



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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Educational Outreach: Jill Reid
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Photographer: Vacant

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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).

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

We will NOT be Zooming or recording this meeting.

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

9:30 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: Break-out Sessions

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



The June Potluck Main Dish – Taco Bar!!

— Taco meat and shells will be provided —

Suggested side dishes to bring:

- Taco toppings such as: chopped tomatoes, chopped avocado, guacamole, shredded cheese, cilantro leaves, sour cream, shredded lettuce, etc.
- Mexican related side dishes such as: bean dishes, salads, etc.
- Desserts



If you would like to sign up to be one of the providers of a main dish or a side dish/dessert for the June meeting, you can contact Bill Hicks at [redacted] or potluck@co-parkinson.org, no later than Wed. June 8th and tell him what you would like to bring.

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



Over the years, we have shared some delicious potluck dishes at our monthly meetings and many of you have expressed interest in making those recipes available to the membership. It just so happens that years ago, probably close to 30 years ago, the support group did put together a cookbook featuring some of the group's favorite potluck recipes.

Sherry Whitaker has volunteered to lead a new effort to add new favorite recipes to the original cookbook using your favorite recipes – old or new family recipes, newly discovered favorite recipes, etc. We only want recipes that you have actually tried and liked – not ones that you think should be good but haven't tried or tasted. They don't have to be gluten-free or Keto. We will, however, indicate which ones fit those categories. We will also add a conversion table that will tell you how to convert ordinary recipes into gluten-free or Keto recipes if you would like to know how to do that.

All favorite recipes are welcome
Send them to Sherry at project@co-parkinson.org.

The President's Corner

| Jill Reid - Acting President, CPF & CSPSG

For those of you who have heard my "Parkinson's 101" presentation and attended our meetings, you know that I advocate humor as a positive tool for living well with Parkinson's disease. During the annual "Parkinson's 101" presentation, I urge listeners to watch as many funny movies or TV shows as possible and to laugh a lot. I tell silly jokes at our monthly meetings. I'm very intentional in both.

I found a relevant article by Laverne H. Bardy in May 2022's [Life After 50](#). It spells out why humor is so important to everyone, but especially to people living with chronic disabilities and diseases. Here it is, with one editorial remark:

"The more you can find to laugh at, the happier you'll be. Plus, laughing has many health benefits, such as: lowered blood pressure, reduced stress [a killer of carb-levo, by the way], diminished depression, and reduced aggression. Studies show that laughing more may be as important as exercising, not smoking, and eating right. Laughter also produces an overall sense of well-being and makes your heart healthier. It's the pressure valve that gets us through daily obstacles and challenges.

"Funny things happen all around you all the time if you're tuned in. Like the time I waited for over half an hour in a crowded deli store before

realizing I'd forgotten to take a number. Even though life isn't fair, when you laugh at yourself or at your situation, you're in control of your life."

Laverne is spot on.

I always admired my brother-in-law's use of humor to put people he was meeting for the first time at ease when he couldn't hide his Parkinson's symptoms. He'd introduce himself, his hands shaking as usual, and say, "I make a great martini—shaken, not stirred." Or "At campouts, I'm the expert in making the Jiffy Pop popcorn." Or "I'm especially good at spreading grass seed by hand." Anything that made light of his symptoms and put the listener at ease. It helped him, too, to diminish what could otherwise have loomed overwhelmingly large in his life.

So, the moral of the story is that we all should incorporate humor into our lives. Every day!

Have you heard the one about the pterodactyl going to the bathroom? You can't hear it because the "p" is silent.



Getting To Know You: Travis Chastain

| by Mike Koloski

I love my job! I have never had a job (for pay or as a volunteer) in which I have met, interviewed, and learned so much about and from truly interesting and amazing people! **NO** you can't have it!



Today, I urge you to meet, talk with, and get to know Travis Chastain, a native of Colorado. Travis was born and raised in Eagle-Vail. As a youth he skied his heart out. And — when not on the slopes he

was in the Do-Jang learning, practicing, and eventually teaching Taekwondo or Hapkido. Through martial arts Travis developed a love for teaching others. He was convinced that becoming an educator was his calling. Such was the case until he picked up a guitar and began to play.

It was love at first sight (or rather strum). Travis studied and played classical guitar for four years and it became the center of his life.

Travis explains, "When I was introduced to the classical guitar there was something so deep, so warm, and so amazing about it. It spoke to me deeply and it became the passion in my life."

After that 4 years of private study he auditioned and got into the University of Denver to study classical guitar performance. After he had attained his Bachelor's Degree he continued work towards a Masters degree in music performance. Travis was convinced he had found his life's work but Life had a further challenge in mind.

Here's how Travis tells the story. "In my senior year of college I was involved in a car wreck that would change my life forever. My neck cracked during the accident and a time bomb was set to go off. Two years later after a gradual and painful degrading of my health, I lost function in my right arm and no longer could play the guitar."

After exhausting traditional therapies such as physical therapy, massage therapy, and spine surgery with no improvement in his health, Travis used the Alexander Technique. The Alexander Technique is a 150-year-old educational method that teaches one how to organ-

ize and align on-self optimally in movement, to gradually improve posture on and off the guitar. It proved so successful that he could return to the guitar and finish his Masters degree.

Travis feels that "the Alexander Technique saved my life. It gave me a way to manage what was unmanageable in the past. It gave me a way to improve without undue strain and to move in all things healthfully. Most importantly it gave me hope. Hope that I could still play music, and live the life that I wanted."

Travis decided to become a certified Alexander Technique teacher, and undergo the 3 year- 1600-hour training process to become one. Says Travis, "It has become a passion and obsession of mine to research the Technique, lecture, and teach it to help people with Parkinson's disease manage their symptoms. To help people with chronic back pain move towards health. To help people with chronic joint pain, performance anxiety, or breathing and speech difficulties move towards Freedom."

I urge fellow PWPs to meet and Get to Know Travis Chastain. Travis has helped me — perhaps he will help you.

DBS, but not Medications, Seen to Ease Gait Changes Tied to Fall Risk

By Lindsey Shapiro, PhD – Parkinson's New Today, 5/18/22

Gait variability, or changes in stride while walking that associate with a greater risk of falls in people with Parkinson's disease, significantly eased with patients' use of deep brain stimulation (DBS) but not dopamine-increasing medications, a study showed.

"We found that ... DBS reduced step-to-step variability in a range of lower limb gait parameters in

[Parkinson's], whereas dopaminergic medication had no significant effect," the researchers wrote.

These findings suggest that gait variability may not be driven by dopamine-dependent mechanisms, with the scientist proposing that a specific group of nerve cells, which DBS can modulate, are involved instead.

The study, "Deep Brain Stimulation and Levodopa Affect Gait Variability in Parkinson Disease Differently," was published in *Neuromodulation: Technology at the Neural Interface*.

Parkinson's is characterized by the progressive loss of motor abilities and other non-motor symptoms arising from the degeneration of dopamine-producing nerve cells in the

brain. Levodopa, a dopamine precursor that is found naturally in the body, and other dopamine-enhancing medication are often used to treat patients.

Deep brain stimulation (DBS) is sometimes also used alone or in combination with dopaminergic medications. DBS involves the delivery of electrical pulses to the brain's subthalamic nucleus,

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A Phenomenological Study of Wives Caring for Their Husbands with Parkinson's Disease



Dawn R White, PH.D., MS, RT(R)
May 2022



CPF Presentation May 14, 2022

Dr. Dawn White introduced herself and thanked the 13 spouses who participated in her study and the Colorado Parkinson's Foundation for the support it provides to people with Parkinson's and their caregivers. She then explained that "phenomenological" simply means lived experiences of the wives caring for their loved ones with Parkinson's.

History and Background

Discovered by James Parkinson in 1817, the disease became commonly known as Parkinson's disease in 1865. Hallmark symptoms include brain fog, tremors, muscle rigidity, depression, anxiety, difficulty with walking and balance, dystonia, rigidity, and cognitive decline. 68% of people with Parkinson's are men, and 65% of caregivers are unpaid female spouses.

Hoehn and Yahr Stages I-IV

Stage	Parkinson's Disease Symptoms	Implications for Daily Activities	Caregiver Responsibilities
1	Involvement on one side with little or no impairment.	These patients have fewer symptoms and most symptoms are associated with aging.	There is no need for caregiver intervention at this stage. Life is normal.
2	Bilateral involvement without balance concerns. Some patients begin to notice tremors.	Patient notice mild symptoms and daily living becomes more difficult. Walking, balance, and facial expressions become challenging.	There is a need for more assistance as walking become increasing difficult. Patients are still able to manage daily care.
3	Mid-stage with more severe total body involvement. Decreased reflexes and equilibrium unsteadiness.	Patient is still able to work in certain circumstances. Still able to live independent but their disabilities are mild to moderate.	Some assistance with movement; however, the increase chance of falling put caregiver on alert.
4	Severely disabled and independence is reduced. Walkers are required.	Limitations occur with all aspects of daily living. Unable to leave home unassisted.	Increased assistance as patient is unable to eat, bath, dress or walk without help.
5	Confinement to bed and wheelchair. Debilitating stage with delusions, sleep disturbances and cognitive changes	Patient is unable to do anything on their own. All activities of daily living occur with outside assistance.	Complete care and caregivers usually search for outside assistance.

Although there are five Hoehn and Yahr stages of Parkinson's disease, this study only looked at those in Stages 2, 3, and 4. In Stage 2, spousal caregivers notice that the spouses are starting to have trouble walking. In Stage 3, their focus is on preventing falls. In Stage 4, their loved ones need help with most activities of everyday living, such as eating, dressing, and bathing.

The caregivers tend to try to meet all their spouses' needs, but this takes a toll on the caregivers. They experience increasing stress (for instance, from financial issues) and physical pain (women caregivers over 65 have their own physical limitations). Caregivers forget to take care of themselves.

Caregivers experience both burden and benefit. Their burdens come from caregiving's becoming a full-time job, leading to overwhelming exhaustion and perceived low quality of life. **But there are a lot of benefits for the caregivers as well.** They operate in love and compassion and experience personal growth in learning how to listen to what their spouses are saying, increasing their patience and understanding, gaining mutual respect, and building inner strength.

Conceptual Framework and Study Methods

Dr. White used three theories to understand the how wife adjusts to her role

as caregiver:

1. Caregiver Identity Theory. The caregiver alters her goals in order to concentrate on the spouse's needs. This results in isolation, anxiety, and a deterioration in the spousal relationship.
2. Self-Determination Theory. The caregiver focuses at the "why" of caregiving. Once the caregiver identifies her autonomy, competence, and relatedness to the spouse, she experiences increased well-being and improved mental health.
3. Theory of Human Caring. This theory explains how nurses work with patience. It uses the lens of carative factors, caring relationship, and tender moments. It enables the caregiver to see the relationship as a relationship between a wife and a husband as opposed to a relationship between a caregiver and a patient. If it's done properly, the caregiver experiences kindness, faith, hope, sensitivity, and spirituality.

The purpose of Dr. White's study was to capture the caregivers' lived experiences and to identify the support needed to maintain their pre-Parkinson's disease social connections and live a healthy lifestyle independent of their spouses' condition. Consequently, she asked the question, "What is the lived experience of women caring for their male spouses living with Parkinson's disease in their homes?"

The study used a qualitative phenomenological descriptive design, recruiting from the Colorado Parkinson Foundation through flyers and emails. She recruited 13 participants, wives who were aged 50-85 and were living in Colorado Springs. In order to be a participant in the study, each woman had to be a current caregiver of a male spouse who had Parkinson's disease and was in H-Y stages 2, 3, or 4. She had to be 50+ years old, live in the home in Colorado Springs, and speak fluent English. Excluded were wives whose spouses were in H-Y stage 1 or 5, who had been caregiving for less than 6 months, who spent less than 50 hours a week caregiving, whose spouses were not living at home, and who were unable to speak English fluently.

Dr. White collected her data by conducting a 30-60-minute conversational interview with each participant. These were audio-recorded using Zoom. She received signed informed consents from each participant. She continued the interviews to data saturation, the point at which she was stopped getting different answers to her interview questions. Once she received verbatim transcripts of the interviews, she reread them and compared them to the audio recording. From the data she collected, she identified one main concept, five themes, and 15 subthemes. She may try to take the same study to Peru with a colleague there.

Dr. White found the data she collected to be trustworthy and all ethical considerations met, including confidentiality. Each participant was known only by the name of a flower that the participant chose to represent her.

Study Results

The overarching concept of the collected data is that there is no cure for the caregiver. According to Rose, "I don't know if there's anything in any study that could help the caregiver. What could you people possibly do for a caregiver? I don't know. I have my son-in-law coming in and relieving me sometimes which is the only thing that you need a break. I thank God for that, I do have a break, but **there is no cure for caregiver.** There is no cure." The participants saw caregiving as a responsibility with the emotionally- and physically-demanding

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Recipe of the Month: Mexican Summer (Olive) Salad | Serves 4-6

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.

- Dressing:** 2 tsp whole cumin seeds
2 tsp whole coriander seeds
*1 chili de Arbol, torn into small pieces
- Salad:** ¼ C pitted & halved Kalamata olives
¼ C pitted & halved green olives
¼ C halved assorted colored cherry or grape tomatoes

- ¼ C pine nuts
½ C olive oil
Kosher salt & pepper

- ¼ C chopped cilantro
8 oz feta cheese, cubed



In a small, dry skillet, toast cumin, coriander, chili & pine nuts over medium high heat, stirring constantly, until fragrant, about 3 minutes. Transfer the dressing to a serving bowl & whisk in the olive oil. Season with salt and pepper, to taste. Add the olives, tomatoes, cilantro and cheese. Toss gently to combine and serve.

*The dried chili can also be cut into small rings using scissors.

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

Parkinson's Caregivers Support Group
All family caregivers of persons with Parkinson's are invited to come and participate in our discussion meetings. We meet the 3rd Thursday of each month from 10:00 to 12:00 at 6310 Gemstone Way, Colo Spgs, 80918. Contact Brenda Hicks at [redacted] or [redacted] to let her know you are coming.

Tri-Lakes Parkinson's Support Group
Meets the 3rd Saturday of every month at 10 am at the Monument Community Presbyterian Church, 238 3rd Street, Monument. For more information contact Barry Hanenburg at [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 & cleanup at the last meeting!

Born in June
HAPPY BIRTHDAY! ENJOY YOUR MONTH!
Your birthday isn't listed? Fill out the membership form and check BD listed "YES".

- | | | | |
|---------------------|------------------|----------------|-----------------|
| Robert Adams | Donna Kring | Ronald Morris | Mary Sauvain |
| Donald Ader | Mark Lekarczyk | Bill Noe | Danel Skousen |
| Penny Austin | Michael McCraley | Jon Nordby | Cindy Stempson |
| Deloit (Dee) Beatty | Rusty Merrill | Ronald Null | Celine Terrell |
| Mark Finger | Suzanne Metzler | Patricia Plank | Sherry Whitaker |
| Carla Holland | Marty Mille | Julie Rush | |
| Mike Koloski | Art Moore | Larry Rush | |
| Charles Kovac | Dave Moross | Jean Saunders | |

June Executive Committee Meetings
June 14th 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.

July/August Newsletter Input Deadline: June 15th
Call or e-mail Julie at: [redacted]
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 and down a staircase. This one is for a 14 step or less straight staircase with no turns. If you would like to borrow any of the equipment listed here, please contact: Rich Sauvain at [redacted].	3-wheeled walker	1	Double exercise pedals	1	Swivel seat	1
	Back brace	1	Exercise bike	1	Toilet arm assist	1
	Bed cane	3	Lift chairs	2	Toilet seats	3
	Bed pan	1	Lift-ware tremor compensating utensils	1 set	Transport chairs	3
	Bed rails	1	Pick-up assist	6	Tub rail	2
	Bed risers	1 set	Shower benches	9	U-step	4
	Bedside toilets	6	Sock helper	2	Walkers with wheels & seat	11
	Canes	7	Stair chair rail system	1	Wheelchairs	7
	Crutches	2 sets				

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 jlclayton@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]

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.

A CPF Charitable Giving Opportunity!

Another reminder about an easy and painless way for you to help CPF. An ongoing charitable giving opportunity each time you order merchandise from Amazon. It's called **Amazon Smile**. Colorado Parkinson Foundation (which includes CSPSG and all its other support groups) is listed with Amazon Smile as a charity that you can generate donations for. Rather than starting your Amazon shopping by pulling up **Amazon.com**, type in **SMILE.AMAZON.COM** instead.

The first time you do that you will have to designate Colorado Parkinson Foundation, Inc. as the recipient of charitable donations based on your purchases. From then on 0.5% of the eligible purchase prices you place through Amazon Smile will automatically generate donations from Amazon to CPF – at no cost to you!

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

SAD NEWS



Rev. Alan Filippi, 73, returned to his Lord and Savior on April 6, 2022. He was born in California and attended Fresno State and Northwest Christian College in Eugene, Oregon, graduating in 1971 with a Bachelor of Theology.

Alan met his wife, Dorothy, at Northwest Christian College as both were members of the college music groups. They married in 1970 and in 1971, he was ordained into the ministry of the Christian Church, Disciples of Christ.

He attended Brite Divinity at Texas Christian University in Fort Worth. While there, they served student pastorates at Princeton and Plano, Texas. After receiving a Master of Divinity in 1974, they moved to Fort Collins where they were on staff at First Christian Church. In 1985 they moved to Colorado Springs to a church pastorate and in 1990 he became a chaplain at Penrose Hospital. Due to health issues, he retired in 2010.

Alan is survived by his wife, son, daughter-in-law and four grandchildren.

Alison Meyer, 72, passed away on April 4th. Alison was raised in Tonawanda, NY and was a vivacious, beautiful, smart and caring person who was connected to her family and friends, being the glue that kept many together. She was generous of spirit and a caring person, always willing to support the people in her sphere. Nature and stunning landscapes thrilled her, and well-crafted language in good books fed her soul.

Alison is survived by her husband, Randy, her son, Todd, two granddaughters and two sisters.



Jack Dashosh passed away on May 19th. Jack was born on the Lower East Side of Manhattan in a 5-story tenement. After his family moved to Brooklyn, he graduated from New Utrecht High School in 1959, received a B.A. from the Baruch School of Business in Manhattan and attended New York University Law School where he received a Juris Doctorate Degree in 1965. After working for several law firms in New York, he became the General Counsel to Vornado, Inc. in New Jersey and opened his own law firm in 1979.

Jack met and married his wife, Pat, in late 1968. They were both active in the local community theatre group and in The Garden State Yacht Club in New Jersey where he became the Commodore in 2007.

In 2015 Jack was forced to retire because of health issues and they moved to Colorado to be near their daughter, Danielle. He was diagnosed with Parkinson's Disease in November of 2017.

Jack is survived by his wife, 3 children and 12 grandchildren.

(...continued from page 2)

which has been implicated in Parkinson's. These pulses are thought to disrupt abnormal nerve signaling and restore more normal nerve firing.

The greater the gait variability, or stride-by-stride fluctuations, in people's Parkinson's, the greater is their likelihood of postural instability and falls. While the effects of levodopa or DBS on other gait features, like speed, are well-established, their effects on gait variability remain unknown.

Researchers, largely in the U.K., evaluated several gait measures in 26 Parkinson's patients while both on and off treatment with dopaminergic medications or DBS. Participants were recruited through the Oxford Quantification in Parkinsonism study (NCT04139551) at the John Radcliffe Hospital in Oxford.

Among those with Parkinson's, 15 used dopaminergic medications only and 11 had undergone DBS. Of note, 10 or 11 people using DBS were also on dopaminergic medications, which remained in use throughout the study.

All participants wore a device called inertial measurements unit (IMU) – with synchronized sensors positioned on both wrists and feet, the trunk, and lumbar area of the lower spine – and performed a walking test during on- and off-therapy phases. For patients using DBS, this meant they performed the test either when the stimulator was turned on or 30 minutes after it was turned off. For those on medication only, the test was performed one hour after taking medication and again at least 12

hours after a last dose.

The study also included 42 age-matched healthy volunteers, who were used to calculate age-matched normal ranges for the gait analysis.

Patients' mean age in the DBS group was 58.9 years, and their average disease duration was 10.7 years. Among the dopaminergic-medication group, the mean age was 64.9 and the disease duration was 8.8 years.

Participants were asked to walk for two minutes along an uncarpeted 15-meter (almost 50-foot) corridor.

Results generally showed that DBS use, but not dopaminergic medications, led to a lesser gain variability in a number of lower limb gait measures, including toe-out angle and single-limb support.

"We found that STN [subthalamic nucleus] DBS reduced step-to-step variability in a range of lower limb gait parameters in PD, whereas dopaminergic medication had no significant effect," the researchers wrote.

Dopaminergic medication did, however, lead to significant improvements in other lower and upper limb features, including a more normal stride length and foot strike angle – the angle at which the foot hits the ground during a step. Benefits were also seen in a better range of motion of the arms and trunk.

DBS also led to significant improvements in foot strike angle.

The findings overall suggest that while dopaminergic medication may improve some features of gait, "STN stimulation, but not dopa-

minergic medication, modulated the [nerve] circuits that control gait rhythm," the researchers wrote.

It has been suggested that gait rhythm disturbances may not be caused by dopamine dysfunction, but instead by the degeneration of cells that produce a neurochemical called acetylcholine in the brain's predunculo-pontine nucleus (PPN). The subthalamic nucleus communicates with the PPN, and thus DBS could indirectly target these cells, the researchers suggested.

"Because the proposed mechanism is cholinergic [involving acetylcholine], this is something that dopaminergic medication should not do," they added, which could explain the observed lack of effect of medication on gait variability.

While DBS, by lowering gait variability overall, may be helpful in preventing falls in Parkinson's patients, it cannot be determined that gait variability alone causes such falls, the researchers pointed out. Further assessments are needed to "know if the difference in the effect of DBS and medication on gait variability is large enough to be clinically important."

Researchers also noted that "the lack of effect of medication" on gait variability seen in this study "is at odds with previous literature," which they suggested could be due to differences in "the way in which variability is being measured."

Results in tests of patients under DBS, however, "back the conclusion of an earlier work," the team added.

(...continued from page 3)

work required to support their husbands as the Parkinson's progressed.

There is No Cure for Caregiver

➤ Caregiver Who?

- Early Years
- More Caring Less Curing
- Living in the Shadows

➤ Taking it Day by Day

- Golden Years
- Who's Gunna Help Me?
- Climbing the Mountain

➤ Not Sure What to Do Next

- It's My Way Now
- Nursing without a Degree
- Emotional Roller-coaster

➤ Just Too Much

- Physical and Mental Overload
- I'm Just so Angry
- Managing the Crazy

➤ Caring is Your Souls Growth

- Please God Help Me
- Finding my Inner Strength
- How Can I Help You?

The above are the five themes of the study. "Caregiver Who?" describes how the participants are lost in the disease process, almost becoming invisible even to themselves. "Taking It Day by Day," the caregiver never knows what each day will bring; she had been looking forward to the freedom of retirement years but the reality had become that her equal partner was no longer her equal and that there was no freedom for her. "Not Sure What to Do Next" describes the moment that the caregiver realized that her whole life had changed; she was forced to become a caregiver, to run the home, to take on all the chores, to become the only driver in the house—a big adjustment for these women—and to become an unpaid nurse and doctor on call. It's "Just Too Much" to figure out how to adjust to the emotional and physical overload, how to manage the craziness, and how to handle the anger at the situation that they've found themselves in. Recognizing that "Caring is Your Soul's Growth, these women have found various ways to cope: God, humor, inner strength. All of the participants realize now how hard caregiving is and want to help those who are just starting out.

Study Details

1. Caregivers address activities of daily living, and as the stages progress, they lose their identity while disappearing into the background. Dr. White found the following already documented in literature: As a patient moves through the Hoehn and Yahr stages, they require more intense assistance; however, physicians have little knowledge of how to help the caregiver.
2. Caregivers begin nursing and parenting their spouses. They expressed not having help and losing their husbands' companionship. In literature, she found documented that the caregivers shift from being a wife to becoming a caregiver and parent to the spouse. The caregiver becomes a type of unpaid nurse.
3. Caregivers described anger and guilt towards their spouses and the situation. Most described looking for inner strength through religion, spiritual beliefs, and support from others. Dr. White found that literature discusses that finding ways to deal with these feelings helps with personal growth. When they address these feelings, they shift from being self-centered to a more caring and patient person/caregiver.
4. Small activities like driving become a major concern for the caregiver. They were not accustomed to being the sole driver in the relationship. Dr. White found that becoming the sole driver is rarely mentioned in the literature and should be looked into further.

Study Limitations

1. Participants came from only one organization and one city in Colorado. To offset this limitation in future studies, they should be done using participants from outside these parameters.
2. Solely focused on females caring for their spouses with Parkinson's disease. The study did not include family or male spouse caregivers. A study to include men would give a different dimension of caregiver experiences.
3. Age demographic (over 50). This excluded children or other family members.

Future Research

Several participants indicated that they would like doctors to have a list of resources and what to expect. They suggested a focus group could put together such lists.

A systematic review of all caregivers should be done to see if their needs are equal and whether we as a population could assist them in their hour of need.

Health Policy

Public health issues also came out of this study. Many participants described feelings of stress and anxiety and a fear of leaving their spouses unattended. A way to combat these is to require insurance companies to pay for telemental health counseling for caregivers, which would increase the number of caregivers receiving mental health counseling while not leaving their homes.

Contact Information

If you would like to have a copy of the themes with their associated quotes, please send Dr. White an email at dawn.white.phd@gmail.com.

Questions and Answers

1. In a future caregiving study, would Dr. White include other types of caregivers, such as those for children with disabilities? Answer: Yes. She's working on such a systematic review.
2. Would she include the children of Parkinson's patients in future studies, even if they were only involved in the caregiving but not doing it full-time? Answer: She's not sure yet since there so many things she wants to do and that is definitely one of them. She has a friend whose husband recently died of ALS, and her children were forced at a young age (10 and 13) to become part-time caregivers; the friend is looking into how that effected her children. So some of that work is being done now.
3. Was Dr. White surprised by any of the results, other than the driving? Answer: Anger and guilt were big things without the participants' actually saying anything, but she could see the pain in their eyes. Their faces revealed much more than their words what they were actually feeling. The driving was a really big deal, probably influenced by the gender demographic she chose for the study. She knows in her case that when she and her husband get in their car, he does the driving. She suspects that's true for most couples, so the driving issue most likely would not have come up had the study had only male spouses in it.
4. A gentleman with Parkinson's commented that as a passenger in a car being driven by his wife, he finds himself anxious and startled by the cars whizzing past them, and involuntary yelps not meant to intimidate the driver just pop out of his mouth. Answer: That's probably a product of shifting from being in control to being a passenger. It's just one more thing the caregiver has to do—try to reduce the anxiety level of the passenger with Parkinson's.
5. A caregiver commented that when a spouse is engaged with the caregiver and asks how he can help to ease the caregiver's burdens and then does those things, that really helps the caregiver and the relationship. Answer: In her complete list of comments from the participants, this was brought out by some of the participants.
6. Did she notice any difference in answers based on the participants' ages since it was a wide range of ages? Answer: Not really. But perhaps she should include both the caregiver and the Parkinson's patient and ask them the same questions at different times in future studies. She'll add this to her list.

Dr. White stopped the recording at this point. However, the emcee let the audience know that many cars have a lane-assist feature that keeps the driver in the lane and keeps him from running up on the car in front. This is becoming a standard feature, and even some less expensive cars, like Kia, have it. You don't have to break the bank to get such a car. So if running up on the car in front and not being able to stay in the lane are the only reasons the spouse or family member is having to do all the driving, there's a solution. It restores independence to both the person with Parkinson's and the caregiver.

Also, the Colorado Parkinson Foundation website has a complete list of resources here in Colorado Springs. The website is co-parkinson.org; click on the Resource tab and then on Other Resources.



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]

Colorado Parkinson Foundation, Inc.

1155 Kelly Johnson Blvd.

Suite # 111

Colorado Springs, CO 80920

Parkinson's Perspective

JUNE 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)

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

October 8th: Reg Mtg–10 am; **Program:** TBD

November 12th - Reg Mtg at First United Methodist Church – 10 am; **Program:** Breakout Sessions

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

December 10th - Reg Mtg at First United Methodist Church – 10 am; **Program:** Christmas Party!!!!!!

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://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.youtube.com/playlist?list=PLkPIhQnN7cN6dAJZ5K5zQzY84btUTLo_C);

[https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-
parkinson-disease-caregivers](https://www.michaeljfox.org/foundation/news-detail.php?self-care-tips-for-parkinson-disease-caregivers); pmdalliance.org