



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

Acting President:

Jill Reid [redacted]
president@co-parkinson.org

President Emeritus: Ric Pfarrer

Vice President: Jill Reid

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Members at Large:

Janet Adams, Dee Beatty,
Annette Garcia, Carole Henrichsen,
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Parkinson's Awareness Day:

Vacant

Photographer: Annette Garcia

Lending Locker Coordinator:

Mary Sauvain [redacted]

Main Dish Coordinator:

Bill Hicks [redacted] or
potluck@co-parkinson.org

Picnic: Carole Henrichsen

and Janet Adams

Media Relations: Mary Sauvain

Medical Advisor:

Dr. Brian Grabert, MD

New Member Table Chairmen:

Norm Tuinstra

Sunshine (Cards):

MJ Thompson [redacted]

T-Shirt Chairman: Vacant

Webmaster: Julie Pfarrer

webmaster@co-parkinson.org

Newsletter Editor:

Kristy Schleiker

Address/Email/Database

Updates and Newsletter

Coordinator:

Contact Julie Pfarrer at

db_mgr@co-parkinson.org or
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)

THIS NEWSLETTER COVERS BOTH JULY & AUGUST

Next Meeting: Saturday, July 6th – 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.

July Program Topic: Therapies in Parkinson's Disease

Speaker: Dr. Steven Swank, PharmD, BCACP

Dr. Steven Swank is a Clinical Pharmacist Specialist and a Board-Certified Ambulatory Care Clinical Pharmacist (BCACP). In 2013 he was awarded his Doctorate of Pharmacy (PharmD) from Butler University. He completed his PGY 1 & 2 Ambulatory residencies at Indiana University. He then worked in Primary Care at Ft. Carson before joining PEAK Neurology in 2022. He has also worked at the University of Kansas Medical Center's Parkinson's Disease and Movement Disorder Center and did some educational work with the Parkinson's Foundation.

He considers it an honor to serve his patients by providing the best comprehensive neurologic care possible. His special interests include Parkinson's Disease, Parkinsonism, Autonomic dysfunction, Neurodegenerative diseases, and Drug-induced neurologic conditions. In his free time, he enjoys running, hiking, cooking, reading and spending time with his family.

Please bring any questions you may have concerning the drugs you are taking now or those you have heard about and you want more information on.

The meeting will be followed by a potluck

The July Potluck – Red, White & Blue Food!

Try to bring red, white or blue food for a colorful Independence Day theme.

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, July 3rd 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!



Directions to Venezia Park:

– From I-25 take the Briargate Parkway exit. Go east on Briargate Parkway where there will be the entrance to the first parking lot that is next to the Bunkhouse Pavilion. A second entrance off of Briargate Parkway takes you to the parking lot that is east of the pavilions or you can go all the way to Union and turn right.

– From Union Blvd., Turn west at the light at Family Place into the park (across from the King Soopers). Wind around until you see the windmill and the large pavilions with the green roofs. The easiest parking lot is the one to the right (east, next to the HOUSE pavilion) – no inclines or ramps. There is another parking lot on the west side of the 3 large pavilions but you have to navigate an incline (ramp) to reach the pavilions.

SUMMER PICNIC - SATURDAY, AUGUST 3RD, 11AM – 1PM

Our annual summer picnic will be August 3rd at Venezia Park at the corner of Union Blvd and Briargate Parkway. Look for three large pavilions with green roofs. The BARN pavilion is the large middle pavilion. There is a parking lot on the west side of the pavilions but you will have to climb a ramp because that parking lot is down a hill from the first pavilion. The main parking lot next to the restrooms (east of the pavilions) is also available.



Main Dish – your choice of fried or baked chicken & water will be furnished. If you would like to drink something else, please bring your own.

In order to assure that we have a good variety of side dishes, Bill would like for you to let him know what you're bringing to the picnic by contacting him at [redacted] or potluck@co-parkinson.org.

Attire – if you own one, wear your 'safety green' (actually neon yellow) Parkinson's shirts so we stand out in the crowd by 'glowing'. If not, wear whatever Parkinson's Support Group apparel you might have, otherwise, wear something comfortable.

There are picnic tables with seats furnished but you're welcome to bring a lawn chair.

IF YOU WOULD LIKE TO HELP SET UP OR CLEAN UP, CONTACT: CAROLE HENRICHSEN AT [redacted] OR BY EMAIL AT [redacted] —OR— JANET ADAMS AT [redacted] OR BY EMAIL AT [redacted]

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



It's been a while since I gave you a rundown of happenings in and behind the scenes in the world of Parkinson's in Colorado Springs. We actually have a lot going on, and I want to make sure you know about them all.

Of course, you all know that NeuroPong, the exciting program invented by Dr. Antonio Barbera to help overcome the symptoms of neurological disorders, has started at the downtown YMCA. Dr. Barbera first told us about NeuroPong (think "ping pong on steroids") last November. You were all so impressed by his presentation that you gave him the only standing ovation you've ever given to one of our speakers, going all the way back to 1995 when I joined the support group!!! On the spot, we pledged to him that we would find a venue for his program in Colorado Springs. Enter Travis Lerma and the YMCA. By April, Dr. Barbera, Travis, and the Colorado Parkinson Foundation (CPF, the not-for-profit 501c3 that we fall under and provides us with all our funding) had identified the downtown Y's 2nd floor small gymnasium as NeuroPong's first home in Colorado Springs. CPF purchased all the equipment, Dr. Barbera trained Larry Rose and his assistants, and the Y took registrations. NeuroPong got off to a great start on June 4.

More big news: Our application for CPF to be included in the 2024 Combined Federal Campaign was accepted. That gives every Federal employee in the Rocky Mountain Region the opportunity to donate to CPF during the 2024 fundraising campaign that starts this fall. Federal employees also have the option to donate to the Combined Federal Campaign without designating a charity; those funds get evenly distributed to all the charities on the Rocky Mountain Region list. We'll receive any of the funds donated to us sometime next year. This has the potential to be a big win for us!!!!

CPF recently approved funds for a memorial park bench to be placed near our Parkinson's butterfly at Nancy Lewis Park. When it is placed sometime this summer (we hope in July), you can sit and enjoy our beautiful butterfly with the park's pond and fountain in the background. The bench was paid for in large part by donations given in memory of Rich Sauvain, a long-time member of the support group and member-at-large on the support group's executive committee. Also honored by the bench will be Worth McCue, who was a long-time member of the support group and whose widow made a large donation in Rich's memory.

In cooperation with Dr. Melanie Tidman and her research team of Dr. Dawn White and Dr. Timothy White, we are writing a survival "guide" for people with Parkinson's and their caregivers. We expect it to be published in the spring of 2025, assuming that CPF approves the funding for its publication. We think that sales of the book will reimburse CPF fully for the cost of publication. All the potential publishers that we have spoken to have told us that there is currently no other book like this one.

On September 15, the Parkinson Foundation (formerly the National Parkinson Foundation) will sponsor a walk-a-thon for Parkinson's awareness at Memorial Park. While all the funds raised will go to the Parkinson Foundation, your executive committee voted to encourage our members' participation in the walk since we benefit from the Parkinson's Foundation by way of their free publications and potential monetary grants. More on the walk-a-thon in future issues.

This month's comedy is based on one of my favorite novels by Jane Austen: *Emma*, starring Gwenneth Paltrow. I would say that most of Austen's novels are on the more serious side with some comedic relief, but *Emma* is the opposite: while it has its serious moments, it is light and fun overall. Watch as the book's namesake makes a total mess of things while trying play match maker for a poor and socially "inferior" woman in the village. Gwenneth Paltrow does a great job of remaining true to Jane Austen's delightful *Emma*.



REFLECTIONS ON ORMAO'S DANCE FOR PARKINSON'S

CSPSG's April meeting featured a program presented by the Ormao Dance Company's Dance For Parkinson's class members. Several of our members participate regularly in this program and we have feedback that we'd like to share with you.

Norm Tuinstra had this to say:

"I was welcomed with open arms, and soon realized that there was NO judgement of anyone's 'dancing' skill. The teachers accommodated everyone, regardless of their abilities. They genuinely celebrate everyone attending. I am inspired by both the teachers and fellow dancers every time I attend a class session...by the compassion shown for each of the dancers, including speaking to a person one-on-one if they see someone struggling."

"The classes have benefited me both physically and cognitively. After the first class I attended I was amazed by the cognitive improvements I experienced - the Parkinson's "fog" disappeared for a short time. From a physical symptoms standpoint my stiffness and rigidity have improved to the point where they do not affect my daily activities."

Another group member, Dee Beatty, shared:

"Don't let the word 'dance' scare you off. It's not the ballroom stuff you think of first. It's like PT but a lot more fun! Instead of repetitious movements, it keeps you moving and flowing. Most of the time we are seated and if something is done standing, it can be done sitting just as well... your choice. I really notice the physical benefit. I enjoy the music, all the others in the class, and the friendly instructors. I also like that my wife can do it with me. Try it at least once."

There are other members of our group that are regular 'dancers' and any one of them would be happy to answer any questions you may have. Classes are held Tuesday 11:30 to 12:30 (leaving just enough time to get to the Y for Neuro-Pong) and Friday 11:00 to 12:00. Flyers are available on our information table.

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, db_mgr@co-parkinson.org.

DBS, The Bionic Option for Parkinson's Disease

By Peter Dunlap-Shohl, NW Parkinson's Foundation Parkinson's Blogger

To what lengths are you prepared to go, to maintain your quality of life with a neurodegenerative illness? Would you exercise regularly? Take your pills faithfully on a strict schedule? How about undergoing a delicate, hours-long bit of brain surgery to become a bionic human?

Yes, you could be like the six-million-dollar man, (42 million in today's dollars) the hero of that mid-nineteen-seventies TV show about a test pilot who nearly dies, and then is super-rehabilitated with electronic parts after a disastrous accident. The option he undergoes gives him preternatural strength and speed, among other nice-to-have qualities. You too can be rebuilt, made better than you were. Or at least passable. How? Deep Brain Stimulation surgery (DBS).

What is DBS? It is a surgical operation that involves implanting two electrical leads deep in the brain. A battery-fueled generator is then installed in your chest to deliver a mild pulse of electricity to calm a hyperactive part of the brain.

What does DBS have to offer? Unfortunately, not the ability to run down a cheetah, or lift a car off an unfortunate pedestrian. But realistically, how often are you required to perform either of those feats? Once or twice a decade, tops. Whereas you could use a break from your symptoms daily if not hourly.

DBS can give Parkinson's patients relief from stiffness, slowness, and tremors, increasing "on time," time when your medication is working its best, by as much as 5 hours a day, according to the Medtronic website. It can allow reduction of the amount of medication you must take, enabling patients to function well while avoiding complications such as dyskinesia from high loads of their meds.

DBS does little for non-motor symptoms, constipation, difficulty in multi-tasking, troubles with balance, depression, etc... although in my case, I can report sleeping better and less bladder urgency following DBS. The cost? Much less than \$6 million. The price tag of surgery (including the implanted device, hospital fees and anesthesia) can range from \$35,00 to \$100,000. Because it has been approved by the FDA, private insurance policies and Medicare will cover some or all of the treatment costs for those who are eligible for the surgery. So, who is that?

The health website Healthline reported a 2015 study estimated that about 2% of people who qualify for the treatment actually received it. The true percentage may be higher, but larger studies are needed to confirm it. This seems like a tiny number, especially considering the benefit the procedure offers those who are highly qualified for it.

Why wouldn't a person grasp this opportunity to enhance their quality of life? One reason is they may not be a good prospect to undergo the operation. A good candidate has a strong response to levodopa, is in good health, Parkinson's aside, and doesn't have dementia. According to the University of Florida, "in general, the best PD surgical candidates have idiopathic Parkinson's (not Parkinsonism which includes other diagnoses such as multiple system atrophy, progressive supranuclear palsy, Lewy body disease, corticobasal degeneration), tend to be younger (below age 69, but may be older), have a great response to medication (at least 30% improvement, but preferably higher), be medication refractory to symptoms (wearing off of medications prior to the next dose, on-off fluctuation, dyskinesias, etc.), and have no or little cognitive dysfunction. Perhaps the most controversial aspect of patient selection often involves defining unacceptable cognitive dysfunction, especially since many PD patients suffer from frontal and memory deficits, but are quite functional in their daily lives. A general rule is that PD patients with a lot of memory or cognitive problems, and those who get disoriented frequently are poor candidates and can be made worse from surgery.

Besides not qualifying for the operation, what else might be deterring the potential numbers of those who might actually undergo it? One factor may be a simple lack of knowledge that the procedure exists. Another reason to pass up DBS: fear. Anything that starts with drilling holes in your head and attaching a heavy metal "halo" with screws to your brow is bound to be suspect; rightly so. It is, after all brain surgery, which we all know is right up there with rocket science on the difficulty scale.

There are real dangers, possibility of a brain bleed leading to a stroke from the insertion of the leads. There is also risk of an infection, which could be fatal if not recognized in time. There is the fact it plain doesn't work for some; we don't know why. There is the risk of speech and cognitive impairment.

Given the nature of the procedure, you should be as picky about choosing your DBS doctor as they are about choosing their patients. You want one with plenty of experience with the operation, with hundreds of successful implants, and few, if any, complications.

DBS is relatively safe when the patient has been properly screened, with brain injuries occurring in 1% of patients. When deciding whether or not to undergo the procedure the risks must be balanced against the rewards. Some things are impossible to know, the final say is up to you.

Nobody said being bionic was easy.

LENDING LOCKER INVENTORY		Items that are free for the taking:	
<i>If you would like to borrow any of the equipment listed here, please contact: Mary Sauvain at [REDACTED].</i>		<i>Contact Julie Pfarrer at db_mgr@co-parkinson.org if interested in any of these items</i>	
Back brace	1	Aluminum walker tennis balls	4
Bed cane	7	Aluminum walker tray	1
Bed pan	1	Bedside toilet commode liners: 3 big boxes with 6 smaller boxes in each	
Bed rails	1	Bibs	8
Bed risers (set)	1	Blood Pressure Monitor	1
Bedding lifters	2	Disposable bed pads	7
Bedside toilets	5	Easy sip hydrate bottle	1
Canes	8	Gate belt	8
Chair/sofa cane	2	Hospital bed bedding: 2 sets of sheets 1 mattress pad	
Crutches (set)	2	Hospital gown	1
Double floor exercise pedals	1	Hospital slippers – XL & XXL	2
Freestanding toilet rails	1	Male portable urinals, new in individual packages – 32 oz capacity	4
Hospital bed	2	Plastic handicap plate	2
Hospital bed food trays	2	Plastic handicap bowl	1
Hoyer Lift	1	Pill crusher, storage, & drink cup combination	1
Lazercue for freezing help	1	Rehab squeeze balls	2
Lift chairs	0	Reusable bed pads	8
Lift-ware tremor compensating utensils	1 set	Waterproof twin mattress protector	1
Monthly med carousel with reminder alerts	1	Weighted utensils	6
Pick-up assist	6	Thick-it	1
Shower seats/benches	7	Transfer pads – can handle a person up to 300 lbs	4
Sock helper	2	Attend advanced briefs, maximum protection–large–24 count	3 pkgs
Stand-up assist	1	Cardinal health guards for men - extra heavy absorbency -14 count	2 pkgs
Standup Walker	1	Depend men's guards – 52 count – 1 unopened and 3 opened with a few missing	8 pkgs
Squatty potty	2	Fitright guards for men – 52 count	1
Swivel seat	1	Generic briefs, L/XL – 18 count	4 pkgs
Toilet arm assist	1	Prevail daily male guards – one size fits all – maximum absorbency-14 count	2 pkgs
Toilet rail	1	Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size – maximum absorbency-16 count	2 pkgs
Toilet seats	3	Women's Always Discreet s/m/ p/m maximum protection underwear – 42 count	2 pkgs
Transfer pole	0	Women's Always Anti-Bunch extra long panty liners. Extra protection – 92 count	1 pkg
Transport chairs	11		
Tub rail	1		
U-step	1		
Walkers with wheels & seat	9		
Waterproof mattress protector (Twin)	1		
Wheelchairs	8		

Thank You!

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

September Newsletter
Input Deadline: August 16th

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

**July & August CSPSG
Executive Committee Meeting**

July 9th & August 6th at 09:30 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. Kevin Scott, MD – Neurologist at UCHealth; (719) 365-7300

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

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

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

Denver

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

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

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

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

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

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



AUGUST

Jyl Alexander
Calvin Anderson
Tim Binkley
Gary Bradley
Sally Clark
Mala Cobey
Andy de Naray
Shelly Fly

Shirley Gloss-Soler
Rex Helmsing
John Henricks
Delories Heyliger
Brenda Jensen
Gary Jensen
Heather Johnson
Louise Maestas

Patricia Meredith
Ruth Modaff
Debbie Nelson
Beverly Noe
Julie Pfarrer
Lorraine Scott
Steve Telatnik

Kathy Ader
Bethany Andreen-Bailey
Becky Arneson
Randall Austin
Allen Beauchamp
Charles Bogues
Terry Bresee
Sharon Carlson
Barbara Carr
James Coen

Marc Collins
Mike Davis
Melinda Drinen
Jim Egolf
Reva Epler
June Essing
Freda Frazer
Larry Grubaugh
Lorraine Helminski
Sonya Hero
Roger Hill

Andre Joiner
Lowell Kayser
Michael Lippincott
Ed Mangold
Carl McKellip
Manuel Pedraza
Jim Prior
Frank Quidachay
Lil Ray
Catherine Reed
Mark Ruport

Alfredo Serrano
Mary Taylor
Bruce Terrell
MJ Thompson
Ron Thompson
Alice Wilson
Carol Zier
Charlie Zinn

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

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: CAULIFLOWER MAC & CHEESE

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.

Ingredients:

- 24 oz cauliflower florets
- 2 C cheddar cheese
- 1/2 C heavy cream
- 1/4 C water
- 4 oz cream cheese
- 1 1/4 tsp ground mustard
- 1/2 Tbl garlic powder
- 1/2 t parsley
- 1/4 tsp pepper
- 1/2 tsp salt

Directions:

- Place all ingredients into a crockpot & mix well.
- Cook on low for 3 hours stirring occasionally.
- Optional: put in a casserole dish & bake at 400° for 10 minutes for a crispy top layer.

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 [redacted] 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 Hanen-burg [redacted].

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

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

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

Classes are canceled for the week of July 1st (July 1-5) so that our Dance for Parkinson's Team can take a Summer Break.

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

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Dance for Parkinson's Benefits Patients & Their Relatives: Study

By Marisa Wexler, MS – Parkinson's News Today, 5/17/24

Participating in a weekly dance class may not only help people with Parkinson's disease improve their mobility, but also can be an important source of joy that helps patients feel closer to their loved ones.

That's according to a new study from Sweden that investigated the impact of the Dance for Parkinson's Disease program — begun in the U.S. in 2001 and now available in 28 countries — on various aspects of patients' lives.

Taking part in the dance program led to both physical and emotional benefits for patients and their family members, the researchers found.

"Dancers and relatives consistently experienced being part of a joyful and healthy exercise, testifying to the positive effects that [the Dance for Parkinson's Disease program] has on subjective well-being and body functioning for persons with [Parkinson's] and their relatives," the team wrote.

Titled "The impact of Dance for Parkinson's Disease on subjective well-being and functioning as experienced by dancers and their relatives – A descriptive study," the work was published in the *Journal of Bodywork and Movement Therapies*.

BRAZILIAN DANCE BOOSTS LOWER LIMB STRENGTH BETTER THAN OTHER EXERCISES

SMALL STUDY LOOKED AT IMPACT OF DANCE FOR PARKINSON'S DISEASE PROGRAM

Staying physically active is an important part of managing Parkinson's disease. Dance can be a great way to get moving while also having fun and socializing, and several studies have illustrated that participating in Parkinson's-focused dance classes can have health benefits for patients.

In this study, a team of scientists from Halmstad University sought to investigate how participating in dance classes could affect life not just for the person with Parkinson's who is attending the classes, but also for care partners and loved ones.

To that end, the scientists surveyed 25 people with Parkinson's who participated in a Dance for Parkinson's Disease program, also known as Dance for PD, with hour-long classes held weekly for four months. In the questionnaire, patients were given various statements about the dance classes and asked to rate whether they agreed or disagreed.

The results showed that, for most participants, the dance classes had both emotional and physical benefits: 23 of 24 respondents agreed with the statement "Dancing makes me happy/brings me joy," and 17 of 21 said that the dance classes had helped improve their balance.

The scientists next conducted interviews with 15 relatives of the participating patients. In line with findings from the questionnaire, the relatives frequently reported that dance had led to improved mobility.

"All relatives describe that the participants in [Dance for Parkinson's Disease] move more easily when they feel the rhythm of the music and discover that they can perform movements better than they think," the researchers wrote.

The smiles and laughter that come through and in the dance are special and those smiles are not visible in everyday life.

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DBS Reduces Toxic Clumping in Parkinson's Rat Brain Cells: Study

By Margarida Maia, PhD – Parkinson's News Today, 5/31/24

Preclinical study could point to new uses for old treatment

Aside from easing motor symptoms of Parkinson's disease, deep brain stimulation (DBS) may also slow disease progression by keeping misfolded forms of alpha-synuclein from building up in the brain and harming nerve cells, a preclinical study involving rat brain cells suggests.

If the findings hold true in humans, they could provide a rationale for using an already existing treatment in new ways, according to a team led by Suneil Kalia, MD, PhD, and Lorraine Kalia, MD, PhD, senior scientists at the Krembil Brain Institute at the University Health Network (UHN) in Toronto.

Their study, "*Reduction of alpha-synuclein oligomers in preclinical models of Parkinson's disease by electrical stimulation in vitro and deep brain stimulation in vivo*," was published in the journal *Brain Stimulation*.

"DBS has been used to treat Parkinson's since the late 1990s but it is only now that we are learning about its disease-modifying properties," David Aguirre-Padilla, PhD, one of the study's first authors and a former postdoctoral researcher in the Kalia labs, said in a press release from funder UHN Foundation.

Parkinson's motor symptoms result from the loss of dopaminergic neurons — the nerve cells that release dopamine, a chemical messenger involved in motor control — in a structure, called the *substantia nigra*, that is part of the basal ganglia near the center of the brain.

DBS EASES PARKINSON'S SYMPTOMS, BUT EFFECT ON PROGRESSION NOT KNOWN

DBS is a surgical procedure in which one or more leads are implanted into the basal ganglia. A pulse generator implanted under the skin in the chest delivers an electrical current via the leads that is expected to correct abnormal brain activity, thereby easing motor symptoms.

Though DBS is a widely and long-used surgical procedure, little is known about if and how it protects dopaminergic neurons from damage caused by harmful clumps of misfolded proteins like alpha-synuclein, which could slow Parkinson's progression.

"A driving factor in most neurodegenerative diseases is the accumulation of misfolded proteins within or outside of brain cells," said Suneil Kalia, who is also a neurosurgeon at Krembil and associate professor at the University of Toronto's department of neurosurgery. "In [Parkinson's], we see a buildup of a misfolded form of the protein alpha-synuclein."

To know more, the researchers delivered a high-frequency electrical current, akin to

that sent out by DBS, to neurons that were isolated from the brain of young rats and then grown in the lab. These neurons were engineered to produce a mutant form of alpha-synuclein that is known to cause familial Parkinson's.

Compared with non-stimulated neurons, those stimulated with a high-frequency electrical current had significantly lower levels of a mutant form of alpha-synuclein, called A53T. When delivered over 24 hours, the electrical current also prevented A53T from sticking together into harmful clumps.

STIMULATION REDUCES ALPHA-SYNUCLEIN

To find out how well high-frequency electrical stimulation works in the body, the researchers used an animal model of Parkinson's in which rats produced high levels of a fluorescent alpha-synuclein that only lights up when it clumps in dopaminergic neurons.

When delivered to the rats' *substantia nigra*, but not the more commonly targeted subthalamic nucleus — also part of the basal ganglia — high-frequency electrical stimulation significantly reduced the overall levels of alpha-synuclein, including its clumped forms.

"We regularly apply DBS to one of three functionally connected regions of the basal ganglia, depending on the patient and their specific symptoms — most commonly the subthalamic nucleus," Suneil Kalia said.

But refining the technique may offer additional benefits.

"This finding [that DBS reduces the levels of alpha-synuclein] tells us that the disease-modifying actions of DBS may depend to some extent on the brain region being targeted — this will be an important consideration when optimizing treatment plans for individual patients," Suneil Kalia said.

While the number of dopaminergic neurons was similar in both non-stimulated and stimulated rats, the researchers suggested that DBS may have neuroprotective effects. How exactly DBS acts upon alpha-synuclein, however, remains unknown.

"The better we understand how DBS works, the more we can refine the therapy to enhance its benefits for each patient," said co-author Eun Jung Lee, MD, a former postdoctoral researcher in the Kalia labs. "This approach could really change the landscape of [Parkinson's] treatment."

"DBS therapy could have a role beyond symptomatic treatment, with potential disease-modifying properties that can be exploited to target pathological [disease-causing] proteins in neurodegenerative diseases," the researchers wrote.

Researchers Propose Prescribing Exercise as Medicine in Parkinson's

By Margarida Maia, PhD – Parkinson's News Today, 5/1/24

PHYSICAL EXERCISE MAY REDUCE RISK OF DISEASE AND EASE SYMPTOMS: REVIEW

Physical exercise may reduce the risk of developing Parkinson's disease, as well as effectively control patients' symptoms, according to a review analysis by researchers in Europe.

Moreover, some studies suggest that exercise might be a potential disease-modifying treatment, working to slow disease progression and stabilizing, or even reducing, the amount of medication needed to control the disease symptoms.

"Based on current evidence, we propose a paradigm shift: Exercise should be prescribed as medicine for people with early-stage Parkinson's alongside conventional medical treatment," Martin Langeskov Christensen, PhD, associate professor at Aarhus University, in Denmark, and first author of the study, said in a university press release.

"[Exercise] can really improve the patient's quality of life," Christensen added.

The review article, "*Exercise as medicine in Parkinson's disease*," was published in the *Journal of Neurology, Neurosurgery & Psychiatry*.

HIGH-INTENSITY EXERCISE CAN BOOST DOPAMINE SIGNALING IN THE BRAIN

EXERCISE AS MEDICINE MAY BE A DISEASE-MODIFYING THERAPY

Parkinson's is caused by the dysfunction and death of dopaminergic neurons, nerve cells in the brain responsible for producing dopamine — a signaling molecule neurons use to communicate. The loss of these neurons causes problems with nerve signaling, ultimately leading to the disease's symptoms.

To date, there are no available medicines that can prevent or revert disease progression, although there are therapies that can help control some of Parkinson's symptoms. According to the researchers, the "identification of interventions that prevent, slow, halt or mitigate the disease is therefore pivotal."

One of the most promising interventions is exercise, with early studies showing it can help control the disease's symptoms. Also, more recent studies propose exercise may be disease-modifying by slowing Parkinson's progression — and may even reduce the risk of developing the neurodegenerative condition. Such findings indicate that treating exercise as a medicine for Parkinson's may have more beneficial effects that might change clinical practice.

To learn more, a team from Denmark and Sweden reviewed the existing evidence on the effects of exercise in Parkinson's disease. Their focus was on disease prevention, symptom control, and slowing disease progression.

Two review studies reported that exercise is generally considered safe, considering the very limited number of reported adverse events. These events included transient pain, joint inflammation, dizziness, falls, or tiredness, although only a few were found to be related to the exercise intervention.

Moreover, evidence supports that people practicing high levels of moderate to high-intensity physical activities, particularly in middle or later life, have a lower risk of having Parkinson's disease. It also can potentially delay the time of disease diagnosis.

"There is strong evidence that moderate to high-intensity physical activity significantly reduces the risk of developing Parkinson's," said Christensen, also a researcher at Viborg Regional Hospital. "Existing studies show that high levels of physical activity have been found to

reduce the risk by as much as 25 percent."

RESEARCHERS SUGGEST PERSONALIZED EXERCISE PROGRAMS TAILORED TO PATIENT NEEDS

Regarding Parkinson's symptoms, current evidence suggests that several disease manifestations — particularly those for which there is no available medicine or specific treatment — may be controlled with exercise. According to the researchers, patients should receive personalized exercise programs according to their particular needs, together with their standard-of-care medications, and be continuously monitored by healthcare professionals.

"For example, many people with Parkinson's disease have difficulty walking, and exercise can minimize that significantly," Christensen said. "If you struggle getting up from your chair, you may need to focus on strength or balance exercises. If you're at risk of high blood pressure, do cardio."

Christensen noted that "it's important to have a tailored exercise plan because we can't expect the individual to know which exercises will improve their symptoms."

The core message is that it's better to do something, because the benefits far outweigh any potential downsides. Exercise is a safe, cheap, accessible and effective intervention.

The researchers also noted that several studies have shown that exercise may have a preventative effect on disease progression, as assessed by improvements seen in the MDS-UPDRS part III, which assesses motor signs of Parkinson's disease. Other studies have shown that physical activity may stabilize, or even reduce, the amount of medication patients take.

Evidence on whether exercise may help slow down disease progression associated with the loss of dopaminergic neurons is less robust, although it is probable.

As for exercise modalities, both weight training and cardio training function for different disease manifestations.

"If you have Parkinson's disease, you should do the type of exercise you like best," Christensen said. "You're already hampered by low levels of dopamine — so even finding the motivation might be difficult."

Patients who have difficulty performing high-intensity exercise can still achieve positive results by performing low-intensity activities, the team noted.

"The core message is that it's better to do something, because the benefits far outweigh any potential downsides. Exercise is a safe, cheap, accessible and effective intervention," Christensen said.

Help Spread Some Sunshine to Our Members!

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



(...continued from page 6) *Dance for Parkinson's benefits patients and their relatives: Study*

The emotional benefits of dance classes also were clear to relatives, who said dance offered a way to find joy even when Parkinson's makes life hard. One relative said that, when the family member with Parkinson's is feeling angry or sad, "ABBA songs come to the rescue, and we start dancing."

"The smiles and laughter that come through and in the dance are special and those smiles are not visible in everyday life," another relative told researchers.

Overall, the team concluded that the dance program had notable physical and emotional benefits that were felt not just by the individuals with Parkinson's but also by their family members. The scientists highlighted, however, that this was a small study conducted at a single center, so the findings might not be applicable in other settings.

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

PARKINSON'S PERSPECTIVE

JULY & AUGUST 2024

Coming Events

See inside for more information

July 6th - Reg Mtg at Central United Methodist Church – 10 am

Program: Therapies in Parkinson's Disease; **Speaker:** Dr. Steven Swank, PharmD, BCACP

August 3rd - Annual Picnic at the Barn pavilion at John Venezia Park!!! (see front page)

September 7th - Reg Mtg at Central United Methodist Church – 10 am

Program: Scam Prevention; **Speaker:** Scott Mathis, CSPD

October 6th - Reg Mtg at Central United Methodist Church – 10 am

Program: Pat Yourself on the Back – You're Making Such a Difference in the Parkinson's World!

Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP

November 2nd - Reg Mtg at Central United Methodist Church – 10 am

Program: Break-Out Sessions; Caregivers & Parkinsonians separate into different rooms to talk

December 7th - Reg Mtg at Central United Methodist Church – 10 am

Program: Christmas Party!!!! – The Song Spinners will entertain us!

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