



FEBRUARY 2023

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
(with exceptions to be noted
in this newsletter).

February Meeting: Saturday, February 11th – 10:00 am – 1:30 pm

We will NOT be Zooming or recording this meeting

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

9:30am – Come early for a group sing-along with music therapist, Heather Johnson.
See more about Heather's business under 'Other Opportunities' later in this newsletter.

9:45am – Everyone else come a few minutes early to check in, greet other members and ask questions.

First time visitors: Be sure to sign in, get a name tag and proceed to the visitors' table for some special attention and information.

Knowledge is power and enables us all to live well, so plan to attend the meetings at First United Methodist Church.



Program: Break-out Sessions

Moderator for Parkinsonians: Steve Locke

Moderators for Caregivers: Dave Moross

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

The program will be followed by a potluck.

The February Potluck main dish – A Brunch Theme

Pancakes will be provided.

Suggested side dishes to bring: Egg dishes, Hashbrowns, Breakfast Meats

If you would like to sign up to be a provider of a side dish for the February meeting, you can sign up through our website or you can contact Bill Hicks at [REDACTED] or potluck@co-parkinson.org, no later than Wed. Feb 8th 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!

December 10th, 2022

The Annual
Christmas Party
was enjoyed by all!

(see more pictures
on page 6)



The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



IMPORTANT: in January, we started a monthly fundraising campaign for the Colorado Parkinson Foundation (CPF), our parent 501c3 charity. It's a very easy fundraiser, **BUT WE NEED YOU TO HELP. HOW?** you might ask. **Really, really simple:** go each month to the specific restaurant on the day we tell you, show the coupon or flyer that we

will provide you, and buy lunch or dinner! The restaurant will donate to CPF an agreed-upon percentage of your total ticket. In our newsletters and during the monthly meetings, we will continue to announce the participating restaurants and the dates they will honor our coupons/flyers. Give the coupons/flyers to as many people as possible so we'll maximize the fundraising or ask them to mention the Parkinson's fundraiser when they order their food. February's restaurant is Parry's Pizzeria and Tap-house at 5697 Barnes Rd, #130, Colorado Springs, 80917. Go there on Wednesday, February 15, between 3 pm and 8 pm; show the cashier the flyer in this newsletter or just tell them you're there for the Parkinson's fundraiser. Parry's will donate 20% of your bill to CPF. Can't get any easier than that, and you will be doing your part to help the support group.

Sadly, one of our easiest fundraising programs-- participation in Amazon Smile--is shutting down as of February 20, 2023. But we welcome any ideas you may have of another EASY (that's the operative word!) fundraiser that we could do regularly without burn-out.

The butterfly that the Colorado Parkinson Foundation won at the Rotary Club auction will be installed, unveiled, and presented as a gift to the City of Colorado Springs on behalf of all people with Parkinson's Disease at a Parkinson's Awareness Month ceremony at Nancy Lewis Park on March 6, 2023, at 1:30 pm. The public (especially our members!) is welcome! The butterfly will rotate to other locations every two years.



Lastly, in keeping with my campaign to get you to laugh as much as possible, I'm recommending a funny movie for you to watch. For February, in honor of winter, you should watch *Snow Dogs*, starring Cuba Gooding, Jr. Be prepared to laugh out loud and have tears streaming down your face

**Thank
You!**

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

Tom Andrew
Carol Arthur
Jan Atha
Patricia Beatty
Elaine Ceagne

Jane Cole
Jerry Donley
Kathleen Foster
Ron Geist
Laura Hallas

February Executive Committee Meeting

Feb 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 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.

March Newsletter Input Deadline: Feb 17th

Call or e-mail Julie at:

db_mgr@co-parkinson.org



Deborah Herrman
Gene Ireland
Ann Jaeger
Amy Kennedy
Linda Koloski

Dale Kraiss
Cindy Page
Ann Ringler
Tom Small
Timothy Stuehmeyer

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, or sending an email to kmathews@ppacg.org, or by calling 719-886-7526. Registration opens on Monday, February 20th and closes on Monday, March 20th. The event is limited to 100 registered caregivers.

January 14th, 2023: Program Review

| by Heather Johnson

PARKINSON'S 101 - Presented by: Jill Reed, Educational Outreach

Each of you is at a different part of your Parkinson's journey each year; one purpose of this information is to update your knowledge as your disease progresses.

New things in PD

- DAT scan – diagnoses for PD now available
- Duopa: also called Duo-dopa. New medication delivery system, however has problems – don't recommend quite yet
- Sleep Deep Brain Stimulus surgery – more accurate, much shorter and while sleeping
- Free "Aware in Care" hospital kits available from Parkinson Foundation – go to www.parkinson.org

Deep Brain Stimulation surgery

- Truly improves quality of life and better health
- Treats slowness, freezing, facial expression, rigidity, tremors, fine and coarse motor skills, flexed elbows and wrists, and stooped posture
- Does not treat balance
- Usually only after 4 years after diagnoses

Other helpful tech

- Voice recognition software
- Tremor-compensating eating utensils
- iPhone – movement-compensating camera
- Lane assist cars
- Duopa medication delivery system
- Theracycle forced exercise
- Plate rings to help with eating
- Hot straws – allows you to keep lids on hot liquids
- Nosey cups to reduce choking
- Squatty Potty for constipation

Intro to Parkinson's

- Neurological disorder that progresses very slowly
- Caused by your brain's loss of and no longer producing dopamine
- Effects each person differently
- Dr. Grabert likens treating PD like diabetes – including self-medicating
- Pill management is KEY to maximize quality of life and longevity

Dr. Nirenberg's Presentation

- Lack of facial expression and staring common early symptom
- You don't have to have tremors to have PD
- Misconception - PD only effects movement; non-motor symptoms often overlooked
- Can have pain or tingling, sleep troubles – sometimes acts out dreams, cognitive difficulties – hard to multitask (i.e. having a conversation while eating), constipation, lightheaded when standing up, mood changes – severe anxiety or panic attacks, depression or apathy, and fatigue
- People can be biased to what they see, however important to address the hidden symptoms described above
- Most non-motor symptoms are treatable
- Misconception – if you look great then you're doing great. PD has phases described as "on" and "off"
- Tell your doctor if you are on or off at your appointment, dosage routine information and if it's working or not – keep a diary of med routine to share
- Myth – patients should wait until their med are worn off to take more. This makes the

meds less effective. Take meds to stay "on" so you don't crash and have to go back up. Timer is recommended

- More movements may mean you are over medicated, not need more. **Tremor = symptom Dyskinesia = side effect**
- Important to note NOT everything is caused by PD, important to address cause if not PD related. Parkinson's is very slow. If you're having pain or symptoms that are sudden, it is not PD. (i.e. sudden back pain)
- Myth – medications stop working after 5 years. This is not true.
- Myth – PD is predictable. Everybody's PD experience is different.
- Exercise makes tremendous improvement in quality of life
- All walkers are not equally beneficial with PD – walkers with regular brakes that operate by squeezing the handles to activate the brakes are dangerous. Walkers with reverse brakes that you have to squeeze in order for the walker to move are the only safe walkers for people with PD.

Additional PD facts:

- Primary med – carbidopa-levodopa = carblevo = Sinemet
- Need to be treated by a neurologist, PA, or NP who specializes in Parkinson's
 - In Colorado Springs – Beth Harmon, PA, Dr. Adams, Dr. Komatinieni, NP Michelle McClendon, and Dr. Andrea Manhart at UCHealth
- Intervals between taking PD meds is more important than set scheduled times

FIVE STAGES

Stage 1

- Most newly diagnosed PD in stage 1
- May or may not be prescribed carblevo
- Don't have ons and offs yet
- Symptoms are only on one side of the body
- Possibly will see some or all of these
 - greatly reduced eye blinks
 - Tired arm or leg muscle
 - One arm that doesn't swing
 - Stiffness
 - Difficulty getting out of a chair
 - Slight stopping
 - Tremors
 - Reduced fine motor skills (notice when writing)
 - Slightly dragging foot
 - Orthostatic hypotension

Stage 2

- Now symptoms on both sides of the body and worse
- Possible additional symptoms
 - Shorter gait
 - Balance problems with occasional falls
 - Chocking
 - Difficulty pivoting
 - Reduced motor skills
 - Cognitive issues
- Good medication management becomes critical!
 - One big on period that lasts all day
 - No off periods
 - Take your next dose before the previous

dose wears off

- One trick that may help is take a nap if dose is taken too late; may reset effectiveness
- Time between pills is more important than scheduled times (take meds every X hours, not the same scheduled times every day). If your provider is making you them at scheduled times, find a new provider
- You can adjust meds on your own and let doctor know with a log

Stage 3

- Can be avoided!!
- Symptoms are worse
- Likely new ones
 - Shuffling
 - Festination
 - Slower and stiffer
 - Less stable
 - Falls more frequent
 - May be difficult to pivot without help
 - May need a walker
 - Freezing may start – psychological symptom
 - Change the cognitive mindset – tell yourself or PWP to pick up knees not feet, step up like climbing stairs, step backwards, step over a log, point a light, marching music. Anything to get your brain off that walking attempt
 - Never pull or push a PWP who is freezing!

Stage 4

- Can definitely be avoided!!
- Can't walk without a walker
- Pivoting extremely difficult
- Freezing a lot
- Can't get out of chairs without help
- Lots of falls
- Lots of choking

Stage 5

- CAN BE AVOIDED!!
- Need a wheelchair
- Bed-ridden
- Feeding tube for food, fluids, and meds

Protein VS. Carblevo

- Compete for absorption and uptake into brain – protein wins every time
- Avoid protein within one hour of carblevo OR take extra carblevo
- Protein can be used when too much has been taken to "kill off" the extra

Carblevo causes nausea, that's why it's accompanied by carbidopa, an anti-nausea drug

Constipation is very common – Miralax works really well and not addictive

Choking and swallowing issues are all fixable – therapies and "use it or lose it"

- Swallow hard and forcefully
- Tuck chin when swallowing
- Add thickening fluids
- Suck on ice cubes
- Take pills with sparkling water
- Or grind up pills and put in apple sauce, honey, or jam (non-protein!)

For vision problems – Neuro-ophthalmologists and optometrists will help!

Continued on page 7...

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 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

or Syble Krafft at

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 and click on "Dance for Parkinson's" under the "Outreach" tab to get the Zoom link.

Questions: Contact Laura at 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 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

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

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

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

Falcon Exercise Group

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

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

New!

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.*

Question #1: Is forgetting who a loved one is part of Parkinson's dementia? I've heard that PD dementia includes hallucinations and forgetting words, but not forgetting people.

Answer: This question relates to the whole issue of dementia in Idiopathic Parkinson's Disease [IPD] and distinguishing dementia in Parkinson's Disease (PDD) from what is called "DEMENTIA with LEWY BODIES" [DLB]. First of all, remember the definition of dementia is: Progressive cognitive decline of sufficient magnitude to interfere with normal social or occupational function. Dementia is an "umbrella" term. Alzheimer's is the most common in the general population but PDD and DLB are the two most common diagnoses in those with signs of Parkinsonism. Cognitive decline is assessed in what is called domains. There are 5 common domains of cognition:

- Memory
- Executive Functioning
- Language
- Attention / Processing Speed
- Visual Spatial abilities.

For a diagnosis of dementia, usually there needs to be impairment in 2 or more domains. Episodic Memory recall is not always the first domain affected but usually becomes impaired eventually in all dementias. Forgetting the name of a casual friend or acquaintance is common in the geriatric age group [over 65] but forgetting the name of a "loved one" would suggest possible dementia. Individuals with Idiopathic Parkinson's Disease are at about 3X more likely to develop dementia than age matched controls without IPD. [It varies from study to study anywhere from 2X to 6X].

DLB is probably a distinct clinical disorder that requires first a diagnosis of dementia then requires 2 of 3 other criteria:

1. Fluctuations in cognition with pronounced variation in attention and alertness.
2. Well-formed visual hallucinations
3. Signs of Parkinson's Disease.

The diagnosis of dementia is operationally required to occur simultaneously with the diagnosis of PD or within the first year after a Parkinson's Disease diagnosis.

Two easily administered screening tests to assess cognition are the Montreal Cognitive Assessment test [MOCA] and the newer Saint Louis University Mental Status test [SLUMS]. These are superior to the Mini Mental Status Exam [MMSE] and take only 10 minutes to complete. The total best score on both the MOCA and SKUMS is 30. In my experience if you score in the normal range [27–30] you likely do NOT have dementia. If you score 19–26 you may need further testing and if your score is 18 or less you probably DO have dementia. These can be administered by any health care professional trained in their use.

Question #2: I've been experiencing a lot of unusual skin problems that my dermatologist said was folliculitis. Have you

heard of skin conditions being connected to Parkinson's?

Answer: Disorders of the skin are common in Parkinson's Disease. The most common is seborrheic dermatitis [SD]. It is manifested as red scaly patches and plaques, most often seen on the face but can occur on many body surfaces especially those with higher concentrations of sebaceous glands [sweat glands]. Folliculitis is an inflammation of the hair follicles and should be able to be distinguished from SD. The member may want to ask his/her dermatologist if what they are calling folliculitis is really SD?

A very good review on The Skin & Parkinson's Disease is available with free access in the journal called:

MOVEMENT DISORDERS:CLINICAL PRACTICE;
January 2017, page 21. by M. Skorvanek.

It should also be remembered that the most serious skin disorder, melanomas, are increased in patients with PD.

A 2011 meta-analysis found the risk of developing a melanoma was 3.6 X more common in PD individuals.

Question #3: Would testosterone therapy help overcome apathy in people with Parkinson's?

Answer: Treating low testosterone does not improve mood, cognition, apathy, sexual function or much of anything except an increase in muscle mass.

Question #4: In order for aerobic exercise to slow down PD progression, what should my target heart rate be and how long do I need to maintain that heart rate?

Answer: Let's start with "National Recommendation" for exercise for anyone over 65 years. The US Department of Health and Human Services, Office of Disease Prevention and Health Promotion, and the World Health Organization recommend that individuals older than 65 years of age should do "at least 150 min of moderate intensity aerobic physical activity throughout the week or at least 75 min of vigorous-intensity aerobic physical activity throughout the week or an equivalent combination of moderate and vigorous intensity activity (WHO, n.d.)." Moderate intensity exercises include brisk walking at 2.5 miles per hour, cycling less than 10 miles per hour, and playing doubles tennis. Vigorous intensity activity consists of running, swimming laps, hiking uphill, and cycling greater than 10 miles per hour (American Heart Association, n.d.). This intensity of exercise is similar or identical to what has been studied in individuals with Parkinson's Disease. In virtually every study those who exercised had better motor scores, better Quality of life scores, better cognitive scores, less anxiety and less depression. This recommendation gives one the types of moderate and vigorous intensity exercises and the accumulative weekly time needed to exercise. I suggest breaking the total time into more serial daily exercise times [e.g. 30 min. 5days/week; 40 min. 4 days a week, 50 minutes 3 days a week]. For those who want a "target heart rate goal", aim for 70% of maximum heart rate [HR] for moderate intensity exercise. Maximum heart rate is calculated as 220 minus your age. If you have a Garmin watch or Apple watch you can easily track your average HR and maximum HR. So let's get moving. Two of my favorite quotes from Tom Petty are "Never slow down, never grow old" and "If you don't run, you rust".

Helpful Swallowing Exercises

The leading cause of death in people with Parkinson's is aspiration pneumonia. THIS CAN BE PREVENTED!!! As we all know, Parkinson's affects the muscles including the throat/swallowing muscles. With weakened throat/swallowing muscles, it becomes difficult to control the pathway of food and drink when swallowing. Rather than going into the esophagus, it can easily go into the airway instead which can cause aspiration pneumonia. The following are swallowing exercises that have been proven to help strengthen those muscles.

1. **Resistive Tongue Exercise (RTE)** - improves tongue strength and control of food and drink.
 - Push tongue hard against roof of mouth
 - Push tongue hard against each cheek
 - Push tongue hard against a tongue depressor or spoon
 - Hold for 5 seconds
 - 3-5 times twice a day*
2. **Jaw Open**
 - Open mouth as wide as possible
 - Move jaw back and forth and close
 - 5 times, twice a day*
3. **Yawning** – helps upward movement of the larynx (voice box) and the opening of the esophagus
 - Open jaw as far as you can and hold for 10 seconds
 - Rest for 10 seconds
 - 5 times, twice a day*
4. **Masako (tongue hold)** – helps strengthen tongue muscles needed for swallowing
 - Gently "bite" tongue tip between front teeth (3/4" outside of mouth) – you should feel it pull forward in your mouth
 - Swallow hard and imagine the back of your throat working hard to reach your tongue
 - If that's too difficult, push tongue firmly against the roof of your mouth while swallowing
 - *Only saliva swallows*
 - 5 times, twice a day*
5. **Effortful Swallow** – improves movement of the tongue base and pharynx (throat)
 - As you swallow, imagine you have a golf ball stuck in your throat
 - Squeeze as hard as you can with your throat muscles
 - 5 times, twice a day*
6. **Chin Tuck Against Resistance (CTAR)**
 - A. Sit with your back straight and forcefully hold rolled up towel under your chin and hold for 60 seconds
Twice a day
 - B. Sit with your back straight and position the towel under your chin and forcefully bring chin down on towel and then lift your head
20 times, twice a day
7. **Epiglottic Control** – improves airway protection when you swallow
 - Open your mouth wide
 - Exhale the air from the lungs through the nose but do not allow any air to escape from your mouth. Your airway should remain closed. You will be exhaling against a closed throat so air cannot escape
 - 5 times, twice a day*
8. **Mendelsohn Maneuver** – promotes movement of the epiglottis. Improves the function of the larynx and strength of the esophageal opening
 - When swallowing, hold larynx in a raised position (at highest point) by squeezing your throat and tongue muscles (half way through the swallow) for 1 to 2 seconds
 - Then finish the swallow
 - 10 times, twice a day*
9. **Hyoid Lift Maneuver** – builds swallowing muscle strength and control
 - Place multiple small pieces of paper on a towel in front of you
 - Next, place a straw in your mouth and suck on the straw, allowing the paper to get picked up by the tip of the straw
 - Keep sucking on the straw as you carry the straw over to a cup, and stop sucking to release the paper into the cup
 - You should aim to successfully place all of the pieces of paper into the cup
 - Start out with just 3 to 5 pieces of paper and slowly increase to around 10*

December 10th, 2022



Christmas Party
photos continued
from cover

(...continued from page 3) Jan 14, 2023: Program Review—PARKINSON'S 101

Walkers – U-Step II or Upright walkers (Medicare and insurance will pay for U-Step II)

- U-Step II can come with a laser or metronome type device to help with freezing

Hospitals

- Are hazardous for PWP – there's a list of safe hospitals in the area on CPF website
- Must have a strong advocate during hospital stays
- Recommend giving a Medical Durable Power of Attorney to someone you trust so they can protect you – do not have a living will because it trumps medical durable power of attorney and puts life-and-death decisions into the hands of two doctors who don't know you
- DO NOT SIGN the form that consents to "observation only" in the situation of a 2nd visit for issues not resolved during a first visit, or you'll get billed for the second visit. They sometimes will leave you in the waiting room to avoid penalties of a 2nd visit
- Take your medicine with you to ensure meds are taken on time

Humor helps PWP! Exercise, socialization, and participating in life-long interests helps as well.

Exercise can slow down the progression – and sometimes reverse symptoms! (150 minutes per week of increased heart rate) Do your best to fight the apathy!

Exercises you can do

- Walking 2 ½ miles per hour
- Hiking
- Stationary bike
- Water aerobics
- Ping pong
- Moving to music
- Rowing machines
- Chair exercises
- Boxing
- PWR! Moves (YMCA have classes)
- Wii sports
- Stretching
- Tai Chi

Therapies that help

- Touch therapy
- Physical therapy
- Occupational therapy
- Speech therapy
- Music therapy

Other helpful hints

- Socialize
- In-home safety is key
- Find creative solutions
- Don't coddle
- Try not to rush
- Involve people with PD – cooking, playing card games, family outings. For parties, minimize thin liquids and difficult foods (offer finger foods)
- Go to support group meetings

Colorado Springs Parkinson's Support Group

- All-volunteer group striving to improve quality of life by offering knowledge and information, socializing, emotional support, and training care givers.
- Provides reimbursement for transportation to this support group events if needed
- Meets second Saturday of every month First United Methodist Church at 10 am – singing groups starts at 9:30 am
- Meetings include guest speakers and potlucks
- Informative monthly newsletter
- Every August meeting is an outdoor picnic
- Encourage family and loved ones to come!

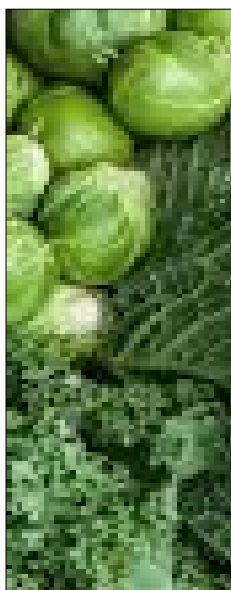
Helpful websites – links on the foundation website

- Davisphinnneyfoundation.org
- Michaeljfox.org
- pubmed
- Dr. Nirenberg's complete talk (currently private on YouTube, however check periodically)

Recipe of the Month: Kale and Brussels Sprouts Salad

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.

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



Ingredients

- | | |
|---|---|
| 3 C Brussels sprouts | 1/2 C olive oil |
| 1 large bunch Tuscan kale, center stems discarded | 1/2 C toasted pine nuts |
| 1 small clove of garlic | 2 Tbl Dijon mustard |
| 1 small shallot | 1 small lemon, zested & juiced or 3 Tbl lemon juice |
| 1 C finely grated pecorino | Salt and Pepper |

In a food processor fitted with a slicing blade, shred the Brussels sprouts and then the kale. Add the garlic and shallot and shred. Set aside.

In a large bowl, whisk together the pecorino, olive oil, pine nuts, mustard, lemon zest and juice and salt and pepper to taste.

Add the shredded veggies and toss well to combine. Let the salad sit for 10 minutes before serving to allow the dressing to permeate the greens.

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



Another 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.

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

PARKINSON'S PERSPECTIVE

FEBRUARY 2023

Coming Events

See inside for more information

February 11th - Reg Mtg at 10 am; Program: Breakout Sessions
Moderators: Steve Locke – Parkinsonians; Dave Moross – Caregivers

March 11th - Reg Mtg at 10 am; Program: TBD

April 8th - Reg Mtg at 10 am; Program: TBD

May 13th - Reg Mtg at 10 am; Program: TBD

June 10th - Reg Mtg at 10 am; Program: TBD

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

August 5th - Program: Picnic at John Venezia Park!!!!!!

More useful websites:

<https://parkinsonsnewstoday.com>; www.parkinsonrockies.org; www.parkinson.org; www.nwpcf.org; michaeljfoxfoundation.org;
<http://caremap.parkinson.org>; <https://www.brainhq.com/world-class-science/published-research/active-study>;
www.davisphinneyfoundation.org/living-pd/webinar/videos/cognitive-nonmotor-symptoms-parkinsons; www.parkinsonheartland.org;
<https://www.pdself.org>; https://www.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C; pmdalliance.org;