parkinson's motor symptoms and those with a poor response to other therapies. With DBS, electrodes are surgically placed that deliver electrical stimulation to specific areas of the brain. The electrical current, which is generated by a battery-powered neurostimulator implanted under the skin, blocks the signals that underlie Parkinson's motor symptoms, such as tremors.

DEEP BRAIN STIMULATION SURGERY ALLOWS GUITARIST TO PLAY ONCE AGAIN

TESTING URIS FOR PARKINSON'S

Stimvia's URIS device uses electrodes placed near the peroneal nerve in the lower leg to modulate electrical activity that stimulates specific nerve pathways in the brain.

It functions as a noninvasive alternative for DBS to modulate the activity of specific brain nerve pathways. A built-in monitoring system lets doctors monitor the brain's response to the stimuli, adjusting the neurostimulation as needed.

Twelve women with Parkinson's disease and essential tremor in the pilot clinical trial (NCT06036368) used the URIS device daily for 30 minutes over six weeks. They were all followed for another six weeks without any stimulation to monitor the treatment's persistence.

The main goal was to assess the safety and tolerability of the URIS device. Its effectiveness was assessed using the clinician-assessed Patient Global Impression of Improvement scale. Other Parkinson's efficacy exploratory parameters included changes in overall disease and motor symptoms, and quality of life.

"Since the URIS technology demonstrated a positive impact in treating Parkinson's disease, Stimvia plans substantial investment in further clinical trials to validate the method's efficacy and safety. We believe our technology can introduce new, additive treatment modalities for millions of patients who currently have no other options, potentially offering a positive disease-modifying impact on those with Parkinson's disease," said Lukas Dorskocil, Stimvia's CEO.

The URIS nerve stimulation device was also tested in a clinical trial (NCT05211193) involving people with overactive bladder. The results showed it reduced the urge to urinate by 80%. The study also observed significant activation of brain regions involved in perceiving bladder fullness. ■

(...continued from page 6: Method Generates Dopaminergic Neurons Lost in Parkinson's Disease)

neurons' development and function, and some studies suggest activating Wnt signaling may have neuroprotective effects or promote dopaminergic neurons to regenerate.

NEW METHOD DEvised TO GENERATE DOPAMINERGIC NEURONS

GENERATING DOPAMINERGIC NEURONS FROM STEM CELLS

Here, researchers used established protocols to differentiate hPSCs into neural stem cells, or progenitor cells, from different brain regions. Then, using antibodies specific to FZD receptors, they identified the FZD5 receptor as being highly active in neural stem cells that defined the midbrain region.

The FZD5 receptor is a protein on the surface of cells and part of the Wnt signaling pathway. Activating it can stimulate the production of new neural cells in the midbrain that closely resemble dopaminergic neurons.

The receptor levels were regulated by several genes, including the one that encodes OTX2, a protein involved in defining the pattern of neurons in the midbrain, an analysis showed. Based on the data, the researchers hypothesized that selectively activating FDZ5 using specific antibodies against this receptor would efficiently induce the neuronal pattern of the midbrain.

"We can selectively activate this pathway to direct stem cells in the midbrain to develop into neurons by targeting specific receptors in the pathway," Angers said.

When the effect of activating FDZ5 receptors using a GSK3 inhibitor or a specific antibody were compared, both methods led to a similar differentiation of midbrain neural progenitor cells, as assessed by the activity levels of specific genes.

The researchers also confirmed that the progenitor cells obtained from activating the FDZ5 receptor could differentiate into dopaminergic neurons by evaluating the activity of genes specific to these neurons such as tyrosine hydroxylase, an enzyme critical for dopamine production. They also observed that the obtained neurons had an activity profile consistent with dopaminergic neurons.

"We developed an efficient method for stimulating stem cell differentiation to produce neural cells in the midbrain," said Andy Yang, first author of the study and PhD student at the Donnelly Centre. "Moreover, cells activated via the FZD5 receptor closely resemble dopaminergic neurons of natural origin."

To see if the progenitor cells obtained using the new method could originate functional dopaminergic neurons in the brain, the researchers implanted the cells in a rat model of Parkinson's disease that displayed locomotor impairment.

Three months after the implantation, the animals who received the progenitor cells recovered their locomotor function, which persisted up to 32 weeks, or about eight months.

"These data suggest that the [midbrain] progenitors derived from [the new] treatment give rise to bona fide [dopaminergic] neurons and are functional in vivo to efficiently rescue motor dysfunction," the researchers wrote.

"Our next step would be to continue using rodent or other suitable models to compare the outcomes of activating the FZD5 receptor and inhibiting GSK3," said Yang. "These experiments will confirm which method is more effective in improving symptoms of Parkinson's disease ahead of clinical trials." ■

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PARKINSON'S PERSPECTIVE

**DECEMBER 2024
& JANUARY 2025**

Coming Events

See inside for more information

December 7th - Reg Mtg at Central United Methodist Church – 10 am;
Program: Christmas Party!!!! - The Song Spinners will entertain us!

January 4th - Reg Mtg at Central United Methodist Church – 10 am;
Program: Parkinson's 101; **Speaker:** Jill Reid, Education Outreach

February 1st - Reg Mtg at Central United Methodist Church – 10 am;
Program: Break-Out Sessions; Caregivers & Parkinsonians separate into different rooms to talk

March 1st - Reg Mtg at Central United Methodist Church – 10 am;
Program: Scam Prevention; **Speaker:** Scott Mathis, Colorado Springs Police Department

More useful websites:

<https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpcf.org; michaeljfoxfoundation.org;
<http://caremap.parkinson.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>;
www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons; www.parkinsonheartland.org;
<https://www.pdself.org>; https://www.youtube.com/playlist?list=PLkPlhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org;
<https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers>