

2021



Parkinson's Perspective

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

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

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Pat Dashosh, John Farley,
Carole Henrichsen,
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Committee Chairmen

Programs: Jill Reid

Educational Outreach: Jill Reid

Membership: Carole Henrichsen

Chaplain: Rusty Merrill

Parkinson's Awareness Day:

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Photographer: Vacant

Lending Locker Coordinator:

Rich Sauvain [redacted]

Main Dish Coordinator:

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Picnic: Carole Henrichsen

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Pat Dashosh

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AGAIN, DON'T FORGET ABOUT OUR NEW MEETING LOCATION!

Parking at First United Methodist Church is on the north end of the building - a smaller parking lot with handicapped spots next to the building and a larger one across St. Vrain Avenue. Enter the door facing the parking lots, continue to the end of the main hallway and turn right. Elevators are on the right and stairs are at the end of that hallway. After exiting the elevators jog a bit to the right and go straight down the hallway in front of you. If you take the stairs follow the hallway at the bottom of the stairs and take the first right. Part way down that hallway you'll see a sign that points to Fellowship Hall on the left. We will try to have signs in strategic places so you don't get lost. Give yourself a little extra time because it's a longer walk than getting to the meeting room at 1st Pres or Academy Christian.

Next Meeting: Saturday, November 13th — 10:00 am - 1:30 pm

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

9:45 am – 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 to live well with Parkinson's, so plan to attend the meeting at First United Methodist Church or join us on Zoom.

The program will be followed by a potluck lunch.

Speaker: Travis Chastain, Neuro-Musclar Rehabilitation & Movement Topic: The Alexander Method & Parkinson's



About the Speaker: Travis Chastain began his study of the Alexander Technique while pursuing his Masters in Music degree in classical guitar performance from the University of Denver.

He sought out the Alexander Technique as a last-ditch effort to solve back-pain issues which threatened to end his performance career. Using the Alexander Technique, he was able to heal himself from his back injury and became inspired to teach the Alexander Technique to others who also feel left behind by traditional therapies.

Travis Chastain was certified in the Alexander Technique in 2018, and has made it his mission to promote the technique's therapeutic benefits and the growing medical literature on back and neck pain relief, Parkinson's disease, Postural modification and many others.

He has worked with and successfully helped students manage their Parkinson's symptoms, eliminate chronic back pain, neck pain, joint pain, knee arthritis, chronic voice loss, anxiety, and manage Ehlers-Danlos symptoms and has collaborated with Physical therapists, Chiropractors, mental health specialists, artists, performers, business men and women on the practical importance of the Alexander Technique for enhancing one's quality of life.

The November Potluck – Thanksgiving Dinner!

CPF will be providing the main dish of turkey and gravy for November's lunch.

We are asking members to bring appropriate side dishes or desserts to compliment the main dish.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

Members-at-Large Needed!!

The Colorado Parkinson's Support Group Executive Committee really needs your ideas and inputs; they are absolutely vital to the continued success of the support group. Sadly, only two of the 11 members-at-large have attended the monthly Executive Committee meetings in recent months. Can you commit to attending at least half the meetings for the next year? We can't operate well without you! See the information on page 4 of this newsletter for the date and time of the next Executive Committee meeting. Thanks!



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).

The President's Corner

| Jill Reid - Acting President, CPF & CSPSG



The ability to communicate through words is one of the things that separate human beings from the rest of the animal world. And when you think about it, each and every language in existence today is amazing in its own right.

At the ripe old age of 13, I learned some important lessons in the necessity of using a common language in order for two people to communicate fully. Dad had retired from the Air Force late that spring; and, realizing that 30-day vacations were a thing of the past, we went back East for one last visit with the many relatives who lived well east of the Mississippi River. But our plans to return to Sacramento after the vacation were turned upside down when Dad was offered a job in Kingsport, Tennessee, a job that was too good for a 45-year old man with three school-age kids to pass up. Dad accepted the job, and we started down the road of learning a new language, the version of English spoken in East Tennessee. The misunderstandings that ensued during those first several months, as we struggled to understand what the East Tennesseans were saying, were amusing, to say the least.

Early on, while shopping in a local grocery store, Mom couldn't find seed for our pet parakeet. So she

asked the cashier where bird seed could be found. The woman responded, "Wald bard sayed?" That response made absolutely no sense to Mom, who tried again by asking the cashier to repeat it. "Wald bard sayed?" Still no go. In the meantime, Dad had deciphered that she was asking Mom if she was looking for wild bird seed. Doubled over in laughter, he ducked down behind the nearest set of shelves so he wouldn't embarrass the poor woman—now, whether that "poor woman" was Mom or the cashier, I can't say. In any case, Mom never did understand her and gave up the effort. When he could stop laughing, Dad translated what the cashier had said. We must've eventually found the "bard sayed" section, because Perry the parakeet had dinner that night.

Later, we went property hunting and got lost in the back roads. Dad stopped to ask directions, having apparently not learned the "wald bard sayed" lesson. The gentleman pointed in the direction we were headed and said, "It's down thar somers." Very brightly, Dad responded, "Oh, you mean Sommer-ville?" The rest of us in the car had translated the gentleman's words correctly to be "It's down there somewhere," but Dad missed it completely.

In the middle of that first school year, we rented a house out in the county, and Julie and I transferred from city schools, where the accents were tough enough, to a county school with a whole other level of heavy accents. On my very first day, I found my-

self in a class called Civics (I had never heard of such a subject), and the teacher chose that day to give an oral pop quiz. I was doing OK until he asked, "What are the three pairs of the govment?" I got that "govment" meant government, but I was totally stumped by the "three pairs" part of the question. I managed to come up with the House of Representatives and the Senate as well as the President and Vice President. But for the life of me, I couldn't think of a third pair. Needless to say, I didn't get 100% on that quiz because what he was actually saying was, "What are the three powers of the government?"

Like East Tennessee and other parts of the country (Boston comes to mind), Parkinson's has its own language, and, to add to the confusion, some of the words are ones we've used all our lives but have different meanings. We have to learn the Parkinson's language if we are to manage the disease successfully. "Sinemet," "carbidopa/levodopa," "carb/levo," "dyskinesia," "dystonia," "freezing," "activities of daily living," "UPDRS," "on/off," "substantia nigra," and my personal favorite, "festination"—when we say these words to anyone outside the Parkinson's world, they have no clue what we're talking about. In a way, it makes us special—we get to speak in code that others don't understand. But if we aren't in on the code, we're equally lost. So if during our meetings or in our newsletter, we use words that you don't understand, stop us and ask. We're all happy to translate!

Recipe of the Month: Keto Almond Cake

Our low carb/good fat ketogenic study that was completed this 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 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 2 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:

- 1/3 C sliced almonds
- 10 Tbl softened butter, divided
- 3/4 C plus 3 Tbl powdered erythritol-based sweetener, divided
- 5 large eggs, room temperature
- 2 C fine almond flour
- 1 tsp almond extract
- 1 tsp vanilla extract

Preheat oven to 350 degrees. Grease 9" cake pan with a thin layer of butter, then layer on a circle of parchment paper to just cover the bottom of the pan, then grease the paper. Set aside.

Scatter the almond in a single layer on a rimmed baking sheet. Toast until golden, tossing once during cooking, 4 to 6 minutes. Let cool.

In the bowl of a stand mixer fitted with the paddle attachment (or a large bowl, and using an electric hand mixer), combine 8 tablespoons of the butter and 1 1/4 C of the sweetener. Beat on medium speed, scraping down the sides of the bowl as necessary, until the mixture is pale yellow, light and

fluffy, 1 to 2 minutes. Beat in the eggs one at a time until incorporated into a curdled-looking thin batter.

In a medium bowl, whisk together the almond flour, baking powder and 1/2 tsp salt.

With the mixer at medium speed, add the flour mixture a little at a time to the egg mixture until combined. Mix in the almond and vanilla extract.

Pour the batter into the prepared cake pan. Bake, rotating once during cooking, until the top is deep golden and springs back when lightly touched and a toothpick inserted into the center comes out clean, about 45 minutes.

Let cool on a wire rack for 15 minutes. Slide a small knife around the edges to release and invert the cake and place it on a wire rack set over a baking sheet to cool completely.

Melt the remaining 2 Tbl of butter in a small saucepan over medium heat. Whisk in the remaining 2 Tbl of the sweetener and a few tsp of water. Add the toasted almonds, toss to combine, and quickly pour over the top of the cake, using a small spatula or fork to evenly distribute.

Sprinkle with the remaining 1 Tbl sweetener and serve.

Antioxidant Agent May Prevent Chronic Kidney Disease and Parkinson's Disease

By Osaka University - Medical Press

Oxidative stress is the result of reactive oxygen species (ROS) generations, and can be damaging to cells and tissues. In a new study, researchers from Osaka University developed a novel dietary silicon (Si)-based antioxidant agent that suppressed the development and progression of kidney failure and Parkinson's disease in rodents.

ROS are generated as a result of metabolism and the immune response, but also during certain disease processes, contributing to continued tissue damage. Chronic kidney disease and Parkinson's disease are among those diseases that have been shown to result from oxidative stress. Although ROS encompass several different molecules, not all ROS are alike. While Hydroxyl (OH) radicals are highly damaging to tissues through their effect on cells and DNA, others, like hydrogen peroxide and superoxide anions, are important components of the normal immune response.

"Eliminating only hydroxyl radicals is important to avoid disrupting normal physiological process." Says lead author of the study Yuki Kobayashi. "Previous attempts to do so, like taking the hydrogen-rich water or breathing in hydrogen-containing air, have shown limited results. We wanted to develop a new dietary agent that efficiently enables the elimination of damaging hydroxyl radicals."

To achieve their goal, the research-

ers produced a novel Si-based agent from Si powder. Because the agent is taken by mouth, the researchers first evaluated the efficacy of the agent in an environment similar to that in bowels, that is, a pH of 8.3 and at 36 degrees C. 1g of the new agent was able to generate 400 ml of hydrogen-rich water. The new agent thus enabled the continuous production of thigh amounts of an OH-eliminating molecule.

But was I sufficient to protect tissues from being damaged by ROA? To address this question, the researchers turned to animal models of chronic kidney disease and Parkinson's disease. When they fed rats who had 5/6 of their kidneys removed with Si-based agent, kidney function was preserved and tissue levels of oxidative stress as well as inflammation was significantly lowered, as compared with those of control animal. Similarly, when they fed animals with Parkinson's disease with the Si-based agent, degeneration of neurons responsible for the disease was significantly attenuate.

"These are striking results that show that our Si-based agent is effective in preventing the progression of chronic kidney disease and Parkinson's disease in well-established animal models." Says corresponding author Shoichi Shimada. "Our findings could provide new insights into the clinical management of patients with these diseases, for which currently no curative approach exists."

(October 9, 2021: Program Review)

| Linda Christian, Secretary

Your Questions Answered by a Parkinson's Expert - Presented by – Dr. Brian Grabert, MD

Dr. Grabert began his presentation by stating that he would first begin with a presentation of the 2020 Updated American Academy of Neurology Parkinson's Disease Measurement Set released in August 2021. He went on to say that the last update occurred in 2015. Dr. Grabert explained that he likes to discuss Parkinson's Disease as related to the future, present, and the past. He stated that he feels the future for Parkinson's Disease looks good. Currently, movement disorders consist of 70 % Parkinson's, 20% Essential Tremors and 10% Dystonia. His six-month goal is to actively recruit Movement Disorder Specialists for the Colorado Springs area.

Dr. Grabert then explained that there are about one million individuals in the US with Parkinson's Disease and six million worldwide. Parkinson's Disease doubled from 1990 – 2015 and is expected to double again in the next 25 years. He then discussed immunotherapies, stating that there are also 53 trials ongoing for Parkinson's Disease through organizations like the Michael J. Fox Foundation and others with only 3 to 4 of them in phase 3, the final trial phase.

Dr. Grabert shared a story with the audience regarding a friend that was visiting from back east. His friend asked him what he thought about the tremor she had. It was a resting tremor which he told her could be Parkinson's Disease. Dr. Grabert recommended that his friend see a neurologist or movement disorder specialist when she returned home. His friend then asked, "Is this a death sentence?" Dr. Grabert responded to his friend telling her by no means is it a death sentence. He then discussed the results of a European study that if it's Parkinson's and if you do not get dementia, your life expectancy is the same as anyone who does not have Parkinson's Disease. He went on to add that if you do get dementia, your life expectancy may be 1 ½ to 2 years less, which is not bad. Dr. Grabert added that since 1985, life expectancy for individuals with Parkinson's Disease has more than doubled because of medications.

Next, Dr. Grabert provided the following handout of the 2020 Updated AAN Parkinson's Disease Measurement Set to the audience. He added that you should get each of the ten items addressed at your visits with your neurologist during the year, noting that not all assessments would be addressed in one visit. He tries to cover some of the ten items on the table each time he sees his patients during the year. Dr. Grabert discussed the 32-item questionnaire he asks his patients to complete during their appointments with him. This covers some of the items on the table.

Dr. Grabert then began covering each title in the Table on page 6 and as follows:

1. Annual Parkinson's Disease Diagnosis Review:

- Dr. Grabert explained this annual review determines what stage of Parkinson's the patient is in.
- He also explained that the Retropulsion Test (Pull Test) helps to determine what stage you're in. Dr. Grabert asked the audience if they knew how many stages there are in Parkinson's Disease, and most responded, five. He agreed, but added that there may be six.
 - When the patient is pulled backwards, takes 1 to 2 steps, and stops without a fall, that would indicate they are in stage 2. On the other hand, if a patient takes 3 – 5 steps and stops without a fall, he places them at stage 2.5 adding what he considers the sixth stage of Parkinson's Disease.

2. Contraindicated Dopamine-Blocking Medications:

- Dr. Grabert explained that contraindicated dopamine-blocking medications consist of anti-psychotic such as Risperidone and Abilify that Parkinson's patients may be on. He mentioned an A-typical medication Seroquel, which is not a dopamine blocker. An annual medication check is advisable.

3. Assessment of Parkinson's Disease Medication-related Motor Complications:

- Dr. Grabert provided 3 examples of medication-related motor complications such as dyskinesia, involuntary, erratic, writhing movements of the face, arms, legs, or trunk. Dystonic Dyskinesia can occur in younger individuals with Parkinson's disease.
- He then offered the comparison to medication off-times, when your PD medication, like levodopa, wears off throughout the day and tremors, slowness, and other Parkinson's disease symptoms return. The third example is unpredictable on- and off-times.

4. Parkinson's Disease Rehabilitative Therapy Referral:

- Dr. Grabert promotes rehabilitative assessment yearly for Parkinson's patients. These are assessments to evaluate the patients' need for physical, occupational, speech, and recreational therapy. He recommends both LSVT Big and LSVT Loud as therapies beneficial for Parkinson's disease adding there are no other certified programs. Dr. Grabert told the audience that most insurances cover these therapies at least once a year. If your neurologist or movement disorder specialist does not discuss this with you, ask for a referral for these therapies.

5. Exercise or Physical Activity Counseling:

- Dr. Grabert told the audience that exercise is the best medicine for Parkinson's disease, adding that any exercise is good. He also mentioned that the Tango has been shown to be one of the best exercises for Parkinson's. Dr. Grabert recommends 45 minutes three times per week or 30 minutes four times per week of aerobic exercise, whatever fits your schedule. The most important aspect is to get heart rate up high enough to be effective; that is your exercise target heart rate, and that's based on your heart rate reserve. He then discussed how to calculate your heart rate reserve providing an example based on himself.

▪ His maximum heart rate	170
▪ His baseline heart rate	<u>60</u>
▪ His 50% of heart rate reserve	10/2=55
▪ Add 50% HRR to baseline	55+60=115
	<i>his target heart rate</i>

- The following formula is from the Mayo Clinic website in case you would like to calculate your Heart Rate Reserve (HRR) and your target heart rate zone. Example also taken from the Mayo Clinic
 - How to determine your target heart rate zone
 - Use an online calculator to determine your desired target heart rate zone. Or there's a straightforward way to do the math yourself. If you're aiming for a target heart rate in the vigorous range of 70% to 85%, you can use the heart rate reserve (HRR) method to calculate it like this:
 - Subtract your age from 220 to get your maximum heart rate.
 - Calculate your resting heart rate by counting how many times your heart beats per minute when you are at rest, such as first thing in the morning. It's usually somewhere between 60 and 100 beats per minute for the average adult.
 - Calculate your heart rate reserve (HRR) by subtracting your resting heart rate from your maximum heart rate.
 - Multiply your HRR by 0.7 (70%). Add your resting heart rate to this number.
 - Multiply your HRR by 0.85 (85%). Add your resting heart rate to this number.
 - These two numbers are your average target heart rate zone for vigorous exercise intensity when using the HRR to calculate your heart rate. Your heart rate during vigorous exercise should be between these two numbers.
- Example of HRR method:
 - For example, say your age is forty-five and you want to figure out your target heart rate zone for vigorous exercise using the HRR method. Follow these steps:
 - First, subtract 45 from 220 to get 175 — this is your maximum heart rate.
 - Next, check your resting heart rate first thing in the morning. Say it's 80 beats per minute. Calculate your HRR by subtracting 80 from 175. Your HRR is 95.
 - Multiply ninety-five by 0.7 (70%) to get 66.5, then add your resting heart rate of eighty to get 146.5.
 - Now multiply ninety-five by 0.85 (85%) to get 80.75, then add your resting heart rate of 80 to get 160.75.
 - Your target heart rate zone for vigorous exercise is 146.5 to 160.75 beats per minute.

6. Assessment of Mood Disorders and Psychosis:

- Dr. Grabert explained that the GAS15 and the GAD7 questionnaires are used to assess mood disorders. He added that about 50% of Parkinson's patients will have depression, which is treatable. He stated that anxiety is harder to treat but that Yoga is the best thing for anxiety.

7. Assessment of Impulse Control Disorders:

- Dr. Grabert provided examples of the 4 major impulse control disorders:
 - Gambling
 - Hypersexual behaviors
 - Shopping
 - Excessive eating

Continued on Page 6...

Other Local Support Groups: Due to Coronavirus concerns, check ahead to see if canceled

<p>Ladies w/ Parkinson's Support Group</p> <p>The leader of this support group, Carla, is stepping down. The group meets once a month to do various fun activities such as lunch, crafting, baking, etc. If you are a fun-idea person and would like to make sure that this group that has been so valuable to its members continues, please consider volunteering to lead the group. If you're interested please notify Julie Pfarrer at db_mgr@co-parkinson.org or [REDACTED].</p>	<p>Parkinson's Caregivers Support Group</p> <p>Brenda had to be called away for October's meeting because of a family emergency. With the Thanksgiving and Christmas holidays ahead, Brenda thought it best to postpone the caregivers support group meetings until the new year. Hope to see you in January!</p>	<p>Tri-Lakes Parkinson's Support Group</p> <p>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].</p>	<p>Essential Tremor Support Group</p> <p>The essential Tremor Support Group is moving from Monument to Colorado Springs starting October 16th. The meetings will be in the ENT conference room at Pikes Peak Library District, Colorado Springs Library 21c, 1175 Chapel Hills Drive. For questions contact Jim Sanchez at [REDACTED].</p>
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Other Opportunities: Due to Coronavirus concerns, check ahead to see if canceled

<p>LSVT BIG & LOUD at Home</p> <p>At Home Healthcare offers the LSVT BIG & LOUD therapy program for individuals with Parkinson's Disease in the comfort of their homes. Their therapists are LSVT certified and can accommodate patients' home schedules. Medicare covers outpatient therapy at 80% and home health therapy at 100%. If you have questions about this service or would like a referral coordinated through your primary care provider please call their office at: (719) 227-8624.</p>	<p>Creativity Lab</p> <p><i>On sabbatical for the time being.</i></p> <p>With concerns for the health and safety of our participants, we at The Unsteady Hand have suspended all in person programing. We hope to resume around the first of the year.</p> <p>www.TheUnsteadyHand.org Re-Imaging Parkinson's - Mo</p>	<p>Adult Speech Therapy at Home</p> <p><i>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.</i></p> <p>Treating:</p> <table border="0"> <tr> <td><i>Parkinson's: Voice & Swallowing</i></td> <td><i>Swallowing</i></td> </tr> <tr> <td>- SPEAK OUT!</td> <td>- Neuromuscular Electrical Stimulation Therapy</td> </tr> <tr> <td>- LSVT, an evidenced based voice treatment program designed for Parkinson's patients</td> <td>- Respiratory Muscle Strength Training</td> </tr> <tr> <td></td> <td><i>Aphasia following stroke</i></td> </tr> <tr> <td></td> <td><i>Cognitive-Linguistic Deficits</i></td> </tr> </table> <p><i>For more info, contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or by phone at (719) 338-8165.</i></p>	<i>Parkinson's: Voice & Swallowing</i>	<i>Swallowing</i>	- SPEAK OUT!	- Neuromuscular Electrical Stimulation Therapy	- LSVT, an evidenced based voice treatment program designed for Parkinson's patients	- Respiratory Muscle Strength Training		<i>Aphasia following stroke</i>		<i>Cognitive-Linguistic Deficits</i>
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HAPPY ■ HAPPY



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

Steven Boswell	Richard (John) Hero	John Reid
Eric Brewner	Brenda Hicks	Jack Risley
Ron Brown	Harry (Bill) Killa	John Rogers
Fred Carrico	Joan Lydon	Joanne Snelling
Jerry (Smokey) Chism	Donna MacDonald	Karen Wilson
Susan Coddington	Carolyn Mangold	Diane Winkler
Dorothy Filippi	Pat Murphy	Marilyn Wisler
Dick Geist	Jane Nielson	
Doug Gibb	Neal Purdy	

Thank You!

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

November Executive Committee Meeting
November 16th at 12:00 at a place to be determined. (you will be notified by email)

Contact Linda at secretary@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 Linda can contact you if anything changes.

December/January Newsletter Input Deadline: November 19th
Call or e-mail Julie at:
db_mgr@co-parkinson.org.

LENDING LOCKER INVENTORY			
3 wheeled walker	1	Black back brace	1
Arm assist for wheelchairs	1	Canes	5
Arm splint	1	Chair/Sofa Cane	1
Bed Cane	3	Crutches	2
Bedpan	1	Exercise bike	1
Bed rails	1	Hospital bed	2
Bedside toilet	5	Ice man - therapeutic for knee replacement surgery	1
		Knee splint	1
		Lift chair	1
		Lumbar traction belt	1
		Pickup assist	5
		Raised toilet seats	4
		Shower benches/ chairs	9
		Stair Chair Lift System	1
		Stand-up walker	1
		Suction cup hand rail	1
		Tub rail	1
		Transport chairs	4
		U-Step	1
		Voice amplifier	2
		Walkers with wheels and seat	9
		Wheelchairs	6

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

If you would like to borrow any of the equipment listed here, please contact:
Rich Sauvain at 719-337-7911.

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 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.

Max Capacity NeuroFitness

is offering PWR Boot Camp classes, donation based Power Punch Boxing, pole walking classes and individual PD specific fitness training.

NEW LOCATION: 525 E. Fountain Blvd. Suite 150. Park on the S. Royer side of the building.

Boxing: Tues/Thur – 4:00 to 5:00pm and Sat – 9:00am to 10:00am

PWR Boot Camp: Mon/Wed – 3:30pm to 4:30pm

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

YMCA PD Exercise Classes

We utilize exercise as medicine to increase quality of life so that you can get better and stay better.

NOTE: All classes have been suspended except the following:

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

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.

PWR!Moves Class

Skyline Wellness & Aquatics Center is partnering 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.

We are located within Brookdale Skyline at 2365 Patriot Heights 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.

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 East 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].

Coronavirus and Parkinson's Disease

For information on coronavirus and Parkinson's Disease go to: www.parkinson.org/CoronaVirus.

NeuroRehab Project at ORA Water and Movement Classes

Note: We were told that these classes have been discontinued, check ahead to see if canceled.

Improve your mobility in the water:

We offer warm water (92 degrees) pool classes for people with movement disorders. Mondays and Wednesdays from 1:30-2:30. \$10.

Parkinson's Wellness Recovery Exercise Class:

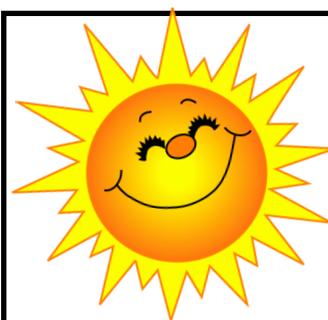
Power Moderate level. Fri at 1:30. \$10

Parkinson's Wellness Recovery Exercise Class:

Power Advanced level. Wed at 1:30. \$10.

Danielle Spivey, PT and Rachel Johnson, SLP have created these opportunities to augment skilled Physical and Speech Therapy.

Location: Pikes Peak Athletics, 602 Elkton Drive in Rockrimmon. Please call us at (719) 559-0680 for information and to get signed up.



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].

Table 1 2020 Updated AAN Parkinson's Disease Measurement Set

QM	Title	Numerator	Denominator	Exclusions
1	Annual Parkinson's Disease Diagnosis Review	Patients who had their diagnosis reviewed annually for the first 5 y after initial diagnosis of PD	All patients with a diagnosis of PD	None
2	Contraindicated Dopamine-Blocking Medications	Patients currently prescribed a contraindicated dopamine-blocking agent	All patients with a diagnosis of PD	Patients taking clozapine or quetiapine or domperidone
3	Assessment of Parkinson's Disease Medication-related Motor Complications	Patients who were assessed for dopaminergic medication-related motor complications once during the measurement period	All patients with a diagnosis of PD on a dopaminergic medication	Patients who are not able to participate in assessment and no knowledgeable informant available
4	Parkinson's Disease Rehabilitative Therapy Referral	Patients who were referred to physical, occupational, speech, or recreational therapy once during the measurement period	All patients with a diagnosis of PD	Patients and/or care partners decline referral Clinician determines patient does not require referral Patients already receiving physical, occupational, speech, or recreational therapy during the measurement period
5	Exercise or Physical Activity Counseling	Patients counseled on an exercise or physical activity regimen once during the measurement period	All patients with a diagnosis of PD	Patients and/or care partners decline counseling Comorbid condition that deems the patient unfit to participate in physical activity Patients who are not able to participate in counseling and no knowledgeable informant available
6	Assessment of Mood Disorders and Psychosis	Patients who were assessed for depression, anxiety, apathy, and psychosis once during the measurement period	All patients with a diagnosis of PD	None
7	Assessment of Impulse Control Disorders	Patients who were assessed for impulse control disorder once during the measurement period	All patients with a diagnosis of PD currently taking medications for PD	None
8	Assessment of Sleep Disturbances	Patients who were assessed for sleep disturbances once in the past 12 mo	All patients with a diagnosis of PD	None
9	Assessment of Cognitive Impairment or Dysfunction	Patients who were assessed for cognitive impairment or dysfunction once in the past 12 mo	All patients with a diagnosis of PD	Patients and/or care partners decline assessment Patients who are not able to participate in assessment and no knowledgeable informant available
10	Assessment of Autonomic Dysfunction	Patients who were assessed for symptoms or signs of autonomic dysfunction once in the past 12 mo	All patients with a diagnosis of PD	None

Abbreviations: AAN = American Academy of Neurology; PD = Parkinson disease.

The above measures were approved by the work group. Providers are encouraged to identify the 1 or 2 measures that would be most meaningful for their patient populations and implement these measures to drive performance improvement in practice.

- He added that one patient lost his home because of gambling while another's marriage ended in divorce because of excessive shopping. Dr. Grabert explained that at baseline, 16% have impulse control disorders and within 5 years the percentage more than doubles.

8. Assessment of Sleep Disturbances:

- Dr. Grabert explained that this assessment should cover the following three sleep disorders:
 - Insomnia
 - Maintaining sleep
 - REM sleep disorder (acting out dreams)

9. Assessment of Cognitive Impairment or Dysfunction:

- Dr. Grabert described the assessment of cognitive impairment or dysfunction utilizing the following four components:
 - Language
 - Attention
 - Memory
 - Working memory
- The example for an assessment is to ask his patient the following questions:
 - What is the day before the day after tomorrow? Or
 - What is the day after the day before yesterday?

- He then told the audience that if a patient is unable to answer these questions in ten seconds, it may not be dementia. You may just have a problem in one of the four areas listed above.

10. Assessment of Autonomic Dysfunction:

- Dr. Grabert provided examples of autonomic dysfunction:
 - Drooling
 - Sweating
 - Urinary frequency

- Sexual dysfunction
- Erectile dysfunction
- Gastrointestinal dysfunction
- Orthostatic hypotension (drop in blood pressure of 20 points or more after standing 1-3 minutes)

- Dr. Grabert explained that 20% of individuals know that they have orthostatic hypotension and 80% do not know that they have it. Not treating this problem has long-term risks; it can double or possibly triple your risk of dementia. This assessment should be performed during visits with your neurologist or movement disorder specialist.

Dr. Grabert explained that of the ten items covered above, Movement Disorder Clinics only completed five of the ten assessments and neurologists who are not movement disorder specialists completed only three of the ten assessments in a given year.

Dr. Grabert went on to explain that when he started his residency in 1985, there were only three drugs for the treatment of Parkinson's Disease. He mentioned two of them, Sinemet and Amantadine, stating that Sinemet is still the gold standard. Dr. Grabert discussed a 14-year study in the UK where individuals who started taking Sinemet when first diagnosed were happier than those individuals that did not start taking Sinemet as their Parkinson's Disease medication until later in the diagnosis.

As of 2021, Dr. Grabert told the audience, there are no drugs that slow the progression of Parkinson's Disease. He told the audience what he likes about Parkinson's disease is that it's very clinical, you can see it unlike, a migraine.

Dr. Grabert then moved to the question-and-answer section of his presentation.

Q & A Session with the Audience

Q: Is Parkinson's one disease or several related diseases and if it's several related diseases, how does that affect clinical trials?

A: *For the most part, it's a single idiopathic disease. A DaTscan can help determine if an individual has Parkinson's disease. Three common symptoms of Parkinson's are tremor, bradykinesia (slowness of movement), and rigidity (stiffness). There are several Pheno types, but the individual still has Parkinson's Disease. In a major study, 15% of patients that participated in the study had normal DaTscans; these patients were diagnosed incorrectly by 2 doctors.*

Yes, it does influence clinical trials. Participants have to get DaTscans to be able to participate in most clinical trials.

Q: The cognitive test you gave us earlier—is it given verbally or written down?

A: *If it's written down, that adds a visual component and changes the test. Verbally is the way the test is generally given. I have written it down for individuals that are deaf or hearing impaired.*

Q: Most Parkinson's patients think they know more than their neurologists about the disease.

A: *If that is so, it's possible that their neurologist is not a Parkinson's specialist. Dr. Grabert shared the following with the audience, I started in Pediatric Neurology; we were discussing ADHD and use of Ritalin as treatment for the disorder and I mentioned to my mentor that I did not know that we were treating ADHD with Ritalin. My mentor replied, "Brian, don't be ignorant, if you knew the literature, you wouldn't make that statement." She was telling me then that you must keep up with the literature so you can support your statements.*

Q: During Dr. Tidman's Keto Diet Study, participants complained of Dystonia. Can you address this?

A: *Did this come out in the study? Did the researchers address this during the study? Dystonia can cause cramping in arms, hands, legs, and feet as well as spasms or twisting and curling. DID Dystonia go away as medication gets to therapeutic level and comes back as you get closer to next dose.*

You could stop the diet and see if it goes away. [CLARIFICATION: some study participants who had dystonia before the study hoped that the diet would ease their symptoms; the diet did not help ease those symptoms.] — The bottom line, I can't answer that.

- Q: Is Botox an effective treatment for Dystonia?
 A: Yes, a good option if medication adjustment does not work.
- Q: What if you take enough Sinemet to control tremors and develop orthostatic hypertension?
 A: Is the quality of your life better without the tremors, if the answer is yes, maintain the Sinemet level to control tremors and treat the orthostatic hypertension. If the answer is no, reduce Sinemet. 64 ounces of fluid a day is recommended for everyone. An extra teaspoon of salt a day can help with orthostatic hypertension if you can do it. Place a teaspoon in a bowl and try to use it throughout the day.
 Dr. Grabert also mentioned an article on the internet that we might find interesting, *Are We Dumbing Down by Standing Up: Orthostatic hypertension, cognition, and Parkinson disease: Dumbing down by standing up* (<https://pubmed.ncbi.nlm.nih.gov/27903812>)
- Q: Can you provide the formula again for heart rate reserve?
 A: Example:
- | | |
|---|-------------------|
| Maximum Heart Rate | 170 |
| Baseline (resting) Heart Rate | 60 |
| Heart Rate Reserve | $170/2 = 55$ |
| Add ½ of heart rate reserve to baseline | $60 + 55 = 115$ |
| | target heart rate |
- Q: I take 20 mg of Doxepin for sleep and have read that I should be only taking 6 mg.
 A: Avoid more than 6 mg of Doxepin a day as a sleep aide. Trazodone is the best sleep medication.
- Q: My husband suffers from orthostatic hypertension, and he is currently on Amlodipine and Midodrine and has vivid nightmares. His doctor has prescribed Florinef and is taking him off the Midodrine, but I'm concerned because he had kidney stones and has been on a low salt diet.
 A: Is he taking 1 or 2 tablets? She does not know because she hasn't picked up the prescription yet. I would recommend that you talk to your cardiologist. If your husband takes Florinef, you may need to add potassium depending on the dosage prescribed; good sources are bananas and apricots. I would try the Florinef; it should help; it's best to talk to your cardiologist. [Dr. Grabert usually lets cardiologists prescribe treatments for orthostatic hypertension.]
- Q: What do you think about caffeine?
 A: A good drug for Parkinson's; it helps with fatigue and alertness and is not harmful.
- Q: My husband has tremors when he reaches for something.
 A: Parkinson tremors are typically resting tremors. A Dystonic tremor is an action tremor. A DaTscan will show whether it's a Parkinson tremor or not.
- Q: Can Carbidopa/Levodopa cause nausea? My partner was taking 25/250 3x's a day and was nauseous; when reduced to 2 ½ 25/100 tabs, the sickness went away. Went back to the 25/250 and during a sleep study, the study determined overdosed, too high limit.
 A: Yes, Carbidopa/Levodopa can cause nausea at certain levels; The 25 number in Carbidopa/Levodopa is the carbidopa, an anti-nausea medication. 250 units of Levo in the 25/250s can cause nausea because it doesn't have sufficient carbidopa for some patients; the best way to deal with it is to go back to your original solution: 2 ½ tablets of 25/100s 3x's a day. As for the sleep study, it sounds like a strange interpretation.
- Q: My husband experienced hallucinations, delusion, and confusion; can this be from the Carbidopalevodopa?
 A: Can be driven by medications. Nuplazid is the only approved medication for Parkinson's hallucinations.
- Q: About a month ago, my coordination got worse; last week I dropped the dosage of my carbidopa-levodopa, and now my coordination is more stable. My DBS setting is at the maximum level on one side; can it be readjusted to help with my coordination issue?
 A: Lowering medication is good. We can adjust your DBS limit when you come in for your next appointment.

After Dr. Grabert completed his question-and-answer session, Dr. Dawn White joined the meeting via Zoom to present information regarding her upcoming study. She opened by telling the audience that we'll need caregivers for the increase that Dr. Grabert discussed regarding the doubling of individuals with Parkinson's disease in the next 25 years.

Please note, Dr. Grabert's and Dr. White's presentations are available on the CPF website.

A Phenomenology Study of Wives Caring for their Husbands with Parkinson's Disease

Sponsored by
the Colorado Parkinson Foundation, Inc.
Dr. Dawn White



Dr. White began by providing background for her study.

In general, female caregivers will spend a minimum of 50 hours per week caring for a patient-spouse with a debilitating chronic illness like Parkinson's disease. Caregivers often fall victim to fatigue, sleepiness, and depressions from pure exhaustion. However, they push forward because it improves the patients' quality of life, which drives caregivers to continue. Caregivers shoulder additional responsibilities like ensuring compliance with medical treatment plans and providing daily hygiene care. Given the complexity of the disease and overwhelming needs, married patients receive most of their care from their spouses.

Next, Dr. White provided information regarding the purpose of the study,

The purpose of this study is to understand the phenomenon of being a female caregiver to a male spouse living with Parkinson's disease through lived experiences and to ensure the caregivers receive the support they need to function independently from their spouse's illness.

She then explained the eligibility criteria requirements of the study,

- Female spouse caregiver
- Male husband diagnosed with Parkinson's Disease stage 2-4 on the Hoehn-Yahr scale
- 50 years of age or older
- Living at home in Colorado
- Been a Parkinson's caregiver at least 6 months
- Spends a minimum of 50 hrs. per week caregiving and offering direct assistance.

Dr. White's next slide provided detailed information regarding what is meant by 50 hours per week caregiving,

- Helping with chores, cooking, cleaning
- Daily hygiene
- Doctor appointments
- Medication monitoring/organization
- Socialization (CPF meetings)
- Transportation
- Not 50 hours straight (see example)
 - Example: 5 hours each evening after work, 12-13 hours on the weekends.

What is required of participants was the next item covered by Dr. White,

- Meet the study eligibility criteria
- Contact the researcher with your desire to participate
- Read through the informed consent and agree to participate
- Set time for interview
- Help future caregivers

Dr. White concluded her presentation by asking if there were any questions, none were raised by the support group attendees. She then provided her contact information for individuals interested in participating in the study.

Please contact Dr. Dawn R White:
757-576-1029 (Est) or email @
dawn.white.phd@gmail.com

Please include name, address, phone number, and email address



Colorado Parkinson Foundation, Inc.

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Colorado Springs, CO 80920

Parkinson's Perspective

NOVEMBER 2021

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 August Picnic)

November 13th: Reg Mtg at First United Methodist Church – 10 am; **Program:** The Alexander Method & Parkinson's; **Speaker:** Travis Chastain, Neuro-Muscular Rehabilitation & Movement Specialist

December 11th: Christmas Party with Entertainment by the Song Spinners!!

January 8th: Reg Mtg – 10 am; **Program:** Parkinson's 101; **Speaker:** Jill Reid

February 12th: Reg Mtg – 10 am; **Program:** Results of the 24 week CPF Study on the effects of a low-carb/healthy fat diet on PD, biomarkers, depression, anxiety & quality of life; **Speaker:** Melanie Tidman DHSc, M.A., OTR/L, MHP

March 12th: Reg Mtg–10 am; **Program:** Breakout Sessions; Moderators: Jill Reid–Parkinsonians; Julie Pfarrer–Caregivers

April 9th: Reg Mtg – 10 am; **Program:** Wealth Preservation & Planning for Long Term Care
Speaker: Kim Searles, Beneficent – LTC Consulting Group

May 14th: Reg Mtg – 10 am; **Program:** TBD

June 11th: Reg Mtg – 10 am; **Program:** TBD

July 9th: Reg Mtg–10 am; **Program:** Breakout Sessions; Moderators: Jill Reid–Parkinsonians; Julie Pfarrer–Caregivers

August 13th: 11 am; Picnic at John Venezia Park!!!!!!

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