



# 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:**

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**Main Dish Coordinator:**

Bill Hicks [redacted] or

potluck@co-parkinson.org

**Picnic:** Carole Henrichsen

and Janet Adams

**Media Relations:** Mary Sauvain

**Medical Advisor:** Curt Freed, MD

**New Member Table Chairmen:**

Vacant

**Sunshine (Cards):** Sharon Carlson

[redacted]

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Contact Julie Pfarrer at

db\_mgr@co-parkinson.org or

call [redacted]

### Next Meeting: Saturday, September 10th – 10:00 am – 1:30 pm

We will NOT be Zooming nor recording this meeting

**Location:** First United Methodist Church, 420 N. Nevada Ave, downtown just south of St. Vrain.

9:30 am – 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.

9:45 am – Everyone else come in 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 First United Methodist Church.

### September Program: Break-out Sessions

**Moderators:** Parkinsonians: Steve Locke and for the caregivers: Jill Reid & Julie Pfarrer

The Parkinsonians get together in one room and the caregivers in another to discuss their questions and concerns about their PD journey.

### The September Potluck - Baked Potato Bar

Potatoes will be provided and all others bring toppings such as chili, cheese, sour cream, broccoli, bacon bits, etc. or salads, side dishes or desserts.

If you would like to sign up to be one of the providers of a topping, salad, side dish or dessert for the September meeting, you can contact Bill Hicks at [redacted] or potluck@co-parkinson.org, no later than Wed. September 7th and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

**We look forward to seeing you there!**

### The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



On Saturday, August 13, we had our annual summer picnic at the House pavilion at John Venezia Park. For those who didn't attend, you really missed out. It was the perfect Colorado summer day—gorgeous and sunny but not hot. The get-together was pretty well attended—about 35 people came, up from the past post-COVID years — but the main indicator that everyone was glad he came was that no one left early!! We were so enjoying each other's company that we lingered long after we stopped eating. By the time I finally left (after everyone else), it was nearly 2 o'clock!

And it was wonderful to have some new people attend—Luann and Randy Rogers, who came with their daughter and grandchildren, and Sven (whose last name I didn't catch). It was great meeting you and we look forward to seeing you again at our regular meeting in September.

Over the years, we've held our annual picnic at various venues—Otis Park, America the Beautiful Park, Black Forest Regional Park, and Palmer Park. John Venezia Park, while not as centrally located as Palmer Park, has the best attributes of all of them—ease of handicap access to the pavilions, close-in parking, roomy and shady pavilions, nearby restrooms, paved walkways, plenty of picnic tables (no need to bring folding chairs), trash receptacles, and safe surroundings.

It's a beautiful venue, and each of its three pavilions is large enough to accommodate us all AND keep us in the shade. Before COVID, we averaged more than sixty people at our picnics, and we needed the largest of the pavilions, the Barn. But the Barn was really too big for us the last couple of years. So we moved to the House pavilion last year, and it was just right! It is also conveniently situated right next to the restrooms. We plan to reserve the House again for next year's picnic.

A big thank you to all who helped set up, serve, and clean up—Executive Committee members Julie Pfarrer, Janet Adams, Mary and Rich Sauvain, Carole Henrichsen, and Bill and Brenda Hicks and Katherine Reed, who always steps in to help. And a heartfelt thanks to all who brought side dishes and desserts. We didn't lack for food by any stretch of the imagination.

If you have to pay for transportation in order to come to our events, remember that CPF will reimburse you for the cost -- just give your receipts to our treasurer, Julie Pfarrer. Lack of transportation should never be the reason that you can't come to any of our events. We'd love to see everyone at the picnic next year!

The Colorado Springs  
Parkinson's Support Group  
(part of CPF) meets the second  
Saturday of each month at 10AM  
(with exceptions to be noted  
in this newsletter).

## July 9, 2022 | Program Review

### Avoiding Scams and Frauds

Colorado Springs Police Department — Officer Scott Mathis

What is a scam? A dishonest trick used to cheat someone out of money. Scams can be in person or via the phone, email, or mail. It's important to know that scammers do not care about you personally.

#### Four signs of a scam

- Scammers PRETEND to be from an organization you know (i.e., claim to be from Amazon and ask for your information for an Amazon gift card)
- Scammers say there's a problem or a prize
- Scammer PRESSURE you to act immediately
- Scammer tell you to PAY in a specific way

Unknown phone calls/numbers – A good rule of thumb is if you don't know the number, don't answer. If someone legitimate is trying get in touch with you, they will likely leave a voice mail or message.

Email phishing – the fraudulent practice of sending emails purporting to be from reputable companies to get you to send personal information, such as passwords, credit card numbers, etc.

Legitimate companies don't usually request your sensitive information! Legitimate companies usually call you by name, spell correctly, don't force you to their website, and don't send unsolicited attachments. Be aware that fraudulent emails will often use copies of a company's logo or fake official-looking emails, such as IRS or banks.

TIP – If an email has a link, hover your mouse over the link (don't click on it), and it will show you what it will send you to. If it is not sending you to the company's website, delete immediately.

#### Common types of scams

- Romance scams – convince you there is a romantic connection; on average, \$12,700 is lost per scam, and it happens to both men and women
- Tech support scams – claim there is an issue with your computer/smartphone
- Grandparent scams – you get a call or email claiming to be from your grandchild asking of money immediately, often asking for bond money. Note that this is not how the bond system works!
- Government impersonation scams – for example: claims to be the IRS and tells you owe more on your taxes
- Sweepstakes/charity/lottery scams – for example: claims you won a prize cash amount when you haven't entered any contest
- Home repair scams
- TV/Radio scams
- Family/Caregiver scams – caregiver scamming the person to whom they are providing caregiver services. For example: writing checks in their name

- Police warrant scams – claims there is a warrant out for your arrest. Note – law enforcement agencies will NEVER call you to say to pay to get rid of a warrant. Police officers will always say their name and their badge number, if you're not sure, call the nonemergency line to verify legitimacy.

Scammers will try to keep you on the phone or in contact as long as possible, pressing for money be sent immediately.

Text scams, taken advantage of during COVID, will ask for personal information via text. These often end in "text STOP to stop messages", DO NOT respond since responding in any way only confirms your phone number is legitimate. Do not text stop or any type of response.

Note – don't click on links in text messages from anyone you don't know.

How to report unwanted text messages – you can report to your mobile carrier by forwarding it to a specific number. Forwarding the message to 7726 will forward the number to your phone carrier for them to flag.

QR code scans – don't scan any unknown QR codes. In general, scan QR codes with the camera on your phone. Do not download apps that scan QR codes because these are less reliable in security.

Unfortunately, 60+ is the age group most effected by scams. FBI reported in 2020 60+ age bracket lost over \$1 billion, but only an estimated 23% of those scammed actually reported the scams. Obviously, the total loss is much, much higher. Colorado is fifth highest state in average number of victims. The chances of any money being recovered is very small.

#### Protect yourself!

- Recognize scam attempts and end all communication with perpetrators
- Search online for the contact information and their proposed offer
- Resist the pressure to act quickly!
- Be cautious of unsolicited phone calls, mailings, and door-to-door services offers
- Never give or send any personally identifiable information, money, jewelry, gift cards, checks, or wire information to unverified people or businesses.
- Make sure all computer anti-virus is up to date
- Disconnect from the internet and shut down your device if you see a pop-up message or locked screen
- Always be careful what you download
- Take precautions to protect your identity if a criminal gains access to your device or account
- Report suspected scams to 911 if it's an emergency or the nonemergency line. Report to [www.ic3.gov](http://www.ic3.gov) if any scam crime has occurred

## 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).



## 10 Top Tips for Traveling with Parkinson's

By Timo Montonen – Parkinson's Life, 8/4/22

Like hundreds of other people with Parkinson's, I planned to attend the fourth World Parkinson Congress (WPC) in Portland. But living in Finland, I was faced with a long-distance trip across the Atlantic to the US – which I decided would be better with a team of friends. Besides, it's more fun, safer and cheaper to travel in a group.

We traveled by planes and vans to the west coast, visiting San Francisco, Los Angeles and Las Vegas on the way to Portland. The two-week journey was a success and we discussed afterwards what we could have done to make it even better. As a result, we created the following list of advice for other groups of people with Parkinson's who wish to travel.

### Role Play

Start planning well before the trip to avoid stressful situations. Decide everyone's role in advance – in particular, who will be group leader. The schedule must be arranged according to the slowest member of the group. Keep the budget clearly in mind and follow it. Research the different ways to travel as a group. Assess the pros and cons of using different vehicles such as airplane, train, ship, coach and minivan.

### Mind your medication

Make sure that you have all the medication that you need for the journey – and also take enough for a few extra days in case of delays. Take care of the medication schedule. Put prescriptions, and all other documents – such as a ['Parkinson's Passport'](#) – necessary for traveling, in one folder to make them easy to find when needed.

### Be aware of technical hitches

If you have deep brain stimulation equipment, artificial joints or pacemakers, take all documentation with you so that you can inform staff at the airport. Internal metal plates can be detected by body scanners at security checks – be ready to explain any medical implants to security staff.

### Pack light

Always remember to pack your essentials, but try and travel light. If you use a seat cushion, pack it in your cabin bag along with the other things that you'll need during the flight. Eating while on the plane is easier if you bring your own spoon and non-slip mat that you can place under your plate. Take straws with you to help with drinking, and extra napkins for any accidental spillages, as the plane does not always have them. Ankle supports, a back support and a seat cushion will all help tired muscles.

### Comfort over style

Dress comfortably in loose clothing. Wear support stockings to prevent the lower legs from swelling. Take comfortable shoes that are easy to put on and take off. Bring warm socks or slippers on the plane with you to wear when walking up and down the aisle for bathroom breaks.

### Queue jump

Inform the airport check-in staff and the plane personnel about the condition of your group – that you cannot stand for a long time in queues, for example. It's possible that you may be able to 'fast-track' your way to the front of queues. If you use walking aids and/or wheelchairs contact your travel agency or flight operator in advance to ask for extra assistance at the airport.

### Less pain on the plane

Remember to stand up and stretch regularly while on the flight – bend the knees, stretch your legs, rotate your ankles, stretch your back, bend your upper body from side to side, raise your hands above your head. When it's time to leave the plane remain, in your seat until the plane is almost empty – it's no fun to stand and wait in a crowd.

### Fast food

Try to eat breakfast in your usual manner. When the group is on the road, having lunch can take a surprisingly long time, as you have to find a restaurant, order, eat and get the bill. To save time, eat a packed lunch during the day and have a sit down dinner in the evening.

### Rest and focus

Start mornings in peace. Remember to take rest breaks during the day. If the group is lacking energy, leave something out of the schedule to focus on the most important or most comfortable option. It's OK to take a day off from the planned itinerary if the group could benefit from a rest day.

### Take care of the team

Take care of all members of the group. Make sure that all are able to cope with the schedule. Work creatively according to the situation, but don't assume that all will follow the plan. Don't leave anyone alone. Make sure you're prepared if there is an emergency. Remember, worrying too much about Parkinson's disease will not help you or your team.

*Above all, enjoy the trip!*

## Patients' Depression Often Carries Over to Care Partners

By Steve Bryson, PhD – Parkinson's News Today, 8/12/22

More disability and higher levels of depression in Parkinson's disease patients predicted an increase in burden and depression of their care partners, such as family and friends, over two years, a study concluded.

The findings underscore the need to monitor the burden of care partners over time.

Treatment targeting disease severity, such as medication management, may ease care partner burden, while interventions aimed at alleviating patient depression could prevent future care partner depression, the researchers noted.

Because care partners for those with Parkinson's provide care for several years, early intervention may help the emotional well-being of both the patients and their care partners, they added.

The study, "[Prospective Predictors of Care Partner Burden and Depression in Parkinson's disease](#)," was published in the *International Journal of Geriatric Psychiatry*.

People with Parkinson's disease face physical and mental disabilities. As a result, they often rely on others for physical, emotional, social, and economic support. This includes informal caregivers, or those without formal training, such as family and friends.

Cross-sectional studies – those conducted at one point in time – suggest higher levels of burden and depression in care partners of Parkinson's patients.

Due to Parkinson's progressive nature, it is important to understand changes in care partner burden and depression over time (longitudinally) to identify factors contributing to caregiving burden. Such knowledge may provide key information for assessing and treating depression and burden in care partners of individuals with Parkinson's.

Scientists based at the VA San Diego Healthcare System in California followed a group of 88 adult Parkinson's patients without dementia and an equal number of self-

identified care partners for two years to assess burden and depression.

"This is the first longitudinal study to examine changes in and predictors of care partner burden and depression in [Parkinson's disease] over time," the scientists wrote.

### STATISTICAL PROFILES

Participants with Parkinson's were primarily male (72%), older than 65, and college educated, while their care partners were primarily female (71%), older than 60, and college educated. Among the care partners, 88.64% were spouses, 6.82% were their children, 3.41% were friends, and 1.14% were siblings.

At the beginning of the study (baseline) and about two years later (mean 2.42 years), care partner burden was evaluated with the Zarit burden inventory (ZBI). Care partner depression was assessed with the geriatric

*(continued on page 6...)*

**Other Local Support Groups:**

*Due to Coronavirus concerns, check ahead to see if canceled*

**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 [redacted] or [redacted] to let her know you are coming.

**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 [redacted].

**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 [redacted].

**Ladies w/ Parkinson's Support Group**

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

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

**Other Opportunities:**

*Due to Coronavirus concerns, check ahead to see if canceled*

**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, an evidenced based voice treatment program designed for Parkinson's patients

Swallowing  
- Neuromuscular Electrical Stimulation Therapy  
- Respiratory Muscle Strength Training  
Aphasia following stroke  
Cognitive-Linguistic Deficits

For more info, 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.

**Thank You!**

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

**September Executive Committee Meetings**

September 13th at 11:00 a.m. | Location: Place to be determined (you will be notified by email)

Contact Jill at 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.

**October Newsletter Input Deadline: Sept 14th**

Call or e-mail Julie at:

[redacted]  
db\_mgr@co-parkinson.org.



Mike Ballo  
Teri Ballo  
Dale Bowman  
Jackie Casey  
Larry Christian  
Ray Coddington  
Janet Conover

Gerald Costanzo  
Nancy Crosier  
John Fletcher  
Karen Fletcher  
Carole Henriksen  
Patrick Holland  
Alan Knight

Maralyn Legleiter  
David Lydon  
Paul Metzler  
Corinne Nelson  
Marge Parrott  
Ric Pfarrer  
Carol Rushing

Gary Shrewsbury  
Dennis Smith  
Judith Stauffer  
Shanti Stuehmeyer  
Onda Waller  
Alan Whitaker

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

**LENDING LOCKER INVENTORY**

**Note:** A stair chair lift system has been donated to us. It's a seat on a rail that takes you up and down a staircase. This one is for a 14 step or less straight staircase with no turns.

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

3-wheeled walker	1	Double exercise pedals	1	Swivel seat	1
Back brace	1	Exercise bike	1	Toilet arm assist	1
Bed cane	3	Lift chairs	2	Toilet seats	3
Bed pan	1	Lift-ware tremor compensating utensils	1 set	Transport chairs	3
Bed rails	1	Pick-up assist	6	Tub rail	2
Bed risers	1 set	Shower benches	10	U-step	3
Bedside toilets	6	Sock helper	2	Walkers with wheels & seat	12
Canes	7	Stair chair rail system	1	Wheelchairs	6
Crutches	2 sets				

**Help us 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 by calling [redacted].



**PD Exercise Classes: Due to Coronavirus concerns, check ahead to see if canceled**

**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

**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

**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

**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

**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

**Falcon Exercise Group**

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

**A CPF Charitable Giving Opportunity!**

Another reminder about an easy and painless way for you to help CPF. An ongoing charitable giving opportunity each time you order merchandise from Amazon. 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** 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!

**Coronavirus and Parkinson's Disease**  
For information on coronavirus and Parkinson's Disease go to: [www.parkinson.org/CoronaVirus](http://www.parkinson.org/CoronaVirus).

**Recipe of the Month: Bulgogi (a Korean dish)**

Our low carb/good fat ketogenic study that was completed this past year 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 the caregivers who chose to change their diet along with their Parkinsonians). 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 at our potlucks.

- 2 lbs sirloin
- \*3 scallions
- \*4 cloves of garlic
- \*5 T wheat-free soy sauce
- \*2 T sesame oil
- \*¼ C low carb sugar substitute (ex. erythritol, monkfruit)
- \*2 T apple cider vinegar OR ½ T sherry vinegar
- \*¼ C beef stock
- \*1/8 t black pepper
- approx. 7 oz sweet potato noodles (not Keto but low glycemic)

Slice sirloin thinly and score each slice with an X. Combine with other ingredients in a large bowl. Let marinate in refrigerator 48 hours.

Before cooking, cook sweet potato noodles in boiling water for 3 minutes. Add cooked and drained noodles. Cook a little at a time in an electric wok.

**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).**

\* – if doubling or more the liquid amounts and using apple cider vinegar, dilute the vinegar by substituting half the amount with water.

(...continued from page 3)

depression scale (GDS). At the same time, patients underwent standard clinical examinations for disability, dementia, and depression, as well as self-reported questionnaires for anxiety and apathy. At baseline, the average disease duration was five years.

Mean patient GDS scores at baseline and follow-up met the clinical criteria for depression. Of care partners, 27.3% met the criteria for depression at baseline and follow-up

There was no significant difference between patient baseline and follow-up MDS-UPDRS Part-III scores for motor function, and levodopa equivalent dose (LED), the combined total of Parkinson's medications. In patients, there was a small, significant decline in global cognitive abilities as assessed by the Mattis dementia rating scale.

On average, Baseline ABI total scores indicated mid-to-moderate burden, with 20.5% of the care partners scoring within the clinically significant range. At follow-up, ZBI total scores also showed mid-to-moderate burden, with 33% scoring within the clinically significant range.

Notably, 13 care partners who were not burdened at baseline became clinically burdened at follow-up. In contrast, two care partners who were burdened at baseline did not meet the follow-up criteria for clinical burden.

The mean baseline and follow-up GDS scores suggested clinically significant depression in care partners, with 9.1% meeting clinically significant depression at baseline and 12.5% at follow-up. Here, five participants' depressive symptoms increased to clinical significance from baseline to follow-up, while two care partners were no longer clinically significant at follow-up.

Compared to Parkinson's patients, the care partner group had significantly fewer depressive symptoms.

#### INCREASED CARE PARTNER BURDEN

Based on these findings, statistical analysis revealed significantly greater care partner burden and depression at follow-up compared to baseline. Over time, an increased burden was experienced by 615% of care partners, 8% remained stable, and 31% reported a decreased burden. Depression increased for 45% of care partners, remained stable in 25%, and declined in 30% of these participants.

At both baseline and follow-up, the care partner's expression and burden also were associated significantly.

Higher baseline disability (Hoehn and Yahr staging), LED, and longer disease duration in patients was correlated significantly with increased care partner burden over the two-year follow-up.

All other patient and care partner demographics and patient psychiatric measures were unrelated to changes in care partner burden. Moreover, baseline care partner burden scores were not associated with changes in partner burden scores.

In comparison, increases in care partner depression over two years were significantly correlated with higher patient apathy, anxiety, and depression at baseline. All other care partner characteristics were not related to changes in care partner depression over time, including care partner depression at baseline.

Finally, at baseline, greater patient disability predicted increased care partner burden over time, while higher levels of patient depression significantly predicted higher care partner depression over time.

"The best predictors of care partner burden and depression were both [Parkinson's disease] patient symptoms, rather than care partner factors, suggesting that these distinct phenomena could benefit from different, targeted treatments," the researchers concluded.

"Treatments aimed at controlling disease severity associated with disease stage (e.g. medication management) may prevent worsening of care partner burden, while interventions focused on ameliorating patient depression could prevent future care partner depression," the researchers added.

## Physical Activity Linked to Larger Volume, Increased Health of Brain

By Vanda Pinto, PhD – Parkinson's News Today, 8/8/22

Physical activity may be beneficial to brain health, including for people with neurodegenerative diseases such as Parkinson's disease, by promoting increases in brain volume, a long-term follow-up study suggests.

"Our study results indicated that even small behavioral changes, such as walking 15 minutes a day or taking the stairs instead of the elevator, may have a substantial positive effect on the brain and potentially counteract age-related loss of brain matter and the development of neurodegenerative diseases," Ahmad Aziz, MD, PhD, principal investigator of the research project and study author, said in a press release.

The study, "**Association Between Accelerometer-Derived Physical Activity Measurements and Brain Structure: A Population-Based Cohort Study**," was published in *Neurology*, the medical journal of the American Academy of Neurology.

According to a few studies, certain regions of the brain can atrophy over time in people with Parkinson's. researchers believe that larger brain volumes offer better protection against neurodegeneration than smaller ones.

Although regular exercise is thought to help delay brain aging and the progression of neurodegenerative diseases, how it impacts the brain and which regions it affects the most is still unknown.

To learn more, scientists from the Population Health Sciences, German Center for Neurodegenerative Diseases (DZNE), and the University of Bonn, in Germany, analyzed physical

activity data and MRI brain images from 2,550 people who participated in the Rhineland Study. What is the Rhineland Study?

The Rhineland Study is a large-scale population-based study conducted by DZNE that seeks to include up to 30,000 participants to evaluate changes in the body and brain over a person's lifespan. Its primary goal is to develop strategies to prevent dementia and other age-related diseases.

Researchers tracked the physical activity of volunteers using a device called an accelerometer which was worn on the upper thigh for seven days. Brain volume and thickness of the cortex was assessed from MRI scans.

Participants' ages ranged from 30 to 94 years and their mean age was 54.7 years. More than half (57.6%) were women.

Physical activity had a noticeable effect on nearly all the investigated brain regions. "Generally, we can say that the higher and more intense the physical activity, the larger the brain regions were, either with regard to volume or cortical thickness," said Fabienne Fox, lead author of the study.

This observation was particularly true for the region of the brain considered the control center of memory – the hippocampus.

However, the findings revealed larger volume increases when they compared inactive and only moderately physical active study participants, especially in people older than 70.

People who participated in moderate to intense physical activities also had high brain volumes,

however, only slight differences were observed compared to those who were even more active, thus indicating that the beneficial effects tended to level off.

"With our results, we want to provide a further impetus to become more physically active – to promote brain health and prevent neurodegenerative diseases," Fox said, "Even modest physical activity can help. Thus, it's just a small effort – but with big impact."

Next, the team searched databases for genes that are particularly active in brain areas which benefited most from physical activity – the motor and cortical regions. They identified genes necessary for mitochondria (organelles within cells that generate energy) to work.

Increased blood flow is needed to supply the large number of mitochondria present in these brain regions with oxygen. This may be the reason why physical activity benefits the brain in these areas, Aziz said.

Further analysis found a large overlap between genes whose expression is affected by physical activity and those involved in neurodegenerative diseases such as Alzheimer's, Parkinson's, and Huntington's. the team hypothesized that this could be why physical activity has a neuroprotective effect.

"While young adults may particularly profit from additional high-intensity activities, older adult may already benefit from light-intensity activities," the researchers concluded. "Physical activity and reduced sedentary time may be critical in the prevention of age-associated brain atrophy and neurodegenerative diseases."

## Brain Training App Useful in Early Parkinson's Cases: Pilot Study

By Steve Bryson, PhD – Parkinson's News Today, 8/12/22

The cognitive exercise smartphone app NeuroNation, which combines personalized tasks and gamification, is useful and feasible for adults with mild Parkinson's disease, a pilot study concluded.

The researchers noted the app was a success in terms of the patients' perception of its usability and in achieving cognitive improvements, and may be an effective for providing cognitive rehabilitation at home.

Despite the small sample size and limited patient population, the researchers recommended further studies with larger groups of patients to evaluate changes in cognition.

The pilot study, "**Feasibility and usability of a non-immersive virtual reality tele-cognitive app in cognitive rehabilitation of patients affected by Parkinson's disease,**" was published in *Psychogeriatrics*.

Cognitive impairment, ranging from mild thinking problems to dementia, represents one of the most common non-motor symptoms of Parkinson's disease. Accordingly, cognitive rehabilitation strategies may help delay cognitive deficits from occurring or getting worse.

However, cognitive rehabilitation protocols performed in hospitals or clinics may not be easy for those with movement disorders. As such, performing rehabilitation tasks remotely could be a valid alternative to face-to-face activities.

Researchers at the University of Catania, Italy evaluated in a pilot study the feasibility and usability of a smartphone application that

combines virtual reality (VR) with cognitive exercises in 16 adult patients with mild Parkinson's without dementia.

The application — NeuroNation-Brain Training — available for free download to a smartphone, is an online brain training program with a combination of personalized tasks and gamification.

The program includes 27 tasks with 250 levels to enhance memory, executive function, attention, logical thinking, and cognitive speed. It can be customized to a user's personal preferences, strengths, and cognitive potential and provides performance motivation and self-assessment with audio-video feedback.

Following an initial face-to-face clinic visit to set the level of difficulty according to the patients' characteristics, participants performed the training remotely at home for six weeks. The exercise involved three weekly sessions, lasting 20 minutes for a total of 18 sessions.

At the end of each week, the program applied a test to determine cognition level and provided a performance report, which was sent to examiners via text message. Weekly telephone consultations were included to resolve any difficulties. After six weeks, participants reported on the feasibility and usability with a questionnaire.

All 16 participants (nine men, six women) with a mean age of 58.4 years and a mean disease duration of 4.6 years, completed the training. There were no significant differences between men and women regarding age or education. During the study, all were treated

with levodopa, a standard Parkinson's therapy.

The system usability scale questionnaire measured the acceptance of the application regarding hardware, mobile devices, applications, and websites. The usability was based on 10 items rated on a five-point scale from "strongly agree" to "strongly disagree," with higher scores indicating better usability.

After six weeks of cognitive training, the mean system usability scale score across all participants was 83.4, which indicated it was considered "good and promising." In comparison, scores above 90 are deemed "exceptional."

The goal attainment scaling questionnaire assessed participants' perception of the goals achieved during the intervention. Each goal, agreed upon by the patient, was evaluated on a five-point scale, from "much worse" to "much better," with an ultimate outcome of improved cognitive ability.

Compared to before the study, there was a significant improvement in goal attainment scaling scores after six weeks of training, rising from a mean of 38.5 to 65.6.

"Our pilot study suggests that cognitive tele-rehabilitation using a smartphone-based VR app could be an effective way to provide [Parkinson's disease] patients with home cognitive rehabilitation," the researchers concluded. "We believe that further studies using larger samples should be promoted, also evaluating changes in cognitive and emotional functioning."

## Poor Sleep Seems to Worsen Parkinson's Symptoms

By Lindsey Shapiro, PhD – Parkinson's News Today, 7/17/22

Poor quality of sleep is linked to worse motor and non-motor symptoms in people with Parkinson's disease, a study has found.

Greater deviations from an estimated ideal bedtime, time in bed, and duration of sleep are linked to more severe symptoms, data show.

"Sleep disorders have a significant effect on the burden of [Parkinson's] symptoms. The current findings provide new insights into the monitoring and management of sleep and [Parkinson's] and need to be further explored in the future studies," the researchers wrote.

The study, "**Worse Sleep Quality Aggravates the Motor and Non-Motor Symptoms in Parkinson's Disease,**" was published in *Frontiers in Aging Neuroscience*.

Sleep problems, including insomnia, nightmares and restless sleep, are common non-motor symptoms of Parkinson's that can influence life quality significantly. It has been reported that sleep disturbances sometimes occur years before a Parkinson's diagnosis, when the hallmark motor symptoms of the neurodegenerative disease emerge.

Researchers in China aimed to investigate the relationship between sleep characteristics and other Parkinson's symptoms among 328 Parkinson's patients seen at their clinic from October 2014 to October 2021. The mean age of patients was 60.5, and 145 were women.

Participants completed the Pittsburgh Sleep Quality Index (PSQI), a self-reported questionnaire relating to sleep quality, and then were categorized as having poor, general, or good. Sleep.

Among the group, 99 had good sleep, 147 had general sleep, and sleep was poor in 82 participants.

Overall, poor sleep, reflected by high PSQI scores, was associated significantly with more severe motor symptoms, as measured by the Hoehn and Yahr scale, the freezing of gait questionnaire (FOG-Q) and the Movement Disorder Society-Unified Parkinson's Disease Rating Scale Part 2 (MDS-UPDRS-II).

Non-motor symptom burden, as measured by the MDS-UPDRS Part I and the Non-Motor Symptoms Scale (NMSS), also was linked to worse sleep, as were measures of several

specific non-motor symptoms, including cognitive function, depression, anxiety, life quality, autonomic dysfunction, apathy and fatigue.

Required doses of levodopa, or similar antiparkinsonian medications, were higher among those with worse sleep. Specific sleep components, such as sleep quality, durations, disturbances, daytime dysfunction and used of sleep medications, were linked similarly to some motor and non-motor symptoms.

Investigating further, the researchers found the ideal bedtime was about 9:52 p.m., with greater deviations from that time associated with worse MDS-UPDRS-II scores, which reflect activities of daily life such as speech, handwriting or walking.

Further, the optimal time in bed was determined to be about 8-9.2 hours, with both insufficient and excessive times linked to a higher burden of non-motor symptoms. With regard to actual sleep duration, 6-7 hours per day was found to be optimal.

Various non-motor symptoms were shown to influence the relationship between sleep, life quality and Park-

inson's severity, with the strongest relationships observed for anxiety, depression, and overall non-motor symptom burden.

The team noted that both nerve cell changes in the brain and Parkinson's symptoms themselves might contribute to sleep changes for Parkinson's patients, adding that it may be "more difficult, but important, for them to obtain sufficient sleep."

Overall, the findings provide "new insights for clinical practice to intervene in [Parkinson's] deterioration with sleep disorders," the researchers wrote, adding that the data also "highlight the importance of increasing the awareness of sleep problems in patients with [Parkinson's]."

"The treatment of sleep problems will likely improve [non-motor symptoms] but also postpone [Parkinson's] progression. It can potentially reduce the overall disability and thereby improve the lives of patients and their caregivers," the team concluded.

Future longitudinal studies will be needed to further support the relationship between sleep disturbances and Parkinson's symptoms, the researchers noted.

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**PARKINSON'S PERSPECTIVE**

**SEPTEMBER 2022**

# Coming Events

**See Inside for More Information**

*(Current location for all meetings listed below is the First United Methodist Church with the exception of the annual August Picnic)*

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

Moderators: Steve Locke–Parkinsonians; Jill Reid & Julie Pfarrer–Caregivers

**October 8<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Parkinson's Update, Questions & Answers;

**Speaker:** Dr. Brian Grabert MD

**November 12<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Breakout Sessions

Moderators: Steve Locke – Parkinsonians; Jill Reid & Julie Pfarrer – Caregivers

**December 10<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Christmas Party!!!!

**January 14<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Deep Brain Stimulation; **Speaker:** Dr. Amit Ayer MD - Neurosurgeon

**February 11<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Breakout Sessions

Moderators: Steve Locke – Parkinsonians; Jill Reid & Julie Pfarrer – Caregivers

**March 11<sup>th</sup>** - Reg Mtg - 10 am; **Program:** Parkinson's 101; **Speaker:** Jill Reid, Educational Outreach

**More useful websites:** <https://parkinsonsnewstoday.com>; [www.parkinsonrockies.org](http://www.parkinsonrockies.org); [www.parkinson.org](http://www.parkinson.org); [www.nwpcf.org](http://www.nwpcf.org); [michaeljfoxfoundation.org](http://michaeljfoxfoundation.org); [www.parkinsonheartland.org](http://www.parkinsonheartland.org); <https://www.pdself.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>; <http://caremap.parkinson.org>; [www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons](http://www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons); [https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo\\_C](https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C); [pmdalliance.org](http://pmdalliance.org); <https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers>