

April
- 2022 -

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

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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: Curt Freed, MD

New Member Table Chairmen:

Pat Dashosh

Sunshine (Cards): Sharon Carlson

[REDACTED]

T-Shirt Chairman: Vacant

Webmaster: Julie Pfarrer

webmaster@co-parkinson.org

Newsletter Editor: K. 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).

April Meeting: Saturday, April 9th – 10:00 am – 1:30 pm

We will be Zooming the presentation but not recording it.

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.

Program: Wealth Preservation & Planning for Long Term Care

Speaker: Kim Searles & Stacy Osborne, Beneficent – LTC Consulting Group



Kimberly Searles received her BA from California State University East Bay and is a Certified Senior Advisor (CSA)® and Director of Education at Beneficent. She educates healthcare professionals including Social Workers and Case Managers on how Certified Medicaid Planners can help qualify clients for long-term care costs not covered by Medicare. Kim specializes in serving the middle class, preserving assets while securing funding for Long-Term Care Medicaid and VA Aid & Attendance programs---serving clients who have been told they "make too much" or "have too much" to qualify.

Stacy Osborne, CEO and Owner of Beneficent, received an MBA from the University of Texas at San Antonio and a BS degree from Texas A&M University. She is a Certified Medicaid Planner with a 100% success rate in qualifying families for financial assistance not covered by Medicare. Stacy is currently the president of the Chaffee County Rotary, Financial Advisor for the Senior Resource Council Board and a presenter at American Residential Services National Conferences and Home Depot Regional Conferences across the US.



The April Potluck main dish – Soups & Stews!

If you would like to be one of the providers of the main dish or a side dish/dessert for the April meeting, please contact Bill Hicks at [REDACTED] or potluck@co-parkinson.org to let him what you plan to bring.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

**Register
by
April 15th!**

Caregiver Pampering Day!

Take 5!: Soothe All of Your Senses

Sponsored by PPACG Area Agency on Aging

**See Page
3 for
details!**

When: Saturday April 30, 2022, 8:30 AM to 1:00 PM

Where: Colorado Springs Senior Center, 1514 N. Hancock Ave

Admission: Free with registration

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



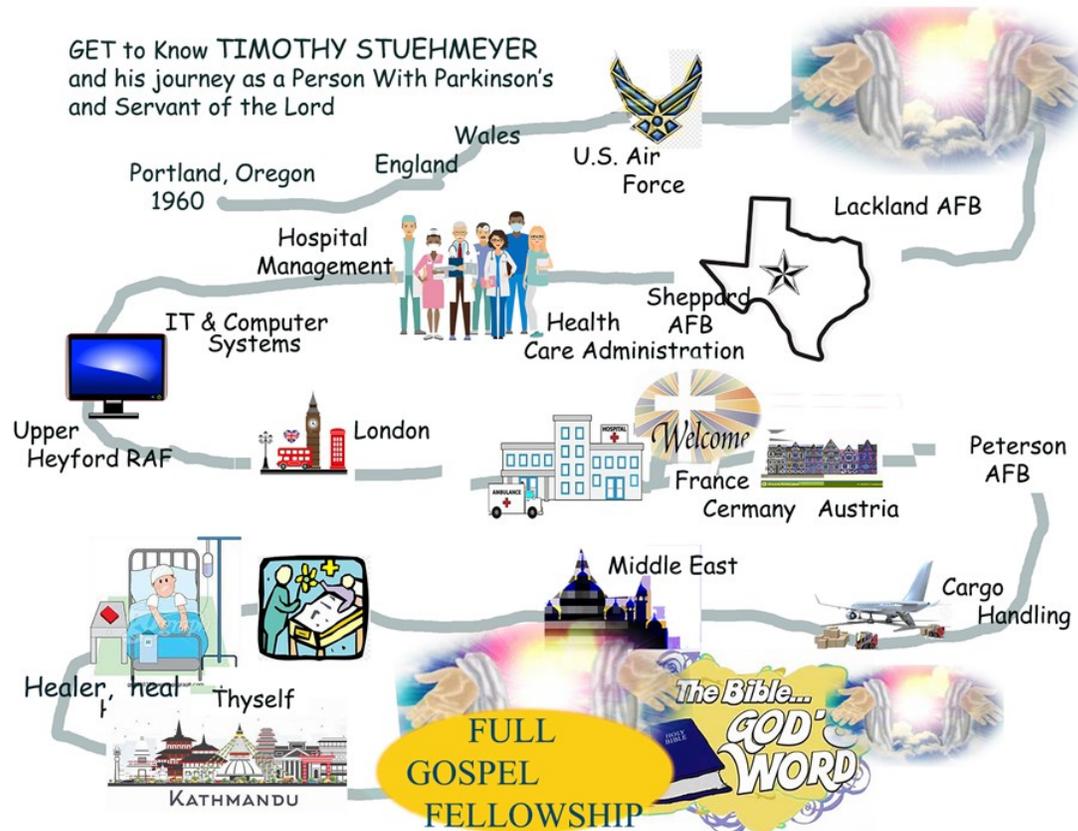
When I was in high school in Bristol, Tennessee, one year during Christmas break, which was only a week long in those days, it started snowing around 8:30 on Christmas morning. By the time the snowfall ended several hours later, we had two feet of snow on the ground. That was a lot of snow for our town, and it shut it down for nearly two weeks. Our one-week Christmas break lasted two full, glorious weeks. The scenery was magical, and we took the beauty and the extra time off for what they were—a HUGE opportunity to play, have fun, and glory in the scenery. We sledded down streets that would normally be crawling with automobile traffic, Dad pulled us on our sled behind our Volkswagen bug on one of the only level streets in town (Bristol is in the foothills of the Smokey's—we used to joke that whatever came down had to go back up!), and, of course, we built snowmen and had snowball fights. No homework and no worries!

In stark contrast to how I viewed that blizzard, when the blizzard of October 1997 hit Colorado Springs and shut us down with 4 1/2 to 6 1/2 feet of snow, I only saw the work that the blizzard caused me. I wasn't able to hunker down at all during the blizzard because I had to check on the horses every hour and dig paths through the accumulating snow so that they could get to their water troughs. A nine-foot berm developed between the house and the barn, making the hourly 100-yard trek to the barn that much more difficult. After the blizzard ended and the sun came out, I think I shoveled 3 tons of snow by hand between the house and the barn because my tractor was marooned at my sister's house because I was mowing her meadow in 70 degree weather the day before (several days later, my neighbor came by and plowed out the rest of my driveway); I even had to cut a tunnel from my walk-out basement to the yard so that my renter, who lived in the basement, could get out her door. I shoveled all the snow off the garage roof to keep it from collapsing. I didn't go sledding, didn't build any snowmen, and didn't have any snowball fights—I could have, but I didn't. And to add insult to injury, that snow stayed on the ground on the rest of my property until May!!!! I didn't see any of the blessings that were in front of my eyes—the beauty, the needed moisture, the opportunity to play, the freedom from worry (I chose to worry about getting dug out!).

Isn't that like life for many of us? Two nearly identical events, and two completely different attitudes toward them. Was it because I was still a teen during the first one and an adult during the second? Was it because I knew how to play and enjoy golden opportunities when I was younger, and the challenges of adulthood had jaded my view of opportunities to the point of seeing them as one big pain in the neck? Whatever the reason, my attitude had shifted in a negative direction, and I needed to do something about it—choose to see the best possible in all situations, good or bad.

I think that we can do that with every situation, even with Parkinson's. Choosing to make the best of things is so much more emotionally AND physically healthy than choosing just to survive or worse, choosing to wallow in self-pity. Sure, keeping a positive outlook in the face of adversity isn't easy—it can be tough—but it's worth the battle.

Getting To Know You: Timothy Stuehmeyer



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!

Colorado Parkinson Foundation Inc
has received as of March 2022
\$716.44

All US charities have received
\$334,286,080.29
as of March 2022

All worldwide charities have received
\$377,951,346.33
as of March 2022

Caregiver Pampering Day! TAKE 5!: SOOTHE ALL YOUR SENSES

Sponsored by PPACG Area Agency on Aging

When: Saturday April 30, 2022, 8:30 AM to 1:00 PM
Where: Colo Spgs Senior Center, 1514 N. Hancock Ave
Admission: Free with registration

The event is for family members who are caring for another family member who is 60+ years of age.

The day includes a catered continental breakfast, pampering time, drop in activities, classes, and catered lunch.

Scheduled classes will include:

— **The Healing Power of Music:** Join us as we explore how music relaxes us, brings us joy and lifts our mood. We will use our voices as well as other instruments to blend together in perfect harmony!

— **Being Present Through Your Senses:** Mindfulness is a powerful tool that heightens our awareness through our senses. It brings into a clearer focus how we respond to the events in our lives. Come learn a simple method to be more aware.

— **Sit and Fit:** Join us and combat osteoporosis while strengthening your muscles using resistance bands and small free weights. A great class for those looking to improve balance and standing endurance.

— **Be A Creative Cookie:** Learn how to make those cookies that everyone says are "too pretty to eat" but are just too delicious not to. You'll get a chance to decorate 2 fresh baked cookies and go home with no fail recipes to start your tasty journey.

— **Flooding, Fires and Blizzards oh my!:** As a caregiver are you ready for the next Colorado disaster? Come and learn helpful tips to be ready for the next big "thing" that could impact you and the ones you love.

— **Aromatherapy—Not Just for the Smell of It:** Come learn about natural, plant based essential oils and how they can support sleep, mood, energy and focus. Learn a simple gentle hand touch technique for calming and take home a sample essential oil.

— **Caring Conversations:** Making time for yourself is difficult. Meet with other caregivers who understand the difficulties and challenges associated with caring for a loved one. Come sit, listen and talk with others in a non-judgmental safe space to be open and honest.

**Registration began on March 21, 2022
and closes on April 15, 2022.**

Registration can be done:

Online: ppacg.org/pamperingday

Email: kmathews@ppacg.org

Phone: 719-886-7526

For more information or to have questions answered please call Kent Mathews MSW at 719-471-2096 or email Kent at kmathews@ppacg.org.

Trial to Test Brain Stimulation Device for Balance Problems

By Marisa Wexler – Parkinson's News Today, Dec 9, 2021

A new clinical trial is testing a novel noninvasive brain stimulation technology developed by Highland Instruments in people with Parkinson's disease who have postural instability – difficulty with balance and the reflexes that help a person to stand upright.

The trial (NCT03981055), which is funded by the National Institutes of Health (NIH), is recruiting participants at Spaulding Rehabilitation Network Research Institute in Charlestown, Massachusetts. The trial is open to adults ages 40 to 90 who have Parkinson's disease and balance problems, and are on a stable dose of medication.

All participants in the double-blinded, randomized, controlled trial will be given physical therapy to help with balance issues. In addition, some participants will receive electrical stimulation of their brains with Highland Instruments' Electrosonic Stimulation (ESStim) device. Other participants will get a sham

stimulation.

The trial seeks to build on results of an earlier Phase 1 clinical trial, called JANUS 3A, that had a similar design. According to Highland, results from the Phase 1 trial showed that participants given stimulation with ESStim performed better on objective measures of balance and posture control than those given sham treatment. ESStim treatment also eased Parkinson's symptoms, as indicated by improvements on the Unified Parkinson's Disease Rating Scale.

Participants treated with ESStim in the Phase 1 trial also reported better quality of life, with marked improvements in their ability to move around and participate in activities of daily living, as well as improvements in emotional domains.

"Results from the first phase of the study demonstrated Parkinson's Disease patient improvement in

gait and postural impairments which are known to be among the greatest factors affecting quality of life in Parkinson's disease patients," Felipe Fregni, MD, PhD, said in a press release. Fregni is a professor at Harvard Medical School, and the principle investigator for the trial at the Spaulding Rehabilitation Hospital site.

"Parkinson's Disease patients with postural instability have limited treatment options and thus the ESStim combined with O (physical therapy) approach could be quite impactful in these patients," Fregni said.

"The second phase of the study will expand the patient pool, provide therapy for an extended period, and gather data which could optimize ESStim therapies for patients with postural instability. We are excited to have patients now underway in the Phase II study," he added.

Parkinson's Disease Linked to Gene Targeted by Blue-Green Algae Toxin | By University of Queensland

An article in the Medical Press

Scientists have discovered a possible link between Parkinson's disease and a gene impacted by a neurotoxin found in blue-green algae.

University of Queensland scientist Dr. Jacob Gratten said the findings increased the understanding of the environmental risk factors of Parkinson's disease.

"We looked for a link and changes in the human genome that control how genes are turned on and off, because these changes can be influenced by the environment," Dr. Gratten said.

"We found a gene, previously not known to be linked to Parkinson's, which displayed reduced activity in people with the disease."

"This same gene is known to be targeted by a blue-green algae neurotoxin."

Blue-green algae is found in inland waterways and poses a health risk to people, domestic animals and stock that come into contact with the toxic algal blooms.

The research team at MRI-UQ made the discovery in collaboration with Professor George Mellick at Griffith University and colleagues from New South Wales and New Zealand.

Their findings are the culmination of more than a decade of scientific effort.

Neurotoxins released by blue-green algae reduce activity of the gene identified in the study.

Researchers predict this will lead to higher oxidative stress levels in nerve cells associated with Parkinson's disease, which can lead to cell death.

Dr. Gratten said that while the study does not provide a direct link with Parkinson's, blue-green algae had previ-

ously been associated with other neurodegenerative diseases such as motor neurone disease.

"This gives us confidence that we're moving in the right direction towards understanding the environmental causes of Parkinson's disease," Dr. Gratten said.

UQ geneticist Professor Peter Visscher, from the Institute of Molecular Bioscience, who co-led the study, said Parkinson's disease affects 1 in 100 people over 60-years-old and that figure is projected to double by 2040 as the population ages.

"This disease destroys lives and devastates families, so we're determined to unlock the mystery behind Parkinson's," Professor Visscher said.

"More work is needed to confirm our findings, and to explore other possible explanations for the link between this gene and Parkinson's disease, such as pesticides."

Recipe of the Month: Greek Spaghetti Squash | Serves 2

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:

- 1 medium spaghetti squash
- 1 boneless skinless chicken breast cut 1/2" cubes
- 1/2 C chopped onion
- 1/2 C chopped sweet red pepper
- 2 garlic cloves, minced
- 1/4 t dried oregano
- 1/4 t dried basil
- 1/8 t salt
- 1/8 t pepper
- 1 T olive oil

- 1 C baby spinach
 - 1/2 C artichoke hearts
 - 1/3 C chopped pitted, Greek olives
 - 2 T crumbled feta cheese
- Cut squash in half lengthwise; discard seeds. Place squash cut-side down on a microwavable safe plate. Microwave, uncovered on high for 15-18 minutes until tender.

Meanwhile, in a skillet, sauté chicken, onion, red pepper, garlic, oregano, basil salt & pepper in oil until chicken is no longer pink. Stir in spinach, artichokes and olives; cook until spinach is wilted.

When squash is cool enough to handle, use a fork to separate strands. Serve chicken mixture over 2 cups of squash. Sprinkle with feta cheese.

Note: you can also buy spaghetti squash already shredded in the frozen food section of the grocery store.

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 bbhicks54@gmail.com or [redacted] to let her

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 [redacted] or

Syble Krafft at [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.

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].

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 & clean-up at the last meeting!



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

Loretta Bogues
Naomi Boswell
Margaret Bush
Tracy Cologne
Jane Krueger
Roger MacDonald
Rita Maguire

Doug Malmgren
Worth McCue
Malcolm Nordaby
Fern Quidachay
Bob Ray
Gregory Ritscher
Phylis Ritscher

Brenda Rogers
Judith Rowe
Steve Runkle
Joyce Schmattz
Allen Snelling
Howie Vroman

April Executive Committee Meetings

April 12th 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.

April Newsletter Input Deadline: April 20th

Call or e-mail Julie at:

db_mgr@co-parkinson.org.

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 & 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 Black Back Brace	1 Knee Splint	1 Suction Cup Hand Rail	1
Arm Assist for Wheelchairs	1 Canes	5 Lift Chair	1 Tub Rail	1
Arm Splint	1 Chair/Sofa Cane	1 Lumbar Traction Belt	1 Transport Chairs	4
Bed Cane	1 Crutches	2 Pickup Assist	5 U-Step	2
Bedpan	3 Exercise Bike	1 Raised Toilet Seats	4 Voice Amplifier	2
Bed Rails	1 Hospital Bed	2 Shower Benches/Chairs	9 Walkers with Wheels and Seat	9
Bedside Toilet	1 Ice Man - therapeutic for knee replacement surgery	1 Stair Chair Lift System	1 Wheelchairs	6
	5	1 Stand-up Walker		

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:

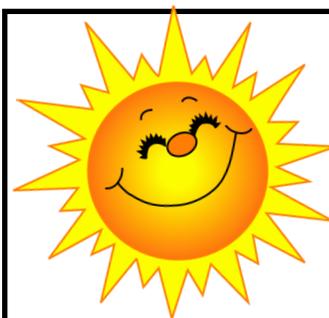
Power Moderate level. Fri at 1:30. \$10

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].

Six People with Parkinson's Disease on the Power of Music

By Johanna Stiefler Johnson – Parkinson's Life, December 9, 2021

NOTE: A new Parkinson's Sing-a-Long Group has started with Heather Johnson, a music therapist, to help you with your speech & swallowing – see the section "Other Opportunities" on page 4 for details. Also Heather conducts a group sing-along 30 minutes before the start of our meetings. Here are even more reasons to join her each month at our meetings starting at 9:30.

Over the years, we've been lucky enough to talk to interviewees whose talents range from adventuring and painting to composing, performing and producing music. In this Parkinson's Life 'playlist', we share what six inspiring people from the Parkinson's community have to say about music – and its role in helping them to face the challenges of the condition.

WALTER J. ARCHEY III, RAPPER

When we caught up with US rapper and filmmaker Walter J Archey II, who's been in the business since 1980, he opened up about his experience of living with Parkinson's. "The fact that I'm a younger-looking African American person with Parkinson's has been a challenge. The first thing that a lot of people think when they see you is: 'Man, this dude is clearly on drugs,'" he said.

"It's just something you have to deal with. You have to be light-hearted about Parkinson's. you can't let it get you down."

How has his approach to his art changed since diagnosis? "Rapping out loud can really help your vocal cords when you have Parkinson's, but I can't rap the way I used to because I run out of breath," he explained. "You need good breath control to be a great MC."

Facing these challenges head-on, inspired by the achievements and attitude of people like Stephen Hawking, Walter told us: "When you see me, I'm going to have a gold chain and be with some fly ladies, making beats and rapping – and you're not even going to think about the Parkinson's."

ROBBIE TUCKER, SINGER – SONGWRITER

We first got to know Canada-based Robbie Tucker as a guest on our 'Love, sex and Parkinson's' podcast episode, as he opened up about his experience of Parkinson's disease – and its impact on dating and relationships.

It was during the recording that we learned about his musical talents, which have seen him produce at least seven solo albums as a singer, composer and instrumentalist – after writing his first song lyrics at the age of eight. "I'm a musician, I have been since I was a little kid," he said.

Diagnosed with Parkinson's in his late 20's, Robbie told us that, two decades later, despite the challeng-

es of the condition: "I'm still making music and trying my best to be a functional human being in the world."

TONY COFFEY, COMPOSER AND PIANIST

Tony Coffey has found that Parkinson's has impacted his ability to play piano – with his left arm falling behind his right. "So the only thing left to me now is to write music," he told us in an interview last year.

Driven by his passion for songs, Tony – who is from the Channel Islands – said he was a "busy bloke" throughout his career, working with young people in choirs and classrooms, teaching practical music-making, writing music for theatre – and more. Since he was diagnosed, music has been an "almost miraculous" source of inspiration. He's released an album, 'Out My Head' – a reflection on life with Parkinson's.

"Music can shake up our emotions and also straighten them out," he said. "I love dancing around the studio listening to a track that I have just recorded. A Beethoven symphony or a Benjamin Britten opera, or the White album can all take me to a special place in my head that Parkinson's can't get to."

LAURA HANF, DJ

What's it like to be a DJ with Parkinson's? US-based Laura Hanf told us all about her role on Radio Parkies, an online radio station dedicated to the international Parkinson's community.

Laura said that, despite some challenges with speech and fatigue that can arise due to her condition, "music often makes me realize how fortunate we all are. I think people can relate to lyrics more that they can relate to having a discussion and generally, music brings out a lot of emotion in me,"

When asked why people should consider tuning in to the station, Laura added: "Not only does music help you feel good, but if you need to exercise then you can have a dance while listening. We can offer

you words of encouragement about your Parkinson's journey, or you can just sit back, relax and enjoy the music."

GERALD GANGLBAUER, MUSIC PRODUCER

For Australian and Austrian producer, Gerald Ganglbauer, music is part of a "toolkit to communicate and educate the public".

"Higher numbers of listeners and readers can help to put more pressure on lobby groups, and bring about change," he said. This desire to spark change let Gerald to found the organization Parkingsong, which aims to raise Parkinson's awareness through music.

"Music helps all people, not just people with Parkinson's," he told us. "But with Parkinson's, rhythm can help you walk and singing can help you speak. And if you've got a song in your head, it might take your thoughts away from your pain."

HAROLD CHAPLIN, COMPOSER

UK-based composer and retired teacher Harold Chaplin started writing songs more than 30 years ago. Following his Parkinson's diagnosis in 2007, he began to write music about life with the condition.

"The music has this amazing, temporary but powerful, healing effect because I can literally fling my walking stick aside when I finish singing and walk quite normally for an hour or two," he explained. "I can walk around and talk to friends and they forget I have Parkinson's – and for a moment, I forget too."

When we interviewed Harold during the festive season a couple years ago, the UK's Hertford Choral Society was gearing up to prepare two of his Christmas carols at their holiday concert – where donations would be accepted for Parkinson's research. "I hope to get my songs about Parkinson's online, too, to increase awareness," he said. "That's what my incentive is."

Safinamide Associated With Pain Improvement in Patients With Parkinson's Disease

By Matthew Gavidia – AJMC, Sept 4, 2021

Results of the SAFINOMOTOR open-label study found that safinamide was safe and effective in improving pain of patients with Parkinson's disease at 6 months.

Safinamide may significantly improve pain in patients with Parkinson's disease, according to study findings published in the Journal of Personalized Medicine.

Affecting up to 50% of patients with PD, pain has been identified as a common nonmotor symptom (NMS) that is frequently under-recognized and inadequately treated. With experiences of pain varying by each patient, identifying what type of pain is present can be vital in finding effective treatment, noted the study authors.

In prior research dopaminergic therapy and neurotransmitters have been implicated in the management of pain. Moreo-

ver, some studies have suggested the possible benefit of safinamide, an oral alpha-aminoamide derivative marketed for the treatment of PD, with the treatment having been associated with improvements in several pain scales, such as the King's Parkinson's Disease Pain Scale (KPPS), and in global NMS burden, particularly for sleep, mood, and urinary symptoms.

"We observed very recently an improvement in the global NMS burden in 50 patients with PD from the SAFINOMOTOR study," added researchers. "In this analysis, a secondary objective of the SAFINOMOTOR study, we evaluated in detail the change in pain throughout the 6-month follow-up in PD patients treated with safinamide."

Leveraging data from the prospective open-label SAFINOMOTOR study of patients with PD from 5 centers in Spain,

efficacy of safinamide on pain was evaluated via change in KPPS score from V1 (baseline) to V4 (6 months), a measured by Wilcoxon's rank sum test.

In the analysis, 44 patients with PD (mean age [SD], 68.5 [9.12 years]; 58% women; 6.4 [5.1] years from diagnosis) were included between May 2019 and February 2020.

Compared with baseline, a lower KPPS total score was found in 28 patients (65.1%), the same score in 6 patients (13.9%) and a higher score in 6 patients (13.9%). Overall, the KPPS total score was significantly reduced by 43.6% from V1 to V4 (40.04 [36.18] vs 22.60 [21.4]; $P < .0001$). by domains, improvement was observed in several pain manifestations:

- musculoskeletal (-35.9%; $P = .009$)
- fluctuation-related (-51.7%; $P = .020$)
- nocturnal (-46.1%; $P = .001$)
- discoloration and/or edema/swelling (-50.4%; $P = .009$)
- radicular pain (-40.1%; $P = .048$)

There were 21 adverse events recorded in 11 participants (22%). 5 being severe, but not related to safinamide.

"In conclusion, safinamide is well tolerated and could improve pain in PD patients," said the study authors. "Well-designed randomized double-blind trials are necessary to analyze in detail the effect of safinamide on pain. Especially interesting could be the analysis of pain with objective methods and with regards to action mechanism, dopaminergic and/or glutamatergic, in patients receiving safinamide."

Ask the Expert: How Does Parkinson's Impact Dreams?

By Parkinson's Life

What is the link between Parkinson's and dreams?

Sleep disturbances are very common in people with Parkinson's and can comprise the entire spectrum of sleep disorders. Studies suggest that rapid eye movement (REM) sleep behavior disorder, or RBD, can be one of the first symptoms of Parkinson's disease – occurring years before motor symptoms and clinical diagnosis.

RBD is a sleep disorder characterized by the acting out of dreams that are vivid, often intense and frightening. People with this disorder do not experience the normal temporary paralysis of limbs during REM sleep, and have been known to yell, carry out conversations to hit themselves or their bed partner while asleep. These are known as dream enactment behaviors.

Vivid dreams are typically present in people with Parkinson's and RBD. The content of dreams, namely dreams with negative emotions, seems to predict long-term cognitive decline in people with Parkinson's.

Are there any common themes in dreams linked to the condition?

Dreams among people with Parkinson's tend to involve more aggressive subject matter – overall, they're described as vivid, action-filled and nightmarish. Dreams can involve being chased or defending oneself from animal attacks – including dogs, snakes, lions and bulls. These can be accompanied by typical nocturnal behaviors that include talking, yelling, gesturing, punching and kicking.

Why are some dreams particularly vivid or negative for people with Parkinson's?

REM sleep plays a pivotal role in processing emotional events, and several studies have shown that the consolidation of emotional memories occurs in this sleep stage. Vivid dreams tend to be more frequent when awakening from REM sleep, the stage disrupted by Parkinson's some drugs used to treat Parkinson's can also accentuate dream vividness.

Many people with the condition describe the content of their dreams as negative. The vividness and emotional description of dream reports correlate with the limbic system – an area of the brain associated with our emotional life. Although the reasons why people with Parkinson's often experience negative dreams have not been fully explained, this is likely due to damage in a particular area of the brain.

What impact can this symptom have on the lives of people with Parkinson's?

Sleep disturbance is associated with increased severity and frequency of non-motor features of Parkinson's, such as depression, and poorer subjective motor performance, injuring their bed partners and themselves, while asleep, is very common. Sleep disorders can also greatly impact daily life.

Since REM sleep behavior disorder can be one of the first symptoms of Parkinson's, there is now growing recognition that the use of experimental neuroprotective agents may be more useful at this stage. In future, this could provide an effective pathway to future developments and opportunities for early intervention.

What treatment options exist for those experiencing sleep disturbance and bad dreams?

Bad dreams are a perfectly normal occurrence and can be triggered by many factors, including stress, anxiety, sleep deprivation and medication. However, when bad and vivid dreams are accompanied by dream-enacting behavior, people with Parkinson's can take some simple steps to minimize injury.

A safe sleeping environment is essential, so modifying sleeping arrangements should be the first step to treat REM behavior disorders. Placing a mattress on the floor, padding corners of furniture, protecting windows and removing potentially dangerous objects from the bedroom are all simple and practical steps. It's also best to avoid alcohol intake, as this can trigger or aggravate RBD.

Two medications commonly prescribed to treat RBD are clonazepam and melatonin. Clonazepam should be used with caution in patients with dementia and gait disorders. Melatonin may have the advantage of fewer side effects and a longer-acting version, but in certain cases, only higher doses of melatonin will work.

Dreams and Parkinson's disease

Nine in 10 people living with Parkinson's disease experience sleep disturbances, ranging from vivid dreams and nightmares to insomnia and daytime napping. Some of these problems can be alleviated through good sleep hygiene procedures, such as improving sleeping environment, maintaining a healthy diet and keeping a routine. Make sure to discuss these symptoms with a healthcare professional.

HHS Civil Rights Office Tackles Health Care Discrimination of People with Disabilities

| By Joseph Shapiro NPR

Civil rights officials at the Department of Health and Human Services issued a series of actions to protect people with disabilities from health care discrimination by medical providers during the pandemic.

The actions, by the Office of Civil Rights, or OCR, at the Department of Health and Human Services, specifically address discrimination related to the denial of treatment for people with disabilities who have COVID-19 or the symptoms of COVID-19. They include:

- The start of a process to write regulations that explicitly prohibit medical workers from denying care to people with disabilities based on subjective decisions about the quality of their life or by issuing a Do Not Resuscitate order without the patient's consent or against their stated preference.

- A revision to the guidelines of four health care systems, in North Carolina, North Texas, Southwest Texas and the Indian Health System, to assure that people with disabilities and older people are not passed over for scarce care, like drug treatments and ventilators."

These problems were the subject of a series of NPR stories about how people with disabilities were denied ventilators and other pandemic care in Oregon. NPR's stories were cited in OCR's proposal.

"We said during COVID-19, our civil rights are not suspended," HHS OCR director Roger Severino told NPR. "People will not be subject to age or

disability discrimination when the going gets tough."

Sarah McSweeney, whose death was the subject of one of NPT's stories on health care rationing, was a 45-year-old woman with multiple disabilities. She dies at an Oregon hospital in May after doctors questioned her quality of life and pressured her guardian and others who cared for her to sign a Do Not Resuscitate order to allow doctors to withdraw care.

The new OCR action makes clear that doctors cannot issue a blanket DNR and cannot substitute their subjective beliefs about the quality of a disabled person's life over the person's own wishes.

Severino says the actions are intended to make clear "that discrimination against persons with disabilities will be absolutely forbidden and stereotypes about their usefulness should never be part of a discussion when we allocate care."

If the OCR action – which takes on a range of issues of discrimination – becomes formalized, it would become a significant expansion of disability civil rights lay.

Severino's office wanted to make a formal rule but could not get the action through all of the steps of the approval process before the end of the Trump administration. Instead, it was issued as a "request for information", which is usually an appeal to stakeholders for information to help make a rule.

But a final rule exists in draft form, according to a source at HHS, with hopes that new Biden Administration officials will pick it up.

Alison Barkoff, of the Center for Public Representation, a disability civil rights group, said the OCR actions reflect parts of the disability agenda that President-elect Joe Biden had promised in his campaign.

"This is a great signal and we're really please," says Barkoff, who helped write more than a dozen complaints to OCR about treatment of people with disabilities during the pandemic.

In addition, OCR announced four settlements over what are called "state crisis standards of care." These are guideline by state governments to health care providers about how they can determine who gets medical care if it gets scarce. The rules are guideline for events like natural disaster, terrorism or pandemic.

At the start of the coronavirus pandemic, disability groups across the country filed complaints with OCR, claiming their state's guidelines allowed doctors and hospitals to deny care to people with disabilities and the elderly. OCR had already announced several previous settlements with states, including ones with Alabama, Pennsylvania, Tennessee and Utah over policies to triage care including decisions about who gets a ventilator.

Some states standards, for example,

allowed scarce care to be denied to people with moderate dementia, or who used portable ventilators, even though many people who use ventilators to help them breathe still hold jobs and live full lives.

The final four agreements – including in Texas where hospital staff say they are facing shortages in the latest spike of the coronavirus – include language to guarantee doctors will not pressure patients to sign Do Not Resuscitate orders and not exclude people from treatment based on their disability alone.

The steps taken by OCR to stop medical discrimination reflect the findings of a series of papers on bioethics and disability, issued by the National Council on Disability, an independent federal agency that makes recommendations to Congress and the White House on disability policy. Those reports alleged widespread discrimination in medical settings against people with disabilities – from who gets organ transplants to how bias that disabled people can't have a good quality of life is used to deny medical treatment.

"Disability discrimination in health care is among the most insidious – with life and death consequences – and it's hard to root out," Neil Romano, chairman of the National Council on Disability told NPR.

The action by OCR, he says, "sends an unequivocally clear message that we will not accept health care that relegated people with disabilities to last in line or 'lost cause.'"

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

Parkinson's Perspective

APRIL 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 August Picnic)

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:** Results of the CPF Phenomenological Study of Wives
Caring for their Husbands with Parkinson's Disease. **Speaker:** Dawn White, PhD, RT (R)

June 11th: Reg Mtg–10 am; **Program:** Breakout Sessions;
Moderators: Steve Locke–Parkinsonians; Jill Reid & Julie Pfarrer–Caregivers

July 9th: Reg Mtg–10 am; **Program:** Scam Prevention;
Speaker: Colorado Springs Police Department

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

September 10th: Reg Mtg–10 am; **Program:** Breakout Sessions
Moderators: Steve Locke–Parkinsonians; Jill Reid & Julie Pfarrer–Caregivers

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