

Parkinson's Perspective

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

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president@co-parkinson.org

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Educational Outreach: Jill Reid

Membership: Carole Henrichsen

Chaplain: Rusty Merrill

Parkinson's Awareness Day:
Vacant

Photographer: Annette Garcia

Lending Locker Coordinator:
Mary Sauvain [redacted]

Main Dish Coordinator:
Bill Hicks [redacted] or
potluck@co-parkinson.org

Picnic: Carole Henrichsen
and Janet Adams

Media Relations: Mary Sauvain

Medical Advisor:

Dr. Brian Grabert, MD

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Norm Tuinstra

Sunshine (Cards):

MJ Thompson [redacted]

T-Shirt Chairman: Vacant

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webmaster@co-parkinson.org

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Kristy Schleiker

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Coordinator:**

Contact Julie Pfarrer at
db_mgr@co-parkinson.org or
call [redacted]

The Colorado Springs Parkinson's
Support Group (part of CPF) meets
10AM, the first Saturday of each month
at the Central United Methodist Church,
4373 Galley Rd, Colo Spgs, 80915

(with exceptions to be noted
in this newsletter)

Next Meeting: Saturday, October 5th – 10:00 am – 1:30 pm

We will be Zooming and recording this meeting

Location: Central United Methodist Church, 4373 Galley Rd-just east of Murray Blvd.

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

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

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

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

OCTOBER PROGRAM

Topic: Pat Yourself on the Back–You're Making Such a Difference in the Parkinson's World!

Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP



Dr. Tidman will be presenting an overview of her five years of Parkinson's research funded by Colorado Parkinson Foundation (CPF). Her research involves the investigation of treatment methods and treatments for people with Parkinson's Disease (PD) using a natural, nutritional, low-carb/Ketogenic approach not only to help reduce the symptoms of PD but also to improve general metabolic health. Many people with PD have other conditions, including Type 2 Diabetes, GI disorders, sleep disorders, anxiety, and depression. This important ongoing research demonstrates significant improvements in PD symptoms and biomarkers of health, reduced blood pressure, improved sleep quality, improved mobility, reduced motor symptoms, and reduced symptoms of depression and anxiety. The results of her completed research have been published worldwide in multiple medical journals since 2019 and have been cited more than 100 times in other research papers and trials.

Dr. Tidman and CPF have become known and respected internationally thanks to both the unique design and high quality of the research she and her team have done for us. According to New Zealand's Dr. Matthew Phillips one of the world's premier researchers on PD, our research is groundbreaking and is opening up a whole new approach to understanding the significance of a specific dietary regimen on mitigating PD symptoms and repairing neurological damage.

The meeting will be followed by a potluck

The October Potluck Theme - Your Favorite Pot Luck Dish!

JUST AS A REMINDER, WE ARE EXPECTING A LARGER THAN NORMAL CROWD!

If you would like to sign up to be a provider of the main dish or to bring a side dish/dessert for the meeting, you can contact Bill Hicks at [redacted] or
potluck@co-parkinson.org, no later than Wednesday, October 2nd
and tell him what you would like to bring.

Remember that bringing food for the potluck is voluntary.

We look forward to seeing you there!

The President's Corner

Jill Reid-Acting President, CPF & CSPSG



Exciting news for those of you who liked the t-shirt that I wore to our September meeting!!! As you saw, that bright tennis-ball yellow t-shirt is very eye-catching and makes it look like I have a tan in spite of the fact that I haven't had one in years! But the main reason that I like to wear it is that it starts conversations and gives me a chance to tell strangers about our support group. Usually, the folks who stop me and ask me about the shirt know someone who has Parkinson's, and they want to know more

about us so they can tell the people who need us. I wore it to our August picnic, and several of you wanted to know where I had acquired the shirt and expressed the desire to have one. With that in mind, I touched base with Marty Taylor, one of the Directors of the Colorado Parkinson Foundation and owner of a screen-printing business here in town, and asked if he would be willing to produce similar t-shirts. Since he said yes, I wore it to the September meeting and invited any of you who would like to purchase a similar t-shirt to sign up on a "interest-only" basis. Thirty-three of you responded—enough to meet Marty's minimum order amount. Here is the current idea for our t-shirt; your executive committee is working with Dave in the company's art department to tweak the design, but it will be close to what you see here.



Small, medium, large and extra large shirts will cost \$18; XXL will cost a flat \$20. We will take orders and payment at the October meeting and at the November and December meetings if needed. You can also place your order by calling Julie at [REDACTED] or email her at treasurer@co-parkinson.org. We won't put the order in until we have at least met the company's minimum order numbers. Come August of next year, there will be a sea of bright yellow, eye-catching t-shirts at our picnic at John Venezia Park!

This month's recommended comedy movie is an oldie but goodie from 1966: The Glass Bottom Boat, with Doris Day (one of my favorites), Rod Taylor, Arthur Godfrey, Dom DeLuise, Paul Lynde, Dick Martin, and Eric Fleming. It combines spies, a sexy mermaid (Doris), mistaken identity, and the military industrial complex bumbling along during the space race.

Ask the Doctor!



Dr. Grabert has generously agreed to answer your questions pertaining to Parkinson's Disease each month in our newsletter column called:

"Ask the Doctor!"

If you have questions you'd like to submit to Dr. Grabert, email them to Julie, our newsletter coordinator, db_mgr@co-parkinson.org.

LENDING LOCKER INVENTORY

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

Back brace	1
Bed cane	7
Bed pan	1
Bed rails	1
Bed risers (set)	1
Bedding lifters	2
Bedside toilets	5
Canes	8
Chair/sofa cane	2
Crutches (set)	2
Double floor exercise pedals	1
Freestanding toilet rails	1
Hospital bed	2
Hospital bed food trays	2
Hoyer Lift	1
Lazercue for freezing help	1
Lift chairs	0
Lift-ware tremor compensating utensils	1 set
Monthly med carousel with reminder alerts	1
Pick-up assist	6
Shower seats/benches	7
Sock helper	2
Stand-up assist	1
Standup Walker	1
Squatty potty	2
Swivel seat	1
Toilet arm assist	1
Toilet rail	1
Toilet seats	3
Transfer pole	0
Transport chairs	11
Tub rail	1
U-step	1
Walkers with wheels & seat	9
Waterproof mattress protector (Twin)	1
Wheelchairs	8

Items that are free for the taking:

Contact Julie Pfarrer if interested in these items at db_mgr@co-parkinson.org

7-day/7 compartments per day pill dispenser	1
7-day medium-size pill dispenser	1
Aluminum walker tennis balls	4
Aluminum walker tray	1
Bedside toilet commode liners: 3 big boxes with 6 smaller boxes in each	
Bibs	8
Blood Pressure Monitor	1
Disposable bed pads	7
Easy sip hydrate bottle	1
Gate belt	8
Hospital bed bedding: 3 sets of sheets, 1 mattress pad, 2 washable bed pads (new)	
Hospital gown	1
Hospital slippers—XL&XXL	2
In-bed knee lift	1
Male portable urinals, new in individual packages – 32 oz capacity	4
Plastic handicap plate	2
Plastic handicap bowl	1
Pill crusher, storage, & drink cup combination	1
Rehab squeeze balls	2
Reusable bed pads	8
Waterproof twin mattress protector	1
Weighted utensils	6
Seat cushion	1
Thick-it	1
Transfer pads – can handle a person up to 300 lbs	4
Attend advanced briefs, maximum protection—lg-24 ct	3 pkgs
Cardinal health guards for men - extra heavy absorbency -14ct	2 pkgs
Depend men's guards—52ct – 1 unopened and 3 opened with a few missing	8 pkgs
Fitright guards for men—52ct	1
Generic briefs, L/XL – 18ct	4 pkgs
Prevail daily male guards – one size fits all – maximum absorbency-14ct	2 pkgs
Prevail Nu-fit daily briefs w/ fastener tabs – 32"-44" size – maximum absorbency-16ct	2 pkgs
Women's Always Discreet s/m/ p/m maximum protection underwear – 42ct	2 pkgs
Women's Always Anti-Bunch extra long panty liners. Extra protection – 92ct	1 pkg

Program Review: September 7, 2024

| by Patricia Beatty, Secretary

Greg Ritscher, "Rising Above Parkinson's"

Those who came to our September 7th Support Group meeting were met with a bit of a surprise! They were expecting a Break-Out Session rather than the scheduled presentation from CSPD officer Scott Mathis who was unable to present his Scam Prevention program, and lo and behold another change...an inspirational speaker! And what a speaker he was! "That's the best speaker we've ever had!" was heard from more than one person who appreciated **Greg Ritscher's** down-to-earth approach of living with and Rising Above Parkinson's. Prior to 2022, Greg was part of our Support Group but he now resides in Florida. He is the author of a book appropriately titled Rising Above Parkinson's.

After his 2011 diagnosis of Parkinson's, Greg had a variety of thoughts:

- What is Parkinson's
- How did I get it?
- F.E.A.R. (future expectations appear real)
- Will I become a burden?
- Will I lose my job/career/influence?
- Will I lose my independence?
- What does this mean for my lifespan?

I imagine these are much the same thoughts and questions you had when you (or your loved one) were first diagnosed with PD, and it is because of these shared feelings that he resonated so well with the group. He knows whereof he speaks!

Greg came up with a Vision, a Goal, and an Action Plan that has guided his way of living with PD.

As he researched his "new normal" he found out that PD is the 2nd largest neurological disease in America (the first being Alzheimer's).** Just as you use a compass for direction, he came up with the idea of finding the **True North for your PD Journey:**

- NORTH - INTELLECTUAL**
- SOUTH - SPIRITUAL**
- EAST - EXERCISE**
- WEST - SELF-EFFICACY**

North: Know the history of PD - +200 years
Ongoing learning of motor, non-motor, psychological symptoms
Establish a baseline - PLA, Hoehn and Yahr Scale
Numbers - 10M, 1M, \$25B

East: The Great Elixir of **exercise** - neuroplasticity
No two Parkinson's symptoms are the same
Dance/Boxing/Walking/Hoop/Yoga/Tai Chi/
Meditation/Music - 528 or 420 Hz
Neuroprotective properties

South: Just because our lives are out of our control, does not mean they are out of control!



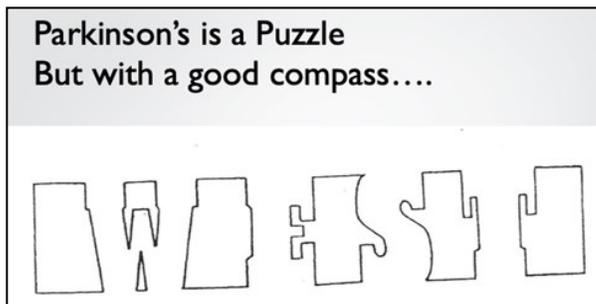
- Vision – Make Parkinson's wish it had never met me
- Goal- Be there to see my granddaughter walk down the aisle.
- Action Plan -THRIVE

FAITH does not make you better, it makes you "new" - my story
"Fear Not" +360X

West: Self-Efficacy... *A personal power or capacity to produce an intended effect.*

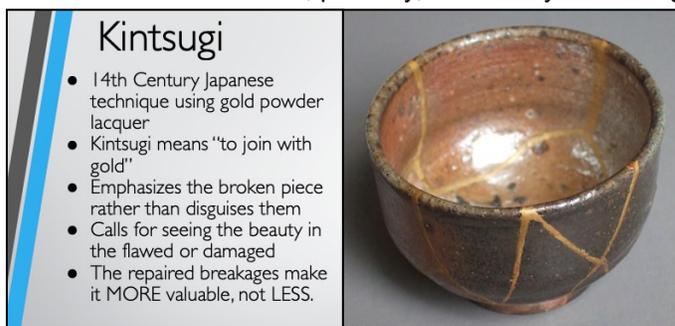
- PD Community!
- The placebo effect
- Power of positive thinking
- The power of attraction
- National, State and Local Advocacy

NOTE: Those in attendance were privileged to be inspired by Greg's explanation all of the "compass points" but they may not be obvious to you as you read them without the benefit of his elaboration. You may want to look into getting a copy of his book, "Rising Above Parkinson's" (Greg Ritscher), which is available on Amazon.



Do you see it? Can you read it? Once you do it pops out at you! His point was that, as a PWP we need to look at things differently to see things clearly.

Kintsugi... Never heard of it? Well, neither had we! Greg introduced us to a new word and, possibly, a new way of thinking:



- 14th Century Japanese technique using gold powder lacquer
- Kintsugi means "to join with gold"
- Emphasizes the broken piece rather than disguises them
- Calls for seeing the beauty in the flawed or damaged
- The repaired breakages make it MORE valuable, not LESS.

Kintsugi is a great way of looking at something differently. You can see how this can be applied to the way a person looks at him or herself. We aren't broken or of less value because we have PD!

Greg's title of an "inspirational speaker" is so appropriate. His insights to living with PD are truly inspirational and are evidenced by his enthusiasm and physical appearance. He is certainly living up to his initial aspirations and I am sure he will reach that goal of being at his granddaughter's wedding and seeing her walk down the aisle. True to his plan of action, Greg Ritscher is not just living with Parkinson's, he is thriving!

** Reports have now indicated that Parkinson's Disease has actually surpassed Alzheimer's as the most prevalent neurological disorder in the world.

Thank You!

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

November Newsletter
Input Deadline: October 11th

Call or e-mail Julie at:
[REDACTED]
db_mgr@co-parkinson.org

October CSPSG Executive Committee Meeting

October 8th at 09:30 am at a place to be determined

Contact Jill at president@co-parkinson.org if you haven't been to an Executive Meeting so we will know that you're coming and to get the address. Leave your email address so Jill can contact you if anything changes.

Parkinson's Disease Related Providers:

If you are seeing a provider not listed here that has given you excellent care with any Parkinson's issue, let Julie know at db_mgr@co-parkinson.org so that they can be added to this list.

The following providers have been recommended by multiple members:

Colorado Springs

Dr. Bradley Priebe, MD – Neurologist at Peak Neurology, PC; (719) 445-9902

Steven Swank, PharmD, BCACP – Peak Neurology, Clinical Pharmacist Specialist; (719) 445-9902

Dr. Aparna Komatineni, MD – Neurologist at Centura Penrose Hospital and UCHealth; (719) 694-3595

Dr. Andrea Manhart, DO – Neurologist at UCHealth; (719) 365-7300

Dr. Lael Stander, MD – Neurologist at UCHealth; (719) 365-7300 Note: Does well w/PD vision issues

Elizabeth Harmon, PA – UCHealth; (719) 365-7300

Melinda McClenden, NP – UCHealth; (719) 365-7300

Dr. Kevin Scott, MD – Neurologist at UCHealth; (719) 365-7300

Dr. Monica Stanton, MD – Primary Care Physician at UCHealth in Monument; (719) 364-9930

Dr. David Stevens – Neurologist at CS Neurological Associates; (719) 473-3272

Bettner Vision – Neuro-Ophthalmology Vision Therapy; (719) 282-0400

Denver

Dr. Michael Korsmo, MD – Neurologist at UCHealth, Anschutz Medical Campus; (720) 848-2080

Dr. David VanSickle, MD – Neurosurgeon at Neurosurgery One; (720) 638-7500
Note: DBS expert

Erin Van Dok, OD – Neurological Optometrist at UCHealth Sue Anschutz-Rodgers Eye Center; (720) 848-2020

Dr. Victoria Pelak, MD – Neuro-ophthalmology, UCHealth Sue Anschutz-Rodgers Eye Center; (720) 848-2020

Dr. Trevor Hawkins Neurologist at UCHealth Neurosciences Center, Anschutz Medical Campus; (720) 848-2080



Judy Allgeyer
Kathryn Allie
Steve Booth
Ann Brand

Joshua Campbell
Roger Christiansen
Richard Cobey
Mike Cunningham
Ruby Doyle
Eddie Edwards
Bobbie Hamilton
Phil Horton
Betsy Hughes
Steve Kozeliski

Linda Krager
Elaine Laue
Rudy Legleiter
Katja Pinion
Ed Pope
Sean Prescott
Gary Robinson
Ed Santos
Marda Santos
Maria Serna

Linda Marie Shrewsbury
Keith Smith
Jan Suhr
Rick Thomas
Scott Van Pelt
Charles Wells
Helen Zinn

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

Potluck Favorites—Shakin' & Bakin' Cookbook Now Available!

The updated cookbooks are here!

The price is a donation or free if you can't afford to donate. You can order them from Julie Pfarrer at db_mgr@co-parkinson.org.

The cookbooks are bound so that new recipes can be added in the future. So continue to send in your favorite recipes – old or new family recipes, newly discovered favorite recipes, etc.

We only want recipes that you have actually tried and liked – not ones that you think should be good but haven't tried or tasted.

All favorite recipes are welcome.

Send them to project@co-parkinson.org.



Recipe of the Month: Tomato Cucumber Salad with Cumin Vinaigrette

Our low carb/good fat ketogenic study showed incredible results. Not only was there remarkable improvement in the symptoms of Parkinson's but also with overall health in general (including the health of caregivers who chose to change their diet along with their Parkinsonian). Since it seems clear that everyone's health would improve exponentially if we all changed our diet to eat this way and since we have potlucks, we thought we would feature an easy low carb/good fat recipe or two in the newsletter each month to promote healthy eating.

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

Ingredients:

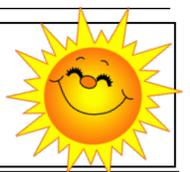
3 Tbl olive oil	Kosher salt
½ tsp (or more) cumin seeds, lightly crushed with the side of a knife	4 medium vine-ripened tomatoes, chunked or chopped
1 medium shallot, finely chopped	1 seedless cucumber, chunked
2 Tbl lemon juice	½ C chopped fresh fresh cilantro

Directions:

- Heat olive oil in small skillet over medium heat
- Add cumin and cook, stirring until fragrant, about 2 minutes
- Pour cumin oil into a large bowl and add the shallot, lemon juice and 12 tsp salt; cool slightly
- Add tomatoes, cucumber and cilantro and serve immediately

Help Spread Some Sunshine to Our Members!

If you know of a Parkinsonian or PD caregiver that is having a tough time (illness, surgery) or one of our members has passed away, please let our Sunshine Chairman, MJ Thompson know. She can be reached at [REDACTED].



Other Local Support Groups:

Parkinson's Caregivers Support Group

All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings. We meet the 3rd Thursday of each month from 10:00 to 12:00 at the Central United Methodist Church, 4373 Galley Rd, Colo Spgs, 80915. Contact Brenda Hicks at [redacted] or [redacted] to let her know you are coming.

Ladies w/ Parkinson's Support Group

If you are a fun-idea person, please consider volunteering to lead this valuable group. If you're interested please notify Julie Pfarrer at db_mgr@co-parkinson.org or [redacted].

Essential Tremor Support Group

Meeting Location: ENT Conference Room - Pikes Peak Library District.; Colo Spgs Library 21c, 1175 Chapel Hills Drive. For meeting dates/times or for questions, contact Jim Sanchez at [redacted] or [redacted].

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 info contact Syble Krafft at [redacted] or Barry Hanen-burg [redacted].

Other Opportunities:

Adult Speech Therapy:

Outpatient speech therapy services. Personalized speech therapy for restoration of function due to illness or injury.

Treating:

Parkinson's: Voice & Swallowing
- SPEAK OUT!
- LSVT

For more information, contact Jana Hothan, MA, CCC-SLP at slp@janahothan.com or by phone at (719) 338-8165.

Parkinson's Sing-a-Long Group:

Square Music Co offers individual music therapy services with Heather Johnson, MT-BC! Individual sessions can be held in person in the Colorado Springs area or via telehealth. Heather has over 5 years of experience working with neuro populations and hosts a Parkinson's singing group before each support group meeting at 9:30 am as well! Music therapy with Parkinson's works towards vocal strength, control, and longevity, increasing fine and gross motor skills, gait training, and other types of therapeutic goals through individualized music experiences. To learn more or schedule a free consultation, call/text Heather at (719) 345-2887 or email her at heatherjohnson@squaremusic.co.

PD Exercise Classes:

Falcon Exercise Group

Mon & Fri: 11:00 – noon, Grace Community Church. For more info contact Catherine Reed at [redacted]

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

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. Cost: \$10 a class

When: Every Friday at 10:30 am

Where: 525 E Fountain Blvd.

MACS–corner of Fountain & Royer

One-on-One Physical Therapy

For people with Parkinson's Disease and all movement disorders. Provided by Danielle (Spivey) Mulligan, PT, MSPT who is a Physical Therapist, Certified Vestibular Therapist, LSVT and PWR for Parkinson's.

Where: 5818 N. Nevada Avenue, Suite 325
Phone Number: (719) 365-6871

Neuroping for Parkinson's

Table tennis for Parkinsonians who want to improve both motor and non-motor symptoms and avoid mental decline.

WHEN: Tuesdays & Thursdays

TIME: 1:00 - 3:00 p.m.

LOCATION: Downtown YMCA

207 North Nevada Avenue
In the Small Gym

To sign up call the front desk at (719) 473-9622

For more information contact Travis Lerma at (719) 495-5130 or tlerma@ppymca.org. Neurologicrehab.com

Rock Steady Boxing – Boxing with Love

New Rock Steady Boxing for folks with Parkinson's Disease at the Boxing with Love Gym Tues @ noon (please come 15 min early if your first time) 1710 Briargate Blvd. Ste 100 (Next to Dicks Sporting Goods).

For more info contact Karen Bishop PT, DPT at love@rsbaffiliate.com

Max Capacity NeuroFitness

Free Boxing, PWR Bootcamp and Cardio Circuit for people with Parkinson's. Cognitive Cardio class available for \$10/class!

Physical therapist Emily Moncheski at Max Capacity, PLLC, offers individual Parkinson's physical therapy, most insurance accepted Conveniently downtown

525 E. Fountain Blvd. Suite 150

Contact Emily at emily@maxcapacitypt.com or call: (719) 213-3996, fax: (719) 284-4624

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 Tuesday at 11:30 am and 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. Contact Laura at laura.hymers@gmail.com or (719) 640-8478

YMCA PD Exercise Classes

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

Tri-Lakes YMCA: PWR!Moves;
Tues & Thurs, 1:00-2:00 PM

Briargate YMCA: PWR!Moves;
Mon, Wed, Fri, 1:30-2:30 PM

YMCA at 1st & Main; PWR!Moves;
Mon & Wed, 1:15-2:15 PM

For more info contact Travis Lerma at tlerma@ppymca.org

Colorado Springs Rocksteady Boxing

"Let's kick some PD BUTT!" Tues, Wed, & Thurs: 10am–11:15am & 11:45am–1:00pm
Location: Otis Park. 731 Iowa Ave. For more info, call Bill O'Donnell at (719) 243-9422

Neuro Logic Rehabilitation and Wellness

One-on-one physical therapy and wellness services for people with Parkinson's Disease and other movement/neuro disorders in the comfort of their home with outpatient mobile services. We come to you, to meet you where you are in your treatment & diagnosis!

Board Certified Clinical Specialist in Neurologic Physical Therapy Certified PWR! (Parkinson's Wellness Recovery) Moves Therapist

For more information, contact Ryan Mueller, PT, DPT, NCS at (719) 306-0009 or ryan@neurologicrehab.com

Neurologicrehab.com / Fax: (719) 691-7994

Ask Ann Bradley about the most amazing ping pong shot in the month of August!
Just call her Annie Oakley of Neuropong!



When Sleep and Parkinson's Disease Don't Behave as Allies

By Christine Scheer – Parkinson's News Today, 4/26/24
EVEN IF SLEEP ISN'T AN ISSUE, GETTING INTO BED CAN BE

Lying down and sleeping seems like such a natural thing to do. I remember when one of my mother's caregivers said to me, "I finally got your mother to lie down." What? My mother didn't know how to lie down? It's true: Dementia had robbed her of that seemingly straightforward part of her bedtime routine.

After I was diagnosed with Parkinson's disease in 2015, I wasn't the best sleeper. I would usually wake up in the middle of the night with tremors and worry for a few hours, then finally fall back to sleep about 20 minutes before my alarm went off.

Sleep hasn't been an issue since my deep brain stimulation surgery in 2021, but getting into bed is another story. John, my husband, calls it my reverse triple cannonball. He exaggerates on occasion.

AUTONOMIC IMPAIRMENT LINKED TO SLEEP PROBLEMS IN PARKINSON'S

The problems started when we got a new mattress two years ago. It's super comfy to sleep on, but it is 1 or 2 inches higher than the old one. It's difficult for me to climb onto it, so I kind of do a backward leap, then roll to the left, roll to the right, and eventually get comfortable. Meanwhile, if John has gone to bed first, all this commotion wakes him up.

The other option is to climb onto the mattress on my hands and knees, but then I usually freeze with indecision about how to lie down from that position. Then I have to wake John up for help, anyway. Triple cannonball it is.

Luckily, I sleep very soundly these days, only waking up if nature calls or I have a terrible dream. These nightmares have only happened to me a couple of times, but the most recent one was the most alarming. Some people with Parkinson's have frequent nightmares. There doesn't seem to be a specific reason; it's just another unasked-for gift from Mr. Parkinson's.

Don't you hate it when people insist on telling you their dreams? I won't tell you the dream, but I will tell you that it happened on our holiday in Portugal, and John had to wake me up because I screamed so loudly I woke up all the dogs in the neighborhood. Who knows about the other hotel guests? If I didn't wake them, the barking dogs probably did. I think they were probably relieved to see us both at breakfast in the morning, just to ease their minds that nobody was murdered during the night.

WHEN IT'S SNOWING INDOORS

I follow all the advice about getting a better night's sleep. Keeping the room cool is one crucial factor. We usually open our windows, even in the middle of winter, and snowflakes often blow in. Honestly, I don't even mind that. Even though it might be cold getting into bed, my body temperature has skyrocketed within 20 seconds, and I'm usually kicking the covers off.

Once awake, turning over in bed is very awkward. You can get special silky sheets that make turning over easier, but I have yet to go there. I'm worried I'll slip and slide right onto the floor. In the meantime, I use my regular cotton sheets to help me move. If they are tucked in correctly, I can get enough leverage to flip myself over. It's not graceful, but it works.

How did a simple good night's sleep become so complicated and my body so unwieldy? These are good questions — best answered in the morning.

Being a Caregiver is Hard, Making Self-Care and Support Crucial-Asking for Help Makes Me a Better Caregiver and Partner

By Jill Hammergren, Parkinson's News Today, August 22, 2024

Many of us readily lend a hand when a loved one, friend, or neighbor needs support, especially if it's a one-time occurrence. These are typically straightforward things like driving them to an appointment when their car isn't working, providing a meal when they've had an illness or death in the family, or gathering the mail while they're on vacation. However, few of us sign up to be full-time caregivers.

Sometimes we assume that role, though, because a loved one faces challenges with abilities or illness. In my case, I'm married to someone with Parkinson's disease.

Former First Lady Rosalynn Carter had great insight into caregiving when she created the Rosalynn Carter Institute for Caregivers in 1987. "There are only four kinds of people in the world," she once said, "those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers."

FINDING A SUPPORT NETWORK

Each year, tens of millions of adults in the U.S. care for a child, parent, or other relative. Many of us who care for our spouses also do so for children, and if we're in that "sandwich generation," we also care for parents or grandparents. A recent report by AARP noted that 38 million of us are unpaid family caregivers providing the equivalent of \$600 billion worth of care each year.

No one prepares you for the rigors or the emotional toll of caregiving. I'm embarrassed to admit that my loving nature, of which I'm proud, often instantly turns into sharp-tongued and short-tempered reactions, which I always regret. I quickly apologize to Eric, my husband of 29 years, when I let the anger, frustration, stress, and other emotions get the best of me. I never want to be that person. I love Eric and hate how Parkinson's has changed both him and me.

That's not an excuse, though, and I'm not seeking a pity party. The truth is that we caregivers need support, too. Eric and I are in the 10th year of his Parkinson's journey. Two years ago, I finally turned to a counselor to help me focus more on self-care. Since then, I've learned to meditate, keep a journal, and go for walks. Today, I have a fantastic support network.

Me and my Rock Steady Boxing support group besties. From left, Shirley Blackorby, Bev Manifold, Jill Hammergren, Liza Gettles, Julie Crisson, Faye Woodall, Betty Hardy, Sylvia Wilson, Dee Laughner, and Rhonda Miller. (Courtesy of Julie Crisson)

Eric and his fellow fighters attend Rock Steady Boxing classes three times a week, where they share experiences and fight to live their best lives possible. The spouses of this group, myself included, also share something profound. We rely on one another for friendship, love, and support. I don't know what I'd do without those incredible people. We laugh and cry together, share ideas, and lament difficult situations. We're in it together, and I'm forever grateful to have them in my life.

Additionally, even though it's hard to do, I've occasionally asked for help so I can do things to fill my own cup. I've learned that it's something I must do to be a better caregiver and partner for Eric. One such event happened last year when I swallowed my pride and asked Eric's brother, Dave, if he would travel from Minnesota to North Carolina to stay with Eric while I went to Berlin to volunteer for the Special Olympics World Summer Games. I'm so grateful that he agreed to do it.

The Special Olympics Media SOS team in Berlin in 2023. From left, Polly Bruce, Nance Larsen, Steve Bruce, Sarah O'Toole, and Jill Hammergren. (Courtesy of Jill Hammergren)

I've volunteered for the Special Olympics for over three decades, and it brings me joy and inspiration to see the athletes' incredible talents and the heart-centered people involved in the organization. I'm part of a uniquely talented team that facilitates media coverage for the athletes and the global movement. These enduring friendships are something I deeply treasure, and I'm truly grateful for all of the love and support I receive.

As a caregiver, it's easy to think that I'm alone in the struggles of trying to do everything right for Eric. But I'm not alone, and neither are you. We don't exist in a vacuum. At some point in our lives, we all provide care and need to receive care. I must remind myself (and every other caregiver) that it's OK to reach out and ask for help, and that it's vital that we practice self-care.

Drug's 'Life-Changing' Effect on Man with Parkinson's

By Dan Martin, BBC News, July 18, 2024

A man living with Parkinson's has said a new drug has transformed his life in a matter of days.

Damien Gath, 52, has experienced years of daily involuntary shaking and pain caused by the neurological condition, which he said made everyday tasks a struggle.

Mr Gath became the first patient in the East Midlands to be treated with a new drug, Produodopa, last week.

His wife Amanda filmed him before treatment and its "extraordinary and life-changing" effects two days later.

Mr Gath was first diagnosed with the disease, a condition in which parts of the brain become progressively damaged over many years, 12 years ago.

Parkinson's does not directly cause people to die, but the condition can place great strain on the body and make some more vulnerable to serious and life-threatening infections, the NHS says.

Mr Gath underwent treatment with new infusion therapy on 10 July.

Before the treatment, Mrs Gath

filmed him at home shaking as he tried to make a cup of coffee.

She then recorded him doing the same thing two days later with no involuntary movements.

"I almost can't believe that's me in the video," Mr Gath told the BBC.

"For the last three years I have been shaking uncontrollably for two to three hours a day, every day.

"It's early days but now I shake for five or 10 minutes a day."

He added: "It's been extraordinary and life-changing – just shortly after first having the treatment, I was able to make a cup of coffee more easily.

"I can go to the supermarket without throwing eggs all over the aisles.

"I can go to the pub without people thinking I'm just really drunk.

"I can start to think about getting back to a normal life."

HOW DOES PRODUODOPA WORK?

Produodopa is a combination of two drugs - foslevodopa and foscarbidopa.

It works by turning foslevodopa into

the chemical dopamine, which helps transmit messages between the parts of the brain and nerves that control movement.

That helps manage Parkinson's symptoms, such as excessive movement or tremors.

The infusion enters the patient's bloodstream through a cannula under the skin and is controlled by a small, automatic pump, releasing a steady flow of the treatment 24 hours a day to stay on top of symptoms.

It also has the option of a manual boost if needed.

Mr Gath said his condition had been getting worse, and he had been taking four separate oral drugs, six times a day, to try to control his symptoms, which have also included constant muscle pain.

He said he had been in considerable pain at night and unable to sleep, experiencing significant fluctuations in his condition as the effect of the oral drugs reduced during the night.

He said the pump now steadily released medication into his bloodstream around the clock.

"The massive difference is that there are now no fluctuations," he said.

'NEW ERA OF TREATMENT'

Mrs Gath said: "We have always tried to continue to do normal everyday things like going out for a meal.

"But sometimes it was difficult to deal with the lack of understanding from people around you and that made me very protective of Damien.

"Now, we are just like any other couple enjoying themselves."

Mr Gath, from Derby, has been in the care of Sherwood Forest Hospitals (SFH) NHS Foundation Trust in Nottinghamshire since 2016.

The trust's consultant geriatrician and service lead for Parkinson's, Dr Nishantha Silva, said: "We are proud to be the first trust in the East Midlands to offer this and aim to build on this success by expanding access to Produodopa.

"The successful implementation of Produodopa at SFH heralds a new era in the management of advanced Parkinson's disease."

Spinal Cord Stimulation May Aid Parkinson's Posture Problems: Study

By Lindsey Shapiro, PhD, Parkinson's News Today, June 11, 2024

In SCS, small electrical currents are delivered directly to nerve cells in the spine

Spinal cord stimulation (SCS) was able to safely improve postural problems for people with Parkinson's disease, according to a very small trial in China.

Among the six patients who had the procedure, some gains in aspects of motor function were observed, although the findings were variable, but the researchers say they offer proof-of-concept for more studies to explore the benefits of SCS in Parkinson's.

"The short-term and long-term effects of SCS on patients with [Parkinson's disease] constitute a highly valuable research topic," the scientists wrote in "[Spinal cord stimulation for postural abnormalities in Parkinson's disease: 1-year prospective pilot study](#)," which was published in *BMC Neurology*. "Clinical trials with a large number of participants are needed."

Problems with posture are common in Parkinson's. They can arise from muscle stiffness and rigidity or from changes in nerve circuits in the brain and spine involved in automatically correcting posture.

Postural issues may include anterior thoracolumbar flexion, where the trunk of the body leans forward, or is "hunched" toward the ground, or lateral trunk flexion, where the trunk leans to one side. These issues can make patients less stable when walking, increasing the risk of falls.

The symptoms don't always seem to respond to standard Parkinson's medications, especially as

they become more advanced, so new ways to manage these issues are needed.

DBS may best help Parkinson's patients with posture and gait issues

TREATING POSTURAL ISSUES WITH SCS

SCS, where small electrical currents are delivered directly to nerve cells in the spine, has been considered for various symptoms of Parkinson's disease. It's not known exactly how it works, but it's thought to be able to reset motor nerve circuits in the spinal cord.

It's similar to deep brain stimulation (DBS), an approach already used to ease Parkinson's motor symptoms, but targets nerve cells in the spinal cord rather than the brain.

Small studies and case reports have found the procedure can ease pain and improve gait problems for patients. SCS didn't improve mobility in advanced Parkinson's patients in a clinical trial, however.

Here, the scientists reported findings from a pilot study (ChiCTR1900024326) wherein SCS surgery was performed in six patients with postural abnormalities (mean age, 70), at their hospital in China.

The surgery involved implanting small electrodes into the lower thoracic area, a middle section of the spine, to which an external stimulation device can deliver electrical currents to nerve cells.

The patients were followed for a year after surgery, during which time they continued on any

standard Parkinson's medications. Assessments of posture and motor function were performed when the patients were actively on medication and the SCS stimulator was turned on.

A significant improvement in posture was observed at the one-year follow-up compared with before the surgery, or baseline. Specifically, the mean lateral trunk flexion degree improved by 58% and the anterior thoracolumbar flexion degree improved by an average of 32%.

Motor function didn't significantly improve, but most patients saw some improvements in rigidity, finger and toe tapping, and motor function of the lower extremities.

Three patients were tested separately in the SCS on-state and off-state to confirm the surgery's efficacy. These patients generally saw improved spine angles and better motor function scores when the stimulator was on than when it was off.

The surgery and stimulation were safe and no adverse events were reported.

The researchers believe the findings support using SCS for managing posture problems in Parkinson's.

"Lower thoracic SCS may be effective for improving [postural abnormalities] in [Parkinson's disease] patients, but further studies are needed to confirm this conclusion," wrote the researchers, who noted the "mechanism of how SCS works on posture is not very clear" and may involve various areas of the spinal cord and brain.

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PARKINSON'S PERSPECTIVE

OCTOBER 2024

Coming Events

See inside for more information

October 5th - Reg Mtg at Central United Methodist Church – 10 am

Program: Pat Yourself on the Back – You're Making Such a Difference in the Parkinson's World!

Speaker: Dr. Melanie Tidman, DHSc, M.A., OTR/L, MHP

November 2nd - Reg Mtg at Central United Methodist Church – 10 am;

Program: Break-Out Sessions; Caregivers & Parkinsonians separate into different rooms to talk

December 7th - Reg Mtg at Central United Methodist Church – 10 am;

Program: Christmas Party!!!! - The Song Spinners will entertain us!

January 4th - Reg Mtg at Central United Methodist Church – 10 am;

Program: Parkinson's 101; **Speaker:** Jill Reid, Education Outreach

February 1st - Reg Mtg at Central United Methodist Church – 10 am;

Program: Break-Out Sessions; Caregivers & Parkinsonians separate into different rooms to talk

March 1st - Reg Mtg at Central United Methodist Church – 10 am;

Program: Scam Prevention; **Speaker:** Scott Mathis, Colorado Springs Police Department

More useful websites:

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