



# Parkinson's Perspective

*Newsletter of the Colorado Springs Parkinson's Support Group*  
**Colorado Parkinson Foundation, Inc.**  
www.co-parkinson.org | (719) 884-0103

## Acting President:

Jill Reid [REDACTED]  
president@co-parkinson.org  
**President Emeritus:** Ric Pfarrer  
**Vice President:** Jill Reid  
**Secretary:** Vacant  
**Treasurer:** Julie Pfarrer

## Members at Large:

Janet Adams, Beth Clarke,  
Gene Clarke, John Farley,  
Carole Henrichsen, Steve Locke,  
Paul Mackendrick, Dave Moross,  
Mary Sauvain, Rich Sauvain

## Committee Chairmen

**Programs:** Jill Reid

**Educational Outreach:** Jill Reid

**Membership:** Carole Henrichsen

**Chaplain:** Rusty Merrill

**Parkinson's Awareness Day:**  
Vacant

**Photographer:** Vacant

**Lending Locker Coordinator:**  
Rich 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:**

Vacant

**Sunshine (Cards):** Sharon Carlson  
[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 the second  
Saturday of each month at 10AM  
First United Methodist Church  
(with exceptions to be noted  
in this newsletter).

## The March Support Group Meeting has been Cancelled!

Because the St Patrick's Day parade assembles in the church parking lot, there will be nowhere for us to park on our normal meeting day. In addition, Dr. VanSickle who was the speaker scheduled for our March 11th meeting is not available any other time in March.

**We regret any inconvenience  
this may cause anyone.**

Meeting  
Cancelled

## The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



This week finds Julie Pfarrer, her cat Lily, and me crammed together in a 21-foot RV in an RV park near New Orleans, Louisiana, while we sort out the care that our ailing brother may need in the near and not-so-near future. We have both left our husbands in Colorado (and you, too, for that matter—thanks, Steve Locke and Dave Moross, for stepping in for us at the February meeting) to carry on as best they can without us for who knows how long, and we know that Ric, Julie's husband who has Parkinson's, is having a difficult time without the person who in recent months has become his full-time caregiver.

As in our case, Parkinson caregivers may find it necessary to leave their Parkinson's spouses behind while they answer the call of other family members who need help. It can be a difficult dilemma—who takes precedence, the out-of-state family member or the at-home person with Parkinson's? Can the person with Parkinson's manage on his own for an extended period of time? Does the person with Parkinson's have enough Parkinson's medication for the duration? Can the person with Parkinson's pay the bills, if need be? Can he get to doctor's appointments on his own? Is there any way to take care of the person with Parkinson's from a long distance? Does the caregiver even dare leave?????

These were all issues confronting Julie when our brother's friends called for help because they could no longer take care of him and keep him safe. She had to choose between Ric and our brother (really, between Ric and our brother's friends, who were overwhelmed with how much care his condition required of them).

There are a number of solutions to caring for a person with Parkinson's from long distance, should you caregivers ever have to choose that option. Firstly, you can recruit a local family member, if you're fortunate enough to have one, to step in for you.

Secondly, you can hire in-home caregiving companies like Sages Elder Care, who can provide temporary care for your people with Parkinson's. They have been trained in the needs of people with Parkinson's and can help with organizing medications, making sure the meds are taken, cooking meals, washing clothes, doing light housekeeping, shopping for groceries, driving the patient to doctor's appointments, and providing companionship, among other things.

Thirdly, respite care is available at some assisted living facilities. We have not trained the staffs at any of the assisted living facilities in our area in some years, unfortunately, so we cannot advise which ones offer respite care. But some caregivers in our group have used respite care and may be able to give you recommendations.

After this experience, we hope and pray that none of you will ever have to leave your loved one behind. But, should you have to, it's good for you to know that there is help out there for you.

My recommended comedy for March: The Replacements, starring Keanu Reeves.

**Thank  
You!**

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

### March Executive Committee Meeting

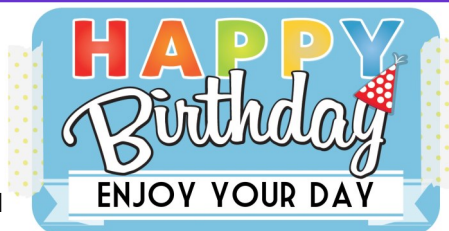
March 14th at 11:00 a.m. at a place to be determined  
(you will be notified by email)  
Contact Jill at [president@co-parkinson.org](mailto:president@co-parkinson.org) if you haven't been to an Executive Meeting so we will know that you're coming.  
Leave your email address so Jill can contact you if anything changes.

### April Newsletter Input Deadline: March 17th

Call or e-mail Julie at:  
[REDACTED]  
[db\\_mgr@co-parkinson.org](mailto:db_mgr@co-parkinson.org).

John Baker  
Karen Baker  
Marci Braithwaite  
Donna Deis Rickett  
Terry Fabian

John Farley  
Stephanie Graczyk  
Judy Horton  
Mary Lekarczyk  
Donna Lee McDonald



Keith Mitchell  
Marty Purdy  
Ken Rowe  
Shelly Runkle  
David Smith

Patrick Smith  
Karl Stengel  
Marny Weckwerth  
Keith Woestehoff

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

### 20th Annual Caregiver Pampering Day

*"Caregiving Is No Joke!  
Take Care of Yourself"*

*Save the Date*

*Saturday, April 1st, 2023*



Pikes Peak Area  
Council of Governments  
Communities Working Together

The 20th Annual **Caregiver Pampering Day** will be held this year in person.

The event, *Caregiving Is No Joke-Take Care of Yourself*, will be held on Saturday, April 1, 2023 at the Colorado Springs Senior Center located at 1514 N. Hancock Street.  
Check in begins at 8:30 am and the event will end with a catered lunch at 1:00 pm.

The event is for any family member taking care of a loved one who is 60 years of age or older. The day includes a catered continental breakfast, pampering time, drop-in activities, and classes. In-home care will be available if needed but will be limited to the first 20 caregivers who request the care.

Attendance is by registration only. Caregivers can register online by going to [www.ppacg.org/pamperingday](http://www.ppacg.org/pamperingday), or sending an email to [kmathews@ppacg.org](mailto:kmathews@ppacg.org), or by calling 719-886-7526. Registration opens on Monday, February 20<sup>th</sup> and closes on Monday, March 20<sup>th</sup>. The event is limited to 100 registered caregivers.

### Recipe of the Month: Chicken 'n' Squash Soup

(Serves 16 2-cup servings)

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](mailto:db_mgr@co-parkinson.org).**

#### Ingredients

- |   |   |  |
|---|---|--|
| 1 broiler/fryer chicken<br>(5 1/2 lbs)        | 1 head cauliflower, cut<br>into bite sized pieces | 1 Tbl oregano, dried                   |
| 18 C water                                    | - green beans, bite sized                         | 1 Tbl crushed rosemary,<br>dried       |
| 2 bunches kale, chopped                       | 1 large spaghetti squash,<br>optional             | 1 tsp (or more) garlic salt            |
| 2 large onions, chopped                       | - Brussels sprouts, optional                      | 3 Tbl Fennel spice (recipe<br>follows) |
| 1 head cabbage, cut<br>into bite sized pieces | 2 Tbl regular salt                                | 3 Tbl ground cumin                     |

*Note: you can add pretty much any low-carb vegetables you'd like into this soup*

- Place chicken & water in a large (16 qts or so) stockpot. Bring to a boil. Reduce heat, cover & simmer for 1 hour or until chicken is tender.
- Remove chicken from broth.
- Add the vegetables. Bring to a boil. Reduce heat, cover & simmer for 25 to 30 minutes or until vegetables are tender.
- When chicken is cool enough to handle, remove meat from bones & cut into bite-sized pieces. Add chicken, salt, herbs & spices to soup & heat through.

#### Toasted Fennel Spice

Toast in skillet until hot & fragrant. The coriander seed will begin to pop. Spread to cool and once cooled, grind - I have a coffee grinder that I use exclusively for grinding spices.

- |                          |
|--------------------------|
| 1 C fennel seeds         |
| 3 Tbl coriander seeds    |
| 2 Tbl white pepper corns |
| 3 Tbl kosher salt        |

### Potluck Favorites: Shakin' & Bakin' Cookbook!!!



**A**nother reminder about a new CSPSG endeavor to add new recipes to the original cookbook the support group created years ago. Sherry Whitaker has volunteered to lead this effort to add 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. They don't have to be gluten-free or Keto. We will, however, indicate which ones fit those categories. We will also add a conversion table that will tell you how to convert ordinary recipes into gluten-free or Keto recipes if you would like to know how to do that.

All favorite recipes are welcome

Send them to Sherry at  
[project@co-parkinson.org](mailto:project@co-parkinson.org).

## Ask the Doctor!

| Dr. Brian Grabert, MD, a Parkinson's Specialist



Dr. Grabert has generously agreed to answer your questions pertaining to Parkinson's Disease each month in our new newsletter column called "Ask the Doctor!". *If you have questions you'd like to submit to Dr. Grabert, send them to our newsletter coordinator, Julie, at [db\\_mgr@co-parkinson.org](mailto:db_mgr@co-parkinson.org).*

**Question #1:** You mentioned Parkinsonism [in last month's Q & A]. Could you explain the difference between Parkinson's Disease and Parkinsonism?

**Answer:** Parkinsonism is the presence on the neurological EXAM of various combinations of bradykinesia [slowness of movements, decreased arm movement, decreased facial expression, etc.], rigidity, resting tremor and postural impairment. Parkinsonism is NOT a diagnosis but an objective exam finding or neurological sign. Hence the terminology "Signs of Parkinsonism".

Parkinson's Disease is a **diagnosis** which requires the combination and integration of symptoms [a subjective report from the patient], objective signs on exam and often a positive response to a L-dopa trial.

Signs of Parkinson's while most often is seen in "Idiopathic" Parkinson's Disease, can be present in Dementia with Lewy Bodies, Normal Pressure Hydrocephalus [NPH], Multi-System Atrophy, Alzheimer's Disease, Cortical-Basal Degeneration, Progressive Supra-Nuclear Palsy [PSP], Drug Induced Parkinsonism, vascular Parkinsonism and advanced age [especially > 80].

**Question #2:** What can help someone with PD sleep through the night?

**Answer:** Sleep disorders in Parkinson's Disease are very common and often difficult to diagnose.

First of all, it is important to establish a framework for Sleep Complaints to direct preliminary diagnosis and treatment. Three major categories are usually cited in the literature:

1. Disorders of Initiating and Maintaining Sleep [DIMS]
2. Disorders of breathing during sleep [sleep apnea, coughing or loud snoring] [usually requires a bed partner to confirm]
3. Disorders called parasomnias [restless legs syndrome, sleep myoclonus, sleep related hallucinations, REM sleep behavior disorder, several "others"]

I am going to assume the questioner has DIMS. The first suggestion is to improve sleep hygiene. There are abundant resources available on the internet by searching: Tips for Good Sleep Hygiene, so I won't list those here. Following these tips often is helpful especially if the prob-

lem is initiating sleep although better sleep hygiene helps maintaining sleep as well. If the problem is maintaining sleep, the next question is what wakes you up? Is it nocturnal motor symptoms? one of the parasomnias? nocturia? medication wearing off? others?

I obviously didn't answer the question but the above is a starting framework to address the sleep complaint. May I suggest searching the 2012 article in J. Neurology by M. Louter called: "**Recognition and diagnosis of sleep disorders in Parkinson's disease**", it is Open Access and can be downloaded by anyone. It is crucial to have an accurate classification of your sleep disorder before your treating practitioner can recommend adjusting or stopping medications, adding a medication or referring for a sleep study [polysomnogram].

**Question #3:** Is it possible to overdose on carbidopa/levodopa [CD/LD] or can I take as many as I feel that I need at any given time?

**Answer:** In general you should take as much CD/LD as needed to control motor symptoms, but not more than is needed. It is very rare to see doses exceeding 2400 mg /day of L-Dopa. There is an infrequent condition called dopamine dysregulation [DDS] where the individual takes more CD/LD than needed to control motor symptoms. It usually accompanied by excessive dyskinesia, hypomania, compulsions, mood swings, and functional decline. DDS is seen more often in Parkinson's patients with a history of Impulse Control Disorders. DDS is more often seen in males [ > 80%] and more often in those with earlier onset PD.

**Question #4:** Why do people with Parkinson's not seem to know how softly and fast (and therefore, slurred) they are speaking? Is there a trick to getting to them to speak clearly and loudly. Telling them to speak up and slow down doesn't seem to work more than for a few words. My husband has had 2 rounds of speech therapy and does really well during the practice sessions but he doesn't seem to be able to apply it in normal conversations.

**Answer:** There are really 3 questions here:

1. Low volume and monotone speech is almost universal in PD. A recent study using a speech artificial intelligence algorithm was able to correctly classify 90 % of PD patients. Patients rarely, in my experience, are aware of their early lowered or monotone voice changes. Slurred or fast [pressured] speech often coincides with dyskinesia and again is not recognized by the individual with PD.
2. There is no trick to getting them to speak more clearly and loudly, other than the exercises suggested by the speech therapist. The literature on Lee Silverman Voice Therapy [LSVT] suggests prolonged effects on increasing voice intensity even beyond a year.
3. I assume the 2 rounds of speech therapy were from a certified LSVT LOUD therapist? I would talk to the therapist about the lack of carry over to normal conversations.

## A CPF Charitable Giving Opportunity!!!

We have received conflicting information from Amazon whether the Amazon Smile program will continue or stop on February 28th. We encourage you to try to use it anyway in case it remains active. It's an easy and painless way for you to help CPF. An ongoing charitable giving opportunity each time you order merchandise from Amazon.com. It's called Amazon Smile. Colorado Parkinson Foundation (which includes CSPSG and all its other support groups) is listed with Amazon Smile as a charity that you can generate donations for. Rather than starting your Amazon shopping by pulling up Amazon.com, type in [smile.amazon.com](https://smile.amazon.com) instead. The first time you do that you will have to designate Colorado Parkinson Foundation, Inc. as the recipient of charitable donations based on your purchases. From then on 0.5% of the eligible purchase prices you place through Amazon Smile will automatically generate donations from Amazon to CPF – at no cost to you!

## Sad News



Maralyn Legleiter passed away on February 2nd, 2023. She was born in Greeley, Kansas, and graduated from Fort Hays State University, with a degree in Elementary Education. It was there she met Rudy, her husband of 64 years. They had three daughters, Lynette, Stefanie and Suzanne. Maralyn had a 25-year career as an elementary school teacher. She loved music, quilting, RVing and everything family. She is survived by Rudy, two of her daughters, her sister and her 5 grandchildren.



## 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 6310 Gemstone Way, Colo Spgs, 80918.

Contact Brenda Hicks at

or 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

**Essential Tremor Support Group**

Meeting Location:  
ENT Conference Room  
Pikes Peak Library District.  
Colorado Springs Library 21c,  
1175 Chapel Hills Drive.

For meeting dates/times or for questions, contact Jim Sanchez at jimdjs22@gmail.com or

**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 information contact Barry Hanenburg at bhanenbu@hotmail.com or Syble Krafft at 719-488-2669.

## 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**

No music experience necessary! Join board certified music therapist, Heather Johnson, every Monday at 1 pm as we participate in group singing focused on improving breath control, strengthening of the throat muscles, and improving voice control, volume, and quality! Parkinson's Sing-a-Long is held at Square Music Co, located at 2332 Vickers Drive in Colorado Springs. An online participation option is available as well. Square Music Co also offers individual music therapy to work towards motor movement goals along with the voice qualities listed above. For more information or to sign up, please email heather@squaremusic.co or call/text 719-345-2887.

## PD Exercise Classes:

**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 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](http://www.ormaodance.org) and click on "Dance for Parkinson's" under the "Outreach" tab to get the Zoom link.

Questions: Contact Laura at [laura.hymers@gmail.com](mailto:laura.hymers@gmail.com) or 719-640-8478

**PWR!Moves Class**

Skyline Wellness & Aquatics Center has partnered with the YMCA to help the PWR! Moves class be more available to everyone.

We are reaching out to help individuals who may be located on the south side of town and need a closer location to their home.

LOCATION: 2365 Patriot Heights (located within Brookdale Skyline, near Bear Creek Dog Park)

Our classes are held every Tuesday and Thursday from 12:30-1:30 pm.

If you have any questions, please contact the Fitness Coordinator Karisa Dreyer at (719) 867-4658

**PWP: Parkinson's With Poles**

Come join Emily Moncheski and Eileen O'Reilly for a great exercise workout at Monument Valley Park.

Every Friday, 9 am at the north parking entrance of Fontanero and Culebra streets. Poles are provided. Everyone is welcome!

**Max Capacity NeuroFitness**

PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training. LOCATION: 525 E Fountain Blvd. Suite 150. Park on the S. Royer side of the building.

Boxing: T/Th – 4:00 to 5:00pm and Sat – 9:00am to 10:00am

PWR Boot Camp: M/W – 3:30pm to 4:30pm

Boxing is free of charge, Boot Camp packages available! Contact Emily Moncheski at (719) 213-3996 or email [emily@maxcapacitypt.com](mailto:emily@maxcapacitypt.com) for info

**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](mailto:CAL@uccs.edu)

**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 Tuesday & Thursday, 1:30-2:30 PM

Briargate YMCA: PWR!Moves Monday, Wednesday & Friday, 1:30-2:30 PM

For more information contact Jamie Clayton at [jclayton@ppymca.org](mailto:jclayton@ppymca.org)

**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.

WHEN: Every Friday at 10:30  
LOCATION: 525 E Fountain Blvd.  
MACS—corner of Fountain & Royer  
Cost: \$10.00 a class

**Colorado Springs Rocksteady Boxing**

"Let's kick some PD BUTT!!!"

Tuesday, Wednesday and Thursday 10 am – 11:15 am & 11:45 am – 1:00 pm  
Location: Otis Park. 731 Iowa Avenue  
For more information, contact Bill O'Donnell at 719-243-9422

**Falcon Exercise Group**

Mon and Fri – 11:00 – 12:00 noon, Grace Community Church. For more information contact Catherine Reed at

**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  
Location: 5818 N. Nevada Avenue, Suite 325  
Phone Number: 719-365-6871



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, Sharon Carlson know.

Sharon can be reached at

## Exergame-based Program Shown to Be Feasible for Parkinson's Rehab

By Marisa Wexler, MS – Parkinson's News Today, 1/25/23

Simultaneous motor and cognitive training may improve balance, cognition

A cognitive-motor training program featuring a video game platform that promotes exercise is feasible for people with Parkinson's disease to use, a new study demonstrates.

Patients using the program along with standard rehabilitation showed comparable and greater motor and cognitive improvements relative to those on standard rehabilitation alone. These preliminary results support further large-scale testing to assess the effectiveness of this type of program, the researchers noted as part of the study, "Feasibility and effects of cognitive-motor exergames on fall risk factors in typical and atypical Parkinson's inpatients: a randomized controlled pilot study," which was published in the *European Journal of Medical Research*. The work was funded by the Swiss Federal Institute of Technology in Zurich.

In Parkinson's disease, both motor and non-motor symptoms can substantially impact quality of life and a person's ability to function day to day. Along with medication, care for people with Parkinson's commonly include physiotherapy and exercise training.

Increasing evidence suggests simultaneous motor and cognitive training "has great potential to improve balance, [walking] and cognition in PD [Parkinson's disease] patients and that fall rate can be significantly reduced," the researchers wrote.

Exergames are video games that require a player to actively move in order to play; the arcade staple Dance Dance Revolution (DDR) is a well-known example of an exergame. The games promote physical exercise and also work the brain as players must follow continual instructions to grow their score.

While some small studies have shown exergame-based inpatient rehabilitation programs are safe, feasible, and effective, most patients used exergame systems originally designed for teenagers to use recreationally.

"An exergame-based training system that has been specially developed for clinical use in older adults could have an even better effect," wrote a research team led by scientists in Switzerland who conducted a small trial (NCT04872153) where they evaluated a cognitive-motor training program based on an exergame system called the Dividat Senso.

Intense Rehabilitation Can Help People at Earlier Disease Stages, Study Finds

Feasibility of exergame-type program in Parkinson's rehabilitation

The system resembles a classic DDR arcade game, with a large platform where the patient stands and moves to play the game and a screen that shows the game itself.

The study's main goal was to test the feasibility of the exergame-based program, as assessed by how well patients stuck with it and whether there were problems using it. The secondary goal was to assess preliminary efficacy signs on cognitive and motor functions. Positive results would provide support for large-scale testing, the researchers noted.

The trial included 42 people with Parkinson's or atypical parkinsonism who were prescribed rehabilitation. Participants were randomly assigned to the exergame-based program in addition to a standard rehabilitation program (21 patients) or a standard rehabilitation alone (21 patients).

All programs were conducted at the Center for Neurological Rehabilitation in Zihlschlacht, Switzerland. The standard rehabilitation program included physical and occupational therapy, and the exergame program consisted of five weekly sessions, with each session lasting around 15 minutes.

During the study, two patients in the combined approach dropped out for reasons unrelated to the rehabilitation or exergame-type program.

"There were no dropouts due to the intervention," the researchers wrote, adding the remaining 40 participants (90% with Parkinson's) completed the majority of scheduled therapy appointments.

The average intervention lasted nearly two weeks, ranging from about a week to nearly a month, with each tailored to a patient's specific therapy goals.

No safety issues were reported and patients generally reported enjoying the exergame-based program. The average enjoyment rating was more than 4.5 on a 5-point scale. Most said the frequency and intensity of the program were optimal.

At the start and end of the intervention, participants took a series of motor and cognitive function tests. Across all measures, improvements from the exergame-based intervention were either comparable to or better than the standard training alone. In both groups the overall change in performance after the intervention was not statistically significant on most tests, however.

The researchers emphasized that the small study was not designed to test the exergame-based program's effectiveness. Still, the generally positive effects on motor and cognitive functioning support testing of efficacy in larger patient groups.

"The main message of our pilot trial is that the process of integrating this novel treatment option into a clinical setting is doable and safe," the researchers wrote. "Since there is already a positive tendency to improve physical and cognitive functions in this short period of time, it is to be expected that significantly positive effects can be achieved by extending the intervention time. Consequently, future studies should look at extending the period of intervention in the area of outpatient rehabilitation or also as home training."

## Parkinson's Patients Less Likely to Catch Common Cold: Study

By Margarida Maia, PhD – Parkinson's News Today, 12/6/22

Fewer cases of colds with Parkinson's than Alzheimer's, migraine, epilepsy, stroke

People with early-stage Parkinson's disease may be about 70% less likely to catch the common cold than those with other common brain diseases,

The study, "Are patients with Parkinson's disease at a lower risk of catching the common cold? Propensity score matching," was published as a short communication in *Parkinsonism & Related Disorders*.

People with Parkinson's appear to have more brain inflammation than those without the disease, which is thought to contribute to its development and progression.

But inflammation can call on immune cells for protection, which has led a team of researchers in Japan to speculate that people with Parkinson's may be kept safe from mild infections such as the common cold, at least while the disease is at its early stages.

They drew on data from people, ages 40 years or older, who filed insurance claims in the country between 2010 and 2021, including 726 people with a diagnosis of Parkinson's who were at the early stages of disease. As a control, the researchers collected data from 11,753 people with other common brain diseases, including Alzheimer's, mi-

graine, epilepsy, or stroke.

Those with Parkinson's were significantly older (70.3 vs. 67.4 years) and included a significantly greater proportion of men (54.6% vs. 50.1%). Most (75.3%) Parkinson's patients were followed by a neurologist.

Results showed that there were significantly fewer cases of common cold among people with Parkinson's (3.4%) than among those with Alzheimer's (9.8%), migraine (13.3%), epilepsy (11%), or stroke (8.8%).

After adjusting for potential influencing factors, such as age, sex, specific disease, and periods of before or after the onset of the COVID-19 pandemic, the researchers found that a Parkinson's diagnosis reduced the odds of catching the common cold by about 70%. The pandemic period was also associated with a 50% less chance of reports of the common cold.

Being a woman and being followed by a neurologist were found to be independently associated with an increased chance of catching the common cold — by 59% and 30%, respectively.

The researchers used a method called propensity score matching to match each Parkinson's patient followed by a neurologist to one or more people from the other groups who had similar characteris-

tics and who were also followed by a neurologist in order to better adjust for the effects of potential influencing factors.

A total of 276 Parkinson's patients were matched to 276 people with Alzheimer's, also a neurodegenerative disease. After matching, the rate of common colds was still significantly lower among people with Parkinson's (3.4%) than among those with Alzheimer's (8.2%).

Similar results were seen when matching 547 Parkinson's patients to 547 people with non-neurodegenerative diseases (3.1% vs. 13%).

"Our data demonstrated a low incidence of colds in PD [Parkinson's disease] relative to that observed in other kinds of common brain diseases," the researchers wrote, adding this might be due to Parkinson's patients not complaining "about common cold symptoms (or requested medications) even when symptomatic" or to a possibility that "the [disease-associated] features of PD might reduce the risk of catching a cold relative to other brain diseases."

More research is needed to confirm these findings, assess whether this lower risk covers other types of mild infections, and determine the reasons for this potentially lower risk among early-stage Parkinson's patients, they said.

## How to plan nutritious easy-to-chew meals for people with Parkinson's

By Kathrynne Holden, RD – Parkinson's Life

*Preparing nutritious meals for people with Parkinson's who have chewing and swallowing difficulties doesn't have to mean compromising on taste. Here, dietician Kathrynne Holden, shares her tasty tips*

Parkinson's disease can slow the normal swallowing movement of the throat (peristalsis). This condition is called dysphagia and can lead to choking, or the inhaling of food into the lungs. Together with chewing problems – another common symptom – this means mealtimes can become difficult for patients. In the long run, chewing difficulty and/or poor oral health can also lead to malnutrition.

This article does not apply to the condition of dysphagia, only to chewing difficulty. If swallowing is a problem, or if you have choked, it's very important to ask your doctor for a referral to a speech therapist. They can determine whether you are at risk, and can demonstrate safe swallowing techniques. If needed, they may order a special diet of pureed foods and thickened liquids.

### Digestion difficulty

Let's think about what happens to a piece of boiled potato just after we place it in the mouth. The teeth chew the potato, grinding it up into smaller pieces. If not for the teeth, the potato might be too large to swallow, and we would choke. Besides that, the stomach would have a hard time with a

single, large piece of food – it can digest small pieces much better than large ones.

The teeth and tongue also move the potato around the mouth, and that movement stimulates the taste buds, which helps us enjoy our food. After the food is chewed, the tongue pushes it to the back of the mouth in position for swallowing.

But for some people with Parkinson's chewing can be difficult. Nerves that guide the muscles of the jaw and tongue become weaker. It may take an unusually long time just to chew a bite of food. Then the tongue has a difficult time moving food to the back of the mouth in position for swallowing. I've known people who have needed three to four hours to finish just one meal, which means there is hardly enough time in the day to eat the amount of food necessary to maintain a healthy weight and get all the necessary nutrients.

Besides the nerve damage that Parkinson's can cause, there are other concerns. Dry mouth, which is common in patients; poor oral hygiene, due to difficulty managing a toothbrush; and sugary foods, can all cause tooth decay and/or tooth loss.

### Soft solutions

If your ability to chew food properly is affected, you'll need to focus on eating soft foods that can be easily swal-

lowed, but also a variety of foods for good health. Nutrition is just as important, perhaps even more so, when it's hard to eat.

### Protein

When looking for softer proteins, ground or pureed meat and flaky, canned fish are good choices, as they don't require much chewing. Cottage cheese contains high-quality protein, and adds texture and flavour to casseroles and other dishes. Grated cheese mixed with mayonnaise is a good option. Eggs can be scrambled, fried, or soft/hard-boiled and diced for egg salad. Cooked dried beans are not only high in protein but are also rich in fibre. They can be mashed and thinned, or thickened as required. Peanut butter can be blended into smoothies as it can get stuck in the mouth or throat when eaten on its own.

NOTE: for those who use levodopa and are especially sensitive to protein, plant proteins such as beans may not block levodopa absorption as severely as animal proteins.

### Vegetables and fruits

These are important sources of vitamins, minerals, antioxidants, and fibre but can be hard to chew. Cooking and pureeing solves the problem – for example, making apple or pear sauce. Bananas can be difficult to move to the back of the mouth for swallowing, but they are very easy to swallow when blended with liquids into a smoothie.

Vegetables such as potatoes, sweet potatoes, squashes, turnips, carrots and peas can be cooked and mashed. You can make a hearty soup of green beans, courgette, squashes, tomatoes and sweet peppers. Make sure that they are finely chopped and cooked with broth and ground meats.

Cutting into small pieces will make this snack easier to chew

### Grains

These have complex carbohydrates and fibre as well as trace minerals and vitamins. Cooked cereals such as oatmeal, bread pudding made with whole-wheat bread, and rice pudding made with brown rice are all good choices. Sandwiches may not work well, but sauces, gravies, and cream soups can be poured over whole-grain bread to moisten it and make it easier to chew.

### Dairy products

Milk, yogurt, custard, and puddings are all easy to chew and are rich in protein, calcium and B vitamins. You can add fresh or dry milk to casseroles, cooked cereals and soups.

NOTE: some people who use levodopa find that milk protein blocks levodopa absorption to a greater extent than other proteins. Others are allergic to dairy. If so, consider one of the milk alternatives – almond, soy, or coconut milks and vegan cheeses.

## Engineered Stem Cells Found to Ease Pain in Parkinson's Mouse Model

By Marisa Wexler, MS – Parkinson's News Today, 1/24/23

Beneficial effects of resulting VEGF seen 1 week after transplant

Treatment with stem cells engineered to produce a signaling protein called VEGF – which drives the growth of blood vessels – was found to lead to pain relief in a mouse model of Parkinson's disease.

Researchers say engineering stem cells for use in transplant "may potentiate the therapeutic efficacy" of these cells to aid in easing pain due to Parkinson's.

"Our data suggest that [such treatment] is safely therapeutically appropriate for treating [Parkinson's disease]-related pain," they wrote.

The study, "VEGF-Expressing Mesenchymal Stem Cell Therapy for Safe and Effective Treatment of Pain in Parkinson's Disease," was published in *Cell Transplantation*.

Stem Cell-derived Therapy Eases Motor Deficits in Parkinson's Model

Treatment leads to pain relief in Parkinson's mouse model

Pain is a common and bothersome non-motor symptom of Parkinson's, and available treatments are usually not effective at completely controlling this symptom.

Mesenchymal stem cells, or MSCs, are cells that are able to grow into certain other cell types. This includes fat and connective tissue cells. These cells also can secrete a number of signaling molecules to influence the activity of nearby cells.

Due to their immunosuppressive, anti-inflammatory,

neuroprotective, and regenerative properties, MSCs have become increasingly explored as a therapeutic platform.

Previous studies suggested that MSCs engineered to produce high levels of VEGF – fully, vascular endothelial growth factor – may be used to reduce nerve damage-related pain.

VEGF is a signaling molecule that plays important roles in coordinating the growth and development of blood vessel cells, but also is involved in nervous system signaling.

Now, a quartet of scientists at Huazhong University of Science and Technology, in China, tested whether treatment using VEGF-producing MSCs could lead to pain relief in a mouse model of Parkinson's.

For these experiments, the researchers compared the effects of VEGF-producing human MSCs versus unmodified human MSCs when injected directly into the brains of mice with Parkinson's-like disease.

Specifically, they used a model in which a neurotoxic chemical called 6-OHDA is applied to one side of a mouse's brain to generate Parkinson's-like disease.

Pain was assessed with the Von Frey test, which involves applying gradually increasing amounts of pressure to the animal's paw to detect the minimum amount needed to evoke a flinching response.

Prior to an MSC transplant, the minimum threshold of such a response was low in the mouse model – 0.79 g on average – suggesting heightened sensitivity to touch and increased pain.

In mice given unmodified MSCs, the minimum pres-

sure that provoked a flinching response did not change substantially up to six weeks after treatment. However, mice treated with VEGF-producing MSCs showed a significant increase in the pressure needed to evoke such a response after six weeks (1.52 g), nearly reaching normal thresholds.

Beneficial effects were seen as early as one week after transplant.

*Our data suggest that [such treatment] is safely therapeutically appropriate for treating [Parkinson's disease]-related pain.*

No significant changes in the number of dopamine-producing neurons, which are progressively lost in Parkinson's, were observed between the two groups of mice. Dopamine is a major brain chemical messenger involved in motor function.

However, brain analyses indicated that treatment with the VEGF-producing MSCs led to a decrease in the levels of a protein receptor called TRPV1, which is known to play a central role in how the brain processes pain.

In addition, simultaneous pharmacological activation of TRPV1 eliminated VEGF-producing MSCs-mediated pain relief, "indicating that the mechanism of action of [this treatment] involves, at least in part, downregulation of TRPV1," the researchers wrote.

The researchers concluded that MSCs modified to produce VEGF "showed better pain relief and TRPV1 suppression... than conventional [unmodified] MSCs."

## Stress and Drama Are a Bad Mix for Parkinson's

### Both motor and non-motor symptoms are damaged by unanticipated problems

It's difficult for people, even family, to understand the serious effects of stress on someone living with Parkinson's disease (PD).

A 2021 Nature article, "Stress and mindfulness in Parkinson's disease — a survey in 5000 patients," suggests that stress has "considerable and detrimental influence on quality of life and on symptom severity." Furthermore, patients surveyed in this study reported that stress significantly worsened both motor symptoms and non-motor symptoms.

"Patients with Parkinson's disease (PD) are very vulnerable to the negative effects of psychological distress," according to another 2021 article, "Stress and Mindfulness in Parkinson's Disease: Clinical Effects and Potentially Underlying Mechanisms," in the journal Movement Disorders. The authors state that stress causes non-motor symptoms, such as anxiety and depression, to be prevalent; motor symptoms, such as tremor, to worsen; and medication to be less effective.

The study also suggests that chronic stress may accelerate disease progression.

### Stress Linked to Harsher Parkinson's Symptoms, but Mindfulness May Help

Dealing with stress is a fundamental part of my Parkinson's self-management toolkit. All of us (with Parkinson's or not) try to avoid stress whenever we can. A blip in the road is manageable, if we've anticipated the stress. When we know that something difficult is going to be on the calendar, we can adjust our days before and after to allow time for recovery.

By Dr. C – Parkinson's News Today, 12/16/22

I visited the dentist recently. There's no way for me to make that a non-stressful event. I knew logically there wouldn't be any pain from a routine evaluation, but still, it's the dentist! It was also an hour-long drive each way, which, unfortunately, fell on a "bad day." Thus, a sum of factors exacerbated the stress.

By the end of the visit, all my motor and mind malfunctions were screaming. It took several days for all my PD symptoms to quiet down from their raging levels. But we've learned to manage this.

However, when stress is unanticipated, as the result of other people being inconsiderate of the illness' issues, then it becomes a huge challenge.

### A mile in my shoes

Mrs. Dr. C and I call unanticipated stress triggered by the actions of others "drama." Stress occurs to everyone all the time. But there are major problems on my end when other people's needless emotional intensity and thoughtlessness, caused by how they handle their own stress, spill out into our home.

Emotional, stressful situations are not quickly overcome these days. Before Parkinson's, I could easily roll with the punches. My compassion levels were much higher then. Now, the anxiety, anger, and irritability toward the drama displayed by others has an enormous impact on my Parkinson's life.

After enduring these situations, it takes two or three days to find my emotional balance and return to homeostasis in my motor and non-motor symptoms. During these two or three days of recovery, I'm thrust into a "bad day," or worse, a day with the "beast."

My only solution is to stay away from the drama.

We've tried to explain this. It's difficult to tell people that their drama causes me to have an extremely negative Parkinson's experience. It's more difficult to tell them and then have them ignore what I'm sharing. "But he isn't like he used to be," they say. No, I'm not. I have Parkinson's disease.

The non-motor malfunctions associated with Parkinson's are invisible to most observers. While they might perceive something's not right, they attribute it to something I could control if I just tried harder. I work at not affecting other people's lives with my PD issues. But the problems still arise internally, and I'm left to manage myself (with Mrs. Dr. C's help) through 72 hours of unnecessary drama-inflicted dysfunction.

The cost to my health is something I'm no longer willing to pay.

There's no way around stress in our lives. But family and friends must take the time to walk in my shoes. The invisible aspects of Parkinson's are tough on family, particularly because they can't see those issues. Family is not present in our lives every day.

At home, I can use the refrigerator magnet system to communicate to Mrs. Dr. C how I'm doing. She's well-tuned now to the physical signs that make the invisible visible. Family members who visit only occasionally don't benefit from this intimate knowledge of how I live with Parkinson's. They arrive with their own agendas, their own preconceptions of who we are, and baggage.

It would be enlightening if they could see what I experience with this disease. For now, I'm just asking for them to leave drama at their doorstep and not ours.

## COGNISANT Boosts Short-term Memory in Older Adults: Study

By Patricia Inacio, PhD – Parkinson's News Today, 10/17/22

A new strategy that combines online cognitive therapeutic games with a noninvasive brain stimulation technique – called COGNISANT – may help boost short-term memory in older people, according to a new study.

The findings may prove important for people with Parkinson's disease who often experience a decline in short-term, or working memory, that can affect their ability to perform everyday tasks.

"Although cognitive decline in the elderly is an inevitability, approaches such as COGNISANT, in combination with regular physical exercise, can stem this decline and provide individuals with a higher quality of life," professor Kim Shapiro at the University of Birmingham's School of Psychology and Centre for Human Brain Health, U.K., and one of the study's authors, said in a university press release.

The study, "Older adults with lower working memory capacity benefit from transcranial direct current stimulation when combined with working memory training: A preliminary study," was published in Frontiers in Aging Neuroscience.

Intense Rehabilitation Can Help People at Earlier Disease Stages, Study Finds

Working memory, a brain function that allows people to keep information over a short interval and is key for decision-making processes and everyday life functioning, declines with age. This decline is likely to cause more severe impairments in the daily lives of people with neurodegenerative diseases, such as Parkinson's.

An international team of scientists and clinicians from the University of Birmingham; Dalhousie University, Nova Scotia, Canada; and the University of Trento, Italy, developed a new working memory training program to mitigate this decline.

COGNISANT combines cognitive training and a noninvasive brain stimulation technique, called transcranial direct current stimulation (tDCS). Its developers include Shapiro, a cognitive neuroscientist, along with biomedical engineer Sara Assecondi, formerly at Birmingham but now at Trento's Centre for Mind/Brain Sciences (CIMEC).

"We hypothesized that individuals with lower working memory capacity would benefit the most from the combined regimen," the researchers wrote.

In their study, cognitive training was conducted using online therapeutic games developed by neuropsychologist professor Gail Eskes, at the department of Psychology & Neuroscience, and Psychiatry, Dalhousie University.

"Intensive exercises at just the right difficulty are important for increasing brain capacity or efficiency. And the game-like aspects increase motivation and make it easier to stick with the challenging sessions," Eskes said.

For the brain stimulation, participants used a mobile wireless device that sends low-level electric currents to two brain regions, including the prefrontal cortex, the front part of the brain that's important for attention and executive functions.

The team tested the effectiveness of COGNISANT in 28 healthy adults, age 56–76. Participants were split into two groups, one that underwent brain stimulation using a device that resembles a swimming cap and the other that received a sham procedure without any electrical current. The procedures took 20 minutes and both groups performed their cognitive training by playing online games for 20 minutes a day over five days.

Participants' working memory capacity (WMC) were evaluated before the study and two days after its completion. WMC was assessed by asking the participants to perform five tasks that relied on different aspects of working memory.

The results showed all participants significantly improved their WMC independently of their age or whether they received brain stimulation.

However, older participants – age 69.5–76 – with lower initial WMC benefited the most from the combination of cognitive training and brain stimulation.

"Future work should consider developing individualized treatments by considering individual differences in cognitive profiles," the researchers wrote.

The team plans to conduct further studies to see if other forms of brain stimulation can prove more effective and are finishing a study that's assessing COGNISANT's benefits in post-stroke patients with publication expected soon.

**Colorado Parkinson Foundation, Inc.**

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

**PARKINSON'S PERSPECTIVE**

**MARCH 2023**

# Coming Events

See inside for more information

**March 11<sup>th</sup> - Cancelled due to the staging of the St. Patrick's Day parade on church grounds**

**April 8<sup>th</sup> - Reg Mtg** at 10 am; **Program:** Neuro-ophthalmology Issues  
Speaker: Dr. Erin Van Dok, Neuro-Ophthalmologist

**May 13<sup>th</sup> - Reg Mtg** at 10 am; **Program:** Breakout Sessions

**June 10<sup>th</sup> - Reg Mtg** at 10 am; **Program:** New study on the effects of good dietary oils on health and the Parkinson's; Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP

**July 8<sup>th</sup> - Reg Mtg** at 10 am; **Program:** Scam Prevention  
Speaker: Officer Scott Mathis, Colorado Springs Police Department

**August 5<sup>th</sup> - Program:** Picnic at John Venezia Park!!!!!!

**September 9<sup>th</sup> - Reg Mtg** at 10 am; **Program:** Breakout Sessions

***More useful websites:***

<https://parkinsonsnewstoday.com>; [www.parkinsonrockies.org](http://www.parkinsonrockies.org); [www.parkinson.org](http://www.parkinson.org); [www.nwpf.org](http://www.nwpf.org); [michaeljfoxfoundation.org](http://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](http://www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons); [www.parkinsonheartland.org](http://www.parkinsonheartland.org);  
<https://www.pdself.org>; [https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo\\_C](https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C); [pmdalliance.org](http://pmdalliance.org);